Ethics & Medicine

An International Journal of Bioethics

Vol 30:2
SUMMER 2014
ISSN 0266-688X

Ethics & Medicine An International Journal of Bioethics Vol 30:2 SUMMER 2014 ISSN 0266-688X

EDITOR: C. Ben Mitchell
Union University, Jackson, Tennessee, USA
bmitchell@uu.edu

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: Taylor Hare
taylor.hare@my.uu.edu

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.

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 ~ 2014 ~ Subscription Rates

Individual Rates - D(domestic) I(international) 1 year below - 2 & 3 year subscriptions available on website				
Print	D - $72	I - $93 £61	Surface Delivery included Air Delivery - Add an additional $30/year	
Online IP Authenticated	D - $61	I - $77 £49		
Print + Online	D - $99	I - $119 £72		
Archives— PDF Online	1985-2012	D - $95 I - £60	2013	D - $55 I - £35
Institutional Rates - D(domestic) I(international) 1 year below - 2 & 3 year subscriptions available on website				
Print	D - $170	I - $198 £121	Surface Delivery included Air Delivery - Add an additional $30/year	
Online IP Authenticated	D - $149	I - $170 £110		
Print + Online	D - $187	I - $225 £144		
Archives— PDF Online	1985-2012	D - $180 I - £115	2013	D - $80 I - £50

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

CONTENTS

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 hard-copy 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 of 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
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.

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

ABSTRACTS AND INDEXING

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

SCOPUS, ELSEVIER
North or Central America
South America
Europe, Middle East or Africa
Japan
Asian and the Pacific
info@scopus.com
www.scopus.com

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: +1-419-353-8920
info@philinfo.org
www.philinfo.org

LAYOUT AND TYPESETTING

Original design by Wyane Kijanowski
Trinity International University

Typesetting by Andrew DeSelm
andrewdeselm@gmail.com

PRINTING

Excel Print Media
Michelle FM Loke
michelle@excelprintmedia.com

CONTRIBUTORS

Bhumika Aggarwal, MBBS, DTCD, MBA, MPM, is a Pulmonolgist, MBA (IIM), with a Masters of Science in Pharmaceutical Medicine (Hibernia College, Dublin). She practices in Mumbai, India.

Lindsey A. Beaman, BSCR, is a Clinical Research Coordinator at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Cristóbal S. Berry-Cabán, **PhD**, is a Clinical Researcher/Epidemiologist at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Jonathan M. Cahill, is a recent graduate of Gordon-Conwell Theological Seminary with a Master's of Arts in Ethics and Society and is pursuing a PhD at Boston College in Theological Ethics in Chestnut Hill, Massachusetts, USA.

William P. Cheshire, Jr., MD, is Professor of Neurology at the Mayo Clinic in Jacksonville, Florida; Chair of the Ethics Committee for the Christian Medical and Dental Associations; and Senior Research Fellow in Neuroethics at the Center for Bioethics & Human Dignity, Jacksonville, Florida, USA.

Mayank Gurnani, MBBS, MBA, is a Physician with an MBA (IIM) who has research interests in pharmaceutical industry, healthcare and biopharma. He practices in Mumbai, India.

Jessie Jalal Hanna, MD, is a resident physician in the Department of Psychiatry at the Icahn School of Medicine at Mount Sinai in New York, New York, USA.

Kyle L. Hoedebecke, MD, is a Family Medicine Staff Physician at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Lauren Navallo, MD, is a resident physician in the Department of Pediatrics at New York Presbyterian-Weill Cornell Medical Center in New York, New York, USA.

Cheri L. Portee, BSN, is the IRB Administrator at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

EDITORIAL

SHOULDN'T CHILDREN WANT PARENTS OF THEIR OWN?

C. BEN MITCHELL, PHD

Children are among the most vulnerable members of the human community. Because they cannot protect their own rights and interests it is incumbent on others to do so on their behalf. Yet almost every discussion about infertility and assisted reproductive technologies (ARTs) focuses exclusively on the reproductive rights of adults. If the well-being of children born from ARTs *is* discussed, the focus seems nearly always to be on either the general health of the offspring, or on eugenic concerns – whether or not the offspring possesses or does not possess this or that desirable or undesirable trait. It is largely assumed that (1) since it is the right of the adult(s) 'to have a *child of their own*,' (2) any lawful reproductive arrangement they employ is, therefore, licit. Prospective parents' rights to choose if, when, and how to have offspring trumps other goods or rights, including the rights of the children born from their gametes.

Might it be the case, however, that, as McGill University law professor Margaret Somerville has argued, children have a human right to natural biological origins? In other words, might it be the case that children have 'a right to biological *parents of their own*'? Or, to put the question in a slightly different form, 'what do we owe children ethically?'

The human right to have two natural biological parents seems to me to be secured (1) as a natural human right, (2) as an entailment of procreation in marriage, and (3) as a matter of global consensus.

The most fundamental natural human right of every person is the right to be born from natural human origins. This seems to be a first principle for which no argument is necessary. For millennia of human history, sundering the child-parent bond has been seen either as a tragedy, travesty, or both. If the child-parent link was severed by the death of the parents or by their not wanting the child, the child became an orphan. These tragic circumstances led compassionate members of society to establish orphanages, children's homes, and a legal system supporting adoption as a means of rescuing children who have been unlinked from their biological parents. When children were separated from their biological parents by war, kidnapping, or other travesties, compassionate societies have recognized the threat to children and made every effort to locate and restore those children to their biological parents.

As Somerville has said, 'It is one matter for children not to know their genetic identity as a result of unintended circumstances. It is quite another matter to deliberately destroy children's links to their biological parents, and especially for society to be complicit in this destruction.'[1] Yet the looming problem of complicity is becoming increasingly acute in the face of emerging reproductive technologies such as the use of synthetic gametes and other techniques that would result in, very literally, parentless children. For the sake of the children we should resist the temptation to create the conditions that cause a child to ask, 'who are my parents?' **E&M**

Endnotes

1. Margaret Somerville, “Children’s Human Rights to Natural Biological Origins and Family Structure,” a paper delivered at a symposium on The Jurisprudence of the Family: Foundations and Principles, Bratislava School of Law, Bratislava, Slovakia, May 28-29, 2010.

GREY MATTERS

Dignifying Intellectual Disability

WILLIAM P. CHESHIRE, JR., MD

Three generations of imbeciles are enough. – Justice Oliver Wendell Holmes, Jr.[1]

But I say to you that everyone who is angry with his brother will be liable to judgment; whoever insults his brother will be liable to the council; and whoever says, 'You fool!' will be liable to the hell of fire. – Jesus of Nazareth[2]

Abstract

The highly offensive epithets, "moron, imbecile, and idiot," were once accepted clinical terms denoting patients with subnormal intelligence. How their meaning has degenerated over time exposes the danger of allowing hubris a voice in place of Hippocrates at the bedside. Healthcare professionals should exercise moral probity when choosing words that describe their patients and in all circumstances avoid the "neuroslur"-- use of language that denigrates others by imputing inferior intellectual capacity.

Introduction

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, which is the universal authority for psychiatric diagnosis, last year replaced the traditional diagnosis of "mental retardation" with the gentler term, "intellectual disability."[3] In keeping with that revision, the term "mentally retarded" no longer appears in United States government health and education policy documents. On October 5, 2010, President Barack Obama signed into federal law S.2781, also known as "Rosa's law,"[4] replacing the stigmatized term with the more inclusive and respectful "individuals with intellectual disability."

"Mental retardation" has not always been a denigratory designation. Seen through a scientific lens, the term is an objective descriptor of subnormal intellectual functioning whose use continues in the medical literature, albeit at a declining frequency since the National Library of Medicine has followed suit and updated its diagnostic categories with the terms "intellectual disability" and "intellectual developmental disorder."[5] This is because, as seen more broadly through a social lens, the term "mental retardation" and its comingled slang variations, "retarded" and "retard," have been widely used to insult and malign children, adolescents, and adults who happen to have brain disorders that impair their cognitive capacities.[6]

Pejorative application of the originally clinical term "mentally retarded" has so permeated the vernacular that, regardless of intent, its use may offend. A new term is needed, not because the former term was not objective enough but rather because it has acquired the taint of negative connotation. To understand why, it is necessary to explore briefly some examples from the history of intellectual disability and examine not only those named but also their namers.

Mismeasure of Minds

The impulse to name, measure, and categorize others according to their mental ability has existed since antiquity.[7] In the fourth century B.C., Plato recognized that philosopher-kings, whom he envisioned would be best qualified to rule in his ideal *Republic*, might have a problem explaining their privileged status to ordinary citizens. Thus, his protagonist, Socrates, proposed couching the message in respectful terms: "Citizens, we shall say to them in our tale, you are brothers, yet God has framed you differently."[8]

Many centuries later, slight variations in the cranial dimensions of the human frame were the basis for the pseudoscience of phrenology. Its founder, the eighteenth century German neuroanatomist Franz Joseph Gall, sought to explain the development of personality and moral faculties by palpating the external contours of the skull, the uneven bumps of which were presumed to have expanded in response to pressure from brain activity underneath.[9] Following a brief period of popularity, phrenology was eventually shown to lack any scientific validity.

The development of cranial anthropometry in the nineteenth century introduced techniques for empirical quantification of the dimensions of the human skull. Chief among its enthusiasts was the French surgeon and anthropologist Paul Broca, who pioneered the localization of articulated language in the left frontal lobe. On the basis of cranial measurements, Broca undertook with prejudice to rank human races along a scale of mental worth and to verify what he believed to be the intellectual inferiority of women as compared to men. In the final analysis, his cranial data proved nothing, but only reasserted his *a priori* conclusions.[10]

During the early twentieth century, following the publication of Charles Darwin's *On the Origin of Species* and *The Descent of Man*, some scientists interpreted intellectual disabilities within an evolutionary paradigm. Postmortem studies of the brains of profoundly intellectually disabled human patients drew comparisons, for example, to the brains of apes and chimpanzees.[11]

In the twenty-first century, contemporary neuroscience methodologies with unprecedented resolving power are mapping out the specific brain regions involved in every category of thought.[12] As more detailed images come into focus, the historical lessons about erroneous interpretations of the human cranium should not be forgotten. Otherwise, neuroimaging has the potential to become just another, albeit more complex and colorful, phrenology.[13]

To Name is Not to Understand

Mental retardation is the latest in a lineage of clinical terms for intellectual impairment that, like the word "idiot," originally meant something inoffensive but gradually acquired, as Willard van Orman Quine puts it, "harshness by the grim process of euphemism."[14] The original meaning of the word "idiot," according to the *Oxford English Dictionary*, derives from the Greek word ἰδιώτης, meaning a "private person, common man, ... a person without learning; an ignorant, uneducated man." As the word "idiot" entered into other languages, over time its English meaning became "a person so deficient in mental or intellectual faculty as to be incapable of ordinary acts of reasoning or rational conduct." Eventually the word came to be applied also as "a term of reprobation for one who speaks or acts in what the speaker considers an irrational way, or with extreme stupidity or folly; a blockhead, an utter fool."[15]

There exists an even larger glossary of clinical terms that have devolved from category to curse. This taxonomy includes "imbecile" and "moron," which derive from the Latin word *imbecillus*, meaning weak or weak-minded, and the Greek word μωρός, meaning dull. The American psychologist Henry Herbert Goddard introduced these terms into clinical use in the early 20th century to denote people with intellectual disability. Advancing the prospect of scientific diagnosis of the mind, he was the first to promote categorization of cognitive deficiency on the basis of the Binet Intelligence Quotient (IQ) scale, dividing the intellectually disabled along a scale consisting of morons (those with an IQ of 50-69), imbeciles (IQ of 20-49), and idiots (IQ of below 20).[7] The IQ scale generally defines abnormally low intelligence as being less than two standard deviations from the mean (IQ of 100), which, depending on the version of IQ test used, is approximately an IQ score of below 70.[16,17] Goddard was the leading proponent of using intelligence testing in schools, hospitals, the legal system, and the military. He advocated for reforms to provide special education programs for children with intellectual disabilities. He also concerned himself that "people who are doing the drudgery are, as a rule, in their proper places, ... encouraged and made happy, but not promoted to work for which they are incompetent."[18]

Faulting the Feeble-Minded

Goddard was also a eugenicist intent on keeping feeble-minded people from reproducing their kind, as he believed that their numbers would "clog the wheels of human progress."[19] "The idiot," he wrote, "is not our greatest problem. He is indeed loathsome... Nevertheless, he lives his life and is done. He does not continue the race with a line of children like himself.... It is the moron type that makes for us our great problem."[20] Starting from the flawed premise that low intelligence is fully determined by genetics and thus propagated to succeeding generations and, like other eugenicists of his era,[21-23] conflating intellectual disability with criminal instinct and culpability, he asked, "What will be the effect upon the community in the spread of debauchery and disease through having within it a group of people who are thus free to gratify their instincts without fear of consequences...?"[24]

Goddard's answer to this question was published in *The Kallikak Family*,[25] a then influential and now notorious pseudoscientific treatise that Stephen J. Gould called the "primal myth of the eugenics movement."[26] The book was a distorted chronicle of the genealogy of a poor family from rural New Jersey whose members were, for generations, allegedly feeble-minded, illiterate, delinquent, chronically unemployed, immoral, and criminal.[27,28] The family's progenitor, Martin Kallikak, Sr., had purportedly sired this degenerate pedigree through a one-time dalliance with a nameless, feeble-minded tavern maiden. The supposedly feeble-minded descendants of Kallikak had, over six generations, come to number over a hundred. Goddard concluded that "society has had to pay the heavy price of all the evil he engendered," for "no matter where we traced them, ... an appalling amount of defectiveness was everywhere found."[27]

Beyond the Hypothetical

Ideas have consequences. Some are intended and predictable; others are unintended or unforeseeable. History is replete with ideas that, in their abstract formulations, seemed at first to be reasonable, even beneficent, yet in their implementation by others turned out to be expedient rationales for oppressive ideologies...During the twentieth century, approximately 40,000 Americans labeled as feeble-minded were sterilized involuntarily.[27,29] The American epileptologist William G. Lennox advocated on economics grounds for involuntary euthanasia for "idiots and monsters," arguing that the "selection of the congenitally and hopelessly mindless for elimination would offer no more difficulties than their selection for lifelong incarceration."[23] Lennox maintained that physicians "occupy a strategic position with respect to genetics" and referred to imbeciles as "clock cases without works whose only relief is death."[23]

The logical outcome of a worldview that regarded children with intellectual disabilities as a menace to the health of the nation, a worldview that lost sight of the Judeo-Christian understanding of the innate dignity of all human beings as bearers of the image of God, was one that misperceived the grade of the steepest of ethical slippery slopes. Physicians in America and Europe, having forgotten Hippocrates, were easily led astray by utilitarian rationalizations and, lowering their art to the status of mere procedure, began to participate in medical killing. Some of them proceeded next, as Nigel Cameron recounts, to "the euthanasia program with which pre-war Germany busied itself, exterminating its own citizens and beginning with mentally defective children."[30] The horrors that followed palpably discredited to the world what had been a mainstream eugenics movement that took as its earliest victims the lives of the feeble-minded.[31-33]

Correcting the Record

Subsequent research into the family on which the Kallikak myth was based demonstrated that Goddard's findings were incorrect. Their real story was not unlike that of many poor families in an era of limited educational opportunity, scarce resources, and social change.[27] Furthermore, close inspection of Goddard's published photographs of members of the Kallikak family has shown that their facial features had been retouched to suggest a stupid, depraved, or sinister appearance.[34]

IQ tests, which have been abused for eugenic as well as racist purposes,[35,36] are now recognized to be beset with flaws.[37] Only about half of intelligence is hereditable, as it is strongly influenced by environmental factors, neuronal plasticity, and self-discipline.[38] Moreover, intelligence is not unilinear or measurable by a single number. Intelligence encompasses multiple complementary and distinguishable cognitive domains that include spoken language, reading, writing, mathematics, musical ability, abstract reasoning, fund of knowledge, short and long-term memory, empathy, social judgment, interpersonal communication skills, and athletic ability.

The relationships between intellectual disability and criminality are complex and the subject of ongoing research. Whereas epidemiologic studies have found a higher incidence of arrest for violent offenses among people with intellectual disabilities,[39-41] it should be noted that the vast majority of people with intellectual disabilities do not engage in criminal behavior.[42,43] Confounding factors in these groups include coexisting psychiatric disorders, substance abuse, exclusion from stable social environments, stigmatization, and impaired communication skills for deescalating potentially violent situations.

Warping Words

The English language is littered with epithets that derive from condescending views of the intellectually disabled.[44,45] Words like dolt, dullard, dunce, dope, dumbo, pinhead, peabrain, cretin, ignoramus, nitwit, halfwit, numbskull, ninny, birdbrain, airhead, zombie, and fool have no place in civil discourse. These and other contemptuous words are the rhetorical equivalent of craniometry.

Some might conclude that mild insults are essentially harmless. After all, anatomical metaphors such as spineless, heartless, and blind seem to be accepted examples of poetic idiom that enrich expression. A moral boundary is crossed, however, when people, rather than ideas, are mocked and vilified. In comparison to critical comments about other bodily organs, disapproving remarks about brain function are particularly hurtful. If spoken by someone in the healing professions, the harm can be profoundly disproportionate to the intent. Repeatedly calling anyone stupid can eventually compel belief that the accusation is true.[46]

Use of disparaging language over time also coarsens the attitude and demeanor of the speaker. George Orwell was correct in observing that, “if thought corrupts language, language can also corrupt thought.”[47] Physicians and other healthcare professionals should never use derogatory or pejorative language to describe patients. Such language is erosive to compassionate care and historically has led to deplorable outcomes.[33]

Virtue demands that healthcare professionals be guarded in the habits of word usage, remembering the warning of Aristotle, who wrote that, “In the case of our habits we are only masters of the beginning, their growth by gradual stages being imperceptible, like the growth of disease.”[48] The erudite have no need of neuroslurs. Meaningless and mean-spirited, such words belong to the hateful lexicon of hecklers. Crude language demeans and debases and ultimately reveals more about the character of the namer than the mind of the named.

Whether the current term “intellectual disability” will eventually acquire derogatory tones, casting disrepute on those disabled in other ways, is uncertain given the record of human nature. One can only hope that society will continue with compassion to value and respect disabled individuals of every category. Creative use of language opens the possibility of even moving beyond the neutrality of the word “disability” to more positive meanings. The autism community, for example, is advancing the message that people with autism have, not “disabilities” but “different abilities.”

Conclusion

Whether one is a genius or a goofus, we share in a common humanity. The mastermind and the moron are, as Gilbert Meilaender wrote, “equidistant from Eternity”[49] as individual persons having inestimable worth that is grounded, not in any particular cognitive measure, but in the belief that all are equally distant from and, through grace,[50] near to God.

References

2. *Buck v. Bell*, 274 U.S. 200 (1927).
3. Matthew 5:22, *English Standard Version Study Bible*. Wheaton, Illinois: Crossway Bibles, 2008.
4. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)*. Arlington, VA:

American Psychiatric Publishing, 2013.

5. https://www.govtrack.us/congress/bills/111/s2781/text
6. National Library of Medicine Medical Subject Headings. Accessed at http://www.nlm.nih.gov/cgi/mesh/2014/MB_cgi
7. Special Olympics. Rosa's law, September 23, 2010. Accessed at: http://www.specialolympics.org/Regions/north-america/News-and-Stories/Stories/Rosa-s-Law.aspx
8. Terman LM. *The Measurement of Intelligence*. Cambridge, MA: Houghton Mifflin, 1916.
9. Plato, *The Republic*, trans. B. Jowett (Oxford, UK: Clarendon Press, 1871), Book III. Accessed at: http://www.online-literature.com/plato/republic
10. O'Dell SE. *Phrenology: Essays and Studies, 2nd edition*. London, UK: The London Phrenological Institution, 1925.
11. Gould S.J. *The Mismeasure of Man*. New York: W. W. Norton & Co, 1981, pp. 73-112.
12. Macnamara N.C., Burne R.H. The cerebrum of a microcephalic idiot. *Journal of Anatomy and Physiology* 1903; 37:358-365.
13. Cheshire W.P. Till we have minds. *Ethics & Medicine* 2009; 25(1): 11-16.
14. Shermer M. A new phrenology? *Scientific American* 2008; 298: 46, 48.
15. Quine W.V. *Quiddities: An Intermittently Philosophical Dictionary.* Cambridge, MA: Harvard University Press, 1987, p. 92.
16. *Oxford English Dictionary.* Oxford, UK: Oxford University Press, 1971.
17. Voeller K.K.S. Mental retardation. In: T.E. Feinberg, M.J. Farah, editors, *Behavioral Neurology and Neuropsychology, 2nd edition*. New York: McGraw-Hill, 2003, pp. 843-852.
18. American Psychiatric Association. *Intellectual Disability Fact Sheet*, 2013. Accessed at: http://www.dsm5.org/Documents/Intellectual%20Disability%20Fact%20Sheet.pdf
19. Zenderland L. *Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing.* Cambridge, UK: Cambridge University Press, 2001, p. 296.
20. Goddard, cited in Gould, p. 169.
21. Goddard, cited in Gould, p. 162.
22. Tredgold A.F. The feeble-minded--a social danger. *The Eugenics Review* 1909; 1: 97-104.
23. Tredgold A.F. Moral imbecility. *Proceedings of the Royal Society of Medicine* 1921; 14: 13-22.
24. Offen M.L. Dealing with "defectives": Foster Kennedy and Willian Lennox on eugenics. *Neurology* 2003; 61: 668-673.
25. Black E. *War Against the Weak: Eugenics and America's Campaign to Create a Master Race*. New York: Four Walls Eight Windows, 2003, p. 78
26. Goddard H.H. *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness*. New York: MacMillan, 1912.
27. Gould, p. 168.
28. Smith J.D, Wehmeyer M.L. Who was Deborah Kallikak? *Intellectual Developmental Disabilities* 2012; 50: 169-178.
29. Zenderland, pp. 169-185.
30. Black, p. 123.
31. Cameron N.M.deS. *The New Medicine: Life and Death After Hippocrates*. Chicago: Bioethics Press, 2001. p. 70.
32. Proctor R.N. *Racial Hygiene: Medicine Under the Nazis*. Cambridge, MA: Harvard University Press, 1988, pp. 177-194.
33. Cheshire W.P. Turning a Blind Eye: An Ethical Assessment. *Ethics & Medicine* 2011; 27 (1): 7-11.
34. Pressel D.M. Nuremberg and Tuskegee: lessons for contemporary American medicine. *Journal of the National Medical Association* 2003;95:1216-1225.
35. Gould pp. 171-173.
36. Black, pp. 78-79; Gould pp. 121-122, 150-158.
37. Zenderland, pp. 261-281.
38. Schönemann P.H. On models and muddles of heritability. *Genetica* 1997; 99: 97-108.

39. Devlin B., Daniels M., Roeder K. The heritability of IQ. *Nature* 1997; 388: 468-471.
40. Hodgins S. Mental disorder, intellectual deficiency, and crime. Evidence from a birth cohort. *Archives of General Psychiatry* 1992; 49: 476-483.
41. Assher J.J., van der Put C.E., Stams G.J. Differences between juvenile offenders with and without intellectual disability in offense type and risk factors. *Research in Developmental Disabilities* 2012; 33: 1905-1913.
42. Lindsay W.R. People with intellectual disability who offend or are involved with the criminal justice system. *Current Opinion in Psychiatry* 2011; 24: 377-381.
43. Hippler K., Viding E., Klicpera C., Happé F. No increase in criminal convictions in Hans Asperger's original cohort. *Journal of Autism and Developmental Disorders* 2010; 40: 774-780.
44. Robinson D.N. *Wild Beasts and Idle Humours: The Insanity Defense from Antiquity to the Present*. Cambridge, MA: Harvard University Press, 1998.
45. Panek P.E., Smith J.L. Assessment of terms to describe mental retardation. *Research in Developmental Disabilities* 2005; 26: 565-576.
46. Rose D, Thornicroft G, Pinfold V, Kassam A. 250 labels used to stigmatise people with mental illness. *BMC Health Services Research* 2007; 7: 97.
47. Peate I. Don't call me stupid. *Nursing Standard* 1994; 9: 48.
48. Orwell G. *Politics and the English Language*. Accessed at: http://www.george-orwell.org/Politics_and_the_English_Language/0.html
49. Aristotle, *The Nichomachean Ethics of Aristotle*, trans. F.H. Peters, M.A. 5th edition (London, UK: Kegan Paul, Trench, Truebner & Co., 1893), Chapter 5.
50. Meilaender G. *Neither Beast nor God: The Dignity of the Human Person*. New York: Encounter Books, 2009, p. 6.
51. Isaiah 49:6; Joel 2:32; Matthew 3:2, 10:7; John 3:16-17, 10:9; Acts 2:21, 16:31; Romans 10:6-9,13; Ephesians 2:8-9,13; Philippians 4:5.

William P. Cheshire, Jr., MD, MA, is Professor of Neurology at the Mayo Clinic in Jacksonville, Florida; Chair of the Ethics Committee for the Christian Medical and Dental Associations; and Senior Research Fellow in Neuroethics at the Center for Bioethics & Human Dignity. The views expressed herein are his own and do not necessarily reflect the positions of the professional organizations with which he is affiliated. He currently resides in Ponte Vedra Beach, Florida, USA.

DO NO HARM

JESSIE JALAL HANNA, M.D. & LAUREN NAVALLO, M.D.

It was a Friday afternoon in April, rainy and cold – much colder than normal for a spring day in New Jersey. I sat across from M.B., a 40-year-old man with paranoid schizophrenia, as he spoke with his psychiatrist of ten years. Accompanied by three other medical students from various institutions, I was given the opportunity to spend the day shadowing a psychiatry team in an outpatient mental health facility. A second-year medical student at the time, my exposure to the realm of psychiatry up until this point was solely in the form of textbooks and question stems. Thus, this experience was an unsettling one, to say the least.

M.B. was tall and of athletic build. He had young blue eyes, but his shaggy hair and unruly beard aged him by several years. He was soft-spoken and tearful at times, particularly as he recounted the attempted poisoning of his 1-year-old daughter by federal agents who were angered by his marijuana usage in high school. His story was a florid manifestation of his illness, but his pain was real. My heart broke as he began weeping, lamenting "It's my fault my baby was almost killed." From the attending psychiatrist, we ultimately learned that M.B was refusing to take his neuroleptic, and although a candidate for sustained release medication, his insurance was not covering his treatment.

While answering the questions of the psychiatrist, M.B. shared his take on his illness. He also revealed a history of sexual and physical abuse, interspersed with various flights of ideas, such as his love for chocolate ice cream and his ability to make the best cup of coffee in the world. As he spoke, two of the medical students sitting to my left began to laugh. They continued to chuckle as he went on, and laughed uncontrollably when he showed his "radiation spots." They exchanged glances with each other, and even went so far as to whisper – very audibly – "what a wacko." I was horrified. I was mortified. I was embarrassed. And I was disgusted.

I could not believe the lack of respect demonstrated by my peers… colleagues and future physicians. After speaking with the attending psychiatrist, I learned that this was not the first time and would not be the last time that such respect was displayed by members of the medical community. Yet, although I was angered by their behavior, I was more disappointed in myself. I sat there and watched them laugh; I didn't do anything to change the situation. Maybe I was just as guilty as they were, not stopping them but just turning the other way.

I am sorry, M.B.

Jessie Jalal Hanna, M.D., is a resident physician in the Department of Psychiatry at the Icahn School of Medicine at Mount Sinai in New York, New York, USA.

Lauren Navallo, M.D., is a resident physician in the Department of Pediatrics at New York Presbyterian-Weill Cornell Medical Center in New York, New York, USA

Vol. 30:2 Summer 2014

Freedom For Life: Karl Barth, Transhumanism and Human Flourishing

JONATHAN M. CAHILL, M.A.

Abstract

As evidenced in various religions and myths throughout history, societies have yearned for improvements in the human condition and the obtainment of immortality. This longing has recently taken on new forms as modern technology has made advances in enhancing health and extending life. This is most clearly demonstrated in the transhumanist movement, whose stated goal is a human flourishing understood as the elimination of aging and increased human capabilities through biotechnologies guided by "life-promoting principles and values." While these principles and values are not explicitly laid out, a close reading of the leading transhumanist organization's writings reveals four primary principles and values: (1) life imbued with pleasure and the absence of suffering is the ultimate good to be sought after, (2) humans have moral obligations to use human reason and technology to transcend human limitations to bring about this world free of suffering, (3) individual autonomy should be promoted and (4) humans are not essentially embodied, bodies may in fact prove dispensable. This paper argues transhumanism makes religious claims about salvation and eschatology and proceeds to compare these claims to the theologian Karl Barth's perspectives on life. Barth conceived of life as a loan deserving of respect, which holds significant implications for an understanding of human existence. First, life is a good but not absolute good and thus the absence of suffering cannot comprise the highest aim in life. Second, life includes creaturely independence and power, but in a limited way such that lasting joy can only be accomplished by the Creator. Third, life is lived not in isolation but in freedom for God and others. This provides an alternative to an individual autonomy detached from community that inevitably leads to self-centeredness. Finally, life is understood as a unity of soul and body, an embodied existence. Thus it is not simply the mind that requires salvation but the whole person. In this way, Barth offers a constructive approach towards technology that promotes human flourishing based on life as a gift, but within limits and as a qualified good.

Introduction

Throughout human history, a longing has existed for improvements to the human condition and the obtainment of immortality. This outlook is evidenced in numerous religions and philosophies that have attended to humanity's finitude and have attempted means for the realization of a better future. This yearning has recently taken on new forms as modern technology has made advances in enhancing health and extending life. Within its most radical manifestation there is a movement known as transhumanism. Transhumanism, as defined by Humanity+, its most prominent organization, is,

> The intellectual and cultural movement that affirms the possibility and desirability of fundamentally improving the human condition through applied reason, especially by developing and making widely available technologies to eliminate aging and to greatly enhance human intellectual, physical, and psychological capacities.[1]

Transhumanism understands humanity to be in a relatively early stage of the evolutionary process, where the next phase in evolution will be guided by humans using technologies as the instrument whereby the human condition is improved and life is extended. Thus, transhumanism calls for the promotion and use of all technologies that will further this cause. The implications of this philosophy are wide-ranging and, as a result, there are various disciplines that can prove constructive in evaluating its claims and methods. From a Christian perspective, a central assessment must derive from the theological domain. Transhumanism does not allege to be a religious system, but it makes claims about the human and about salvation that properly belong in the religious arena. Therefore, after laying down some groundwork and further background to the movement, this paper will aim to show that transhumanism indeed lays claim to religious themes and will subsequently put these ideas in dialogue with the 20th century theologian Karl Barth, interacting with his views on life and human flourishing.

Laying the Groundwork

Transhumanists call for the development of and investment in technologies that will serve to overcome the finitude of the human condition. With the extraordinary biotechnological advances in recent decades, transhumanists find hope that this ideal will be accomplished. As evidence, they often point to the rapid developments in the fields of nanotechnology, regenerative medicine, stem-cell therapy, genetic engineering, synthetic biology, and the applied cognitive sciences. The end goal of this development is the realization of the posthuman, that is, a being so distinctly different from the current understanding of what it means to be human that it can only be classified in a wholly different category. What exactly does this posthuman look like? The transhumanists liken this question to the scenario of a prehistoric chimpanzee imagining human existence today. The possibility of envisioning such an existence is beyond their brain's capacity. In the same way, Humanity+ asserts, "posthumans may have experiences and concerns that we cannot fathom, thoughts that cannot fit into the three-pound lumps of neural tissue that we use for thinking."[2] Beyond mental capacities, transhumanists expect the posthuman physical existence to be vastly different from current human bodies, with possibilities ranging from new genetically engineered beings to cyborgs to "uploads." An upload is a common notion among transhumanists, where the brain will be scanned in order to digitalize the intellect, memories and experiences. That data can then be transferred to a computer or network. In this posthuman state, the body is no longer necessary; one can continue existence in a virtual reality. This posthuman state is their future goal and is distinct from the transhuman phase that exists at the present. The transhuman represents an intermediate stage, where one has not reached the objective of becoming posthuman, but is progressing toward that end goal.

Clarification of Terms

Before going further, it should be stated that the terms "transhumanism" and "posthumanism" are very slippery. The movement is very diverse, with people from disparate perspectives. The term "posthuman" is particularly diverse in its appropriation. Use of the word falls primarily into two camps, what Hava Tirosh-Samuelson calls the philosophical-cultural posthuman and the technoscientific posthuman (or conversely, what Jeanine Thweatt-Bates calls the "cyborg" versus the "upload" posthuman construction).[3] The latter upload or technoscientific posthuman position is derived from the enlightenment tradition, and comprises a high view of human rationality and confidence in the human ability to bring about progress. This focus on the rationality of the human leads to a sort of substance dualism that elevates the mind over the biological body. The philosophical-cultural or cyborg posthuman, on the other hand, is a postmodern perspective that is largely critical of enlightenment thought. The posthuman and cyborg metaphors are used as a means to overcome oppression often accompanied with an appeal to an embodied future.[4] In this paper, it is the upload or technoscientific posthuman ideal that will be the subject of analysis. Even within this group there are a vast array of perspectives and views, thus, characteristic positions of the movement will be recounted, but these will not represent all who claim the label "transhumanist." In order to examine the broad principles of the movement, I will be making use primarily of the Transhumanist FAQ, an overview of the movement approved by the World Transhumanist Association and subsequently adopted by Humanity+.

Why Talk About Transhumanism?

To many, the attitude and vision espoused by transhumanists sounds more like fantasy than reality. Why spend time analyzing this movement? Is the topic not better suited for the sci-fi book section of one's local library? I would like to suggest that there are two reasons why it is important to think about this subject. First, while the official movement is indeed relatively small (only about 5,000 individuals based primarily in North America and the UK), its impact is much greater than its numbers would suggest.[5] Its adherents include a number of influential people such as Nick Bostrom, a philosopher at Oxford University who runs the Future of Humanity Institute, William Sims Bainbridge and Mihail Roco at the National Science Foundation, and Ray Kurzweil, the Director of Engineering at Google. These individuals and others have brought the transhumanism discussion onto the world stage. One example of how they are shaping culture is found in Singularity University, which Ray Kurzweil helped found before joining Google. The institution offers summer graduate programs and executive programs on one of NASA's campuses through partnership with Google, Nokia, Cisco, the Kauffman Foundation, among others.[6] The "singularity" in the institution's name refers to a future point in history to which transhumanists look forward when "the rate of technological development becomes so rapid that the progress-curve becomes nearly vertical. Within a very brief time (months, days, or even just hours), the world might be transformed almost beyond recognition."[7] In his book *The Singularity is Near*, Kurzweil explained that the Singularity refers to "a future period during which the pace of technological change will be so rapid, its impact so deep, that human life will be irreversibly transformed."[8] He continues, it "will represent the culmination of the merger of our biological thinking and existence with our technology… there will be no distinction, post-Singularity, between human and machine or between physical and virtual reality."[9] Singularity University seeks to anticipate this moment and prepare for it through its programs. So, while small in number, this movement has influential people who will continue to shape society's imagination through spreading their vision of the future.

Second, it is important to evaluate and discuss this topic because many of the underlying claims of the transhumanist movement are finding their way into popular culture through mediums such as video games, film, and pop-science books and magazines.[10] In addition, technologies that report to improve the human condition and offer the possibility of extended life are widespread in the media. Biotechnologies such as genomics, regenerative medicine, prosthetics with neural interfaces and robotics are reported and consumed enthusiastically. It seems every day new examples are offered that present an exciting new development. Recently, scientists have constructed 3D printers, which print the scaffolding for human tissue to be grown,[11] have generated human organs and successfully implanted them in patients,[12] have developed prosthetic arms that can be controlled by one's mind,[13] and have created wearable computers to "augment reality" – a prominent example being the recent release of Google Glass.[14] Articles such as the recent *New York Times* piece with the tantalizing title, "Can a Jellyfish Unlock the Secret of Immortality?" kindle the imagination of the public by feeding the great desire to extend life.[15] Even if most people will not assent to the Humanity+ aspirations to an upload and virtual existence, the improvement of the human condition and extension of life captures the imagination and influences society and culture. Theologian Philip Hefner calls this popular manifestation "lower case transhumanism" compared with "upper case Transhumanism" where there is an explicit connection to the movement.[16] While the reality of immortality via technology may be doubtful, the prospect of enhancement and extending life through a technological war on aging captures the hearts and minds of many today and, thus, merits a closer examination.

How to Talk About Transhumanism?

Since transhumanism represents such a significant subject, the question follows of what methods and disciplines should be utilized in evaluating the Humanity+ proposal naturally follows. Their transhumanist vision of the future has far reaching consequences for nearly every area of society and has resulted in many forms of engagement. From a political perspective, Francis Fukuyama and Leon Kass have offered critiques of the movement's desire to alter human nature by claiming it involves an existential risk to society, undermining the basis of morality and, therefore, democracy.[17] Recently, Gilbert Meilaender has assessed the implications that protracted years would have on intergenerational relationships and the subsequent effect on society.[18] Others have evaluated the movement philosophically, examining their conception of human nature, personhood, and the good.[19] Still others consider ethical and social concerns, especially regarding the poor and marginalized of society and the likelihood that current disparities around access to these technologies are sure to be exacerbated.[20] A fifth approach is theological engagement, and it is on this that the rest of this paper will focus.[21] This paper presents a theological analysis of transhumanism as a religious movement as, for Christians, this raises the fundamental issues in need of evaluation. While transhumanism does not classify itself as a religious movement, essentially what it portrays is a series of religious claims.[22] In general, religions are interested in providing meaning and purpose in life. They seek to provide a view of human flourishing that diagnoses the human situation while prescribing a way to ameliorate this reality, i.e. a way of salvation. In addition, religions commonly hold a great interest in eschatology, in what the future holds. As will be shown, it is the attempt to diagnose the human condition and the prescription of actions to arrive at a future utopia that governs the thought structures of transhumanism, and thus it can rightly be called a "functioning religion."[23] As it acts as a functioning religion, there are a number of areas of correspondence between Christianity and transhumanism that emerge. For example, both claim that the world is not as it should be, that an ontological transformation is desired (soteriology) and both provide a vision of the future that looks forward to a better world (eschatology). But there are also significant differences rooted in how to articulate the good, i.e. human flourishing, and how the good can be brought about. As this presents the core issue for Christians, this paper will use the influential Christian theologian Karl Barth to join in dialogue with the transhumanist movement. While transhumanism was not at the fore of discourse in the middle of the twentieth-century, the underlying theological concepts regarding perception of life,

Meaning, and human flourishing were as relevant then as they are today.

The Transhumanism Worldview

Transhumanism aspires to the elimination of aging and increased human capabilities through biotechnologies guided by "life-promoting principles and values."[24] These principles and values are never explicitly laid out, but a close reading of the Transhumanist FAQ reveals four primary principles and values: (1) never-ending life imbued with pleasure and the absence of suffering is the ultimate good to be sought after, (2) humans have great capabilities to transcend current limitations and altering human nature for good is a noble and glorious act, (3) individual autonomy should be promoted, and (4) humans are not essentially embodied, bodies may in fact prove dispensable. To these four principles this paper now turns.

Human Flourishing as Pleasure and the Absence of Suffering

Transhumanism as a worldview strives to provide purpose and meaning to life. Proponents claim to offer "a sense of direction and purpose and suggest a vision that humans can achieve something greater than our present condition."[25] They propose the experience of pleasure and the absence of suffering are fundamental to human flourishing and should drive human pursuits. As transhumanism advocates observe the world, they see enormous suffering – both physical and mental – and insist there must be a better alternative. The world is full of sickness, bodily decline, mental illness, and depression that result in pain and sorrow. And while life does provide moments of great pleasure, those moments are too often fleeting. The world has seen broad progress in reducing physical pain, and, thus, transhumanists propose that humanity increase such efforts and continue this trajectory, not stopping until humanity arrives at a point where people can choose to experience absolutely no pain and where pleasure will never end. Proponents invite society to imagine a world where those brief moments of intense pleasure can be sustained and intensified. Thus, there is inherent in the transhumanist agenda a threefold goal: (1) the overcoming of all involuntary suffering, (2) an increased capacity for pleasure and (3) the extension of life to carry on this pleasure endlessly.

This objective is what David Pearce, one of the co-founders of the World Transhumanist Association and primary contributor to the Transhumanist FAQ, calls the "Hedonistic Imperative." He writes,

> The Hedonistic Imperative outlines how nanotechnology and genetic engineering will eliminate aversive experience from the living world. Over the next thousand years or so, the biological substrates of suffering will be eradicated completely. "Physical" and "mental" pain alike are destined to disappear into evolutionary history. The biochemistry of everyday discontents will be genetically phased out too. Malaise will be replaced by the biochemistry of bliss. Matter and energy will be sculpted into life-loving super-beings animated by gradients of well-being. The states of mind of our descendants are likely to be incomprehensibly diverse by

> comparison with today. Yet all will share at least one common feature: a sublime and all-pervasive happiness. This feeling of absolute well-being will surpass anything contemporary human neurochemistry can imagine, let alone sustain. The story gets better. Post-human states of magical joy will be biologically refined, multiplied and intensified indefinitely.[26]

Pearce believes "it will be technically feasible to rewrite the vertebrate genome, redesign the global ecosystem, and use biotechnology to abolish suffering throughout the living world."[27] The absence of suffering is vital to the transhumanist vision of human flourishing and this goal provides purpose and meaning to life. Of course, happiness as a core concept to human flourishing is not a novel idea and has roots at least as far back as Aristotle with his exposition of *eudaimonia*. However, happiness in Aristotle and the Judeo-Christian tradition is understood as a comprehensive and holistic flourishing in which human well-being is located in conformity to one's given nature.[28] In contrast, the transhumanist understanding is more akin to the nineteenth-century utilitarian view of happiness as subjective experience of self-fulfillment.[29] Certainly, the Christian tradition agrees that there is a place for pursuing pleasure and the elimination of suffering. The difference, as will be shown, lies in the ordering of this good to other goods. For transhumanism, an immortal existence comprised of a subjective life of pleasure is the highest good that should be sought by all means.

Human Obligation To Bring About This Good Future

Transhumanism has immense confidence in the ability of humans to bring about progress. This attitude originates with their self-identification as an extension of the humanist project. In the spirit of Francis Bacon, the enlightenment tradition sought to use reason to promote the good. Gerald McKenny calls this the "Baconian Project," and it is characterized by its aspiration for a "technological utopianism." McKenny highlights the emergence of a dual commitment that permeates western society to this day, namely, "technological control over nature (including the human body) and a moral commitment to relieve suffering by preventing the harms and eliminating all the conditions and limitations that threaten bodily life."[30] While Bacon did not find these goals antithetical to faith in God, transhumanists (and many of their humanist predecessors) have detached these commitments from a theistic framework, focusing on human obligations to achieve this better world. As the Transhumanist FAQ expresses, "Transhumanists seek to make their dreams come true in this world, by relying not on supernatural powers or divine intervention but on rational thinking and empiricism, through continued scientific, technological, economic, and human development."[31] While they do not purport that advances in technology will necessarily result in an improved world (far to the contrary, they are quite aware of the existential risks many technologies bring), they do see as "almost inevitable that humans will sooner or later have the option of becoming posthuman persons."[32] This is not a fact to regret or oppose, for "changing nature for the better is a noble and glorious thing for humans to do."[32] This vision of a noble and glorious new existence provides a moral imperative that directs humanity to work towards this techno-utopian future, utilizing the resources of human rationality and technology.

Promotion of Individual Autonomy

Individual freedom and liberty are important tenets to transhumanists. They are committed to promoting the individual right to choice, especially in terms of what is done to their bodies. This commitment does not preclude concern for the poor and just distribution of goods, but this concern is framed in providing freedom of choice for all. Transhumanists Nick Bostrom and James Hughes founded the Institute for Ethics & Emerging Technologies (IEET) partly to dialogue about how to ensure that "all sentient beings [are] protected in their rights for self-augmentation, enhancement, or modification, and… [all] have fair and equal access to such treatments."[34] Their vision of the utopian society includes equal opportunity for everyone to choose enhancement technologies which will result in a better society for all. Their presentation of the ideal society has individual freedom and "bodily autonomy" at its root. It is a libertarian freedom, where freedom is comprehended as the availability of options, from which the individual can then choose the option they think best. As the Transhumanist FAQ explains,

> Transhumanists advocate individual freedom, especially the right for those who so wish to use technology to extend their mental and physical capacities and to improve their control over their own lives. From this perspective, an improvement to the human condition is a change that gives increased opportunity for individuals to shape themselves and their lives according to their informed wishes.[35]

Once again the subjective construct of the good is exhibited, now finding its fulfillment in a society epitomized by individual choice. This individual freedom is particularly underscored as a defense against accusation of eugenics. If the world would be improved if all human bodies were enhanced and modified, should not society demand they do so? Attempting to differentiate themselves from the twentieth-century atrocities in the name of eugenics, they adopt a libertarian framework. "Mindful of these historical lessons, transhumanists are often deeply suspicious of collectively orchestrated change, arguing instead for the right of individuals to redesign themselves and their own descendants."[36] The result is an individual freedom that tends to be self-centered and self-aggrandizing. Choices are made on the basis of what is best for me rather than an others-directed posture. This individual focus is particularly evident in their notion of the upload, a virtual existence where dependence on other corporeal beings is made obsolete. Here they are not only free to live life however they desire, but are freed from even the restrictive confines of corporal existence.[37] This leads to the fourth premise of transhumanism's religious claims: their anthropology, that is, what it means to be (post)human.

Humans Are Essentially Their Minds

In this envisioned world where the body is perceived as an optional component for the individual, a definite view of what it means to be a person is presented. The person is not primarily her body, but is simply her intellect and memory. Humans are essentially the 100 billion neurons with their accompanying trillions of connections, and once the capability to map and record these is reached, the totality of the individual will be known. This understanding of personhood has a consequence. The body is viewed as something to be possessed but is not constituent to the person. Paired with autonomy, this concept leads to the conclusion that humans are free to manipulate and alter their bodies as they choose to reflect peculiar aesthetic and individual desires. Once the possibility of upload becomes reality, persons can then be freed to fully escape the confines of the body. Now, it is not mandatory that everyone embrace a disembodied existence; this will always be a choice. While many will indeed choose to "jettison their bodies altogether and live as information patterns on vast super-fast computer networks," others may choose some sort of artificial embodied existence. Those who do choose to upload themselves may still have experiences that, albeit virtual, are experienced as if they were bodily. However, amidst all these qualifications, the underlying assumption that humans are not essentially their bodies remains, and in its most radical expression, it is the leaving of one's finite bodies that constitutes human flourishing.

Summary

Religions impart a worldview that provides purpose and meaning to life, a particular view of what it means to be human, and a means for the obtainment of salvation. All of these elements are present in the transhumanist worldview and, thus, a theological evaluation is warranted. Transhumanists declare the goal of human existence is the elimination of suffering and the choice to live immortally. To obtain this objective of altering the human condition, human rationality is employed in developing technologies that will overcome human finitude. It is this human rationality and the mind that essentially constitute the person and, in this, the individual as a solitary being is exalted. Salvation is thus comprised of an escape for the person (understood as the mind) from mortal existence and suffering. The implications of their core convictions are wide ranging and allow numerous approaches in which to interact with it, but for the Christian, these beliefs are primarily religious and call for a theological engagement. While there are areas of agreement between the Christian faith and transhumanism, there are also significant differences. To explore these convergences and divergences, we will now turn to Karl Barth.

The Concept of Life in Karl Barth's Theology

Karl Barth is considered by many to be the most influential theologian of the twentieth-century. His *magnum opus* is the unfinished *Church Dogmatics* which consists of over 9,000 pages, published from 1932-67. Barth believed that ethics was inseparable from the dogmatics project and therefore aimed to weave ethics throughout his work, including several sections on special ethics.[38] In Volume III, the *Doctrine of Creation*, Barth finished with a book covering the ethics of creation. Here, an alternate vision of human life to that of transhumanism is articulated. The transhumanists view biological life, i.e. one's body, as a personal possession with which one has an autonomous right to do with as one pleases. Barth, on the other hand, understood all of life as a loan. This is most clearly laid out in his writing on "Respect for Life" at the beginning of a section entitled "Freedom for Life."[39] While one might expect that an ethic of life would have begun his ethics of creation, Barth first established that the command of God the Creator comes to humans as "Freedom Before God" and then as "Freedom in Fellowship." He finds a person's position in relationship to God and fellow humanity as what centrally constitutes his being. Humanity exists in order to be for God and for fellow-humanity.[40] The concept of life cannot become a supreme principle; however, it nonetheless remains important for theological ethics.[41] Borrowing from Albert Schweitzer's phrase "Respect for Life" (*Ehrfurcht vor dem Leben*), Barth suggests that life received as a loan is deserving of respect. "As God the Creator calls man to Himself and turns him to his fellow-man, he orders him to honour his own life and that of every other man as a loan, and to secure it against all caprice, in order that it may be used in this service and in preparation for this service."[42] Life is an unmerited gift from God that, when accepted as gift, summons the person to freedom for true human existence. Receiving life as a loan implies that life is not ultimately one's own to handle as one chooses, but must be treated with respect, care and awe. When life is received as a loan, it leads to a view of humanity that differs substantially from transhumanism.

Life as a Good But Not Absolute Good

Barth would agree with transhumanists that life is a good. Indeed, he argues that the command of God comes as the order to "will to live," and that humans should seek to be healthy and not sick, to live and not die.[43] Barth affirms, "the command of God, claiming him as a living person, inscribes upon his heart the fact that, coming wholly from God, it is always (whether recognized or not) an advantage, a good and worthwhile thing, for everyone to be alive."[44] But in contrast to transhumanism, he asserts that life is not the ultimate good. Based on his understanding of life as a divine gift, Barth writes that life, "is not wholly an advantage nor absolutely good and worthwhile."[45] It must be seen as a good within the context of the ability to worship God and to serve others and must not be elevated to the position of a "second god."[46] When life is lifted to this ultimate position, it is transformed into a form of idolatry. "The respect due to life" begins to "rival the reverence owed to God."[47] For Barth, the will to live cannot become absolute; the fundamental purpose of life does not entail simply ensuring prolongation of life under all circumstances but is fundamentally comprised of living for God and fellow humanity.

Comfort and avoidance of suffering are likewise not absolute and must be seen in relationship to respect for God and for others. As mentioned, health is indeed a good. Barth goes as far as to claim that the command of God includes a "will to be healthy," that is, a will for a life consisting of "capacity, vitality, and freedom."[48] But health is a relative good and must not become the highest goal in life.[49] The command of God also comes as a "will for joy, delight and happiness."[50] But this joy is not mere pleasure that is fabricated by humanity, but is a gift bestowed by God and deserving of gratitude. To know what true joy is, one must look to humanity's Creator and to Jesus Christ, the only one who lived as true human.[51] Christ did not exhibit a life consisting only of pleasure, but one that also included sorrow and pain. It included the cross. This demonstrates that true joy is not mutually exclusive to suffering and that the pursuit of a subjective experience of pleasure cannot comprise an absolute allegiance.

Creaturely Independence and Limits

Like transhumanism, Barth recognizes that humans have impressive capabilities to bring about change in the world. God has granted humanity independence and distinctive creative abilities. The human person is a productive subject, "capable of making for himself a new beginning with his being, conduct and action… of planning something new and his very own." But this independence that Barth refers to is qualified as a "creaturely independence," not an absolute one.[52] Only God is truly and absolutely independent, and this has consequences for the extent of change that can be expected through human effort. Later in Church Dogmatics III/4, Barth includes a section entitled the "Active Life," in which he makes the claim that humans do indeed have a special ability to accomplish and create things "as he directs his energies to do so."[53] But Barth stresses that human action as creators is always in correspondence to God's work as the Creator, and not independent of one's relation to God. Humans must not mistake their limited capabilities for God's boundless wisdom and power. Transhumanists unquestionably admit that humans are limited, but they see this as a deficiency and challenge to be overcome. Conversely, Barth portrays these inherent limits as goods, for otherwise humanity would be under the "intolerable destiny of having to give sense, duration and completeness to his existence by his own exertions and achievement." Accepting human limits thereby frees humanity from "the view that he must and may and can by his own strength and powers eternally maintain, assert and confirm himself, attaining for himself his own dignity and honour."[54] God guarantees that he will perform this task for his covenant partners and confirms it by giving humans a temporal and limited life. Thus, there emerges a freedom in limits that enables humans to live in accord with humanity's created purpose.[55]

In our current existence, finitude results in pain and suffering, but humanity's ultimate destiny is a never-ending joy. Present human existence also includes joys, but these are but "provisional fulfillments," for in this world humanity continues to live under the shadow of divine judgment.[56] On this point, Barth is in agreement with transhumanism, that the current joys and pleasures experienced are often fleeting and that humans should yearn for a day when joy will be deepened and made never-ending. Earthly joys are only provisional and anticipatory, they point toward "the eternal joy and felicity which in all cases of joy is the only one in which it can be lasting and complete joy."[57] This eternal joy is not something that will ever be possible to upload into a computer program; it is fellowship with God, and fulfillment of humanity's meaning and purpose as created beings. While humans do have a capacity to create and achieve impressive things in the world, freedom from suffering and lasting joy can only be accomplished by God the Creator.

Human Flourishing as Freedom for Others

Similar to transhumanists, Barth places a major emphasis on freedom, but it is a very different conception from the libertarian freedom that transhumanists proclaim. For transhumanists, to be free is to have the ability to choose among options, especially in regards to individual bodily autonomy. In contrast to this approbation of individual autonomy, which goes as far as allowing the possibility of a disembodied existence independent from all others, Barth understands human freedom as the ability to choose the good which comes to us in a dynamic encounter with the command of God. In *Church Dogmatics* III/2, Barth contends that,

> freedom cannot be equated with neutrality but is capable of only the one positive meaning that it is freedom which is exercised in the fulfillment of responsibility before God… It is certainly freedom of choice. But as freedom given by God, as freedom in action, it is the freedom of a right choice. The choice is right when it corresponds to the free choice of God.[58]

In other words, freedom is liberation to obey. As sinful beings in rebellion before God, humans are naturally prone to reject the good. But through the Spirit, persons are liberated to act according to their created purpose in service of God and others. As Daniel Migliore explains, for Barth, "true human freedom is freedom for God and each other that corresponds to God's way of being and acting in loving freedom for the world. Human freedom is freedom to be who we truly are in Jesus Christ."[59] For Barth, this is human flourishing at its most basic level. It is the freedom to choose the good in obedience to God's command.[60]

In regards to the understanding of life, this freedom consists of treating one's own life and the life of others as a loan.[61] It is not freedom to be self-centered and self-focused, but freedom to live for God and others. This idea is built on the earlier sections of *Church*

Dogmatics III/4 entitled “Freedom before God” and “Freedom in Fellowship.” Freedom before God means that the life given by God is to be lived “for the One to whom it belongs and from whom it has been received as a loan.”[62] God has created humanity for this as his covenant partners, and, thus, humans are to live in service of God. Humanity has also been determined for fellowship with fellow-humans. The gift of life is a gift given to all persons and, as a result, humans should live in solidarity with others as those in co-existence.[63] Barth wrote, “the will to live which is the form of respect for life will always… consider the existence and life of others together with its own, and its own together with that of others.”[64] In contrast to the egotistical individualism espoused by transhumanism, the freedom granted enables persons to affirm and respect fellow humans and to serve God.

Humanity as Unity of Soul and Body

As is characteristic of his theology, Barth grounds his anthropology in Christology. God’s intentions for humanity are not known through the analysis of individuals, but rather by studying the human nature of Jesus. It is Jesus, the “real man,” who is decisive in determining what it means to be human.[65] Thus, when Barth turned to the question of the relation of the soul and body earlier in the *Church Dogmatics*, he started by considering Jesus. He wrote, “we find our bearings and our instruction as we look to the constitution of the humanity of Jesus… He is one whole man, embodied soul and besouled body.”[66] Jesus existed not simply soul or spirit, but he lived a bodily life, followed by a resurrection of the body through which he now lives and reigns at the right hand of God. Barth argued strenuously against any reductionism that understood human persons either as simply material organisms or as souls with superfluous bodily shells (as in the Greek understanding of the immortal soul). For Barth, humans are “simultaneously both soul and body, always and in every relation soulful, and always and in every relation bodily.”[67] Thus, when Barth turns to his section entitled “Respect for Life,” the human life, which is to be regarded in awe, consists of the unity of soul and body.[68] Humans cannot be reduced to merely physical parts, but neither can an existence absent from bodies be envisioned. A person does not merely possess her body, she is her body. Thus, the transhumanist conception of a world of disembodied persons living a virtual existence uploaded onto computers or networks mightily misconstrues what it means to be a human.

Anthropology is of great consequence because it influences how one understands soteriology and eschatology. For the transhumanists, what needs to be saved is simply the mind with its intellect and memories. However, in the Christian tradition it is the whole person, body and soul, that requires deliverance. Thus, Brent Waters maintains,

> “it is embodiment that decisively separates posthumanists and Christians, for their assessments of what it means to be human lead to differing beliefs about salvation. Unlike posthumanists, Christians have never believed that humans are creatures who unfortunately happen to have bodies… Consequently, humans are not saved from their bodies, but it is as embodied creatures that they are claimed, redeemed, and renewed by God.”[69]

To understand what salvation looks like, Jesus Christ must be looked to once more. Here we see true humanity lived out and we witness the first fruits of the new creation in his resurrected body. As Christians rightfully look around at our broken world and yearn for transformation, Jesus Christ presents the perfect image of God and our future hope.[70]

Conclusion

While the members of the Transhumanist group are few, they manage to wield influence far beyond their numbers. Many who will never formally join Humanity+ nor arrive at their most extreme positions will yet find transhumanist notions infiltrating their worldviews. This fact is demonstrated in our culture's preoccupation with technologies that offer hope in life extension and a "war on aging" and in the modern tendency toward a functional dualism, separating the self from the finite body. Above all, the influence of transhumanism is seen in society's penchant for looking to science and technology as the ultimate hope for creating a better world and for salvation. Barth provides an alternate paradigm, by which life is understood as a loan from God. Christians should affirm that technology can be used for good out of a respect and awe of the life that has been given.[71] It can be used to promote the common good, following the example of Christ and in the anticipation of the biblical vision of the new heavens and new earth. Scientists and engineers work towards the flourishing of all of creation when human life is respected and when they act as stewards in care of creation. Out of the sinfulness and finitude of humanity, great harm can also come of technology, thus it is the responsibility of society to evaluate through shared reflection the development and application of technologies and their embedded values. This means a particular emphasis must be given to the ways technology may effect on others in society, especially the marginalized. Through this shared reflection and in service of God and others, technology offers the possibility of great good and benefit for our world. But in the end, ultimate hope remains in God alone, who has promised to bring about a new heaven and new earth.

References

1. Nick Bostrom, et al., "Transhumanist FAQ 3.0," Humanity+, http://humanityplus.org/philosophy/transhumanist-faq/ (accessed April 30, 2013), 1.1. Note: due to the length of this document, subsections are cited.
2. Ibid., 1.2.
3. Hava Tirosh-Samuelson, "Transhumanism as a Secularist Faith," *Zygon* 47, no. 4 (2012): 715; Jeanine Thweatt-Bates, *Cyborg Selves: A Theological Anthropology of the Posthuman,* (Burlington, VT: Ashgate Publishing Company, 2012), 5. Also, cp. Andy Miah, "A Critical History of Posthumanism," in *Medical Enhancement and Posthumanity,* eds. Bert Gordijn and Ruth Chadwick (New York: Springer, 2008), 84. Available online at http://www.andymiah.net/wp-content/uploads/2009/Miah2008PosthumanismCriticalHistoryWeb2.pdf (accessed May 1, 2013).
4. Thweatt-Bates, 77ff.
5. Tirosh-Samuelson, 717-8.
6. Singularity University, "Singularity University FAQ," http://singularityu.org/faq/ (accessed April 30, 2013).
7. Transhumanist FAQ, 4.7.
8. Ray Kurzweil, *The Singularity is Near: When Humans Transcend Biology,* (New York, NY: Viking, 2005), 7.
9. Ibid., 9.
10. See Robert M. Geraci, "Video Games and the Transhuman Inclination," *Zygon* 47, no. 4 (2012): 735-56.
11. Ed Yong, "3-D Printer Makes Synthetic Tissues from Watery Drops," National Geographic, http://phenomena.nationalgeographic.com/2013/04/04/3-d-printer-makes-synthetic-tissues-from-watery-drops/ (accessed May 3, 2013).
12. Henry Fountain, "A First: Organs Tailor-Made With Body's Own Cells," New York Times, http://

www.nytimes.com/2012/09/16/health/research/scientists-make-progress-in-tailor-made-organs.html (accessed May 3, 2013) and Ed Yong, “Lab-grown kidneys transplanted into rats,” Nature, http://www.nature.com/news/lab-grown-kidneys-transplanted-into-rats-1.12791 (accessed May 3, 2013).

13. Josh Fischman, “Bionics,” National Geographic, http://ngm.nationalgeographic.com/2010/01/bionics/fischman-text (accessed May 3, 2013).
14. Google, “What it Does,” Google Glass, http://www.google.com/glass/start/what-it-does/ (accessed May 3, 2013).
15. Nathaniel Rich, “Can a Jellyfish Unlock the Secret of Immortality?,” New York Times, http://www.nytimes.com/2012/12/02/magazine/can-a-jellyfish-unlock-the-secret-of-immortality.html (accessed May 3, 2013).
16. Philip J. Hefner, “The animal that aspires to be an angel: the challenge of transhumanism,” *Dialog* 48, no. 2 (June 1, 2009): 158.
17. Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution,* (New York: Picador, 2002).
18. Gilbert Meilaender, *Should We Live Forever? The Ethical Ambiguities of Aging,* (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2013), ch.4, 57-73.
19. For example, Susan Schneider, “Future Minds: Transhumanism, Cognitive Enhancement and the Nature of Persons,” University of Pennsylvania Neuroethics Publications, http://repository.upenn.edu/neuroethics_pubs/37/ (accessed May 1, 2013).
20. Karen Peterson-Iyer, *Designer Children: Reconciling Genetic Technology, Feminism, and*
21. *Christian Ethics,* (Cleveland: Pilgrim Press, 2004), ch.6 “The Limits of Genetic Control,”170-210; Maxwell J. Mehlman, *Transhumanist Dreams and Dystopian Nightmares: The Promise and Peril of Genetic Engineering*, (Baltimore, MD: The Johns Hopkins University Press, 2012) ch.5 “.Maxwell J. Mehlman, *Transhumanist Dreams and Dystopian Nightmares: The Promise and Peril of Genetic Engineering* esp. Ch. 5 “Broader Consequences for Society,” 91-111.

    See also Ronald Cole-Turner, ed. *Transhumanism and Transcendence: Christian Hope in an Age of Technological Enhancement*, (Washington, D.C.: Georgetown University Press, 2011); Gilbert Meilaender, *Should We Live Forever? The Ethical Ambiguities of Aging,* (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2013); Brent Waters, *From Human to Posthuman: Christian Theology and Technology in a Postmodern World,* (Burlington, VT: Ashgate, 2006); Celia Deane-Drummond, *Christ and Evolution: Wonder and Wisdom,* (Minneapolis, MN: Augsburg Fortress, 2009).
22. Cp. Hefner, 164-5.
23. Tirosh-Samuelson, 721. Cp. Brent Waters, *This Mortal Flesh: Incarnation and Bioethics,* (Grand Rapids, MI: Brazos Press, 2009), 154ff. It is interesting to note that there are a number of people in the transhumanist movement who are attempting to make the explicit claim that they are a religious movement. See Gregory Jordan, “Apologia for Transhumanist Religion ,” *Journal of Evolution & Technology,* vol. 15/1 (2006): 55-72; Guillermo Santamaria, “Why Christianity & Transhumanism Are Not Enemies,” Humanity+ Magazine, http://hplusmagazine.com/2011/10/04/why-christianity-transhumanism-are-not-enemies/ (accessed May 1, 2013); Patrick D. Hopkins, “Toward a Transhumanist Theology,” Metanexus, http://www.metanexus.net/essay/toward-transhumanist-theology (accessed May 1, 2013). However, a majority still claim to be atheist or agnostic and deny any religious connection. James J. Hughes, “The Compatibility of Religious and Transhumanist Views of Metaphysics, Suffering, Virtue and Transcendence in an Enhanced Future,” Institute for Ethics and Emerging Technologies, http://ieet.org/archive/20070326-Hughes-ASU-H+Religion.pdf (accessed April 29, 2013), 5.
24. FAQ, 1.1.
25. FAQ, 6.3.
26. David Pearce, “The Hedonistic Imperative,” http://www.hedweb.com/hedethic/hedonist.htm#naturalisation (accessed May 1, 2013).
27. FAQ, 6.2. Therefore, today, the “reduction of existential risks, and development of means for the preservation of life and health, the alleviation of grave suffering… should be pursued as urgent priorities, and heavily funded.” “Transhumanist Declaration #5,” Humanity+, http://humanityplus.

org/philosophy/transhumanist-declaration/, (accessed May 1, 2013).

28. Hava Tirosh-Samuelson, "Engaging Transhumanism," in H+/-: Transhumanism and Its Critics, eds. Gregory R. Hansell and William Grassie (Philadelphia, PA: Metanexus Institute, 2011), 36.
29. Ibid., 38.
30. Gerald P. McKenny, *To Relieve the Human Condition: Bioethics, Technology, and the Body,* (Albany, NY: State University of New York Press, 1997), 19.
31. FAQ, 6.3.
32. FAQ, 2.2. That they are aware of the existential risks see FAQ, 3.3,4 and the Institute for Ethics and Emerging Technologies, http://ieet.org/ (accessed, May 4, 2013).
33. FAQ, 5.2.
34. Institute for Ethics & Emerging Technologies, "IEET's Purposes," http://ieet.org/index.php/IEET/purpose (accessed April 26, 2013).
35. FAQ, 3.7. Cp. Transhumanist Declaration #8: "We favour allowing individuals wide personal choice over how they enable their lives. This includes use of techniques that may be developed to assist memory, concentration, and mental energy; life extension therapies; reproductive choice technologies; cryonics procedures; and many other possible human modification and enhancement technologies."
36. FAQ, 6.1.
37. Paradoxically, in transhumanism's attempt to use technology to free humans from the limitations of their body, they envision a future that is dictated by human-made machines. Tirosh-Samuelson, 731.
38. "Dogmatics itself is ethics; and ethics is also dogmatics." Karl Barth, *Church Dogmatics I/2* (Peabody, Massachusetts: Hendrickson Publishers, Inc., 2010), 793. Hereafter, the *Church Dogmatics* texts will be cited like this: *CD* I/2, 793. Cp. Barth's posthumously published comment, "Theological ethics can be understood only as an integral element of dogmatics" in Karl Barth, *The Christian Life: Church Dogmatics IV, 4 Lecture Fragments* (Grand Rapids, MI: William B. Eerdmans Publishing Company, 1981), 3.
39. CD III/4, 324-97.
40. Ibid., 325.
41. Ibid., 326-7.
42. Ibid., 324; cp. 335.
43. Ibid., 341, 367, 356ff.
44. Ibid., 336.
45. Ibid., 342.
46. Ibid.
47. Ibid., 342.
48. Ibid., 356-7.
49. In fact, it is possible to retain a "will to be healthy" amid sickness. See Ibid., 357ff.
50. Ibid., 375.
51. It is "outside our power to try to discover unequivocally and conclusively what constitutes the real pleasure of our real life, and in what the fulfillments which summon us to gratitude actually consist. We think we should seek them here or there because this thin or that appears as light or alleviation, as warmth, benefit, refreshment, consolation and encouragement, promising us renewal and the attainment of that which hovers before us as the true goal of all that we do and refrain from doing. But do we really know this true goal and therefore our true joy? God knows it. God decides it. But this means that our will for joy, our preparedness for it, must be wide open in this direction, in the direction of His unknown and even obscure disposing, if it is to be the right and good preparedness commanded in this matter. It should not be limited by the suffering of life, because even life's suffering (or what we regard as such) comes from God, the very One who summons us to rejoice." Ibid., 382-3.
52. Ibid., 330.
53. Ibid., 471,4.

54. Ibid., 372-3.
55. This theme is important to Barth and he thus returns to it later in this book under the title "Freedom in Limitation" where he spends 120pgs expanding on this idea. See also, Waters, *Mortal Flesh,* 39-43.
56. CD III/4, 383-4.
57. Ibid., 384-5; cp. 377.
58. CD III/2, 196-7. Cp. Karl Barth, *The Humanity of God,* (Louisville, Kentucky: Westminster John Knox Press, 1960), 76. Of course, this freedom to choose involves a "natural freedom" to choose between options. Ibid., 75, 84; John Webster, *Barth's Moral Theology: Human Action in Barth's Thought*, (Edinburgh, Scotland: T&T Clark Ltd, 1998), 109.
59. Daniel L. Migliore, "Commanding Grace: Karl Barth's Theological Ethics," in *Commanding Grace: Studies in Karl Barth's Ethics*, ed. Daniel L. Migliore, (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2010), 13.
60. Nigel Biggar, "Karl Barth's Ethics Revisited," in *Commanding Grace: Studies in Karl Barth's Ethics*, ed. Daniel L. Migliore, (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2010), 37: Barth "characterizes the human good or human flourishing as 'freedom' - the freedom of humans to act and to be in a manner befitting their status as sinful creatures whom God has reconciled to himself and whose redemption he is completing."
61. CD III/4, 335.
62. Ibid., 331.
63. Ibid., 331, 335.
64. Ibid., 341.
65. CD III/2, 132ff.
66. Ibid., 327. Cp. "It is true humanity in the person of Jesus which allows us no other starting-point" than the unity of body and soul. Ibid., 371.
67. Ibid., 372.
68. "The Word of God decides and reveals that man may never understand himself as merely physical, nor as merely psychical, nor in a mere juxtaposition or higher synthesis of these determinations, but that he must understand himself in this event of his existence as the soul of his body, that he should be in the event, and that this should be his particular human life." CD III/4, 328.
69. Waters, *Mortal Flesh,* 158.
70. Deane-Drummond, 279ff, 286.
71. "What is at stake here is not a Luddite reaction against all applications of technology, but the motivation behind transhumanism." Ibid., 281.

Jonathan M. Cahill, is a recent graduate of Gordon-Conwell Theological Seminary with a Master's of Arts in Ethics and Society and is pursuing a PhD at Boston College in Theological Ethics in Chestnut Hill, Massachusetts, USA.

DEVELOPMENT OF ETHICAL GUIDELINES FOR CLINICAL RESEARCH: SERENDIPITY OR EULOGY

BHUMIKA AGGARWAL, MBBS, DTCD, MBA, MPM & MAYANK GURNANI, MBBS, MBA

Abstract

Clinical studies conducted today have the advantage of referring to the various adopted guidelines or codes in ethical research. There is a spectrum of standards of ethics used to judge clinical research dating back in history to the Nuremberg Code. As an end result of these guidelines, the dilemma is no longer the ambiguity in determining what constitutes unethical experimentation. The fundamental goal of each of these guidelines is essentially to protect the rights of subjects by ensuring the most ethical, qualified and certified standards of research. To understand how these guidelines evolved over the years is a revelation, a journey which unravels the self-debate that – were these guidelines founded on the path of scientific discovery or were these outputs of unspeakable atrocities and carnage in the era gone by. It is important, therefore, to understand the development of these guidelines for 'ethics in clinical research.' This article highlights the milestones in history that led to the current form and shape of these clinical research standards.

The Nuremberg Code

Historical Perspective: From 1939 to 1945, during the Second World War, medical experiments such as involuntary sterilization, phosphorus burn experiments, radiation exposure experiments, high altitude or low pressure experiments, freezing to induce hypothermia, infection with malaria and tuberculosis, and many others were carried out on Nazi concentration camp prisoners. These experiments were conducted without the consent of the research subjects, and often resulted in tremendous pain, injury, and death.[1-3] Many Nazi scientists and researchers involved in these experiments underwent trials in Nuremberg, Germany in 1946 – 1947.[4]

The Nuremberg Code, issued subsequent to these trials by the Nuremberg Military Tribunal in 1947, assembled ten principles for ethical experiments on human subjects.[5] Most importantly, this was the first international document that advocated voluntary participation in research trials and the informed consent of participants in these trials. The Nuremberg Code was not biding by law and, even though it has never been formalized by any state or international body, it has formed the basis of almost all future guideline documents related to ethics in research. To emphasize the importance of informed consent in research trials, the very first line of the Code states: "The voluntary consent of the human subject is absolutely essential."[4,5]

The ten points of The Nuremberg Code can be summarized as:[5,6]

1. Consent of human subjects should be voluntary and informed. Voluntary consent is defined as the willingness of the subject without any means of force, coercion, fraud or deceit. Informed consent means informing the subject on any kind of hazards they may face or any inconvenience they might experience. Any risk

to the health of the subject should be disclosed and the subject should be well-informed about the nature of the project or experiment and what it constitutes.

2. The experiment results should benefit the society as a whole. The results should not be obtainable by any other methods or means of research.
3. Experimentation of animals should precede the experiment, and results of animal experimentation should form the basis of the design of the experiment.
4. Any kind of physical or mental suffering to the subject should be avoided.
5. If there is reason to believe that the experiment will cause a disabling injury or death to the subject, the experiment should not be performed.
6. The risks should never exceed the benefits.
7. Preparations and facilities should be adequate and proper so as to avoid even the remote possibility of harm, injury, or death to the subject.
8. Only scientifically qualified must perform the experiment. The highest degree of skill and the utmost care should be taken throughout every stage of the experiment.
9. The subject may withdraw from the experiment at any point or stage due to physical or mental exhaustion or not being able to continue any further.
10. The investigators must be prepared to terminate the experiment at any point or stage, if they believe the experiment will cause harm, injury, disability or death to the subject.

After Effects*:* As an immediate after effect of the Nuremberg trials, the World Medical Association was formed in 1947.

The Declaration of Helsinki

Members of the World Medical Association issued a code of medical ethics in 1949 – called the *Declaration of Geneva* – to condemn the atrocities by the Nazi scientists.[7] This code was amongst the first signs of the establishment of formalized medical ethics. To remove any ambiguity in terms of language and to clearly define research ethics, the World Medical Association approved the ‘Ethical Principles for Medical Research Involving Human Subjects,’ also called as the *Declaration of Helsinki*, in 1964. The *Declaration of Helsinki* shifted the emphasis from the protection of human rights through informed consent, as advocated by the Nuremberg Code, to the protection of human welfare through physician responsibility.[8]

The *Declaration of Helsinki* was revised in 1975, 1983, 1989, 1996, 2000, with updates in 2002 and 2004 and the most recent revision in 2008.[9, 10] The *Declaration of Helsinki* now contains three sections with 35 articles in the 2008 updated version (the original 1964 version had 11 articles). Each of the revisions to the *Declaration* added certain articles, which were reached on a consensus by the World Medical Association. The most significant of these revisions were the first revision in 1975 (due to the influence of the Tuskegee Syphilis study), the fourth revision in 1996 (due to the AIDS clinical Trial and the controversy over use of placebo in clinical trials), and the fifth revision in 2000 (due to the Articles 29 and 30 added to the *Declaration*).[11]

The Revisions: The First Revision to the Declaration of Helsinki (1975)

Historical perspective: The Tuskegee Syphilis Study (1932 -1972) carried out at Tuskegee, Alabama, by the US Public Health Service recruited about four hundred African-American patients with syphilis and two hundred healthy controls. The aim of the study was to observe the natural progression of syphilis when left untreated. The participants were not told that they were in a trial, and the tests done on them were alleged to be curative treatments. At the onset of the trial in 1932, there was no effective treatment for syphilis. However, by 1947 penicillin had become the standard and effective treatment for syphilis. The study participants were denied treatment with penicillin until long after it was available. The immoral aspects of the trial did not come to light until 1972. The trial was only stopped by the U.S. Department of Health, Education, and Welfare in 1973, but by then only 74 subjects remained alive, 40 of their wives had been infected and 19 children had been born with syphilis.[12-14] The aftermath of Tuskegee led to the formalization of ethics review in America, and was influential in the fourth revision of the *Declaration of Helsinki*, which introduced the requirement for the independent review of all research.

After Effects: As a consequence of the repercussions from the Tuskegee Syphilis Study, the National Research Act of 1974 was passed. This act created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which identified the basic ethical principles that underlie the conduct of research involving humans and developed also guidelines in accordance with those principles.

The Second and Third Revisions to the Declaration of Helsinki (1983, 1989)

These subsequent revisions were relatively minor.

The Fourth Revision to the Declaration of Helsinki (1996)

Historical perspective: The AIDS Clinical Trials Group Study of Zidovudine in maternal-infant transmission of HIV was a placebo-controlled trial showing reduction in the risk of transmission. As a result of this trial, Zidovudine became the standard of care. Further placebo controlled trials carried out in developing countries like Africa and Thailand, funded by the US Center for Disease Control or National Institutes of Health, raised concerns as patients in trials in the US had unrestricted access to Zidovudine, while patients in the developing countries did not.[15,16] The 'Meeting on Prevention of Mother-to-Infant Transmission of HIV by Use of Antiretrovirals' of World Health Organization in 1994 in Geneva concluded that "Placebo-controlled trials offer the best option for a rapid and scientifically valid assessment of antiretroviral drugs to prevent HIV transmission."

The Fourth Revision was one of the most significant and controversial revisions to the *Declaration*, due to the addition of the phrase, "This does not exclude the use of inert placebo in studies where no proven diagnostic or therapeutic method exists,"[17] which fired the still ongoing debates over the ethicality of the use of placebos in clinical research[18,19] and of the conduction of research in developing countries.[20]

After Effects: The US Food and Drug Administration disregarded the fourth revision and all subsequent revisions to the *Declaration of Helsinki*.[21] Similarly, the European Union only cites the fourth revision – 1996 version – in the EU Clinical Trials Directive published in 2011.

The Fifth Revision to the Declaration of Helsinki (2000)

Article 29 and Article 30 form the most controversial and debated principles of the *Declaration*. Article 29 states that new treatments should be tested against standard treatment, thus forbidding use of placebo when a treatment exists. Article 30 states that, at completion of the study, all the study participants must be guaranteed access to the "most appropriate" treatment as identified by the results of the study.[22-26] The articles in the

Declaration of Helsinki can be grouped into three sections:[27]

> **Section A** defines human research and its necessity and emphasizes on the responsibility of the physician to prioritize participant health. This section stresses that special populations – economically and medically disadvantaged, those who cannot give informed consent (or who may be doing so under coercion), those who will not benefit personally from the research, those for whom research is combined with care – involved in research must be closely monitored.
>
> **Section B** discusses basic principles for medical research and reiterates the points of the Nuremberg Code, such as the need for planning a human trial rationally based on available evidence. However, the *Declaration of Helsinki* significantly expands the Nuremberg principle of voluntary consent to state that potential subjects should only give consent after being fully informed of the study's setup, goals, and sources of funding; potential conflicts of interest; researcher affiliations; risks and benefits; and their right to withdraw. Only populations likely to benefit from the research should be targeted for recruitment, and vulnerable populations should not be used when other populations are available and appropriate. In all cases, a researcher should not unjustifiably influence a patient to give consent.
>
> **Section C** discusses research combined with medical care and states that research can only be combined with clinical care if it has the potential to prevent, diagnose, or treat. In all such cases, subjects must be made aware of aspects of their care that are experimental. Section C also contains the two most controversial statements in the document: Articles 29 and 30 (discussed elsewhere in this article). The list of the articles of the Declaration, sub grouped as fundamental and key operational articles,[28,29] can be accessed in Table 1.

After Effects: The *Declaration of Helsinki* formed the basis for the Good Clinical Practices guidelines used today. It also recommended formation of safety committees that later became data safety monitoring boards (DSMB) and Institutional Review Boards.[11,30] All of these historical cases provide evidence of the atrocities that have occurred in the past in unregulated research, and these have been the principle driving force behind the development of ethical codes and laws to govern research. Concerns about the effectiveness of the existing regulations arose when attention was drawn to various ethical issues in ongoing research long after the Nuremberg Code and the *Declaration of Helsinki* had been issued. The landmark Beecher Paper (1966)[31] exposed studies done to expand scientific knowledge showing little or no concern to how the participants in the studies would be affected.

The Belmont Report

Historical Perspective: After the infamous research studies carried out in the United States, exemplified by the Tuskegee syphilis experiments (1932 - 1972),[32] the National

Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established in 1974. The Commission met at the Belmont Conference Center from 1974 to 1978, drafting a set of national guidelines for research.[33] This report was called 'The Belmont Report: Ethical Principles and Guidelines for Research Involving Human Subjects.' The Belmont Report is a statement of basic ethical principles and guidelines addressing the ethical problems that surround the conduct of research with human participants. The Belmont Report points out the differences between "practicing medicine on patients" and "performing medical research on human research subject volunteers."[33] The three basic principles and their corresponding applications are summarized[33] in Table 2.

After Effects: Although never officially adopted or endorsed, the Belmont Report has served as an ethical framework for protecting human subjects internationally.[34] The Belmont Report formed the basis for the dissemination of federal regulations in 1981 that were later revised (in 1983 and 1991) and adopted by 16 federal agencies (and is therefore referred to as the "Common Rule"). The Common Rule elaborated in detail the ethical fundamentals of how federally funded human research studies should be carried out. Many of the Belmont Report's recommendations have been incorporated into Health and Human Services regulations Title 45 CFR Part 46 and Food and Drug Administration's Title 21 CFR Part 50.[34] The Belmont Report advised for the Institutional Review Board system to be initiated. The role of the Institutional Review Board is to protect the rights and welfare of individual research subjects. The Institutional Review Board has to approve that these requirements are followed before they approve a research study and must review these documents on, at the least, an annual basis.[34]

Conclusion

Having gone through the history of research ethics – not just of the formation of the guidelines in ethical research but also their reasons for being – it is conceivable that, despite ethical codes of clinical research, data from unethical experiments may still come to the awareness of the clinical and medical community. Ongoing through these established principles, it is clearly evident that a noteworthy concurrence exist across several decades of thought on the defining aspects and boundaries of ethical research. This allows for the conclusion that, whether or not particular countries/nations have their own guidelines, researchers can be expected, at a minimum, to adhere to the ethical practices described by the Nuremberg Code, the *Declaration of Helsinki* and the Belmont Report.

References

1. The brutalities of Nazi physicians. *Journal of American Medical Association*. 1946; 132:714-715. Editorial.
2. The Nuremberg Issue. *Journal of American Medical Association*. 1996; 276: 1657-1683.
3. Spitz V. Doctors from Hell: The Horrific Account of Nazi Experiments on Humans (Boulder, CO: Sentient Publications, 2005).
4. Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law 10. 1949; 2: 181-182. http://ohsr.od.nih.gov/guidelines/nuremberg.html (Accessed online on 1st July 2013).
5. The Nuremburg Code. *Journal of American Medical Association*. 1996; 276:1691.
6. Annas GJ and Grodin MA. The Nazi Doctors and the Nuremberg Code. *New York: Oxford*

University Press. 1992; 127 – 131.

7. Declaration of Geneva. Adopted by the General Assembly of World Medical Association at Geneva Switzerland, September 1948.
8. Declaration of Helsinki: Recommendations Guiding Medical Doctors in Biomedical Research involving Human Subjects (1997). World Medical Association. *Journal of American Medical Association*. 1997; 227:925-926.
9. Williams J. The Declaration of Helsinki and public health. *Bulletin of the World Health Organization*. 2008; 86(8).
10. Rid A and Schmidt H. The 2008 Declaration of Helsinki — First among Equals in Research Ethics? *The Journal of Law, Medicine & Ethics*. 2010; 38 (1): 143–148.
11. Declaration of Helsinki: ethical principles for medical research involving human subjects. World Medical Association. *Journal of American Medical Association*. 2000; 284:3043–5
12. Heller J. "Syphilis Victims in U.S. Study Went Untreated for 40 Years; Syphilis Victims Got No Therapy". New York Times. Associated Press. 1972. Available at http://select.nytimes.com/gst/abstract.html?res=F40616F6345A137B93C4AB178CD85F468785F9 Accessed on 1st July 2013.
13. Dracobly A (2003). Ethics and experimentation on human subjects in mid-nineteenth century France: the story of the 1859 syphilis experiments. *Bull Hist Med*; 77(2):332-366.
14. Katz RV, Kegeles SS, Kressin NR, et al.The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research. *Journal of Health Care for the Poor and Underserved*. 2006*; 17 (4): 698–715.*
15. Connor EM, Sperling RS, Gelber R et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. *New England Journal of Medicine*.1994*;* 331 (18): 1173–1180.
16. Lurie P and Wolfe SM. Unethical trials of interventions to reduce perinatal transmission of the human immunodeficiency virus in developing countries. *New England Journal of Medicine*. 1997; 337(12): 853–856.
17. Temple R. Impact of the Declaration of Helsinki on medical research from a regulatory perspective. Address to the Scientific Session, World Medical Association General Assembly, September 2003.
18. Rothman KJ and Michels KB. The continuing unethical use of placebo controls. *New England Journal of Medicine*. 1994; 331:394–398.
19. Appelbaum PS. Drug-free research in schizophrenia: an overview of the controversy. *IRB: Rev Hum Subj Res*. 1996; 18(1):1–5.
20. Guidance for industry: acceptance of foreign clinical studies (2001).Center for Drug Evaluation and Research.
21. Lurie P and Greco DB. US exceptionalism comes to research ethics. *Lancet*. 2005; 365 (9465): 1117–9.
22. Brennan TA. Proposed revisions to the Declaration of Helsinki—will they weaken the ethical principles underlying human research? *New England Journal of Medicine*. 1999; 341(7):527–531.
23. Levine RJ. The need to revise the Declaration of Helsinki. *New England Journal of Medicine*. 1999; 341(7):531–534.
24. Macklin R. Future challenges for the Declaration of Helsinki: Maintaining credibility in the face of ethical controversies. Address to Scientific Session, World Medical Association General Assembly, September 2003, Helsinki.
25. Riis P. Perspectives on the fifth revision of the Declaration of Helsinki. *Journal of American Medical Association*. 2000; 284(23): 3045- 3046.
26. Carpenter WT, Jr., Appelbaum PS, Levine RJ (2003). The Declaration of Helsinki and clinical trials: a focus on placebo controlled trials in schizophrenia. *American Journal of Psychiatry*; 160:356–362.
27. Bernard A and Fischer IV. A summary of important documents in the field of Research Ethics *Schizophrenia Bulletin*.2006; 32 (1): 69–80.
28. Declaration of Helsinki, Document 17.C (2002) Available at: http://www.fda.gov/ohrms/dockets/dockets/06d0331/06D-0331-EC20-Attach-1.pdf Accessed on 1st Declaration of Helsinki (2012)

Available at: http://en.wikipedia.org/wiki/Declaration_of_Helsinki Accessed on 1st July 2012

29. July 2012
30. Declaration of Helsinki. World Medical Organization. *British Medical Journal.* 1996; 313(7070):1448-1449.
31. Beecher H. Ethics and clinical research. *New England Journal of Medicine.* 1966; 274, (24): 1354–1360.
32. Jones J.H. Bad blood: the Tuskegee syphilis experiment. New York: Free Press. (1981).
33. The Belmont report: ethical principles and guidelines for the protection of human subjects of research (1978). U.S. National Commission for the Protection of Human Subjects of Biological and Behavioral Research. Department of Health, Education, and Welfare (DHEW) Publication No. (OS) 78-0012, Appendix I, DHEW Publication No. (OS) 78-0013, Appendix II, DHEW Publication No.(OS) 78-0014. Washington, DC: U.S. Government Printing Office.
34. Code of Federal Regulations, Title 45 Public Welfare: Part 46, Protection of Human Subjects (1981, revised 1983, 1991). http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm Accessed on 1st July 2013.

Bhumika Aggarwal, MBBS, DTCD, MBA, MPM, is a Pulmonolgist, MBA (IIM), with a Masters of Science in Pharmaceutical Medicine (Hibernia College, Dublin). She practices in Mumbai, India.

Mayank Gurnani, MBBS, MBA, is a Physician with an MBA (IIM) and has research interests in pharmaceutical industry, healthcare and biopharma. He practices in Mumbai, India.

Table 1

Fundamental and Key Operational Articles of Declaration of Helsinki

Fundamental Articles of the *Declaration of Helsinki*:

Article 8	respect for the individual
Articles 20, 21 and 22	right to self determination and the right to make informed decisions regarding participation in research, both initially and during the course of the research
Articles 2, 3, 10, 16 and 18	the investigator's duty is solely to the patient or volunteer
Article 5	the subject's welfare must always take precedence over the interests of science and society
Article 9	ethical considerations must always take precedence over laws and regulations
Article 8	the recognition of the increased vulnerability of individuals and groups calls for special monitoring
Articles 23, 24, 25	when the research participant is incompetent, physically or mentally incapable of giving consent, or is a minor, then allowance should be considered for surrogate consent by an individual acting in the subject's best interest. In which case their assent should still be obtained if at all possible

Key Operational Articles of the *Declaration of Helsinki:*

Article 11 and Articles 16, 17	the research should be based on - a thorough knowledge of the scientific background and a careful assessment of risks and benefits
Article 19	the research should have a reasonable likelihood of benefit to the population being studied
Article 15	the research should be conducted by suitably trained investigators
Article 13	the research should use approved protocols, subject to independent ethical review and supervision by a properly convened committee
Article 14	the research protocol should address the ethical issues and indicate that it is in compliance with the *Declaration*
Article 17	studies should be discontinued if the available information indicates that the original considerations are no longer satisfied
Article 16	information regarding the study should be publicly available
Article 27	ethical publications extend to publication of the results and consideration of any potential conflict of interest
Article 29	experimental investigations should always be compared against the best methods, but under certain circumstances a placebo or no treatment group may be utilised
Article 30	the interests of the subject after the study is completed should be part of the overall ethical assessment, including assuring their access to the best proven care
Article 32	wherever possible unproven methods should be tested in the context of research where there is reasonable belief of possible benefit

Table 2

The three basic principles and their corresponding applications

Principle	Definition	Application
Respect for Persons	Treat individuals as autonomous Persons with limited autonomy need additional protection, even to the point of excluding them from activities that may harm them. The judgment that any individual lacks autonomy should be periodically re-evaluated, and will vary across situations.	Informed Consent Information - Does the consent provide all the information necessary to make a reasoned decision? Comprehension - Is the consent in a language understandable to the potential participant? Voluntariness - Does the consent clearly indicate that participation in the research is voluntary? What additional points can be in place to protect those with limited autonomy? How to determine whether one lacks the autonomy to make a reasoned decision?
Beneficence	Obligations of beneficence affect both the researcher and society – investigators are required to maximize benefits and reduce risks that may be involved in the research society should recognize the longer term benefits and risk that may result from the improvement of knowledge	Assessment of Risks and Benefits Risk refers to the probability of harm; both the probability and the severity of the envisioned harm should be considered; benefit refers to something that promotes health, well-being, or welfare. What are the risks of harm to the participants (physical, psychological, social, and economic harms)? Are the risks justified? Can they be minimized? Can the research design be improved to minimize risk and maximize benefit? What are the benefits (to the participant; to society)?

Justice	Treat people fairly Do not exploit those who are readily available Fair distribution of the risks and the benefits of research based upon the problem under investigation	Selection of Subjects Is the potential subject pool appropriate for the research? Is it appropriate to involve vulnerable populations (e.g., economically disadvantaged; limited cognitive capacity) in the research or are they being enrolled because it is convenient or because they are easily manipulated as a result of their situation? Are the recruitment procedures fair and impartial? Are the inclusion and exclusion criteria fair and appropriate?

READABILITY OF RESEARCH CONSENT FORMS IN A MILITARY TREATMENT FACILITY

CRISTÓBAL S. BERRY-CABÁN, PHD; CHERI L. PORTEE, BSN; LINDSEY A. BEAMAN, BSCR; KYLE L. HOEDEBECKE, MD

Human subject protection statement:

No human subjects were involved in the conduction of this project.

Abstract

Readability of the consent form is one area of the informed consent process often overlooked by researchers. The following assesses the readability levels of Institutional Review Board (IRB)-approved consent forms located at a large military hospital. Data were obtained from 10 IRB-approved consent documents for research conducted at Womack Army Medical Center (WAMC). Grade-level standards were assessed using 3 readability scales. The mean reading level of the 3 readability formulas was 12.2. Both the IRB-provided template and the 3 readability scales suggest that the 10 consent documents analyzed were written at a reading level 3 to 5 grades higher than the suggested standard. Despite general guidance that forms be simplified to a 6th to 8th grade level, most consent forms are written at or above an 11th grade reading level. There is a need for effective changes that will provide subjects with a consent form that is clear, concise and comprehensible.

Key Words: *Consent form; Informed consent; Readability; IRB; Readability formulas*

Introduction

The consent form is a document used during the research informed consent process to convey information to prospective subjects for the purpose of warranting individuals to make a voluntary decision whether or not to participate as a research subject. Most Institutional Review Boards (IRBs) suggest that the consent document be written in lay language at a 6th to 8th grade reading level so the intended subject can easily comprehend the information being conveyed.[1]

Often identified as an "ethical framework for protecting human subjects," the *Belmont Report's* three basic ethical principles guide the conduct of human subject research− respect for persons, beneficence, and justice. As a part of "respect for persons," the consent form should provide subjects with sufficient information to make an informed decision, should be constructed in lay language, and should identify that the subject's participation is strictly voluntary.[2] Further suggestions identify the need to "adapt the presentation of the information to the subject's capacities" as limited by his or her ability to comprehend as "a function of intelligence, rationality, maturity, and language." Investigators must include information about potential risks to the subject and ensure prospective subjects understand the material provided.[2]

Millions of Americans lack adequate literacy and numeracy skills, as revealed by the National Adult Literacy Survey (NALS). The results reveal that an estimated 21% to 25% of the American population is functionally illiterate, another 25% possess marginal literacy skills, and the remaining 50% have limited literacy. As education level is the most common estimation of reading ability, the NALS reports that the "average" American reads at or below the 8th grade level. Furthermore, a significant proportion of the population reads even below that level, yet do not admit such deficits for reasons such as self-deception or embarrassment.[3]

Further evidence of Americans' poor reading abilities was demonstrated in the 2003 National Assessment of Adult Literacy (NAAL). Only 21% of respondents performed at the highest literacy levels with recipients of government assistance, older adults, racial or ethnic minorities, and disadvantaged or inner-city populations having higher illiteracy rates.[4] Furthermore, most people at the lowest levels did not perceive that they had an issue with reading; they described themselves as being able to read "well" or "very well."[3-4]

Readability is the quality of written material that makes some texts easier to read than others. It is often confused with legibility, which concerns typeface and layout. While there are several good definitions of readability,[5-7] Dale and Chall's definition may be the most comprehensive: "The sum total (including all the interactions) of all those elements within a given piece of printed material that affect the success a group of readers have with it. The success is the extent to which they understand it, read it at an optimal speed, and find it interesting."[8]

In the 1920s, educators discovered a way to use vocabulary difficulty and sentence length to predict the difficulty level of a text. This method was translated into readability formulas. By the 1950s, educators such as Flesch, Klare, Dale, and Chall brought the formulas and the research supporting them to the marketplace.[8-11] The importance of readability results from three factors: (1) the increase in the amount of reading required for success (2) the decline in reading skills of high school graduates and (3) the simplification of text as a partial solution for the combination of increased reading and decreased reading skills.[11] These formulas were widely used in journalism, research, health care, law, insurance, and industry. By the 1980s, there were over 200 formulas and over a thousand studies published on the readability formulas attesting to their strong theoretical and statistical validity.[5]

A number of readability tests are readily available to include their integration into most word processing programs by 2010. The majority utilize formulas based on comparisons of the number of sentences to the number of polysyllabic words within a passage. Therefore, materials with several short sentences consisting of short words score at a lower reading level. Three of the most common readability formulas are the Flesch-Kincaid, the Fry, and the SMOG.

While most IRBs suggest consent forms be written at a 6th to 8th grade reading level, these standards are often ignored.[13] Although IRBs are responsible for protecting human subjects, including persons with low literacy levels, the literature suggests that they often have a role in authorizing the use of consent forms that are difficult to comprehend.

The following study assesses the readability of IRB-approved consent documents in a military treatment facility. Additionally, the presence of readability standards and implications of these standards are examined.

Methods

Data Sources

Data were obtained from 10 IRB-approved consent documents from research conducted at Womack Army Medical Center (WAMC), a large military hospital serving approximately 120,000 healthcare beneficiaries. Two protocols from each year were randomly selected from 2008-2012, for a total of 10 protocols.

These consent forms were examined for material explaining readability standards and grade-level standards (at or below an 8th grade reading level) were assessed.

Readability Scores

The readability level of each consent form was measured using 3 readability scales: the Flesch-Kincaid Readability Formula, the Fry Readability Graph, and the SMOG Readability Formula.

The Flesch-Kincaid Readability Formula is an automated function in Microsoft Word that measures the average number of syllables per word and the average number of words per sentence. The calculated score, 0.0-100.0, is translated to an estimated grade level required to understand the material. The Flesch-Kincaid Grade Level scale has the ability to calculate readability on grades of 16 or higher, suggesting a college reading level.[8]

The Fry Readability Graph calculates the grade reading level by averaging the number of sentences (y-axis) and syllables (x-axis) per 100 words. The number of syllables in each 100-word passage provides a measure of the number of "hard words." These averages are plotted on a graph and the intersection of the x and y-axes determines the reading level of the text.[14]

The SMOG (Simple Measure of Gobbledygook) Readability Formula is one of the most commonly used readability scales. This formula proves particularly useful in shorter materials such as research consent forms through production of a readability score based on the number of polysyllabic words in a 30-sentence segment. Once this number is derived, the square root is calculated and 3 is added to produce the SMOG Grade. The final number is the estimated years of education needed to comprehend a text.[15]

Several authors have validated these tests.[12-14] Mesmer discusses Harrison's analysis of the validity of readability formulas. Harrison measured the number of indicators of each formula, and his analysis showed that the Flesch-Kincaid and the Fry formulas have similar levels of validity with four indicators, followed closely by the SMOG formula with three indicators.[18]

Description of the Consent Forms

WAMC uses a standard research consent template. In 2011, the Health Insurance Portability and Accountability Act (HIPAA) language requirements were embedded into the consent form that specifically address the requirements defined in 32 CFR 219.116 and 117, as well as the *Belmont Principles* for informed consent.[2, 19]

WAMC's Standard Operating Procedure (SOP) for writing consent forms states that the text must be written in language understandable to the subject. However, the SOP does not provide any instruction that the text must be written at a 6th to 8th grade reading level.

Ten research consent forms were randomly selected by a non-study member. The average page length of the 10 consent forms was 6.7 pages. The average sentence length of the 10 consent forms was 20.5 words. *See Table 1.*

Statistical Analysis

A t test was used to compare readability scores with readability grade level standards. All P values were derived from 2-sided tests; 95% confidence intervals (CI) were determined for all means. Analyses were conducted with SPSS, version 18. This study was submitted to the WAMC, IRB and determined to be a process improvement project.

Results

The IRB-provided template was analyzed to be at a reading level of 11.2 by the Flesch-Kincaid, 12.3 by the Fry, and12.8 by the SMOG. The analysis of the 10 consent forms by the Flesch-Kincaid produced a mean reading level of 12.3 (95% CI 11.7-12.9; $P < 0.001$). The Fry Readability Graph resulted in a mean reading level of 13.0 (95% CI 11.6-14.3; $P < 0.001$). Lastly, the SMOG grade produced a mean reading level of 11.2 (95% CI 10.1 - 12.4; $P < 0.001$). Overall the IRB template resulted in a combined grade reading level mean of 12.1 while the selected consent documents resulted in a mean of 12.2. *See Table 3.*

Discussion

The consent form is one of the central elements of participant research. The informed consent process requires potential subjects to be fully informed and capable of making a rational decision to participate in a research study. Additionally, the informed consent process is the critical means by which researchers can establish the trust and gain the confidence of prospective participants. While there is vast literature describing the elements of informed consent (the document structure and template, and the safeguards that the form provides), there is limited research on readability levels.[1, 20, 21]

Readability of the informed consent process is crucial to the underlying issue of volunteer comprehension. Without an appropriate level of readability, the informed consent document is inadequate and ineffective. The informed consent document must be written at a level that allows volunteers to truly understand all aspects of the research study.

A study in the *New England Journal of Medicine* compared IRB readability standards to informed consent form templates of 123 U.S. medical school web sites using the Flesch-Kincaid scale. The authors found the average readability score for text provided by IRBs was 10.6.[13]

Cassileth et al. found that while 60% of subjects participating in a study understood the purpose and nature of the medical procedures to which they had signed written consent just 1 day prior, only 40% of the participants reported that they had carefully read the form. This study determined that the complexity of the text introduced barriers to the subjects' understanding of information.[20]

Despite recommendations that forms be simplified to a 6th to 8th grade level, most consent forms are written at or above an 11th grade reading level. Prospective volunteers may feel embarrassed by the inability to understand what he or she is reading. Therefore, the volunteer may not ask questions that require clarification. This can be a significant barrier to a truly informed consent process.

This project discovered several areas of concern. Firstly, the WAMC consent form template had a mean reading level of 12.1. An assessment of the 10 consent forms, using the 3 readability formulas produced a mean reading level of 12.2. Additionally, the analysis of the IRB template and the 10 consent documents analyzed are written at a reading level 3 to 5 grades higher than the suggested standard.

There are several suggestions that can help ensure that consent forms conform to the appropriate reading level – thus improving patient comprehension.[6, 23] Readability formulas, investigator training, and IRB review and monitoring are also important to ensure that an appropriate, effective informed consent process is in place.

Specialized writing skills focusing on the design of the consent form can be utilized to simplify the flow of ideas and evade confusion. A process should be in place to confirm that consent forms are written at an appropriate reading level through implementation of a valid readability formula.

Investigators have a critical part in ensuring that volunteers understand the materials being presented. This is an ethical and professional responsibility. Investigators may find it useful to complete training on the informed-consent process. Furthermore, IRBs can require this as part of the submission and approval process.

The standard consent form template should be generated to provide consistency and assure that the text appears at the appropriate grade reading level. To further increase comprehension, educational materials and multimedia measures such as DVDs, brochures, and web sites should be considered when providing consent to a subject.[24] Lastly, the legal liability of an inadequate informed-consent process should be expressed to investigators and sites.[6]

Prompted in part by the threat of litigation, the consent form and the informed-consent process have grown longer as more legally motivated text has been incorporated.[17, 18] Therefore, the legal liability of an inadequate informed-consent process should be expressed to investigators and sites.

Research has shown that there is need for improvement in the informed consent process. Prospective research subjects often fail to receive the information in a manner that measures up to standards, resulting in a lack of comprehension. Readability is not the only barrier to comprehension; however, it is a barrier that is within the researcher's and IRB's control to minimize.

References

1. Amdur R, Bankert EA. The Consent Process and Document. In: Amdur R, Bankert EA, editors. Institutional Review Board: Member Handbook. Sudbury, MA: Jones and Barlett Publishers; 2011. p. 49-54.
2. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. Washington, DC: Department of Health, Education, and Welfare, 1979 April

18. Report No.

3. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. Adult Literacy in America: a first look at the findings of the National Adult Literacy Survey. Washington, DC: U.S. Department of Education, 1993 Contract No.: NCES 1993–275.
4. Kutner MA, Greenberg E, Jin Y, Paulsen C. The health literacy of America's adults: National Institute for Literacy; 2006.
5. Dubay WH. The Principles of Readability. Impact Information. Costa Mesa, CA; 2004:1-4.
6. Goldfarb NM. Readable Informed Consent Forms Are Not Optional. Journal of Clinical Research Best Practices. 2005.
7. Dale E, Chall JS. A formula for predicting readability. Educational Research Bulletin. 1948;27:1-20, 37-54.
8. Flesch R. A new readability yardstick. The Journal of Applied Psychology. 1948;32(3):221-33.
9. Klare GR. Measures of the readability of written communication: An evaluation. Journal of Educational Psychology. 1952;43(7):385-99.
10. Chall JS. Readability: An appraisal of research and application. Columbus, OH: Ohio State University Press; 1958.
11. Klare GR. Readability. In D. Pearson (Ed.). Handbook of Reading Research. 1984(1):681-685.
12. Bailin A, Grafstein A. The Linguistic Assumptions Underlying Readability Formulae: A Critique. Language & Communication.2001;21:285-301.
13. Paasche-Orlow MK, Taylor HA, Brancati FL. Readability standards for informed consent forms as compared with actual readability. New England Journal of Medicine. 2003;348(8): 721-6.
14. Fry E. Fry's readability graph: Clarifications, validity, and extension to level 17. Journal of Reading. 1977. p.242-52.
15. McLaughlin GH. SMOG grading: A new readability formula. Journal of Reading. 1969;12(8):639-646.
16. Kern R. Usefulness of Readability Formulas for Achieving Army Readability Objectives: Research and State-of-the-Art Applied to the Army's Problem. U.S. Army Research Institute for the Behavioral and Social Sciences. 1980. p.5-7, 14, 24.
17. Heydari P. The Validity of Some Popular Readability Formulas. Mediterranean Journal of Social Sciences. 2012. P. 423.
18. Mesmer H. Traditional readability formulas. Tools for Matching readers to text. New York: The Guilford Press; 2008. p. 13-42.
19. Code of Federal Regulations - Title 32: National Defense, (2010).
20. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Informed consent—why are its goals imperfectly realized? New England journal of medicine. 1980;302(16):896-900.
21. Davis TC, Berkel HJ, Holcombe RF, Pramanik S, Divers SG. Informed consent for clinical trials: a comparative study of standard versus simplified forms. Journal of the National Cancer Institute. 1998;90(9):668-74.
22. Goldfarb NM. Measuring informed consent readability in Microsoft Word. Journal of Clinical Research Best Practices. 2006;2:1-6.
23. Emanuel EJ, Menikoff J. Reforming the regulations governing research with human subjects. New England journal of medicine. 2011;365(12):1145-50.
24. Jaynes, T. Informed Consent: Imparting Knowledge or Signing a Form? Applied Clinical Trials. 2005.

Cristóbal S. Berry-Cabán, **PhD**, is a Clinical Researcher/Epidemiologist at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Cheri L. Portee, BSN, is the IRB Administrator at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Lindsey A. Beaman, BSCR, is a Clinical Research Coordinator at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Kyle L. Hoedebecke, MD, is a Family Medicine Staff Physician at Womack Army Medical Center in Fort Bragg, North Carolina, USA.

Table 1. Description of Consent Forms

Protocol	Protocol Description	Year	Length in pages	Average words per sentence
Template	IRB-Provided Template [a]	N/A	7	18.9
1	Maternal Fetal Medicine	2008	8	21.0
2	Gardasil Vaccination	2008	4	22.4
3	Gastric Bypass Surgery	2009	6	20.2
4	Smallpox/Influenza Vaccination	2009	6	24.3
5	Neurology/Traumatic Brain Injury	2010	8	21.2
6	Orthopedics Rehabilitation	2010	6	18.4
7	Traumatic Brain Injury/Post-Traumatic Stress Disorder	2011	10	20.8
8	Human Papillomavirus	2011	5	18.7
9	Behavioral Health	2012	8	20.6
10	Occipital Neuralgia	2012	10	19.6

[a] In 2011, the Health Insurance Portability and Accountability Act (HIPAA) language requirements were embedded into the consent form.

Table 2. Readability Scale Results of Consent Forms (n = 10)[a]

Readability Scale	Mean	SD	CI (95%)	*P*-value
Flesch-Kincaid	12.3	0.8	11.7-12.9	<0.001
FRY	13.0	1.9	11.6-14.3	<0.001
SMOG 1	11.2	1.6	10.1-12.4	<0.001

[a] The mean readability scores for the IRB template were as follows: Flesch-Kincaid, 11.2; FRY, 12.3; SMOG 1, 12.8.

Table 1. Characteristics of Literacy Tools

Literacy Tools	**Variables and Computation**	**Passage Length**		**Interpretation**	**Strengths**	**Weaknesses**
Flesch-Kincaid	Sentence length (number of words) and word length (number of syllables)	Three 100-word passages	Quick: Computer Software	Reading grade level	Quick administration with software; highly correlated with other instruments	Computer scores underestimate difficulty; longer manual administration
Fry	Sentence length (number of words) and word length (number of syllables)	100-word passage	Quick: Computer Software	Reading grade level	Validated in Spanish; ease of administration	Longer administration time compared to Flesch-Kincaid
SMOG	Polysyllabic words	30 sentences (10 near the beginning, 10 in the middle, 10 at the end)	Time-consuming: manual computation	Reading grade level	Recommended for use in healthcare; highly correlated with other instruments	Score based on strict criterion of 100% comprehension; time-consuming

Book Reviews

Beyond Humanity?: The Ethics of Biomedical Enhancement

Allen E. Buchanan. New York: Oxford UP, 2011.

ISBN: 978-0-19-958781-0; 286 PAGES, CLOTH, $35.00.

Better Than Human: The Promise and Perils of Enhancing Ourselves

Allen E. Buchanan. New York: Oxford UP, 2011.

ISBN: 978-0-19-979787-5; 208 PAGES, CLOTH, $21.95.

Allen Buchanan, PhD, is the James B. Duke Distinguished Professor of Philosophy at Duke University and has served on US national-level bodies on bioethical issues. His two recent books address the ethics of enhancement using biotechnology.

Beyond Humanity? is the longer and more academic of the two. Buchanan's primary goal is to bring clarity to discussions of enhancement and better frame the ethical issues involved (19). Acknowledging not all enhancements are beneficial and that no one is an unlimited supporter of human enhancement, Buchanan categorizes ethicists as being either "anti-enhancement" or "anti-anti-enhancement" (13), placing himself as in the latter category. He aims to examine the "real" ethical issues related to human enhancement and "debunk the murky rhetoric" (18) of those he classifies as anti-enhancement (in some or all circumstances), including Leon Kass, Juergen Habermas, George Annas, and Nick Bostrom.

Buchanan's perspective is that of evolutionary biology. From that point of view, his arguments are logical. Humans are merely the latest example of the species with the highest level of development on earth. Human success in terms of reproductive efficiency and survival does not mean further improvement is unwarranted or undesirable.

> Evolution does not create harmonious, "complete" organisms . . . it produces tentative, changing, perishing, cobbled-together *ad hoc* solutions to transient design problems . . . Nature is not wise (or unwise) and evolution is not like a Master Engineer; it is more like a morally insensitive, blind, tightly shackled tinkerer, (2)

than a blind watchmaker. Indeed, evolutionary biology puts no limits on continual change to produce beings more fit in terms of survival. Thus, Buchanan accepts no arguments based on nature or natural law. He criticizes those who do for holding underlying theistic views disguised as arguments based on nature. Nature is the result of evolution, not design. Humans are far from ideal. Enhancement may be mandatory to survive and adapt to threats such as pollution and global warming. Enhancement, like globalization, is inevitable. The anti-enhancement stance is unrealistic at best (16). Those who support enhancements are not necessarily motivated by hubris, desire for perfection, or immortality (9).

Buchanan systematically examines questions related to enhancement, deconstructing them and their underlying philosophies in light of evolutionary biology. He examines enhancement's impact or implications with respect to human productivity and (economic) development, personal character, (human) nature, the moral status of persons, unintended consequences, and justice, while setting aside vitally important issues he briefly acknowledges, such as research on enhancement, abuses of enhancement technologies, and eugenics implications (21). He gives examples such as literacy and use of caffeine as cognitive enhancements already widely accepted and practiced, making it illogical to forbid additional enhancements purely because they employ biotechnology (24). In chapter 5, Buchanan challenges assumptions about biotechnology that may be unwarranted and need further examination, such as that such technology would necessarily be expensive, increase distributive injustice, benefit individuals solely rather than society, and be available through the commercial market rather than government programs.

The final chapter, "Distributive Justice and the Diffusion of Innovations," deals with much broader issues than human enhancement. It seems out of place, although Buchanan attempts to connect it to his discussion of enhancement. It would be better published separately.

Buchanan's shorter book, *Better Than Human,* is utilitarian in reasoning and reveals that his purpose is not purely "scientific," but also political. His audience is the general public. Enhancements are here to stay. The only question is whether they will come in the "front door" (encouraging study of their long-term effects in normal humans) or the "back door" (7), whether they will be available in the US or elsewhere (88). The book covers much of the same ground as *Beyond Humanity*, but with more emotionally laden language. For example, his discussion of human nature (chapter 3) criticizes "Christian fundamentalists" and others whose "subjective" definition of marriage is that of a man and woman, while failing to acknowledge from an evolutionary standpoint that only such pairings facilitate reproduction and survival of the human species. He fails to deal with how we can judge what enhancements are beneficial without an agreed underlying definition of human good or even why human survival is important in a world where evolution rules. He rails against "simpleminded conservatives" (75), and the alienation of significant segments of society with such unnecessarily offensive rhetoric detracts from his "scientific" aims and tone. It impedes, rather than facilitates, his desire for a societal consensus on enhancement, implying some should be excluded from the process.

I agree that opposing all human enhancements involving biomedical technologies, even if judged desirable, is unrealistic, especially in a democracy. Nearly everyone would support human use of technologies external to the body, such as computers, helmet-mounted displays, weight bearing exoskeletons, and the Internet. Many would prohibit or at least proceed slowly and deliberately with drugs and technology that must be internalized. Those who value human life with its current capacities, whether from a humanistic or religious perspective, may not be able to block licensing or acceptance of internalized biotechnologies for normal people, but should at least push for efforts similar to current FDA processes to evaluate the impacts of internalized biomedical drugs or technology on normal humans prior to their widespread availability in society.

Reviewed by Sharon A. Falkenheimer, MD (Aerospace Medicine), MPH, MA (Bioethics), who has taught bioethics at the University of Texas Health Sciences Center in San Antonio, TX and at Trinity College in Trinity International University in Deerfield, IL. She is an Academician of the International Academy of Aviation and Space Medicine, a Fellow of the Aerospace Medical Association, and an Associate Fellow at the Center for Bioethics and Human Dignity at Trinity International University, Deerfield, IL, USA.

The Christian Art of Dying: Learning From Jesus

Allen Verhey. Grand Rapids, MI: Eerdmans, 2011.

ISBN: 978-0802866721; 423 PAGES; PAPER, $30.00.

The words "How to Die" simply and boldly fill the cover of a recent issue of *Time Magazine* (vol. 179, no. 23; 2012), reflecting a culture searching for direction in the midst of the changing landscape of an aging population faced with limited but powerful medical advances. In *The Christian Art of Dying: Learning from Jesus*, Allen Verhey, inspired by his own battle with a life-threatening illness, addresses this question of dying from a decidedly particular and partial perspective. Limiting his address to "three episodes in the history of death, the 'medicalized' dying of the mid-twentieth century, the 'art of dying' [*Ars Moriendi*] in the fifteenth century, and the death of Jesus in the first century" (3), Verhey seeks to inspire Christian communities to care for the dying both inside and outside the church by attending to the story of Jesus and the traditions of the church.

The Christian Art of Dying begins with a persuasive argument that, in the wake of dramatic medical progress, contemporary Western society has almost entirely relinquished care for the dying into the hands of medical professionals. He affirms the benefits of organized medicine, but laments the one-sided nature and the potential harms of its care. "Death," Verhey states, "threatens to alienate us from our own flesh, from our communities, and from God" (17), and medicalized dying can often appear to make good on these threats of isolation before death even comes. For Verhey, the complacency of Christian churches is the most sorrowful aspect of this present situation.

Not satisfied with the major alternatives to medicalized dying, Verhey critically engages the tradition of *Ars Moriendi*, a veritable Christian self-help book for the late medieval Christian who was dying. This selected text, indicative of a broader tradition, addresses the temptations faced when dying and the virtues that can overcome these trials. Where the first section of *The Christian Art of Dying* demonstrates astute analysis of medicalized dying, the second section expresses Verhey's ability for creative interpretation of the text and, more profoundly, the artwork that accompanies it (reproduced for his reader). This combination of a theological and ethical reading of the art and text of *Ars Moriendi* is perhaps *The Christian Art of Dying*'s most fascinating and unique contribution to Christian ethical scholarship.

Unwilling to reproduce the message of *Ars Moriendi* uncritically, the final section attends to the Gospel narratives of Jesus' death and the practices of the communities proclaiming this story. Verhey ultimately seeks to inspire his readers to create a contemporary "art of dying," rooted in the story of Jesus. This section reveals Verhey's ability for constructive theology and practical ethical application.

The one potential deficiency in *The Christian Art of Dying* is identical to one of its greatest strengths: its particular and limited perspective. Once the reader recognizes that this book does not speak to every aspect of dying, the reader is free to take and appropriate the theological and ethical groundwork Verhey has provided, and with this recognition *The Christian Art of Dying* becomes a valuable resource and inspiration for Christian communities who wish to care for the dying in light of the story of Jesus and the practices of the church.

Reviewed by Mathew A. Crawford, MA, ThM, who is matriculating for a Doctorate in Theology at Baylor University, Waco, TX, USA.

Development of Bioethics in the United States (Philosophy and Medicine Vol. 115)

Jeremy R. Garrett, Fabrice Jotterand, and D. Christopher Ralston (Eds.). NY: Springer, 2013.

ISBN: 978-94-007-4010-5; 279 PAGES, CLOTH, $129.00

Although the editors of *Development of Bioethics in the United States* may not be household names in bioethics, the chapter authors certainly are. Not all founders of the field are represented, but the result is nevertheless a valuable historical and biographical contribution, as well as a volume providing an overview of bioethics to date.

This collection of essays is divided into four parts, each with a different emphasis: a history of the birth of bioethics, the cultural and philosophical nature of the field, the professional dimensions of its practice, and its future. Each chapter is written from the perspective of a major player in development of the field; each section also gives a taste of the controversies, many of which continue in the field today. References at the end of each chapter offer many valuable links to foundational writings and topics of the period while the aggregate traces the transition from the predominance of Hippocratic medical ethics to one based on a liberal, secular perspective.

The text covers the origins of bioethics-related institutions such as the Hastings and Kennedy Centers and the American Society of Bioethics and the Humanities. However, disappointingly but not surprisingly, it fails to mention the development of Protestant bioethics centers, the best known of which is the Center for Bioethics & Human Dignity at Trinity International University.

The scarcity of libraries including this work in its holdings and the price of this collection of essays – over $100 even for the Kindle edition – may discourage many from accessing it. However, it is, in my view, well worth the cost. Laurence McCullough's chapter on "The Role of an Ideology of Anti-Paternalism in the Development of American Bioethics" alone is a must read, offering an important corrective to numerous bioethical publications misinterpreting or misrepresenting the content of often-quoted historical medical ethical publications. He demonstrates how the Oken Study (1961) has repeatedly been used to support the assertion that physicians have historically been overly paternalistic, withholding the truth from their patients. However, McCullough points out that Oken employed qualitative, rather than quantitative, methods and used a convenience sample of physicians from one location that cannot, with validity, be generalized to the entire American physician community – despite the fact that many have done so. In addition, he also examines and reviews the original writings of physicians John Gregory (1724-1773) and Thomas Percival (1740-1804), showing that errors in their interpretation have been repeated by authors who have based their works on secondary sources or on brief quotes taken out of context.

Reviewed by Sharon A. Falkenheimer, MD (Aerospace Medicine), MPH, MA (Bioethics), who has taught bioethics at the University of Texas Health Sciences Center in San Antonio, TX and Trinity College in Trinity International University in Deerfield, IL. She is an Academician of the International Academy of Aviation and Space Medicine, a Fellow of the Aerospace Medical Association, and an Associate Fellow at the Center for Bioethics and Human Dignity at Trinity International University, Deerfield, IL, USA.

Business for the Common Good: A Christian Vision for the Marketplace

Kenman L. Wong and Scott B. Rae. Downers Grove, IL: IVP Academic, 2011.

ISBN: 978-0-8308-2816-6, 288 PAGES, PAPER, $24.00

How can Christians act as good Christians when working in the world of business? What contribution can they make to business ethics? These are the kind of questions discussed by Kenman Wong and Scott Rae in *Business for the Common Good: A Christian Vision for the Marketplace*. Answers are sought by taking Biblical teachings as a starting point.

Work, so it is argued in the first chapter, is not only for what might be called reasons of utility or necessity. That is to say, work is good not only insofar as it is a means of making sure one is not a burden to the community nor simply as a means to make sure that one's family has enough to eat. Work is good also inasmuch as it is a means of offering up our gifts and skills in the service to God. As attested to in Genesis 2:15, work is not a divine punishment in a fallen world. Work, in order to care for creation, is part of God's original design. Work is also part of the prophetic vision of Isaiah 2:4. In Isaiah's vision of the kingdom peace after the end of time, swords will be beaten into ploughshares and spears into pruning hooks.

The Biblical vision of work referred to throughout this book is one of working in cooperation with God as His servants, created in His image. This is a vision of humans as creatures with whom God wishes to have a special relationship. In this vision, then, it is God's desire to be in a fruitful relationship with us – that is to say, a relationship in which we flourish and help others do the same, especially the poor and needy. It is a relationship that brings healing to the human heart as well as to the world at large. It is one that helps us "to live in a spirit of true harmony with others and with the earth (Jn 13:35; Rom 12:18; Col 2:12-15)." (70)

In the second chapter, the authors provide a number of practical guidelines for business as work in the service of God. And in the third chapter, while reminding us of the gift of Sabbatical rest and worship, they show how God may employ business for our spiritual formation and as a path to the virtues of service, trustworthiness and respect for others, perseverance and diligence. Work for work's sake, or for the ceaseless accumulation of riches, is of little value according to the fourth chapter. While the value of the virtues of fairness, justice, and love of neighbour come to the fore in the sixth chapter on globalisation, the seventh and eighth chapters point to the importance of the virtues of integrity, self-control, kindness and even humility for good leadership and ethics in the workplace. In the ninth chapter, castigating some of the vices of marketing, the authors call for marketing that is honest and which appeals "to higher, rather than to debased or unconscious, values" (225). In short, these chapters set out criteria for good and bad business practices.

The last two chapters are about stewardship, sustainability, and new morally responsible business practices nicely round out this many-faceted discourse about business ethics in a Christian spirit. With reference to the Genesis story of creation, that of Noah as well as Romans 19-21, the concept of stewardship as care for creation is explored here as well as our role as God's co-workers, called to travel as carers with the rest of creation to its ultimate restoration. We are reminded that not only does it matter what businesses do and do not do, what we, as customers of goods and services, do also matters. Businesses should not promote bad habits for the sake of profit, nor should we encourage them to do so by being indulgent.

Couched in non-technical everyday language and written with reference to fictional life-stories of choices, problems, and pleasures encountered by people in business, this book makes for an easy and enjoyable read. It can therefore be recommended to any reader interested in the question of what business can do for the common good.

Reviewed by Agneta Sutton, **PhD,** who is a Lecturer at Heythrop College in the University of London, UK.

Ethics, Sexual Orientation, and Choices about Children

Timothy E. Murphy. Cambridge, MA: The MIT Press, 2012.

ISBN: 9-780262-018050; 181 PAGES, CLOTH, $27.00.

Since the mapping of the human genome, there has been an ongoing scientific search for genetic markers or indicators of disease and behaviors (including sexual orientation), with the ultimate goal of enabling parents to make prenatal decisions that could affect their child's future. Of the issues that have arisen, one is a question as to whether or not parents should ethically make decisions that might affect the behavior of their pre-born child, realizing that some of these choices might limit the child's opportunity for an open future. *Ethics, Sexual Orientation, and Choices About Children* specifically explores the question of whether or not parents should be able to choose the sexual orientation of their children, if it is ever possible to do so.

Murphy points out some of his concerns that such a genetic technology and parental choice could create. For instance, is research in this area morally legitimate, morally neutral, or potentially morally harmful in terms of the additional burdens that homosexuals might experience as a result? Would choosing a child's sexual orientation limit his/her open future? Would the number of homosexuals decrease through parental non-selection and, if so, what would the effect be on the existing homosexuality community? The author addresses these questions by providing a chronological review of the literature as well as an engagement with the arguments and positions throughout the literature.

This author argues in favor of prenatal choice for sexual orientation, if it becomes a possibility. However, his main concern is about the motives that would drive such a decision; for example, he considers heterosexism to be wrong. He also challenges the apparently common argument that parental choice would necessarily decrease the numbers of homosexuals and subsequently weaken their influence in society, arguing that even if smaller, the advocacy of this group could still be significant.

This book provides a nice overview of the issue of pre-natal choice with regard to sexual orientation, and explores both sides of the argument, particularly through a review of the literature. The appendix is particularly helpful in clearly summarizing possible motives, processes, and effects for all involved. However, the way the literature review is conducted allows the same arguments to be addressed several times resulting in a great deal of repetition. The book is also a bit self-aggrandizing, with the author frequently referring to his previous works. While the ability to test definitively for sexual orientation is highly improbable due to the complexity of human sexuality, this presentation as a thought experiment concerning one of the most fundamental aspects of human nature – our sexual orientation – is certainly an issue worth exploring.

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

Standing on Principles: Collected Essays

Tom L. Beauchamp. New York: Oxford UP, 2010.

ISBN: 978-0-1997-3718-5291; 291 PAGES, CLOTH $55.00.

The name of Tom L. Beauchamp is well known to all students of bioethics. His work, *Principles of Biomedical Ethics*, co-authored with James Childress and now in its seventh edition, has been the key text in bioethical scholarship and teaching for decades. The principle approach that the book advocates locates moral considerations in four *prima facie* principles: autonomy, beneficence, nonmaleficence, and justice. These principles have served as the "common coin" of bioethical reasoning, as Albert Jonsen noted in *The Birth of Bioethics* (1998). They have facilitated discussion across the seemingly insurmountable barriers of professional affiliation, philosophical perspective, and religious commitment, and helped to make the bioethical enterprise as successful as it is today.

Beauchamp teaches in the Philosophy Department at Georgetown University and serves with the Kennedy Institute of Ethics. In 1975, he became a staff philosopher at the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, where he was primarily responsible for writing *The Belmont Report* (1978), in which a version of the principle approach first appeared. In Part I of *Standing on Principles*, entitled "The Belmont Report and the Rise of Principles," Beauchamp gives a fascinating history of his work developing the principle approach and argues that this report has "influenced nearly every sphere of activity in bioethics" (29-30). In particular, this approach has influenced the practice of both research and clinical medicine (29-30).

In Part II, Beauchamp addresses a variety of ethical issues from his principlist perspective, including informed consent, autonomy, paternalism, hastened death, and protection of the vulnerable in pharmaceutical research. With regard to hastened death, Beauchamp suggests that physician killing of a patient for whom the alternative is "a desperate and harmful circumstance" need not be wrong (126-127).

Part III is of particular interest to those concerned with the theoretical foundations of bioethics. Here, Beauchamp recognizes that the principle approach has suffered multifaceted opposition: "Beginning in the mid-1980s, the paradigm of a system of principles was aggressively challenged" (153). Alternative approaches were proposed, including casuistry and virtue theory. Rather than reject the alternatives, Beauchamp embraces them, but on his terms. Beauchamp argues, "The various proposed alternative approaches do not replace principles. The leading alternatives are thoroughly compatible with a paradigm of principles" and with principles they are "mutually supportive" (153).

Since the third edition of *Principles*, Beauchamp and Childress have appealed to the idea of "common morality," following Alan Donagan's account in *The Theory of Morality* (1979). Beauchamp remains committed to the conviction that there is indeed a common morality which is "the set of norms shared by all persons committed to the objectives of morality…of promoting human flourishing by counteracting conditions that cause the quality of persons' lives to worsen"(176). The purpose of the norms of common morality is that "[t]hese norms are necessary to ameliorate or counteract the tendency for the quality of people's lives to worsen or for social relationships to disintegrate" (177).

The common morality "is applicable to all persons in all places, and all human conduct is to be judged by its standards" (176). The norms of this morality are such that "virtually all people in all cultures grow up with an understanding of the basic norms that morality makes upon everyone" (176). Beauchamp is boldly endorsing a universal moral code, opposing ethical relativism in all forms.

The common morality can be expressed in "standards of action" such as do not kill, do not cause pain or suffering to others, prevent evil or harm from occurring, rescue persons in danger, tell the truth, nurture the young and dependent, keep your promises, do not steal, do not punish the innocent, and treat all persons with equal moral consideration. This morality can also be expressed as virtues, or "moral character traits," including nonmalevolence, honesty, integrity, conscientiousness, trustworthiness, fidelity, gratitude, truthfulness, lovingness, and kindness. Beauchamp defends this notion of common morality against a variety of criticisms.

In the final chapters he questions whether ethical theory will continue to be wedded to bioethics or whether a "divorce" might be forthcoming, and addresses problems in the use of personhood by various sides of the bioethical debates, proffering a position that moral status does not require personhood at all. Finally, he raises the question of whether one can judge one's predecessors for their moral lapses, such as questionable research practices. He maintains that judgments of the violations of standards, and of the culpability of past agents, can and must be made.

Standing on Principles will reward the reader with an insight into the mind of one of the pioneers of bioethics, into the historical circumstances in which the field took shape, and into the enduring questions of the field.

Reviewed by David B. Fletcher, PhD, who is an Associate Professor of Philosophy at Wheaton College in Wheaton, IL, an Adjunct Professor of Bioethics at Trinity International University in Deerfield, IL, and a Fellow at the Center for Bioethics and Human Dignity in Deerfield, Illinois, USA.

Against Moral Responsibility

Bruce N. Waller. Cambridge, MA: The MIT Press, 2011.

ISBN: 978-0-262-01659-9; 364 PAGES, CLOTH, $40.00.

What would it be like to live in a world without moral responsibility – a world where there was no commendation or condemnation, no praise or blame, no reward or punishment? It is for such a world that Bruce N. Waller argues vigorously in his book *Against Moral Responsibility* – a world in which no one is ever held morally responsible because, as Waller maintains, no one ever *is* morally responsible.

Waller is truly against moral responsibility. His argument is grounded on a naturalist presupposition that understands life as a random series of chance happenstances over which we have no control and, hence, no moral responsibility. Our existence is governed by sheer luck – or lack thereof. In that light, Waller insists that our system of moral responsibility is merely a primitive visceral emotive reaction, supported by belief in "gods and miracles and mysteries" (vii), but unsupported by our scientific knowledge of human behavior, which leaves no room for such a concept.

The majority of the book is oriented towards dismantling and defeating various claims for moral responsibility. Waller methodically critiques many arguments in its support, addressing issues of free will, the ability to "take responsibility" without being morally responsible, character development, and the social entrenchment of the "benefits" of moral responsibility.

But there are difficulties with his arguments. Waller confuses "influence" with "causation," a significant flaw in his argument (66); and the distinction he attempts to make between "take charge" responsibility (which we can assume) and "moral" responsibility (which we cannot possess) is a construct that renders responsibility meaningless. Moreover, he paints portraits in dualistic black and white colors: backgrounds and historical forces are either "fortunate" or "unfortunate;" individuals have either been "blessed" or "cursed." But human life is never that unambiguous, and lack of resources does not equate with moral irresponsibility, as he repeatedly implies. Despite his religious upbringing, he has forgotten (or refused to acknowledge) that we ALL are broken and fallen.

Waller ends by attempting to construct a world without moral responsibility but is unable to provide a concrete, well-developed alternative. He insists that once character flaws are acknowledged, strides can be made to change those flaws, to protect others from those flaws, and to change the systems that shaped the flawed characters, all apart from any allusion to moral responsibility. But how to do so remains unanswered, since to do so would entail self-transcendence, which by his naturalist account he has repeatedly stated we do not possess. Ultimately, his blameless system amounts to blame shifting.

As a physician, I should rejoice at his proposed system; it would spell the end of medical malpractice! But I would not want to live in "Waller's World," a world where no one is morally responsible and everyone is merely a victim of circumstances; where there is no justice for victims because the perpetrators are held to be victims as well; where there is no encouragement for virtue; where, despite his claims to the contrary, there is no hope for change since we are unable to transcend the forces that have shaped us. In the end, his is a hopeless world.

But Waller is against more than moral responsibility; he is also vehemently against God. Sadly, there is profound irony in the preponderance of biblical quotes in a book whose philosophical presuppositions deny the reality of God. Waller cites a Southern Baptist upbringing and gives abundant evidence of scriptural knowledge, making frequent allusions to Biblical and theological concepts. Yet he does so with derision, sarcasm, and flagrant hostility. One can only wonder at the forces and situations that have shaped Waller.

There are several valid points made in midst of Waller's argument against moral responsibility. Indeed, there is a need for compassionate consideration of the powers that shape those whose behaviors are violent or consistently socially unacceptable, and there is a need to seek systemic solutions to systemic problems where they exist and can be identified. But such grains of wheat are so widely scattered among the tares of his religious antagonism that they are often too difficult to glean.

Reviewed by Susan M. Haack, MD, MA, MDiv, FACOG, who is a consultative gynecologist at Mile Bluff Medical Center, Mauston, WI, USA.

Saving Babies? The Consequences of Newborn Genetic Screening (Fieldwork Encounters and Discoveries Series)

Stefan Timmermans and Mara Buchbinder. Chicago & London: University of Chicago Press, 2013.

ISBN: 978-0-226-92497-7, 307 PAGES, CLOTH, $30.00.

A little known healthcare fact is that virtually every baby born today in the United States is required to undergo mandatory genetic screening for over 50 disorders, usually without their parents' explicit consent. This relatively benign procedure requires a drop of blood drawn from the baby's heel. In light of this widespread practice, the authors undertook a three-year ethnographic study at a genetics clinic in California to study the impact on families who received news that their child had a marker for a metabolic disorder.

The authors provide an overview of newborn genetic screening, its chronological expansion throughout the United States and the impetus behind it, the impact on what they call the "patients-in-waiting" (both the child and the parents), the criteria for normalcy, the limits of prevention (especially with regard to saving lives), and possible futures for newborn genetic screening. The key question addressed is whether newborn genetic screening is beneficial for the individuals tested and their families, not really addressing its benefit for society as a whole. A key premise of the book is, in the authors' own words, "Newborn screening is what it does" (10). Thus, "the power of the genetic gaze" (85) entails impacts that are perhaps not initially realized.

This book is not primarily about the arguments for and against newborn genetic screening (although these are addressed along the way), since most geneticists and virtually all parents whose children have tested positive for a metabolic disorder agree that it is a good practice; rather, it is about the emotional, social, and financial toll on parents after being informed that their baby has a disorder. The assumption behind newborn screening is that if knowledge is gained through early testing, then it is more likely that preventative care can mitigate the effects of any disorder uncovered.

The authors are proponents of newborn genetic screening, but also detail how its promise often falls short of cure. While they provide excerpts of some of their interviews, this is not simply a summary of their study, rather it is well integrated with research in the larger field. Overall, this volume is extremely interesting and worth reading for anyone working in the field of bioethics because it addresses a little-known but very important topic in such a way that the final product is extremely well-written, extensively researched, easy to read, and eye-opening.

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

Ethics & Medicine

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

CONTENTS

VOL 30:2, SUMMER 2014
HTTP://WWW.ETHICSANDMEDICINE.COM

bioethics PRESS