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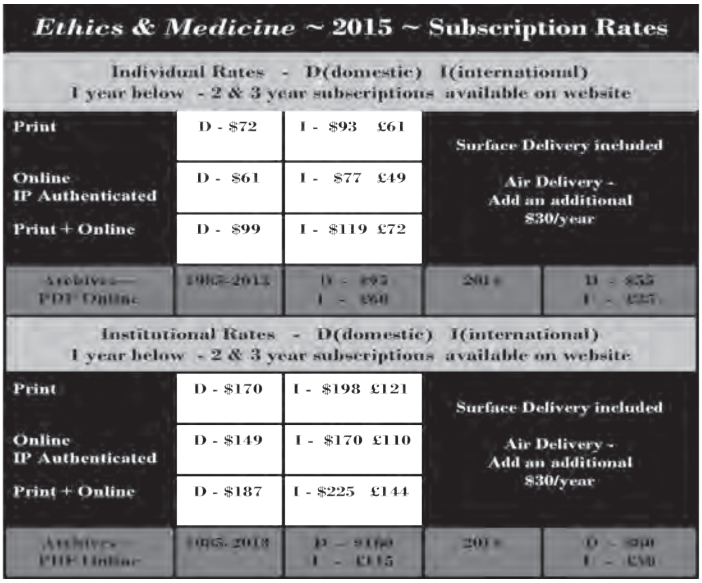

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EDITORIAL

DYING WELL

C. BEN MITCHELL, PHD

Approaching major surgery is a time to take stock. It's a time to recall what matters in life and what matters in death. By the time you read this I should be well on the road to recovery from hip replacement surgery. As I anticipate the surgery, I am profoundly grateful for the splendid medical resources available in my community. I am especially thankful for the orthopedic surgeon and his team of caregivers.

'We should not think about death,' some will say. 'It's too morbid.' Not at all. In fact, down the ages many Christians embraced a reflective practice known as *memento mori*. *Memento mori* (Latin for "remember death") is the practice of meditating on our own mortality, the vanity of life, and the blessings to come. This practice is completely foreign to a death-denying culture like ours, but we need to recover it. Why? Well, for one, we are all going to die and it is important to die well.

Life is a great gift. We did not bring ourselves into the world and we will not—or should not, I would argue—remove ourselves from the world. Dying reminds us that we are radically dependent creatures. Not only do we depend on the One who gives us all life and breath, but we depend on others as well. I was dependent on my mother and father more than a half-century ago when I was born. I have depended on the skill of an excellent surgeon and the compassionate care of others in my recovery. I have depended on the presence of a top-tier medical center. And on it goes. The poet John Donne was right: "no man is an island."

Dying also reminds us of the power of the virtue of love. An act of love brought most of us into the world. Love nourishes, sustains, and enhances our lives in rich and meaningful ways. The price of love is the pain we feel when we lose someone we love to death. Those who have loved deeply, hurt deeply. So, thinking about our death should make us love more intensely.

Dying also reminds us that this life is brief and fleeting. The longer I live, the shorter life is. For some, the brevity of life makes them cling tightly to people, things, or status, but, as the sage has said, 'you can't take it with you.' The brevity of life should, therefore, make us hold loosely to the people and things around us. We are stewards, not owners, of talents, children, and other goods.

Patience is another important virtue for facing dying. This virtue involves not Stoic resignation, but persevering dependence on the goodness of God. Patience trains us to receive care graciously and gratefully. It trains us to accept the dependency of others and our own. Unlike Stoic resignation, Christian patience does not celebrate suffering. The Stoic answer to suffering included the option to end one's own life, but Christian patience makes no place for suicide. In fact, early theologians were consistent in their insistence that suicide was sub-Christian at best, because hope and love sustain patience.

In this way, major surgery proves to be a *memento mori*, at least for me. It is a time to re-examine what it means to live well and die well. **E&M**

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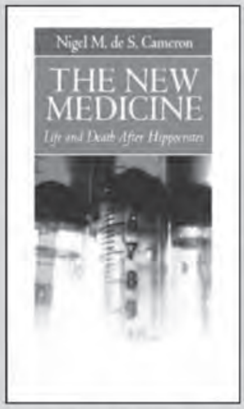
Bulletin Board

THE NEW MEDICINE : LIFE AND DEATH AFTER HIPPOCRATES

By Nigel M. de S. Cameron



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In the reprinting of a very important book for our current times, Dr. Cameron links the rise of the "new medicine" and the fall of the Hippocratic tradition to society's increased acceptance of the practices of euthanasia and assisted suicide. He states that "the medical profession is liable to follow any fundamental shift in society's values" and point to the relationship between Nazi Germany and the Nuremberg "medical crimes" as an example. In the absence of the Hippocratic prohibition against the killing of patients by their physicians, the fundamental value of protecting life is displaced. "the desire of society to avoid suffering, financial burden, and the inconvenience then lead to increasing support for physician-assisted suicide and euthanasia. The author contends that it is imperative for the medical profession to return to its Hippocratic roots.

"In the post-WWII era physicians began to water down the basic tenets of the Hippocratic tradition, and then they abandoned them. That's what this important book is all about: the rise and fall of Hippocratic medicine."
C. Everett Koop, Former US Surgeon General

"In **The New Medicine,** *Dr. Cameron has done much to earn the title of a second Hippocrates."* **Harold O.J. Brown, Professor of the Theology and Philosophy Reformed Theological Seminary**

"The New Medicine *is a persuasive manifesto that should be welcomed by those who have the courage to join a movement to reform aimed at restoring medicine to its healing mission."* **Richard John Neuhaus, Director Religion and Public Life**

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GUEST COMMENTARY

A TRADITIONALIST PROTESTANT RESPONSE TO ROMAN CATHOLIC RULES ABOUT THE INDUCTION OF UNBORN ANENCEPHALIC BABIES

THOR SWANSON, MD, MDIV, THM, MA, DBE

About once per year, as chair of the ethics committees at the Protestant and Catholic Hospitals in Sioux City, a case of anencephalic pregnancy comes to my attention. Inevitably, questions immediately arise: Is it morally appropriate for the mother to choose to induce the unborn baby before going into normal labor? If so, will one or both hospitals allow that to happen on their campus? And if so, at what point in the pregnancy (pre-viability, viability, term) will that be allowed? Over the course of time, the two hospitals have ended up with different practices, the Protestant hospital allowing induction any time after diagnosis and the Catholic hospital requiring that the pregnancy be continued to term except for life-threatening circumstances. In our community, the Catholic hospital has been criticized for her more stringent policy. This paper examines current Catholic standards, which demand that the pregnancy be taken to term, and offers an ethical defense for those women who choose to induce the pregnancy earlier, between 26 and 37 weeks.

Medical Background

Anencephaly is a medical condition that is one type of what embryologists and medical doctors call a neural tube defect, in which the neural tube of the developing fetus fails to close properly. In anencephaly, when the neural tube fails to close on the cranial endodermal neurotube,[1] the result is either complete (holoencephaly) or partial (meroencephaly) absence of the brain.[2]

With anencephaly, large portions of the scalp, cranial bones, and brain (including both cerebral cortex and white matter) are missing in the fetus.[3] In fact, complete absence of the brain (holoanencephaly) accounts for about 65% of cases and partial absence of the brain (meroanencephaly) up to 35% of cases.[4] Further, brainstem, cerebellum, and spinal cord are present, but often these too are malformed, as are the cardiac system (15%), gastrointestinal system (1-16%), and renal system (1-6%).[5]

In the United States, all neural tube defects (including anencephaly and a few other variants[6]) have traditionally occurred (in the days before serum and ultrasound screening) at a frequency of about 2 per 1000 live births.[7] Interestingly, females predominated in ratios between 3:1 to 7:1 in series studies.[8] The known causes of anencephaly are many and include: 1) chromosomal abnormalities, 2) material hyperthermia, 3) and deficiencies of folate, zinc and copper.[9] In recent years, the incidence of these births in the United States and Western countries has decreased, due both to prevention through prenatal administration of folic acid and to termination of these pregnancies after implementation of universal maternal serum alpha-protein screening and highly reliable ultrasound diagnosis.[10]

Historically (before screening), the diagnosis of anencephaly was usually made at birth. However, anencephaly can be anticipated if the mother's pregnant serum level of alpha-fetoprotein and acetylcholine esterase are elevated in basic screening tests.[11] If these serum tests are abnormal, the pregnant mother will usually have an ultrasound to further work up the abnormal screening test. These abnormal alpha-fetoprotein and acetylcholine esterase tests are even more reliable if they are elevated in the amniotic fluid, as attained by amniocentesis.[12]

Diagnosis of anencephaly by prenatal ultrasound is fairly obvious as the affected fetus completely lacks a calvarium and neocortex, an observation that even an introductory ultrasonographer could make. Anencephaly is one Central Nervous System anomaly that can routinely be detected in the first trimester of pregnancy by ultrasound and confirmed in the second trimester to a degree of accuracy of virtually 100%.[13] On ultrasound, besides the fetal malformations, polyhydramnios is often noted.[14]

In terms of disease progression, 65% of anencephalic fetuses die in utero and almost 100% die by the end of the first postnatal week.[15] When anencephalic babies survive a few days, startle reactions, movement of limbs, spontaneous respirations, pupillary light reactions, ocular movements, and corneal reflexes may be witnessed. In a small percentage, avoidance reactions occur and crying and feeding reflexes may be elicited, showing that only basic brain stem functions are necessary for these activities.[16]

In the days before screening tests and ultrasounds, anencephaly would usually be diagnosed at birth. However, the rise of reliable serum screening tests, ultrasound, and amniotic fluid tests have raised the issue of how to handle these pregnancies when they are discovered prior to birth, especially in the first and second trimesters.

Roman Catholic Regulations and Perspectives

In light of serum testing and ultrasound diagnosis of anencephaly, many physicians and bioethicists advocate termination of pregnancy (abortion) if the anencephaly diagnosis is made early in pregnancy or, if discovered later, early induction of labor shortly after diagnosis. For instance, in their well-known book *Neonatal Bioethics*, John Lantos and William Meadow state that "anencephaly . . . is widely recognized as a syndrome that leads to a quality of life below the threshold at which treatment should be considered obligatory. For many people, anencephaly represents a paradigm case of medical futility. That is, they see it as a condition in which treatment is always inappropriate and ought never to be provided."[17] The strongest argument of induction before viability or after viability and before term is to help the mother avoid "psychological anxiety" and "possible physical complications throughout the remainder of the pregnancy."[18] As with other issues in bioethics, The Roman Catholic Church and its people have had to respond to these bioethical challenges.

The Bishops of the Roman Catholic Church formulated a response to the anencephalic bioethical challenge on September 19th, 1996 in a work entitled "Moral Principles Concerning Infants With Anencephaly." In that document, the US Bishops noted that "According to the well-established teaching of the Catholic Church, the rights of a mother and her unborn child deserve equal protection because they are based on the dignity of the human person whatever the condition of that person."[19]

And further, the Bishops stated, “Consequently, it can never be morally justified directly to cause the death of an innocent person no matter the age or condition of that person.”[20] While the Bishops never cite a source for the “well-established teaching of the Catholic Church,” the document is certainly consistent with and perhaps even rooted in the 1994 *Catechism of the Catholic Church*. There, in paragraph 2770,[21] in discussing the commandment “You Shall Not Kill,” the Catechism teaches, “Human life must be respected and protected absolutely from the moment of conception . . . from the first moment of his existence, a human being must be recognized as having the rights of a person – among which is the inviolable right of every innocent being to life.”[22] The Catechism then continues further in paragraph 2271[23] and reads, “Since the first century the Church has affirmed the moral evil of every procured abortion . . . this teaching has not changed and remains unchangeable. Direct abortion, that is to say, abortion willed either as an end or a means, is gravely contrary to the moral law.”[24] And finally, the Catechism further notes in paragraph 2274,[25] “Since it must be treated from conception as a person the embryo must be defended in its integrity, cared for, and healed, as far as possible, like any other human being.”[26] In the RCC Catechism and the Bishop’s document, the Roman Catholic authorities are clearly trying to protect the human dignity of the unborn anencephalic baby. Thus, any moral decision in regard to the pregnancy has to acknowledge that basic dignity which includes the right of every innocent person not to be killed.

In their 1996 document, the Bishops then acknowledged that some people in the world would teach that “anencephalic children may be prematurely delivered . . . this argument . . . [was] based on the opinion that because of their apparent lack of cognitive function, and in view of the probable brevity of their lives, these infants . . . [would not] be the subject of human rights, or at least have lives of less meaning or purpose than others.”[27] However, the Bishops refused these reasons as support for early induction. Again, anencephalic babies are to have full human dignity and rights accorded to them. Just because a baby lacks upper brain function, that does not mean that the child lacks human dignity or personhood.

Further in their document, the Bishops then reaffirmed the then current Ethical and Religious Directives for Catholic Health Care Services (ERD) Directive 45 that “Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted. Every procedure whose sole immediate effect is the termination of pregnancy before viability is an abortion . . . “[28]

Were there exceptions to the command to never allow an action that resulted in the death of an unborn child? Yes, said the Bishops, as their paper noted, “It is permitted to treat directly a pathology of the mother even when this has the unintended side-effect of causing the death of her child, if this pathology left untreated would have life-threatening effects on both mother and child, but it is not permitted to terminate or gravely risk the child’s life as a means of treating or protecting the mother.”[29] Thus, it is permissible to treat a life-threatening condition of the mother that indirectly results in the death of the child, but it is not appropriate to undertake termination of the child simply for the mother’s choice or convenience.

Did possible psychological or physical trouble carrying an anencephalic pregnancy to term constitute grounds for an induction before or after viability? In their document in 1996, the Bishops wrote, “It is clear that before ‘viability’ it is never permitted to terminate the gestation of an anencephalic child as a means of avoiding psychological or physical risks to the mother. Nor is such temptation permitted after ‘viability’ if early delivery endangers the child’s life due to complications of prematurity.”[30] The Bishops here were saying that potential, but not real trouble, of the kind seen with any pregnancy was not a ground for an induction of the unborn baby. Just as a regular pregnancy is not induced and discarded for potential trouble or maternal psychological trouble, so an anencephalic pregnancy must not be either.

By 1996, some ethicists and Roman Catholic lay people had already raised the possible scenario of inducing anencephalic babies prior to term. The Bishops responded to that by saying,

> It is clear that before ‘viability’ it is never permitted to terminate the gestation of an anencephalic child as the means of avoiding psychological or physical risks to the mother. Nor is such termination permitted after ‘viability’ if early delivery endangers the child’s life due to complications of prematurity . . . the fact that the life of a child suffering from anencephaly will probably be brief cannot excuse directly causing death before ‘viability’ or gravely endangering the child’s life after ‘viability’ as a result of complications of pregnancy.[31]

In the document, the Bishops seemed to be ruling out any induction before term of anencephalic babies, unless there was truly a “life-threatening” pathology of the mother other than the routine pregnancy.[32] Just because the child carries a terminal diagnosis, that does not mean others have the right to hasten its death. Such a child may die, but one can’t speed that death up without a proportionate reason.

In their book, *Health Care Ethics: A Catholic Theological Analysis*, Catholic theologians Benedict Ashley, Jean DeBlois, and Kevin O’Rourke affirm that Catholic teaching holds that, as its basic practice, anencephalic babies should not be induced before term. As they say,

> Delivery before viability seems to be a direct abortion because the moral object of the act is to end the pregnancy, and the child dies as an inevitable result . . . [and further] it seems the moral objects of early delivery for an anencephalic or a genetically deprived infant is to hasten or cause the death of the infant . . . thus it is our opinion that anencephalic infants and genetically deprived infants should be allowed to go to term, be baptized, and be allowed to die in their parent’s arms. . . this opinion is in accord with norms published by the National Conference of Catholic Bishops.[33]

For this group of traditionalist Catholic theologians, along with many others,[34] the perspective is clear that Roman Catholic hospitals and people should not be inducing anencephalic pregnancies before term without reason.

In their work, Ashley, DeBlois, and O’Rourke all go on to question whether induction for psychological stress, as some claim should be allowed, is valuable anyway. As they say, “Some have maintained that early delivery before viability would be licit because it may help the mother avoid psychological suffering . . . [in fact] early delivery of seriously impaired infants does not seem to relieve psychological suffering . . .”[35] Ashley and all agree with the Bishops therefore that the anencephalic pregnancy is not enough to warrant induction, even if the mother should claim psychological difficulty from it.

In evaluating when early induction might be morally licit, Roman Catholic writers Peter Cataldo and T. Murphy Goodwin, representing the perspective of the National Catholic Bioethics Center, write that “In Catholic moral teaching and tradition, all cases of induction of labor may be evaluated by the principle of double effect.”[36] After noting the four conditions of the double effect principle, these theorists note that inducing pregnancy for a potentially lethal maternal pathology – such as preeclampsia or preterm premature rupture of membranes – meets the criteria as morally licit, but inducing pregnancy for a fetal anomaly does not.[37] Thus, in a mother carrying a child with a fetal anomaly, “the benefit of early induction compared to continuation of the pregnancy is weighed in the same way it is for any pregnancy.”[38] And thus, because the anencephalic baby has just as full human dignity as an otherwise normal baby, induction criteria should be equally stringent.

Cataldo and Goodwin concur with Ashley and his co-authors that simple proposals supporting induction don’t hold up. For those who might say the mother should be prevented future physical danger in pregnancy, they respond that “Early induction of labor or early termination of pregnancy by other means (abortion) provides no physical benefit to the mother under normal circumstances;” thus, induction cannot be undertaken to prevent potential problems.[39] Further, they too don’t feel psychological factors warrant the intervention. As they say, “In the absence of a physical malady in the mother, some have contended that the emotional burden of continuing the pregnancy when the child will ultimately die at birth should be weighed against the benefit of continuation of fetal life, and that this could justify early induction of labor in some cases. However, this proposed psychological benefit of early induction of labor has not been demonstrated scientifically. Its use in considerations of early induction of labor is speculative and has been specifically proscribed.”[40]

The Bishop’s Document and these two representative responses briefly explain the current Roman Catholic position regarding anencephalic pregnancies and their resolution at Catholic Hospitals. That is, the fact of an anencephalic pregnancy is not enough to morally warrant an early induction before viability, or induction after viability but before term. Instead, only serious pathology, like preeclampsia or preterm premature rupture of membranes, might qualify the pregnancy for induction. Further, potential physical suffering or alleged psychological suffering of the mother also do not meet the criteria. The justification for the Roman Catholic position is human dignity – that unborn anencephalic child is to be treated as human and is just as entitled to the continuation of pregnancy as an otherwise normal unborn child. Just because the anencephalic child will die shortly after birth, that doesn’t mean that death ought to be hastened. These teachings and this practice have been taught and upheld at the Catholic Hospital at Sioux City, and early inductions, simply for anencephaly, have not been authorized under my leadership of the Ethics Committee.[41]

A Traditionalist Protestant Response

How does this traditionalist Luthero-Reformed Protestant[42] Christian respond to these Roman Catholic rules and regulations, besides ensuring that the Catholic standards are upheld at the Catholic hospital?

First, traditionalist Protestants should support the Roman Catholic Church’s desire to respect the Imago Dei in all humans, born and unborn.[43] Traditionalist

Protestants affirm with Roman Catholics that all humans are created in the Image of God, and that that Image is worth protecting. All humans have dignity, because God gives it to them and such dignity means they are innocent people worthy of being protected from being killed. As Evangelical Traditionalists Scott Rae and Paul Cox note, "The sacredness of innocent human life is the foundational premise on which the proper theological view of the human person is based. The fifth commandment (You shall not murder . . .) was intended to safeguard innocent human life . . . The reason innocent human life is sacred is because human beings are created in the image of God."[44] Traditionalist Protestants agree with the Roman Catholic Church that any policy concerning anencephalic pregnancies must begin with respect for and protection of humans, as individuals created by God.

Second, traditionalist Protestants should support the Catholic Church's desire to respect the dignity and sanctity of all unborn life, regardless of birth defects or lethal anomalies. To be human is to be made in the Image of God (Genesis 1:26), and that fact should be reaffirmed in all the unborn,[45] including those unborn children with anencephaly. Too many secularists and liberal Protestants are too willing to say that that unborn anencephalic is "just a bunch of tissue."[46] While one might be tempted to say and think that that perspective is not too dangerous in the cases of some anencephalic pregnancies, the 20th Century showed us the slippery-slope phenomena and how quickly that thinking became lethal when extended to those with Trisomy 21,[47] other birth defects, and even to those of the "wrong" race (Jewish et. al).[48] While these horizons seem distant in our current land, the speed of a few Weimer elections from 1931 to 1933 showed how close human dignity always is to ceasing to be respected, and how quickly that slippery slope can incline sharply.[49]

In fact, some traditionalist Protestants have brought up the fact that instead of supporting society's move against the diseased unborn, it is specifically the church and Christianity that must be standing up for the crippled and diseased unborn. As Rae and Cox again say, "The notion of God as the protector of the weak and powerless suggests that all vulnerable persons, particularly embryos and fetuses, are deserving of protection . . . for example, in Psalm 139 . . . [and] Finally, the biblical notion of parenthood under God suggest that embryos and fetuses should be regarded as valued persons and should not be used as means or treated as products of conception."[50] The Catholic Church is right that any policy concerning anencephalic pregnancies should protect the unborn's dignity as one of the powerless, created children of God.

Third, traditionalist Protestants should support the Catholic Church's desire to honor the eternal moral law of God.[51] As the documents and writings in the Catechism and Bishops' Document say, the command "You shall not murder" is central to 2,000 years of Christian moral theology. And further, the majority of Bible-respecting Christians (Protestant, Catholic, Orthodox) over that 2,000 years have felt that those commands do extend to unborn fetal life.[52] The permissiveness of Christians toward the abortion of unborn life is a late 20th Century phenomenon that, not surprisingly, largely overlaps with the secular feminist movement. The Catholic Church is right that any policy concerning anencephalic pregnancies must begin with the Christian tradition's defense of life.

Fourth, traditionalist Protestants should support the Catholic Church's desire to respect the pregnancy process. Unlike with some birth defects that are overwhelmingly fatal and miscarried in the first trimester, a maternal body appears readily able and often willing to carry many of those babies to later pregnancy and even to term. Even if the pregnancy is known to be anencephalic, there can be something very normal, even natural, about a mother carrying this unborn life to term, even if she knows it will die shortly after birth.[53] Traditionalist Protestants have probably been too quick to deny the value of a full pregnancy for some women, wrongly encouraging these women to end these pregnancies as soon as possible. As Protestant Bioethicist Allen Verhey says about anencephalic pregnancies, "A good mother may find it hard to 'disconnect' herself emotionally from the fetus, and it may be the course of wisdom to continue the pregnancy to win the opportunity to hold the child, to welcome if for long enough to say goodbye to it. It is a decision to be made by the mother, but the burden of the decision is not to be borne alone."[54] The Catholic Church is right that women who respect the pregnancy process and keep the child to term should be supported and deserve special pastoral care by our providers.[55]

Fifth, traditionalist Protestants should support the Catholic Church's teaching that medical conditions that bring a significant and fairly immediate threat to the mother's pregnancy, such as pre-eclampsia or preterm premature rupture of membranes, and which would lead to the induction of pregnancies in other settings, should also prompt anencephalic delivery. Catholic reasoning in these situations is usually based on the principle of double effect.[56] Most traditionalist Protestants will usually base their justification for quick delivery in these settings on the mother's right to self-defense. That is, the mother has the right to defend herself from an attacker in pregnancy (albeit an unintentional one), just as the Protestant has the right to defend himself from attack in society.[57] Thus, the commandment "You shall not kill" is not considered, in Protestantism, to be absolute in all situations – or as other Protestants might say it – not every killing is murder (could be self-defense). The Catholic Church is right that any anencephalic policy should seek to defend and support the mother's life.

Sixth, traditionalist Protestants should support the Catholic Church's effort to use science to see what psychological and medical conditions truly endanger the mother in an anencephalic pregnancy.[58] While many people assume that carrying an anencephalic pregnancy would lead to increased psychological or medical risks, those assumptions may or may not be true. Protestantism should follow Catholicism's lead in letting the best of science help direct her theology, ethics, and practice, even in regard to anencephalic pregnancies.

Seventh, traditionalist Protestants should support the Catholic Church's observation that a pre-viability induction looks little different than, and may in fact be little different than, an abortion. The Catholic Church is right that that similarity should affect any anencephalic policy. The Catholic Church's teaching that the question of when to deliver these pregnancies rightly breaks down into three alternatives – term, post-viable but pre-term, and pre-viable – is correct. The Catholic Church is right that any anencephalic policy should address these three possibilities.

As one can see, traditionalist Protestants share a lot of perspectives with Roman Catholics on anencephalic pregnancies. However, differences may also arise.

First, traditionalist Protestants do not necessarily have to agree with Roman Catholics that respecting the human dignity of the anencephalic demands that the pregnancy be carried to term rather than just to the point of viability. The reality is that while that anencephalic baby is a human being who deserves human dignity, that baby is also a human being who is actively dying with fatal and lethal defects. That situation makes the anencephalic pregnancy different from another normal pregnancy where a child will be born who is expected to live a normal life span. The Catholic Church believes that any induction should respect the complications of prematurity in both the normal pregnancy and the anencephalic one; however, it is exactly these complications of prematurity (retinopathy, seizures, long-term IQ damage, etc)[59] which will not affect the anencephalic baby because that baby will not live longitudinally to suffer those effects. Thus, the biggest reason to hold off induction in viable normal pregnancies (prematurity) doesn't in practicality affect anencephalic ones. While babies of non-anencephalic pregnancies who are induced just after viability are born into complications of prematurity and possibly even death due to prematurity, anencephalic babies that are induced after viability are not induced to complications and death. However, they still have a life expectancy not much different from that of their delivery at term.

Second, many traditionalist Protestants, sharing a Catholic concern for the live birth and baptism of their child, might actually argue for early induction. A Roman Catholic will press for a term delivery of the anencephalic because that is "closer to normal;" however, carrying a baby that will likely die in utero and definitely after is hardly normal. In fact, inducing this anencephalic pregnancy earlier than term, when the baby is still alive, could be argued to be "closer to normal." In a pregnancy that is otherwise normal, when an intrauterine baby is in danger of dying, we do not "let this pregnancy take its course" and leave the baby to possibly die. Instead, we do immediate induction or C-section to deliver the baby alive. In anencephalic cases, we know the baby is dying. Might it not be the right thing to induce it so that it can be born alive, like in other pregnancies? And further, some traditionalist Protestants may desire live birth of their child followed by baptism of that child. Inducing this child after viability so that the baptism of a live child can occur becomes a different way of respecting the dignity and personhood of this child. This traditionalist Protestant thinks that this approach too is a reasonable option for traditionalist Protestant Christians.

Conclusion

Based on the above, I affirm the following: 1) Traditionalist Protestants (and all women) who carry the anencephalic child to term and deliver are to be commended for their respect for pregnancy and life. 2) Traditionalist Protestants (and all women) who carry the child to the point of viability and then induce the anencephalic baby, with the goal of supporting their child's dignity through a live birth and baptism, are also to be supported. 3) Traditionalist Protestants (and all women) should be discouraged from inducing the anencephalic pregnancy before the point of viability, where their action will look little different than an abortion.[60] 4) Real threat to the mother's life, such as preeclampsia or preterm premature rupture of membranes, justifies and even commends immediate delivery of the anencephalic baby.

References

1. Robert D. Creasy, Robert Resnik, Jay D. Iams, Charles Lockwood and Thomas R. Moore, *Creasy and Resnik's Maternal-Fetal Medicine*: Principles and Practice, 6th ed., (Philadelphia: Saunders

Elsevier, 2009), p. 281. For a recent paper discussing the causation of anencephaly see: Andrew J. Copp, Philip Stanier, and Nicholas D E Greene, “Neural Tube Defects-recent advances, unsolved questions and controversies” in *Lancet Neurology*, 2013 august; 12 (8) 799-810.

2. Roger Stevenson and Judith G. Hall, *Human Malformations and Related Anomalies*, 2nd ed., (New York: Oxford University Press, 2006), p. 715.
3. Allan H. Ropper and Martin A. Samuels, *Adams and Victor’s Principles of Neurology*, 9th ed., (New York: McGraw-Hill, 2009), p. 964.
4. Stevenson, *Malformations*, pp. 716-717.
5. Ropper, *Principles of Neurology*, pp. 964-65; Stevenson, *Malformations*, pp. 716-17.
6. For instance, Encephlocele and Spina Bifida. For information see Creasy, pp. 281-82.
7. Creasy, p. 281.
8. Ropper, p. 964.
9. Ropper, p. 964.
10. Creasy, p. 281.
11. Ropper, p. 965.
12. Ropper, p. 965.
13. Creasy, p. 281.
14. Ropper, p. 965.
15. Ropper, p. 965. Ropper, p. 965; Stevenson, Malformations, p. 717 says, “The natural history of anencephaly is about even divided between live births and still births.” The fact these sources give slightly different numbers is multiple but includes, 1) the difficulty in tracking fetal defects, 2) the decreasing number of these pregnancies going to term today to give numbers, and 3) the degree (or non-degree) to which theses fetal defects were ever logged properly in obstetrical records.
16. Ropper, p. 965.
17. John D. Lantos and William L. Meadow, *Neonatal Bioethics: The Moral Challenges of Medical Innovation*, (Baltimore: The Johns Hopkins University Press, 2006), p. 110; See also Peter J. Cataldo and T. Murphy Goodwin, “Early Induction of Labor,” chapter 9 in *Catholic Health Care Ethics: A Manual for Practitioners*, 2nd ed., edited by Edward J. Furton, Peter J. Cataldo, and Albert S. Moraczewski (Philadelphia: The National Catholic Bioethics Center, 2009), p. 116. For an account of a woman who described even her usually pro-life obstetrician trying to convince her to induce early, see “Difficult Moral Questions, Question 48: May a woman agree to inducing delivery of her nonviable defective baby” at http://www.twotlj.org/G-3-48.html .
18. “Moral Principles Concerning Infants with Anencephaly,” published by United States Conference of Catholic Bishops on September 19th, 1996. Available on-line at: http://www.usccb.org/issues-and-action/human-life-and-dignity/end-of-life . For a discussion of the ethics of pregnancy and impaired fetuses see chapter 10,,, pp. 631-686, “Impaired Infants and Medical Futility” in Ronald Munson, *Intervention and Reflection*: Basic Issues in Medical Ethics, 7th ed., (Belmont: Wadsworth, 2004).
19. “Moral Principles”
20. “Moral Principles”
21. The historic roots of paragraphs 2270-2274 are detailed in *The Companion to the Catechism of the Catholic Church: A Compendium of Texts Referred to in the Catechism of the Catholic Church* (San Francisco Ignatius Press, would 1994), pp. 792-796.
22. *Catechism of the Catholic Church*, p. 547.
23. The historic roots of paragraph 2270-2274 are found in *Compendium*, pp. 792-796.
24. *Catechism of the Catholic Church*, p. 548.
25. The historic roots of paragraphs 2270-2274 are found in *Compendium*, pp. 792-796.
26. *Catechism of the Catholic Church*, p. 548.
27. “Moral Principles”
28. “Moral Principles”
29. “Moral Principles”
30. “Moral Principles”

31. “Moral Principles”
32. “Moral Principles”
33. Benedict Ashley, Jean DeBlois, and Kevin D. O’Rourke, *Health Care Ethics: A Catholic Theological Analysis*, 5th ed., (Washington D.C.: Georgetown University Press, 2006), pp. 81-82.
34. On page 115, in their chapter “Early Induction of Labor” in *Catholic Health Care Ethics: A Catholic Theological Analysis*, Roman Catholic writers Peter Cataldo and T. Murphy Goodwin, representing the perspective of the National Catholic Bioethics Center, further support the same conclusions as Ashley and all. In their chapter, they write that “ . . . under no circumstances may actions be taken for the purpose of hastening the child’s death, as is argued above concerning the moral status of emotional distress. This approach to decision-making when a fetus has a lethal anomaly is the same throughout the pregnancy, both before and after the limit of newborn viability at about twenty-three weeks gestation.” Cataldo and Goodwin agree that the Roman Catholic position clearly stands against any unwarranted hastening of the child’s death.
35. Ashley, *Health Care Ethics*, pp.82-83.
36. Cataldo, p. 113.
37. Cataldo, pp.113-14.
38. Cataldo, p. 114.
39. Cataldo, p. 114.
40. Cataldo, p. 114.
41. I have been the chair of the Ethics Committee at Mercy Medical Center in Sioux City since December 2008. The Bioethics department has been unofficially charged with monitoring the activities of the OB-GYN department.
42. This author describes himself as a traditionalist Protestant Christian, the tradition of those who uphold the Apostles and Nicene Creeds, the final authority of the Scriptures, and the Solas of the Reformation including Sola Gratia (salvation by grace alone), Sola Fide (salvation through faith alone), Sola Christi (salvation through Christ alone), and Sola Scriptura (Salvation as given and described through Scripture alone). In both his education and systematic theology, the author has been highly influenced by both the Lutheran and Reformed traditions.
43. For a discussion of the Imago Dei in traditional Lutheran theology, see John Theodore Mueller, *Christian Dogmatics* (St. Louis: Concordia Publishing House, 1953), pp.205-216. For the discussion of the Imago Dei in a representative Evangelical Protestant systematic theology, see Wayne Grudem, *Systematic Theology* (Grand Rapids: Zondervan Publishing House, 1994), pp. 442-450. For an Evangelical Protestant discussion of the Image of God and how it affects Christian bioethics, see Scott B. Rae and Paul M. Cox, *Bioethics: A Christian Approach In A Pluralistic Age*, (Grand Rapids: Eerdmans Publishing House, 1999), esp. pp. 128-156.
44. Scott B. Rae and Paul M. Cox, *Bioethics: A Christian Approach in a Pluralistic Age*, (Grand Rapids: Eerdmans Publishing Co., 1999), pp. 130-131.
45. For a traditionalist/Evangelical Protestant defense of this perspective, see, Ronald J. Sider, *Completely Pro-Life*, (Downers Grove: InterVarsity Press, 1987), esp. pp. 44-51.
46. The words are those of my pro-choice aunt. For an excellent discussion of the way that secularists and liberal Protestants view the personhood (or non-personhood) of the fetus, see Bonnie Steinbock, *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses*, 2nd ed., (New York: Oxford University Press, 2006), esp. pp. 36107.
47. For Evangelical Protestant reflections on Trisomy 21 and disability, see Amos Young, *Theology and Downs Syndrome: Reimagining Disability in Late Modernity*, (Waco: Baylor University Press, 2007).
48. For some insight into Hitler’s Nazi Death Machine, its’ targets, and those who stood up against it, see Eric Metaxas, *Bonhoeffer: Pastor, Martyr, Prophet, Spy*, (Nashville: Thomas Nelson, 2010). For some insights by a professional Evangelical Christian Ethicist see, David Gushee, *Righteous Gentiles of the Holocaust: Genocide and Moral Obligation*, 2nd ed., (New York: Paragon House, 2003).
49. The potential slippery slope from deformed fetuses to Nazi-type social experiments and genocides is noted by Sider, Completely Pro-Life, pp. 50-51.
50. Rae and Cox, Bioethics, 1999, pp. 138-139. See also Donal Mathuna, “Abortion and the ‘Image

of God,'" in *Bioethics and the Future of Medicine: Toward a Christian Agenda*, ed. John F. Kilner et. al. (Grand Rapids: Wm Eerdmans, 1995), pp. 199-211 esp. p. 207; See also David Atkinson, "Some Theological Perspectives on the Human Embryo," in *Ethics and Embryos: The Warnock Report in Debate*, ed. Nigel D. S. Cameron (Edinburgh: Rutherford House Books, 1987) pp. 43-57 but especially pp.55-56.

51. Traditionalist Lutheran and Reformed Christians have been consistent in saying that the command to love one's neighbor is part of the moral law, commanded to non-Jewish inhabitants of the world before Christ, Jewish followers of God in the world before Christ, and Christians living after Christ. Other elements of the universal moral law accepted by traditionalist Christians have included the duty to promote life and avoid murder, to avoid theft and do positive labor, to avoid lying and speak truthfully, to avoid extra-marital infidelity, and promote intra-marital love and faithfulness. For an extensive discussion by Lutheran Bioethicist Gilbert Meilaender, see The *Freedom of a Christian: Grace, Vocation, and the Meaning of our Humanity* (Grand Rapids: Brazos Press, 2006), esp. chapter2. For a call for Protestants to be more aggressive in using the moral law in bioethics, see J. Daryl Charles, *Retrieving the Natural Law: A Return to Moral First Things*, (Grand Rapids:William Eerdmans, 2008).
52. For an Evangelical Protestant argument see Michael Gormon*, Abortion and The Early Church: Christian, Jewish and Pagan Attitudes in the Greco-Roman World*, (Downers Grove: InterVarsity Press, 1982). For some supportive Lutheran Protestants see, Robert C. Baker, General Ed., *Natural Law: A Lutheran Reappraisal* (St. Louis: Concordia Publishing House, 2011). In that volume, see especially Carl E. Braaten "A Lutheran Affirmation of the Natural Law," pp. 3-16 and Thomas D. Pearson, "Luther's Pragmatic Appropriation of the Natural Law Tradition," pp. 39-64.
53. For one of many accounts of a couple carrying an anencephalic baby to term with many benefits to parents and family, see Cheryl McCormack, "Everlasting Grace," in Inspired Woman Magazine, April 5th, 2012 edition. Available on-line at http://inspiredwomanonline.com/1461/everlastingrace/ .
54. Allen Verhey, *Reading the Bible in the Strange World of Medicine* (Grand Rapids: Wm. Eerdmans, 2003).
55. As noted by the Bishops in 1996 in their "Moral Principles."
56. As noted by the Bishops in 1996 in their "Moral Principles" when they say, "The phrase sole immediate effect is further explained by Directive 47 which states: 'Operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child."
57. For an example of these arguments applied to pregnancy by a traditionalist Protestant, see Gilbert Meilaender, *Bioethics: A Primer for Christians*, 2nd ed., (Grand Rapids: Eerdmans Publishing House, 2005), pp. 33-35.
58. For a Protestant defense of the use of science, medicine and physicians by Christians today, see Martin E. Marty, *Health and Medicine in the Lutheran Tradition* (New York: Crossroad, 1983), esp. pp. 82-97 and Kenneth L. Vaux, *Health and Medicine in the Reformed Tradition* (New York: Crossroad, 1984).
59. For brief discussions of prematurity see William W. Hay Ft. et. al. *Pediatrics: Current Diagnosis and Treatment*, 19th ed., (New York: McGraw-Hill, 2009). pp. 30-62.
60. The issue of whether a Protestant hospital should allow induction of anencephalic pregnancies before 26 weeks for the choice of non-Christians or Christians who choose it is a different issue which this paper did not take up.

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GREY MATTERS

Multitasking and the Neuroethics of Distraction

WILLIAM P. CHESHIRE, JR., MD

Not all those who wander are lost. – J. R. R. Tolkien[1]

Abstract

Multitasking, which requires shifting mental focus among simultaneous tasks, has become increasingly prevalent in our digitally connected culture. Whereas the clinical environment necessarily entails attending to multiple demands competing for the healthcare professional's time and attention, excessive multitasking has been shown to lead to distraction, information loss, and cognitive overload with the potential for medical error. Moral reasoning, which is essential for clinical ethics, engages brain systems that may also be susceptible to impaired performance when external streams of information intrude or interrupt. Intentionally limiting multitasking habits is important for the sake of both patient safety and medical ethics.

Introduction

One of my most beloved professors at Princeton was the inspiration for Walt Disney's 1961 movie *The Absent-Minded Professor.* The late Hubert Alyea,[2] an emeritus professor of chemistry, was known far and wide for his lecture on "Lucky Accidents, Great Discoveries, and the Prepared Mind."[3] From the first moment it was clear that this was no ordinary lecture. With sprightly exuberance, the professor began by hurriedly scribbling chemical formulae on the chalkboard, while almost-overflowing flasks bubbled and sputtered. His captivating narrative on the history of scientific discovery was punctuated with a series of well-timed colorful chemical reactions and startling though harmless explosions. Edifying stories were interspersed with the unexpected – a sudden kaboom, a flaring fireball, and, when they were least expecting it, squirts of distilled water aimed at the audience, who all the while remained in suspense, wondering whether the professor's animated expression was a reassuring smile of delight or the mischievous grin of momentary craziness.

A Mindful Absent-Mindedness

As an undergraduate I had the privilege of knowing Professor Alyea personally. He was not absent-minded in the sense of a brilliant academic whose intense focus on science causes him to forget or ignore his surroundings, including the potential flammability of the building and the safety of his audience. I have known absent-minded academics; Alyea was not one of them. On the contrary, he was a remarkably innovative educator who understood that a vapid, predictable presentation would have failed to attract the most imaginative minds into a serious study of the sciences.[4]

Alyea understood the value of surprise as an aperitif for the curiosity that motivates scientific inquiry. His entertaining spectacles were not diversions but rather invitations to marvel at nature and learn without limits. Transforming the lecture hall into a theater, he exemplified the mental playfulness that is ever open to discovery, new knowledge, and fresh insights. Even those lacking in a scientific education left with a better understanding of chemistry, while all gained an enhanced appreciation for the mental discipline and preparation needed to recognize when an unexpected phenomenon signals a conceptual breakthrough.

The Neuroscience of Novelty

The human brain is wired to detect novelty. The hippocampus, which plays a key role in the formation of new memories, does so selectively. Current theory holds that the hippocampus compares incoming sensory impressions with prior predictions, and when it detects a mismatch, it signals the substantia nigra and ventral tegmental area in the midbrain in a feedback loop that enhances memory retention.[5] The hippocampus thus responds more strongly to novel than familiar sensory impressions.[6] This model, which is supported by psychological and functional magnetic resonance imaging (fMRI) studies, provides a neurobiological basis for the conclusion that, when the brain evaluates new information, the element of surprise promotes retention of that information.[7] These studies expand on what Professor Alyea already knew through personal experience: that strategic use of novelty could enhance his students' capacity to remember his teaching.

Another important brain structure attuned to detecting discrepancies is the part of the cerebral cortex that wraps around the anterior corpus callosum deep within the frontal lobes. The anterior cingulate cortex plays a central role in diverse aspects of cognitive control, including reward anticipation, affective assessment of pain, decision-making, initiation, motivation, expression of internal emotional states, empathy, and integration of autonomic and endocrine responses.[8-11] Electroencephalographic[12] and, more recently, fMRI[11] studies have shown that the anterior cingulate cortex is activated during error detection tasks, signaling alarm[13] in response to conflict or disparity.

Through these and other neural connections, novel sensory stimuli can arrest attention, ignite passion, and engage the mind to reflect on what the brain tags as significant.

Senses Saturated

Suppose that the brain were to interpret everything as novel. Every image would seem astonishing, every sound startling, every thought enthralling, all directions dizzying, the slightest infringement distressing. Such a state would be mentally paralyzing.

There are numerous examples of brain disorders characterized by abnormally heightened sensitivity to one or more types of stimulation. During a migraine, for example, many people become exquisitely sensitive to light, sound, or certain patterned or moving visual stimuli. People with chronic neuropathic pain caused by injury to sensory neurons can develop allodynia, in which stimuli that normally are nonpainful, such as a breeze or light touch, become painful. People with paranoid personality disorder may be hypersensitive to criticism and easily insulted. People with obsessive-compulsive disorder may experience intrusive thoughts leading to great anxiety. People suffering from post-traumatic stress disorder will experience recurrent, intrusive recollections of disturbing events leading to distressing hyperarousal and vigorous activation of autonomic stress responses.

The brain might be flummoxed by sensory overload if not for sensory processing systems that selectively filter distractions by suppressing extraneous stimuli. The prefrontal cortex plays an important role in suppressing irrelevant stimuli,[14] which allows the anterior cingulate cortex to function with greater focus, intention, and purpose.

Deluge of Disruptions

If Professor Alyea were lecturing today, he would compete with a lecture hall filled with smartphones, tablets, and other digital devices, all wirelessly connecting the members of his audience live to the Internet. His students might be taking notes on their WiFi-enabled laptop computers while occasionally launching a search engine to pull up articles elaborating on the lecture material. At the same time, tiny red balloons popping up on their digital screens would alert them to incoming e-mails, instant messages, or social media posts. An easy tap of the screen or a slide of the cursor would open the window to a side conversation, an interesting image, or a viral video. After typing an emoticon in reply, the nimble-minded student would smile, look up again toward the professor, and feel a sense of self-satisfaction at having mastered the skill of multitasking.

The professor's showmanship would be no match for the colorful liquid crystal displays dancing on handheld digital devices throughout the lecture hall. His virtuoso whiz-bang performance could not compete for long with the silent explosions of popup windows and cyberspace invitations in the immediate view of his audience. With their brains in a state of constant attentiveness, the modern audience is capable of being alerted by all things while being focused on none.

A generation ago, this so-called absent-minded professor taught profound lessons made to look like distractions. Today, a digitally hyperconnected world attends instantly to so many distractions that it has become, in effect, absent-minded. Accordingly, two Cornell physicians warn of an "epidemic of distraction" brought on by overuse of personal electronic devices promoting cognitive overload.[15]

Clinical Multitasking

Multitasking, or the process of executing multiple tasks concurrently rather than sequentially, originated as a term applied to computer multiprocessors. Multitasking maximizes a computer's processing resources by overlapping and interleaving the execution of several programs.[16] Distinct from *computer* multitasking is *human* cognitive multitasking, in which a person handles more than one task at the same time. A contemporary form of this is media multitasking, which is a person's consumption of multiple media forms at the same time or in conjunction with one another.[17] Media multitasking is increasingly prevalent in modern society[18] and may foster habits of multitasking in other spheres of life, including medicine.[19]

Media multitasking may alter the structure of the brain. A voxel-based morphometry study found that individuals who engaged in more frequent media multitasking activities had smaller grey matter density in the anterior cingulate cortex.[20] The study demonstrated association, but not causation. Whether media multitasking caused the anterior cingulate cortex to shrink or whether those with smaller anterior cingulate cortices were more likely to engage in multitasking is unknown.

Although some physicians who engage in cognitive multitasking during hospital duty have self-reported better performance, albeit at the cost of greater psychological strain,[21] the weight of evidence indicates that frequent multitaskers are less able to filter out irrelevant environmental stimuli and as a result are more susceptible to making mistakes during tasks that require switching mental focus repeatedly.[22] This is because the brain is not identical to a computer. Whereas a computer's operating system can without error process multiple streams of data in parallel, the brain, with the exception of certain automatic or well-practiced behaviors such as walking, is able to focus attention on only one cognitively demanding task at a time. What may seem like multitasking in many cases involves rapidly shifting back and forth between tasks.[23] When performing multiple tasks that compete for attention and memory, performance declines.[24]

In the clinical environment, physicians and other healthcare professionals engage a complex environment with multiple competing demands on their time and attention. The structure of busy clinical workflow requires constant alertness to numerous changing details, shifting among tasks, continual reassessment of information, and dynamic reprioritization of tasks, all of which add to clinicians' cognitive load. Such multitasking is a necessary skill in the clinical workplace. Excessive multitasking, however, can add to cognitive overload and inefficiency and thereby contribute to medical error.[25,26] Frequent distractions, information loss during interruptions, and repeated task shifting have been shown to create conditions that can potentially compromise patient safety.[27]

One emergency department study found that multitasking resulted in measurable gaps in clinical information transfer.[27] Multitasking increases the frequency of interruptions, which further strain clinicians' cognitive load. Attending and resident physicians were interrupted, on average, every 9 and 15 minutes, respectively, which further contributed to breakdown of information flow.[27]

Another study, which examined the impact of interruptions on clinical task completion in the emergency department of a large teaching hospital, found that physicians were interrupted on average every 9 minutes by pagers, telephones, other patients, and other staff. Physicians failed to return to 18.5% of interrupted tasks.[28] An observational study of 200 Australian clinicians over 1000 hours found that, among 8370 tasks observed in the emergency department, there were 1269 task switches (6.0 per hour) and 1942 instances of multitasking (9.2 per hour).[29]

These studies were carried out in a paper chart environment. Electronic medical record alerts and prompts and social media messages represent potential added sources of interruption in the current clinical environment.

Interruptible clinical tasks have been divided into three broad categories, which comprise procedural, problem-solving, and decision-making tasks.[30] Categorizing the types of interruptions and affected clinical cognitive tasks may be useful in guiding the development of information systems and workflow processes that are resilient to interruptions.[30] The aim of minimizing distraction-induced medical error is in keeping with the Hippocratic principle of first doing no harm.[31]

Ethics and Multitasking

There is a further aspect to medicine that the tools of information technology, cognitive neuroscience, and systems analysis, though informative and instrumental to the design of a well-functioning healthcare system, may sometimes overlook. The moral dimension of medicine intertwines with procedural, problem-solving, and decision-making tasks, while also transcending them.

Returning to neuroanatomy, some of the same brain systems involved in sensory error detection participate also in moral reasoning. Psychologist Joshua Greene and colleagues have advanced a dual process theory in which abstract rational and intuitive emotional processes represent competing moral subsystems in the brain.[32] Using fMRI, they found that certain regions of the frontal, temporal, and parietal cortices exhibited increased activity during impersonal utilitarian judgments, whereas the medial prefrontal cortex, cingulate cortex, striatum, amygdala, and other brain regions exhibited increased activity during personal moral judgments. They theorize that ethical dilemmas in which utilitarian values clash with personal moral valuations are resolved in the dorsolateral prefrontal cortex and anterior cingulate cortex.[32] Other fMRI studies combined with studies of patients with localized brain lesions support the conclusion that the anterior cingulate cortex mediates the emotional and rational components of moral reasoning when they conflict.[33,34]

The discovery of this shared neural circuitry invites the question whether multitasking might impair not only abstract problem-solving but also the quality and depth of ethical reflection. Excessive interruptions and distracting task shifting would seem as likely to intrude on moral reasoning as on routine problem-solving and decision-making tasks. Moral reasoning might be all the more vulnerable to cognitive disruption because it takes time to think through complex moral dilemmas. Perceived time pressures from anticipated further interruptions might promote a rush to premature judgment. Further, it might be difficult to recognize when multitasking habits have contributed to errors in ethical thinking.

The cognitive tasks of weighing multiple competing principles or considering alternative perspectives are themselves a kind of internal multitasking. Thinking ethically about clinical dilemmas requires mental effort, focus, and time. Imposing additional external multitasking demands on the ethical brain might disrupt the careful thinking that is required when grappling with moral dilemmas in medicine. The clamorous intrusion of external stimuli may also compete with the occasional welcome interruption by the quiet, internal voice of conscience.[35]

Conclusion

A culture of multitasking, in which the attention of the digitally hyperconnected is so scattered as to verge on absent-mindedness, may have limited capacity to think deeply about crucial human problems, whether in science, medicine, or ethics. Paradoxically, in the absence of adequate thought or insightful reflection, having access to more information might lead to wrong answers.

Professor Alyea was fond of citing Louis Pasteur, who famously remarked in 1854 that, "Chance favors only the prepared mind."[36] In a culture of multitasking, mental preparation is needed to guard against cognitive exhaustion and philosophical and spiritual depletion. The hyperconnected must occasionally disconnect from noise in order to reconnect with life, to find meaning, and to strive with purpose. Online enthusiasts must occasionally unplug from chats with avatars to converse with people. From time to time the digitally pummelled must pause and make time to reflect, to focus intentionally, and to think through problems prospectively in order to have a ready plan once time pressures return.

Only by keeping a healthy distance from the mob of distractions can one cultivate a truly interruptible mind receptive to ideas and perspectives one might not have otherwise considered.

References

1. Tolkien JRR. *The Fellowship of the Ring* (1954). New York: Ballantine Books, 2012, p. 193.
2. Princeton University press release. Hubert Alyea, innovator in science teaching, dies at 93, October 22, 1996. Accessed at: http://www.princeton.edu/pr/news/96/q4/1022alye.html
3. Princeton University Archives. Accessed at: http://www.youtube.com/watch?v=jSw7cHfxbu8
4. Thean T. The science teacher you wish you had. Life.com. Accessed at: http://life.time.com/culture/hubert-alyea-the-science-teacher-you-wish-you-had/#1
5. Kumaran D, Maguire EA. Which computational mechanisms operate in the hippocampus during novelty detection? *Hippocampus* 2007; 17: 735-748.
6. Kumaran D, Maguire EA. Novelty signals: a window into hippocampal information processing. *Trends Cogn Sci* 2009; 13: 47-54.
7. Fenker D, Schütze H. Learning by surprise. *Scientific American* 2008 December 17. Accessed at: http://www.scientificamerican.com/article/learning-by-surprise/
8. Devinsky O, Morrell MJ, Vogt BA. Contributions of anterior cingulate cortex to behaviour. *Brain* 1995; 118: 279-306.
9. Shenhav A, Botvinick MM, Cohen JD. The expected value of control: an integrative theory of anterior cingulate cortex function. *Neuron* 2013; 79: 217-240.
10. Fuchs PN, Peng YB, Boyette-Davis JA, Uhelski ML. The anterior cinculate cortex and pain processing. *Front Integr Neurosci* 2014; 8: 35.
11. Shirtcliff EA, Vitacco MJ, Graf AR, et al. Neurobiology of empathy and callousness: implications for the development of antisocial behavior. *Behav Sci Law* 2009; 27: 137-171.
12. Bush G, Luu P, Posner MI. Cognitive and emotional influences in anterior cingulate cortex. *Trends Cogn Sci* 2000; 4: 215-222.
13. Eisenberger NL, Lieberman MD. Why rejection hurts: a common neural alarm system for physical and social pain. *Trends Cogn Sci* 2004; 8: 294-300.
14. Barbas H.. Zikopoulos B. The prefrontal cortex and flexible behavior. *Neuroscientist* 2007; 13: 532-545.
15. Weksler ME, Weksler BB. The epidemic of distraction. *Gerontology* 2012; 58: 385-390.
16. http://www.britannica.com/EBchecked/topic/397270/multitasking
17. Lin L. Breadth-based versus focused cognitive control in media multitasking behaviors. *PNAS* 2009; 106: 15521-15522.
18. Pew Research Internet Project. Mobile technology fact sheet, 2014. Accessed at: http://www.pewinternet.org/fact-sheets/mobile-technology-fact-sheet/
19. de Ruiter HP, Demma JM. Nursing: the skill and art of being in a society of multitasking. *Creat*

Nurs 2011; 17: 25-29.

20. Loh KK, Kanai R. Higher media multi-tasking activity is associated with smaller gray-matter density in the anterior cingulate cortex. *PLoS One* 2014; 9: e106698.
21. Weigl M, Müller A, Sevdalis N, Angerer P. Relationships of multitasking, physicians' strain, and performance: an observational study in ward physicians. *J Patient Saf* 2013; 9: 18-23.
22. Ophir E, Nass C, Wagner AD. Cognitive control in media multitaskers. *PNAS* 2009; 106: 15583-15587.
23. Hamilton J. Think you're multitasking? Think again. National Public Radio, October 2, 2008. Accessed at: http://www.npr.org/templates/story/story.php?storyId=95256794
24. Yoo SS, Paralkar G, Panych LP. Neural substrates associated with the concurrent performance of dual working memory tasks. *Int J Neurosci* 2004; 114: 613-631.
25. Westbrook JI, Woods A, Rob MI, et al. Association of interruptions with an increased risk and severity of medication administration errors. *Arch Intern Med* 2010; 170: 683-690.
26. Flynn EA, Barker KN, Gibson JT, et al. Impact of interruptions and distractions on dispensing errors in an ambulatory care pharmacy. *Am J Health Sys Pharm* 1999; 56: 1319-1325.
27. Laxmisan A, Hakimzada F, Sayan OR, et al. The multitasking clinician: decision-making and cognitive demand during and after team handoffs in emergency care. *Int J Med Inform* 2007; 76: 801-811.
28. Westbrook JI, Colera E, Dunsmuir WT, et al. The impact of interruptions on clinical task completion. *Qual Saf Health Care* 2010; 19: 284-289.
29. Walter SR, Li L, Dunsmuir WT, Westbrook JI. Managing competing demands through task-switching and multitasking: a multi-setting observational study of 200 clinicians over 1000 hours. *BMJ Qual Saf* 2014 23: 231-241.
30. Li SY, Magrabi F, Colera E. A systematic review of the psychological literature on interruption and its patient safety implications. *J Am Med Inform Assoc* 2012; 19: 6-12.
31. Hippocrates, *Epidemics*. Book I, Section XI.
32. Greene JD, Nystrom LE, Engell AD, et al. The neural bases of cognitive conflict and control in moral judgment. *Neuron* 2004; 44: 289-400.
33. Moll J, de Oliveira-Souza R, Eslinger PJ. Morals and the human brain: a working model. *Neuroreport* 2003; 14: 299-305.
34. Fumagalli M, Priori A. Functional and clinical neuroanatomy of morality. *Brain* 2012; 135: 2006-2021.
35. Cheshire WP. When conscience meddles with ethics. *Ethics & Medicine* 2011; 27(3): 139-145.
36. Pasteur L. "Dans les champs de l'observation le hasard ne favorise que les esprits préparés." Cited by Vallery-Radot R, *The Life of Pasteur*, translated from the French by R. L. Devonshire. Garden City, NY: Garden City Publishing Co., 1926, p. 76.

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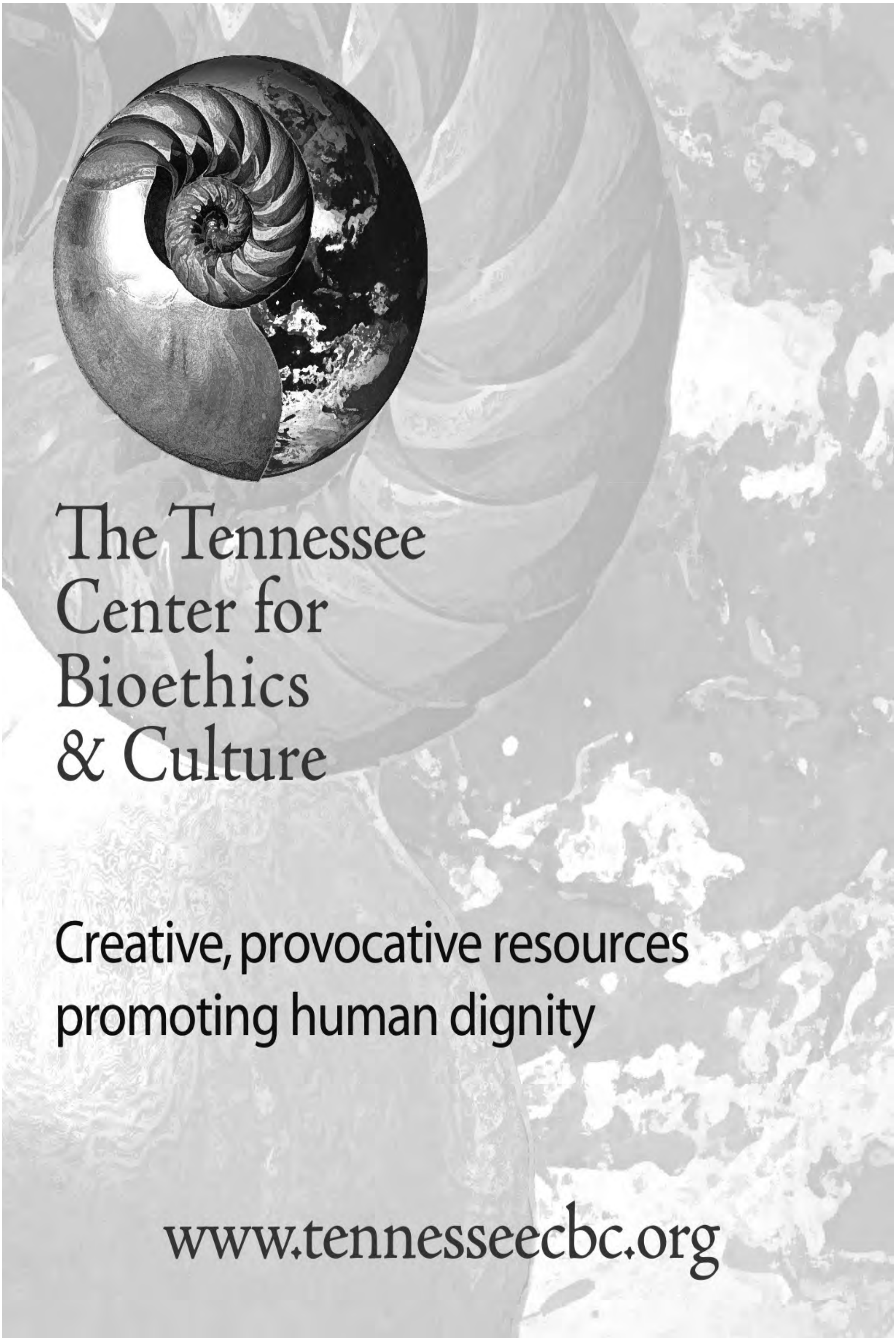

CLINICAL ETHICS DILEMMA

Choosing Birth or Death – before Birth

ROBERT D. ORR, MD, CM

Editor's note: *This column presents a problematic case – one that poses a medical-ethical dilemma for patients, families, and healthcare professionals. As this case is based on a real situation, identifying features and facts have been altered in the scenario to preserve anonymity and to conform to professional medical regulations. In this case the family is required to make a difficult decision regarding their unborn child.*

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Question

What are the ethically permissible therapeutic options for this pregnant woman who is carrying a fetus that cannot survive? [The ethic consult has been requested by the staff at the High-Risk Obstetrics Clinic.]

Case Presentation

This 28-year-old woman has 2 healthy children and is now at 14 weeks gestation in a wanted pregnancy. Two weeks ago, an ultrasound showed oligohydramnios (diminished amount of amniotic fluid). She has subsequently had 3 Emergency Room visits because of bleeding. Today she was seen in the High Risk OB Clinic and repeat ultrasound shows complete absence of amniotic fluid but persistent fetal heartbeat. It is presumed that she has had premature rupture of the membranes, which was not clinically recognized because of the small amount of fluid and bleeding. Two high-risk OB specialists agree that this pregnancy has zero chance of continuing to the point of viability.

Three management options are under discussion: (a) observation, awaiting spontaneous abortion; (b) medical termination of pregnancy using misoprostol and a prostaglandin to induce labor; or (c) surgical termination of pregnancy by dilatation and extraction (D&E).

The clinic team recommends against option (a) because of a high risk of maternal infection. They point out that option (b) at 14 weeks gestation carries with it some maternal risk (including failed induction requiring subsequent D&E, incomplete abortion requiring D&C, and even a small risk of uterine rupture) and significant maternal burden (unpredictable duration of labor, cramps, and diarrhea). Option (c) is felt to be the safest for the mother, but it involves fetal destruction.

The ethics consultant spoke with the patient and her husband. They were appropriately grieving, and asked if it would be possible to restore the amniotic fluid in order to continue the pregnancy. When they were again informed that this was not clinically feasible, they thoughtfully contemplated options (b) and (c), considering the pros and cons of each.

Discussion

When it is clear that an early pregnancy cannot survive, the professional's obligation to the woman takes precedence over obligations to the non-viable fetus, though the latter do not become zero. When it has been decided to terminate pregnancy, in almost all circumstances it is ethically preferable to use a non-destructive procedure if there is a living fetus. However, when non-destructive means involve significant risks or burdens to the woman, it may be ethically permissible to consider a destructive procedure as long as the presumed ability of the fetus to feel pain is addressed.

In this case, the risks and burdens to the mother of a medical abortion are significant. While a non-destructive method of terminating the pregnancy would be ethically preferable from a fetal perspective, the choice to use a surgical method that involves fetal destruction is not ethically impermissible from a maternal perspective.

Recommendations

1. It is ethically permissible to terminate this pregnancy even though the fetus is still alive since he or she cannot survive and continuing the pregnancy would place the mother at significant risk.
2. Termination of this pregnancy using a non-destructive method would be ethically preferable from a fetal perspective.
3. Since medical termination places the patient at some risk and burden, it is not ethically impermissible for her to choose a destructive method as long as measures are taken to ensure the fetus is non-sensate during the procedure.

Comment and Follow-up

Though the ethics consultant felt that option (b) was the moral high-ground, he also felt that maternal discretion should prevail between options (b) and (c). The patent and her husband requested the surgical D&E and it was performed the following day without complication.

Editor's Comment

Medical procedures that destroy life seem unnatural and morally wrong. Unfortunately, sometimes a decision of this magnitude must be made. Often, there is no way to avoid the pain that is associated with such a difficult choice.

References

Hauerwas, Stanley. *God, Medicine, and Suffering.* Grand Rapids: William B. Eerdmans Publishing, 1990.

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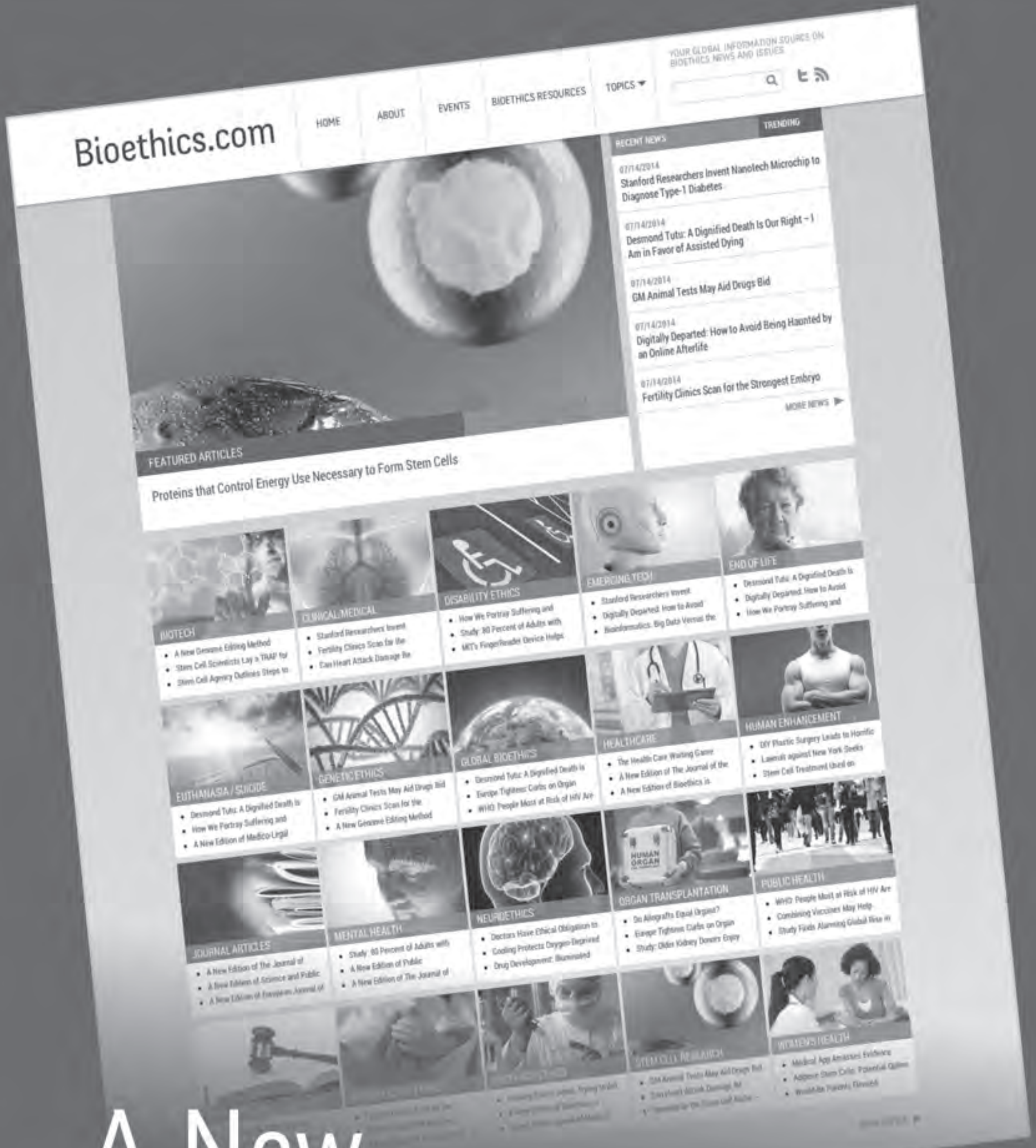

HUMAN ORGAN

EUTHANASIA AND THE EXPERIENCES OF THE YORUBA PEOPLE OF NIGERIA

ABORISADE OLASUNKANMI

Abstract

This work set out to examine euthanasia and the experience of the Yoruba people of Nigeria. Euthanasia is a death that results from the intention of one person to kill another person, using the most gentle and painless means possible, for the best interests of the person who dies. In the course of this work, we discovered that legalization of euthanasia has taken place in some countries, while other countries refuse to legalize it. No known parts of Africa have attempted to legalize euthanasia except the Yoruba people in Nigeria. Their custom practice, which is similar to western euthanasia, is the reason this work has set out: to interrogate the type of euthanasia going on in Yoruba Nigeria. We discovered that the Yoruba conception of euthanasia failed to meet western criteria of euthanasia, which required the presence of a physician, the presence of a patient, a clinical setting, and informed or proxy consent on the part of the patient. We then concluded that any attempt to legalize euthanasia in Yoruba (Nigeria) is an attempt to kill an innocent person. We then admonished the Nigerian government to maintain a body of laws consistent with respect for the dignity and worth of every human being.

Key words: Africa, Country, Euthanasia, Interrogate, Legalization, Motivation, Parliament

Introduction

Etymologically, euthanasia comes from two Greek words, *eu* and *thanatos*, literally meaning “easy or gentle death” (Wood, 1968:210). It refers to the practice of intentionally ending a life in order to relieve pain and suffering. This occurs when someone is considered incurably or distressfully sick and his/her life is terminated through a scientifically approved, painless method in order to put an end to the suffering. This may not be on the basis of the victim’s consent (Wood, 1968:210). Francis Bacon in the 17th century described euthanasia as an easy, painless, happy death, during which it was a “physician’s responsibility to alleviate the physical sufferings; of the body” (*Francis Bacon* 2008). While the British House of Lords Select Committee on Medical Ethics defines euthanasia as “a deliberate intervention undertaken with the express intention of ending a life, to relieve intractable suffering” (Harris, NM. 2001). According to Saunders (1994), euthanasia is the act of taking the life, out of mercy, of a person who is hopelessly ill.

Euthanasia is divided into two kinds, namely passive and active. Passive euthanasia is allowing a patient to die when he or she could have been kept alive by the appropriate medical procedures (Vere, 1997); for example, withholding of common treatments, such as antibiotics, necessary for the continuance of life (Harris, NM. Oct 2001). Active euthanasia entails the use of lethal substance or forces – such as administering a lethal injection – as a direct action to end a life. According to Caddell and Newton (1995), active euthanasia can be defined as any treatment initiated by a physician with the intent of hastening the death of another human being who is terminally ill and in severe pain or distress with the motive of relieving that person from great suffering.

Further distinction is made between voluntary, involuntary, and non-voluntary euthanasia. Voluntary euthanasia is conducted with the consent of the patient. This takes place when the physicians' decision to terminate life corresponds with the patient's desire to do so, and the patient willfully consents to its implementation. Involuntary euthanasia is conducted against the will of the patient. It occurs when the decision to end life is implemented against the patient's wishes (Gillett, 1994). Non-voluntary euthanasia is conducted when the consent of the patient is unavailable. It refers to cases involving patients who are unable to make their wishes known; for example, a person who is brain dead and in a vegetative or irreversible coma (Gillett, 1994).

Legalization of Euthanasia

The issues surrounding the legalization of euthanasia and physician-assisted suicide are preoccupying legislators, the judiciary, health care practitioners, legal scholars, ethicists, and the general public to an ever-increasing degree around the world. Those who are against euthanasia argue for the sanctity of life, while proponents of euthanasia rights emphasize self-determination, alleviating suffering, and personal autonomy (John Griffiths et el 1998). As of 2002, euthanasia is only legal in the Netherlands (2002), Belgium (2002), and Luxembourg (2008). Assisted suicide is legal in Switzerland, Germany, Albania, Japan, and in the US states of Washington, Oregon, Vermont, and Montana. In the Northern Territory of Australia it was legalized in 1995 and overturned in 1997 owing mainly to pressure from religious groups. In Colombia the status is still unclear; it was approved by the Constitutional Court in 1997 but never ratified by Congress. Euthanasia is decriminalized in Mexico, Thailand, Estonia, and the US State of California. Different arguments have been put forward about the acceptability of active and passive euthanasia in different parts of the world, but this work is focusing on the experience of the Yoruba people in Nigeria. In this work we examine the acceptability of euthanasia among the Yoruba of Nigeria, based on their culture and their ways of life.

Euthanasia and Yoruba Nigeria

In Nigeria, "Yoruba" refers to a group of cultures linked by a common language. The Yoruba are a group that inhabits the southwestern part of Nigeria – bounded by the Niger River – the eastern parts of Benin Republic (formerly Dahomey), and the western part of Togo. Euthanasia among the Yoruba is not a major concern. To the Yoruba, the potential for modern medical technology to extend human lives far beyond what they were in the past is not a fundamental right for anyone, but rather a *prima facie* obligation, because a case can only be treated as special in its own right. This means that the moral rightness or wrongness of euthanasia is determined by the circumstances that surround each case (Mawere 2009, 109). There are cases among the Yoruba that warrant euthanasia and there are others that may not warrant euthanasia. That is exactly what I want to discourse here.

Among the Yoruba, any act of euthanasia is tantamount to suicide. Death is the inevitable lot of every person who comes into the world, but according to the Yoruba, it is worst when a person commits suicide. In the Yoruba culture, there is no fitting funeral ceremony for someone who commits suicide, even at an old age. No one is allowed to cry or weep publicly for such a person. There is no cooking or drinking. Finally, cleansing ceremonies are performed by the deceased's family so that such an evil will not happen again. The elders would offer sacrifices for peace in the land and for the extinction of such suicidal thoughts from the land. Suicide is seen as the most evil thing a person can do. It is referred to as an abomination and as a sin against the earth. For the Yoruba, suicide is not accepted in any form and at any age as a solution to any problem regardless of the complexities of life. This is anchored on the resilient character of the Yoruba paradigm. According to Elebuibon, a Yoruba icon, "Yoruba do not support suicide. Their belief is that if somebody commits suicide, they will be punished in the hereafter. They also believe that suicides would not be allowed passage into heaven rather, their souls would just be wandering until their naturally appointed time comes" (Falade, 2013). This punishment also involves not being able to be reincarnated, another aspect of the Yoruba faith.

In African communities, the family inheritance is highly placed; there is no African man that does not have inheritance. Now, a situation where euthanasia is defined as the painless killing of a patient suffering from an incurable and painful disease or an irreversible coma may lead to counterexamples. The motives for killing a person suffering from an incurable disease may involve personal gain; such as to claim an inheritance. This would constitute murder rather than euthanasia. It is common in this part of the world for some overzealous individual to eliminate even an able body because of an inheritance. Because of the laxity of the law in Nigeria, in a situation where a family has a comatose individual as a joint heir to an inheritance, the patient may be eliminated by the evil ones in the family who claim that euthanasia is legalized and therefore the patient should not be allow to live.

Another area of contention is the decision for the patient to be euthanized. A Yoruba man believes given consent is required for anything done to him. A medical man may not treat or operate on a human being without his consent. It makes no difference if the person needs treatment or will die if he does not get it. If the consent has not been obtained, it is no defense that the operation was skillfully performed and saved the patient life. If the patient is unconscious and needs immediate treatment, it could be done, but if the husband or wife is present, his or her consent may be necessary. But in the case of legalized euthanasia, the consent of the people concerned may not necessarily be needed. In such a case no choice would be given to the patient himself. Nobody knows what he would prefer, but the decision is made for him because the law says so, and his life will be taken away.

This is, however, totally against what the Yoruba believe. It would be contrary to any legal system which purports to protect and enforce a just social order to legalize a killing justified by the belief that certain lives lack worth. Why? Justice in society itself requires a non-arbitrary and non-discriminatory way of identifying those who are the subjects of justice. But the only way to avoid arbitrariness in identifying the subjects of justice is to assume that all human beings, simply by virtue of being human, are entitled to just treatment and certain basic human rights. In other words, the basic human dignity and worth which are recognized in respecting human rights must be seen as attached to our humanity. Basic dignity and worth would not, however, entail just treatment if human beings were thought capable of losing them. They are, so to speak, ineliminable features of our humanity.

However, the interesting aspect of this issue is that some provisions of the Criminal Code in Nigeria do not speak in favour of euthanasia. Odunsi, for instance, cites Section 308 of the Code to indicate that involuntary euthanasia is unlawful. It says: "Except as hereinafter set forth, any person who causes the death of another directly or indirectly, by means of whatever, is deemed to have killed that other person" (Cited by S.B. Odunsi 2001). This shows that euthanasia is likened to homicide. Also, Sections 299 and 326 of the Criminal Code confirm that it is an act of criminality for someone to consent to an act that will cause or lead to his own death, and that it is illegal for any person to procure another to kill himself, counsel another to kill himself, and to aid another in killing himself. Any person found or caught in any of these is guilty of felony and is liable to imprisonment for life (Cited by S.B. Odunsi 2001). This implies that euthanasia, whether voluntary, involuntary, active, or passive, is illegal and thus punishable under the Criminal Code and related laws in Nigeria.

The Yoruba are highly religious; everything they do is embedded in religion. Be it traditional African religion, Christianity, or Islam, the Yoruba participate very effectively and live by their religious ethics. The three known religions among the Yoruba attach a unique and continuing moral and spiritual significance to individual persons. This has been instilled in their lives and daily activities. Since the world is God's creation, each of the elements that make it up has an appropriate value and a corresponding ethical status. That is the reason the three religions agree on the point that suicide is bad, and that euthanasia is just one variation of suicide. In traditional African religion, suicide is a taboo; the victims are not given full funeral rites because they have offended gods and humanity. So also, most Christians are united in their opposition to assisted suicide and voluntary euthanasia (Gill, 1998). Some church leaders suggest that to accept that one is not going to get well and therefore to request help to die is an act of faithless misery, a decree of hopelessness, and, as such, an offence against two of the central theological qualities, faith and hope (Vere, 1997). The Muslims also made a declaration that euthanasia is impermissible under any circumstances. Some leading Islamic jurists have likened euthanasia to murder and therefore concluded that the practice is *Haram*. Al-Qaradawi, for instance, issued a *fatwah* equating euthanasia with murder (Yusuf Al-Qaradawi 2009). The top jurisprudential authority of Saudi Arabia under its grand *mufti*, Shaikh Abdul-Aziz bin Abdullah bin Baz, also declared it un-Islamic for anybody to decide the death of a person before he is actually dead. Islamic jurists also unanimously declared as futile the efforts of some doctors to keep the patient in a vegetative state by artificial methods when it had been scientifically proven that life could not be restored (K.Aramesh & H. Shadi, 2007). The Islamic Code of Medical Ethics issued by the First International Conference on Islamic Medicine equates euthanasia with suicide, concluding that:

> Mercy killing like suicide finds no support except in the atheistic way of thinking that believes that our life on this earth is followed by void. The claim of killing for painful hopeless illness is also refuted, for there is no human pain that cannot be largely conquered by medication or by suitable neurosurgery (Kuwait, 1981).

However, when it comes to the issue of autonomy and right, the Yoruba allow individuals to make choices which, in most cases, fall into the area of euthanasia. But the Yoruba's conception of euthanasia, when critically examined, does not meet western criteria because it fails to involve all three parties: the dying patient, the family of the dying patient, and the doctor who is to carry out the action. The dying patient, out of distress, may use his initiative to voluntarily request a doctor to terminate his life. This type of euthanasia is regarded as voluntary euthanasia. Euthanasia becomes involuntary when it is carried out without the consent of the patient but with the knowledge of the patient's relative, who becomes disturbed by the patient's pain and distress and so asks the doctor to terminate the patient's life. In the case of the doctor taking charge, he may choose to terminate the life of the dying patient by prescribing an overdose of painkillers – active euthanasia – or by withdrawing certain treatment or switching off the patient's life support machine – passive euthanasia. The Yoruba type of euthanasia lacks the three parties put together, and may not even be carried out under clinical settings. For example, the Yoruba concept of euthanasia "is captured in the idea of Ikuyajesin (which means death is preferable to loss of dignity)" (Lare-Abass 2010), leading to the tendency to believe that death is more honourable than protracted pain and suffering due to chronic illness (Bambose, 2004). Suicide has been reflected in the Yoruba's thought as *iku ya j'esin* (death is preferable to shame, dishonor and indignity). According to Lare-Abass (2010), the consideration of dignity played a significant role in the choice of suicide by the individual concerned. That an individual chooses death (*iku*) means he or she considered it to be a better option than shame (*esin*). The desire to preserve personal dignity in the face of impending shame is a major factor that moves some individuals to commit suicide. Here, death (*iku*) is conceived as a better option than shame (*esin*). Death is preferable due to the harrowing circumstances of life in which the individual concerned did not wish to compromise his honour, or in which he discovered that he is approaching public ridicule. Mazrui (1965) explained further the Yoruba rationale for suicide when he wrote, "suicide becomes respectable when the life which it ends had at once aspired to great heights and is now descended to such depths." Lanre-Abass (2010) avers that such a life, in essence, lacks quality and value, devoid of the features of a good life and thus not worth living. John Broome (2006) explains that when we say that a life is worth living, we are referring to the life's personal value and not its general value. The Yoruba describe such a life as worth living: a*ye alaafia, irorun ati idera* (a healthy life devoid of pain and suffering) and not a life that is generally better not lived than lived (*aye inira, irora ati aini alaafia*).

Also, thoughts of euthanasia do take place amongst the Yoruba if the patient is schizophrenic (an example of mental disorder). In the words of Gbadegesin:

> In some cases, (mercy?) killing is excused when it is determined that the individual is not only suffering pain, but that the illness is also affecting his/her mental functioning. For instance, in some cases, an infirm old man or woman may become schizophrenic and may start uttering incoherent statements which may cause embarrassment to the family. In such a case, the family may take a painful decision to end her life before an irreparable harm is done to them (Gbadegesin, S. 1993: 259).

This is a common occurrence among the Yoruba and they dare not joke with it, lest the name of the family concerned be smeared forever. This example clearly exposes the attitude of the Yoruba to mercy killing as evaluated in light of their idea of personhood. It shows that the rightness and wrongness of mercy killing is dependent on the case of an illness leading to loss of personhood.

There are some other tragic issues that do demand euthanasia among the Yoruba, such as the issue of defective newborns – children born with blindness, deafness, and extremely low intelligence – that must have all their needs taken care of by others. The Yoruba think that life is meaningless to such children, and that they should be allowed to forego such lives. Many homes do try to keep this set of persons alive with the hope that miracles may happen and change may come, but that is only possible in homes where the means are available. In a home where poverty is highly manifested, attempts to prolong the lives of a defective newborn will not succeed. Beside this, the child would bring shame to such homes, as the Yoruba are experts in tag making before the family concerned knows what is going on. The family would have been quickly tagged with a name associated with that child, and if care is not taken such a shameful name may remain permanent.

Furthermore, dignity of a person may be more important than the need to preserve life, especially when all measure to prevent suffering has failed. At that point, each competent person has a right to decide for himself or herself that his or her life should end. For the Yoruba, when it comes to the issue of autonomy and competence as regards deciding on suicide, they would metaphorically claim that *bose wuni lase imole eni* (one determines one's faith the way one deems fit). This understanding of life creates room for suicide. The desire (which sometimes borders on duty) to preserve personal and family honor in the face of impending ignominy has been the major factor that moved many individuals to seek euthanasia. Far from being 'victims,' they made the most of disadvantageous situations and turned circumstances around to earn themselves sympathy in death instead of the original ridicule that would have been their lot.

Another crucial point in this theory is the collectivity of honor. This applies to social groups such as families, lineages, and kin groups. Within such groups, an act of dishonor by a single member will affect all others, just as a single member could bask in the honor of the group. Thus, where status is ascribed by birth, 'honor derives not only from individual reputation but from antecedence' (Rivers, 1973). Mbiti (1970) has classically proverbialized the community-determined role of the individual when he wrote, "I am because we are and since we are, therefore I am." The community, according to Pantaleon (1994), therefore gives the individual his existence and education. That existence is not only meaningful, but also possible only in a community. Thus, in the Yoruba land, no one can stand in isolation, for all are members of a community; to be is to belong, and when one ceases to belong, the path towards annihilation is opened wide. According to Azeez (2005), "When the sense of belonging is lost, mutual trust betrayed, we-feeling is destroyed and kinship bond broken, then the individual sees no meaning in living." In the Yoruba society, everybody is somebody; everyone has commitment towards the other, and shares in the experience of the other. The community gives each person belongingness and cultural identity for self-fulfillment and social security. The fear of tarnishing collective honor can cause an individual – who found himself or herself at a cross road or any incurable disease (schizophrenic or epileptics) that may tarnish the collective honor – to commit suicide to save the community from disgrace. Whatever the case, it makes sense to assume that in societies where honor is highly prized, people would be afraid of conduct that is dishonorable.

Conclusion

In this work we have looked into euthanasia from the western conception, its legalization by many counties in the world, and the Yoruba conception of euthanasia. In our research we discovered that there are similarities between the Yoruba conception and the western conception of euthanasia, but these similarities alone cannot justifying categorizing certain cases as cases of euthanasia, because the Yoruba conception of euthanasia fails to meet with the western criteria of euthanasia – criteria which require the presence of a physician, the presence of a patient, a clinical setting, and informed or proxy consent on the part of the patient. The Yoruba concept of euthanasia is one of the reasons euthanasia should not be legalized in this part of the world, because what the Yoruba have been doing is killing for killing's sake, which cannot be legalized. Therefore, any attempt to legalize euthanasia in Nigeria is like killing an innocent person. It is the fundamental task of civil authority in Africa to protect the innocent, but if the claim that a person lacks a worthwhile life is held to make killing lawful, then the state has ceased to recognize the innocent as having binding claims to protection. Therefore, it is of critical importance to every state to maintain a body of laws consistent with respect for the dignity and worth of every human being.

References

Azeez, B. (2005). Belongingness as a solution to the problem of suicide in Africa. In G. Ukagba (Ed.). *Father Kpim: Philosophy and theology of Pantaleon Iroegbu* (pp. 253-261). Ibadan: Hope.

Bacon, Francis and Brian Vickers (Editor). *Francis Bacon: The Major Works*. Oxford University Press: 2008. Paperback, 864 pages, Language English, ISBN: 0199540799.

Caddell, D.P., & Newton, R.R. (1995). Euthanasia: American attitudes toward the physician's role. *Social Science and Medicine, 40(12*), 1671-1681.

Cited by S.B. Odunsi, (2001). "Euthanasia Under Nigerian Law - A Call for Change"; *Nigerian Law and Practice Journal*, vol. 5, No. I; Council of Legal Education, Nigeria Law School. p.63.

Falade, Kayode. (May 11, 2013). Yoruba culture abhors suicide. *National Mirror*.

Gillett, G. (1994). Letting die. *Journal of Christian medical fellowship, 40.1(157*), 20-24.

Gill, R. (1998). *Euthanasia and the churches*. London: Biddles Ltd.

Gbadegesin, S. 1993. Bioethics and culture: an African perspective. Bioethics ; 7 (2-3): 257.

Harris, NM. (Oct 2001). "The euthanasia debate". *J R Army Med Corps* **147** (3): 367–70

John Griffiths, Alex Bood, Heleen Weyers – (1998) Euthanasia and Law in the Netherlands

K. Aramesh & H. Shadi (2007) "Euthanasia: An Islamic Ethical Perspective" *Iranian Journal of Allergy, Asthma and Immunology*, vol. 6, Suppl. 5, (February). pp. 35- 38.

Kuwait, (1981) Islamic Organization of Medical Sciences, *"The Islamic Code of Medical Ethics endorsed by the First International Conference on Islamic Medicine;"*. p. 65.

Lanre-Abass, Bolatito Asiata 2010, Suicide and Human Dignity: An Africa Perspective. In *Humanity and Social Sciences Journal* 5(1) 50-62.

Mazrui, A. (1965). Sacred suicide. *Transition 21.* 28-36

Mawere, M. 2009. "The Shona Conception of Euthanasia: A Quest to Depart from Zimbabwe Tradition". *Journal of Pan African Studies*, Vol.3 No.4, December 2009, pp.101-116.

Mbiti, J.S. *African Religions And Philosophy.* London: Heinemann, 1980.

Pantaleon, I. (1994). *Metaphysics: The Kpim of Philosophy.* Owerri: IUP

Rivers, 1973 "Honour and Social Status", 27; Hatch, "Theories of Social Honour", 23.

Saunders, P. (1994). Abortion. *Journal of the Christian medical fellowship, 40.4(160)*, 12-17.

See http://www.islamonline.net for the question and answer on euthanasia as responded to by Yusuf Al-Qaradawi. (Accessed on 25th May 2009).

Vere, D. (1997). Euthanasia: death, dying and the medical duty. *Journal of Christian medical fellowship. (April*), 12-17.

Wood, Thomas. (1968). "Sacredness of Life." *A New Dictionary of Christian Ethics*,1968 ed., 210.

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The Sociocultural and Ethical Issues behind the Decision for Artificial Hydration in a Young Palliative Patient with Recurrent Intestinal Obstruction

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Summary

The decision to employ artificial hydration (AH) at the end of life is a complex process that must necessarily be made upon holistic consideration of a particular patient's situation. To highlight the complex interplay of ethical, clinical, practical, and psychosocial considerations behind such a decision, we discuss the decision-making process behind the determination to commence AH for a young 24-year-old Chinese woman with progressive metastatic ovarian adenocarcinoma who maintained a good functional status despite recurrent episodes of intestinal obstructions.

Background

The employ of Artificial Hydration (AH) and Artificial Nutrition (AN) amongst palliative care patients remains controversial in light of poor empirical evidence to suggest symptomatic and survival benefit for patients with advanced disease and limited prognoses.[1-3]

The current evidence suggests that AN should only be offered to patients who maintain a good functional status despite advanced disease causing malignant bowel obstruction. In these patients, AN serves as a life-prolonging intervention as well as improvement of quality of life.[4-8] Complication rates are also low and are usually perceived by patients and family members to be beneficial.[9]

However, AH alone without AN for this group of patients has not been supported in any studies or case reports. Thus, the decision about the use of AH alone in young palliative patients who continue to have a good functional status must rely on appropriate balancing of regnant ethical, legal, professional, and social issues, as well as the patient's personal, clinical, practical, familial, cultural, and spiritual considerations.

This case report will illustrate the difficulties faced in implementing AH but not AN in a young cancer patient who maintained a good performance status, despite suffering from recurrent episodes of bowel obstruction due to an underlying diagnosis of ovarian cancer, and subsequently chose to have only AH but not AN upon discharge.

Case Presentation

Miss Adeline was a 24-year-old Chinese woman who was diagnosed with ovarian cancer four years ago after presenting with a 2-week history of per-rectal bleeding.

Computer tomography (CT) at that time showed a large 12 cm by 10 cm by 12 cm mixed solid and cystic mass in the pelvis that was suspicious of ovarian malignancy.

The findings at laparotomy confirmed that Adeline did not suffer from any distant metastasis and she underwent a debulking procedure and subsequent adjuvant chemotherapy. Adeline enjoyed a clinically uneventful 3 years following this procedure and completed her university education.

Adeline had just begun working in a Human Resource department for 3 months when she presented with intestinal obstruction due to an intra-abdominal recurrence of the cancer. Over the subsequent 2 years Adeline underwent 2 further laparotomies as a result of 3 episodes of intestinal obstruction.

Her latest presentation also resulted from intestinal obstruction and this time she was deemed unsuitable for further surgical intervention, partly as a result of the speed of the recurrences and partly as a result of Adeline's wishes. Adeline was thus kept nil-by-mouth and started on intravenous hydration. Her pain was symptomatically treated with Fentanyl, which was titrated up to a dose of 75 micrograms/hour, and her vomiting was managed with the insertion of a naso-gastric tube (NGT).

Although the NGT was subsequently removed after a week with no recurrence of her vomiting, Adeline was only able to tolerate a few sips of water. As a result, intravenous artificial hydration was maintained via a peripherally inserted central catheter (PICC), which allowed Adeline to receive about 1.5 litres of Dextrose Saline per day.

Total parenteral nutrition (TPN) was offered to the patient in view of her maintained functional status and age. However, the patient declined in view of the burden of having TPN infusions at home with regular venesection for monitoring of electrolytes and lipid levels, as well as the higher costs involved compared to AH alone.

In light of her well-maintained functional status, her ability to care for herself, and her family's support of her decision to go home, Adeline requested to be discharged from hospital. This decision raised questions about the benefit of the continual administration of AH when the patient had declined TPN, as well as the practical and financial concerns that accompany such a decision.

Adeline believed that her elder sister, her younger brother, and her mother would be able to care for her. Her father, who was the sole breadwinner working as an executive in a financial company, was keen to support her wishes and was willing to shoulder the burden of her treatment costs at home.

Investigations

Abdominal Radiography: Multiple fluid levels are seen in the dilated small bowel loops.

Computer tomography (CT) scan: New multiple peritoneal nodules suspicious for metastases. New multiple anterior abdominal wall nodules suspicious for metastases. A new large heterogeneously enhancing conglomerate of peritoneal masses contiguous with the left para-aortic and left iliac lymph nodes noted with stable left hydro-nephroureter. Stable indeterminate presacral soft tissue, which may be due to post-surgical changes or residual tumor.

Outcome and Follow-up

Adeline was discharged after 3 weeks of hospitalisation. She was on intravenous hydration throughout her hospital stay and this was continued upon discharge. The AH was stopped one week after discharge upon the patient's request. Adeline passed away 3 months after discharge. She maintained a good functional status reported to be grade 2 on the Eastern Cooperative Oncology Group performance status[10].

Discussion

To fully comprehend the intricacies surrounding the determination to employ AH in Adeline's case, it is important to consider the particular clinical evidence and guidelines upon the use of AH at the end of life, prevailing professional and legal standards, and relevant sociocultural considerations.

Clinical evidence

At present most prevailing clinical guidelines advocate an individualised and holistic approach to determinations as to the employ of AH at the end of life. This is given the relative scarcity of empirical data on the consideration of using AH amongst palliative care patients at the very end of life.[1-3, 11-15] Good et al. in their Cochrane review suggest that there is little evidence to suggest AH either increases prognosis or improves symptom control.[16]

While many patients, families, and professionals believe that death by dehydration is uncomfortable, Sullivan, Smith, and Ellershaw et al. have reported the converse. Smith and Sullivan reported that dehydration led to a reduction in oedema, dyspnoea and secretions.[17-19] Critically, McCann et al. reported that dying patients do not experience thirst.[20]

The traditional arguments for and against the use of AH at the end of life are summarized by del Rio et al., who forward the table below.[21] (Table 1)

Table 1. Arguments for and against hydration at the end of life

Arguments for hydration	Arguments against hydration
Basic human requirement and a basic minimum standard of care	Does not recognize the normal dying process
Source of physical and psychological comfort	Can be painful and cause increased edema, secretions and dyspnoea
Reduces the presence of opioid accumulation and neurotoxicity	Ketone accumulation provides a natural anaesthetic
Relieves thirst	Does not prolong life
Prevents concerns about abandonment and allows for continued efforts to improve quality of life and comfort	
Prevents a slippery slope towards the routine cessation of other treatments	

However, the current available studies were done mainly in patients with limited prognosis of less than 3 months and a poor functional status. Because of the differences between Adeline's situation and these patients' situations, these studies may not be applicable to Adeline. Also, since it has been suggested that AN can prolong life and improve quality of life in certain patients, would AH have the same effect?

Local guidance

There exists no local guidelines on the subject of the use of AH or AN within the palliative care setting, although Krishna found amongst local palliative care and oncology patients that AH in the last 48 hours of life confers neither survival nor symptomatic benefit.[22]

In the absence of clinical evidence and local guidelines on the subject of AH amongst young patients with relatively good performance status, Adeline's surgical and oncological teams suggested that AH be continued.

Prevailing legal standards

The position to err on the side of caution does appear to echo the regnant legal position in Singapore. Singapore's Advanced Medical Directive Act (AMD) 2007 suggests that routine clinically assisted hydration and nutrition (CANH) be continued unless medically contraindicated. [23] This position in turn echoes the House of Lords Select Committee on Medical Ethics Report, which, led by the Bland case, suggests that cessation of CANH should only be considered if it is a burden to the patient.[24]

Multiple authors have commented in local case reports, studies, and commentaries that there is a pervading sociocultural and increasingly professional expectation for the continuation of AH at the end of life.[25-28] While such a position would be contrary to both the central tenets of the practice and to the ethics of palliative care that recognizes "the existence of a natural dying process," it does appeal to another palliative care ethic: the need to review each particular case holistically and upon its own merits.[29]

Dev et al. argue that any decision with regards to the application of hydration at the end of life in the absence of clear evidence must necessarily include an assessment of whether the treatment will be distressing to the patient, and if administration of AH will improve the patient's quality of life and/or alleviate their symptoms.[30] Indeed, it was a combination of these issues and a holistic review of the patient's particular situation that influenced our efforts to balance Adeline's particular needs.

Sociocultural beliefs, norms and expectations

Reviewing the situation over a wider platform, it becomes clear that there are a number of sociocultural considerations, norms and expectations to consider.

Societal

Despite the diversity of Singapore's ethnic, cultural, and religious citizens, local authors note that Singaporeans, like most Asians, maintain a common belief that the provision of food at the end of life is a sign of affection and concern.[25-28] Many families maintain that cessation of AH is tantamount to "killing" or at the very least starving their loved ones to death.[31] As a result, there remains an undeniable expectation amongst many patients and their families that AH and even AN be continued even in the terminal phases of life. Krishna and Chai et al. also note that for many patients and families, this maintenance of AH is a sign of medical non-abandonment.[25, 27] These positions and beliefs are not exclusive to the local setting.[21, 32-33]

Cultural

The presence of an almost homogenous view of hydration at the end of life as a form of care and a reflection of respect and concern within Singapore's multicultural, multiracial, multi-religious society is a testament of Singapore's national ideology that maintains a strong, Confucian-inspired, family-centric flavor.[34-36] Here, support of the family is key.

The provision of AH is seen to have the symbolic meaning of "fighting on" and maintaining hope. Local families see it as a means of improving the survival of ill family members, including those in a terminal state.[25, 27]

Filial piety

A significant part of this family-centric belief is inspired and overseen by the Confucian notion of filial piety, or the obligatory duty of children to care for their elders in recognition and appreciation of the care they received.[26, 28, 37-56] Part of this filial obligation is in providing material and psychosocial support for their elders. This includes provision of food and water, which in a sociocultural context are seen as similar. Failure to meet this duty is widely conceived as a failure in one's filial obligations.[26]

In Adeline's case the roles are reversed, since a daughter is the patient instead of an older parent. Interestingly, this brings about unique aspects of the sick role that

Adeline plays. To fulfill her filial piety to her elders, prolonging life and striving to maintain good functional status despite a terminal disease would be important issues that she would consider at the end of life. Her wish to continue AH would also be consistent with the societal and cultural values locally, where provisions of AH as basic care with hope of prolonging life and "fighting on" are common expectations amongst patients and families alike.

Professional

Despite the well-established clinical, ethical, and legal basis for maintaining that the cessation of AH is not akin to causing death, many professionals share the belief that death may be hastened by stopping AH. Studies in other Confucian-inspired countries reveal that healthcare professionals do report personal, moral, and cultural difficulties in not providing AH.[31,57]

Konishi et al.'s review of the attitudes of Japanese nurses in withdrawing AH and AN revealed that many nurses felt the provision of AH and AN at the end of life was part of their professional obligation to provide comfort.[58]

Ethical

With physicians being cognizant of the above expectations, patients and families' concerns can then be addressed and considered in the decision-making process, striking a fine balance between sociocultural expectations and medical ethics.

One prime concern is this: in the face of equivocal evidence to its benefits and potential for harm, would it be ethical to start such treatment?

A. Futility. Whilst there was little evidence as to the efficacy of AH in the long term, there is some transposed evidence from studies on the use of Total Parental Nutrition in patients with ovarian cancer which suggests that the application of AH could be of some help in the physical function maintenance of patients like Adeline.[59,60]

B. Harm. The beneficial effect of AH on the patient's and family's psychological state cannot be understated. Especially when this translocated evidence and the absence of complaints of harm in the form of infection, pain, and bleeding with prolonged use of AH suggest that it would be difficult to argue that AH be withheld in this case.

C. Overarching duty. A significant consideration in this deliberative process is determining the overarching duty that must be abided to. Accepting the overarching duty of care in this case can be difficult, as there have been some patients and families who maintain that the discontinuation of AH would be a breach of religious doctrine. This is underpinned largely by a fear that such cessation would precipitate a hastening of death. The Catechism of the Catholic Church does accept that "*discontinuing medical procedures that are burdensome, dangerous, extraordinary or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous treatment. Here one does not will to cause death; one's inability to impede it is merely accepted*".[61]

This position is congruent with the position taken by Krishna and Chin in forwarding the Duty of Palliative Care (DoPC) that is constructed on the World Health Organization's definition of palliative care. Here the DoPC states that "[t] he primary focus becomes comfort and maximising the quality of life of the patient without hastening death or prolonging the dying phase”.[61]

This position is also congruent with the British Medical Association’s statement requiring all health care professionals to consider the patient’s own goals, their likely reaction to their present condition, the value they would place upon how they wish to live and be treated, and if the treatment would be humane and comfortable.[63]

Unlike Slomka’s position that decisions must be clinically and evidence led, a holistic approach is adopted.[31, 62] Here we adopted Jonsen, Siegler, and Winslade’s 4-Topics approach that duly considers four main domains (Table 2): (1) The medical indications for the procedure which consists of balancing the Principles of Beneficence and Non-maleficence, (2) patient preferences which considers respect for Adeline’s autonomy, (3) an estimation of her quality of life which considers the Principles of Beneficence, Non-maleficence and Respect for individual autonomy, and (4) contextual issues surrounding Adeline’s case.[64]

Table 2. Jonsen, Siegler, and Winslade adapted 4-Topics approach

Medical indications	**Patient Preferences**
Beneficence and Nonmaleficence	Respect for Patient Autonomy
Risk- benefit assessment ~Clinical background ~Goals of care ~Treatment options	Patient’s ability to consent and the acceptability of the consent process itself
Quality of Life	**Contextual Features**
Beneficence, Nonmaleficence and Respect for patient Autonomy	Loyalty and fairness
Balancing possible outcomes with patient’s own views of quality of life and goals of care	Consider the wider psychosocial considerations that impact these determinations

Practical Considerations

It is in considering the contextual features highlighted in the above 4-Topics approach that the practical issues surrounding the decision to apply AH in the community come to the fore. These include issues of training, financing, and psychical and psychological support for both Adeline and her family.

To begin with, caregiver training (CGT) had to commence immediately to ensure adequate competence in achieving Adeline’s physical needs as well as the maintenance of her PICC line once she was discharged. This was not without difficulties as Adeline’s mother was not medically trained and harboured her own reservations. Despite this, CGT was completed within 1 week. In the meantime, the AH regimen was also simplified to include only nocturnal infusions that did not require an infusion pump.

Details of the discussions held were then handed over to the home hospice team. They were reminded to closely monitor Adeline for complications of AH and signs of any deterioration in her general condition as a result of her progressive disease, especially given Adeline's mother's fears of coping and the potential need for respite support.

Clinically, Adeline maintained some level of hydration despite minimal oral intake. Psychologically, initiating and continuing AH upon discharge from the hospital provided reassurance that there was no abandonment of care and set the stage for further discussions about extent and goals of care by the home hospice team in future.

It is upon balancing all these factors that the final decision to apply AH for Adeline was made. Yet, such a determination is part of a fluid process that is continuously reviewed in light of evolving conditions.

Continuous review of the goals of care

To highlight this point, Adeline requested for AH to be stopped 1 week after discharge. This was in light of further improvement in her ability to tolerate fluids and the inconvenience of her nocturnal AH schedule that interrupted her sleep. Adeline suffered no other ill effect from the AH.

Adeline remained asymptomatic and tolerated small amounts of clear feeds for a further 2 months before she deteriorated.

This case study illustrates some of the individualized, complex and interrelated facets involved in the deliberative process of considering AH in young patients with complete intestinal obstruction, particularly when many like Adeline enjoy a good quality of life and function in between bouts of intestinal obstruction.

During this period, it may be difficult for physicians to withhold AH or AN, as well as for the patient and family to resist asking for such interventions. In this case, AH was only decided after multiple discussions to address the patient's and family's ideas, concerns, and expectations about AH. The availability of a competent carer also allowed the continuation of AH at home.

Most importantly, AH was not a means to unrealistic expectations like improving survival. Instead, it functioned as a tool in facilitating the accomplishment of some of the patient's hopes and expectations.

In conclusion, the approach to AH should be individualised to the patient's needs. AH at home is feasible with good family support and a home hospice team. However, it should not be viewed as a means of prolonging survival, and both patient and family must understand the possible complications before the initiation of AH.

Applications

1. The use of Artificial Hydration (AH) at home in a young patient with good functional status with intestinal obstruction is possible.

2. Such a decision must be made upon a holistic review of the particular patient's context and be based upon honest discussions about the aim and end points of such an intervention.

3. Jonsen, Siegler, and Winslade's adapted 4-Topics approach provides a viable tool in the weighing up of the overall goals of care and in addressing sometimes competing duties.

Patient's Perspective

Adeline's care was aided by the coadunation of having a medical team that was willing to consider her clinical situation in its entirety and a family that supported her wishes. This also allowed her to achieve acceptance of her condition and aid in her planning of care. Adeline managed to achieve her goal of being with her family in her own home at her demise as a result of the combined efforts of all concerned and represents a triumph of patient- family – health care team cooperation.

References

1. National Council for Hospice and Specialist Palliative Care Services. Artificial Hydration for People who are Terminally Ill. Eur JPalliat Care 1997; 4:29.
2. Bruera E, Hui D, Dalal S, Torres-Vigil I, et al. Parenteral Hydration in Patients with Advanced Cancer: A Multicenter, Double-blind, Placebo-controlled Randomized Trial. J Clin Oncol 2013 Jan1;31(1):111-8.
3. Raijimakers NJ, van Zuylen L, Costantini A, Clark J, et al. Artificial Nutrition and Hydration in the Last Week of Life in Cancer Patients. A Systematic Literature Review of Practices and Effects. Ann Oncology 2011 Jul;22(7):1478-86.
4. Melissa K. Whitworth, Andrea Whitfield, Søren Holm et al. Doctor, Does This Mean I'm Going to Starve to Death? J Clin Oncol Jan 2004 22:199-201
5. Bo-Guang Fan, Parenteral Nutrition Prolongs the Survival of Patients Associated With Malignant Gastrointestinal Obstruction, J Parenter Enteral Nutr 2007 Nov-Dec; 31(6):508-10.
6. L.A. King, L.F. Carson, N. Konstantinides et al. Outcome Assessment of Home Parenteral Nutrition in Patients with Gynecologic Malignancies: What Have We Learned in a Decade of Experience? Gynaecol Oncol, December1993 3:377–382.
7. Madhok BM, Yeluri S, Haigh K et al. Parenteral nutrition for patients with advanced ovarian malignancy. J Hum Nutr Diet. Apr 2011;24(2):187-91.
8. Dy SM, Enteral and parenteral nutrition in terminally ill cancer patients: a review of the literature. Am J Hosp Palliat Me. Oct- 2006; 23(5):369-77.
9. David A, Deborah Thorn, Rosemarie L Fisher et al. Home Parenteral Nutrition for Patients with Inoperable Malignant Bowel Obstruction. J Parenter Enteral Nutr. 1991 May-June;15(3):323-7.
10. Eastern Coorperative Oncology Group performance status.http://www.ecog.org/general/perf_stat.html. Published 27th July 2006(Last accessed 10th March 2014).
11. Morita T, Bito S, Koyama H, Uchitomi Y, Adachi I. Development of a National Clinical Guideline for Artificial Hydration Therapy for Terminally Ill Patients with Cancer. J Palliat Med June 2007;10(3):770-80.
12. Amadori D, Bruera E, Cozzaglio L, Corli O, et al. Guidelines on Artificial Nutrition Versus Hydration in Terminal Cancer Patients. Nutrition Mar1996;12(3):163-7.
13. Cerchietti L, Navigante A, Sauri A, Palazzo F. Hypodermoclysis for control of dehydration in terminal-stage cancer. Int J Palliat Nur 2000; 6:370–4.
14. Morita T, Hyodo I, Yoshimi T, Ikenaga M, Tamura Y, Yoshizawa A, et al. Association between Hydration Volume and Symptoms in Terminally Ill Cancer Patients with Abdominal Malignancies. Ann Oncology 2005;16:640–7.
15. Bruera E, Sala R, Rico MA, Moyano J, Centeno C, Willey J, et al. Effects of Parenteral Hydration in Terminally Ill Cancer Patients: A Preliminary Study. J Clin 2005; 23:2366–71.
16. Good P, Cavenagh J, Mather M, Ravenscroft P. Medically assisted hydration for adult palliative care patients. Cochrane Database of Syst Rev 2008 Apr 16;(2):CD006273. doi: 10.1002/14651858.

CD006273.pub2.

17. Sullivan RJ. Accepting Death without Artificial Nutrition or Hydration. J Gen Intern Med 1993; 8:220–224.
18. Smith SA. Controversies in Hydrating the Terminally Ill Patient. J Infus Nurs 1997;20:193–200.
19. Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the Dying Patient. J Pain Symptom Manag, 1995;10:192–197.
20. McCann RM, Hall WJ, Groth-Juncker A. Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration. J Am Med Assoc 1994; 272:1263–1266.
21. Del Rio MI, Shand B, Bonati P, et al. Hydration and Nutrition at the End of Life: A Systematic Review of Emotional Impact, Perceptions, and Decision-making among Patients, Family, and Healthcare Staff. Psycho-Oncology Journal,2012; 21: 913–921.
22. Krishna L. Artificial Hydration at the end of Life in an Oncology Ward in SingaporeIndian J Palliat Care,Sep-Dec 2010; 16(3): 168–173.
23. Advanced Medical Directive Act 2007. Ministry of Health Singapore. http://www.moh.gov.sg/content/moh_web/home/policies-and-issues/advance_medical_directiveamd.html. Published 16 Aug 2013(Last accessed 10 June 2014)
24. House of Lords Select Committee on Medical Ethics Report. Her Majesty's Stationery Office; 1994;251-257.
25. Krishna L. Nasogastric Feeding at the End of Life: A Virtue Ethics Approach. Nurs Ethics 2011;18:485-494.
26. Ho MZJ, Krishna L, Yee ACP. Chinese Familial Tradition and Western Influences: A Case Study in Singapore on Decision Making at the End of Life. J Pain Symptom Manag 2010;40(6):932-6.
27. Chai HZ, Krishna L, Wong VHM. Feeding: What It Means to Patients and Caregivers and how these Views Influence Singaporean Chinese Caregivers' Decisions to Continue Feeding at the End of Life. Am J Hosp Palliat Care. 2014 Mar;31(2):166-71.
28. Goh CR. Culture, Ethnicity and Illness. Palliative Med,2007; 51-54.
29. Ashby M Stoffell B. Artificial Hydration and Alimentation at the End of Life. J Med Ethics 1995; 21:135-140.
30. Dev R, Dala S, Bruera E. Is There a Role for Parental Nutrition or Hydration at the End of Life? Curr Opin Support Palliat Care. 2012 Sep;6(3):365-70.
31. Slomka J. Withholding Nutrition at the End of Life: Clinical and Ethical Issues. Cleve Clin J Med. 2003 Jun;70(6):548-52.
32. Lehup BF, Plot E, Goetz C, et al. Withdrawal of Artificial Nutrition. Am J Hosp Palliat Care Feb 2014 doi 1049909114522688.
33. Kitzinger C, Kitzinger J. Withdrawing Artificial Nutrition and Hydration from Minimally Conscious and Vegetative Patients: Family perspectives. J Med Ethics doi:10.1136/medethics-2013-101799.
34. Liu Q. Core Culture Values and Beliefs of Singapore. American Journal of Culture and Philosophy, 2007. http://www.ncl.ac.uk/ecls/assets/documents/pdf/countryfiles/CCC-Singapore.pdf Published 2007(Last accessed 10th June 2014).
35. The White Paper on Shared Values of Singapore. Singapore National Printers 1991.
36. Tan C. Our Shared Values in Singapore; A Confucian Perspective. Educational Theory 2012; 62(4):449-63.
37. Krishna L. Decision Making at the End of Life: A Singaporean Perspective. Asian Bioethics Review. 2011; 3(2):118-126.
38. Krishna L. Consent in Terminal Sedation. Indian J Med Ethics. 2010 Jul-Sep;7(3):161-4.
39. Krishna L. The Position of the Family of Palliative Care patients within the Decision Making Process at the End of Life in Singapore. Ethics Med. 2011, 27(3):183-190.
40. Chan TE, Peart NS, Chin J. Evolving Legal Responses to Dependence on Families in New Zealand and Singapore Healthcare. J Med Ethics. 2013 DOI:10.1136.
41. Laidlaw K, Wang DH, Coelho C, Power M. Attitudes to Ageing and Expectations for Filial Piety Across China and British Cultures: A Pilot Exploratory Evaluation. Aging and Mental Health 2010;14[3]:283-92.

42. Hamilton GG. Patriarchy, Patrimonialism and Filial Piety: A Comparison of China and Western Europe. Br J Sociol. 1990; 41[1]:77-104.
43. Lieber E, Nihira K, Mink IT. Filial Piety, Modernization, and the Challenges of Raising Children for Chinese Immigrants: Quantitative and Qualitative Evidence. Ethos, 2000; 32[3]:324-7.
44. Liu QP. Filiality versus Sociality and Individuality: On Confucianism as ‘Consanguinity’. Philosophy East and West, 2003; 53[2]:234-50.
45. Tzeng HM, Yin CY. Family Involvement in Inpatient Care in Taiwan. Clinical Nursing Research, 2008; 17[4]:297-311.
46. Tan CB. Chinese Religion in Malaysia: A General View. Asian Folklore Stories, 1983; 42(2):217-52.
47. Lee TS. Chinese Theatre, Confucianism and Nationalism: Amateur Chinese Opera Tradition in Singapore. Asian Theatre Journal 2007; 24[2]:397-421.
48. Tu WM. Confucian Traditions in East Asian Modernity. Bulletin of the American Academy of Arts and Science 1996; 50[2]: 12-39.
49. Payne AS, Seymour JE, Chapman A, et al. Older Chinese People’s Views on Food: Implications for Supportive Cancer Care. Ethnicity & Health, 2008; Vol 13: 497-514.20.
50. Lai DW, Surood S. Chinese Health Beliefs of Older Chinese in Canada. Journal of Aging and Health, 2009; 21: 38-62.
51. Chen XY, Fan RP. The Family and Harmonious Medical Decision making: Cherishing an Appropriate Confucian Moral balance. Journal of Medicine and Philosophy, 2010; 35:573-86.
52. Khan H. Social Policy in Singapore. A Confucian Model? World Bank Institute Publications. Vernon 2001.
53. Chiu T, Hu W, Chuang R, et al. Terminal Cancer Patients’ Wishes and Influencing Factors toward the Provision of Artificial Nutrition and Hydration in Taiwan. J Pain Symptom Manag ,2004; 27: 206-214.
54. Shih F-J. Concepts related to Chinese patients’ Perceptions of Health, Illness and Person: Issues of Conceptual Clarity. Accident and Emergency Nursing,1996; 4:208-215.
55. Kwok T, Twinn S, Yan E. The Attitudes of Chinese Family Caregivers of Older People with Dementia towards Life Sustaining Treatments. J Adv Nurs. 2007 May;58(3):256-62.
56. Bowman KW, Singer PA. Chinese Seniors’ Perspectives on End-of-life Decisions. Soc Sci Med. 2001 Aug;53(4):455-64.
57. Ke L, Chiu T, Lo S, et al. Knowledge, Attitudes and Behavioural Intentions of Nurses Toward Providing Artificial Nutrition and Hydration for Terminal Cancer Patients in Taiwan. Cancer Nurs. 2008 Jan-Feb;31(1):67-76.
58. Konishi E, Davis AJ, Aiba T. The Ethics of Withdrawing Artificial Food and Fluid from Terminally Ill Patients: an End-of-life Dilemma for Japanese Nurses and Families. Nurs Ethics. 2002 Jan;9(1):7-19.
59. Abu-Rustum NR, Barakat RR, Venkataraman E, et al. Chemotherapy and Total Parenteral Nutrition for Advanced Ovarian Cancer with Bowel Obstruction. Gynecol Oncol. 1997 Mar;64(3):493-5.
60. Brard L, Weitzen S, Strubel-Lagan SL, et al. The Effect of Total Parenteral Nutrition on the Survival of Terminally Ill Ovarian Cancer Patients. Gynecol Oncol. 2006 Oct;103(1):176-80.
61. Catechism of the Catholic Church. Washington: United States Catholic Conference, 1994 no. 2278.
62. Krishna L, Chin J. Palliative Sedation within the Duty of Palliative Care within the Singaporean Clinical Context. Advanced Biomedical Rev, 2011; 3(3): 207-15.
63. British Medical Association. Medical Ethics Today. London. Brit Med J, 1993;147-179.
64. Jonsen AR, Siegler M, Winslade WJ. Clinical ethics: a practical approach to ethical decisions in clinical medicine. 6th ed. New York: McGraw-Hill; 2006.

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INFORMED CONSENT DOCUMENTATION IN PHARMACEUTICAL INDUSTRY-SPONSORED CLINICAL TRIALS

AGATA BLOSWICK; DR. HAB AGNIESZKA SKOWRON

Keywords: Informed consent, drug research, clinical trials, GCP guidelines

Rationale

Demand for new therapies and medicines is only increasing as the population in developed countries ages. The average life expectancy of 48 in the mid-20th century rose to 65.6 in 2005, and is predicted to rise to 85 for females in 2030.[1] This has led to rapid growth in the pharmaceutical industry in recent decades. However, with many companies present on the market, the competition in developing new drugs is enormous. Drug patents expire after only 20 years, and the time needed to perform appropriate tests *in vivo* and *in vitro* is reaching up to 11 years, with staggering costs of up to $802 million per drug. Currently, only 1 in 5 compounds will be marketed as safe and efficient. Recent industry's experiences with the FDA (Food and Drug Agency) and EMA (European Medicines Agency) show that the requests for safety data grow with time, as does the cost and time needed to introduce a new drug to patients. [2]

Pharmaceutical companies know that they constantly have to work on new products, not only to improve the healthcare of patients, but also to ensure the survival of a company when its patents expire. As the patents for drugs expire, other companies get to market generic versions of these drugs. This is why a pharmaceutical company must invest so heavily in research (i.e. Pfizer has spent $7.945 billion on R&D in 2008, 16% of its annual income).[3]

With the growing demand for new drugs and new therapies and the need to plan for the long term financial stability of the pharmaceutical companies, it is important to remember that behind every clinical trial there are doctors, their patients, and a multitude of health care employees and research scientists. For this reason, there are certain laws and regulations which apply in order to protect all the stakeholders in the industry. The first guideline for the conduct of clinical trials and patient protection was issued in 1964 with the Declaration of Helsinki, which clearly outlined the need for patient protection and the importance of putting a patient's well-being above all other interests. It also drew attention to informed consent, patient's dignity, and the right to self-determination.[4] Some years later, a stronger fundament of the clinical trial participant's protection was issued, the Belmont Report, which has three ethical principles in mind:[5]

- Respect for persons, aiming to protect the autonomy of each individual and give them the right to informed consent
- Beneficence, the "do no harm" rule, minimizing risks while maximizing the research benefit

- Justice, justifying reasonable and fair distribution of the procedures and benefits for the research subjects

In the early 1980s, the European Economic Community (now the European Union) together with Japan and the USA formed the International Conference of Harmonization (ICH) to create a common standard of conduct for clinical trials as a set of guidelines of Good Clinical Practice (GCP). Their principles were as follows:[6] ethical conduct of the trial; research described in the protocol; risk identification; benefit-risk assessment; review by IRB/EC; protocol compliance; informed consent, ongoing review/risk-benefit assessment; investigator/staff qualifications; records integrity; confidentiality; good manufacturing practice; and quality systems.

These standards are the current set of rules for performing clinical trials, and are applied by all medicinal regulatory agencies including the EMA and FDA (implemented in the Code of Federal Regulations, CFR). From all the above-mentioned principles of GCP, this text focuses on Informed Consent and ways of documenting a subject's approval for clinical trial participation. It should be noted, however, that all of the principles are related to one another, so some of the others will also be discussed. The aim of the paper is to discuss current standards applied to Informed Consent Form preparation. This work will present an alternative to the currently used format, as well as propose additional actions which could be implemented to increase the readability of the form for the benefit of the patient.

Current situation

Informed consent is the process of informing a patient about the nature of the clinical trial, the risks, benefits, underlying procedures, and alternative treatments. For clinical trials this process does not fundamentally differ from informed consent for any standard medical procedure, thus it includes the following elements:[7]

- Description of the patient's condition
- Procedures required by a clinical trial
- Benefits/risks of the clinical trial
- Alternative procedures and related risks and benefits, including the risks/benefits of withholding treatment

This information shall be presented directly to the patient, and then appropriately documented by signature of the Informed Consent Form and by an appropriate comment in the subject's medical records. The patient needs to be given ample time to make an appropriate decision, meaning a period of time to consult with family members or to seek a second opinion from another doctor. After the study has been explained to the patient and the prospective trial subject has agreed to participate in the study, the doctor shall present the Informed Consent Form for signature. The form itself undergoes an ethical review process by the appropriate body – Institutional Review Board (IRB) in the USA, or Ethics Committee in other countries. The Informed Consent Form has two obligatory parts: information for the subject, and consent form.

ICH, GCP, and CFR have certain sections dedicated to the content of informed consent.[8, 9] The requirements state that this document shall be prepared with understandable language, allowing the patient to become familiar with its content and meaning. The FDA regulation states that the readability of the document shall be presented in an understandable language.[10] In practice this is often assessed as grade 6-8 level. None of the regulations state what shall be the layout of the document, nor its recommended length.

Where limitations on the length of Informed Consent Forms are not strictly defined by national laws, it is common practice among some European Ethics Committees responsible for the approval of trials to request the shortening of ICFs. For example, in the Czech Republic, it is commonplace to receive requests from the approving body to limit the length of the ICF. In Spain, requests are consistently made to keep the documents "reasonably short." In other cases, such as the Netherlands, ECs issue nonbinding guidelines regarding the length of Informed Consent Forms, advising keeping the information to patients short (up to 3 pages long) and moving all non-critical sections of patient information to the annexes at the end of the document.[11] In these examples, submitting a longer ICF would generally mean receiving comments or rejection of the document by the Ethics Committee. The Czech Republic even submitted comments issued by the Czech Regulatory Authority for Clinical Trials (SUKL) to the European Commission's concept paper on the revision of the Clinical Trials Directive 2001/20/EC. In their comments, SUKL wrote: "In recent years, frequent discussions have been held on document of Patient Information and Informed Consent, but no significant changes have been achieved so far. Clear rules on what information to include in this document with regard to the health status of the patient vs. length of the text should be given. Experience has shown that harmonization of this document and proposals for improvement are needed."[12] This proves that there is a clear need to impose a limit of pages in the Informed Consent Forms for European clinical trials.

Readability

In 2011, the Executive Agency for Health and Consumers of the European Union funded a functional health literacy study in eight participating countries in Europe (Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland, and Spain). Results of the study showed that almost 21% of responders are very likely to be of limited literacy, and that another 25% of responders are possibly limited in literacy.[13]

The US New National Literacy Survey performed in 1992 among 13,600 individuals aged >16 showed that 47% of the respondents were at level 1-2 of literacy in a 5 level scale. This means that they demonstrated limited skills in understanding and drawing conclusions from the texts provided, including prose, document, and quantitative reading samples.[14] The results of the literacy studies cast doubt on the ability of patients to read and understand the document they are presented with by the doctor. ICF may thus be regarded as a legally-binding contract rather than an aid in understanding the risks and benefits of a procedure or medication. Evaluating these findings by the standards of the Belmont Report – regarding patients' rights – we can conclude that the present informed consent documents are still too complicated for the average patient to use in making a well-informed decision.

This raises the question: what is the purpose of the informed consent form in its present state? Is it a document to protect the patient, or simply to provide legal protection for the doctor and/or the sponsor of the trial (the pharmaceutical company)? While seeking to be legally well-protected is an understandable concern of the doctors and sponsors, it would be beneficial for all parties involved if the informed consent form was better understood by the patient, thereby reducing the risk of unexpected consequences. It is in the best interest of all clinical trial stakeholders to change the sponsor-oriented ICF form to a patient-oriented document. This may not only improve a patient's compliance with procedures and protocol, but also make the patient more aware of his responsibilities (including spontaneous safety reporting and return for follow-up visits), and in the end lower subject drop-out rate and ameliorate the credibility of data. Improved understanding of the nature of the clinical trial will also improve the physician's relationship with the patient – from research-oriented to patient-oriented – facilitating trust and cooperation.

Ongoing discussion about the informed consent issue can be observed among clinical trials professional groups. Many of these professionals indicate that the Informed Consent document serves simply as documentation of the discussion that takes place between a patient and his doctor, and that it is not the only source of information a patient may have about the study. Per GCP requirements, it is correct to view the ICF as only one of multiple means to educate the prospective patient. However, oftentimes even the best investigators, rather than asking the patient to come to the clinical site to propose participation in the study, would ask the patient over the phone about potential interest in the study, and then email or fax the Informed Consent Form. Only if a patient is interested in the study would there be a face-to-face discussion about the study, at which time willingness to participate would be documented on the Informed Consent Form. Quite often, though, patients would either decide not to take part in the study after reviewing the ICF independently, or if they do agree, they would return to the site with the intention of participating without further discussion with the investigator. In the first case, a more readable Informed Consent Form might not have turned away individuals who might otherwise have participated. In the second case, patients may have decided to participate in the study without fully understanding the risks or their responsibilities as participants. In both cases, a well-thought and patient-friendly Informed Consent Form would be a solution to the problems.

What could be done?

Three proposed solutions to improve the Informed Consent Form will be presented in this section. All parties associated with the development and approval of the ICF, as well as with documenting the informed consent (the sponsor, representatives responsible for development of the document, IRBs, and physicians performing clinical trials) should be involved in the process.

The first step in improving the Informed Consent Form is a change in the appearance of the document. Doctors are obliged to present all aspects of the clinical trial to patients. The vital details are normally covered in the Informed Consent Form. The ICF document is protocol-specific and includes all information related to the trial. Investigators (doctors) usually use the ICF as a guideline to informing the patient, in combination with their own medical knowledge and familiarity with protocol. Visual aids, like pictures, tables, flowcharts, and colors to highlight the most important parts, could help doctors to keep patients' attention and to explain the most difficult sections. Research shows that pictures – in comparison to plain text – affect patients' attention to healthcare materials and enhance comprehension of the text.[15] The content is then better remembered and adhered to. A graphic-intensive format should also be applied to the ICF in clinical trials. Simplification of the language, bulleted lists of procedures, or flowchart use instead of full sentences will not make the document any longer. On the contrary, it will limit the number of pages while making the document easier for the patient to read. In this way, what is now a plain-text contract would become a useful and concise source of information which the patient may refer to during the course of the study.

A combination of pictures with written and oral instructions enhances a patient's understanding of medical information.[16] Highlighted pictures or texts must not, however, be used to encourage the patient to participate in the trial, nor should font differentiation emphasize the benefits and hide the risks of clinical trial participation. Legal regulations do not limit or encourage the use of visual aids; instead, they focus mostly on the informative aspects of the Informed Consent Form. Therefore, special attention to the IRB/EC during the review process should be advocated when examining the intent behind any applied visual aids.

Another way to improve the current format of the Informed Consent Form is to involve the doctors in the process of designing the form instead of leaving it in the hands of the sponsor's representatives. Physicians know the population under study and should know what would be the best way of presenting the information to patients. Certainly, there is a particular way of presenting information to elderly patients, to young adults, to adolescents, or to patients with chronic diseases. All Informed Consent Forms undergo an ethical review by authorized bodies. Current regulations regarding the ethical review process focus on the expertise of the review bodies. The IRB in the US, as granted by law, must have at least 5 members with "enough experience, expertise, and diversity to make an informed decision on whether the research is ethical, informed consent is sufficient."[17] Similarly, Polish law requests at least 11-15 members who are specialists in the field of the proposed research, as well as one of each of several other professions: i.e. pharmacist, lawyer, priest, nurse.[18] This means that ethical review bodies consist of a group of highly educated people, but lack patient representation. Including a layperson in the review process might be advisable to help ensure the readability of the ICF.

Lastly, in order to properly administrate the informed consent process, proper notation is required in the subject's medical records. Patients' medical files serve as documentation of the course of the treatment, and are meant to record all discussions which take place in the doctor's office. Therefore, it is obligatory not only to file a signed copy of the ICF in the medical records, but also to document the informed consent process in the patient's files.

In order to comply with the GCP principle of Record Integrity, the investigator should not only note the fact that the patient consented for participation, but also how the subject was proposed participation in the trial, if the patient consulted any aspects of the study with anyone else (from the investigative team, or outside), and any questions, doubts, or concerns expressed by the patient. Records should also include information about the amount of time given to the subject to consider participation, given that regulations do not define the “ample time” rule precisely. In the end, the record should contain information that the patient signed the appropriate Informed Consent Form, including the version number and date.

Fulfilling the protocol compliance and ongoing risk-benefit assessment principles of the GCP, an Informed Consent Form is a document which undergoes regular revisions when any new, relevant information about the study is available, including drug safety information, procedural revisions, or administrative changes. In case any of these changes apply, especially when safety concerns arise, a patient should be appropriately informed by the Investigator as soon as possible, even if the revised Informed Consent Form is not available or approved by the EC/IRB. After the form’s approval, the new version is presented to a patient for signature. However, the informed consent process has to be documented as it happens in case of orally-presented changes and expressed consent of the patient, and the signature shall be documented as two separate entries in the medical records, as only ongoing recording of the current events in the trial – including a patient’s will to continue participation in the trial – will allow investigators to comply with the record integrity requirements of the GCP.

This poses a question about why it is so important to document informed consent of the patient and why a signed Informed Consent Form is not enough to protect a patient. Clinical trials undergo regular quality revision both by the sponsor (and its contracted auditors) and regulatory agencies. The purpose of this documentation is to follow the principle of quality systems availability, which means that all processes performed in the trial should present a full audit trail. GCP defines an audit trail as “Documentation that allows reconstruction of the course of events.”[19] For this reason, informed consent documentation is a crucial aspect of the clinical trial performance and should not only be limited to Informed Consent Form signature, but it should also be considered to be a process with the purpose of protecting and documenting the patient’s will to ongoing participation in the research study.

Conclusion

To summarize, Informed Consent Forms at present may not be aiding patients considering participation in clinical trials to the extent intended by existing laws and medical conventions. The content of these forms tends to serve as a legal catchall for the protection of doctors and pharmaceutical companies, thereby becoming overly complex and difficult for a patient to utilize to the extent practically and ethically desired. As Informed Consent Forms are typically used as a guide in outlining the risks and benefits of a clinical trial to a prospective patient, a vital opportunity is missed to ensure that the patient has a clear understanding of the clinical trial. This is not only to the detriment of the patient, but also to the disadvantage of doctors and pharmaceutical companies, increasing the risk of undesirable complications or even failure of the clinical trial, as the patient may not be adequately prepared for participation.

Addressing several elements of the informed consent process might serve to improve this situation. First, the appearance or format of the document might be clarified to make it easier for the average patient to make use of. Organizing complex, legalese text into succinct and clearly-worded points should be considered with the intention of improving the patient’s understanding. Visual aids can be used to keep the patient’s attention and better explain difficult topics. Second, involving doctors and patients in the preparation of Informed Consent Forms might help to tailor the presentation of critical information to better suit the needs of patients. Doctors are more familiar with their patients’ needs, and patients or laypersons in general could act as a sounding board for the readability of the information. Finally, it is critical to detail in a patient’s medical records information on the informed consent process, including any new information that arises during the course of the trial which might change a patient’s desire to participate. This would help to increase the medical institution’s sense of accountability to the patient’s wellbeing during pharmaceutical trials. The measures recommended here, if implemented, though not exhaustive, would be a positive step toward a more effective and more patient-oriented informed consent process.

References

1. Prentice T., WHO presented on Health and Philanthropy: Leveraging; University of Indiana; August 2006.
2. Walter M., Badania kliniczne – organizacja, nadzór, monitorowanie, OINPHARMA Sp. z o. o., wyd. 1, Warszawa 2004, str. 44
3. http://media.pfizer.com/files/annualreport/2008/chairmans_report2008.pdf;
4. WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects, *Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964*
5. The Belmont Report, Ethical Principles and Guidelines for the Protection of Human Subjects of Research, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, April 18, 1979
6. ICH Topic E 6 (R1) Guideline for Good Clinical Practice
7. Braddock C.H., How Doctors and Patients Discuss Routine Clinical Decisions; Journal of General Internal Medicine; Vol. 12 Issue 6, p. 339
8. ICH GCP sections 4.3, 4.7, 4.8
9. 21 CFR Parts 50.20, 50.25 and 50.27
10. 21 CFR Part 50.20
11. Information letter template; CCMO – provisionally revised version 8 November 2012
12. Comments of the Czech Republic on the European Commission’s concept paper submitted for public consultation to the “Revision of the “Clinical Trials Directive” 2001/20/EC; May 2011.
13. HLS-EU CONSORTIUM (2012): Comparative report of health literacy in eight EU member states.. The European Health Literacy survey HLS-EU, online publication: HTTP://WWW.HEALTH-LITERACY.EU
14. I.S. Kirsch; Adult Literacy in America. First look at the findings of the national adult literacy survey; US Department of Education, Third edition 2002.p. XVI
15. Houts P.S.; The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence; Patient Education and Counseling 61 (2006) 173–190
16. Katz M.G.; Use of pictorial aids in medication instructions: A review of the literature; Am J Health-Syst Pharm—Vol 63 Dec 1, 2006; 2391-2397
17. Food and Drug Administration, 21 CFR 56.107
18. Rozporządzenie Ministra Zdrowia z dnia 11 maja 1999 r. w sprawie szczegółowych zasad powoływania i finansowania oraz trybu działania komisji bioetycznej (Dz. U. Nr 47, poz. 480); §3.2.4
19. ICH Topic E 6 (R1) Guideline for Good Clinical Practice

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Book Reviews

Law and the Bible: Justice, Mercy & Legal Institutions

Robert F. Cochran, Jr. and David VanDrunen, editors. Downer's Grove, IL: IVP Academic, 2013.

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Christians of every age, living under every political regime, have pondered the justice of legal systems, governmental regimes, and how they compare with the teaching of the Bible. With an emphasis on theology rather than law, *Law and the Bible* goes a long way in helping Christians answer those questions without getting into legal complexities. Lawyers will find it thought-provoking, while non-lawyers will find it very readable.

Law and the Bible is co-edited by two top scholars with an introduction by a third. Taking a unique approach, the Old and New Testaments are divided into nine sections. Each section is addressed in a separate chapter co-authored by both a lawyer and a theologian. This approach contributes to the richness and balance of the analysis and insight. Every chapter is not only clear and well written but thought-provoking. Many of the authors are expressly conscious of the necessity and significance of prudence (practical wisdom oriented toward the Good) in this fallen world.

The editors endorse Scripture as "the supreme standard for all aspects of life" (17) but also encourage reflection on natural law, defined as "the idea that God has ordered this world—and human beings' place in it—in such a way that it communicates the basic requirements of his moral will, and that human beings perceive this law through their reason and conscience." (18) In other words, "[s]cripture is God's special revelation, and natural law is an aspect of God's general revelation." (18) Though they are respectful of and draw from Catholic philosophers like Augustine and Thomas Aquinas, all the contributors "affirm the traditional Protestant belief that church tradition is not an authority on par with either of these [Scripture or natural law]." (18) Reading Scripture in context is emphasized.

A few highlights will convey some of the themes. Chapter 1 ("Civil law in Genesis") addresses the implication of the Fall for limited expectations of what human law can accomplish. Among the general lessons that can be drawn from Genesis is the limits of human government.

Chapter 2 ("Law and Political Order") "traces Israel's forms of government and also provides an overview of the Old Testament's history of Israel" (49) for its insights on civil law. The authors conclude, "the Bible's goal is not to endorse a single set of political arrangements as best for all places and times. The latter position is the one most consistent with the bulk of the Christian tradition…." (61)

Chapter 3 provides an overview of Mosaic law with three core principles in mind—God's nature revealed in Scripture, the nature of Israel, and the role of the land. The authors explore implications of the Mosaic law for the regulation of criminal law, economics and commercial law, and marriage, divorce and sexuality.

Chapter 4 ("Law in the wisdom literature") provides an overview of the perspective on law in the books of Proverbs, Psalms, Job, Ecclesiastes, and Song of Solomon.

Chapter 6 ("The Kingdom of God, Law and the Heart," to which the late Dallas Willard contributed) looks at Jesus' teaching about civil law.

The authors of each chapter examine possible applications to contemporary law and public policy, while highlighting the prudential and contextual limits. While general principles can guide modern law, it is difficult to apply particulars as requirements of contemporary law, when we realize that "[n]o modern government is in a covenantal relationship with God." (121) Still, Scripture, and the fundamental principles of justice and natural law reflected in it, should guide modern political leaders.

Law and the Bible is invaluable for giving Christians a balanced view of the limits and possibilities of contemporary public policy. Readers will have a better understanding of how Scripture may or may not apply to modern legal and public policy problems. This compelling book will be rewarding to lawyers, those interested in politics and justice, and those interested in a deeper understanding of Scripture. It is worth reading and re-reading.

Reviewed by Clarke D. Forsythe, JD, MA (Bioethics) who serves as Senior Counsel for Americans United for Life, and is the author of *Abuse of Discretion: The Inside Story of Roe v. Wade* (Encounter Books, 2013).

Playing God: Redeeming the Gift of Power

Andy Crouch. Downers Grove: InterVarsity Press, 2013.

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Once in a great while one encounters a book that is simultaneously engaging, inspiring, and provocative. *Playing God: Redeeming the Gift of Power* by Andy Crouch is just such a book.

We live surrounded by power. Defining power as the “ability to make something of the world” (17), Crouch calls us to recognize that power is not ontically evil, but is the current of life, a dangerously good gift that enables not only human flourishing but creative “meaning-making” in our world. However, as with any gift in our broken world, it is corrupted, abused, and too often used for anti-flourishing purposes. Moreover, as with Thielicke, Crouch understands that power is not just something we possess as a gift; it is a function of our image-bearing identity and character. Therefore, our use of power is ultimately about Christian stewardship and witness.

The bookends for Crouch’s biblically grounded argument are Creation (Genesis 1-2) and the New Creation (Revelation 22). Peppered throughout are sections entitled, “Explorations” in which particular biblical events are addressed for the insight into power they provide. While Crouch’s argument is biblical, it is also broad-based, touching on secular perspectives (Foucault, Nietzsche, Milbank) as well as physics (the Law of Thermodynamics) and their impact on our understanding of power. Yet it is neither highly academic nor deeply philosophical, containing no formal footnotes or bibliography. Instead, Crouch skillfully imbricates a rich biblical theology of the gift of power into an exploration of the cultural manifestations of that power, gleaning examples from his own personal experiences, including such diverse topics as poverty, playing the cello, enjoying wine, human trafficking, iPods, loan sharks, economic systems, and the Olympics.

Despite his biblical grounding, Crouch takes a more global view of human flourishing than the Bible depicts. Scripture grounds human flourishing in a relationship with God who enables the flourishing of His chosen people for His Kingdom’s purposes; Crouch, while acknowledging God’s role as the giver of the gift of power, focuses on power as a generic gift of the Creator to humankind—His image-bearers—for socio-cultural-political flourishing, a distinction that renders his perspective more anthropocentric and impersonal than the biblical counterpart. In this book, Kingdom purposes are present in the subterranean stream of Crouch’s thought but never explicitly addressed, being shrouded by socio-political goals and largely confined to image-bearing in the world. As a result, passages like Zechariah 4:6 (“Not by power nor might but by my Spirit, says the Lord”) are never addressed.

Despite this caveat, *Playing God* is highly commendable reading for any student of scripture who longs for a deeper understanding of how we, as stewards and witnesses, are to use our gift of power to live and flourish in this world between Creation and New Creation. It will inspire your heart and engage your mind, while simultaneously confronting and challenging any strongholds of power that you may cherish.

Reviewed by Susan M. Haack, MD, MA (Bioethics), MDiv, FACOG, a consultative gynecologist at Hess Memorial Hospital and Mile Bluff Medical Center in Mauston, Wisconsin, USA.

The Ethics of the New Eugenics

Calum MacKellar and Christopher Betchel, editors. New York and Oxford: Berghahn Books, 2014.

ISBN 978-1782381204, 244 PAGES. CLOTH, $90.25.

The result of a collective work undertaken by the Scottish Council on Human Bioethics, this volume edited and penned by Calum Mackellar and Christopher Betchel starts by differentiating the New Eugenics from the Old. Thus, while it is noticed that the Old Eugenics was part of an enforced state policy, the New is, as shown, constituted by policies and practices allowing individual choice. But, both New and Old Eugenics endorse practices of choice and selection with the aim of promoting “good births” and avoiding “disability.”

After this introduction of terms used, there is an overview of the history of eugenics showing that eugenic thinking was prevalent in many parts of Western Europe outside of Germany, as well as in the Soviet Union and the United States, well before the Nazis enforced their brutal eugenics program.

Having thus situated eugenic ideology in its historical context, the authors present a comprehensive account of past and current eugenic procedures, accompanied by an equally comprehensive overview of international and national legislations. Prenatal and pre-implantation diagnosis, sex selection before or after implantation, infanticide and adoption are discussed, as are procedures involving selection of a partner in light of genetic information. Examples of the last-mentioned kind of practice are premarital genetic testing in Cyprus in order to avoid having a child with beta-Thalassaemia and premarital genetic testing among Ashkenazi Jews in order to avoid having a child with Tay-Sachs disease. Also discussed at some length are the possibilities of future selection procedures by means of cloning and the creation of genetically modified children.

This first, largely descriptive, half of the book is followed by a longer more discursive part, consisting of a short chapter spelling out arguments in favour of eugenic practices and a longer chapter presenting arguments against eugenic practices. One argument in favour of eugenic practices is empathy with the suffering, as might be argued in the de-selection of embryos and foetuses with abnormalities. Other arguments that may be put forward are respect for procreative freedom and promotion of a healthier society with related social savings. Some advocates of the New Eugenics even hope for a general enhancement of humanity.

Noted among the manifold arguments against eugenic procedures (such as pre-implantation diagnosis and prenatal testing) is the observation that these procedures involve the destruction of human life. But of course, as recognized, this argument is only weighty in the eyes of those who see the embryo and foetus as our equals in human dignity and worth. Among other arguments against selective practices are the possible limitation of genetic variability and the concept of “playing God,” the authors cautioning against human hubris. As further pointed out, eugenic practices might also result in a widened definition of disability and discrimination against the disabled. Furthermore, the availability of eugenic measures might result in pressure to use them. Alternatively, some procedures might be affordable only by the rich and so lead to social inequalities. As shown and perhaps most important, there are weighty arguments for giving the child an unconditional welcome. Parental attitudes matter; they are important for inter-generational relations. As argued, as fellow members of humanity, children should not be treated as objects of parental design but should be welcomed as gifts.

Clearly written and highly informative about international and nations laws, as well as about past, current, and possible future eugenic practices and arguments for and against the same, this volume makes for valuable reading not only for students of medical ethics but can be recommended to anyone wanting to learn more about arguments for and against current and possible future reproductive selection procedures.

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

Truly Human Enhancement: A Philosophical Defense of Limits

Nicholas Agar. Cambridge, Massachusetts and London, England: The MIT Press, 2014

ISBN 978-0-262-02663-5, 216 PAGES, CLOTH, $35.00.

Endorsing moderate, but not radical human enhancement in *Truly Human Enhancement*, Agar takes a stand against transhumanists who want to change us utterly. Efforts to enhance human attributes and abilities to levels greatly exceeding what is currently possible in humans could result in creation of post-persons. Post-persons, he warns, would constitute a threat to ordinary or mere persons. This is because they would probably be recognized—by themselves and others—as beings with a higher moral status. As a result, mere persons could easily come to be sacrificed for the sake of post-persons, just as today we sacrifice animals in medical research for the sake of humans because we see ourselves as morally superior.

Lesser degrees of human enhancement might, however, be prudentially valuable for ordinary humans, Agar argues, irrespective of whether they involve genetic modification or environmental enhancement (e.g., education or electronic supplements to human brains). Indeed, Agar presents several reasons for dismissing the view that there is a morally significant difference between genetic and environmental enhancement, arguing that the effects might be much the same. Either might produce changes of similar magnitude and pose a similar threat to our humanity. Neither is more natural, fairer, or riskier, and neither need rule out autonomy on the part of the enhanced individual. But is there not an important difference between genetic and environmental enhancement? Environmental enhancement, such as education, involves person-to-person interaction. Is not genetic enhancement depersonalising? Is the genetically modified subject not treated as product of *homo faber*?

Less controversially, Agar also dismisses the distinction between therapy and enhancement. For, as he notes, therapy might be seen as a form of minor enhancement.

His distinction—borrowed from Alasdair MacIntyre—between instrumental and intrinsic values of human abilities is, however, convincing and important. For example, a good chess player might win prize money. In this sense his ability has instrumental value. By contrast, the intrinsic value of his ability is found in the very playing and evaluation of strategies. We can empathize and feel enthusiastic about the good chess player, as Agar notes, but we might feel cool about the super-human—or radically enhanced—player. Thus Agar shows that radical enhancement could change the way we evaluate human achievements. Worse still, he argues that if we were radically enhanced we might no longer identify with our old selves. And so, the best means of achieving instrumental value, he argues, is improvement of human technologies rather than enhancement of human minds or bodies.

Agar's warnings that transhumanist aspirations would lead to a dystopian future should be taken seriously. This book is an important contribution to the debate about human enhancement.

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

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