Ethics For the second s



Vol 25:3 FALL 2009 ISSN 0266-688X

EDITOR: C. Ben Mitchell

Union University, Jackson, Tennessee, USA bmitchell@uu.edu

FOUNDING EDITOR: Nigel M. de S. Cameron nigelcameron@aol.com

ASSOCIATE EDITOR: Henk Jochemsen

Prof Dr. G. A. Lindeboom Instituut, Ede, The Netherlands lindinst@che.nl

MANAGING EDITOR: Carol Marlin

The Bioethics Press, Ltd info@bioethicspress.com

EDITORIAL ASSISTANT: David C. Cramer david.c.cramer@gmail.com

BOOK REVIEW EDITOR: Sharon F. Billon

sbillon@sbcglobal.net

EDITORIAL ADVISORY BOARD:

Francis J. Beckwith Baylor University, Waco, Texas, USA

Don Buckley Spanish Trail Family Medical Center, Pensacola, Florida, USA

George L. Chalmers Honorary Physician, Glasgow, Scotland

E. David Cook Wheaton College, Wheaton, Illinois, USA

Scott E. Daniels Virginia Commonwealth University, Richmond, Virginia, USA

Andrew Fergusson Christian Medical Fellowship, London, UK

David Fletcher Wheaton College, Wheaton, Illinois, USA

Nick Hallam Consultant Virologist, Edinburgh, Scotland

C. Christopher Hook Mayo Clinic, Rochester, Minnesota, USA

Tom Kennedy Berry College, Mount Berry, Georgia, USA

John F. Kilner Trinity International University, Deerfield, Illinois, USA

Jennifer Lahl Center for Bioethics and Culture, San Ramon, California, USA

Calum MacKellar European Bioethical Research, Edinburgh, Scotland

Donal P. O'Mathuna Dublin City University, Dublin, Ireland

Robert D. Orr Department of Clinical Ethics, FAHC, Burlington, Vermont, USA Barbara Parfitt Glasgow Caledonian University, Scotland

John Peppin Center for Bioethics, Pain Management & Medicine, Des Moines, Iowa, USA

Scott Rae Talbot Theological Seminary, La Mirada, California, USA

Peter Saunders Christian Medical Fellowship, London, England

Joyce Shelton Trinity International University, Deerfield, Illinois, USA

Robert Song University of Durham, England

Agneta Sutton Centre for Bioethics and Public Policy, London, England

Allen Verhey Duke University Divinity School, Durham, North Carolina, USA

Gordon Wenham Trinity Theological College, Bristol, England

Stephen Williams Union Theological College, Belfast, Ireland

Donald K. Wood University of Illinois College of Medicine at Chicago, Illinois, USA

PUBLISHER

The Bioethics Press, Limited 2421 W. Pratt Blvd. #420 Chicago, IL 60645-4666 USA Phone/Fax: +1.530.482.3248 info@bioethicspress.com www.ethicsandmedicine.com

SUBSCRIPTIONS

Ethics & Medicine is published three times a year by The Bioethics Press, Ltd. Subscriptions may be obtained and address changes can be made with the publisher at the address above.

RATES FOR 2009

INDIVIDUAL			
1 YEAR	\$52	€34	£26
2 YEARS	\$94	€63	£49
3 YEARS	\$139	€92	£72
INSTITUTION			
1 YEAR -	\$112	€73	£59
2 YEARS -	\$213	€137	£106
3 YEARS -	\$274	€177	£139

The mission of *Ethics & Medicine* is to reassert the Hippocratic consensus in medicine as seen through the lens of the Judeo-Christian tradition on the conviction that only a robust medical professionalism is able to withstand the challenges of emerging biotechnologies and their clinical applications.

Ethics & Medicine: An International Journal of Bioethics ISSN: 0266-688X © 2008 by The Bioethics Press, Limited



An International Journal of Bioethics

CONTENTS

- 131 CONTRIBUTORS
- 133 EDITORIAL ON HUMAN BIOENHANCEMENTS C. Ben Mitchell, PhD
- 135 GUEST COMMENTARY THINK IT'S GREED? IT MIGHT BE PDMD: A PUBLIC SERVICE ANNOUNCEMENT Marc E. Keller and Bert M. Bieler, MD
- 139 GREY MATTERS FACEBOOK AND FUSIFORM GYRUS William P. Cheshire, Jr., MD
- 145 CLINICAL ETHICS DILEMMAS CONTINUING "FUTILE" ICU SUPPORT AT RELATIVE'S INSISTENCE Robert D. Orr, MD, CM
- 149 TRACKING CHROMOSOMES, CASTRATING DWARVES: UNINFORMED CONSENT AND EUGENIC RESEARCH Paul A. Lombardo, PhD, JD
- **165** THE FUTURE OF THE HUMAN SPECIES Brent Waters, DPhil
- 177 "GIVE ME CHILDREN OR I'LL DIE!" IS IT TIME TO CONSIDER THE UTERUS AS A NON-VITAL ORGAN TRANSPLANT? Gregory W. Rutecki, MD
- 187 BOOK REVIEWS

INSTRUCTIONS TO CONTRIBUTORS

Articles for publication are welcomed by the editors. Ethics & Medicine is peer reviewed. Material submitted may be returned for revisions. Articles should be submitted in both electronic and hardcopy format. Authors should supply removable cover sheet with the title of the article and author's name. No other personal attribution should appear at the head of each article. Contributors will be notified as soon as possible of editorial decision, though the process can take some time. Contributors are asked to follow the pattern published material for length, subheading, and so forth. Different referencing conventions are acceptable provided consistency is maintained throughout the paper. An outline C.V. should accompany each contribution.

MANUSCRIPTS FOR PUBLICATION SHOULD BE SENT TO

C. Ben Mitchell, Ph.D., Editor Ethics & Medicine Union University 1050 Union University Drive Jackson, Tennessee 38305 USA Phone: +1-731-661-5915 Fax: +1-731-661-5118 bmitchell@uu.edu

ADVERTISING AND SALES

Ethics & Medicine is pleased to accept advertising; contact The Bioethics Press, Ltd. where current rates are available. No editorial endorsement is implied in the advertising.

COPYRIGHT

Copyright for articles and book reviews will be retained by the author(s). If authors or reviewers wish to republish all or part of their contribution elsewhere within twelve months of publication in Ethics & Medicine, permission should be sought from the editor and mention made of its publication in the journal. Publication in Ethics & Medicine assumes permission to publish in electronic format. Permission to make multiple copies must be sought from the publisher.

ABSTRACTS AND INDEXING

RELIGIOUS AND THEOLOGICAL ABSTRACTS 121 South College Street Myerstown, PA 17076 USA

THE PHILOSOPHER'S INDEX c/o The Philosopher's Information Center 1616 East Wooster Street Bowling Green, Ohio 43402 USA Phone: +1-417-353-8830 Fax: +1-419-353-8820 info@philinfo.org www.philinfo.org

PROQUEST INFORMATION AND LEARNING 789 E. Eisenhower Parkway PO Box 1346 Ann Arbor, MI 48106-1346 USA Phone: 1.734.761.4700 X 3333 Fax: 1.734.997.4229 info@il.proquest.com www.il.proquest.com

Ethics & Medicine is published in association with:

THE CENTER FOR BIOETHICS AND HUMAN DIGNITY 2065 Half Day Road Bannockburn, Illinois 60015 USA Phone: +1-847-317-8180 Fax: +1-847-317-8101 info@cbhd.org www.cbhd.org

PROF. DR. G. A. LINDEBOOM INSTITUUT Postbus 224, NL6710 BE Ede, The Netherlands Phone: +31-318-69633 Fax: +31-318-696334 lindinst@che.nl www.lindeboominstituut.nl

LAYOUT AND TYPESETTING

Original design by Wayne Kijanowski Trinity International University

Typesetting by Andrew DeSelm andrewdeselm@gmail.com

PRINTING

Excel Print Media Michelle FM Loke michelle@excelprintmedia.com

CONTRIBUTORS

Bert M. Bieler, MD, earned his undergraduate degree from the University of Pennsylvania and his M.D. from Temple University, completing his residency in Family Medicine at Brown University. He is a recipient of the Dr. Joseph Nathan Grossman Prize in Family Medicine (2002) and a member of the American Academy of Family Physicians. He is a Family Practice Physician in Newark, Delaware, USA.

William P. Cheshire, Jr., MD, is Professor of Neurology at Mayo Clinic in Jacksonville, Florida, and Consultant in Neuroethics at the Center for Bioethics and Human Dignity. The views expressed herein are his own and do not necessarily reflect the positions of Mayo Clinic or Mayo Foundation, USA.

Marc E. Keller earned a B.A. in Medical Anthropology and a Master's degree in Bioethics & Urban Studies, both from the University of Pennsylvania. He has been a journalist in Philadelphia and San Diego and has published numerous pieces of short fiction. His work experience includes stints in Penn's Department of Psychiatry, the Health Federation of Philadelphia, and in pharmaceutical marketing research. He lives and works in Philadelphia, Pennsylvania, USA.

Paul A. Lombardo, PhD, JD, is Professor of Law at the Center for Law, Health and Society at Georgia State University's College of Law. He has lectured at numerous colleges and universities in the US and Canada and in 2004 was a Visiting Professor at Aga Khan University in Karachi, Pakistan. He has previously served on the faculty of the Schools of Law and Medicine at the University of Virginia, where he directed the Center for Mental Health Law at the Institute of Law, Psychiatry and Public Policy and the Program in Law and Medicine at the Center for Biomedical Ethics, USA.

Robert D. Orr, MD, CM, is Professor of Bioethics at Loma Linda University and Director of Clinical Ethics at Loma Linda University Medical Center, Loma Linda, California. He is also Professor of Bioethics at the Graduate College, Union University in Schenectady, New York, Consultant in Clinical Ethics, Center for Bioethics and Human Dignity, and Professor of Bioethics at Trinity International University, Deerfield, Illinois, USA.

Gregory W. Rutecki, MD, is Professor of Internal Medicine in the Division of Nephrology at the University of Southern Alabama College of Medicine in Mobile, Alabama, USA.

Brent Waters, DPhil, is the Stead Professor of Christian Social Ethics, and Director of the Stead Center for Ethics and Values at Garrett-Evangelical Theological Seminary, Evanston, Illinois, USA.

What is up ahead?



- Keeping pace with important developments in the field of bioethics and public policy
- Analysis and application of biotechnology

We are here to help.

www.bioethicspress.com

EDITORIAL

ON HUMAN BIOENHANCEMENTS

C. BEN MITCHELL, PHD

Human beings are obsessive innovators. *Homo sapiens* (knower) is by nature *Homo faber* (fabricator). Life without what philosopher Michael Novak has called 'the fire of invention' doubtless would be nasty, bloody, and brutish. Since biomedicine and biotechnology are two spheres where innovation is especially rewarded, it is no surprise that we stand on the threshold of the development of human biological enhancements.

We have attempted enhancement in many different ways, especially for our children: diet, exercise, music lessons, tutoring, athletics, and even cosmetic surgery. But for many people, there is something deeply troubling about bioenhancement technologies, whether they are reproductive, genetic, neurological, or prosthetic technologies. By 'bioenhancement' I mean that these technologies magnify human biological function *beyond species typical norms*.

Therapy versus Enhancement

Ethical reflection about these technologies requires that we make some distinction between therapy and enhancement. Therapies would include medical interventions that restore human functioning to species typical norms. So, kidney dialysis, lasik surgery, and angioplasty are therapies; but adding twenty IQ points to someone who already has a normal IQ would be an enhancement.

Both proponents and critics of bioenhancements have argued, however, that the line between therapy and enhancement is vanishingly thin. But it may not be as faint as some imagine. I was once in a conversation with a prominent fertility specialist who used preimplantation genetic diagnosis (PGD) to help couples have children without genetically-linked diseases. He told of a couple who came to him requesting that he assist them to have a child who would have perfect musical pitch. Since they were both orchestral musicians and because there may be a gene associated with aural acuity, they wanted a child to follow in their footsteps. He steadfastly refused. He said he could not say exactly why, but his intuition was that it was unethical. Just because we cannot always make finely tuned distinctions does not mean distinctions are impossible. Just because a bright line may not be drawn does not mean no line can be drawn.

We should resist human bioenhancement technologies at least for a number of reasons, including their inconsistency with the goals of medicine, their violation of the principle of justice, and their complicity with cultural stereotypes.

The Goals of Medicine

Human bioenhancements should be resisted, first, because they are inconsistent with the goals of medicine. The first goal of medicine is healing for the "patient's good." The principle of medical beneficence assumes either that a patient is enjoying homeostasis, and the role of the physician is to assist him or her to maintain or optimize normal functioning, or that a patient is suffering diminished capacity due to illness or disease, and medicine's role is to help restore as much normal function as possible. This aim of medicine is as old as the Hippocratic Oath. Whether we call it healing, wellness, or shalom, the goals of medicine are restorative and preventive.

Only recently have we begun to imagine medicine as a way to move beyond therapy. Medicine is seen less today as a profession and more as a commercial service. Physicians are not seen as professionals, they are merely body plumbers (no offense to plumbers). Consumerism thrives on giving the customer what he or she desires. While human bioenhancements are not consistent with the traditional aims of medicine, they are very consistent with desire-satisfaction where, as ethicist Carl Elliot so elegantly puts it, "American medicine meets the American dream." So now consumers employ doctors to make them "better than well."

The Principle of Justice

Another reason to reject bioenhancements is the principle of justice. Having recently witnessed the Olympic games in Beijing, and heard the hoopla over doping in the Tour de France, we should be sensitive to the ways even the hint of enhancements threaten the fairness of competition. By analogy, technologically enhanced IQ, speed, dexterity, hearing, musical ability, etc., would create injustices, at least in cultures where those qualities are valued. The enhanced individual potentially would have unfair advantage over others in employment or life, just as blood-doping and steroids created advantages over other athletes. Furthermore, enhancing already wealthy Westerners while so many individuals lack access to basic therapeutic medicine, seems patently unjust. In fact, most of the world's people do not want enhancements, they want basic healthcare.

The Problem of Cultural Complicity

Georgetown philosopher Margaret Little has argued that enhancements contribute to cultural differences that lead to personal dissatisfaction and even stigmatization. For instance, Western culture's valorization of the Barbie-doll figure leads to body dysmorphic disorder among American teenage girls. Some Asian girls are having cosmetic surgery to make their eyes rounder and less almond-shaped in order to fit the Western ideal. For a culture to legitimize enhancement is to be complicit in these pathologies. And this would seem especially heinous after spending untold social capital, tax-dollars, and educational resources trying to convince our culture that persons with disabilities should be respected equally as those without them.

Human bioenhancements seem to be a very dubious investment of time and other scarce resources. Only those already well-off can afford the luxury of enhancements. The sick need a physician. **E&M**

VOL. 25:3 FALL 2009

GUEST COMMENTARY

THINK IT'S GREED? IT MIGHT BE PDMD: A PUBLIC SERVICE ANNOUNCEMENT

MARC E. KELLER AND BERT M. BIELER, MD

Clinical research scandals. Drug company bribes. You've probably heard horror stories about doctors and their industry ties. You may even criticize these doctors as "bad" or "unethical." But did you know they are actually suffering from a treatable disorder? Profit Driven Medicine Disorder (PDMD) affects thousands of doctors in all specialties. Fortunately, the Coalition to Raise Awareness of PDMD (CRAP) is committed to getting doctors the help they need.

All doctors deserve to be well-compensated for their skills and dedication. However, physicians and researchers with PDMD feel an overwhelming urge for profit and prestige that improperly influences their research and patient care. But it's not their fault. Health professionals with PDMD can't control their behaviors and decisions. And due to widespread lack of understanding and stigma, most doctors with PDMD suffer in silence and secrecy.

Doctors with PDMD:

- · regularly accept money or expensive gifts from pharmaceutical companies
- serve as paid speakers for specific drugs and treatments
- · conduct Big Pharma-funded clinical research
- manipulate, suppress, or fabricate clinical trial data to help companies sell more drugs
- put their names on ghostwritten papers or sell their raw data to commercial organizations

Why do Doctors get PDMD?

No one knows for sure why some doctors get PDMD, while others don't. Like other mental illnesses, PDMD reflects biological dysfunctions in the brain. Scientists believe that family background and life experiences are also involved, and they are beginning to discover certain genes that make doctors vulnerable to PDMD.

Of course, we cannot forget about stress. When doctors do not feel like they are receiving the level of respect or compensation owed to them, it may result in PDMD. Life events such as purchasing a home or automobile, or getting married and having children, can also trigger symptoms in individuals predisposed to PDMD.

How Does PDMD Affect Your Profession?

Profit Driven Medicine Disorder affects all doctors and researchers—even those who are not specifically suffering from the disorder. According to a national survey conducted by CRAP, seven out of ten doctors agreed that the disorder has a negative impact on their profession. Each time an instance of PDMD is reported in the news, the public loses trust in the medical field. PDMD can also cause ineffective and unsafe drugs to be rushed to the market, or kept on the market, in the interest of industry profits.

Is There Help?

There is hope for people with PDMD. In fact, most doctors who seek treatment for PDMD see significant improvement. The first step is to talk to a mental health specialist about symptoms. Once PDMD is diagnosed, there are various treatment options. Some patients have found relief through cognitive-behavioral therapy (CBT), which helps sufferers understand how PDMD influences their thought patterns. CBT can also help patients resist temptations, such as invitations for industry-sponsored drug dinners, or research grant offers.

Prescription medications have also been shown to help relieve PDMD. Of course, these can only be prescribed by a licensed practitioner. Keep in mind that a medicine may take a few weeks to start working, so doctors undergoing treatment for PDMD should remain patient.

Many doctors find that treatments are most effective when they have a network of trusted people to keep them on track, especially if they feel their symptoms returning. Local PDMD support groups are a great way for sufferers to connect with each other and offer assistance. These support groups already exist in many cities across the country, and with the help of CRAP, more are popping up all the time.

It is important to remember that there is no single "right" treatment. What works for one person may or may not be the best choice for someone else. Ask your health care provider to explain why a particular type of treatment is being recommended, what other options are available, and what you need to do to fully participate in your recovery. And don't lose hope: tremendous advances in the understanding and treatment of this debilitating illness are emerging.

PDMD Stories

"I would analyze my data, over and over, until I found something positive to say about an ineffective and expensive drug. I knew it didn't make any sense, but I was terrified of losing my funding and my perks. I thought I would wind up poor and on the streets if I didn't grab every dollar offered to me by the drug companies. Sometimes I felt so anxious that my hand would tremble when I endorsed the honoraria checks. I thought I was going crazy—until I found out I had PDMD and started treatment." —David, anesthesiologist

"At first I was too embarrassed to get help, but I'm glad I did. I was so relieved to put a name to my problem and discover that there are other people like me. I took the medicine my doctor gave me. I'm also working with a counselor to cope with my PDMD. It wasn't easy, but I'm back to working for the health of society, not Big Pharma's bottom line."—Kelly, psychiatrist It takes courage to ask for help. These doctors did. You can too.

Conflict-of-interest disclosure: "This article was sponsored by a grant from the Coalition to Raise Awareness of PDMD."

Marc E. Keller earned a B.A. in Medical Anthropology and a Master's degree in Bioethics & Urban Studies, both from the University of Pennsylvania. He has been a journalist in Philadelphia and San Diego and has published numerous pieces of short fiction. His work experience includes stints in Penn's Department of Psychiatry, the Health Federation of Philadelphia, and in pharmaceutical marketing research. He lives and works in Philadelphia, Pennsylvania, USA.

Bert M. Bieler, MD, earned his undergraduate degree from the University of Pennsylvania and his M.D. from Temple University, completing his residency in Family Medicine at Brown University. He is a recipient of the Dr. Joseph Nathan Grossman Prize in Family Medicine (2002) and a member of the American Academy of Family Physicians. He is a Family Practice Physician in Newark, Delaware, USA.





Now available in



Which works best for you?

* Email address required for online subscription*



GREY MATTERS

FACEBOOK AND THE FUSIFORM GYRUS

WILLIAM P. CHESHIRE, JR., MD

Ethics has gone digital. From Twitter to Tweeples, the ever accelerating world of online connectivity is reshaping the culture of bioethical discourse. While books and journals remain indispensable to serious ethical discussion, cyberspace has evolved features that enhance words with vibrant imagery, immediacy and individual participation. Among these embellishments, the inclusion of faces personalizes ideas and magnifies the potential of words to stir human affections and motivate conduct. This essay considers how the new face of online networking might affect the social aspect of bioethics and explores the deeper question of how the human face influences ethics.

Peeking at Facebook

Within the past few years, online social networking has become a prevalent international cultural phenomenon. The Internet-based social network Facebook, for example, hosts a number of online bioethics discussion groups available to its more than 200 million active users. The format of these discussion groups is more personal than chat rooms and e-mail listservers—earlier online technologies from a pre-Windows world. Faces now accompany users' comments, which are linked to personal profiles, status updates and social networks.

The online elements needed for a fledgling global bioethics community are in place. As advances in information technology propel online networking toward increasing connectivity, online bioethics communities will be challenged to steer their growth in constructive ways. The direction chosen will be a matter for ethical reflection as well as of technological performance.

Ethics of Remote Networking

In grappling with the ethical implications of using remote networking technology to expand the bioethics community, it is important to consider the consequences of the technology for harmful or useful ends, as well as fair access, equitable distribution of benefit, respect for individual autonomy and protection from competing interests.

Communication technologies represent a special category for bioethics because they engage the brain and its neural connections which underlie social interaction and ethical reasoning. Ethical decisions regarding the use of communication technologies thus swing back to affect the shape of ethics itself. Choices of layout, functionality, access, and method of dialogue in online social settings will, in turn, influence the formation and dissemination of ethical perspectives.

Many advantages of online bioethics networking are apparent. For one, the global digital bioethics community has considerable potential for demographical inclusiveness. Wherever computers are available, a connection to colleagues can be made. Teens,

women, and African-Americans are highly represented among Facebook users¹ and have distinct perspectives to contribute. The democratization of bioethical discourse on issues relevant to all would be a welcome benefit. Broader participation could also enhance the breadth of public understanding of medical science and assist nonexperts to consider, inquire about, and debate the implications of scientific innovation. Since 70% of Facebook users reside outside the United States,¹ and Facebook currently ranks as the top social networking site in the majority of European countries,² online bioethics networking could potentially enlarge the global bioethics community, crossing national boundaries and bridging cultures.

Online networking also offers a number of practical advantages over journeying to conferences and society meetings to engage in dialogue and develop professional relationships. Booting a personal computer can avoid the time and expense of travel. Remote links can thus enhance the professional's efficient use of limited time. They can also provide access to underfunded and geographically remote scholars for participation in mainstream professional and cross-disciplinary dialogue, just as advances in distance education have done for medicine.^{3,4} Remote video conferencing was suggested at the 2008 Neuroethics Society meeting as a potential means to invite broader participation at future meetings by those lacking travel funds. At such meetings, individual or group participants would have the opportunity to interact face-to-face over the Internet via desktop webcams running audiovisual software.

No useful technology is without risk or trouble. There are a number of potential drawbacks to be considered, recognized and managed. One of the disadvantages of online networking would be its risk of adding to the deluge of information from the Internet pouring into personal computers and handheld devices. The quantity of ready information competing for attention is already overwhelming for many to try to absorb and process. Worldwide e-mail traffic among 1.4 billion users in 2009 is 247 billion messages per day, and by 2013, that figure is projected to reach 507 billion messages per day.⁵ Approximately 80% of e-mail is spam, the annual cost of which is estimated at \$130 billion worldwide.⁶

A related difficulty would be the proliferation of inaccurate information which, once posted and disseminated, could be difficult to correct. The Internet is a rumormonger's playground as much as it is an information highway.

The average Facebook user spends three hours per month on the site.² Worldwide, users spend more than 3.5 billion minutes on Facebook each day.¹ The countless small ethical choices regarding where and how to direct one's attention together amount to an enormous ethical decision about how to invest one's time and effort. The danger of engaging too frequently in virtual communities online is that such activity can compete with and potentially impoverish personal connections with family, friends and neighbors.⁷

Another drawback would be the difficulty of managing conflicts of interest. As online bioethics networking grows in volume and contributes to the shaping of attitudes that form public policy, the bioethics community should be alert to the potential intrusion of market interests. The current online practice of targeting users by selecting banner advertisements based on the user's personal demographic data entered onto social networking pages^{8,9} is a troubling precedent. Similar business practices might exploit

bioethics discussion groups by interjecting content intended to influence decisions affecting the use of controversial or potentially lucrative technologies. Responsible website management should frown upon such inappropriate encroachments. Maintaining a high standard of objectivity in bioethical discourse may become increasingly difficult over the Internet, where powerful market influences may be embedded less transparently than in traditional settings.

A further drawback would be nonparticipation by people who have valuable perspectives to contribute but are, for various reasons, less inclined to communicate via the Internet. Older people, as a group, tend to be less likely to utilize online resources for communication, which might mean that, for cyberspace dwellers, their wisdom learned from years of life experience could go unheard. Additionally, government restrictions may impede citizens' access to bioethics networking in some localities.¹⁰

Women, though less likely than men to engage in blogging,¹¹ at the time of this writing are the fastest growing demographic group signing on to Facebook.¹² That preference models the collaborative online culture needed for bioethics networking to succeed. In contrast to the partisan and individualistic style of communication found in the untame territory of the blogosphere, social networking sites tend to emphasize connectedness and community. Whereas the blogosphere abounds with vitriolic remarks toxic to the advancement of cordial online bioethics discourse, social networking sites offer a civil milieu in which to share ideas, provided that prejudice and bigotry are not allowed to creep in. Social networking pages also provide an added level of accountability. Facebook users can comment on one another's postings and invite or rescind friendship connections.

Disturbingly, the Internet has accentuated the vulnerability of anyone who ventures an opinion through electronic media. This is especially true for those articulating moral convictions, who become fair game for distorted and disparaging epithets. Blog assaults, once broadcast on the world-wide-web, can multiply a million-fold. Bully bloggers who malign character not only harm the person targeted but may also dissuade others, and particularly those with minority viewpoints, from participating in dialogue. One reason for such verbal unrestraint is the relative anonymity of online discourse, which may give confidence to some spiteful bloggers to write remarks that they should feel inhibited to express if speaking to another person face-to-face.

Keeping Bioethics' Human Face

The Facebook model is a smile in the right direction, in that the self-posted faces of users add a layer of humanity to online discourse. Even though such faces are still images lacking the range of expression and animated responsiveness of live conversation, their inclusion personalizes remote dialogue in a way that encourages users to treat other users as people and not as objects. By contrast, the substitution of avatar faces on some other webpages indicates a much thinner veneer of personalization.

The face, although not necessary for human interaction, is a persuasive social signal. The human brain is, in fact, wired to respond to faces. Human infants instinctively attend to faces and, moments after birth, will track a moving face farther than other moving patterns of comparable complexity, symmetry and contrast.¹³ Within a few days, infants learn to recognize their mother's face and imitate facial expressions.^{13,14} The primacy of

nonverbal facial communication in the human infant's exchange of gestures is thought to lay the foundation for verbal turntaking later in development.¹⁴ Verbal turntaking and empathetic exchange of facial expressions are essential paradigms for genuine human dialogue, whether in conversation or online.

Visual information about faces is processed in the fusiform face area, which is a specialized perceptual module within the fusiform gyrus on the ventral surface of the temporal lobe of the brain. Lesions of the fusiform gyrus can result in the neurological disorder prosopagnosia, or face blindness. A famous case of prosopagnosia was a gentleman, W.J., who, following a series of strokes, changed careers and went into sheep farming. Although no longer able to recognize most humans, he learned to recognize the faces of his sheep.¹⁵ From the study of cases of prosopagnosia, it may be concluded that the brain's face recognition system is anatomically distinct from perceptual systems that recognize objects.¹³

Another clue to the social importance of face recognition is the impaired interpersonal interaction that occurs in autism. Children with autism, a developmental disorder, seldom make eye contact with others and do not watch faces for signals regarding appropriate behavior. Nor do they engage in imaginative social play or sensitive conversation but may focus intensely on restricted interests. Neurons in the fusiform gyrus are hypoactive and less numerous in autism.¹⁶ Consequently, patients with autism have marked deficits in face processing, which impairs their capacity to understand the emotional state of others and hence to interact socially. The structured online networking environment of Facebook, interestingly, has facilitated the social interactions of at least one young man with autism, who finds joy in connecting with friends online and writes, "Facebook is for autism.... Good visual cues."¹⁷

The development of Facebook-style networking to assist the autistic to develop positive social connections would be an admirable goal. At the same time, technologies that filter out facial cues or dilute other human signatures of interaction could render communication in general slightly more autistic in quality. Several years ago at an airport in Florida, a businessman waiting for a connecting flight was asked how he liked his bluetooth wireless cell phone earpiece. He replied, "I like machines a lot better than humans . . . I just have to interface with humans to do business."¹⁸ In medicine, physicians communicating with patients remotely by telemedicine have been found to express empathy and praise less frequently than in face-to-face consultation.¹⁹

United with the cognitive innate abilities and learned skills to interpret and respond to facial expressions, a human face personalizes communication. Faceless dialogue, by contrast, lacks elements essential for robust dialogue. Social psychology research has shown that people are more likely to be hostile or critical when speaking over the telephone than when interacting face-to-face.¹⁴ Likewise, e-mail text messages are sometimes interpreted differently than intended.²⁰ The same is true of instant text messaging over cellular telephones. While gratifying the desire for immediate feedback that would be intuitively discernible from watching others' facial expressions,⁷ text messages omit the facial and vocal paralinguistic cues available in face-to-face conversation. In the absence of such cues, the listener may err on the side of interpreting affectively ambiguous statements negatively, since common experience teaches that curtness in ordinary conversation can imply hostility or indifference. The inclusion of a face can affect not only the style and tone of communication but also its outcome. Research suggests that, in some situations, the party with the stronger rational case in a negotiation may be more likely to prevail when communicating via telephone than when meeting face-to-face.¹⁴

A fascinating study presented at the 2008 meeting of the Radiological Society of North America found that radiologists shown a photograph of the patient's face alongside a computed tomography (CT) scan were more likely to render a more meticulous reading. Yehonatan Turner, the lead investigator, concluded that, "the addition of a photograph enables a more personal approach to the interpretation, especially when the radiologist is not in physical contact with the patient."²¹ Radiologists participating in the study commented that seeing the photographs of their patients' faces made them feel "more like physicians."²² Jonathan Halevy, director of the medical center where the study was conducted, observed that, "when there is a picture, your attitude and approach change—the human aspect is inserted." ²²

The human face asserts the power of feeling, which enlarges understanding and connects abstract ideas with our shared humanity. From the startlingly human face of the preborn infant visualized by ultrasonography, to the wrinkled face of the dying patient in need of palliative care and pain management, bioethics must be seen as well as read.

A thought-provoking question for twenty-first century bioethics is how changes in the technology of communication might influence the attitudes, beliefs, distinctions, arguments, negotiations and consensus-building that constitute bioethics. The moral analysis might turn in one direction or another depending on whether it were conducted through online networking or face-to-face. Perhaps deontologic arguments would seem more influential over media incorporating visual and facial cues. Perhaps consequentialist arguments would gain more acceptance if conveyed by text alone. Understanding how communication technologies engage the brain may help to design social networking systems that make use of all available cognitive resources in addressing ethical questions.

Bioethics, whether on Facebook or in real life, will continue to reflect on and debate the significance of the human face. Skeptics, wishing to dismiss the face as nothing more than a convenient marker evolution has shaped to secure social behaviors advantageous for the survival of the community, may assert that too much moral significance is accorded to the human face. Others may appreciate that the human face reflects more than a ripple in the fusiform gyrus. Perhaps human thoughts are inadequate to fathom all that the face represents as a distinctive sign of human dignity.

Finally, this discussion would be incomplete without mention of the Christian understanding of the human condition in relation to God, who initiated the most wonderful of relationships, not distantly, and not only with words conveying ethical principles, but personally, incarnately, intimately, ... face-to-face.²³

References

1. Http://www.facebook.com/press/info.php?statistics

Http://www.comscore.com/layout/set/popup/Press_Events/Press_Releases/2009/4/Facebook_ Top_Social_Network_in_Spain

ETHICS & MEDICINE

- Hill P. Distance education: strategies for maintaining relationships. Pac Health Dialog 2000; 7:71-73.
- 4. Binks S, Benger J. Tele-education in emergency care. Emerg Med J 2007; 24:782-784.
- 5. Http://www.radicati.com/?p=3237
- 6. Http://www.ferris.com/research-library/industry-statistics/
- 7. Bargh JA, McKenna KYA. The internet and social life. Annu Rev Psychol 2004; 55:573-590.
- Vara V. Facebook gets personal with ad targeting plan. Wall Street Journal, August 23, 2007, p. B1. Accessed at: http://online.wsj.com/article/SB118783296519606151.html
- Greene J. Microsoft and Facebook hook up. Business Week, October 25, 2007. Accessed at: http://www.businessweek.com/technology/content/oct2007/tc20071024 654439. htm
- 10. Chao L. Facebook gets poked in China. Wall Street Journal Blogs, July 1, 2008. Accessed at: http://blogs.wsj.com/chinajournal/2008/07/01/facebook-gets-poked-in-china/
- 11. Benen S. Women's opinions. Washington Monthly, February 20, 2005. Accessed at: http://www. washingtonmonthly.com/archives/individual/2005_02/005691.php
- 12. Http://www.insidefacebook.com/2009/02/02/fastest-growing-demographic-on-facebook-women-over-55/
- 13. Farah MJ. The Cognitive Neuroscience of Vision. New York: John Wiley & Sons, 2000, pp. 115-146.
- 14. Bruce V. What the human face tells the human mind: some challenges for the robot-human interface. IEEE International Workshop on Robot and Human Communication. IEEE Xplore 1992:44-51.
- McNeil JE, Warrington EK. Prosopagnosia: a face-specific disorder. Q J Exp Psychol A 1993; 46:1-10.
- 16. van Kooten IAJ, Palmen SJMC, von Cappeln P, et al. Neurons in the fusiform gyrus are fewer and smaller in autism. Brain 2008; 131:987-999.
- 17. Http://www.spectrumpublications.com/pdf/myblog/can-facebook-cure-autism.pdf
- Kruse M. In-your-face interface. St. Petersburg Times, October 5, 2006. Accessed at: http://www. sptimes.com/2006/10/05/Floridian/In_your_face_interface.shtml
- 19. Liu X, Sawada Y, Takizawa T, et al. Doctor-patient communication: a comparison between telemedicine consultation and face-to-face consultation. Intern Med 2007; 46:227-232.
- Kruger J, Epley N, Parker J, Ng ZW. Egocentricism over e-mail: can we communicate as well as we think? J Pers Soc Psychol 2005; 89:925-936.
- 21. Photos increase radiologist-patient connection. RSNA News, March 2009. Accessed at: http:// www.rsna.org.Publications/rsnanews/March-2009/Photos_feature.cfm
- 22. Kraft D. Radiologist adds a human touch: photos. New York Times, April 6, 2009, p. D5. Accessed at http://www.nytimes.com/2009/04/07/health/07pati.html
- 23. John 14: 6-11; Philippians 2: 3-8

CLINICAL ETHICS DILEMMAS

CONTINUING "FUTILE" ICU SUPPORT AT RELATIVE'S INSISTENCE

ROBERT D. ORR, MD, CM

The following consultation report is based on a real clinical dilemma that led to a request for an ethics consultation. Some details have been changed to preserve patient privacy. The goal of this column is to address ethical dilemmas faced by patients, families and healthcare professionals, offering careful analysis and recommendations that are consistent with biblical standards. The format and length are intended to simulate an actual consultation report that might appear in a clinical record and are not intended to be an exhaustive discussion of the issues raised.

Question

Must we continue "futile" ICU support for this dying man at the insistence of his son?

Story

Malcolm ("Mac"), age 64, is an architect who was found to have an incurable cancer of the esophagus 5 months ago. He came to the Emergency Department 35 days ago with shortness of breath and it was found that his tumor was compressing the large airways going into both lungs. He was emergently intubated, admitted to the ICU, and given ventilatory support which has now continued for more than a month. Vigorous treatment has failed to shrink the tumor, and the ICU physician and oncologist are both convinced that his condition cannot be improved. Efforts have been made to awaken him to discuss limitation of treatment, but he remains too confused to understand or to engage in meaningful conversation. Because of his unawareness and his very poor prognosis, his professional caregivers have said they believe continued ICU care is futile.

His only son, Paul, and wife, Lindsey, have been very attentive and willing to consent to any therapy that has been suggested so far. When presented a few days ago with information about his terminal condition and imminent death, however, they were unwilling to consider or even discuss any limitation of treatment, insisting that he remain in the ICU, on ventilator support, on a "full code" status. They stated that their deep religious faith (Methodist) required them to do everything possible to preserve life, and they were counting on God to perform a miracle. They report that the patient was also a man of deep faith who would likewise insist on this approach.

Mac's ICU nurse reports that he remains unresponsive and does not appear to be uncomfortable. She further reports overhearing a conversation between Paul and Lindsey about the need to get the patient's signature on a document that would finalize a real estate venture that he and his son have developed. An attorney came to the ICU to obtain the patient's signature a few days ago, but Mac was unable to understand or to sign the document.

Discussion

When it is clear that a patient is dying, is unaware, and cannot improve, it is appropriate to review his treatment and to consider limiting life-extending treatment. Decisions for or against the use of such therapies should be based on the patient's wishes, expressed by him in writing or verbally. While it may occasionally be suspected that family members have "another agenda," the presumption in most cases should be that they best know the patient's wishes and values, and their decisions should almost always be honored. Exceptions to this generalization include (a) if the treatment is clearly physiologically futile, as determined by at least two physicians, or (b) if the treatment will be unable to restore the patient's awareness and it is also causing him unrelievable suffering.

In this case, the patient's professional caregivers are convinced that he is dying and will never again have awareness, and they interpret this to mean that continued treatment is futile. However, his family believes that he would want to continue treatment while they are praying for Divine intervention. Since his current ICU care is postponing his death, it is not truly futile.

Recommendations

(1) It is appropriate to continue ICU care, using all reasonable attempts to postpone this patient's death.

(2) His son and daughter-in-law should periodically be updated on his condition and prognosis, and should occasionally be asked to consider limitation of treatment if he shows no signs of improvement. These requests should not be too frequent or too forceful so as to be perceived as badgering.

Follow-up

Mac continued to live in the ICU, on full support for the next 13 months without recovering awareness. He had several episodes of sepsis and was successfully resuscitated from four cardiac arrests. Two more ethics consultations were requested at intervals, essentially asking the same question, with essentially the same recommendations. When he did not survive the final resuscitative attempt, the ICU physician called his son, saying, "We did everything we could, but I'm sorry to report that your father has died." His frustration with his father's lack of improvement came through in his response: "Well, you obviously didn't do enough!"

Comment

Talk about frustration—Mac's professional caregivers were exceedingly frustrated, believing that their heroic efforts had no reasonable expectation of helping the patient. They believed that they were being poor stewards of medical resources. (Mac's care for this hospitalization exceeded \$2,500,000.) It is very easy in retrospect to confirm their belief that this extent of treatment was "inappropriate," but it clearly was not futile in the literal sense since it did postpone his death for many months.

VOL. 25:3 FALL 2009

Orr / Continuing "Futile" ICU Support

Robert D. Orr, MD, CM, is Professor of Bioethics at Loma Linda University and Director of Clinical Ethics at Loma Linda University Medical Center, Loma Linda, California. He is also Professor of Bioethics at the Graduate College, Union University in Schenectady, New York, Consultant in Clinical Ethics, Center for Bioethics and Human Dignity, and Professor of Bioethics at Trinity International University, Deerfield, Illinois, USA.

This column is an adaptation of a case report that will appear in Dr. Orr's forthcoming book, Medical Ethics and the Faith Factor, to be released by Eerdman's Publishing Co. in 2009.



Get the word out!

Do you have a book, newsletter, website, college or grad course, etc., that you would like to share with others?

The Bioethics Press now offers ad space in our print materials...





... or on our websites!

> Ask for our media rate kit. Get the word out.

www.bioethicspress.com

DWARVES: UNINFORMED CONSENT AND EUGENIC RESEARCH

PAUL A. LOMBARDO, PHD, JD

Abstract

In 1929 Charles B. Davenport, a prominent biologist and leader in the American eugenics movement, carried out an experimental castration of a "Mongoloid dwarf" at a New York State mental institution. His goal was to retrieve tissue for chromosomal analysis in an attempt to understand the basis of syndromal mental retardation. Davenport was assisted in the research by cytologist T.S. Painter, who later achieved scientific celebrity for his work in counting human chromosomes. Davenport also invited George Washington Corner, who eventually contributed to the discovery of progesterone, to participate in the experiment. Davenport planned and carried out the surgery using the questionable promise of therapeutic benefit to elicit consent from a parent with limited mental capacity on behalf of an even more seriously impaired institutional resident. Archival evidence demonstrates that even at that date scientists like Davenport and the physicians he collaborated with were sensitive to ethical issues such as the necessity for consent and questions of decisional capacity, as well as the potential for negative publicity for mistreatment of "research subjects."

Keywords: Mongolism, Chromosome analysis, Informed consent for research, Eugenic research

In 1929 Charles Davenport planned and carried out an experimental castration in New York's Letchworth Village for the Feebleminded. Davenport was a leader in the U.S. eugenics movement. Two men who would later become famous for their scientific accomplishments assisted him. Anatomist George Washington Corner performed the castrating surgery on the asylum inmate; renowned cytologist T.H. Painter analyzed the tissue Corner removed. The experiment, which was designed by Davenport to provide insight into the "inherited defect" of "mongolism," addressed an important concern of the eugenicists. It also focused on dwarves, a "striking and much studied" group within public institutions.¹

The field of eugenics took its name from the work of Francis Galton, focusing on "all influences that improve the inborn qualities of a race."² The word itself meant "well-born." While people who supported eugenics spanned many political and ideological boundaries, and the movement encompassed a number of innocuous or even praiseworthy goals,³ the term is now used almost exclusively as a pejorative term linked to the atrocities of the Holocaust. Many recent books have focused on linkages between the eugenics movement in the United States and its eventual expression as a social program of Hitler's Third Reich. It is becoming more widely appreciated that some of the more toxic expressions of eugenics, such as laws mandating coercive sterilization, racial categorization and separation, and ethnically targeted immigration restriction were in place in the U.S. long before Hitler came to power.⁴

But *de jure* eugenics in the U.S. was far from the only insidious U.S./Nazi parallel. Another historical link between the German version of eugenics and its American cousin can be seen in the research focus of the movement in both countries. For years, U.S. scientists doing biomedical research found convenient research subjects in the abundance of "unfit" residents in mental hospitals, sanataria, orphanages and asylums. Some of the largest and most notorious institutions, like Virginia's Colony for Epileptic and Feebleminded, were the site of research over the years not only by civilian doctors, but also by the military.⁵ The Eugenics Record Office (ERO) also stressed the importance of research and championed the use of institutional inmates as research subjects. E.E. Southard, Harvard Medical School neuropathologist and member of the Special Board of Directors of the ERO, compared public institutions to mines, waiting "to be explored for the ore of progress." Katherine Bement Davis, executive secretary of the Bureau of Social Hygiene, said that we should look at "our great state institutions as human laboratories." ⁶

It 1947, sentiments like these landed Nazi doctors in the dock at Nuremberg, forced to defend themselves against charges of "Crimes Committed in the Guise of Scientific Research." Some of the most notorious crimes of which they stood accused were sexual sterilizations performed in concentration camps using excessive x-rays or toxic chemicals.⁷ Yet fully fifteen years before Hitler's henchmen were charged with war crimes for honing the eugenic technology of sterilization in the death camps, Charles Davenport's study, involving surgery on a "defective" resident of a New York State institution, was designed and completed to explore the chromosomal basis of what is now known as Down syndrome.

Charles Davenport and Mongolism: Degeneration, Mental Defect & the Chromosomes

Charles Davenport (1866-1944) was the founding Director of the Eugenics Record Office (ERO) which opened in 1910 in Cold Spring Harbor, New York. Davenport completed a Ph.D. at Harvard, taught there and at the University of Chicago and later directed the Carnegie Institution of Washington's Station for the Experimental Study of Evolution. During his thirty year tenure at the ERO, Davenport earned a spot among America's scientific elite, with memberships in the National Academy of Sciences and the National Research Council.⁸ Among Davenport's many biological interests was the cause of "mongolism."

"Mongolism" was the term long assigned to a condition we now designate by its etiology as trisomy 21. Children born with that condition have three (rather than the usual two) twenty-first chromosomes. Trisomy 21 is linked to mental retardation and assorted physical anomalies, as well as a characteristic physical appearance.⁹

British physician Langdon Down (1828-1896) described and named the condition in the nineteenth century. In that era, Down proclaimed his interest in "the possibility of making a classification of the feebleminded, by arranging them around various ethnic standards." Having found "among the large number of idiots and imbeciles" he had observed a "considerable portion" that seemed to be members of "one of the great divisions of the human race other than the class from which they have sprung,"¹⁰ he noted that "[a] very large number of congenital idiots are typical Mongols." He described his findings as an example of degeneracy—a retrogression from one racial type (e.g. European or Caucasian) to what was considered a "lower type" (e.g. Asian or Mongolian). This kind of chance degeneration was also known as "atavism"—an example of evolutionary throwback. The "degeneracy thesis" was consistent with the comparative racial anthropology of Down's time.¹¹

A related controversy of Down's era had to do with developing theories of human origins and the concept of "race." Some rationalized what they observed as the disparate racial divisions of mankind by arguing for a "separate creation" for each race, or "polygenesis." However, Down, consistent with biblical orthodoxy, argued for "monogenesis"—a single creation for *homo sapiens*. The occasional appearance of Mongoloids in families of Caucasians required "further explanation" thought Down, and his theory of "mongolism" as a disease of degeneracy provided that explanation.

If these great racial divisions are fixed and definite, how comes it that disease is able to break down the barrier, and to stimulate so closely the feature of another division? I cannot but think that the observations I have recorded are indications that the difference in the races are not specific, but variable. These examples of the result of degeneracy among mankind appear to me to furnish some argument in favour of the unity of the human species.¹²

By the early 1920s, Charles Davenport had published papers suggesting that chromosomes were the critical determinants of mongolism. Davenport's Eugenics Record Office colleagues were intrigued by the condition, which was a predictable feature of many residents in every home for the "mental deficient" or "feebleminded." Those institutions were focal points for eugenics research and investigation into "the manner of inheritance of specific human traits" was a critical activity on the ERO agenda.¹³ Davenport openly advocated for aggressive research efforts in the mental hospitals and colonies for "defectives" that housed the social problem groups he hoped eventually to eradicate.¹⁴

Discovering the causes of mongolism became an area of prime concern to Davenport. By 1910 psychologist Henry H. Goddard, working at the Psychological Research Laboratory of the New Jersey Training School at Vineland, identified variables such as parental meningitis, syphilis, overwork during pregnancy, or tuberculosis as possibly contributing to mongolism, and he also observed that affected children were often the last born to a large family, or had parents of advanced age. Goddard believed that mongolism was congenital—appearing at birth—but not hereditary, since children with the condition were often born to families with no previous hereditary problems.¹⁵ Davenport cited Goddard's pedigrees of the "mongolian imbecile" and echoed Goddard's speculations on the "racial" significance of mongolism in his own text, *Heredity in Relation to Eugenics*.¹⁶

The complex interplay among ideas about race, mental defect and the mechanisms of heredity was also reflected in Davenport's involvement with Robert Bennett Bean (1874-1944). Bean was trained as a physician, but his career as a researcher in human anatomy and anthropology focusing on racial differences led to several books such as *Racial Anatomy of the Philippine Islanders* (1910) and *Races of Man* (1932) and his

eventual reputation as one of the key figures in the field later disparaged as "scientific racism." 17

Exchanges between Davenport and Bean also demonstrate how regularly they both used institutional residents as research subjects. In 1924 Bean told Davenport how he "had examined about 100 mongoloids at Vineland and other places in New Jersey the past summer in connection with the measurement of the feebleminded" and that he was interested in Davenport's own work in this area.¹⁸ Bean later reported that he had made X-rays of the "Mongoloid Dwarfs" at Vineland and wished to pursue further research there. He wanted to compare the measurements of Vineland residents with his own of Filipino children, believing that "the Mongoloid Dwarfs are very much like the Hypomorph Filipino children."¹⁹ Davenport responded by giving Bean a list of the children he had examined at Vineland and data based on measurements he had taken of them.²⁰

Bean endorsed the interrupted evolution thesis. He thought the Mongolian idiot was really a case of "incomplete metamorphosis." He also referred to mongoloids as "unfinished children." He quoted earlier researchers such as British physician F.G. Crookshank, saying that the condition of mongolism could be traced to the thirteenth century invasion of Europe by Mongol descendants of Genghis Kahn.²¹

But by the mid-1920s, Davenport had moved away from the degeneracy thesis suggested by Down and later by Bean and others. Some scientists believed that mongolism was caused by problems with a "disordered thymus gland,"²² and Davenport took the glandular etiology hypothesis into account as he later speculated about the cause of "mongoloidism," alternately looking at a chromosomal basis for the syndrome, then a hormonal or endocrinal connection that explained it. He admitted that the "cause of mongoloidism has not been ascertained." But in looking at mutations, Davenport would soon conclude that the chromosomes were the locus for what eugenicists had long referred to as source of heredity—the "germ-plasm."²³ The soundness of genetics as a science must wait, Davenport said, until "how the chromosomes do their work" was better understood. ²⁴ One means to such understanding lay in the talents of the younger investigators who visited Davenport at his research station on Long Island.

Assembling the Research Team

From 1910 until the Second World War, the laboratories at Cold Spring Harbor—both at the Station for the Experimental Study of Evolution and the Eugenics Record Office—were magnets for the best scientific talent in America. Young researchers motivated to learn about heredity and the burgeoning science of genetics invariably landed there. Two of those who sampled the Cold Spring Harbor summer life were Theophilus S. Painter and George Washington Corner. Their talents were eventually enlisted in Davenport's research agenda to discover the causes of mongolism.

Theophilus Painter (1989-1969) is best known for his pioneering work in cytology and his attempt to count human chromosomes accurately. He took his biology Ph.D. at Yale in 1913. For the next fifty years he rose through the ranks of the University of Texas from assistant professor to an endowed chair, spending time along the way as University President.²⁵

Painter was among the first to assert that every normal human had forty-eight chromosomes, and his 1923 paper announcing that number lead to a long-held and commonly accepted belief within the scientific community that the matter was settled.²⁶ Painter's count was not disproven until 1955 when cytologists using newer techniques established with certainty that the actual number of human chromosomes was only forty-six.

Painter's career began studying the common fruit fly, drosophila, in the laboratory of geneticist and later Nobel Laureate H. J. Muller. Initially Painter's own studies concentrated on insects such as spiders, but he soon moved on to demonstrate the operation of sex chromosomes in determining the gender of the opossum. He eventually investigated other mammals, including humans. Painter met Davenport on a visit to Cold Spring Harbor in the early 1920s. He also met George Washington Corner there.

George Washington Corner (1889-1981) was an anatomist who received his medical degree in 1913 from the Johns Hopkins University, and in time served on the medical faculties at Hopkins, the University of California and the University of Rochester. Corner later became chair of the National Research Council's Committee on Research in Problems of Sex, where he became a conduit for support to the study of human sexuality by Alfred Kinsey.²⁷ He is credited as a discoverer of the hormone progesterone.²⁸

Corner and Painter were exact contemporaries, twenty three years younger than Davenport. Like Painter, Corner found himself in Davenport's "celebrated laboratory devoted to the study of heredity" in 1920.²⁹ Corner spent that summer and the next at Cold Spring Harbor, studying problems of inheritance in sheep. Corner and Painter both had occasion to work with Harry Laughlin during their visits to Cold Spring Harbor.

Chromosomes, Race and the Challenge of Obtaining "Experimental Material"

Laughlin (1880-1943) was one of the most successful propagandists of the American eugenics movement, particularly in advocating immigration restriction and sterilization laws. At Cold Spring Harbor he managed the daily affairs of the ERO as Superintendent. He shared Davenport's interest in mongolism, also had a long-standing interest in chromosomes, and was very familiar with the literature on their number and function.³⁰ He had attempted to devise an abacus that would "illustrate the basic geography of the chromosome" and provide a mathematical model of heredity.³¹ He had written often on race and racial traits.³²

In 1921 Laughlin was in charge of assembling exhibits for the 2nd International Congress of Eugenics, which was to be held at the Museum of Natural History in New York City. Herman Muller suggested that Laughlin contact T. S. Painter to solicit an exhibit on chromosome counting.³³ Painter created a six-foot high exhibit that was shown at the Eugenics Congress.³⁴

The exhibit Painter sent to Laughlin contained a racial comparison of chromosomes black compared to white—an issue of some contention at the time. Wisconsin geneticist Michael Guyer had argued "with assurance" in 1914 that the "number of chromosomes [in whites] is considerably in excess of those found in my negro material." Painter's study concluded, in contrast, that as to white and black chromosomes, "They are alike in general form and in number."³⁵ That conclusion was consistent with findings of a number of other scientists, such as Thomas Hunt Morgan and Laughlin.³⁶

In his review of the controversy over the difference between numbers of chromosomes in "negro and white man," Laughlin concluded that such conjecture has "proved to be wrong." At the time, said Laughlin, it had been "clearly demonstrated" that there were forty-eight chromosomes in females, forty-seven in males. Part of the difficulty in making a proper count lie in getting the "human sex gland," but that problem had been overcome within "one of the institutions where they are sterilizing by castration [and] human testes were secured."³⁷ Laughlin's comment made clear how human tissue was obtained to do chromosome experiments—a point that was sometimes obscured by researchers.³⁸

Experimental "material," as tissue obtained for research was commonly designated, was not difficult to obtain from species like insects or opossums, but finding recently excised human gonads was a different matter. Painter had several sources. A former student of his who practiced medicine at a Texas mental institution supplied him with "fresh human testicular tissue" on occasion when castrations were done for unspecified "therapeutic reasons." Other experiments were done on material thought to have been taken from criminals who had been executed at a nearby prison.³⁹ Noting the "great difficulty" that stood in the way of solving the puzzle of numbering human chromosomes, Painter described the problems researchers had encountered with "obtaining suitable material for cytological study."⁴⁰ Coming from executed prison inmates, most material was "stale." Painter, however, had the "good fortune to obtain for preservation fresh testicular tissue from three individuals." Painter later explained in detail how he got the tissue for a chromosomal analysis.

The material upon which this study is based was obtained from three inmates of the Texas State Insane Asylum, through the interest and cooperation of Dr. T. E. Cook, a physician at the institution. Two of these individuals were negroes and one was a young white man. In all three cases the cause for removal of the testes was excessive self-abuse coupled with certain phases of insanity which made the removal of the sex glands desirable. Dr. Cook, being interested not only with the problems directly concerned with his profession, but also with the larger questions of " the greater medicine" biology, placed this valuable material at the disposal of my colleague, Prof. D.B. Casteel.

Casteel turned the material over to Painter "for comparison with my results with the opossum." Painter went on to explain that the operations were done under local anesthesia, with little or no pain to the subjects. Painter also concluded, in contrast to some earlier investigators, that there was no visible difference between the races in number or shape of chromosomes.⁴¹

Charles Davenport also seemed to have less difficulty than other scientists in finding human tissue for use in research. G.W. Corner reported that early in his own career, Davenport was able to supply "a pair of human ovaries" for use to quiz Corner on the mechanism of twinning. The ovaries had been taken during an autopsy from a woman who had died approximately a week after delivering triplets in a New York hospital.⁴²

Corner returned to Cold Spring Harbor to teach visiting students experimental surgery in mammals for several weeks each summer from 1929-1933. His experience in animal surgery equipped him to teach "basic methods of anesthesia, asepsis...the use of special instruments and practical suturing." The study subjects then were white rats, cats and rabbits.⁴³

Castrating the Mongoloid Dwarf: Planning the Experiment

Painter also maintained contact with Charles Davenport for many years after their initial meeting in 1920, and had so impressed the senior scientist that Davenport invited him to move to Long Island and become part of the staff of the Station for Experimental Biology.⁴⁴ Painter declined the position, but in 1929 Davenport wrote again to recruit Painter for a new and bold experiment. Davenport planned to castrate a "mongloid dwarf" at Letchworth Village, a New York asylum for feebleminded children.⁴⁵ Painter's skills as a cytologist and Corner's experience in surgery would be critical. The plan was sketched in a letter:

I have for some years been interested in the problem of the Mongolian dwarf as found in institutions for the feeble-minded. I have made detailed measurements of some 500 of them. I am now tabulating the results.

Scores of papers and not a few books have been written upon the problem of the Mongolian dwarf. No satisfactory interpretation has been secured. It is doubtful whether there is any certainly hereditary factor present. They occur in an overwhelmingly high proportion at the end of a large fraternity—so frequently that a physiological factor is certainly present. Naturally my attention is directed to irregularities of the chromosomal complex as a principal cause of the defect. I have talked with the people in charge of Letchworth Village and they think it is quite possible that they might be willing to operate on a Mongolian boy, thru the removal of one testis for cytological examination. There are occasionally cases of retained testes but I doubt if they should be used, lest the criticism might be made that the abnormal conditions of temperature may be responsible for chromosomal irregularities. Not many of the Mongolians reach the age of puberty but some of them do and I think it might be possible to induce the superintendent to authorize a unilateral castration.

Do you expect to be in the east next summer? If so, would you be interested in this problem?

If you are not to be in the east possibly you could interest the superintendent of the Texas School for the Feeble Minded in this problem and get the required material at that institution. I believe the State School is in Austin and Mongolian dwarfs can no doubt be obtained there as they constitute about 2% of the institutional population.⁴⁶

Painter responded promptly, alerting Davenport that he would be "very much interested in getting hold of some of this material" but uncertain and "not overly optimistic about being able to determine if this peculiarity is conditioned by a chromosomal abnormality." Because of the difficulty of chromosome analysis, he felt that it might not be possible to "spot the source of the trouble when there are 48 chromosomes concerned."⁴⁷

Painter promised to arrange his summer travel plans and "run up to Cold Spring Harbor" and asked Davenport to talk to the Superintendent of Letchworth Village about the project.⁴⁸ Davenport confirmed that he would "take up again more systematically the possibility of getting cytological material of the sort mentioned."⁴⁹

By June, Davenport had enlisted George Washington Corner, who though not licensed in New York, had a medical degree, and was "glad to assist at the operation." In addition to his teaching experience at Cold Spring Harbor, Corner's major experience as a surgeon was operating on dogs.

Obtaining Parental Consent

Getting consent to do the operation was not a simple issue. The superintendent at Letchworth, Dr. Little, did not think it necessary to get written consent from one candidate's mother. "However," noted Davenport, "he is not sure what the law would be in this state. It might be well to take legal advice. The operation would naturally be performed as a therapeutic one."⁵⁰

Davenport faced a quandary in getting consent from different parents, noting that in one case the mother was "so intelligent" that her authorization "would be significant"— though likely more difficult to obtain. Another mother was less capable but as a consequence, "her permission would probably have no legal standing."⁵¹ Painter left those details to Davenport and agreed to travel to Cold Spring Harbor during a summer vacation. "[I]f the superintendent is willing for me to get the material and can arrange for the castration" he said, "I shall be glad to so arrange my plans as to preserve it." ⁵²

One doctor at the institution was "always ready to co-operate in any undertaking" that might answer a problem concerning "mental deficiency" but he reiterated the problem of getting parental consent. "To secure this is a very delicate undertaking which can be accomplished only through the greatest diplomacy." Warning Davenport that he could anticipate "adverse criticisms" if the surgery became publicly known, he nonetheless felt that the project was feasible and should "be carried through to a successful conclusion."⁵³

Davenport focused his attentions on the "possibility of making a study of the chromosomal conditions in the cell divisions of the testes of a Mongoloid."⁵⁴ He had identified a 13 year old boy, whose father was dead and whose mother was "of low mentality," as a potential research subject. This was the same woman identified earlier as so lacking in comprehension that her consent would probably not be legally valid. The boy presented two compelling arguments for inclusion in Davenport's research. He demonstrated "typical traits" of this condition and extensive medical and observational records about him were available. Just as importantly, Davenport suggested that it was possible that excising one testicle could be justified as a potential benefit to the boy. "[A] case could be made," he said, for performing the surgery "on therapeutic grounds." The boy exhibited "a rather marked eroticism and this probably bothers him some, as it doubtless does his attendants." Davenport considered that both the boy's behavior as well as his "general health" would be improved by the surgery. ⁵⁵ This was not a new idea, and

in the nineteenth century some doctors believed that surgery was a proper intervention to correct sexual deviance and even treat mental illness.⁵⁶ The assertion that castration was "therapeutic" was primarily speculative, but it offered a rationale to justify the surgical intervention that Davenport was quick to endorse.

Davenport then contacted Painter, confident that the operation could be completed consistent with the Texan's schedule; he made preparations for Painter's involvement in the experiment.⁵⁷ Painter promised to bring the laboratory supplies necessary for his work and set the date for the surgery in August, 1929.⁵⁸

The clinical director at Letchworth Village alerted Davenport that he had solicited a signed permission from the mother of the boy they had identified; no reference was made to concerns expressed earlier about her limited ability to comprehend the procedure she had authorized. The doctor did not allow his colleagues—physicians in the institution— to perform the surgery, saying instead that it was "highly advisable that an outside surgeon" be responsible for the operation, and he left the task of selecting a surgeon to Davenport's "good judgment."⁵⁹ Corner was enlisted for this role.

Following the surgery, Painter reported his procedures for preserving the "material" he had collected during his New York visit.⁶⁰ Davenport suggested various types of analyses, such as comparing the material at different stages of metaphase. ⁶¹ When Painter's report did not arrive, Davenport pressed for more details, saying that the people at Letchworth Village had asked about the ongoing study, and that he was anxious to "learn whether you are making progress on this material."⁶²

Painter was looking for an abnormality in the chromosomes themselves. He explained that "unless there is some very gross abnormality in the chromosome constitution it could not be detected without prolonged study. I shall continue on this material until I can convince myself that it is entirely normal."⁶³ No record survives to reveal whether Davenport ever got a positive "final report on the matter of the chromosomes of the Mongoloid."⁶⁴ Apparently the study yielded no new insights.

Conclusion

Painter also presented another poster on human chromosomes for Laughlin at the 1932 International Congress of Eugenics, but his future publications did not mention the New York experiment. He continued to collaborate with both Davenport and Laughlin on chromosome studies in horses and humans.⁶⁵

Painter's human chromosome count, as presented at the Eugenics Congresses, stood from 1921 until 1955, when J.H. Tijio, using a very different technology and reviewing lung tissue, concluded that there were in fact only 23 pairs of chromosomes in human beings. ⁶⁶

The specific genetic mechanism for producing the phenotype formerly known as "mongoloidism" is still not completely understood. ⁶⁷

So what are we to make of this window into Davenport's research and the involvement of Painter and Corner? At one level, it shows us how much more work is necessary to understand how complex the history of eugenics is. We might have expected Davenport to look to his research subjects to confirm Down's racial taxonomy—Mongolian Idiot as evolutionary throwback. That avenue would have highlighted the importance of racial studies to the eugenics movement, and precluded the flexibility for investigating alternative hypotheses about the causes of "defective" conditions. But Davenport, at least in this instance, looked beyond expected prejudgment in search of what turned out to be the actual answer to the quandary of Down's syndrome—a chromosomal abnormality. In the search, he left us with a series of new questions for historical inquiry.

Experimental Surgery on Inmates

How common was it for researchers in institutions for "defectives" to do surgery on residents? To some nineteenth century physicians, surgery was considered a reasonable though clearly controversial option when used to treat both sexual deviance and some mental illness. Some traced "imbecility and idiocy" to masturbation, and recounted stories of how castration had been used as a "remedy" for that particular malady.⁶⁸

Experimental surgery had occurred in a number of institutions, despite opposition from both lawyers and doctors. In 1893, Dr. Joseph Price of the Pennsylvania State Hospital for the Insane reported removing the ovaries of women patients as a means of treating their insanity. A legal opinion condemned the surgery as "illegal and unjustifiable." The *Journal of the American Medical Association* said that castration of women for therapeutic purposes was disfavored. ⁶⁹ Other doctors disagreed, but recommended court approval in cases where a woman's insanity was expressed in erotic misbehavior.⁷⁰ In all those cases, the surgery at issue was not considered research, but merely innovative therapy.

There were some notorious public reports of unsanctioned surgery. In 1890 Kansas physician Dr. F. Hoyt Pilcher castrated fifty-eight boys and girls at the Winfield, Kansas Institution for Feebleminded Children in an attempt to deal with masturbation.⁷¹ In his Massachusetts asylum, Dr. Everett Flood performed twenty-six castrations as therapy for epilepsy.⁷² Pennsylvania's Dr. Issac Kerlin advocated state laws to legalize such surgery.⁷³ A survey of more than sixty institutions at the time revealed that castration was a favored surgical intervention for most, though controversial enough that respondents were unwilling to admit they had done such experimental "therapy" themselves.⁷⁴ Clearly novel as therapeutic interventions, in most cases neither these castrating operations nor later, less radical vasectomies were characterized as "experimental" nor would they fall under our more recent understanding of research.

The Therapeutic Misconception and the Need for Consent

What was the state of understanding among researchers about the need for consent from guardians or parents, when surgery was contemplated for children or legally incompetent institutional inmates? Davenport's correspondence confirms that concerns about liability or at least bad publicity were afoot in the 1920s and issues such as the capacity of parents to consent were significant then as now. Castration itself, except for clearly medical purposes (such as to remove cancerous tissue) remained very controversial.⁷⁵

We know that some treatises condemned surgery done without consent years before Davenport and his colleagues operated at Letchworth Village. One text specified the need for consent for any clinical examination or treatment, and said that no patient should be taken to the operating-room without written consent, signed by the patient. For minors or the incapacitated, consent was required from next of kin. According to that text, even the cutting of children's hair to allow treatment of lice required parental consent.⁷⁶

In the legal realm, consent for surgery was undoubtedly required, and doctors who operated without it could expect lawsuits in response.⁷⁷ But other considerations emerged surrounding consent for research that had no obvious patient benefit. A major scandal had erupted in New York City in 1912 that had to heighten any researcher's awareness of the potential controversy that could follow experiments on humans.⁷⁸ Antivivisectionists, opposed to using both animals and children in research studies, criticized work undertaken at the Rockefeller Institute in an attempt to develop diagnostic tests for syphilis. As part of that research, numerous institutional patients and some children were injected with attenuated syphilis cells. When details of the experiment were made public, the outcry threatened to stifle any research that used children or people in public institutions. Davenport and his colleagues' concern about the potential for "adverse criticisms" no doubt referred to the earlier scandal.

A text written by Albert Leffingwell, a prominent critic of vivisection, recited instances where invasive research had been done on "children...the feebleminded...and ...lunatics in public institutions." Of course, none of those people were considered capable of giving "intelligent and full consent." The "sick, the friendless, [and] the poor" had all filled the role of unwitting "victims" in medical research.⁷⁹ Under the heading of "Justifiable Experimentation in Man" Leffingwell prescribed written consent as a precondition of all experiments done on "men and women of ordinary intelligence" after they had been "fully informed of the nature of the investigation and whatever distressing or dangerous consequences are obviously liable to result," and had received "satisfactory compensation for all risks."⁸⁰

Although Davenport may not have known Leffingwell's ethical arguments, he certainly knew of the well-publicized controversies that had arisen following allegations of research on children or similarly vulnerable subjects.⁸¹ His desire to use the excuse of therapeutic prerogative as the mask behind which to hide his true goals—suggesting that surgery was for the patient's benefit rather than primarily to aid scientific discovery—indicates his sensitivity to the potential that others would find such research both legally and ethically problematic.

Because it is not clear that the mother of the boy who endured surgery at Letchworth was told or was likely to understand the real purpose of the experimental castration, the case raises questions of how "informed" her consent really was. The potential for relying on speculative benefits perceived by patients as the basis of consent suggests that what we now refer to as "the therapeutic misconception" may have been operating. The researchers used the patient's (or their surrogate decisionmaker's) hope of cure, or at least acquiescence to treatment, as leverage for advancing an agenda more concerned with research than therapy. Both informed consent and the therapeutic misconception remain major issues in research ethics today. Davenport and his colleagues' sensitivity to secrecy and the need to hide the true reasons for surgery from those who gave consent and from the larger public suggest that attention to such issues in the context of medical research are longstanding concerns, far from novel even in the 1920s. These sensitivities were patent long before the 1947 Nuremberg Trials of the Nazi Doctors, which

condemned abusive medical research done on captive populations and have long been considered an important starting point for discussions of research ethics in the U.S.

We are left with the discomforting fact that Davenport and his cohort engaged in activities that were perilously similar to some of the very medical crimes that were later prosecuted at Nuremberg. Future research in the history of research ethics might profitably be focused on other examples of clinical medical research carried out at the intersection between the newly developing field of genetics and its now discredited cousin, eugenics.

Endnotes

- Davenport used the designation "dwarf" in its original sense as a term signaling short stature, and not to describe specific conditions such as achondroplasia. That term-suggesting an absence of cartilage—was coined as a description of an Egyptian diety, see Parrot, J.M. "Sur les malformations achondroplasiques et le dieu Ptah," Bull. Anthropol. (Paris) 1, 296 (1878). Davenport repeated the term "dwarf" regularly in summarizing his research. For example, he used the term to describe "a great variety of undersized persons." Davenport, CB, "Postnatal Development of the Human Extremities" Proceedings of the American Philosophical Society 85, no. 5, (November, 1944): 375-455, at 441-443. Research funding for a major anthropometric study of institutional populations (among whom the "mongolians" were estimated to constitute approximately 5%) was secured from the Carnegie Institution of Washington, Columbia University, Letchworth Village, the National Academy of Sciences, the National Research Council, the American Academy of Arts and Sciences and the federal Works Progress Administration. Davenport noted that one of the researchers at Letchworth Village had taken "annually repeated" x-rays of the hands of one hundred children at that institution. He thanked the infants themselves for their participation as research subjects, saying they had "cooperated in so friendly a manner." Ibid., 376.
- Francis Galton, "Eugenics: Its Definition, Scope and Aims" American Journal of Sociology, volume X, July, 1904, 1-25.
- 3. For example, various kinds of competitions including children—such as the Better Baby contests—were eventually designated as "eugenic" events, see Stephen Selden, "Transforming Better Babies into Fitter Families: Archival Resources and the History of the American Eugenics Movement, 1908–1930," *Proceedings of the American Philosophical Society*, vol. 149, June, 2005, 199-225. In the medical arena, the eradication of childhood diseases or disabilities related to infections was the goal of one branch of the eugenics movement. See H. E. Jordan, "The Eugenical Aspects of Venereal Disease," *Transactions of the American Association for the Study and Prevention of Infant Mortality* volume 3 (1912-1913) 156-163.
- 4. See Elof Axel Carlson, *The Unfit: A History of a Bad Idea*, Cold Spring Harbor Press, 2001; Victoria F. Nourse *In Reckless Hands: Skinner v. Oklahoma and the Near-Triumph of American Eugenics* (Norton, 2008) and Stefan Kuhl, *The Nazi Connection: Eugenics, American Racism, and German National Socialism* (2002). Despite extensive historical attention to eugenics, the episode described in this article is not mentioned in any of the many recent histories of eugenics nor does the standard text on that topic, Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (1985) mention the involvement of T.S. Painter and G.W. Corner with Charles Davenport.
- See, for example, Paul A. Lombardo, "Of Utmost National Urgency': The Lynchburg Hepatitis Study, 1942," in *In the Wake of Terror: Medicine and Morality in a Time of Crisis*, ed. Jonathan Moreno (Cambridge: Massachusetts Institute of Technology Press, 2003) 3-315.
- E.E. Southard, "Social Research in Public Institutions," in *Proceedings*, 43rd National Conference on Charities and Corrections (Chicago: Hildmann, 1916), 376-387; 377, 386-387.
- 7. Paul Julian Weindling, *Nazi Medicine and the Nuremberg Trials: From Medical War Crimes to Informed Consent* (London: Palgrave Macmillan, 2004) 101-102, 159. Medical killing itself had been initiated first in mental institutions, even before it was deployed more fully in the death

camps, see Henry Friedlander, *The Origins of Nazi Genocide: From Euthanasia to the Final Solution* (Chapel Hill: University of North Carolina Press, 1995).

- Garland E. Allen, "The Eugenics Record Office at Cold Spring Harbor, 1910-1940: An Essay in Institutional History," *Osiris* 2 (1986): 225-264, at 228.
- 9. The condition was first described as a trisomy in 1959. J.Lejune, M. Gautier, R. Turpin, "Etude des chromosomes somatique de neuf enfants mongolien," *C.R. Acad. Sci.* 248 (1959): 1721-1722.
- 10. Langdon Down, "Observations on an Ethnic Classification of Idiots," *London Hospital Reports* 3 (1866): 259-262.
- Mark Jackson, "Changing Depictions of Disease: Race, Representation and the History of 'Mongolism," in *Race, Science and Medicine*, 1700-1960, ed. Waltraud Ernst and Bernard Harris (London and New York: Routledge, 1999).
- 12. J. Langdon H. Down, "Observations on Ethnic Classification of Idiots, "Journal of Mental Science 13 (1867): 123. The syndrome Down described retained the name "mongolism" for more than a century. See, for example, A.F. Tredgold, A Text-Book of Mental Deficiency, 6th ed. (Baltimore: William Wood and Co., 1937), 207. Today, "mongolism" has taken on the eponymous label of "Down Syndrome."
- Henry H. Goddard, *Heredity of Feeblemindedness*, Eugenics Record Office Bulletin No. 1 (Cold Spring Harbor, N.Y.: Eugenics Record Office, 1913).
- 14. Charles Benedict Davenport, *Heredity in Relation to Eugenics* (New York: Henry Holt, 1913) 261-263.
- Henry H. Goddard, *Feeblemindedness: Its Causes and Consequences* (New York: The Macmillan Company, 1910) 368.
- 16. Heredity in Relation to Eugenics 70, fig. 36.
- 17. See, for example, Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton, 1981) 77-88.
- Bean to Davenport, 16 October 1924, *Davenport Papers*, American Philosophical Society, Philadelphia (hereafter cited as APS).
- Bean to Davenport, 8 March 1925, *Davenport Papers*, APS. For Bean's comparisons between Philipino children and mongloids, *see also* Bean to Davenport, 4 May 1925, *Davenport Papers*, APS.
- 20. Davenport to Bean, 2 April 1925, Eugenics Record Office Papers, APS.
- Robert Bennett Bean, "Some Anatomical Characters of the Mongoloid, a Hypomorph White Type," (49th Annual Session, American Association for the Study of the Feebleminded, 1925) 3, 12. Bean later credited Davenport with "recently bringing in the genes or the chromosomes as determiners of Mongolism."
- 22. "Mongoloid Idiots," Science, n.s. 61 (1925): xiv.
- Chas. B. Davenport, "Light Thrown by Genetics on Evolution and Development," *Scientific Monthly* 30, April, 1930, 307-314, at 314.
- 24. Chas. B. Davenport, "Chromosomes, Endocrines and Heredity," *Scientific Monthly* 20, May, 1925, 491-498, at 495, 497.
- 25. As President of the University of Texas, Painter achieved a different kind of notoriety as the defendant in the Supreme Court's civil rights case of *Sweatt v. Painter* (1950). The plaintiff in that case challenged the policy of excluding Blacks from the University of Texas. U.T. had the state's only law school at the time, but attempted under Painter's leadership to establish a second state school run separately and exclusively for "Negro" students in order to fulfill the legal requirement ensconced in contemporary Constitutional doctrine as "separate but equal." Painter remained President of U.T. from the initiation of the suit in 1946, until it was decided in 1950, and the inadequacy of the new, separate law school was determined in court. At that time segregation at the University of Texas Law School was declared unconstitutional.
- Theophilus S. Painter, "Studies in mammalian spermatogenesis. II. The spermatogenesis of man," *Journal of Experimental Zoology* 37, no. 3 (1923): 291-336; and Theophilus S. Painter, "Further Observations on the Sex Chromosomes of Mammals," *Science* (September 28, 1923): 247-248.

- 27. Vern L. Bulloch, "The Rockefellers and Sex Research," *The Journal of Sex Research* 21 (1985): 113-125, at 121.
- Carl G. Hartman, "The Scientific Achievements of George Washington Corner, M.D.," The American Journal of Anatomy 98 (1956): 5-19.
- 29. George W. Corner, *Ourselves Unborn: An Embryologist's Essay on Man* (New Haven: Yale University Press, 1944), 94.
- Harry Hamilton Laughlin, "Calculating Ancestral Influence in Man," Proceedings of the National Academy of Sciences 6 (May 15, 1920): 235-242.
- Harry H. Laughlin, "Illustrating the Structure and Mathematics of the Human Germ-Plasm," Journal of Heredity 11 (April 1920): 185-189.
- 32. Harry H. Laughlin, "Race Assimilation by the Pure Sire Method," Journal of Heredity 11 (July-August 1920): 259-263; and "The Relation between the Number of Chromosomes of a Species and the Rate of Elimination of Mongrel Blood by the Pure Sire Method," Proceedings of the Society for Experimental Biology and Medicine 16 (1919): 132-134. See also, Harry H. Laughlin, "The Relation between the Number of Chromosomes of a Species and the Rate of Elimination of Mongrel Blood by the Pure Sire Method," Proceedings of the Society for Experimental Biology and Medicine (1919): 132-134.
- 33. H.H. Laughlin to T. S. Painter, 27 July 1921, Laughlin Collection, Truman State University.
- 34. Painter to Laughlin, 29 July 1921, Laughlin Collection, Truman State University.
- 35. Harry Laughlin, *The Second International Exhibition of Eugenics* (Baltimore: Williams and Wilkins, 1923) Plate I.
- 36. Anon, "A note on the accessory chromosomes of man," *Science*, n.s. 39 (May 15, 1914): 721-722; and T.H. Morgan, "Has the white man more chromosomes than the Negro?" *Science* 39 (June 5, 1914): 827-828. See also, H. L. Weiman, "The Chromosomes of Human Spermatocytes," *American Journal of Anatomy* 21 (January 1917): 1-21.
- 37. H. H. Laughlin, "Eugenics in America," *Eugenics Review*, April, 1925, reprint, Laughlin Collection.
- Painter's students later claimed he would never tell them where he obtained his "material." Bentley Glass, "Theophilus Schickel Painter: August 22, 1889—October 5, 1969," *Biographical Memoirs* 59, (Washington, D.C.: National Academies Press, 1990) 309-337.
- Id., 309-337, at 315. Glass speculates that use of tissue from people "with mental disorders" 39 may have been the source of Painter's error in counting chromosomes-since supernumerary chromosomes are linked to some genetic disorders characterized by cognitive deficits. Ibid, at 317. Other researchers apparently had less difficulty than Painter obtaining gonadal material from medical examiners and coroners, and Robert T. Morris related his own experience doing both testicular and ovarian transplants in his biography Fifty Years a Surgeon (New York: E.P. Dutton, 1936) 221-224. Morris also describes a voluntary experimental graft to treat a "patient with sex perversion." The operation was done for therapeutic purposes, but failed. Others, like famous surgeon G. Frank Lydston used gonadal transplantation to treat ailments such as psoriasis, see G. Frank Lydston, Impotence and Sterility with Aberrations of the Sexual Function and Sex-Gland Implantation (Chicago: Riverton Press, 1917) 264-265, and also transplanted testicular material in mental patients, G. Frank Lydston, "The So-Called Interstitial Gland Implantation: To Whom is the Credit Due?" American Journal of Surgery, vol. xxxiv, no. 3, March 1920, 77-80. Extensive experimental transplants were performed by San Quentin prison surgeon Leo Stanley. In almost every case, the "donor" of tissue was a cadaver, see Susan E. Lederer, Flesh and Blood: Organ Transplantation and Blood Transfusion in Twentieth - Century America (New York: Oxford, 2008) 167-169.
- 40. Theophilus S. Painter, "The Spermatogenesis of Man," *Journal of Experimental Zoology* 37 (1923): 291-335 at 292.
- 41. Id. Painter reasserted his conclusions in later publications such as "The Sex Chromosomes of Man," *American Naturalist* 58 (Nov-Dec 1924): 506- 524. "Recent studies in human spermatogenesis have cleared up the doubt...over the number of chromosomes possessed by mankind." Ibid, 506. He reiterated the story finally in "Chromosomes and Genes Viewed from
a Perspective of Fifty Years of Research," *Stadler Genetics Symposium*, ed. Gordon Kimber and G.P. Redei (1971), 33-41.

- 42. George W. Corner, *The Seven Ages of a Medical Scientist: An Autobiography* (Philadelphia: University of Pennsylvania Press, 1981), 155.
- 43. Ibid, 259-260.
- 44. Painter to Davenport, 20 November 1923, APS.
- 45. Davenport's access to Letchworth Village undoubtedly benefited from the presence of Mary W. Harriman on its Board of Directors. Harriman had been the primary benefactor in founding Davenport's Eugenic Record Office. He noted her involvement with Letchworth in his publications describing research that took place there. See, for example, Charles Benedict Davenport, "Post-Natal Development of the Head," *Proceedings of the American Philosophical Society* 83, (July 20, 1940): 1-215.
- 46. Charles B. Davenport to Prof. T.S. Painter, 22 January 1929, APS.
- 47. Painter to Davenport, 7 February 1929, APS.
- 48. "Letchworth Village Name Changed to Hudson Valley DDSO," New York State Office of Mental Retardation and Developmental Disabilities Reports 11 (July, 1999), 1. Letchworth Village was opened in 1913 as a small institution with several dozen "feeble-minded and epileptic" residents; it eventually grew to house more than 4000. State of New York, Report of the State Commission to Investigate Provision for the Mentally Deficient (Albany: J.B. Lyon Co., 1915), 305-311.
- 49. Davenport to Painter, 12 February 1929, APS.
- 50. Davenport to Eugene W. Martz, Clinical Director, Letchworth Village, 30 June 1929, APS.
- 51. Ibid.
- 52. Painter to Davenport, 6 July 1929, APS.
- 53. Martz to Davenport, 18 July 1929, APS.
- 54. Davenport to Martz, 20 July 1929, APS.
- 55. Ibid.
- 56. J.H. Kellogg, Plain Facts for Old and Young (Burlington, Iowa: I.F. Segner, 1884), 370-371, 456.
- 57. Davenport to Painter, 30 July 1929, APS.
- 58. Painter to Davenport, 4 August 1929, APS.
- 59. Martz to Davenport, 5 August 1929, APS. This comment from Martz is all the more interesting since unlike Martz, Davenport was not a physician.
- 60. Painter to Davenport, 28 September 1929, APS.
- 61. Davenport to Painter, 9 October 1929, APS.
- 62. Davenport to Painter, 2 April 1930, APS.
- 63. Painter to Davenport, 8 April 1930, APS.
- 64. Davenport to Painter, 15 April 1930, APS.
- 65. See, for example, Theophilus S. Painter, Department of Zoölogy, University of Texas "Studies in mammalian spermatogenesis. V. The Chromosomes of the Horse," *Contribution no. 167, Department of Zoology, University of Texas, and Study no. 1 of the Walter J. Salmon Researches into the Genetics of the Thoroughbred Horse, under the direction of H. H. Laughlin.*
- 66. Malcolm Jay Kottler, "From 48 to 46: Cytological Technique, preconceptions, and the Counting of Human Chromosomes," *Bulletin of the History of Medicine* 48(4) (1974): 465-502. The key article was Joe Hin Tjio and Albert Levan, "The Chromosome Number in Man," *Hereditas* 42 (1956): 1-6.
- 67. L.E. Olson, et al., "A Chromosome 21 Critical Region Does not Cause Specific Down Syndrome Phenotypes," *Science* 306 (2004): 687-690.
- 68. J.H. Kellogg, Plain Facts for Old and Young (Burlington, Iowa: I.F. Segner, 1884), 370-371, 456.
- 69. "Removal of the Ovaries as a Therapeutic Measure in Public Institutions for the Insane," *Journal* of the American Medical Association 20 (Feb. 4, 1893): 135-137, at 135-36.
- 70. H. B. Young, "Removal of the Ovaries etc., in Public Institutions for the Insane," *Journal of the American Medical Association* 20 (March 4, 1893): 258.

ETHICS & MEDICINE

- 71. Philip R. Reilly, *The Surgical Solution: A History of Involuntary Sterilization in the United States* (Baltimore and London: Johns Hopkins University Press, 1991), 29.
- 72. Martin W. Barr, *Mental Defectives: Their History, Treatment and Training* (Philadelphia: Blakiston's Son, 1904), 196.
- 73. Issac N. Kerlin, "President's Annual Address," *Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons* (1892) 274-285, at 278.
- 74. Martin W. Barr, *Mental Defectives: Their History, Treatment and Training* (Philadelphia: Blakiston's Son, 1904) 192-193.
- Savas Nittis, "The Hippocratic Oath in Reference to Lithotomy: A New Interpretation with Historical Notes on Castration," *Bulletin of the History of Medicine* II, July 1939, 719-728.
- John Allan Hornsby and Richard E. Schmidt, *The Modern Hospital* (Philadelphia: W. B. Saunders Company, 1913), 282, 341, 339.
- 77. Paul A. Lombardo, Phantom Tumors & Hysterical Women: Revising Our View of the Schloendorff Case, *Journal of Medicine and Ethics* 33 (2005): 791.
- Details of the controversy are contained in Susan Eyrich Lederer, "Hideyo Noguchi's Leutin Experiment and the Antivivisectionists," *ISIS* (1985) 76: 31-48.
- 79. Albert Leffingwell, An Ethical Problem or Sidelights upon Scientific Experimentation on Man and Animals (New York: Farrell, 1916) 291.
- 80. Ibid., 323.
- 81. "Baseless Charge Against Dr. Noguchi," New York Times, May 21, 1912.

Paul A. Lombardo, PhD, JD, is Professor of Law at the Center for Law, Health and Society at Georgia State University's College of Law. He has lectured at numerous colleges and universities in the US and Canada and in 2004 was a Visiting Professor at Aga Khan University in Karachi, Pakistan. He has previously served on the faculty of the Schools of Law and Medicine at the University of Virginia, where he directed the Center for Mental Health Law at the Institute of Law, Psychiatry and Public Policy and the Program in Law and Medicine at the Center for Biomedical Ethics, USA.

THE FUTURE OF THE HUMAN SPECIES

BRENT WATERS, DPHIL

If a number of pundits are correct, we have already taken some initial steps toward creating a posthuman future.¹ The goal of this project is nothing less than the perfection of the human species. Specifically, human performance will be enhanced and longevity extended through anticipated advances in pharmacology, biotechnology, and bionics. Drugs, for example, can lessen the need for sleep; genetic engineering will slow the aging process; artificial limbs will enhance strength and agility; and brain implants will enhance the speed of interacting with computers. The cyborg becomes the next stage of human evolution.² Some visionaries foresee a day when, with the aid of artificial intelligence and robotics, endless lives might be achieved. The underlying binary information constituting one's personality would be uploaded into a computer and then downloaded into robotic bodies or virtual reality programs. With sufficient and reliable memory storage, the process could, in principle, be repeated indefinitely, thereby achieving virtual immortality.³ In the posthuman future, humans become self-perfected artifacts by blurring, if not eliminating, the line separating the natural from the artificial.⁴

The promise of the posthuman project is the creation of beings that live healthy, productive, and happy lives, and most importantly beings that live for very long time—perhaps forever. The ultimate promise is immortality. The accompanying peril, however, is that the cost is exorbitant. The price of perfecting humankind is its destruction, for in becoming posthuman humans cease being human. The peril of the posthuman project, in short, is that its optimism disguises an underlying death-wish for the human species.

One might be tempted to object that any worry about this peril is misplaced. The peril presupposes a promise that is far from certain. Few, if any, of the requisite technological advances have yet been achieved, and the likelihood of dramatic breakthroughs any time soon is slim at best. A so-called posthuman future is based on science fiction, not science. Consequently, time should not be wasted worrying about a peril that might, but probably will never present itself.

There are two reasons why this temptation should be resisted. First, even in the absence of the technical advances and breakthroughs that would be required, we nonetheless must come to terms with the extent to which technology is shaping the character and trajectories of contemporary life. As Martin Heidegger and others have observed, technology has become the ontology of our age; our mode of being in the world by mastering and reshaping it in an image of what we want the world to become.⁵ In large part, humans now live, and move, and have their being within fabricated environments that have become their natural habitats. It is through technology that they increasingly express who they are and what they aspire to become. This is not a mere acknowledgement of the ubiquitous presence of machines and gadgets within the fabric of daily life, but that in increasingly turning to medicine to control their behavior, regulate their biological processes, and repair and sculpt their bodies humans are literally coming to embody a technological age. Focusing on the prospect of a posthuman

future, which is admittedly far from certain, helps us to come to terms with the fact that, to invoke George Grant's phrase, "in each lived moment of our waking and sleeping, we *are* technological civilisation."⁶ To ponder the prospect of becoming posthuman requires that we also ask the question of what it means to be human, and any answer we offer cannot avoid the question of technology.

Second, even if most, if not all, of the more immodest expectations-such as immortality—never come true, posthuman discourse is nevertheless shaping a vision of the future, and thereby derivatively our moral imagination. Like it or not, how we envision the future informs our moral convictions and conduct in the present, and it does not matter how improbable, strange, or fantastic such a vision might appear to be in exerting such influence. Whether, for example, I believe that I will either live a long and sickly life or a short but robust one, goes a long way in shaping how I spend my time and money in the meantime. Whether or not either scenario is likely is largely irrelevant, for I become a certain kind of person in reaction to what I believe the future entails; if I believe that my life will be short and sweet, I become a free-spending bohemian. In a similar vein, if we believe, either implicitly or explicitly, that we can and should exert greater mastery over nature and human nature, that belief goes a long way in shaping what we do and how we treat each other in the present. In this respect, N. Katherine Hayles is correct in asserting that "People become posthuman because they think they are posthuman."7 Such posthuman thinking should, at the very least, prompt some deliberation on its good or ill effects in forming our moral imagination, particularly in light of growing technological power and potential for further development.

If I have persuaded the reader that the peril of the posthuman project is, after all, worthy of some scrutiny, how might we best proceed? A promising avenue is suggested by the early work of the President's Council on Bioethics in which its members discussed Nathaniel Hawthorne's short story, *The Birthmark*.⁸ Although the exercise was derided by many reporters and bioethicists as a waste of time, it reflected the insight of its chairman, Leon Kass, that fiction is often quite perceptive in revealing fundamental convictions, hopes, and aspirations, offering a fruitful starting point for moral deliberation and discernment.

The Birthmark is a tale about a brilliant scientist who marries a stunningly beautiful woman. Her appearance is perfect in every regard except for a tiny birthmark on her cheek. The scientist becomes obsessed with this tiny, barely imperceptible flaw, and he concocts various potions to remove it. Over time his efforts succeed. The birthmark disappears, but only at the moment that his wife dies. In Hawthorne's words: "As the last crimson tint of the birthmark—that sole token of human imperfection—faded from her cheek, the parting breath of the now perfect woman passed into the atmosphere..."

Hawthorne offers a sobering warning: the quest for perfection leads to a deadly destination. The cost of removing the flaw is a corpse. The applicability of this story to the posthuman project is obvious: humans must first be killed in order to perfect them. The extinction of the human species is certainly one possible consequence that should give some pause in assessing the prospect of a posthuman future, but I do not think it is the most likely outcome. Rather, technological reconstruction may eventually produce a new species that is deemed to be superior, but to what extent these new beings can be said to be perfect is question begging: by what standard of perfection is this

judgment made, and what are the costs of attaining this perfect state? In other words, the underlying and unacknowledged death-wish driving the posthuman project is not an overt desire to exterminate humankind, but an ill-advised attempt to strip away the vulnerability and imperfections that enable humans to be human and humane. It is not the death of humankind but its humanity that is at stake. We can begin to unfold this more subtle endeavor by taking a look at another short story by Hawthorne.

In *Rappaccini's Daughter* we encounter the highly acclaimed physician, Dr. Rappaccini, his lovely daughter, Beatrice, and a young medical student, Giovanni, who is living in the guest room. One of the chief features of the villa is a large garden that is filled with exotic plants, each one of them highly poisonous. The slightest contact is lethal, and even a quick sniff of their aroma causes illness. To stroll through this garden, one must keep his distance. Yet Beatrice is seen embracing the plants and breathing deeply of their fragrance. As the story unfolds we learn that since her birth her father has been slowly giving her increased dosages of the poisons he has been extracting from the garden. The effect has been to make her immune and invulnerable to any disease.

Giovanni and Beatrice fall in love. Yet through their courtship they never embrace, kiss, or hold hands for, as with the plants from the garden, Beatrice is lethal to the touch. We also learn that Dr. Rappaccini has been administering the same procedure to Giovanni without his knowledge. The father wants to create an intimate companion for his lonely daughter. When Giovanni learns that he too is being made invulnerable by becoming poisonous, he is appalled. A rival of Dr. Rappaccini on the medical faculty gives Giovanni an antidote that purportedly will make both he and Beatrice normal again. The couple makes a pact, but Beatrice insists that she take antidote first, and she dies.

This sad tale offers three lessons that may guide an assessment of the posthuman project: First, the cost of invulnerability is high. Dr. Rappaccini has purportedly achieved his goal of preventing his daughter, Beatrice, from contracting any deadly disease. She will be spared needless pain and suffering, and given a power and invincibility that few enjoy in confronting a cruel world. But it will also be an isolated life, devoid of any physical contact. She can neither touch nor be touched by others, for she is literally poisonous to anyone other than herself. Her life will also be devoid of any intimate and lasting relationships, a crushing fate as her father recognizes in his desperate attempt to transform Giovanni into a suitable, and equally poisonous, companion. Beatrice's invulnerability has made her something less than human. May we not say, then, that in attempting to transform humankind into a superior species we run the risk of the death of our humanity?

Second, there is no going back. When Beatrice finally finds someone with whom she can purportedly share her life with fully, Giovanni is appalled by what he is becoming. Out of her love she agrees to forsake her invulnerability and return with her lover to a natural state where together they may risk a vulnerable embrace. The attempt, however, proves futile and deadly, for her transformation had been complete and irreversible. In Hawthorne's haunting words: "To Beatrice—so powerfully had her earthly part been wrought upon by Rappaccini's skill—*as poison had been life*, so the powerful antidote was death."⁹ May we not say, then, that once we travel very far down the posthuman path, it may prove difficult, if not impossible, to turn back?

Third, even if the promise is achieved, the consequences are ambiguous and uncertain. Because of Beatrice's death we never know how the life of a poisonous couple might unfold. Would they be able to fully embrace, or would their respective lives prove too toxic to interlock in any meaningful sense? Moreover, is there a significant difference between the embrace of two invulnerable beings as opposed to vulnerable creatures? Would they be able to have offspring? If so, would their children share with them a life of poison, or would they be unable to touch what they have begotten until Rappaccini's skill worked its transformation once again? May we not say, then, that even if the posthuman promise of a superior species is achieved, we do not know what will become of the human spirit and soul, and thereby whether or not these new beings will prove to be truly superior?

Hawthorne's stories—written in the early nineteenth century—help to expose the posthuman project for what it really is, namely, a religious movement, and not a new or original one at that. The central posthuman precept may be summarized as follows: finitude and mortality represent the dire plight of the human condition. It is irrational and unfair that humans suffer, grow old, and die. In response, posthumanists offer the salvation of human transformation and perfection, culminating in virtual immortality.

Hawthorne reminds us that this is an old complaint. Few, if any, of our ancestors warmly embraced their mortal limits. There is also nothing novel about the proffered solution. Hawthorne's plants and potions are simply exchanged for genetic engineering, miniaturization, silicon chips, and binary code. Consequently, it should not be surprising if Christians hear some familiar notes in this posthuman tune, for they have encountered similar themes before in what they identified as false religious beliefs. In more formal terms, posthuman discourse is based largely on philosophical or theological precepts about nature, human nature, and human destiny that are derived from what may be described as heretical doctrines. There are three prominent strands that we may focus upon for the purpose of this essay.

We may conveniently call the first strand *nihilism*. Nihilism is a modern philosophical orientation which posits that the world is devoid of any purpose or meaning. Consequently, there are no objective moral standards, only a subjective will to power. We assert this will over inanimate objects such as stones and cars, animate things such as plants or animals, or other people such as children and students. As late moderns, technology is the principal means that is used to assert this power. We transform minerals into steel to build cars; we use genetic engineering to produce better plants and animals; and we use drugs and psychological techniques to control the behavior of children and students. The world, our lives, and the lives of others are artifacts that we construct, and the future is largely what we make of it and will it to be.

Friedrich Nietzsche has become closely associated with this philosophical orientation. It should be noted, however, that although he accurately describes the nihilism of late modernity in all its lurid details, he does not commend it. Indeed, he is alarmed by its destructive potential. Nihilists can too easily conclude that in a world where there is nothing noble to will, it is better to will nothing at all—a despair leading to unspeakable violence. This is why he places his hope in the *Übermensch* or Overman, a superior being that will rise above the fray and provide some meaning and purpose in a meaningless and purposeless world. Perhaps Nietzsche's hope can be become real

in the transformation of the human into the posthuman. Why not direct the otherwise directionless will to power toward the constructive goal of creating and perfecting a superior species?

This leads to the second strand that we may call *Pelagianism*. Pelagianism is a theological doctrine that is derived from that arch heretic Pelagius who caught the wrath of St. Augustine. The central tenet is that Adam's fall did not corrupt human nature. Subsequent generations are not infected by original sin. They possess an innate ability to know the difference between right and wrong, and may choose the former without God's assistance. Salvation resides within each human heart, and does not depend upon the initiative of a divine redeemer. It is ultimately human action, not God's that counts. Consequently, humans can will themselves to be good; they can even will themselves to be perfect. And they can use their technological ingenuity to help accomplish this perfection.

In their more sober moments, nihilists and Pelagians recognize, however, that there are severe constraints that must be overcome in asserting the will to power and the will to perfection. This leads us to the third strand, which we may call *Manicheism*. Manicheism is a dualistic teaching that draws a sharp divide between the physical body and what may be variously described as an immaterial spirit, soul, or will. It is this immaterial essence which defines who we are and what we aspire to be. Unfortunately, this essence is trapped within a weak and fragile body that constrains the will to power and perfection. No matter how much in my youth I may have willed myself to be a major league pitcher, I did not have the body which would enable me to perfect a blazing fastball and killer curve. No matter how much we may will ourselves to live, eventually our bodies fail us and we die. What Manicheans in every age long for is to be rescued, to be saved from their bodies. The promise of virtual immortality, a life free of embodied limitations, then, is also the promise of salvation.

Given these formative strands, Christians are rightfully skeptical of the posthuman project, for it represents a corruption of their faith. Christians may, in good faith, concede that the patterns and trajectories of human life are to a large extent a matter of the will, and such willing certainly entails gaining and asserting various kinds of power. In the absence of such willful power civil communities, for instance, could not exist. What Christians do not affirm is that power itself is a proper object to be willed; rather, power is a means of achieving that which is willed.

What is the highest or greatest good that humans should will? The short answer is, of course, God. If we direct our will toward any lesser goods, our subsequent desires and lives become misdirected, disordered, or, to use a word that is falling out of favor, sinful. And the consequences of sin are grave. When the will is misaligned, for example, our attempts to fulfill the great command to love God and neighbor ends up as love of self, which we expect God and our neighbors to honor and support. The will to power, in short, is little more than a thin justification for narcissistic self-indulgence. The great moral task of any generation is not the triumph of the self-oriented will, but to align what we will in obedience to God's will.

Knowing God's will—much less aligning ourselves to it in faithful obedience—is, admittedly, no easy task. The ways of God are inscrutable and unsearchable. Contrary to Pelagius and his latter-day disciples, we do not have it within us to know the mind and

will of God, and therefore we cannot know how to will and perfect the good. The great danger of Pelagianism is its underlying arrogance that if we just keep trying harder we will somehow achieve perfection, but the endeavor itself is a fantasy. In his book, *The Perfectibility of Man*, John Passmore examines the unhappy legacy of Pelagius within the history of Western civilization.¹⁰ One of the more prominent problems is that the ideal perfection to be achieved is a moving target, subject to changing social, cultural, and political circumstances. At various times contemplation, virtue, reason, politics, revolution, and eugenic purification have been lifted up as models of the perfect life that should be pursued. As Passmore notes, all of these projects failed miserably, and he adds the grim observation that whenever the idea of perfection—whatever it may happen to be—has seized public attention, there is increased intolerance directed against those judged to be incapable or unwilling to attain the proffered goal.

What Pelagians of any age fail to recognize is that what little we know about what perfection might mean is not a result of our will to power, but is a gift of grace. We cannot will ourselves to be perfect; we can only admit that in our imperfection we have been embraced and upheld by God in Christ. Receiving this gift of grace should not only inspire a response of gratitude, but should also make us mindful of the limits which are inherent to us as finite creatures that are in great need of this gift. Consequently, humans are not called to live lives in which they are constantly trying harder to obtain a perfection that cannot be obtained, but to live grace-filled lives of confession, repentance, and amendment of life. Or in other words, to live lives as creatures of God who accept their finitude and mortality as a blessing rather than curse.

It is in respect to bodily limitations that humans encounter with great intensity the inherent limitations of their creaturely status. Humans are not only creatures; they are *embodied* creatures. As such they are also finite and temporal beings, and therefore subject to bodily limitations. Humans cannot do everything they want, and they cannot live forever since their bodies are unable to withstand the ravages of time and natural necessity. Posthumanists can only respond to these limits with a Manichean disgust and disdain for the body, because it is the chief obstacle preventing them from successfully achieving the will to power and perfection.

This means, however, that the posthuman project is predicated upon a fundamental contradiction: in order for humans to achieve their full potential they must destroy their bodies, but in doing so they destroy the very thing which makes them human. Despite all their rhetoric about enhancing the performance of bodily functions, the posthuman project is nevertheless driven by a hatred and loathing of the body. Extending longevity and improving physical and mental functions is merely an interim strategy until such time that virtual immortality is achieved, liberating humans from their weak and fragile bodies. Yet is not this high-tech Manichean dream tantamount, as Paul Ramsey once observed, to a suicidal death-wish for the human species?¹¹

It is embodiment which decisively separates posthumanists and Christians, for their assessments of what it means to be human leads to differing beliefs about salvation. Unlike posthumanists, Christians have never believed that humans are creatures who unfortunately happen to have bodies. Rather, to invoke Ramsey's imagery again, humans are inextricably embodied souls *and* ensouled bodies.¹² Consequently, humans are not saved from their bodies, but it as embodied creatures that they are claimed,

redeemed, and renewed by God. This is why Christians are not driven by a death-wish, for as St. Paul reminds them, death remains the final enemy that is not to be fraternized with, much less warmly embraced.¹³ But humans consent to their mortal and finite limits because they are *creatures* who have been created in the image and likeness of God; it is as embodied creatures that they love, serve, and are in fellowship with God. The finite and temporal limits which posthumanists loathe and hate are received by Christians as a blessing, for these limits enable them to be the creatures that God intends us to be. To despise the constraints and fragility of embodiment is to also despise the work of the Creator.

If my portrayal of the posthuman project as a religious movement incorporating the formative strands of nihilism, Pelagianism, and Manicheism is at all correct, then there are good reasons why Christians should not only be skeptical but should also oppose it. There are, to be sure, rich resources within their theological tradition they may draw upon in making their case against the underlying false and heretical beliefs. But it is not enough to be against something; simply opposing the posthuman project will not do. A constructive proposal regarding what Christians affirm must also be offered. If Christians are to help shape contemporary culture—particularly in a setting in which I fear the posthuman message will prove attractive, if not seductive—then they must offer an alternative and compelling vision; a counter theological discourse so to speak. In the remainder of this essay I want to sketch-out what some of the contours of this theological discourse might entail by focusing on two anthropological questions: *What does it mean to be human*? and *What is the destiny of the human species*?¹⁴

In addressing these questions, Christians begin with the simple affirmation that anthropology *is* Christology. What this admittedly inelegant phrase is meant to convey is that "Jesus Christ" is the short answer to both questions. One turns to Christ to learn what being human means and to catch a glimpse of our destiny as a species. In making this anthropological claim, it is important to keep in mind that in fixing our gaze on Christ, we are also encountering the triune God. The God who is in Christ the redeemer is the same God who is the Creator and sustainer—the God who is also Father and Holy Spirit. Being attentive to Christ is also attending to God in his fullness, the eternal One who is the origin and end of creation and thereby the One who gives creation and its creatures their direction and purpose. It is only in this respect that Christ's otherwise immodest claim that he is the *Alpha* and *Omega* is explicable and illuminating.¹⁵

What might we find by fixing our gaze on Jesus Christ? An exhaustive answer is beyond the scope of a single paper, or the career of any single theologian for that matter. More modestly, allow me to suggest three things to look for.

First: the *Incarnation*. The centerpiece of the gospel is the extraordinary claim that in Jesus Christ God became a human being. The Word became flesh and dwelt among us full of grace and truth.¹⁶ We may say, then, that in the Incarnation the necessity of finitude and mortality, of human limitations more broadly, are affirmed rather than eliminated. It is important to stress, however, that in emptying himself and taking-on human likeness, Christ also shares the human condition, complete with its suffering, pain, and death.¹⁷ In his life and ministry Jesus does not avoid or escape the constraints of finitude, but embraces them, and in doing so reconfirms a divine blessing. The life and lives of God's creatures, however vulnerable, fragile, and imperfect they might be, are nonetheless good precisely because they have been created and blessed by God, a doxology that is sung, in a manner of speaking, in the Incarnation. Most importantly, Jesus does not cheat death. Again, it is important to stress that Jesus *dies* on the cross; the events of Good Friday produce a corpse that is placed in a tomb. How could it be otherwise if indeed the Word had become mortal flesh?

But death is not the final word, which leads to the second item to look for in Jesus Christ: the *resurrection*. Drawing upon the work of Oliver O'Donovan,¹⁸ the resurrection of Jesus Christ from the dead vindicates Jesus' life and ministry. Moreover, since God is incarnate in human life, the vindication extends to all of creation. Because humans were not "allowed to uncreate what God created,"¹⁹ there is a created order to be discerned because it has been vindicated by its Creator. The resurrection of Jesus Christ, in short, entails the resurrection of humankind and with it the renewal of creation.

What exactly does this vindication and renewal of creation entail? First and foremost, it discloses a *created order* which provides an objective standard and teleological order against which human desires are both judged and conformed. This objectivity is seen in what O'Donovan describes as the "natural ethic."²⁰ Contrary to the posthuman project, the moral life is not a constructed artifact that is designed to enable the will to power and perfection. Rather, Christ's resurrection discloses in greater clarity that human life and lives should be oriented toward certain moral structures and relationships that are inherent to the order of creation. Women and men, for instance, are drawn to each other not merely to reproduce in perpetuating the species, but to also form bonds of affection between themselves and with their offspring. The generations are literally linked together through a natural chain of mutual and sacrificial love.

The teleological order of creation can be seen in social structures which order and promote these bonds of love and affection. Marriage, for example, is oriented not only toward enriching love, affection, and mutuality between spouses, but also promoting mutual and self-sacrificial bonds between parents and children. It is through one generation surrendering itself to the following one that human life and lives flourish over time. What is especially noteworthy is that the embodied character of human life is absolutely crucial in obtaining these goods of marriage and family, for it is only as embodied creatures that humans can interact and love one another in any meaningful sense.²¹ The physical, finite, and temporal limitations which posthumanists decry are the very features which provide the rich texture of human life beyond the bare minimum of natural necessity. It is the creaturely finitude and mortality which are affirmed in the Incarnation and vindicated in the resurrection that the posthuman project wishes to annihilate.

A vindicated and renewed creation is also genuinely liberating, because it provides the foundation of *obedient freedom*.²² Through Christ's resurrection we simultaneously look back to the origin of creation in Christ *and* to its destiny in Christ. This Janus-like vision leads to the third and final theological feature, namely, *eschatology* or the destiny of the human species.

In the absence of this dual orientation, humans become enslaved to a false perception of nature in which any inkling of a natural moral order is perceived as a threat. Consequently, finitude and mortality are inimical to their survival and flourishing; they are threats to human welfare which must be vanquished. Hence, the posthuman project of transforming humans into an invulnerable and immortal species. The project, however, is based on the false assumption that freedom is expanded by overcoming all finite and temporal limits. Only the invulnerable and immortal being is purportedly free.

But the posthuman project is actually enslaving, for it leads to an inability to be obedient, and as such disabled beings, humans disfigure their proper dominion over and stewardship of creation into a domination and mastery of nature and human nature. By looking to creation's destiny in Christ, however, these so-called "threats" are revealed as given and necessary limits that define and order human life and lives; humans are free to love their fate, because it has already been taken up into the eternal life and fellowship of their Creator and redeemer. In this respect, true freedom is a gift of the Spirit that frees us to be obedient to the definitive limits which shape our lives as finite and mortal creatures. In short, we are free only by being limited. To return to the previous example, we are only free to be married when we limit our intimacy exclusively to one other person; we are only free to be parents when we constrain our self-interests for the benefit of our descendants.

More broadly, Christ's resurrection from the dead discloses the destiny of creation and its creatures. There is a future trajectory revealed in the resurrection of the incarnate One, signifying its destiny in the exalted Christ. Such a future orientation inspires an ordering of human life that is teleological rather than perfectionist. Creation and its creatures will be transformed in the fullness of time, and humans will contribute to this transformation. Posthumanists are correct in this regard, but they have been seized by a half-truth which in its incompleteness proves destructive and dangerous. For our transformation is shaped by Christ, and not our attempts to overcome the finite and mortal limits of a created order. The Creator who has vindicated creation will also redeem it fully in the fullness of time. In this respect, a life of obedient freedom is also a life of preparation for eternal and timeless fellowship with God instead of a quest for immortality and endless time, a consenting to God's will being done on earth rather than the triumph of our will to power and perfection. In this respect humans look forward to this completion, this divine perfection, when even the created and natural goods of marriage and family, for instance, are no longer necessary, for the roles of wife, husband, parent, and child are transformed into the eternal fellowship of sisterhood and brotherhood in Christ.

If the preceding analysis is at all correct, then we are offered sharply contrasting options regarding the future of the human species. On the one hand, the posthuman project, with its will to power and perfection, and hatred of the body, offers the construction of a superior and immortal species. On the other hand, there is the Christian offer of eternal fellowship with God through a life of obedient conformity to God's will, but it is not a future that offers any escape from finitude, suffering, and death. We must be careful about which destiny we choose, taking precautions that our choice is not the result of inattention or naivety. The practical decisions that are made today in regard to research and development in such areas as medicine, biotechnology, nanotechnology, bionics and the like, will not be inconsequential for the future. We must choose wisely, for contrary to the spirit of our age the future is not something we choose.

In his essay, "Thinking about Technology," George Grant provides an insightful meditation on this question of destiny.²³ He contends that we perceive technology as a collection of neutral instruments that we use in ways that we choose. Like any other technology, we use a computer, for instance, to read an e-book, keep a ledger, or surf the Internet. The computer simply does not impose upon its user the ways it should be used.²⁴

Grant believes that this reassuring image of technological neutrality is misleading. Of course the computer, like any technology, imposes the ways it should be used upon its users; otherwise it could not be used for the purposes for which it was designed. Reading an e-book, for instance, is not the same as reading a printed book. More broadly, we cannot easily pick and choose how technologies are used because they incorporate certain values and purposes which cannot be separated. Any project of technological development enfolds and shapes its users in its accompanying logic and destiny. As Grant has observed: "To put the matter crudely: when we represent technology to ourselves through its own common sense we think of ourselves as picking and choosing in a supermarket, rather than within the analogy of the package deal. We have bought a package deal of far more fundamental novelness than simply a set of instruments under our control. It is a destiny which enfolds us in its own conceptions of instrumentality, neutrality and purposiveness."²⁵ Technological development inevitably transforms, for good or ill, those who are undertaking the project in the first place; it transforms who they think we are, and what they aspire to become.

If Grant is right then we should be wary of the posthuman project, for once we initiate a process of transforming the human species, we become enveloped in a destiny that takes-on a life of its own, one that is not subject to our control. And like any destiny it imposes itself, and its imposition has stark and unavoidable moral consequences. Again in Grant's trenchant words: "The coming to be of technology has required changes in what we think is good, what we think good is, how we conceive sanity and madness, justice and injustice, rationality and irrationality, beauty and ugliness."²⁶

Although Grant overstates his case for technological determinism, he nonetheless offers salient and sobering advice in regard to the posthuman project, that once we start down the road of transforming ourselves it will be difficult to slow the momentum, much less change or reverse course. The danger is that such momentum might carry humankind toward a destiny whose consequences are both unforeseen and unwanted. Yet we become locked into a new set of circumstances that we can neither change nor control, for there is no going back. To return to the computer as an example, when the Internet was introduced with the great promise of easy and instant access to abundant information, who foresaw that it would also become a cesspool of pornography, child predators, and financial theft and fraud? Yet are there any serious proposals for tearing-up or even staying-off the information highway?

To a large extent, Grant reinforces the messages of Hawthorne's stories: be careful how you go about creating beautiful, invulnerable, and perfect people, for the projects may enfold you in a deadly destiny. This is an especially poignant warning, for it reminds us that the evil we commit is more often than not the result of a myopic moral vision than a wicked heart. Dr. Rappaccini loved his daughter, but he cared, in Hawthorne's words "infinitely more for science than for mankind," and as the brilliant scientist looked upon his now perfectly beautiful but dead wife, Hawthorne notes "he failed to look beyond the shadowy scope of time, and, living once for all in eternity, to find the perfect future in the present."

Is not finding the perfect future in the present the moral and religious challenge that confronts us in the prospect of a posthuman future? And is this not a particularly difficult challenge in a late modern world which has largely forgotten how and where to look? This difficulty stems largely, I think, from a prevalent cultural conceit regarding creativity. We have come to believe that we are a creative people who have the power to create our world, ourselves, and our future. We are a creative people who are masters of our own fate, so why bother to look in the present when our gaze is fixed permanently toward the future?

Yet arguably as creatures we create nothing, for that is a task that is reserved exclusively by and for *the* Creator. We make things, but that does not make us creative. Art best exemplifies the difference between making and creating. Artists make such things as paintings and sculptures. Skilled artists make beautiful objects, but they do not create beauty. Rather, their art reveals the beautiful, drawing the beholder into a realm that is beyond either the work of art or the artist. In this respect, art at its best is iconic, for it points beyond itself to the Creator of beauty. When we encounter good art we look in and through it to the source of its beauty. Art is, in short, revelatory of something greater than itself, and is debased when it serves only to glorify and immortalize the so-called creativity of the artist.

In a similar manner, may we not say that the posthuman project is the attempt to *create* a superior species as the triumph of the will to power over nature and human nature, and thereby draws attention to its own ingenuity and creativity? And in recreating ourselves as self-made artifacts of the will to perfection, are not posthumanists trying to glorify and immortalize their own skill and creativity? Yet the end result will not so much be a superior and perfected species, but a debased humanity that has forgotten that they are creatures and not creators. In short, posthumans can point to nothing greater than themselves: beings that have drunk deeply from the poisonous wells of Manicheism, Pelagianism, and nihilism.

As we take our first, tentative steps toward a posthuman future, it is not enough for Christians to be critics only. They must also embody and bear witness to an alternative future, a perfect future which in Christ is already in the present. In this respect, they must insist that technology generally should be developed and used in iconic ways which reveal the ways of the Creator who is the source of all that is good, true, and beautiful. In particular, Christians must strive to recover and preserve medicine as a healing art that discloses Jesus Christ as the true nature and destiny of the human species.

Endnotes

1. See, e.g. Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Strauss and Giroux, 2002).

See, e.g. Philip Hefner, *Technology and Human Becoming* (Minneapolis, MN: Fortress Press, 2003).

ETHICS & MEDICINE

- 3. See, e.g. Ray Kurzweil, The Age of Spiritual Machines: When Computers Exceed Human Intelligence (New York: Penguin Books, 2000), and The Singularity Is Near: When Humans Transcend Biology (London and New York: Penguin Books, 2005); see also Hans Moravec, Mind Children: The Future of Robot and Human Intelligence (Cambridge, MA and London: Harvard University Press, 1988) and Hans Moravec, Robot: Mere Machines to Transcendent Mind (Oxford and New York: Oxford University Press, 1999).
- 4. I examine the emergence of a posthuman world in much greater detail in my book, *From Human to Posthuman: Christian Theology and Technology in a Postmodern World* (Aldershot, UK and Burlington, VT: Ashgate, 2006).
- See Martin Heidegger, *The Question Concerning Technology and other Essays* (New York and London: Harper and Row, 1977); see also Michael E. Zimmerman, *Heidegger's Confrontation with Modernity: Technology, Politics, Art* (Bloomington, IN and Indianapolis, IN: Indiana University Press, 1990).
- 6. George Parkin Grant, *Technology and Justice* (Notre Dame, IN: Notre Dame University Press, 1986), p. 11 (emphasis added).
- 7. M. Katherine Hayles, *How we became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics* (Chicago and London: University of Chicago Press, 1999), p. 7.
- See "Meeting Transcript," January 17, 2002, http://www.bioethics.gov/transcripts/jan02/ jan17full.html#2
- 9. Emphasis added.
- 10. See John Passmore, The Perfectibility of Man (New York: Charles Scribner's Sons, 1970).
- 11. See Paul Ramsey, *Fabricated Man: The Ethics of Genetic Control* (New Haven, CT and London: Yale University Press, 1970), pp. 151-152.
- 12. See ibid., pp. 87-88.
- 13. See 1 Corinthians 15.26.
- 14. For a more detailed explication see Waters, From Human to Posthuman, pp. 95-150.
- 15. See Revelation 1.8.
- 16. See John 1.14.
- 17. See Philippians 2.6-8.
- See Oliver O'Donovan, *Resurrection and Moral Order: An Outline for Evangelical Ethics* (Grand Rapids, MI: Eerdmans, 1986).
- 19. Ibid., p. 14.
- 20. See ibid., pp. 16-21.
- 21. See Robert Spaemann, *Persons: The Difference between 'Someone' and 'Something'* (Oxford and New York: Oxford University Press, 2006), pp. 78-80.
- 22. See O'Donovan, Resurrection and Moral Order, pp. 22-27.
- See George Parkin Grant, *Technology and Justice* (Notre Dame, IN: Notre Dame University Press, 1986), pp. 11-34.
- 24. See ibid., pp. 19-21.
- 25. Ibid., p. 32.
- 26. Ibid.

Brent Waters, DPhil, is the Stead Professor of Christian Social Ethics, and Director of the Stead Center for Ethics and Values at Garrett-Evangelical Theological Seminary, Evanston, Illinois, USA.

This article is adapted from a lecture given at the conference, Bioethics Nexus: The Future of Healthcare, Science, and Humanity, *held at Trinity International University, Deerfield, Illinois, 14 July 2007.*

"GIVE ME CHILDREN OR I'LL DIE!" IS IT TIME TO CONSIDER THE UTERUS AS A NON-VITAL ORGAN TRANSPLANT?

GREGORY W. RUTECKI, MD

Organ transplantation and assisted reproduction have inhabited separate ethical domains. Since they have evolved disparately, neither has found it necessary to overlap the other—either technically or ethically. That status quo is changing. Organ recipients are now biological parents. The journal Clinical Transplantation has been reporting pregnancy outcomes after solid organ transplantation. Included are parents and children sharing the burden of immune suppression.¹ A portion of the organ recipient cohort was most likely assisted by reproductive technology, although this data is confidential. In this solitary context, minimal overlap has not been problematic. Informed titration of immune suppression has protected parent, transplanted organ, and child. The risks of organ rejection, cancer, or teratogenicity have not been untoward.

The techniques of reproductive technology have been impressive, although arguably more problematic than those inhabiting transplantation. Ethical ramifications continue to be debated.^{2,3,4,5} Examples include expanded insurance coverage, implications of pre-implantation genetic testing, frequency of multiple gestations and the contingency of "selective reduction." The questions surrounding cryopreservation with disposal or donation of embryos for stem cells persists. As with pregnancy in transplant recipients, risks attendant to the procedures may affect parent and child. For mothers, they include ovarian hyperstimulation syndrome, and for offspring, the incidence of cerebral palsy, learning disabilities, and birth defects may be increased.

Contentious overlap of these ethical domains may be forced upon bioethics. Human organ retrieval efforts have expanded to uteri—the latest technology proposed for a minority of infertile couples.⁶ Activities to date may be perceived as a significant step towards a human uterine transplant. Prior small studies or case reports have stopped at either storage or transplantation of female reproductive tissues, particularly after aggressive treatment (surgery or chemotherapy) of gynecological malignancies.^{7,8,9} Framing the ethics of uterine transplantation is critical and must be proactive. The retroactive debate engaging face transplants cannot be repeated. What questions might be asked? Should uterine transplantation become accepted treatment for select infertile couples? Are the ethical constructs to be debated unique, or rather, variations on themes from each domain's history? Has the international controversy regarding other nonvital organ transplants (hand, larynx, and face) reached a consensus so that uteri may join this evolving list? It is the author's opinion that a moratorium should be declared immediately upon any activity with human uteri. Why this conclusion has been posited will occupy remaining discussion.

Where Would the Human Uterus Fit into Established Transplantation Ethics?

The complexity contingent with two potentially overlapped bioethical agendas can be simplified, at least initially. Women rendered infertile as a result of either an absence or a non-functional uterus, hypothetically at least, may become pregnant after a uterine transplant. The assist of additional reproductive technology may be unnecessary, or limited, for example, to something like artificial insemination. As a result, ethics surrounding uterine transplantation may be probed, at least in the beginning, from the solitary perspective of transplantation. However, if reproductive technology engenders additional ethical concerns after an admittedly "sectarian" approach (psychological barriers to consent in barren women, for example), issues will be added to transplantation's "incomplete" contribution.

Beginning with that simplified premise, one can arguably condense solid organ transplantation ethics—where uteri would venture—into five categories followed by justifications for exclusions. They are:

- 1.) How Death is defined prior to organ retrieval
 - a.) by whole brain criteria or by
 - c.) cardiac criteria, or by
 - d.) any future definitions
- 2.) Donor and recipient safety, dignity, and justice (micro and macro) in the context of
 - a.) living donor, *single* organ donation (for example, liver)¹⁰ as well as a result of
 - b.) designated or paid donor policies.^{11,12}
- 3.) Utilization of vulnerable donor pools to increase organ supply from individuals with either (examples):
 - a.) Persistent Vegetative State, or
 - b.) anencephalic infants.
- 4.) The novel ethical issues inhabiting transplantation of non-vital organs (that is, those organs not required for survival such as faces, hands, and larynxes).¹³
- Justice (macro) in the distribution and allocation of scarce organs/ resources¹⁴

Although there have also been alleged quality and safety oversights by the United Network for Organ Sharing (UNOS), they are in an early investigative stage.¹⁵ The same may be said for xenotransplantation. At the time of this writing, its ethical attachments were not completely developed.

The pressure on policy makers to expand the pool of donors, in regard to considerations 1, 2 and 3, typically has been a result of people dying for want of a scarce organ donor (usually for single organs such as a heart or liver). Cardiac Death policies and living, single organ donor protocols (liver) were direct responses to this pressure. Both bore initial criticism for their presumed ethical downsides, but adjustments

since have been salutary. A similar statement can be made for designating recipients or paying donors, that is, that they too represent responses to organ shortfalls. Since uterine transplants may evolve into a procedure reserved for the "affluent," potential ramifications of "paying for uterine organs" must be addressed in detail later. Without designation or pay, there would also be an organ shortfall for uteri. But it would probably be reasonable to say that categories 1 and 2 will probably not be altered substantively. Women awaiting uterine transplants are not at risk of dying, and in this way are dissimilar to vital organ recipients.

Since the definition of death seems to be established, at least for the near future, and non-vital organs have less impact in this area, what is germane to remaining ethical discourse? Full development of ethical constructs for uterine grafts requires: reasonable guarantees of human safety proceeding from animal studies, appreciation of lessons learned from non-vital organ transplantation to date and discussion of the novel quagmires of donor selection and vulnerability, preparation, and an exit strategy if uterine grafts fail.

An Ethical Path Followed? Uteri from Animals to Humans

Since the uterus is a solid organ, we should begin asking how it differs from other transplantable organs. First, uteri join the category of non-vital organs (faces, hands, and larynxes). Patients on the waiting list for vital single organs (heart, liver, and lung) die without transplant. Non-vital organs create their own brand of ethical deliberation. As well as risks entailed, these organs are not essential to survival. Should patients risk surgery and immune suppression when the "organ" itself is not essential? These demanding questions will warrant debate in later sections. Secondly, the uterus, unlike other solid organs, must be able to function throughout two separate physiological states-non-gravid and gravid. Therefore, in a purely technical sense, proposing uterine transplantation should entail preparation and guarantee safety for both contingencies. Is the initial technique, that is, the act of transplanting a non-gravid uterus experimentally proven to be safe? Are the vascular connections reliable? When would rejection typically occur? After these questions are definitively answered, and only then, may one proceed to see if the transplanted uterus responds appropriately to hormones, ovum, sperm, and/ or a developing human being. All of this has to occur with acceptable risks. If not, the first phase, non-gravid accomplishment is meaningless. The answers to these questions have to be made available from animal studies.

In 1988, Moore published four criteria necessary for innovative surgical procedures to begin within the discipline of transplantation.¹⁶ The first two are: 1.) the *scientific background* of the procedure and 2.) the *skill and experience* of the team performing the surgery. The following paragraphs will address both of these in the context of skills attained through a reasonable volume of animal work. The remaining two criteria will be weaved in later and are: 3.) the ethical climate of the institution performing the surgery, and 4.) the open display and professional discussion and evaluation of the procedure itself.

Animal experimentation with uteri has experienced two distinct periods. *Pub Med* was searched under "uterine transplantation, uterine transplantation in animals, and animal transplantation." The first peak in the transplantation of animal uteri occurred

in the 1960s and 70s.17 Why then? Since "reproduction technology" was nascent, uterine transplantation was proposed as a "potential" technology for infertile couples. In the words of one investigator, this "undistinguished" period did not answer "the mechanisms of uterine rejection, suitable immunosuppressants and the tolerability of the transplanted uterus in regard to pregnancy."18 In the same publication, it was observed, "the mechanism of rejection of uterine grafts had not been particularly investigated." Another group versed in laryngeal transplants—non-vital composite tissue bearing a similarity to uteri-commented, "Detailed studies of graft rejection are required in fully functioning and surgically accessible (animal) models, prior to clinical (people) trials" (italics and parentheses are this author's).¹⁹ Unless technique is perfected first in animals, unexpected ischemia in grafts increases the likelihood of rejection and graft failure. If the transplanted uterus rejects according to a predictable schedule, antirejection therapy can be refined prior to human transplants. Six animal studies were cited as examples of this period, but are then criticized.¹⁸ None adequately characterized rejection. The paucity of data is an ominous parallel to limited animal studies preceding living, partial liver donation (category 3a, transplant ethics).¹⁰ Since the exact size of the liver to be grafted was not forthcoming from animal study directed at livers, donors and recipients suffered prohibitive morbidity and mortality. If excessive liver tissue was removed from donors, they also could develop liver failure. These were healthy people prior to donation. Some donors were left in need of a liver transplant or died as a direct result of donation. Conversely, if too small a portion of liver was removed, recipient liver failure progressed. After early surgeries, recipients underwent risks without measurable benefit and were harmed. Some died as a direct result of the liver transplant itself. The first humans became a de facto experimental group for liver transplants. Mortality can be attributed to inadequate animal study.

The second period for experimental uterine transplantation in animal models is still in progress.^{18,19} Why now? After the initial enthusiasm of the 60s and 70s, work on uteri was "tabled" when other reproductive technologies were successfully implemented. Immune suppression was obviated by the "other" technologies. But the horizon for reproductive technology has been firmly established and a minority is still outside its pale. Women without a uterus as a result of congenital anomalies or hysterectomy presently have recourse solely to adoption or surrogate technology. Women who cannot bring pregnancy to term (because of a leiomyoma, for example) or who have lost reproductive potential from cancer surgery (hysterectomy) would similarly qualify. To address those still infertile despite the technology of 2007, animal studies have resumed. As during the first period of animal experimentation, data thus far are inchoate.

Since transplanted uteri in mice have led to normal offspring, one group has begun to re-study uterine transplantation in this specific animal model. The investigators have also graduated from a syngeneic mouse to an allogeneic model.¹⁸ With allogeneic uteri, a substantial portion of the animals studied had to be excluded from the trial because of postoperative complications. This was not a good omen. Reduced uterine blood flow was a complication in all animals utilized in experiments. Ischemia increases rejection and organ wastage. Rejection in survivors resembled that in human heart recipients, which is good to know. These data were published in 2006 and a technical chasm persists with animal models addressing uterine transplants. At present, that chasm mainly involves non-gravid uteri. There should not be any bridges to humans at this juncture, period. If a

human transplant of a non-gravid uterus succeeds, what about the feasibility and conduct of pregnancy? Since this is an as of yet unanswered question, it would be a recipe for disaster.

Despite meager animal evidence, a human "Case Report" of a uterine transplant has already been published.²⁰ This modus operandi is exactly how the first face transplant was accomplished and why it evoked a firestorm of controversy. The report of a uterine transplant demonstrated serious drawbacks, unfortunately in a person, not an animal. The transplant was performed "in a vacuum," that is, at an isolated center, without accountability to the larger medical/ethical community. The story: a 26 year old woman received a 46 year old donor's uterus (dead by whole brain criteria) and received cyclosporine, azathioprine, and steroids for immune suppression (uninformed by animal precedent). Although rejection was not diagnosed, the result was catastrophic. At 99 days, there was tension and/or torsion (technical problems) of vascular grafts and a hysterectomy (of a non-gravid uterus) was performed. Without this surgery, the recipient could have died. Using an accepted "from bench to bedside" ethic, that is iterative testing in animals, one may characterize this effort as ill-advised and unethical. Is there any suspicion that other premature human attempts may be close?

Another publication can serve as an example of tentative, albeit "one-sided," technique in humans (i.e. retrieval without transplant). It also does not appear to be an extension of animal models. The results, however, seem to be aiming at human uterine transplantation. Nine non-gravid uteri were successfully retrieved from heart beating human donors (donors declared dead by whole brain criteria).⁶ This study stopped at the point of retrieval and initial pathological studies that did not demonstrate either gross or microscopic ischemic changes in the retrieved myo- or endometria. Since these uteri were not connected to arteries and veins in recipients (thankfully), the absence of ischemia is a most preliminary observation. The manuscript itself completely skirted ethical implications. The authors stated "non-vital organ transplantation raises ethical issues." They then do not elaborate what these "issues" are. "Hand and facial" transplants are then mentioned as non-vital, but the larynx is not. Furthermore, there has been only one face transplant and limited in follow up. Then the authors said, "but the only uterine transplant carried out in the human was controversial and unsuccessful." They were referring to the single, ill-advised uterine transplant already discussed. The "why" for the word *controversy* was not elaborated on. The authors continue, "For the fetus, transplant safety data are reassuring." This statement is merely a "straw man." The word "reassuring" is accurate only for parents who have had other transplanted vital organs prior to pregnancy (liver, kidney, heart), not a uterus.

The history preceding the only larynx transplant serves as a striking contrast. In regard to requisite animal studies, not only were they extensive, but the surgeon who performed the first transplant of a human larynx (Marshall Strome)²¹ also had impressive experience in laryngeal animal work. Strome's caution and timing before the first human recipient was also impeccable. That transplant was informed appropriately by recipient preparation, physical as well as psychological (risk acceptance), prior to surgery. The surgeons on the human uterus retrieval team do not appear to have similar experience with animal models that have survived peer review.

In summary, animal studies on uteri to date are not sufficient to address safety issues, especially since they have not furnished answers to fundamental questions. Therefore, safety has not been demonstrated. Previous negative experience with adult, living liver transplants, as well as positive by contrasting the single laryngeal transplant suggests caution. Moore's traditional criteria thus far have not been satisfied.

Lessons from Other Non-vital Organ Transplants

Non-vital organs—larynx, face, and hand—have been successfully transplanted, but in small numbers (between 20-30 for hands, 1 each for face and larynx).^{22, 23} Questions of long-term durability have yet to be answered. If a facial graft would reject (calling for an "exit strategy"), for example, where would one consult consensus on how to proceed in a patient's best interests? Despite a continuing "learning curve," there are examples of "dos and don'ts" for non-vital transplants. To be included is transparency—alternatively called Open Display and Public and Professional Discussion and Evaluation (number 4 from the original publication of Dr. F. Moore). Also, a growing need for international oversight of newer techniques is strongly suggested. To date, transparency/open display has been sparse in regard to human uterine transplantation. That critical defect is one "don't" already plaguing other non-vital organs, particularly the first face transplant. What is this ethical "transparency" comprised by? It is the open sharing of data, the acceptance of criticism, and accountability to unbiased safety and quality oversight. One excellent example of transparency or open display is the "Louisville Committee" or the International Symposium on Composite Tissue Transplantation.²⁴ The multidisciplinary (and especially note International) group first met in November of 1997. Diverse experts from the immunology, transplant, plastics and hand surgery, research and ethics community met and continue to meet annually to "evaluate the scientific, ethical and clinical barriers to hand transplants." What was their first order of business in 1997? For the first two days the committee reviewed the adequacy of animal research with hand composite tissue as an essential prelude to human work! Reliance on a committee such as this one protects against single center isolation. Being the first to transplant an organ is a compelling temptation. This is what Moore understood when he talked about the reputation of the team and center performing early transplant innovations. The Royal College of Surgeons and French National Ethics Advisory Board had already given a red light to face transplants.¹³ Without stricter standards, no transplant center has to comply, and the first face transplant in France is proof. Does this "isolationism" extend to other transplant venues? Recent criticisms of UNOS were a response to alleged "partiality."¹⁵ Why exactly? Decisions regarding transplants presently reside with transplant surgeons or people who work for transplant centers. Unbiased oversight should be entrusted rather to a proportion of transplant "outsiders." That is what the word "open" means. Ethicists, prior transplant recipients or immediate family members of either donors or recipients would qualify. These "others" should have little to gain from an increase in non-vital transplants. The type of oversight is analogous to Safety Monitoring Committees for pharmaceutical studies. Any unexplained complications have to be addressed and all members of a transplant team have to be accountable to unbiased "outsiders."

Where No One Has Gone Before: Uterine Transplantation as Unique

The Royal College of Surgeons has produced a Working Party Report on Facial Transplantation.¹³ It should also come as no surprise that myriad psychological and societal issues impact facial transplants. Some, but not all, of the considerations would also affect uteri. Unfortunately, many would be unique to uterine grafts and therefore not yet studied.

How should recipient selection policies for uteri be structured? It is clear that there are some questions heretofore unasked. Attention to justice would necessitate objective criteria that are free of social valuations. How can one objectively "score" need when an organ is not only non-vital, but is not necessary for dexterity (hands), identity (face), or communication (larynx)? Contrast the lack of any objective selection criteria for uteri (and in some degree for other non-vital organs) to the MELD¹⁴ score for donor selection with livers. The person receiving a liver should be the sickest who can still benefit. Social value criteria (race, income, age) cannot be allowed to intrude into what should be as objective of a decision as possible. How exactly are infertile couples "sick"? How can their need be quantified objectively and justly? In light of successful surrogacy obtained in uteri of individuals older than the fifth decade, should there be an age limit? Moreover, social value criteria will likely not be excluded from the uterine scenario. Race and income will intrude because uterine transplantation will not garner third party payers. Rather, uterine transplantation will become "boutique" surgery for those who can afford it. Whether affluence will also lead to paying vulnerable donors for a non-vital and previously "used" organ is unanswered, but disconcerting. Whether the wealthy could travel to unregulated locations for a uterine transplant is also a disturbing possibility. Would the indigenous population provide the organ supply? This is an arena that has to be informed by precedent from reproductive technologies, specifically surrogacy, rather than transplantation. Precedent is available.²⁵ People have begun to provide their eggs/sperm to produce embryos later implanted in Indian women! In a commentary, Kilner²⁵ strongly opposes this commercial surrogacy which is tantamount to baby-selling. Uterine transplants could achieve the same exploitative potential as one alternative to surrogacy.

The potential benefits to the transplant team, especially to be the "first," will also exert undue pressure and stimulate "proceeding in a vacuum." After the first face transplant, there were allegations regarding media payment to the patient for her sensational story.¹³ Others alleged that the surgery team was also reimbursed. How can consent be informed when financial incentives intrude? The media circus that would surround the first uterine transplant will mimic the first face transplant. Forget confidentiality. The Louisville group has stated unequivocally, "If desires for *enhanced reputation, financial reward*, professional vanity, and so on motivate those involved . . . then the ethical climate . . . is no longer acceptable for therapeutic innovation."²⁴

Risk acceptance is also an important but inadequately addressed topic for uteri. How much risk is an individual willing to shoulder (from the immune suppression, surgery, and possible rejection of a graft followed by additional surgery) in an effort to have a child? To begin with, the question is difficult to answer since safety has not been defined by animal study. In contrast, the Louisville Instrument for Transplantation (LIFT) has 237 questions that attempt to address risk acceptance in potential recipients.²⁶ For example, LIFT has demonstrated that risk acceptance for a kidney transplant was about the same as for a two-hand transplant. Obviously, for a single organ like the heart, risk acceptance would be higher because without transplant death supervenes. When respondents were asked if they would accept the risk of laryngeal transplant knowing there was a 50/50 chance of rejection, more than half answered *No!* Since there are no rejection data for uteri, and since there are no human data addressing the eventual likelihood of pregnancy, how can respondents consent and/or accept risk? Unwarranted dreams of success in this arena would prey on a vulnerable and distraught population.

Finally, what and when would an "exit strategy" be comprised by? What if a recipient begins to reject, receives higher doses of immune suppressants in response, and still cannot get pregnant? What if the psychological vulnerability of a serious clinical situation such as this precludes a patient from agreeing to a hysterectomy? "Give me more time, please" is the response. Is a fatal infection or cancer at a later date justified as a result? And lastly, should a failed first attempt to conceive, followed by a rejected uterine transplant allow for a second transplant before another potential recipient gets a first? Unless and until these questions are addressed and answered by overwhelming consensus, further human work is foolhardy.

Conclusions

The debate surrounding the decision to drop the first nuclear bombs on Japan is informative.²⁷ From the perspective of a minority of scientists, ethical deliberation was unnecessary; the decision to proceed was solely scientific. Percy Williams Bridgman, a mathematics professor at Harvard University, argued that it was unreasonable for scientists to do any more than their "scientific" profession. Isidor Isaac Rabi of the Massachusetts Institute of Technology insisted that scientists were responsible only for the boundaries of science good enough to be published objectively. J. Robert Oppenheimer warned that moral prohibitions would only impede science. The mentality necessary to "bracket" scientific progress in a domain completely separated from ethics is disturbing. Unfortunately, that same bracketing has recently infected medical and surgical practice. The "corporate transformation of medicine" has empowered physician-entrepreneurs to invent, test, utilize, and profit from technology, refusing the "intrusion" of ethics. Post-Hippocratic Medicine is testing the boundaries of science, business, and ethics in the pursuit of science for personal gain (reputation as well as financial).

Transplantation has been accepted because it has faithfully represented the "Gift of Life." It has prospered not only because it relieves the burdens of suffering and death, but also because, for the most part, it has followed the rules. Recently, transplantation has entered a new arena, that of non-vital organs. It is now helping to give people newer "gifts" of dexterity (hands), speech (larynxes), and identity (face). With dexterity and speech, the scientific component has attempted to partner itself congenially to ethics, proceeding cautiously. The jury is not in yet on faces, but the opening salvo eerily echoes Bridgman and his colleagues, standing in direct opposition to Moore's accepted criteria for innovative surgeries.

Uteri are "not ready for prime time." The paucity of animal work in general and more specifically by a leading teams in the discipline, the lack of attention given to approximating ethical constructs for non-vital organs, and the lack of precision in identifying donors as well as recipients, preserving their dignity (through informed consent and risk assessment) are disconcerting.

From this author's worldview perspective, it seems that Jacob's response to Rachel's plaintive cry of "Give me children, or I'll die" is a wise one. "Am I in the place of God?" There are appropriate times to say a resounding no to technology, especially when excessive risks strive for the unreasonable and are accompanied by prohibitive risks to vulnerable beings. This "gloom and doom" scenario is posed by a lack of accountability in uterine transplantation. In the case of a barren mother and her hoped for child or a donor who is poor, uterine transplantation will prey on the disempowered. In fact, a permanent red light may become the only safe and ethical manner in which to act.

References

- Armenti VT, Radomski JS, Moritz MJ, Gaughan WJ, Hecker WP, Lavelanet A, McGrory CH and Coscia LA. Report from the National Transplantation Pregnancy Registry (NTPR): outcomes of pregnancy after transplantation. Clin. Transpl. 2004
- Ludwig M. Infants conceived by assisted reproductive technologies have a greater risk of birth defects—meta-analysis. Evidence-based Obstetrics and Gynecology 2005; 7. Accessed on mdconsult.com. (1-19-07).
- Zadori J. Assisted reproductive technology pregnancies were associated with an increased risk of specific negative outcomes. Evidence-based obstetrics and Gynecology 2006; 8. Accessed on mdconsult.com. (1-19-07).
- 4. Nunley WC. The slippery slopes of advanced reproductive technologies. Am. J. of Obstetr. and Gynecol. 2004; 191:588-92.
- Rand L, Eddleman KA, Stone J. Long-term outcomes in multiple gestations. Clin. Perinatol. 2005; 32: 495-513.
- 6. Del Priore G, Stega J, Sieunarine K, Ungar L, and Smith JR. Human Uterus Retrieval from a Multi-Organ Donor. Obstet. Gynecol. 2007; 109: 101-104.
- Chalian R, Licciardi F, Rebarber A, Del Priore G. Successful infertility treatment in a cancer patient with a significant personal and family history of cancer. J Women's Health 2004; 13: 235-237.
- Del Priore G, Smith JR, Boyle DC, Corless DJ, Zacharia FB, Noakes DA. Uterine transplantation, abdominal trachelectomy, and other reproductive options for cancer patients. Ann NY Acad. Sci. 2001; 943: 287-295.
- Silber SJ, Lenahan KM, Levine DJ, Pineda JA, Gorman KS, Friez MJ. Ovarian transplantation between monozygotic twins discordant for premature ovarian failure. N Engl J Med 2005; 353: 58-63.
- 10. Rutecki GW. "The Gift of Life"? A perspective on adult partial liver donation. Ethics and Medicine 2004; 20:167-178.
- 11. Rutecki GW. Sharing scarce organs with others: designated donation as a model of giving. The Center for Bioethics and Human Dignity, December, 2004, www.cbhd.org/resources.
- 12. Rutecki GW. Is it ethical to buy organs? One physician's perspective. The Center for Bioethics and Human Dignity, June 26, 2002, www.cbhd.org/resources.
- 13. Rutecki GW. The transplantation revolution: from vital to non-vital organs and finally to faces? The Center for Bioethics and Human Dignity, December 15, 2005. www.cbhd.org/resources.
- 14. Rutecki GW. Liver transplants: how do we choose who should live when not all can? The Center for Bioethics and Human Dignity, June 25, 2004, www.cbhd.org/resources.
- Ornstein C, Weber T. Transplant monitor lax in oversight. Los Angeles Times 2006; October 22nd, page 2.

ETHICS & MEDICINE

- 16. Moore FD. Three ethical revolutions: Ancient assumptions remodeled under pressure of transplantation. Transpl. Proceed. 1988; 20 (Suppl. 1): 1061-1067.
- Yonemoto RH, Du Sold WD, Deliman RM. Homotransplantation of uterus and ovaries in dogs. A preliminary report. Am J Obstet Gynecol 1969; 104: 1143- 1151.
- 18. El-Akouri RR, Molne J, Groth K, Kurlberg G, Brannstrom M. Rejection patterns in allogeneic uterus transplantation in the mouse. Human Reproduction 2006; 21: 436-442.
- Barker E, Murison P, Macchiarini P, Jones A, Otto C, Rothkoetter HJ, Haverson K, Bailey M, Birchall M, Stokes C. Early immunological changes associated with laryngeal transplantation in a major histocompatability complex-matched pig model. Clin. Experim. Immunol. 2006; 146: 503-508.
- Fageeh W, Raffa H, Jabbad H, Marzouki A. Transplantation of the human uterus. Intern. J. of Gynecol. and Obst. 2002; 76:245-251.
- 21. Pub Med search under key name Marshall Strome (1-15-07) and personal conversation with Dr. Strome.
- 22. Majzoub RK, Cunningham M, Grossi F, Maldonado C, Banis JC, Barker JH.Investigation of Risk acceptance in hand transplantation. The Journal of Hand Surgery 2006; 31A: 295-302.
- 23. Barker JH. Furr A, Cunningham M, Grossi F, et al. Investigation of risk acceptance in facial transplantation. Plast. Reconstr. Surg. 2006; 118: 663-670.
- 24. Wiggins OP, Barker JH, Martinez S. On the ethics of facial transplantation research. AJOB 2004; 4: 1-12.
- Kilner JF. Overseas surrogacy: How far may we go. www.cbhd.org, 2007-02-09, accessed 2-26, 2007.
- Reynolds CC, Martinez SA, Furr A, et al. Risk acceptance in laryngeal transplantation. Laryngoscope 2006; 116: 1770-1775.
- Guelzo AC. In "The American Mind" from the Great Courses Series by the teaching Company, 2005; Lecture 31: Science under the cloud.

BOOK REVIEWS

Caring for Those in Crisis: Facing Ethical Dilemmas with Patients and Families

Kenneth P. Mottram. Grand Rapids, MI: Brazos Press, 2007. ISBN: 978-1-58743-191-3; 160 PAGES, PAPER, \$17.99

A military friend once remarked, 'It is much better to prepare for war in advance rather than wait until you hear the tanks coming down the road.' Hopefully, the militaristic metaphor will not distract readers from acknowledging the more straightforward and obvious point of the statement. Inasmuch as it is possible, there is wisdom in being prepared for difficult circumstances long before actually being faced with them. This certainly is sage advice for Christian leaders who have served or will serve families in the throes of medical crises.

Caring for Those in Crisis is written to inform and equip Christian leaders and health care workers for some of the ethical dilemmas faced by patients and their families that occur daily in medical centers. Mottram notes that Christians are often unable to provide the needed spiritual support for families facing medical emergencies since many are ill-equipped concerning the smattering of ethical issues that undoubtedly emerge in the context of health care. Based on years of experience as a hospital chaplain and interaction with hospital ethics committees, Mottram has a three-fold purpose for his text. First, he wants to acquaint those working in the ministry with some of the common issues *in* and the language *of* medical ethics. Further, he seeks to equip these spiritual leaders to address the ethical dilemmas of families who seek spiritual leadership and guidance in morally complex situations. Moreover, he sees his book as assisting health care workers to seriously consider the 'voice of spiritual leaders as a guide in difficult situations' that should serve 'as a reminder of ultimate values' (21-22).

He provides a nice introduction to the historical development of medical ethics and its key ethical principles. He identifies and briefly discusses many of the key ethical issues that emerge in community medical centers such as 'dilemmas surrounding . . . end-of-life choices, alternatives in patient treatment, withdrawal or withholding of life support measures, organ donation, truth telling, informed consent, and patients' rights' (81). He helpfully weaves personal stories with actual cases, personalizing the dilemmas so that the reader is reminded that these are not just ideas, but that these issues involve real people. He also includes a standard decision-making model used by medical ethics committees for addressing ethical dilemmas. Mottram rightly points out how personal histories, traumatic experiences, personal values, and ethical principles converge to form the 'operational value system' that guides the decisions people make in a given situation. He wisely instructs Christian leaders to be aware of their own operational value system and recognize that they may have experiences that do not allow for the needed objectivity in some situations. The more aware people are of these tendencies the better able they are to respond to the needs of those they seek to support.

Writing from a distinctively Christian perspective, he provides a basic biblical theology for engaging in patient advocacy by seeing medical ethics in the context of God's revealed character, the importance of the *imago dei* as the basis for the value of human life, and the book of Philemon as a biblical model for a non-coercive approach for advocacy in difficult decision-making dilemmas. He provides excellent chapters that underscore the need for churches to train Christians to harness the vast resources available from a Christian worldview to meet the needs of patients and their families.

It was not the aim of *Caring for Those in Crisis* to address the myriad of ethical issues in a philosophically precise manner. Instead, it should be viewed as a primer that introduces the topic and provides a framework in approaching the complex nexus of ethical issues in medical contexts. Therefore, to respond to the call Mottram sets out for the church in the book, it would be beneficial to read it in tandem with other works that address the specific issues in biomedical ethics in a more rigorous theological and

philosophical way. Nevertheless, I do think that *Caring for Those in Crisis* accomplishes its intended goal and is of benefit not only to Christian leaders, but also to those working in the context of health care as well.

Reviewed by Patrick T. Smith, MDiv, MA (philosophy), PhD (candidate in philosophy), who is an Assistant Professor of Theology and Philosophy at Gordon-Conwell Theological Seminary, South Hamilton, Massachusetts. He also serves as the Director of the Ethics Department at Angela Hospice Care Center in Livonia, Michigan, USA.

Easeful Death: Is There a Case for Assisted Dying?

Mary Warnock & Elisabeth MacDonald. Oxford University Press: Oxford, UK, 2008. ISBN 978-0-19-953990-1; 155 PAGES, HARDCOVER, \$26.

Death and Medical Power: An Ethical Analysis of Dutch Euthanasia Practice

Henk ten Have & Jos Welie. Open University Press: Berkshire, England, 2005. ISBN: 0 335 21755 9 (PB) 0 335 21756 7 (HB); 141 PAGES, PAPER, \$113 (US)

Euthanasia and the Law in Europe

John Griffiths, Heleen Weyers, & Maurice Adams. Hart Publishing: Oxford, UK, 2008 ISBN 978-1-84113-700-1; 595 PAGES, HARDCOVER, £60 (UK)

Just as Oregon is the 'laboratory' for physician-assisted suicide (PAS) in North America, The Netherlands and Belgium are on-going experiments for euthanasia and assisted suicide in Europe. In fact, the entire world looks to these social pioneers. This review looks at three recent publications about the European theory and practice of hastening death.

In Easeful Death, a philosopher (Warnock) and oncologist (MacDonald) look at the theoretical arguments in favor of legalization of physician-assisted suicide and euthanasia (PAS/E). Their brief treatise focuses on patient autonomy ('autonomy, far from standing in opposition to the sanctity of life, is actually what makes a life "sacred," at least for the person who lives it, '9) while stating their goal as 'can we devise a law that allows us to relieve the suffering of those who want to die without endangering others who do not want to?' (12) They promote allowing PAS/E for competent patients who request death, for some patients with intractable mental illness, and for neonates who cannot survive and are suffering. For neonates who might survive with a very low quality of life, they support withdrawal of life-supporting treatment, but not euthanasia because 'the taboo against killing is extremely powerful' (49). They leave unresolved the question of PAS/E for incompetent patients, though they do support withdrawal of treatment, fluids and nutrition from an incompetent adult who has signed an advance directive requesting such. The authors address the sanctity of human life, dismissing it as a religious argument that doesn't apply to others, concluding, 'So it seems that there must always be exceptions to the assertion of the absolute and overriding value of human life' (70). They share concerns about the consequential ('slippery slope') arguments against PAS/E, but conclude that well thought-out legal safeguards can be sufficient to ward off the dire consequences ('the aim of legislators, if the law is to be changed, must be to block the slippery slope, or render it less slippery,' 89) In their final chapter, they dismiss the Rule of Double Effect and physician reluctance to participate in PAS/E and go on to make an important distinction between 'palliative sedation' and 'terminal sedation,' recognizing that the latter is really euthanasia. They conclude, 'We believe that debate in this area should no longer be dominated by a minority of critical, often faith-led voices . . . Those who disagree have every right to voice their

disapproval and not to participate but they should not impose their convictions on the quiet majority' (123).

Ten Have and Welie are both physicians and philosophers, and Welie is also an attorney. Their book, Death and Medical Power: An Ethical Analysis of Dutch Euthanasia Practice, looks first at the Dutch practice as an exercise of medical power, and then they review the response of the legal/judicial profession. They concede that advocates for euthanasia have made a strong case, stating that 'all important principles of medical ethics are fulfilled' by this practice (1). They go on to conclude that the prudential counter-arguments of euthanasia opponents are inadequate. In spite of this, they strongly oppose the practices of euthanasia and assisted suicide. Their opposition is based on a unique perspective of power in medicine. They point out that scientific and technological advances in the past fifty years have given physicians real power over disease and death. In response to this medical power, patients have sought their own empowerment-the authority to decline unwanted treatment and the right to demand euthanasia and assisted-suicide. Paradoxically, in their view, by restricting the practice of PAS/E to physicians, Dutch courts and parliament have actually increased physicians' unilateral power rather than equalizing it between patient and physician. For all the talk about patient autonomy, the actual decision-makers are physicians. Physicians' assessment of whether a patient qualifies for PAS/E is a quality of life determination made, not by patients, but by physicians. This, they argue, should be a great cause for concern by both proponents and opponents. The authors argue not for a 'good death,' but rather for a 'good dying process.' They thus make a strong case for improved palliative care at the end of life. This book is a well-referenced review of the history of the societal debate, attempts at regulation, and the practice itself. In addition, it discusses important and insightful distinctions (active-passive; omission-commission; outcomes-intentions). The unique basis for their conclusion makes an outstanding contribution to the literature.

In contrast to these two books which take positions pro and con, *Euthanasia and the Law in Europe* by Griffiths, Weyers and Adams is a dispassionate report of the societal and legal changes in the practice of euthanasia in Europe over the past thirty years. It is a scholarly reference book (of which I have read only portions). One suspects in reading between the lines that the authors do not disapprove of the legal changes that have occurred. The length of each section of the book varies with the duration of the societal discussion and the volume of statutory and case law on the topic in each jurisdiction: 200 pages for the Netherlands, 90 pages for Belgium, and 150 pages combined for England and Wales, France, Italy, Scandinavia, Spain, and Switzerland. It is a valuable and up-to-date resource for serious students of the European experiment with euthanasia and assisted suicide.

Reviewed by Robert D. Orr, MD, CM, who is Professor of Bioethics at Loma Linda University and Director of Clinical Ethics at Loma Linda University Medical Center, Loma Linda, California. He is also Professor of Bioethics at the Graduate College, Union University in Schenectady, New York, Consultant in Clinical Ethics, Center for Bioethics and Human Dignity, and Professor of Bioethics at Trinity International University, Deerfield, Illinois, USA.

Embracing Our Mortality: Hard Choices in an Age of Medical Miracles

Lawrence J. Schneiderman, MD. New York: Oxford University Press, 2008. ISBN 978-0195339451; 219 PAGES, HARDCOVER, \$21.95.

Listening to experienced elders is to be commended for all who will learn. With this in mind, I looked forward to reviewing this book by an established authority in the field of clinical medical ethics. There were many things we agreed upon, his anecdotes of patient encounters were engaging, but his lack of insight into his poorly informed anti-Christian bias was annoying.

ETHICS & MEDICINE

Embracing Our Mortality is an eclectic collection of essays, some previously published, focusing broadly on end of life issues, advance directives and futility, then concluding with Schneiderman's take on the problems of our current healthcare system.

Schneiderman begins by stating that unlike the false hopes offered by 'New Age gurus' regarding end of life care, he and others like him 'are grounded in a deeper, more enduring, and satisfying reality. We know someday life will end. Therefore, every day, every moment, we appreciate it all the more. We enjoy the simple sensation of living as much and as long as our minds and bodies let us. In other words, we embrace our mortality' (3-4). It is all here and now—what you see is what you get. From this unsatisfying premise he continues self-assuredly forward.

Nonetheless, Schneiderman is a good story teller. He is skeptical of over-medicalizing life, yet remains a defender of the scientific process. He attacks Alternative Medicine but unfortunately doesn't define what this means. Advocates of Complementary and Alternative Medicine often lump things into this category that we all would agree do not belong in CAM: massage, prayer, physical exercise, and special diets.

Schneiderman takes potshots at 'fundamentalist Christians' by blaming this group, whoever they are, for encouraging late entry into established care, increasing morbidity and mortality for its adherents. He fails to relate that much of modern scientific process is rightly traced to persons who, in fact, fall under this broad Christian rubric.

Schneiderman reveals a woeful lack of knowledge of stem cell research, totally omitting mention of non-destructive embryonic stem cell research. He predicts that when cures are found in embryonic stem cell research all 'sanctity of life' objectors will drop their arguments 'on behalf of the cluster of early embryonic cells' (149) in the same way that early religious objections of airplanes were soon dropped and forgotten.

Schneiderman's final chapter is an extended Op-Ed piece on what's wrong with American healthcare. While one may disagree with him on specifics, he has picked out some of the better current ideas for repairing the system, which he offers in an incompletely developed fashion. These are complex issues, and he might actually supply better long-term answers than many of our politicians—assuming he had the political will to make his ideas reality. He correctly notes that as a country we cannot provide all people with everything.

Reviewed by Robert E. Cranston, MD, MA, FAAN, who is Medical Director for Medical Subspecialties at Carle Clinic Association in Urbana, Illinois, and a clinical associate professor of medicine (Neurology) at the University of Illinois College of Medicine in Urbana-Champaign, Illinois. He is a fellow of CBHD and also serves on the CMDA Bioethics Committee, USA.

Human Stem Cells: Source of Hope and of Controversy

Henk Jochemsen, Elisa Garcia, Asher Meir and Ron Harris. Chicago and London: The Bioethics Press, 2005.

ISBN 0-9711599-4-7; 162 PAGES, PAPER, \$30.00.

Co-authored by an international team of four, this book provides an in-depth study of the scientific possibilities of embryonic as well as adult stem-cell research. With an emphasis on embryonic stem-cell research, it critically examines the ethical issues relating to the instrumental use of human embryos in research. It also provides a discussion of ethical issues relating to the patenting of human stem cells (in particular embryonic stem cells) then gives an overview of patenting law in the United States.

Though technical and detailed, the review of stem cell research by Dr Elisa Garcia and Dr Henk Jochemsen is very informative. Though pedagogical, this part is not the easiest read for the proverbial

'man on the omnibus.' That said, while dated, the chapter remains a useful source of information for students and professionals interested in the technicalities of stem-cell research and curious about the future that it might hold.

Forming the centre-piece of the book, Jochemsen and Garcia discuss the ethics of stem-cell research and the moral status of the human embryo which begins with a rather elementary introduction of different ethical systems. It soon becomes clear, however, that the main ethical value embraced by the authors is that of human dignity and their main ethical principle is respect for human dignity—applied to the human being from conception onwards no matter mental or physical capacities.

The authors' conclusion is drawn in light of two arguments. First, a biological one is based on an examination of embryological development, a continuous process guided by the embryo's own genetic constitution. Second, a philosophical argument is presented on the inherent potentiality and spiritual nature of the embryo from the start. These arguments are well developed and easy to follow.

There is also a well argued discussion about the commodification and commercialisation of human body parts. Since the authors view the body as an integral part of the individual rather than as property, they argue that the body should not be treated as a thing and an object of barter. Additionally, no human research subject should be treated as a mere means to an end – they include not only the mature or 'born' human but also the human embryo whether created *in vitro* or *in vivo*.

It is convincingly argued that the creation and destruction of the human embryo for research, whether by IVF or cloning, harms society in general by undermining respect for the intrinsic value and dignity of each and every human individual. Thus, even if the ultimate end of the research is to relieve human suffering by the development of new therapies, this does not justify the use of means involving the deliberate destruction of human life, nor does it justify the exploitation of women as egg donors or of the poor as organ donors.

The chapter on patents, by economist Dr Asher Meir, also expresses fears about the commodification of body parts and human tissue. Thus, Meir notes that intellectual property rights over body parts, tissues and cells produced by new technologies – as distinct from intellectual property rights over processes and techniques – might promote commodification and commercialisation of the patented products. However, he argues that, since patents constitute an inducement to research that might be of benefit to mankind, patents are justified even on these kinds of product, provided patent regulations are carefully drafted so as to counteract the tendency to view such products as objects of commerce. Some readers might well take issue with this view.

If the aforementioned parts of the book are addressing an international auditorium, this is less so in the case of the last part of the book. Written by Ronald Harris, an expert on international property law, this chapter is specifically concerned with American patent law. Thus, it seems directed mainly at the American reader or those with a special interest. While this might leave the reader with the impression of a certain imbalance, it is a bonus that each chapter of the book can be read as an independent whole.

That the book would have benefited from more careful proof-reading is a minor draw-back. Overall, the book is warmly recommended to anyone with an interest in the science and ethics of embryonic stemcell research.

Reviewed by Agneta Sutton, PhD, who is a Senior Lecturer at Chichester University and a Visiting Lecturer at Heythrop College at the University of London, both in the UK.

Babies by Design: The Ethics of Genetic Choice

Ronald M. Green. New Haven and London: Yale University Press, 2007. ISBN 978-0-300-12546-7; 279 PAGES, HARDCOVER, \$26.00

ISBN 9780300143089; 279 PAGES, PAPER \$17.00

Ronald M. Green's most recent work on the ethical, legal, and social implications of the Human Genome Project focuses on the idea of modifying/designing our offspring. The questions of whether and to what extent we should engage in genetic therapies (to prevent or mitigate disease) or genetic enhancements (to improve upon 'normal' characteristics) are the focus of this volume.

His thesis is very clear: he wants to challenge the negative views that underlie opposition to genetic modifications, believing that increased genetic control will ultimately create a 'better' human species. Much of the resistance to genetic modifications he attributes to what he calls the 'status quo bias,' or what he maintains is a human tendency to resist change even if it seems to be for the better. Rather, he postulates that we must take a multifaceted approach to decision-making in these kinds of situations and not simply reject technologies out of hand by reference to one or two concerns.

In his book, Green considers both the physical risks of genetic interventions as well as challenges to the concept of family. He raises potential social justice concerns, particularly with regard to how these technologies might further widen the divide between the affluent and the poor. He then addresses whether or not we might be 'playing God,' and argues that we may be slaves to a primitive theology. Outlining the direction in which we are headed with regard to sex selection, he discusses wrongful-birth and wrongful-life lawsuits and the greater availability of choices before us. In conclusion, he offers four guidelines for genetic intervention as we move forward: they should be aimed at what is reasonably in the child's best interests, be as safe as natural reproduction, not reinforce or increase unjust inequality and discrimination, and interventions that confer only positional advantage should not only be discouraged but avoided.

The book does suffer from a few minor weaknesses. Some may find his liberal or libertarian views problematic or troubling. At times, Green seems to suggest that opposition to these new genetic technologies may be the result of irrational fears rather than genuine reasoned concerns. Even so, the book has considerably more strengths than weaknesses. It is extremely well written and is appealing to both laypersons and scholars alike. He also demonstrates something beyond the grasp of most ethicists working in the area—a deep knowledge of genetic science, which is no small feat. Although he espouses liberal views, he has a clear grasp of the arguments of his opponents, which he carefully articulates and systematically challenges. His observation that most people resist new genetic technologies due to a 'status quo bias' may be truer than we might want to admit. In sum, Green presents a coherent and strong case for an ethics of genetic modification that should largely be left in the hands of parents, have limited regulatory oversight, and be open to the development of a newer and better human species.

Reviewed by Donna Yarri, PhD (Religious Studies), who is an Associate Professor of Theology at Alvernia University in Reading, Pennsylvania, USA.

HUMAN REPRODUCTION

Volume 15:2

Fall 2009 and

G

Е

Ν

CONTENTS INCLUDE:

Abortion and Dawkins' Fallacious Account of the So-called 'Great Beethoven Fallacy'

Prof. Hugh V. McLachlan, School of Law and Social Sciences, Glasgow Calendonian University, SCOTLAND

Abortion and Protection of the Human Fetus: Religious and Legal Problems in Pakistan

Muhammad Ilyas, Mukhtar Alam, Habib Ahmad and Sajid-ul-Ghafoor, Department of Genetics Hazara University Mansehra, NWFP, PAKISTAN

Early Education is De Rigueur in Planning Late-life Pregnancies Shirin Karsan, Master of Bioethics Program, University of Pennsylvania, USA

Therapeutic Cloning: The Ethical Road to Regulation—Part I: Arguments For and Against & Regulations Alistair Brown, Department of Law, University of Glasgow, SCOTLAND

International Editorial Board includes:

Founding Editor-Dr. Calum MacKellar ~ *Scotland* Assist. Prof. Mohammad Rasekh ~ *Islamic Republic*

Mr. Castro-Rios ~ *Spain* Assoc. Prof. E. Gefenas ~ *Lithuania* Dr. P. Metzger ~ *France* Dr. R. Andorno ~ *Switzerland* Dr. G. Incovorti ~ *Italy* Mr. R. Gramma ~ *Moldova* Dr. A. Ogilvie ~ *United Kingdom* Dr. S. Holloway ~ *Scotland* Dr. C. Trouet ~ *Belgium* Prof. B. Yudin ~ *Russian Federation* Cr. G. Javashvilli ~ *Georgia* Dr. G. McGee ~ *USA* Dr. B. Aucker ~ *USA* Prof. Dr. Vasile Astarastoae ~ *Romania* Rev. D. Dormor ~ *United Kingdom*

bioethics

Among recent themes Developed:

- Artificial Fecundation
 and Reproduction
- Biotechnology
- Eugenics
- Human Genome Analysis, Human Cloning, and Human Gene Therapy
- Privacy of Genetic Data and Screening





Published twice a year, *HRGE* brings international expertise from all perspectives to bear on research trends, while also informing an international public of the important issues and developments in those fields of bioethics and public policy. Participation is encouraged from all disciplines concerned with genetics and society. Arguments from scientific, moral, social, economic and juridical fields with their different outlooks are positively considered. *HRGE* is of indispensable assistance to all those working in the ethical analysis of these procedures.

For more information visit
www.geneticethics.org



In Association With:

The Center for Bioethics and Human Dignity, Bannockburn, Illinois, USA The Prof Dr G A Lindeboom Instituut, Ede, THE NETHERLANDS

CONTENTS

- 131 CONTRIBUTORS
- 133 EDITORIAL ON HUMAN BIOENHANCEMENTS C. Ben Mitchell, PhD
- 135 GUEST COMMENTARY THINK IT'S GREED? IT MIGHT BE PDMD: A PUBLIC SERVICE ANNOUNCEMENT Marc E. Keller and Bert M. Bieler, MD
- 139 GREY MATTERS FACEBOOK AND FUSIFORM GYRUS William P. Cheshire, Jr., MD
- 145 CLINICAL ETHICS DILEMMAS CONTINUING "FUTILE" ICU SUPPORT AT RELATIVE'S INSISTENCE Robert D. Orr, MD, CM
- 149 TRACKING CHROMOSOMES, CASTRATING DWARVES: UNINFORMED CONSENT AND EUGENIC RESEARCH PAUL A. LOMBARDO, PHD, JD
- **165 THE FUTURE OF THE HUMAN SPECIES** Brent Waters, DPhil
- 177 "GIVE ME CHILDREN OR I'LL DIE!" IS IT TIME TO CONSIDER THE UTERUS AS A NON-VITAL ORGAN TRANSPLANT? Gregory Ww. Rutecki, MD
- **187 BOOK REVIEWS**

VOL 25:3, FALL 2009 http://www.ethicsandmedicine.com

