

TRANSITIONS IN WOMEN'S HEALTHCARE: THE IMPACT OF THE NEW POPULATION PARADIGM

BY SUSAN HAACK, MD, MDIV, MA

GUEST CONTRIBUTOR

The concept of the profession of medicine has undergone an unparalleled paradigm shift in recent decades, the result of the invasion of capitalistic market forces, the exponential expansion of information technology, and the encroachment of bureaucratic control. An additional seismic shift has more recently occurred as a revision in the approach to prevention combined with new administrative mandates have altered the horizon of healthcare, shifting the focus from the individual to the population, thereby further threatening to disrupt the physician-patient relationship, which has been foundational to care. These changes are particularly prominent in women's health where prevention and the physician-patient relationship have been key components of care.

The Way We Were . . .

Humans are holistic and relational beings; and medicine was a holistic and relational art. Nowhere is that seen more clearly than in the biopsychosocial model of holistic care that dominated medicine and women's health for the last three decades. The term, coined in 1977 by George Engel,¹ was a reaction against the materialistic and reductionist orientation of medical thinking, and an attempt to apply complex causality and the emergent properties of systems to healthcare.² It was conceptualized through the use of three overlapping circles of influence, acknowledging that biological, psychological, and socio-economic factors were all integrally important aspects of human health and well-being. Under the aegis of this model, healthcare was distinctly individualistic, yet maintained a corporate perspective, understanding that individual health was part of a greater systemic whole. The focus, however, remained on the individual.

Prevention and education were essential aspects of this holistic approach to women's health that centered on screening for cervical abnormalities and sexually transmitted diseases (STDs), and the counseling and provision of contraception. The Pap smear was the heart of gynecologic care. Beginning at age 16 or the onset of sexual activity, it was continued yearly

for life, providing an opportunity to establish relationships and build rapport with adolescents in addition to addressing contraceptive needs, STD screening, and sexual health. Admittedly, the frequency of Pap smear screening at that time was founded on an erroneous understanding of the human papillomavirus (HPV), the organism responsible for most cervical abnormalities. Scientific knowledge had suggested that the viral infection was life-long and accounted for a cascading continuum of progressive disease from cervical intraepithelial neoplasia (CIN or dysplasia) to cancer, reinforcing the need for frequent screening visits.

Contraception, another preventive issue in women's health, was prudently coupled with Pap smear and STD screening. In the 1980's, the available contraceptive methods were primarily oral or barrier; other methods such as intrauterine devices were available but not widely utilized. Dispensing oral contraceptives on a yearly basis provided opportunities to reinforce compliance, to educate young women concerning sexual and life-style choices, and to perform STD screening.

As patients matured, so did their health concerns: breast care and mammograms entered the picture. At yearly clinical exams, patients were taught how to perform breast self-exams and encouraged to take an active role in their own breast health. By the 1970's, studies by Gershon-Cohen, Egan, and then a randomized-controlled trial by Shapiro revealed a benefit to routine mammographic screening for women,³ but provided no guidelines for the frequency of such exams. Original recommendations included a baseline examination at 35-40 and after 50 yearly for life, but no consensus existed.

Surgical techniques and technology were also quite limited 30 years ago. Gynecologic procedures were limited to tubal ligations, hysterectomies (vaginal or abdominal) and vaginal repairs. Laparoscopy and lasers were just entering the scene. More invasive procedures were normative, requiring longer hospitalizations, extended recovery, and lengthier physician involvement.



from the director's desk

BY PAIGE C. CUNNINGHAM, JD
EXECUTIVE DIRECTOR

SCHOLARSHIP WITH A PURPOSE: LOVING GOD WITH ALL YOUR MIND

Friends of CBHD know that we stress academic rigor and broad accessibility, characterized by charitable critique and thoughtful engagement. As a Christian bioethics research center, we feel a serious responsibility to our various audiences to offer credible resources.

Within the realm of bioethics in particular, and in the academy more broadly, Christians—especially evangelicals—are accused of anti-intellectualism. To be sure some streams of Evangelicalism have a history of anti-intellectualism with roots in 18th century Revivalism and Pietism, the move toward the German research university model in the 19th century, and the Modernist-Fundamentalist conflicts of the 20th century. Anti-intellectualism persists as a problem not only in the evangelical world, but in contemporary American culture, which prizes entertainment and emotional experiences. But doing ethics by emotion is inadequate at best, and shameful at its worst. Instead, we are expected to love God with *all our mind*.

Although the commandment applies to all Christians, loving God with all your mind is a powerful motivation for scholars.

So, just how does one become such a *scholar*? As a cognate of “school,” both words imply organization and focus. A school might be organized around age groups or a focused interest, such as law. A scholar focuses on a particular area of study, such as the history of medicine, and through professional or academic organizations associates with other similarly engaged people. A distinctive of the scholar is the love of learning. (My husband Jay is bemused by the pile of books on my nightstand. Why would anyone want to read Newman’s *Apologia Pro Vita Sua* or Birkert’s *Gutenberg Elegies* for pleasure?)

Let me tell you about three recent exchanges that have helped form me as a scholar.

The Academy of Fellows met near Chicago on a cold January weekend, to welcome new Fellows and hold a consultation themed on academic mentoring. Mentoring is not only professor-to-student, but also colleague-to-colleague. And that is what transpired. Ten fellows presented works in progress, on a variety of topics ranging from enhancement to synthetic biology to Ebola ethics. Comments were appreciative, candid, charitable, and thoughtful. Among fellow Christians, remarks do not have to be carefully weighed so as not to offend or alienate secular sensibilities. Mutual respect in the offering and receiving of comments was genuine, even when differing perspectives were raised.

I was challenged to think more deeply. For example, how does the use of engineering language affect our perception of biological life, cells, and organisms? “Construction-of-the-cell” language may lead us to regard the cell as a machine, whose defective parts can be interchanged at will with healthy replacements. The metaphor can disguise or distort the reality.

Two weeks later, the Center hosted another scholarly event. This time, instead of covering a broad array of topics, we plunged deeply into just one: the mechanisms of action of levonorgestrel (“Plan B”). There has been an ongoing debate about the drug’s possible embryocidal effect, which would of course have ethical ramifications. In this by-invitation-only gathering, presenters spoke freely about what they think the evidence shows. Because we all share a commitment to respect and not harm or destroy human embryos, we were free to emphasize minor points of difference.

I learned more about the female hormonal cycle in six hours than I did through a college education and three pregnancies. I pressed the presenters for their assessment of the validity, reliability, and generalizability of the studies. And, the conversations have continued via email, posing technical questions for the experts.

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University.

“Exploring the nexus of biomedicine, biotechnology, and our common humanity.”

Dignitas is the quarterly publication of the Center and is a vehicle for the scholarly discussion of bioethical issues from a Judeo-Christian Hippocratic worldview, updates in the fields of bioethics, medicine, and technology, and information regarding the Center’s ongoing activities.

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The third example of doing scholarship is consulting with experts in the field. On a couple of recent occasions, I checked with Dr. David Prentice (also a CBHD Advisory Board member) about specific studies or techniques. Once, he corrected my draft of a column that misrepresented a study using human embryo stem cells to treat diabetes, and on another occasion, clarified for me an inaccurate news report about the creation of primordial germ cells from two men (for the ultimate goal of creating a child genetically linked to two male parents, colloquially called the “two-dad” embryo).

A scholar does not claim to know everything. In bioethics, this would be foolhardy, if not impossible given the breadth of the interdisciplinary nature of the conversation. Instead, we participate in a community of scholars, seeking and sharing expertise. There is no shame in making mistakes. The greater harm would be in refusing to admit error, or covering it up. Intellectual hubris benefits no one, and epistemic humility is in short supply. Yet, a humble, open attitude unlocks the possibility of deeper learning.

One need not be a scholar with rarified expertise to love God with all your mind. You simply need to love learning, and do it for the rest of your life, to the glory of God. ●●●

QUESTIONS?

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.

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In all these aspects of women's health, the physician-patient relationship was a central and essential component of that care. The requirements of regular visits for preventive screening and education, as well as the prolonged post-operative recovery and care, established and supported the physician-patient relationship, so vital to ongoing healthcare for women. But women's healthcare is changing rapidly along with the rest of healthcare.

The Way We Are Today . . .

The focus of healthcare has changed, shifting from the idea of complex causality to structural causality. Distinct evidence-based algorithm boxes that provide no room for context and leave no room for contingencies have replaced the biopsychosocial model of healthcare that acknowledged the complexity of human health. The educational aspects of healthcare have likewise taken on new forms as education has been reduced

from a relational enterprise of sharing knowledge to a technological transfer of information. Technology (apps) and social media are replacing relationally-based educational methods, greatly improving access to information and availability of healthcare resources, but forfeiting the care and accountability associated with relational teaching and

becoming a serious problem, but about preventing the abnormality in the first place. While this approach is highly advantageous, it has had significant consequences for women's healthcare. In screening for cervical abnormalities, no longer is the focus on preventing the progression of cervical abnormalities, but on preventing the cause of the

In all these aspects of women's health, the physician-patient relationship was a central and essential component of that care.

learning. While these new approaches have been considered "personal," they are not relational: the ideas have been conflated and confused.

The concept of prevention has shifted subtly, yet dramatically, in recent years as well. No longer is prevention about preventing an early abnormality from

abnormality by means of HPV vaccinations. Yet, with administration from ages 9-11, HPV vaccination falls outside the scope of the obstetrician-gynecologist as we have now defined it, diminishing the opportunity for contact with adolescent women. Additionally, as our knowledge of HPV has grown, the





onset of Pap screening has been delayed from 16 to age 21, and the frequency of screening has decreased from yearly to every 3-5 years. While this cost-effective change in Pap smear frequency has eliminated unnecessary procedures it has also reduced opportunities for physician-patient contact. Moreover, there is now no effective mechanism for STD screening, a vital concern for sexually active young women.

But another change is on the horizon. In 2014, the FDA approved Cobas® for primary cervical cancer screening.⁴ Cobas® is a new qualitative assay of a sample of cervical cells, providing specific genotype information for HPV types 16 and 18 with pooled screening for 12 other high-risk HPV types.⁵ It has been recommended that screening now be delayed to age 25 with Cobas® alone. If the screen is negative for HPV 16 and 18, screening is to be repeated every 5-6 years. If the screen is positive for HPV 16 or 18, colposcopy is advised. If the screen is positive for another high-risk viral type, cytology and colposcopy are indicated.⁶ And again, opportunities for contact are diminished.

Contraception has undergone two major changes in the past few years that have likewise impacted care: the expansion of long-acting reversible contraceptives (LARCs) and promotion of over-the-counter post-coital contraception. The shift to LARCs has contributed to the diminished rate of unplanned pregnancy by providing 3-5 years of

Services Task Force (USPSTF)⁷ and is no longer recommended by any organization, removing another opportunity for education and relationship building from the armamentarium of physicians. Even the annual clinical breast exam has been eliminated by many organizations except for the American College of

“What we are gaining in efficiency and effectiveness, we are rapidly losing in the relational aspects of healthcare.”

coverage and eliminating compliance issues. But it has also jettisoned another compelling reason for a healthcare visit. Likewise, the availability of post-coital contraceptives without age limits or discretionary control has further diminished physician contact and eliminated another means of STD screening.

The approach to breast health has also seen significant alterations. Teaching of the breast self-exam was eliminated in 2009 by the United States Preventive

Obstetricians and Gynecologists (ACOG) where it is considered a discretionary aspect of the well-woman care.⁸ Mammographic screening has also come under scrutiny as studies have repeatedly questioned its value. Based on SEER data from the National Cancer Institute, the USPSTF in 2009 recommended screening only every 2 years from 50-69.⁹ A recent Canadian National Breast Screening Study with 25 years of data also found significant over-diagnosis and no decrease in mortality for screened women.¹⁰ For

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Thursday, June 18 (morning)

Workshop led by Lauris Kaldjian, MD, PhD and Ryan Nash, MD, MA, FACP, FAAHPM

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Thursday, June 18 (afternoon)

Workshop led by Ed Grant, JD



screening to be effective it “must meaningfully change mortality,” but this raises the question, “meaningful for whom?” Evidently, the answer is population-based. There currently exist three different sets of recommendations for screening frequency from various medical organizations, all of which claim to be “evidence-based.”

In light of this compendium of changes, several entities have called for elimination of the yearly examination, citing its lack of cost-effectiveness.¹¹ While the American College of Obstetricians and Gynecologists has understandably not concurred with those recommendations, the 2012 Committee Opinion description of what is to be included in the “Well-Woman Visit” (vital signs, BMI, palpation of the abdomen and inguinal lymph nodes, and assessment of overall health) is so meager and meaningless as to constitute tacit agreement.¹² Even breast and pelvic exams are deemed discretionary. Moreover, in a May 2014 publication entitled, “The Initial Reproductive Health Visit,”¹³ ACOG elaborated new recommendations for an adolescent visit. This exam, offered at ages 13-15, entails a general exam and visual genital exam only, the purpose of which is to “start a physician-patient relationship and counsel regarding healthy behaviors.” However, to expect a parent to take a healthy adolescent out of school, to pay a premium co-pay to see a “specialist” for something that can be done by family physicians, and that offers no immediate benefit is unrealistic. And with no additional visits until age 25, one visit is unlikely to constitute a relationship.

Surgical care has transitioned from primarily invasive to predominantly minimally invasive techniques. Almost all major procedures are now considered “outpatient” regardless of physician judgment, further diminishing relational contact with patients. Robotic surgery entered the gynecologic operative suite but has increasingly been found to be less than ideal. Furthermore, due to the time consuming nature of robotic-training, instruction in

traditional surgical techniques has been greatly reduced thereby diminishing the armamentarium of gynecologic surgeons.

The Way We Will Be . . .

There have been tremendous changes in the area of women’s health that fall under the rubric of progress and are no doubt advantageous from the perspective of efficiency and effectiveness. But to paraphrase the First Law of Thermodynamics, all gains within systems entail losses, and this is no less true in medicine. What we are gaining in efficiency and effectiveness, we are rapidly losing in the relational aspects of healthcare. Persons have been replaced with data, and relationships with technique, as that enigmatic concept of “health” is now being defined not by individual characteristics but by population statistics. Technology, information, and concerns about population health have replaced the personal interactions of touching and talking. Furthermore, changes that have sought to diminish healthcare costs have provided more fuel to the fire of depersonalization by shifting the focus of prevention from the individual to the population and diminishing the opportunity for relational contact. In the pursuit of *population* health, we have relinquished *individual* care. But how important are the relational aspects of healthcare to health? Will the pursuit of technological mastery of population health and the ensuing loss of relationship ultimately be beneficial or detrimental? Only time will tell whether health is fundamentally about quality or a quantifiable reality, and whether improved population health is possible apart from relational care. ●●●

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ACADEMY OF FELLOWS CONSULTATION 2015

BY DÓNAL O'MATHÚNA, PHD,
CHAIR OF THE ACADEMY OF FELLOWS

On January 23-24, 2015, the Academy of Fellows of The Center for Bioethics & Human Dignity (CBHD) met for its fourth consultation. The two previous consultations focused on specific topics: justice and bioethics in 2013, and synthetic gametes in 2012 (video from these events is available on CBHD's YouTube channel at youtube.com/bioethicscenter). This year's consultation took a different approach. The overall purpose of the Academy of Fellows is to "engage in thoughtful discussion, charitable debate, and mutual support." To facilitate this, most of the recent consultation involved Fellows presenting 'works in progress' in order to help Fellows develop their ideas and move them towards publication or other public dissemination.

A significant emphasis of the Academy of Fellows is the desire to mentor future Christian bioethicists. To explore tangible possibilities of academic mentoring with the Academy of Fellows, the consultation began with a presentation by Donald Guthrie, professor of educational ministries and director of the doctoral program in educational studies at Trinity Evangelical Divinity School. Guthrie outlined current scholarship on academic mentoring and described the importance of providing both challenge and nurture within the same environment. One key aspect is that mentors allow their mentees to attempt assignments that stretch their skills while providing constructive feedback. The presentation led to an engaging discussion about the practicalities of promoting such mentorship within the Fellows' various academic settings.

The overall purpose of the Academy of Fellows is to "engage in thoughtful discussion, charitable debate, and mutual support."



Paige addresses the Fellows at the CBHD 2015 Academy of Fellows Consultation.

Saturday began with Distinguished Fellow Gilbert Meilaender presenting his on-going research on a theological response to biomedical enhancement. Meilaender was on the President's Council on Bioethics when it published *Beyond Therapy*. For his theological analysis, Meilaender examined ideas proposed, but not developed, by Karl Barth in his unfinished *Dogmatics*. In particular he explored how the perfection of our bodies, which enhancement imagines, can fruitfully be examined through the theological lens of redemption and how this lies in the future. Given the engaging discussion stimulated by Meilaender's work in progress, we look forward to reading his completed work.

Other Fellows gave shorter presentations, beginning with William Cheshire. As Chair of the Ethics Committee of the Christian Medical & Dental Associations (CMDA), Cheshire also has grappled with the difficult ethical decisions that

enhancement raises. These include considering the proper ends and means of medicine, distinguishing between healing and enhancement, evaluating the just distribution of medical resources, and, in partnership with patients, deciding how best to honor the patients' wishes when societal pressures may diminish their autonomy. The Ethics Committee has developed recommendations for healthcare professionals facing ethical challenges with enhancement technologies. Cheshire discussed the status of these recommendations, and acknowledged the expert input provided to the Ethics Committee by CBHD and several members of the Academy of Fellows.

Fabrice Jotterand continued the focus on enhancement through examining issues raised by neurotechnologies, such as brain imaging. Claims are made that damage to specific regions of the brain correlate with predispositions to bad or criminal behavior (psychopathy). The suggestion that material factors are responsible for bad or criminal behavior seems to challenge commonly held understandings of the nature of morality and the basis of moral and criminal responsibility. Jotterand explored some of the implications of neuroscientific

conceptions of self for our understanding of moral agency in psychopathy, critically evaluated some of the arguments attempting to establish the neural correlates of morality, and explored the implications of such arguments for forensic psychiatry and moral (and criminal) responsibility.

The final presentation of the morning was made by Chris Ralston. He described his ongoing work at Joni and Friends International Disability Center and the Christian Institute on Disability. These activities included a “Call for Papers” for an upcoming thematic issue on disability and bioethics for the *Journal of the Christian Institute on Disability*, and the launch of the course “Beyond Suffering Advanced Studies: A Christian Perspective on Healthcare Humanities.” This online course addresses practical reasoning, self-knowledge, and action in the care of the sick and the marginalized, with a special emphasis on people with disabilities. Finally, Joni and Friends is partnering with Tyndale House Publishers to create the *Beyond Suffering Bible*, forthcoming in 2016. This aims to help readers love, reach, serve, and disciple people with disabilities through understanding what the Bible says about suffering and disability.

In the afternoon session, Henk Jochemsen presented ongoing work on potential social problems if synthetic biology is successful. He described the importance of symbolic order for society. Symbolic order is a set of widely shared and strongly entrenched concepts that cultures use to categorise reality. Society uses such powerful metaphors to draw boundaries in terms of dichotomies like life-death and natural-artificial. Synthetic biology uses many metaphors (like biobricks or cell-chassis) that challenge symbolic order and therefore strongly, but subtly, influence society. Yet some synthetic biologists will admit that such metaphors are invalid, even scientifically (e.g., that living cells are like machines). The impact of such metaphors needs careful analysis and may provide fruitful ways to critique the claims of synthetic biology.



Donald Guthrie, EdD, presents at the consultation.



A group photo of those in attendance at the CBHD 2015 Academy of Fellows Consultation.

Russell DiSilvestro presented an on-going project that aims to show how the “capabilities approach” to moral and political philosophy, initiated by Martha Nussbaum and Amartya Sen, might best address the debate about the relationship between human rights and sex-selective abortion. This debate predictably migrates through familiar questions about balancing the rights of adult women against the rights (and moral status) of prenatal human life. Although some of Nussbaum’s work suggests that prenatal human life has a *low* moral status, her recent paper with Rosalind Dixon, “Abortion, Dignity, and a Capabilities Approach,”¹ claims that the capabilities approach supports something like a *gradualist* position. However, they acknowledge the possibility and plausibility that this approach offers to defend a *high* moral status for prenatal human life. This proposal will receive further careful deliberation by DiSilvestro and colleagues.

Shari Falkenheimer gave an overview of her plans for her doctoral dissertation and ideas for related comprehensive papers on whole person medicine and the continuing professional development of physicians. Her preliminary plans include a qualitative project involving interviews with people who have taken the Partners in International Medical Education (PRIME) course on whole person medicine. This project would explore what attracted participants from multiple cultures and faith groups to take the course, what they valued about it, and whether and how it affected their practice after the course. She received valuable feedback from the Fellows and plans to develop her project further.


John Kilner gave an overview of his new book, *Dignity and Destiny: Humanity in the Image of God* (Eerdmans, 2015) and his further plans for this material. *Dignity and Destiny* includes an examination of all biblical passages on the image of God. Kilner’s view is that people, made according to (or in) the image of God, have a special connection with God and are *intended* to be a meaningful reflection of God. Because of sin,

they do not *actually* reflect God very well, but are still fully in God's image. Renewal in God's image entails a more intimate connection with God through Christ and an increasingly actual reflection of God in Christ, to God's glory. This connection with God is the basis of human dignity. Kilner concluded with a reflection on the tremendously liberating impact that a sound understanding of God's image can have in the world today, including within bioethics.

Calum MacKellar discussed a current project he is working on in the area of emerging technology and neuroethics. He detailed how current and near-future research suggests the possibility of fusing the human brain with computers, and the human mind with cyberspace. Rudimentary, and current, examples of such technology include Google goggles linking the user to the web, and cochlear implants linking brains with computers. These developments raise challenging ethical questions whose answers are neither obvious nor easy to reach. The proposed book takes an inter-disciplinary approach that blends research from disciplines such as neurobiology, philosophy, sociology, and psychology.

Dónal O'Mathúna gave an overview of recent ethical debates triggered by the Ebola outbreak in West Africa. These include the ethics of quarantine, research ethics during infectious disease outbreaks, and ethical issues with collecting and storing biospecimens for Ebola research. These led to the Presidential Commission for the Study of Bioethical Issues requesting public commentary on Ebola ethics. The Academy discussed setting up a working group to examine ethical issues in Ebola response and research for which a Christian perspective could make a distinct contribution.

After a packed and engaging day and a half, the consultation concluded. Through the consultation, presenters received helpful comments and constructive feedback. The breadth of bioethical issues being addressed by members of the Academy was impressive. On-going projects moved a little further towards completion, and seeds for new projects were sown. New collaborations were forged as Fellows saw areas of common interest. Also important, a sense of camaraderie and common purpose was renewed that will stay with the Fellows as they return to their own bioethical front lines.

The Academy of Fellows expresses its gratitude to all the staff at CBHD for organizing the consultation so well. In addition, the Academy is especially grateful to the anonymous donor whose gift funded this consultation and other Academy activities over the past few years. 

¹ Rosland Dixon and Martha Nussbaum, "Abortion, Dignity and a Capabilities Approach," in *Feminist Constitutionalism: Global Perspectives*, ed. Beverly Baines, Daphne Barak-Erez, and Tsvi Kahana, 64-81 (New York: Cambridge University Press, 2012).

ACADEMY OF FELLOWS: ADDITIONS & PROMOTIONS

During the Academy of Fellows consultation in January, several new Fellows were admitted into the Academy (full details on the new Fellows are available at www.cbhd.org/about-cbhd/meet-fellows).

Distinguished Fellow:

H. Tristram Engelhardt, Jr., MD, PhD

Fellows:

Theo Boer, PhD

Fabrice Jotterand, PhD

Lauris C. Kaldjian, MD, PhD

Ryan Nash, MD

Associate Fellows:

Todd Daly, PhD

Russell DiSilvestro, PhD

Patrick Smith, PhD

D. Christopher Ralston, PhD

Additionally, several Fellows received promotions in the Academy that were recognized at the January consultation.

Distinguished Fellows:

Robert D. Orr, MD

Daniel Sulmasy, MD, PhD

Senior Fellows:

William P. Cheshire, Jr., MD

Fellow:

Mary B. Adam, MD, PHD

BOOK REVIEW:

BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END.

BY ATUL GAWANDE. NEW YORK: METROPOLITAN BOOKS, 2014.

REVIEWED BY DANIEL J. HURST, THM

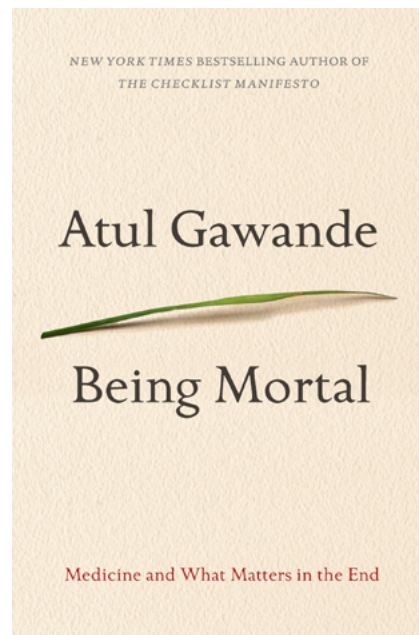
GUEST CONTRIBUTOR

In Tolstoy's masterful novella *The Death of Ivan Ilyich*, the main character, Ivan, falls off a ladder and develops a pain in his side. The pain, nonetheless, is not assuaged as time goes on; it worsens. Ivan grows depressed, debilitated, and his friends and colleagues avoid him. After a series of ever more expensive doctors attempt to diagnose and treat him, unsuccessfully, Ivan rages over his situation. However, Tolstoy writes that what bothered Ivan the most was "the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and he only need keep quiet and undergo a treatment and then something very good would result." Indeed, death was not a subject that his physicians, family, or friends could tolerate.

Tolstoy's story of Ivan Ilyich is a tale of those around him failing to acknowledge what was happening to him. In a similar manner, Atul Gawande, a general surgeon at Boston's Brigham and Women's Hospital and professor at Harvard Medical School, in his latest work, *Being Mortal: Medicine and What Matters in the End*, has a similar diagnosis for modern medicine. Gawande's exploration of aging, disease, death, and his profession's mishandling of these is profoundly insightful and deeply personal. Masterfully weaved throughout Gawande's book is the story of his own father, also a surgeon, and the trials he experienced when faced with his own mortality and the reality that what medicine can do often runs counter to what it should. As Gawande notes, oftentimes modern medicine sees death as a failure. While death may be the ultimate limitation of his profession,

Gawande recognizes that "Death is not a failure. Death is normal. Death may be the enemy, but it is also the natural order of things" (8).

In this manner, Gawande's book is a call for reform in the philosophy of healthcare. As Gawande sees it, "The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes



life significant. The problem is that they have had almost no view at all" (128). He suggests the idea that a life worth living is possible for all stages of life. The job of medicine is not simply to ensure health and postpone death, but to enable well-being. The well-being that Gawande speaks of is elucidated in the form of engaging stories from his own medical practice and personal experience. Gawande trails a hospice nurse as she attends to patients, visits a geriatric physician for greater perspective, and

writes at length about the abundant need for nursing home reform. It is through these various stories, carefully intertwined throughout his book, that Gawande is able to clarify his idea of well-being and that the ultimate goal of humankind is not a good death but a good life.

Near the end of his book, Gawande offers a brief discussion of euthanasia. While Gawande flatly states that he would support laws of assisted suicide, a view undoubtedly contra the Judeo-Christian tradition, he critiques end-of-life policy in the Netherlands. "[T]he fact that, by 2012, one in thirty-five Dutch people sought assisted suicide at their death is not a measure of success. It is a measure of failure. Our ultimate goal, after all, is not a good death but a good life to the very end" (245). Gawande questions whether the Dutch have been slower than other countries to develop palliative care programs because "their system of assisted death may have reinforced beliefs that reducing suffering and improving lives through other means is not feasible when one becomes debilitated or seriously ill" (245).

Being Mortal is an esteemed contribution to the rather sparse literature on aging and death. Gawande is a gifted storyteller, and he does not spare the reader from descriptions of bodily aging. Identifying no perfect solutions to the problems inherent in bodily decline, Gawande asks his reader to commit to making choices with the goal of a purposeful life in mind. His writing is certainly intellectually provocative as it confronts the reader with their own mortality and the limits of medicine and themselves. ●●●

BIOENGAGEMENT:

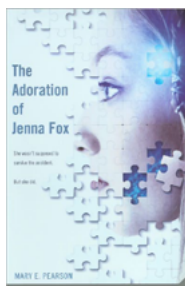
The promise and perils of advances in technology, science, and medicine have long been fertile fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium 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 <http://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:

Mary Pearson, *The Adoration of Jenna Fox* (Square Fish, 2009).

Biotechnology, Cognitive Uploading, Nanotechnology, Neuroethics, Personhood, Vitalism.

From all appearances Jenna Fox is your typical teenage girl, except that she cannot remember anything about her past prior to the coma from which she has recently awoken. Something is off. Her legs and hands just do not seem right. When she accidentally cuts herself in the kitchen with a knife, it is clear she is not the same Jenna Fox as before the terrible car accident that caused her to be in the coma. In this first volume of the Jenna Fox Chronicles, Mary Pearson masterfully explores the personal and societal implications when parental desires to protect their children collide with vitalism and biotechnology.



Neal Stephenson, *Diamond Age: Or, a Young Lady's Illustrated Primer* (Bantam Spectra, 1995).

Nanotechnology, Neuroethics.

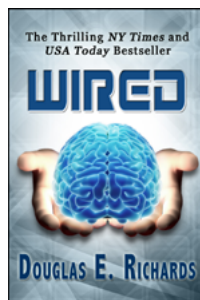
Labelled a postcyberpunk novel, the author of *Snow Crash* revisits a technologically advanced future now revolutionized by nanotechnology. As the narrator poignantly notes early in the narrative, “Now nanotechnology had made nearly everything possible, and so the cultural role in deciding what should be done with it had become far more important than imagining what could be done with it.” The plot follows a coming-of-age narrative of two young girls who receive stolen copies of a digital interactive book (*Young Lady's Illustrated Primer*) that lead them from modest beginnings to navigate the sociopolitical realities of the global tribalism of their day. Prescient in its anticipation of e-books, telepresence, and 3D printing, the novel explores the social impact of emerging technologies and their potential to be transformative influences on individuals.



Douglas Richards, *Wired* (Paragon, 2012).

Bioterrorism, Genetic Engineering, Human Enhancement, Neuroethics, Posthuman, Radical Life Extension, Research Ethics.

Former special forces officer David Desh is recruited for a black ops mission turned conspiracy theory. His target, Kira Miller, is a brilliant genetic engineer suspected by the U.S. government to be involved in a bioterror plot with global implications as she seeks to explore breakthroughs at any cost in cognitive enhancement and longevity research.



BIOETHICS AT THE BOX OFFICE:

The Fault in Our Stars (2014, PG-13 for thematic elements, some sexuality and brief strong language). *End of Life*.



Maze Runner (2014, PG-13 for thematic elements and intense sequences of sci-fi violence and action, including some disturbing images). Based on the book by the same title by James Dashner. *Emerging Technology, Neuroethics, Research Ethics*.



The Giver (2014, PG-13 for a mature thematic image and some sci-fi action/violence). Based on the book of the same title by Lois Lowry. *Designer Babies, Eugenics, Euthanasia, Genetic Engineering, Neuroethics, Personhood, Reproductive Technology, Surrogacy*.



Transcendence (2014, PG-13 for sci-fi action and violence, some bloody images, brief strong language and sensuality). *Artificial Intelligence, Emerging Technology, Human Enhancement, Nanotechnology, Neuroethics, Transhumanism/Posthumanism*.



BOOK NOTES FROM MARIE BUTSON, MDIV, MA

Ben Bova and Eric Choi, eds. *Carbide Tipped Pens: Seventeen Tales of Hard Science Fiction* (Tor, 2014).

Artificial Intelligence, Biotechnology, Genomics, Human Enhancement, Personhood.

Carbide Tipped Pens is an anthology of seventeen short stories in the sub-genre of ‘hard science fiction,’ described by the editors as a “literature of change . . . that examines the implications—both beneficial and dangerous—of new science and technologies” (11-12). Together with tales of outer space, aliens, and the survival of human beings, advancements in biotechnology likewise are creatively explored in the narratives. “Old Timer’s Game” imagines sports medicine’s transformation into performance enhancement that alters not only the players, but the popular world of professional sports. Meanwhile, “Skin Deep” envisions biomedical advancements through a custom-designed medical tattoo that shifts medicine from healing into more nefarious purposes. Without shying away from the technical aspects, these short stories intelligently explore the impact of advancing technology upon individuals and culture while making the ‘science’ in ‘sci-fi’ very practical and accessible to the reader.

Neal Shusterman, *Unwind* (Simon and Schuster, 2007).

Neuroscience, Organ Procurement and Transplantation, Reproductive Technologies.

Unwind follows four teens fighting for their lives in a future America in which 13- to 19-year-olds can be “unwound”—a

process of harvesting organs and body tissue for the use of others. The country has suffered through a Second Civil War pitting pro-life and pro-choice groups in combat over abortion. The passage of the “Bill of Life” along with a dramatic advance in organ transplantation capabilities by means of the development of “neurografting” (a procedure that makes use of 99.4% of the human body) have restored social order and begun to remedy cultural divisions that plagued the country by promoting human health. The Bill of Life offered a compromise by prohibiting abortion, but parents may retroactively abort their teen-aged children by “unwinding” them—harvesting all of their useful organs and tissues such that the children were said to not die, but physically live on. The teens in the story recognize their vulnerability and dispensability to their parents and society as a whole that results from this policy.

The Bill of Life feigns preserving human life and dignity, but commodifies a demographic desired only for their tissues and organs. *Unwind* (and its sequels in the Unwind Dystology series *UnWholly*, *UnSouled*, and *UnDivided*) follows the teens and their resistance against forces promoting a casual view of human life and an expanding role for government and commercial power over the nation. How far should organ transplantation go? How does a nation slide into indifference toward its youth for personal, national, and commercial gains? *Unwind* is a tense read intended for a young adult audience, graphically exposing the possibilities of biomedical technology and the importance of a moral framework as necessary to keep safeguards on the advance of technology and medicine.

TOP BIOETHICS NEWS STORIES, DECEMBER 2014 - FEBRUARY 2015

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

“TIME Person of the Year 2014: The Ebola Fighters” by David von Drehle with Aryn Baker, *Time*, December 10, 2014

Why, in short, was the battle against Ebola left for month after crucial month to a ragged army of volunteers and near volunteers: doctors who wouldn't quit even as their colleagues fell ill and died; nurses comforting patients while standing in slurries of mud, vomit and feces; ambulance drivers facing down hostile crowds to transport passengers teeming with the virus; investigators tracing chains of infection through slums hot with disease; workers stoically zipping contagious corpses into body bags in the sun; patients meeting death in lonely isolation to protect others from infection? (<http://tinyurl.com/mpa4ute>)

TIME magazine's person of the year for 2014 went to the Ebola fighters. In March 2014, news reports said that sixty-six people had died of Ebola in western Africa. A year later, the death toll is estimated at 9,800 people, but has slowed down considerably since the beginning of the year. A recent report from Liberia announced that the last Liberian with Ebola has recovered and is going home from the hospital. In the midst of this outbreak, many of the volunteer healthcare workers died, while others endured the ravages of the disease, survived, and went back to help others.

“CIA Used Brutal Methods, Misled Leaders, Report Finds” by Mark Mazzetti, *Boston Globe*, December 10, 2014

The Senate Intelligence Committee issued a sweeping indictment Tuesday of the Central Intelligence Agency's program to detain and interrogate terrorism suspects in the years after the Sept. 11, 2001, attacks, drawing on millions of internal CIA documents to illuminate practices that it said were more brutal — and far less effective — than the agency acknowledged either to Bush administration officials or to the public. (<http://tinyurl.com/mplwb34>)

The CIA report on the use of torture in the wake of the September 11, 2001 attacks created a significant controversy in its release. Questions remain as to the validity of the claims as well as whether it is a complete picture or a partisan politicization. From a bioethics standpoint, this is a case where questions of human dignity and the “greater good” are also of concern. Revelations of the close involvement of medical professionals in interrogation practices has raised questions of whether it is ethical for medical professionals to assist in any way in torture techniques.

“Rudimentary Egg and Sperm Cells Made from Stem Cells” by David Cyranoski, *Nature*, December 24, 2014

Israeli and UK researchers have created human sperm and egg precursor cells in a dish, starting from a person's skin cells. The achievement is a small step towards a treatment for infertility, although one that could face significant controversy and regulatory hurdles. The experiment, reported online in *Cell* on 24 December, recreates in humans parts of a

procedure first developed in mice, in which cells called induced pluripotent stem (iPS) cells—‘reprogrammed’ cells that can differentiate into almost any cell type—are used to create sperm or eggs that are subsequently manipulated to produce live births by *in vitro* fertilization. (<http://tinyurl.com/n6hwkpr>)

Researchers were able to produce precursor cells to sperm and eggs from human stem cells. Not only are there ethical issues if they are able to produce sperm and egg cells, but the experiments to make the progenitor cells had some ethical controversy. The researchers accomplished the experiments using both embryonic and induced pluripotent stem cells. They also compared the epigenetic factors in their precursor cells to those in aborted fetuses. If researchers are able to produce eggs and sperm from these cells, the only way to know if the synthesized gametes can produce a healthy child is to do the experiment, which would result in creating an embryo for experimental purposes. Finally, because stem cells can be genetically modified, this may open the door to genetic modifications of gametes. Researchers noted that there are many technical hurdles to overcome for two males to produce biological children, and even more for females, as they do not have the Y chromosome necessary for sperm production.

“California Measles Outbreak Grows to 73 Cases” by Ralph Ellis, *CNN*, January 28, 2015

California has reported more measles cases. The number of cases has

increased to 73, with 50 of those cases linked to an outbreak at Disneyland, the California Department of Public Health reported Monday. Last week, public health officials reported 59 cases since December; 42 with a Disney connection. In addition, 13 cases linked to the outbreak have been reported in six other U.S. states: five in Arizona, three in Utah, two in Washington, and one each in Nebraska, Oregon and Colorado. Also, one case linked to it has been reported in Mexico. (<http://tinyurl.com/oda97rs>)

“Doctors Turning Away Unvaccinated Children” by Brittny Mejia, *Los Angeles Times*, February 10, 2015

Amid the current measles outbreak, Goodman and a growing number of other pediatricians nationwide are turning away parents who refuse to vaccinate their children. Of the more than 100 people who have contracted the virus so far, the majority were unvaccinated, according to the Centers for Disease Control and Prevention. (<http://tinyurl.com/kl8begs>)

Dozens of children contracted measles while at Disneyland in California resulting in an explosion of opinions in the media on whether parents should be required to vaccinate their children or not. Mandatory vaccinations of children place personal (and parental) autonomy and public health concerns in direct conflict. In the wake of these developments, some pediatricians are electing to no longer treat unvaccinated children as a precautionary measure for their already vaccinated patients who may not have developed immunity. This practice of refusing patients raises questions on whether doctors should withhold medical treatment to those who are unvaccinated due to conscientious objection and/or to protect their other patients.

“Obama’s Precision Medicine Plan Seeks \$214m for Genetics-Based Treatments” by Lauren Gambino, *The Guardian*, January 30, 2015

Barack Obama on Friday unveiled details of a major research initiative that would invest \$215m in the development of medical treatments tailored to a person’s genetics, as part of a wider effort to fund science and research. The centerpiece of the president’s Precision Medicine Initiative is a research consortium containing the health data of a million volunteers, which researchers can use to develop new medicines and treat individuals. (<http://tinyurl.com/oz8nb9p>)

President Obama set forth in his State of the Union address plans for a biomedical research initiative that would involve collecting large amounts of genetic data so scientists can make tailor-made drugs. Among the bioethical concerns in this and other “Big Data” initiatives are issues of privacy and access, as well as who has control of the data. Given the increasing issues of data breaches in financial contexts, significant concerns are raised regarding the security of such personal medical information.

“Dying Dutch: Euthanasia Spreads Across Europe” by Winston Ross, *Newsweek*, February 12, 2015

In 2013, according to the latest data, 4,829 people across the country chose to have a doctor end their lives. That’s one in every 28 deaths in the Netherlands, and triple the number of people who died this way in 2002. The Dutch don’t require proof of a terminal illness to allow doctors to “help” patients die. Here, people can choose euthanasia if they can convince two physicians they endure “unbearable” suffering, a definition that expands each year. Residents here can now choose euthanasia if they’re tired of living with Lou

Gehrig’s disease, multiple sclerosis, depression or loneliness. The Dutch can now choose death if they’re tired of living. (<http://tinyurl.com/kcsrkhq>)

Physician-assisted suicide continues to appear in media headlines. After Brittany Maynard’s highly publicized death, several states have proposed bills that would allow for some form of physician assistance in death. Quebec recently voted to legalize physician-assisted suicide, and several countries in Europe, including France and Britain, have either legalized some form of physician-assisted suicide or have bills that they are going to vote in the coming months.

“Beyond the Genome” *Nature*, February 18, 2015

The Greek prefix *epi-* can signify upon, on, over, near, at, before, and after. Most of those could apply to its use in the term ‘epigenetics’ — particularly the last of them. It is some 14 years, almost to the day, that *Nature* published the draft sequence of the human genome. Now, in this issue, we publish results from a subsequent study on the non-genetic modifications to the genome — epigenetic modifications — that crucially determine which genes are expressed by which cell type, and when. (<http://tinyurl.com/ncbeyh8>)

An issue of *Nature* was dedicated to the results of the Roadmap Epigenetic Project, a multi-year NIH-directed project that looked at the parts of the genome that control how genes are expressed and regulated. Scientists now believe that many diseases, including certain cancers that do not have a direct gene-to-disease link, may be due to these epigenetic factors.

updates & activities

HEALTHCARE ETHICS COUNCIL

In early December, CBHD sponsored the first webinar for our Healthcare Ethics Council (HEC), featuring Dr. Ryan Nash who expertly presented the topic of "Ebola Ethics: Bedside and Boardroom considerations." The webinar is available for viewing both on cbhd.org and our YouTube channel (youtube.com/bioethicscenter).

PLAN B CONSULTATION

CBHD hosted an invitation-only consultation in early February exploring the mechanism of action and potential effects of levonorgestrel (Plan B) on the embryo. Participants engaged presenters and respondents on the current state of the medical and scientific literature and the implications for assessing ethics of use as an emergency contraceptive.

NEW CBHD STAFF

CBHD welcomed Michael Cox, MA, as a research analyst. Michael is currently completing a PhD in Old Testament studies at Trinity Evangelical Divinity.

MEDIA RESOURCES



CBHD.org on
Twitter: @bioethicscenter



Bioethics.com on
Twitter: @bioethicsdotcom



The Bioethics Podcast at
thebioethicspodcast.com



Facebook Page at
facebook.com/bioethicscenter



Linked-In Group at linkd.in/theqbhd



YouTube at
youtube.com/bioethicscenter



The Christian BioWiki
christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD

- Advised on Tennessee bill regarding mandatory reporting of egg donor and sperm donor information.
- In early January was interviewed by "Karl and June Mornings" (Moody Radio) on 3-parent children
- Presented "Wish List Children," a lecture on genetic screening and unexpected prenatal diagnosis, at the Culture of Life Seminar at March for Life in Washington, DC in January.
- Interviewed in February by ABC/KSRO (Radio) Morning News on 3-parent children

MICHAEL SLEASMAN, PHD

- In November represented CBHD at the annual meetings of the Evangelical Theological Society and American Academy of Religion professional meetings in San Diego.
- Interviewed by *Relevant Magazine* in December for a background material on Christian engagement with bio-ethical issues for future articles.
- In early January represented CBHD at the annual meeting of the Society of Christian Ethics.
- Became co-chair of the editorial board in January for *Ethics and Medicine: An International Journal of Bioethics*.
- In late January completed a white paper exploring ethical considerations for medical marijuana to the leaders of an evangelical denomination and met to discuss follow-up questions.

- In February completed an entry on nanotechnology for the forthcoming *Encyclopedia of Global Bioethics*, edited by Henk ten Have.

JENNIFER MCVEY, MDIV

- In February co-hosted (with Michelle Kirtley) a congressional briefing in Washington, DC featuring Rosalind Picard who spoke on "Improving Emotional Connection in the Digital Age: Affective Computing and Assistive Technologies."
- Following the February briefing, Jennifer hosted several meetings in DC developing strategic relationships on behalf of CBHD and exploring next steps for Her Dignity Network.

MICHELLE KIRTLEY, PHD

- In February co-hosted (with Jennifer McVey) a congressional briefing in Washington, DC featuring Rosalind Picard, and offered a response on ethical considerations for affective computing and assistive technologies.

R. DANIEL DAKE, MA

- In January facilitated the theological bioethics roundtable discussion with Michael Sleasman. The roundtable included a dozen participants that included graduate and doctoral students from Trinity Evangelical Divinity School and CBHD staff discussing *This Mortal Flesh: Incarnation and Bioethics* by CBHD Fellow Brent Waters.

ON THE CBHD BOOKSHELF

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

On the Bookshelf:

Morozov, Evgeny. *To Save Everything, Click Here: The Folly of Technological Solutionism*. (Public Affairs, 2013).

Overall, Christine. *Why Have Children? The Ethical Debate*. (MIT Press, 2012).

Articles of Note:

Best, Megan, Phyllis Butow, and Ian Oliver. "Spiritual Support of Cancer Patients and the Role of the Doctor." *Supportive Care in Cancer* 22, no. 5 (2014): 1333-1339.

Bishop, Jeffrey, Joshua Perry, and Amanda Hine. "Efficient, Compassionate, and Fractured: Contemporary Care in the ICU." *Hastings Center Report* 44, no. 4 (2014): 35-43.

D'Alton-Harrison, Rita. "Mater Semper Incertus Est: Who's Your Mummy?" *Medical Law Review* 22, no. 3 (2014): 357-83.

COMING SOON: ETHICAL CONSIDERATIONS WITH ELECTRONIC HEALTH RECORDS