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AFFECTIVE COMPUTING: AN UPDATE

MICHELLE KIRTLEY, PHD BIOETHICS & PUBLIC POLICY ASSOCIATE

In early 2015, The Center for Bioethics & Human Dignity sponsored a briefing on Capitol Hill featuring Rosalind Picard, ScD, founder and director of the Affective Computing Research Group at the Massachusetts Institute of Technology (MIT) Media Lab and co-director of the Things That Think Consortium. We asked Professor Picard to update Congressional staff in Washington, D.C. about recent advances in her research and the associated ethical implications.

Professor Picard's pioneering work (which she also described at CBHD's 2015 annual conference) has led to the development of several technologies that enable computers to decipher correlates of human emotion. Motivated by fundamental beliefs about what it means to be human, Professor Picard has long insisted that computers will most effectively assist human activities if they can decode and respond to human emotion. In collaboration with computer scientist Rana el Kaliouby, Professor Picard developed a complex algorithm that allows computers to "read" human facial expressions recorded on video. This technology has been used to help individuals on the autistic spectrum better decode subtle human social-emotional communication. Picard and Kaliouby founded the private company Affectiva to commercialize this technology for a range of applications.

Professor Picard's work in affective computing also led to an unexpected discovery about the correlation between the autonomic stress response—the fight-or-flight response—and an oncoming grand-mal seizure, the type of seizure that leads to violent muscle contractions and a loss of consciousness. At Picard's company, Empatica, a team of engineers and product designers has harnessed this information to develop a device that enables caregivers to monitor seizures in epilepsy patients. The Embrace watch can also help monitor stress or sleep disruptions.¹ With a firm belief in the power of technology to better the human condition, Professor Picard works with a seemingly tireless enthusiasm, stewarding her significant gifts and talents for the common good.

From the beginning, Professor Picard has given thoughtful consideration to what it means to be human and to the role emotion

and affect play in nuancing human communication and social interaction. The importance of social-emotional communication is not new to psychologists and social scientists, who have begun to document the effects of substituting digital connection for human interaction in our ever-more-wired culture. But in computer science and robotics, Professor Piccard was one of the first to call for including a social-emotional dimension to the development of "smart" technologies.

Picard has also consistently attended to the often complicated ethical questions that are raised by giving computers the ability to read and imitate human emotion. She devoted a chapter of her groundbreaking book, *Affective Computing*, to considering the short and long-term implications of her research, and she has collaborated with philosophers, scientists, engineers, and others seeking to address many of the ethical questions raised by her work.

So what are some of the most pressing of these ethical considerations?

Privacy is one of the most immediate concerns raised by technologies that can "see" and quantify what we are feeling. Not surprisingly, the advertising sector quickly perceived the value of being able to assess emotion in real-time. In an age where marketers are increasingly competing for our attention—which is now divided among various devices (your television, computer, smartphone, tablet, electronic game platform, etc.) and myriad different programs or apps on those devices—companies highly value the ability to accurately target an advertising message to the appropriate individual at the appropriate time. Samsung has already been criticized for voice activation technology on its SmartTVs which can listen and record conversation, and for pushing ads into apps that are streaming content from your *personal* video library.²

But many of us share an intense desire to keep our emotions private. What control will consumers have over what marketers can see? Should this information be in the hands of employers for the purpose of detecting disgruntled employees? While this knowledge could potentially prevent workplace violence, it could also be used to assess productivity and job satisfaction.

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from the director's desk

BY PAIGE C. CUNNINGHAM, JD EXECUTIVE DIRECTOR

ne of my favorite parts of getting around Washington, D.C. is the Metro system. The zip of the metro fare card that opens the gate, the flashing lights that announce the incoming train, and the garbled announcements of the upcoming station create a vivid collage. But the long entrance/exit rides, such as on Rosslyn station's 270-foot escalator, induce a bit of vertigo. The wide stainless steel divider tempts brash or drunk riders to emulate their childhood prowess on the playground slide. Large discs mounted at strategic intervals along the divider deter all but the most foolhardy. It is dangerous to descend that slippery slope.

As many of us are well aware, the "slippery slope" image is also a kind of argument, one that is usually dismissed out of hand. The basic idea is this: If doing X is not bad or wrong, but by permitting X we must also permit Y, and Y is wrong, then we should not permit X. Although X is not bad in and of itself, reason tells us that it will lead to Y. The proponent of the argument may marshal evidence to show that X is a *causal* link to Y, or that it is linked to Y as a *probability*.

The slippery slope argument is often rejected as fallacious when the proponent fails to introduce evidence or warrants that support the conclusion that X leads to Y. This one-thing-leads-to-another argument is reminiscent of the "camel's nose under the tent" image, or the "if you give a moose a muffin" children's story. The argument is rejected because of the piling up of increasing improbable probabilities, or the extreme nature of Y.

This is not to say that the slippery slope should never be employed. There are times when X *does* lead to Y. Recently, bioethicist Art Caplan admitted that the euthanasia slope was indeed slippery. As recently as one year ago, Caplan favored legalization of assisted suicide with "careful regulation." Euthanasia would be limited to people with a terminal illness and intractable pain.

Yet, in an August commentary co-authored with Barron Lerner, Caplan questioned whether euthanasia might not be on a slippery slope. Addressing the notable increase in euthanasia deaths in Belgium and the Netherlands, Caplan wrote of his discomfort in expanding euthanasia to people who were healthy but sad or grief stricken. The assisted suicide rate in Belgium more than doubled in 2013, increasing from about 2% to almost 5% of all deaths, with an increase in the Netherlands to 3.3% of all deaths.

The initial *reasons* given for speeding up death soon expanded to physical suffering (not necessarily terminal illness) without hope of improvement, loneliness, and being "tired of living." Doctors in Belgium and the Netherlands have hastened the death of people who are depressed, or distressed over the results of sex change surgery; who have autism, blindness, anorexia, chronic fatigue syndrome, schizophrenia; and who are dependent upon others for care.

A similar broadening slide occurred among the *people* included: first, only adults could consent. Then, babies were added to the list (with parental consent). Next, children ages 12–16 were deemed able to choose assisted suicide, again with parental consent. Not surprisingly, pediatricians are now arguing that the law discriminates against the child of eleven years and nine months, and that no child's age should disqualify them from a physician-assisted death. At the end of the slippery slope are real people, those who are old, poor, disabled, minorities, and people with psychiatric impairments.

These scenarios were predicted by opponents of assisted suicide and euthanasia of patients who did not or were unable to consent. Hindsight and the data provided by Belgium and the Netherlands confirm that the trajectory of opening the door to assisted suicide was indeed a downward, slippery slope. Caplan does not think the European experience will cross the Atlantic, yet we have seen legalized physician-assisted suicide expand from Oregon to include Vermont, Washington, and Montana, with a California bill sitting on the governor's desk as of this writing.

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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trinity international university

2065 HALF DAY ROAD | DEERFIELD, IL 60015 USA V 847.317.8180 | F 847.317.8101 INFO@CBHD.ORG | WWW.CBHD.ORG Other bioethical arguments reflect the kind of wisdom that may be veiled within a "slippery slope" argument. The law of unintended consequences comes to mind, along with the precautionary principle. Because it is so difficult to reverse course, prudence dictates circumspection. (This is not a tacit acceptance of the original approval of euthanasia; I am making a more general point about permitting that which was previously forbidden or restricted.) Of course, it is good news when prominent bioethicists publicly admit that some slopes are indeed slippery, and that "part of the problem with the slippery slope is you never know when you are on it."3

The moose's muffin and the camel's nose are not simply images. They depict the truth that disastrous outcomes can ensue from seemingly benign, small beginnings.4 And, in the current undermining of care for the vulnerable, unlike the Metro escalator discs designed to prevent sliding, there appear to be few obstacles to a drastic expansion of whose death should be speeded along. While the concerns about endless expansion of assisted suicide are valid, there is a more serious problem. We must reject the underlying premise that X—a "good death" for a few—is good for anyone. The rush toward physician-assisted suicide is an "escalator" no one should be riding.

- 1 Barron Lerner and Arthur L. Caplan, "Euthanasia in Belgium and the Netherlands: On a Slippery Slope?" JAMA Internal Medicine 175, no. 10 (2015): 1640-1641.
- Raf Casert, "Study: Euthanasia Cases More than Double in Northern Belgium," AP News Archive, March 17, 2015, http://www.apnewsarchive.com/2015/ Study%3A_Euthanasia_cases_more_than_double_in_northern_Belgium/id-c947d09361894bb78c349685631de9c6. Cf. Winston Ross, "Dying Dutch: Euthanasia Spreads across Europe," Newsweek, February 12, 2015, http://www.newsweek.com/2015/02/20/choosing-die-netherlands-euthanasia-debate-306223.html.
- 3 Lerner and Caplan, "Euthanasia in Belgium and the Netherlands," 1641.
- 4 I have borrowed "small beginnings" from Leo Alexander, the chief medical consultant at the Nuremberg War Crimes Trial, who noted that "Whatever proportion these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings." Leo Alexander, "Medical Science under Dictatorship," New England Journal of Medicine 241, no. 2 (1949): 44.

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Similarly, if a car could sense when its driver becomes agitated or enraged and respond—either by reminding the driver to calm down, alerting other drivers, or through internal controls—perhaps accidents could be prevented. But who should have access to such information? Law enforcement? Automotive insurance companies? People at-risk for suicide could be monitored by health professionals or trusted friends. But how can we ensure that their dignity will be honored against unwanted or unhelpful invasions of privacy? Should such monitoring be connected to our electronic health records? What about law enforcement's desire to assess criminal intent in a potential suspect or improve lie detection capabilities? As with other technologies, efforts to preserve individual privacy must be balanced against concerns for the common good, and it is not always clear where to draw the line.

Another important ethical issue raised by giving computers the ability to "see" our emotions is the potential for emotional control and manipulation. Advertisers are already on morally questionable ground here. Is it good to sell children on the "value" of a sugar-laden cereal? As a society we have decided that marketing tobacco to minors is wrong, but tobacco is bad for the health of every-

And it does not take much imagination to conjure more sinister versions of such emotional manipulation for those wanting to enrich political power, for example, or to groom suicide bombers or terrorists. Neuroscientists, psychiatrists, and psy-

As with other technologies, efforts to preserve individual privacy must be balanced against concerns for the common good, and it is not always clear where to draw the line.

one, all the time. What if advertisers could selectively place an advertisement for a delicious-yet-unhealthy treat—a treat which would not be harmful for most individuals if consumed in moderation—in front of an already-obese individual who is depressed after losing a job or a loved one and struggles with using food to assuage emotional pain? Integrating information gleaned from "big data" about our purchasing habits and the websites we visit with our emotional state gives advertisers a lot of subtle power.

chologists have confirmed that emotions sear memories into our brains. Thus the potential for emotional manipulation is a serious concern that should be monitored, and various consent mechanisms must be put in place allowing consumers to "opt-in" or, at the very least, "opt-out" of emotion-sensing technologies, which will likely be integrated into the "internet of things" as it develops.

Specifically regarding applications that assist people with disabilities, as a society we must wrestle with the question



of what is normative when it comes to human emotion. Clearly it is beneficial to help people with autism interpret human affect so that they can better navigate their social environment, but potentially harmful if they feel that they must artithe nature of emotional data should be part of that larger debate. For instance, should research participants, rather than researchers, own their emotional data, which empowers them to take action that promotes their own emotional, psycho-

Specifically regarding applications that assist people with disabilities, as a society we must wrestle with the question of what is normative when it comes to human emotion.

ficially adopt such affects themselves in order to be accepted or considered "normal." The question of what is "normal" human emotional-social interaction is not unlike other questions that emerge when evaluating assistive technologies and their capacity for human enhancement.

So what can and should be done to develop policies to ensure that these technologies serve rather than subvert human dignity and the common good?

Many of these questions are not easily addressed through legislation. The issues are complex and context-dependent, and the technology is rapidly changing. But as Congress debates the larger issues of privacy and consent in the context of the massive amounts of data available to both government and the private sector, specific consideration about

logical, and physical health. This would help preserve the autonomy and dignity of the research subject even as their data is used to further the field.

Congress should also continue to encourage (and fund) thoughtful, ethical reflection by scientists like Professor Picard who are trying to shape the direction and use of the technologies they are developing.

More concretely, there may well be a need for legislative protection from discrimination on the basis of emotional data, akin to the Genetic Information Nondiscrimination Act, to prevent employers, for example, from discriminating against someone for being depressed or for reacting negatively to instructions given by their boss. In addition, basic standards governing human-computer interactions should be developed, a process well

underway in the UK and in the EU more broadly.

Of course, this only scratches the surface. Technological advancement often outpaces the ability of Congress and various social institutions to establish the kinds of standards that ensure that what is developed promotes human dignity and flourishing. At The Center for Bioethics & Human Dignity, we hope that by providing opportunities for policymakers to consider and reflect on technological advances and their ethical and legal implications, they will be better positioned to respond thoughtfully.

- "Embrace," Empatica, https://www.empatica. com/product-embrace (accessed September 29, 2015).
- 2 "Not in Front of the Telly: Warning over 'Listening' TV," BBC News, February 9, 2015, http://www.bbc.com/news/technology-31296188 (accessed September 29, 2015); Claire Reilly, "Samsung Smart TVs Forcing Ads into Video Streaming Apps," CNET, February 10, 2015, http://www.cnet.com/news/samsung-smart-tvs-forcing-ads-into-video-streaming-apps/ (accessed September 29, 2015).

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.

SCIENCE, RESEARCH, AND LIMITS OF BIOETHICS

JENNIFER L. MCVEY, MDIV EVENT & EDUCATION MANAGER

In many of our past conferences, the Center has addressed some aspect of science, research, and technology as we explored a particular theme. However, we have never focused an entire conference on how bioethics relates to these specific areas. This summer that all changed, as we turned the collective attention of our 22nd annual summer conference in June to *Science, Research, and the Limits of Bioethics*.

Why this focus? Each year the Center is purposeful in choosing a theme for our conference that is relevant to what is occurring in academic bioethics, as well as issues that are on the horizon of our contemporary societal landscape at the intersection of medicine, science, technology, and our common humanity. We continue to witness the speed at which cutting-edge innovations in medical, scientific, and technological inquiry advance. As Nigel Cameron noted at this year's conference, we are only at the very beginning of the digital revolution and change is exponential. "We have seen nothing yet." While there are beneficial improvements transforming health and quality of life, these powerful advances do raise critical challenges in their implications for our individual and common humanity. We need to make ethical decisions today on both what we are for and what we would caution against, not waiting until potential uses of emerging technologies have moved so far down the road that we can no longer walk them back.

Dr. Michael J. Sleasman, the Center's managing director and research scholar, reminded us during his opening address "Framing the Discussion" that there are many ethical dimensions in the rapidly evolving arenas of research. He outlined several questions for our consideration: How might we reclaim science as a noble pursuit of knowledge that stands in awe and wonder of God's creation? Should medicine and technology function solely in the service of human flourishing, and if so, what are the implications? Does an ethics of non-power have something to offer us at the limits of bioethics?

Outstanding plenary speakers from across the spectrum of

scientific and technological research, law, philosophy, and theology helped us answer these questions directly or indirectly through explaining what was on the horizon in their area of research. Topics ranged from "three parent embryo" techniques to treat mitochondrial disease, to the limits of moral bio-enhancement; from considerations of privacy and availability of data in a post-genomic era, to explaining the science and potential of affective computing and social robots, as well as addressing the need for further dialogue regarding the "ethical uses of scientific advancement" between the scientific and religious communities. Robert P. George, JD, DPhil; Maureen Condic, PhD; Rosalind Picard, ScD; Jimmy Lin, MD, PhD, MHS; Fabrice Jotterand, PhD; Jennifer J. Wiseman, PhD; and Nigel M. de S. Cameron, PhD, MBA provided wonderful insights in their respective fields. Each speaker reminded us of the awe and wonder of God's masterful creation encountered in scientific inquiry, yet with the need to continue to raise ethical considerations.

In the final plenary session, Dr. Cameron summed up the conference theme well by focusing on where the future of technology is heading and how we might respond. As a society, we are poor at reflecting upon the future, but, as he noted, "only when we look ahead can we make proper decisions about what we should be doing now... today's choices will set the parameters."

Might we, as Dr. Sleasman suggested, learn something from an ethics of non-power? Might we choose to impose limits on our technological prowess, such that we would choose not to do everything that technology will make possible for us to do? According to Willem H. Vanderburg, "An ethics of freedom must be coupled with an ethics of non-power." Adhering to an ethics of non-power could possibly lead to a reduction of power, helping to keep things on a human scale. Vanderburg goes on to argue that

an ethics of non-power would help to restore a certain control over life and the possibility of a society in which personal relations can be meaningful. To undertake almost



Top: Nigel M. de S. Cameron, PhD, MBA, left: Jimmy Lin, MD, PhD, MHS, right: Maureen Condic, PhD, deliver their plenary addresses at CBHD's 2015 annual summer conference.

everything made possible by technique, as is presently the case, undermines all non-technical values and hence the benchmarks by which non-technical behavior receives its meaning and value. This in turn leads to a reinforcement of 'what can be done ought to be done.' An ethics of non-power would break this vicious circle which is so destructive of human culture. It would thus lead to action that does not contribute to the growing power of technique.'

Dr. Cameron reminded us that the ethical enterprise is primarily about choices and the solutions we need are integrative in character. He proposed embedding the ethics into the technology in a similar way that an ethical vision for medical practice is embedded in the Hippocratic Oath. We need more than a list of rules, such that "we must practice technology with respect for the dignity of the individual and we must embed the moral vision in the technology and in our assumptions about the way it's being applied." He went on to mention just a few considerations we need to keep before us, "What is the agenda for human dignity, for privacy, for freedom, for the individual which lies at the heart of our vision of the *Imago Dei*? . . . in a world in which these pervasive technologies have significance which grows by the day."

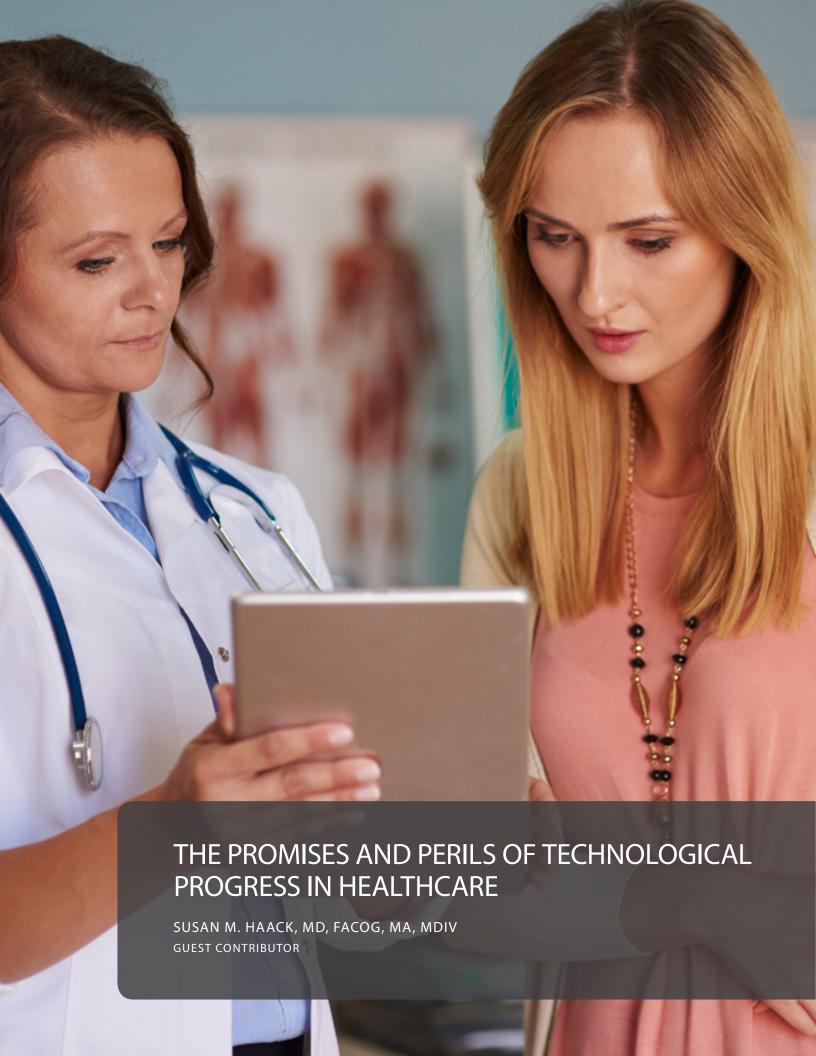
We are only at the cusp of the digital revolution. Will we be proactive in these early years and start to tackle these questions in light of our theological understanding and bioethical principles? If left alone, who will fill in the gap? This was a conference filled with significant insights for our medically, scientifically, and technologically advanced culture, but we just began to scratch the surface of some of the possible answers to these questions. There is, no doubt, further reflection and work to be done

The Center invites you to join us in furthering our Christian bioethical engagement through next summer's conference, *Transformations in Care*, June 16–18, 2016. This will be our 23rd summer conference, and we are looking forward to having the following individuals join us as plenary speakers: Robert D. Orr, MD, CM; Carol R. Taylor, RN, PhD; Kevin FitzGerald, SJ, PhD, PhD; Gary B. Ferngren, PhD; and Michael J. Balboni, PhD, ThM, MDiv. Topics will include the transformations in clinical care and clinical ethics, professionalism and spirituality, along with developments in precision medicine and changing paradigms of care. We look forward to seeing you there for a wonderful charitable dialogue, networking, and fellowship!

1 "Willem Vanderburg, "Technology and Responsibility: Think Globally, Act Locally, according to Jacques Ellul," in *Technology and Responsibility*, ed. Paul Durbin (Dordrecht, Holland: D. Reidel Publishing, 1987), 128



Top-right: Jennifer J. Wiseman, PhD, top-left: Michael Sleasman, PhD, bottom-right: Fabrice Jotterand, PhD, bottom-left: Robert P. George, JD, DPhil, deliver their plenary addresses at CBHD's 2015 annual summer conference.



echnological progress brought many changes in the field of medicine that promise significant improvements in life and health. But these promises are accompanied by perils that threaten medicine as we have known it. In the Spring 2015 issue of Dignitas, trends in women's healthcare were explored to examine the impact of the exponential expansion of information technology, the invasion of capitalistic market forces, and the encroachment of bureaucratic control. These forces, however, are not peculiar to women's health alone as they have encompassed all of healthcare. This article will consider the ways in which technological developments are collectively altering the face of medicine by disrupting its foundation the physician-patient relationship.

The Rise of Big Data & Technology in the Physician-Patient Relationship

Several recent developments have affected the character of medical care, one of which has been a subtle shift in the meaning of prevention. Historically, prevention entailed intervening in a process to prohibit a potential problem from progressing to a more serious condition. But now prevention seeks to impede the initiation of the process through the promises of technology, in particular, vaccinations and genomic medicine. While this is a positive development, it has the undesirable side effect of diminishing physician-patient contact and hindering the need for relationship.

A second notable shift has occurred as we have entered the era of "Big Data" in which data management is rapidly replacing patient management as a primary concern. Patient information is projected to expand exponentially in the near future; acquiring and entering that data will pose the first major challenge. The ability to meaningfully process all of the acquired data, to populate final forms with appropriate data, and to assist patients in personally processing the data will pose additional challenges. These tasks are far from complete. Only in 2011 was health IT or informatics instituted as a new medical specialty by the American Board of Medical Specialties

to address these issues.¹ Similarly, Northwestern University has developed a new collaborative venture between physicians and engineers for redesigning healthcare delivery systems.² These developments reflect the "systems orientation" that is occupying healthcare concerns and superseding the classic conception of healthcare as a profession.

With the reign of big data, the focus of care is shifting from the individual to population health, substantiated by the proliferation of algorithms and mandated guidelines based on current evidence. This will have tremendous implications for the fiduciary physician-patient relationship. Despite our desire to reimagine medicine as a purely scientific endeavor, we have forgotten that evidence-based medicine is transient and never completely objective, always vulnerable to new data—data that must be subject to interpretation. Moreover, human beings,

have moved to employed status, that relationship has been severed, effectively allowing for greater governmental control over the services physicians provide. Not only are physicians subject to governmental regulation to an extent that was not possible in the past, they now are forced to serve the employer, instead of the patient. The increasing transition of physicians to hospitalist status will only augment that outside control.

As technology continues its hegemony over all aspects of healthcare, personto-person contact will diminish further. Patient portals that lessen contact with clinical staff are already prevalent; patient kiosks eliminate the need for receptionists; and the use of mobile apps for monitoring medical conditions will continue to reduce the need for contact with medical personnel.⁴ Video exams and conferencing through the rise of telemedicine, developed for use in remote or

Moreover, human beings, in our uniqueness and variability, do not fit well into algorithm boxes; population statistics correspond poorly to any particular patient, for patients are persons, not mere data points or statistics."

in our uniqueness and variability, do not fit well into algorithm boxes; population statistics correspond poorly to any particular patient, for patients are persons, not mere data points or statistics. What has been rejected in this shift is the art of medicine—the role for intuitive knowledge and physician judgment in the care of patients.

Not only has the means of practice altered the doctor-patient relationship, but so has the form of practice. As a result of increasing costs of mandated technology, more and more physicians transition from private and group practices to hospital-employed status due to increasing costs of mandated technology.³ Until recently, governmental control of healthcare extended to hospitals but not to independent physicians who claimed and maintained the sanctity of the physician-patient relationship. But as physicians

rural areas, are predicted to move progressively into the mainstream of medical care due to anticipated physician shortages and demands for efficiency.⁵

Indeed, the stimulus for many of these technological changes is cost, efficiency, and compensation. The need for accurate billing and coding for reimbursement has driven development of the electronic health record (EHR); improved patient care is a secondary concern. The traditional concept of fee-for-service is likewise being supplanted by pay-forperformance, but performance is judged not by the care an individual receives but the health of a particular population, a criterion that is subject to the fickleness of patient compliance and behavior. This renders it an erroneous attempt to quantify quality.

The implications of increasing use of these technologies to the physician-patient relationship suggest that informed consent concerning the costs of care will pose a burgeoning ethical issue. In a market-based healthcare system, healthcare is a commodity and patients are consumers; it then follows that providers are vendors who must disclose costs. But interposing monetary considerations into the interaction will disrupt the traditional fiduciary physician-patient relationship, interfering with care and imperiling trust.

The Costs of Efficiency, Evidence, and the EHR?

There are great benefits to technological progress. Over the years the gains in knowledge of disease processes, effective methods of prevention, treatment modalities, and technological means of diagnosis and treatment have benefited innumerable persons, changing atti-

may indeed bring benefits, it must not be forgotten that mere data is not knowledge, and that greater information is not the same as greater understanding.

Depersonalization resulting from the focus on efficiency, evidence, and the EHR is one of the greatest adverse effects of the "new medicine." But this loss of the individual person goes deeper still. The subjective person is lost through elimination of the personal encounter: technological data gathering has replaced subjective physical findings as diagnoses are no longer based on touch, smell, sight, or even careful physical evaluation, but rather on metrics from diagnostic equipment and other quantifiable data. The shift is one away from a focus on the individual and toward a focus on increased data and population health. This shift exacerbates depersonalization as non-quantifiable factors such as personal context and idiosyncrasies are subordinated to data.

While such increased data may indeed bring benefits, it must not be forgotten that mere data is not knowledge, and that greater information is not the same as greater understanding."

tudes and expectations of life and health. Moreover, there has been a great expansion of accessible data about patients and disease processes that has aided the quest for improved health and life. Some other gains are, as yet, merely promises: gains in efficiency, cost control, and enhanced patient education.

But these technological gains must be weighed in the balance against personal and interpersonal losses, and these cumulative losses are significant. Not only is there improved access to data, but that data may also become a burden to physicians who are increasingly bombarded by patient information, a fact that will only accelerate as wearables and smartphones are incorporated into patient management. As more and more data is collected, information management will become an escalating issue for physicians. While such increased data

This triad of efficiency, evidence, and the EHR eliminates the narrative on which identities and relationships are built. In the EHR we have "faces" but no story, as personal narrative has no place in the template of the EHR. Instead, the focus becomes gathering data, not listening to stories. Yet, we are a storied people and our stories are central to human life and society—the basis of relationship. Additionally, these stories are performative, not only recounting events but creating identities and giving meaning to the circumstances of our lives. In this sense there is little meaning to the medical history generated in template boxes.

The Inertia of Efficiency, Evidence, and the EHR

As Sir William Osler presciently stated in 1892, "If it were not for the great variability among individuals, medicine might as well be a science as an art."6 What is lost in these technological gains, as Osler so wisely understood, is the art of medicine—that intuitive knowledge that grows out of relational understanding and personal experience—the kind of knowledge that cannot be quantified or objectified. The art of medicine has been replaced by the science of medicine; relational knowledge has been replaced by medical evidence. Alarmingly, it has been predicted that intuition and complex problem-solving skills may potentially be lost as they are replaced by clicking buttons linked to utilization data and reimbursement.7 Not only will we employ robots, we will become them.

What is lost, therefore, is care—that critical component in healing that is related not to what we do but to who we are as physicians. It is the component that grows out of relationship—out of the sharing of the story, looking into the eyes and the soul of another person, sharing in their joys and sorrow, their pain, suffering, and struggles. The role of the personal relationship in health and healing-the accountability that is so important to caring and curing, even if not wholly efficient—has been set aside, forgetting that the personal relationship is one of the most powerful healing tools of the physician.

Healthcare is a microcosm of technological changes impacting our culture, which is certainly in a tremendous state of transition. There is no doubt that remarkable gains in health and life have been realized through the expansion of knowledge and the progress and promise of technology. But these advancements have come at a great price: loss of the physician-patient relationship. The traditional role of physician as healer in a fiduciary relationship has been replaced by physician as provider of a commodity for the healthcare enterprise, and is now being converted to that of a physician-technician in a healthcare industry-a cog in a wheel. Additionally, the role of the patient has been objectified and reduced to data.

Depersonalization, loss of narrative, and the disintegration of the healing relationship are the tremendous costs of the industrialization of healthcare. Ideally, it would be desirable to retrieve the losses and restore the relational aspects of healthcare without relinquishing the gains, but, given the inertia of technological progress, that is unlikely to occur—or even be deemed necessary. As the wheels of progress continue to roll, only time will tell if the promised benefits outweigh the perilous losses.

- Juliana Bunim, "New Medical Specialty Aimed at Harnessing Data to Improve Patient Care," UCSF Educational Bulletin, December 2013, https://www.ucsf.edu/news/2013/12/110836/ clinical-informatics-subspecialty-launched-ucsf (accessed on June 3, 2015).
- 2 "Northwestern University Feinberg School of Medicine Center for Engineering and Health," Northwestern University, http://www.feinberg. northwestern.edu/sites/ipham/centers/engineering-health.html (accessed June 3. 2105).
- 3 "More U.S. Doctors Leaving Private Practice Due to Rising Costs and Technology Mandates," Accenture, October 31, 2012, https://newsroom. accenture.com/news/more-us-doctors-leavingprivate-practice-due-to-rising-costs-and-technology-mandates-accenture-report-finds.htm (accessed March 21, 2014).
- 4 Alex Rudansky, "Remote Patient Monitoring: 9 Promising Technologies," *InformationWeek*, July 30, 2013, http://www.informationweek.com/mobile/remote-patient-monitoring-9-promising-technologies/d/d-id/1110968?page_number=2 (accessed March 17, 2014).

- 5 Bruce Japsen, "ObamaCare, Doctor Shortage to Spur \$2 Billion Telehealth Market," Forbes, December 22, 2013, http://www.forbes.com/ sites/brucejapsen/2013/12/22/obamacaredoctor-shortage-to-spur-2-billion-telehealthmarket/ (accessed March 14, 2014).
- 6 Amalia Issa, "Personalized Medicine and the Practice of Medicine in the 21st Century," McGill Journal of Medicine 10, no. 1 (2007): 53-57.
- 7 Stuart Wolpert, "Is Technology Producing a Decline in Critical Thinking and Analysis?" UCLA Newsroom, January 7, 2009, http://newsroom.ucla.edu/releases/is-technology-producing-a-decline-79127 (accessed June 3, 2015).

The Center for Bioethics & Human Dignity presents
THE 23 RD ANNUAL SUMMER CONFERENCE

TRANSFORMATIONS IN CARE





Call for Proposals

Proposals are now being accepted for the upcoming CBHD summer conference. All abstracts must be submitted prior to **February 15, 2016 cbhd.org/cfp** for more information.

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:



Dan Wells, *Partials Sequence Series Partials* (Balzer & Bray, 2013). *Fragments* (Balzer & Bray, 2014). *Ruins* (Balzer & Bray, 2014).

Bioterrorism, Genetic Engineering, Human Enhancement, Neuroethics, Personhood, Posthuman, Research Ethics.

The trilogy follows Kira Walker, a young medic in a postapocalyptic U.S. Genetically enhanced humans known as Partials were developed by the U.S. government and the biotech firm ParaGen as a final military solution to the ongoing crises of global wars. After successfully completing their military campaigns, Partials returned to the U.S. in a failed attempt to integrate into society. Civil war broke out, and a genetically modified pathogen (the RM virus) was released, decimating human civilization. The remaining human population has been sequestered in East Meadow, New York as they seek to find a cure for RM—a virus that has prevented a human baby from surviving more than a few days in over 13 years. Kira Walker sets out to find a cure in a bold move that leads her to encounter the Partials directly, and learns a disturbing truth. The Partials are built with a biological time clock that causes them to expire after 20 years, and many of them are quickly approaching the deadline. Is there a solution that can benefit humans and Partials alike?

BIOETHICS AT THE BOX OFFICE:



Avengers: Age of Ultron (2015, PG-13 for intense sequences of sci-fi action, violence and destruction, and for some suggestive comments). Artificial Intelligence, Personhood, Robotics.



Interstellar (2014, PG-13 for some intense perilous action and brief strong language). *Embryo Cryopreservation*.



Chappie (2015, R for violence, language and brief nudity). *AI, Personhood, Robotics*.



Still Alice (2014, PG-13 f or mature thematic material, and brief language including a sexual reference). End of Life, Euthanasia, Mental Health

PRIMETIME BIOETHICS:



Chuck (2007–2012) Human Enhancement, Neuroethics, Cognitive Enhancement, Neuro-Enhancement.



Orphan Black (2013–) Biotechnology, Gene Patents, Human Cloning, Human Enhancement, Research Ethics, Stem Cell Research, Transhumanism/Posthumanism.



INTRODUCING OUR 2015 GBEI SCHOLAR

Since 2009, CBHD has hosted both rising and established international professionals and scholars who will further advance contextually sensitive Christian bioethical engagement globally through our Global Bioethics Education Initiative (GBEI).

Jennifer Castañeda, MD, PhD (2015 Recipient)



Dr. Castañeda was born in the Philippines, but has been residing in Poland for the past 20 years, where she finished medical studies in the Collegium Medicum, Jagiellonian University in Cracow, and did her PhD in the field of oncogenetics in the Pomeranian Medical University of Szczecin. She completed the specialization program in Clinical

Genetics in the Department of Medical Genetics of the Institute of Mother and Child in Warsaw, where she currently combines work in the Genetic Counseling Unit of the Department with research. Dr. Castañeda's interest in bioethics has increased over her years of direct contact with patients in genetic counselling and in the context of emerging technological possibilities in genetics, especially in prenatal diagnostics. She finished a two-year postgraduate program: "Ethics in Medical Practice in Perinatology and Pediatrics," a joint project of the Institute of Mother and Child and the *Paris-Est Marné-la-Valée* University, with a paper entitled "The Ethical Requisite of Non-Directive Genetic Counselling in Prenatal Diagnostics." She presented this work as a parallel paper during the Center's annual conference.

Her main areas of interest in bioethics are ethics in genetics and genetic counseling, prenatal diagnostics, and emerging genetic technology. Clinical genetics is a relatively new field of specialization in Poland, and ethical reflection among specialists is still at an incipient stage. As a GBEI scholar, Dr. Castañeda spent the summer utilizing the resources of the Center's Research Library to explore literature relevant to her areas of interest. She plans to continue promoting and contributing to profound ethical discussions among specialists in Poland.

For more information about GBEI, visit www.cbhd.org/gbei or contact Jennifer McVey, MDiv, CBHD Event & Education Manager at jmcvey@cbhd.org for more information.

TOP BIOETHICS NEWS STORIES: JUNE - AUGUST

BY HEATHER ZEIGER, MS, MA RESEARCH ANALYST

"U.S. Top Court Backs Obamacare, President Says It's Here to Stay" by Lawrence Hurley, *Reuters*, June 25, 2015

Roberts was joined by fellow conservative Justice Anthony Kennedy and the court's four liberal members in a ruling that may ensure Obamacare becomes a lasting element of the nation's social programs. The ruling means the current system will remain in place, with subsidies available nationwide. If the challengers had won, at least 6.4 million people in at least 34 states would have lost subsidies worth an average of \$272 per month. (http://tinyurl.com/oamllrc)

Two court cases this past summer upheld the regulations laid out in the Affordable Care Act. A Supreme Court case ruled in favor of keeping nationwide tax subsidies. Additionally, lower courts did not rule in favor of The Little Sisters of the Poor, an order of Catholic nuns, who objected to the opt-out provision for contraception coverage which provides such coverage to women who want contraception even if the religious organization they work for has opted-out of such coverage.

"Final Step in Sugar-to-Morphine Conversion Deciphered" by Robert F. Service, *Science*, June 25, 2015

The last piece of the poppy puzzle is now in hand: Plant geneticists have isolated the gene in the plant that carries out the last unknown step in converting glucose and other simple compounds into codeine, morphine, and a wide variety of other medicines. The discovery sets the stage for splicing the full suite of genes needed to produce these drugs into yeast, which could then produce safer and cheaper versions. (http://tinyurl.com/q6aoyjj)

In a breakthrough in synthetic biology research, scientists are now able to reproduce all of the steps that the poppy plant takes to make morphine. Earlier this year researchers published the steps to make the first half of the morphine synthetic pathway in yeast, and another research group had already reported the second half of the pathway. This article reports the final step linking the two pathways. The hope is to tailor opioid drug dosages as well as possibly make opioid pain killers that are less addictive. However, there is also concern that some people may try to make their own home-brewed versions of synthetic morphine.

"Give Children under 12 the Right to Die, Say Dutch Paediatricians" by Justin Huggler, *The Telegraph*, June 19, 2015

Doctors in the Netherlands have called for terminally ill young children to be given the right to die. The Netherlands is one of few countries in the world where euthanasia is permitted for terminally ill patients. But the Dutch Paediatric Association said that existing laws do not go far enough and called for an age limit to be scrapped. (http://tinyurl.com/pmh6ted)

"Physically Healthy 24-Year-Old Granted Right to Die in Belgium" by Eilish O'Gara, *Newsweek*, June 29, 2015

Doctors in Belgium are granting a 24-year-old woman who is suffering from depression but is otherwise healthy the right to die as she qualifies for euthanasia under the Belgian law, even though she does not have a terminal or life-threatening illness. (http://tinyurl.com/nuw5veq)

In countries where physician-assisted suicide is legal, the law continues to expand who qualifies for euthanasia. In Belgium, a young woman who did not have a terminal condition was allowed to undergo physician-assisted suicide because she was suffering from depression. In the Netherlands, children over twelve years old can ask to die, but some doctors believe this age is arbitrary, calling for a removal of the age restriction. A poignant article in *The New Yorker* by Rachel Aviv (http://tinyurl.com/ngxws4n), published in June, suggested that there are larger cultural issues in countries like Belgium that spur the increase in those wishing to die to relieve their psychological distress.

"California Aid-in-Dying Bill Shelved for the Year" by Patrick McGreevy, *Los Angeles Times*, July 7, 2015

Stalled by the deep personal beliefs of many lawmakers, a proposal that would allow physicians to prescribe lethal doses of drugs to terminally ill patients in California was sidelined Tuesday. The measure passed the state Senate last month. But on Tuesday, the authors concluded that it did not have enough support to pass the Assembly Health Committee and withdrew it from a scheduled hearing. (http://tinyurl.com/nq9c5j3)

In July, the California Aid-in-Dying bill died in committee. However, in September this bill was back on the floor for vote. The bill subsequently passed the California legislature and was signed by Governor Jerry Brown. Right-to-die legislation has been picking up steam across the United States in recent months, including a bill that is being debated in New York.

"Tiny Brain Clumps Offer New Clues into the Cause of Autism" by Mike Orcutt, MIT Technology Review, July 16, 2015

news update

By turning stem cells taken from autistic patients into tiny "organoids" that closely resemble the brains of human embryos, researchers have gleaned potentially valuable insights into what may go wrong during brain development in people with autism. (http://tinyurl.com/pdkj758)

"The Boom in Mini Stomachs, Brains, Breasts, Kidneys and More" by Cassandra Willyard, *Nature*, July 29, 2015

In 2008, researchers in Japan reported that they had prompted embryonic stem cells from mice and humans to form layered balls reminiscent of a cerebral cortex. Since then, efforts to grow stem cells into rudimentary organs have taken off. (http://tinyurl.com/ns4c3vs)

"Miniature Brain-in-a-dish Could Help Advance Alzheimer's Research" by Michelle Starr, CNET, August 19, 2015

The brain was created from adult human skin cells, and grew to about the development of the brain of a five-month-old foetus, containing around 99 percent of the genes present in the foetal brain. This will allow the testing of experimental drugs, unlike tests that are performed on rat or mouse brains. (http://tinyurl.com/oevuhxt)

Organoids, tissues grown in the lab that mimic the structure and function of organs, are an area of research that has garnered much interest and controversy. These organoids have been used to test drugs, such as using liver organoids to test drug uptake, or model diseases, such as Alzheimer's. Originally, many of the organoids were made from embryonic stem cells, but recent studies show that some of these organoids, include those made of neural cells, can be made from induced pluripotent stem cells.

"Successful Ebola Vaccine Provides 100% Protection in Trial" by Ewen Callaway, *Nature*, July 31, 2015

An experimental Ebola vaccine seems

to confer total protection against infection in patients at high risk of contracting the virus, according to preliminary results of a trial in Guinea that were announced today and published in *The Lancet*. They are the first evidence of any kind that a vaccine protects humans from Ebola infection. (http://tinyurl.com/nujjm6a)

Over 11,300 people have died and over 28,000 have been infected by Ebola since the onset of the outbreak early in 2014. Researchers have been scrambling to find a cure or vaccine. This past July, researchers from Canada found that a vaccine. rVSV-ZEBOV, seems to be effective in preventing Ebola infection. Because the study involved a small number of participants, further research is needed to confirm if it is truly 100% effective and for how long, but preliminary results showed none of the subjects in one ring of the study (meaning all of the close contacts of an individual who have contracted the disease) contracted Ebola.

"The Planned Parenthood Controversy over Aborted Fetus Body Parts, Explained" by Sarah Kliff, *Vox*, August 4, 2015

Five sting videos from an anti-abortion group, released throughout July, show Planned Parenthood executives and other workers discussing how the organization provides fetal organs and tissues to researchers. The videos led to a new, Congressional investigation of Planned Parenthood—a Senate vote to defund Planned Parenthood, which ultimately failed on Monday. The videos also open a debate that split bioethicists decades ago: Is it ethical to use the remains of aborted fetuses for medical research? (http://tinyurl.com/q3199q3)

As of this writing, there have been ten videos released, five this past summer, by the Center for Medical Progress (CMP). Representatives from the CMP posed as buyers interested in fetal tissue from abortions and covertly recorded

conversations in which Planned Parenthood and StemExpress appear to have admitted that Planned Parenthood is selling fetal tissue, changing their abortion procedures to keep certain body parts intact, conducting late-term abortions, and conducting the procedure in unsanitary conditions. Thus far, several congressional hearings are underway and the House has passed a bill to stop federal funding for Planned Parenthood for a year.

"China's Black Market for Organ Donations" by Martin Patience, *BBC*, August 11, 2015

China suffers from a huge organ shortage. For years it harvested the organs of executed prisoners to help meet demand. Following international condemnation, Beijing says it ended the practice at the start of this year—although officials admit it will be tough to ensure compliance. Now the government says it will only rely on public donations. (http://tinyurl.com/pys5f7o)

The Epoch Times has been reporting on the use of Chinese prisoners of conscience as sources of organs along with those from executed prisoners for several years. Additionally, other reports have surfaced that there is a large black market industry in China for organs. And, in August, a Canadian documentary called Human Harvest: China's Organ Trafficking was released, exposing China's history of illegal organ trafficking. China has a large organ shortage, due in part to the belief that the body must be buried intact. China agreed to stop procuring organs from prisoners at the beginning of the year, but rights groups believe this practice continues and are calling on the UN to intervene (http://tinyurl.com/orlvjla).

updates & activities

"BARE LIFE, MORAL LIFE" SYMPOSIUM

Shortly after the Center's annual summer conference in late June, CBHD co-sponsored a symposium in Madrid, Spain. The multiday event was hosted by the Albert Gnaegi Center for Health Care Ethics, Saint Louis University and co-sponsored by both CBHD and the Notre Dame Center for Ethics and Culture. Held on the Madrid campus of Saint Louis University, the event gathered scholars from Europe, Israel, and the U.S. across a wide-spectrum of disciplines and religious commitments to explore fundamental questions related to reductionisms of human life through the discussion of such topics as genetic determinism, neuro-essentialism, disability, and medical futility at the end of

STAFF TRANSITIONS

NEW STAFF

CBHD welcomed several new staff over the fall:

Hope Prinkey, MA

(Full-Time Communications Manager & Executive Assistant)

Andrew Kaake

(Part-Time Research Assistant)

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/thecbhd



YouTube at youtube.com/bioethicscenter



The Christian BioWiki christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD

- Was interviewed by "Karl and June Morning" (Moody radio) on three different occasions, discussing: the German grandmother of quadruplets, mitochondrial diseases, and auditory brainstem implants.
- In June, guest-lectured in the Intensive Bioethics Summer Institute.
- On July 20, filed a letter with Michael Sleasman on behalf of CBHD with the Presidential Commission for the Study of Bioethical issues emphasizing the need to welcome religious values and perspectives in the public square.
- In August, interviewed on "Let's Talk with Mark Elfstrand" (WYLL Chicago) on neural drug implants.
- In last half of August, conducted a two-week adult forum at College Church on the subject of fetal tissue research in the wake of the Planned Parenthood videos.
- Wrote "Biohazards" columns for Salvo magazine on head transplants (Summer 2015), and gene editing of embryos (Fall 2015)

MICHAEL SLEASMAN, PHD

- The May/June issue of Relevant magazine included quotes from an interview with Michael in the article, "The Science of Life."
- In June, taught the Advanced Bioethics Summer Institute, and guest-lectured in several other bioethics courses leading up to the Center's annual summer conference.
- In June, gave the opening address "Framing the Discussion: Science, Research, and the Limits of Bioethics" at CBHD's 22nd annual summer conference.
- In late June, presented a response to Adam Green at the "Bare Life and Moral Life" symposium in Madrid, Spain.
- In July, co-authored an article entitled, "What's Wrong with Designer Genes," on DesiringGod.org with Paige about CRISPR and Chinese researchers involved in gene editing of human embryos.

HEATHER ZEIGER, MS, MA

- Presented the paper "Big Data and the Scientific Method" at the CBHD annual conference
- Published "On-Call Ethics Consultants in Human-Subject Research" at bioethics.com in May.

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.

Articles of Note:

Easton, Douglas, Paul Pharoah, Antonis Antoniou, Marc Tischkowitz et al. "Gene-Panel Sequencing and the Prediction of Breast-Cancer Risk." New England Journal of Medicine 372, no. 23 (2015): 2243-2257.

Howard, David. "Adverse Effects of Prohibiting Narrow Provider Networks." New England Journal of Medicine 371, no. 7 (2014): 591-593.

Jacobs, Douglas, and Benjamin Sommers. "Using Drugs to Discriminate: Adverse Selection in the Insurance Marketplace." New England Journal of Medicine 372, no. 5 (2015): 399-402.

Jameson, J. Larry, and Dan Lango. "Precision Medicine: Personalized, Problematic, and Promising." New England Journal of Medicine 372, no. 23 (2015): 2229-2234.

Janssen, William M. "A 'Duty' to Continue Selling Medicines." American Journal of Law & Medicine 40, no. 4 (2014): 330-392.

Johnson, Sandra. "Death, State by State." Hastings Center Report 44, no. 3 (2014): 9-10.

Kahn, Jeremy. "Virtual Visits: Confronting the Challenges of Telemedicine." *New England Journal of Medicine* 372, no. 18 (2015): 1684-1685.

Knoche, Jonathan. "Health Concerns and Ethical Considerations Regarding International Surrogacy." *International Journal of Gynecology and Obstetrics* 126, no. 2 (2014): 283-186.

Lander, Eric. "Brave New Genome." New England Journal of Medicine 373, no. 1 (2015): 5-8.

Lee, Patrick, Christopher Tollefsen, and Robert George. "The Ontological Status of Embryos: A Reply to Jason Morris." *Journal of Medicine and Philosophy* 39, no. 5 (2014): 483-504.

Matlack, Samuel. "Confronting the Technological Society." *The New Atlantis: A Journal of Technology & Society* 43 (Summer/Fall 2014): 45-64.

**Meilaender, Gilbert. "No to Infant Euthanasia." *The Journal of Thoracic and Cardiovascular Surgery* 149, no. 2 (2015): 533-534.

COMING SOON: SPECIAL ISSUE ON POLST