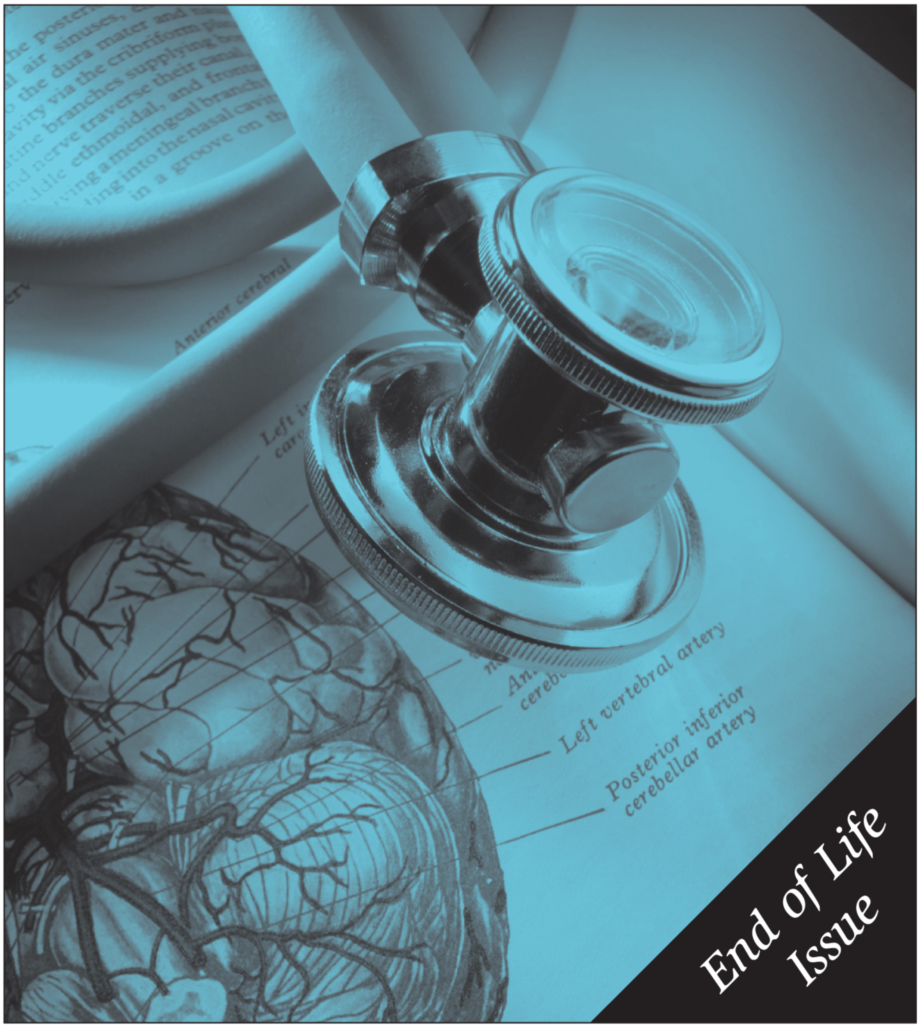
Ethics & Medicine

An International Journal of Bioethics



End of Life Issue

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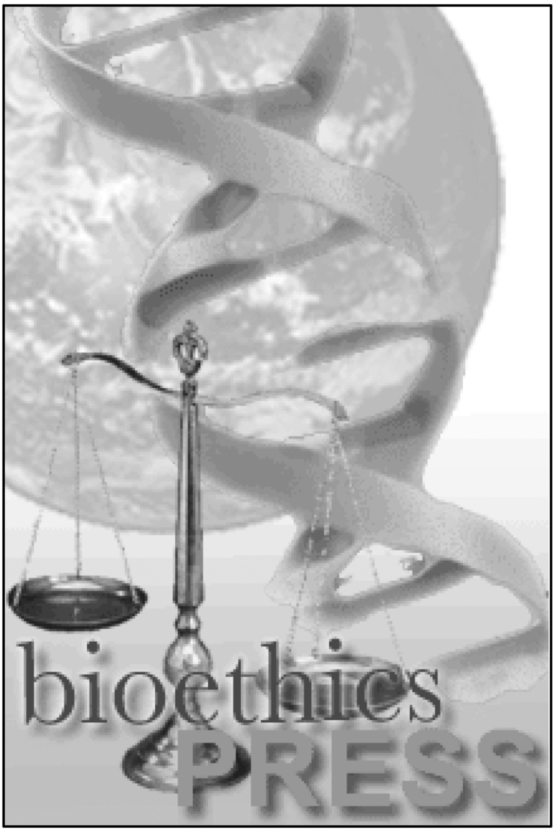
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PRESS

GUEST COMMENTARY: END OF LIFE ISSUES

A GOOD DEATH

JOHN DUNLOP, MD

Introduction

Congratulations to Ben Mitchell, the *Ethics & Medicine* staff, and the Editorial Board for putting together this fascicle. The ethical dilemmas presented at the end of life are increasingly frequent and complex. At least two factors contribute: First, the dramatic developments of medicine over the past three decades have significantly decreased the incidence of sudden death in developed countries. We now have a national 911 system ready to summon advanced life support ambulances staffed by excellently trained emergency medical teams and portable defibrillators. They transport the critically ill to hospitals where teams are waiting to do emergency angioplasties, offer trauma units, and have ICU's to preserve the life of the critically ill. As a result many who formerly would have died suddenly are now dying gradually of other diseases; many at an advanced age.[1] Sudden death does, after all, avoid many ethical ambiguities. Gradual death raises more ethical challenges. Second, we have new life sustaining technologies becoming available at an unprecedented rate. It is rare for people to come to the end of life today without some decision to limit care. One study showed that 90% of ICU deaths came only after such a decision.[2] Each of these decisions is replete with ethical implications and, consciously or not, is founded on a set of ethical presuppositions. With somewhere around 10,000 souls dying each day in the United States alone, the sheer numbers of these ethical dilemmas are legion when compared to other areas of interest to Bioethics and to this journal. *Ethics & Medicine* is, indeed, well to devote this entire fascicle to end of life issues.

End of Life Issues

Consider this scenario: Grandma, who is 97 years old, called me one morning a few weeks ago saying that she could not breath. I immediately called 911. The Emergency Room Doctor examined her and said she heard a loud murmur from a heart valve that was leaking. Did I want her to call a cardiologist to do a heart catheterization to see if the valve needed replacement? I agreed and later that evening the specialist reported that Grandma's mitral valve had ruptured. She predicted Grandma could not live more than several days unless she had the valve surgically repaired. The surgeon needed an immediate answer to schedule surgery the next day. I gave the go ahead and though Grandma made it through the surgery, she has now been in the ICU for the past three weeks. She is dependent on a ventilator, her kidneys have failed, and she is in coma. I know that she is going to die, but I feel uncomfortable about just taking her off the machine. Would that be killing her? Instead, I asked her doctor if he could

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just give her something to speed up her death.

This story is apocryphal, but it well illustrates the quagmire of ethical issues that are commonly faced. No decision made on Grandma's behalf was without ethical impact. Rarely is there time or philosophic clarity to answer these questions carefully. As a result the default of modern medicine is pursued, and one technological intervention is added to another. In consequence a level of care is imposed on the patient that is far beyond what they ever wanted. This may prompt a look for an unacceptable way out, such as asking to "speed up her death." A death like this leaves patients and their families ill prepared. They had been living in denial while trusting the medical system to pull Grandma through. In the end, they are disillusioned and unhappy. This does not make for a "good death."

It is an understatement to say that there is a crying need for more ethical reflection on end of life care. This must involve the caregivers and the receivers, including patients and loved ones. *Ethics & Medicine* is committed to ethical values consistent with the Hippocratic tradition as it has come to us through traditional Judeo-Christian teachings. It is in that context that I will discuss the ethical issues raised at the end of life. The secular literature on end of life issues is growing daily. Much of this material is excellent and fully consistent with the values embraced by *Ethics & Medicine*. These values are often foundational to the hospice and palliative care movements. One of those values is that, as death approaches, life is equally precious to what it was in more active days. These values affirm that even in dying there can be healing and strives for that. The end of life is the time when the patient can come to closure with this life and bring completion to relationships, reconciliation with problems of the past, and a feeling of spiritual peace. Allowing for these activities contributes to a truly "good death." These things do not happen by default. They require time and intention. One tragedy is that medicine, by continuously offering one more treatment to deny or delay death, can prevent these very things from happening. On the other hand, preparing for death is not incompatible with aggressive medical care. It requires that even while we hope for life we must prepare for a good death. The question remains: What constitutes a good death?

A Good Death

Before you get into the essays in this fascicle let me share with you some things that can contribute to a "good death." First we must recognize that it is practically impossible to define a good death without a spiritual context. I am writing within the broad spectrum of Hippocratic physicians who believe in Judeo-Christian values. Within that larger community, I am a confessing Christian and will use the Bible as my authoritative guide to faith and practice. Some of these principles, however, will be applicable in other faith traditions as well.

1) *A good death is the natural trajectory of faith commitments made earlier in life.*

Many have said that we die the way we live.[3] This should be particularly true for Christians. There should be no discontinuity between the faith we live by and the faith we die by. Scripture teaches that Christ has defeated the enemy of death.[4] Death does not ultimately need to be feared though it need not be embraced. Christ's death and resurrection have purchased for his followers a hope of resurrection to eternal life, and in that hope they can approach their own demise. As a believer faces death, the sting of death is therefore removed.[5] A believer finds ultimate value not in this life but in an eternal relationship with God in Heaven. Therefore, a death that comes only as a fight to the finish after every possible technology has been exhausted may be a practical denial of the fact that death has been defeated and may not appropriate for a believer.

2) *A good death may require advance planning.*

A degree of control and self-direction is essential if we expect our later days to be consistent with our faith. This will typically require some form of advance directive and in depth discussion of your values with the individual whom you appoint as your power of attorney. It is imperative for that document to be carefully worded so as to be consistent with one's faith.

3) *A good death has completed relationships including those that need reconciliation.*

Ira Byock is the author of one of the seminal volumes in the death and dying literature, *Dying Well*. He speaks of the four things that need to be said as life comes to an end: *I love you*, *thank you*, *I forgive you*, and *forgive me*.[6] These represent Christian values as well. Byock reminds us that we may not have said these things enough in our active days. The more people who hear these things, the stronger our survivors will be when we are gone. These four statements also provide an occasion to reconcile relationships that have been broken.

4) *A good death comes after we cease clinging to the things and values of this world and increasingly embrace eternity.*

The apostle John wrote:

> Do not love the world or the things in the world. If anyone loves the world, the love of the Father is not in him. (1 John 2:15)[7]

A believer is to slowly give up on this world. This is not where ultimate joy and satisfaction lie. She is to be more caught up with the values and things of Heaven. She should be longing more for God's presence. This is a gradual process that should occur over the span of our Christian life. The example of the Psalmist is a model:

> O God, you are my God; earnestly I seek you;
>   my soul thirsts for you;
> my flesh faints for you,
>   as in a dry and weary land where there is no water.
> So I have looked upon you in the sanctuary,
>   beholding your power and glory.

> Because your steadfast love is better than life,
> my lips will praise you. (Psalm 63:1-3)

It is when we slowly loosen our grasp on this world and reach out for God that we prepare to die well.

5) *A good death comes to the one whose spirit has been enriched by the difficulties of the end of life.*

Gradual death is rarely easy. It includes difficulties that often include pain and suffering. Scripture teaches that "through many tribulations we must enter the kingdom of God."[8]

God can use these same difficulties to allow us to experience his grace more and in the process come to know him in a more intimate way. That is the basic message of the book of Job. It is what the prophet means when he speaks of us being the clay, while God is the potter.[9] It is what the apostle affirms when he writes that tribulation leads to endurance, character, and hope.[10] The most striking benefit is what Paul mentions in Philippians when he says that in sharing in the suffering of Jesus we are able to have fellowship with him. Fellowship implies not only that we experience his suffering but that he is there to help us when we suffer.[11] It is common to experience that the people we are closest to are the ones we have gone through difficulties with.

6) *A good death will often come after a carefully considered decision not to pursue life-sustaining treatment.*

The challenge is where we draw the line. At what point is it appropriate to pursue life-sustaining treatment and when is it licit to pursue comfort care only? We must not give up too easily. Scripture teaches that life is precious, our bodies are the temples of the Holy Spirit, and we must care for them as good stewards.[12] A Christian will therefore refuse suicide and euthanasia. But does that necessitate a vitalist position that pursues earthly life at all costs? That is a most important and most difficult question. Scripture does not give any explicit guidance for us. However, we can glean a suggestion from the apostle Paul by what he wrote to the Philippians.

> [A]s it is my eager expectation and hope that I will not be at all ashamed, but that with full courage now as always Christ will be honored in my body, whether by life or by death. For to me to live is Christ, and to die is gain. If I am to live in the flesh, that means fruitful labor for me. Yet which I shall choose I cannot tell. I am hard pressed between the two. My desire is to depart and be with Christ, for that is far better. But to remain in the flesh is more necessary on your account. Convinced of this, I know that I will remain and continue with you all, for your progress and joy in the faith, so that in me you may have ample cause to glory in Christ Jesus. (Philip.1:20-26)

Paul did not have multiple technologic options to choose from. He was simply facing the possibility of death and was trying to decide whether to hope to live or to die. His response was that he would hope to live if he could continue to serve others in their spiritual walk. Nevertheless he recognized that "to depart and be with Christ" was the natural end of a life spent serving others, and he would hope for that if he were no longer able to serve. With the many options that technology gives us today it may be reasonable to say that if there is reasonable hope that we will be able to serve others in any way, we should have our lives prolonged. That may include a scenario where we are totally dependent on some life sustaining technology or on other people but still able to pray for and encourage others. A distinction like this is very functional. I do not believe that my worth as a human being is in any way attached to my ability to function. Nevertheless, it may be appropriate to use a functional distinction like a reasonable expectation to be able to serve others as an indicator of when to forgo burdensome life-sustaining technology.

7) *A good death is peaceful, for the dying person knows that it will lead to resurrection and eternal life in God's presence.*

Death for a Christian is not the end; it is the beginning. It is the means by which God takes his child home to his eternal reward.[13] Paul did not have his sights set on a wonderful life here on earth. He was pressing on so that he would someday hear God's call to take him to Heaven.[14]

I believe these are some of the essential ingredients of a good death. You may note that some of the values traditionally considered to make up a good death are conspicuously absent. What about avoiding pain and suffering? What about maintaining one's dignity? I would never want to discount these values as things to strive for. Nevertheless, I believe they lose much significance when one comes to the end of life with a passion for God and his glory.

In This Journal

Listed above are some of the bigger picture items that go into a Christian view of dying well. We must keep them in mind and allow them to set the context for our further reflection. The big picture, however, is always made up of smaller parts. It is some of these that you will consider as you read the essays included in this edition of *Ethics & Medicine*.

Greg Rutecki demonstrates the tension between respect for the autonomy of an individual and her community and the respect for life. He discusses a tragic real-life case that shows how best intentions and generosity can confound medical ethics when they come face to face with cultural biases that promote lack of understanding. We are confronted with the reality that medical ethics are not straightforward.

Sylvia Dianne Ledger further emphasizes the complexity of end of life issues. She demonstrates how medicine has traditionally done a poor job with end of life palliative care. That has been especially true in the Netherlands and has driven not only a right to die movement but a cry for assisted suicide and euthanasia. She rightly argues for a higher standard of end of life care.

Kalman Kaplan gives us interesting insight into how our worldview will inform our interpretation of the difficulties of life and therefore do much to determine our response to them.

The final two essays force us to rethink some time-honored distinctions that have been held in end of life ethics:

A. A. Howsepian challenges the distinction between killing and letting die. Using some newer experimental data from neurophysiologist Libet, he asks if there is in fact a defensible distinction between the two. He shows that whereas in the philosophical world there may be a spectrum that can span from the libertarian to the determinist with the compatiblist in the middle, there is no such moral spectrum of culpability. Our actions and equally our inactions are either right or wrong, and we are responsible for them. It is unfairly reductionistic to say that killing is wrong and letting die justified.

Archimandrite Makarios Griniezakis speaks to some of the ambiguities involving brain death and thereby challenges some contemporary practices and legal definitions.

These essays will not lead us to easy answers to the complex ethical choices faced toward the end of life. The fact is that they may tend to muddy the water even further. Nevertheless, this type of careful scrutiny is good. I was taught years ago that "The more you know the more you know you don't know." This is particularly true here. If we are able to distill complex issues down to simple truths, it will only be after wrestling profoundly with the problems. I trust that reading this volume will help you to wrestle profoundly and that as a result you will be enriched in your understanding of these complex issues.

Our task is not to spout off quick answers. Rather, it is as was articulated so clearly 2500 years ago when the prophet wrote:

> He has told you, O man, what is good;
>   and what does the Lord require of you
> but to do justice, and to love kindness,
>   and to walk humbly with your God? (Micah 6:8). E&M

Endnotes

1 Kiernan, Stephen. *Last Rights*, St. Martin's Press, 2006. This is the general thesis of the book.

2 Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine, Truog et all, Critical Care Medicine 2001, Vol 29 No. 12 2332-2348

3 Kiernan, 67.

4 1 Cor. 15:26: "The last enemy to be destroyed is death." 1 Cor. 15:54-57: "When the perishable puts on the imperishable, and the mortal puts on immortality, then shall come to pass the saying that is written: 'Death is swallowed up in victory.' 'O death, where is your victory? O death, where is your sting?' The sting of death is sin, and the power of sin is the law. But thanks be to God, who gives us the victory through our Lord Jesus Christ."

5 1 Cor. 15:55: "O death, where is your victory? O death, where is your sting?"

6 Byock, Ira. *The Four Things that Matter Most*, Free Press, 2004, and *Dying Well*, Riverhead Press, 1997. This is the subject matter of *Four Things* and is also prominent in *Dying Well.*

7 All biblical quotations are from the English Standard Version (ESV) unless otherwise noted.

8 Acts 14:22.

9 Isaiah 64:8: "But now, O Lord, you are our Father; we are the clay, and you are our potter; we are all the work of your hand."

10 Romans 5:3-5: "More than that, we rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not put us to shame, because God's love has been poured into our hearts through the Holy Spirit who has been given to us."

11 Philip. 3:10 (NIV): "I want to know Christ and the power of his resurrection and the fellowship of sharing in his sufferings, becoming like him in his death…"

12 1 Cor. 3:16-17: "Do you not know that you are God's temple and that God's Spirit dwells in you? If anyone destroys God's temple, God will destroy him. For God's temple is holy, and you are that temple." 1 Cor. 6:19: "Or do you not know that your body is a temple of the Holy Spirit within you, whom you have from God? You are not your own…"

13 2 Cor. 5:6: "So we are always of good courage. We know that while we are at home in the body we are away from the Lord…"

14 Philip. 3:14: "I press on toward the goal for the prize of the upward call of God in Christ Jesus."

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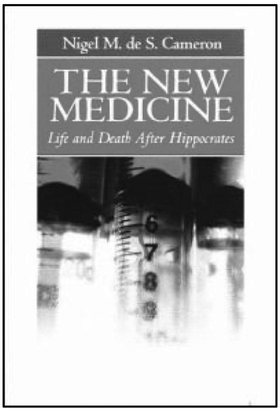
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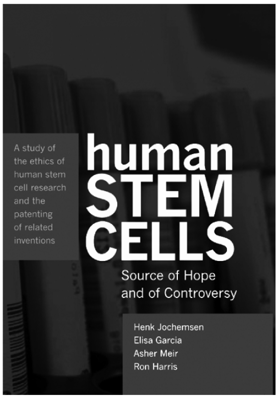
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CLINICAL ETHICS DILEMMAS: END OF LIFE ISSUES

PERMISSIBILITY TO ACCEPT REFUSAL OF POTENTIALLY LIFE-SAVING TREATMENT

GREG RUTECKI, MD

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

Column editor: Robert D. Orr, MD, CM, Consultant in Clinical Ethics, CBHD.

Question

Is it ethically permissible to accept this patient's refusal of potentially life-saving treatment?

Case

A 22 year-old woman has been re-admitted for treatment of active tuberculosis. She emigrated with her family from Somalia approximately 18 months ago.

Three months ago, she came to the hospital because she was coughing up blood. Work-up revealed pulmonary tuberculosis without evidence of spread outside the lungs. The organism was not resistant to standard therapy. She was not critically ill, had not lost weight, and was Human Immunodeficiency Virus negative. Active disease in family members was excluded. Her prognosis for cure was good. In addition, her inpatient and outpatient treatment was to be provided without charge by a religious hospital that exercised a prominent mission to the indigent community.

Therapy was begun, but she frequently refused medication and occasionally said she wanted to die. Her nurses suspected that she induced vomiting after taking her medication. She refused treatment by injection. Because of concern about compliance and contagion, the Health Department recommended inpatient, monitored anti-tuberculosis therapy for 6 weeks rather than discharge for outpatient treatment.

Multiple management conferences were held with translation services. Her parents and siblings were included, as well as a Muslim cleric, but support could not be engendered for the prescribed treatment goals. The Somalis perceive

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tuberculosis as a death sentence and could not be convinced otherwise in spite of hearing repeatedly that in contrast to the dire prognosis of tuberculosis in Somalia, the treatment here would have a high likelihood of success. She and her family were consistently resistant to the necessity of inpatient treatment and subsequent outpatient follow up.

She was diagnosed as depressed, but she also refused treatment for depression. Psychiatric, Palliative Care, Health Department, and Ethics committee consults were obtained. All the consultants were consistent in their exhortations for her to comply with therapy. She again refused injections and began to pull out intravenous lines. She completed the 6 week course, such as it was, had improvement in her symptoms and chest x- ray findings. She was sent home, presumably cured. She did not return for scheduled ambulatory visits.

She is re-admitted now, three months later, with fever and intermittent mental confusion. She has been found to have recurrent pulmonary disease plus tuberculosis inside her skull, both meningitis and a cerebellar abscess. It was surmised by the Infectious Disease Consultant that there were substantial medication gaps in her hospital regimen during the last admission. When lucid, she again refuses or expectorates her medications and pulls out her intravenous lines. Her family supports her decision to refuse medication. The attending physician has asked the ethics consultant to address the question: “Is it ethically permissible to accept this patient’s refusal of potentially life-saving treatment?”

The professionals caring for this patient understand that, like other African immigrants, Somalis have a high incidence of tuberculosis and complications.[1] One-fifth of infected Somalis have drug resistance compared to 2% of Americans. In this 22 year-old, the organism was sensitive to standard therapy (3 months ago), all drugs could be administered orally, with a significant portion of treatment performed at no cost in an ambulatory setting, and with a good prognosis for cure. Treatment at that time did not appear to be burdensome from the professional perspective. Now, three months later, her burden of treatment is considerably higher and her prognosis is much worse. Without aggressive treatment, she will likely die soon.

Discussion

Those involved in this patient’s care are experiencing a sense of helplessness and frustration. They are trying to prevent an untimely and avoidable death. Initial discussion should dissect why caregivers are being resisted by the patient, her family, and possibly their culture. What is animating their decision to forego life-saving therapy? With an expanding interface between the West and increasing diversity, this case may be a portent for the future. Specific questions should be answered by the consultant. What principles may inform the withholding of treatment when cultures clash? Is the burden of treatment reasonable? How can one remain culturally respectful while retaining personal moral agency?

To begin with, respecting others' beliefs is good. So how might this assertion simultaneously inform care and draw moral boundaries? Patients' preferred method of communication should be honored. Cultural assessments, such as the *Culture and Health Belief Assessment Tool* can assist.[2] Translating content like "what do you fear most about your illness" is critical, adding transparency to healing relationships.[3] How to break bad news, prayer, and identifying cultural bias to Western medicine are important. Healthcare is ministry and individuals should be involved in decisions, in a manner respecting their humanity. Respect for a diverse culture seems to be present here. Drawing mutual boundaries may be more difficult.

The consultant has learned that in Somalia, persons with tuberculosis are shunned.[4] There, tuberculosis is a death sentence, period. After moving to America, the stigma persists. Her family would be ostracized while she remained with them. As a family, they have no emotional support outside the Somali community, all of whom reside within a few miles. Her death would free the family from culturally-imposed isolation. So, they continue to refuse even after a complete cure has been repeatedly "guaranteed." The patient accepts this line of reasoning and is basing her refusal on her understanding of her obligation to her family.

Recommendations

(1) Based on this patient's poor prognosis and her firmly entrenched cultural beliefs, it is ethically permissible, though regrettable, to accept her (and her family's) refusal of potentially life-saving treatment. It may still be appropriate to attempt persuasion while therapy might be effective, but since this avenue has been used exhaustively, it is not likely to be effective. If her disease progresses to the point of irreversibility, further attempts at persuasion should be discontinued.

(2) If the patient continues to refuse curative therapy and it is expected that she will not survive, it is appropriate to offer palliative care measures, though the purpose of these (patient comfort) will need to be fully explained to her family.

Follow-up

Despite multiple multidisciplinary conferences with her family and community elders, each individual from her cultural background again agreed with her decision to decline treatment. She progressed to ventilator dependence as a result of progressive pulmonary and neurological complications. Her clinical situation worsened, she became comatose, and her family requested that ventilator support be withdrawn. She died immediately.

Commentary

Since life is so important, did we do enough? Should she have been forced to take potentially life-saving medications? Forcing this patient to take therapy, in the presence of family—restrained and sedated—would be cruel. It also would have to be forced by "foreigners."

How far can we proceed in defending life amidst a cacophony of cultures? Can we be more proactive? Is not cultural diversity a mission field in our communities? Might future Somalis be amenable to similar therapies if education can be provided in advance, before they are critically ill? Do diverse "others" (for example, those from other locations in Asia, Africa, or Latin America) have access to care as well as necessary relationships to develop mutual trust with caregivers? Or, are diverse groups in general outside the treatment pale because of lack of insurance? Sincere, non-judgmental efforts over time may prevent similar refusals, thereby transforming "diversity" into healing partnerships.

The efforts of the healthcare team and community in caring for this woman are commendable. Unfortunately, this young Somali's course will be played out in various scenarios as increasing diversity is imbedded into a "one size fits all who can pay" system. Either society is going to be politically correct and establish diversity itself as an absolute good—an easy way out—or shared decision-making will change for the better with caregiver compassion and education changing hearts. E&M

Endnotes

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THEMED ARTICLE: END OF LIFE ISSUES

EUTHANASIA AND ASSISTED SUICIDE: THERE IS AN ALTERNATIVE

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Abstract

People request euthanasia or assisted suicide if suffering is unrelieved; however, it is argued that patients stop asking to have their lives foreshortened when their symptoms are well controlled. The claim that a suffering individual has a right to die (i.e. receive euthanasia or assisted suicide) is discussed; however, the concept that an individual has a right to die is rejected on the basis that death is an inevitability, not a right. It is argued that the rejection of values, such as the sanctity of life and the intrinsic value of life, and the acceptance of euthanasia and assisted suicide erode the moral and social foundations of society. The practice of euthanasia and assisted suicide in the Netherlands is critically discussed, including: Dutch legislation, the decline in the number of reported cases of euthanasia and evidence of involuntary euthanasia. The doctrine of double effect is considered in relation to the use of opiates, and it is argued that appropriate use of opiates does not foreshorten life; indeed, it may even extend life. Finally, it is observed that rejection of euthanasia and assisted suicide by nurses and doctors results in a duty to relieve patient suffering. Experts in Palliative care need to disseminate specialist knowledge of holistic care and symptom control so that all dying people receive appropriate terminal care.

Introduction

Suffering and the relief of suffering raise many challenges for nurses and doctors, especially when the patient who is suffering requests active voluntary euthanasia or assisted suicide. The following seeks to explore the concept of pain and suffering and discusses issues relating to euthanasia and assisted suicide and alternative ways of relieving suffering.

According to Cassell[1] human suffering is "a state of severe distress associated with events that threaten the intactness of the person." It occurs when a person perceives the impending destruction of themselves, and is associated with a loss of hope. It effects the individual's physical, psychological and spiritual well being. Reich[2] also recognised the harmful consequences of suffering on a person; however, he argued that suffering was associated with anguish rather than distress. He stated that there was a difference between suffering and experiencing pain. Reich recognised that acute and chronic pain could cause physical, mental or emotional distress. He argued that this distress was not necessarily associated with physical pain, but could be due to mental agony caused by a number of

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factors including feelings of injustice, powerlessness, victimisation, dependency, shame and fear of obliteration following death.

The account of the suffering experienced by Diane Pretty[3] (table 1) and Lillian Boyes[4] (table 2) appears to reflect the physical, mental and emotional pain, anguish and agony identified by Cassell[5] and Reich.[6]

Table 1

In 2001, Diane Pretty wanted her husband to assist her to die, at the time of her choosing because she had end stage motor neurone disease. She went to the European Court of Human Rights in an attempt to obtain a court ruling to protect her husband from prosecution, if he assisted her to die. The European Court of Human Rights denied her the right to choose the time and manner of her death. Doyal and Doyal[3] argued that this decision was morally wrong because she believed that "she faces a death that she believes will entail indignity and suffering…physically, she cannot kill herself."

Table 2

Lillian Boyes suffered with rheumatoid arthritis and many other medical problems. Although she received 50 mg of diamorphine hourly, this dying lady's pain and suffering remained unrelieved. She, therefore, pleaded with Dr Nigel Cox, her consultant, to end her life. Despite the patient's immense suffering, Lillian Boyes was not referred to the palliative care team. Having attempted unsuccessfully to relieve this lady's pain, Dr Cox eventually granted Lillian Boyes her request for euthanasia, administering potassium chloride, which resulted in her death. Dr Cox was subsequently found guilty of attempted murder and was given a 12 month suspended jail sentence.[7] The judge ordered Dr Cox to work alongside a palliative care team for 3 months.

Ongoing, unrelieved suffering gives rise to loss of hope and despair. The patient whose symptoms have not/cannot be adequately controlled may ask for euthanasia or assisted suicide to escape their suffering and/or "restore" their dignity.

Unremitting pain is one symptom that causes much suffering, distress and anguish, yet there is on-going evidence that pain control is often poorly managed by nurses and doctors in different areas of care in the UK. Apparently "Pain is the most commonly perceived symptom in adults. In the UK, 40.7% of patients present to their GP with a pain problem, and many are under treated or suffer from incomplete pain relief".[8]

Shuttleworth[9] identified that pain management techniques had advanced tremendously during the last two decades; however, she reported that the Pain in Europe survey (2003) identified that about 800,000 adults in the UK live with chronic unrelieved pain. Nearly one third of these people experience severe pain, and about half experience constant pain. For the sufferer, the cost of living with chronic pain was huge. Shuttleworth reported that 16% of people living with chronic pain said that their pain "was so bad some days that they wanted to die."

From an international perspective, Shuttleworth[9] identified that because of poor international pain management, the International Association for the Study of Pain wanted pain relief to be recognised as a human right. On a national level, Wood, a freelance pain adviser, felt that the Department of Health should have included pain management in the Essence of Care.[9] This was a lost opportunity to highlight the need for appropriate pain management for those who continue to experience unrelieved pain. This is particularly significant as 86% of nurses reported that they had inadequate knowledge to provide effective pain management for their elderly patients, and 97% of these nurses desired to have more training relating to pain management.[10]

In relation to pain relief in terminal care, Billings[11] claimed that "Almost all pain faced by terminally ill people can be adequately relieved"; however, he stated that "clinical practice continues to be characterised by unrelieved pain, illogical prescribing of analgesics and widespread "opiophobia". It appears that some doctors (and nurses) remain reluctant to prescribe and administer appropriate opiates to relieve the pain and suffering. Harrison[12] said that "talking about morphine as a drug that will hasten the death of a patient is unsound and reflects a view that was held when we were very ignorant of the drug, considering it to be highly addictive and dangerous…" Harrison argued that lives can even be extended by appropriate use of opiates "under controlled circumstances".

Holdcroft and Power[13] recognised that pain does not only arise from physical disorders but may be "combinations of physiological, pathological, emotional, psychological, cognitive, environmental and social factors." Mann[14] also considered the multidimensional nature of pain and argued that "applying a traditional biomedical model that just looks for an organic cause of pain may fail some sufferers." She identified practical ways of improving pain control including "good communication, comprehensive assessment of the patient, and giving a proper and thorough explanation of treatment options."

From the above discussion, it is evident that many people continue to experience unrelieved pain and that many nurses and doctors fail to relieve their patients' pain adequately. This may be due to inadequate assessment of pain, failure to perceive the multi-dimensional nature of pain, inadequate knowledge of how to relieve different types of pain, inadequate prescribing and administration of analgesia and/or inadequate evaluation of the effectiveness of pain management. As many patients have a history of poor pain management, they may well believe that pain relief is not achievable. If dying patients experience continuous, unrelieved pain or other unrelieved symptoms, euthanasia or assisted suicide may appear to them to be the only option.

The word euthanasia is derived from the Greek *eu*, meaning well, and *thanatos*, meaning death, and means "1) The act of causing death painlessly to end suffering, especially in cases of incurable, painful diseases, 2) an easy and painless death."[15]

Active voluntary euthanasia therefore ends suffering and enables the individual to have a dignified and peaceful death. The fear of facing a degrading and undignified death is therefore removed. From the sufferer's perspective, it seems unjustified to deny such a request. It is argued that if a person's suffering remains unrelieved and they ask for euthanasia, then surely it is reasonable to respect their autonomous request. Kuhse[16] stated

> Mercy for a hopelessly ill and suffering patient and, in the case of voluntary euthanasia, respect for autonomy, have been the primary reasons given by those who have argued for the moral permissibility of euthanasia. Today there is widespread popular support for some forms of euthanasia and many contemporary philosophers have argued that euthanasia is morally defensible.

The Voluntary Euthanasia Society[17] strongly supports this view, and argue that everyone has a right to choose how they die and to control their own destiny. In 2005, Godfrey[18] reported that "legislation to allow assisted suicide and voluntary euthanasia has moved one step closer to being implemented with the publication of a House of Lord's select committee report last week." Despite the fact that the committee was divided on the necessity to change the law, the report on Lord Joffe's Assisted Dying for the Terminally Ill Bill recommended early debate of assisted suicide and voluntary euthanasia as separate issues, in the current session of parliament. The BMA[18] and the RCN[19] oppose such changes to the law. Maura Buchanan, RCN deputy president, said that "we firmly believe that with proper pain control and psychological care, patients are unlikely to ask for clinical help to die. We are also concerned about the position of the most vulnerable who may feel they should ask to die in order to avoid being a burden to their families."

The Right to Die

The right to die is a fundamental value of the Voluntary Euthanasia Society (2000). According to Beauchamp and Childress,[20] a right is a justified claim that a person can make upon another individual or society. It, therefore, follows that if a person has a right to die, then someone has a duty to help that person to die. However, it could be argued that no one can claim the right to die (or be killed) if the other person or society believes in the sanctity of life/intrinsic value of life.

In England, the right to life is fundamentally respected, and this value is reflected in the law and medical and nursing codes of practice. This value was confirmed by The European Court of Human Rights, which ruled that Dianne Pretty's husband could not be granted immunity from prosecution if he assisted in helping her to die. This ruling protected the fundamental right of society to live, not to die or be killed.[21]

Wilkinson[22] rejected the concept of "the right to die" arguing that "death was man's destiny rather than a right". He said that the phrase "the right to die" created confusion between an individual's rights and liberties. Referring to liberties, he stated that an individual could choose to commit suicide, thereby choosing the time, the means and the circumstances of their death. Wilkinson said

> If we are to speak of a right in relation to death and dying, it is not a right to die but a right to expect to be given all necessary and available support during the process of dying, a right to the relief of suffering and the alleviation of distress so that the person who is dying approaches death in comfort and in peace.

The hospice movement was founded on these values.

Objections to Euthanasia

Arguing from a Christian perspective, Wilkinson[23] said that "euthanasia implies that suffering is meaningless, therefore man must not be allowed to suffer". He rejected this argument stating that suffering can be meaningful and can give rise to much creativity. He stated that "out of suffering has come much of the world's greatest art, music and literature, and out of the suffering of the Son of God came the reality of our redemption. It is therefore not true to say that suffering has no meaning."

Wilkinson strongly supported the prevention and alleviation of needless suffering. But he rejected the idea that euthanasia could be justified because suffering was meaningless. He argued that "the doctor's task is to prevent or alleviate the suffering, not deliberately to end the life of the sufferer prematurely."

The BBC[24] reviewed the beliefs of different religions regarding euthanasia and assisted suicide and found that most religions disapproved of euthanasia and assisted suicide and some absolutely forbade it. Smith,[25] however, argued that mercy killing was not allowed under any religion. He said that Christianity, Hinduism, Buddhism, Judaism and Islam all refused to allow euthanasia to be practised. It is, however, recognised that whilst many people do not identify with any formal religion and concepts such as the sanctity of life, many atheists and agnostics respect the intrinsic value of life.

Christians believe that human life is sacred, and therefore, human life may not be destroyed. This concept is often referred to as "the sanctity of life", a phrase which does not specifically appear in the Bible. However, Vere[26] identified the biblical basis for human life being regarded as sacred, and stated that the sanctity of life refers to: "the particular respect which is owed to human life as the gift of God (Acts 17:25)"; that man was "created in God's image (Genesis 1:26-27)"; that everyone "has a duty to conserve and respect human life (Genesis 9:5 and 4:8-10 and 15)"; and that everyone has "to accept responsibility for the life of their fellow humans (Genesis 4:9 and Deuteronomy 21:1-9)."

Smith[27] reflected on the compassionate nature of God in Scripture, stating that the Bible shows God's "deep concern for the poor and weak, the fatherless and the widow." He argued that "nowhere in scripture is there a hint that the weak and frail should be helped to die, but rather they should be supported and cared for."

Chalmers[28] considered the importance of Christian ethical thinking which recognises the intrinsic and equal worth of every human being "regardless of age, health or any other extrinsic factor." According to Chalmers, caring for the sick and disabled is "a high social priority which characterises a compassionate society." He stated that Christian values underpin much of English law and social policy, and are "the basis for safe and responsible medical practice." He argued that "any erosion of such a core value weakens the foundations, not only of medical practice, but of society itself."

From a medical perspective, professional codes of practice, from the time of Hypocrites to the present day, have never sanctioned the killing of patients. Saunders[29] stated that "Voluntary euthanasia violates historically accepted codes of medical ethics". Indeed, Myers[30] argued that "The hallmark of a healthy society is how well it looks after its weakest and most vulnerable members. Rather than looking to provide a 'way out' for these people, we should be looking for more effective ways of caring for them".

A Review of Euthanasia in the Netherlands

Not everyone accepts that society would be damaged by accepting euthanasia as an alternative way to end life. Since 1973, the Netherlands have accepted the practice of euthanasia to relieve human suffering.[31] Euthanasia was decriminalised in the Netherlands in 1989 and was legalised in 2000 (table 3). It is estimated that every year about 3600 people receive voluntary euthanasia in the Netherlands.[32] Fewer than 400 children a year request euthanasia and those who request it are predominantly suffering with cancer or AIDS.[33]

Table 3

*The Dutch law and euthanasia**

According to Sheldon,[32] Dutch doctors must:

- be "convinced" that the patient's request is voluntary and well considered
- recognise that the patient is facing "unremitting and unbearable" suffering
- advise patients of their situation and prospects
- reach a firm conclusion with the patient that there is "no reasonable alternative solution"
- consult with "at least one other independent physician."

* the law legally recognises written euthanasia declarations

* minors aged 12-16 to may request euthanasia with their parents' consent

In 1995, a Dutch study estimated that only 41% of euthanasia and assisted suicide were being reported to the appropriate authority. In 2001, 2054 cases were reported, compared with 2216 cases in 1999. Sheldon[34] was concerned about this, but identified two possible reasons why reporting euthanasia and assisted suicide had decreased: a) it is possible that doctors are less willing to report cases of euthanasia to the euthanasia assessment committees because they could be seriously questioned regarding their decisions; b) there may be less cases of euthanasia and assisted suicide as doctors' knowledge of palliative care may have improved since 1997, when the Ministry of Health promoted palliative care in the Netherlands. However, in 2004, Dutch research identified about 3500 cases of euthanasia every year, but the percentage of cases not being reported to the appropriate Dutch authorities had increased to about 50%. Sheldon[35] reported that "a wider range of penalties" were being considered for doctors who did not follow legal guidelines relating to euthanasia and assisted suicide in the Netherlands.

The Slippery Slope: Non-voluntary Euthanasia

It has been argued that if voluntary euthanasia is accepted and made law, that non-voluntary euthanasia will follow. The Voluntary Euthanasia Society[36] rejected this argument. However, Dr Zylicz, a Dutch palliative care physician in the Netherlands, argued that non-voluntary euthanasia was becoming widespread in the Netherlands, thereby contravening the 1984 guidelines on euthanasia.[37] Chalmers[38] also reported concerns related to the use of non-voluntary euthanasia in the Netherlands. He stated that in 1993, the medical questionnaires relating to euthanasia was changed “to include a section related to active termination of life without express request.” According to Chalmers, the non-prosecution of doctors who undertook euthanasia in the Netherlands was thought to lead to an increased use of euthanasia. Apparently, an estimated 950-1000 people receive non-voluntary euthanasia every year in the Netherlands.

The question needs to be asked as to why euthanasia came to be practised in the Netherlands in the first place. Dr Zylicz, a Dutch palliative care physician in the Netherlands, argued that there were only 70 specialist palliative care beds in the country and only a few doctors were trained in palliative medicine. Doctors therefore resorted to euthanasia because they had no other means of relieving their patient’s suffering when their suffering became too great.[39]

In 2005, the findings of a three year Dutch Medical Association inquiry stated that doctors could assist patients to die “even though they may not be ill”.[40] Such patients would be “suffering through living”. According to Sheldon,[40] the report has “reopened a fierce debate over what constitutes the grounds for requesting euthanasia.” For people to be given euthanasia, Dutch law states that the individual must be “suffering hopelessly and unbearably”, however, it does not define the cause of the suffering as arising from a physical or mental cause.

An Alternative to Euthanasia

In 1988, Wilkinson[41] predicted “With the rise of the hospice movement and the availability of its knowledge and experience in the control of distressing symptoms in terminal disease, there is no longer any real indication for euthanasia.” Nine years later, Saunders[42] confirmed that patients who said “let me die” on admission, usually, after effective symptom control, were glad that “their request was not acceded to”. Dr Zylicz also identified that a quarter of the patients admitted to his hospice asked for euthanasia, “but none had actually used it.”[43]

As stated, one of the priorities of palliative care is excellence in symptom control. The National Council of Hospices and Specialist Palliative Care Services (NCHSPCS)[44] identified this, saying that “The intention of good palliative care for dying patients is to relieve their physical, emotional, social and spiritual suffering in the context of respect for their individuality, and without intent to shorten life.”

As far back as 1993, the NCHSPCS claimed that “with modern palliative methods almost all pain can be relieved, and can always be reduced”.[45] In the same year, the British Medical Association[46] reported that most pain could appropriately be relieved; however, it acknowledged that pain relief was not achievable for a very small minority of dying patients, despite the use of specialist methods of pain control. The World Health Organisation also reported that 87% of patients were rendered pain-free, 9% experienced acceptable pain relief and the remaining 4% experienced only partial pain relief.[47]

The risk of foreshortening life when giving dying patients symptom control, particularly opiates, has been the topic of much debate. Much of this debate pivots around the doctrine of double effect (table 4). This doctrine permits health care professionals to give treatment to dying patients, knowing that the treatment will foreshorten the patients' lives, provided that their moral intention is to relieve suffering rather than promote death. Death is merely the unintended consequence of relieving suffering.[48]

Table 4

The doctrine of double effect

- The act itself must be good or morally neutral
- The person must intend the consequences of the act to be good, not harmful.
- The person must anticipate and tolerate harmful consequences; however, good consequences must also arise from the act.
- The good consequences of the act must outweigh the bad consequences. It would be immoral to use bad acts to bring about good results.[48]

The doctrine of double effect was particularly highlighted during the trial of Dr David Moor, the General Practitioner who was acquitted of murder in 1999, as a result of giving his patient, George Liddell, a lethal dose of diamorphine.[49] Gillon[50] reported "breathing a sigh of relief" at Dr Moor's acquittal. He stated that, like Dr Moor, he had given large doses of diamorphine to patients "to relieve distress but foreseeing that my action might hasten death." Gillon argued that some philosophers claim that there is no difference between foreseeing and intending a harmful outcome arising from an action. This he strongly rejected on the basis that foreseeing and intending are different "logically, experientially, conceptually, legally and morally." The author, argues, however, that it is almost impossible to prove moral intention to another. Only the person involved in making a moral decision can know their own moral intention.

Regarding the doctrine of double effect, Twycross[51] was unhappy that morphine was often used to illustrate this doctrine, because it presented the false impression that the use of morphine was high risk. He argued that "when correctly used, morphine and other strong opiates are very safe." From clinical experience, he also suggested that the patients who have good pain control live longer than those whose pain remains uncontrolled.

Harrison[52] also rejected the notion that morphine foreshortened life. He asked for evidence that morphine kills people and questioned what constituted "a lethal dose of morphine." He cited different situations where he had given patients up to and exceeding one gram of morphine and stated the morphine did not appear to hasten the death of any of his patients. Indeed, he believed that these patients' lives may have been extended because adequate pain control removed the patients' desire to die.

It is recognised that even palliative care specialists cannot always relieve a minority of patients' symptoms. In such situations, Twycross[53] argued that "it may occasionally be necessary (and acceptable) to render a patient unconscious" in order to relieve suffering; however, he said that "it remained unacceptable (and unnecessary) to cause death deliberately." The foreshortening of such a patient's life would not be the doctor's moral intention; such a death would be an unintended consequence of treatment. Such treatment would be justified by the doctrine of double effect.

However, Rachels[54] rejected the doctrine of double effect, arguing that it is the consequences of a person's decision whic determines whether an act is morally right or wrong, not the moral intention of the person making the decision. According to Rachels, there would be no difference between intentionally ending the life of a patient like Lillian Boyes using potassium chloride, and the administration of morphine to a dying patient, knowing that morphine would foreshorten the patient's life. For Rachels, the moral intention of such decision makers may be different; however, the consequences would be the same, both patients would be dead. Whilst recognising Rachel's argument, the author argues that there is a difference between foreseeing and intending the consequences in professional practice.

Improving Care for the Dying: Medical and Nursing Education

a) Religious / spiritual care

Much has been written about the philosophy and claims of the hospice movement in relieving pain, distress and suffering of the dying by addressing the biological, psychological, social and spiritual needs of dying people. Meeting the religious and / or spiritual needs of dying people is particularly relevant in the light of the UK Census.[55] The Census identified that 71.6% of people said they were Christian and 76.8% of people claimed to have a religion.

According to Gatrad et al,[56] a good death should include religious perspectives because "faith is so important to so many people during their last days". They identified the fact that in America, 65 medical schools offer modules on spirituality and health and recommended that such "examples of good practice needed to be emulated in Britain". Nurses and doctors in the UK would surely benefit from such courses.

Gatrad et al[57] recognised that some people from migrant communities may find it difficult to access hospice care because they believe that "hospices, with their Christian roots, cater only for white Christian communities." This needs to be addressed because some dying people may, therefore, not access hospice care, and may seek euthanasia as a means to relieving their suffering. It appears that there is a need to develop multi-faith hospices and help nurses and doctors to further develop their knowledge and skills in multi-cultural palliative care. According to Gatrad et al,[57] there is currently no effective national training programme for healthcare professionals in transcultural medicine and most health care professionals have had little opportunity to learn about death and dying from a multi-cultural perspective.

b) Symptom control for people with malignant and non-malignant conditions

Traditionally, the hospice movement has provided care for people with cancer, focussing on a broad range of symptom control. However, the NCHSPCH and the Scottish Partnership Agency for Palliative and Cancer Care[58] identified the need to provide palliative care for people with progressive non-malignant disease. Higginson[59] picked up this theme, saying that in 1995 only 3.3% of new patients with non-malignant conditions were referred to hospital palliative care teams and only 3.7% of patients were referred to community palliative care teams. O'Brien et al[60] also identified the need for palliative care specialists to disseminate their knowledge and expertise in caring for patients with non-malignant conditions because "many symptoms experienced by cancer and non-cancer patients are similar." They argued that people with cancer sometimes suffer with more severe symptoms but that people with non-malignant conditions tended to have more prolonged symptoms.

Murray et al[61] stated that some patients with non-malignant disease had even greater unmet needs than patients with cancer. They regretted the fact that the new general medical services contract has not identified palliative care as a priority. However, they identified that the Gold Standards Framework would allow primary palliative care to gain momentum.

Evidence that palliative care principles are being applied to caring for people with non-malignant conditions was highlighted by Ellershaw and Ward.[62] They identified that the national service framework for coronary heart disease required cardiologists and palliative care specialists to develop evidence based guidelines for caring for people who were dying of heart failure. Intensive Palliative Care was developed for the dying patient with heart failure and includes physical, psychological, social and spiritual care for the patient and relatives. This care is divided into three aspects of care: symptom control, psychosocial care and bereavement care. Evidence-based guidelines have been developed to address all of these aspects of care. The quality of life for the person dying from heart failure will have been greatly enhanced by the application of hospice principles.

c) Improved symptom control by improved medical and nursing education

In 1995, Saunders[63] identified that poor medical and nursing education was a reason why pain control was poorly managed in terminal care. She stated that "until recently, the care of dying has rarely been included in the training of doctors and nurses. With a few notable exceptions, medical and surgical textbooks have ignored the problems of pain control." Ellershaw and Ward[64] identified that "The palliative care component is increasing in medical schools across the UK; the mean number of taught hours in a recent survey was

20". This may not be adequate, but it is a start. It is interesting to note that California has actually passed a law "requiring doctors to take courses in pain management and in care of people at the end of life."[65] Maybe the UK needs a similar law for nurses and doctors.

According to Wilkinson[66] doctors are servants of their patients' health and well-being—and should in no circumstances become their executioners. Doctors and nurses, therefore, have a duty to receive appropriate education, and practice appropriate symptom control so that patients are not driven to ask for euthanasia. Cicely Saunders has set us a shining example of what can be achieved in symptom control, we all need to catch her vision.

The NCHSPCS[67] stated that "the intention of good palliative care for dying patients is to relieve their physical, emotional, social and spiritual suffering in the context of respect for their individuality, and without intent to shorten life." If the Council believes "there is no place for the direct killing of patients at their own request," then patients need to be offered appropriate symptom control so that they do not feel the need to ask for euthanasia. As the House of Lords (1994) report on the Select Committee on Medical Ethics reported, "Rejection of euthanasia as an option for the individual entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled."[68]

Conclusion

Dying people who suffer from poor symptom control ask for euthanasia or assisted suicide. Poor pain control specifically gives rise to such a request. As there is evidence of poor symptom control in the UK, people will continue to ask for euthanasia. The right to die was explored, but this was rejected on the basis that death is an inevitability and not a right; however, the right of the patient to receive appropriate symptom control was presented. It was argued that euthanasia and assisted suicide do not demonstrate respect for the sanctity of life and the intrinsic value of life. The Dutch experience of euthanasia was critically considered. The hospice philosophy and expertise in palliative care was presented as an alternative to euthanasia and assisted suicide. It was argued that the expertise of the hospice movement needs to be extended much more to people who are dying from non-malignant conditions, and that there needs to be a greater emphasis on multi-faith hospice care. It was recommended that all nurses, doctors and students receive palliative care education and that they have the opportunity of working alongside palliative care experts in order to gain expertise in holistic care and in particular, symptom control. This would enable all nurses and doctors to achieve the best quality of life for people who are dying so that each dying person can "live until they die".[69,*] E&M

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THEMED ARTICLE: END OF LIFE ISSUES

ZENO, JOB AND TERRY SCHIAVO: THE RIGHT TO DIE VERSUS THE RIGHT TO LIFE

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Abstract

The stories of Zeno and Job are used to analyze the concept of rational suicide, the death of Terry Schiavo and the attendant collision between the right to die and the right to life movements in America. Zeno stubs his toe, interprets this minor event as a sign from the gods that he should depart and holds his breath until he dies. Job, in contrast, meets extreme losses with a deepening of his faith, and affirms his life. The inherent sense of life meaning and life value provided by biblical religion is contrasted with the relativity of life value so endemic to Zeno's behavior. This contrast is applied to the debate regarding the life and death of Terry Schiavo. Implications are drawn for medical ethics.

Introduction

The collision between the "right to die" versus the "right to life" movements crystallized around the death of Terri Schiavo in April, 2005. The controversy burst into public consciousness around the issue of legalized abortion emerging from the 1973 Roe vs. Wade decision of the United States Supreme Court.

Abortion right supporters marched under the banner of "freedom of choice" and have framed their argument as a civil liberty. Those opposing abortion promoted the "right to life" on the grounds that abortion represented nothing short of murder and the protection of the defenseless and innocent fetus. In reality, the issue of abortion inherently involved the balancing of two rights: that of the mother and that of the unborn fetus. And much of this turned on the question of when life begins and when a fetus achieves legal personhood. Advocates of abortion rights did not similarly advocate the right of a mother to commit infanticide, nor did opponents of abortion rights typically deny a mother the right to make other private decisions about her health.

The controversy came into clearer focus around the issue of physician-assisted suicide and euthanasia (deriving from the Greek term for a "good death.") spurred on by the continuing *de facto* physician-assisted suicides (PAS's) performed by Jack Kevorkian and his associates in Michigan. In 1997, The United States Supreme Court overturned two lower court rulings in denying that there is a constitutional right for physician-assisted suicide (*Washington vs. Glucksberg, 1997)*. More recently, however, the Supreme Court refused to hear the appeal of Oregon's "Death with Dignity" act, which was passed in

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1994 and reaffirmed by the voters of Oregon in 1998. The upshot of the present court position is to deny that PAS is a constitutional right. However, it does not preclude individual states from enacting laws to either allow or forbid PAS.

The Terry Schiavo Case

The unsettled nature of this controversy exploded around the case of Terri Schiavo. Her case is concisely described by Paul McHugh in is excellent article in the June 2005 issue of *Commentary*.

> In 1990, when Terri Schiavo was in her mid-twenties, she suffered a severe cerebral anoxic injury (low amount of oxygen in the body's tissues-and coma). From this coma, she emerged gradually, setting for the next fifteen years into an impaired state of consciousness. She could swallow, breathe, sleep, and awaken without assistance and could react to sudden sounds with a glance, or to pain by grimacing or groaning. But she was apathetic to inner needs and external events. She was mute, mostly immobile, incontinent, psychologically blank (*119 (6)*, pp. 27-28)

During the several years before her death, Terri Schiavo was being treated in a hospice for terminally ill people. The hospice provided nursing care for Terri's basic bodily needs (being bathed and turned on schedule) and she received nutrients through a feeding tube that had been inserted through her abdomen into her stomach. She developed frequent bedsores, and a good deal of tooth rotting, and muscle contractions that twisted her limbs into a fixed contorted position. Terri <u>was</u> sustained by the regular attention of a devoted staff and family (her parents and her siblings) and was financially supported by money her husband Michael had won for her treatment through a successful malpractice suit.

Terri would have remained in this condition until, within a period of years, an infection, a blood clot, or some cardio-respiratory difficulty would have ended her life. "What changed," McHugh tells us, "was not her physical condition but her husband's mind."

Terri's husband Michael was her legal guardian and had first battled for her care and support. However, he gradually lost hope and perhaps interest in her further recovery. This change of attitude was evidenced by his resistance to permitting antibiotic treatment for a recurring bladder infection. He ultimately demanded the withdrawal of all sustaining treatments, including the gastric tube that provided nutritious fluids to Terri or any feeding of her by spoon or cup.

Terri's parents, however, strongly disagreed with Michael's view that Terri was beyond hope of recovery and launched a long legal fight with him for her guardianship, with the intention of continuing her hospice care and her feeding whether by the feeding tube or by mouth.

McHugh provides a chilling summary as to the disposition of this case.

> Through a series of court battles, legislative enactments, and executive

> mandates, the husband's right of guardianship was upheld, the gastric tube was removed, and all-hospice staff, parents, siblings, onlookers were forbidden by court order to give her food, or drink orally. Even a chip of ice to relieve the pain of a parched mouth and throat was judicially prohibited, and local sheriffs were alerted to prevent it. Within thirteen distress–filled days, she died of dehydration. (p. 28)

McHugh cogently examines the question of how this terrible state of affairs came to be. He points out that the overarching principle of hospice medical staff is that while they may help a patient *surrender* to death, by foregoing active medical procedures when these seem to be futile, they must never *betray* a patient to death, or act directly to kill him. In a hospice the staff does not provide a ventilator or cardiac monitoring at a patient's bedside, because there is no plan to transfer a patient back to acute treatment. However, the hospice will treat the symptoms of certain potentially deadly fatal conditions, such as bowel obstructions and blood clots, but will not treat the conditions themselves. Under no circumstances does hospice care deprive the patient of being kept clean and receiving food and water. In Terri Schiavo's case, just as the team did not withdraw her bladder catheter, which helped to keep her clean, so did it not withdraw the gastric tube. These judgments may be somewhat ambiguous, or even arbitrary, but they are usually clear.

McHugh argues that in this phase the treatment of Terri Schiavo went terribly wrong. Terri's husband, Michael, began to feel hopeless regarding her and perhaps his own future as well No functional studies (like an MRI) were done to determine whether her cerebral cortex, the brain region most responsible for coherent behavior, showed any evidence of recovering. Further, there was a good deal of inconsistency in the testimony of bedside observers. Some observers reported evidence of some small and slow steps toward consciousness, while others thought that she displayed only reflex reactions. Michael was told that Terri's diagnosis was "persistent vegetative state", an unfortunately loaded term encouraging those who no longer saw her as an animate being and infuriating those who believed it labeled her as a vegetable. McHugh suggests that a more dispassionate neuropathological term would have described Terri as being in a "decorticate" condition.

At this point, Michael, Terri's guardian husband, was no longer willing to allow her to be fed, and under Florida law he had the right to demand that her nutrition be stopped. And it is here that McHugh makes his most telling point.

> As soon as Terri Schiavo's case moved into the law courts of Florida, the concept of "life under altered circumstances" went by the boards – and so, necessarily, did any consideration of how to serve such life. Both had been trumped by the concept of "life unworthy of life," and how to end it… (p.31)

McHugh uses the term " life unworthy of life" advisedly, as he is aware that the phrase originates in a book coauthored by Hooch and Binding, a lawyer and a psychiatrist, and published in Germany in 1920, entitled *Die Friegabe der Vernichtung Lebensunwertes Leben*, which translates into English as *Lifting Constraint from the Annihilation of Life Unworthy of Life*. The concept of "life unworthy of life" of course was instrumental in the Nazi T-4 euthanasia program and became the subject of one of the leading propaganda films of the Nazi Party in 1939: *Dasein ohne Leben* (Existence without Life).

McHugh argues that "Terri Schiavo's husband, and his clinical and legal advisers, believing that hers was now a life unworthy of life, sought, and achieved its annihilation." McHugh asks the question of how this could happen in America in 2005. This, after all, is not Nazi Germany. McHugh tellingly argues that we have created our own "culture of death, whose face is legal and moral and benignly individualistic rather than authoritarian and pseudo-scientific." McHugh concludes his incisive analysis with a chilling summary, which unfortunately mirrors our own clinical and professional experience.

> Contemporary bioethics has become a natural ally of the culture of death… In Terri Schiavo's case, it is what won out over the hospice's culture of life, overwhelming by legal means, and by the force of advanced social opinion, the moral and medical command to choose life, to comfort the afflicted, and to teach others how to do the same. ...More of us will die prematurely; some of us will even be persuaded that we want to." (p.32)

The Biblical Case against Rational Suicide

Let us examine McHugh's analysis within a comparison of the classical Greek philosopher Zeno and the Biblical figure of Job (Kaplan et. al., in press). According to the ancient Greek chronicler Diogenes Laertius, Zeno, the founder of the Stoic school of philosophy, wrenched his toe on the way home from lecturing at the *Stoa* (porch) and subsequently voluntarily held his breath until he died (Diogenes Laertius, 7.28). Leaving aside the question of whether it is possible to commit suicide in this manner, the event as described above seems curious from a common-sense perspective. Why should Zeno kill himself after so seemingly minor an annoyance as wrenching his toe? The leap from wrenching one's toe to killing oneself seems monumental.

Understanding Zeno's actions necessitates examining more closely the Stoic school of thought regarding suicide. Suicide must not be undertaken frivolously, "but if he [god] gives the signal to retreat as he did to Socrates, I must obey him who gives the signal, as I would a general." (Epictetus, *Discourses*, 1.29).

In this quote, the contemporary writers, Droge and Tabor (1992, 29-39), find a precedent for "rational suicide," which has provided the justification for physician-assisted suicide (PAS). Voluntary suicide is condoned when it is necessary (Greek: *anangke*) and rational; it is condemned when it is irrational. A rational suicide is preceded by an apparently divine signal that the time to die is at hand. In other words, Zeno killed himself by holding his breath, not because he broke his toe, nor because he was in pain, nor even because he was depressed, but because he bought into the notion that the event of stubbing his toe represented the divine signal to depart (Droge and Tabor 1992, 31).

The Biblical figure of Job, in contrast, does not commit suicide despite being assailed by far more serious misfortunes. First Job is stricken the loss of his great wealth, and then the deaths of all his children. He reaffirms his faith in God: "Naked came I out of my mother's womb, and naked shall I return thither; The Lord gave, and the Lord hath taken away; Blessed be the name of the Lord." (Job 2:21)

Finally, he was inflicted with severe skin inflammations all over his body. He took a potsherd to scrape his boils as he sat in ashes. And now, his wife urges him to blaspheme God and die (Job 2:9). Job rejects his wife's view: "What, shall we receive good at the hand of God, and shall us not receive evil?" (Job 2:10). Though he is deeply grieved, he reaffirms his relationship with his Creator. "Though He slay me, yet will I trust in Him." (Job, 13.15)

Droge and Tabor's argument that Zeno's actions represented a precedent for rational suicide is curious as they do not seem to fall into the usual criteria for rational suicides outlined by Siegel (1986) or Werth (1996) which themselves are extremely problematic. For Siegel, the defining characteristics of a rational suicide are: (1) the individual possesses a realistic assessment of his (or her) situation; (2) the mental processes leading to his (or her) decision to commit suicide are unimpaired by psychological illness or severe emotional distress; and 3) the motivational basis of his (her) decision would be understandable to the majority of uninvolved observers from his (or her) community or social group (Siegel, 1986, p. 407). It is difficult to conclude that Zeno's behavior meets any of these criteria. Zeno is not realistic regarding the relatively minor effects of stubbing his toe. He seems unduly distressed regarding such a minor event. Finally, Zeno's actions are definitely not understandable to an average uninvolved observer.

Consider Werth's three criteria for determining whether a patient's decision to die is "rational" and thus "sound". First, the person considering suicide must have a *hopeless condition*. Second, the person must make the decision as a *free choice*. Third, the person must be engaged in a *sound decision-making process* (Werth, p. 61). Zeno's behavior is definitely not hopeless. He does seem to be making his decision out of free choice, but sometimes the definition of free choice is not so clear. Finally, his decisions do not seem to reflect a sound decision-making process.

Given all this, Droge and Tabor may yet be correct in citing Zeno's actions as a precedent for rational suicide. However, they may not be focusing on what is rational in Zeno's act. *Zeno's rationality lies not in his interpretation that stubbing his toe represents a sign from the gods that he should depart, but rather in his need for the events in his life to have meaning*. Zeno is aging and feels alone, and he deludes himself into thinking that the act of stubbing his toe has cosmic meaning. Zeno becomes a hero, even if he dies in the process. Its inherent rationality is not that stubbing his toe is a sign to depart, but that it is better to have a world in which one's actions are given meaning, even destructive meaning, than one in which they are not. In the absence of a religious system, which gives life meaning, Zeno is cast adrift, forced to over-interpret events in an attempt to feel less adrift and isolated.

Job, in contrast, has no need for this over-interpretation. He is anchored in a sense of a personal Creator who is with him from the moment of his birth and will be with him into his death and beyond. Thus, he can withstand far greater misfortune than can Zeno without the need to attribute cosmic meaning to it. Job is able to maintain his sense of innocence to his Creator even while expressing his faith in Him. He has no need to give cosmic interpretation to his misfortune, or to be a hero. This does not make Job less rational, but simply anchors his interpretive structure in his relationship to his Creator. Job's God gives and takes away life, but does not give signals that it is time for Job to depart. Job is not obsessed with death, nor does he need to control it, nor does he need to worry that it is timely. Job thus does not interpret each event as a signal to exit, but as a challenge to live the life that has been given to him in dignity.

Job knew his God gives and takes away life but does not give signals that it is time for him to depart because of any imperfection or disability. The value of each human life is infinite in biblical thought (see Jacobovits, 1959; Maimonides, 1962; Rosner, 1998; and Sherwin, 1998, for a somewhat different view). Job did not focus on the "quality of his life." Life is life, and it is whole and of one piece. As such it does not allow arithmetic operations that compare one life against another. One cannot divide, multiply, add or subtract infinity. Life is life, indivisible and whole, and each life is of unique and unqualified value and cannot be compared to any other life.

Job does not focus on any particular attributes that make life worth living or not. Indeed this is not a question that even occurred to Job. Our experience with Nazi euthanasia must make us worry of any philosophy suggesting that some lives are not worth living. Even familiar and seemingly benign bromides—such as the Cartesian assertion, "I think therefore I am" (*Cogito ergo sum*) (Descartes, *Les Discours de la Method* IV) and Socrates' "the unexamined life is not worth living" (Plato, *Apology* 38)—must be viewed cautiously with eyes wide open. Though usually interpreted as statements in praise of self-examination and knowledge, they can easily be turned into an attack on the right to life of the cognitively impaired.

This latter direction has emerged in the utilitarian bioethics of Peter Singer (1975, 1979, 1995). While Singer's original work championed animal rights, his argument degenerates into a morally dangerous obliteration of the traditional and biblical distinction between humans and nonhumans. In the biblical world, human beings are distinguished from animals. They have dominion over the animals and must watch out for them. For Singer such distinction between human beings and animals is *specieism*. Singer instead offers a functional distinction between persons and non-persons. Persons, whether human or animal, are beings that feel, reason, have self-awareness, and look forward to a future. In other words, Singer's "persons" are sentient. Non-persons, in contrast, are beings that do not have these capabilities—in other words are non-sentient. For Singer, the category of persons includes sentient nonhumans, such as porpoises. One can debate this argument, and even seen his argument as humane. However, it is the second part of his reasoning that is so chilling:

the category of non-persons includes cognitively impaired human beings, for example, human beings with Alzheimer's. The killing of such human beings would not be described as murder, as these nonsentient creatures would not be distinguished from non-sentient animals. It is but a small step from Zeno the Stoic to Singer's non-sentient human being to Terri Schiavo. None of the above has sufficient quality of life to justify its continuation. For Zeno the Stoic, the death sentence is self-imposed; for Terri Schiavo it is imposed from without.

Job, in contrast, clung to the knowledge that his misfortunes did not make his life less worthwhile in his Creator's eyes. Though Job questioned the justice of his suffering, if anything, these tests ultimately served to deepen his faith. It is true that Job suffered grievously and indeed did not understand why this suffering had come upon him. However, he knew he had done nothing evil to warrant these miseries, and he rejected his wife's suggestion to "curse God and die." (Job, 2:9)

Her suggestion neither made much sense nor was it at all positive. Was cursing God supposed to cause death? Probably not. Job's wife was merely expressing her deep hurt and anger, and her feeling that life was useless and that it would be best to end it. His wife's response was similar to the attitudes that relatives too often show to a family member who seems very ill. Either the relatives feel the patient cannot bear continued suffering or, because they themselves do not wish to have to deal with his sufferings, the relatives may actually encourage euthanasia (so called) or even direct suicide, whether unaided or doctor-assisted, as in some of Kevorkian's many cases and perhaps in the death of Terri Schiavo. The patient comes to feel that he is no more than a burden to his "loved ones" and may accept euthanasia or suicide as a means of relieving and releasing them from what he perceives as the burden he has placed on them.

Though Job despaired to the point of cursing the day of his birth (Job, 3:1), he nevertheless held to his conviction that even in the midst of his suffering his God greatly preferred life to death. Job rejected his wife's view and began his long and determined course of questioning that finally did bring him to a new closeness to God and to a higher understanding, both intellectual and emotional, of the purposes of human life. He refused to give in either to his wife's unthinking rejection of God's gift of life or to his friend's suggestions that Job must have sinned and was therefore being punished by God. Job, indeed, lived through his many sufferings, despite the pressure from his wife and his friends.

Job was not obsessed with death, nor did he need to control it, nor did he need to worry that it is timely. Job thus does not need to interpret each event as a signal to exit, in a fruitless attempt to find meaning in the heroic. Job simply needed to live the life that has been given to him in dignity.

And this is the best alternative and antidote to the obsession of death with dignity and rational suicide so endemic to Zeno the Stoic, Nazi euthanasia, and considerable trends in contemporary bioethics. These contemporary forces are working to turn the default in medicine from patient life to death. This must be combated with all our strength and a biblically-based ethic in this regard is a good place to start. E&M

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THEMED ARTICLE: END OF LIFE ISSUES

CEREBRAL NEUROPHYSIOLOGY, 'LIBETIAN' ACTION, AND EUTHANASIA

A. A. HOWSEPIAN, MD, PHD

Abstract

I assess, in this essay, some of the philosophical implications of a unique research program under the direction of neurophysiologist Benjamin Libet. Some of the conclusions reached by Libet extend far beyond physiological bounds into the metaphysician's arena and, hence, have been hotly debated in both the scientific and the philosophical literature.[1] *Libet claims to have discovered empirical evidence for the existence of a novel neurophysiological mechanism compatible with the operation of libertarian free will in human subjects. Before one fully raises his skeptical brow, the sheer ingenuity of Libet's key experiments must be adequately appreciated. I will, therefore, initially attempt to impart the essentials for any such appreciation. I next shall argue that although Libet has not supplied metaphysicians with the specifically libertarian 'freedom-friendly' neurophysiology that they may have been hoping for, his proposed neurobiological model has potentially important implications for the cogency of an internal theory of action. I further argue that the adoption of an internalist action theory informed by Libet's interpretation of his experimental results would, in turn, force us to restructure our action-theoretic accounts of activity and passivity as they are typically understood in metaphysical and ethical discourse, primarily as they appear in the field of medical ethics in which there is a frequent invocation of an alleged morally relevant distinction between 'killing' and 'letting die'. I conclude by suggesting that, if Libet is correct, there is good reason to believe that our ordinary conceptions of what constitute 'active' and 'passive' euthanasia are deeply mistaken.*

I

Neurophysiologist Benjamin Libet believes that he has discovered empirical evidence for the existence of a cerebral mechanism by which libertarian free will might operate in human subjects. Understanding Libet's key research result depends critically upon adequately understanding both the notion of a *readiness potential* (RP) and the notion of a *voluntary act*. The RP is defined by Libet as a "scalp-recorded slow negative shift in electrical potential generated by the brain and beginning up to a second or more before" a self-initiated, apparently voluntary motor act.2 (Libet: 1985, p.529) Additionally, Libet stipulates that

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> …an act is regarded as voluntary and a function of the subject's will when (a) it arises endogenously, not in direct response to an external stimulus or cue; (b) there are no externally imposed restrictions or compulsions that directly or immediately control subjects' initiation and performance of the act; and (c) most important, subjects feel introspectively that they are performing the act on their own initiative and that they are free to start or not to start the act as they wish. (1985, p.529)

Voluntary acts in Libet's experiments consisted of "simple quick flexion[s] of the wrist or fingers at any time [subjects] felt the 'urge' or desire to do so." (Libet: 1985, p.530) The main negative RP shifts in Libet's experiments preceded such acts by an average of 550 milliseconds.

Although RP measurements and EMG (electromyogram) measurements of hand-finger movements were fairly straightforward and unproblematic, measurements of the most crucial variable (i.e., the subject's conscious intention to act) called for more creative techniques. The goal here was to time, as precisely as possible, the subject's conscious awareness of intending (or deciding) to act. Of course subjects were unable *physically* to register such intentions at the precise moment of their experiential appreciation due to the physiologically determined, physically necessary time-lag between the neural genesis and the corresponding muscular terminus of any neuromuscular event. According to Libet:

> For present purposes the experience of the time of the first awareness of wanting to move ("W") was related by the subject to his observation of the "clock position" of a spot of light revolving in a circle on the face of a cathode ray oscilloscope (CRO); the subject subsequently recalled and reported this position of the spot.... Thus, the timing of this experience was converted to a reportable, visually related spatial image, analogous to reading and later recalling the clock time for any experience. This indicator of the time of first awareness of the intention to move could then be compared to (a) the actual time of the voluntary motor act, as indicated by the EMG recorded from the appropriate muscle, and (b) the time of appearance of the simultaneously recorded RP that is generated by the brain in advance of each act. For all self-initiated acts studied, the actual mean Ws for each series of 40 acts averaged about-200 ms…; that is, subjects reported becoming consciously aware of the urge to move 200 ms before the activation of the muscle (EMG).[3] (Libet: 1985, p.532)

Across all studies and all subjects, RPs were followed by an awareness on the part of the subject of intending to move (W). Furthermore, counter to expectation, these RPs were consistently found to *precede* Ws by an average of approximately 350 ms. One apparent implication of this finding is that the cerebral initiation of a *voluntary* motor act *begins unconsciously*. Now if this were the end of the story, libertarians might feel compelled to acquiesce and join the chorus of strict determinists in singing a dirge for liberty.[4] But more remains to be told. Libet has also discovered that subjects were able *consciously* to ‘veto’ actual motor performance during the approximately 150 ms *after* the conscious appreciation of the intention to act.[5] This further finding has led Libet to conclude that “voluntary acts can be initiated by unconscious cerebral processes before conscious intention appears but that conscious control over the actual motor performance of the acts remains possible.” (Libet: 1985, p.529)

Given these research results, Libet proposes the following thesis (T):

> ... conscious volitional control may operate *not* to *initiate* the volitional process *but to select and control it*, either by *permitting* or triggering the final motor outcome of the unconsciously initiated process or by *vetoing* the progression to actual motor activation. (Libet: 1985, p. 529, emphases not in original)

The philosophical implications of (T) are understood by Libet to be as follows:

> ... [I]t is important to emphasize that the present experimental findings and analysis do not exclude the potential for “philosophically real” individual responsibility and [libertarian] free will. Although the volitional process may be initiated by unconscious cerebral activities, conscious control of the actual motor performance of voluntary acts definitely remains possible. The findings should therefore be taken... as...affecting the view of how free will might operate. Processes associated with individual responsibility and free will would “operate” not to initiate a voluntary act but to select and control volitional outcomes. (1985, p.538.)

Libet claims, therefore, not that he has demonstrated the existence of incompatibilist freedom in human subjects, but only that he has discovered a mechanism by way of which libertarian free will might operate in human agents.

In spite of Libet’s philosophical appraisal of his empirical results, it may initially appear, from the libertarian’s point of view, that (T) has no metaphysical promise at all. Although, as suggested by Libet, the physiological framework which supports (T) surely allows for libertarian freedom (as might a number of other biological frameworks) it does not, on the face of it, seem to *recommend* such a view. How, after all, would such a recommendation go? The intractability of the free will problem is widely attributed to the inability of philosophers to identify (to anyone’s satisfaction) a *tertium quid* between determinism and what is thought to be the essential *randomness* (or *arbitrariness*) that is the mark of simple indeterminism. What new light might a neurophysiologist shed on this situation? Libet proposes that the agent’s “conscious volitional control” might somehow “operate” by “either...permitting or triggering the final outcome of the unconsciously initiated process or by vetoing the progression to actual motor activation.” (Libet: 1985, p. 529) But even if each component of (T) could be sharpened and clarified, the dilemma of freedom remains, viz. Does one’s ‘conscious volition’ operate randomly or deterministically? If randomly, such that one’s apparent selection and control of unconsciously initiated motor processes is in some sense random or arbitrary, then it is hard to see how any human action could be a *free* action; and if deterministically, then, by metaphysical libertarian lights, (in spite of an *apparent* 'ability' freely to 'veto' the physiological progression to motor activation) again, the subject in question would be no free agent at all.[6]

Thus, in Libet's scheme, the dilemma of freedom has merely been pushed back one step to involve the conscious *veto* of a neuromuscular event. One is then left to ask, Would not this relatively *indirect* veto mechanism be somehow more hospitable to the instantiation of specifically libertarian freedom than would some more *direct* neurophysiological mechanism? I do not see how it would. At least there is no obvious advantage to an indirect, as opposed to a direct, neurobiological mechanism in this domain as far as the metaphysical libertarian is concerned. Hence, as far as I can tell, *Libetian* neurophysiology does not appear to offer the metaphysical libertarian a biological system that is obviously more hospitable to incompatibilist free will than other contemporary neurophysiological alternatives.

So, is Libet's neurophysiology *completely* devoid of philosophical merit? I will presently argue that, philosophically speaking, there is more to be said for Libet's account than might initially meet the eye. Although (T), even if true, fails immediately to give the libertarian what she wants, the action-theoretic principles suggested by (T) may be of acute philosophical (specifically, action-theoretic) interest.

An illustration at this point might prove to be illuminating. Suppose that you witness Jones' right arm move vertically at t_1. Further suppose that when asked, "What did you do at t_1?", Jones replies, "I raised my right arm at t_1." If, however, Libet is right, then it appears that Jones is mistaken: if Libet is right, it appears clearly *not* to be the case that raising his right arm at t_1 is something Jones *did*. Rather, if Libet is to be believed, Jones appears merely to have *allowed* his right arm to move vertically at t_1. An unconsciously generated cerebral process, not an agent, *initiated* this movement and Jones, in virtue of his *intending* to move his arm, *allowed* this neuromuscular process to unfold without interruption.

It is *not* as if Jones *intended to allow* his right arm to move vertically at t_1. Jones, let us suppose, is wholly unaware of Libet's research and, hence, is wholly unaware of the possibility that his right arm's moving vertically is the sort of thing that he could have merely *allowed* in this situation. Rather, Jones allowed his right arm to move vertically *in virtue of* intending to raise his right arm.

Thus, if we are correct in saying that Jones did not *raise* his right arm at t_1, i.e., if Jones merely allowed his right arm to move vertically at t_1, then it seems that the only action involved in Jones' right arm moving vertically at t_1 is Jones' *allowing* his right arm to move vertically, not Jones' *actually moving* his right arm vertically at t_1.

It would be a confusion, in any case, to run together a(n) (active) doing with that which is allowed. No one, for example, would claim that Jones' allowing Peters to rake the leaves entails that Peters' raking the leaves is something Jones did. Nor would we want to claim that Jones' allowing the lamp to fall entails that the lamp's falling was something Jones did. Likewise, we must not be tempted to think that Jones' allowing his right arm to move vertically entails that Jones' moving his right arm vertically was something Jones did. Clearly, both the lamp's falling and Jones' right arm's moving are happenings (or events) which Jones allows, not actions which he performs. But if this is so, then the only action which Jones performed at t_1 was his allowing his right arm to move vertically. Jones, therefore, did not perform an action at t_1 that entails Jones' moving his body.

Next suppose that at time t_2 you notice that Jones' right arm is *not* moving. Further suppose that when asked about what he is doing at t_2 Jones responds, "I am refraining from moving my right arm." On further questioning, Jones emphatically denies that his right arm is merely *not moving* at t_2; rather, he asserts that he is not moving his right arm at t_2 in spite of the urge *to* move his right arm at t_2. He is explicit about his *intending to refrain* from moving his right arm at t_2, and adamant in his *denial* that he is *merely not intending* to move his right arm at t_2.

So, if Libet is to be believed, we are to understand Jones' action at t_2 as his vetoing the spontaneously and unconsciously generated chain of neural events whose terminus was to be the movement of his right arm. Because Jones' body did not move at t_2, it is very clear in this instance that Jones' action at t_2 also did not involve Jones' moving his body. Thus, because Libet's neuropsychological interpretation of his empirical results allows for only two sorts of activities on the part of an agent, viz. *allowings* and *vetoes*, no *Libetian* actions involve an agent's causing any musculoskeletal events and, therefore, no human actions involve one's moving one's body.[7]

Libet's neurophysiological scheme, therefore, suggests a particular *theory of action*, *viz*. a theory in which human actions are all *internal* to agents. Of course even if Libet is incorrect, this may in fact be the correct metaphysical analysis of human action. So, it appears that even though Libet has not obviously supplied us with a distinctive libertarian-friendly neurophysiology, his neurophysiological results appear, forcefully, to recommend an internal theory of action.

In this light, it is of interest to note that (among others) Brian O'Shaughnessy (1973) and Jennifer Hornsby (1980) defend theories of action in which (a) all actions are internal to agents, and (b) all actions are identical to an agent's 'tryings' – or, alternatively, to what Roderick Chisholm (1979) calls an agent's 'undertakings'. Although space constraints prohibit a detailed explication and evaluation of these minimalist theories, it is important to point out that these theories do seem to have virtues which non-minimalist theories of action lack *inter alia* theoretical simplicity as well as a clear, sharp demarcation between actions and their consequences.

II

What implications might a Libetian theory of action have for the larger philosophical community? I would like to suggest that one especially noteworthy implication of Libet's theory is its impact on our understanding of active and passive agency, especially as it arises in the domain of medical ethics. Much of the current discussion concerning ethics at the end of life hinges on an alleged moral distinction between intentionally killing a person S and intentionally letting S die. The former act-type of killing in medical contexts is often termed 'active euthanasia' while the latter act-type is often termed 'passive euthanasia'.[8] There are some philosophers, of course, who do not endorse a 'killing/letting die' (and, hence, an 'active/passive' euthanasia) moral distinction. (See, for example, Rachels, 1975.) Nevertheless, those who do think that there is such a distinction often base this distinction on the extent of neuromuscular activity (and subsequent environmental manipulation) involved in various types of human activity.

So, for example, Dr. Kevorkian's administering a lethal injection to a woman with early Alzheimer's Disease is thought to be a paradigmatic case of active killing. On the other hand, Dr. Kevorkian's withholding antibiotic therapy from a similarly mildly cognitively impaired patient, mindful of the lethal consequences of his withholding while at the same time intending her death, is thought to be a clear case of allowing that patient to die. Many ethicists believe that the latter action, in which a debilitated patient is allowed to die, is, or at least could be, morally permissible; whereas the former action, in which the same patient is actively killed, is in every instance morally impermissible.

But in Libet's model it appears that this 'killing/letting die' distinction is to be understood in a radically different way. The administering of a lethal injection, rather than being an *active* process, is something that Dr. Kevorkian *allows* his body to 'do'. Dr. Kevorkian, in this instance, merely refrains from vetoing the unconsciously generated cerebral process which eventuates in his patient's death. The *apparent* activity, on the other hand, of administering a lethal injection is, when viewed through Libet's lens, really a species of action-theoretic *passivity*. Rather than being a set of actions that Dr. Kevorkian directly performs, the bodily movements involved in Dr. Kevorkian's administering a lethal injection to a woman suffering from early Alzheimer's Disease have their origin in unconscious cerebral processes which Dr. Kevorkian merely allows to unfold.

On the other hand, one's refraining from moving one's body (whether that bodily movement from which one is refraining would have eventuated in the administration of a poison for purposes of killing or in the administration of antibiotics for purposes of healing) is an active process on Libet's scheme. According to Libet, in cases of refraining (or vetoing), the agent *actively blocks* the distal neuromuscular expression of an unconsciously initiated proximal cerebral process.

Thus, given the cogency of Libet's action-theoretic account and applying this account to conceptions of human activity and passivity as commonly understood in contemporary discussions concerning the ethics of euthanasia, it appears that what is typically considered *active* euthanasia (or 'killing') might actually be a *passive* process, and what is typically considered *passive* euthanasia (or 'letting die') might actually be an *active* process. The ethical implications here ought to be clear for those who believe that there is a morally relevant distinction between active and passive agency in the context of the euthanasia debate. The dominant voices of the western medical tradition have always proscribed all instances of active human killing in medical contexts, but permitted certain instances of passive 'killing'. (For an example of a document that discusses the alleged moral relevance of this distinction see the 1973 statement from the House of Delegates of the American Medical Association.)

What is being considered *active* in this domain is one's *refraining* from *some particular* action or other, whether this action is the administering of a poison or the action of administering an antibiotic – *not* one's acting without any (non-refraining, external) action in mind at all. *Refraining* from action A is more than *simply not doing A*. Person S can not do A at time t in two ways: (i) by *simply* not doing A at t, i.e., such that S does not do A at t *and* S does not refrain from doing A at t (i.e., such that S does not *intend not* to do A at t), and (ii) by *refraining* from doing A at t, such that S does not do A at t *and* S *intends not* to do A at t. In typical medical cases of what is called 'letting die', certain treatments are *intentionally* foregone (or removed). For example, one *intends not* to administer a life-preserving antibiotic, thereby *refraining* from administering life-preserving treatment that might, thereby, result in one's patient's death.

So, *if* my analysis of action based on Libet's neurophysiology is accurate, and *if* actively, intentionally killing our patients is unethical, *then* all instances of what is *currently* called 'passive euthanasia' are in fact unethical, *and*, based on the fact that at least some cases of what is currently called 'passive euthanasia' are unethical, it follows that at least some cases of what is currently called 'active euthanasia' are also unethical. (I am thinking of cases, for example, in which a relative assigned as durable power of attorney for a patient who is not competent to make her own medical decisions hates the patient for which he is the surrogate decision-maker and wants the patient dead both because he hates her and in order to collect on a life insurance policy and, therefore, on these grounds alone declines the administration of potentially life-preserving treatment on the patient's behalf.)

It is important to note that the traditional metaphysical distinctions concerning activity and passivity and the moral distinctions that are parasitic on these – independent of Libet's contributions to this discussion – were clearly never meant to denote mere *bodily* activity and passivity; rather, it is activity and passivity of *agency* that is central. Suppose, for instance, that Dr. Jones were, in one instance, to undergo partial complex seizure activity during which his fists were to beat violently against patient Smith^1's cachectic, malignancy-riddled frame resulting in Smith^1's immediate death. Then suppose, in a second instance, that (all the while being mindful of its lethal consequences and primarily in order to lessen his clinical work-load) Dr. Jones were to refrain from administering anti-cancer chemotherapeutic agents to patient Smith^2 resulting in Smith^2's death. (Smith^2, let us say, is also cachectic and malignancy-riddled, but very much wants to live and has been predicted to live with an adequate quality of life for another six months.) We clearly would not, of course, want to say that in the former instance, merely because Dr. Jones' *body* was the active instrument of Smith^1's death, that Dr. Jones, *the agent*, *actively* killed Smith^1, and, therefore, that Dr. Jones' action with respect to Smith^1 was unethical, while Dr. Jones' action with respect to Smith^2 was passive and, therefore, simply for that reason, ethically permissible. In this latter case, the agent, Dr. Jones, one might say, *actively* refrained from preserving his patient's life for morally culpable reasons. And in the former case, Dr. Jones was not acting in the capacity of an agent at all. Clearly, therefore, one's body's moving is not a sufficient condition for the *activity of that agent* whose body moves.[9] Of course, if Libet is right, neither is it a necessary condition.

But if there is a metaphysical distinction between bodily activity and the activity of an human agent, and if there is a morally relevant difference between active killing and passive killing, and if Libet's neurophysiological framework is an accurate model of human action, then it seems that those who have argued that active killing entails bodily activity of a given sort while passive killing is (in those instances in which life-preserving interventions are withheld) marked by one's refraining from making certain bodily movements have been deeply mistaken. What I am suggesting then is that, if Libet is right, persons who were once thought to be making sound ethical decisions concerning the treatment of the dying, might actually be the agents of those evils which they have, all along, been attempting to avoid.[10] E&M

Endnotes

1 See, for example, Churchland (1981), Libet (1981, 1985), Libet, Freeman, and Sutherland (1999), and Dennett (1991), especially chapter 6.

2 Given the subjects' explicit self-directed vigilance during the experimental procedures it appears that, when not executing "self-paced, apparently voluntary act[s]" (Libet 1985, p.529), subjects were *intending not* to execute such acts. The RP therefore seems to be an electrophysiological phenomenon which consistently precedes the awareness of an intention to undertake only apparently *voluntary* motor acts (as opposed to *apparently* voluntary acts which do not have any motor effects, e.g., intendings *not* to move). The subjects may be most accurately viewed here as *intending not to move*, not as merely *not intending to move*.

3 It is important to note that 'W' (what Libet, early in this passage, calls "the first awareness of wanting to move") is in fact more accurately (later in this same passage) referred to as "the first awareness of *intention* to move" (emphasis added). Clearly not all wants to perform some action A need result in intentions to perform A.

4 Where *strict* determinism entails an *incompatibilism* between determinism and free action. If strict determinism is true, therefore, no actions are free. Of course, even without the discovery of the neurophysiological *veto* mechanism to be discussed, the libertarian need not feel compelled to defect to the determinist camp, whether strict or otherwise. Should it be possible *freely* to form an *unconscious intention* which precedes and causally contributes to both the RP and the *conscious intention* W, for example, then one may still find some neurophysiological room for (specifically libertarian) liberty. I am indebted to Thomas P. Flint for bringing this point to my attention.

5 See Libet, et al (1982 and 1983) for details of these veto measurements.

6 Of course, by *compatibilist* lights, determinism is no *barrier* to free action; in fact, some versions of compatibilism *require* it. Libet, however, is concerned with how the cerebral neurophysiological mechanisms that he has discovered might be hospitable to the interests of specifically *libertarian* metaphysics. It might be of interest in this context to note that, although it remains substantial, the distance between libertarian and compatibilist metaphysics has recently been narrowed. See Howsepian (2004).

7 This is not, of course, the only manner in which to interpret Libet's empirical results. Sir John Eccles, for example, has proposed a psychophysiological model of human volition which is compatible with Libet's data, "but that nevertheless preserves fully the role of conscious intention in initiating...movement" (Libet, 1985, p.542).

8 What is crucial to active and passive euthanasia rightly understood is that they both involve the intention that one's patient dies. One can, of course, imagine myriad clinical scenarios in which treatment is withheld or withdrawn in which one's intention is not one's patient's death but, for example, relieving patient suffering or some other (non-intrinsically evil) motive.

9 Although Dretske (1988) correctly dissociates an agent's bodily movements from the concept of an agent's action (e.g., *not-moving* can also be an action according to Dretske), he does not take the further step of suggesting that *not-moving* might signal a species of action-theoretic *activity* while *moving* might signal a species of action-theoretic *passivity*.

10 I would like to thank William C. Davis, Thomas P. Flint, and Benjamin Libet for helpful comments on earlier versions of this essay.

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THEMED ARTICLE: END OF LIFE ISSUES

LEGAL AND ETHICAL ISSUES ASSOCIATED WITH BRAIN DEATH

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Introduction

People seem occupied with the war in Iraq on a daily basis. While this threat is real, especially to those living in the immediate surrounding region, a greater, and far more "realistic" threat remains hidden behind closed doors. While people are killed in the blink of an eye during battle, the drawn out debate over the status of "brain death" appears to have long-term effects on the lives of human beings. The far-reaching discussion around the end of life and the moment thereof has brought to light great uneasiness.

The difficult issue may be tackled from a variety of perspectives, each presenting a case for or against the use of the phrase "brain death" when defining the end of human life. This article focuses on the legal and ethical concerns. Specifically, by pointing to numerous problematic issues surrounding brain death, it calls for caution when using a cortical definition of death. The medical declaration of brain death seems to overturn otherwise tested and needed medical measures and precautions, especially those of advanced medical directives and informed consent, and ethical considerations regarding autonomy and personhood.

Legal Issues

Testing for Brain Death

Inevitably, one interested in the medical definition of death has to encounter the limitations on the definition that have been established by the law. Physicians may have personal beliefs about the constituent elements of death, but the law limits the implementation of these personal opinions. Oftentimes, the law rightfully sets limits for the medical field; overzealous physicians, in their effort to help others, as well as patients in vulnerable circumstances, need a protective mechanism that will help avoid further complications and injury. Baumgartner clearly understands the crucial role of the law in the medical field when he states, "What physicians need is a clear legal framework to be able to deal with difficult and often extremely conflicting clinical decisions consistently" [1].

In the definition of brain death, the law throughout the world has come up short. Surely, the law has established certain criteria for the determination of brain death as written in the Uniform Declaration of Death Act, but in essence, it has allowed physicians the freedom to interpret and implement the law in ways

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they *personally* deem acceptable[2]. The problem with testing for brain death may also stem from the fact that most states in America "…require no special qualifications or training, beyond a general medical license for the individual performing brain death examinations"[2]. If physicians do not obtain special training that thoroughly explains the legal criteria for brain death, the methods available for its testing, and the social and ethical dilemmas involved, then a physician may use his/her preconceived understanding of brain death and perhaps wrongfully diagnose death.

Additionally, one can see evidence of laxity in American law in the fact that most states do not specify medical tests necessary for confirming brain death. Many physicians realize that the nature of the law established to direct medical practice, specifically dealing with brain death, forces physicians to seek answers to their legal dilemmas beyond the American legal system. Physicians in the United States have consequently begun to refer to literature from around the world, and have made the mistake of implementing many of the legal practices of foreign countries within America. Because of this international conversation, "…the practice of many physicians declaring brain death in the United States may have changed from the Uniform Determination of Death Act of the 1980s, although medical and legal definitions of brain death in the United States have not changed"[3].

Advanced Directives

A possible answer to the entire brain death issue includes advanced medical directives (AMDs). As Finnerty states, "An advance directive is an individual's legal way to document wishes for medical care in advance of loss of capacity from illness or injury"[4]. Although advance directives protect an individual's right to make personal decisions about the care that s/he desires, especially in the event when one loses the capacity for conscious decision-making, they do not have the same function in cases of brain death. If medicine believes that a brain dead person ceases to exist, then that person—already viewed as deceased—in effect loses all rights that s/he previously possesses.

Advanced directives do offer insight into whether or not a person wants to donate his/her organs, and it may even prohibit the use of life support. In the later case, brain death does not become an issue because the person will eventually die from cardiac and pulmonary failure. Although advanced directives may prevent the initiation of life-support, physicians and family members run into problems when the person requests to remain on life-support regardless of his/her medical condition. In cases where people find themselves in a vegetative state; i.e., where the person shows signs of cortical activity, physicians and the law cannot ignore such a request. On the other hand, one wonders if a brain dead person's wish has the same legal and medical stance. If one supports Beresford's statement that, "Brain death is synonymous with death of the person and has legal significance,"[5] then a conflict arises between personal rights and the medical definition of death[6]. One can therefore conclude that although advanced directives provide some legal and medical insight in brain death cases, they have little to offer once the person has died.

Informed Consent

Although informed consent has little to do with the diagnosis of death—no one can consent to be considered dead—it finds its way into the present discussion because oftentimes family members provide the consent to cease life-support when the patient has lost consciousness. This usually takes place with comatose individuals in the United States, who possess some cortical function, but whose condition appears seemingly irreversible. In cases of brain death, "…physicians needn't obtain their [i.e. family members] permission to stop mechanical support when someone has been declared brain-dead. This is quite different from 'withdrawing treatment' from a living patient. You can't 'treat' or 'withdraw treatment' from someone who's dead"[7]. This circumstance seems to parallel the issues surrounding advanced medical directives; a person who has died ceases to exist and therefore does not have rights nor receives treatment.

Informed consent plays a critical role in brain death cases when the procurement of human organs comes into play. When physicians diagnose brain death, the family members have the opportunity to donate their loved one's organs if they feel that such action represents his/her desire. In order for a family to properly provide consent, the physicians should first try and determine the family's conception of death, otherwise, "…consent will surely be invalid" [8]. If those who offer consent do not adhere to a cortical definition of death, then organ procurement—even with "informed consent" from the patient before his/her current condition—may in fact constitute an act of murder in their eyes. In addition, some family members may still consent to the donation of the organs after a thorough understanding of the medical position. In a recent Australian opinion, people expressed that physicians can look after the viability of future transplant programs by simply telling the truth about brain death[8].

Some further concepts derived in order to procure organs from potential donors include "presumed consent" and "mandated choice." In cases of presumed consent, legislation would allow doctors to procure organs from eligible donors unless s/he objected before death or the family objected at the time of the diagnosis of death. This appears sensible at first, but soon one realizes that many people have a deep reverence and respect for the body even after death, which presumed consent might violate. In addition, if presumed consent represents normal practice in the procurement of organs, then physicians might overlook or ignore providing proper information to the family members, which may prove vital to their decision.

Mandated choice would force individuals to state their preference regarding organ donation, e.g., at the time of driver's license renewal. Such legislation might solve the lack of organs for donation, but one must ask how seriously a person has studied and thought about the topic in the short span of time between renewing one's driver's license. Mandated choice becomes problematic for young people because, "Most young persons do not contemplate losing capacity and being in a terminal state and have no incentive to consider end-of-life decisions"[4].

Ethical Issues

Autonomy

The ethical issue of autonomy has recently made its way into the legal discussions of bioethical issues. Faden and Beauchamp acknowledge this reality when they write, "…autonomy is the most frequently mentioned moral principle in the literature on informed consent"[9]. In our modern society, 'autonomy' has come to imply the right of "self-determination, self-rule, and individual choice"[10]. This means that each individual has the right to accept or reject treatment if s/he feels that this will benefit him/her, regardless of the fact that this treatment may ultimately have a beneficial or detrimental outcome. As each person has the right to be an autonomous agent, one can argue that the physicians and the researchers have a duty to protect and respect the autonomy of each person who steps into the hospital or the laboratory. Physicians must do everything in their power to protect and maintain the ailing person's autonomy by making them active participants in their therapy.

A problem arises with one's autonomy when the individual in question is said to be categorically brain dead despite respiratory and cardiac functioning. When physicians have the ability to pronounce a person on life-support as dead, his/her autonomy ceases to exist as well. Such a person, along with the respective family members, does not become an active participant in the medical treatment. The patient never receives that opportunity; once physicians make the diagnosis of brain death, they understand the patient as a cadaver and merely a potential organ donor. Van Norman brings the issue into perspective when he states, "Once a patient is dead, s/he ceases to have autonomy. Indeed, once dead, an individual ceases to exist at all"[3].

Personhood

From within the entire discussion between medicine, law, ethics, and religion on the constitution and definition of death, there emerges a need to grasp the constituent elements of personhood. The President's Commission struggled with this question and tried to set strict criteria to determine its cessation. It concluded that personhood has a direct link to cortical function[3]. Following this line of thought assumes that personhood represents something that an individual can acquire or lose at some point in life. By extension, one can assume that degrees of personhood may exist depending on the degree to which the brain functions.

A definition of personhood based on cortical function has both grave ontological consequences as well as deep ethical consequences. If one can determine degrees of personhood based on the level of cortical function, then unborn humans arguably do not possess personhood, or at best very small traces of it. Further, Anacephalic human beings would not possess any personhood, and the mentally retarded and the elderly, who may have possessed great amounts of personhood at one time or another, now possess a diminished or limited personhood. Once this type of thought penetrates society's understanding of a person, several injustices may occur against those classified as having little or no personhood. In the case of the brain dead—who by definition do not possess any personhood—physicians might take it upon themselves to end life-support arbitrarily and procure organs without taking the necessary steps to protect the patient's rights.

Conclusion

Despite those arguably positive aspects of the category of brain death, the use of such a class has troubled the ethical and legal waters. It is difficult, if not impossible, for a physician to confidently come to an absolute and certain conclusion over the status of a brain dead patient; uncertainty and doubt is present when pronouncing brain death because of the unclear line between life and death. The variety of legal guidelines throughout the world and the physician's own beliefs concerning life and death hinder the chances of arriving at a positive pronouncement of brain death. The use of advanced medical directives and informed consent measures has been shown to have very little value in cases of brain dead individuals. The argument may be made that these two topics should not be discussed along with that of brain death, but they are extremely important when the patient and his/her family reject a definition of death surrounding the cessation of brain functioning. The traditional ways of viewing autonomy and personhood also come into conflict with brain death. If a patient is considered brain dead, then his/her desires and rights as autonomous persons are automatically restricted or eliminated altogether.

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GREY MATTERS

Glimpsing the Grey Marble

WILLIAM P. CHESHIRE, JR., MD

Quiet as an eyeblink clicked the camera shutter from the window of Apollo 17. Astronauts Cernan, Evans, and Schmitt on December 7, 1972 captured the first clear and fully illuminated image of Earth ever taken from space. This historic and widely circulated “Blue Marble” photograph of our fragile globe, depicted in vibrant blue, green and white and suspended in the vast blackness of silent space, has stirred the imagination of a generation.

Having glimpsed the Earth as a whole, the way we think about our world is forever changed. Now we have seen the Blue Marble and recognize it as our common home. Viewed from space, no political, military, racial or linguistic divisions disrupt its contours. Planet Earth is one world and a shared habitat. All who dwell on the geologic wrinkles of its rotating topography belong to a global community.

Earth is also a special home. No other known planet’s surface temperature is so finely tuned that water can exist in its threefold phases of ice, liquid and gas. Plentiful water, sunlit and tranquil, gives Earth its distinctive celestial beauty. In years past, only portions were visible from the surface. Seen from space, the full expanse of gleaming glacial shelves, deep blue oceans’ shimmering waves, and cumulus clouds’ soaring swirls all burst into brilliant view.

From space one can also appreciate that planet Earth is a vulnerable milieu. Its life-giving atmosphere delicately clings to the globe as a thin rim insulating its surface from the void beyond. Rivers flow as tiny bright trickles. Mossy forests’ margins dwindle. Fertile plains extend to finite borders. Natural resources that seem, from the surface perspective, to stretch as far as the eye can see are, from the vantage point of space, precious and limited and not to be taken for granted. The awe-inspiring Blue Marble image fosters a sense of shared responsibility.

Another historic image acquired from an orbiting perspective is transforming our mental view of human nature. 1972 was also the year that Hounsfield and Cormack invented computed tomography (CT), for which they were later awarded the Nobel Prize. Its first medical application was to acquire images of the human brain. The patient undergoing a CT scan lies motionless on a table within a doughnut-shaped tube, while a beam-emitting x-ray tube and corresponding detector rapidly encircle the body, gathering a series of images from sequential angular positions. In this way the CT generates cross-sectional representations, or slices, of human anatomy. CT provided the first clear and anatomically detailed images of the living human brain. All the gyral folds of

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grey matter previously hidden beneath the skull have come into splendid view, arrayed in shades of digital grey on the computer display.

This "Grey Marble" image of the human brain is increasingly capturing the imagination of humanity. Images of the human brain now abound in a world that ponders what neuroscience is revealing about the three pounds of neural tissue that reflects on the origin and purpose of itself and the universe.

Whereas there is one image bearing the name Blue Marble corresponding to the one Earth, there are in medical clinics worldwide multitudes of Grey Marble images representing just a fraction of the billions of people inhabiting the Earth. Grey Marble images lack sufficient detail to show individual particularities and do not distinguish among differences in gender, ethnicity, language or nationality. The Grey Marble is thus a fitting portrait of our shared human cognitive nature. Yet we also know that each brain is biologically and biographically unique and that every person is special.

Viewed as a whole, a number of features of the Grey Marble stand out. The frontal, temporal, parietal and occipital lobes are not physically disconnected as are earthly continents but merge one into another. While each cortical area has its own specific function, brain regions are also integrated and interactive. The dynamic behavior of widely distributed neural fields compose the neural correlates of consciousness. This intangible quality of self-awareness still eludes full explanation by neuroscience, for the subjective and the spiritual aspects of life encounter a dimension of reality as imperceptible to empirical investigation as is wind to the camera. Words, like clouds, briefly outline their direction, and then fade away. Within the brain, streams of thought meander through unanticipated contemplative terrain. Seasons of passion and lassitude come and go. Ideas sail the seas of surging neurochemistry, while emotions keep their curious ebb and flow. Within this paradoxical seat of human intelligence coexist the potential for stormy anger and gracious kindness. And at each extreme of polarized debate lie accretions of icy obstinacy.

The Blue Marble has aroused an ethic of ecology concerned with the responsible use and preservation of Earth's natural resources. Environmental awareness extends also to the brain, for it matters what kind of thoughts we choose to fill our brains with.

Wrapped within the Grey Marble is a world of ideas. Just as planet Earth is home to complex ecosystems hosting amazing diversity of life not easily visible from space, the brain is far more complex and subtle than whole brain imaging studies can represent. The Grey Marble is emblematic of interconnectedness. Each of its hundred billion neurons has, on average, 3000 synaptic connections with other neurons. Some individual neurons receive as many as 150,000 contacts. A cubic millimeter of cerebral cortex contains about a billion synapses. When disease severs those connections and neurons fail to communicate with one another, the brain functions poorly. Visualizing the brain as a whole evokes an understanding of intelligence consisting of a variety of cognitive functions combined into a community of thoughts. The brain is a unit, though it is made up of many parts, and though all its capacities are many, they form one mind. Hence when reason conflicts with intuition in grappling with an ethical dilemma, all the brain's resources are needed to discover wisdom. Just as humble microorganisms are essential to healthy flourishing of advanced life on Earth, even the pathways in the brain that seem to be weaker are indispensable. If one part suffers, the whole brain suffers with it. The fusiform gyrus needs the calcarine cortex. The prefrontal cortex needs the amygdala.

There are limits to what images can convey. Although digital technologies are reconstructing images of the Earth and of the brain in progressively finer detail, it must be remembered that, just as pictures of Earth from space detect only its surface, images of the brain visualize only its material nature. Moreover, at any given time, the Blue Marble is only half a picture of planet Earth. The brain, too, has its bright side and its dark side.

These wondrous marble images are reminders that the Earth, its inhabitants, and its minds are gifts and not things of our own making. How their images are rendered, whether as dull or vivid, affirming or dismissive, cynical or hopeful, will shape how our culture thinks about human cognitive nature from its tenuous beginning to its earthly end.

Through scans we perceive the grey matter as in a mirror dimly. Nevertheless, the human mind open to the light of truth shines with rainbows of understanding, thanksgiving and blessing. The full potential of the human mind can be realized once the brain is full of the knowledge of the LORD as the waters cover the sea. E&M

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BOOK REVIEWS

The Ethical Dimensions of Psychoanalysis: A Dialogue

W.W. Meissner. Albany, N.Y.: State University of New York Press, 2003.

ISBN 0-7914-5690-0; 371 PAGES, PAPERBACK, $29.95

W. W. Meissner addresses the complex interaction between ethics and psychoanalysis with painstaking attention to the intricacies of Freudian thought. He takes a comprehensive approach with chapters specifically devoted to psychoanalysis and ethical systems, freedom of the will, ethical decision-making, and deception and values.

One of the difficulties in describing the interaction between psychoanalysis and ethics is the evolution of psychoanalytic theory through Freud's career as well as developments by Freud's immediate followers. Psychoanalysis takes a rather broad view of ethics as a set of rules or codes governing right and wrong behavior. Freud made little distinction between morality and ethics; he felt that morality was self-evident.

At the very outset, Meissner attempts to deal with Freud's view of ethics. Freud felt that psychoanalysis was ethically neutral and focused instead on *metaethics* to describe *how* ethical rules came into being for an individual as well as a society. Meissner quickly points out the inconsistencies in Freud's stated position and his disclaimers of the "…moral rigidities of traditional views and societal norms." (p.9)

Meissner is careful to point out some of the conflicts as well as the common ground between psychoanalysis and Christianity. Freud quickly came to a position that humans were unworthy and that psychoanalysis doesn't make for goodness. While he initially believed psychoanalysis would help people become better human beings, in due time he realized that it didn't. Common ground between psychoanalysis and Christianity is the acknowledgement of evil and a belief that it is basic to human nature

Meissner describes several places where Christianity and psychoanalysis part ways. In what I believe is his clearest chapter, Chapter 8: "Ethical Perspective of Psychoanalysis," Meissner states Freud found *agape* love to be "…impossible and ethically perverse." (p.167) Freud believed that *agape* love encouraged false allusions because not everyone is equally lovable. He also felt that the paradoxical effect of attempting *agape* love would lead to destructiveness and unnecessary guilt. Instead, Freud felt that people need to adjust their moral precepts to each person's psychological capacity. Unfortunately, Meissner does not present how this position allows for cultural standards or civil laws.

In several sections of the book, the author illustrates unsuccessful attempts by psychoanalysis to take firm positions devoid of value judgments. For example, in the last chapter of the book, "Values," Meissner shows that psychoanalysis holds that "…values and value systems are essential components of personality organization and, therefore, of the self." (p. 291) He then goes on to show that psychoanalytic personality theory contains "ideal-types" and that certain kinds of personality organization were desirable. Certainly, "ideal types" and "desirable kinds of personality organizations" qualify as values.

Meissner explicates well the complex interaction of psychoanalysis and ethics. Since psychoanalysis does not contain an identifiable ethical doctrine, this is an especially difficult task. Further, delineating inescapable ethical values in a theoretical system that expressly disavows them is like climbing a slippery slope.

This book is technical and comprehensive. It would not be of interest to a general audience because it requires a moderate understanding of psychoanalytic theory.

Reviewed by James A. Tahmisian, PhD (Clinical Psychology), who is in private practice in Santa Maria, California USA.

Why Animal Experimentation Matters: the Use of Animals in Medical Research

Ellen Frankel Paul and Jeffrey Paul, Editors. New Brunswick (USA) and
London (UK): Transaction Publishers, 2001.
ISBN 0-7658-0685-1; 224 PAGES, PAPERBACK, $24.95 /£18.95

Recent protests by animal rights activists at Oxford University form a pertinent contextual backdrop for the book *Why Animal Experimentation Matters: the Use of Animals in Medical Research.* This collection of essays seeks to promote public understanding of the work and dedication of scientists to the advancement of human knowledge through animal research, for which, they contend, there is no sufficient substitute.

While the editors acknowledge the accusation of animal rights activists that no distinguishing criterion has been identified that would permit the sacrifice of animal lives to human interests (attributed to the ideologies of Peter Singer and Tom Regan), they, likewise, fail in that endeavor. Despite various attempts to ground moral justification for animal research in utilitarian, Darwinian, and humanistic arguments, the authors are ultimately unable to do so while simultaneously prohibiting both the abuse of animals and the use of vulnerable humans—their moral arguments cannot simultaneously accommodate both ends of the moral spectrum.

The most provocative essay was by H. Tristam Engelhardt, Jr. who, believing that morality is a human construct and that secular moral authority is grounded in consent, carries his assertion to such absurdity that his essay could be read as a work of irony reminiscent of Jonathan Swift's *A Modest Proposal*! He claims that animals have "rights" granted them by humans (since only humans are "ends in themselves"), but the "rights" so granted are to be used for human welfare, including the "right" to be hunted, skinned, eaten, used for entertainment, etc. He prohibits malevolence towards animals claiming that it contradicts the concept of morality as "pursuit of the good," but as an arbitrary constraint it is theoretically justifiable as well!

Throughout this book, one haunting question remains subliminally present: Could similar arguments be used to justify human embryo research? It is answered affirmatively by R.G. Frey, who contends that a utilitarian argument is impotent to distinguish between animal and human interests, since animal abilities and capacities exist in an overlapping continuum with humans. No rational argument cedes any and all human life to have greater value than any and all animal life. He concludes that if there is no valid argument against the use of animals in medical research, then there is no valid argument against the use of humans.

Such is the fallacy of Protagoras' popular aphorism: "Man is the measure of all things." With man as the source of moral authority, no humanly derived approach is able to appropriately balance human and animal interests. The weakness of such secular arguments reveal the strength of the Judeo-Christian perspective, where man is a privileged being created in the image of God with corresponding responsibility for stewardship of God's creation. Only from this perspective can moral limits for *both* the use *and* abuse of God's other creatures be derived. We have indeed made great strides in medicine due to the sacrifice of animal lives. But if further progress requires the sacrifice of human lives, will we have the moral capacity to say "no"?

Reviewed by Susan M. Haack, MD, MA (Bioethics), FACOG, who is in the private practice of consultative gynecology at Mile Bluff Clinic/Hess Memorial Hospital, Mauston, Wisconsin, USA.

Managing Ethically: An Executive's Guide

Paul B. Hofmann and William A. Nelson, Editors. Chicago: Health Administration Press, 2001.

ISBN 1-56793-14 9-9; 270 PAGES, PAPERBACK, $16.00

Managing Ethically: An Executive's Guide is a collation of short essays written between 1992 and 2001under the title "Healthcare Management Ethics." The authors of these essays are administrators, educators, ethicists, physicians, and scholars who – in spite of the variety of professions – desire the development of ethical leaders and the betterment of ethical healthcare organizations. In their introduction, the editors opine "An ethical organization is achieved not only by having well-crafted policies and procedures, it is achieved when the leadership and entire staff acknowledge the importance of ethical thinking and behavior in the routine and ordinary life of the organization...." (pp.xiii)

Hofmann and Nelson successfully edit this eclectic collage of essays into a mural of important ethical applications including the many concerns of leadership and the importance of good community relations, coupled with advice regarding human resources, organizational ethics, and institutional issues. The editors offer us a time capsule, of sorts, that presents to the reader commentaries and suggestions from the 1990's that address medical, ethical, legal, and social problems that, for the most part, began in the 20th century and will span ahead well into the 21st century. In many cases, all that the reader need do is to insert her or his organization's name into the essay in order to develop a germane and appropriate ethical discussion.

Physicians, particularly those in executive leadership positions, will find these essays succinct yet stimulating. The medical-ethical issues scrutinized in this collection are important because of their transparency as well as their transcendence. Here, the physician will appreciate acknowledgement of the problems of managed care coupled with a concern for access to healthcare. Furthermore, the physician will see the direct impact of important issues such as the protection of patient rights and the procurement of institutional advance directives from the executive perspective.

The real 'gem' in this book lies in the sections dealing with organizational ethics issues and institutional resources. In considering a governing board, one essay not only suggests the ethical purpose of specific policies, but also offers a way to assess the ethical foundation of the organization (and the board). In dealing with conflict of interest, another essay suggests that in recognizing and acknowledging a potential conflict, the insight and awareness of a single executive can positively impact the direction of the organizational hierarchy. In addition, those individuals participating on ethics committees are challenged to not only evaluate the committees' effectiveness, but to assess and improve its usefulness and appeal throughout the healthcare organization.

The goals and desires of the administrative executive and the health care provider need not be mutually exclusive. Even though written for healthcare executives, these writings – in espousing quality patient care, physician involvement, community awareness, and ethical behavior – directly encourage the partnership of executives and physicians.

Reviewed by Ferdinand D. (Nick) Yates, Jr., MD, MA (Bioethics), who is a Fellow of the Center for Bioethics and Human Dignity, Senior Pediatrician at Genesee-Transit Pediatrics, and Director of Medical Ethics, Mercy Hospital of Buffalo, New York, USA.

Marriage, Health, and the Professions

John Wall, Don Browning, William J. Doherty, and Stephen Post, Editors.
Grand Rapids, MI and Cambridge, UK: Wm. B. Eerdmans.

ISBN 0-8028-4392-1; 327 PAGES, PAPERBACK, $30.00

Some books are intended to be *interesting*, some to *inspire*, some to plead for *involvement*, some to *intentionally* focus on a theme – this book is designed to *inform*. It carefully presents one major theme, with five separate emphases, and if one is interested in one or more of those emphases, it is a worthwhile read. It is aimed at the five professions it addresses – law, medicine, ministry, therapy and business – including graduate and undergraduate students in these fields.

We are reminded that issues surrounding marriage receive little attention in the professions. On the whole, these groups prefer to leave marriage issues for partners to deal with on their own, considering that marriage lies outside of their professional responsibility. With a list of at least 20 major contributors, research becomes the main presentation of each chapter and the volume moves from place to place, largely influenced by lists of polls and research questions that have been used.

"Good health and successful marriages are positively related." (p. 167) In a day when so much emphasis is given to the disestablishment of families and the common practice of simple cohabitation rather than formal marriage, this book holds out hope in its finding "that married persons are more likely to have built in supports for a healthy life style." (p. 167)

As a Protestant Minister, I was encouraged by the chapter on Ministry. The question is asked, "Do religion and spirituality contribute to marital and spiritual health?" This book clearly indicates "YES," and sites several studies which show that more frequent religious participation was clearly linked with increased marital stability. (p. 284) "Therefore the more frequently husbands and wives attended church, the more personally and structurally they were committed to staying married." (p. 285) In sum, it would appear that "more religious and/or spiritual individuals may have more stable marriages because they are better able to adjust to marriage, to find more satisfaction and harmony in their marriages and to take steps to make marriages better." (p. 292)

The chapter on Therapy concludes "our field cannot be intellectually honest or professionally responsible unless we openly grapple with the deeper moral, spiritual, and communal meaning of marriage." (p. 232) Max DePree is quoted as saying some years ago that in the era ahead business would need to take on more responsibility for family life. "Business professionals are important players in this process." (p.279) Law, medicine, ministry, therapy, and business are all vital parts in helping to bolster successful and vibrant marriages.

Reviewed by Paul E. Toms, BA, BD, who served as Senior Minister of Park Street Church, Boston, Massachusetts, for 25 years, 33 years as a Trustee (and six years as Dean of Chapel) at Gordon-Conwell Theological Seminary, South Hamilton, Massachusetts, and prior to that traveled to various parts of the world teaching and preaching on the mission field.

Kidney for Sale By Owner: Human Organs, Transplantation, and the Market

Mark J. Cherry. Washington, D.C.: Georgetown University Press, 2005.

ISBN 1-58901-040-X; 258 PAGES, HARDCOVER, $26.95

Those interested in the ethics of organ procurement and distribution will find this book thorough, well documented and well presented. It is, however, not a book for the faint-hearted or the casual reader; rather, it is a serious treatment of the concept of the fee-based sale of human organs in a regulated marketplace in order to increase the supply.

The book opens by pointing to the current shortage of organs available for transplant; those in need of a transplant greatly exceed the number available. Bioethicist Mark J. Cherry introduces the concept of a fee-based market for paired or “redundant” human organs (e.g., kidney) and discusses controversies which clamor for answers. He explores how commercialism may influence consent for donation, comparing this with altruistic consent. He also discusses the potential repugnance some may have to transplantation of organs, explores concepts of human dignity, exploitation and justice. He asks, of these, which would prohibit the sale of organs?

Beginning with presuppositions which might affect viewpoints regarding the sale of organs, including governing metaphysics, morality and political theory, Cherry discusses personhood, body and self, ownership and liberty. Included are four aspects of liberty and how they might impact organ transplant. He reviews the philosophical and religious constructs of Thomas Aquinas, John Locke, Immanuael Kant and Robert Nozick and argues that although each has a different perspective, none would prohibit a fee-based market in human organs.

What are the costs and benefits of a market in human body parts? What about the moral costs and benefits? How does the need for transplantable organs affect altruistic donations? Would scientific excellence be affected by a fee-based market for transplantable organs? What are the roles of virtue and free choice? While many would disagree, Cherry concludes that a market for human organs would impact each of these favorably.

In his final chapter, Cherry laments the lack of moral consensus created by differing world views, and concludes that there is a need for a health care policy that embraces moral pluralism and avoids an unjustified coercion of legislated moral monism. In conclusion, this well referenced and documented treatise is an interesting read for those who would like to explore the issues surrounding a fee-based market for transplantable organs. One wonders, however, if a market economy for body parts would open the door for a free-for-all, to the detriment of those most desperate.

Reviewed by Phyllis Clatterbuck, DMin, MRE, BS (Nursing), who is a Retired Professor of Theology from Seminario Batista do Teresina, Brazil, and who also taught at the Seminario Batista do Noreste, BRAZIL.

The Language of God: A Scientist Presents Evidence for Belief

Francis S. Collins. New York: Free Press, 2006.

ISBN: 0743286391; 294 PAGES, PAPERBACK, $26.00

I have always thought that .Dr. Francis Collins is a pretty cool guy. When I first met him in 1992, I was impressed by his engaging personality, his love of playing the guitar and riding motorcycles, and his unabashed Christian faith.

Nowadays, Dr. Collins is the head of the National Human Genome Research Institute and directs the Human Genome Project, the $3 billion project to define the DNA sequence of human beings. The first 'rough draft' of human DNA was completed in June 2000, essentially complete in April 2003.

As a geneticist, physician and an evangelical Christian, Dr. Collins speaks from these various perspectives to harmonize science and faith in his best-selling book, *The Language of God: A Scientist Presents Evidence for Belief* (Free Press). He refers to the genetic code as "God's Instruction Book," and attests to the creativity and beauty inherent in this most basic blueprint of our biological nature.

After sharing his personal journey into faith, Collins makes a compelling case for his commitment to theistic evolution. Some Christians will disagree his conclusions, yet most will appreciate his love of God, and his willingness to see that human beings are more than their genes: "[The] DNA sequence alone… will never explain certain special human attributes, such as the knowledge of the Moral Law and the universal search for God"(p. 140).

This common knowledge of God's Moral Law is why we have such broad agreement on ethical basics across many cultures and worldviews. And, according to Collins, the yearning after God can never be ascribed to natural selection and the survival of the fittest.

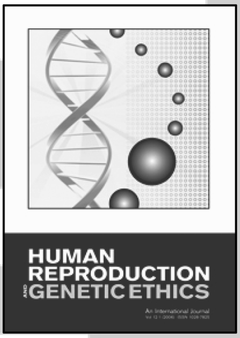
The Language of God is not primarily about ethics, but Collins has helpfully added an appendix to the book, with the title, "The Moral Practice of Medicine: Bioethics." He shows how new insights in the genetic markers for breast cancer risk (especially the BRCA1 gene) will inform decision-making for women. He goes on to briefly summarize the major ethical concerns about genetic privacy (as DNA testing becomes more commonplace), and makes a good case for legislative protection against genetic discrimination by employers and health insurance providers. He also nicely summarizes the current debate over genetic enhancement.

In the area of stem cell research and cloning, however, Collins goes seriously astray. He fails to accord the presumption of moral value to embryos, even though conception is the biological starting point for human species membership. He goes on to use the utilitarian rationale for the destruction of excess frozen embryos from reproductive technologies, since "the vast majority . . . will ultimately be discarded" (p. 251). This ignores issues of complicity with moral evil. He also fails to compare or contrast destructive embryo research with abortion in general, which I assume he opposes, though he curiously never discusses the issue.

Collins makes his biggest philosophical error when he claims that somatic cell nuclear transfer creates an entity different from a human embryo, because it is "not part of God's plan to create a human individual" (p. 256). He gives no other justification for this conclusion, other than a vague form of natural law.

So read *The Language of God* with thoughtful care. Despite my disagreements with his evolutionary viewpoint, and my feeling that his bioethical reasoning is flawed, Francis Collins nonetheless demonstrates that science and faith are not incompatible. I would be glad to have coffee with him and talk about the things of the Lord. Maybe sometime he'll even give me a ride on his motorcycle.

Reviewed by Dennis Sullivan, MD, MA (Ethics), who is Professor of Biology at Cedarville University and Director of the University's Center for Bioethics, Cedarville, Ohio, USA.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