The Moral Burdens of Biotechnology

One Nurse’s View of Patient Decision Making

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Abstract. Biomedical devices and biotechnological treatments are different types of health intervention. In general, biomedical devices, such as deep brain stimulators implanted for treatment of movement disorders, can help patients without imposing moral burdens. Biotechnological interventions, on the other hand, require the use of biological substances, which are often obtained by the destruction of human life or unusual tampering with it, as in embryonic stem cell research, cloning, and fetal tissue transplantation. Biotechnology imposes a moral burden on patients, who may not fully understand what it involves and the effects its use might have on them later. This essay is a reflection on the serious losses patients experience before they consider biotechnological options and on their sense of moral burden after they have consented to their use. National Catholic Bioethics Quarterly 9.4 (Winter 2009): 671–679.

As a registered nurse with expertise in the specialty of neuroscience nursing, I have been asked many disturbing questions in my career. Some of those questions were prompted by patients who were experiencing unbearable suffering, especially from a loss. A sense of loss pervades the work I do. Most of all, the loss of hope pervades the lives of people who receive diagnoses of neurological illnesses.

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Who among us wants to hear that our recent clumsiness in dropping small objects or tripping over our own feet is actually the beginning of Lou Gehrig’s disease, or amyotrophic lateral sclerosis (ALS)? There is no cure for ALS yet, and in our culture of independence, self-reliance, and autonomy, a diagnosis of ALS is threatening, since it means a progressive loss of every physical power while cognitive abilities remain strongly, painfully intact.

Imagine a sixty-four-year-old man who has been a bit stiff in his joints and moving more slowly than usual lately. In a brief but momentous conversation, the neurologist breaks the unforgettable, unforgiving news to him: his stiffness and cramped writing are actually signs that Parkinson’s disease has started. If you have known anyone who has had this disease, you know that a slow rigidity will creep into this man’s body so stealthily and steadily that, at one point down the road, he may choke on his own saliva. This is not a pleasant prospect.

The diagnoses my patients have received over the years have been hard to hear and hard to bear. Most neurological diagnoses are not delivered with much hope for cure, since permanent cures for many of these illnesses have not been found. At best, physicians can offer pretty good temporary management of the symptoms.

When someone receives a devastating diagnosis of this kind, it is such a shock that stunned silence seems to be the only way to respond. Yet the shock does not linger long. In fact, in today’s world the shock turns quickly into a text message, a blog entry, or more importantly, into a search for disconfirming information. Patients and families search for information that they believe their physicians failed to learn in medical school. They are determined to let their doctors know that there are answers out there. Many times, the answers take the form of untested, alternative therapies whose risks patients are willing to accept in order to hold onto hope. Neurologists are aware of alternative therapies; they also know the risks involved. So this raises the question about what technology, especially biotechnology, can offer patients who are seeking life and hope at any price.

**Biotechnology: Help or Hope?**

Biotechnologies and biomedical devices are in two different categories of health intervention. It is important to know that there are wonderful biomedical devices that help patients and that should be considered by patients. For example, there is research underway on a defibrillator for the brain that would help people with intractable epilepsy by sensing and stopping the spread of epileptic seizure activity before it can be detected by the person.\(^1\) There is also a device called a deep brain stimulator that can be implanted to reduce tremors in people with Parkinson’s disease and certain other movement disorders.\(^2\) These are biomedical devices, a form of technology that has helped patients very much.

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\(^1\)John Milton and Peter Jung, eds., *Epilepsy as a Dynamic Disease* (New York: Springer, 2003).

In contrast, biotechnological interventions require the use of biological substances, which are often obtained by the destruction of human life or unusual tampering with it. Some areas of biotechnology include human embryonic stem cell research, whereby stem cells are harvested from human embryos; cloning, which can involve the development of transgenic beings (meaning half human and half cow, or half human and half pig); and fetal tissue transplantation, whereby brain, adrenal, or other tissue is removed from a human fetus for transplantation into an adult. All these activities raise at least two moral concerns: (1) technologists are using and destroying human beings for the sake of research, and (2) they are doing this research without the consent of those human beings. These are not the only moral issues, of course, but I mention them because they clearly show ways in which human life is not recognized as life in unique, individual human beings until after they have passed through the birth canal alive.

Some pharmaceutical companies today are heavily invested in biotechnologies that combine human eggs with bovine or porcine proteins to produce transgenic beings that will be used to mass-produce organs or tissues for transplantation or, more importantly, to mass-produce new medications. The amount of money that has already been invested in this type of pharmaceutical research is staggering, which means that the profits from this work are expected to be equally astounding.

Although this kind of technological development has been possibly (but not necessarily) preempted by more recent scientific discoveries, that new knowledge does not mean that the former approaches to biotechnology, such as using and destroying human embryos, will soon end. Too many people have too much money invested in this work to let it come to a sudden halt. Specifically, since certain adult stem cells have been recognized to have the property of pluripotency, meaning they are as capable of being reprogrammed for therapeutic use as human embryonic stem cells are, the scientific rational for pursuing human embryonic stem cell research has lost its force. Nevertheless, on March 10, 2009, President Obama approved an executive order to provide federal funding for human embryonic stem cell research.

The reason I bring up these technologies is that they are not just quackery taking place at the edges of society. Biotechnology is now part of mainstream thinking. It

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6 Velander, Lubon, and Drohan, “Transgenic Livestock.”


promises the hope sought by patients with conditions like Parkinson’s disease or with spinal cord injuries, promising permanent cures rather than just lifelong management of symptoms.

For many years it seemed that Parkinson’s disease affected only elderly people; very few people under the age of sixty-five were diagnosed with this illness. A common assumption was that Parkinson’s disease might be related to an aging process gone awry; therefore, researchers generally did not look for the disease among youth. This does not mean that Parkinson’s disease did not occur in young people, however. In 1979, two young chemists developed Parkinson’s disease after being poisoned by a substance they were working with, the compound 1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine (MPTP). Several years later, in California, Maryland, and British Columbia, small clusters of sudden-onset Parkinson’s disease were found among a group of young adults who had been using synthetic meperidine (Demerol) that was found to have traces of MPTP. These events led the medical community to recognize that young people could suffer from Parkinson’s disease. Researchers also found that they could cause Parkinson’s disease in mice by injecting the mice with MPTP.

It used to be that very little could be done medically to help patients who had Parkinson’s disease. In 1969, a doctor had discovered great benefits that a new drug, levodopa, could offer his patients who were suffering from a parkinsonian illness about twenty years after an encephalitis epidemic of the 1920s. Penny Marshall’s film *Awakenings* is based on this story. The drug provided dramatic improvement in symptoms, but its effectiveness in individual patients proved to be only temporary.

Tremendous strides in research were made in the 1990s, and neurologists now know a great deal more about medications to treat Parkinson’s disease. Patients who receive the diagnosis today thus have more hope than did patients twenty years ago. In addition, biomedical devices, such as the deep-brain stimulator, offer some patients help and hope that they can become tremor-free. Yet many patients do not want to accept treatment options and symptom management—they want to be completely free of the disease. They are thus willing to risk the use of biotechnological options like fetal tissue transplants.

In 1998, a double-blind study of patients with Parkinson’s disease was conducted. All the patients underwent neurosurgery, meaning that surgeons opened their skulls and cut into their brain tissue. Half the patients received fetal tissue transplants during the surgery, while the other half underwent the surgery

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12 *Awakenings*, directed by Penny Marshall (USA, Columbia Pictures Corporation, 1990), based on a book by Oliver Sacks.

without receiving the transplants. (In other words, they received a sham surgery.)
The neurosurgeries were conducted at a hospital in Colorado, but the follow-up
examinations of patients were conducted in New York and Maryland, so that the
team of neurologists who examined the patients was completely separate from the
team who performed the surgeries. As the study progressed, patients who received
the transplants had many more adverse events than those who did not. Enrollment
in the study was stopped early, but the condition of patients who received the trans­
plants was still monitored. Over time, some of the patients who received transplants
developed a new type of movement disorder.

This biotechnological offer of hope failed in many ways, especially among
people over the age of sixty, which is still when the majority of patients are diagnosed
with Parkinson’s disease. Despite such findings, fetal tissue transplantation is still
celebrated by some neurologists as offering great hope.

A Poignant Reality

When the actor Christopher Reeve fell from a horse and injured his spine, the
injury rendered him quadriplegic. He became a crusader for fetal tissue research so
that spinal cord injuries like his could someday be “healed.” Ron Kovic was a soldier
in Viet Nam who sustained a T-6 spinal cord injury that left him paralyzed in the
lower half of his body. After his injury, Kovic, whose life was beautifully portrayed
in Oliver Stone’s film Born on the Fourth of July, asks his father, “Who will ever love
me, Dad? Who will ever love me?” 14 His question is a poignant reminder, like the
crusade of Christopher Reeve, that what we are talking about in terms of a cure is not
just a piece of tissue but an entire human person who yearns for the fullness of life.

If you have not known anyone who has had a life-changing spinal cord injury,
you might not fully understand what such an injury means in terms of his daily life.
First is the obvious chore of mobility. Although an electronic wheelchair is something
that might make others marvel, if it happens to be your chair, it is another story. Even
a lesser spinal cord injury lower down in the body, whereby one is rendered paraplegic
rather than quadriplegic, has implications that are extremely painful to accept.

Unlike Parkinson’s disease, which predominates in people over age sixty, most
patients who suffer spinal cord injuries in our country are unmarried young men who
are injured in a motor vehicle, while diving, or in another type of accident. When
a young patient with paraplegia or quadriplegia hears that a fetal tissue transplant
might be the thing that will cure his injury, it is not something he can easily reject
as immoral. He will think about it, come to yearn for it, and eventually, perhaps, be
willing to risk everything for it.

Someone like me, an older, experienced nurse working the night shift, will
have seen that the quiet of the midnight hour is just the time when this question will
come to the lips of a patient. He might start out by saying something like “I heard
that there is some research with fetal tissue and stem cells and that there might be a
cure for this some day. What do you think about that?”

14 Born on the Fourth of July, directed Oliver Stone (USA, Universal Pictures, 1989),
based on a book by Ron Kovic.
As nurses we are taught to not give our personal opinions to a patient, but to draw him into a therapeutic conversation by using an open-ended questioning technique, so that we can fully come to understand his concerns. So I might respond by asking, “Well, what do you think about that?” If the patient says he thinks it is a wonderful idea, the question is whether I should talk to him about the truth as I see it and the moral issues related to taking someone else’s innocent life, or whether I can guide him through engaged conversation to help him discover the truth about this issue on his own.

I would ask the patient if he understands where the embryonic stem cells and fetal tissue for research come from. I would let the patient know that all adults have their own stem cells readily available for research, which would eliminate the need to use human embryonic cells or fetal tissue. And I would explain that neither human embryonic stem cell nor adult stem cell research is close to having answers for him yet. Therefore, I would want to know if he has some alternative plan for seeing himself and his life as valuable even if he never recovers from this particular injury. Then I would do my best to convince this young man that his life is valuable, even if he never recovers the use of his legs, bowels, bladder, and sexual functioning.

Ecclesiastes has a familiar and very meaningful passage: “There is an appointed time for everything, and a time for every affair under the heavens. A time to be born, and a time to die; ... a time to kill, and a time to heal; ... a time to weep, and a time to laugh” (3:1–4, NAB). As a Catholic Christian nurse in this era of biotechnology, I would add that there is a time for respectful silence, and a time for speaking the truth; a time to share another’s sorrows, and a time to encourage another’s hope. After all, the truth of our faith is not a matter of producing a clear and solid line beyond which “good” people would not step. It is rather a matter of recognizing our common humanity and walking arm in arm with each other through life’s thickets, inevitably getting scratched and scraped, dirty and disheveled, while believing that the goodness of the human being we are encountering is more than the sum of their choices, actions, faults, and limitations, because they were created and brought into being by the Almighty God of Infinite Love.

**Biotech Babies: Hope or Hype?**

Let us consider what should be a happier, more encouraging area of biotechnology: in vitro fertilization. This, after all, is not about destroying embryos but about producing them. In the past ten years, I have encountered many young women undergoing injections of fertility drugs so that they could have a child. They were married. They wanted a family. They were able to provide for a family. Certainly, a family is not something evil or wrong to desire. Yet IVF is not approved by the Catholic Church, for reasons that are deeply rooted in Catholic Christian faith. IVF violates the human dignity due to an embryo, and robs the child of his or her right to be “conceived and to be born within marriage and from marriage.” In bypassing sexual union, IVF techniques also oppose “the dignity both of human procreation and of the conjugal union.”

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One of my quick conversational explanations to non-Catholics is that the Church likes us to engage in life in a more natural way, so that we can leave the supernatural stuff to God. If people really do not understand that, I explain that family planning using natural means is actually preferred by our Church, since the Church wants parents to be responsible for their children and themselves. Yet artificial family planning is not really the same, since it unnaturally turns off or sets up a barrier to one area of the body that is actually necessary to be a whole person. So my explanation of being natural is part of helping people see that if we are people of faith, we are also people who trust God for all that He gives us. We even trust Him, as the psalmist says, when we are sorely afflicted (Psalm 116).

Yet biotechnology seems intended to outsmart God, as if that were possible. And this is where it becomes difficult as a Catholic Christian to respond with love, when others do not see anything wrong with using IVF techniques to produce a child. Perhaps the most loving response would be one that helps couples understand these issues better. But the news that a couple means to use IVF often comes as an announcement of a fait accompli, not as a plan on the horizon. What faithful lay Catholics need today is to know how to engage in these important conversations before married couples make this choice.

The process of IVF involves several steps. First, the woman’s body is prepared with chemicals so that when she ovulates, she will produce not just one egg but as many as seven or eight. When her body has produced the eggs, each one is harvested by the insertion of a needle through the vagina and into the follicle. Her husband then comes to a laboratory with fresh semen, and technicians mix the eggs and semen in the hopes of fertilizing the eggs. If fertilization occurs, then a doctor uses a tube to return some of the embryos to their mother’s womb in the hopes that one or more will implant in the wall of her uterus.

The first week or two after implantation is a strenuous yet exciting time for an infertile woman—the first time she goes through this. She imagines that in several months she will give birth and will finally be blessed, technologically speaking, with a family of her own.

There is a bit more to this process, though. What I began to understand as I listened to these young women is a recurring series of hopes and dreams as well as a series of unheeded cautions.

The women spoke with confidence of their wonderful physicians, who would not treat them like “cattle” or “dogs” by making them give birth to multiple babies. Their physicians were promising to implant two or at most three embryos. The rest of the embryos could be stored in deep freeze—in case they wanted to use them in the future. If all three embryos “took,” their physician could “handle that”: they could do a selective reduction abortion. If a woman had, for example, four babies growing within, as one woman did, two could be “removed.”

Then I noticed a shift of sentiment. The three embryos of the first round miscarried. The other frozen embryos remained in deep freeze. Six months later, a new round of injections and hopes began, but this time, some of the cautions seemed to have started to sink in. Less jubilant, but still very hopeful, these young women were
excited as various blood levels started to rise, indicating that indeed new life was growing and developing within. And then a second set of miscarriages occurred, followed by profound sadness. Finally, a third round of injections began. This time, the secrecy surrounding the injections surpassed anything the CIA might use, yet you cannot really fool your friends who are nurses. The injections make women hyperactive, and if an infertile woman has already gone through unsuccessful IVF cycles, the third round makes her hyperactive but very quiet and somewhat skeptical.

What was apparent, and sad, even in women the first time around, was that the women were not yet thinking and acting like mothers. The commodification of pregnancy, which is how I have come to view these infertility treatments, delays thoughts of motherhood that used to arise immediately when a woman first suspected she was pregnant. Let me elaborate with a clear example.

A friend told me of one young woman who was regaling all her neighbors in a small town with her decision to have two of her four IVF fetuses aborted two days after Christmas. I asked my friend if the mother-to-be’s husband agreed with her decision. No, I was told, he and her family did not agree, but it was her body, and she could do as she pleased. I asked my friend if the mother-to-be was planning to send her two remaining children to kindergarten in that same town in five years. “Why?” she asked. I said it seemed to me that if the mother-to-be was really thinking ahead, she might wonder what kind of taunts her two remaining children would have to handle in kindergarten, since everyone else in town knew that she was aborting two of their siblings.

For this woman, as for many others, technology was not just making it possible to become pregnant and have a family. Technology, technicians, and a third-party physician had distanced the woman from her own children. After accepting a large sum of money from her, they had taken one of the most intimate and private experiences of married family life, the conception of a child, and placed it in a laboratory setting during the clinic’s working hours, when the mother and father were not likely to be present. They had made it possible for the mother-to-be to examine her living babies on an ultrasound screen and decide which ones would live and which ones would die.

When young women receive assurances from their ultra-confident physicians before beginning the IVF process, they are in a sort of honeymoon phase, thinking they have the best physician in the world, someone who has thought ahead for them and has answers for all the problems that might arise. Yet for this woman and for others, such promises now meant that the birth of two children was contingent on the death of two others, and the mother herself would have to decide.

**The Aftermath of Choice**

Technology offers some hope, but lately more and more of the hope it offers seems to be shrouded in someone else’s death or destruction. Such hopes place a heavy moral burden on patients, which they might not be able to foresee at the time when they make their decisions.

In the film *Sophie’s Choice*, based on the novel by William Styron, we see this played out in the experiences of Sophie Zawistowski, a Polish Catholic who
was sent to Auschwitz with her children. Sophie’s choice was to keep herself and her son alive by handing over her young daughter to a Nazi guard to be taken to the crematorium. This is dramatically portrayed in the film as a moment of true violence and cruelty, as a Nazi guard is ordered to take both children but Sophie releases her daughter, shouting, “Take my little girl!” Throughout the film, Sophie often refuses to help others so that her own survival is assured. But I think the movie is really about Sophie’s second choice. After surviving the war and coming to America, just when a new life seems possible, Sophie chooses death and commits suicide because she can no longer live with the choices she made in her past.

Sophie’s choice to hand her daughter over to the Nazi guard was a choice made under extreme duress. Duress is also there for patients who experience unbearable suffering and choose to participate in biotechnological research and treatment programs.

Interestingly, one of the fundamental principles of research ethics is respect for a person’s freedom to consent to participate in research and to withdraw consent at any time. This principle was developed after the trials of Nazi war criminals at Nuremberg and was written into the Nuremberg Code of Ethics. It is a principle that still stands today. Except that it does not extend to human embryos, because human embryos are not always viewed as human beings. Embryos developed through IVF, especially those who have not been implanted in their mother’s wombs, are being denied human dignity and respect through the very means by which they came into being.

When people have asked me over the years whether I believe in fetal tissue transplants for patients with spinal cord injuries or Parkinson’s disease, I say no. I explain as gently as I can that I cannot personally think of sacrificing someone else’s life, especially not that of an innocent unborn child, in order to extend mine or anyone else’s just a bit longer. Some people conclude that I have not encountered any setbacks or sorrows in my life, and imagine that if I had, I would see things differently. But we each have sorrows and losses in our lives. It is because of my own losses that I feel so cautious about taking away anything so precious as a human life from someone else. Sometimes, the time for respectful silence yields to a time for speaking the truth.

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