

# Ethics & Medicine

*An International Journal of Bioethics*



Vol 22:2  
SUMMER 2006  
ISSN 0266-688X

**EDITOR: C. Ben Mitchell**

Trinity International University, Deerfield, Illinois, USA  
 bmitchell@tiu.edu

**FOUNDING EDITOR: Nigel M. de S. Cameron**

nigelcameron@aol.com

**ASSOCIATE EDITOR: Henk Jochemsen**

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

**MANAGING EDITOR: Carol Marlin**

The Bioethics Press, Ltd  
 info@bioethicspress.com

**ASSISTANT EDITOR: Amy deBaets**

The Wilberforce Forum  
 adebaets@bioethicspress.com

**EDITORIAL ASSISTANT: David C. Cramer**

zdcrame1@tiu.edu

**EDITORIAL ADVISORY BOARD:**

David Atkinson

Southwark Cathedral, London, England

Francis J. Beckwith

Baylor University, Waco, Texas, USA

Harold O. J. Brown

Reformed Theological Seminary, Charlotte, North Carolina, 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

Center for Bioethics and Human Dignity, Bannockburn, Illinois, USA

David Fletcher

Wheaton College, Wheaton, Illinois, USA

Nick Hallam

Consultant Virologist, Edinburgh, Scotland

C. Christopher Hook

Mayo Clinic, Rochester, Minnesota, USA

Tom Kennedy

Valparaiso University, Valparaiso, Indiana, 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

University of Ulster, Coleraine, Northern 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

Department of Theology and Religious Studies

University of Gloucestershire, England

Stephen Williams

Union Theological College, Belfast, Ireland

Donald K. Wood

Veterans Administration Medical Center, Chicago, Illinois, USA

**PUBLISHER**

The Bioethics Press, Limited

2421 W. Pratt Blvd. #420

Chicago, IL 60645-4666 USA

Phone/Fax: +1.530.482.3248

info@bioethicspress.com

www.ethicsandmedicine.com

**SUBSCRIPTIONS**

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

**RATES FOR 2006****INDIVIDUAL**

1 YEAR	\$40	€38	£24
2 YEARS	\$75	€73	£43
3 YEARS	\$110	€108	£63

**INSTITUTION**

1 YEAR -	\$88	€86	£50
2 YEARS -	\$158	€156	£90
3 YEARS -	\$215	€213	£123

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

***Ethics & Medicine: An International Journal of Bioethics***

ISSN: 0266-688X © 2006 by The Bioethics Press, Limited

BIOETHICS  
 PRESS

# Ethics & Medicine

*An International Journal of Bioethics*

## CONTENTS

**67**

### CONTRIBUTORS

**69**

### EDITORIAL

Cordelia Taylor, R.N.: Healthcare Heroine  
*C. Ben Mitchell, Ph.D.*

### ERRATA

**71**

### GREY MATTERS

Neuroscience, Nuance, and Neuroethics  
*William P. Cheshire, Jr., M.D.*

**75**

Supporting Organ Transplantation in Non-Resident Aliens Within Limits  
*Katrina A. Bramstedt, Ph.D.*

**83**

Direct-to-Consumer Online Genetic Testing and the Four Principles:  
An Analysis of the Ethical Issues  
*Katherine Wasson, Ph.D., M. Ph., E. David Cook, M.A., Ph.D., D. Litt.  
and Kathy Helzlsour, M.D., M.H.S.*

**93**

Assisted Procreation: Too Little Consideration for the Babies  
*Carlo V. Bellieni, M.D. and Giuseppe Buonocore, M.D.*

**99**

Exploring Ethical Justification for Self-Demand Amputation  
*Floris Tomasini, Ph.D.*

**117**

### Book Reviews

**123**

Biotechnology Update  
*by Amy Michelle DeBaets*

VOL 22:2, SUMMER 2006

<http://www.ethicsandmedicine.com>

## 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 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  
Trinity International University  
2065 Half Day Road  
Deerfield, Illinois, 60015 USA  
Phone: +1-847-317-8022  
Fax: +1-847-317-8141  
bmitchell@tiu.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 review will be retained by the author(s). If authors or reviewers wish to republish all or part of their contribution elsewhere within twelve months of publication in *Ethics & Medicine*, permission should be sought from the editor and mention made of its publication in the journal. Publication in *Ethics & Medicine* assumes permission to publish in electronic format. Permission to make multiple copies must be sought from the publisher.

## ABSTRACTS AND INDEXING

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

THE PHILOSOPHER'S INDEX  
c/o The Philosopher's Information Center  
1616 East Wooster Street  
Bowling Green, Ohio 43402 USA  
Phone: +1-417-353-8830  
Fax: +1-419-353-8920  
info@philinfo.org  
www.philinfo.org

*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

THE CENTRE FOR BIOETHICS AND PUBLIC POLICY  
51 Romney Street  
London SW1P 3RF UK  
Phone/Fax: +44-(0)171-587-0595  
info@cbpp.ac.uk  
www.bioethics.ac.uk

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

## LAYOUT AND TYPESETTING

Original design by Wayne Kijanowski  
Trinity International University

Typesetting by Jasen A. Swafford  
Melbourne, Australia  
jasenswafford@mac.com

## PRINTING

Excel Print Media  
Michelle FM Loke  
michelle@excelprintmedia.com

## CONTRIBUTORS

**Carlo Bellieni, M.D.**, is a member of the European Society of Pediatric Research and of the Bioethics Centre of the University of Siena, and Professor of Neonatal Therapy in the Pediatrics School of the University of Siena, ITALY.

**Dr. Katrina A. Bramstedt, Ph.D.**, is a bioethicist at the Cleveland Clinic Foundation. Her areas of specialization are the ethical issues with heart and liver transplantation, artificial organs, and research ethics. She completed her PhD at Monash University Faculty of Medicine, and a Fellowship in Biomedical & Research Ethics at UCLA, USA.

**Giuseppe Buonocore, M.D.**, is Professor at the Department of Pediatrics, Obstetrics, and Reproductive Medicine, and the Institute of Preventive Pediatrics and Neonatology, University of Siena, ITALY.

**William P. Cheshire, M.D., M.A., F.A.A.N.**, is Associate Professor of Neurology at Mayo Clinic in Jacksonville, Florida, serves on the Ethics Commission of the Christian Medical Association, and is Director of Biotechnology Ethics for The Center for Bioethics and Human Dignity, USA.

**E. David Cook, M.A., Ph.D., D. Litt.**, is a Fellow at Green College, University of Oxford, UK, and the Arthur F. Holmes Professor of Faith and Learning at the Department of Philosophy at Wheaton College, Wheaton, Illinois, USA.

**Amy Michelle DeBaets, M.A.**, is a Master of Divinity student at Princeton Theological Seminary in Princeton, New Jersey, USA, and Editor of the Biotech Update for the Council on Biotechnology Policy for The Wilberforce Forum. Ms. DeBaets obtained her MA in Bioethics from Trinity International University.

**Kathy Helzlsouer, M.D., M.H.S.**, is Director of the George W. Comstock Center for Public Health and Prevention at the Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, USA.

**Floris Tomasini, Ph.D.**, is Research Associate and Teaching Assistant at the Institute for the Environment, Philosophy and Public Policy, Furness College, Lancaster University, Lancaster, UK.

**Katherine Wasson, Ph.D., M.Ph.**, is a Fellow in Ethics and Cancer Prevention of the Cancer Prevention Fellowship Program at the Division of Cancer Prevention, National Cancer Institute, National Institutes of Health in Bethesda, Maryland, USA.



EDITORIAL

## CORDELIA TAYLOR, R.N.: HEALTHCARE HEROINE

C. BEN MITCHELL, PH.D.

The night that Martin Luther King, Jr. was assassinated, Cordelia Taylor joined a march in downtown Milwaukee, and in a fit of anger, threw a rock through a department store window.

It seemed like glass fell for an hour... It came to me clearly that I was not marching for the right reasons. The hatred had built up in my heart, and I was doing anything I could to get relief. That night God spoke clearly to me and said, *This is not what I want you to do. This isn't truly from me.* You have to do it my way. I have been free since the evening I broke the window. I have not marched another march. I have never again looked at anybody with hatred in my heart because of the color of their skin. And I thank God for it.<sup>1</sup>

Despite being the mother of eight children, Cordelia went back to school at the age of thirty-seven to study nursing. The administrator of the nursing program told her that she would never be able to complete the degree with eight children, because she could only miss three days of class. She only missed one hour! And she later went back successfully to complete her Registered Nurses (R.N.) degree.

Determined to make a difference, Cordelia took a job at a large nursing home facility. She especially wanted to help poor people. But she was overwhelmed by the fact that care was often governed by costs and that “people who had a sparkle in their eye when they came in . . . lost the motivation to live.”<sup>2</sup>

So, at her husband's challenge, Cordelia opened her own long-term care facility to serve those who needed assistance, regardless of their ability to pay. Intentionally moving to an inner-city neighborhood, they established Family House in the middle of a crime- and drug-ridden section of Milwaukee. It was such a bad neighborhood that one night, angered by the brazen drug trafficking, Cordelia confronted a dealer who pulled a gun on her. “I told him to go ahead and shoot. He'd just get me to heaven faster than I planned to go.” The man lowered the gun, put it in his pocket and walked away saying, “I won't be back, lady. You can have this neighborhood.”<sup>3</sup>

Today, Cordelia Taylor operates Family House, Inc., “a Christ-centered ministry dedicated to serving the Lord by providing a comfortable home to homeless senior citizens and disabled adults where they are given Christian love, respect, and a sense of dignity.”<sup>4</sup> The ministry provides 24-hour long-term care for 58 senior adults. Family House has also expanded the scope of its ministry: their food pantry feeds 3,000-4,000 per year; they offer job training and provide classes to teach mothers how to shop economically and prepare

nutritious meals. Family House also has an after-school program for neglected children. Finally, through a collaborative venture with the Medical College of Wisconsin, Family House operates a medical clinic that offers care to anyone who walks in the door.

Oh, and remember the drug dealer who told Cordelia that she could “have the neighborhood”? Family House now owns and operates its more than \$2 million a year ministry on an entire city block of downtown Milwaukee.

## Endnotes

- 1 Cited in Barbara J. Elliott, *Street Saints: Renewing America's Cities* (Philadelphia: Templeton Foundation Press, 2004), p. 16.
- 2 Ibid.
- 3 Ibid., p. 17.
- 4 <http://www.familyhouseinc.com/>

## ERRATA

Regrettably, the piece by Katrina A. Bramstedt, Ph.D., “Supporting Organ Transplantation in Non-Resident Aliens Within Limits,” (22:1 [Spring 2006]: 39-45) was published without its accompanying tables. It has been rerun in its entirety with the tables in this issue.

Further, the Guest Commentary by Matthew Eppinette, M.A. and Andrew Fergusson, M.R.C.G.P., “Human Dignity: Still Defying Devaluation,” (22:1 [Spring 2006]: 5-7) was published without its accompanying endnotes. They are printed below.

- 1 Adam Schulman, “Bioethics and Human Dignity: Staff Working Paper,” *The President's Council on Bioethics*, December 2005 [http://www.bioethics.gov/background/human\\_dignity.html](http://www.bioethics.gov/background/human_dignity.html) (accessed December 15, 2005).
- 2 WordNet, s.v. “Dignity,” <http://wordnet.princeton.edu/perl/webwn?s=dignity> (accessed December 15, 2005).
- 3 *Encyclopedia of Bioethics*, 3rd ed., s.v. “Human Dignity.”
- 4 William P. Cheshire, “Toward a Common Language of Human Dignity,” *Ethics & Medicine* 18 no 2 (Summer 2002): 10.
- 5 Ibid., 8.
- 6 *Encyclopedia of Bioethics*, 3rd ed., s.v. “Christianity in Bioethics.”
- 7 Andrew Fergusson, “What Has the Church Done Historically?” *Hard Questions about Health and Healing*, Chapter 6.

With apologies,

E & M Editors



GREY MATTERS

## NEUROSCIENCE, NUANCE, AND NEUROETHICS

WILLIAM P. CHESHIRE, JR., M.D.

A primary task of ethics is to recognize valid distinctions in the face of uncertainty concerning moral obligations. When wrestling with life's toughest questions, facts are often incompletely accessible or their interpretations ambiguous. Available theoretical approaches often yield conflicting solutions. When confronted with healthcare dilemmas, in particular, people differ in how they prioritize and apply their personal values to reach decisions that entail life-altering consequences.

These are the grey matters of bioethics. Their blurry contours outline what is known, what can be done, and what should be done. Somewhere between bright evidence and unfathomable unknown, between lucid right and shadowy wrong, between decisive resolve and oblivious apathy, lies a vast expanse of ethical grey.

Bioethical greyness is anything but dull. Things unelucidated challenge the mind to explore and wonder. Matters undecided invite heartfelt reflection, abstract reasoning, serious discussion, and debate. Greyness allows openness to creative interaction.

Nor is greyness absolutely impenetrable. For those who dwell amidst ethical grey, greyness teaches the worth of clarity, which must be patiently sought. Greyness is an ever present reminder of human finitude. Its ambiguity inhibits our fixation on things that are fading and of no lasting consequence. Its indefiniteness suggests that what most strongly motivates us may not be what is immediately visible. The lack of clarity along grey's continuum compels the restless mind to seek what lies beyond. How life is lived depends on what grey-dwellers make of shades of grey. Grey matters.

It is, of course, grey matter that bioethicists bring to bear on these grey matters. The grey matter refers to that part of the brain which, if sliced open, appears grey in contrast to myelinated white matter and consists of the cerebral cortex as well as the subcortical nuclei such as the hippocampus, thalamus and basal ganglia. In general, cerebral grey matter is that part of the brain responsible for information processing, whereas white matter, which connects regions of grey matter, is responsible for information transmission. Grey matter thus has connotations both anatomical and philosophical.

Neuroethics is the realm where cerebral and ethical grey matters interpenetrate. The discipline of neuroethics considers the ethical implications of advances in the neurosciences, drawing from the fields of clinical neurology, neuropsychiatry, neuropsychology, neuroimaging, neuropharmacology, neurogenetics, neuropathology, nanomedicine, and computer science. The

neurosciences are yielding exciting capabilities to measure healthy and disordered brain function, to detect and alter the course of brain diseases, as well as to understand the nature of the neural processes that correspond to the human mind. The potential health benefits of neuroscience are enormous. The implications for ethics are profound, for the object of neuroscientific study is the very organ that engages in ethical contemplation.

As neuroscience probes the intricate structure and cellular behavior of grey matter, the scientifically informed brain is challenged in new ways to comprehend its own nature, its origin, its purpose, and its relationship to others. Not only are bodily perception and movement subject to scientific investigation, but with the advent of functional imaging techniques and less invasive methods of stimulating the brain, neuroscience is able to offer increasingly sophisticated descriptions of the neural basis of higher cognitive functions. These include aspects of moral reasoning, intention, consciousness, empathy, belief, and spiritual experience. Functional imaging studies of higher cognitive functions are identifying and mapping configurations of grey matter activation that correspond to thoughts which previously were the exclusive domain of private reflection or which occur beneath the threshold of conscious awareness.

The neural pathways that subserve moral judgments and ethical reasoning are coming into scientific view in unprecedented detail. Their interpretation falls to grey matter. How society assigns meaning to the brain phenomena that correspond to social interactions, personal beliefs, moral conscience, philosophical analysis, as well as the drive to conduct scientific research has intriguing implications for human self-understanding and its translation into culture.

Consider the far-reaching implications of neuroscience for ethical decision-making. Do subjective judgments carry moral weight if they can be shown to arise from brain states describable in physical terms? Might physical models of the brain invalidate the wisdom of moral repugnance?<sup>2</sup> Should what has been called the “yuk factor,”<sup>2</sup> be understood simply as a conditioned neurochemical reflex? Are reason and logic reducible also to cerebral biochemistry? Can physical models of the brain succeed in explaining away religious belief? How might human thought be a given reality, and how might it – and ethics – become subject to reshaping?

Neuroethics also has subtle implications for the character of human interaction. What boundaries should be respected in order that innovative freedoms of communication do not excessively intrude into personal privacy? As powerful new computers augment their performance by more closely imitating the brain, and become more user-friendly by mimicking the outward expression of human emotions, shall we in turn find ourselves imitating our computers in a quest for maximum efficiency? What is it about human language that transcends sheer information transmission?

Further questions for neuroethics concern the proper place and limits of medical models of human thought and behavior. Should drugs be used to enhance cognition in normal individuals? When is it appropriate to manage social misbehavior with psychotropic medications? Would it be wise to edit away unpleasant memories if that were possible?

Neuroethics also has implications for the integrity of personal responsibility. Can neuroscience demonstrate whether mental agency is determined or free? What should be the role of neuroscientific evidence in ascertaining legal responsibility for crimes?

Many readers will recall Agatha Christie's fictional detective, Hercule Poirot, who brilliantly solved crimes by use of what he called his "little grey cells."<sup>3</sup> Poirot's success notwithstanding, contemporary neuroscience recognizes that intelligence is also a matter of how well the grey regions of the brain intercommunicate. Whereas grey matters, grey is not all that matters.

Likewise, neuroscience matters, but it should be remembered that physical descriptions cannot supply a complete explanation of the human mind. A nuanced view of neuroethics recognizes that, between the lines of black and white data that neuroscience generates lie shades of meaning irreducible to material mechanisms. Great thoughts do not consist in clusters of reflexively firing neurons, although neurons may represent them. Amazingly, it is neurons that give expression to the human longings that inspire moral imagination. Such aspirations brightly overshadow the greyest grey.

As we welcome progress in neuroscience, let us conscientiously explore the fullness of neuroethics. The journey into neuroethics will not have been exhausted when the hairs of generations to come have turned grey.

## References

1. Kass, Leon R. "The Wisdom of Repugnance." *New Republic* Vol. 216 Issue 22 (June 2, 1997).
2. Morton, Oliver. "Overcoming Yuk." *Wired*, January 6, 1998.
3. Christie, Agatha. *The Mysterious Affair at Styles*. London: Bodley Head, 1920, Chapter 10.

---

**William P. Cheshire, M.D., M.A., F.A.A.N.**, is Associate Professor of Neurology at Mayo Clinic in Jacksonville, Florida, serves on the Ethics Commission of the Christian Medical Association, and is Director of Biotechnology Ethics for The Center for Bioethics and Human Dignity, USA.

The views expressed herein are his own and do not necessarily reflect the positions of Mayo Clinic or Mayo Foundation.



# SUPPORTING ORGAN TRANSPLANTATION IN NON-RESIDENT ALIENS WITHIN LIMITS

KATRINA A. BRAMSTEDT, PH.D.

## Abstract

It is common knowledge that the supply of cadaveric organs does not meet demand. This shortage is often used as ethical argument against transplantation in Non-Resident Aliens; however, this fact in isolation does not present a comprehensive picture of organ allocation in USA. Even though approximately 153 cadaveric livers, kidneys, and hearts are transplanted into Non-Resident Aliens each year, roughly another 85 livers, kidneys and hearts are recovered as usable for transplantation but are not transplanted due to inability to find a recipient. These organs are also unable to be exported due to logistics or lack of patient matching. Because usable, recovered allografts are discarded on a yearly basis, there is no justification to use “allograft scarcity” as argument against transplantation in Non-Resident Aliens. Further, consistent with other countries, a system of two waiting lists which allocates organs to US Residents with the first right of refusal (with Non-Resident Aliens having access to organs refused by or not matched to US Residents) is ethically appropriate. Justification for this two-list system lies in deconstructing “who” is the transplant community, and who are “guests” of the transplant community.

*Keywords:* transplant, organ allocation, ethics, justice, discrimination, foreign national

## Introduction

Allograft scarcity across all organ types continues to be documented by the United Network for Organ Sharing (UNOS).<sup>1</sup> In general, attempts to increase organ donation have not been very successful, with the number of organ donors increasing by only 3% each year.<sup>2</sup> There is concern that the number of organs needed will never meet demand, thus there is an ethical imperative to allocate them fairly to patients with the capacity to benefit from them.<sup>3</sup> Currently, UNOS permits Non-Resident Aliens (NRA) to be registered on the transplant waiting list and to receive allografts under the same allocation policies as that of United States (US) Residents.<sup>4</sup> UNOS considers NRAs as those individuals “granted permission by the US Government to enter the US on a temporary basis as a non-immigrant alien for purposes which include tourism, business, education, medical care, or temporary employment”.<sup>4</sup> Residents are those who have the legal right to live permanently in the US.

---

*Ethics & Medicine, 22:2 (2006): 75-81.*

©2006 by Katrina A. Bramstedt

UNOS allows each transplant center to allocate up to 5% of cadaveric transplants to NRAs.<sup>4</sup> Approximately 153 cadaveric livers, kidneys, and hearts (total) are transplanted into NRAs each year.<sup>1</sup> Most of these cases never receive media attention; however, when this does happen, the spotlight shines directly on US transplant policy. Emotions range from anger that NRAs “take” organs that “should” go to US Residents, to compassion for these needy individuals who are frequently poor, very sick, and unable to access transplant services in their own country.<sup>5,6,7</sup>

### US Transplant Data

As of 27 May 2005, patients registered on the UNOS transplant waiting lists are in need of 95,618 organs (some patients need more than one type of organ). Sorted by citizenship, there are 88,656 US citizen registrations, 3483 Resident Alien registrations, and 851 NRA registrations. Specifically, NRA registrations comprise 0.89% of all registrations, 0.98% of kidney registrations, 0.91% of liver registrations, and 0.38% of heart registrations (www.unos.org). Between 1996 and 2003, NRAs were the recipients of 661 liver transplants, 399 kidney transplants, and 161 heart transplants. During this same period, US Residents were the recipients of 35,660 liver transplants, 64,479 kidney transplants, and 17,580 heart transplants (Table 1).<sup>1</sup> Donated livers, kidneys and hearts that were clinically suitable for transplant but were unused during this period totaled 679 (Table 2).<sup>1</sup> These organs (approximately 85 per year) may have either been unmatched (no suitable donor found), or matched, but the potential recipient was unable to be contacted to arrange transplantation.

Table 1. Cadaveric Organ Transplants: Recipient Residency Status (1996 – 2003)

	1996	1997	1998	1999	2000	2001	2002	2003	Total	mean
Heart	R 2316 NRA 16	R 2259 NRA 18	R 2314 NRA 27	R 2162 NRA 21	R 2179 NRA 18	R 2180 NRA 21	R 2134 NRA 21	R 2036 NRA 19	R 17580 NRA 161	R 2198 NRA 20
Liver	R 3833 NRA 82	R 3919 NRA 100	R 4285 NRA 84	R 4370 NRA 98	R 4485 NRA 98	R 4581 NRA 80	R 4897 NRA 67	R 5290 NRA 52	R 35660 NRA 661	R 4458 NRA 83
Kidney*	R 7627 NRA 64	R 7682 NRA 56	R 7913 NRA 58	R 7961 NRA 49	R 8061 NRA 49	R 8158 NRA 59	R 8461 NRA 67	R 8616 NRA 45	R 64479 NRA 399	R 8060 NRA 50

\*Extended criteria and non-extended criteria cadaveric kidneys

NRA Non Resident Alien  
R Resident

Table 2. Unused\* Cadaveric Donor Organs (1996 – 2003)

	1996	1997	1998	1999	2000	2001	2002	2003	Total	mean
Heart	6	4	5	4	3	2	0	1	25	3
Liver	19	8	16	12	18	11	10	12	106	13
Kidney	52	65	63	72	76	86	62	72	548	69

\*Organs deemed usable but not used for transplant (USA or export) due to inability to locate a matched donor, or inability of the organ to match a patient on the waiting list

## Organ Exporting v. NRA Transplants

In addition to allowing NRAs to receive organ transplants, UNOS also allows cadaveric organs donated in the US to be exported to other countries.<sup>8</sup> These exports are distinctly separate from using organs for research in that the exported organs are for human transplant. UNOS policy allows such export to occur as long as no suitable UNOS waiting list matches are identified. Not unexpectedly, the primary export location is Canada, as logistics prevent export to distant countries. In the 10-year period between 1994 and 2003, 78 hearts, 29 kidneys, and 5 livers were exported to transplant centers in foreign countries.<sup>1</sup>

The practice of organ export raises the question, *Is there an ethical difference between exporting organs to other countries and keeping the organs in the US and giving them to NRAs?* Both the NRA and the patient who receives the exported organ are non-residents of the US. While the NRA is physically present in the US, he/she is subject to living outside of the US (due to voluntary return to their home country or deportation) just as the export organ recipient resides outside the US. The latter patient is not receiving transplant management care in the US, and the NRA patient will not have US medical management when he/she leaves. Notably, US Residents don't bear the surgical and medical costs of transplantation when organs are exported; however, they often do in the case of NRAs, as these patients receive their transplant in the US and often require financial assistance to pay for their expenses. Another matter is the fact that NRAs compete for cadaveric organs on equal footing with US Residents (until the 5% quota is reached), whereas organs that are exported to other countries are the result of not finding suitable matches in the US. This said, recipients living in foreign countries take second place to US Residents and NRAs who have priority for the organs in an equal manner.

Appropriate organ allocation must reflect on both pre- and post-transplant issues. While UNOS and US physicians have no control over the psychosocial assessment of patients receiving exported organs, facilities receiving these organs are approved by UNOS via "formal organ exchange agreements".<sup>8</sup> Optimally, these approvals should reflect on post-transplant treatment quality and accessibility. In the case of NRAs receiving organ transplants in the US, the transplant facility should conduct a thorough psychosocial assessment that reflects upon the transplant management services available in the country that the NRA would return to if he/she left the US. This investigation should identify what transplant-related medications are available in the patient's home country, as well as the financial costs and accessibility (private insurance versus national health care). NRA patients are of special concern, as often their country of origin lacks appropriate facilities and medications for post-transplant care. In such settings, these patients are at risk for substandard medical care (or no medical care), thus putting the donated organs at risk for rejection, and ultimately, clinically preventable patient death.<sup>9</sup>

## **Illegal Aliens**

Illegal aliens (“undocumented aliens”) are those who have entered the US illegally without the proper authorization and documents, or who have entered the US legally but have since violated the terms of the status in which they entered or have overstayed their permitted time limit ([www.irs.gov](http://www.irs.gov)). UNOS organ allocation policies do not address the matter of transplantation of illegal aliens.<sup>4,5</sup> Specifically, the policy dealing with foreign nationals addresses allocation to NRAs and does not mention illegal aliens at all. It is unclear why UNOS does not discuss this group. By default, one could assume that organ allocation to illegal aliens is not allowed just as employment of illegals is prohibited,<sup>10</sup> but UNOS policy is silent on this matter. Indeed, transplantation of illegal aliens is ethically problematic as these individuals frequently lack the financial means to pay for their surgical and post-transplant care, as well as a stable support system to assist them post-transplant. Also, they are subject to deportation at any time, disrupting post-transplant care. Such deportation often occurs to countries that lack appropriate medical services for transplant patients,<sup>9</sup> or the care is not accessible due to high cost.

Further complexity is found when one considers that NRAs can become illegal aliens after they are placed on the transplant waiting list. It is unclear if these individuals have their immigration documentation routinely reviewed by anyone (UNOS, transplant center) to ensure that NRAs who are wait-listed maintain legal status or if these individuals get removed from the waiting list if determined to be illegal aliens, rather than NRAs. Have individuals who were listed with NRA status but shifted to illegal status while listed been transplanted anyway? UNOS does not keep such statistics. Also, there is the matter of people entering the US “legally” with a formal determination of NRA that is based on a false premise of tourism or education, when in fact, these individuals are seeking organ transplantation. Should UNOS or the transplant team become the “Immigration Police”? Should they inform the US Government if they suspect or identify fraud? In Los Angeles (CA), San Diego (CA), Stockton (CA), New York (NY), Chicago (IL), Miami (FL), Austin (TX), and Houston (TX), no hospital or physician can report immigration violators to the Department of Homeland Security’s Bureau of Immigration and Customs Enforcement”.<sup>11</sup>

While allocating organs to illegal aliens can result in poor resource stewardship, Beth Israel Medical Center (NY) takes the controversial position that they will allocate organs to these individuals. Under their policy, however, they will not subsidize the individual’s inpatient or outpatient clinical expenses or medications. Further, the hospital requires that these individuals provide a deposit to cover all anticipated costs, unless they can provide proof that they are entitled to State or Federal healthcare funds.<sup>5</sup> In the past, the publicity about organ allocation to foreign nationals has been shown to reduce organ donation rates,<sup>9</sup> thus the practice has the potential to negatively impact US Residents who are in need of transplant (by reducing the number of organs available to them). This negative potential is likely further fueled by the inclusion of undocumented aliens in the construct of “foreign national” as these individuals reside in the US illegally, and have little, if any, healthcare funds.



## Waiting for a Transplant

Patients waiting for a transplant are often troubled by many fears including anxiety about not knowing how long their wait will be, or if they will die before getting a transplant.<sup>12</sup> Some patients experience clinical deterioration while they await a donor organ, and decline to a state in which they are no longer considered transplant candidates. In the case of NRAs, when these individuals receive media attention about their organ need there can be a perception that the extra focus will facilitate transplantation of the NRA sooner than others [US Residents] who are waiting for an organ. Review of UNOS heart transplant data for the six-year period of 1998-2003 finds that the median time to transplant for US Residents was 297 days (+/- 69 days), whereas the median time to transplant for NRAs was 43 days (+/- 15 days).<sup>1</sup> During this period, US Residents waited nearly seven times longer for a donor heart than did NRAs (39% of whom were children). This data alone does not provide reasons for the significant disparity among waiting times for heart transplant recipients, but the matter warrants further research. It is possible that there is a preponderance of NRAs living in geographic regions that are known to have shorter waiting times compared to other regions,<sup>13</sup> that these individuals are less likely to be sensitized,<sup>10,14</sup> and/or that media attention is occurring and playing a role in directed donation to identified NRAs.<sup>15</sup>

## A Proposal

As shown, dozens of donated organs are discarded each year in the US, as these organs are unmatched to US Residents, NRAs, or patients on Canada's transplant waiting list, or the organs are matched but the patients cannot be contacted to arrange transplant. The fact of organ discard, and the issues surrounding organ allocation to foreign nationals raises two philosophical questions, *Who is the transplant community* and *Who are guests of the transplant community*?

There are several ways to define "transplant community". This community could be seen to comprise those explicitly permitted by regulations to be organ recipients (NRAs and US Residents), people willing to be organ donors (living or cadaveric) regardless of their residency status, or anyone (regardless of their willingness to be an organ donor or their residency status). If one takes the position that non-US Residents should not be allowed to receive organ transplants in the US because these individuals don't donate to the organ pool, this fails to acknowledge the fact that many US Residents are also not organ donors. In the US, willingness to be an organ donor is not a transplant eligibility criterion; however, UNOS does give kidney organ allocation preference to individuals who have been living donors of any organ (rather than those who consent to be cadaveric donors).<sup>16</sup>

An argument that only taxpayers should be allowed organ allocation is faulty because it assumes only US Residents are taxpayers. NRAs who have the legal right to work in the US and who are employed are often subject to income and Medicare taxes, and they do pay tax on consumer goods. Illegal aliens do not have the right to work (and do not pay the associated taxes) but they do contribute to the local tax base through their daily consumption of taxed

consumer goods. While their contributions do not equate to the taxes paid by US Residents, to say that foreign nationals do not make economic contributions is false.<sup>17</sup>

Having made these assertions, I pose that it is appropriate to consider the “transplant community” as US Residents because in general, this is the community from which organ donation arises and from which the majority of financial input is received.<sup>18</sup> This does not mean, however, that foreign nationals should be excluded from transplant; rather, they should be viewed as “guests” of the community. As guests, these individuals should not be on an equal playing field for access to allografts, but rather they should have access only after it has been determined the no suitable allocations can be made to US Residents. A similar policy is standard practice in Australia and New Zealand.<sup>19</sup>

Formally, this organ allocation system should be comprised of two waiting lists, one for US Residents and one for NRAs.<sup>20</sup> The second list should not include illegal aliens as this group has the highest risk of deportation, the highest risk of disrupted post-transplant care (due to issues of cost and access), and the lowest potential for contributing to the US transplant community as donors. Both standard and extended criteria organs (marginal organs)<sup>3</sup> should be allocated using the two list system. Both NRAs and US Residents should demonstrate the ability to pay for their pre- and post-transplant care either via their own financing, access to insurance, or verified charitable donation. All hospitals should provide a small amount of charity care<sup>18</sup> for transplant patients on a yearly basis, as they do for other medical specialties. The amount should consider their current and projected case load, costs, and funding, as well as the worthy goal of assisting the stewardship of donated organs.

NRA transplants should be allowed; however, these should occur only if the organs are unable to be used by US Residents or are refused by them—essentially giving US Residents priority on the UNOS waiting list due to residency status. In this manner, donated organs belong to the community from which they were donated. They can be shared with guests outside of the community only after it is determined that the community cannot benefit from the donations, and it is confirmed that the guests can respect the gifts (access to suitable follow up medical care). The practice of medicine has a compassionate nature in that it seeks to reduce suffering and improve quality of life, thus a person’s national origin itself should not be an exclusion criterion for the provision of care. However, in a setting where finances are limited and allografts are scarce (and require significant maintenance), allocation must reflect on many variables.

For the reasons discussed, it is not unethical to give US Residents first priority for organ transplantation, or to deny organ transplants to illegal aliens. In fact, untamed allocation can have a net effect of harming the transplant community by reducing organ donation.<sup>9</sup> Further, if US educational efforts eventually succeed in significantly increasing the rate of organ donation, the group that should reap the benefit is the “transplant community”; that is, the community from which the donations originated. If there is an excess, such should be shared with those outside the community. Lacking excess, the “community” should be served first by having priority access to cadaveric organs. Additionally, the number of “unused” organs should be reduced to zero; that is, any usable organ that is unmatched amid the two-list system, as well as

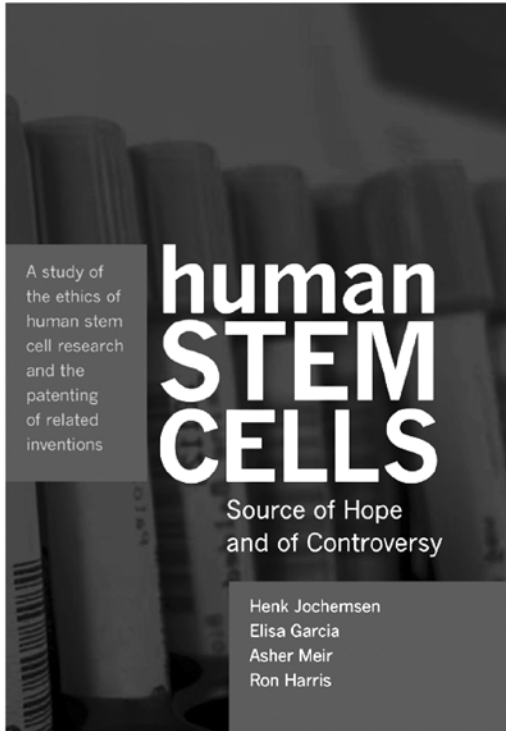
for export transplant, should be used for research or educational purposes. No donated organ should go to waste.

## References

1. 2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994-2003. Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation, Rockville, MD; United Network for Organ Sharing, Richmond, VA; University Renal Research and Education Association, Ann Arbor, MI.
2. Joint Commission on Accreditation of Healthcare Organizations. *Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients*; 2004.
3. Bramstedt KA. Why an alternate recipient list for heart transplantation is not a form of ageism. *New Zealand Bioethics Journal* 2001;2(2):27-31.
4. United Network for Organ Sharing. *UNOS Policy 6.0 Transplantation of Non-Resident Aliens*; 25 June 2004.
5. Gottlieb L, Zucker MJ. Organs for undocumented aliens? A transplantation dilemma. *Cambridge Quarterly of Healthcare Ethics* 1995;4(2):229-38.
6. Greenwald D. Far From Home, Girl Waits for New Heart. *UCLA Today* 1997;17(16):1.
7. Robinson B. The Transplant Dilemma. *Las Vegas Review-Journal*. 04 April 1997, p. 15B.
8. United Network for Organ Sharing. *UNOS Policy 6.4 Exportation and Importation of Organs—Developmental Status*; 25 June 2004.
9. Department of Health and Human Services, Office of the Inspector General. *The Access of Foreign Nationals to US Cadaver Organs*. Report number P-01-86-00074; August 1986.
10. United States Immigration and Customs Enforcement. *Fact Sheet: ICE Border Security & Immigration Enforcement*; 17 June 2004. Available on-line at [http://www.ice.gov/graphics/news/factsheets/061704det\\_FS.htm](http://www.ice.gov/graphics/news/factsheets/061704det_FS.htm). Accessed 14 June 2005.
11. Cosman MP. Illegal aliens and American medicine. *Journal of American Physicians and Surgeons* 2005;10:6-10.
12. Porter RR, Krout L, Parks V, Gibbs S, Luers ES, Nolan MT, et al. Perceived stress and coping strategies among candidates for heart transplantation during the organ waiting period. *Journal of Heart and Lung Transplantation* 1994;13(1 Pt 1):102-7.
13. Ellison MD, Edwards LB, Edwards EB, Barker CF. Geographic differences in access to transplantation in the United States. *Transplantation* 2003;76(9):1389-94.
14. Davis DS. Organ transplants, foreign nationals, and the free rider problem. *Theoretical Medicine* 1992;13(4):337-47.
15. Moray G, Karakayali H, Demirag A, Bilgin N, Haberal M. Media effect on organ donation and transplantation. *Transplantation Proceedings* 1999;31(8):3284-5.
16. United Network for Organ Sharing. *UNOS Organ Distribution Policies §3.5.11.6 (Donation Status)*; November 2004.
17. Dwyer J. Illegal immigrants, health care, and social responsibility. *Hastings Center Report* 2004;34:34-41.
18. Prottas JM. Nonresident aliens and access to organ transplant. *Transplantation Proceedings* 1989;21:3426-3429.
19. The Transplantation Society of Australia and New Zealand. *Organ Allocation Protocols*. Available on-line <http://www.racp.edu.au/tsanz/oapmain.htm>. Accessed 20 June 2005.
20. Kleinig J. Organ transplants: the just and human expectations of Nonresidents. *Transplantation Proceedings* 1989;21:3430-3431.

---

**Dr. Katrina A. Bramstedt, Ph.D.**, is a bioethicist at the Cleveland Clinic Foundation. Her areas of specialization are the ethical issues with heart and liver transplantation, artificial organs, and research ethics. She completed her PhD at Monash University Faculty of Medicine, and a Fellowship in Biomedical & Research Ethics at UCLA, USA.



*Human Stem Cells*  
is available  
in paperback  
and now  
a new hardcover edition.  
Find it in your bookstore,  
at [amazon.com](http://amazon.com) or  
[bioethicspress.com](http://bioethicspress.com)

ISBN: 0-9711599-4-7 and 0-9711599-5-5



**Human Stem Cells**  
*Source of Hope and of Controversy*  
An International Study

- *A literature study of the real therapeutic possibilities of stem cells from different sources*
- *An examination of the ethical issues associated with research and the use of human (embryonic) stem cells*
- *An examination of the economic and ethical issues associated with the patenting and commercialization of the stem cell*
- *A description of the present patenting regime in the USA and its problems when it comes to biomedical finding*

On the basis of these chapters, the authors have formulated some main recommendations for policy(-makers) with respect to research on human (embryonic) stem cells and related patents.

Compiled from writers in Europe, the US, and Israel, this international study discusses the present day issues of human stem cell research and its ethical implications.

# DIRECT-TO-CONSUMER ONLINE GENETIC TESTING AND THE FOUR PRINCIPLES: AN ANALYSIS OF THE ETHICAL ISSUES

KATHERINE WASSON, PH.D., M.PH.

E. DAVID COOK, M.A., PH.D., D. LITT.

AND KATHY HELZLSOUER, M.D., M.H.S.

## Abstract

The development of genetic tests marketed and sold direct-to-consumers (DTC) via the internet raises moral concerns and debate about their appropriateness and ethical and clinical significance. These tests are offered for a wide range of diseases and conditions, and the mutations have variable penetrance and associated risk. A number of these tests lack data on their accuracy and reliability, making interpretation of results difficult. DTC genetic testing is undertaken outside the context of the physician-patient relationship and may lack appropriate individual and family genetic counseling, leaving the consumer vulnerable to potential harms, such as misinterpretation of results, including false positive or false reassurance, with limited or no benefits. Beauchamp and Childress's four principles of biomedical ethics provide a framework for analyzing the ethical issues raised by DTC genetic testing. We argue that the potential harms outweigh the potential benefits of such tests, that respect for autonomy should be limited in light of potential harm from DTC testing, and that the availability of genetic testing over the internet may be considered unfair and unjust and affect resource allocation by placing an unfair burden on primary care physicians. In light of the moral issues posed by these tests, practical responses are suggested in the areas of consumer education, medical education, and interaction with commercial companies.

## Introduction

As the popularity of the World Wide Web increases, more and more people have access to a wide range of information, goods and services at their fingertips. This includes a host of health related areas, and genetic testing is no exception. Ethical issues surrounding the sales, advertising and marketing of direct-to-consumer (DTC) genetic tests have been raised.<sup>1,2,3,4</sup> This wave of genetic tests continues to expand and be developed and raises important moral questions. Examination of the nature of DTC genetic tests, their results, and the ethical issues they pose for individuals, the medical profession, and the wider public requires careful scrutiny and public discussion.

## **What are Direct-to-Consumer Genetic Tests?**

Recent developments in genetics have led to a series of tests being developed which are available over the internet and direct-to-consumers.<sup>5,6</sup> DTC genetic tests include a spectrum of high and low penetrant genes, such as the identification of single nucleotide polymorphisms (SNPs) associated with cardiovascular disease (CVD), breast, ovarian, colon and uterine cancers, osteoporosis, detoxification defects, metabolic deficiencies, and immune system defects.<sup>7,8,9</sup> Penetrance is the probability that a gene or genetic trait will be expressed.<sup>10</sup> Both gene penetrance and the associated risk, which may be linked to potentially harmful or beneficial effects, vary. Such risk can sometimes be affected by environmental and lifestyle factors. Even if a person has a genetic mutation associated with a particular disease or condition, this does not necessarily predict when it will develop, if at all, or its severity. This variance, and the fact that a number of the specific disease associations have not been established, makes interpretation of many DTC genetic tests difficult and their clinical utility less than clear.

The testing process offered by these companies often includes taking a cheek swab and returning the testing kit to the company. The sample is analyzed and the results sent to the consumer in approximately three weeks.<sup>11,12</sup> Depending on whether the test is for a single genetic mutation or multiple mutations, the cost ranges from approximately 200 to 3000 dollars.<sup>13,14</sup>

That these genetic tests are offered directly to consumers, outside the parameters of the medical or clinical genetics context, raises ethical concerns. Four principles from bioethics—non-maleficence, beneficence, respect for autonomy and justice—offer a way of framing and critically examining the ethical issues.<sup>15</sup>

## **Non-Maleficence**

At present, both the testing process and the results from the DTC genetic tests leave room for inaccuracy and misunderstanding. Collecting biological samples at home might or might not maximize the reliability of results, as individuals may not follow the protocols sufficiently closely. In addition, it would be difficult to verify to whom the sample belongs and there could be a danger that an individual would send in another person's biological sample, for example, that of a child or spouse (with or without that person's knowledge of the genetic testing). The laboratories themselves may or may not be certified under the Clinical Laboratory Improvement Amendments (CLIA), which strengthened federal oversight to assure the reliability and accuracy of test results,<sup>16</sup> and the processes used to conduct the genetic analyses and glean results are not transparent, making assessment of reliability and validity difficult.<sup>17</sup> Standards of sample collection and their processing may vary and lead to misinformation or mal-information, which could be harmful in itself and/or if people act on it.

Many strides have been made in genetic research, particularly in identifying genetic markers and mutations that may be linked to diseases and conditions.

Yet, just because a technology is possible, does not necessarily mean it should be offered at all or without limits. Although the technological imperative is viewed as strong, it is not absolute. The potential, or actual, benefits of any technology should be weighed against its potential, or actual, harms and risks to individuals, communities, and the wider public. Technology has moral limits based on harm to individuals or groups. With this particular technology, DTC genetic tests, it is important to ask: Is there a specific need to know about our genetic make-up? If so, how far does it extend and who defines it? The strength of this right's claim would need to be weighed in the context of harms and benefits of the tests.

With most predictive (or screening) tests, there is a margin of error. The sensitivity is the ability of the test to identify correctly those who have the disease or condition. The specificity is the ability of a test to identify correctly those who do not have the disease or condition.<sup>18</sup> The higher the sensitivity and specificity, the more accurate the test. Currently, this information is not available for many DTC genetic tests.<sup>19</sup> The rate of false positives and false negatives is unknown to the general public and general medical professionals. Without this information, it is not clear how reliable or valid many of these tests are. A false positive result can create unnecessary anxiety or fear, while a false negative result may create an unwarranted sense of security and lack of action. Individuals may act or fail to act based on these test results, which might carry costs, side effects and harms. Such steps may be necessary or unnecessary, helpful or unhelpful. A man receiving a false negative result regarding a genetic susceptibility to CVD might incorrectly believe he need not worry about developing it, or at least not more than other men his age. He might fail to see his physician or modify his diet and exercise patterns. These omissions could be harmful because he would lose the potential benefit from these modifiable factors which could aid prevention of CVD. The potential for harm from DTC genetic tests is exacerbated because the correct interpretation of test results is uncertain or unknown. Many of the disease associations are not established; therefore, their clinical significance and utility is unclear and debatable.<sup>20,21</sup>

The context in which DTC genetic tests are offered and accessed is very different from clinical genetics tests. The latter involves physicians, nurses and genetic counselors who are trained in helping people think through the implications of having versus not having a particular test, with known predictive value, reliability and validity for the individual and his/her family. The decision to take a DTC test can be made alone or on a whim, with no pre-test or post-test counseling, and the results are sent to the individual to be interpreted, often without the guidance of a physician or genetic counselor. This shift in context can be considered potentially, if not actually, harmful.

The American College of Medical Geneticists recommends that any genetic testing should be provided to the public only through an "appropriately qualified health care professional", who will order and interpret the test.<sup>22</sup> The Human Genetics Commission in the United Kingdom recommends that genetic testing be accessed primarily through health care services and professionals.<sup>23</sup> The context emphasized is one where a health care professional, physician, or genetic counselor provides guidance to a particular patient about what is, or is not, in his/her best interests. The motivation for these recommendations is to

protect patients, ensure a patient is properly informed about a genetic test and its significance (or lack of), and provide appropriate information and guidance to the patient about actions to take or avoid in light of results. Both professional bodies highlighted the complex and sensitive nature of genetic information, the potential difficulties in understanding and interpreting the results, the potential harms associated with this information, and the need for caution and guidance of health care professionals.<sup>24,25</sup>

One reason people might choose to access genetic tests directly is to protect their confidentiality and privacy. They may want their genetic information to remain outside the realm of medical records and insurance companies. The reality might be different as consumers may be unaware of what could be done with their results. Some companies offering DTC genetic tests have privacy statements, but questions can be raised about third party access to private genetic information (whether de-identified or not) and use of it or genetic material in the development of further technologies. In contrast, having received DTC results, individuals may not fully realize their significance and could pass them on to an insurance company or employer, which could have harmful implications for them and their families.<sup>26</sup>

The potential harms of DTC genetic testing for individuals and their families are not insignificant, but should be considered in light of potential benefits.

## **Beneficence**

One benefit of DTC testing is that it might provide accurate results about genetic susceptibility and status regarding a specific disease or condition. True positive or true negative results would enable individuals to act on that information, e.g. making lifestyle, occupational or environmental changes, which could benefit them and aid prevention of certain diseases. Though a true positive result may indicate a person has mutation and, therefore, is at elevated risk, it would not necessarily predict the time of onset or severity of a disease or condition.

Individuals also may seek the advice of their physician about possible preventive measures, such as stopping smoking or altering diet and exercise, on the basis of such results, which would be beneficial. Bringing people in to see their physician is double-edged as it requires more time, but may also open communication about genetics, genetic testing, and lifestyle choices that could provide overall benefit to individuals and their families. In this way, DTC genetic tests would be a means to a potentially beneficial end, rather than necessarily a beneficial end in themselves.

On the other end of the spectrum, DTC tests allow freedom of access without necessarily requiring a medical or health care professional. Such tests also circumvent having these genetic results in medical records, which could be accessed by insurance companies and might mean higher (or lower) premiums. Although the benefit of such freedom and testing may be questioned, it could be useful for people who do not fall into high risk categories and are, therefore, not eligible for more traditional clinical genetic testing services. Such tests could offer them feedback and insight into their genetic make-up, which might be beneficial. A few DTC genetic companies even offer personally 'tailored' products



on the basis of their tests for nutritional deficiencies or beauty products. These may be viewed as potentially beneficial by some.

The benefits of DTC genetic testing fall mostly into the possible, rather than the probable range at present, and are minimal when weighed against the potential harms. One additional benefit would be to facilitate individual autonomy and choice.

## **Respect for Autonomy**

Western society has a strong tradition of individual rights and freedoms. Respecting autonomy is the primary concept that gives moral significance to rights and freedoms.<sup>27</sup> Autonomy literally means self-rule or government, but has come to mean the ability to make individual choices and decisions. Respecting autonomy means giving people the freedom to make choices and decisions for themselves. One argument supporting the development and availability of DTC genetic tests is promotion of individual autonomy and a 'right to know' about personal genetic make-up. People should be free to access their own genetic information, and these tests facilitate that freedom and right.<sup>28</sup>

Rights do not exist in a vacuum, and they are linked to duties and responsibilities.<sup>29,30</sup> If there is a 'right to know' about our genes, it is not clear who should or would have the duty to ensure that right is upheld—the companies, primary care providers, medical geneticists, health professionals, the government? Furthermore, what would such a duty look like?

When discussing rights, there may be a practical confusion between rights and freedoms.<sup>31,32</sup> Rights are justified or justifiable claims to something and may be legal or moral, positive or negative. Freedoms indicate liberties people have or should have without interference from others. Individuals are free to obtain access to their genetic information, but this does not necessarily mean there is a 'right' to this information with a correlative responsibility placed on a third party to ensure it happens. Alternatively, people may be free to access this information because it relates to their own bodies, health and well-being, but still not have an enforceable 'right' to it. In either situation, both rights and freedoms are not unlimited.

In reality, society limits autonomy, liberty and rights when there is danger of harm or risk to individuals or groups. For example, governments limit personal freedom and liberty in the name of national security to protect the wider public. Since September 11, 2001, traveling in the United States requires additional security checks, e.g. removal of shoes and possibly being searched, in an attempt to increase national security. Individuals may claim this infringes on their autonomy, liberty and/or rights, but such claims are not generally seen as justifiable in light of preventing greater harm to the public with minimal infringement. Autonomy, freedom and rights can be and are limited for the protection of individuals, groups, and the wider public.

Respecting people's autonomy is one positive duty in health care, but it is not without limits, and it should be balanced with potential harms to the self and/or others.

## **Justice**

The ethical principle of justice highlights the issues of access, equality and fairness regarding DTC genetic testing. Obtaining these tests is limited to those with computers and internet access and the knowledge/skills to use them. People must have the financial means to order the tests (200-3000 dollars). Both factors indicate DTC genetic testing is biased toward those with greater financial means, and those with fewer financial resources may find it more difficult to utilize these tests. This bias may be viewed as inequitable and unfair, particularly if the tests offer potential health benefits.

More broadly, DTC genetic tests may consume scarce resources. Individuals receiving these test results may not be able to understand or interpret them. Because DTC genetic tests do not generally offer genetic counseling, consumers may turn to their own primary care physicians for advice.<sup>33</sup> These physicians are already under tremendous pressure, usually having only a few minutes per patient. Understanding and interpreting genetic information is often complex and time consuming, and requires specialist training. This is time taken away from other patients and duties. Primary care providers may want, or feel a duty, to help patients interpret such results, but might not have sufficient time or skills to do so. This places increased pressure on the physician and practice staff, may be an unfair burden on time and other resources, and may be unfair to other patients.<sup>34</sup>

Physicians must balance their duties and responsibilities to individual patients and to all their patients. Should not the emphasis of their practice be on caring for and curing patients, where possible, rather than interpreting unclear genetic test results? A cost benefit analysis of these tests versus other health care needs (both individual and societal) might be helpful. Are there higher priorities for using health care resources, both in finance and time?

One might ask the broader question of whether the commercialization of genetic testing is appropriate and should be allowed.<sup>35</sup> Whether the federal government has legal jurisdiction to regulate the sale of or advertising of DTC genetic tests, as well as the appropriateness of such regulation (by the Food and Drug Administration or Federal Trade Commission), has raised concern and stimulated debate.<sup>36,37</sup> It could be argued that the free market will regulate itself, and if people do not want to purchase such tests, they are not being forced so to do. Leave the choice up to consumers.<sup>38,39</sup> Yet, to make an informed choice, consumers need clear and accessible information about any test or product. Furthermore, genetics' language may communicate a higher degree of certainty to the general public than it necessarily warrants. Such language in the advertising and results might lead people to think such tests are more reliable and accurate than they are at present. Given that these tests are offered and not federally regulated, how do we protect people from potentially false or misleading commercialization? Is the motive for developing and offering these tests for the good of people or commercial profit and gain or both? Protecting the public from unfair, unjust, and improper commercialization should be a priority.

Analyzing DTC genetic tests based on the principle of justice highlights an inequitable and unfair bias toward people with the means to access and

purchase them, potential unfair burden on scarce resources, and concerns around commercialization of such testing.

## Conclusions

In examining the ethical issues of DTC genetic testing, non-maleficence was the first—and is a crucial—ethical principle in medicine, health care and society as a whole. It is a key motivation for physicians and other health professionals. Many DTC genetic tests have limited, if any, information for potential consumers on their reliability and validity, as well as unclear results or clinical significance; they are offered outside the context of the physician-patient relationship or without genetic counseling. These tests pose potentially significant harms at worst and very limited benefits at best. On the basis of unclear or false positive or false negative results, individuals may act or fail to act, which could do them harm. Whether and how potential benefits outweigh the potential harms, at least at this point in the development of many DTC genetic tests, is unclear and a cause for careful consideration.

In any society, autonomy, freedom and rights are limited if and when they pose harm to an individual or others. DTC genetic tests do pose harms to individuals and wider society. Genetics is a developing and expanding area, but we still do not understand the significance of many of the findings or potential genetic markers for susceptibility. This degree of uncertainty should evoke caution. It is important to deal appropriately with current DTC genetic tests, as the field is likely to continue to expand with even more tests offered in this manner. How we deal with these tests currently will set the standard for future DTC tests. Furthermore, the ethical considerations of justice expose the unequal and unfair bias toward those with the means to purchase DTC tests and the strain on resources which such tests are likely to be, particularly for primary care physicians.

Given that regulation seems unlikely in the near future either in the US or UK, how might we move forward? In the arena of consumer education, we should ensure that individuals are clearer about what these tests can and cannot offer and what to do in light of results. To this end, one approach would be tighter controls over the advertising and marketing of such tests. Another possible option is to involve (more) medical geneticists who are not employed by commercial firms in an attempt to verify the quality and significance of the DTC tests, which are currently unclear for many of these tests, and to verify the transparency of the process of development.

Second, the medical and genetics communities could attempt to work with companies offering DTC genetic tests to clarify and develop their ethical duties regarding the information provided about the tests, test results, their significance (or lack of), implications for individuals, families and groups, actions taken or not, and attempts to reduce misplaced fear, anxiety or security. Even better, clearer information may increase sales to the public, benefiting the companies and protecting potential consumers.

Third, medical education could be encouraged to include more information on genetics and the specific category of DTC tests to prepare future physicians

to understand, interpret and apply them, particularly since genetics is a rapidly growing and developing field. This may be difficult in the context of full curriculum, but even a relatively small increase at that stage could be beneficial in future. Already, it is commonplace for patients to bring vast reams of internet information to their physicians and ask for help in ascertaining its relevance and significance. DTC genetic tests may pose a parallel situation which will only increase with time.

At best, the physician-patient relationship is one of partnership, where the goal is to act in the best interests of a particular patient. Currently, DTC genetic tests operate outside of this supportive context, leaving individuals who access them vulnerable to the harms they pose with limited potential benefits. Given the difficulty of understanding and interpreting DTC genetic tests, the lack of clarity, clinical significance or utility of many DTC genetic tests, and dangers of commercialization, it is important to engage with and reflect on the moral implications for individuals, families, wider society, as well as physicians and other health professionals.

## Endnotes

- 1 SE Gollust, SC Hull, BS Wilfond (2002). Limitations of direct-to-consumer advertising for clinical genetic testing. *JAMA* 288(14): 1762-1767.
- 2 SE Gollust, BS Wilfond, SC Hull (2003). Direct-to-Consumer sales of genetic services on the internet. *Genetics in Medicine* 5(4): 332-337.
- 3 S Gray and OI Olopade (2003). Direct-to-Consumer marketing of genetic tests for cancer: Buyer beware. *Journal of Clinical Oncology* 21(17): 3191-3193.
- 4 GH Javitt, E Stanley, K Hudson (2004). Direct-to-Consumer Genetic Tests, Government Oversight, and the First Amendment: What the government can (and can't) do to protect the public's health. *Oklahoma Law Review* 57(2): 251-302.
- 5 C Rudebeck. 'Health: These are testing times.' *The Independent* (London), Wednesday, August 14, 2002.
- 6 SE Gollust, BS Wilfond, SC Hull (2003). Direct-to-consumer sales of genetic services on the internet. *Genetics in Medicine* 5(4): 332-337.
- 7 S Barrett and H Hall. Dubious Genetic Testing. <http://www.quackwatch.org/01QuackeryRelatedTopics/Tests/genomics.html>. Accessed on April 3, 2003.
- 8 T Agovino. 'Genetic tests to get marketing push.' *Miami Herald*, Thursday, June 6, 2002.
- 9 See the DNA Direct at <http://www.dnadirect.com/>. Accessed on March 31, 2005.
- 10 See Human Genome Project Glossary. [http://www.ornl.gov/sci/techresources/Human\\_Genome/glossary/glossary\\_p.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/glossary/glossary_p.shtml). Accessed on April 1, 2005.
- 11 See the Nugenix website at <http://www.nugenix.com/theScienceBehindOurProduct.asp>. Accessed on June 7, 2002.
- 12 See the Myriad Genetics website at <http://www.myriad.com>. Accessed on April 13, 2003.
- 13 H Pearson. 'At-Home DNA tests are here.' *Wall Street Journal*, Tuesday, June 25, 2002.
- 14 See DNA Direct at <http://www.dnadirect.com/>. Accessed on March 31, 2005.
- 15 TL Beauchamp and JF Childress (2001). *Principles of Biomedical Ethics*, 5<sup>th</sup> edition. New York: Oxford University Press.
- 16 GH Javitt, E Stanley, K Hudson (2004). Direct-to-Consumer Genetic Tests, Government Oversight, and the First Amendment: What the government can (and can't) do to protect the public's health. *Oklahoma Law Review* 57(2): 251-302.
- 17 SE Gollust, BS Wilfond, SC Hull (2003). Direct-to-consumer sales of genetic services on the internet. *Genetics in Medicine* 5(4): 332-337.
- 18 L Gordis (2000). *Epidemiology*, 2<sup>nd</sup> edition. Philadelphia: Saunders, chapter 4.

- 19 LL McCabe and ERB McCabe (2004). Direct-to-consumer genetic testing: access and marketing. *Genetics in Medicine* 6(1): 58-59.
- 20 SE Gollust, BS Wilfond, SC Hull (2003). Direct-to-consumer sales of genetic services on the Internet. *Genetics in Medicine* 5(4): 332-337.
- 21 LL McCabe and ERB McCabe (2004). Direct-to-consumer genetic testing: access and marketing. *Genetics in Medicine* 6(1): 58-59.
- 22 American College of Medical Genetics (2004). ACGM statement on direct-to-consumer genetic testing. *Genetics in Medicine* 6(1): 60.
- 23 Human Genetics Commission (2003). Genes Direct: Ensuring the effective oversight of genetic tests supplied directly to the public. London: Department of Health.
- 24 American College of Medical Genetics (2004). ACGM statement on direct-to-consumer genetic testing. *Genetics in Medicine* 6(1): 60.
- 25 Human Genetics Commission (2003). Genes Direct: Ensuring the effective oversight of genetic tests supplied directly to the public. London: Department of Health.
- 26 ED Cook (1999). Genetics and the British insurance industry. *Journal of Medical Ethics* 25: 157-62.
- 27 T Beauchamp and L Walters (1999). *Contemporary Issues in Bioethics*, 5<sup>th</sup> edition. CA: Wadsworth Publishers, chapter 1.
- 28 M Levitt (2001). Let the Consumer Decide? The regulation of commercial genetic testing. *Journal of Medical Ethics* 27: 398-403.
- 29 A Sommerville and V English (1999). Genetic Privacy: orthodoxy or oxymoron? *Journal of Medical Ethics* 25:144-50.
- 30 TL Beauchamp and JF Childress (2001). *Principles of Biomedical Ethics*, 5<sup>th</sup> edition. New York: Oxford University Press.
- 31 K Wasson (2002). How do we address human needs and wants in health care? *Whitefield Briefing* 7: 1-4.
- 32 M Lappé (1986). Ethics and Public Health. In *Maxcy-Resenau Public Health and Preventive Medicine*, 12<sup>th</sup> edition., John M. Last ed. Norwalk, CT: Appleton-Century-Croft, 1867-1877.
- 33 Morbidity and Mortality Weekly (2004). Genetic Testing for Breast and Ovarian Cancer Susceptibility: evaluating direct-to-consumer marketing (Atlanta, Denver, Raleigh-Durham and Seattle, 2003). 53(27): 603-606.
- 34 TH Lee and TA Brennan (2002). Direct-to-Consumer Marketing of High-Technology Screening Tests. *NEJM* 346: 529-31.
- 35 B Williams-Jones (2003). Where There's a Web, There's a Way: commercial genetic testing and the internet. *Community Genetics* 6:46-57.
- 36 NA Holtzman (2004). Are Genetic Tests Adequately Regulated? *Science* 286(5439): 409.
- 37 GH Javitt, E Stanley, K Hudson (2004). Direct-to-Consumer Genetic Tests, Government Oversight, and the First Amendment: What the government can (and can't) do to protect the public's health. *Oklahoma Law Review* 57(2): 251-302.
- 38 M Levitt (2001). Let the Consumer Decide? The regulation of commercial genetic testing. *Journal of Medical Ethics* 27: 398-403.
- 39 B Williams-Jones (2003). Where There's a Web, There's a Way: commercial genetic testing and the internet. *Community Genetics* 6:46-57.

---

**Katherine Wasson, Ph.D., M.Ph.**, is a Fellow in Ethics and Cancer Prevention of the Cancer Prevention Fellowship Program at the Division of Cancer Prevention, National Cancer Institute, National Institutes of Health in Bethesda, Maryland, USA.

**E. David Cook, M.A., Ph.D., D. Litt.**, is a Fellow at Green College, University of Oxford, UK, and the Arthur F. Holmes Professor of Faith and Learning at the Department of Philosophy at Wheaton College, Wheaton, Illinois, USA.

**Kathy Helzlsouer, M.D., M.H.S.**, is Director of the George W. Comstock Center for Public Health and Prevention at the Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, USA.



# ASSISTED PROCREATION: TOO LITTLE CONSIDERATION FOR THE BABIES?

CARLO BELLINI, M.D. AND GIUSEPPE BUONOCORE, M.D.

## Abstract

Recent studies have revealed much higher risks of cerebral palsy and malformations in babies conceived by *in vitro* fertilization (IVF) than in babies conceived naturally. Here we question whether parents can legitimately accept this risk on behalf of offspring. We argue that parents can expose their baby to a risk only to preserve it from a worse possibility, and this is not the case of IVF, which is not a therapeutic tool for children because when the IVF decision is taken, the child has not yet been conceived. It is concluded that procreative techniques require considerably more research before being made available to couples.

*Keywords:* in vitro fertilisation, newborn, embryo

About 1% of children in developed countries are now conceived through in vitro fertilization (IVF). In 2002 at least 8000 IVF babies were born in the UK. In the period 2000 to 2001, 21.8% of all IVF cycles were successful and 25.1% of those in women under 38 years. About 1600 pairs of twins and 100 sets of triplets were born.<sup>1</sup> The bioethical debate has been very hard in two fields. First, on the field of human reproduction control. On this argument feminist bioethicists also expressed their opinion. For instance Australian feminist Robyn Rowland contends that threats to the welfare of women have received too little attention in discussions about embryo experimentation: "Other elements of the social context that raise the potential for abuse of women's bodies are the increasing commercialisation of reproductive technologies and the increasing control by the male-dominated medical profession over the process of procreation."<sup>2</sup> Second, on the field of the debate on human right to life, since usually during or after each fertilisation cycle some embryos have to be eliminated with the aim of obtaining the desired baby or a healthy baby. Of course the supporters of the idea that embryos are persons do not accept that human embryos may be sacrificed, while those who argue that future parents' autonomy overwhelm embryos' right to live, do. Now, recent studies have revealed risks for babies conceived by in vitro fertilisation, so what is the extent of these risks, and what is the ethics of choosing a risk the consequences of which will be paid not only by those who accepts the risks but also by the baby?

## **The State of the Art**

In February 2002 a group from Uppsala, Sweden, reported a retrospective cohort study linking and comparing neurological disorders among 5,680 infants born after IVF with 11,360 matched controls. In general children born following IVF were more likely to require the services of a habilitation centre than controls, and the odds ratio for cerebral palsy was 3.7. Most of the difference was among singletons. In a study from Australia, 8.6% infants conceived by intracytoplasmic sperm injection (ICSI) and 8.9% infants conceived by IVF had major birth defects, two-fold greater than controls.<sup>3</sup> It appears that the risk of having a baby with a major handicap is higher after assisted reproduction, compared to natural conception.<sup>4</sup>

Infants who have low birth weight are at increased risk for short- and long-term disabilities and death. Three large studies were published in 2002 which showed that the use of assisted reproduction technology is an important contributor to the rate of low birth weight in the United States: there is a higher rate of low birth weight among singleton infants conceived with assisted reproduction technology than among naturally conceived singleton infants.<sup>5</sup> Children born after IVF have an increased risk of developing neurological problems, especially cerebral palsy,<sup>6</sup> and infants conceived with use of ICSI or IVF have twice as high a risk of a major birth defect as naturally conceived infants.<sup>7</sup> These studies were followed by others and many of these show that being born with IVF is more risky than with common conception.

These observations are obvious to neonatologists: multiple births and prematurity, though trivialized by the mass-media (remember the exultation for the birth of quintuplets), pose severe risks for mothers and babies. JP Relier reports that a high number of hospitalisations in his neonatal intensive care unit (Port Royal Hospital, Paris), were due to IVF.<sup>8</sup> This is not an unknown problem for neonatologists: twins have a higher risk of death and neurodevelopmental impairment than single births,<sup>9</sup> and premature babies have similar risks<sup>10</sup>: “Grand multiparity is one of the risks of assisted reproduction and can lead to preterm birth.”<sup>11</sup> The news is that even for single-embryo pregnancies conceived by IVF, the risk is higher than for normal pregnancies. A recent analysis of 25 scientific studies published in the *British Medical Journal* concludes: “Singleton pregnancies from IVF have a significantly worse perinatal outcome than non-assisted singleton pregnancies”, however, “this is less so for twin pregnancies.”<sup>12</sup> Other risks for genetic pathologies are raised: “Intracytoplasmic sperm injection may increase the risk of imprinting defects”,<sup>13</sup> and some hypotheses are given to explain this.<sup>14</sup> The debate over the safety of assisted reproduction has now spread to rare disorders affecting genetic imprinting. Andrew Feinberg of Johns Hopkins University in Baltimore, Maryland, and Michael DeBaun of Washington University in St Louis, Missouri, were struck by the fact that 4.6% of their registered patients were conceived by assisted reproduction, a high proportion given that less than 1% of the general population is conceived artificially. Most recently five Dutch children conceived by assisted reproduction have been diagnosed with retinoblastoma, a childhood cancer of the retina that occurs in just 1 in 17,000 births.<sup>15</sup>



Last but not least, a recently published book by a famous French psychiatrist provokes a reflection on the long-term risks of IVF.<sup>16</sup> Though many progresses have been done in this field in the last few years and its safety has recently improved, IVF is an in progress technique and it has to be improved before we can say it has reached the gold standard of “natural” conception. A recent paper is reassuring,<sup>17</sup> but a few concerns are still raised by some observations: ICSI technique introduces sperm into the oocyte not by fusion of the cell surfaces, but by an injection that does not take part in normal fertilisation; embryos obtained with defective sperm may inherit the sperm defect and produce humans who are in turn infertile, bypassing the natural selection of certain pathologies; oocytes of aged women are at risk for genetic problems.

## Accepting the Risks

This short review shows that the risks of IVF for babies:

- Are not negligible
- Are not due only to twin pregnancies
- Are due to techniques, but also to bypassing a natural self-defence barrier which do not allow “old” oocytes or defective spermatozoa to create a new human being.

This argument raises a question: is it right to use a technique which has such a failure rate? If a drug which could double the risk of brain damage was to be produced, it would be rapidly withdrawn. This is the case of the common Acetylsalicylic acid: as it was demonstrated to produce in certain cases a severe syndrome (Reye’s syndrome), its use has been proscribed for children and pregnant women. This is also the case of the “mad cow” syndrome: for few cases of spongiform encephalitis, cow meat use has been prohibited in Europe. Now, the problem would not be raised if we would deal with adults accepting for themselves a certain risk, or accepting the risk on behalf of their baby for his/her interest. But in this case is the baby’s interest the goal for accepting the risk? Someone may answer that the good goal is bringing him/her to the world, as he/she would not be born without IVF. But in this case, at the moment of deciding, the baby has not already been conceived. We are not benefiting an “actual baby”, but an hypothetical “future baby”; with IVF we do not improve his/her health, because he/she does not exist. In other words, IVF is not a therapy to the baby<sup>1</sup>: if being killed is the loss of “something” (life, health...) for the person, not being conceived is not a loss for him/her, because we are not taking away life from a person but from a hypothesis. The crucial point is that with IVF we are not improving babies’ state (he/she does not exist), but we are exposing them to a risk. Some may say that accepting this risk should be the woman’s choice,<sup>18</sup> though we should wonder whether this risk is consciously accepted: some gynaecologists write that “even with counselling the risks of triplets are generally underestimated by parents.”<sup>19</sup> But even if we admit that being conceived is better than not being conceived, we cannot admit superficiality and permit the use of a so far risky technique. Moreover, in several cases sterility of either male or female is not even verified on clinical parameters, so assisted reproduction (and its risks) may indeed be

unnecessary<sup>20</sup>: “A real concern is that the increased marketing of these services will lead to their use by couples who, in previous years, would have waited longer before seeking help. We can expect that such marketing will attract at least some couples who would have conceived without assisted reproduction technology had they tried to conceive naturally for a few months longer.”<sup>21</sup>

## **Prudence**

At this point one may say: “Yes, IVF is risky, it is not an improvement for the baby’s health, as he/she does not exist yet, but bringing children into life is however worthy, so we should consent to conceive children in a risky way.” We suggest that this objection may be rejected on the ground that an obligation to shield children from preventable induced impairments must be balanced against the parental right to try to create a child.<sup>22</sup> Mothers who assume drugs potentially harmful to their child-to-be are commonly discouraged, in the interest of their future child, from falling pregnant until they use them. The haste with which IVF has been made available is criticised in various papers, which highlight the need for extensive study in animal models before applying them to humans.<sup>15</sup> “Some therapies, which on any assessment are highly empirical or unproven, are being used in human subjects before they have been validated by proper cell culture experiments or detailed animal research.”<sup>14</sup>

Thus we believe that a serious reflection is necessary: it is an ethical principle that one should be exposed to a risk *only* in the name of his/her health or happiness. M. Häyry paradoxically wrote that it is immoral to conceive children as life is very frequently painful and sad. We do not agree with his pessimism, because life is not negative in itself; and, if bearing children is a risk, this risk is acceptable and worthy. However, he is right when he argues that “it is morally wrong to cause avoidable suffering to other people”; to risk somebody’s health without his/her permission is intolerable.<sup>24</sup> Thus, is it ethical to perform IVF “here and now”?

If we decided to cure an illness with a dubious substance like urine, would it be correct to say *a priori* that we refuse to use it because it is an unworthy bodily waste? Or that we must use it because the result justifies the means? Before judging its morality, it is obviously necessary to determine whether it really works and is without unacceptable side-effects.<sup>24, ii</sup>

The same approach should be used for IVF. We may accept them acritically; we may go on and make an analysis of the damages we have provoked some years later; or we may suspend it until we are sure it is absolutely safe. We suggest this last solution: the *children’s defender* of the French Parliament, Claire Brisset, has asked for a moratorium on the ICSI technique in the interest of the future children conceived by this technique. The French Ethical Committee is moving in this direction.<sup>iii</sup> The New York State Task Force on Life and the Law has suggested that physicians are “entitled to consider the welfare of any child who might be born” as a result of reproductive and genetic procedures.<sup>25</sup> Although the task force staunchly supports procreative liberty, it does, in the name of child welfare, identify circumstances that may warrant refusing prospective parents access to assisted-reproductive services. Consequently, despite a general reluctance to address well-being issues in reproductive policy,

there are precedents for defining limits to procreative liberty in the name of child welfare in public policy.<sup>22</sup> Should we not feel a sense of responsibility for the increasing frequency of brain damage, with personal and social costs, caused by these techniques?

We cannot ignore the clouds lowering over IVF. This could have a profound influence on the progress of medical sciences, not only in this high-profile field, but in others too.<sup>14</sup>

Without IVF many babies would not have been born, and many couples would have remained childless. Nevertheless the fear exists that the choice to procreate may outweigh the choice of children's health.

## Endnotes

- i However, some argue it is a therapy for the mother or for the couple. This argument is still under debate.
- ii "Perhaps we can make more sense of the choice by starting, as the HFEA seems to imply we should, from the situation of the child born through assisted conception and born sick or disabled. Has he been wronged? If he has, does this permit us to frame a rule that would bar the use of the technique in general, or bar its use for some parents who can be characterised as being at a qualitatively greater risk than baseline?"<sup>26</sup>
- iii Even the concept that the risk of conceiving impaired children may be accepted because of the possibility of choosing medical abortion is misleading, as most pathologies provoked by IVF are not detectable before birth, and because abortion is obviously not universally accepted.

## References

- 1 Tindall G: Mixed blessings: ethical issues in assisted conception. *J R Soc Med* 2003;96:34-35.
- 2 Rowland R. Making women visible in the embryo experimentation debate. *Bioethics*. 1987 Apr;1(2):179-88.
- 3 Koren G: Adverse effects of assisted reproductive technology and pregnancy outcome. *Pediatr Res* 2002;52: 136.
- 4 Anonymous: Neurological sequelae and major birth defects in children born after in-vitro fertilization or intracytoplasmic sperm injection. *Eur J Pediatr* 2003;162: 64.
- 5 Schieve LA, Meikle SF, Ferre C, Peterson HB, Jeng G, Wilcox LS: Low and very low birth weight in infants conceived with use of assisted reproductive technology *N Engl J Med* 2002; 346(10):731-7.
- 6 Stromberg B et al: Neurological sequelae in children born after in-vitro fertilisation: a population-based study. *Lancet* 2002;359:461-5.
- 7 Hansen M et al: The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilisation. *N Engl J Med* 2002;346(10):725-30.
- 8 Relier JP: *Adrien, ou la colère des bébés*. Ed J'ai lu, Paris 2003.
- 9 Shinwell ES, Blickstein I, Luskay A, Reichman B: Excess risk of mortality in very low birthweight triplets: a national, population based study. *Arch Dis Child Fetal Neonatal Ed* 2003;88:F36-F40.
- 10 Hansen BM, Greisen G: Preterm delivery and calculation of survival rate below 28 weeks of gestation. *Acta Paediatr* 2003;92:1335-8.
- 11 Greisen G: Multifoetal pregnancy and prematurity: the costs of assisted reproduction. *Acta Paediatr* 2002;91:1449-50.
- 12 Frans M Helmerhorst et al: Perinatal outcome of singletons and twins after assisted conception: a systematic review of controlled studies. *BMJ* 2004;328:261.
- 13 Cox GF et al: Intracytoplasmic sperm injection may increase the risk of imprinting defects. *Am J Hum Gen* 2002;71:162-4.
- 14 Winston RM, Hardy K: Are we ignoring potential dangers of in vitro fertilization and related treatments? *Nat Med*. 2002 Oct;8 Suppl:S14-8.

- 15 Powell K: Seeds of doubt. *Nature* 2003;422:656-9.
- 16 Bayle B : L'embryon sur le divan. *Psychopathologie de la conception humaine*. Masson, Paris 2003.
- 17 Ponjaert-Kristoffersen I, Bonduelle M, Barnes J, Nekkebroeck J, Loft A, Wennerholm UB, Tarlatzis BC, Peters C, Hagberg BS, Berner A, Sutcliffe AG. International collaborative study of intracytoplasmic sperm injection-conceived, in vitro fertilization-conceived, and naturally conceived 5-year-old child outcomes: cognitive and motor assessments. *Pediatrics*. 2005 Mar;115(3):e283-9.
- 18 Chervenak FA, McCullough LB, Rosenwaks Z : Ethical considerations in newer reproductive technologies. *Sem Perinatol* 2003;27(6):427-34.
- 19 Fisk NM, Trew G: Commentary: Two's company, three's a crowd for embryo transfer. *Lancet* 1999;354:1572-3.
- 20 Fanny-Cohen B: *Un bébé mais pas à tout prix*. Ed J'ai lu, Paris, 2004.
- 21 Mitchell AA: Infertility treatment- More risks and challenges. *N Engl J Med* 2002;346:769-10.
- 22 Parens E, Knowles LP: Reprogenetics and public policy. Reflections and recommendations. *Hastings Cent Rep*. 2003 33(4):S1-24.
- 23 M Häyry :A rational cure for prereproductive stress syndrome *J Med Ethics* 2004;30:377-378.
- 24 Thompson JG, Kind KL, Roberts CT, Robertson SA, Robinson JS. Epigenetic risks related to assisted reproductive technologies: short- and long-term consequences for the health of children conceived through assisted reproduction technology: more reason for caution? *Hum Reprod* 2002;17(11):2783-6.
- 25 Dimitriou G, Pharoah PO, Nicolaidis KH, Greenough A: Cerebral palsy in triplet pregnancies with and without iatrogenic reduction. *Eur J Pediatr*. 2004;163(8):449-51.
- 26 Ashcroft R: A fragile hold on life: the ethics of intensive care of children born through assisted conception. In *Proceedings of the Meeting of the Forum on Maternity and the Newborn of the Royal Society of Medicine*, November 14, 2002.
- 27 New York State Task Force on Life and the Law, *Assisted Reproductive Technologies*, X.

---

**Carlo Bellieni, M.D.**, is a member of the European Society of Pediatric Research and of the Bioethics Centre of the University of Siena, and Professor of Neonatal Therapy in the Pediatrics School of the University of Siena, ITALY.

**Giuseppe Buonocore, M.D.**, is Professor at the Department of Pediatrics, Obstetrics, and Reproductive Medicine, and the Institute of Preventive Pediatrics and Neonatology, University of Siena, ITALY.

# EXPLORING ETHICAL JUSTIFICATION FOR SELF-DEMAND AMPUTATION

FLORIS TOMASINI, PH.D.

All men by nature desire to know.  
(Aristotle, *Metaphysics*.)

A hospital in Scotland acknowledged this morning that it had carried out limb amputations on two patients who had nothing *physically* wrong with them. Falkirk and District Royal Infirmary said that they were both suffering body dysmorphic disorders.<sup>1</sup>  
(BBC transcript of “Complete Obsession,” a *Horizon* documentary.)

## Abstract

Self-demand amputees are persons who need to have one or more healthy limbs or digits amputated to fit the way they see themselves. They want to rid themselves of a limb that they believe does not belong to their body-identity. The obsessive desire to have appendages surgically removed to fit an alternative body-image is medically and ethically controversial. My purpose in this paper is to provide a number of normative and professional ethical perspectives on whether or not it is possible to justify surgery for self-demand amputees. In doing so I proceed dialogically, moving between empirical context and normative theory, revealing the taken for granted normative assumptions (what I call the natural attitude—a technical term borrowed from phenomenology)<sup>2</sup> that provide ethical limits to justifying the treatment of self-demand amputees. While I critically examine both Kantian responses against as well as Utilitarian responses for amputation on demand, I conclude that neither normative tradition can fully incorporate an understanding of *what it is like to be* a self-demand amputee. Since neither theory can justify the apparent non-rational desire of amputation on demand, ethical justification, I argue, falls short of the recognition that there may be a problem. To end, I introduce a meta-ethical idea, “the struggle for recognition,”<sup>3</sup> opening up the theoretical possibility of a hermeneutics of recognition before ethical justification that may be more sensitive to the problem of radical embodied difference exemplified by self-demand amputees.

## **A Strong Kantian Justification Against Amputation on Demand and its Partial Refutation**

Amputation of an organically healthy limb is anathema to me as a surgeon. The very thought of it disgusts me, when the limb(s) poses no imminent threat to life. I cannot see how it can be justified when it undermines the intrinsic worth of the human good that rests on preservation of a person's physical and mental integrity.

This hypothetical professional view expresses a standard response to a request for amputation on demand. The normative force of this view can be morally and ethically justified through Immanuel Kant, where in his *Lectures on Ethics*, he argues that we have duties towards our own body. To fully appreciate a Kantian response to the ethical problem posed by the treatment of self-demand amputees, we first need to understand the “internal goods”<sup>4</sup> of Kant's own arguments vis-à-vis duty to ourselves as embodied beings.

### *Exegesis of Kant's self-regarding duty to the body*

Kant's theory is deeply embedded in a strong moral justification of what we ought to do—rather than what is good to do or what is good to be—accounting for the obligations that we hold. Kant's notion of self-regarding duties towards self and the body, which could justify the normative view expressed above, is no exception. Indeed, in *Lectures on Ethics* he clearly states that our duty towards ourselves is not to be understood as being motivated for prudential reasons; that is, “The basis of such obligation is not to be found in the advantages we reap from doing our duty towards ourselves.”<sup>5</sup> By doing so, he shuns any psychologically consequential motivating factors; in his own words, “the principle of self-regarding duties is a very different one, which has no connexion with our wellbeing or earthly happiness.”<sup>6</sup>

Kant's moral justification for self-regarding duty lies in his deeply held view of the intrinsic value of human worth. So, accordingly, “the man who has violated the duties to himself has no inner worth.”<sup>7</sup> And more strongly, “Even if all his amenities of life are sacrificed, maintenance of the worth of humanity makes up for the loss of them all, and sustains approbation, and *if all else is lost we still have an inner worth*” (italics mine).<sup>8</sup>

If Kant's justification for self-regarding duties towards oneself and the body lies in his view of the intrinsic value of human worth, what does he mean by this? There are two intimately related answers: metaphysical and psychological principles that found the logic of self-regarding duty and another in which such reasons justify a number of applied ethical examples that Kant himself uses—for example, suicide, care of one's life, sexual propriety and even a passing remark about selling parts of the body itself!<sup>9</sup>

The metaphysical principles that support his idea of self-regarding duty to the intrinsic worth of oneself and body are the categorical imperative and freedom.

In *Lectures on Ethics*, Kant often moves from the specific to the universal, from human worth to a respect for humanity in general. This move can only be

fully understood through the *Groundwork of the Metaphysic of Morals*, where he argues that the content of our duty is determined by the categorical imperative; for example, we should always treat humanity, whether in our person or in that of another, as an end, and never a means only.<sup>10</sup> This implies a fundamental symmetry of moral recognition—because we recognize the intrinsic ideal of human worth in our selves, we have obligations to ourselves *qua* humanity. In other words, what is intrinsically degrading to us is also intrinsically degrading to humanity.

The primacy of freedom is another metaphysical principle that he mobilizes to show up the illogicality of both the mind-body problem and the contradiction of human worth in any act that is intrinsically degrading. This is nicely illustrated in Kant's invective against suicide.

The body is the total condition of life... and since the use of our freedom is only possible through the body, we see that the body constitutes part of our self. So far, then, as anyone destroys his body, and thereby takes his own life, he has employed his choice to destroy the power of choosing itself... If freedom is the condition of life, it cannot be employed to abolish life.<sup>11</sup>

As well as providing metaphysical reasons for respecting human worth for itself, he gives both positive and negative psychological reasons for why we should value this. A positive reason for preserving human worth is that it leads to self-esteem, rather than happiness and wellbeing. Again, according to Kant, "The *principium* of self-regarding duties does not consist in self-favor, but in self-esteem."<sup>12</sup> If a positive reason for maintaining human worth is self-esteem, then a negative psychological reason for not wanting to see it degraded and violated are the reactions it brings up in us: suicide overwhelms us with "horror," while sexual improprieties prompt a visceral "disgust" response.<sup>13</sup>

Having provided some of Kant's foundations to self-regarding duties towards ourselves, in which the body is an indivisible part, I will now critically examine how this may be extended to a line of argument as regards the treatment of self-demand amputees. From here on in I shall use the following abbreviations: SDAm refers to self-demand amputation; SDA refers to self-demand amputee; SDAs/ SDA's/ SDAs' will refer to self-demand amputees/ self-demand amputee's/ self-demand amputees'.

### *A Kantian response to SDAm*

It is fair to say that Kant, and most Kantians, would probably refuse SDAs the treatment they ask for, on principle. This is because amputating an organically healthy limb violates a self-regarding duty towards our self and our body. Since self-regarding duties involve a preservation of an intrinsic human worth, an amputation of this sort would be intrinsically degrading to human worth. A Kantian could elaborate what preserving human worth means in relation to our corporeality. This may be achieved by accepting Rom Harré's "organic integrity"<sup>14</sup> amendment, in which he further specifies what preserving human worth is in relation to our embodiment. Even so, given this further Kantian gloss, SDAs would still be refused amputations on the grounds that such a desire clearly contravenes any ideally orientated sense of what it might be to preserve a human organic integrity.

If pushed for further justification, there are two main arguments that a Kantian might use to deny SDamp. While one argument is purely philosophical, i.e. preserving organic integrity, and the other is quasi-psychological, i.e. preserving human worth, both rely on a strong rational justification of a human ideal. I outline both arguments respectively.

If one accepts a human ideal of organic integrity, then violating this is clearly not rational in terms of Kant's categorical imperative. That is, the personal desire to have a leg amputated is not sufficient for it to be universalized as a good human end in itself. This resonates with a practical worry: if SDAs are aware that choosing to have a healthy limb off is not an ideal end in itself for human-kind, how could they sanction their non-rational desire for an amputation without acknowledging that it might be a *mere* means to further non-rational desires, say, having another leg off? (This is one of the worries professionals that sanction such amputations share!)

Another argument inspired by Kant, where one might infer his implicit disapproval of amputation on demand (if he had encountered it), rests on his remarks in "Of Suicide," where he provides an important caveat for amputations that preserve life and organic integrity. Kant employs an implicit and indirect notion of harm when he says, "Thus, a man can have his foot amputated, for example, in so far as it impedes him in life."<sup>15</sup> Given the context of his remarks here, it is fair to say that what he probably means by "impedes" him in life is either it impedes him in life per se, perhaps directly threatening life, or it impedes him in the course of his life. If this is what he means, then in both senses amputation on demand is wrong. Firstly, it is wrong because amputations of this kind are not at all necessary operations to preserve life—it is a psychological harm that *may* only indirectly lead to physical self-harm. Secondly, it does not impede the course of life. Indeed, quite the reverse: it would have probably appalled Kant, as SDamp is tantamount to voluntarily choosing disablement! Furthermore, if medical professionals felt psychologically compelled by SDAs who threaten to self-harm, this could reasonably be construed as constraint on professional autonomy, upon which basis authentic ethical choice to offer a medical resolution rests.

There is a further illogicality that a Kantian may draw upon to justify a refusal to treat SDAs. Since Kant states in "Of Suicide" that the body represents the embodied possibility of freedom, its destruction is illogical because it violates this very possibility. Although this is clearly evident through a suicidal act, it is an argument that could be extended to a SDA urge for elective disablement. That is, while voluntary disablement obviously does not threaten the very potentiality of freedom, it severely hampers human freedom as a capacity for living a fully active physical life. Whereas for a Kantian this would offer a compelling reason not to consider amputation on demand, this sort of reasoning also plays a part for those medical professionals who might consider such an operation—not least because it involves professional complicity in performing an, arguably, non-necessary operation on a patient who has voluntarily elected to have limb(s) removed.

As well as mobilizing philosophical arguments for the non-rationality of amputation on demand, Kantians might also draw on psychological reasons, namely, arguments that cast doubt on the psychological rationality of the



desire to have organically healthy limbs amputated. For Kantians amputation on demand is a violation of human worth and dignity. It is an act that shows little respect for an ideal human worth and as such provokes strong negative emotional responses, characterized by Kant as disgust. Interestingly this disgust reaction is mirrored in many people who first come across the condition because it violates their own taken for granted sense of bodily integrity. Even professionals who choose to treat SDAs sometimes refer to the desire with pejoratives such as “mutilation” to convey their implicit personal feelings of disgust.

Again, if further psychological justification were necessary, a Kantian could respond by saying that SDAmP is wrong because, rather than frustrating a consequentially driven notion of well-being, it damages self-esteem operating at the heart of our internally driven sense to preserve human worth. From a Kantian perspective, then, SDAmP is prompted by a lack of self-esteem in integrity of human worth, which is ultimately an affront to the dignity of humanity *qua* respect for the moral law.

Having looked at some Kantian responses to SDAmP, I would like to look at some of the taken for granted normative assumptions—which I will refer to as the natural attitude—that pervade this perspective, critically assessing whether or not it is sufficiently sensitive to the ethical phenomena that arise from the lived world of SDAs.

### *Assessing the natural attitude of the Kantian response to SDAmP*

Before moving beyond the natural attitude of the Kantian response to the SDA problem by exposing conceptual assumptions about embodiment and human worth, I would first like to outline the advantages for a strong professional justification denying treatment.

Because Kantian approaches to duty regarding the body rely on an *ideal* view of embodiment (a normalized view of organic integrity and intrinsic human worth), any *deliberate* failure to respect this can be shown to be a non-rational desire. Moreover, such an argument is based on a very deep and intuitive sense of what it is to be *wholly* human; that is, to elect to have a leg off is not only morally reprehensible in a rational sense because of its very incomprehensibility and illogicality, it is also counterintuitive in a deep emotional sense: self-mutilation filling most people with a powerful feeling of disgust. While disgust may, on the surface, seem a simple negative emotion, it is a deeply Janus faced form of emotional recognition; the visceral disapproval projected towards the other is only possible through an introjection of sympathy towards a sense of organic integrity experienced at the heart of the self.

Summing up, any Kantian-added ethical justification for why voluntary amputation is wrong simply supports the natural attitude that able-bodied organic integrity represents. There are, of course, a number of important caveats that, once again, fit comfortably with the natural attitude; that is, amputations are sometimes necessary to save life and preserve organic integrity. Notwithstanding the Kantian precedent to approve of life saving and preserving operations, no other precedents exist in the Kantian canon to justify elective amputation. Such views are aligned with common sense, and they are

also enshrined in a very strong reading of medical professionals' interpretation of the Hippocratic Oath. Thus doing "no harm" can be understood as preserving the *overall* organic integrity and human worth that is psychologically entangled with this material ideal. In conclusion, the common sense view is premised on an ideal view of the preservation of organic integrity of human beings, which because of its strong medical and ethical justifiability, understandably leads the majority of medical professionals to refuse treatment.

The problem with the Kantian view is that it cannot account for embodied difference—a view of embodiment that significantly deviates from what we normally consider organic integrity and human worth to be constitutive of. This is because Kantians have already assumed that all human beings naturally conform to certain identity norms, whether this is expressed physically, in terms of self-regarding duties towards preserving life and body, or psychologically, in terms of how the preservation of such norms should make us feel in ourselves. While this seems eminently sensible for most people who are orientated to this unspoken human ideal, it denies the very possibility of SDAs and their lived experience of not existentially belonging to an able bodied norm. Kantians have no way of understanding authentic embodied difference, other than through moral disapproval. Since they assume organic identity and human worth must conform to a stereotypically ideal type, Kantians have no way of dealing with SDAs who might just express human worth and integrity in a completely alternative way:

Inside I feel that my legs don't belong to me ... I don't want to die, but there are times that I don't want to keep living in a body that doesn't feel like mine ... My legs are extraneous. They shouldn't be there; it doesn't feel right that they extend beyond where I feel my body should end.<sup>16</sup>

The desire that I have is for an amputation of above the knee of the right leg ... It's still the reality that it seems like my body stops at mid-thigh my right leg. It's the rest of not me. [sic]<sup>17</sup>

In my view such expressions of embodied difference have to be treated seriously because if SDAs *really need* amputations to regain a sense of belonging to and in themselves, then the act of sanctioning and performing surgery is justifiable on perfectly rational grounds of restoring their own sense of organic integrity and human worth. This cannot easily be dismissed if there really are a plurality of body-images and identities that defy a common sense view of the human ideal. So, if we accept that there may be another way of understanding organic integrity that leads to plurality of body identities, then it may be justifiable to treat SDAs. This is a view understood by a consultant surgeon and psychiatrist (respectively) who have freely chosen to operate on such patients:

It is quite a difficult change of view on my part really—to remove a healthy limb is anathema to a surgeon, but I've become convinced over the years that there is a small group of patients who genuinely feel that their body is incomplete with the normal four complement of limbs.<sup>18</sup>

In sum, if we suspend the natural attitude about what organic integrity ought to be constitutive of—an argument strongly justified by Kantians who can rule out SDamp on principle—then it might be possible to find other forms of medico-ethical justification, perhaps utilitarian ones, to provide professionally defensible reasons for treatment. It is to a utilitarian ethical justification that I turn next.

### **A Medium Strong Utilitarian Justification for Amputation on Demand and its Partial Refutation**

There are a small number of SDAs who genuinely feel incomplete with the usual complement of two arms and two legs. It is my belief that by carefully distinguishing between those who are bona fide SDA patients and those who are not, we, as professionals, are in a position to offer the treatment they need. We have to review such decisions, on a case by case basis, making sure that the benefits of carrying out such operations outweigh the harms.

This hypothetical view represents a small minority of medical professionals who believe there is a case to be made for amputation on demand. The normative force of this view can be morally and ethically justified through an understanding of contemporary utilitarianism where classical as well as modern restatements have been significantly revised in a quest for a universal altruism. Again, to fully appreciate contemporary utilitarian responses to the ethical problem posed by the treatment of self-demand amputees, we first need to understand the “internal goods” of such arguments.

#### *A brief exegesis of universal altruism and its utilitarian defense*

Universal altruism, in its very simplest form, is based on the belief in an impartial concern for all sentient beings, always: balancing good over perceived harm to effect maximum satisfaction of overall good. This involves universalizing what is good as opposed to what is harmful, rationally discriminating between ethical priorities as well as ensuring equality *either* on the basis of like interests (interest utilitarianism)<sup>20</sup> *or* on the grounds of perceived duties towards different categories of moral subjects (liberal utilitarianism).<sup>21</sup> There are at least three core utilitarian tenets operating at the heart of universal altruism:

- The first concerns utility, the aggregative rule of satisfying interests and/or needs—interest utilitarianism requires the greatest satisfaction of interests,<sup>22</sup> while liberal utilitarianism operates on a need-satisfaction principle.<sup>23</sup>
- The second involves a balancing of priorities—prioritizing major interests over minor interests in the case of interest utilitarianism<sup>24</sup> and/or defending a principle of hierarchical needs in the case of liberal utilitarianism.<sup>25</sup>
- The third implies an important difference in understanding altruistic

priorities—interest utilitarianism is based on a radical form of equality,<sup>26</sup> while liberal utilitarians are more concerned with a principle of autonomy<sup>27</sup> that discriminates between beings on the basis of moral standing.

While on the surface there are some significant similarities in the first two tenets, there is a crucial difference most clearly expressed in the third core idea. If one is an interest utilitarian, like Peter Singer, the primary motivating principle—equal consideration of interests—has its roots in the classical utilitarianism of Jeremy Bentham;<sup>28</sup> whereas, if one is a liberal utilitarian, like Matti Häyry, then the working out of a need satisfaction principle is going to depend on a liberal interpretation of duty (see J. S. Mill for example<sup>29</sup>). This has important consequences for practical approaches to universal altruism. While interest utilitarians prize egalitarian reasoning over everything else, rallying against the illogicality of perceived differences implicit in gender distinctions, racism and speciesism, liberal utilitarians offer fine distinctions between sentient beings and their perceived levels of awareness and autonomy, upon which they base a graded system of moral obligation vis-à-vis a defense of duties and rights. As a consequence, liberal utilitarians find a stronger ethical justification than interest utilitarians by concentrating on the notion of needs and liberal interpretations of duty.

To avoid confusion between the two theories, I will only provide a finer distinction when assessing *further* justifications of SDAm where the differences between applied ethical outcomes are more evident. In providing further justification, I consider a liberal utilitarian argument. In the meantime, I will give a more general interpretation in the next sub-section of how SDAm may be defended from a utilitarian perspective of universal altruism. So, having provided a very brief sketch of some contemporary utilitarian foundations to universal altruism, I critically examine whether this helps us to decide whether or not the treatment of self-demand amputees is ethically justifiable.

### *Assessing the universal altruist response to SDAm*

One major practical advantage a contemporary utilitarian defense of universal altruism has over a Kantian approach in its applicability to SDAm is that it does not automatically, as a matter of principle, rule out the possibility of such amputations. This is because there are no ideal presuppositions about human-worth and organic integrity, which prejudice medical professionals of a utilitarian persuasion from taking on any such unusual cases of amputation. For utilitarian universal altruists, ideal presuppositions about human worth and organic integrity do not play a prominent role in ethical decision-making about amputations, because amputation is a decision that has to accord with the first utilitarian tenet: utility and the aggregative satisfaction of interests and/or needs. In medical terms this may translate as a decision to minimize overall harm, where *overall* harm is a contextually significant judgment about how to best satisfy a patient's interests and/or needs in any given situation.

At first glance this may provide a basis upon which to justify the more controversial forms of amputation required by SDAs. To understand this within the parameters of minimizing overall harm, it is useful to provide a hypothetical example:

Terry, a self-demand amputee, is given a single above the right knee amputation based on the judgment of medical experts who believe it will restore his sense of self and bodily integrity, quelling the considerable psychological harm of having an amputee identity disorder. An amputation of an organically healthy limb totally alleviates the psychological harm, restoring his sense of self and bodily integrity. The amputation thus gives Terry a renewed sense of meaning and purpose to his life, while vanquishing any potentially life-threatening urges Terry had about self-harming and forcing surgeons to treat a traumatic injury that may have led to death rather than the desired amputation. Unfortunately Terry is now an amputee, leaving him physically harmed and permanently disabled.

While we might say that the surgery did Terry *some* harm, in the sense that he has elected to become disabled, we could also logically argue that the amputation did him “no *overall*” harm. This is because we are using the notion of harm in different senses. In the first sense, *some* harm, we are implicitly appealing to an ideal state, since, obviously Terry is harmed in some way because *ideally* it would be better if he were not an amputee at all. Arguably, this option is not available to SDAs, because their obsession to become amputees and realize their alternative body-identity is not preventable by any other form of medical treatment. Provided this is a true fact, we may more usefully employ this second sense of harm, *overall* harm, to understand Terry’s case—harm in this sense being a way of satisfying overall interests and/or needs of a patient in any given medical situation. It is not the case, therefore, that Terry is any worse off than he otherwise would have been had he not had the amputation; indeed, Terry is cured of his psychological obsessive compulsion without suffering severe disablement (a bilateral amputation), quelling the urge to possibly self-harm and become a potential danger to himself.

From this perspective the utilitarian altruist seems more sensitive to the normative *context* of SDAs, attending to the possible reality of a radical embodied difference, where an *ideal* of organic integrity and/or intrinsic human worth does not become the limiting criteria to refuse treatment. Predictably, however, there are a number of further explicit and/or implicit principles that such an approach relies upon in order to justify controversial amputations of this sort. I call these “natural attitudes” because, while they offer further explicit ethical justification, they also present limits to understanding, the roots of which are taken for granted and insufficiently explored. It is to these further justifications and natural attitudes that I now turn. Here any further utilitarian justifications are grounded in liberal utilitarianism.

### *Assessing the liberal utilitarian response to SDamp*

Any apparent claim to satisfy the greatest satisfaction of needs, upon which an overall conception of harm can be understood, relies on a series of further professional procedures that ensure medical and ethical best practice.

Given that a liberal utilitarian could possibly countenance the possibility of this very controversial and unusual form of amputation, the greatest challenge for professionals of this persuasion is to assess and justify whether their patients *really need* this operation. This is, I believe, where the difficult challenge exists for the liberal utilitarian. There are at least two major obstacles. The first involves a possible confusion that may exist between *perceived* and *actual* harm. To put it bluntly, what a SDA says about what they need cannot be taken as the primary form of justification for amputation without making expert professional judgment obsolete (other than in the technical sense of carrying out a successful amputation). If this were the case, anybody proclaiming an urge to have a limb off could demand that a professional satisfy his or her desire. This sense of desire, desire as consumer demand, is blatantly absurd—not least because performing such operations would, potentially at least, leave a number of people permanently disabled who say they are a SDA but actually are not. This could open the way for serious accusations of professional negligence through wrong diagnosis and treatment, either leaving mentally competent patients regretful about acting from wrong desire, having had an elective amputation and changing their mind, or by encouraging mentally incompetent patients in their delusion to identify with amputees by becoming one themselves. So, professionals who are courageous enough to accept the possibility that this might be the right course of action in a select number of cases need a rigorous medical and ethical defense to support a rationale to justify amputation on demand.

Part of the judgment of *really needing* a voluntary amputation has to rely on sound diagnosis. Until quite recently in the United Kingdom, when few such operations were sanctioned at Falkirk Royal Infirmary, the diagnosis of SDA involved having enough discriminative understanding to recognize it as a genuine medical condition that left professionals with limited medical options. In the words of a consultant psychiatrist:

I think in this sense it is a psychological obsession. These people are not mentally ill ... They're not hearing voices, they're not deluded. It's not as if some force is telling them to have their limb off and following their paranoid delusion to do that. If that were the case then they would be psychotic ... neither is the cause of the problem neurosis, depression or sexual fetish ... When a person wanting an amputation comes to a psychiatrist the options are fairly limited. On the one hand you could give them drugs to see if that cheers them up, or they're psychotic, give them an anti-psychotic. As we've said, they're not psychotic so that's not going to be of any use. Counseling, psychotherapy, cognitive behavioral therapy helps them focus on the positive things in life and get away and forget about the negative things, the wanting to have an amputation. Unfortunately talking treatments don't make a scrap of difference in these people. They are so fixed ... in a sense so locked in to what they want for themselves that you can talk till the cows come home and it won't make a scrap of difference. They're still going to want the amputation and I know for a fact, certainly in the case of Gregg.<sup>30</sup>

A competent medical diagnosis has a number of important ethical implications that further justify the case for amputation on demand. Minimally speaking, assessing mental competency has implications for a principle of autonomy (see liberal utilitarianism).<sup>31</sup> In other words, by pronouncing a SDA mentally fit enough, professionals are in effect identifying them as autonomous persons who are aware of their own capacity to make ethical judgments and moral choices. In practice this means that their needs to have their limb(s) amputated must be taken much more seriously—more so in fact than someone who is mentally ill—not least because if they are psychotically deluded, this would not be what they really needed.

Paradoxically their obsessive nature about what they need in combination with their *de facto* psychiatric mental competence makes them curiously well informed when it comes to signing the informed consent form. In the words of an experienced general consultant surgeon who has taken on SDAs:

The patients that I've seen, I've had psychiatric reports on them and the psychiatrists have indicated that these patients perfectly understand the consequences of what they're requesting. They are probably the best informed patients that I have ever had to deal with.<sup>32</sup>

*Bona fide* SDAs who have had amputations all report that they feel considerably better for having elective surgery to remove an organically healthy limb—ironically—because the amputation restores *their* sense of organic integrity and human worth. Given this fact and their awareness of what it is they need, there are still serious problems justifying such operations. Oddly enough, the reason lies at the very heart of medical practice which assumes that “doctor knows best”, the paternalistic assumption behind informed consent. Informed consent assumes that the doctor fully understands the condition of their patient and that this understanding, once communicated and understood by the patient, leads them to freely give their consent to whatever medical procedure is deemed necessary. Not only does it imply an implicit “expert-lay divide”<sup>33</sup> where the doctor always knows more than the patient about their condition, it also assumes a “deficit model of understanding”<sup>34</sup> where the doctor simply informs the patient until they freely give their consent. In effect SDAs reverse the principle of informed consent by “demanding” that medical professionals satisfy *their* needs, based on their “superior” subjective, first-person perspective of what is wrong with them. In this way the subjective interiority of the patients’ own lived world and understanding of their own condition throws into stark relief the lack of available objective understanding of what this medical condition actually is. Not only does this reverse the implicit “expert-lay divide” that is normally operative in doctor-patient relationships, but it eschews where the deficit of understanding actually originates—lack of understanding comes from the doctor not the patient.

Understanding runs deeper than a mere objective diagnosis, since subsequent treatment recommendations require medical doctors to recognize, at a very deep personal level, that the desire to have limb(s) off is a rational desire for a human being to have. This poses a problem for more unusual medical treatments like SDAm. The inability to recognize the significance of a patient’s problem can either lead to downgrading the significance of operations

and their prioritization, or it may lead doctors to doubt the veracity of the worth of any objective medical judgment whatsoever in the even more controversial case of SDamp. In the case of the former for example, the scheduling of gender reassignment for transsexuals is often given a low priority amongst other more standard National Health Service procedures. Whereas the latter provides a good reason to refuse SDAs any treatment, lack of understanding remains a key issue for those willing to recommend treatment. In a consultant psychiatrist's words:

When I met Gregg it was very clear that he was very sane and there was absolutely no question that he was thought disordered in any way or mentally ill or sexually bizarre. He wasn't, he was an ordinary, nice man who wanted his limb off. It seemed to me at the time that it was incongruous for a nice, rational man to want his limb off. It seemed very strange. I couldn't quite, to be honest, I couldn't understand it.<sup>35</sup>

In a strong justificatory sense, needing to have such a radical operation can only be grounded in this deeper form of understanding where diagnosis conforms to some sort of empathetic recognition of what it is to be *wholly* human, with desires that we share with other human beings. Now, if it proves difficult to comprehend from the perspective of consultant psychiatrists and surgeons who have some understanding and sympathy for the plight of such unusual patients, one can better understand why professionals unfamiliar with this condition will respond negatively, refusing treatment by upholding the natural attitude. The heart of the matter lies prior to ethical justification; it is, first and foremost, an issue of recognition, a recognition that depends on *some* understanding *what it is like to be a self-demand amputee*. It is from understanding as recognition, misrecognition and non-recognition that further ethical justification arises.

The ticklish issue of recognition also arises in assessing the treatment options for such patients where a hierarchy of need satisfaction might discriminate who may and who may not be treated, the recognition of a more basic need satisfaction taking priority over a less basic need satisfaction. For example, in one case a consultant psychiatrist who had approved an amputation of a right leg above the knee on one SDA, had refused to approve a double above knee amputation on another SDA on the grounds that the request was too extreme. In his words: "To be rid of one leg is, you know, O.K. To be rid of two is a disaster."<sup>36</sup>

While this may seem a plain contradiction when both patients had been correctly diagnosed as being bona fide SDAs, it can *plausibly* (although *not necessarily*) provide professionals of liberal utilitarian persuasion an opportunity to introduce a hierarchical needs satisfaction principle as a basis to discriminate between single and bilateral amputations. In other words, the need to satisfy amputation on the grounds of the psychological trauma that a patient experiences by not feeling that they belong to their body outweighs the need satisfaction of remaining able-bodied *unless it involves a double amputation that leads to severe physical disability*. This is clear from a further explanation provided by the consultant surgeon:



Physically it is perfectly feasible to do bilateral amputations, but I think from a surgeon's point of view it's really asking a bit much to take this on. I agree that there is an irrepressible logic that if you're prepared to remove one leg why shouldn't you be prepared to remove two if the patient has this particular problem, but to a surgeon that's a very difficult concept to take on board.<sup>37</sup>

In practice it seems that while amputation may be considered for one limb—the psychological need for amputation taking priority over the physical need to be able bodied—this hierarchy of need reverses when a double amputation is requested. Although this may seem intelligible to a liberal utilitarian, the reason given not to offer a bilateral amputation is based on a refusal to recognize the SDA's need because it contravenes the recalcitrant professional identity of a surgeon who must draw a definite line at what is and is not acceptable in the balance of minimizing overall harm. In some ways this justification, almost definitely based on a liberal interpretation of the Hippocratic Oath, is not altogether different from more conservative surgeons who refuse SDA treatment on principle! However, unlike the Kantian who offers an ethical justification for *non-recognition*, the utilitarian who is brought to the brink of his or her professional “comfort zone” where justification runs out, *refuses* to recognize the SDA once they ask too much. Prima facie, while the utilitarian argument is more sensitive to some kinds of amputation on demand, they eventually fail once recognition can no longer be squared with the ethical justification that professional identity demands.

This kind of reasoning exposes the limits of the professional identity and the ethical justification needed to secure it. Is there any way to progress beyond giving a complete medical and ethical justification for self-demand amputation? Before answering this question, I want to reprise arguments given.

## Reprise

I have critically examined two normative ethical justifications for the treatment of SDAs.

The first justification is Kantian, and refuses treatment per se, on the grounds that SDA intrinsically degrades any ideal of human worth through compromising any recognizable sense of organic integrity. While this understandable reaction is perfectly justifiable within its own ideally orientated terms of reference, it discounts the contextual evidence that SDAs may represent an altogether different sense of human worth and organic integrity. Kantian ethics cannot, it seems, deal with embodied difference. The Kantian argument for not treating SDAs is ultimately a justification for the *non-recognition* of embodied difference.

The second justification is a utilitarian defense of universal altruism. While this seems much more promising than Kantian arguments in dealing with the practical context of embodied difference, it is much more difficult to justify whether or not SDAmP is ethically legitimate. To be more precise, while it delivers a medium strong ethical justification for such amputation through principles such as greatest need satisfaction, hierarchical needs and

autonomy, it raises a number of deeper questions about the limits of professional justification. Utilitarian justifications eventually fail once the recognition of the extremity of the demand outstrips the ethical justification that the professional identity demands. This leads to *refusal* of recognition.

What the utilitarian ethical argument shares with Kant is that it cannot square justification with recognition. In other words, there is a tension between ethical justification—which cannot completely escape the need to couple an ethical ideal with what the human form ought to represent—and recognition that may be more accepting of embodied difference for what it is. The questions that now arise are: Is recognition of embodied difference possible without ethical justification? And, is recognition without normative ethics a possible alternative in maintaining a professional identity when treating SDAs?

### **Recognition Without Ethical Justification?**

The failure for complete ethical justification lays in the struggle for recognition, an ultimately hopeless struggle where doctor and SDA cannot wholly escape what Georg Wilhelm Friedrich Hegel has called the Master-Slave relation.<sup>38</sup> The professional doctor-SDA relation is like Hegel's master-slave relation precisely because the master (doctor) refuses to fully recognize the slave (patient), denying him the affirmation of his full humanity<sup>39</sup> and thus ultimately refusing to acknowledge the slave's perceptions (of his own embodied difference) by forcing his own view of the world on the other (his view of what normal embodiment ultimately represents). Hence, recognition is achieved through a "violent" struggle that fails to have any convincing justificatory validity. As Alexandre Kojève puts it:

The relation between Master and Slave ... *is not recognition properly so called...* The Master is not the only one to consider himself the Master. The slave also considers him as such. Hence, he is recognized in his human reality and dignity. But this recognition is one-sided, for he does not recognize in turn the Slave's human reality and dignity. Hence, he is recognized by someone whom he does not recognize. And this is what is insufficient—what is tragic—in his situation... For he can be satisfied only by recognition *from one who he recognizes as worthy of recognizing him*<sup>40</sup> (italics mine).

To make the parallel with the dilemma of non-recognition and/or mis-recognition, let me juxtapose and analyze a quote from a SDA:

The desire that I have is for an amputation of above the knee on my right leg. Now that's very specific and I have no way to understand it, comprehend it or to explain it to anybody in the world. Let alone explain it to myself and you sitting out there think it is nuts, I'm sitting in here thinking it is nuts, but I can't help it.<sup>41</sup>

As in the Master-Slave dialectic, recognition mutually reinforces a normal and deviant identity here. By recognizing the normality of wanting to be able-bodied, Gregg is reinforcing what is normal at the expense of what is not—

projecting the reality of what is normal and what is not, the domain where the doctor (master) has ultimate control, while at the same time introjecting the abnormality of his subjective interiority. The real tragedy here is that recognition is not reciprocated, either not at all, by doctors who refuse treatment (non-recognition), or only partially, by doctors who will only reluctantly consider single limb as opposed to bilateral limb amputations (limited recognition).

The problem of recognition is twofold. It is first a problem of diagnosis and perceived harm. Professionals only have a moral obligation to treat SDAs if they recognize SDAm as being a legitimate procedure to minimize *overall* harm. This rests on harm being an evaluative (rather than a naturalist) concept; embodied difference of a SDA is not in dialectical opposition to normality but in *relation* to its classifiable difference. The evaluation of classifiable difference from a human norm or ideal involves a deeper form of recognition still—the partial recognition of *what it is like to be a SDA* and whether or not it is possible to imagine radical difference as an elective amputation. It is this kind of hermeneutic recognition that precedes normative ethical justification. Understanding in the act of normative justification is actually a defense of our own reality and its congruence with a projected human ideal. Its rationality lies in the symmetry of recognition, where normality and ideality reflect one another in what we share with countless others. By contrast, the origin of hermeneutics engagement entails an asymmetry of recognition, where we have to project into a world of meanings outside our own immediate subjective sphere of reality.<sup>42</sup> Hermeneutic understanding presupposes another's alternative reality, which must be something unknowable from the vantage point of subjective interiority. A hermeneutic engagement, or hermeneutics of recognition as I call it, requires attentiveness to alterity, or as Hans-Georg Gadamer so beautifully puts it, "Coming to an understanding ... presupposes that the partners are ready for it and that they allow for the validity of what is alien and contrary to themselves."<sup>43</sup> Such understanding is difficult but possible through our shared soma, where, for example, corporeal identification is grasped indirectly through other more socially identifiable and less alien conditions. For instance, that which prepares one consultant psychiatrist "to extend to that, which is more alien and contrary to him" is a prior recognition posed by transsexuals, providing the all important lateral bridge to be ready to understand the more alien urge for SDAm. In his words,

Certainly when I first heard of people wanting these amputations it seemed bizarre in the extreme but then I thought well, I see transsexuals and transsexuals want healthy parts of their body removed in order to adjust to their idealized body-image and so I think that was the connection for me.<sup>44</sup>

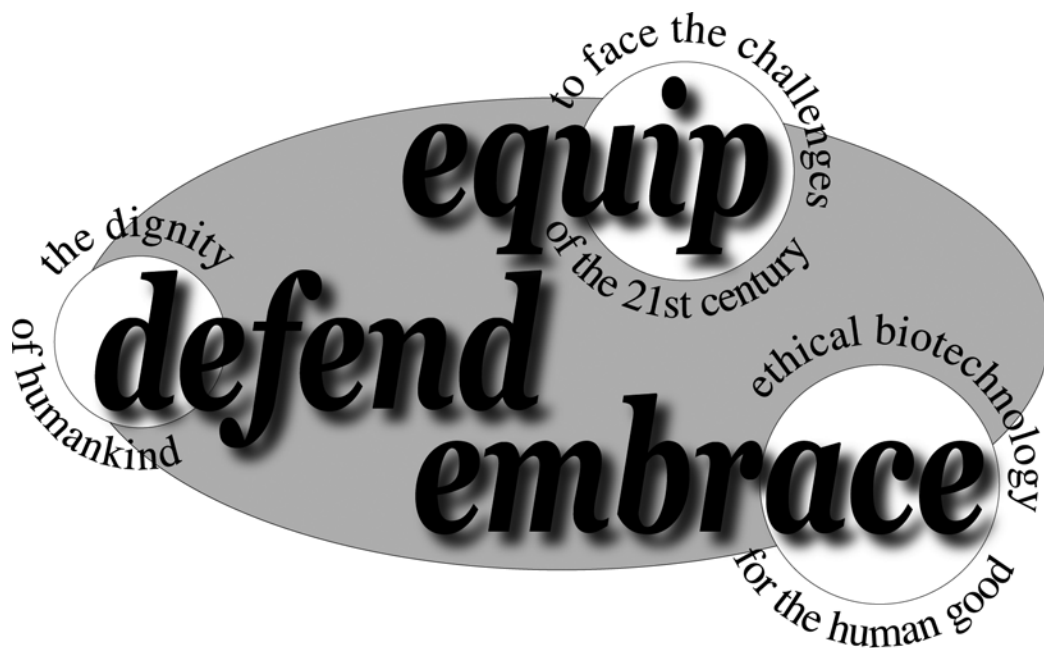
Interestingly the recognition of some sense of shared humanity, no matter how different, spurs on the search for ethical justification. The real dilemma bites when the recognition of authentic embodied difference eventually outstrips the normative justifications that professional ethics needs. Since normative explanatory justification remains the benchmark of professional identity, any serious transgression is not practically possible without leaving medical professionals open to accusations of un-professionalism. Those who are

willing to “push the envelope” of professionalism are still limited by the desire to maintain a credible professional identity. So, even though there is a form of hermeneutic recognition before ethical justification, professionalism tends to err on the side of being ethically normative and conservative. This does not mean that the right thing to do can always be justified, let alone completely, in the way that maintaining a professional identity demands!

## Endnotes

- 1 Body Dysmorphic Disorder is actually a wrong classification. For this reason such patients with this rare obsession have been classified as having an amputee identity disorder. Instead of this technical term, I use the common description of self-demand amputation throughout. See, e.g., Gregg M. Furth and Robert Smith, *Amputee Identity Disorder: Information, Questions, Answers and Recommendations about Self-Demand Amputation* (Bloomington, IN: Authorhouse, 2002), p. 5.
- 2 The term was first characterized by Husserl. See, e.g., Edmund Husserl, *Cartesian Meditations*, trans. by W. R. Boyce Gibson (London: Allen & Unwin, 1931).
- 3 See, e.g., Axel Honneth, *The Struggle for Recognition—The Moral Grammar of Social Conflicts* (Cambridge: Polity Press, 1996).
- 4 One way of approaching applied ethics is to carefully attend to the internal meanings, what MacIntyre calls ‘internal goods’, of traditional contexts and forms of life. This seems a minimal requirement if one is going to further assess the appropriateness of theory in a practical context. See, e.g., Alasdair MacIntyre, *After Virtue—A Study in Moral Theory* (London: Duckworth, 1987).
- 5 Immanuel Kant, *Lectures on Ethics*, trans. by Louis Infield (New York: Harper Row, 1963), p. 121.
- 6 *Ibid.*, p. 117.
- 7 Immanuel Kant, *Lectures on Ethics*, ed. Peter Heath and J. B. Schneewind, trans. by Peter Heath (Cambridge: Cambridge University Press, 1997), p. 123.
- 8 *Ibid.*, p. 125.
- 9 See, e.g., Kant, *Lectures on Ethics*, ed. Heath & Schneewind, pp. 122-222.
- 10 Immanuel Kant, *Groundwork of the Metaphysic of Morals*, trans. by H. J. Paton (London: Hutchinson, 1948), p. 91.
- 11 See, e.g., Kant, *Lectures on Ethics*, ed. Heath & Schneewind, p. 144.
- 12 *Ibid.*, p. 127.
- 13 *Ibid.*, p. 127.
- 14 Rom Harré, “Body obligations,” *Cogito*, 1 (1987), pp. 15-19.
- 15 See, e.g., Kant, *Lectures on Ethics*, ed. Heath & Schneewind, p. 145.
- 16 BBC transcript of “Complete Obsession,” a *Horizon* documentary (BBC2 9.30 p.m., Thursday, 17 February 2000), p. 2.
- 17 *Ibid.*, p. 3.
- 18 *Ibid.*, p. 1.
- 19 *Ibid.*, p. 5.
- 20 See, e.g., Peter Singer, *Practical Ethics* (Cambridge: Cambridge University Press, 1979).
- 21 See, e.g., Matti Häyry, *Liberal Utilitarianism* (London and New York: Routledge, 1994).
- 22 Utility for Singer can be thought of as ‘best consequences’, i.e., meaning what, on balance, furthers the interests of those affected, rather than merely what increases pleasure and reduces pain. See, e.g., Singer, *Practical Ethics*, pp. 12-13.
- 23 The greatest need satisfaction principle states that: “An act, omission, rule, law, policy or reform is the right one if and only if it produces, or can be reasonably expected to produce, at least as much need satisfaction as any other alternative which is open to the agent or decision maker at the time of choice.” See, e.g., Häyry, *Liberal Utilitarianism*, p. 124.
- 24 “The principle of equal consideration of interests does not allow major interests to be sacrificed for minor interests.” See, e.g., Singer, *Practical Ethics*, p. 55.
- 25 The principle of hierarchical needs states that: “When the need satisfaction produced by various action alternatives is assessed, those needs which are hierarchically at a less basic level shall be

- considered only if the action alternatives in question do not, or cannot be expected to, produce an effect upon the satisfaction of needs at a more basic level." See, e.g., Häyry, *Liberal Utilitarianism*, p. 124.
- 26 "The essence of the principle of equal consideration of interests is that we give equal weight in our moral deliberations to the like interests of all those effected by our actions." See, e.g., Singer, *Practical Ethics*, p. 19.
- 27 The principle of autonomy states that: "When the need satisfaction produced by various alternatives is assessed, need satisfaction which is freely and informedly chosen by autonomous individuals shall be preferred to the need satisfaction of the same individuals which is not." See, e.g., Häyry, *Liberal Utilitarianism*, p.125 & pp. 142-145.
- 28 See, e.g., Jeremy Bentham, *Utilitarianism and Other Essays*, ed. A. Ryan (Harmondsworth, Middlesex: Penguin Books, 1987). Singer's debt to Bentham is quite evident in eulogy of equal consideration of interests.
- 29 See, e.g., John Stuart Mill, "On Liberty," J. S. Mill, *Three Essays*, ed. Richard Wollheim (Oxford and New York: Oxford University Press, 1975). By contrast Häyry is influenced by J.S. Mill rather than Bentham.
- 30 See, e.g., "Complete Obsession," pp. 3-4.
- 31 Häyry, *Liberal Utilitarianism*, p. 125.
- 32 See, e.g., "Complete Obsession," p. 5.
- 33 See, e.g., Brian Wynne, "Misunderstood Misunderstandings: Social Identities and Public Uptake of Science," *Misunderstanding Science*, ed. A. Irwin and B. Wynne (Cambridge: Cambridge University Press, 1996).
- 34 *Ibid.*
- 35 See, e.g., "Complete Obsession," p. 4.
- 36 *Ibid.*, p. 7.
- 37 *Ibid.*, p. 9.
- 38 Georg Wilhelm Friedrich Hegel, *Phenomenology of Spirit*, trans. by A. V. Miller (Oxford: Oxford University Press, 1977).
- 39 *Ibid.*, pp. 116-117.
- 40 Alexandre Kojève, *Introduction to the Reading of Hegel*, trans. J. H. Nichols (New York: Basic Books, 1969), p. 19.
- 41 See, e.g., "Complete Obsession," p. 3.
- 42 Josef Bleicher, *Contemporary Hermeneutics* (London: Routledge, 1990), p. 57.
- 43 Hans-Georg Gadamer, *Truth and Method*, trans. Sheed & Ward (New York: Seabury Press, 1975), p. 348.
- 44 See, e.g., "Complete Obsession," p. 2.



## The CBC Mission:

**Equip. Defend. Embrace.** These are the three fundamental principles that drive what we do at CBC. Become a member or sign up for our free online newsletter and find out why **Dallas Willard** says of CBC's work, "Great stuff. Praise you and Praise the God of Truth."

Get your finger on the pulse of the bioethics debate.

## The CBC Interviews: Finding Common Ground

A hallmark of CBC's work is to bring people together from opposing viewpoints - religious, political and otherwise - to open, serious conversations towards a common goal of ensuring our human future.

Through this vision, a series of powerful and thought-provoking interviews have come together over the years. Those interviewed include David Prentice of the Family Research Council, Wesley J. Smith, author of *Forced Exit*, William Hurlbut - Stanford University and member of the President's council on bioethics, Christine Rosen, author of *Preaching Eugenics*, and many more.

Please contact [info@cbc-network.org](mailto:info@cbc-network.org) for a copy of *Finding Common Ground: Interviews on Life and Death*



PO Box 20760  
Oakland CA 94620  
925.828.9123  
[www.cbc-network.org](http://www.cbc-network.org)  
[info@cbc-network.org](mailto:info@cbc-network.org)

**the center for bioethics and culture network**  
*bringing people together for a human future*

## BOOK REVIEWS

### **Attending Children (a doctor's education)**

Margaret E. Mohrmann

Washington, D.C.: Georgetown University Press, 2005

ISBN 1-58901-054-X; 209 PAGES, CLOTH, £17.95

Do you remember, as a child, how you enjoyed being told stories?

Well then, grab this book, sit back, and – once again – enjoy being told stories!

The stories here, however, are not for children: although all of them are about children. These stories are not for entertainment, although, they are captivating and create a vivid mental picture. These stories are for education, and they carry a profound message for the practicing physician who is engaged in the care of children (and non-children).

In this book, Dr. Mohrmann – a Hopkins-trained pediatrician who has since hung up her stethoscope – shares intimate glimpses into her personal training as a pediatric resident and attending. There are stories of living and death; gifting and hope; speaking and knowledge. But, perhaps, the most important story is listening and observation. The author suggests that we put aside our bias (regarding a critically child in the intensive care nursery) and take time to hear with the mother's ears: not the beep of a monitor or the drone of a machine, but the cry of the infant and the name of the child. Coupled closely with hearing (listening) is the issue of waiting. For many physicians, waiting is equally as difficult as listening. In the 'hurry-up and fix-it' world of the medical doctor, waiting is often extolled, but rather rarely practiced. In Mohrmann's words, "...my job was to wait for her call, to wait to hear what she had to say, to wait for her to articulate the pain and distress, to wait for the mysteries of her life to become clearer...." (p.184).

In addition to listening and waiting, Dr. Mohrmann's third major division deals with the issue of accompanying. The practice of medicine is a journey, and the doctor walks along side of the patient. The pediatrician walks along side of not only the patient, but also the parent(s). Common parlance holds that a parent should not have to bury her child. Whereas this may indeed be intuitively acclaimed as 'a truth', experientially it is not a reality. Mohrmann observes that there is "...enormity of the pain of also losing present joy and treasured companionship." (p.88). A deceased child's tricycle in the driveway is a memento of a profound loss, not an object to be tossed aside as the car drives into the garage. Mohrman observes that we are social creatures with community and that our interconnectedness is vital.

This is a book for those who care and those who wish to know more about caring.

In providing care for our patients, let it never be said that there is nothing more that can be done.

**Ferdinand D. (Nick) Yates, Jr., M.D., M.A. (Bioethics), A.A.P., A.C.P.,** is Director of Medical Ethics, Mercy Hospital of Buffalo, and Senior Pediatrician and Partner, Genesee-Transit Pediatrics, Buffalo, New York.

## **Lifelines**

Muriel R. Gillick, M. D. New York: W. W. Norton & Company, 2001.

ISBN 0-393-32241-6; 265 PAGES, PAPERBACK, \$13.95.

This well written book “seeks to help the frail elderly and their families cope with their condition by describing some of the most common causes of frailty and discussing the medical, ethical and social issues they engender.” (backcover) Frailty is defined as “impairment in multiple domains leading to profound difficulty functioning in daily life.” (p. x) Through a presentation of four patients, the author describes how frailty might begin and some of its common causes including aging, accidents, and diseases including Alzheimer’s.

The first example presented is Ben Frank, a healthy, independent man who cared for his wife through various illnesses until she died. After falling, he was diagnosed with congestive heart failure. Gillick follows the changes that occurred in his life and lifestyle, as well as changes necessary for his family to face. The author looks at the other disease processes uncovered and the difficult onset of frailty.

Throughout the book, Gillick follows the changes that occurred in Ben’s life and lifestyle, defining what can be fixed, what cannot be fixed, the need for change in Ben’s living situation, and the effects on his family. The author intertwines the life of Ben Frank and three other frail individuals, looking at each patient’s unique problems and personalities and the solutions for each. She stresses the importance of appropriate healthcare as well as discussion and counsel with both the patient and the patient’s family.

The author looks at the total needs of the family, not just physical or medical needs, but also the importance of self worth, pleasure, possible new careers, and self-fulfillment. She looks at the reality of illness and disability that lead to frailty, the need for a change in housing, personal care, coping and what all of this will mean in the patient’s life as well as what it will mean to his family and friends – what will give meaning to the lives of the frail, and the role of family and others.

In the final chapter, the author discusses preventive strategies, psychological needs (including symptoms of sadness and depression which often take place in frail patients’ lives), physical needs (such as exercise and mobility), symptoms of dementia and the challenges in the social domain. The increasing lifespan today makes the study of frailty important both for those who are frail, but also for their families and healthcare professionals.

The narrative style of the book makes it very interesting reading for both the professional and the layman. The language is clear, thoughts are well expressed and the reader comes away with a better understanding of frailty and its consequences. I would highly recommend the book to families and professionals who work with the frail and for those involved in counseling and ministering in church settings. The book is both positive and hopeful as it discusses solutions.

**Phyllis Clatterbuck, D. Min., M.R.E., B. S. (Nursing)**, is a Retired Professor of Theology from Seminario Batista do Teresina in Brazil and also taught at the Seminario Batista do Noreste in Brazil.



## **Fifty Years After the Declaration: The United Nations' Record on Human Rights**

Teresa Wagner and Leslie Carbone, Editors. Lanham, Maryland: University Press of America, Inc; and Oxford, UK: Cumnor Hill, 2001.

ISBN 0-7618-1842-1; 162 PAGES, PAPERBACK, \$15.00

With the recently approved Human Rights Council replacing the widely discredited United Nations' Human Rights Commission, *Fifty Years After the Declaration: The United Nations' Record on Human Rights* is a timely and, indeed, a necessary read. Whatever one's interpretation of the United Nations' beginnings, history, or current functioning, a retrospective consideration of that body's Universal Declaration of Human Rights, published in 1948, is a task worthy of the time required to digest this short work.

Having experienced two world wars in little more than thirty years' time, those who composed the United Nations' Universal Declaration of Human Rights in 1948 were hopeful of preventing another outbreak of such carnage. It is perhaps understandable that they should scribe in that document's Preamble, "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world . . ." and then present thirty articles toward the end of recognizing, naming, and defending those rights on the world's stage. The declaration was proclaimed from Paris, the meeting place of the UN General Assembly in 1948, and has enjoyed wide support over the years — perhaps.

Habib C. Malik, whose late father helped in the genesis of the 1948 document, offers an excellent historical view in the book's introduction. Exactly what has the fifty years since the declaration wrought for the world's peoples, in terms of human rights? Seventeen chapters in this compilation of essays by the Family Research Council detail experiences in differing nations in light of various articles of the declaration. How has religious freedom fared? Or the right to life? David Alton looks at "The Paramount Human Right: The Right to Life." Other subjects include the right to health; the role of the UN in drug control; and whether cloning and euthanasia are compatible with the declared human dignity and consequent rights. Not only is the compatibility of these issues with human rights assessed, but also the history of the United Nations' actions or inactions is considered. If one issued a report card to the UN regarding the fulfillment of that body's stated goals in the declaration, a reckoning would follow. The final chapter is an excellent dissection of some basic presumptions in the United Nations, as well as the venerable document known as the Universal Declaration of Human Rights, by a former ambassador to the UN, Alan Keyes. His pithy analysis brings the book to a strong conclusion.

One cannot read this book without becoming acutely aware of the deficits that abound — in our own country as well as in the world — in the area of human rights. From an international group, with the horrors of war fresh on its collective mind, seeking some promise of "never again," the UN has become increasingly the pawn of ideologues with funding as their trump card. "Human rights" have metamorphosed from the right to life to include aspects of individuality that masquerade as rights, such as the right to health that is defined as "a state of total physical, social and mental well-being, not merely the absence of disease or infirmity." (p. 26). It is most definitely time to thoughtfully consider where we are going with respect to the Universal Declaration of Human Rights.

**D. Joy Riley, M.D., M.A. (Bioethics)**, serves as Executive Director of the Tennessee Center for Bioethics and Culture.

## **At the Beginning of Life: Dilemmas in Theological Bioethics**

Edwin C. Hui. Downers Grove: IVP, 2002.

ISBN 0-8038-2667-X; 416 PAGES, PAPERBACK, \$23.95

Edwin Hui, a professor of biomedical ethics and Christianity, presents a technically informed and sophisticated study regarding beginning of life issues from a theological perspective. Through a comprehensive survey of the personhood controversy, Hui argues for a multidimensional unity which then serves as the framework for discussing assisted reproductive technologies (ARTs) and abortion.

To discern a proper understanding of personhood, Hui eschews reducing the human person to only a biological, psychological, existential or relational dimension, advocating instead for a multidimensional unity. Though charitable, he critically navigates contemporary perspectives while charting biblical and historical Christian conceptions. Departing from the individuality and narrowness of Western views of personhood, Hui emphasizes the importance of relationality and dipolar personhood manifested in a psychosomatic unity (the individual self) and the “toward-other” pole of relationality (most significantly expressed in the relationship between God and humanity). Similarly, temporal and eschatological dimensions of personhood resist any human inclination to pursue a genetic utopia.

Describing the increasingly pervasive struggles of infertility and swiftly exploring the variety of ARTs (artificial insemination, *in vitro* fertilization, surrogate mothering, human cloning & stem cells, and the human genome project) in Part Two, Hui advocates a pursuit of these technologies within a framework that consistently upholds the integrity of multidimensional personhood. By tackling “reproduction as a right” and the selfish motivations standing behind many assisted reproductive pursuits, Hui challenges the reader to a position of “reproduction as responsibility” that cautiously proceeds fully aware of the potential for harm to the personhood of the parents (including third party donors and surrogates) and their progeny. Wary of the specter of eugenics, he warns against the inherent danger of ignoring the values laden within ARTs or the temptation to believe in a technological utopianism with its promise of a perfect humanity.

In Part Three, Hui examines abortion in the context of personhood. In so doing, he offers a progressive alternative to the perceived reductionism of the extreme liberal position of maternal autonomy and the extreme conservative position of the absolute right to life. Claiming that each extreme fails to account sufficiently for the complexity of the issues of personhood, the status of the unborn, and the nature of rights, Hui promotes a high respect for the personhood of the unborn as intrinsic rather than developmentally obtained or bestowed, while simultaneously acknowledging the pragmatic factors that complicate abortion issues. He challenges the current preoccupation with maternal and fetal rights by advocating a holistic relational model that includes paternal responsibility, the maternal-fetal dyad, and the growing recognition of the fetus as patient. Throughout, Hui highlights several overlooked parallels by connecting abortion and the trend toward abortifacients in contraception, as well as the apparent contradiction between advances in fetal diagnosis and therapy as contrasted to a preoccupation with the termination of pregnancies and the destruction of embryos.

Hui is to be commended for a comprehensive resource that successfully combines several discourses into a single compelling discussion. Indeed, one could easily envision that this book could have been divided into two or three volumes, but would have been impoverished in the process. His attempt to transcend the standard impasses through a multidimensional personhood, no doubt will alienate some from both sides of the traditional discussion. By maintaining a consistent emphasis upon the intrinsic status of human personhood as emerging from God’s loving creation of each human being, Hui demonstrates a significant concern for the welfare of the unborn. While he openly develops assumptions which undergird this conception of personhood, one detects a tendency toward natural law ethics

that is neither clearly disclosed nor consistently developed. This is most evident in his analysis of contraceptives and the so-called unitive-procreative link, which is treated as suspect when employed by conservative pro-lifers. Overall, though, this work is heartily endorsed as a valuable resource on personhood and its bearing on reproductive technologies and abortion.

**Michael J. Slesman, Ph.D., is Instructor at Trinity International University, Deerfield, Illinois, USA.**

## Legal and Ethical Aspects of Anaesthesia, Critical Care and Perioperative Medicine

Stuart White and Timothy Baldwin. Cambridge, UK; New York, NY; Melbourne, Australia; Madrid, Spain; and Cape Town, South Africa: Cambridge University Press, 2004.

ISBN 1-841-10209-1; 216 PAGES, PAPERBACK, \$43.00

The rise of bioethics as a discipline has led to the recognition that there is a deficiency of ethics education during medical training. This has prompted the General Medical Council to the acknowledge importance of teaching medical ethics and law to medical students in the UK. A consensus statement by those that teach ethics and law in medical schools in the UK proposed a number of objectives and set forth a core curriculum for medical education. It is this core curriculum that forms the basis of *Ethical and Legal Aspects of Anaesthesia, Critical Care and Perioperative Medicine* by Stuart White and Timothy Baldwin.

The first three chapters introduce the reader to the core curriculum and set the basis of the discussion by outlining the legal system in the UK and briefly outlining the ethical theory and principles in the context of medical ethics. The chapters that follow cover the various aspects of the core curriculum as the authors delve into such topics as human rights, consent, negligence, confidentiality, abortion, products liability, research, death, organ donation, professional regulation, and resource allocation.

Each curriculum chapter begins with a brief discussion of the ethical issue of the topic in question by outlining some of the differing positions taken by competing theories such as deontology and utilitarianism and puts them in the context of ethical principles. The authors are careful to avoid taking sides as they discuss the issues. The text then moves to the legal aspects of the topic outlining some of the notable cases with their outcomes. The book ends with an appendix of important legal cases and a number of questions to ponder and discuss.

The authors cover a lot of material in a concise manner without being too comprehensive for the uninitiated. The unfortunate consequence of this is that many questions arise that are unanswered. The most notable arises when the authors suggest that religious doctrine should not serve as a source of moral direction, yet it has a role in the formation of opinions about medical ethics. They never elaborate on what they mean by this statement.

The majority of the text covers the legal aspects and brings out an interesting difference in the view of autonomy from that held in North America. Paternalism plays an important role in treatment decisions in the case of the incompetent or noncompliant patient.

Overall, White and Baldwin cover a lot of material in a very brief introductory text. They bring out issues that occur every day in the practice of medicine. The brevity of the text, however, does not develop the topics presented to any great depth and for that reason it would best serve as a springboard to guide further reading.

**Jeffrey G. Betcher, M.D., F.R.C.P.C., M.A. (Bioethics)**, practices anesthesiology and critical care medicine at the Regina Qu'Appelle Health Region in Regina, Saskatchewan, Canada.

## **Ethical Issues in Maternal-Fetal Medicine**

Donna L. Dickenson, Editor.

Cambridge, UK: Cambridge University Press, 2002.

ISBN 0-521-6647-81; 353 PAGES, PAPERBACK, \$60

Once upon a time there was a special kind of physician – an “obstetrician” – charged with the responsibility of caring for pregnant women and their unborn children. The uniqueness of the maternal-fetal relationship posed significant but rewarding challenges for the physician whose goal was the well-being of two intimately intertwined individuals. Times have changed; now there is only one legitimate patient. This change has profoundly impacted the specialty and the physician-patient relationship as well. In that light, *Ethical Issues in Maternal-Fetal Medicine*, is a provocative and yet disturbing perspective on the world of maternal-fetal medicine as seen through the paradigmatic grid of secular feminism. It is a poignant depiction of the ideologies and laws that have been the driving force for the dramatic changes in our specialty, portraying not only how we have arrived where we are, but the trajectory along which those forces continue to impel us.

Dickenson’s book, a collection of essays that comprehensively cover ethical issues in maternal-fetal medicine, is unapologetically feminist (19 of the 22 contributors are women). The narrative framework corresponds to the stages of pregnancy: generic (“pre-inception”) issues, inception, first and second trimesters, third trimester, and neonatal life. Woven through these sections are four ethical issues: paternalism/autonomy, new technologies and diseases, disability and enhancement, and “difference” (cultural, religious, or gender).

Undergirding the essays is the primacy of procreative freedom, including the premise that the fetus is not a person independent of and separate from the mother. Beneficent obligations of the mother or physician toward the fetus are largely unrecognized. For instance, Carson Strong sets the stage as he argues from a consequentialist perspective that infants have merely a conferred moral status, bestowed to a lesser degree on the term fetus but not the embryo. Eileen McDonagh carries this ideology to the extreme by depicting the fetus as a non-consensual intruder and the physiologic changes of pregnancy as “harmful.” Self-defense, she claims, justifies not only abortion but also government funding for abortion under the Equal Protection Act.

This collection of essays also reveals the variety of beliefs within feminist ideology. Two authors maintain that screening for Down’s syndrome is morally problematic because Down’s syndrome is a characteristic, not a disease. Likewise, Priscilla Alderson argues that prenatal counseling makes pregnancy pathologically tentative and parenthood a provisional relationship: children become consumer commodities rather than imperfect mortals to be loved as ends in themselves. In “Restricting the Freedom of Pregnant Women,” Susan Bewley thoughtfully addresses the problem of addictive behaviors in pregnant women by arguing that both pregnant women and society have obligations to the unborn and that both need to take reasonable steps to ensure that the child is born in the best possible health. Her discussion of addictive behaviors and their management is enlightening, particularly as she notes that addicted women are not free (autonomous).

In conclusion, with its basis on a framework of rights and equality, this book leaves little room for the concept of obligations or responsibilities, and in that sense is often reactionary and unbalanced. However, it is an important read for anyone interested in developing a greater understanding of the feminist ideology, and the tremendous impact feminism has had on ethical issues in maternal-fetal medicine.

**Susan M. Haack, M.D., M.A. (Bioethics)**, FACOG, is in the private practice of consultative gynecology at Mile Bluff Clinic/Hess Memorial Hospital in Mauston, WI.

## BIOTECHNOLOGY UPDATE

BY AMY MICHELLE DEBAETS, M.A.

### Hands Off Our Ovaries – A New Movement and Manifesto

A new movement is growing that is bringing together pro-life and pro-choice advocates to support women's health by calling for "a moratorium on egg extraction for research purposes until such time as global discourse and scientific research yields information sufficient to establish adequate informed consent."<sup>1</sup> Multiple egg extraction has occurred for years in the context of fertility treatments, but in those cases, the women were willing to take the significant medical risks involved with repeated hormone injections and surgery to remove the eggs either to have a baby themselves or for the significant monetary gain involved in "donating" eggs to be purchased by couples wanting to have children. It is now common for women giving eggs for fertility treatments to be paid between \$5,000 and \$10,000 per cycle, a figure that could never feasibly be matched for research purposes. Women providing eggs run a high risk of having ovarian hyperstimulation syndrome (OHSS), which can result in fluid collecting in the lungs and abdomen, decreased future fertility, kidney damage, and increased risk of abnormal blood clotting, as well as nausea, vomiting, and abdominal pain. Women in vulnerable social and economic situations are particularly likely to be coerced into providing eggs for research and undertaking these risks without proper informed consent and monitoring, and women who provide eggs for research unnecessarily undertake risks for no medical benefit to themselves or others.

The manifesto, which has been signed by over 125 physicians, attorneys, ethicists, professors, and others on all sides of the political spectrum, is printed in full below:

*Keep your hands off our ovaries!*

*Because losing even one woman's life is too high a price to pay.*

Our message is simple and clear; it is our call to action.

Biotechnological research and development often affects women more directly than men. In the case of human embryonic cloning, women's health and safety have already been affected—adversely. Sadly, there have been too many instances of coercion and deception, and violations of informed consent. Left uncontrolled, research demands will place undue burdens on young, poor women. We deserve a biotechnology that is not degrading and destructive to women's health. The ends do not justify these sorts of means.

The recent South Korean cloning scandal—an example of global co-operation between American and Korean researchers—illustrates our concerns only too well. At the heart of the scandal are the abuses suffered by women for the sake of risky, highly speculative, fraudulent research. The effort involved more than 2,200 ova obtained by paying and coercing women, some of whom were in subordinate positions within the research lab. Now, thirty-five Korean women's groups are seeking compensation on behalf of the nearly 20 percent of the Korean women "donors" who were harmed by the egg extraction procedures. Two women (one in London and one in Dublin) are known to have died recently from complications associated with egg extraction.

In 2004, science-entrepreneurs rushing to research with little regard for women's health tried to prevent crucial information from reaching the public. During the "Proposition 71" campaign

to induce Californians to fund cloning technology, they brought legal action attempting to prevent feminists from telling the state's voters that the proposed stem cell research program involved human embryo cloning and would require eggs from thousands of women. Eggs, they told the court, represented less than one percent of research being done and that research could proceed using "surplus embryos."

But the very next year, when talk of a moratorium on egg donation was in the air, one of the very same proponents—a stem cell researcher—told the press that a moratorium on egg donation would have "a chilling effect and be very damaging for the research." Why should women believe anything that researchers with vested interests and conflicts of interest have to say about the risks and benefits of egg extraction? Can women trust the judgment of bioethicists? Not those who consult for biotech companies or otherwise rely on that industry for their information and assessments.

Join women and men from around the globe in the effort to see science and technology move forward in ways that respect women's health, safety, and lives -- because losing the life of even one woman is too high a price to pay.

## IN THE NEWS

### *Adult Stem Cell Advances*

Menstrual blood has been recently found by researchers in Japan to be a good source of stem cells. The stem cells from young women's menstrual blood were discovered in significant quantities, approximately 30 times more than stem cells from bone marrow, which were then cultured to form heart cells.

Kerr, Martha. "Menstrual blood yields stem cells," *Reuters*, March 14, 2006.

[http://www.abc.net.au/science/news/health/HealthRepublish\\_1590861.htm](http://www.abc.net.au/science/news/health/HealthRepublish_1590861.htm)

### *Mice, mens' testicles yield 'ethical' stem cells*

Several new studies have confirmed the usefulness of stem cells obtained from testes in both mice and human males. In the Gottingen study, mouse stem cells from testicular tissue were found to be able to be grown into any type of body tissue. Human trials using men's testicular cells are also beginning, with the stem cells being numerous and easily accessible; another study conducted by PrimeGen Biotech LLC, California, using human male testicular cells, produced stem cells which became nerve, heart, and bone cells.

Coghlan, Andy. "Mice testicles yield 'ethical' stem cells," *New Scientist*, March 24, 2006, <http://www.newscientist.com/article/dn8892-mice-testicles-yield-ethical-stem-cells.html>.

Weiss, Rick. "Embryonic stem cell success: In mouse experiment, cells from testes are transformed," *Washington Post*, March 25, 2006, p. A11,

[http://www.washingtonpost.com/wp-dyn/content/article/2006/03/24/AR2006032401721\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2006/03/24/AR2006032401721_pf.html).

Fox, Maggie, "US company claims to make stem cells from testes," *Reuters*, April 1, 2006.

### *Umbilical cord blood – the future of stem cell research*

According to a new *National Geographic* report, researchers at the University of Minnesota found that stem cells from umbilical cord blood could be used to effect the reversal of effects of stroke in mice, that the use of stem cells from umbilical cord blood is becoming a common therapy for blood diseases, and that these stem cells had been thought to only become blood cells but are now understood to be more flexible and have been used to treat 70 different diseases. Cord blood stem cells are easier to match to the patient than stem cells from bone marrow and cord blood now routinely being banked in both public and private banks for future use.

Lloyd, Erica. "Umbilical cord blood: The future of stem cell research?" *National Geographic News*, April 6, 2006,

[http://news.nationalgeographic.com/news/2006/04/0406\\_060406\\_cord\\_blood.html](http://news.nationalgeographic.com/news/2006/04/0406_060406_cord_blood.html).

### *Adult stem cells in complex jell-o may heal spinal cord injuries*

Spinal implants made of hydrogels that include adult stem cells as well as amino acid polymers in a jelly-like soft base helped regrow nerve tissue by filling in gaps in rats, which regained significant limb function within weeks.

Svoboda, Elizabeth. "Jell-O fix for spinal cords," *Wired*, March 29, 2006,

<http://www.wired.com/news/technology/medtech/0,70513-0.html?tw=rss.index>.

### *Personal story of adult stem cells used to regrow heart tissue*

A recent personal interest story featured on the Atlanta news was that of Bob Grinstead, who had been left near death after a series of heart attacks. He and his family traveled to Thailand, where he had stem cells harvested from his blood that were regrown and injected into his heart. According to his physicians, the stem cells caused growth of new blood vessels that carried more blood into his heart, allowing him greater function and strength.

Hall, Ted. "Saving lives with adult stem cells," *WXIA-TV Atlanta*, May 4, 2006

[http://www.11alive.com/news/news\\_article.aspx?storyid=79461](http://www.11alive.com/news/news_article.aspx?storyid=79461)

### *President's Council on Bioethics April 2006 Meeting*

The April 2006 President's Council on Bioethics meeting focused on several issues, including strategies for increasing organ donation rates in the United States, discussing children in clinical research, specifically risk-taking in nontherapeutic research, the regulation of pediatric research, the current status of the Belmont Report as it relates to research involving children, and a case study discussion regarding pediatric research. The full text of the meeting is available online at: <http://www.bioethics.gov/transcripts/>.

### *Political Ramifications of Hwang Cloning Scandal*

A new article in the *National Review* is promoting the idea of using the recent cloning scandal in South Korea as an opportunity for the scientific community and policymakers in the United States to rethink cloning policy in the US. The fraudulent research that used hundreds of women's eggs, including coercion of junior researchers, and proved to be utterly fruitless should serve as a warning sign to American researchers that more ethical reflection is needed, not simply greater supervision for the research. Problems like massive human

egg requirements and the likelihood of coercion of female donors must be considered as substantial moral issues surrounding cloning research itself, and the politicization of the research as a litmus test for being “pro-science” needs to end. The weight of the scandal should provoke the scientific community to use its creative resources to develop less ethically problematic solutions to the problem of finding cures for deadly diseases and move resources away from human cloning and embryonic stem cell research.

George, Robert and Eric Cohen. “Embryonic problems: The South Korean cloning scandal offers a good opportunity to rethink stem-cell research,” *National Review*, March 20, 2006,

[http://www.nationalreview.com/comment/george\\_cohen200603200801.asp](http://www.nationalreview.com/comment/george_cohen200603200801.asp).

### *Type-I Diabetes Cure for Mice Replicated; Human Trials to Begin*

Dr. Denise Faustman, a researcher from Harvard, has published several papers that indicated that the pancreas’ ability to heal itself may be basis for the cure for diabetes. When her 2001 study was published, it was ignored by the Juvenile Diabetes Research Foundation and other diabetes groups because it claimed that embryonic stem cells were likely unnecessary for curing diabetes. Faustman’s experiments have been replicated and verified by three other groups at University of Chicago, Washington University, and Harvard University that have published their findings. A new \$11 million grant to continue Faustman’s line of research has been given by the Iacoca Foundation. In Faustman’s experiments, 67% of mice in the trial were cured entirely of type-I diabetes. She is beginning to develop protocols for human trials, and there is already a long waiting list.

Kolata, Gina. “A Controversial Therapy for Diabetes is Verified,” *New York Times*, p. A11, March 24, 2006.

Begley, Sharon, “Scientists back work on diabetes cure,” *Wall Street Journal*, March 24, 2006.

### **Nanotechnology Update**

Advances in nanotechnology raise significant worker safety questions – no federal or state worker protection laws currently on the books specifically cover the issues raised by nanotechnology. Potential toxicity problems exist where there are particles small enough to enter the bloodstream, and the National Institute for Occupational Safety and Health (NIOSH) is looking to study risks based on particle size, length of exposure, and density of exposure for workers in nano factories. These particles have the potential to clog airways and trigger strong immune reactions; they carry greater explosion risks than larger particles as well. As of the current fiscal year, only \$3 million out of the \$4 billion federal nanotechnology budget is going to address workplace safety concerns involving nanoscale particles.

Weiss, Rick. “Nanotech raises worker-safety questions,” *Washington Post*, April 8, 2006, p. A1, <http://www.washingtonpost.com/wp-dyn/content/article/2006/04/07/AR2006040701725.html>.

### *California gives out first wave of grants for cloning, stem cell research; legal challenge fails*

In a recent California court decision, the state agency itself was deemed constitutional, and initial grants of \$12.1 million have been given away using “bond anticipation notes.” Significant conflicts of interest with many of the investments remain critical, as those who are



making funding decisions are often the ones to profit from those decisions. A separate legal challenge regarding the funding mechanisms of Proposition 71 are still under appeal.

Marshall, Carolyn. "In end run around legal challenge, California gives out stem cell research grants," *New York Times*, April 11, 2006, <http://www.nytimes.com/2006/04/11/us/11cell.html>.

Elias, Paul. "Judge says Calif. Stem cell agency legal," *Washington Post*, April 22, 2006, <http://www.washingtonpost.com/wp-dyn/content/article/2006/04/21/AR2006042101657.html>.

### *Gene patenting holds up promising research*

A new article highlights the issues surrounding gene patenting and its effects on modern medical research. In the American intellectual property context, approximately 20% of each person's genome is held under some kind of patent, and patients whose genes are patented have been regularly ruled to have no legal rights to their own genes, including royalties gained from patents on those genes. The current patent situation also has had the effect of stifling much promising research, as pharmaceutical companies and others hold tightly to their patents so that they can maintain profitability on treatments that are often less than fully effective.

LaFee, Scott. "Patent offending: Does legal ownership of genes, stem cells and other biological materials go beyond the pale?" *San Diego Union-Tribune*, April 19, 2006. <http://www.signonsandiego.com/news/science/20060419-9999-lz1c19patent.html>.

### *US Government to fund genetic enhancement research*

A \$773,000 grant has been given by the National Institutes of Health to Case Western Reserve University for the development of guidelines for human genetic enhancement research. This grant is intended to fund studies of the differences between therapy and enhancement, and to promote "proper" uses of enhancement. The move has been strongly denounced by conservatives as funding transhumanist research and objectives.

"Case Law School Receives \$773,000 NIH Grant To Develop Guidelines For Genetic Enhancement Research," *Medical News Today*, April 29, 2006,

<http://www.medicalnewstoday.com/medicalnews.php?newsid=42331>.

Mitchell, C. Ben. "Analysis: NIH eugenics project a flashback to Nazi research," *BP News*, May 4, 2006,

<http://www.baptistpress.org/bpcolumn.asp?ID=2238>.

For more information on the promises and problems with human enhancement research see the

President's Council on Bioethics Report: *Beyond Therapy*, available at <http://www.bioethics.gov/reports/beyondtherapy/index.html>.

# New from Hendrickson Publishers

## Science, Faith, and Ethics

### *Grid or Gridlock*

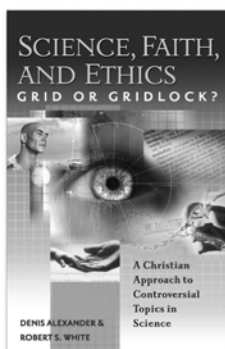
DENIS ALEXANDER AND ROBERT S. WHITE

**\$16.95 retail • ISBN 1-59856-018-2 • Paper • 208 pages • 5 1/2 x 8 1/2 inches**

*Available through Hendrickson Publishers only in the U.S. and its dependencies and Canada.*

Cloning, the environment, stem cell research, reproductive technologies, genetic engineering . . . splashed across television screens and newspapers and argued in classrooms and over the water cooler, these are among the most hotly-debated issues of our day.

But does the Christian faith have anything to contribute to this debate? Does religion belong in the laboratory?



Authors Alexander and White, gifted scientists and committed Christians, argue that Christianity has much to contribute to the scientific and ethical debates facing today's world. They deftly survey the issues at hand, introduce relevant biblical principles, and then ask the hard ethical questions raised by some of the greatest scientific developments of the age.

#### **Topics include:**

- the new genetics
- reproductive technologies
- cloning
- the significance of evolution
- the environment and climate change
- sustainable consumption

An outstanding resource for college science classes, this book will also assist thoughtful laypeople who desire a well-reasoned, biblical perspective as they seek to formulate an informed opinion on these controversial issues.

*Denis Alexander and Robert S. White are scientifically trained, committed to the Christian faith, and biblically and theologically astute. In **Science, Faith, and Ethics** they ably defend the legitimate practice of science from the distortions of both postmodernism and religious extremism, and clearly articulate a mainstream view that science and religion, properly understood, represent complementary ways of knowing the various dimensions of reality. They do not hesitate to address important and controversial topics including creation, evolution, intelligent design, genetic engineering, and global warming. Not all will agree with every conclusion presented, but every reader concerned about the relationship of science to Christian faith will benefit from reading this book.*

—John Jefferson Davis, PhD, Professor of Systematic Theology and Christian Ethics Gordon-Conwell Theological Seminary, author of *Frontiers of Science and Faith: Examining Questions from the Big Bang to the End of the Universe*

*This is a must-read for all thoughtful Christians and is indispensable for those who are students and teachers in the natural sciences.*

—David B. Fletcher, PhD, Associate Professor of Philosophy, Wheaton College

**Denis Alexander** is chairman of the Molecular Immunology Program at the Babraham Institute in Cambridge. He is the editor of the journal *Science and Christian Belief*.

**Robert S. White** is Professor of Geophysics at the University of Cambridge. He serves on Great Britain's National Committee of Christians in Science.

**Outside the U.S.: 978-532-6546 • E-mail: [orders@hendrickson.com](mailto:orders@hendrickson.com) • Fax: 978-531-8146**

**800-358-3111**

**[www.Hendrickson.com](http://www.Hendrickson.com)**

**HENDRICKSON  
PUBLISHERS**



# Ethics & Medicine

In Association With:

The Center for Bioethics and Human Dignity, Bannockburn, Illinois, USA

The Centre for Bioethics and Public Policy, London, UK

The Prof Dr G A Lindeboom Instituut, Ede, THE NETHERLANDS

## CONTENTS

67

### CONTRIBUTORS

69

### EDITORIAL

Cordelia Taylor, R.N.: Healthcare Heroine

### ERRATA

71

### GREY MATTERS

Neuroscience, Nuance, and Neuroethics

*William P. Cheshire, Jr., M.D.*

75

Supporting Organ Transplantation in Non-Resident Aliens Within Limits

*Katrina A. Bramstedt, Ph.D.*

83

Direct-to-Consumer Online Genetic Testing and the Four Principles:

An Analysis of the Ethical Issues

*Katherine Wasson, Ph.D., M. Ph., E. David Cook, M.A., Ph.D., D. Litt. and Kathy Helzlsouer, M.D., M.H.S.*

93

Assisted Procreation: Too Little Consideration for the Babies

*Carlo V. Bellieni, M.D. and Giuseppe Buonocore, M.D.*

99

Exploring Ethical Justification for Self-Demand Amputation

*Floris Tomasini, Ph.D.*

117

### Book Reviews

123

Biotechnology Update

*by Amy Michelle DeBaets*

VOL 22:2, SUMMER 2006

<http://www.ethicsandmedicine.com>



BIOETHICS  
PRESS