Ethics & Medicine

An International Journal of Bioethics

Vol 36:1
SPRING 2020
ISSN 0266-688X

PUBLISHER

The Bioethics Press, Limited
32 S. Michigan Avenue
Suite 1032 - B985
Chicago, IL 60604 USA
Phone/Fax: +1.530.482.3248
info@bioethicspress.com
www.ethicsandmedicine.com

SUBSCRIPTIONS

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

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

***Ethics & Medicine* ~ 2020~ Subscription Rates**

Individual Rates - D(domestic) I(international)
1 year below - 2 & 3 year subscriptions available on website

Print	D - $81	I - $103 £85	Surface Delivery included	
Online IP Authenticated	D - $70	I - $86 £70	Air Delivery - Add an additional $30/year	
Print + Online	D - $115	I - $133 £109		
Archives— PDF Online	1985-2018	D - $105 I - £85	2019	D - $65 I - £53

Institutional Rates - D(domestic) I(international)
1 year below - 2 & 3 year subscriptions available on website

Print	D - $220	I - $255 £210	Surface Delivery included	
Online IP Authenticated	D - $186	I - $219 £178	Air Delivery - Add an additional $30/year	
Print + Online	D - $243	I - $283 £231		
Archives— PDF Online	1985-2018	D - $220 I - £180	2019	D - $100 I - £82

ISSN: 0266-688X

Contents

3 CONTRIBUTORS

5 EDITORIAL

Medicine: Contract or Covenant?
C. Ben Mitchell, PhD

7 GUEST COMMENTARY

The Dignity of Human Life: Sketching Out an "Equal Worth" Approach
Helen Watt, PhD

19 POLICY ANALYSIS

"Complex Family Planning" and the Assault on Conscience
Patrick Marmion, MD, MPH, FACPM

27 GREY MATTERS

Cerebral Organoids and the Threshold of Consciousness
William P. Cheshire, Jr., MD

37 CLINICAL ETHICS DILEMMA

Daring to Deploy a DNR Directive
Robert D. Orr, MD, CM; Ferdinand D. Yates, Jr., MD, MA (Bioethics)

41 **The Pain Principle: An Ethical Approach to End-of-Life Decisions**
Carlo V. Bellieni, MD

51 **Clinical Science after Flexner's 1910 Report on Medical Education: A Research Ethos Inhabited by Racial Prejudice, Colonial Attitudes, and Eugenic Theory**
Gregory W. Rutecki, MD

63 **Book Reviews**

INSTRUCTIONS TO CONTRIBUTORS

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

MANUSCRIPTS FOR PUBLICATION SHOULD BE SENT TO

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

ADVERTISING AND SALES

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

COPYRIGHT

Ethics & Medicine is published in association with:

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

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

ABSTRACTS AND INDEXING

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

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

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

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

TYPESETTING

Typesetting by Andrew DeSelm
andrewdeselm@gmail.com

PRINTING

Kelvin Printing (1993) Pte Ltd
Michelle FM Loke
michelle@excelprintmedia.com

Contributors

Carlo V. Bellieni, MD, is a medical doctor, neonatologist, and pediatrician. He is a professor of pain treatment at the Pediatric School of the University of Siena. He is the author of more than 400 papers, chapters of books, and books mainly devoted to babies' pain treatments and the ethical treatment of the child. Dr. Bellieni has created a pain scale to assess pain in newborns and has validated a non-pharmacologic tool to prevent babies' pain called Sensorial Saturation. He is member of the Ethical Board of the Presidency of the Region of Tuscany (Italy) and of the Pontifical Academy for Life. He is member of the Directive Board of the Pain and Analgesia Study Group of the Italiana Neonatologic Society. He currently resides in Siena, Italy.

William P. Cheshire, Jr., MD, MA, is Professor of Neurology at the Mayo Clinic in Jacksonville, Florida. He is also Senior Fellow in Neuroethics at the Center for Bioethics & Human Dignity. In 2019, the Christian Medical & Dental Associations awarded him Educator of the Year. The views expressed herein are his own and do not necessarily reflect the positions of the professional organizations with which he is affiliated. He currently resides in Ponte Vedra Beach, Florida, USA.

Patrick Marmion, PhD, MPH, FACPM, is an Associate Clinical Professor at Washington State University's Elson S. Floyd College of Medicine. He is a Diplomate of both the American Board of Preventive Medicine and the National Board of Physicians and Surgeons. Prior to relocating to the Pacific Northwest, he was the Executive Director and Chief Medical Officer at Healthy Beginnings, a pro-life perinatal health care center, where he received several awards for innovation from The Health Foundation of Greater Cincinnati. He has been a member of the Maternal Mortality Review Board for the State of Washington since 2017, and he serves on the Medical Advsory Committee for the Pregnancy Resource Centers of Greater Portland. The views expressed herein do not necessarily reflect the positions of the professional organizations with which he is affiliated. He currently resides in Battle Ground, Washington, USA.

Robert D. Orr, MD, CM, has practiced family medicine in Vermont for 18 years before receiving a post-doctoral fellowship to study clinical ethics at the University of Chicago. Thereafter, he served as consultant and professor of medical ethics at Loma Linda University (CA), Trinity International University (IL), the Graduate College of Union University (NY), and the University of Vermont. He is now retired and currently resides in Vermont, USA.

Gregory W. Rutecki, MD, is an Emeritus Internal Medicine, Cleveland Clinic, as well as an Emeritus Fellow CBHD. He was previously a nephrologist and the E. Stephen Kurtides Chair of Medical Education Evanston Northwestern Healthcare and Professor of Medicine the Feinberg School, Northwestern University. He currently resides in Lyndhurst, Ohio, USA.

Helen Watt, PhD, is Senior Research Fellow at the Anscombe Bioethics Centre and Research Fellow at Blackfriars Hall, Oxford. Her publications include *Life and Death in Healthcare Ethics* and *The Ethics of Pregnancy, Abortion and Childbirth*, together with several edited volumes, including *Incapacity and Care* and *Fertility and Gender*. Her research interests include reproductive ethics, gender, action theory, and issues of cooperation and complicity. She currently resides in London, United Kingdom.

Ferdinand D. Yates, Jr, MD, MA (Bioethics), is a medical staff member at Children's Healthcare of Atlanta and has a private pediatric practice in the Atlanta area.

Ethics & Medicine
An International Journal of Bioethics

Bulletin Board

ISBN—13 : 978-1509509560
ISBN—10 : 1509509569
Hardcover - $40
Paperback - $13
Kindle - $12

will robots take your job?

By Nigel M. de S. Cameron

The trend that began with ATMs and do-it-yourself checkouts is moving at lightning speed. Everything from driving to teaching to the care of the elderly and, indeed, code-writing can now be done by smart machines. Conventional wisdom says there will be new jobs to replace those we lose – but is it so simple? And are we ready?

Technology writer and think-tank director Nigel Cameron argues it's naive to believe we face a smooth transition. Whether or not there are "new" jobs, we face massive disruption as the jobs millions of us are doing get out-sourced to machines. A twenty-first-century "rust belt" will rapidly corrode the labor market and affect literally hundreds of different kinds of jobs simultaneously.

Robots won't design our future – we will. Yet shockingly, political leaders and policy makers don't seem to have this in their line of sight. So how should we assess and prepare for the risks of this unknown future?

The ***E&M*** **Bulletin Board** is now open for posting!
Please send your announcement or ad to
info@bioethicspress.com

EDITORIAL

Medicine: Contract or Covenant?

C. BEN MITCHELL, PHD

In an increasingly consumerist culture—not to mention an increasingly litigious one—physicians and patients are tempted to view their relationship as purely contractual. To do so is not only a violation of the canons of good medicine but also ultimately dangerous. Think of a legitimate contractual agreement, like that of one and one's plumber. A contract is:

- Egalitarian (between equals).
- Limited in duration (the extent of the agreement).
- Quid pro quo—"this for that" (services for money).
- Enforced by law—because the contract, not relationship, is the glue.
- Based on self-interest—consumerism drives it.

In a contractual plumbing agreement, the customer wants a working toilet, and the plumber uses his skills in exchange for the monetary gain. In contractual medicine, physicians have a product (treatment) and patients (consumers) have a good to exchange (money). In this consumerist culture, the customer is always right. Hence, contractual medicine encourages a kind of schizophrenia—minimalism in one way and maximalism in another. This is how William E. May puts it in *The Physician's Covenant: Images of the Healer in Medical Ethics*:

> The kind of minimalism that a purely contractual understanding of the professional relationship encourages produces a professional too grudging, too calculating, too lacking in spontaneity, too quickly exhausted to go the second mile with patients along the road of their distress.
>
> Contract medicine encourages not only minimalism, it also provokes a peculiar kind of maximalism, "defensive medicine." Under the pressure of the fear of disease and death, patients often push for the maximum in tests and procedures, and physicians often yield to (or exploit) these fears, because they fear malpractice suits. Paradoxically, contractualism temps the doctor simultaneously to do too little and too much for the patient—too little in that one extends oneself only to the limits the contract specifies, and too much in that one orders procedures that are useful in pampering the patient and protecting oneself, even though the patient's condition does not demand them.

Covenants—like the ancient covenants between God and his people—describe a relationship between persons, not between "providers" and "clients." One of the words the Hebrew Bible uses to describe the covenant is a relationship of "hesed" (steadfast and enduring love). This is surely different from a contract. Covenants are:

- Based on an dis-equal relationships—physicians offer clinical art and skills, including competency in science, powers of caring and healing, over against the patient's *dis*-ease.
- 24/7—there is never a time when a physician is not a physician.

- Relational—grounded in an ethic of care for patients as persons, not labs to be interpreted and problems to be solved.
- Donative (gift relationship)—although physicians are remunerated, they don't practice for the money or for or what patients can do for them, but for what they can do for patients.

Even language offers testimony of this relationship. A "patient" is a "sufferer" or "one who endures suffering." A "customer" is "one who purchases goods or supplies." In medieval Latin, the word referred to a toll-gatherer or tax-collector. Surely, this does not describe the relationship between patients and their physicians.

If medicine becomes just another consumer good, then the customers tell the providers what they want, and the providers either respond accordingly or are left behind in the market. The best therapy goes to those who have the most money to offer.

Resistance to the consumerist drive in medicine takes courage and sacrifice from physicians and understanding and trust from patients. Without those virtues, caring physicians will evacuate their offices, patients will turn against them, and medicine will collapse. The answer is to re-humanize the physician-patient relationship, seeing that relationship through the lens of a covenant, not a contract. E&M

Vol. 36:1 Spring 2020

GUEST COMMENTARY

The Dignity of Human Life: Sketching Out an "Equal Worth" Approach

HELEN WATT, PHD

Abstract

The term "value of life" can refer to life's intrinsic dignity: something non-incremental and time-unaffected in contrast to the fluctuating, incremental "value" of our lives, as they are longer or shorter and more or less flourishing. Human beings are equal in their basic moral importance: the moral indignities we condemn in the treatment of e.g. those with dementia reflect the ongoing human dignity that is being violated. Indignities licensed by the person in advance remain indignities, as when people might volunteer their living, unconscious bodies for surrogacy or training in amputation techniques. Respect for someone's dignity is significantly impacted by a failure to value that person's very existence, whatever genuine respect and good will is shown by wanting the person's life to go well. Valuing and respecting life is not, however, vitalism: there can be good and compelling reasons for eschewing some means of prolonging life.

Key Words

Human dignity, equality, moral status, quality of life, value of life

Introduction

What is life? And in what sense, or senses, might the lives of human beings—their activities or simply their presence, whether lively or quiescent—have a claim on our respect? Here I offer a brief illustrated sketch of one approach to the concepts of human life and the dignity of human life—with, of course, no illusion that these and their applications are addressed in anything like the depth they deserve.

The word "life" covers a range of meanings, including *whole life-span*: lives can be *long*, or *cut short*. Alternatively, "life" can refer to our existence *at some moment*, as when we speak of "signs of life." Then again, it can refer to *spheres* of life: aspects of life on which we will sometimes focus—*work* life, *married* life, *reproductive* life. And it seems these spheres can themselves have "dignity" or a claim on our respect, apart from any dignity attached to our being here at all.

However, the term "life," when used simply on its own, often refers to our *whole* life, including when we are very young, asleep or very ill, or otherwise mentally *hors de combat*. Life normally involves a huge range of bodily activities, many of which remain quite unknown to us, impressive as they doubtless are. Note, though, that in some cases, a living "whole" or organism may have merely a *tendency* to act: a frozen embryo, perhaps in the future a frozen adult, is alive but "halted in mid-stream," retaining the tendency to resume bodily activities if treated in a certain way.[1]

Life can be seen, then, as either the *process of functioning* as a whole or as existence with the *tendency* to function: "functionality,"[2] whether or not currently expressed. With all these senses of "life," we are, of course, referring to *bodily* existence—the existence of the kind of beings we are: embodied wholes, not disembodied ghosts. While reflecting on the mind and its possible expressions after death may help us better understand our bodily selves, the survival of a mind awaiting a body to animate is not "life" in the normal sense of the term. It is the bodily lives of whole human beings and their dignity understood in this worldly terms that I am concerned with here.

Equal Human Dignity

If "life" for the purpose of this paper means either entire life-span or existence at some particular time, what does "dignity" mean? I will use the term as a placeholder for whatever makes it morally/reasonably *appropriate to honour* the subject of that dignity. Although dignity refers to morally/reasonably appropriate honouring, the subject or "moral person" is often being honoured for something other than moral virtue.[3] While someone can certainly grow in *acquired* dignity or excellence in regard to moral/other traits, the sense of dignity I mostly want to discuss is the *intrinsic*, "core human" dignity ascribed to the kind of being we are and seen indeed as grounding the moral enterprise of making choices befitting that dignity of others and ourselves.

Many of us subscribe to some notion of *human equality*, believing that human beings are "equal" in some sense, not in abilities or attainments, but (*mutatis mutandis*) in basic rights and, more generally, in basic standing or moral importance. We think that, for example, human beings are *irreplaceable* by any other human being, irrespective of any similarities[4] apart from their humanity and features inseparable from that. This kind of dignity attaches to everyone, including deeply immoral people, who do not lose their human rights or turn into some lesser, "subhuman" or "subpersonal" kind of being. For that matter, our own activities in practice, as opposed to our orientation to more admirable activities, are not always something to be proud of, as few of us would deny. It is what I am oriented *towards* in terms of rational/relational flourishing, not how I behave in fact, which gives me my core human dignity as opposed to any acquired dignity, bearing in mind that however special a kind of being we are (and it *is* very special), many of our choices are quite mundane or flawed morally or otherwise.

Dignity and Shame

The word "undignified" is a somewhat "lesser" word—one less likely to have strong moral connotations—than either "dignity" or "*in*dignity." Sometimes, we look or feel undignified in ways not immediately related to our moral choices or those of others, even if our shame or embarrassment does have something to do with the imagined or actual presence of other people. Loss of control over bodily functions is one obvious example. The shame or embarrassment we feel may be no one's fault and not particularly a *moral* issue, unless by that we simply mean that those around us, where they cannot prevent our plight, should respond with kindness and tact. Different

societies will have different ways of doing this, just as they and the individuals in them may see different situations as undignified.

Other times, however, shame attaches to our *choices* which, either in fact or in someone's perception, are in some *moral* sense unbefitting. Then the danger is that any shame felt by us or others can elicit a radical turning away from what our human dignity now requires—even, in the most extreme cases, turning us or others against our very lives. We see this with honour killings and suicides connected with scandals of some kind, whether relating to criminal behaviour or to non-criminal but socially frowned-on behaviour, such as extramarital affairs. Of course, the dignity of the person is far better served by facing, if need be, some degree of social shame and/or punishment, avoiding both self-harm and harm inflicted by violent individuals or groups. Such scenarios may sound remote from our own experience, but in secular Western countries, too, feelings of shame and fear can trigger a life-ending response, often involving a pregnancy a girl or woman feels driven to abort. One moral indignity, such as sexual exploitation, can lead to another, even if the pregnant woman may still sense, in her desperation, that her own dignity is once again being violated.

Moral Indignities

Moral indignities inflicted by others come in many forms, bearing in mind that we can also be mistaken in feeling disrespected. Again, the fact that I can undergo genuine moral indignities (and behave in a morally unfitting way myself) testifies to the dignity, and perhaps the *intrinsic* dignity, which is being dishonoured. This also applies to situations where other people are not so much hostile as indifferent to us or, at least, to something about us which deserves more consideration. Nor does it seem that the victim must perceive the moral indignity as what it is (slaves, for example, may have internalised others' view of them) or even be mentally capable of perceiving it in the longer term. The moral indignities we condemn in the treatment of elderly people with dementia, for example, are a sign that, despite their cognitive impairment, they have dignity that is being violated. As Alexander Pruss points out:

> It is no indignity for a rock to have mud poured over it. Making fun of a monkey does not harm the monkey. Moreover, only a being with great dignity can suffer a great indignity. Thus, that some beings suffer horrendous indignities entails that these beings have great dignity.[5]

Note that moral indignities can be licensed by the person himself/herself, whether at the time or in advance, while remaining moral indignities. For example, some have entertained the possibility of treating permanently unconscious people in ways intended to help other people but which, nonetheless, seem to demean the one so treated. They have mooted the idea of people volunteering, in advance of entering a permanently unconscious state, to be used in dangerous non-therapeutic experiments,[6] while one author suggests that women might volunteer to be surrogate mothers, should they fall into an unconscious state.[7] If the living human being has intrinsic human dignity, then surely such actions will violate that dignity, despite being carried out with the subject's prior consent. There is little respect in the first case for the value of one's remaining health[8] as an aspect of the welfare of the kind of being one is or, in the second case, for the rich social meaning that human pregnancy and the human acts initiating pregnancy should carry. Our intrinsic dignity and what

inherently violates that dignity is not up to us to determine, any more than it is up to others. Moreover, moral indignities we request or authorise can have bad effects on those in a similar condition to our own. We will come back to this later on.

Dignity and Foetal Anomaly

Questions of dignity often arise in relation to end-of-life care, often care of the very elderly. Less often, end-of-life care will be *perinatal* care of babies diagnosed prenatally as having a life-limiting condition.[9] Here again, terms like dignity or related terms like "honour" and "respect" are sometimes used by women who continue the pregnancy after the child's condition is disclosed. Thus, one woman describes her devastation at hearing the result of her ultrasound scan, followed immediately by the offer of abortion:

> I felt as though no one in the medical profession valued our baby because of her genetic makeup…I wanted to love and honour the life of our little girl and I wanted everyone else to do so too.[10]

It is striking that parents who, in contrast, choose abortion in these heartrending situations tend to use the word "honour" more in relation to the baby's remains or memory or perhaps her spirit, not the living child, focused on while she was still alive.[11] The child scheduled for abortion may be *loved* while she is still alive, but the questions remain: is her dignity fully respected and is her "being" fully appreciated? These are painful questions, but for love to be fully respectful and unsentimental, it would seem there must be full appreciation of the loved one's presence, not just a desire to confer some benefit on the loved one: in this case, the perceived benefit of death. Alexander Pruss[12] identifies three aspects of love—appreciation, beneficence, and a desire for "union" of some kind—which do not seem to be unambiguously present where death is sought as a benefit for the loved one (we will return to this below). The significantly worse emotional aftermath for women of abortion, compared to continuing the pregnancy where the child has a life-limiting condition,[13] may suggest that wanting to honour one's child in death is no substitute for knowing that one honoured and accepted her unreservedly in life. (Worth noting is the strongly dualist tone to many parents' reflections following these profoundly disturbing abortions, where the "real" child is seen more as the child's spirit "released" by death than as the living, bodily unborn child herself.[14])

Incremental "Value"; Intrinsic Dignity

Returning to the perspective of those who continue the pregnancy after a terminal diagnosis, the remarks of one mother suggest that "value" is being used in a sense more like "intrinsic dignity," one different to the sense in which life's "value" would seem to be variable and incremental. Susan says of her son Frankie:

> All of us have an inevitable death in the offing. Frankie was no different from the rest of us. We began to see that we could not measure the value of our baby's life in terms of years or even months or days.[15]

The mother of another child, Corinne, had this to say:

> We were transformed by the experience of embracing life without putting expectations or limits on her value…. Our devotion to a child who was brought into this world

> not because of what she could do for us but for the dignity she brought simply as a human being and member of our family emphasized to [our other children] their own worth…They know now more concretely the unconditional love we have for each of them and that their worth is not predicated by their looks or accomplishments.[16]

Often, when we talk about the *value* or *worth* of life, we are really talking about life's intrinsic dignity, a dignity which is non-incremental and time-unaffected, in contrast to the fluctuating, incremental "value" of our lives[17] as they are longer or shorter and more or less flourishing. Life is no different from other "human goods" or aspects of human fulfilment in that we can have more or less of it—more or less life, as we might have more or less friendship, say, or more or less knowledge. There is no problem with saying that thirty more years of life are, in themselves, more valuable for me than three minutes more of life, or with saying that those thirty years are, in themselves, worth more to me—since physical "full-being" is a dimension of human flourishing—if my health is good, rather than poor. (Note that I am not speaking here of the moral and social sense in which, sometimes, more importance may be achieved in three minutes—say, in terms of making peace with estranged family members—than I may have achieved in the past thirty years.)

Childhood is for later adulthood; there is a real sense in which my life as a developed adult is worth more to me in the short term than my life as a three-year-old child, when, however, I had significant *long*-term interests in developing those more mature capacities, projects, and relationships. However, when it comes to the intrinsic, core *dignity* of life, then three minutes, three years, or even thirty years cannot add to or subtract from this dignity in any way. Morally, I matter in my very being, and this applies to every minute and every second, just as I am no more or less a human being if I have a minute or second more to live.

Fulfilling Humankind

What might this intrinsic dignity be, though? Remember that even the youngest and most damaged human being is a member of the human kind: a special *rational* kind, different from any other kind of animal we know. Her body, simply as a human body, is oriented to rational fulfilment, even if such fulfilment will be unattainable for the remainder of her life. Even a baby missing much of her brain is "missing" that part because that part is one she *should have*, as other parts testify (for example, her lower brain which "ought" to support the missing part or indeed her vocal cords which "ought" to help her speak when she is old enough to do so). A dying baby is no less a rational kind of being for the fact she is too sick to grow up to think, just as she is no less a mammal for the fact she is too sick to feed from her mother or to grow up and perhaps feed a baby of her own.

Health and sickness are value terms to be applied to particular kinds of being whose flourishing depends on particular features. We do not let the illness define the person, as if it made him or her a different kind of being, but it is by looking at other humans and how they function and flourish that we understand illness and how it might be treated. Something similar can be said of non-human animals, but while it is a pity that some seagulls cannot fly, it is vastly more of an issue if a being who should be able to *think* is injured in that or some other function. We can value animals' lives

and their health without denying the very obvious chain of being in our world where humans are clearly at the top of that chain and seagulls far below.

As human beings, we differ amongst ourselves in many ways, including the precise form our health interests take: a baby, but not an adult, has an objective, long-term interest in growing up (including sexual maturation), while a girl, but not a boy, has an interest in acquiring the capacity to conceive and gestate a child. However, we are all the same basic *kind* of being, whose form of fulfilment is shared by those of our own kind (with some adjustments for age and sex) and whose fulfilment is always morally important, as the *same* fulfilment in the life of one and the same living being. The status of human life cannot be demoted by disease to that of the life of a lower animal. Human beings have interests in a far richer range of goods than non-rational animals, whose range is very much their own. When things go badly for us, there is more of which we are deprived: more value *missing*, for the very reason that there is also more value ("dignity") *present* in the orientation to rationality that we always possess. Our interests matter, not as free-floating entities, but as *our* interests—those of the persisting members of the rational bodily kind that we always were.

Valuing Human Existence

If we respect and even love our fellow human beings, we should appreciate them in a special way and, so I am claiming, strongly value their existence as irreplaceable beings. Respect for someone is significantly dented by a failure to value that person's very existence, whatever genuine respect and good will is shown by wanting the person's life to go well. As Stephen Brock observes:

> It would be a mistake to think that in "wanting good for some being" what is wanted must always be other than the being that it is wanted for. This would make little sense. In loving a friend, one does not just want other goods to exist, for him; one surely also wants him to exist, for him. One wants his wellbeing. A necessary element of this is his simply being... the object of love of friendship, as such, is not only a being for which good is wanted, but also a good that is wanted—for itself.[18]

Part of complete respect and love for someone is the perception: it is good that you exist. Nor need this always be linked to any beneficent *action*, even in the context of health care. Rather, the carer will sometimes be simply acknowledging and appreciating the sheer presence of the person cared for, as something valuable in itself. Life can and should be valued, even at moments when it is not being actively promoted.

Dignity and Deliberate Ending of Life

If the dignity of human life must always be acknowledged, is that ever compatible with deliberate *ending* of life or deliberate lethal force applied to the person? Certainly, no one should be killed, not as a current aggressor or as someone who may deserve punishment for a past crime, but simply because they are in our way and/or their death can serve our ends. To treat people simply as obstacles to our plans, for example, and deliberately end their lives for that reason is not to treat them as having equal human dignity to our own. And as regards the value of life, as opposed to the perceived utility of death to other people, it would be quite wrong to suggest that

the lives of prisoners on Death Row, for example, had *no value*. A society troubled enough to want to execute its criminals needs to find a better argument than that.

In contrast, with euthanasia the message may indeed be that life has *no value or dignity*, or at any rate that no value or dignity is present of a kind that prevents the deliberate taking of the life in question. It is one thing to say that life is not "good" (long or flourishing) enough to justify burdensome means of life extension; it is something else entirely to say that life is not "good" enough and does not have "dignity" of a kind to prevent its deliberate termination. A conundrum for legislatures where euthanasia can be requested in advance of loss of mental capacity is what to say about the elderly person who now has dementia but seems quite contented: should such a person be euthanised merely because he or she requested it earlier, no doubt on the basis that life with dementia was seen as lacking dignity? If society carries out choices made, perhaps quite explicitly, on the grounds that life in such conditions has no dignity, is not society *seeming* at least to *endorse* that unflattering view of the person's life? And what does such endorsement say about the dignity of other people living with dementia?

A similar argument can be made about other conditions where the person is mentally competent and expects to remain so but recoils from dependency or "being a burden": what message does it give to endorse that choice but not the choice of healthier suicidal people, where the message given rather is that their lives have value *despite* how they themselves view their lives? Yes, aspects of one's medical care—even good, respectful[19] medical care—may be "undignified" in the more trivial sense mentioned earlier, and one may *feel* them, at least in anticipation, as shameful and/or morally unfitting. However, to say that those aspects and the very life they support *are in fact* shameful or morally unfitting seems a kind of insult,[20] however unintended, to others living with the relevant condition.

Nothing about us makes us infallible guides on the value of our lives or, indeed, on other aspects of our welfare. If I say that friends are unimportant and money is all that counts, my opinion is one thing; reality is another. Just as I can disrespect friendship or knowledge, I can disrespect the value and dignity of my own life, whether now (because I see *current* dependency as a state lacking dignity) or in some imagined future (because I see *future* dependency and perhaps cognitive impairment as constituting such a state).

Dignity and Autonomy

Of course, many will claim that appeals to the dignity of life, at least in the case of competent patients, should give way to appeals to the dignity of *choice* or *personal autonomy*. And certainly, there are cases, such as refusal of unwanted treatment, where health care providers and the State do need to step back and allow people to make their own decisions and their own mistakes in a matter that concerns them first and foremost. That said, there are forms of harm, especially deliberate harm, of oneself and others with regard to which no State and no health care provider can afford to remain passive, let alone become involved. Homicide and suicide are paradigmatic cases of personal choices of pressing public concern. That includes cases where people are killed "for their own sake": because they wanted this, and/or because—in their view and/or their carers' view—their life has "no dignity." We might ask: is this

any less a failure of respect than using someone after loss of consciousness in harmful or lethal research, or perhaps to train medical students in, say, amputation? Is it any less harmful and demoralising to society, bearing in mind that many more people will feel suicidal for one or other reason[21] than will want to die in lethal research—not to mention those likely to be killed non-voluntarily once euthanasia, in particular, has been legalised?[22] The latter scenario may not be morally worse than, but certainly adds to, the moral disvalue of life-ending projects shared between doctors and those patients who are competent to choose death.

It is worth remembering that even our legitimate concern to defer to people's preferences where possible is often a matter of respecting the person rather than valuing the preferences themselves. People are more than their preferences, which can be unworthy of them to form and unworthy of us to endorse, even in those kinds of cases where we do need, at least, to "step aside." The faculty of choosing, like our other mental faculties, is valuable precisely as (albeit imperfectly) geared towards genuinely good ends: forms of human fulfilment such as life and health, knowledge, and friendship that at times we freely pursue. Choices should respect oneself and others; there are also some limits to the leeway that society should allow people to choose in ways that show—whatever the good faith of those who make those choices—especially serious disrespect. Even if some latitude must be allowed in the service of privacy and freedom to choose well (including under personal pressure), whether that applies to a particular kind of choice will depend entirely on what is being chosen.

Caricatures of Respect for the Dignity of Life

All that said, there are many ways in which respect for the dignity of life is often misunderstood and indeed caricatured, both as regards end of life situations and refusal of treatment during pregnancy. Respect for the dignity of life does not mean "vitalism": taking all conceivable means to prolong life. There are many cases where life-prolonging interventions should be withheld or withdrawn, whether because these are rejected by a competent patient (who has first responsibility for his or her own health) or simply because the burdens they create for the patient are unwarranted by any slight benefits they may bring. Life is not the only human good, and we are often entitled to pursue other goods (for example, "quality time" at home with our families), even when life and health will be foreseeably impacted. Respect for the dignity of life means, in the first place, *refraining*— refraining from deliberate attacks on life (including deliberate attacks by omission) where there is no question of crime or attacks on others on the part of the person killed.

Similarly, with pregnancy, respect for the dignity of life—applying simultaneously to two separate, though intimately linked, living beings—does not require promoting at any cost the perceived health interests of either the woman *or* her baby. We might think of caesarians, which might be refused[23] by a competent woman confronting a difficult labour: whether she is right or wrong to refuse in a particular case, her guardianship over her baby, and also over her own body that would be invaded, surely extends this far.

Conscientious Refusal of Life-Saving Treatment

Other interventions may be refused by the patient and/or the doctor because those interventions are judged by the patient or the doctor to be morally unjustified. For example, a cardiac patient might refuse a heart transplant out of concerns about the determination of death in "beating heart cadavers." Returning to pregnancy, a woman carrying triplets or quadruplets might refuse "pregnancy reduction," i.e. a lethal injection for one or more of the foetuses she is carrying. She might refuse this even to promote the safe delivery of her other babies, and even this could also safeguard her own health, which might be threatened by a multiple pregnancy. Pregnancy is, it can be argued,[24] a human relationship, not a relationship between two things or between a person and a thing. Just as the woman should not be reduced to a "carrier" (she is a pregnant mother, not a subhuman object), so her baby or babies should not be reduced to "carried contents" of the womb or "products" of their own conception. The dignity of the woman's life, her child's life, and their pregnancy relationship demands more respect than that.

Conclusion

The dignity of life should be perceived as a matter of second nature, producing some degree of awe in us that protects us from temptations to take life unjustly or helps us resist these if they arise. Beginning in our own minds, there is an onus on us to think of each other's existence in respectful terms or, at very least, not in *dis*respectful terms. In the practical arena, we respect the dignity of life by, first of all, "stepping back": this is about choices we should *not* make in the first instance, as opposed to those we should. Choices to end life, or to assault lethally an innocent person who is attacking no one, are choices to avoid, whether the individual is a suicidal elderly person, a pregnant woman, or the foetus she is carrying. That said, when such negative duties have been respected, there are many strong, if contingent, *positive* duties to support human life, whether via healthcare or in other ways. And going beyond duty, there are many further positive opportunities to promote the welfare of old and frail and disabled people and pregnant women and babies, whether these are members of our own families or of the wider family from which we all come. The *absolute* moral implications of the dignity of human life may be wholly or largely negative, but a world in which only such negative duties were recognised would be a poor world indeed.

Endnotes

1. Such treatment need not be practically available for the frozen being to be still alive: if treatment for reviving frozen embryos (or adults) has not yet been developed, or if the last person who knows how to give this treatment has just died, this does not change the vital status, as opposed to the prospects, of the beings in question.
2. Watt, H. 2015. Life and Health: A Value in Itself for Human Beings? *HEC Forum* 27: 207-228.
3. Pellegrino, E.D., A. Schulman, and T.W. Merrill, eds. 2009. *Human Dignity and Bioethics.* Notre Dame, IN: University of Notre Dame Press.
4. As Stephen Brock points out, irreplaceability is not the same as uniqueness: "We do not have to suppose that every person makes a unique or outstanding 'contribution' to the world—as though, if no category were overlooked, every person would find his or her way into the book of world records. Even if this were true, it would not establish the person's value as one who exists just for

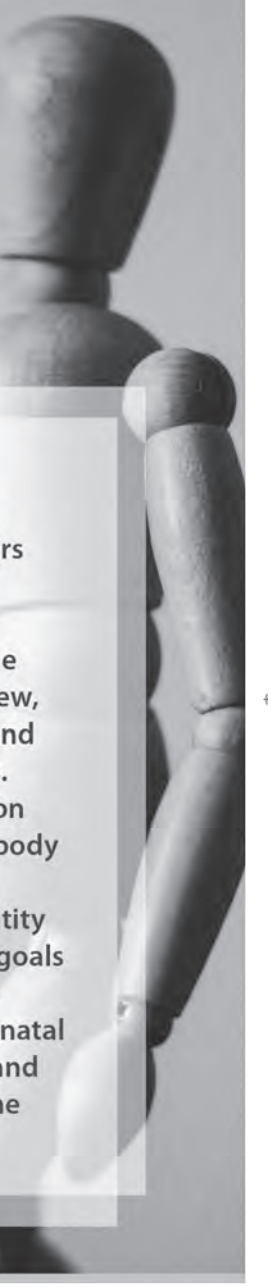
his or her own sake. It would only establish the value of something that the person has—some quality or work. What we are seeking is something else: the value pertaining to the very subject, the person himself or herself, in his or her sheer 'selfhood.'" Brock, S. L. 2005. Is Uniqueness at the Root of Personal Dignity? John Crosby and Thomas Aquinas. *Thomist* 69: 173-201.

5. Pruss, Alexander. Blogpost 4 January 2011. Horrendous evil and indignity. http://alexanderpruss.blogspot.com/2011/01/horrendous-evil-and-indignity.html Accessed 15 September 2018.
6. Ravelingien, A., F. Mortier et al. 2004. Proceeding with clinical trials of animal to human organ transplantation: a way out of the dilemma. *Journal of Medical Ethics* 30: 92–98; Ravelingien, A., F. Mortier et al. 2006. Authors' reply: A body at Will. *Journal of Medical Ethics* 32: 609–611; Sparrow, R. 2006. Right of the living dead? Consent to experimental surgery in the event of cortical death. *Journal of Medical Ethics* 32: 601-605.
7. Ber, R. 2000. Ethical Issues in Gestational Surrogacy. *Theoretical Medicine* 21: 153-169.
8. Watt, 2015.
9. Kuebelbeck, A., and D.L.Davis. 2011. *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to be Brief.* Baltimore: The Johns Hopkins University Press; Cobb, A.D. Acknowledged dependence and the virtues of perinatal hospice. *J Med Philos* 2016; 41: 25-40.
10. Kuebelbeck and Davis, 2011, 23-4.
11. The word "dignity" appears once in the 46 parents' narratives in *Our Heartbreaking Choices*, a collection on abortion for medical reasons, and only then in relation to the right to choose, though the words "honor" and "respect" are used in the narratives in relation to dead if not to living babies. Brooks C., ed. 2008. *Our Heartbreaking Choices: Forty-Six Women Share Their Stories of Interrupting a Much-Wanted Pregnancy.* Bloomington: iUniverse.
12. Pruss, A. (2013). *One Body.* Notre Dame, IN: University of Notre Dame Press.
13. Cope, H., M.E. Garrett, S. Gregory, and A. Ashley Koch. 2015. Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. *Prenatal Diagnosis* 35:761-8.
14. Watt, H. 2017. Abortion for life-limiting foetal anomaly: beneficial when and for whom? *Clinical Ethics* 12: 1-10.
15. Kuebelbeck and Davis, 2011, 48.
16. Corinne's Story, at http://www.prenatalpartnersforlife.org/Stories/HPE_Corrine.htm Accessed 13 September 2018.
17. Watt, 2015.
18. Brock, 2005.
19. Genuine moral indignities will in contrast be present in the person's care if this is callous or perfunctory in some way and thus unresponsive to the person's intrinsic dignity.
20. Jones, David. 2013. Is Dignity Language Useful in Bioethical Discussion of Assisted Suicide and Abortion? In: *Understanding Human Dignity* (pp. 529-542), C. McCrudden (ed.). Oxford: Oxford University Press.
21. Jones, David Albert and David Paton. 2015. *How does legalization of physician assisted suicide affect rates of suicide? Southern Medical Journal* 180: 599-604.
22. Keown, John. 2018. *Euthanasia, Ethics and Public Policy: An Argument against Legalisation*. 2nd Ed. Cambridge: Cambridge University Press; Jones, David Albert, Chris Gastmans, and Calum MacKellar, eds. 2017. *Euthanasia and Assisted Suicide: Lessons from Belgium*. Cambridge: Cambridge University Press.
23. The woman's special guardianship of her baby's body as well as her own separate body should certainly be recognised in cases where she competently *refuses* interventions, whether rightly or wrongly. When it comes to *requesting* interventions from others, which will sometimes be unnecessary and/or harmful, we are in a different situation. A request for thalidomide for morning sickness would be one example.
24. Watt, H. 2016. *The Ethics of Pregnancy, Abortion and Childbirth: Exploring Moral Choices in Childbearing.* New York and Abingdon: Routledge.

Helen Watt, PhD, is Senior Research Fellow of the Anscombe Bioethics Centre and a Research Fellow of Blackfriars Hall, Oxford. Her publications include *Life and Death in Healthcare Ethics* and *The Ethics of Pregnancy, Abortion and Childbirth*, together with several edited volumes, including *Incapacity and Care* and *Fertility and Gender*. Her research interests include reproductive ethics, gender, action theory, and issues of cooperation and complicity. She currently resides in London, United Kingdom.

27TH ANNUAL CONFERENCE

Bioethics & the Body



Preconference Institutes
June 22–25, 2020

CONFERENCE
JUNE 25–27, 2020

Postconference Seminar
June 29–July 1, 2020

NICANOR P. G. AUSTRIACO, PHD, STD
Providence College

JEFFREY P. BISHOP, MD, PHD
Saint Louis University

JONI EARECKSON TADA
Joni and Friends

BETH FELKER JONES, PHD
Wheaton College

DONNA J. HARRISON, MD
AAPLOG

KIMBELL KORNU, MD, PHD
Saint Louis University

KARLA A. POLASCHEK, MD
Medical Arts Associates, Ltd.

D. CHRISTOPHER RALSTON, PHD
Joni and Friends Intl. Disability Center

PETER J. SMITH, MD, MA
The University of Chicago

Join us for our 27th annual conference, *Bioethics & the Body*. Distinguished speakers will examine foundational concepts and bioethical considerations related to the myriad ways in which we view, interact with, manipulate, and analyze our physical bodies. Plenary sessions will focus on understanding the human body through a theological lens, disability and issues of identity in a bioethical context, the goals of medicine with respect to disease, pregnancy and prenatal testing, and the biological and technological merging of the human and nonhuman.

THE CENTER FOR BIOETHICS & HUMAN DIGNITY
TRINITY INTERNATIONAL UNIVERSITY

LEARN MORE | **CBHD.ORG/CONF2020**

In Partnership with:
American Association of Pro-Life OB|GYNS
American College of Pediatricians
Americans United for Life
Charlotte Lozier Institute
Christian Legal Society
Christian Medical & Dental Associations
Nurses Christian Fellowship

Sponsored By:
Albert Gnaegi Center for Health Care Ethics - Saint Louis University
Alliance Defending Freedom
Bioethics Defense Fund
Joni and Friends
Pellegrino Center for Clinical Bioethics
The Ohio State University Center for Bioethics

POLICY ANALYSIS

"Complex Family Planning" and the Assault on Conscience

PATRICK MARMION, MD, MPH, FACPM

The Problem

In January 2019, the American Council for Graduate Medical Education [ACGME] approved a new subspecialty, Complex Family Planning [CFP], for the American Board of Obstetrics and Gynecology [ABOG]. "Complex Family Planning" is a euphemism for late-term abortion: the purposeful destruction of living prenatal babies who could survive if born. It is never medically necessary.

This new subspecialty will train experts to dismember living prenatal babies. If an intact extraction is planned, the abortionist will kill the prenatal baby with a lethal intra-cardiac injection of digoxin or potassium chloride beforehand in order to ensure that there will be no survivors. In order to meet the obligated number of performed procedures, fellows will use directed, negative message framing to victimize vulnerable women, increasing the number of late-term abortions performed in these academic health centers.

A report published in 2018 revealed that 93% of obstetricians and gynecologists will not perform abortions when requested by their patients,[1] increasing 7% over the preceding seven years.[2] Embedded CFP Fellows in academic OB-GYN residency training programs will intensify the politicization of medical education, applying increasingly severe pressure on medical students and residents to participate in abortion.

Development

Planning for the new ABOG subspecialty in performing complex late-term abortions began in 1991 when the Bixby Center for Global Reproductive Health [Bixby] at the University of California, San Francisco, implemented its Fellowship in Family Planning [FFP].[3] FFP is a two-year commitment with one new fellow being admitted per site per year. It was expanded to eight additional academic health centers by 1999 when Bixby was able to secure funding from a secret charity aggregator.[4] This money allowed Bixby to set up additional FFP programs in academic health centers throughout the United States, bringing the 2018 total to 27 sites.

Flush with this unlimited funding in 1999, Bixby abortion advocates advanced to Phase 2 of the development of the planned abortion training subspecialty in OB-GYN. Using charity aggregator funds, it implemented a national initiative in abortion training, the Kenneth J. Ryan Residency Training Program [Ryan Program] led by FFP-trained coordinators. Bixby endowed the Ryan Program with these funds to entice OB-GYN residency program directors, already under pressure by the Bixby-inspired ACGME abortion-training mandate of 1996, to participate by pledging to pay the salary of FFP-associated physicians if they were appointed as faculty at

academic health centers and charged with training OB-GYN residents in abortion techniques. Bixby annually funnels $42 million to support FFP, the Ryan Program and the SFP. Bixby's secret charity aggregator provides approximately $17.6 million, while Bixby's federal DHHS and NIH grants provide $21.8 million.

Phase 3 began in 2002 when Bixby and its FFP experts implemented the blueprint for the Society for Family Planning [SFP], launching it in 2004. Editors of the journal *Contraception* abdicated, granting sponsorship of the journal to SFP.[3] *Contraception* editors are FFP graduates and current FFP or Ryan Program directors. As a specialty organization involved in medical education with its own journal, SFP was now positioned to achieve its objective of initiating the ABOG abortion subspecialty. Garnering support during the Obama administration (2008-2016) with pledges from its DHHS Centers for Medicare and Medicaid to supplant private foundation support with public Graduate Medical Education [GME] funding, the principals were finally ready to implement the final phase: the adoption of this new abortion subspecialty. The private foundations are eager to re-direct their $17.6 million annual investment to fund initiatives authorizing midlevel practitioners to perform surgical abortions and requiring OTC availability of the medical abortion pills, mifepristone and misoprostol.

Politicizing Medical Education

Bixby, FFP, Ryan Program, ABOG, and ACOG leaders are in essence the same people. For example, over half of ACOG's Board are or have been associated with Bixby. A core goal of Bixby-supported programs is abortion advocacy. Bixby proposed an activity to meet this goal: initiate the Ryan Program "to establish formally integrated opt-out rotations for residents."[5] FFP graduates champion abortion and are leaders in advocacy organizations. Graduates now lead the Centers for Disease Control and Prevention Abortion Surveillance Report. As a stooge for Bixby, ACOG has joined forces with the ACGME, the ABMS, and ABOG to support its extreme abortion advocacy.[3]

Bixby and its FFP programs and ACOG were not content to merely legitimize legal induced abortion; they wanted to force OB-GYN residency training programs to offer abortion training. In 1996 they imposed their will by forcing ACGME (a physician-led group that determines the curriculum for graduate medical education) to mandate that OB-GYN residency programs must provide an "opportunity" for training and performing first and second trimester abortions. This effort was stymied by the federal Coats amendment of 1997 that legitimized the accreditation of non-complying OB-GYN residency training programs. Undeterred, the ACGME collaborated with Bixby to start the Ryan Program in 1999. The Ryan Program pays the salary of university medical school faculty who are positioned there as abortion advocates. Dr. Donna Harrison, Executive Director of the American Association of Pro-Life Obstetricians & Gynecologists [AAPLOG], said, "The Ryan fellows are there to promote abortions and to put pressure on those medical students and residents who do not want to do abortions." Besides meeting the ACGME mandate of 1996, Dr. Harrison notes, "The lure for the medical school is that it is a funded faculty position" and, "The medical school gets another warm body to teach, and they don't have to pay for it." Between the ACGME 1996 mandate and 1999, abortion training in OB-GYN

residency programs was "opt-in"; that is, the program would accommodate those who wished to perform abortions. In order to get around the Coats amendment of 1997, initiating Bixby's Ryan Program was key to establishing OB-GYN residency training programs that include mandatory abortion training—cleverly making abortion training as an "opt-out" program. This required a medical student or resident with conscientious objections to request to be excluded from abortion training.[6]

What is the big deal about "opt-out" abortion training? Dr. Harrison replied, "There is more than one way to put pressure on medical students and residents in training." She added, "Residency is a very lonely experience, and you're exhausted. To have to fight additional pressure to violate your conscience is very, very difficult." She noted that residency is also a time to develop camaraderie and develop professional relationships to help throughout your career.[7] Refusing to participate in abortion causes professional ostracism and limits career opportunities, especially in academia. Medical students and residents who "opt out" are:

- required to prepare dissertations about women's rights, etc;
- required to undergo "just culture" and "values clarification" training;
- given the worst "on-call" shifts and holiday schedules;
- ridiculed as "anti-abortion, natalist, speciesist and/or misogynist;"
- forced to endure verbal harassment and scornful glances.

Many succumb to the pressure. In 2013, Bixby's reported that 31% of those who "opted-out" finally participated in at least one elective abortion and that 16% of these previously "pro-life" residents planned to do abortions in their practice.[8]

In 2009 ACOG published Committee Opinion 424 (re-stated as CO 612 in 2014) recommending universal "opt out" training policies, which place the burden on the resident and establish a culture of marginalization and stigmatization of physicians with pro-life convictions.[9] Since then, Ryan Programs have almost completely penetrated OB-GYN residency training programs. In 2014, while just one-third were affiliated with the Ryan Program, almost two-thirds of the OB-GYN residency programs had accepted the principle to make abortion training "opt-out." Only 31% were still "opt-in."[10] A survey of Chief Residents published in 2014 confirmed that only 30% of OB-GYN residency training programs still had an "opt-in" choice for abortion training,[11] but that number is shrinking. By 2018 the Ryan Program was active in 90 OB-GYN residency training programs, increasing its penetration from 31% to 37% in just four years.[10]

There were 306 residencies in 1979 but only 246 in 2016.[12] Of these remaining residencies, 25 were at faith-based hospitals that had only "opt-in" abortion training programs or no abortion training program at all.[13] There were 47 other community hospital programs that were still "opt-in." When OB-GYN residency training programs close, the Affordable Care Act mandates that the allotted resident slots be transferred to other residency programs.[14]

ABOG's CFP fellowship program will increase the number of mandatory "opt-out" abortion programs in three ways:

- It is expected that community-based, especially faith-based, OB-GYN residency training programs will be forced to close or merge with academic health centers. ACGME and ABOG will ensure that the liberated resident slots will be transferred to the new CFP fellowship programs;
- ABOG expects to expand CFP fellowship sites from the current 27 academic health centers to 67;
- Bixby expects to add five Ryan Programs each year through 2024,[15] positioning faculty in enough of the remaining 72 noncompliant OB-GYN residency training programs to ensure that all programs offer only "opt-out" abortion training.

The subspecialty "Complex Family Planning" will enhance Bixby's carrot-and-stick Ryan Program and *de facto* accomplish the requirement for mandatory abortion training, sparing the ACGME from pro-life legislative ire if it were to attempt to do so. The anti-life movement to bring abortion into the mainstream of medicine has been very successful.

Politicizing the Practice of Medicine

The history of ACOG's Board of Directors abortion advocacy and duplicity predates the 1973 *Roe v Wade* Supreme Court decision. After legalization, pro-life academic physicians were purged by attrition, elevating only abortion advocates to influential academic appointments. Academic programs heatedly competed for grants from the pharmaceutical giant Upjohn to perform clinical trials with its abortifacient Prostin E before the FDA approved it for use in hospitals in September 1977.[16] It became the mantra that pro-life medical students need not apply to academic health center OB-GYN residency training programs. In 1979 the UCSD OB-GYN Residency Program was discovered to have created separate match lists for several years: one for pro-abortion and the other for pro-life applicants. It preferentially filled its match only from the first. Pro-life OB-GYN residents were harangued and dismissed.[17]

ACOG designates that 8% of its membership dues be used for lobbying.[18] Having over 58,000 members, ACOG spends more than $3 million each year on political abortion advocacy.

Bixby and SFP supported ACOG as it sought to force pro-life health care professionals to either participate in abortion or leave the profession.[19] In 2005, ACOG wrote to US Senators in support of violating the right of conscience, but this was challenged by AAPLOG, the largest Special Interest Group in ACOG. Emboldened by the success of the Ryan Program, the ACOG Committee on Ethics published its infamous Committee Opinion 385 limiting conscientious refusals at the end of 2007.[20] In response to the ensuing hubris, ACOG privately backtracked its position in a letter distributed on 26 March 2008,[21] but it never publicly changed CO #385. (In fact ACOG reconfirmed it in 2016.) Despite a generational effort to legitimize legal induced abortion and to force pro-life medical students and OB-GYN residents to be sullied by participating in abortions, a 2008 survey showed that 86% of practicing obstetricians and gynecologists still would not perform abortions if requested by their patients. ACOG dropped AAPLOG as a Special Interest Group in 2014.

ACOG's incestuous relationship with the new CFP fellowship training programs ensures the appointment of these abortion advocates to choice positions in academic health centers. The assault on pro-life health care professionals continues.

Funding "Complex Family Planning" Fellowships

By 2015, Bixby was granting $25 million annually to fund education and training for the 52 FFP enrollees and 90 Ryan Programs.[22] Tax records indicate that the abortion advocate Susan Thompson Buffett Foundation donates to many of the universities that host the Ryan Program.[23] In addition, the Susan Thompson Buffet Foundation has been identified as a funder of the secret charity aggregator;[24] funders may also include the Bill & Malinda Gates Foundation,[25] the David & Lucile Packard Foundation,[26] and the William & Flora Hewlett Foundation.[27]

ABOG projects that the current 26 FFP directors will become the first CFP fellowship faculty and that the fellowship will expand to a total of 67 academic health centers within 5 years. ABOG estimated the cost for each FFP fellow to complete two years of training at $240,000-$280,000.[15] The projected expansion would create a total of 134 CFP fellowship positions at an annual cost of $16 million-$19 million. Such a large number of abortion subspecialists will be required to staff faculty positions for both the projected 115 Bixby Ryan programs and the 67 CFP fellowship training programs.[15]

Extrapolation from the ABOG financial projections and Bixby financial statements indicate that the current Bixby burden for the 26 FFPs programs is at least $6.2 million and its burden for the 90 Ryan Programs is at least $18.8 million. The CFP fellowship is required to have oversight, and the Bixby/FFP faculty embedded in the Ryan programs will become oversight faculty for the CFP fellowship programs. ABOG neglected to include these additional 67 faculty positions in its projected budget when it submitted its application for the new CFP subspecialty to ACGME. Although the average OB-GYN faculty compensation in 2018 was $386,300,[28] Bixby generously granted its Ryan Program faculty $478,725 annually. Within 5 years, these 67 faculty positions will burden the CFP fellowship with an additional $32 million annually. The projected annual public burden for the CFP subspecialty fellowship is $48 million-$51 million. The Ryan Program and the FFP program, currently privately funded initiatives, are about to become taxpayer liabilities.

Since the establishment of Medicare in 1965, the federal government has financed GME. The 1997 Balanced Budget Act capped the number of residents that Medicare pays for in all participating hospitals at 110,000.[29] Even though medical schools have increased enrollment by nearly 30% since 2002, the 110,000 resident cap on Medicare GME support is still in place. Subspecialty fellowships compete with residency training programs for these slots. If the CFP fellowship training programs are unable to obtain the required residency slots, they will not be able to access Medicare GME funding and will have to be privately funded.

Unused residency slots could not be redistributed previously. But the ACGME and ACOG influenced the drafting of The Affordable Care Act to include provisions to allow a re-distribution of GME residency slots and to ensure that these unused residency slots will only be re-distributed to primary care and general surgery residency programs for the next five years. ACOG, ABOG and ACGME have enabled

OB-GYN to be statutorily defined as primary care. Teaching hospitals often shoulder higher patient care costs because of higher staffing levels, advanced services and equipment, and a sicker patient population. To compensate for additional costs, teaching hospitals also receive Indirect Medical Education payments from Medicare, and this applies to re-distributed residency slots as well.[30] ACOG is working with the ACGME and ABOG to corral these re-distributed residency slots for the CFP fellowship. They are also working to create and capture re-distributed slots as they force the closure of faith-based community hospital OB-GYN residency training programs.

With its $3 million annual lobbying budget, ACOG is a heavyweight in Washington D.C. To make more slots available for the new federally funded CFP fellowship training programs, it is pushing the 116th Congress (2019-2020) to pass the Resident Physician Shortage Reduction Act (S.348; H.R.1763) that would increase the number of primary care residency slots. Of course they are doing this surreptitiously; the proposed legislation even has pro-life co-sponsors in both the House and Senate.

Conclusion

Since all obstetricians and gynecologists have been trained to manage miscarriage and fetal demise at all gestational ages, there is no scientific purpose to mandate training in induced abortion of a viable fetus. Instituting the new ABOG abortion subspecialty, Complex Family Planning, will further violate the conscience rights of medical students and resident physicians by forcing them to participate in performing abortions. Taking advantage of the *Blütkeit* phenomenon, elite academic abortionists violate the innocence of young professionals. They force them to be complicit in committing atrocities, victimizing vulnerable girls and women. This rite of initiation ensures their shared responsibility and diminishes the possibility of subsequent moral dissent.

References

1. Desai S, Jones RK, Castle K. Estimating abortion provision and abortion referrals among United States obstetrician-gynecologists in private practice. *Contraception* 2018;97(4):297-302. doi:10.1016/j.contraception.2017.11.004
2. Stuhlberg DB, Dude AM, Dahlquist IA, Curlin FA. Abortion provision among practicing obstetrician-gynecologists. *Obstet Gynecol* 2011;118: 609-614. doi:10.1097/AOG.0b013e31822ad973
3. Wendell GT. ABOG: letter to ACGME. 09 Nov 2018. Retrieved from: https://acgme.orgv/Portals/0/PFAssets/ProposalReviewandComment/Complex_Family_Planning_LOIandProposal.pdf . Accessed 15 Mar 2019.
4. Bazelon E.The new abortion providers. *The New York Times Magazine*. 14 July 2010. Retrieved from: https://www.nytimes.com/2010/07/18/magazine/18abortion-t.html Accessed 15 Mar 2019.
5. Bixby Center for Global Reproductive Health. Kenneth J Ryan residency training program in abortion and family planning. Retrieved from: https://intranet.bixbycenter.ucsf.edu/training/training/kenneth_j_ryan_training.html . Accessed 15 Mar 2019.
6. Guiahi M, Lim S, Westover C, Gold M, Westhoff CL. Enablers of and barriers to abortion training. J Grad Med Educ 2013;5(2):238-243. doi:10.4300/JGME-D-12-00067.1 PMC3693687, Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3693687/ Accessed 15 Mar 2019.
7. Carey A. Ryan residency training program funded by billionaires to mainstream abortion. 05 Feb 2018. Retrieved from: https://www.churchmilitant.com/news/article/secretive-residency-program-

pressures-residents-to-perform-abortions Accessed 15 Mar 2019.

8. Steinauer JE, Hawkins M, Turk JK, Darney P, Preskill F, Landy U. Opting out of abortion training: benefits of partial participation in a dedicated family planning rotation for ob-gyn residents. *Contraception* 2013; 87:88-92. Retrieved from: https://www.contraceptionjournal.org/article/S0010-7824(12)00812-8/pdf, Accessed 15 mar 2019.
9. ACOG Committee Opinion No. 612: abortion training and education. *Obstet Gynecol* 2014;124(5):1055-1059. doi:10.1097/01.AOG.0000456327.96480.18
10. Steinauer JE, Turk JK, Pomerantz T, Simonson K, Learman LA, Landy U. . Abortion training in US obstetrics and gynecology programs. *Am J Obstet Gynecol* 2019;219(1):86e1-86e6. doi:10.1016/j.ajog.2018.04.011, Retrieved from https://www.ajog.org/article/S0002-9378(18)30292-8/fulltext, Accessed 15 Mar 2019.
11. Turk JK, Preskill F, Landy U, Steinauer JE. Availability and characteristics of abortion training U.S. ob-gyn residency programs: a national survey. *Contraception* 2014;89(4): 271-277. doi:10.1016/j.contraception.2013.12.002
12. Rayburn WF, *The obstetrician-gynecologist workforce in the United States: facts, figures, and implications, 2017.* American Congress of Obstetricians and Gynecologists. Washington DC. Retrieved from https://m.acog.org/~/media/BB3A7629943642ADA47058D0BDCD1521.pdf, Accessed 15 Mar 2019.
13. Guiahi M, Hoover J, Swartz M, Teal S. Impact of Catholic hospital affiliation during obstetrics and gynecology residency on the provision of family planning. *J Grad Med Educ* 2017;9(4):440-446. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5559237/ Accessed 15 Mar 2019.
14. Association of American Medical Colleges. *Graduate Medical Education Primers: Residency Caps.* Retrieved from: https://www.aamc.org/advocacy/gme/, Viewed at: https://vimeo.com/130906132. Accessed 15 Mar 2019.
15. Wendel GD, American Board of Obstetricians and Gynecologist (ACOG). *Application for a subspecialty certificate.* Submitted to American Board of Medical Specialties (ABMS). 15 May 2018. Retrieved from: https://www.abms.org/media/194715/abms-application-for-subspecialty-certificate-20180515.pdf Accessed 15 Mar 2019.
16. Schaeffer FA, Koop CE. *Whatever Happened to the Human Race?* Crossway Publisher, Wheaton, IL. 1983. Retrieved from: https://books.google.com/books?id=9ww-Zvp8FYMC&pg=PA20&lpg=PA20&dq=upjohn+abortion&source=bl&ots=2hTeHEYYSB&sig=ACfU3U0bW5mF1wjKQNEFZQZ9vEHATHAc2w&hl=en&sa=X&ved=2ahUKEwibxNTjyYPkAhURvZ4KHWfkAuY4ChDoATAJegQICRAB#v=onepage&q=upjohn%20abortion&f=false Accessed 05 Aug 2019.
17. Civ. No. 26376. Court of Appeals of California, Fourth Appellate District, Division One. July 19, 1983. Retrieved from: https://law.justia.com/cases/california/court-of-appeal/3d/145/72.html, Accessed 05 Aug 2019.
18. ACOG Membership Services Department. Frequently asked questions. Retrieved from:https://www.acog.org/About-ACOG/ACOG-Departments/Membership-Services/Frequently-Asked-Questions?IsMobileSet=false#lobbying, Accessed 05 Aug 2019.
19. Mattox MC, Bowman M. Your conscience, your right: a history of efforts to violate pro-life medical conscience, and the laws that stand in the way. *Linacre Q* 2010;77(2):87-197. doi:10.1179/002436310803888754 Retrieved from: https://www.tandfonline.com/doi/pdf/10.1179/002436310803888754, Accessed 15 Mar 2019.
20. ACOG Committee Opinion No. 385: The limits of conscientious refusal in reproductive medicine. 2007, reaffirmed 2019. Retrieved from:https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Ethics/The-Limits-of-Conscientious-Refusal-in-Reproductive-Medicine Accessed 15 Mar 2019.
21. RE: Committee Opinion #385: Noller, K. ACOG, under fire, vows to review conscience opinion. *Relias Media*. 01 June 2008, Retrieved from: https://www.reliasmedia.com/articles/12780-acog-under-fire-vows-to-review-conscience-opinion Accessed 05 Aug 2019. See also: https://aaplog.org/march-26-2008-letter-from-then-acog-president-noller-to-fellows/
22. Bixby Center for Global Reproductive Health. Annual report 2014-2015. Retrieved from: https://bixbycenter.ucsf.edu/2014report Accessed 15 Mar 2019.

23. Mincer J. Amid clinic closures, young doctors seek abortion training. *Reuters Health Notes.* 11 April 2016. Retrieved from: https://www.reuters.com/article/us-usa-abortion-providers-insight/amid-clinic-closures-young-doctors-seek-abortion-training-idUSKCN0X80ZR Accessed 15 May 2019.
24. Craine PB. Buffett secretly spending million on abortion med-school scheme. *Catholic Online* 2010. Retrieved from https://www.catholic.org/news/national/story.php?id=37450, Accessed 15 May 2019.
25. Bixby Center. Gates Foundation pledges $1.5 billion – did Bixby play a policy role? *Bixby Center for Population, Health & Sustainability.* 30 June 2010. Retrieved from: https://bixby.berkeley.edu/gates-foundation-pledges-1-5-billion-did-bixby-play-a-policy-role/ Accessed 05 Aug 2019.
26. Kopp T. Population and reproductive health. *The David and Lucile Packard Foundation.* 2013. Retrieved from: https://www.packard.org/about-the-foundation/our-people/bio/teresa-kopp/, Accessed 15 May 2019.
27. Grants UCSF: for support of the Bixby Center for Global Reproductive Health Research and Policy. *William and Flora Hewlett Foundation.* 2019. Retrieved from https://hewlett.org/grants/university-of-california-at-san-francisco-for-support-of-the-bixby-center-for-global-reproductive-health-research-and-policy/ Accessed 05 Aug 2019.
28. Kalter L. Faculty salaries increased 2.7% in 2018. *AAMC News.* 11 Jan 2019. Retrieved from: https://news.aamc.org/patient-care/article/faculty-salaries-increased-27-2018/ Accessed 05 Aug 2019.
29. Salsberg E, Rockey PH, Rivers KL, et al. US residency training before and after the 1997 Balanced Budget Act. JAMA 2008;300(10):1174-1180. doi:10.1001/jama.300.10.1174, Retrieved from: https://jamanetwork.com/journals/jama/fullarticle/182532. Accessed 15 May 2019.
30. Association of American Medical Colleges. *Graduate Medical Education Primers: Indirect Medical Education (IME) Payments.* Retrieved from: https://www.aamc.org/advocacy/gme/ Viewed at: https://vimeo.com/130906134, Accessed 15 Mar 2019.

Patrick Marmion, PhD, MPH, FACPM, is an Associate Clinical Professor at Washington State University's Elson S. Floyd College of Medicine. He is a Diplomate of both the American Board of Preventive Medicine and the National Board of Physicians and Surgeons. Prior to relocating to the Pacific Northwest, he was the Executive Director and Chief Medical Officer at Healthy Beginnings, a pro-life perinatal health care center, where he received several awards for innovation from The Health Foundation of Greater Cincinnati. He has been a member of the Maternal Mortality Review Board for the State of Washington since 2017, and he serves on the Medical Advsory Committee for the Pregnancy Resource Centers of Greater Portland. The views expressed herein do not necessarily reflect the positions of the professional organizations with which he is affiliated. He currently resides in Battle Ground, Washington, USA.

GREY MATTERS

Cerebral Organoids and the Threshold of Consciousness

WILLIAM P. CHESHIRE, JR., MD

We cannot confidently conclude that cerebral organoids will forever continue to have no consciousness. – Sawai et al.[1]

Abstract

Cerebral organoids—tiny, primitive, brain-like structures derived from human stem cells—represent a new paradigm for neuroscience. These clusters of neurons are living models for understanding brain diseases at the molecular level without placing human subjects at risk. Some believe they may be a pivotal step toward the elusive goal of repairing injured brains and spinal cords. Recent advances in organoid science have raised ethical questions regarding how this innovative research should be guided and whether limits should be placed. Until recently, it was thought that cerebral organoids lack the intrinsic potential to develop self-awareness, the capacity to feel pain or suffer, or the ability to interact with the external environment. Now we are told that the possible development eventually of such capacities can no longer be excluded, given the trajectory of some lines of current research that seek to generate cerebral organoids that mimic as closely as possible the structure and function of the mature human brain. Whether maximizing cerebral organoids' scientific utility would inevitably cross the moral boundary of creating conscious entities is difficult to forecast. How to think about sentient cerebral organoids is a question wrapped in a quandary entangled within a conundrum.

Introduction

Organoids are self-organizing, three-dimensional cellular structures that resemble, both in structure and in function, tissue-specific phenotypes. They are grown in a dish in the laboratory from fetal or adult stem cells, or they can be generated from directed differentiation of human inducible pluripotent stem cells. Human cerebral organoids recapitulate on a miniature scale the development of the most complex of organs—the human brain. As compared to two-dimensional layers of cultured neurons and animal models that have traditionally been used as laboratory surrogates for human brain research, cerebral organoids represent an exciting new construct for the study of early human brain development, brain diseases, and drug effects on the brain at the morphological, macromolecular, genetic, and epigenetic levels.[2,3]

In what may have been the first published paper to address the ethical implications of human cerebral organoids, this writer argued in 2014 that their creation is ethically permissible and that their use in neuroscience toward the goal of discovering new medical treatments is ethically praiseworthy.[4] Concerns about the potential moral significance of functioning human brain tissue independent of a body were eliminated, I reasoned, because the upper limit for growth of cerebral organoids

was only 4 mm, precluding any possibility of development beyond the very earliest stages of neurodevelopment. That was then.

Current Status

Six years later, notable advancements have occurred in techniques to direct cerebral organoids to self-organize into specific early-stage brain structures. Researchers at a number of centers have induced stem cell aggregates to develop in ways that resemble the cerebral cortex, thalamus, hypothalamus, ventral telencephalon, optic cup, anterior pituitary, hippocampus, and cerebellum.[1] When human embryonic stem cell-derived organoids resembling the developing thalamus were fused with cerebral cortex organoids, reciprocal neural connections formed, providing evidence that cerebral organoids can recapitulate at least some types of structural circuits between cerebral regions as occurs in the brain.[5]

Another set of experiments cultured human embryonic stem cell-derived cerebral organoids at an air-liquid interface, supplying neurons with improved access to oxygen and extending their survival up to a year. They exhibited a high degree of intrinsic organization that matched the tissue architecture and molecular identities of corresponding brain tissue, as well as demonstrating axonal outgrowth and formation of neural networks. Further, they grew long-range projections reminiscent of nerve tracts that established functional connectivity with external targets. When human cerebral organoids were cultured along with sections of spinal columns dissected from embryonic mice, they formed synaptic connections with the mouse spinal cord neurons, and electrical stimulation of the human cerebral organoids evoked concerted contractions of the paraspinal mouse muscles.[6]

The lack of supporting structures such as meninges and a vascular supply to deliver oxygen, until recently, have placed a limit on further growth and differentiation of cerebral organoids. Several research groups have exceeded that limitation by grafting cerebral organoids derived from human embryonic stem cells into the brains of adult mice.[7,8] These grafted organoids integrated readily into their host brains, acquired vascularization from the host, differentiated further, sprouted axonal outgrowths, and formed lasting neuronal circuits with functioning graft-to-host synaptic connectivity. Chimeric models such as these may potentially lead to strategies for human neural repair.

The neuroscientist Madeline Lancaster, who first developed human cerebral organoids, has said, "We like to think of them as mini-brains on the move."[9] Accordingly, the neuroethics calibration must adjust to consider cerebral organoids' growing potential for longevity, complexity, connectivity, and functionality.[10-13]

The Question

At the biological level, we may start by asking this hypothetical question: could a sufficiently complex human cerebral organoid attain consciousness? On the surface this seems a simple question, but on closer examination it leads to deeper questions of what kinds of molecular or cellular complexity matter in the emergence of mind, whether or what forms of interaction with the outside world are necessary for

consciousness, and what empirical tests could validate the presence of consciousness, or exclude it.

Regarding the biologic criteria for defining consciousness, no consensus has formed. The problem is analogous to detecting objective signs of minimal consciousness in a comatose patient who might have subjective thoughts and emotions, yet no one can know this for certain because the patient is neurologically disconnected from the outside world and, even if conscious at some level, cannot communicate to others. Evidence of conscious awareness in a severely brain-injured patient who has lost the ability to speak consists of detecting behavioral signs of understanding, such as consistent yes or no responses to spoken or written questions. Functional magnetic resonance imaging (fMRI) has shown that some severely brain-injured patients retain islands of functioning cerebral cortex isolated from the rest of the brain.[14,15] Whether these islands of preserved neurons harbor hidden conscious thoughts in some patients is a question that no current test can answer consistently or conclusively in the clinical environment. In the research setting, fMRI, electroencephalography (EEG), and transcranial direct current stimulation have suggested that some comatose patients are aware, despite their absence of behavioral responsiveness.[17,18] Detecting covert consciousness must rely on indices of brain function that are independent of executive function or motor output, such as detecting markers of mental imagery or retained language processing.[15,16] These markers may be inconclusive if intentionality cannot be shown.

Detecting covert consciousness would be considerably more problematic on the small scale of organoids. Whether a cellular arrangement only a few millimeters in size could develop the kind of thoughts, sense of existence, or agency that would be recognizable as human seems improbable. It seems reasonable to assume that a much greater number of neurons would be required to receive, store, and process the minimal amount of information needed to produce abstract thought or to represent meaning. As techniques become available to grow larger and more complex cerebral organoids, size constraints might eventually cease to be a barrier. If there is a lower limit on the number of neurons needed to form the biological substrate needed for human thought to emerge, this limit is unknown and might not be scientifically or ethically verifiable.[19]

Instruments for detecting minimal consciousness in the adult human brain would not seamlessly translate to detecting microscopic consciousness on the much smaller scale of cerebral organoids. EEG electrodes are designed to detect changes in electromagnetic potentials over several centimeters of spatial resolution and only over the cerebral cortex surface. Much smaller sensors would be needed to detect signs of sentience in organoids. Deeper probing of neural function with microelectrodes would take detection of minimal consciousness a step further, but not without mechanical disruption of organoid cells. Confocal microscopic imaging of intracellular calcium dynamics has shown preliminary promise as a noninvasive method to detect inducible, dynamic neuronal activity patterns at the organoid level.[20]

The latest method for detecting minimal consciousness in severely brain-injured adults utilizes computer models to assess the complexity and responsiveness of neural networks to transcranial magnetic stimulation.[21-23] This approach, which assigns a probability of consciousness based on a calculated perturbational complexity index,

may hold promise as a potential test of emerging consciousness in cerebral organoids.[24] Unresolved, however, is how criteria for recognizing consciousness should take into account the developmental asymmetry of the two subjects. Consciousness in a cerebral organoid might look very different from residual consciousness in a brain-injured adult. Personal history, relationships experienced, and knowledge acquired may be important aspects of the phenomenon of consciousness in an adult. Incomplete consciousness in dissolution might look very different than incomplete consciousness in development. Tests designed to detect glimmers of fading consciousness might not be applicable to the detection of emerging consciousness.

Finally, there is the question of what defines an organism. By biologic criteria, cerebral organoids are parts, not entities. They are not whole organisms, for they cannot exist independently. If integrated into a compatible host organism, an organoid may differentiate, grow, and form connections, deriving oxygen and nutrients from its host, but those conditions are insufficient to categorize the organoid as a parasitic *organism*, for it has no continued life of its own beyond the host, and its behavior is not oriented toward reproduction of its kind. Organoids are artificial cellular aggregates, having been fashioned by the hand of science, albeit using natural cells and their innate developmental programming.

An apt conceptual model for the organoid is the transplant. If cerebral organoids ever were to attain consciousness, it would most likely be as transplants, drawing from the metabolic resources and neural connectivity available within a host nervous system to develop the complexity required for consciousness. In the medical field of human organ transplantation, the transplanted organ retains its original genetic identity, but no one thinks of a transplanted kidney, lung, or liver as having individuality in its own right. The transplant becomes part of the host into which it is integrated. The transplanted organ also retains its original function, supplying an organic function that the host had lost, which is why an organ transplant is useful to the host.

Consider, then, the cerebral organoid in which its useful function is neural information processing and signaling. If a cerebral organoid comprising a sufficiently complex and organized collection of neurons transplanted into a host were to become capable of thought, would its thoughts be those of the host or of the organoid?

What if the host were a nonhuman animal? Ethical concerns have been raised regarding the creation of human-animal chimeras using human cerebral organoids. Interestingly, more concerns have been raised about the potential "humanization" of host animals than about the potential humanness of transplanted cerebral organoids thinking within an animal brain.[25] Conferring enhanced cognitive capacity to animals could alienate them from their natural environments, rendering them incompatible or in conflict with other animals and humans. No less a moral concern would be the prospect of a human consciousness imprisoned within an animal brain and body, if such a project is possible outside of science fiction.

The Quandary

Still unsettled among philosophers is the question: what exactly is consciousness? Three aspects may be identified. First is awareness through the senses of the external environment, which includes knowledge of tactile, visual, and auditory stimuli and

spatial and temporal relationships. It also includes the ability to feel pain. Whereas disease can impair or obliterate any of these senses, the person's consciousness retains the potential to receive sensory information if inputs are present. Second is phenomenal consciousness, which includes the ability to suffer, to reason, to store and retrieve memories. Third is self-awareness, including one's concept of self, ownership of one's thoughts, and personal identity over time. Related to it is awareness of other persons and the capacity to form emotional and intellectual relationships. Philosophers debate the moral relevance of all of these aspects, and ethicists debate how the philosophical assessment translates to society's moral obligations to the conscious and the partly conscious.

The prospect of creating advanced cerebral organoids proliferates the ambiguities and uncertainties surrounding definitions of consciousness. Many questions arise. Is it possible that, under certain conditions, a sufficiently complex and organized cerebral organoid could develop consciousness? Would it thereby become an organism? A person? Must a mind have a body? Is consciousness unitary, or can it be divided? Would a conscious cerebral organoid within a host brain be a separate consciousness? In theory, and perhaps in future practice, could pieces of organisms be independently conscious? Could they be moral agents?[26] Added to the theoretical problem of defining consciousness is the practical problem of detecting or excluding it in an advanced cerebral organoid.

How healthcare professionals, scientists, philosophers, and the public think about consciousness in adults shapes ways of thinking about the possibility of emerging consciousness in advanced cerebral organoids. Conversely, how we use and think about human cerebral organoids going forward could potentially reshape how society thinks about consciousness in impaired or brain-injured adults and children.

Chimeras represent a further ethical challenge. If two consciousnesses can exist within one organism, is it possible for one to be human and the other not? What defines uniquely human consciousness?

The Conundrum

The essence of the cerebral organoid ethical conundrum is the question of whether it is possible to engineer a brain-like entity to which society would have no moral obligation. From a scientific perspective, the perfect human cerebral organoid would be a functioning brain without the capacity to be a mind, an intellect that is not a person.

If moral significance does not attach to sheer neural information-processing, even if it rises to the level of thought, but requires something more, be it self-awareness, abstract thought, or the capacity to create or suffer, then clarifying what is morally significant takes on increasing ethical urgency as cerebral organoid research advances.

Predominant philosophical approaches to the brain-mind problem are either bottom-up or top-down. A bottom-up physicalist approach considers the mind to emerge once the brain has reached a certain threshold of complexity.[27,28] A top-down essentialist approach considers the mind and brain to be ontologically coexistent from the onset of development.[29,30] Which of these approaches one prefers may determine

where one chooses to place limits on growing cerebral organoids. A difficulty with the physicalist approach is defining or recognizing the threshold for emergence, particularly if the development of consciousness precedes the possibility of detecting it. A difficulty with the essentialist approach is identifying by biologic criteria the moment of conception of the hypothetical thinking organoid, if conception is even the right concept for an entity that is not an organism.

Efforts to grow more advanced human cerebral organoids seek to create an entity that would be a *tertium quid*, literally a "third thing" intermediate between a human person and an inanimate thing, a living brain-like construct pulsing with thought but which could be treated instrumentally as a physical thing to do with what one wishes. It is not clear that such a category exists or could exist any more than can a two-sided triangle. More than a biotechnological problem, constructing a *tertium quid* is a philosophical conundrum.

It is impossible for the scalpel of biotechnology to sever the moral mind from the mature biological brain. The advancing technological scalpel inevitably encounters an impenetrable moral obstacle, in that the closer one gets to crafting a collection of neurons sufficiently organized to have capacity for higher brain function, the closer one comes to creating an intelligence, and self-aware intelligence is tantamount to personhood. If the utility of more advanced cerebral organoids were to lie in their capacity to think, then some form of moral obligation to them seems inescapable. What form of obligation that would be is a perplexingly problematic question if the subject is not an individual but an incomplete or partial organism of a kind that has never before existed.

Utilitarian ethical approaches typically bypass the unresolved moral question of the status of the brain-like entity and justify creating as many of them as necessary to make possible research that would have the laudable objective of reducing human suffering. Such arguments are frequently advanced in regard to human embryo research. Whereas relieving suffering is a compelling goal, it is not an absolute ethical principle. A complete ethical assessment recognizes on independent grounds that intentionally creating entities that are known to be self-conscious only to use and then destroy them would be *prima facie* a moral wrong.

Cerebral organoid experiments that generate human-animal chimeras elevate the conundrum exponentially. The prospect of breeding nonhuman animals with cognitive capacity that is partly or wholly biologically human would be exceedingly disturbing. Enhancing the intelligence of nonhuman animals beyond species-typical norms or conferring human-like cognitive capacities by introducing human neurons into an animal brain would create a host of problems for which we are unprepared.

The Choice

There are at least three ways to categorize the hypothetical human cerebral organoid that has advanced to a state of having thought. Each has further implications. One way would be to include such an entity within the human community just as a human embryo is correctly understood to be a nascent human being. However, although such organoids would have biological similarities to developing humans, they lack key biological attributes. Organoids are not pluripotent. They lack essential supporting tissues necessary for human development. They lack the capacity to reproduce others

of their kind. They are incapable of reaching full cerebral development. Ontologically, their human parentage may be singular, or, in the case of chimeras, their gestation may be nonhuman. These objections seem to be valid reasons not to consider human cerebral organoids to be humans deserving of moral status.

A second option is to group them with all other solid organs used for transplantation. Under this option it would make no moral difference whether a specimen of tissue were a kidney, a liver, or a brain-like entity. In response, it must be remembered that the brain is unlike any other organ. It is the organ of thought. Destroy the brain, and there are no longer signs of consciousness, abstract thought, or personal identity. An organoid may be less than a brain, but it is nevertheless a partial construct of the organ of thought and for this reason deserves special consideration.

A third option is to consider human cerebral organoids as morally special on the basis of the unique status of the human brain to which they aim in development and which they approximate in structure and function. If allowed to develop and differentiate and form sufficiently complex connections, human cerebral organoids may harbor the potential for information-processing that might be regarded as human thought. Further, it may become possible eventually to construct cerebral organoids having limited sentience, perhaps even able to process abstract thought. The prospect of designing thinking cells that are not living beings is a novel category made plausible in our time by the advent of the computer. Thinking machines can beat human chess masters but are not, at least yet, afforded moral status as persons.

There are further aspects to human cerebral organoid thought that would be fundamentally different from human thought. Cerebral organoids lack a human body. Without human eyes, ears, fingers, voices, or hearts, they could not experience the world as humans do. If human cerebral organoids were transplanted into nonhuman animals and integrated into their brains, human neuronal structures might then experience life as an animal does. To devise a chimeric brain composed of human and animal neurons interconnected and functioning as a conscious human mind within an animal body would be a cruel experiment, whether it lived or died. Sedating such creatures with anesthetic agents to suppress consciousness while continuing to experiment on them, as members of a university workshop have suggested,[31] would not obviate the moral problem.

Animal brains enhanced with human neurons might aspire to more than they can know through animal instincts. On the other hand, newfound human cleverness might make them dangerously cunning in pursuit of their natural instincts. A society that allowed the creation of such chimeras could incur enormous moral obligations on their behalf along with unanticipated ills. Bringing into being such creatures would also denigrate the image of God, which humans uniquely bear.

How many neurons it would take to generate a human thought is a question that no mathematical formula can adequately answer. In what configuration or at what stage of development a cerebral organoid would begin to have limited sentience might be detectable with future technology, but probably not in advance of the threshold being reached and the problem already upon us. Ethical decisions to guide cerebral organoid research cannot wait for these questions to be answered definitively. There may be no more difficult question in current neuroethics than what to do with wondrous wisps of grey matter that want to become brains.

References

31. Sawai T, Sakaguchi H, Thomas E, et al. The ethics of cerebral organoid research: being conscious of consciousness. *Stem Cell Reports* 2019; 13(3): 440-447.
32. Mahe MM. Engineering a second brain in a dish. *Brain Research* 2018; 1693: 165-168.
33. Liu F, Huang J, Zhang L, et al. Advances in cerebral organoid systems and their application in disease modeling. *Neuroscience* 2019; 399: 28-38.
34. Cheshire WP. Miniature human brains: an ethical analysis. *Ethics & Medicine* 2014; 30(1): 7-12.
35. Xiang Y, Tanaka Y, Cakir B, et al. hESC-derived thalamic organoids form reciprocal projections when fused with cortical organoids. *Cell Stem Cell* 2018; 24: 487-497.
36. Giandomenico SL, Mierau SB, Gibbons GM, et al. Cerebral organoids at the air-liquid interface generate diverse nerve tracts with functional output. *Nature Neuroscience* 2019; 22: 669-679.
37. Mansour AA, Gonçalves JT, Bloyd CW, et al. An in vivo model of functional and vascularized human brain organoids. *Nature Biotechnol* 2018; 36: 432-441.
38. Daviaud N, Friedel RH, Zou H. Vascularization and engraftment of transplanted human cerebral organoids in mouse cortex. *eNeuro* 2018. doi:10.1523/ENEURO.0219-18.2018
39. Devlin H. Scientists grow "mini-brain on the move" that can contract muscle. *The Guardian* March 18, 2019.
40. Dockrill P. We are "perilously close" to creating sentient mini-brains in a dish, experts warn. *Science Alert*, October 22, 2019. Accessed at: https://www.sciencealert.com/we-are-perilously-close-to-creating-sentient-human-like-mini-brains-experts-warn
41. Edwards C. Scientists worry lab-grown human "mini-brains" may become sentient. *New York Post*, October 22, 2019. Accessed at: https://nypost.com/2019/10/22/scientists-worry-lab-grown-human-mini-brains-may-become-sentient/
42. Sample I. Growing brains in labs: why it's time for an ethical debate. *The Guardian*, April 25, 2018. Accessed at: https://www.theguardian.com/science/2018/apr/25/growing-brains-in-labs-why-its-time-for-an-ethical-debate
43. Sample I. Scientists "may have crossed ethical line" in growing human brains. *The Guardian*, October 20, 2019. Accessed at: https://www.theguardian.com/science/2019/oct/21/scientists-may-have-crossed-ethical-line-in-growing-human-brains
44. Kondziella D, Friberg CK, Frokjaer VG, et al. Preserved consciousness in vegetative and minimal conscious states: systematic review and meta-analysis. *J Neurol Neurosurg Psychiatry* 2016; 87: 485-492.
45. Coleman MR, Rodd JM, Davis MH, et al. Do vegetative patients retain aspects of language comprehension? Evidence from fMRI. *Brain* 2007; 130: 2494-2507.
46. Gosseries O, Di H, Laureys S, Boly M. Measuring consciousness in severely damaged brains. *Annu Rev Neurosci* 2014; 37: 457-478.
47. Gibson RM, Fernandez-Espejo D, Gonzalez-Lara LE, et al. Multiple tasks and neuroimaging modalities increase the likelihood of detecting covert awareness in patients with disorders of consciousness. *Front Hum Neurosci* 2014 Nov 26; 8: 950. doi:10.3389/fnhum.2014.00950
48. Thibaut A, Chatelle C, Vanhaudenhuytse A, et al. Transcranial direct current stimulation unveils covert consciousness. *Brain Stimul* 2018; 11: 642-644.
49. Cheshire WP. The moral musings of a murine chimera. *AJOB Neurosci* 2007; 7(5): 49-50.
50. Sakaguchi H, Ozaki Y, Ashida T, et al. Self-organized synchronous calcium transients in a cultured human neural network derived from cerebral organoids. *Stem Cell Reports* 2019; 13(3): 458-473.
51. Casarotto S, Comanducci A, Rosanova M, et al. Stratification of unresponsive patients by an independently validated index of brain complexity. *Ann Neurol* 2016; 80: 718-729.
52. Casali AG, Gosseries O, Rosanova M, et al. A theoretically based index of consciousness independent of sensory processing and behavior. *Sci Transl Med* 2013 Aug 14: 5(198):198ra105. doi:10.1126/scitranslmed.3006294
53. Comolatti R, Pigorini A, Casarotto S, et al. A fast and general method to empirically estimate the complexity of brain responses to transcranial and intracranial stimulations. *Brain Stimul* 2019; 12: 1280-1289.

54. Lavazza A, Massimini M. Cerebral organoids and consciousness: how far are we willing to go? *J Med Ethics* 2018; 44: 613-614.
55. Chen HI, Wolf JA, Blue R, et al. Transplantation of human brain organoids: revisiting the science and ethics of brain chimeras. *Cell Stem Cell* 2019; 25(4): 462-472.
56. Hostiuc S, Rusu MC, Negoi I, et al. The moral status of cerebral organoids. *Regen Ther* 2019; 10: 118-122.
57. Jeeves M. *From Cells to Souls and Beyond: Changing Portraits of Human Nature*. Grand Rapids, MI: Eerdmans, 2004.
58. Brown WS, Murphy NC, Malony HN. *Whatever Happened to the Soul?: Scientific and Theological Portraits of Human Nature*. Minneapolis, MN: Fortress Press, 1998.
59. Moreland JP, Rae SB. *Body & Soul: Human Nature & the Crisis in Ethics*. Downer's Grove, IL: InterVarsity, 2000.
60. Aiken DW (2004) Why I am not a physicalist: a dialogue, a meditation, and a cumulative critique. *Christian Scholar's Review* XXXIII (2): 165-180.
61. Farahany NA, Greely HT, Hyman S, et al. The ethics of experimenting with human brain tissue. *Nature* 2018; 556: 429-432.

William P. Cheshire, Jr., MD, MA, is Professor of Neurology at the Mayo Clinic in Jacksonville, Florida. He is also Senior Fellow in Neuroethics at the Center for Bioethics & Human Dignity. In 2019, the Christian Medical & Dental Associations awarded him Educator of the Year. The views expressed herein are his own and do not necessarily reflect the positions of the professional organizations with which he is affiliated. He currently resides in Ponte Vedra Beach, Florida, USA.

The Tennessee Center for Bioethics & Culture

Creative, provocative resources promoting human dignity

www.tennesseecbc.org

CLINICAL ETHICS DILEMMA

Daring to Deploy a DNR Directive[1,2]

ROBERT D. ORR, MD, CM; FERDINAND D. YATES, JR, MD, MA (BIOETHICS)

Editor's Note: *This column presents a problematic case, one that poses a medical-ethical dilemma for patients, families, and healthcare professionals. As this case is based on a real medical situation, identifying features and facts have been altered in this scenario to preserve anonymity and to conform to professional medical standards. In this case, the family has difficulty in establishing the placement of a DNR for the patient.*

Column Editor: Ferdinand D. Yates Jr, MD, MA (Bioethics) is a medical staff member at Children's Healthcare of Atlanta and has a private pediatric practice in the Atlanta area.

Question

Is it permissible to write a DNR order for this patient when her 5 children are not in agreement?

Story

Mildred is 70 years old and has a history of diabetes and hypertension. She was admitted to the hospital with a heart attack nearly two months ago, and she had coronary artery by-pass surgery four days after admission. She has been in the ICU since surgery because of multiple complications, mostly involving her lungs. At one time, she was off the ventilator for a few days, but it had to be resumed. Her pulmonary status has recently worsened in spite of continued full treatment. Her ICU and consulting physicians are convinced she will not be able to wean from the ventilator and are recommending a Do Not Resuscitate (DNR) order now with consideration of withdrawal of support soon.

The patient has no written advance directive, and her ability to communicate during her prolonged ICU stay has fluctuated. Her daughter, Betsy, reports that on admission she said she wanted full treatment "temporarily," without elaboration about what that meant. Discussions between the ICU team and her five adult children have concluded that she probably would not want long-term ventilator support, but there is lack of consensus on approval of a DNR order, with two of them adamantly believing she should have "one more chance." Ethics consultation was requested by her social worker to try to resolve this conflict.

The patient has been a housewife all her adult life and has been widowed for 16 years. Her husband was a telephone lineman. She lives alone, next door to Betsy. She has been active and social, quilting and playing cards, a Methodist who has not recently been active in church. The social worker reports that there has been some significant family stress during the past 18 months, apparently involving property, finances, and responsibilities.

Her nurse reports that Mildred has been unable to engage in meaningful conversation most days, but she is more alert today than she has been recently. I spoke with her, in the presence of Betsy and her nurse. I explained my understanding of her condition and prognosis. She agreed that if she should deteriorate with continued treatment, she would not want to be resuscitated. She seemed to newly understand the choice between long-term ventilator support or withdrawal of life support, but she is not ready to make a decision to limit or withdraw the ventilator support.

Discussion

Patients with decision-making capacity should be encouraged to make an informed choice for or against specific treatments, based on their wishes and values. When treatment decisions must be made for a patient without decision-making capacity who has not left a written advance directive, we use "substituted judgment," asking those who know her best to make the decision she would make based on their understanding of her values and wishes.

When a patient has borderline or fluctuating capacity, the goal should be to optimize her cognition and have a discussion with her. If she seems to understand and is able to express her wishes, this should almost always be followed, especially if her choice is consistent with her previously expressed wishes. This is true even if her surrogates are uncertain of what she would choose or what might be in her best interests, or even if they disagree with each other.

In this case, the patient now seems to understand her poor prognosis. She has expressed her agreement to a recommendation for no resuscitation but is not yet ready to make a choice about long-term vent support. Her expressed wish is of greater importance than her daughter's opinion that "she should have one more chance."

Recommendations

1. It is appropriate to write a Do Not Resuscitate order for this patient based on both the very small likelihood of success and her agreement to this recommendation. If any of her adult children object, I would be glad to meet with them along with someone from her care team.
2. It would also be appropriate for her ICU caregivers to talk with her again about the use of the ventilator when she is cognitively clear, preferably with some family present. This should not be repeated so frequently as to be perceived as harassment.

Follow-up

Four days after the consultation, the patient told her physician that she wanted to continue on the ventilator and did not want life-support withdrawn. Plans were initiated for transfer to a long-term ventilator facility, but a bed would not be available for a few weeks. Some of her children became frustrated with her unwillingness to withdraw support and asked if her cardiac medications could be stopped. They were told that since she had been unwilling or unable to switch goals from survival to comfort care, it would not be ethically permissible to do so surreptitiously, unless her death were inevitable and imminent. Over the next two weeks, she gradually

deteriorated with decreased responsiveness and increased swelling, and she developed overwhelming sepsis. She died on the ventilator, with her family present.

Comment

Family conflict about non-medical issues often surfaces in the ICU when important treatment decisions have to be made for a loved one. Lines are drawn, heels dug in, voices raised. Sometimes these tensions can be relieved by a frank discussion, pointing out that we cannot hope to resolve their other differences, but we hope we can set those aside and all agree on seeking the patient's wishes or best interests. Sometimes the clinical dilemma can be resolved by having further conversation with the patient, when that is possible, preferably with family present to observe the patient's responses.

It seems sad that this patient died in the ICU, unable to communicate easily with her family. Could something more have been done to relieve her reluctance to meet death? Could she have benefited from spiritual counsel, from a better understanding of palliative care, from some sense that her children were cooperating? Was there some point in time where the inevitability of her death was sufficiently certain that it might have been justified to withdraw support over her objection? Even in retrospect, questions remain.

Editor's Comment

All too often families encounter end-of-life decision-making and are unprepared for the task of deciding what could or should be done. Even intermediate steps such as providing antibiotics near the end of life (it is unknown in this case if antibiotics for sepsis were either offered, not offered, or refused) can be a problematic decision because of the concurrent medical problems and/or the patient-family preferences.

Towards the goal of appropriate medical decision-making, ideally one of two things should happen: first, as a family member's health deteriorates, the family should make the effort to engage in conversation regarding healthcare preferences; second, once in a medical situation where extensive medical procedures (in this case, heart bypass surgery) is performed, then the attending physicians should make an effort to initiate these discussions. Nevertheless, as in this case, a patient's decisional capacity may fluctuate, and a family member may—as in this case—disagree with the rendered decisions.

Hopefully, this family was counseled regarding the importance of appointing a healthcare proxy for their future medical care needs. One method of doing this would be having a "Proxy Party," where members of the family meet with the loved one who may need to establish medical directives (typically the senior member of the family), for the purpose of identifying the patient's medical preferences as the medical condition worsens and the patient is approaching death. Whereas this can be done at any time, an opportunity often presents itself when families are together for celebrations, such as a holiday or a birthday.[3]

Endnotes

1. The article, as originally published, was untitled.

2. Reprinted by permission of the publisher. “Medical Ethics and the Faith Factor”, William B, Eerdmans Publishing Company. Grand Rapids, Michigan, 2009, 37-40.
3. Pat Bomba, MD, Excellus BCBS, personal communication.

Robert D. Orr, MD, CM, had practiced family medicine in Vermont for 18 years before receiving a post-doctoral fellowship to study clinical ethics at the University of Chicago. Thereafter, he served as consultant and professor of medical ethics at Loma Linda University (CA), Trinity International University (IL), the Graduate College of Union University (NY), and the University of Vermont. He is now retired and currently resides in Vermont, USA.

Ferdinand D. Yates, Jr, MD, MA (Bioethics), is a medical staff member at Children’s Healthcare of Atlanta and has a private pediatric practice in the Atlanta area.

The Pain Principle: An Ethical Approach to End-of-Life Decisions

CARLO V. BELLIENI, MD

Abstract

End-of-life decisions are taken daily in medicine, and the best interest principle (BIP) is one of the most-used criteria. The first aim of this paper is to review the BIP and its criticisms. The second is to propose an alternative criterion to decide when invasive therapies are excessive. We show that the BIP has been criticized for being vague and subjective. Since it is easier to say what harms a person than what should be done for a person's best interest, the Harm Principle has been proposed. Here, we discuss the reliability of a subset of the Harm Principle, the so-called Pain Principle (PP). According to the PP, if the level of pain or stress is very high and untreatable, the invasive treatments can be decreased in intensity, and, sometimes, withdrawn, not with the intention of provoking death but to relieve pain. Nowadays, we can use validated and reliable tools to assess pain and stress in non-verbal patients and decide accordingly whether or not to prosecute the therapies. The PP does not induce to provoke death but to decrease the intensity of treatments when they are manifestly painful and when pain is untreatable. Cases such as those of Vincent Lambert, Charlie Gard, and Alfie Evans, cases when doctors and parents wonder if babies are going through unfair overtreatment, would benefit of a thorough pain assessment, which the PP guarantees.

Key Words

Pain, ethics, end-of-life, best interest

Introduction

Recent British cases of end-of-life decisions have had worldwide media relevance and raised unsolved, huge problems. These are the cases of Charlie Gard and Alfie Evans, two babies with devastating brain damage, whose parents disagreed with pediatricians as to who should decide to withhold life-sustaining treatments. Both parents and doctors claimed that their decisions were taken in the babies' best interest, but this was evidently impossible, since their choices were diametrically different. This is also the case of Vincent Lambert, a former nurse who had been in a vegetative state for over a decade, who died on Thursday in Reims, France, after an intense family dispute over his fate that led to years of legal battles and put him at the center of right-to-die debates. It may seem that respecting life and avoiding therapeutic obstinacy are incompatible; I disagree and propose another way of taking these decisions, providing the due respect for patients' lives, dignity, and suffering, basic principles of any clinical assistance. In this paper, after dealing with the limits of the current principles about withholding treatments in nonverbal people, I will suggest a possible response to most end-of-life dilemmas, respectful of both dignity and life.

The Best Interest Principle

Many difficult decisions have to be taken in clinical practice, some of which relate to life and death, e.g. when to stop the treatments; in too many cases, life-saving treatments are withheld or withdrawn on subjective or probabilistic bases, without the due assessments.[1,2] One of the most used criteria is the Best Interest Principle (BIP), aimed to evaluate the best interest of the patient among two or more possible therapeutic options and to behave consequently. The bases of the BIP are rationally founded. Best interest determinations are formal processes conducted with the involvement of public authorities and professional decision-makers. The objective of the best interest determination is to reach a decision based on rational bases that safeguards the rights of patients and promotes their well-being, safety, and development. Decision-makers weigh and balance all the relevant factors of the case, giving due consideration to all the rights of children and the obligations of public authorities and service providers towards them. The objective of the best interest determination process is the identification of a durable solution. Best interest assessment is carried out when the issues at stake are expected to have significant implications on the patient's present and future life. Beauchamp and Childress define the best interest as that in which "a surrogate decision-maker must determine the maximum net benefit among the available options, assign different weights to the interests the patient has in each option, and actualize or subtract intrinsic risks or costs."[3] This assessment involves a multidisciplinary team of qualified professionals to evaluate and balance all the elements necessary to make a decision in a specific situation for a specific patient or group of patients. The evaluation of the best interest should feature all the facts necessary to arrive to a conclusion on the impact of any action or decision on the patients and their futures.[4] As the BIP relies on the supposed agreement with the patients on their conditions,[5] the BIP is supposed to shy away from a paternalistic criterion.[6] In pediatrics, the BIP is correlated with the Article 3 of the UN Convention on the Rights of the Child, according to which "in all actions concerning minors, undertaken by public institutions or deprived of social assistance, courts, administrative authorities or legislative bodies, the best interests of the minor must be a primary consideration."[7] It has been argued that the current standard should be replaced with the best interests of children, from the child-approach that takes child-focused epidemiological and psychological research into account regarding children's physical, mental, and social well-being.[8]

Criticisms to the Best Interest Principle

Several authors have criticized the BIP.[9] The main objection regards its vagueness, witnessed in the cases of hard decisions about life-saving treatments when both contending parties seek help from the BIP to either suspend the treatments or to prosecute them indefinitely.[10] It is evident that, if the same principle can be used in diametrically opposite ways, it has an intrinsic weakness and can become the realm of subjectivity.[11] When we want to do somebody else's interest, we do all our best in this goal, but who can say which his interest actually is? It is extremely difficult: we can know, at best, a patients' wishes or their preferences, but the utter guarantee of doing their absolute "interest" is beyond any realistic possibility. This vagueness is due to the indefinite concept of "interest," whose limitations we here try to explain.

We should wonder what the word "interest" means. It can be the possibility of having a better life: in this case, it coincides with the word "sake." This becomes critical when decisions are not taken by the patient but by third parties; how can parents or tutors be sure that what they are deciding is actually for the patient's sake? They can understand what can be a harm and decide to avoid it (as we will see later), but someone else's best interest cannot be easily evident to others. "Interest" can also be interpreted as the mere respect of patients' directives, that in many cases can clash with what is the best choice for most doctors (an example is the refusal of transfusions for religious reasons). If we believe that a person's best interest are his/her personal directives, are we sure that a person, in particular when under stress, can be absolutely serene, informed, and free to correctly choose? Or that he would not change his mind, now that the present illness is not only a far hypothesis?[12] Last, I want to focus on a literal incoherence in using the word "interest": "interest" can literally be interpreted as a mental activity aimed to focus one's mind on a single subject: but a comatose patient or an infant cannot focus on anything. Would we assume that they have no interests at all? This may lead us to let the patient impair or die in all those circumstances, when their awareness and attention seem temporarily or definitively compromised.

The BIP may also rely on concepts such as quality of life or human dignity:[13] when an apparent level of quality of life is below a certain threshold, death is considered the best interest for the patient. It is possible to measure the quality of life, giving a score to various factors to obtain a final note; various versions of quality-of-life scores exist.[14] One possibility is to determine the Quality Adjusted Life Years (QALYs);[15] it assumes that health is a function of length of life and quality of life and combines these values into a single index number.[16] Nonetheless, QALYs has been extensively criticized: Rawles et al wrote that the "application of the method leads to undervaluation of life and gross inequality."[17] In fact, a quality-of-life assessment by proxy is hard: it over-evaluates or underestimates the patient's signs and symptoms, and the extrapolations about a future quality of life are only conjectures.[18] Moreover, for most religious people and for many lay philosophers, disabled lives are worth living and have a positive intrinsic value; the equation between disability and unsatisfactory lives is too simplistic and refused by most people with disabilities; studies show that in some cases disabled people's life satisfaction is not so dissimilar from that of the whole population, since most of life satisfaction depends upon the environment, acceptance, and resilience.

The Harm Principle, a Possible Alternative

Diekema and other researchers criticized the BIP as "self-defeating, individualistic, unknowable, vague, dangerous, and open to abuse."[19,20] The central point raised by these critics is that it is hard to define what is "my interest." Thus, a new criterion to take end-of-life decisions on the behalf of nonverbal people was proposed: the harm principle (HP).[21] According to the HP, in end-of-life choices we must proscribe anything that can be an obstacle to health and happiness, rather than presuming to provide ideal conditions for our patients. This is a basic Hippocratic principle of great traditional usefulness.[22] The closest approximation in the Hippocratic Corpus is in Epidemics: "The physician must ... have two special objects in view with regard to disease, namely, to do good or to do no harm."[23,i] The harm principle holds that the

actions of individuals should only be limited to prevent harm to other individuals. In a wider scenario, namely that of personal freedom, John Stuart Mill articulated this principle in *On Liberty*, where he argued that "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."[24] The HP means that we should not assess if either life or death are the best interest of the patient, but we should choose the option that hurts him/her less. According to the HP, in the case of babies or children, parental decisions should in general be accepted, except in those rare cases where a parent's decision places the child at a certain level of harm: "State intervention is justified not when a parental refusal is contrary to a child's best interest, but when the parental refusal places the child at significant risk of serious preventable harm."[25]

However, even the concept of harm is not objective enough, because it has too many faces: a physical harm is possible, but also we have economic, moral, and social harms.[26] It seems impossible to correctly evaluate all these faces of the same matter, to give each one the right weight, and eventually to interpret how important the subject considers them. As Bellieni et al says, "Is it a harm to sustain a poor quality of life? Who are we to decide the hierarchy of harms?"[27] The risk is, even in this case, subjectivity; the harm assessed by a patient can differ from that assessed by his caregivers.[28] "Clinicians have a marked tendency to overestimate the impact of functional impairments and restrictions on personal well being and life satisfaction in disabled adolescents and adults," Wyatt says. "In reality there is no simple relationship between neurological impairment and either 'unbearable suffering' or 'poor quality of life.'"[29] Then the limits of HP make it not substantially better than the BIP: it is easier to know what harms than what makes someone's best interest.[30]

The Pain Principle

Considering the limitations of HP, it is worth to use a restrictive but safer approach to it: considering harm in its objective features, namely pain and stress, rather than "harm." This is the basis of the "pain principle" (PP).[31,32,33] It is a criterion that permits the reduction of the intensity of medical treatment, but only after having assessed the level of pain and stress the patient is experiencing and having seen that they cannot be relieved. The PP can be seen as a subset of the HP, aiming to objectify it. It relies on the fact that pain and stress are measurable, even in people who cannot express their feelings verbally, as in the case of children and mentally disabled people.[34] To this purpose, we can use pain and stress assessment methods, validated according to scientific criteria. We have electronic tools for evaluating pain and stress, such as those which score skin impedance[35,36] and perform EEG brain mapping[37,38] and measure the level of stress hormones in saliva or blood.[39,40] It is important to be aware that these tools have a widespread use and that their assessment is as objective as any other lab tool. Their validation has been developed assessing their sensitivity, specificity, and inter-rater agreement . All these tools are currently available in any hospital and are a useful approach to pain detection and assessment in non-verbal patients.

Detecting untreatable stress and pain acts to avoid further invasive treatments when we see that suffering cannot be relieved. In all patients who cannot express their wills, only intervention that provokes slight pain are to be allowed; but in the case of

subjects with severe irreversible brain damage that completely impedes any level of awareness and interpersonal relationship, no level of stress or pain can be allowed, because no pain-producing procedure would benefit the subject; consequently, all painful therapy should be avoided in this latter group of patients, no matter the level of pain.

But which are the tools we can use to assess pain or stress in a person? To answer, we first point out that, though different, phenomena, pain, and stress have the same markers and can both be detected with the same instruments. The first way to determine pain or stress is using multifactorial scales: these scales encapsulate several parameters, such as heart rate, oxygen saturation, grimaces, consolability, smiling, crying, and others; to each item a score is given according to a range, and the sum of the single scores gives the measure of pain or stress. One of the most used pain scales in this field is the EDIN scale; EDIN is the acronym of French words, and the translation into English is "scale of pain and stress in the newborn."

Another way to measure pain is assessing the activity of the patient's autonomous nervous system, whose changes depend upon pain and stress. This can be appreciated by two means: assessing the variability of the heart rate or the skin electrical conductance, both due to an increase in the activity of the autonomous nervous system.[41,42] In order to detect either changes, dedicated instruments have been produced and validated. Moreover, to detect pain we can measure the changes of some hormones in blood or in saliva, which soar as a consequence of pain and stress. The most used are cortisol, adrenaline, and endorphins. In some patients it is also possible to detect pain using a brain map, done with the computer analysis of electroencephalogram data: pain and stress activate some specific areas of the brain and can be detected in real time. When extreme pain is present, it is mandatory to reduce the treatments that provoke it: it is as if we listened to the patient's voice, though under a form of involuntary language. Removing invasive therapies when very high stress is present and unavoidable can shorten the patient's life, but that is just an effect of a reasonable action, aimed to a reasonable good; this is called the "double effect principle."[43]

The PP would have been useful in cases such as Charlie Gard and the others quoted at the beginning of this paper: if an untreatable and unbearable pain were present, doctors would have been allowed to discontinue intensive treatment and replace them with palliative care. On the contrary, if pain detection had given negative results (absence of pain), doctors would have no reason to forego them.

An objection to the PP can be that suspending invasive treatments when pain is already very high and untreatable is too late; we should not make a baby go through extreme pain when we see alarm signs. Obviously, we not only need to spot pain, but also need to predict it, and to this goal, scientific societies should give accurate guidelines and red flags of future extreme and untreatable stress or pain. This is a delicate point, because it can lead to abuses in continuing or discontinuing treatments if the signs that predict it are not univocal.[44]

Moral Differences Between the Three Principles

We will now consider how these three principles take into account the respect of dignity and of life.

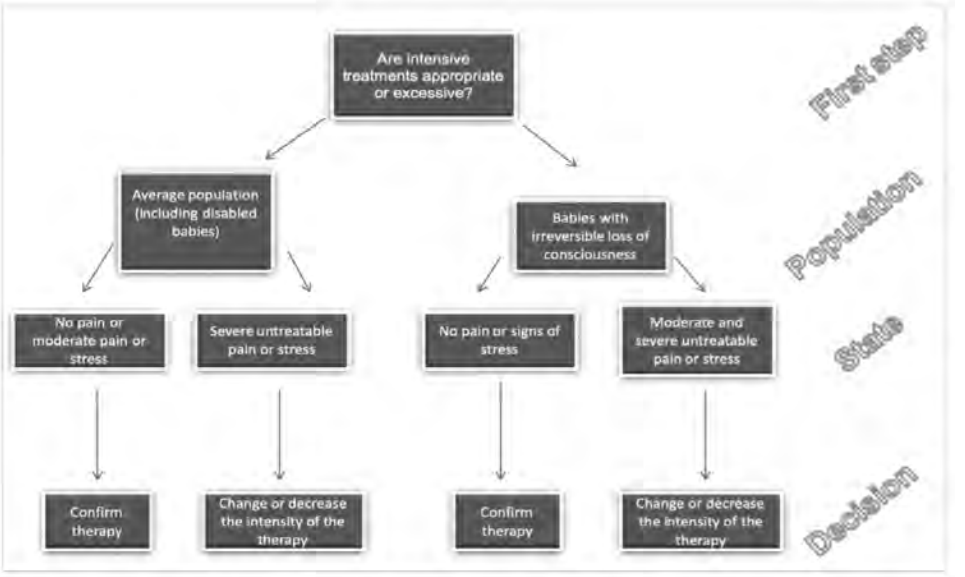
The respect of the patient's dignity means to avoid any overtreatment. The patient is not a guinea pig or a battle field, where we deploy forces until we have technical resources, whatever the outcome. Useless deployment of technical tools is not ethical, with particular emphasis to those cases where it is also painful for the patient: "The well-being of the whole person must be taken into account in deciding about any therapeutic intervention or use of technology. Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient."[45] A precocious clinical abandon of the patient is acceptable for Christian bioethicists; on the contrary, all efforts should be made to cure, even once a diagnosis of a terminal illness has been concluded, but this should happen with the appropriate means, usually with palliative care. Thus, the PP and the HP fit better than the BIP in respecting the patient's dignity.

Respect of life: no action aimed to intentionally provoke death should be ever undertaken, and this is what the PP relies upon, because the definition of PP relates just the aim of not provoking pain, not provoking death. PP is just a criterion to provide analgesia. It encourages the reduction of the intensity of some life-saving treatments when evidently useless and painful, but not the provoking of death. The PP imposes to reduce, in some cases, the invasiveness of treatments, but it also forbids to remove them when no pain or stress are detected (Table 1). This does not mean that those who use the PP do not know when enough is enough, but they should never behave to intentionally provoke death. On the contrary, the BIP can be interpreted as the permission to provoke death, when caregivers suppose that dying is the best option for the person. The HP apparently dodges this risk, because it is difficult to claim that death is not a harm, but someone may extensively interpret life itself as a harm under some physically or mentally challenged conditions.

Conclusion

PP is a yet imperfect but improvable solution to the subjectivity of the BIP. According to the PP, treatments can be decreased in invasiveness or can be replaced with palliative care, if appropriate. Palliative care has a pivotal importance in end-of-life decisions, while the sudden removal of life-saving treatments is not the correct choice. Any protocol that directly provokes death does not respect the patient's life. The PP avoids this; it does not provoke death but allows the decrease of the intensity of treatments when pain is manifest and is untreatable. Involving parents and siblings in these important decisions is of utmost importance, but neither parents nor doctors should take any decision on subjective or emotive bases. The PP is an important tool to offer objectivity and serenity in difficult decisions, such as those of recently reported critic patients Vincent Lambert, Charlie Gard, and Alfie Evans.

Table 1



References

1. Janvier A, Farlow B, Verhagen E, Barrington K. (2017) "End-of-life decisions for fragile neonates: navigating between opinion and evidence-based medicine". *Arch Dis Child Fetal Neonatal Ed.*;102(2):F96-F97.
2. Koper JF, Bos AF, Janvier A, Verhagen AA. (2015) "Dutch neonatologists have adopted a more interventionist approach to neonatal care". *Acta Paediatr.*;104(9):888-93.
3. Beauchamp T, Childress TF, (2001) "*Principles of Biomedical Ethics, 5th* ed" New York: Oxford.
4. Ross LF. (1998) "Children, families, and health care decision making". Oxford University Press, . Oxford UK.
5. DeGrazia D (1995) "Value theory and the best interests standard". *Bioethics* ;9:50–61.
6. Blustein J (2012). "Doing the best for one's child: satisfying versus optimizing parentalism". *Theor Med Bioeth* ;33:199–205.
7. United Nations Organization (1990): "Convention on the Rights of the Child Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with article 49". Available at the following URL: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.
8. Grangeat M, Kruk E, Bergström M, Marinho S. (2018)"Are joint custody and shared parenting a child's right?", The Conversation, October 4.
9. Buchanan A, Brock D (1990). "Deciding for others". : Cambridge University Press, Cambridge UK.
10. Cave E, Nottingham E (2018). "Who knows best (interests)? The case of Charlie Gard". *Med Law Rev.*26(3):500-513.
11. Freckelton I (2018). "Responding Better to Desperate Parents: Warnings from the Alfie Evans Saga". *J Law Med.* 25(4):899-918.
12. Wilkinson D, Savulescu J. 2018 "Alfie Evans and Charlie Gard-should the law change?" BMJ. ;361:k1891.
13. Lagercrantz H. (2018) Observations on the case of Charlie Gard. *Arch Dis Child.*;103(5):409-410.
14. Gomersall T, Spencer S, Basarir H, Tsuchiya A, Clegg J, Sutton A, Dickinson K. (2015)

"Measuring quality of life in children with speech and language difficulties: a systematic review of existing approaches". Int J Lang Commun Disord.; 50(4):416-35.

15. Bobinac A, van Exel J, Rutten FF, Brouwer WB. (2014) "The value of a QALY: individual willingness to pay for health gains under risk". *Pharmacoeconomics*.32(1):75-86.
16. Singer P: (2009) Why we must ration health care. *New York Times.* July 15.
17. Rawles J. (1989) "Castigating QALYs". J Med Ethics.;15(3):143-7.
18. Saigal S, Rosenbaum PL, Feeny D, Burrows E, Furlong W, Stoskopf BL, Hoult L. (2000) "Parental perspectives of the health status and health-related quality of life of teen-aged children who were extremely low birth weight and term controls". *Pediatrics*.;105(3 Pt 1):569-74.
19. Diakema DD (2004): "Parental refusals of medical treatment: the harm principle as threshold for state intervention". *Theoret Med*;25:243-64.
20. Kopelman LM. (1997) "The best-interests standard as threshold, ideal, and standard of reasonableness". *J Med Philos*.;22(3):271-89.
21. Dresser R (2003). "Standards for family decisions: replacing best interests with harm prevention". *Am J Bioeth* ;3:54–5.
22. Reiser SJ (2003): What modern physicians can learn from Hippocrates. *Cancer* 98(8):1555-8.
23. Mill, JS (1859). On Liberty. Oxford, England: Oxford University. pp. 21–22.
24. Diakema DD (2004): "Parental refusals of medical treatment: the harm principle as threshold for state intervention". *Theoret Med*;25:243-64.
25. Bester JC (2018) "Charlie Gard and the Limits of the Harm Principle". *JAMA Pediatr.* 172(3):300-301.
26. Bellieni CV, Cordelli DM, Raffaelli M, Ricci B, Morgese G, Buonocore G (2006) Analgesic effect of watching TV during venipuncture. *Arch Dis Child*. 91(12):1015-7.
27. Oliva EN, Finelli C, Santini V, Poloni A, Liso V, Cilloni D, Impera S, Terenzi A, Levis A, Cortelezzi A, Ghio R, Musto P, Semenzato G, Clissa C, Lunghi T, Trappolini S, Gaidano V, Salvi F, Reda G, Villani O, Binotto G, Cufari P, Cavalieri E, Spiriti MA. (2012) "Quality of life and physicians' perception in myelodysplastic syndromes". Am J Blood Res.;2(2):136-47.
28. Wyatt J. (2007) "End-of-life decisions, quality of life and the newborn". *Acta Paediatr*.96(6):790-1.
29. Birchley J (2016): Harm is all you need? Best interests and disputes about parental decision-making" *Med Ethics*.42(2): 111–115.
30. Bellieni CV (2018a): "End-of-Life Decisions and the "Pain Principle"". *EC Anaesthesia* 4.8: 252-253.
31. Bellieni CV (2018b) "Withdrawing health treatments in pediatrics: a choice respectful of life and suffering is possible". *Medicina e Morale*, 67(4):407-16.
32. Bellieni, C.V., & Buonocore, G. (2019). Using the pain principle to provide a new approach to invasive treatments and end-of-life care. *ACTA PAEDIATRICA*, 108(2), 206-207.
33. Bellieni CV (2019): Protocolo para la toma de decisiones éticas en neonatología *Bioethics UPdate*.5:14-24.
34. Røeggen I, Storm H, Harrison D. 2011 "Skin conductance variability between and within hospitalised infants at rest". *Early Hum Dev*.;87(1):37-42.
35. Barros MA, Dibai-Filho AV, de Oliveira AK, de Jesus Guirro RR. (2018). Reliability of skin impedance in subjects with chronic neck pain. *J Back Musculoskelet Rehabil.* 31(2):331-336.
36. Klarer N, Rickenbacher H, Kasser S, Depoorter A, Wellmann S. (2017) "Electrophysiological Measurement of Noxious-evoked Brain Activity in Neonates Using a Flat-tip Probe Coupled to Electroencephalography". *J Vis Exp.* 29;(129).
37. Beekoo D, Yuan K, Dai S, Chen L, Di M, Wang S, Liu H, ShangGuan W. (2019) Analyzing Electroencephalography (EEG) Waves Provides a Reliable Tool to Assess the Depth of Sevoflurane Anesthesia in Pediatric Patients. *Med Sci Monit.* 30;25:4035-4040.
38. Mörelius E, He HG, Shorey S. (2016) "Salivary Cortisol Reactivity in Preterm Infants in Neonatal Intensive Care: An Integrative Review". *Int J Environ Res Public Health.* 18;13(3).
39. Herbert MS, Goodin BR, Bulls HW, Sotolongo A, Petrov ME, Edberg JC, Bradley LA, Fillingim RB. (2017). Ethnicity, Cortisol, and Experimental Pain Responses Among Persons With Symptomatic Knee Osteoarthritis. Clin J Pain. 33(9):820-826.

40. Okawa N, Kuratsune D, Koizumi J, Mizuno K, Kataoka Y, Kuratsune H. (2019) "Application of autonomic nervous function evaluation to job stress screening". *Heliyon*. 5;5(2):e01194.
41. Aslanidis T, Grosomanidis V, Karakoulas K, Chatzisotiriou A. (2018) Electrodermal Activity Monitoring during Endotracheal Suction in Sedated Adult Intensive Care Unit Patients. *Folia Med (Plovdiv).* 60(1):92-101.
42. Cavanaugh TA, (2006) "Double-Effect Reasoning: Doing Good and Avoiding Evil". Clarendon Press. Oxford: UK.
43. Bellieni CV (2018a): "End-of-Life Decisions and the "Pain Principle"". *EC Anaesthesia* 4.8: 252-253.
44. United States Conference of Catholic Bishops (2009): "Ethical and religious Directives for Catholic Health Care Services": 21. Available at the following URL: http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf.

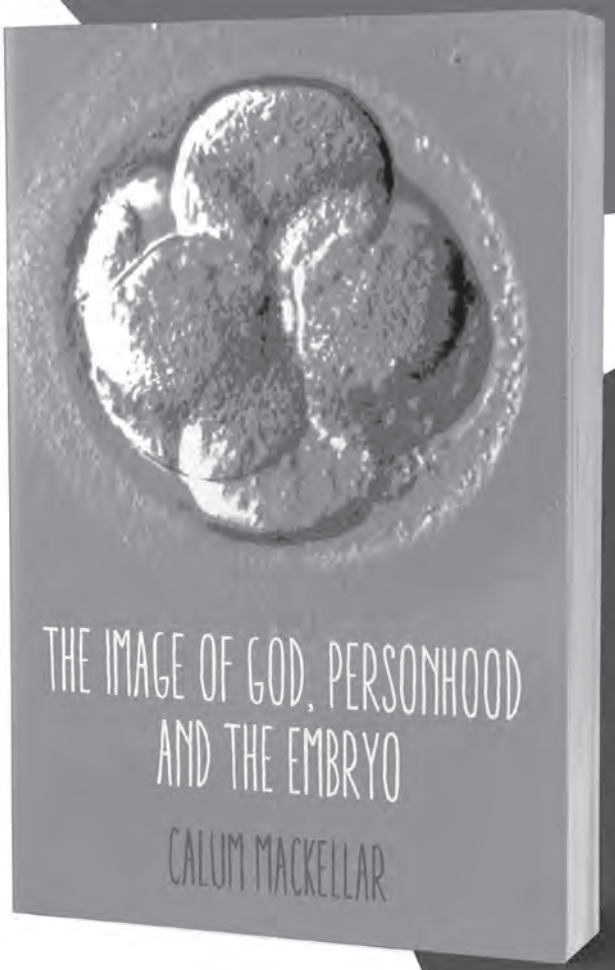
Endnotes

i. Greek: ἀσκέειν, περὶ τὰ νουσήματα, δύο, ὠφελέειν, ἢ μὴ βλάπτειν.: Hippocrates, Apanta 13. Cactus. Athens: 1993. Hippocrates: Epidemics I (Epidemion to Proton) (In Greek).

Carlo V. Bellieni, MD, is a medical doctor, neonatologist, and pediatrician. He is professor of pain treatment at the Pediatric School of the University of Siena. He is the author of more than 400 papers, chapters of books, and books mainly devoted to babies' pain treatments and the ethical treatment of the child. Dr. Bellieni has created a pain scale to assess pain in newborns and has validated a non-pharmacologic tool to prevent babies' pain called Sensorial Saturation. He is member of the Ethical Board of the Presidency of the Region of Tuscany (Italy) and of the Pontifical Academy for Life. He is member of the Directive Board of the Pain and Analgesia Study Group of the Italiana Neonatologic Society. He currently resides in Siena, Italy.

THE IMAGE OF GOD, PERSONHOOD AND THE EMBRYO

CALUM MACKELLAR



"Calum MacKellar has produced an erudite and engaging volume exploring how the image of God is reflected in the human embryo. Carefully argued it is essential reading for Christian students and scholars and students with an interest in bioethics."

Agneta Sutton, Heythrop College, University of London

Vol. 36:1 Spring 2020

Clinical Science after Flexner's 1910 Report on Medical Education: A Research Ethos Inhabited by Racial Prejudice, Colonial Attitudes, and Eugenic Theory

GREGORY W. RUTECKI, MD

Introduction

> "The Flexner Report of 1910 transformed the nature and process of medical education in America with a resulting elimination of proprietary schools and the establishment of the biomedical model as the gold standard of medical training… *the report, embraced scientific knowledge…as the defining ethos of a modern physician*…American medicine profited immeasurably from the scientific advances that this system allowed, but the hyper-rational system of German science (Flexner's prototype for the transformation of American Medical Education) created *an imbalance in the art and science of medicine*."[1]

Typically, and for more than a Century, the Flexner Report (1910)—precipitated by shortcomings in American Medical Education—has been showered with praise. There are bona fide reasons for the report's prestigious reputation. The prominent historian of Medicine, Kenneth Ludmerer, has observed,

> "The revolution in medical education (1910) was necessitated fact that medical schools were not consistently translating the existing body of scientific knowledge into medical practice. The gap between what was known and what was taught was unacceptably wide. The social mission of the Flexnerian Revolution was to ensure, in a democratic society, that the best possible scientific training be made available to every person studying medicine. The revolution succeeded brilliantly…"[2]

After touring medical schools in Europe, purported to be the best in the world, Flexner developed his template for optimally training American physicians.[1] He chose the "German pedagogic style of medical education," a European system that developed the pre-clinical science and laboratory training of early medical school that is still the model today.[1] This preliminary scientific immersion would be followed by a clinical education that fostered ongoing progress in the medical sciences, energizing careers spent furthering the frontiers of medical science.[1] In this regard Duffy surmised, "Science, as the animating force in the physician's life, was the overarching theme, the zeitgeist, in Flexner's conception of the ideal physican."[1] The fruits of Flexner's labors were revised admission standards for medical schools, better physical facilities with well-equipped laboratories, and an academic faculty of physicians committed to applying science at the bedside.[1] The best and brightest twentieth and twenty-first century physicians have been products of this *Flexnerian Revolution.* But what did

Duffy imply about the revolution's character when he suggested the Flexner report created an "*imbalance in the art and science of medicine*"?[1]

Flexner believed that science was *the* means to *all of medicine's ends.* But at the same time, Flexner was oblivious to the state of clinical research ethics in America in 1910. Unethical practices throughout a spectrum of human subject research had been *de rigueur* for nearly a century. American medical practitioners had unethically experimented on African-American subjects prior to the Civil War.[3,4] Despite a previously unethical American research history, Flexner did not propose any boundaries around the variety of clinical research that would dominate American Medicine following his report.

To add insult to injury, Flexner lived at a time when the risks of human subject research would dramatically escalate. In the early twentieth century, harnessing radiation as well as manipulating lethal infectious organisms could lead to fatal outcomes for research subjects. A Hippocratic ethos—arriving with the Nuremberg Trials—would be lagging at least a generation behind. Flexner's culture was also rife with racial prejudices, attitudes of colonial superiority, and alliances between medicine and eugenics.

Dr. Flexner himself admitted that his muse for medical education's transformation was the German physician Doctor Billroth and his textbook, *Medical Education in German Universities.*[1] The book itself contains anti-Semitic aspersions expressed in concert with claims of a superior German stock.[1] Flexner's canonization of science drew from this "German Wellspring" described by an American physician who trained there as follows, "They [German Physicians] would attempt things that in most other countries would be considered unjustifiable…the human element was sorely lacking. The patient was something to work on, interesting experimental material, but little more."[3] The generation of physicians who became soldiers in Flexner's army may have sworn the Hippocratic Oath at graduation, but their burgeoning medical and scientific technique distanced itself considerably from Christian-Hippocratism.

Examples of Research Ignoring Human Dignity

> "Dr. Mark Boyd (1937)…was testing a novel treatment for neurosyphilis—malaria therapy…But the blacks in his experiment seemed to resist infection by the relatively benign plasmodia strain of malaria, so Boyd infected 470 of the syphilitic blacks—but no whites—with the deadly falciparum strain instead, killing some of the black subjects…Boyd resorted to deceit: in his notes, he disguised (the black subjects) causes of death"[4,5]

> "In the 1930s, there was no 'system of normative ethics of human experimentation that compelled medical researchers to temper their scientific curiosity with respect for patient's rights.'"[3]

The early twentieth century was a unique incubator for science. The pace of scientific discovery—especially in physics (radiation and x-rays) and in microbiology (applying the germ theory)—was dizzying. There was Max Planck and quantum theory. There were also Einstein's theories of general and special relativity. Other illustrious names in the science of that era included Niels Bohr and the Curies. In medicine, Landsteiner discovered blood types. Ehrlich developed a "magic bullet" for syphilis.

Pierre and Marie Curie's contributions to physical science provide a facile segue from pure bench science to medical applications during and immediately after Flexner's report. As early as 1903, when Pierre Curie burned his forearm after prolonged exposure to radium, he suggested that radium's effects on living tissue might be applied to rapidly dividing cancer cells.[6] Roentgen's work with x-rays translated into unexpected outcomes as well. X-rays also damaged human cells and were predicted to become a treatment for cancer similar to radium.[6,7] Experiments with these powerful agents would present unpredictable risks and serious complications to human subjects.

The crux of the dilemma was that the time allotted for the *"Bench to Bedside"* translation of basic science research (that is, from experiments not involving human beings to experiments and/or applications on human beings) was dangerously brief and haphazard. Both Puccini and Claude Debussy, the renowned composers, received direct radium to cancer treatment (laryngeal and rectal respectively) in the early twentieth century without ethical oversight or proof of either efficacy or safety.[6] In fact, Puccini died within days of radium's utilization, by way of needles stuck into an incurable laryngeal cancer so large (and vascular) that he could not button his collar![6]

Furthermore, the germ theory of disease would also change medicine drastically.[8] Plague, syphilis, tuberculosis and smallpox—to name only a few infections—were caused by living organisms, not bad air (the etymological root of *malaria*) or miasmas.[8] In the context of the bioethical vacuum prominent in the early twentieth century, these "bugs" had a sinister side as well. They could provide an advantage to warring nations as agents in biological warfare, and they did, albeit primitively, in World War I.[9] Testing their lethal potential on humans (as in the introductory quote to this section) reaped a proverbial whirlwind.

Since the chronological *raison d'être* herein has been to probe the impact of Flexner's report on science in medicine—and since Flexner himself specifically chose the "German" model for his educational transformation—it is worthwhile to return to the introductory quote for this section and juxtapose American physician behavior with that of German contemporaries.

Was Boyd's dangerous use of the falciparum malarial strain an ethical misadventure unique to him? In 1917, the Austrian Dr. Julius Wagner-Jauregg,[10,11,12,13] the pioneer of the malarial fever treatment of central nervous system syphilis and a 1927 Nobel Prize winner, was the first to utilize the falciparum malarial strain in lieu of other less dangerous strains. Some of his subjects died as a result. In fact, because of his introduction of the falciparum strain, overall 15% of recipients were killed by copy cats in worldwide laboratories.[13] Although there is no definitive proof that Boyd was aware of Wagner-Jauregg's fatal missteps, the latter's notoriety suggests the former was well versed in the lethal potential of falciparum. As WWII approached, Wagner-Jauregg advanced eugenic theory, anti-semitism, and extolled sterilization as a eugenic imperative.[12,13] Wagner-Jauregg claimed that "common principles did not apply to him…(and) lived by the motto 'a man with character needs no principles.'"[12]

It would appear that answers to the most fundamental ethical questions plaguing human subject research were not forthcoming in the wake of Flexner's report. First and foremost, how should the duties of a scientifically-minded physician in an

experimenter-subject relationship differ from those in the traditional doctor-patient relationship?[3]

The following sections will focus on how the ethics of medical research were corrupted by the physicians inheriting the Flexner report through the exercise of racial prejudice, attitudes of colonial superiority, and the eugenics movement.

The Tuskegee Syphilis Study: Paradigm for Racial Prejudice in Human Subject Research

> "…the decision not to treat the men of the Tuskegee Study is…a crime of omission… (and choosing) blacks for the riskiest studies; their (that is black Americans) disproportionate selection for non-therapeutic experimentation; the myth of medical distinctiveness (which held that syphilis was manifested differently in blacks); and the myth of hypersexed blacks as 'incorrigible' vectors of sexual disease and dysfunction were at work."[4]

> "…the Tuskegee staff grew to 35 scientists and technicians, who produced twenty thousand tubes of HeLa—about 6 trillion cells—every week…with those cells, scientists helped prove the Salk vaccine effective…Black scientists and technicians, many of them women, used cells from a black woman (Henrietta Lacks) to help save the lives of millions of Americans, most of them white. And they did so on the same campus—and at the very same time—that state officials were conducting the infamous Tuskegee syphilis studies."[14,i]

As might be expected from the research animus already engaged, one would have to suspect that the Tuskegee syphilis study did not occur in a vacuum. Although a larger number of human subjects were recruited than typical (399), the study was inhabited by the same perversion—namely, that African American subjects were expendable and beneath their white counterparts. As a paradigmatic harbinger, the southern black slave had been a long-lived target for human subject research. A Dr. Marion Sims tested his crude repairs of vesico-vaginal fistulae on several black female slaves before the Civil War.[3,4] All of his surgical procedures were performed without anesthetic. The human subjects had to be physically restrained because of pain. After the Flexner report, the scientific abuse of blacks would continue in earnest. What was considered "normative" research ethics during and after the Flexner era was fueled by racial prejudice.

W. Osler Abbott (not to be confused with William Osler) researched the human digestive system at the University of Pennsylvania in the 1930s.[15] What follows is his personal description of his African-American research subjects whom he likened to laboratory animals. At a public forum, he jested "*black animals* enjoyed a much larger intake of corn liquor, pork chops, and chewing tobacco than the white rats at the medical school."[15, 16] Calling his black subjects "*human guinea pigs*," he recounted a jealous black sweetheart firing a gun at her boyfriend (one of Osler Abbott's African-American research subjects) when she saw him with another woman. She shot him in the spine, thereby paralyzing him. Abbott said to other physicians publicly, the episode "led me to wish at times that I could keep my animals in metabolic cages"[15,16] Physicians on a national stage (including members of the U.S. Public Health Service) agreed, "The future of the negro lies more in the research laboratory than in the

schools…When diseased, he should be registered and forced to take treatment before he offers his diseased mind and body on the altar of academic and professional education."[4]

Even research physicians esteemed today, such as Hans Zinsser, the guru of typhus and lice-borne diseases, can be accused of overt prejudice against African-Americans.[15,17] Zinsser described his recruitment of research subjects—characterized by him as "*little-game hunting*"—in contrast to *big game hunting* in Africa.[15,17] He began his analogy by saying big-game hunting "employs 'express rifles' to shoot with, *black boys or goats as bait.*"[15,17] He likened his search for microscopic organisms to "little game hunting." Unfortunately, much as African boys would be used as bait for large game hunting, he had no problem using African American persons as sources for his game--even against their will. For his work on typhus, he attempted to capture *local* lice in Boston, targeting "flophouses and cheap motels."[15,17] When he failed, he asked a policeman for assistance. Zinsser was offered "an old coon that sells pencils down near the South Station."[15,17] The African-American man was dragged to the police station, repeating "I ain't done nothing."[15,17] He was threatened with arrest "in the cause of science," unless he permitted Zinsser to remove nits from his "crinkly hair."[15,17] Susan Lederer appropriately commented that the "vulgar racial characterization…illustrate(s) the casual and explicitly public appropriation by laboratory researchers of the bodies of African-Americans."[15] In this research environment, the design of the Tuskegee study should come as no surprise.

The Tuskegee syphilis study was ostensibly performed to follow the course and complications wrought by syphilis on black men. The flawed hypothesis posited was that the disease manifestations of syphilis were different in blacks and whites. The black subjects however, in contrast to whites, would receive either no therapy or less than standard therapy—despite the availability of potentially curative treatment—without informed consent and through the liberal use of deception. Devious recruiting methods were the rule, not exception. Poor black men, mostly sharecroppers, were manipulated by the promise of free physical exams, free rides to and from the clinic, hot meals on exam days, free treatment of minor ailments, and burial stipends paid to family survivors.[18] However, not one received standard of care from the investigators.[18]

There was a mistaken suspicion that black men were more prone to cardiovascular syphilis and less prone to central nervous system complications than their infected white counterparts. In order to obtain data regarding undiagnosed nervous system involvement in blacks, lumbar punctures (or *spinal taps*) were performed *only* on African-American subjects. The letter sent to subjects explaining this requirement was a bald-faced lie: "Some time ago you were given a thorough examination and since that time we hope that you have gotten *a great deal of treatment for bad blood* (for black men, a euphemism for syphilis). You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment…remember this is your last chance for special free treatment."[4] The lumbar punctures were solely for the benefit of the medical scientists and had no therapeutic intent whatsoever. They were painful and resulted in headaches and time off work. One of the Tuskegee medical scientists had a ploy aimed at the unfortunate subjects in order to get as many taps done before the men realized what was happening: "My idea in bringing them in large groups is to get the procedure completed…before the negro population has been able to find out

just what is going on…the details of the puncture techniques should also be kept from them."[18]

The utilization of African American persons for dangerous human subject research did not end after the Civil War and Reconstruction. In fact, it escalated with the Flexnerian ascendency of science.

Clinical Research Attitudes Directed at Colonized Persons

> "In the nineteenth and early twentieth centuries American physicians and researchers played a critical role in the acquisition of new territories such as Puerto Rico, Cuba, the Philippines, and Hawaiian Islands. The *medical imperial project* involved several key features, including preserving the health of colonizers faced with novel environmental and disease threats such as Yellow Fever and Malaria, as well as the 'civilizing mission' of westernizing 'backward people…' *Medical researchers increasingly appropriated these colonial subjects for their investigations.*"[15]

> "It would be ideal except for the Porto Ricans (sic)—they are beyond doubt the dirtiest, laziest, most degenerate and thievish race of men ever inhabiting this sphere. It makes you sick to inhabit the same island with them. They are even lower than Italians. What the island needs is not public health work, but a tidal wave or something to totally exterminate the population. It might then be livable. I have done my best to further the process of extermination by killing off 8 and transplanting cancer into several more…The matter of consideration for the patients' welfare plays no role here—in fact, *all physicians take delight in the abuse and torture of the unfortunate subjects.*"[19,ii]

The previous pattern of deceit, excessive risks, and prejudiced assumptions regarding humans drawn from "lower strata"—all in the name of medical science—would be repeated on colonial human research subjects. This demographic prospered in countries acquired after the Spanish-American War.

In 1931, the U.S. Army Medical Corps in the Philippines was recruiting "volunteers" for research on the mosquito-borne disease dengue fever. The officers remarked that four "rather primitive Ifugao boys…agreed to volunteer."[3] The methods employed by them to recruit these human subjects were not described. Although dengue fever is usually not lethal, it can be extremely uncomfortable. No deaths were reported consequent to this effort. However, much like the prior rants of Osler Abbott and Hans Zinsser demeaning African Americans, the researchers' animus would be declared vocally: their human colonial subjects were "ignorant [Spanish] immigrants hardly more intelligent than animals"[3]

Unfortunately, the next step would be lethal. Unlike dengue fever, yellow fever—another infection prevalent in the American colonial possessions—has the potential to kill. Since other inducements failed, recruitment of colonial research subjects for yellow fever studies would be obtained via financial coercion. One hundred dollars[3] in gold and a promise of free medical care—dangled in front of an indigent population—the enticement. In fact, it was said, "so appealing was the offer that … immigrants not chosen 'almost wept.'"[3] For such poor subjects, the substantive risks of yellow fever would be ignored for a price, all for the benefit of family.

For the first time, written contracts were utilized, binding researcher to research subject. The deception in the consent form was palpable: "The undersigned understand perfectly well that in case of the development of yellow fever in him, that he endangers his life *to a certain extent, but it being entirely impossible for him to avoid the infection…he prefers to take the chance contracting it intentionally in the belief that he will receive from the (Walter) Reed Commission the greatest care and the most skillful medical service.*"[3] To characterize the consent document as disingenuous is an understatement. Yellow fever infections do not endanger life "*to a certain extent,*" but rather place the infected individual in an extremely risky category. Other than supportive care, there were no antiviral therapies or vaccines available. The "*greatest* care *and the most skillful medical service*" may not have had any salutary effect on the patient. In one of the experimental groups, two Spanish subjects succumbed to physician-administered yellow fever.

Dr. Cornelius Rhoads—like Drs. Osler Abbott and Hans Zinsser—would give voice to the research doctrine embraced in colonial environments. He would express unabashed disdain for the human subjects (the 2nd introductory quote to this section). Although his heinous claims of dispatching Puerto Rican patients—or injecting them with cancer cells experimentally—were never proven, his attitude was in complete opposition to Hippocratic practice.[18] He would not be punished, but rather would become a "poster child" for Flexnerian medical science. He became a prominent cancer researcher.[20] The same perception of a superior research culture and inferior research subject dignity—in the eyes of American medicine—would be shared by African Americans and colonial persons.[15]

The Impact of Eugenics Movement on Flexnerian Medical Research

> "…in (Dr. Cornelius) Rhoads's fantasy, social distance and racial difference could be resolved through medical means…scores of American state legislatures which had enacted laws for the *eugenic sterilization of the 'defective…'* Rhoads envisioned a medical solution for the 'Porto Rican' (sic). In his fantasy, the procedure—transplanting cancer—*would exterminate a 'degenerate' race rather than merely limit its procreative power.*"[15]

> "Racism, group hatred, xenophobia, and enmity toward one's neighbors have existed in almost every culture throughout history. But it took millennia for these deeply personal, almost tribal hostilities to *migrate into the safe harbor of scientific thought, thus rationalizing destructive actions against the despised or unwanted.*"[21]

Similar to the lengthy background of illicit research on African American persons, eugenic theory also had a history preceding Flexner's Report. That history would also be employed as a justification for unethical experimentation. The focus will be two groups of human beings identified as inferior by eugenicists, that is, prisoners and the so-called "feebleminded."

In 1874, Richard Dugale discovered that some of New York's Ulster County prisoners were blood relatives.[21] In fact, forty-two families were represented among the criminals. Dugale traced 709 individuals to a single woman, named Margaret.[21] To his credit, Dugdale himself blamed nurture and not nature.[21] Unfortunately, it became easier for others to blame nature—without a shred of scientific proof—thereby contributing to eugenics under the guise of human betterment.

Fast forwarding to 1903, in the context of prisoners and the "feebleminded" as vulnerable eugenic targets, Davenport opined, "Society…claims the right to deprive the murderer of his life, so also it may annihilate the hideous serpent of hopelessly vicious protoplasm."[21] The "vicious protoplasm" was heterogeneously comprised by two million people, characterized by their racial "superiors" as "destitute, insane, feebleminded, defective, and criminal elements."[21] In the name of human betterment, initially, sterilization and euthanasia were viewed as a merciful solution to the problem. Darwin's brand of natural selection had been glacially slow. Medicine now had an opportunity to move more quickly than nature. Medical doctors became prominent supporters of eugenic theory. As early as 1899, Albert John Ochsner M.D. advocated compulsory prisoner vasectomy in order "to eliminate all habitual criminals from the possibility of having children."[21] Duncan Mckim M.D. said in 1900: "Heredity is the fundamental cause of human wretchedness…The surest, the simplest, the kindest, and most humane means for preventing reproduction among those we deem unworthy of this high privilege (reproduction) is a gentle painless death."[21] The shaman's practice of both "black and white medicine" would be resuscitated. Eugenically-minded physician-scientists targeted prisoners as well as those humans they felt superior to and described as *feebleminded* for their research.

The same verbal warfare applied to blacks and colonial persons would be applied to these human groups as justification. For example, incarceration was equivalent to research availability in medical literature. There would also be an explicit overlapping of racial prejudice with eugenics as "prisoners might simultaneously expiate their debt to society and protect others, *especially African Americans*, by substituting for them *as* unwilling *research subjects*."[4] Even the renowned Psychiatrist Karl Meninger[4] described the incarcerated person as "the spasms and struggles of a sub-marginal human being trying to make it in our complex society with inadequate equipment." Finally, it was observed that "criminals in our penitentiaries are fine experimental material—and much cheaper than chimpanzees."[4]

In 1915, twelve Mississippi prisoners were coerced into an experiment regarding pellagra.[22] Dr. Joseph Goldberger of the U.S. Public Health service needed "white adult males, the one demographic in the population that statistics had shown was least likely to contract the disease (pellagra)."[22] He convinced the governor of Mississippi to grant the prisoners a pardon if they survived the experiment. Each of these individuals was jailed for murder. The human subjects were placed on a near starvation diet. These men grew increasingly ill and complained of pains in their backs, sides, and legs, along with lethargy and dizziness. The prisoners themselves described the ordeal as a "hellish experiment."[22] It is outside the scope of this paper to discuss the rightness or wrongness of releasing a violent population into the community. The action was not received well by the surrounding populace.[22]

In 1918, Dr. L.L. Stanley's study was comprised of "transplanting testicles from recently executed convicts to senile and devitalized men [or "feebleminded"]."[23] Stanley managed to accomplish 1000 transplants without consent from the prisoners or the unfortunate recipients without any criticism.

Then Dr. Udo J. Wile decided upon human "donors" to transmit syphilis to rabbits. He decided that institutionalized paretic victims of syphilis should be subhuman ubjects.[24] A colleague physician—Dr. Edmund A. Christian—gave Dr. Wile access

to six subjects under his care. The original paper has no discussion of consent, family notification, or the pain endured by the paretic individuals. Wile trephined (via a drill) their skulls under local anesthetic![24] In addition to removing brain tissue for study, he needled their ventricles and removed fluid. He injected his samples into rabbits. Experimental syphilis was produced in these rabbits. In his acknowledgements, he thanked his crony Dr. Christian for the use of his "facilities."[24] Human beings with end-stage central nervous system syphilis became less than human and were merely "facilities" for a fatal infectious disease.

To return to Flexner's chosen model of German medicine, as previously with Drs. Boyd and Wagner-Jauregg, the forerunners of Wile's immoral efforts were German physicians.[25] The only difference between the German physicians and Wiles's methods was the initial failure in Germany to successfully transfer syphilis to the rabbits.[25]

Conclusions

> "…medicine, professedly founded on observation, is as sensitive to outside influence, political, religious, philosophical, imaginative, as is the barometer to the atmospheric density."[18,iii]

> "While he could be outspoken and fearless when commenting about issues which pertained directly to education, at times he dissembled, distorted or chose to turn his head."[26,iv]

Since both Abraham Flexner and his report on medical education in 1910 were central to the preceding ethical study of clinical research, his background should be studied. First of all, and possibly most critical, he was not a physician and did not earn a terminal degree. Some of his shortcomings in the context of human subject research were due to a complete lack of experience in that area. However, his single-minded focus on science and education was a detriment to American medicine and its physicians. Since his interest seemed to be education per se, and only education, it is possible that he did choose "to turn his head" on the ethical ramifications of science in medicine. Kenneth Ludmerer described Flexner as "dogmatic, rigid, and acerbic, but incredibly charming and ingratiating when he chose to be."[2] Nevins labeled him a flawed American icon.[26] Flexner was Jewish, but despite the ascendency of anti-Semitism in Germany and the immoral research initiated there, he accepted the German medical education template *carte blanche*.

More disturbing for the profession of medicine however, is to ask why—at a time that was ostensibly Hippocratic—physicians became the villains in human subject research? It seems that they shared a zeitgeist with non-physicians that was permeated with racial prejudice, attitudes of colonial superiority, and the pseudo-science of eugenics. None of these belong within a Hippocratic ethos, even if they predominate in surrounding culture. The continuation of some the same ethically-tainted practices today, in regard to research and mandated transplant donations, both on prisoners, is disconcerting.[18,27] Furthermore, since Hippocratism has been assailed repeatedly in the last fifty years, many of the prejudices that stoked medical science in Flexner's generation may be aroused again.

In order to be thorough and fair, however, it must be understood that there were physicians who risked their reputations protesting the barbaric research of the Flexner era. In response to articles accusing blacks of being free to satisfy their sexual desires, thereby being a "syphilis-soaked race," Dr. John A Kenney observed: "When men high in the medical profession use the leading medical journals of the country to assail and libel a whole race of people, it is time that our…publication should speak…"[28] Dr. Irwin J. Schatz wrote in a public forum regarding the Tuskegee study, "I am utterly astounded by the fact that physicians allow patients with potentially fatal disease to remain untreated when effective therapy is available."[18] Although there were not many who took a stand, there were some who did.

Teaching the historical and ethical content contained in this manuscript may be augmented through the medical humanities, such as Sinclair Lewis' *Arrowsmith*. The non-medical culture contemporary to Flexner sensed the gaping breach between science and compassionate healing within the profession. Lewis' Martin Arrowsmith is a physician not to be emulated. Unfortunately, there were many flesh and blood physicians at his time also unworthy of their special calling. Another possible text is Kurt Vonnegut's *A Cat's Cradle*. Although Vonnegut criticizes physical science leading to the atomic bomb, medical scientists must also be cognizant of discoveries that may be used for bad. Vonnegut's concern hearkens back to Pierre Curie who said, "It can be thought that radium could become very dangerous in criminal hands… The example of Nobel…explosives have enabled man to do wonderful work…(but) they are…a terrible means of destruction. I…believe…mankind will derive more good than harm from the new discoveries."[6] Unfortunately, Curie misread man's fundamental nature.

The actions reviewed should also prompt Hippocratic physicians to volunteer for IRB committees. Any research that probes ethical boundaries, especially resembling post-Flexner research practice, must be identified and blocked by a committed contingent of physicians.[29]

Machiavelli, a more shrewd judge of man's nature, opined, "Whoever wishes to foresee the future must consult the past; for human events ever resemble those of preceding times. This arises from the fact that they are produced by men who ever have been, and ever shall be, animated by the same passions (those universal and consequent to a fallen nature)." This look at human subject research in America's past should stand against any repetition in the future!

References

1. Duffy Thomas P. The Flexner Report—100 years later. Yale Journal of Biology and Medicine 2011; 84:269-276.
2. Ludmerer Kenneth M. Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care. Oxford University Press, 1999. p.6, 3.
3. Lederer Susan E. Subjected to Science: Human Experimentation in America Before the Second World War. The Johns Hopkins University Press, Baltimore and London, 1995. p. 115-116, 7, xv, 2, 115-116, 114, 114, 132, 21, 21, 21, 112.
4. Washington HA. Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present. First Anchor Books, New York, 2008, p. 1-2, 182, 182, 1-2, 10, 163, 245, 248, 244.

5. Boyd MF. & Kitchen SF. Observations on induced falciparum. American Journal of Tropical Medicine 1937; 17:213-235.
6. Rutecki GW. Fin de siècle Science intersecting the Arts: Puccini, Debussy & Radium Therapy. *Pharos of Alpha Omega Alpha*, Fall-Winter 2017-2018; 28-33.
7. Mukherjee S. The Emperor of All Maladies: A Biography of Cancer. Scribner, New York, 2010, p. 73 ff.
8. McMahon D. and Rutecki G.W. In anticipation of the Germ Theory of Disease: Middleton Goldsmith & the History of Bromine. *The Pharos of Alpha Omega Alpha* 2011; 74:4-12.
9. Rutecki GW. A revised timeline for biological agents: revisiting the early years of the Germ Theory of Disease. Medical Hypotheses 2007; 68: 222-226.
10. Karamanou M, Lippias I, Antoniu C, et. al. Julius Wagner-Jauregg (1857-1940): Introducing fever therapy in the treatment of Neurosyphilis. Psychiatriki 2013; 24:208-212.
11. Gambino M. Fevered Decisions: Race, Ethics, and Clinical Vulnerability in the Malarial Treatment of Neurosyphilis, 1922-1953. Hastings Center Report 2015; July-August: 39-50.
12. Gartlehner G & Stepper K. Julius Wagner-Jauregg: pyrotherapy, simultanmethode, and 'racial hygiene.' J. R. Soc. Med. 2012; 105:357-359.
13. Vogel G. Malaria as Lifesaving Therapy. Science 2013; 342:685-6.
14. Skloot R. The Immortal Life of Henrietta Lacks. Broadway Paperbacks, New York, 2011. p.96-7.
15. Lederer SE. "Porto Ricochet": Joking about Germs, Cancer, and Race Extermination in the 1930s. American Literary History 2002; 14:720-746.
16. Abbott Osler W.. The Problem of the Professional Guinea Pig. Proceedings of the Charaka Club 1941; 10:249-260.
17. Summers William C. Hans Zinsser: a tale of 2 cultures.' Yale Journal of Biology and Medicine 1999; 72:341-347.
18. Jones James H. Bad Blood:The Tuskegee Syphilis Experiment, New York Free Press, New York, 1993, p.4,92,123,16,267,168.
19. Aponte-Vazquez P. The Unsolved Case of Dr. Cornelius Rhoads: An Indictment. Publicaciones Prene, 2005, p.25-26, Depositions 173-283.
20. Rhoads CP. Rational Cancer Chemotherapy. Science 1954; 119:77-80.
21. Black E. War Against the Weak: Eugenics and America's Campaign to Create a Master Race. Thunder's Mouth Press, New York, New York, 2004. p.9, 24, 24, *24, 39, 39*, 63, 249.
22. Hornblum A. Subjected to Medical Experimentation: Pennsylvania's Contribution to "Science" in Prisons. Pennsylvania History 2000; 67 (3).
23. Stanley L.L. An analysis of one thousand testicular substance implantations. Endocrinology 1922; 6:787.
24. Wile UJ. Experimental Syphilis in the rabbit produced by the brain substance of the Living Paretic. https://www.ncbi.nlm.nih.gov/pubmed/19867978.
25. Forster E & Tomaszczewski E. Deutsch. Med. Wchnschr. 1913; 39:1237.
26. Nevins M. Abraham Flexner: A Flawed American Icon. Universe, Indiana, 2010, p. ix.
27. Paul NW, Caplan A, Shapiro ME, et. al. Human Rights violations in organ procurement practice in China. BMC Medical Ethics 2017; 18:11-17.
28. Kenney JA. "Syphilis and the American Negro: A Medico-Sociologic Study." J. Natl. Med. Assoc. 1910; 2 (2):115-117.
29. Rutecki GW, Youtsey M, Adelson B. The Institutional Review Board: a critical revisit to the protection of human subjects. Ethics and Med. 2002; 18:135-44.

Endnotes

i. Henrietta Lacks, an African American woman, had her cells cultured and the cell lines that eventuated helped millions of people while blossoming into a multimillion dollar industry. She was never apprised of or repaid for her contributions to humanity. Her children only became aware of the cell lines more than 20 years later!

ii. Written by Dr. Cornelius Rhoads a respected American Physician-Scientist.
iii. Dr. Oliver Wendell Holmes.
iv. A colleague describing Abraham Flexner.

Gregory W. Rutecki, MD, is an Emeritus Internal Medicine, Cleveland Clinic, as well as an Emeritus Fellow CBHD. He was previously a Nephrologist and the E. Stephen Kurtides Chair of Medical Education Evanston Northwestern Healthcare and Professor of Medicine the Feinberg School, Northwestern University. He currently resides in Lyndhurst, Ohio, USA.

Book Reviews

Cyborg Mind: What Brain-Computer and Mind-Cyberspace Interfaces Mean for Cyberneuroethics.

Calum MacKellar, ed. New York and Oxford: Berghahn Books, 2019.

ISBN 978-1789200140, 249 PAGES, HARDCOVER, $134.59

Coined specifically to designate the ethical challenges faced by direct interfaces between the human brain and computer systems, the very term "cyberneuroethics" suggests a novel realm of inquiry about technologies linking humans to computers and taking us into cyberspace. This book, then, is about emerging technologies that may be used for diagnostic purposes and healing purposes in medicine and also for extraordinary enhancement of human capabilities. It is about technologies that may come to be used for military purposes and spying and also for manipulation of individuals, as well as for game playing and solitary escapism. It is a book pointing both to potential benefits and to potential risks for individuals and for society at large.

The entire volume is penned by the editor, Calum MacKellar. However, he draws on a range of contributors who are named in the acknowledgements. Thus, there are several minds behind this encyclopedic review of the technical as well as social, ethical, and philosophical aspects of cyberneuroethics. The book opens with an explanation of the brain and the nervous system and of technologies, such as MRI, PET, and EEG and other non-invasive as well as invasive neural interface systems, including assistive robotic technologies such as computer-directed robotic limbs. Many of these technologies will, of course, be familiar to members of the medical profession and many computer scientists. The book is, however, directed at a much wider audience. Thus, having given the uninitiated reader an insight into the kinds of technology at issue, the book turns to the ethical, social, legal, and philosophical implications of the use of the new brain-computer interface technologies.

Many of the ethical and interpersonal consequences for the individual and for society of blurring the boundaries between humans and machines are highlighted by reference to prophetic futurologists and science fiction. Not only are we told about the aspirations of transhumanists wishing to augment their own and future generation's physical and mental abilities, but also we are told about post-humanists wishing to alter humans altogether by transferring our minds to computers and cyberspace, where we might live on and on but at the risk, or indeed at the cost, of losing not only our privacy but also our personal identity. For your bodily identity is linked to your biological bodies. As is shown, the new technologies, some with a potential to manipulate individuals or alter human personality, raise questions about selfhood, as well as moral responsibility and accountability. As such, they have implications for criminal liability as well as for interpersonal relationships. In medical practice, and many other areas, they will have implications for the concept of informed consent.

The book is timely. Brain-computer interface technologies are bound to have a significant impact on 21st-century society. While the new brain-computer interface technologies have great potential for healing purposes in medicine, their use also pose risks that go well beyond medical risks. Like fire, they can be used for bad as well as for good. Like fire, they could get out of hand. From a philosophical point of view, they face us with questions about the relationship between body and mind and, indeed, with the question of what it means to be human. This is a book for philosophers, bioethicists, lawmakers, and politicians as well, as for anyone directly involved in the use of the new technologies.

Reviewed by Agnetta Sutton, PhD, who is a bioethicist and Associate Lecturer at Maryvale Institute in Burmingham, UK. She received her PhD from King's College in London, UK, and is widely published.

Embodied Hope: A Theological Meditation on Pain and Suffering.

Kelly M. Kapic. Downers Grove, IL: Intervarsity Academic, 2017.

ISBN 978-0830851799, 197 PAGES, PAPERBACK, $15.00

Theologian Kelly Kapic writes this book not only out of theory but also out of personal experience of pain and suffering in his family. Yet the book does not overindulge in personal details; rather, Kapic demonstrates how the Bible and theological tradition provide a firm foundation for faithful perseverance in suffering.

The book proceeds in three parts. In the first, "The Struggle," Kapic describes the way suffering enters the picture, the hard questions about God that such experiences raise, and some tempting answers that aren't acceptable Christian answers. For instance, he explains that we can't answer why and shouldn't try—it doesn't provide the comfort that we think it might, and we're likely wrong anyway. He also helps us see that we cannot view the body as an evil and seek solace in an over-spiritualized account of existence that flees the physical.

The second part, "The Strangeness of God," provides the theological backbone of the book. In this section, Kapic explores the doctrine of the incarnation, Jesus' suffering on the cross, and the hope of the resurrection. He explores these themes with the problem of suffering in mind, but his discussion is rooted deeply in biblical interpretation and the testimony of Christians through the ages. In this section, Kapic demonstrates his ability both to interpret the Bible faithfully and to read it alongside other believers from the past who have had profound insights.

Third, Kapic concludes with "Life Together." In this section he emphasizes the centrality of community in the human experience, especially in enduring pain and suffering. The book is written for Christians, and this section explicitly states the centrality of the church community for those who are suffering. The idea of "bearing one another's burdens" proves significant in this section.

The greatest strength of this book is represented at the start of each chapter. Kapic always begins with quotations: key Bible verses and quotations from Christian writers, ancient and modern. Kapic weaves these sources together in a consistent and robust way that deals seriously with pain and suffering. This book is an excellent place for Christians to go to better understand the place of pain and suffering in a faithful Christian life that avoids easy answers. Christian health care providers should buy and read it to deepen their ministries. So should pastors and family members of those who are suffering. The book is also for those who themselves are walking through chronic pain or sudden suffering, because Kapic is a faithful and helpful guide.

Reviewed by Jacob Shatzer, MDiv, PhD, who is assistant professor of theological studies and associate dean in the School of Theology & Missions at Union University in Jackson, TN.

Ethics & Medicine

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

Contents

3 CONTRIBUTORS

5 EDITORIAL
Medicine: Contract or Covenant?
C. Ben Mitchell, PhD

7 GUEST COMMENTARY
The Dignity of Human Life: Sketching Out an "Equal Worth" Approach
Helen Watt, PhD

19 POLICY ANALYSIS
"Complex Family Planning" and the Assault on Conscience
Patrick Marmion, MD, MPH, FACPM

27 GREY MATTERS
Cerebral Organoids and the Threshold of Consciousness
William P. Cheshire, Jr., MD

37 CLINICAL ETHICS DILEMMA
Daring to Deploy a DNR Directive
Robert D. Orr, MD, CM; Ferdinand D. Yates, Jr., MD, MA (Bioethics)

41 **The Pain Principle: An Ethical Approach to End-of-Life Decisions**
Carlo V. Bellieni, MD

51 **Clinical Science after Flexner's 1910 Report on Medical Education: A Research Ethos Inhabited by Racial Prejudice, Colonial Attitudes, and Eugenic Theory**
Gregory W. Rutecki, MD

63 **Book Reviews**

VOL 36:1, SPRING 2020
HTTP://WWW.ETHICSANDMEDICINE.COM

bioethics PRESS

Ethics & Medicine An International Journal of Bioethics
Vol 36:1 SPRING 2020 ISSN 0266-688X