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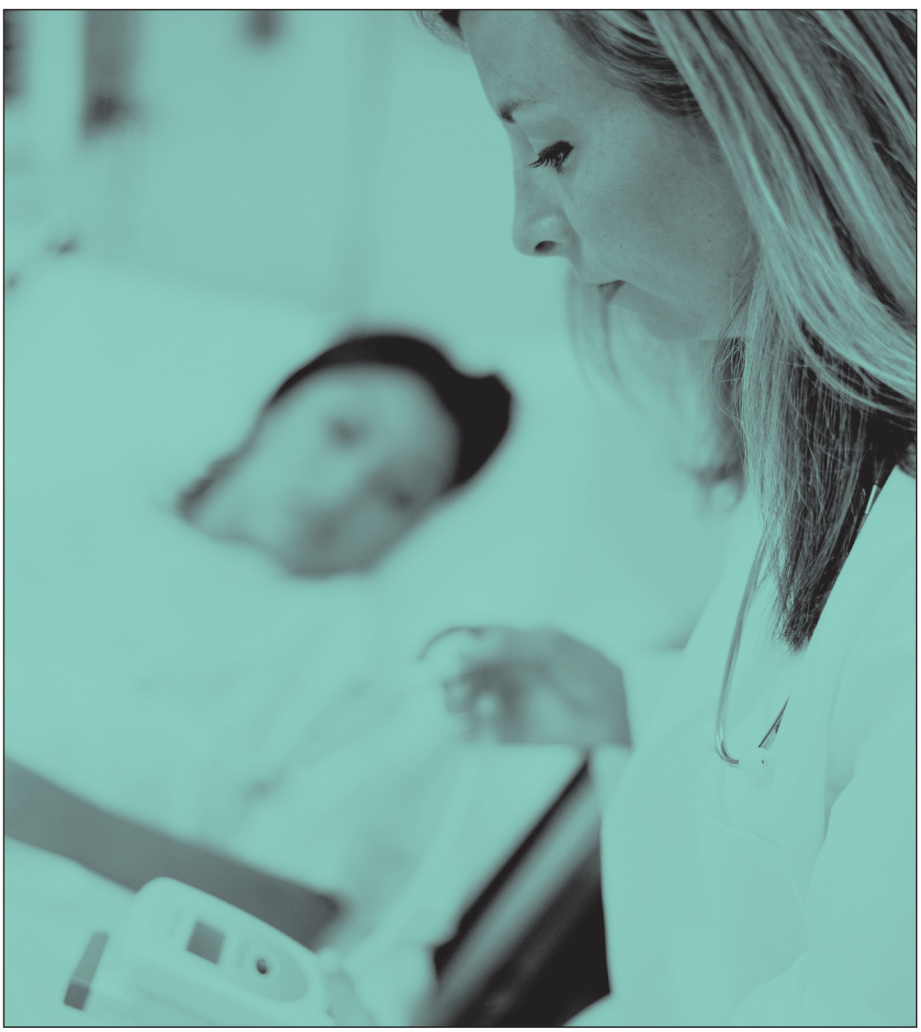
An International Journal of Bioethics



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Advertisement

The Ramsey Award and the Logic of Life, by C. Ben Mitchell.

In the March 26, 2006, issue of Commonweal, the journal for lay Catholics, Notre Dame professor Cathleen Kaveny asked a very perceptive question: "I wonder whether the CBC would consider Ramsey himself suitable for the award that issues in his name?" The answer to the question should be obvious, but I can understand how someone might be confused. So, as the chair of the nominating committee for this year's Ramsey Award, I was asked to clear the air.

The reason professor Kaveny raised the question in the first place is because of what she perceives as a disparity between my own views on the nature of the early human embryo and Ramsey's view. I, on the one hand, hold that from fertilization (or, more precisely, syngamy), the lives of human embryos should be respected and not unnecessarily harmed. On the other hand, as students of Ramsey will know, that was not his view. He thought the status of the very early embryo before was more ambiguous. Prior to possibility of twinning (when the embryo may divide into two embryos), since the embryo had not yet "individuated", it was more difficult to ascribe what we would call a "right to life." After about two weeks from fertilization, after the period of twinning had passed, we could be more certain about the status of this particular individual or individuals, and may, therefore, speak meaningfully of harms to this individual.

Because of the possibility of twinning, it seems reasonable to me that we should alter our language. And, in fact, I have been saying for a long time now, "*at least one* protectable human life begins at conception." That being the case, on my view, destroying an embryo before twinning is not morally permissible and the fact that the embryo may twin only makes it more problematic to do so. Killing twins is not more acceptable than killing a singlet.

But, to the professor's question: would Ramsey be eligible to receive the award that bears his name? The answer is a resounding, YES! First, the Ramsey Award is given in recognition of exemplary work in the area of bioethics, not for one's view of the status of the early human embryo. And the credentials of the first three award winners are indisputable in that regard. **Dr. Edmund Pellegrino** is one of the parents of contemporary bioethics, **Dr. Germain Grisez** helped chart the course for theological engagement in bioethics, and this year's [2006] winner, **Dr. John M. Finnis**, continues to contribute to ethics, law, and policy in extraordinary ways.

Second, in fact, persons have been nominated and considered for the award who hold a view similar to Ramsey's. I do not recall that that point was raised in our discussion and fully believe that someone may well receive the award in the future who holds a relevantly similar view. The measure of one's contribution to bioethics goes beyond embryo ethics. Indeed, some of those considered for the award have not written or otherwise articulated a position on embryo ethics.

Finally, no one should construe my views as the views of everyone associated with the Center for Bioethics & Culture. The Center's positions are clearly outlined on the website and in its literature. The tag line, "Bringing people together for a truly human future," represents the Center's mission. While that agenda may include embryo ethics, it is much broader and more ambitious. And it is to that mission that everyone associated with the Paul Ramsey Project is committed.

Paul Ramsey's legacy is indisputably consistent with that mission. His body of work including *The Patient as Person*, *Fabricated Man*, and *Ethics at the Edges of Life*, have all contributed to our understanding of what a truly human future ought to look like. And for that, I, especially, am most thankful. The Ramsey Award is offered, therefore, most profoundly out of gratitude for the formative influence of a man, who being dead, still speaks.

C. Ben Mitchell, Ph.D., is Editor of Ethics and Medicine, Chair of the Ramsey Award Nominating Committee and a Director at the Center for Bioethics and Culture Network.

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The Paul Ramsey Award: CALL FOR NOMINATIONS

The 4th annual Paul Ramsey Award dinner will be hosted by the CBC on March 30, 2007. This event honors those among us that have and are deeply impacting the bioethics discussion by actively equipping our society to face the challenges of the 21st century, profoundly defending the dignity of humankind, and enthusiastically embracing ethical biotechnology for the human good. The Ramsey Award is given to those who have demonstrated exemplary achievement in the field of bioethics.

Send a 500 word submission to ramsey@cbc-network.org

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EDITORIAL

HUMAN EGG "DONATION"

C. BEN MITCHELL, PH.D.

One of the ethical violations that led to charges against North Korean cloning researcher Hwang Woo-Suk, was that he used female lab assistants as egg donors.[1] Embryonic stem cell research requires cloned human embryos. Embryos are fertilized eggs. So, professor Hwang threw moral considerations to the wind, and used his own assistants as research tools. In fact, increasing numbers of women around the world are being solicited for their eggs for the purposes of medical experimentation. The problems with egg donation for reproductive purposes are sufficiently strong to avoid the practice, but what about egg donation for research? Are there ethical reasons *not* to donate one's eggs?

First, egg donation poses significant health risks. An egg donor receives daily injections of powerful hormones (usually for at least two weeks), serial blood tests, and ultrasounds to determine if eggs are ready to be harvested. The hormone injections are typically tailored to the response. When the eggs are ready to be "harvested"—i.e., surgically removed—the woman undergoes an outpatient surgical procedure known as needle aspiration, where (usually) 10-20 eggs are removed. If all goes well, the bloating and discomfort will only last a few days. Needle aspiration may cause bleeding. In rare cases it is possible to puncture the bowel, bladder, or nearby blood vessels. Though unlikely, major abdominal surgery may be needed to repair serious damage to the pelvic organs.

Another possible complication of egg donation is the development of ovarian hyperstimulation syndrome (OHSS) when too many eggs develop following the hormonal stimulation of the ovaries. This is at least uncomfortable, but may be more harmful, and in rare cases, death can result. In mild OHSS, there may be abdominal pain, pressure, and swelling. In moderate OHSS, careful monitoring, bed rest, and pain medications may be necessary. Severe OHSS is rare, but can cause serious medical complications, which may include blood clots, fluid build-up in the lungs, kidney failure, and shock. The donor's own future fertility may be at risk due to these factors. Add to this mix the emotional baggage of relinquishing parental rights, and the physical and emotional fallout can be substantial.[2]

In addition to the health risks, it is more likely that poorer women will be tempted to sell their eggs than wealthier women. In March 2005, the *Scotsman,* the national newspaper of Scotland, revealed that a clinic in Britain was paying Romanian women for their eggs, exporting the eggs back to England, where British couples were using them for assisted reproduction. The Romanian women were being paid between £200 and £300 (about $350-$550 US), significantly below the "market rate" in other countries.[3] Women who are well off financially will not sell their eggs for those prices, thus, poor women will likely be exploited for their eggs.

While we should support ethical research, egg donation poses risks that should make women and policymakers reject it. Sadly, some women learn too late that egg donation is no fairy tale. In fact, it can be a nightmare. However, concern for the health of donors is not the only factor that should concern Christians. God made every human being in His own image (Gen 1:26-28). Therefore, women—especially poor women—should not be exploited for their "reproductive capacities." Neither should women be treated as egg farms. The rank commercialization of a woman's eggs objectifies women in the same way prostitution and pornography objectifies them. It treats them as "human hens", not as persons. So, no matter how much someone is willing to pay for a woman's eggs for reproduction or research, the grotesque moral and social costs are too high to endorse it.

Endnotes

1 Kim Tae-gyu, "Hwang Admits In-House Egg Donations," *The Korea Times*, 24 November 2005. http://times.hankooki.com/lpage/200511/kt2005112418515810440.htm

2 These complications are outlined in *Thinking of Becoming an Egg Donor?* published by the New York State Task Force on Life and the Law, available at http://www.health.state.ny.us/nysdoh/infertility/eggdonor.htm

3 Karen McVeigh, "Police Probe Clinic Under Suspicion of 'Exploiting' Egg Donors," *The Scotsman,* March 10, 2005. http://thescotsman.scotsman.com/international.cfm?id=261532005

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GREY MATTERS

When Eloquence is Inarticulate

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

The French have an expression—*je ne sais quois*—which refers to an indescribable attractive quality. There is, for example, in addition to the goal of attaining procedural competence, a certain something that draws people to such fields as bioethics. Some of the reasons for one's fascination with a discipline find expression in rational terms, while others may lie just beyond the grasp of explicit language. Like the mood evoked by a faintly familiar melody of forgotten origin is the *je ne sais quois* underlying the inexpressible feature of one's personal aspirations.

One intriguing aspect of bioethics is that novel technologies and the choices their applications present challenge us to reflect anew on what it means to be human. At this frontier of life, at once bright with possibilities and dim with grey uncertainties, the faculty of reason is indispensable for the clarification of ideas. Reason distinguishes what is rational from imagination's apparitions. Reason can be more or less unambiguously stated, its presuppositions defined, its arguments logically arranged, its conclusions tested analytically and confirmed against empirical data. Reason also demands consistency, coherence, and efficiency.[1] Reason is trustworthy, but is it complete? Are there truths essential for bioethics that lie beyond the competence of reason to define or explicit language to express?

This question lies at the heart of the current debate within bioethics over what forms of meaning should be admissible in public discourse in a world where people differ in their views and values. Ruth Macklin, writing in the *Hastings Center Report*, argues that the one true basis of bioethical discussion is reason. Appeals to metaphor, emotion, and moral intuition, according to Macklin, should be excluded because they are not understood in the same way by all people and thus ought not to have a role in the formulation of public policy.[2] On this point Macklin vigorously (an attitude that itself cannot be reduced to rationality) disputes Yuval Levin who, writing in *The New Atlantis*, also advocates for the use of explicit reasoned arguments. These writers disagree, however, on reason's limits. Levin suggests that reason, while necessary, yet is insufficient to encompass the full meaning of human existence.[3] There are, according to Levin, moral truths that are reasonable but not fully rational, that can be understood but not adequately articulated. These, he writes, "are the realms where many ethical limits express themselves not in syllogisms but in shudders."[3] Such insights glimpse a deeper wisdom that, if unheeded, could lead, he cautions, to "a culture without awe filled with people without souls."[3] Likewise, Leon Kass has written persuasively on the wisdom of repugnance.[4] Meanwhile, Macklin insists that these are not arguments.

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Neuropsychology has traditionally emphasized the role of "higher cognition," referring to rational thought, in contrast to affective or emotional thoughts generally associated with intuition. This distinction roughly parallels the division in moral philosophy between consequentialist and deontologic ethical perspectives.[5] Consequentialist perspectives emphasize rationally calculated outcomes aimed at maximizing the greater good, as contrasted with deontologic perspectives, which argue for respecting certain intuitively discerned moral obligations and not crossing certain moral boundaries. Although useful, the distinction blurs, however, where consequentialist ethicists such as Mill may seek to maximize an emotion (happiness), and deontologists such as Kant justify the universality of moral principles on the basis of reason.

It would be unreasonable, if not disappointing, to regard reason and emotionally-laden intuition as categorically independent. In the words of William James, "The universal conscious fact is not 'feelings exist' and 'thoughts exist,' but 'I think' and 'I feel.'"[6] More recent neuropsychological perspectives recognize emotion (affect) and intuition (quick gestalt judgments reached without conscious awareness of a process of thought) along with reason to be aspects of intelligence that correspond to brain processes that inform and drive decision-making.[7] Furthermore, the appreciation that emotional valuations also involve neural information processing underlies the emerging field of affective computing.[8]

Current research is applying functional imaging techniques to chart the brain regions subserving moral judgments. Utilizing functional MRI, Joshua Greene and colleagues have identified specialized brain regions associated with abstract reasoning, including the dorsolateral prefrontal and parietal areas, which become active when the brain is considering impersonal, non-moral dilemmas. In contrast, the medial frontal gyrus, posterior cingulate gyrus, and superior temporal sulcus become active when the brain is presented with personal moral dilemmas that evoke emotion.[9] These investigators theorize that the tensions between reason and emotionally-laden intuition are due to competing neural subsystems.[5] Neuroscience continues to explore how the brain resolves ethical dilemmas where the pathways of reason and emotion converge in the dorsolateral prefrontal and anterior cingulate cortices. There exists within the brain what C. S. Lewis termed a liaison between "cerebral man and visceral man."[10]

To divorce emotion from reason would be to oversimplify wisdom. Both are necessary, yet each is insufficient, for bioethics. Either reason or emotion, if pressed to the extreme and isolated from the other, can mislead and endanger. Solitary reason, unaware of the feelings and values discerned emotionally, overlooks the meaning of compassion. Cold logic offers no compelling reason to be concerned about the suffering of others. Affectively neutral, impersonal, calculatingly bland thought can be blind to empathy. Notably, brain lesions that damage the processing of the emotional content of speech impair understanding by rendering the person deaf to affective nuance.[11] Emotions are the brain's method of assigning value and priority to experiences and their memories. Situations that arouse emotion immediately bring to mind knowledge related to emotions engendered by similar past experiences, which greatly aids decision-making in the face of uncertainty.[12] Moreover, there are reasons why we have

emotions. There are things that ought to be loved or feared.

Reason not only informs the will; it is also instrumental to the will. As a cognitive tool, reason can be applied to good or evil purposes. By use of reason one articulates what the conscience knows to be right or wrong. By use of reason one also rationalizes moral transgressions.

Pure reason, though informative, yet is morally inert. If purged of emotional content, reason is impotent to motivate. Neurologist Donald Calne summarizes that "The essential difference between emotion and reason is that emotion leads to actions while reason leads to conclusions."[1] As regards moral knowledge, the conscience may clarify what is right or wrong in a given situation without producing the desire to act in accordance with that knowledge.[13] J. Budziszewski has proposed the term "paraconscience" to describe the desires and emotions that assist the conscience by arousing motivations consistent with its conclusions.[14]

Nor should we prefer to be guided by uninformed emotion. Unaided by reason, sentiment is unreliable. Rational principles are needed to distinguish valid moral intuition from prejudice, to hold introspectively discerned knowledge to a standard of consistency, and to outline clear moral boundaries. "Compassion is a virtue, not a principle," writes Edmund Pellegrino. "Morally weighty as it is, compassion can become maleficent unless it is constrained by principle…. Compassion, too, must be subject to moral analysis, must have its reasons, and those reasons must also be cogent."[15]

Considering these things together, it must be concluded that there is no single cognitive domain that defines bioethics. It may be that efforts to perfect the discipline of bioethics, or for that matter to perfect human intelligence, by maximizing either sheer sentiment or absolute reason can only result in loss of mind.[16] Soundness of mind entails both restraint and initiative, neither yielding habitually to the brain's most fervent urges nor submitting automatically to control by computations or algorithms. Likewise, a free and flourishing society legislates neither according to those who cry out the loudest nor in obedience to those who calculate most efficiently. And so in bioethical discourse, as in the individual brain, affective intuition and abstract reasoning function best as collaborators. When faced with difficult moral dilemmas, we need all available resources and access to all valid ways of knowing the world and understanding ourselves. The parietal lobe cannot say to the cingulate gyrus, "I have no need of you."[17]

A truly human bioethics thus welcomes poetic expression. A proper union of analysis and imagination would, in the words of poet David Yezzi, "achieve a balance between thought and emotion, such that every word, every sound and rhythm, is responsible for maintaining this mysterious union."[18] Encompassing both code and imagery, conveying both information and metaphor, the nuances of language open wide the possibilities of probing beyond existing knowledge to analyze, to analogize, to reflect, to edify, to warn, to encourage, and to inspire.

A truly human bioethics also acknowledges the finitude of human reason and the fallibility of human emotion. People of faith believe that intelligence finds its origin in the unfathomable mind of the Creator, whose thoughts immeasurably surpass our thoughts,[19] and by whose words the universe came

into being.[20] One hundred billion neurons in the human brain are inadequate to comprehend this great mystery. When contemplating the transcendent, the brain encounters impenetrable unutterables. In humble awareness of this, Jewish tradition rarely pronounces God's ineffable name, but refers to Him indirectly by way of evasive synonyms.[21] All the powers of human reason are speechless in response to why this awesome God would send his only Son to dwell among us and to die for our sake.[22] And though our human brain lacks language adequate to pray as we ought, the Scriptures teach that the Holy Spirit intercedes for those who are in Christ in groanings which cannot be uttered.[23]

A perfectly rational bioethics sanitized of all emotional content and immune to intuitions might seem at first glance reasonable, but would it be wise? Though a bioethicist might write with angelic eloquence, yet dismiss the value of love and other emotions, the conclusions will sound clangingly mechanical.[24] "Men without chests,"[10] in the haunting words of C. S. Lewis, would be eminently qualified to organize an exclusively cerebral bioethics. But reason is not the brain's sole purpose. Intuition, compassion, and prayer, too, are cerebral processes. A fully cerebral, and hence fully human, bioethics must reason. It must also listen, feel, wonder, heed the conscience, remain humble, empathize, and serve others.

Granted, emotions are unpredictable and at times unsafe. Reason may seem more tame, but a fully human bioethics seems preferable to a tame bioethics.

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CLINICAL ETHICS DILEMMAS

LIMITATION OF TREATMENT DECISIONS FOR UNWANTED NEONATE

SUSAN HAACK, M.D., M.A., F.A.C.O.G.

Editor's note: *This column presents a case that poses an ethical dilemma for patients, families and healthcare professionals. It is based on a real case, though some facts have been changed to preserve confidentiality. The story is presented to a Fellow of the Center for Bioethics and Human Dignity, and his or her analysis is published for our readers. Our goal is to offer careful ethical analyses and recommendations that are consistent with biblical standards. Readers are encouraged to comment on our commentaries.*

Column editor: Robert D. Orr, M.D., C.M., Director of Clinical Ethics, CBHD.

Question

Who can make limitation of treatment decisions for this unwanted neonate?

Case

This 7 day old premie was born at approximately 24 weeks gestation weighing 576 grams and was given Apgar scores of 1/2/3/6 (at 1, 5, 10 and 15 minutes). She has been treated aggressively for respiratory distress syndrome, but has had progressive pulmonary problems, and is now on maximal settings of high-frequency oscillation with 100% oxygen. She has also had periods of blood pressure instability requiring alternating pressors and antihypertensives, as well as progressive intraventricular hemorrhages, now at grade II on the right and grade III-IV on the left. She is receiving antibiotics for possible infection, and morphine for agitation. Given her rocky start and her worsening condition, all of her professional caregivers are recommending withdrawal of life-support because they believe continued treatment would almost certainly not allow the baby to survive, and it would be very burdensome to the baby. They are uncertain, however, whether her mother is the appropriate decision-maker to be asked to consent to this withdrawal of treatment.

Her mother is single and 32 years old. She has had 5 full-term deliveries, but 3 are in foster care. She has a history of metamphetamine abuse (baby had positive drug screen). She reports that she went to a clinic to abort this pregnancy, but was turned down because her blood pressure was too high. She had no prenatal care and says she actually thought she had lost the baby when

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she passed a large clot 2 weeks prior to admission. She continued to bleed, developed cramps and came to the ED 7 days ago. She delivered the baby into the toilet in the ED waiting area and, after the placenta was delivered, informed the staff who began resuscitation. Thus it is not certain that the Apgar scores really represent true times; i.e., the baby was immersed, wet, cold, and may have had delayed resuscitation. Though the prognosis for a 24 week premie is quite poor of and by itself, these factors may make the prognosis even worse. After delivery, she didn't want to see or name the baby and did not want anyone told of the delivery. She did sign a general consent for NICU treatment, and subsequently named the infant, but said she wanted to place the baby for adoption. She has not visited the baby, saying she had no child care for her 2 children at home. It is not clear if the man with whom she lives is the father of the child.

The situation has been reported to Child Protective Services, and they have declined to become involved saying (a) the baby is in a safe environment, and (b) the mother has decision-making authority to give the baby up for adoption. An adoption worker has begun an evaluation, but is not proceeding because the baby is so gravely ill.

Assessment

The issues of surrogate decision-making, withdrawal of treatment and medical futility are compounded by their occurrence in this gravely ill, abandoned, 24-week gestation infant.

Discussion

Surrogate decision-making is employed when a formerly autonomous person is no longer competent to make decisions, and involves the determination of what the patient would have wanted based on previous knowledge of their desires. In the case of newborns who have been neither autonomous nor competent, decisions are based on the determination of the patient's best interest, ascertained by consideration of tangible factors such as physical suffering, medical diagnosis, and prognosis. Risk/benefit ratios are utilized to determine the highest net benefit obtainable among the given options.[1] But such determinations are often difficult to disentangle from issues such as quality of life or the family's best interest. In the case of newborns, these decisions are made jointly by the parents and physician. However, parents can be disqualified as decision-makers under conditions of irresponsibility such as child abuse, abandonment, or neglect, in which case appeals are made to the courts for the appointment of a *guardian ad litem* who can serve as advocate for the best interests of the infant.

While withdrawal of treatment in accordance with the wishes of a competent, autonomous individual is both legally and morally permissible, it is fraught with emotional obstacles. How much more so in a newborn! Such decisions, which should be made with an eye to the best interests of the infant alone, too often involve determinations of quality of life and burden to the family, and as such are not clearly focused on the infant.

Medical futility is sometimes defined as treatment of an irreversibly dying patient that provides no physiologic benefit to the patient, or alternatively where the risks of such treatment outweigh the benefits and burdens to the patient. [2] However, even with this looser definition, an assessment of "benefit" is value-laden. Unless the patient has defined "benefit," the value judgments of others may be imposed upon her. Correspondingly, the concept of futility may allow physicians to "medicalize" their subjective value judgments, sanctioning the termination of a life believed to be "not worth living." Even greater ambiguity surrounds such determinations in the gravely ill newborn, where irreversibility is more uncertain.

In this case, there seems to be sufficient evidence to warrant a search for a person other than the mother who will advocate for this infant's best interest. In addition, it is not clear that her treatment is futile. This infant is not yet irreversibly dying; it is still possible that she could stabilize and begin to improve. Moreover, the criterion for determination of futility is unclear in this case. Is it this infant's medical condition or her social condition that is considered futile? Until she has a strong advocate and until her treatment is truly futile, decisions should err in favor of sustaining her life.

Recommendations

(1) Treatment for this infant should be continued until an advocate for the infant can be identified.

   a. Her mother should be asked if she is willing to relinquish decision-making authority to the baby's father or another relative.

   b. If she answers negatively, then appointment of a *guardian ad litem* should be sought through the courts.

(2) If it becomes clear that further treatment for this infant is truly futile, her surrogate may then consent to withdrawal of life-sustaining treatment.

(3) If a decision is made to withdraw life-support from this infant, the moral obligation to continue comfort care and human presence remains.

Endnotes

1 Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 4th ed. (New York: Oxford University Press, 1994), 178.

2 Ibid., 212-213.

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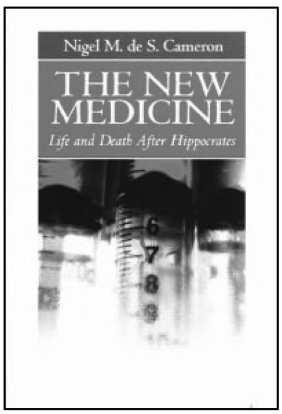
THE NEW MEDICINE: LIFE AND DEATH AFTER HIPPOCRATES
By Nigel M. de S. Cameron



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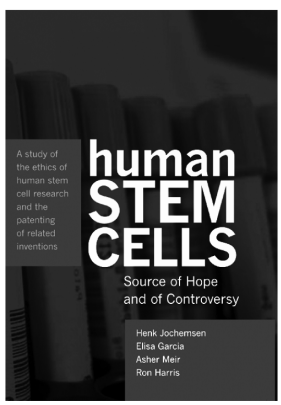

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Are Christian Voices Needed in Public Bioethics Debates?: Care for Persons with Disabilities as a Test Case

JAY HOLLMAN, M.D., F.A.C.C. AND JOHN KILNER, M.A., M.DIV., PH.D.

How can society make progress in addressing the tough life and health issues that make up today's challenging arena of bioethics? In the midst of today's ethical pluralism, is it at least possible to identify a few basic ethical principles for public use that will make such progress possible? We doubt that such is the case as long as the trend to minimize or eliminate explicitly Christian voices in public discussions continues. The care of persons with disabilities is a good example of how contemporary bioethics, exemplified by the widely-used "four principles" approach, can tend toward unsavory positions when it is not influenced by certain Christian sensitivities.

As long as such sensitivities are influential in culture, the contemporary bioethical principles of autonomy, nonmaleficence, beneficence and justice will generally operate well in many respects. But the more that Christian voices are excluded from or marginalized in public discussions of bioethics, the more likely that those discussions will end up justifying ethically dubious practices. The point here is not that biblically-informed Christian ethics is the only possible source of these sensitivities. Rather, the observation is that it is a particularly good and readily available source.

The issue of regard for disabled persons, particularly mentally disabled individuals, is no merely theoretical issue for us. We both have sons with special needs. James Hollman is autistic and Paul Kilner has Trisomy 21 or Down syndrome. Both are teenagers with limited verbal skills. It is our purpose to discuss the strengths and weaknesses of each secular ethical principle and demonstrate how each cannot be relied on, without support from certain Christian sensitivities, to insure that we will end up ethically where we intuitively know we should regarding care for persons with disabilities.

Autonomy

Autonomy has much to do with decision-making. Some mentally limited individuals cannot make wise decisions by themselves. They have the capacity to make simple decisions, such as desiring cake over vegetables, but do not have the ability to make decisions requiring abstract thinking. For this reason, contemporary bioethics would typically shift the responsibility for their decision-making to the closest relative. This is logical, since we would expect those who love and are close to them to make the best decisions for them. As

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children we trust our parents to make decisions on our behalf, and one day when we are mentally incompetent, we might well have to trust our children to make decisions for us. The parent of a child with dependency-level disabilities, however, has a major conflict of interest. Will my first question as the parent be what is best for the child or will it be what is best for me?

Basing decision-making on autonomy is suspect in these decisions because of human selfishness. The Baby Doe case, where a Down syndrome child was denied access to a fairly simple corrective surgery to restore food digestion, illustrates how the desire of the parents not to have their lives changed can supersede their desire for their child's well-being. Such cases rarely make national attention or even the local news. We know of a recent case of a Baton Rouge child with epilepsy and a brain deformity who was allowed to die of an acute abdomen—an easily treatable condition such as appendicitis is usually responsible—because the parents did not want to raise a child with a disability. At autopsy this child's brain defect was the absence of the corpus callosum, a relatively benign finding.

When treating such patients, the physician has an ethical quandary. Are the parents making a bad decision for the child because of poor information, genuine concern for the child, or their own selfishness? If the decision is based on selfishness, to what length should one go to remedy this? Court orders to override the parents' decision and to allow lifesaving surgery are difficult to obtain. To be quite honest, many physicians have great sympathy for a couple desiring only "normal" children. Thus these decisions not to treat "flawed" children are supported privately and not infrequently.

The ethics committee at Woman's Hospital in Baton Rouge was recently called into an emergency meeting to decide the fate of a disabled premature infant born to a physician mother. The parents were initially offered the option of discontinuing the ventilator on the infant. The mother refused this option, treatment was continued, and the child improved to the point that survival was likely. When it was apparent that the child would likely be disabled, the mother requested that treatment be discontinued.

The role of autonomy in the case of mentally disabled children is problematic when there is a great potential for a conflict of interest between parents and their child. Mentally disabled children are in general quite happy in a loving and supportive family and school life. In this regard they are quite similar to intellectually normal children. Life does change for the parents of mentally disabled children in that the period of parental caregiving responsibility is extended and certain activities such as meaningful language interactions with the child may never be possible.

At the same time, there are also special blessings, which parents of disabled newborn children generally do not foresee. We both have non-disabled children in addition to disabled children. While we enjoy the greater independence of our non-disabled children, it comes with a price of at least temporary parental rejection from time to time. We have not experienced this with our special needs children. For us there are many precious times with our disabled children. Times with them are often a haven from our complex professional lives, reminding us, and at times forcing us, to remember to enjoy the simple pleasures of being alive, caring for others, and being loved unconditionally.

What appeal can make contemporary parents behave unselfishly towards their special needs child? These parents could point to the 85% divorce rate among those couples with special needs children and maintain that they are allowing the special needs child to die in order to "save their marriage" or to provide a stable environment for the other, non-disabled children whom they are raising. There is almost a noble humility in such a statement. Nevertheless, biblical teaching reflecting God's special concern for persons who are disabled or otherwise "poor," as explained below, provides a potent counter to such an argument.

Nonmaleficence

Nonmaleficence, another contemporary bioethics principle, affirms that we should do no harm to the patient. Certainly killing or denying ordinary medical care to a patient would be a violation of nonmaleficence. But a problem arises when we begin to ask if this applies to all patients, or only to those whom it is in society's best interest to save. Ethics does not exist in a vacuum—it operates within one's larger understanding of and beliefs about the world. One such belief that has repeatedly had a formative influence on limiting who qualifies for the protection of the nonmaleficence principle is the doctrine of the "survival of the fittest." Based on the assumption that "natural selection" of the strong over the weak is "nature's way," people's ethics often take a utilitarian turn, which has the effect of moving the weakest beyond the sphere and protection of nonmaleficence.

Utilitarianism was behind the eugenics movement of the first half of the twentieth century.[1] Eugenics was by no means limited to Nazi Germany. In the United States, it led to thousands being involuntarily sterilized. Eugenics was funded by the Carnegie and Rockefeller Foundations in the USA. It had the endorsement of legislatures, shaped immigration policy and enjoyed the endorsement of the intellectual elite.

It is well known that the first to die in the gas chambers of Nazi Germany were the "incurably ill". If the German society was to be efficient, then removing the hopelessly ill would free workers for more "productive work". The horrors of gas chambers passed from the incurably ill to the "undesirables" of society: gypsies, homosexuals, Jehovah's Witnesses. The standard of "undesirable" replaced "unfit". The final solution was then extended to the European Jews who were by and large quite productive and successful. Their destruction was not because they were unfit but because the Jews were quite fit and a potential competition with the "Aryan" master race—and therefore undesirable in the hands of those administering the utilitarian calculus.

Ever since, Jewish people have helped the world immensely by keeping the lessons of the Holocaust before us, reminding us that inhumanity knows no limit. This is a strong counter-argument to relying exclusively on contemporary bioethics principles: There is no stopping once we have legitimized the concept that there are lives not worth living—that there are those outside the human community that contemporary bioethics principles are intended to protect. "Undesirable" can potentially be defined by parents or society as anything less

than perfect. The difficulty with rejecting this standard as a societal reason for allowing the unfit to die is that society must then also accept the responsibility of caring for these individuals, when necessary, even if this will make the society less productive in terms of goods and services.

There continue to be strong defenses of the belief that human progress can be guided by careful eugenics. The example of E. O. Wilson as discussed by Arthur J. Dyck is a case in point.[2] Eugenics is not dead, it only changes forms. The larger enterprise of "genetics" has incorporated it. The British journal *Annals of Eugenics* became the *Annals of Human Genetics* in the 1950s and continues to this day under that name. The Cold Spring Harbor Laboratory, headed by Nobel Laureate James Watson, has an ignominious history as a leader of the world eugenics movement in the early part of the 20th century. The evil that is in human beings should be evident to those who study humanity. From Saddam Hussein to the reservists in charge of the prison at Abu Ghraib, we should be clearly reminded that power corrupts. Those who are undesirable, genetically or otherwise, will not necessarily be securely covered by the ethical umbrella of nonmaleficence.

Beneficence

At the same time, disabled children need far more than protection from harm—they also need assistance. Here is where a principle of beneficence, or benefiting, has the potential to make a real contribution. Most disabled children can be made significantly better through comprehensive therapies involving multiple disciplines. Seizures can be treated, infections controlled, and intellectual potential maximized through optimal medical and educational techniques and therapies. The right intervention is not always apparent, however. One can easily become obsessed with finding help for one's disabled child, as Augusto Odone did when one of his sons was diagnosed with adrenoleukodystrophy. His heart-warming story is told in the movie *Lorenzo's Oil*.

While individuals with disabilities may benefit from interventions, those interventions may be expensive. A contemporary principle of beneficence will take the benefit of everyone into account to see if the cost is worth the benefit. Many will look at this calculus in terms of material productivity and gross national product. Unfortunately, being supportive of disabled individuals cannot always be justified on a balance that weighs only dollars and cents. So it is easy for disabled persons to fare poorly under the veil of beneficence.

The irony is that from a different perspective—for example, a Christian perspective—the whole notion of "social benefit" can look very different. Many individuals, as well as society as a whole, can benefit when people with disabilities are treated well. Societies that treat disabled individuals compassionately and maximize their rehabilitation are more advanced societies. It is not difficult to see the advantages of living in a society where the disabled persons are not discarded.

Consider this first on an individual level. In our own families' dynamics, we have non-disabled children who receive a tremendous sense of assurance in knowing that their special needs brother is loved and treated well by their

parents. Certainly we want our other children to achieve to the limits of their ability, but James' brothers and Paul's sister know that love and their acceptance as family members are not performance or achievement based. To be sure, there are times when the added burdens on parents, siblings, and other caregivers are great. But such trials can lead to growth and joy when one is living for God and others rather than for self and material gain, as Henri Nouwen has observed.[3]

This alternative perspective regarding what benefits people applies to entire societies as well. Societies that treat disabled individuals compassionately and maximize their rehabilitation are admirable in a way that more economically productive societies are not. As Leon Kass has reminded us, bioethics should be done in harmony with what a good society is all about, not independently of it.[4]

Justice

With the social context in view, it is natural to turn to the fourth principle, justice. Justice requires giving people what they are due. This concept includes the golden rule of "doing to others as we would want done to us," which occurs in a variety of forms in most major religions and is accepted by most people. But justice is a challenging principle to invoke in bioethics discussions because it is used so differently in various "rights" campaigns involving civil rights, gay rights, abortion rights and even the right to die.

Sometimes justice serves as a standard for giving equal protection to all human lives, but sometimes it does not. The reason for this variability is that in many contemporary settings, there is a tendency to apply the principle of justice equally only to those considered to be human persons. And sometimes in such settings not all human beings qualify as human persons.

For example, personhood or "humanhood" as Joseph Fletcher has called it,[5] applies only to those who meet the minimal requirements to be afforded the privileges of a human being. Fletcher's four primary criteria of humanhood are neocortical function, self-consciousness, relational ability and happiness. The definition of personhood is a complex issue. While there is broad agreement at the extremes—e.g., someone whose entire brain has died is no longer a living person—judgments based on an intelligence quotient or functional traits suggested by Fletcher and others create the potential for abuse. Fletcher would have us see those with an IQ less than 20 as non-human and those with an IQ less than 40 as questionable.[6] Fletcher tells this story to justify his position:

> When a pediatrician at the Texas Medical Center (Houston), whose work takes her daily into service for retarded children, heard me at a grand rounds expound my suggestion that minimal intelligence or cerebral function is the essential factor in being human, she rejected it: "I know a little four-year-old boy, certainly 20 minus or an idiot on any measurement scale and untrainable, but just the same he is a human being and nobody is going to tell me different. He is happy and that makes him human, as human as you or I." By "human" she meant morally, not only biologically. She described the child's affectionate responses to caresses and his constant euphoria. I thought of my neighbor's kitten and recalled the euphoria symptom as

> happiness without any reason for it, and I remembered Huxley's *Brave New World* where everybody was happy on drugs—except the rebellious intellectuals. I asked her if she really meant to say that euphoria qualifies us for humanhood. I took her silence to be an affirmative answer.

To be honest, we find Fletcher's argument to be persuasive from a contemporary perspective. We fear the comparison of our largely non-verbal sons with the most advanced animals because we do not think it would necessarily be favorable at a simple cognitive level, at least in their earlier years. We can understand how people could think that our sons' joy in being with us is not much different from the interactions that we would have with a family pet. The primary reason that we would likely think otherwise is because of biblically-rooted sensitivities, not logical deductions from contemporary principles.

The concern with justice and personhood is not just about the definition of a person, which might deny human rights to individuals below a certain IQ. It also has to do with the misguided judgments about how to treat certain types of people, made by those in a socially influential position. More than one neurosurgeon has said, "it is better to be dead than a quadriplegic." One would think from the surgeons' special knowledge of this condition that they would have great insights into this condition, and that society should therefore withhold lifesaving treatment from such individuals. There is a higher standard of justice than this, but that requires more than the outlook that most commonly informs a contemporary principles approach.

Christian Ethics

What exactly does a Christian outlook bring to the table? On some ethical issues, there is room for a legitimate difference of opinion among Christians who hold a biblical worldview. It is not that God is in two minds concerning these issues, but rather that we do not have enough information from biblical sources to know what God's mind on those issues is. On other issues, however, the evidence is overwhelming and we can be more confident. What our attitude is to be toward disabled individuals is one of those issues.

James, the half brother of Jesus, defined true faith: "Religion that God our Father accepts as pure and faultless is this: to look after orphans and widows in their distress…." God's concern for the downtrodden and those unable to care for themselves is a recurrent theme of the biblical writings. Psalm 82 advises us to "Defend the cause of the weak and the fatherless, maintain the rights of the poor and oppressed. Rescue the weak and needy; deliver them from the hand of the wicked." God puts himself on the side of the afflicted and the oppressed, responding to their needs (Psalm 10:17,18) and providing them a refuge (Psalm 9:9).

In fact, loving and caring for those who are disabled makes us an imitator of God. Even if we were armed with the greatest human strength and the greatest human brilliance, we would be weak and stupid compared to the Creator—God. We, of all generations, should know this best because we truly better understand the extent of the universe and the intricacies of molecular

structure and function. The difference between God and us is far greater than the difference between the most capable of us and the most severely disabled person. Yet God chooses to be concerned about us, desires to be with us and comes to our aid. When we do the same to weak and disabled individuals, we are behaving in a way like God.

In this sense, we should not object when people have the ambition to be like God. Indeed, responding to the calling to be children of God, and brothers and sisters of Christ, people are to manifest many of the attributes of God. The problem with so many who "play God" is that they aspire more to having the authority of God than they do to reflecting the moral character of God. The biblical picture is that God, living among us, is Christ who welcomes the children and the outcast. He does not desire to be served but serves. If we would mimic God, then we should reach across the difference gap to mentally disabled persons with the same compassionate love and caring that characterizes God.

Nowhere is this teaching more clear in the biblical writings than in the parable of the sheep and goats (Matthew 25:31-46). In this passage Jesus tells his followers what will happen on the final judgment day. At this time, people will be divided into two groups: the "sheep" whose rewards will include an eternal life with Jesus, and the "goats" who will take their places with the devil and his demons. The criterion for the division between the two groups will be their true faith and character, demonstrated by the manner in which they have treated the needy. Christ so identifies with the needy, that He considers actions done to them as actions done to Him.

> Then the righteous will answer him, "Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?"
>
> The King will reply, "I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me" (vv. 37-40).

For Christians, there can be no higher ambition than treating Christ as special. This is true because of His divinity, but also because of his great love for humanity, the death he died to pay the price for human selfishness, and his modeling of what God is truly like. People treat Christ as special not only through times of worship but very practically when they show kindness through meeting the needs of the "least of these". Never is such kindness more clearly evident than when people serve mentally and physically disabled individuals.

Conclusion

Arguments based on the four contemporary principles of bioethics can all too easily fall short of supporting the notion that disabled individuals are special—that is, without the prompting of biblical sensitivities. Autonomy is problematic when selfish people are charged to make decisions for others. Nonmaleficence is undermined by humanity's inexorable drift toward utilitarian devaluing of the weak. Beneficence all too quietly shifts from the well-being of the few to

the well-being of the many, particularly when the contribution that the few can make to the many is not immediately evident. Justice can be rendered irrelevant by changing definitions and applications of personhood.

Even if, through appeals to contemporary principles, people can be convinced for the time being that physically and mentally disabled persons deserve a place in our society, that view will be grounded in shifting sand. Such appeals alone will not suffice to consistently anchor the conviction that persons with disabilities are wonderfully special. Such insight is much more safely secured by the welcome presence of a biblically-grounded outlook. Contemporary bioethical debate—in the academy, the media, and public policy, among other arenas—would do well to include biblically Christian voices in more than superficial ways. The reason is not that most people share all their beliefs, but that they are especially likely to bring human sensitivities without which that public debate is impoverished.

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Must Physicians Always Act in Their Patients' Best Interests?

A. A. HOWSEPIAN, M.D., PH.D.

Abstract

Physicians are often admonished to act in the best interests of their patients. One manner in which to conceptualize patient best interest is by way of understanding the manner in which informed consent in clinical contexts might be linked to objective list theories of the good. Depending on the best interest standard that is invoked, the demands of informed consent required, and the ethical theory that underlies these, this admonition to act always in our patients' best interests might, in the end, turn out to be profoundly impractical. The result of this profound impracticality, as pointed out by Robert M. Veatch, signals the death of a core notion of informed consent in clinical contexts. In this essay I examine ways in which a model of 'ethical expertise' that is embedded in a theory of virtue might help inform attempts at better understanding the ability of physicians to gauge patients' best interests and, thereby, might resurrect this core notion of informed consent. Finally, I argue that, even though one's obtaining informed consent that is tightly wed to an objective list-generated patient best interest standard is clinically feasible, physicians have no duty always to act in their patients' best interests.

Physicians are often exhorted, so far as their clinical duties are concerned, to act in their patients' best interests. Psychiatrists, especially, are quick to highlight the 'fiduciary' relationship between psychiatrists and patients—a relationship that is characterized by a physician's accepting the confidence and trust of one's patients to act always in his or her best interests. Healthcare policies often make patients' best interests the centerpiece of their guidelines concerning patient care. In addition, oaths and other professional documents to which many physicians unreservedly swear allegiance often admonish physicians to have their patients' best interests in the forefront of their minds in the process of clinical decision-making. Nothing in the clinical domain, it seems, could be more obvious. Yet, there are those thinkers who believe that patient best interest standards are at best useless, and at worst incoherent.

In fact, the variety of ways that exist for rejecting patient best interest standards reflects the variety of deep, complex, and thorny issues which discussions concerning the utility, propriety, and coherence of best interest standards introduce into clinical medicine and into the domain of biomedical ethics. Robert M. Veatch (1995), for example, in his essay entitled, "Abandoning Informed Consent," links the concept of patient best interest to the concept of informed consent in a manner which, he believes, cause these notions to rise

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or to fall together. As his essay's title suggests, he concludes that we ought to abandon informed consent in clinical practice. In its stead, Veatch suggests, we ought to turn to a model of the doctor-patient relationship in which physicians and patients are paired based on their shared 'deep value' systems. Specifically, Veatch advocates for patients to "[choose their healthcare] providers on the basis of their religious and political affiliations, philosophical and social inclinations, and other deeply penetrating worldviews" (1995, p. 11).

I

According to Veatch, to *consent* is to approve of or to agree with the opinions or actions of another. Consent so characterized, argues Veatch, is merely a "transitional concept," by which he means a concept "that appears on the scene as an apparently progressive innovation, but after a period of experience turns out to be only useful as a transition to a more thoroughly revisionary conceptual framework" (1995, p. 5). What is it that makes consent so problematic according to Veatch? It appears that Veatch understands the notion of consent as it is employed in medical contexts to be intimately tied to the notion of a physician's being able to gauge a patient's best interest and, in virtue of calling this *latter* ability into question, Veatch believes that he also succeeds in calling into question the notion of consent as well. Claims Veatch, "It is increasingly clear if one studies the theory of clinical decision making that there is no longer any basis for presuming that the clinician can even guess at what is in the overall best interest of the patient" (1995, p. 5). He adds that current thinking about axiology also helps illuminate why best interest standards are inadequate. Veatch then gives the following reasons in favor of his assertion that best interest standards are inadequate.

First, claims Veatch, a best interest standard, "if taken literally…is terribly implausible. In fact, no decision-maker is held to it in practice" (1995, p. 6). Second, he points out that often clinical decision-makers have "legitimate moral obligations to people other than the patient" (1995, p. 6). Third, according to Veatch, "For a clinician to guess at what is the best course for the patient, three assumptions must be true regarding a theory of the good. First, the clinician must be expected to determine what will best serve the patient's medical or health interests; second, the clinician must be expected to determine how to trade off health interests with other interests; and third, the clinician must be expected to determine how the patient should relate the pursuit of her best interest to other moral goals and responsibilities[.]" The fundamental problem, says Veatch, is that "it is terribly implausible to expect a typical clinician to be able to perform any *one* of these tasks completely correctly, let along all three of them" (1995, p. 6, emphasis added). Veatch appears to be claiming here (as others have pointed out concerning the utility of consequentialist and deontological moral theories in evaluating voluntary actions in general), that best interest standards in the clinical arena lack the resources to be *action-guiding* and, hence, fail to be *practical*.

Veatch then goes on to outline three concepts of self-interest based on three important theories of the good, namely, hedonistic theories (according to which what makes a person's life happiest is what is in one's best interest), desire-

fulfillment theories (according to which whatever fulfills one's desires is what is in one's best interest), and objective list theories (according to which what is in one's best interest is dependent on what objectively is good for one, i.e., good for one regardless of whether or not one desires those particular goods). Veatch surmises that most best interest standards appeal to some sort of objective list theory, and therefore (given the presupposition made above connecting best interest and consent) that the concept of consent (as Veatch understands it) also relies on an objective list theory. In fact, Veatch appears to favor some *non*-'objective list theory' in this context, for later he claims that "the *only* way to know whether an intervention is good medicine is to ask the patient" (1995, p. 8, emphasis added). (This claim is, of course, demonstrably false in the myriad contexts in which patients, for whatever reason, either do not have the capacity for veridically conveying their desires or who are manifestly confused about what counts as something's being *good* medicine.)

I shall, for purposes of argument, accept this alleged tight connection between consent, best interest, and objective list theories suggested by Veatch, although frankly it seems quite obvious to me that there is no such connection. It is, for example, commonplace in the clinical settings with which I am most familiar to offer a patient a range of treatment options—some of which are, from my point of view, clearly superior to others, and none of which are, from my perspective, the 'best' treatment for that patient—in part because I am familiar with the desires of the patient in question, and I sometimes realize that the patient would not desire the treatments that I deem best. Or, perhaps, I know that the patient would further decompensate if offered only those treatments that I deem best from the objective list standpoint (e.g., electroconvulsive therapy). Instead, in those instances, a desire-fulfillment model of some sort is then invoked. At any rate, I shall proceed as if Professor Veatch's idea here is convincing. (In fact, Veatch himself, in a reply to letters to the editor of the *Hastings Center Report* responding to his 1995 essay on consent and patient best interest, retreats from his earlier suggestion that we abandon the *concept* of informed consent, suggesting instead that we merely "no longer use the term *consent* in the old-fashioned paternalistic way that implies the physician can determine what is best for his or her patient and then merely seek permission to treat" [1996, p. 3]. In any event, my primary interest in Veatch's essay is not his reflections on the concept of consent, but on his discussion of best interest standards.)

Veatch's primary concern with objective list theories is that he does not think that physicians are well-positioned to be the arbiters of what objectively is in their patients' best interests. He claims that "[w]hat is striking here is that even with objective list theories, there is an enormous gap between what it would take to know what is 'objectively in a patient's interest' and what the usual clinician can be expected to know about the patient" (1995, p. 7). Later he writes, "Certainly, a physician is normally not in a good position to determine whether an intervention will contribute to" (1995, p. 7) any of his patients' alleged objective goods. His justification for this claim is that the complexity of clinical decision-making—the numerous medications, procedures, and treatment regimens from which to choose—precludes a simple physician from choosing the treatment that is best. Veatch writes, "In such a situation it is simply hubristic for clinicians to believe that, out of the hundreds

of subtle value tradeoffs to be made, they can come up with just the course that will maximize the patient's well-being" (1995, p. 9). But if this is so, claims Veatch, and if objective list theories are as tightly wed to the concepts of best interest and consent as Veatch imagines them to be, then if objective list theories fail, so do the doctrines of best interest and consent in the context of medical decision-making.

II

Veatch's argument, as far as I understand it, would remain unconvincing even if one were to grant several of Veatch's starting points. To see this, it is important to read in Veatch's own words the *manner* in which he believes that medical decision-making typically occurs:

> It should now be clear why it makes no sense to continue to rely on consent as the mode of transaction between professionals and their clients. In order for a physician to make an initial estimate of which treatment best served the patient's interest, he or she would first have to develop a definitive theory of the relationship among various medical goods, and pick the course that best served the patient's medical good. Then the clinician would have to estimate correctly the proper relationship between the patient's medical good and all other components of the good so that the patient's overall well-being was served.
>
> *Even if this could be done*, there is a final problem. In virtually any moral theory the well-being of the individual is only one element. Plausible consequentialist theories… also insist that the good of other parties also be taken into account. (1995, p. 9, emphasis added)

Is this really how medical, or more broadly ethical, decisions are typically made? Is the ethically-minded physician who is faced with a difficult treatment decision bound to proceed in the manner that Veatch suggests? Perhaps some are so bound, but certainly not all—at least not as I see it. To be so bound is to be in the predicament that Veatch outlines: it is to become overwhelmed both by the amount of knowledge required and by the demand that one's theoretical commitments be largely or wholly without error. On Veatch's view, such a vast storehouse of knowledge is essential to one's making the right decision given the subtle and complex particularities of one's patient's biological, psychological, and social circumstances. In fact, it is hard to imagine how one who is in the predicament that Veatch imagines would even be properly placed to make the right decisions about *one's own* best interest.

Recall that Veatch is presupposing here an objective list theory, a theoretical framework from within which one does not gain any further benefit from any specified degree of *self*-knowledge. If, of course, one were instead to retreat to a desire-fulfillment model of self-interest, then it is at least more plausible to believe that one's actually *being* the individual about whom one is making medical decisions would, at least in many cases, constitute a substantial advantage. (I say only in "many cases" since we certainly are not incorrigible about the contents of all of our desires.) But this advantage disappears in those

cases in which one presupposes objective list theories. So in Veatch's picture of what a best interest standard amounts to in those cases in which one presupposes objective list theories, it seems that not only can one not (except, perhaps by chance) act in *another's* best interest, but it is also the case that one cannot (again, perhaps except by chance) act in *one's own* best interest.

This result would be catastrophic. Fortunately we need not prepare for this particular catastrophe. We will be aided in seeing why this is so by reflecting, first, on the game of chess. When one first learns chess, one learns how to move the pieces, the other rules of the game, and some beginning tactics and strategy. During play, the beginner then painstakingly implements the strategy and tactics that he's learned, representing in his mind a series of possible moves and their consequences, all the while being guided by one's desire to achieve the ultimate goal of the game, viz. checkmating one's opponent's king.

With little alteration in the aforementioned description, this also describes how computers play chess. Consider, for example, how a computer like 'Deep Blue' plays a game of chess. Unlike human beginners, during its widely publicized 1997 match with World Chess Champion Garry Kasparov, Deep Blue had access to a wide variety of entire championship games played by a wide variety of chess international grandmasters. Deep Blue was programmed both to avoid these players' mistakes and to integrate into its chess-playing capabilities the many strong points of these international grandmasters' play. Deep Blue also was able to trace the consequences of its possible moves and the projected possible moves of its human opponents out farther—by several degrees of magnitude—than any mere human is able in a comparable period of time. Deep Blue beat Kasparov. One might think that it did so because of its tremendous advantage in accessing both tactics and strategy culled from some of the best chess playing in history as well as its overwhelming ability to calculate the possible consequences of its and its opponents' moves.

Perhaps this is so. However, what appears more likely is that Kasparov was simply having a bad day (or series of days). In any case, what is of interest to us in the present context is not the hypothesized reasons for Kasparov's defeat, but the fact that no other chess program *prior* to the advent of Deep Blue had been good enough to beat a reigning world champion under regular time controls, much less someone of the caliber of Garry Kasparov. Why not? What is quite clear is that a computer's vastly superior calculating ability—its ability to use 'possible move' algorithms by which it runs through many thousand, or more, possible consequences of its moves in light of the possible moves of its opponent—cannot, by itself, account for a computer's ability to beat reigning world champions in chess. We know this because such computers with such vastly superior calculating capabilities long *predated* the genesis of Deep Blue and none of *these* were able to defeat a reigning chess world champion in under regular time controls. Of course, Deep Blue is exceptional in its degree of technological sophistication as far as computerized chess opponents are concerned. So, it certainly is possible that Deep Blue could do what the others could not, viz. beat an international grandmaster the caliber of Garry Kasparov even if Kasparov were having a *good* day. But Deep Blue's being exceptional in this regard does not help us to understand why its *predecessors*, all of which were profoundly better chess calculating machines than were their grandmaster opponents, were unable therefore to beat these human opponents the way that

Deep Blue beat Kasparov.

In general, then, the profoundly slow speed at which humans are able to run through the number of possible moves that a computer is able to calculate does not appear to place humans at a significant disadvantage in chess matches against computers in part because chess experts simply do not *play* chess the way that computers do. For instance, international grandmasters simply do not, in rigid algorithmic fashion, reflect upon a vast number of possible moves and their consequences prior to making their next move. Rather, as a first approximation, they scan the board, consider a fairly small number of possible moves, then confidently make their move. What is remarkable about all this is that typically the move that is made is just the 'right move' (or something very close to it).

How can a human chess player who appears to be ignorant of so many possibilities happen upon just the right moves with such uncanny consistency? A detailed discussion of the epistemic tools that are activated in the context of an expert's playing complex games such as chess is beyond the scope of our present discussion. What is important is the point itself: unlike beginners who need carefully to consider each element of the game, invoke a certain theory, map the behavior of each element onto the grid of their theory, and then decide what move is best, experts have no need to have at their disposal an explicit algorithm into which they can enter data and from which they can read off the best course of action in a particular context. An expert's *ignorance* of a certain range of explicit data that a *non*-expert *requires* in order to optimize a given choice does not constitute a handicap; it is, rather, one necessary condition for what it is to be an *expert*. For a human to be constrained by an algorithm, like the ones chess programs require, is not to be an expert chess player; it is, rather, to be in a position not to finish the game at all; for the time required for a human to run through all of the possible moves and their consequences that computers are forced to consider prior to each move would result in a game that may outlast the lifetime of a human opponent. Given this criterion for what makes someone an expert, computers are not *expert* chess players of any sort; they are, rather, *beginners* who *inter alia* can rapidly calculate a large amount of chess-related information.

What goes for experts in chess also goes for experts in medicine. Following the evaluation of a patient, a medical student and a University of California Professor of Medicine may, in the end, come up with the same diagnosis and treatment plan, but the *process* whereby these clinical decisions are reached will radically differ. The beginner in medicine simply does not 'see' patients in the same way a medical expert does. The beginner plods through a fairly explicit algorithm, methodically tracing its branches to the 'right answer'; the expert often sees what the right answer is without following anything that resembles the medical student's algorithm. It is for this reason that I am suspicious of much of the literature on medical decision-making: what human *experts* are asked to do in many of these investigations is to impose an explicit algorithmic grid on a decision-making process that arrives at clinical conclusions in what appears to be a radically different way than the experts themselves form medical judgments.

And what goes for experts in chess and medicine also goes for those who

I recognize as being experts in ethics, namely, those individuals who are in possession of the moral virtues, the foremost of which is practical wisdom. The wise person's counsel in matters of ethical importance is not the output of some explicit, exhaustive algorithmic process that, say, a sophisticated computer could carry out if properly programmed; rather, it is the conclusion of a process that is conditioned by the kind of person that he or she is, by his or her past and present experiences, and those ethical, interpersonal and social sensitivities that are guided by that practical wisdom of which he or she is possessed. Aristotle's *phronimos*—his man possessed of practical wisdom—makes decisions about ethical matters in large part by way of *embodying* the moral virtues, allowing his ethical decisions to be guided principally by who he is, by the kind of person that he has come to be in virtue of his past behavior and experiences, and the sensitivities to relevant aspects of his environment that he has cultivated, not merely by what he has studied or certain facts that he knows. Experts do, to be sure, know things; but what makes them *experts* is not primarily *what* they know; rather, what is important is the *way* in which they know and are able to access and utilize that which they know.

In contrast, many institutional ethics committees, at least in my experience and at least for the most part, are composed of beginners; to be sure they are typically composed of very bright, university educated and enthusiastic beginners. But being bright, enthusiastic and university educated are not, by themselves, sufficient for making one an expert in ethics any more than these characteristics are sufficient for making one an expert in chess. One may possess these aforementioned characteristics in spades and yet be both a lousy, plodding chess player and a fool so far as practical judgments are concerned. Many members of ethics committees, for example, make their decisions about institutional ethical matters in large part by appealing to a set of four principles that have been extracted from a popular book on ethics (e.g., *The Principles of Biomedical Ethics*), viz. beneficence, non-maleficence, justice, and autonomy—principles that they are taught need somehow to be 'balanced' in some way or other (depending on the author one happens to be reading at the time) in order to reach a moral judgment. Any normal adult can read about those four principles, understand them to a certain degree, and in virtue of having an interest in ethical matters come to sit on an ethics committee. It is one of the great unspoken scandals of biomedical ethics that it is typically not the case that one explicit requirement for sitting on institutional ethics committees is that one be a *good person*—a person who is in possession of a full complement of the moral virtues.

Evidently, it is commonly thought that being a good person is not required in order to qualify for a position in which one investigates the myriad of important, often quite subtle, complex, ethical questions that arise at the institutional level. Instead, simply being a psychiatrist or a section chief or an attorney or simply having a degree or a certificate in bioethics from a prestigious university is thought to suffice. Can you imagine your particular institution's requiring *goodness of character* of those who it allows to serve on its ethics committee? If you cannot, then there is little hope, from my point of view, that your institution's ethics committee will, except perhaps by chance, arrive at the best decisions for the patients they are asked to evaluate; for, in that case, the process of ethical decision-making that I believe promises most reliably

to generate solutions to ethical problems that are better than its competitors is not central to the decision-making process. What the beginners that sit on most ethics committees are being asked to do, in virtue of these committees largely ignoring questions concerning the goodness of its constituents, is to arrive at sound ethical recommendations in the face of ethics cases with which even *genuine experts* are likely to struggle. This, as I see it, is asking ethics committee members too much.

My main reason for contrasting what is often called an 'ethics of virtue' with the kind of ethical theory that typically informs ethics committees' decisions is that what Veatch appears to have in mind when he dismisses the idea of consent in clinical situations—and with it the idea of acting in someone's best interest—is a form of ethical decision-making that is singularly *non*-virtue-minded. Veatch's way of arriving at ethical and medical decisions is led by what I have been calling a "beginner's" way of decision-making, not by what I have been calling an "expert's". To be sure, Veatch's beginners might be very smart, have huge funds of knowledge, and lots of ethics committee or clinical experience, but these characteristics in themselves are decidedly not sufficient to transform beginners into experts in the sense I have outlined above; that is, these characteristics do not allow one to arrive at ethical or medical decisions like Kasparov arrives at chess decisions; rather, they typically merely catalyze a decision-making process that approximates the manner in which Deep Blue arrives at its decisions about what moves to make in chess. Of course, if one *were* to presuppose that the only reliable mechanism for arriving at sound clinical and ethical decisions required one to consider all the possible branches of a decision-making algorithm that are relevant to that decision, then Veatch appears to be right: there is then no way for a mere human reliably to make sound decisions about these matters in a timely fashion. But what Veatch overlooks is that not all physicians and not all persons involved in making ethical decisions are mere beginners; some are experts, and experts do not require the calculating capabilities upon which Veatch relies in his critique of best interest standards.

III

Even if I am right, however, this does not settle the question concerning whether we ought always to act in our patients' best interests. It might be the case that, *contra* Veatch, we *can* act in our patients' best interests, but *ought* not always so act. This is, in fact, the position that I shall defend. Specifically, I shall defend the view that even if we *could* act in our patients' best interest, we *should* not always do so; rather, we should always act in *our own* best interests, even if this means that our patients suffer, or even die, in the process. Once I know what my best interest is in a given situation, *that* is what I ought to do. And not just me, but you, too. This is being proposed as a rule that is quite general in scope. Veatch states that, "Plausible nonconsequentialist theories, including Kantian theories, natural law theories, much of biblical ethics, and all other deontological theories, hold that knowing what will be in the best interest of persons does not necessarily settle the question of the right thing to do" (1995, p. 9). If Veatch here is referring to the best interests of persons *other*

than oneself, then he is right. But he is mistaken if what he means is that there are instances in which one knows what is in *one's own* best interest and that *this* does not settle what one is supposed to do.

The *asymmetry* between one's self and another to which I am pointing is grounded in the fact that it is *oneself* who will perform the acts in question; it is not *the other* who will be acting. The acting agent—say, the physician—ought, as I see it, only to do *some* things for the passive agent—i.e., the patient—for in the very process of acting, the physician undergoes changes that the patient, in virtue of not acting, does not undergo, and some of these changes may be so destructive of the acting agent's character that this would constitute sufficient grounds for prohibiting the actor from engaging in the action in question no matter what the apparent benefit to the patient happens to be. Consider the following example: Suppose you are a physician who is working in a hospital and that you are commanded by a marauding terrorist to kill an innocent child—say, a little girl age six—or else the terrorist will order a gang of his associates to kill all of the staff and patients in the hospital. What should you do? Well *all* of what you should do is not immediately clear, but one thing that you *must* not do is to kill the innocent child. "Why?" you might ask. The answer, at least in part, is because to kill an innocent little girl, for whatever reason, because you are commanded to do so is, for you, character-changing in a direction that steers you forcefully in the direction of viciousness, a direction that is certainly not in *your* best interest.

But, you say, how about all of those who will die if you do not kill the child? Would this not affect you negatively as well? Of course it would; or at least it *should*. You would not be a well-functioning human being if you were not to feel the emotional force of such a catastrophe. What you avoid, however, in refraining from killing the child is a different kind of catastrophe, a catastrophe involving the very structure of your self—a self that, in the very process of having acted viciously, would have sustained a kind of insult that cannot, even in principle, be delivered *from without*; in other words, in refraining from acting viciously, you avoid inflicting upon yourself a kind of insult that is, of necessity, *an inside job*.

Let's consider a less fanciful example: There is, in psychiatry as in the rest of medicine, a principle of great importance called 'therapeutic privilege'. To be sure, the boundaries of this privilege have been eroded over the past thirty years. In large part I take this to be a healthy trend. This trend, however, will cease being healthy if, in the end, no such privilege survives at all. Simply put, therapeutic privilege is a physician's privilege not to reveal certain diagnoses or treatments to the physician's patients under some circumstances, namely, those circumstances in which such revelations would run a significant risk of seriously harming one's patients. Although it has, as far as I know, never been discussed in quite this way in this context, the exercise of therapeutic privilege is most auspiciously and routinely practiced during the course of psychotherapy.

What psychiatrists learn about their patients in the course of psychodynamically oriented psychotherapy, for example, is difficult to convey. The experience of doing dynamic psychotherapy or of being a dynamic psychotherapy patient resists discursive description. Still, a significant part

(although often not the predominant part and certainly not all) of dynamic psychotherapy is done discursively. When and how an interpretation, for example, is expressed to one's patient can make or break a particular session, or the viability of the therapy itself. Therefore, the doctor keeps much to himself during the course of psychotherapy. The patient is, thereby, kept in the dark about all sorts of diagnostic and treatment conclusions (tentative as they might be) about his condition. The psychiatrist guards this information precisely because sharing it prematurely (or, in some cases, at all) could prove disastrous to the therapy.

Similar situations occur in more supportive therapies. I will, at least early in therapy, typically not reveal to a highly suspicious, very guarded, profoundly thought disordered paranoid psychotic patient that his diagnosis is a paranoid psychotic disorder. Some (although not all) paranoid psychotic patients would not receive this news with unbridled enthusiasm.

There is, however, a significant ethical difference between simply not telling someone something and lying to them. The act of lying is, some have argued, an act that is intrinsically evil and, in virtue of this, never ethically permissible. Therapeutic privilege, at least as I understand it or at least in its most plausible characterizations, does not sanction lying, but simply a certain kind of non-disclosure. Now it would be easy to conjure up examples in which lying to patients about their diagnoses would not cause them nearly as much harm as telling them the truth. In such cases, if in fact lying is intrinsically evil, it is incumbent upon us not to lie, since again although it might be in one's patient's best interest, lying is never something that is in *our own* best interest and we ought always and everywhere act in our own best interest.

It is not as if I am advocating *selfishness* as some kind of virtue. On the contrary, selfishness is always to be eschewed. Properly self-interested acts, however, *are* being advocated. These latter acts are *self-interested* insofar as they benefit the one who acts in virtue of the goods intrinsic to the acts performed. And these acts are *properly* self-interested insofar as they respect the dignity of others, do not employ others as means only, bring the actor further along on the teleological continuum of human flourishing, and they both display and deepen generally human, and well as more specifically medical, excellences.

The view that I am putting forth will sound bizarre to many modern ears. It is a view that is quite ancient, predating the Christian Bible by hundreds of years, although the most well-known formulation of one of its central principles can be found in St. Paul in his Letter to the Romans (chapter 3, verse 8) in which he implies without qualification that we ought never to do evil so that good may result. The reason that St. Paul held to this view is not difficult to discern: in a Christian context, intentionally doing evil for any reason separates us from God, and it is never in our best interest to separate ourselves from God, even in order to benefit another. Some acts, therefore, are under no circumstances ever to be performed. How does this insight inform the manner in which we ought to treat our patients?

There are, typically, many possible courses of action that arise in ethics discussions, both during ethics committee meetings and in other contexts, which appear clearly to be intrinsically disordered, and thereby to be destructive

of the one who would be so acting. Often, during these discussions, ethical principles are weighed, a cost-benefit calculus is carried out, lots of discussion about what is or is not in a patient's best interest takes place, legal documents and institutional policies are consulted, and a vote is taken. Typically, it is the majority that rules. I, at least, am only barely able to recognize what is going on during these discussions as something that has to do with *ethics*.

At any rate, my main point is this: because it is true that sometimes one's *refraining* from performing acts that are intrinsically disordered will lead to situations in which one's patient's best interests are *not* maximized, it follows that I ought not always act in my patients' best interests. But does this then imply that I ought *never* act in their best interests? Certainly not. There will be times—perhaps most times are like this—when what is in my best interest and what is in my patient's best interest will overlap. In such cases, acting in my own best interest and acting in the best interest of my patient do not conflict. In such cases, in virtue of acting, I will have at the same time acted both in my own best interest and in my patient's best interest. Refraining from acting viciously and making excellent clinical decisions for my patients, for example, are both in my best interest (insofar as this contributes to and reflects both my excellence as a practitioner of the medical arts and my excellence as a human being) and in the best interest of my patient (who benefits from both my clinical and human excellences). But such overlap shall not always occur. In those circumstances in which there is no such overlap, acting in one's own best interest should always supercede acting in the best interest of one's patient even if *pace* Veatch one is *able* during those times to act in one's patient's best interest.

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NEWBORN SCREENING: TOWARD A JUST SYSTEM

SISTER RENÉE MIRKES, O.S.F., PH.D.

Abstract

Many characterize America's newborn screening initiatives as the modern-day miracle of our public health systems. Collectively, state programs manage to test the 4 million neonates born every year in the U.S. for at least a minimal number of genetic and metabolic disorders.

These catastrophic diseases, though treatable, are asymptomatic or exhibit no clinical signs in the early neonatal period.[1] *Newborn screening (NBS), then, is the only way to identify the disorders early enough so that treatment can be initiated before it is too late to prevent harm.*[2] *Thanks to post-screening treatment, every year an estimated 3,000 affected infants develop normally instead of succumbing to severe liver disease, physical disability, mental retardation or sudden death.*[3]

My analysis of the ethics of American newborn screening programs (NBSPs) is not a concern about their intrinsic morality. It is concern over the fact that every year more than 2,000 babies die or suffer morbidity[4] *precisely because they were not comprehensively screened. The ethical dilemma plaguing American NBS, then, is that of unequal access to a quality system. Resolving this moral issue is a matter of applying the first principle of justice: "to all equally according to their needs."*[5] *As every infant shares equally in a common human nature and, therefore, experiences the same natural needs for the goods of health, life, and safety, so every newborn is in justice—or by right—entitled to pursue those goods (including quality NBS).*

Here I argue that the cardinal responsibility of state administrators is to develop just screening systems: programs that make it possible for every neonate in every state to have equal access to an advanced, comprehensive and well-coordinated newborn screening system (NBSS).[6]

Part I: Background

America's health-based population screening program—with its current multi-component system of education, follow-up, diagnosis, treatment, and program evaluation—began with the development of a single assay. In 1962, Dr. Robert Guthrie produced the first "simple, sensitive, and inexpensive screening test"[7] for neonates born with a metabolic disorder called hyperphenylalanemia or phenylketonuria (PKU). The latter, a disease most often inherited in an autosomal recessive pattern, involves an inborn error of metabolism (IBEM)[8] that causes a toxic buildup of phenylalanine in the infant's body and, ultimately,

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retardation and death. In the mid-1960s, Massachusetts mandated the first mass NBS program by testing all its infants for PKU. Today all states test for at least PKU, congenital hypothyroidism (CH) and galactosemia (GS).

In the 1990s, laboratory developments produced sophisticated biochemical testing methods such as tandem mass spectrometry (MS/MS).[9] With the capacity to measure for amino acids and acylcarnitines simultaneously in a single, two-minute assay, MS/MS can be used to screen for 20 treatable inborn errors of metabolism (IBEM) and over 30 reportable metabolic disorders. Currently many states utilize MS/MS which, together with high-pressure liquid chromatography and flourometric methods, make it possible to not only screen for IBEM, but also for hematological disorders, endocrinopathies, infectious diseases, and inherited disorders such as cystic fibrosis.[10]

As of June 1, 2005, the March of Dimes reported that 23 states screen for more than 20 of the recommended disorders; 12 states screen somewhere between 10 and 20 disorders; and 15 more states and the District of Columbia screen for less than 10 conditions. As of this writing, Mississippi is the only state that screens for all of the 29 diseases recommended by the American College of Genetic Medicine, the Health Resources and Services Administration (HRSA), the March of Dimes (MOD) and the American Academy of Pediatrics (AAP).

Prior to the newborn's discharge, most NBS tests require a blood specimen, a few droplets of blood drawn from the baby's heel and dried on a piece of absorbent paper. In a well-coordinated NBSS, collecting the blood specimen sets in motion a host of follow-up measures: laboratory analysis of the blood sample; notification of test results to clinicians/parents; repeat diagnostic test for test-positive infants; referral of affected infants to appropriate disease specialists for treatment management; and long-term care support coordinated by the involved primary physician.

Part II: Identifying Weaknesses

Based on NBS studies, I have identified the following design and outcome deficiencies in each of the NBSS components as well as operational weaknesses in the system as a whole.

A. Education

The General Accounting Office reports that there are still a few state programs that do not educate parents about NBS. Of the majority that do, less than one-fourth inform parents of their option to screen for disorders not included in the state-mandated screening panel.[11,12] Most importantly, without uniform guidelines to stipulate content, there is no way, currently, to guarantee thorough NBS education for parents in every state.

NBS information is generally distributed to hospital staff, midwives, pediatricians, primary care providers and local health department staff, with the presumption that the latter will distribute the material to parents. But this dissemination strategy makes it difficult, if not impossible, to track whether the educational materials are ever delivered to parents or whether they adequately understand the disseminated information. Furthermore, only a minority of state

screening programs involve both obstetricians and pediatricians in parental NBS education. And very few programs provide educational information in languages other than English.

More than a few states report that program administrators and some participating health care professionals, particularly primary clinicians, are insufficiently knowledgeable both about the goals and procedures involved in NBS in general and with genetic medicine and the latest genetic tests in particular. Nor has the introduction of mass spectrometry always been accompanied by adequate technical training for both laboratory experts (who are expected to perform the analyses) and medical specialists (who will interpret the large amount of data generated by the blood sample analysis).[13]

B. Screening

Wide variability in the number of diseases screened in each state follows directly from the lack of uniform criteria for screening expansion.[14] Some state programs, for instance, decide to screen for new diseases based on: cost,[15] test availability, and possibility of treatment; others rely on the latest findings of disease research, do not figure in costs, and consider diseases for which there is no documented treatment. Many state programs cannot expand their testing panel to include more than 20 metabolic disorders because they cannot afford the expensive spectrometers needed to screen them.[16]

There are also divergent informed consent practices. Ten states neither notify parents nor procure their consent for screening. Thirty-eight states notify parents but do not ask their consent for the collection of the blood sample. Only 3 states require parents to sign consent forms for NBS.[17]

Forty-eight states allow parents to refuse NBS. Twenty-seven state programs permit parents to refuse screening only for religious reasons, several allow exemptions for any reason. Parents in 5 states are required to give only a verbal notification of refusal to screen when it is for a religious reason, and parents in one state can verbally refuse screening for any reason.[18]

There are no uniform policies specifying the purposes for which residual NBS blood samples can be used[19] or whether the specimens should contain patient identifiers.[20] Although residual specimens are currently being used for research and epidemiological studies, four states' programs do not require researchers to obtain prior approval. Others allow researchers access to the data only upon IRB approval from the state lab or from the state program director. Currently, there is also no consensus amongst state programs about the ethics of using residual NBS samples for forensics purposes.[21]

Some states fund their NBSP, in part or in full, through state tax dollars; others finance their program solely through screening fees. According to one survey, current fees range from ten to sixty dollars, and eight states charge no fee at all. Some programs bundle the cost of genetic counseling, follow-up care, treatment and education into the screening costs; others charge only for laboratory fees.[22]

Twenty-six state NBSPs have advisory committees that include lay membership. Together with other advocacy or community support groups, state advisory committees have raised public awareness of screening for metabolic

and genetic diseases, especially among expectant mothers. In addition, they have exerted political pressure on state health departments to expand and standardize their screening panels.[23]

C. Follow-up

In general, almost all state screening programs are plagued by an unacceptable level of false positive test results, especially in respect to endocrinopathies.[24] Similarly, due to lack of uniform guidelines, programs are also inconsistently successful in avoiding false negatives.[25]

In respect to achieving the needed rapid turn-around time for repeat testing following positive results, some state programs lag far behind others.[26]

Even though many NBS specialists have good reason to argue that repeat testing ought to be universally mandated, only 8 states require that their newborns be screened a second time at a later date. In the other 42 programs, repeat screening is only ordered if the first test was before 24 or 48 postnatal hours.[27]

State NBS notification practices compromise the ability of some parents to actively participate in their child's health care. For instance, in all but 2 state programs, normal screening results are reported to the birth hospital, not to the parents. Then, almost 80% of surveyed pediatricians followed a "no news is good news" rationale in reporting those test results to parents.[28] Fewer than half the states directly notify parents of abnormal results; no state directly notifies parents of normal results.

While each state program keeps a database of its screened newborns in order to track presumptive-positive infants, only two thirds of them are set up for inter-state database networking.[29]

D. Diagnosis

Currently, more than half of America's NBSPs have regulations in place to insure that the diagnostic information they collect is kept confidential.[30] However, the jury is still out on the question at the center of the debate: Do insurance companies have the right to know positive diagnostic test results? Without appropriate access guidelines, there is always the possibility that insurance companies will use NBS diagnostic information to "discriminate in … unacceptable ways."[31] Furthermore, few screening programs have set up a mechanism for educating insurers about the significance of NBS diagnostic results.[32]

Currently, there appears to be no uniform confidentiality guideline stipulating whether parents can withhold their newborn's diagnosis from the primary clinician or whether parents can order the physician not to record the information on the newborn's chart.

State NBSPs vary widely in respect to their provisions for genetic counseling and carrier screening for parents and siblings of an infant diagnosed with a genetic disease. To date, no consensus on best practices has emerged,[33] and there are no national quality assurance standards for the actual counseling services.[34] Disagreements in counseling practice stem from divergent response to pertinent questions. First: How should counseling programs handle carrier

test results that challenge family relationships such as paternity? Second: Is the state screening program responsible for explaining to family members the medical implications of being genetically related to diagnose-positive infants.[35] Third: Should NBSPs inform parents of their carrier status and alert siblings to voluntary carrier screening? Only a minority of state programs provide genetic counseling for parents or siblings who are unaffected carriers.[36,37]

E. Treatment

Some state screening programs neither refer their affected newborns for treatment nor confirm when their care begins. Only 60% of programs annually track affected infants to "ensure continuous access to care, follow-up and support" and to provide "the resources to obtain needed medications and therapies."[38] However, *long-term* treatment management (from infancy through childhood and adulthood)[39] appears to be the weakest link in almost all state programs.[40]

Furthermore, screening programs vary in their ability to connect primary physicians, especially those in rural areas, with clinicians at specialized pediatric centers.

F. Evaluation

There appears to be some limitations within and disparities between state NBSPs regarding the evaluation (continuous oversight and improvement) of their respective systems. To date, only a few screening programs facilitate system excellence by carefully delineating where the activities of each system component begin and end so that the networking of their programs is "seamless and nonduplicative."[41] Not all state NBSPs are consistent about policy formation in respect to quality assurance (QA) standards for all NBS services; to monitoring programs that evaluate whether QA standards are realized; to ongoing improvements in the various parts of the system beyond testing, or to the implementation of duplication-free data collection and networking.

Some sparsely populated states have managed to meet quality assurance standards for testing methods by regionalizing the laboratory component of their NBSSs.[42] A significant number of programs monitor the quality of their screening activities—interpreting complex results as well as tracking diagnostic and treatment service delivery—by purchasing the information-processing technology that facilitates such evaluation.

While most states have advisory committees which recommend ways of achieving system excellence, some have yet to establish this important "public" aspect of program evaluation. Similarly, only a few NBSPs have been built in collaboration with their state's medical or public health professional organizations (e.g., State Maternal and Child Health Program, State Laboratory of Hygiene, State Division of Public Health, Department of Health and Family Services).[43] Furthermore, due to insufficient state-federal cooperation on NBS issues, state screening programs receive limited advice from national advisory committees (ACGM) and national medical (AAP) or public health professional organizations (HRSA, March of Dimes).[44]

NBS studies suggest a link between the non-judicious management of

some state programs and the dearth of uniform quality standards for NBS administration. For example, some screening systems have expanded testing, but have failed to proportionately expand services in downstream system components.[45,46]

Part III: Recommended Resolutions

A. Education

The following national policy guidelines would help to correct the deficiencies threatening the quality of the education component of state programs:

First, *obstetricians should be responsible for parental NBS education in the prenatal period; pediatricians in the postnatal period*. In both phases, the clinicians must reinforce verbal instruction with printed materials. These same clinicians should also provide comparable educational opportunities for non-English speaking parents.

Second, *primary clinicians should be required to discuss specific aspects of NBS with parents*: the importance of having a newborn screened; which diseases are screened by the state, which by private labs; what a normal test results means; what an abnormal test means; the chances of having an affected infant (1 in 1500 births);[47] how and when parents need to respond to a positive test; importance of timely treatment management for affected neonates; and websites (http://genes-r-us.uthscsa.edu/nbsdisorders.pdf) where parents can find more detailed information about NBS in general, individual state programs in particular, and respective parental support and advocacy groups.

Third, *NBS program administrators, obstetricians, pediatricians and their nursing colleagues should be trained in NBS on levels commensurate with their professional involvement*.

- All should be thoroughly acquainted with the nature and goals of a quality NBS program and to what extent their state program has accomplished those goals.
- Primary physicians should, first, understand their respective roles and responsibilities in working toward a quality system and, second, understand the important interface between them and the laboratory and medical specialists involved in diagnosis and treatment.
- Pediatricians must be adequately trained to carry out their duties of initial management following notification of test results: discuss the significance of positive/negative initial screening results; refer the affected infant to appropriate medical centers and subspecialists; coordinate the scheduling of additional tests necessary for a definitive diagnosis, and inform parents of affected newborns about the option of carrier status testing and family genetic counseling.
- Pediatricians must be trained in the basics of human genetics as well as population genetics;[48] have knowledge of the actual tests; be aware of factors that could influence test results (gestational age, early

discharge, diet, and transfusions); and be able to effectively translate technical genetic information into layman's terms so parents can understand it.

Fourth, *genetic specialists involved in NBS diagnosis and treatment must be thoroughly conversant in the etiology, pathophysiology, clinical heterogeneity, and psychosocial issues associated with each of the screened diseases. They should also be required to attend whatever continuing educational opportunities are necessary to maintain their professional competency.*[49]

Fifth, *laboratory technologists must have adequate theoretical and practical training in biochemical testing, especially that of mass spectrometry.*

B. Screening

The following national policy guidelines should help to correct the deficiencies threatening the quality of the screening component of state programs:

First, *the pediatrician (or appropriate health care representative) should notify parents when their newborn's blood specimen is being collected and screened*. (I would argue *against* a policy requiring parental consent for newborn testing. The state has the authority to mandate NBS because it is a safe, simple and beneficial means of carrying out one of its primary responsibilities: protecting the health and welfare of its newborn citizens. In doing so, the state presumes [rightly, in my estimation] that any reasonable person, given the chance, would chose to be screened. In such a context, parental consent is redundant.)

Second, *there are no justifiable grounds for parental refusal of NBS specimen collection and testing*. (I would contend that, in *Douglas County v. Anaya*, the Nebraska Supreme Court put sound legal [and ethical] flesh on the argument that parents do not have a right to refuse NBS for a religious [and, by implication, for any other] reason. The higher court ruled that the screening statute of Nebraska is neutral and of general applicability, that is, it "does not aim to infringe upon or restrict practices because of their religious motivation" and it only incidentally [if at all] imposes burdens on conduct motivated by religious belief. Therefore, the state screening statute is presumptively constitutional and need only have a "rational basis." The reasonable basis—infants "'can grow and develop to be free of a metabolic disease' through a 'blood test administration which is merely a pinprick to the child's heel'"—overcomes the Anaya's constitutional challenge (based in their belief that "life is taken from the body if blood is removed from it and that a person's lifespan may be shortened if blood is drawn").[50]

Third, *every state ought to screen for a uniform set of diseases (Current recommendations: a core panel of 29 [treatable] metabolic and genetic diseases and a secondary panel of 25 reportable disorders for which there are no documented treatments)*.

Fourth, *every state should follow a uniform criteria matrix in adding diseases to their screening pane*. For example: the disease can be detected at a phase when it would not ordinarily be clinically detected; an appropriately sensitive and specific test is available; benefits of early detection include, but are not limited to, treatment of the condition;[51] scientific evidence and expert opinion corroborate screening for the disease(s) in question.

Fifth, *standards for specimen collection should include, first, a consistent, careful technique to ensure an adequate sample and, second, proper documentation from requisition for testing to appropriate processing and follow-up.*[52]

Sixth, *every state screening program should be funded by state tax revenues earmarked for NBS and by affordable uniform screening fees* (covering at least partial costs of education, screening, follow-up, treatment and genetic counseling).

Seventh, *Federal NBS legislation should authorize a national NBS oversight agency to subsidize state screening fees/state tax dollars with federal funding*: facilitating a) the purchase of expensive spectrometers essential to test expansion; b) continuing education for the medical professionals involved in NBS; c) educational materials and services for parents and families; d) long-term support for affected children;[53] and e) payment of screening fees for parents who are poor, uninsured or lack a permanent home. National policy should specify realistic screening fees, relying on the proven cost-effectiveness of NBS where protracted benefits to affected individuals aggregate over costs.[54]

Eighth, *in deciding legitimate uses of residual NBS specimens, the interests of parents and minors must be balanced against those of researchers (the study of medical genetics)*[55] *and forensic experts (the pursuit of law enforcement goals).* If residual blood samples are used for either purpose, proper consent must be obtained from the parent or the patient if they are of age.

Ninth, *screening specimens should be stored in ways consistent with patient privacy* (e.g., using a coding system that prevents researchers from knowing the identity of the newborn but allows authorized individuals to decode a specimen if a future need arises).

C. Follow-up

The following national policy guidelines would help to correct the deficiencies threatening the quality of the follow-up component of state programs:

First, *the level of false positive results must be brought to an acceptable level through mass spectrometry analysis and by designing tests with more specific markers for the detection of the respective diseases,*[56] (particularly congenital endocrinopathies).

Second, *the administration of initial screening and the follow-up of positive tests must be ordered correctly and performed on an appropriate schedule.*

Third, *repeat tests should be mandated for all infants at a specified interval after initial screening.* Mandated repeat testing is necessary because a) newborns tend not to have adequate protein intake by the time of the initial test; b) some infants are transfused prior to the initial screening test; c) some infants receive antibiotics or other interfering substances that could limit the interpretation of results; d) some infants are premature, or e) in the case of heat-damaged specimens, some tests are inadequate or results are inconclusive.

Fourth, *testing laboratories (public and private) should notify primary clinicians of test-positive infants immediately and inform involved clinicians of test-negative infants within 7 days.*

Fifth, *primary clinicians (pediatricians) should promptly report test results to parents verbally and in writing and then discuss their implications*: the chances are good that a test-positive infant does not have the disorder, but more definitive tests need to be scheduled without delay; there is a high probability that a test-negative baby will not evidence the disease later, but parents need to inform the pediatrician immediately when they observe any weakness or developmental delays in their infant.

Sixth, *primary clinicians should follow the "Action Sheet"*[57] *guidelines developed by ACGM for each screened disease to assure an expeditious response to test-positive infants and a step-by-step timely pursuit of diagnosis and treatment.*

D. Diagnosis

I recommend the following national policy guidelines to help correct the deficiencies threatening the quality of the diagnosis component of state programs:

First, *every state NBSP should employ the number of specialists proportionate to the diagnostic demands (testing, analysis) within its system.*

Second, *post-diagnostic genetic counseling and carrier screening for the parents and family of affected newborns must follow appropriate quality assurance standards:* counselors must have adequate genetic and psychosocial training; carrier testing should be available but on a voluntary basis; the best interests of the involved sibling or parent is the driving principle of carrier status screening; potentially untoward information (non-paternity, e.g.) could be withheld as long as the best interests of all others involved are not compromised.

Third, *insurance companies do not have a right to access the genetic information generated by a newborn screening diagnosis.*

Fourth, *parents have the right to instruct the physician not to record positive screening results on the newborn's chart or to request that test results are withheld from the primary physician only if doing so does not compromise the right of the newborn to pursue health and life.*

Fifth, *every state screening program should be a part of a NBS database networking system that tracks affected infants, facilitates genetics research, and avoids needless duplication.*

E. Treatment

The following national policy guidelines would help to correct the deficiencies threatening the quality of the treatment component of state programs:

First, *every state program must refer affected newborns for treatment, confirm when treatment begins and track ongoing treatment including regular access to needed dietary and medicinal therapies.*

Second, *proper uniform referral mechanisms must be in place so that primary physicians, especially in rural areas, can procure treatment for their affected newborn patients with clinicians at specialized pediatric centers.*

Third, *every state screening program should provide long-term treatment management for persons with rare metabolic and genetic diseases.*

F. Evaluation

The following national policy guidelines would help to correct the deficiencies threatening the quality of the evaluation component of state programs:

First, *every state NBS administrator must be adequately trained and required to pursue continuing educational opportunities both in the art of management and in the science of NBS*.

Second, *it is the responsibility of NBS administrators to procure the necessary technological infrastructure for their programs: the most advanced laboratory analysis technology (to efficiently support NBS testing and follow-up) and up-to-date information-processing technology (for effective oversight and evaluation)*.

Third, *it is the responsibility of the NBS administrator to procure state/federal funding for the needed information-processing technology and to train the IT experts who will use it to monitor quality, track outcomes and interpret complex results.*

Fourth, *it is the responsibility of the NBS administrator to establish a state advisory committee with a broadly representative membership and to link it to national counterparts.*

Fifth, *it is the responsibility of the NBS administrator to implement national guidelines defining the quality of each system component and their seamless coordination.*

Conclusion

I have argued that the need for uniform NBS policies is evidenced in the fact that, without federal oversight, state NBSPs have expanded sporadically and with uneven quality. But every child's right to quality NBS can only be realized when every state program is equally excellent. I am confident that the formulation of national guidelines like those recommended above and their universal implementation through cooperative state/national administrative agencies would help to shape a NBSS in every state that is advanced, well-balanced, coordinated and, therefore, *just*. Thus, every newborn, in whatever state they reside, will have equal access to quality NBS services.

Endnotes

1 Diseases such as phenylketonuria (PKU), congenital hypothyroidism (CH) and galactosemia (GS), currently screened in every state, can cause infants irreparable damage if left undiagnosed and untreated. Consequently, public newborn screening programs do not *just* screen. They also provide a comprehensive system of education, follow-up, diagnosis, treatment, and program evaluation.

2 Bradford L. Therell, Jr., "U.S. Newborn Screening Policy Dilemmas for the Twenty-First Century," *Molecular Genetics and Metabolism* 74(2001):64, 67.

3 Gatrell Bryant, Kimberly M. Horns, Nicola Longo, Julieanne Schiefelbein, "A Primer on Newborn Screening," *Advanced Neonatal Care* 4(2004): (p. 1 of online copy available at: http://www.medscape.com.viewarticle/493247).

4 "Senator Dodd Introduces Bill to Encourage Newborn Screening for Life-Threatening Disorders," Press Release, August 28, 2002 (http://caresfoundation.org/news_letter/fall02).

5 Mortimer Adler, *Six Great Ideas* (New York: Touchstone) 1990, 164-173, 180, 191.

6 My thesis agrees with a recommendation from the report of the American College of Genetic Medicine: every state ought to screen their newborns for a core panel of 29 conditions and for an additional 25 conditions that "are a part of the differential diagnosis of a condition in the core

panel or are clinically significant and revealed by the screening technology but lack an efficacious treatment." ("Newborn Screening: Toward a Uniform Screening Panel and System," Executive Summary, 23).

7 Bryant, Horns, Longo, Schiefelbein, "A Primer on NBS," 2.

8 Metabolic disorders or IBEM negatively affect the body's ability to produce or break down compounds such as amino acids, organic acids, and fatty acids into smaller substances that the body needs for energy, growth and repair. Amino acids are the building blocks of proteins, and proteins govern somatic cell functions. Before amino acids can do their work, various enzymes must be present. When these enzymes are missing, *amino acidurias* result. Abnormally large quantities of amino acids in the urine or blood have toxic effects on the body and can cause mental retardation. *Organic acidurias* typically occur when a lack of enzymatic activity causes a missing or malfunctioning step in amino acid catabolism (chemical breakdown*). Fatty acid oxidation disorders* results when oxidation, the process that breaks down fatty acids releasing energy crucial for bodily functions, is interrupted due to missing enzymes. Without treatment, infants with FAODs risk coma and death (ARUP, "Supplemental Newborn Screening," found at: //www.arup-lab.com/home/pediatric_testing/sns_faqs.jsp).

With phenylalanemia (PKU), the neonate lacks the enzyme phenylalanine hydroxylase necessary to process the amino acid, phenylalanine, found in almost all food. Accumulated amounts of phenylalanine impairs development of the CNS. Failure to treat this disease results in seizures and severe mental retardation.

In galactosemia (GS) the infant lacks one of three enzymes (galactose-1-phosphate uridyl transferase, galactokinase, or uridine diphosphate-galactose-4-epimerase) required to break down galactose into glucose. Treatment consists of a galactose-free diet. Failure to treat results in "failure to thrive, mental retardation, liver disease, cataracts, and even death from sepsis or bleeding" (Bryant, Horns, Longo, Shiefelbein, "A Primer on NBS," 6).

9 Tandem mass spectrometry tests compounds in the infant's blood called amino acids and acylcarnitines. Amino acids are the building blocks of proteins that become important parts of tissues, muscles, organs, blood. Carnitines transport fats in and out of the cell's energy factory, the mitochondria. An acylcarnitine occurs when a fatty acid attaches to carnitine. Acylcarnitines are identified by the size of the fat molecules attached to it. A mass spectrometer weighs the acylcarnitines present in the infant's blood and reveals how much of any specific acylcarnitine is present. The report produced by mass spec analysis displays vertical lines distributed across a horizontal axis (a mass spectrum) where the vertical lines identify a compound's mass and the height of the line indicates the amount of the compound. MS/MS is very accurate and is able to measure more than one compound simultaneously in a single, 2-minute analysis. More than 30 metabolic disorders can be screened with MS/MS.

A spectrometer is referred to as a *tandem mass* spectrometer because of its two mass analyzers that are separated by a collision chamber. "It requires a few droplets of blood on filter paper. After the specimen is dry, 4 small circular punch-outs are made and prepared. Next, the sample is injected into the spectrometer where it is ionized, sorted, and given a molecular weight (the ratio of the mass of the ions to their charge) in the first analyzer. The ions then enter the collision chamber where they are broken into smaller fragments. The fragments enter the final chamber where they are resorted and weighed. The info detected is then plotted on a histogram for interpretation. This technique can identify and quantify most amino acids and generate an acylcarnitine profile to screen for disorders of fatty acid oxidation and organic acidemias" (Ibid, 5).

10 ACGM Report, "Newborn Screening," 23. Cystic fibrosis can be detected by screening a newborn's dried blood specimen for concentration of immunotrypsinogen. Dr. Paul Fernhoff, medical director of the Department of Human Genetics at Emory University School of Medicine, points out that cystic fibrosis, absent NBS detection, would probably not be diagnosed until the child is from one to three years of age, by which time he/she would have suffered numerous infections and the family would have been frantically looking for a diagnosis. With early detection comes early treatment and a brighter prognosis for the cystic fibrosis patient. (Patricia Guthrie, "Georgia lags in testing newborns," *The Atlanta Journal-Constitution* 7/12/05 [online at http://www.ajc.com/metro/content/metro/atlanta/0705/12screening.html].)

11 U.S. General Accounting Office Report to Congressional Requesters, "Newborn Screening: Characteristics of State Programs," March, 2003 (available at www.gao.gov/cgi-bin/getrpt?GAO-03-449).

12 As Debra Gara responded after losing her baby who died because her rare, but screenable and treatable, disease was not detected: "I'm angry at the state, too, but I'm more angry at the medical profession for not telling me anything (about supplemental screening options). ("Parents Seek Expanded Newborn Testing," Associated Press, April 28, 2003 [http://www.intelihealth.com/IH/ihtPrintWSIHW000/333/8010/363942.html].)

13 Cf. "Save Babies Through Screening Foundation, Inc" (http://www.savebabies.org/NBS/msms-chace.phb).

14 Therell, "U.S. Newborn Screening Policy Dilemmas," 67.

15 Ibid., 71.

16 "Parents Seek Expanded Newborn Testing," Associated Press, April 28,2003 (http://www.intelihealth.com/IH/jhtPrint/WSIHW0000/333/8010/363942.html). Senators Dodd and DeWine are still looking for their colleagues' support for federal legislation that would help fund the MS/MS technology that would facilitate just such expansion.

17 Kenneth D. Mandl, Shlomit Feit, Cecilia Larson and Isaac S. Kohane, "Newborn Screening Program Practices in the United States: Notification, Research, and Consent," *Pediatrics* 109(2002):272.

18 Ibid.

19 Therell, "U.S. Newborn Screening Policy Dilemmas," 67.

20 Mandl, Feit, Larson and Kohane, "Newborn Screening Program Practices, 271.

21 Therell, "U.S. Newborn Screening Policy Dilemmas," 73.

22 Bryant, Horns, Longo, Shiefelbein, "A Primer on NBS," 2.

23 The inspiring precedent for this was the advocacy work of Dr. Guthrie (whose own child was retarded and whose niece had PKU) who "took his screening ideas to groups for the political support needed to move screening ideas into government-run public health institutions." (Therell, "U.S. Newborn Screening Policy Dilemmas," 65.)

24 Abstract: Kwon C. Farrell PM, "The magnitude and challenge of false-positive newborn screening test results," *Archives of Pediatrics & Adolescent Medicine,* July, 2000 in AAP, HRSA's, "A Compendium of Resources," 4.

25 Some state programs report false negatives, for example, in newborns suffering from GS. The infants falsely tested negative because they were tested before they ingested breast milk or formula containing lactose and, consequently, before high levels of galactose were present. (Therell, "U.S. Newborn Screening Policy Dilemmas," 65.)

26 Bryant, Horns, Longo, Schiefelbein, "A Primer on NBS," online copy, 4. A case in point: some state programs report that their test-positive premature infants who are transferred to another medical facility have not been re-tested in a timely fashion, since the system was not appropriately linked to the infant's current health care provider.

27 Ibid., p. 3

28 Ibid., p. 4.

29 Mandl, Feit, Larson and Kohane, "Newborn Screening Program Practices," 269. This means that only two-thirds of state programs have the ability to efficiently track affected infants and their parents in the event of residence change.

30 U.S. GAO, "Newborn Screening: Characteristics of State Programs," 24.

31 Abstract: O'Neill, O. "Genetic information and insurance: some ethical issues," *Philos Tran. R. Soc Lond B Biol Sci* 1997: 352(1357):1087 in AAP, HRSA's "A Compendium of Resources," 46.

32 It is probably safe to assume that insurance providers, like many other lay people, frequently misunderstand the medical distinction between the diagnosis of "unaffected carrier" for a genetic disease and that of "affected carrier."

33 Abstract: Farrell M. "Genetic counseling and risk communication services of newborn screening programs," *Archives of Pediatrics & Adolescent Medicine.* 155(2):120-6, 2001 Feb in AAP, HRSA's "A Compendium of Resources," 60.

34 Ibid.

35 CM Constantin, A Faucett, IM Lubin, "A Primer on Genetic Testing," *Journal of Midwifery & Women's Health,* 50(2005):202.

36 Unaffected carriers for an autosomal recessive disease have a single copy of the defective gene but do not suffer from the effects of the disease. Affected carriers have two copies of the defective gene (one from their mother; the other from their father) and suffer the disease's effects. If both spouses are unaffected carriers for a particular autosomal recessive disease, they have a 25% chance of having a child with two copies of the abnormal gene, a 50% chance of having a child who is an unaffected carrier and a 25% chance of having an unaffected non-carrier child.

37 AAP, "Ethical Issues With Genetic Testing in Pediatrics," *Pediatrics* 107(June, 2001):1451-53.

38 Bryant, Horns, Longo, Schiefelbein, "A Primer on NBS," 11.

39 Therrell, U.S. Newborn Screening Policy Dilemmas, 73. As one physician put it: "What is the value of a public health screening program in which children fall through the cracks? The importance of follow-up NBS treatment management was discussed after a lecture ("Economics of Newborn Screening") delivered by Jean Ann Wright, MD, MBA at the AAP conference presented

on November 1, 2003 at the Hilton New Orleans Riverwalk: *Ethical Issues in Expanding Newborn Screening*.

40 ACMG report, "Newborn Screening," 2.

41 Therell, U.S. Newborn Screening Policy Dilemmas, 72.

42 Ibid., 65.

43 Abstract: Ciske JB. Hoffman G. Hanson K. Annable KM. Wolff J. Litsheim T. Laessig R. Aronson R., "Newborn screening in Wisconsin: program overview and test addition," *Wisconsin Medical Journal* 99 (2):38-42, 2000, Apr in AAP, HRSA's "A Compendium of Resources," 1.

44 ACGM report, "Newborn Screening," 31.

45 Therrell, Dilemmas, 71. NBS administrators sometimes lose sight of the fact that increased testing means a higher volume of presumptive positive lab results, which require more expert laboratory and medical evaluations, which require more specialist personnel for proper diagnosis and treatment.

46 Ibid., 72. Furthermore, not all state systems have successfully negotiated cooperation between their own and private screening programs. In some instances, state administrators have not made sure that, whenever necessary, the state systems are able to absorb the follow-up and treatment services from private testing labs.

47 While the chances that a baby tests positive for one of the 20 recommended disorders are 1 in 1500 births (Cf. www.aboutnewbornscreening.com/faq.htm), the national incidence of the four most frequently tested diseases varies considerably: for congenital adrenal hyperplasia (1:20,000); congenital hypothyroidism (1:3,000); for galactosemia (1:59,000) and hyperphenylalaninemia (PKU) (1:14,000).

48 Therell, Dilemmas, 70.

49 Ibid.

50 Douglas County, Nebraska, appellee, v. Josue Anaya and Mary Anaya, husband and wife, as parents of Rosa Ariel Anaya, a minor child, appellants. On March 25, 2005, the Nebraska Supreme Court denied the Anaya's religious challenge of NBS. There is a similar case working its way through the Federal court system. The ACLU has filed an amicus brief on behalf of Ray and Louise Spiering who are challenging the Nebraska NBS statute based on the Scientology practice of not disturbing newborns for seven days after birth.

51 The MOD gives three reasons for screening reportable diseases with no documented treatments. First, parents who know that their child is suffering from one of these disorders is spared treatment odysseys. Second, they can be on the lookout and advocate for research that might eventually lead to a treatment for their child's disease. Third, the parents can also use the knowledge of their carrier status to make future reproductive plans as well as deciding about genetic testing for siblings of the affected newborn.

52 Bryant, Horns, Longo, Shiefelbein, "A Primer on NBS," 7.

53 This might include monetary support for anything from helping families afford the dietary and medicinal resources for long-term management of a disease to supporting patient transition from child to adult care to providing low-cost phenylalanine formula for PKU newborns.

54 ACGM report, Newborn Screening, 22.

55 O'Neill, O. "Genetic information and insurance: some ethical issues," *Philos Tran. R. Soc Lond B Biol Sci* 1997:352(1357):1087.

56 Abstract: Kwon C. Farrell, "The magnitude and challenge," in Compendium, 4.

57 ACGM report, Newborn Screening, 5.

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WOMEN, PHYSICIANS, AND BREASTFEEDING ADVICE: A REGIONAL ANALYSIS

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Abstract

The World Health Organization, the Surgeon General of the United States, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and the American Academy of Family Physicians have all endorsed breastfeeding as the optimal method of feeding and nurturing children as scientific data confirms that breastfeeding decreases both maternal and pediatric morbidity and mortality rates.[1,2,3,4,12,33,46]

In the study presented here, a Likert scaled survey derived from the Surgeon General's "Blueprint for Action on Breastfeeding"[2] *was mailed to 500 women who resided in a Midwestern state and who had given birth within the last year. The purpose of this study was to determine what type of breastfeeding information women are receiving from their attending physicians and to ascertain if physician breastfeeding advice impacts maternal feeding decisions. Statistical analyses were performed to assess if significant differences could be detected with regard to: 1) physician specialty, 2) patient income, 3) patient education, 4) patient health insurance, and 5) patient age.*

Results indicate that the majority of women who participated in this study did not receive compendious breastfeeding advice from their attending physicians. Statistical analyses indicated that the type of breastfeeding advice women received was correlated with physician specialty, patient age, and patient education. In addition, results of this study demonstrated that women who are informed by their physicians of the various maternal and pediatric benefits associated with breastfeeding are significantly more likely to practice exclusive breastfeeding.

Introduction

The United States Department of Health and Human Services has stated that breastfeeding rates must increase exponentially.[4] Currently, the United States has one of the lowest breastfeeding rates in the world in spite of the decades of scientific data that demonstrates that breastfeeding decreases both maternal and pediatric morbidity and mortality rates.[2,4] Research documents that physicians are in a unique position to increase breastfeeding rates by informing their female patients of the risks associated with formula feeding and by supporting and encouraging exclusive and long term breastfeeding.[4,46]

Data continues to confirm that breastfeeding is far superior to formula

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feeding, and it is an indisputable fact that observable and measurable differences exist between breastfed and artificially fed children.[7,8,9,10,11,12] Child health and longevity rates are directly affected by maternal feeding decisions, and research confirms that physician breastfeeding advice can significantly impact both the initiation and duration of breastfeeding rates in America.[1,2,3,5,8]

Research confirms that human milk contains secretory immunoglobulin A (S-IgA) which has been found to protect children from bacterial and viral infections, and to defend against a wide variety of diseases by producing antibodies that protect the respiratory and gastrointestinal tracts.[14] S-IgA is not found in other mammalian milk nor are humans able to reproduce S-IgA in formula as it is a dynamic substance which is specific to an individual child's physiological needs.[14] Data has also confirmed that S-IgA is effective in eradicating E. coli, streptococci, staphylococci, pneumococci, and diarrheal diseases.[2,15,46]

Although diarrheal disorders are common in American infants today, this particular ailment is a relatively recent phenomenon. According to the medical literature, these specific gastrointestinal illnesses can be traced to the 1940s during the time that formula was being mass marketed, and breastfeeding rates were falling dramatically.[5,15] Diarrheal disease was analyzed in the early 1940s as a "new disease" with an 82% mortality rate.[16] Researchers in the 1940s found no diarrheal deaths recorded among breastfed populations, as breastfed infants either did not suffer from diarrhea or were able to fight off the illness if it was contracted.[5,16]

Breastfeeding protects against a wide variety of infant and childhood diseases. Scientific studies have documented that respiratory infections are two to five times higher in artificially fed children,[8] and otitis media is more prevalent in artificially fed populations.[2,46] Strictly controlled studies have also confirmed that breastfeeding decreases the incidence of diabetes, as it has been reported in the medical literature that at least 25% of all diabetic cases can be directly attributed to formula feeding in infancy.[18,19]

Studies have also indicated that breastfeeding can reduce the incidence of childhood cancers.[47] Davis and colleagues[9] found a six to eightfold increase in the development of lymphomas in adolescents who were breastfed less than six months. In the United Kingdom, a longitudinal study demonstrated that breastfeeding significantly reduces a wide variety of childhood cancer rates—including, but not limited to, childhood lymphoma.[21] In addition, Shu, Linet, and Steinbuch's 1999 study confirmed that childhood leukemia rates were significantly lower in breastfed populations.[22] The Surgeon General[2] has determined that further studies are needed in order to fully understand the role that breastfeeding plays in the prevention of childhood cancer rates. However, medical data clearly demonstrates that breastfeeding has, and continues to prevent the onset of cancer in child populations.[1,2,4,5,8,9,14,20,21,22,47]

Although allergies are common in children living in western cultures, data indicates that allergic disorders are comparatively rare in cultures that practice exclusive and long term breastfeeding.[5,15] It has been hypothesized that milk proteins are species specific (i.e., each mammal produces milk specific to its offspring)[8,46] and that ingesting another mammal's milk may in fact trigger the

onset of allergic disorders in infants because of their underdeveloped immune systems.[5,15,24] The most common allergen known in infancy and childhood is cows' milk—yet the majority of formulas on the market are bovine based.[23] It has become a common medical practice to "switch formulas" when a human infant displays an allergic reaction to another mammal's milk. Soya based formulas are often used to alleviate the allergic reaction, yet 45-50% of children who are allergic to cows' milk also exhibit allergic symptoms when Soya based formulas are introduced.[23] Formula companies have marketed "hypoallergenic" formulas for those infants who are highly allergic to both cow-based and Soya based milks, yet the American Academy of Pediatrics strongly advises against using "hypoallergenic" formulas, as life threatening anaphylactic reactions may occur in infant populations with a known cows' milk allergy.[23,25] Currently, it is unknown what mechanism triggers the onset of allergic disorders in children. What scientific data has confirmed is that in cultures that practice exclusive and long term breastfeeding, allergic disorders in child populations are relatively rare.[5,8,11,14,15,23,24,46]

Breastfed infants and children require fewer doctor visits, prescription medications, and hospitalizations.[4,48] Breastfeeding impacts not only childhood morbidity and mortality rates, but adolescent and adult physiological functioning as well.[49] Individuals who were artificially fed in childhood suffer from higher rates of obesity,[4] inflammatory bowel disease,[26] Crohn's disease,[27] Celiac disease,[28] diabetes,[17,18] Multiple Sclerosis,[29] cancer,[21,22] heart disease,[30] high cholesterol,[31] and allergies.[23,24] Although there is a common perception that the benefits of breastfeeding are apparent only in infancy, there does exist mounting evidence which suggests that the benefits of being breastfed in childhood continue on throughout the life course.[4,5,26,28,29,31,46,49]

The benefits that women derive from breastfeeding are well documented in the literature. According to medical data, women who breastfeed have a lower incidence of ovarian,[2] breast,[5,33,46] and endometrial[34] cancers. There is also evidence which suggests that the hormonal changes that occur in lactating women may be responsible for increased self-confidence,[2] lowered anxiety levels,[35,50] fewer mood swings,[32] and increased mother-child bonding.[2,5,32,46,51] Furthermore, scientific data indicates that breastfeeding can act as a natural contraceptive. Research confirms that breastfeeding is a highly effective means of contraception as it suppresses ovarian cyclicity postpartum and induces a state of lactational infertility.[36]

Scientific data confirms that historically documented breastfeeding practices, which include exclusive breastfeeding, delaying the introduction of solid food, co-sleeping, unrestricted and high frequency nursing, non use of pacifiers and/or formula supplements, and long term breastfeeding can delay the return of menses for 1-3 years in maternal populations.[5,36,37] However, in countries such as England, Australia, Denmark, and the U.S., these historical breastfeeding patterns have been substantially altered.[36] Currently, nursing 5-6 times per day has become accepted practice in these countries in spite of the data that confirms that limited access to the breast significantly increases ovarian cyclicity.[36] The literature suggests that culturally constructed child rearing practices (i.e., pacifier usage, low frequency nursing, formula supplementation, uni-sleeping practices, and the early introduction of solids) may in fact negate

the contraceptive effects of breastfeeding as research indicates that it is the frequency, intensity, and duration of suckling that prevents ovulation from occurring.[32,36,37]

The term "breastfeeding" is inadequate when describing the myriad of breastfeeding styles that are practiced throughout the world.[38] The vast majority of breastfeeding literature does not distinguish between full and partial breastfeeding, frequency and duration, or the duration of exclusive breastfeeding.[5,38] Considerable variations exist with regard to worldwide breastfeeding practices as cultural mandates dictate if, when, where, and how long a child will receive human milk.[5,38,39,52] According to Neuman (1997)[40] "continuous variables have an infinite number of values that flow along a continuum, while categorical variables are distinct categories" (p. 146). Breastfeeding must not be conceptualized as a simplistic "does" or "does not" variable. The vast array of breastfeeding styles that occur within and across cultures illustrates the need to define breastfeeding as a continuous variable so that precise and accurate data analysis can occur. Clear and universally defined definitions of the various breastfeeding styles would add to the statistical power of a given study, and would deepen our understanding of the dose-response nature of the lactational process.[5,38]

Breastfeeding is unquestionably a dose-response specific variable. Women who breastfeed for two or more years significantly reduce their risks of breast cancer[2,46] and childhood cancers are lower in populations who were breastfed for longer than six months.[9] Women who breastfeed frequently and for long durations delay ovulation,[5,36,37] and the duration of breastfeeding has been correlated with increased I.Q. scores in pediatric and adult populations.[41,49] There is general consensus among scholars in the field that longer durations of breastfeeding provide enhanced immune functioning and protect children from a wide variety of infectious and noninfectious diseases,[2,5,8,32,46,47,48] including SIDS.[42]

We can no longer assume that the term "breastfeeding" is adequate to describe the immense variations that occur with regard to breastfeeding behaviors,[38] nor can we afford to assume that limited and/or partial breastfeeding has the same effect epidemiologically as frequent and long term breastfeeding when it comes to predicting maternal and child health trajectories.[5,38]

The Study

Research has documented that physicians who work primarily with women and children (i.e., Pediatricians, Obstetricians, and Family Practitioners) are in a unique position to positively impact breastfeeding rates.[2,3,4,5] However, data indicates that the majority of physicians educated in the U.S. receive little, if any clinical training in breastfeeding management.[3,6,44,52] The aims of this study presented here were 1) to determine what type of breastfeeding information women in the Midwest are receiving from their attending physicians, 2) to determine if physician breastfeeding advice significantly impacts maternal feeding decisions, and 3) to determine if significant differences could be detected with regard to physician expertise, patient income, patient education,

patient health insurance, and patient age.

Subjects

Data were collected from women who were the mothers of infant children (i.e., 12 months of age or younger). Newspaper birth announcements across a Midwestern state provided the names and addresses of participants. 500 surveys were mailed to new mothers across the state, and 193 were returned (response rate 38.6%).

Survey Design

A three-page survey derived from the Surgeon General's "Blueprint For Action on Breastfeeding" was used to determine what type of breastfeeding information was being disseminated to women by their attending physicians and to determine if this information influenced maternal feeding decisions. Six demographic questions were utilized to assess physician specialty, patient income, patient education, patient health insurance, patient age, and maternal feeding practices. Additionally, 13 Likert scaled questions were used to allow for degrees of agreement/disagreement. Each question was analyzed using a three-point Likert scale to indicate whether the participants were informed or not informed about the benefits of breastfeeding or were unsure about physician breastfeeding advise. The survey was designed to be brief, with completion to take no longer than 10 minutes.

Survey Administration

Surveys were sent to the participants using first class mail. A self-addressed, stamped envelope was included to help ensure a high response rate. The principle investigator included a signed cover letter. No follow-up surveys were sent and no telephone follow-up was employed. Data were collected over an eight-week period.

Method of Analysis

To determine what type of breastfeeding information women were receiving from their physicians, and to determine if this information influenced maternal feeding decisions, frequency distributions were calculated for all categorical variables and statistical analyses were conducted using all relevant data contained in the survey. Chi-square tests and z-tests for proportion were performed to compare responses (informed, never informed, not sure). Chi-square analyses and z-tests for proportion were performed to indicate if statistically significant findings could be detected with regard to physician specialty, patient income, patient education, patient health insurance, and patient age. Responses in each group were considered statistically significant at $p \leq .05$.

Results

Surveys were returned by 193 of the 500 women sampled. The median group age of women participating in this study was 25-30 years and the median income level was $31,000 - $50,000. The majority of participants in this study were college graduates (58%), and were covered by private health insurance (92%). All participants were residents of a Midwestern state.

Chi-square analyses indicated that the majority of participants in this study

were not informed by their physicians of the various ways that breastfeeding can positively impact maternal and child health outcomes. 76% of the participants in this study were never informed that breastfeeding can reduce child hospital admission rates. 71% indicated that their physicians had never informed them that breastfeeding reduces risk of maternal ovarian cancer and 66% were not informed that breastfeeding for two years or more can significantly decrease maternal breast cancer. 62% of the women participating in this study were never informed that breastfeeding may reduce the risks of childhood cancers, and 52% reported that they were not informed that breastfeeding can act as a natural contraceptive. Lastly, about 41 % of the participants indicated that they were never informed that breastfeeding significantly decreases the incidence of childhood allergies.

(See Table 1, p. 183)

Results of the study demonstrated that significant differences exist with regard to physician specialty (chi-square =17.96, df = 4, $p < 0.05$). Z-test for proportion indicated that when Family Practitioners, OB/GYN's, and Pediatricians were compared, Family Practitioners were significantly ($p < 0.05$) more likely to inform their patients of the benefits associated with breastfeeding. Furthermore, z-test for proportion revealed that of the three physician specialties, Pediatricians were the least likely to inform their female patients of the maternal and child benefits associated with breastfeeding.

Results of this study indicate that physician breastfeeding advice varies significantly depending on patient age (value = 12.671, df = 6, $p < 0.05$). Women participants in this study who were 38 years of age or older, and women under the age of 25 reported that they were the least likely to receive accurate breastfeeding advice from their attending physicians.

This study also found that educational level is a significant predictor of the type of breastfeeding information women receive. Participants of this study who were College graduates were significantly more likely than their less educated cohorts to receive accurate physician breastfeeding advice (chi-square value = 63.829, df = 2, $p < 0.05$).

Lastly, z-test for proportion ($p < 0.05$) indicated that women who are informed by their physicians of the maternal and child benefits associated with breastfeeding are significantly more likely to practice exclusive breastfeeding.

(See Table 2, p. 184)

Table 1

	FAMILY PRACTIONERS			OBSTETRICIANS			PEDIATRICIANS		
SURVEY QUESTIONS	Informed	Never Informed	Not Sure	Informed	Never Informed	Not Sure	Informed	Never Informed	Not Sure
My medical provider informed that breastfeeding reduces risk of childhood diabetes	25 13.4%	65 34.9%	13 7.0%	17 9.1%	39 21.0%	10 5.4%	4 2.2%	13 7.0%	0 0.0%
My medical provider informed that breastfeeding reduces certain childhood cancers	23 12.4%	69 37.1%	11 5.9%	24 12.9%	35 18.8%	7 3.8%	4 2.2%	11 5.9%	2 1.1%
My medical provider informed that breastfeeding reduces the risk of child ear infections	45 24.2%	50 26.9%	8 4.3%	37 19.9%	25 13.4%	4 2.2%	10 5.4%	6 3.2%	1 0.5%
My medical provider informed me that formula fed children are more likely to have allergies	46 24.7%	47 25.3%	10 5.4%	36 19.4%	25 13.4%	5 2.7%	10 5.4%	6 3.2%	1 0.5%
My medical provider informed that breastfeeding reduces risk of childhood asthma	39 21.0%	56 30.1%	8 4.3%	3 16.7%	32 17.2%	3 1.6%	5 2.7%	10 5.4%	2 1.1%
My medical provider informed me that breastfeeding may increase child's I.Q.	29 15.6%	63 33.9%	11 5.9%	29 15.6%	31 16.7%	6 3.2%	5 2.7%	10 5.4%	2 1.1%
My medical provider informed that breastfeeding lowers the rate of ovarian cancer	16 8.6%	76 40.9%	11 5.9%	20 10.8%	43 23.1%	3 1.6%	4 2.2%	13 7.0%	0 0.0%
My medical provider informed me that breastfeeding can act as natural contraceptive	47 25.3%	50 26.9%	6 3.2%	25 13.4%	39 21.0%	2 1.1%	6 3.2%	10 5.4%	1 0.5%
My medical provider informed me that formula fed children require more hospitalizations	13 7.0%	82 44.1%	8 4.3%	15 8.1%	48 25.8%	3 1.6%	4 2.2%	13 7.0%	0 0.0%
My medical provider informed me that breastfeeding for 2 years or more may reduce the risk of breast cancer	22 11.8%	76 40.9%	5 2.7%	28 15.1%	38 20.4%	0 0.0%	6 3.2%	10 5.4%	1 0.5%
My medical provider informed that the longer I breastfeed, the more protected my child is against infections	62 33.3%	36 19.4%	5 2.7%	46 24.7%	18 9.7%	2 1.1%	11 5.9%	5 2.7%	1 0.5%
My medical provider informed that breastfeeding is more beneficial than formula feeding	89 47.8%	11 5.9%	3 1.6%	55 29.6%	10 5.4%	1 0.5%	14 7.5%	3 1.6%	0 0.0%

Table 2

SURVEY QUESTIONS	Informed	Never Informed	Not Sure
My medical provider informed that breastfeeding reduces risk of childhood diabetes	49 25.4%	120 62.2%	24 12.4%
My medical provider informed that breastfeeding reduces certain childhood cancers	52 26.9%	120 62.2%	21 0.9%
My medical provider informed that breastfeeding reduces the risk of child ear infections	97 50.3%	82 42.5%	14 7.3%
My medical provider informed me that formula fed children are more likely to have allergies	95 49.2%	79 40.9%	19 9.8%
My medical provider informed that breastfeeding reduces risk of childhood asthma	79 40.9%	101 52.3%	13 6.7%
My medical provider informed me that breastfeeding may increase child's I.Q.	66 34.2%	108 56.0%	19 9.8%
My medical provider informed that breastfeeding lowers the rate of ovarian cancer	42 21.8%	136 70.5%	15 7.8%
My medical provider informed me that breastfeeding can act as natural contraceptive	82 42.5%	101 52.3%	10 5.2%
My medical provider informed me that formula fed children require more hospitalizations	35 18.1%	146 75.6%	12 6.2%
My medical provider informed me that breastfeeding for 2 years or more may reduce the risk of breast cancer	59 30.6%	127 65.8%	7 3.6%
My medical provider informed that the longer I breastfeed, the more protected my child is against infections	125 64.8%	59 30.6%	9 4.7%
My medical provider informed that breastfeeding is more beneficial than formula feeding	164 85.0%	25 13.0%	4 2.1%

Discussion

As with any investigation, it is important to note the limitations associated with this study. First, it is common knowledge that retrospective reporting may not be entirely accurate. Participants in this study were asked to recall what they had been told by their physicians regarding breastfeeding. It is a possibility that the female participants represented in this study were not able to recall all of the breastfeeding information that their physician had provided to them. Secondly, it is a distinct possibility that women who are highly educated may ask more sophisticated and probing questions regarding the feeding of their infants, thus leading physicians to discuss the many benefits associated with breastfeeding. Finally, the generalizability of this study may be limited as the participants in this study were contained within one geographical location.

Various scholars in the field of human lactation have postulated that physicians play a significant role in influencing maternal feeding decisions.[3,8,23,32] Physicians (particularly Family Practitioners, Obstetricians, and Pediatricians) are in a unique position to increase breastfeeding initiation and duration rates, yet data continues to confirm that American Physicians are severely undereducated in the area of breastfeeding management.[3,5,6,23,43,44]

This study is unique in that it follows up on decades of scientific studies which have demonstrated the need for more comprehensive physician education in the area of human lactation. The vast majority of studies conducted thus far have concentrated on the medical community while neglecting to examine what women are experiencing with regard to physician breastfeeding advice.

The majority of women participating in this study reported that their physicians were not informing them of the benefits of breastfeeding and the long term consequences associated with maternal feeding decisions. If we are to meet the goals set forth by the United States government,[2,4] we must address the question, "Why does the United States continue to have one of the lowest breastfeeding rates in the world?" It appears that we are immersed in a culture that is willing to pay lip service to what is best for our women and children, but are unwilling to address the seminal issues which perpetuate the low breastfeeding rates across this country. Physicians, researchers, parents, and concerned others must demand that factual and scientifically substantiated breastfeeding information be disseminated to mothers via the medical community.

It is imperative that women are informed by their physicians of the maternal risks associated with formula feeding. 71% of the women participating in this study were never informed that breastfeeding significantly reduces the risk of maternal ovarian cancer. Approximately 66% were never informed that breastfeeding for two or more years can significantly reduce the risk of maternal breast cancer. Over half of the participants in this study indicated they were never informed that breastfeeding can act as a natural contraceptive. Ovarian cancer, breast cancer, and contraception are important medical issues that effect women across this country. Women have a fundamental right to be informed that breastfeeding and formula feeding are not synonymous feeding methods. Decades of scientific data confirms that breastfeeding reduces maternal breast and ovarian cancers and can effect ovarian cyclicity,[2,5,32,33,36,37] yet the majority of women participating in this study were not informed of these scientifically substantiated facts.

The majority of participants in this study reported they were never informed by their physicians that breastfeeding 1) decreases the risk of child hospitalizations, 2) reduces the risk of childhood cancers, and 3) reduces the risk of childhood allergies. If women are not being informed of the benefits associated with breastfeeding, it is a distinct possibility that the United States will continue to have one of the lowest breastfeeding rates in the world. The goals set forth by the United States government in "Healthy People 2000"[4] have not been met as it appears that we are continuing to inadvertently withhold medical evidence which substantiates that breastfeeding positively impacts both maternal and child health trajectories. Breastfeeding reduces the risk of childhood diabetes,[2,19] child cancers,[2,9,21,22,47] ear infections,[2,46] allergies,[2,24,25]

asthma,[2,46] maternal ovarian cancer,[2] child hospitalizations,[2,13,48] SIDS,[8,14,42] child eye disease,[10] gastrointestinal illness,[2,16,17,46] inflammatory bowel disease,[26] Crohn's disease,[27] celiac disease,[28] multiple sclerosis,[29] heart disease,[30] obesity,[2,31] maternal breast cancer,[2,33,46] and maternal endometrial cancer.[34] Breastfeeding has also been found to increase child I.Q. scores[2,41] and to facilitate optimal attachment between mother and child.[2,5,32,35,39,51] The time has come to embark on a massive educational breastfeeding campaign as women cannot make informed feeding decisions if crucial medical information is systematically withheld.

Participants in this study reported that Family Practitioners were more likely than OB/GYN's or Pediatricians to inform their patients of the benefits associated with breastfeeding. On the surface, it would appear that the reason behind this finding is that Family Practitioners receive more breastfeeding training while in medical school, thus they are better equipped to impart accurate breastfeeding information. However, scholars in the field of human lactation have documented that physician breastfeeding education is limited in obstetric, pediatric, and family practice residency training.[3,6,43,45] It is a possibility that women are more likely to discuss breastfeeding with their Family Practitioners; however, more research is needed in this area in order to fully understand these findings.

Participants in this study who were 38 years of age or older were least likely to receive accurate breastfeeding advice from their attending Physicians. Only 6% of participants in this age range indicated that they were informed of the maternal and pediatric benefits associated with breastfeeding. Furthermore, only 12% of participants 19-24 years of age reported that they had been informed of the benefits associated with breastfeeding. It is apparent that more research is needed in this area in order to understand why significant differences were detected with regard to patient age. Perhaps physicians assume older women are educated in the area of human lactation, however, at the present time, the hypothesis is purely speculative. What is absolutely undeniable is that all women, regardless of age, have a right to be informed of the maternal and pediatric benefits associated with breastfeeding.

Participants in this study who were college graduates reported that they were the most likely to receive accurate breastfeeding information. 80% of participants who were college gradates indicated their physician had informed them of the various ways in which breastfeeding protects both mother and child. It is plausible that highly educated women may be asking more probing questions with regard to infant feeding practices, but currently, there is no data to support this supposition.

Only 2% of women who had not completed high school were informed by their physicians of the benefits associated with breastfeeding. This finding is particularly disturbing in light of the fact that the Surgeon General of the United States[2] has indicated that breastfeeding information is crucial for disadvantaged women as they consistently report the lowest rates of breastfeeding in the United States.[2] The findings contained within this study illustrate the need to provide women of all ages and from all educational backgrounds comprehensive breastfeeding information.

This study found that women who have been informed by their physicians

of the numerous maternal and child benefits associated with breastfeeding are significantly more likely to practice exclusive breastfeeding. It is a distinct possibility that women in this country are not aware of the risks associated with formula feeding and that breastfeeding rates would increase dramatically if women were made aware of the medical facts. Walker[23] has suggested that physicians neglect to inform their patients of the risks associated with formula feeding because to do so would make women feel guilty. Walker[23] also asserts that failing to inform patients generates more anger than guilt in women who subsequently discover the risks of formula feeding at a later date. Lawrence[32] has postulated that parents have a right to be informed of the scientific facts surrounding breastfeeding, and that to deny parents these facts is to deny them their right to informed consent.

Freed[3] takes a somewhat different view with regard to the problem of women not being informed of the risks associated with formula feeding. As a practicing physician, Freed[3] has hypothesized that women are not being informed of the risks associated with formula feeding because physicians in this country are not being properly educated in the area of human lactation during the course of their medical school training.

Results of this study indicate that physicians can positively influence maternal feeding decisions by providing their patients with medically substantiated breastfeeding advice. It is clear that physicians play a pivotal role with regard to breastfeeding rates in this country, but there remains much work to be done. Scholars in the field of human lactation have suggested that in order to increase breastfeeding rates exponentially, the medical community must:

1. include comprehensive breastfeeding education during residency training[3]
2. concentrate on the clinical relevance of breastfeeding during the course of medical school training[3]
3. teach breastfeeding counseling skills to physicians who work with mothers or prospective mothers[3]
4. incorporate lactational consultants with residency training (i.e., include consultants on postpartum and newborn rounds)[3]
5. provide mandatory continuing breastfeeding education to practicing physicians[3]
6. inform patients that formula and breast milk are not equal methods of feeding and there are risks associated with formula feeding[23]
7. inform patients that there is a difference between adequate and optimal development[23]
8. encourage “rooming in” practices during the postpartum period[45]
9. inform patients that the use of pacifiers and/or formula supplementation decreases maternal milk supply[32,45]

10. demand that the economic alliance that exists between the pharmaceutical companies (i.e., formula manufacturers) and the medical community be severed. This includes refusing to give free samples of formula and refusing to provide free advertising for the formula companies in clinics and/or hospitals.[5,8,15]

11. formally question the ethics of medical journals that carry advertisements for formula (a product that is known to increase child morbidity and mortality rates)[5,8]

12. use their "medical expert" status to lobby for warning labels on formula so that consumers are aware of the risks associated with the use of this product[23]

13. inform patients of the numerous maternal and child benefits associated with breastfeeding[2,3,4,12,23,32]

14. inform patients of the increased medical expenses associated with formula feeding (i.e., increased office visits, prescription drug use, and hospitalization).[2,11,12,23]

Any discussion regarding breastfeeding in America must take into account the divergent complexities associated with this issue. While it is certain that physicians influence maternal feeding practices, it must also be acknowledged that breastfeeding practices are contingent upon many other factors which include but are not limited to 1) the lack of breastfeeding role models in the family, the community, and in the mass media,[5,52] 2) federal policies which impede both the initiation and duration of breastfeeding,[5,39,52] 3) cultural ideologies which dictate that a woman's worth is based upon her economic earning power,[5,52] 4) the culture of the self that focuses on the needs of the individual rather than on the needs of children,[5,39,52] and 5) the mass sexualization of the female breast.[5,39,52]

Conclusion

In summary, the findings contained within this study suggest that women are not receiving compendious breastfeeding information from their physicians. Statistical analyses indicated that the majority of participants in this study were not informed by their Pediatricians, Family Practitioners, or Obstetrician/Gynecologists of the various ways in which breastfeeding can contribute to optimal mother and child health trajectories. While this study found that Family Practitioners are more likely than OB/GYN's or Pediatricians to provide women with accurate breastfeeding advice, data indicated that significant, information-based gaps remain with regard to physician breastfeeding advice across specialties.

Further research is needed in order to understand why maternal age and education levels are significantly correlated with physician breastfeeding advice. Perhaps the findings contained within this study illustrate that patients themselves influence the information they receive from their physicians. This analysis is clearly hypothetical and points to the fact that additional research is

needed in this area if we are to understand these findings in full.

Lastly, this study found that physicians who inform their patients of the various maternal and pediatric benefits associated with breastfeeding are more likely to have patients that practice exclusive breastfeeding. It is undeniably clear that physicians play an important role in maternal feeding decisions. Perhaps the time has come to acknowledge the power associated with the position and to work unceasingly to improve maternal and child health outcomes in this country.*

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Book Review

The Social Lives of Medicine

Susan Reynolds Whyte, Sjaak Van der Geest, and Anita Hardon. Cambridge, UK: Cambridge University Press, 2002.

ISBN 0-521-80469-8; 200 PAGES, PAPERBACK, $21.00

It is indeed true that we are creatures of habit who rarely, if ever, consider the meaning or significance of our ordinary or habitual activities. The use of medicinal substances is one such example elucidated by *The Social Lives of Medicines*. We fail to recognize the ways our lives have become medicalized and increasingly controlled by the very substances employed to gain control over uncontrollable aspects of our lives. This phenomenon has broad social and cultural implications.

In *The Social Lives of Medicines*, observations from anthropologic and ethnographic studies demonstrate the symbolic ways in which medicines are used in various cultures throughout the world, and their relationship to the people who use them. Relationships with medicinal agents are evaluated from the perspectives of consumer, provider, strategist, and regulator. Within these categories, issues such as the medicalization of life, symbolic meaning of medical substances, placebo or meaning effect, commodification of health, technological efficacy, and the manufacture of image and perceived need are addressed. Of particular interest was the topic of prescriptions as a form of communication between physician and patient—how the simple act of writing a prescription conveys not only compassion and care, but often signals the end of the encounter as well. The final section of the book describes an attempt by some countries to limit the distribution of medicines to those felt to be safe, effective and affordable, and the opposition that such plans encountered from strategists and consumers alike.

The book is a fascinating perspective on something that American providers take for granted: there is far greater meaning to the use medicinal agents than mere treatment of a medical condition. But for those nurtured by the scientific method and inductive reasoning, studies like this one can be disconcerting and unsettling. Throughout the book there is an expectation that general conclusions will be drawn from the particular observations, but that never occurs with any clarity. The observations made among women of Manila remain with the women of Manila; with the exception of "London skeptics," Western cultures are not addressed. Perhaps it is the nature of anthropology, particularly ethnography, to draw relations and analyses only within a particular culture. However, as members of a common humanity sharing universal fears of illness, suffering and death, it would seem that many of the symbolic meanings and ways in which medicines are used in other countries would be applicable to all cultures (including the West), but this application was left unfinished. Making such comparisons would have made the book seem more pertinent and applicable.

Nevertheless, the book persuasively demonstrates the impact and control that medicinal agents exert in our lives and cultures, even serving as a means of communication between people from disparate walks of life. It draws attention to the growing presence of medicines in our culture and the resultant perceived need for them, and encourages people to define and manage life medicinally.

Reviewed by Susan M. Haack, M.D., M.A. (Bioethics), F.A.C.O.G. who is in the private practice of consultative gynecology at Mile Bluff Clinic/Hess Memorial Hospital in Mauston, Wisconsin.

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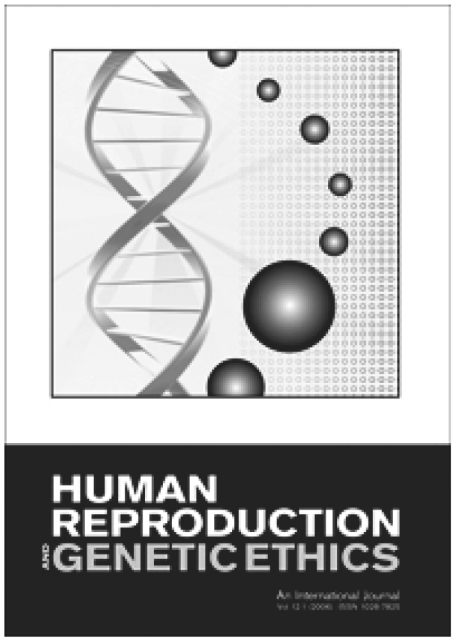

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