



**2007
Holt Bioethics Essay Award
for Medical Students
UT Health Science Center
San Antonio**

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Solomon Azouz

Morality vs. Mortality: The Case of Germline Genetic Engineering

Imagine a world where a baby's eye color, height, or intelligence is all just a check mark away. Babies are no longer created in the conventional sense (though the procedure remains common), but rather, preordered. The beaker babies that bedazzled us in Aldous Huxley's *Brave New World* may soon cross over into non-fiction. But though we may pat ourselves on the back for yet another technological triumph, we must inevitably ask ourselves if perhaps this time we've gone too far. Germline gene therapy, a concept as dangerous as it is mind-boggling may soon change human life. Though it has been revered for its ability to fight disease and cure defects, tampering with human genes must be carefully scrutinized as it delves deep into the realm of ethical debate. Is genetic engineering a power too great to be wielded by humankind, should it be embraced as yet another tool with which to save lives? Before we may attempt to answer questions with such monumental impact, we must first understand the process of genetic engineering and whether or not it is a discovery that we were truly meant to find.

According to McGill Medical School's Torsten Nielsen, germline gene therapy begins by selecting either a naturally or artificially fertilized egg and assessing the genetic condition of the embryo in an effort to determine whether or not it would meet the criteria for use. Then, the cells are allowed to divide and the desired DNA sequence can be transfected. (Nielsen) Transfection, the infection of a cell with purified viral nucleic acid, results in copies of the specific genetic code being integrated into the cell's genome as it divides (Minor). Transfection has been historically implemented many times in both animal and human studies. By inserting an artificially created sequence of DNA into an embryo, scientists could develop a new class of science that would mimic the children who were artificially created for their society's purpose as described by Aldous Huxley's novel. Michael Lemonick, author of *Time*

Magazine's cover story "Designer Babies", presents a theory of a world in which parents could predispose their children to have certain specified characteristics. For example, he asks if it would be ethically acceptable to predispose a child to be attractive, intelligent, or heterosexual (Lemonick). The prospect of parents deciding their child's genetic characteristics implies that the phrase "you are your parents" would no longer be applicable and could one day be replaced by the phrase "you are who your parents choose you to be."

French Anderson is considered by many to be the leading source on genetic engineering and is a scientist who outlines the necessary steps that must be followed before genetic manipulation can be completed. Anderson cites the Nuremburg Code as his basis for such technology, declaring: "The experiment should be so designed, and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study, that the anticipated results will justify the performance of the experiment" (Anderson). Anderson has a list of three of his own guidelines that he considers essential. He claims that there must be large amounts of research with somatic cell gene therapy, a "reliable, reproducible and safe procedure," and a community agreement before actual medical testing can occur (Anderson). While ethical debate and banter is important in determining technology's effects on future generations, the issue of germline engineering currently has more pertinent effects. The issue in this case is not a collective one as proposed by Anderson or Dvorsky, but is rather a problem concerning a physician and his patient. As a medical student at the University of Texas Southwestern Medical Center asserts "medicine is not a science, that it is rather a pseudo-science" (Cler). In other words, a doctor does not care about the means by which he saves a patient, as long as he saves his patient's life. Saving lives is the science that encompasses the field

of medicine. Therefore, there is not necessarily enough time to debate the fine points of legislation for germline genetic engineering as there are many patients who seek it as their only hope for survival.

The BBC News of London, England, reports the desire of one British couple to save their son by selecting an embryo that would be paramount in curing him (Fishel). The embryo that would be selected through genetic screening and marking (Nielson) would be a bone marrow match for their three-year-old child, Zain Hashmi. This child has a medical condition called beta thalassaemia major, in which his blood-iron levels are so high that he is poisoned by them. Once born, the selected embryo would yield an umbilical cord that could later be used as a transplant for Zain and ultimately save his life. The Human Fertilization and Embryology Authority (HFEA) instigated an ethical debate when they allowed the couple the right to proceed in using genetic engineering technologies to select an embryo that would provide a bone marrow match. While the Hashmi couple maintains that they are having a child who will bring the “gift” of life to their older son (Fishel), many governments have begun to institute laws that would regulate germline therapy. They cited that the use of experimental zygotes must be restricted because unforeseen cancers could enter the gene pool (Walman). The procedure that would be involved in providing a cure for Zain would undoubtedly result in the loss of embryos and the birth of a child who may have unforeseen mutations due to his altered DNA (Anderson). Though the practice of genetic engineering may save lives within the near future, many refer to the untested current technology as reason to prohibit clinical experimentation (Dolan). While the technology has been recently approved by the government for use to select an embryo that will be a match for Zain, there is an 8 percent chance that the right embryo will be selected, followed by a 10 percent chance that this embryo would result in a birth because Mrs. Hashmi is already 39 years of age (telegraph.co.uk). This process however, is the

best chance for Zain’s survival. Therefore, it is more important that physicians and scientists save his life even if he and his future brother must be carefully monitored and possibly be unable to have children themselves.

The IVF procedure has a high rate of failure and will be a difficult process in the Hashmi case because it consists of taking nuclei from each cell and reinserting them into an ovum from the mother or a donor. The completed ovum must then be reinserted into the mother’s uterus. This final step of germline genetic engineering is identical to the re-implantation in IVF, and has a 15 percent success rate according to the clinical data of IVF. It becomes less probable with an older mother (Pearson). The entire process would have to yield 10 fully fertilized embryos in order for the procedure to have real promise. Thus, multiple births as well as the loss of several fertilized eggs would be inevitable (Case of ...). Not only does the loss of fertilized eggs spur ethical debate, but from a more practical view point, it causes the process to be inherently frustrating. Such a procedure would be extremely expensive and might not yield a healthy newborn if any of the described steps were to fail. Therefore, Anderson argues that such research should only be used to cure disease (Wadman); yet even if the technology were to be restricted to genetic cures, class warfare could develop between the families who may or may not be able to afford protection for their children from disease. In the future, governments may establish laws that would permit their citizens unequal rights in the legalizing of genetic engineering. Despite the high cost of the technology, there is proof that foundations, friends and families of the victims will be able to raise the money. In the Hashmi’s case their friends and family raised over £50,000 in order to save Zain (telegraph.co.uk). While it is true that some countries lack the technology and funds to enable such a cure, the fact remains that governments cannot prohibit families who raise enough funds from proceeding with this specific treatment.

While the prospect of such technology seems highly difficult to execute, scientist Joseph Tsien and his research group revealed its accessibility when they used genetic modification to enhance the memory and learning of mice. On the premise that the strength of neural synapses dictates the bases for memory and learning, Tsien sought to see if genetically enhancing mouse DNA could accomplish this intensification. By increasing the number of NMDA (N-methyl-D-aspartate) receptor 2Bs (NR2B) in mouse forebrains, the group was able to enhance the neural processing of their transgenic mice (mice whose genome has been altered) and prove that memory and intelligence could be improved in mammals (Tsien). Tsien's research is perhaps the greatest existing proof that germline engineering is possible in mammals. Such research has led scientists like James Watson, discoverer of the double helix, to hail germline genetic engineering as the future of evolution, one in which humans determine their own evolutionary steps (Lemonick). However this implies that if the technology could be utilized in the case where a movie star mother desires her daughter to one day have large natural breasts. Thereby eliminating the daughters need for cosmetic surgery. It is in this case that a government should be able to mandate such behavior as illegal. There is no question that by limiting a person to develop certain physical and mental features parents would infringe on a natural Rubicon. Montaigne asserts in his essay: "On Cannibals" that naturally occurring parts of nature are better than anything man can create,

"... we call wild the fruits that nature has produced by herself and in her normal course; whereas really it is those that we have changed artificially and led astray from common order, that we should rather call wild" (Montaigne 152). In doing so, Montaigne proves that man has sacrificed much of the natural flavor of fruits in cultivating them and thus a parent would sacrifice unknown potentials of a child by utilizing germline genetic engineering for reasons other than medical. Yet in a life or death situation such as the case of Zain Hashmi, there can be no discourse over his potential because if genetic engineering is not attempted his future will forever be lost.

In determining the development of germline technology society must weigh its positive and negative effects. Germline engineering allows for better health care procedures and society must harness the improvements without unnecessary trials and tribulations. Modern science must derive a plan to develop genetic engineering in small steps so as not to cross a Rubicon from which it cannot recover. Moreover, scientists must understand the full magnitude of deleting or adding a gene because it may cause more than one effect. Only then can the science of genetic engineering act as a controlled benefit that improves the lives of humanity men equally. To save a person from death or a lifetime of hardship all avenues must be explored including germline genetic engineering. As the Judaic ethical doctrine *Ethics of the Fathers* mandates, "He who saves one life saves the world entire."

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Ryan Coleman

Mother versus Fetus, Autonomy versus Responsibility

One of the most precious rights a person is blessed with is the ability to choose what happens to his or her own body. Nowhere is the importance of this right to choose more important than with regard to women and their reproductive rights. In 1973, *Roe v. Wade* firmly established a woman's right to choose in that it ruled that laws against abortions violated a constitutional right to privacy and stated that up until the point of viability, a woman had the right to terminate the pregnancy for any reason she chose. However, with this ability to choose comes responsibility. Should a woman choose to carry a pregnancy to term and deliver a child, what are her responsibilities to that fetus throughout the course of the pregnancy? What obligations do physicians have to both the woman and the fetus should the mother be making decisions that endanger the well-being of the child? To which person should the physician's loyalty lie, and to what lengths should the physician go to protect one from the other?

To explore this, take the case of a 25-year-old mother who becomes pregnant and chooses to carry the pregnancy to term. The mother is very excited about the pregnancy, and is looking forward to being a parent. When offered abortion, the mother adamantly declines. At eighteen weeks, an amniocentesis is performed which confirms that the woman is carrying a genetically normal female. Both parents are healthy, and there is no significant medical history in either family of any medical conditions that could result in severe mental retardation. At thirty-five weeks gestation, the mother undergoes a routine HIV screen and learns that she is in fact HIV-positive. The pregnant woman is then given the option of taking HAART therapy to both preserve her own health and protect her infant from potential infection. The anti-retroviral drugs offered to the mother have been shown to not be teratogenic. However, the mother refuses to accept medical therapy as she refuses to

believe her diagnosis, stating that she does not think HIV is a real disease. She has been presented with all current literature such that she cannot argue that her refusal of treatment was due to ignorance resulting from her physician not informing her. Would it be ethical for the physician to force the mother to undergo HAART therapy, if not during the pregnancy, at the time of delivery?

In order to answer this question, a number of more general issues first need to be explored. From a very basic perspective, does a physician have an obligation to a yet-to-be-born fetus? Has the risk to the fetus been well established? If it has been, can a mother ask a physician to abolish his obligation to ensuring the fetus' health and ignore this risk, remembering a physician's most basic responsibility is *primum non nocere*? Is there enough scientific evidence to demonstrate that the medical therapy being recommended is foolproof enough that it can be assumed that the treatment will work? Has it been well established that the therapy recommended to the mother has been shown to be safe for the mother? Are there other situations in the medical field where medical treatment can be forced, and if those are justified, can forced treatment in this circumstance also be justified? For treatment to be forced upon the mother in this case, I believe that the answer to all of these questions needs to be a resounding yes.

Central to this debate is the idea of personhood and whether or not an unborn fetus constitutes a fully realized person and therefore should be afforded the same rights as its mother. One of the strongest arguments that a fetus is not a person is that of Mary Anne Warren, who argues that in order to qualify as a person, the being in question has to be able to perform basic cognitive tasks; that is, she argues for a cognitive criterion¹. There must exist the capacity for the use of reason, self-awareness, consciousness of the

external environment, the ability to communicate and the ability to perform self-motivated acts. Should these criteria not be met, from Warren's perspective, the being does not constitute a full person who should be allowed all the requisite privileges a typical person receives. Though these criteria are not fully inclusive in that they fail to account for the potential of the fetus to develop (among other inadequacies), for this case, let the assumption be made that the fetus is in fact going to become a person capable of meeting the Warren cognitive standards.

Another philosophical component interwoven into this discussion is the notion of viability and at which point in the pregnancy does the fetus gain its right to protection as a person in and of itself. Viability of an infant can be defined as the ability to function independently and successfully outside of its mother's womb. As the field of neonatology continues to advance, that point in gestation in terms of number of weeks continues to come earlier and earlier in pregnancy. Whereas ten years ago to save a fetus at 25 weeks was considered extraordinary, today a child born that early is assumed to survive until proven otherwise. In the case being considering in this argument, the pregnancy is far enough along and there is enough medical evidence to support that this pregnancy is viable, thus fulfilling the viability requirement.

Now that personhood and viability have been established in this case, it can be assumed that the physician's obligation to the fetus has been established. This female fetus is capable of developing into a human being with the ability to meet the Warren cognitive criteria, meaning that in fact the fetus is a person that should be considered independent of its mother. In *People v. Jensen* argued before the Michigan Court of Appeals in 1998, it was established that persons knowingly infected with HIV must disclose their infection to potential sexual partners prior to intercourse so that appropriate protection can be used to prevent infection; failure to do so is considered a crime. That same year, California Senate Bill 705 was passed which

established that it would be a crime to knowingly infect someone with HIV. This all demonstrates that most people actively avoid infection with HIV as infection is often ultimately fatal. Therefore, it can be safely assumed that the fetus in question would actively avoid infection, as this is what most rational humans do. If the physician's therapy is the means by which the fetus can avoid this infection, then the physician has an obligation to provide the fetus with what it needs to accomplish this task.

The risk posed to the fetus by lack of medical therapy needs to be well established for forced treatment of the mother to be ethical. In this case, the risk of vertical transmission has been well documented in the medical literature as substantial should the mother have a high viral load at the time of delivery. It has also been documented that current medical therapies using HAART therapy even at the time of delivery alone can reduce the risk of vertical transmission to virtually zero. Therefore, it can be argued that to refuse medical therapy would be to intentionally infect the fetus as the risks are so high that infection can be assumed to occur. Therefore, to not reduce the risk on behalf of the infant would be unethical.

Another important question to consider is whether or not it would be ethical to allow a mother to decline treatment for her child. In this case, it can be assumed that the mother's consumption of medication is equal to treatment for the infant, as her HAART medication would all but ensure the protection of her infant with regard to the infant's HIV status. Parents are allowed proxy-consent for their children because it is assumed that the parents will make decisions in the best interests of their children. In this case, to opt against treatment is clearly not in the best interests of the child. Should a baby be outside the womb and face a life-threatening condition that could be treated, the hospital would have the ability to invoke the help of child protective services in establishing custody so that the child could receive life-saving treatment. A child in the womb

deserves no less protection simply because it hasn't been afforded the opportunity to be born yet once the mother has committed herself to carrying the pregnancy to term. In the case currently being considered, the infant is far enough along that it could be thought to be viable outside the womb; thus, it deserves to be treated as such and have appropriate medical therapy initiated.

Another question to be considered is whether or not the condition that poses the risk to the infant can be treated without endangering the mother. It would be highly unethical to force a mother to take a medication that is known to be detrimental to her own health. However, in the case currently being considered, the medications are known to be completely safe and would actually be beneficial to the mother's health as well. Because of this, forcing treatment on the mother in this case would not be unethical for this reason.

One of the last questions to be considered is whether or not similar situations exist already in medicine where therapy can be forced on patients if it ultimately proves to be in their best interests. In this case, an example could be taken from psychiatry. Psychiatric patients who present a threat to themselves or others can be held against their will and medicated under orders of protective custody, even if they are competent, as their actions present a danger to society. A mother who knows she is HIV-positive yet chooses not to take medication while pregnant presents this same type of threat to her unborn child. Therefore, it should not be any different to forcibly medicate the pregnant mother at the

time of delivery to protect the health and well-being of her infant than it is to medicate a psychotic individual who is HIV-positive and threatening to rape anyone he comes across. They both present equal threats to others.

Because all of the posed questions have been answered in the affirmative, I would argue that it would be ethical to forcibly medicate a pregnant woman against her will prior to delivery in the hopes of protecting her unborn fetus from the dangers posed by HIV. Though a woman has a right to choose what happens to her body, to decide to continue a pregnancy to term is to accept the responsibility to act in the best interests of the child. Just because the child is still in its mother's womb does not mean that it deserves any less consideration than it would receive outside the womb. From both a physiologic and philosophic standpoint, the child is in many ways an entirely separate being from its mother. It has a separate circulation, separate organs, and the potential to one day grow into a person with ideas, feelings and a way of interacting with the world all its own. To knowingly allow a person to limit that child's ability to fully interact with the world would be ethically wrong on the part of the physician. Once the pregnancy is over, the mother can do whatever she sees fit with regard to her medication. However, while pregnant, she is responsible for not only her own well-being, but for that of the life growing inside of her as well. As the treating physician, there is both responsibility and accountability to both patients involved. Treat the mother, and one day, the HIV-negative child will say thank you.

ⁱ Mary Anne Warren, "On the Moral and Legal Status of the Fetus," *Monist*, vol. 57, 1973, pp43-61.

Katherine Cox

Knowing When to Withdraw Treatment: Decision Making and Neonates

A husband and wife have been eagerly awaiting the birth of their child, and then suddenly, just a week into the third trimester the woman's water breaks, and she experiences contractions. For the parents, the time directly after the birth can be an extremely stressful with guilt, anxiety, and grief. Their child is quickly rushed away into the hands of a neonatologist and a team of nurses in the neonatal intensive care unit (NICU). As the team struggles in the best interest of the child, many difficult decisions must be made. Almost all of these gravely impaired newborns will require medical assistance to breathe, and some must be fed intravenously. When the newborn suffers from other complications, the treatment decisions become much more serious. Ethical questions arise such as, "Is it ever in the child's best interest to die rather than endure meaningless suffering?" and "Who should make the decision to withhold treatment or treat aggressively?" These decisions are given much consideration by the neonatologist and parents, but in the end, a decision must be made based on the best interest of the infant.

The most common medical complications in prematurity arise from low birth weight and immature organs. These conditions often require difficult decisions regarding the care of the infant. Normally through psychiatric and pastoral counseling, a reasonable understanding can be reached between the doctors and the parents about the course of treatment. However, the complex circumstances can lead to extreme reactions by the parents. For example in 1982, a child born in a Bloomington, Indiana hospital was diagnosed with Down syndrome and an esophageal atresia that disallowed food absorption. Although two other physicians insisted on the standard surgery to fix the birth defect, the obstetrician "advised the parents to withhold treatment and let their child die."ⁱ The esophageal atresia would have been fixed immediately in any other child born without

Down syndrome; however, the presence of possible mental retardation greatly affected the parents' decision. The hospital's attorneys took the case to court to obtain consent to operate on the child, but "Baby Doe," died before the case was heard.

There are also cases in the opposite extreme, when the parents seek to aggressively treat the child by any means necessary. In The Hastings Center Report, John Arras asserts, "continued life is obviously in the interest of the normal child, but what of the child impaired by profound brain damage, whose days will be measured by operations and whose pain will be unrelieved by the communication of human sympathy?"ⁱⁱⁱ These children in effect suffer the opposite of not being allowed treatment; instead, they are ruthlessly kept alive by machines when their bodies might prefer death to pain and suffering. Consider the case of the chromosomal disorder Trisomy 13, where the "child's brain is so malformed that she will never possess the capacity to think or to communicate to others... if treated aggressively and vigilantly, however, she might well live for months, or perhaps even for a year."ⁱⁱⁱ Another example is the case of a rare inherited disorder called Lesch-Nyhan Syndrome which induces self-mutilating behavior in infant boys.^{iv} In both diseases, children can be kept alive for some time through demanding treatment, but are destined to an early death of intense suffering and pain without ever having to be able to process information or love.

The difficult question then becomes, when is it proper to withhold treatment from a premature infant, and when should the disease be attacked aggressively? More importantly, who should make the decision of life or death? At the heart of these questions is the human ability to "play God." The infants cannot speak for themselves, and sometimes the parents are too emotionally involved to make

proper decisions; however, “*someone* must decide and, in doing so, appeal to standards of right and wrong... the question is *which* standards will guide us.”^v Dr. James Marshall, the only neonatologist in Abilene, Texas explains, “These are heart-wrenching decisions... there is nothing black or white, rather there is a lot of gray. Most of the time the babies make the decisions for you; it is the ones that linger that make it difficult.”^{vi}

Indeed, ambiguity abounds in the discussion of premature newborns. The infant cannot express his or her consent, which leaves the doctors, parents, and others to make the treatment decision in the best interest of the child. Even when the responsible caregivers decide that the that the discontinuation of treatment is in the best interest of the child, most parents and doctors do not want the guilt that comes along with playing God. Indeed, it is easier when a precarious newborn makes the decision for them by dying of natural causes. However, few infants have this option today.

Technology has become a great triumph in neonatal medicine, but it has also caused a great ethical dilemma. In a personal interview, one neonatologist said he believed “technology is ethically ahead of us.”^{vii} Society has developed technologically so that almost any premature infant can be kept alive for at least some time regardless of their relational ability or self-consciousness. On the one hand doctors are now able to save a large majority of babies born prematurely (about 80 percent at 26 weeks of gestation), but they also have to decide to remove some children from treatment so not to extend their suffering.^{viii} Technology also allows doctors to diagnosis more complications at the birth of the child. However, in the Baby Doe case, “the degree of mental retardation from Down syndrome was impossible to predict,” but because the child was diagnosed with the syndrome the parents choose to let the child die instead of giving their consent to repair the esophageal atresia.^{ix} In the past, doctors would not have been able to diagnosis the complications at all, so less children were affected by parental prejudices at the onset. However, the inferior technology meant fewer children were kept

alive to the point that a crucial decision had to be made by the parents and doctors. Currently in society there is not an overarching answer to these concerns, and thus, most decisions are made on an individual basis. As we continue to advance technologically, we must also continue to advance ethically so that parent and doctors have some guidelines for dealing with preterm complications.

The struggle to deal with ever-advancing technology is not the only issue physicians face when seeking the best treatment for their patients. When parents refuse medical treatment for their premature newborns because they might not want what they view as a flawed child, doctors are often forced to take the parents to court to receive consent to treat the child. Although parents should naturally have a voice in the life-or-death decisions of their child, they may not be the best suited to make the critical decisions because of the anxiety associated with the demanding occasion of a preterm birth. The physician must then act in a paternalistic manner, which often excuses the parents from the guilt and anxiety that comes with making a life-or-death decision about their child. However, there is not a clear black or white answer for the doctors, and Strong concludes that “when there is evidence that the infant will probably be handicapped, the neonatologist often faces a conflict between a duty of nonmaleficence toward the patient and, since aggressive treatment of the infant may result in serious hardship to the family, a duty of nonmaleficence toward parents as well.”^x

Indeed, there are no clear solutions for handling premature newborns that suffer from complications. Confusion over social roles in medicine often leaves both the healthcare team and the parents confused on the best course of treatment. However, there are ways of improving the situation. First, we must clarify the roles of all who are involved with the care of the infant. The newborn cannot give his or her consent, so we must respect the roles of the parents in the decision-making process. As Carson Strong has written:

“our society assigns parents the responsibility of making decisions about how many children to have, how to raise them, and what beliefs and values to instill in them... We can say, then, that the neonatologist ought to permit parents to participate unless professional obligations or other moral considerations dictate, independently of parental wishes, what the decision ought to be.”^{xi}

Although this course of action still has some uncertainty, it is better to include the parents in the team effort to seek the best interest of the child. The physicians will always have more medical knowledge on how to treat the infant, but the parents have been entrusted by society to know what is best for their children. It seems that the best approach does not pit the doctors against the parents, but allows for them to work together as a team in the best interest of the child.

Secondly, “for a great majority of these handicapped infants, radical social reform—not ‘beneficent’ euthanasia—is the answer.”^{xii} Medical treatment should never be withheld from a newborn, whether it is handicapped or not, based on the social situation it will enter into if it is to live. Paul Ramsey clarifies that “if physicians are going to play God under the pretense of providing relief for the human condition, let us hope that they play God as God plays God. Our God is no respecter of persons for good quality.”^{xiii} By that, Ramsey means that when dealing with sickness, God does not show favoritism to anyone. To accomplish this we must have a radical social reform that will support premature children born to underprivileged parents. According to the March of Dimes website, “In 2003, hospital charges for newborns without complications averaged \$1,700. In contrast, hospital costs for infants born too soon or too small averaged a startling \$77,000.”^{xiv} Even with insurance (which is still not available to many people) the costs of prematurity can be staggering for a family. Society must continue to accept and help children born with complications from prematurity, such that “worries about the

child’s future life with a potentially abusive parent or in a hopelessly inadequate state institution should not be allowed to influence treatment decisions.”^{xv}

Finally, we must increase the dialogue in society about not only prematurity, but about acceptance of mentally and physically handicapped people. One of the primary reasons a handicapped child would be allowed to die from an esophageal atresia is because of the lack of acceptance in our society. People often do not know how to react to the news of their friends or family having a premature infant. On one hand, they want to celebrate the birth, but on the other, there is an uncertainty surrounding the life of the child. For these reasons, prematurity is not often discussed, and thus, when parents have to face an early infant, they are left alone and with many questions. More awareness would lessen the need for paternalism in the medical field so that parents can play a larger role in the treatment decision process.

Ambiguity surrounds the decision-making process of premature infants. Parents should have some say in the life-or-death decisions about their children, but often they have incomplete information and are encompassed by anxiety. Technology offers the best hope for saving the newborns’ lives, but it also might serve to only keep them alive longer in their suffering. Any attempt to simplify the issue only disrespects the dignity of the infants and leads to a “counterproductive quest for moral certainty.”^{xvi} With complications that are terminal notwithstanding, only a radical social reform where all children are treated medically equal, will push society to fully accept premature infants born with complications. Most importantly, let us remember the infant is not a “defective neonate,” but a child who is completely dependent on the decisions of his or her physicians and parents.^{xvii} This enormous responsibility leaves everyone to first seek to do no harm, and then to do what is in the best interest on the child.

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ⁱⁱⁱ Arras, 31.

^{iv} "Lesch-Nyhan Syndrome Information Page," National Institute of Neurological Disorders and Stroke <http://www.ninds.nih.gov/disorders/lesch_nyhan/lesch_nyhan.htm> (1 Dec. 2005).

^v Arras, 55.

^{vi} James Marshall, interview by Katherine Cox, 22 November 2005.

^{vii} James Marshall, interview.

^{viii} March of Dimes Web site

^{ix} The C. Everett Koop Papers

^x Strong, 13.

^{xi} Strong, 14.

^{xii} Arras, 28.

^{xiii} Paul Ramsey, "Justice and Equal Treatment," *On Moral Medicine* 2 (1998): 725-726.

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^{xv} Arras, 28.

^{xvi} Arras, 33.

^{xvii} Lammers and Verhey, 680

Scott Crabtree

How Much for a Life: Triageing Friend and Foe

The act of triage is a straightforward, simple process. Quickly assess patients' injuries, obtain a rough prognosis, and decide whether they will be given emergent care, deferred care, or only the care which can be readily given to ease their suffering till they eventually, and likely quickly, pass. Despite its simplicity, however, it is readily obvious even to those who have not experienced such an affair that no step in the process is easy. In the rushed, chaotic environment of mass casualty events determining the extent of patients' injuries accurately and swiftly is not undemanding. Determining whether they can be saved is not simple. And making the decision whether to even try or not is profoundly psychologically and emotionally taxing even if the initial adrenalin rush means the full weight of the experience is not felt till some time later. Despite the gravity of the situation the ethics of the matter are also relatively straightforward. Simply put, with limited resources you must do the best with what you have. Few would disagree that those whose injuries make it so their chances for survival are minimal should receive the devoted attention of an emergency care team when there are two others also slowly dying but whose chances are significantly better. It may be sad to abandon the one in greatest distress, but few would argue against the necessity of such action. Much of this changes, however, when triage comes to the war zone.

In just about every situation a doctor can find himself in he is surrounded by allies. His care is sought after and he is happy to give it. Even if the patient in question has obtained his injuries by engaging in activities the physician is less than supportive of or is a person the physician would not otherwise wish to associate with, the physician graciously extends his services because by default people are people and people deserve

medical care. In armed conflicts this de facto starting position patients have is strained as many times the patients are less ordinary people and more enemy combatants. Sometimes the physician will find he is saving the life of the same person who was only a minute ago trying to take his own. Sides are drawn and each side has sworn to neutralize if not outright kill the other. In settings where the physician can freely care for patients, whether friend or foe, completely and does not have to divide resources, the inherent human worth of the individual carries the day and the physician can, should, and will completely devote his attentions to the injured person. In mass casualty events, however, the physician is once again forced to prioritize. He must decide if the life of a foreign gunman, the life of someone devoted to opposing the mission the physician as a military officer is avowed to, is equal to the life of a comrade, fellow allied soldier. In such situations some would question whether the rules of triage are the same. If, for example, when deployed to a relatively small field hospital a physician finds himself with a wounded enemy combatant rapidly losing blood from a large caliber gunshot wound to the abdomen, a thready pulse, significant pallor and the onset of shock fast approaching and also simultaneously a wounded friendly marine with a crush injury to his upper extremity, shrapnel in multiple locations, and moderate blood loss of his own, who should receive immediate care? Both would be classified as "emergent" under the United States Army's *Emergency War Surgery* handbook – the former perhaps further subcategorized as "immediate" and the latter as "urgent" – but should the limited medical care be devoted regardless of who is who? Or, alternatively, in some circumstances is the character of the patient just as important as the gravity of his injuries?

Turning to conventional medical ethics would certainly be an appropriate start, but many of the basic principles such as autonomy and non-maleficence are not applicable in this problem as we will assume both patients are wanting the fullness of medical care and the physician intends to hurt neither. Even the concept of beneficence is of limited usefulness. The foreign combatant is at great risk of losing his life and hence it would be appropriate for the physician to devote most if not all of his immediate attention to saving it. Likewise, although the allied marine is at less risk of death the chances for serious long term injury and loss of limb are significant and it would be just as appropriate for a physician to devote most if not all of his immediate attention to stabilizing and repairing this injured soldier as well. Clearly both stand to be saved and both need the thorough attention of most the available medical staff. Beneficence would only suggest that we strive our best to help both, but in situations where we cannot it provides little further guidance. It would seem then that in order to obtain any clarity we must turn to the concept of justice.

Justice, the key concept behind the idea of triage, may be what will guide us here.

Using this concept, from a purely medical perspective the standard rules of triage would apply as previously mentioned. The foreign combatant needs immediate care, the allied soldier needs urgent care. Problem solved. Take it back a level to a more public perspective, however, and the costs of such a decision begin to add. A unit removed of one of its normal soldiers is a weaker unit, less effective unit, and a more dangerous unit for the other soldiers still active. Take it back another level to a more political perspective and the costs climb still more. How profitable is the life of a man who only briefly before was violently resisting the power of your nation in its most assertive form and how much more costly is the loss of a marine from duty to the overall

success of the mission and safety of the nation as a whole? And take it into an immensely personal level and the cost is not merely an amputation but a life changed. Combat injuries and amputations are not entirely physical and the psychological wounds are often just as damaging – the effect creeping into the lives of family, friends, and forever altering the way the injured sees himself, the world, and his future. With the scales adjusting, a more nuanced perspective would ascertain that foreign combatants have family and friends too, many of which may be in no way involved with the conflict. Their sense of loss would be just as immense if he were to pass away. Likewise, wars are many times fought for minds as often as they are for neighborhoods and lives. The fair and generous treatment of POWs is key to getting insurgent gunmen to lay down their arms and the people to withdraw their support. With so many angles and so many perspectives to contemplate the consideration of justice has certainly opened up the problem of triage in a combat zone, but in doing so it has laid it out in snarled disarray. The ethical equation has become an endless series of variables with largely debatable coefficients. With the issue becoming so gray where do we go from here?

The problem of such utilitarianism is that while it allows for a more discriminating approach it also has a tendency to deprive ethics of the moral strength it seeks to preserve. The fine measure of a thousand points of contention allows for rationalization as much as it allows for an exacting analysis of a complicated situation. The vast majority of medical oaths in existence whether the be the Oath of Asaph and Yohanan established for ancient Hebrew physicians, the Declaration of Geneva constructed after the abuses of World War II, the Seventeen Rules of Enjuin developed in Medieval Japan, or the Hippocratic oath created millennia ago are straightforward and fundamental. Although this is partly if not

largely due to a need for concision and foundation, there is also strength and clarity in simplicity. When medicine gets mixed with a legion of other issues the central purpose of medicine, healing, quickly becomes diluted. As physicians become less healers and more business men, military officers and judges, the sanctity of life becomes less a commanding value and instead just another option to consider. At times these secondary roles and their duties may be inescapable, but they most always remain secondary. The first step towards gauging the value of a life is the first step away from the soul of medicine, and deciding how much an individual is worth requires a heavy spiritual cost in return. Tending to a seriously injured friendly marine over a sick and dieing insurgent gunman may well be the initial impulse of many a doctor in such a situation, but in doing so he would sacrifice much of what truly makes him a healer. His technical skills may remain, but his soul suffers. If we wish to continue on as doctors and not simply as learned technicians we must hold true to medicine's foundational principles. In a world of competing priorities the defense of life must always remain priority one.

As interesting and debatable as all this may be the reality is significantly less than a thousand physicians enter military service any given year. Few will see any mass casualty events, and, as in the case of Iraq, most Iraqis are treated in Iraqi hospitals, few will ever see a scenario such as this. Its practicality is not where its

usefulness lies, however. Often times ethical principles must be pushed to their extremes to appreciate their merit. One does not value autonomy until one is pressured to resist it and one does not appreciate honesty until one is tempted to ignore it. Likewise it is easy to accept the idea that the preservation of health and life is the underpinning of medicine, but until one is seriously enticed to believe otherwise he will likely never seriously consider it in his daily actions. It will be a nice idea quickly agreed to and quickly forgotten. Without thinking about at what point we would second someone's survival for another purpose we will never think about the smaller ways we are already seconding our patients' health for private incentives and personal biases. We may not be sacrificing insurgent gunmen for the arms and legs of allied marines, but many physicians every day provide a little less care in order to get out of the office a little sooner, a little less consideration to personalities who irritate them, and a little less attention to those they think beneath them. We may question when gross discrimination is acceptable, if ever, but until we do we will never see the hidden discriminations occurring every day. Most physicians will never triage in a war zone, but everyone balances a countless number of priorities every day and the more we think about them and the more honest we are concerning them, the more we will make the right priorities first in our lives and first in our practices.

Anna Diller

Three Paradigms for Medical Justice: Right, Merit, and Need

Finitude is the rule of life. Limits create natural and unnatural disparity. Limited intelligence and educational opportunities preclude acquiring certain information and skills. Finite time, resources, knowledge, and ability impose constraints upon all medical practice. Ultimately, limited income creates socio-economic inequalities, so that patients with limited finances and resources must compete for quality health care.

Thus the need emerges for quantifiable measures with which to gauge the most fair and equitable allocation of resources across the spectrum of patient and situational diversity. The ethical paradigm of justice needs to be defined in a manner which promotes both the understanding and application of the principles and goals of justice. A clear and concise thought rubric will define our application of justice in hospital wards and courtrooms. Such measurable parameters are especially desired in the area of medical ethics, where justice-based decisions often carry life and death consequences.

To establish rules for quantifying justice, we must first consider the limitations from which it arises. Following are five types of limits which concern just action in health care:

1) Natural Limitations (biological and physiological)

Natural limits define the ability of a patient to be physiologically benefited by a certain treatment, from physical therapy and gene therapy as well as dialysis and lobotomies. Given the body's natural abilities to regenerate certain cells or the irreparable cell damage from accident, disease, abuse, or natural aging, certain medical procedures may be deemed useless or impractical.

2) Resource Limitations (fiscal, technological and service sources are finite)

Scarcity of available resources is the most common source of the need for just delegation of those items. The reality of budgets, equipment shortages, and overworked health-care staff imposes very real constraints on the ability to heal all people equally at any given moment. Hospital administrators must make difficult choices for the allocation of respirators, diagnostic tests, emergency room technologies, and expensive, difficult procedures.

3) Accessibility limitations (geographical location defines the distribution of available provisions)

High-quality health care is not equally accessible. Language barriers, illiteracy, lack of insurance, and underserved areas deficient in proper medical resources establish population subsets with the ability (or inability) to utilize medical services. What cannot be accessed cannot be utilized.

4) Cultural and Moral Limitations (set by religion and tradition)

Our values and belief systems establish humane standards for medical care and sometimes define certain areas of research and practice as inappropriate. Operational paradigms and technological expertise inhibit or promote innovations. Integrity limits the use of risky, experimental surgical techniques. Compassion defines palliative treatment. Tradition sets precedents for respect of the human body. Superstitions and religious doctrines set boundaries of acceptable medical knowledge, planning, and treatments. Likewise, cultural backgrounds and world view may restrict adherence to medical procedures or interfere with understanding the

biomedical basis for diagnosing and treating an organic disease.

**5) Societal and Legal Limitations
(established to provide the greatest good for
the common population)**

Finally, insurance companies, pharmaceutical firms, and our legal system enormously influence the parameters of allowable procedures and physician activities. Respect for autonomy and patient rights may conflict with providing comprehensive care for a patient. For example, the laws passed in the mid-70s concerning involuntary hospitalization of the mentally ill impede a psychiatrist from forcefully administering medication to a patient, even when the patient is psychotic and incapable of making sound decisions concerning his or her well-being.

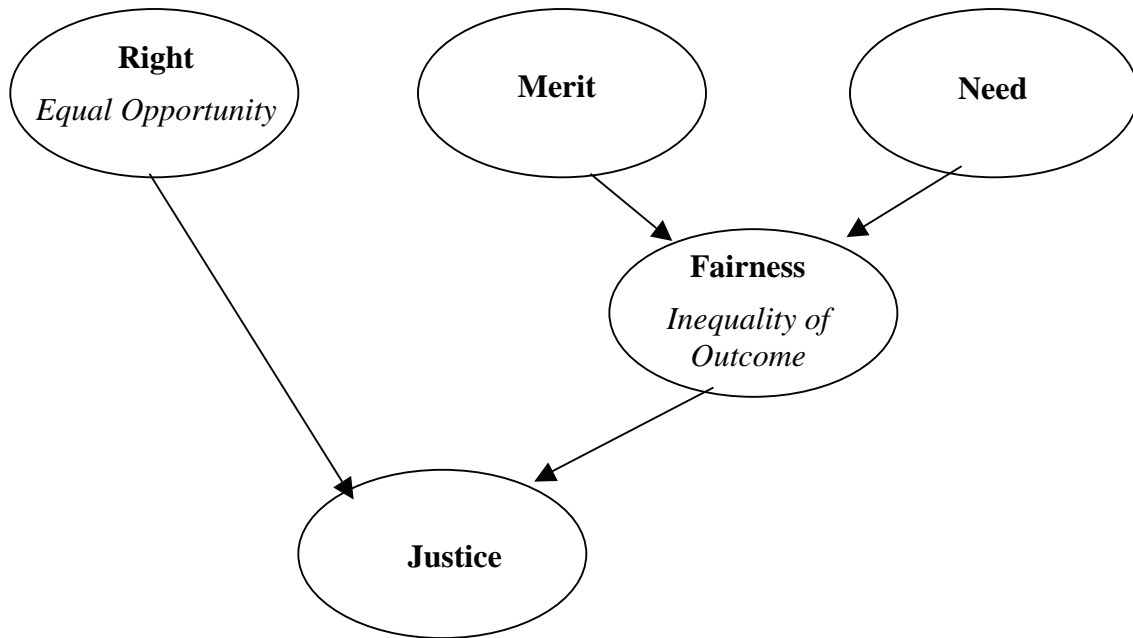
Each of these limitations necessitates regulation or triages the allocation of goods and services at society's disposal. Certain precedents and requirements must be established to uphold the fairest, most equitable, most beneficial distribution and access to those resources. However, conflicting values and fuzzy logic, combined with rampant advances in science and technology within a culture that, at times, clings to archaic models of thought and practice, create a legal and moral atmosphere of confusion, doubt, and indecision. Without a current, coherent model for evaluating justice in health care, many patients' needs are neglected while others who exploit and manipulate the system benefit.

A rudimentary, fundamental basis for evaluating justice is to affirm the ontological ideal "that all persons are equal in inherent worth" (Childress). Equality functions at the level of opportunity by prohibiting discrimination, favoritism, or preference, regardless of natural or created circumstances.

Society should not place any greater barrier, burden, or benefit on one person over another. Equality seeks complete objectivity, the eradication of oppression, and the creation of *equal opportunity*.

From the plane of equality evolves hierarchical standards of fairness; that is, everyone receiving what they need or deserve. As Aristotle stated, "giving to each that which is his due." Fairness is a secondary ideal because it seeks to create balanced distribution in light of the reality that equal opportunity does not guarantee *equal outcome*. Though equal opportunities may exist, equal results cannot be expected. Deservingness, or merit, is derived, in part, from an individual's response to equal opportunity. In an atmosphere of political democracy and *laissez-faire* economy in which society does not intervene to level out innate differences, empirical interpersonal variation creates competition, which progressively favors the best fit – those with the highest level of skill, intelligence, or strength. Need is the second determinant of fairness. Some needs are consequentially based on competition outcome, such as the needs of the poor and uneducated, whereas other needs, such as those of the mentally ill or disabled, are organic or natural.

Justice is an altruistic balance between primary ideals of equality and secondary ideals of fairness. Distributive justice, examined here in regards to health care, cannot inherently be egalitarian due to the five categorical limitations discussed above. Equal distribution is constrained by empirical, demographical, social, economical, and etiological inequalities, to name a few. However, pragmatic, sensible, yet wholly compassionate and non-exclusive criteria can be established as a functional means of evaluating justice.



This justice paradigm is established on three precedents – specifically right, merit, and need. These three ideals of justice should serve as the basis of utility in determining ethical distribution of resources, in economics, society, and medicine.

1) **Right** – perfect, constitutional equality described by Thomas Jefferson as the “inherent and inalienable rights” among which are listed life, liberty and the pursuit of happiness (Declaration of Independence, 1776). Everyone is entitled to equal access and equal consideration, which is not a privilege to be obtained or lost. Even those who have forfeited their freedom through criminal activity and incarceration retain the fundamental value of humanness, which cannot be defined by circumstances, actions, or deservedness. Rights are upheld by establishing *equal opportunity* wherein each and every individual has the necessary provisions to achieve and attain that which they desire, without regard to capacity or ability.

2) **Merit** – a value-judgment defined on the basis of fitness. It can be evaluated on each of the following measures:

a) *Possible outcome* – likelihood of success in the future through the aid of the treatment/procedure. The meritorious use of a limited resource is that which will yield the most successful outcome (curable vs. incurable diseases). A chronic, terminal disease would be less effectively cured than lyme disease.

b) **Contribution to society** – utility and usefulness based on the foreseen benefit to society as a whole. One who is incarcerated and on death row would not be placed as a higher priority for treatment than one who is a working taxpayer.

c) **Nature v. consequence** – source of disease as one resulting from lifestyle choices or as the result of an unpreventable, nondiscriminatory congenital or genetic basis. It may be considered that inequalities which result from a “natural lottery,” wherein the individual cannot be blamed for their affliction, ought to receive means for surmounting their disadvantaged situation. A smoker who develops emphysema would not receive preferential treatment over a child with cystic fibrosis.

d) **Empirical guidelines** – individual personality differences such as mental functioning, access by illegal aliens to programs funded by tax dollars, and ability to provide monetary compensation for treatment (insurance).

3) **Need** – an evaluation of requirements for the human condition. Necessity can be based on Maslow’s Hierarchy of needs, beginning with the most basic being physiological and safety, then progressing through belonging and esteem to self-actualization. Herein, plastic reconstructive surgery (as in cleft palate repair) to provide the body with basic physiological functions is a more pressing need than elective rhinoplasty for self-esteem and personal image.

a) **Severity** – intensity of disease and symptoms, such that the most severe and gravely afflicting conditions receive preferential treatment.

b) **Urgency** – timely requirement for treatment. For example, although one may

have renal failure and be in severe need of a transplant, their health may be maintained through dialysis and therefore their need is not an urgent one.

Justice resists being measured and enforced quantifiably. It is rife with internal conflict arising from the undesirable task of establishing priorities, and thereby discriminating through preferential allocation of limited goods and resources within the constraints of time, law, and society. However, in the medical field, justice is an ongoing discussion that must occur to evaluate effective and humanitarian treatment in light of constant advances in technology and discovery. In the courtroom and at the bedside, physicians are confronted with a reality of relativity and very few ethical absolutes on which to base decisions. By positing the three pillars of right, merit, and need, I hope that a categorical approach to justice ethics may prevail with an efficient outcome of saved lives.

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Catherine Garrett

Supporting Stem Cell Research

The controversy surrounding human stem cell research is anchored in the moral and religious aspects of harvesting the cells, especially from embryos. Multiple types of stem cells have already been found including pluripotent adult cells and virtually totipotent embryonic cells; the most controversial of them being embryonic stem cells because the embryo is destroyed when the cells are removed. Scientists believe that stem cells could have amazing medical and biological applications, but the ethical dilemma of obtaining embryonic stem cells severely hinders research and development. Current policies in the United States prohibit federal funding of new stem cell lines which also hinders exploration of stem cells' applications. On one side of the debate, conservative groups abhor embryonic stem cell research because it kills the embryo, which they consider a person, and they find any further research involving embryonic stem cells immoral and unethical. The other side, composed of the more liberal groups, believes the overall good that could come of the research justifies the harvesting of embryonic stem cells. They believe that extra embryos from in vitro fertilization can be used to obtain stem cells and support federal funding of this research.

The Science Behind Stem Cells

In the President's Council on Bioethics: Monitoring Stem Cell Research, stem cells are defined as multipotent cells that are undifferentiated and unspecialized. They are said to have two characteristics: the "capability for unlimited or prolonged self-renewal" and the "potential to produce differentiated descendant cell types¹." Adult stem cells have been found in the bone marrow, umbilical cord, brain, muscles, skin, digestive system, cornea, retina, liver and pancreas. Hematopoietic cells found in the bone marrow have been proven to differentiate into many different types of blood cells including red and white cells. They are self-

renewing and plastic, meaning they help generate tissues other than those of the blood system. Adult stem cells have proven helpful in treating some medical problems, but they are unfortunately hard and expensive to separate from the other blood cells. In the bone marrow only one out of every ten thousand cells is an undifferentiated stem cell². They are also very difficult to grow in culture so they must be produced in vivo.

Embryonic stem cells are much more versatile and easier to obtain. They were first discovered in 1998 by James Thomson at the University of Wisconsin-Madison². Embryonic stem cells are one type of cells that can be obtained from embryos and are taken from the inner cell mass at the blastocyst stage which is present 5-9 days after fertilization. The blastocyst contains approximately 200 undifferentiated cells that later develop into three primary germ layers¹. These cells can easily be separated from the rest of the embryo and are grown in cultures using a layer of mouse embryonic fibroblast as "feeder cells" that produce growth factors for the human embryonic stem cells². Unlike adult stem cells, embryonic stem cells have the potential to differentiate into virtually any type of cell found in humans; they are the most basic type of cell that give rise to every other cell in the body. Due to this fact, the potential medical benefits of embryonic stem cells are immense and seemingly endless.

Medically, adult stem cells are useful but only in a limited number of ways. Adult stem cells have already been utilized in the treatment of leukemia and diseases that affect the blood. Embryonic stem cells, on the other hand, could have even more medical uses. Doctors speculate that embryonic stem cells could be used for the treatment of severe diseases such as diabetes, Parkinson's, and Alzheimer's. They also believe that embryonic stem cells could be used for treating severe burns, multiple types of cancer, cardiovascular

diseases, autoimmune diseases, osteoporosis, spinal cord injuries and birth defects. Speculations have been made that embryonic stem cells could even be used to significantly reduce the occurrence of transplanted organ rejection and graft versus host disease which is prevalent in current adult bone marrow stem cell transplantsⁱⁱ. Millions of lives could potentially be saved, or at least improved, using embryonic stem cells. Unfortunately, the government currently refuses to fund stem cell research and these medical possibilities cannot be explored.

After much deliberation and debate, on August 9, 2001, President Bush issued a statement explaining that only preexisting embryonic stem cell lines would be funded for further research because “the life and death decision had already been madeⁱⁱⁱ.” He also insisted that only preexisting lines derived from excess in vitro fertilization embryos created for reproductive purposes could be used. He further stipulated that only cell lines obtained with proper informed consent of the donors and not involving financial inducement could be used. Based on this policy, the government will not give any federal funding to create new embryonic stem cell lines, but private funding can be used. When Clinton was in office, the National Institutes of Health Research Panel concluded, “if there is sufficient promise or reason to support research, the claim of a human embryo to ‘serious moral consideration’ could be outweighed by other moral aims or principles.” During this time the preexisting stem cell lines now being researched were created. President Bush’s Council on Bioethics, however, decided to halt the harvesting of new embryonic stem cells based on ethical concerns of destroying the embryo^{iv}.

Liberal Perspective

The moral debate regarding stem cell research focuses mainly on the personhood of the embryo. Conservatives believe the embryo is a person from the moment of conception, while the more liberal supporters side with science saying the embryo becomes a person

later in development. Many ethicists stress the fact that for the first week after fertilization the egg is capable of dividing into identical twins and even sporadically recombining back into one egg^v. Without individuality the egg cannot be classified as a person and since the embryonic stem cells are extracted during this initial week, the embryo is not yet a person. One of the prominent liberal Christian groups, the General Assemblies of the Presbyterian Church (U.S.A.), believes that the embryo has the “potential of personhood” and deserves to be respected, but it is not already a person^{vi}. They believe that it would be morally wrong to put the respect for the embryo above potentially helping people suffering and in pain. Therefore they support embryonic stem cells derived from extra in vitro fertilization embryos because they “do not have a chance of growing into personhood⁷.” They also support the use of aborted fetuses’ tissue because they believe in a woman’s right to morally choose abortion based on religious beliefs.

The liberal groups base their support of embryonic stem cell research on the morally just outcome of helping people suffering from serious illnesses. The Presbyterians state that, “as people of faith we are called to be partners with God in healing and in the alleviation of human pain and suffering⁷.” They believe that it is their job as Christians to help others. It would be morally wrong not to do the necessary research on embryonic stem cells that could lead to helping people suffering from diseases treatable with stem cells. There is no moral harm in allowing embryos that are going to be discarded to be used to harvest stem cells if the outcome could include treating very serious illnesses. If the treatment of these diseases was obtainable through any other method then destroying the embryos would not be necessary, but since the goals are “compelling and unreachable by other means^{vii},” then embryonic stem cells should be harvested.

The liberal groups support federal funding of stem cell research and believe that

Bush's decision limits the medical advances that could result from embryonic stem cell research. They do not think the approximately sixty preexisting cell lines will be sufficient to complete the research necessary. Most of the Conservative groups, however, believe that Bush was wrong to fund any embryonic stem cell research even on preexisting stem cell lines because the means of obtaining the cells was immoral. The conservative groups are not concerned with the profound possibilities stem cell research may have medically and therefore do not support any further research involving embryonic stem cells. This close-minded view severely limits medical advancement because it is unwilling to overlook the means of obtaining the cells to focus on potentially helping millions of suffering people.

Anthropologically, liberal groups would again agree with Joseph Fletcher. Fletcher is optimistic about what humans can accomplish and sees science and technology as the means for societal advancement. He believes that humans are rational beings and that God gave them rational reasoning to change their nature. On a fundamental level, liberal supporters affirm Fletcher's beliefs. They see medical advancement as a moral obligation and stem cell technology as the means to fulfilling this obligation. They believe that God wants them to help heal others and ease their suffering, so it is their duty to support stem cell research as a possible way to accomplish God's goals. In this way, human nature aligns with God's nature because both seek to heal others. Unlike Fletcher, however, they do not equate science and technology with "playing God," but instead believe that science and technology should be used to be "partners with God in healing^{viii}."

Opposition by the Conservative Perspective

Conservative groups strongly oppose harvesting embryonic stem cells and any further research on stem cells. The Catholic Church, one of the largest conservative Christian groups, believes that a "human being

is to be respected and treated as a person from the moment of conception and therefore from that same moment his rights as a person must be recognized^{ix}." The Roman Catholic Bishops of the United States oppose embryonic stem cell research because they believe it is immoral, illegal and unnecessary since "life is sacred from the moment of conception^x." What they fail to address is the medical implications of stem cell research. They do not acknowledge the potential to treat the pain and suffering of millions of people using the stem cells of a discarded embryo. They do not recognize the fact that the embryos will be destroyed and discarded regardless because they are extra and therefore extracting the stem cells does not change the fate of the embryo.

The conservative groups do not just oppose harvesting the cells; they also oppose Bush's policy to research using the preexisting stem cell lines. They do not believe that any federal money should be used to fund stem cell research and would rather the practice be made illegal. A prominent Catholic Bishop, Joseph Fiorenza, addressed Bush's "trade-off" as morally unacceptable and urged Bush, on behalf of the U.S. Conference of Catholic Bishops, not to allow federal funding of research because, "government must not treat any living human being as research material, as a mere means for benefit to others^{xi}". Conservatives only focuses on the means used to obtain the preexisting stem cell lines and would rather the cells be disposed of and go to waste than be used for important medical research.

Stem cell research seems to be a promising field that deserves further exploration. Unfortunately the different views on stem cell research are so conflicting that they inhibit any real advancement. Although much debate clouds the topic making it hard to decipher between moral and immoral or ethical and unethical, the prospective outcome should be clear. If the lives of millions of people across the world can be positively affected by continuing stem cell research, then it should be pursued. Although the current

U.S. policy regarding federal funding of stem cell research reflects a blend between the conservative and liberal perspectives, the majority of the American public supports stem cell research, including embryonic. Morally the lines may be blurry between right and wrong, but the humanitarian aspect of stem

cell research is clear cut and the possibilities are seemingly endless. Stem cells, embryonic stem cells especially, could hold the key to the future of medicine and the potential to cure or at least treat a wide range of diseases and ailments; we need only open the door to further investigation.

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ⁱ The President's Council on Bioethics

ⁱⁱ Stem Cells and the Future of Regenerative Medicine

ⁱⁱⁱ The President's Council on Bioethics

^{iv} The President's Council on Bioethics

^v Stem Cell Research and the Catholic Church

^{vi} Presbyterian Statement on Stem Cell Research

^{vii} Religious Views on Stem Cell Research

^{viii} Presbyterian Statement on Stem Cell Research

^{ix} Stem Cell Research and the Catholic Church

^x Religious Views on Stem Cell Research

^{xi} Stem Cell Research and the Catholic Church

Oscar Hernandez

The Ethical Responsibilities of Physicians in Modern Medicine: The Death Of Jesse Gelsinger

Ethics in the medical field is a fluid and ever-changing discipline. These two attributes are due in great part to the growing advancement of medical technologies as well as the options that these bring in medical treatments. New treatments give the physician and the patient different treatment options. Many times these different options create difficult decision-making processes. A patient who is undergoing chemotherapy may be given a choice of radiation therapy, surgery, organ transplantation, and/or other radical medical treatments that may give different probabilities in successful recovery. These different outcomes and/or probabilities have to be coupled with the personal preference of the patient and physician, in which case may not be the same. Trusting the authority and expertise of physicians, patients undergo certain treatments against their own premonitions. Physicians now enter an area where their sole attention must be focused on the patient's well-being. I will argue that this commitment, once made, must be based on this simple idea: the patient's well being is the ethical and professional obligation of the physician. Moreover, I will argue that a physician must do this virtuously or at least in accordance with virtue ethics, since other theories may fail to give a complete account of the physician's moral justifications according to the four ethical principles in medicine. The issue of gene therapy, a fast-growing medical specialty, in the case of Jesse Gelsinger marked the first widely publicized gene-therapy death and is a good example of the ethical issues in the modern medical world.

Jesse Gelsinger was born with a genetic disorder called Ornithine Transcarbamylase Deficiency. Ornithine Transcarbamylase Deficiency arises when the enzyme Ornithine Transcarbamylase is

produced in low amounts, in a defective form, or is absent. Any of these will hinder or stop the production of Citrulline from Carbamoyl Phosphate and Ornithine, and eventually the urea cycle, which is essential in disposing of nitrogenous compounds. Ammonia and Carbamoyl phosphate are accumulated in the mitochondria, cytoplasm, tissues, blood, and eventually in the entire organism. The side effects of hyperammonemia include anorexia, irritability heavy or rapid breathing, lethargy, vomiting, disorientation, somnolence, asterixis (rare), combativeness, obtundation, coma, cerebral edema, and death. The neurological effects include poor coordination, dysdiadochokinesia, hypotonia or hypertonia, ataxia, tremor, seizures and hypothermia, lethargy progressing to combativeness to obtundation to coma, and decorticate or decerebrate posturing, among others [I]. The Ornithine Transcarbamylase gene is located in the X-chromosome (sex chromosome), and it is a recessive trait. Males, which are usually the ones affected due to the single X-chromosome, have a short life (5 years) and express most symptoms. Jesse did not inherit this condition from his mother. He developed a spontaneous mutation after a couple of cell divisions in the embryonic development. This gave rise to "patchy" expression of the gene, parts of his body produced the enzyme, and parts of his body did not produce it. This, along with a low-protein balanced diet and medication (e.g. Sodium Benzoate), 32 pills/day, gave him a good chance to a normal life [II].

Jesse Gelsinger was seventeen years old when he and his father were approached by Dr. Randy Heidenreich from the University of Pennsylvania. Due to his unique situation, Dr. Heidenreich offered Jesse Gelsinger a chance to participate in a

clinical trial for a gene therapy study in which an adenovirus carrying a functional form of the gene would be inoculated into his system. The Adenovirus has the potential to insert its DNA into its host's genome (latent phase). The viral genes can later be expressed by the host cells and new viral particles will be produced along with the OTC gene. The process of introducing these viral particles into patients is complex and has many risks involved and the chance of giving the patient a viral disease is ever-present in this kind of therapy.

Dr. James Wilson, along with Dr. Mark Bratshaw, showed Paul Gelsinger and his son evidence that this new viral treatment had been successfully implemented in laboratory mice, female carriers, and even some patients. However, their interest in finding out if the therapy worked as a means to reduce the Urea blood levels in patients were not conclusive. These studies could not be performed in children, and Jesse's contribution would be enormous according to University's bioethicist Arthur Caplan. After only one session with the University's Genovo Inc. leaders, mentioned above, they agreed to go through with the procedure.

Jesse went from his hometown of Tucson, Arizona to the biomedical research facilities of the University of Pennsylvania ready to go through the treatment. Jesse was injected with a high dose of Adenoviral particles and was expecting to have a mild immunological response. After he got over his "cold" he was expected to have high urea production (which was previously being measured at 6% of normal values); this would give good evidence of the incorporation and expression of the Ornithine Transcarbamylase gene. Jesse did get the fever that he expected, but his temperature kept rising, and he eventually went into a comma and was placed in a ventilator. Jesse's organs eventually shut down and after two days of the initial viral injection and severe brain damage, the ventilator was turned off by the consent of

Paul Gelsinger. Jesse died on September 17, 1999 [II].

Paul Gelsinger stood by the side of Genovo Inc., and all its researchers, including James Wilson (head of the Project), Dr. Mark Bratshaw (Pediatrician and laboratory trial researcher), Dr. Steven Raper (Jesse's research surgeon), and Dr. Randy Heidenreich (researcher, and the person who first contacted him and Jesse about the project). However, when the press and the FDA conducted their reports on the incident, it was not only clear that The Gelsinger family was misled and misinformed about the true risks of the procedure, but about their true motive as well. The researchers, and especially the head of the project and the founder of Genovo, Inc. James Wilson, had a tremendous conflict of interest, since this therapy would earn those in charge of the project millions of dollars, had it given successful results. James Wilson, when he first spoke to Paul Gelsinger, stated that he was an "unpaid research consultant," and did not tell him that he owned an estimate of 30 percent of Genovo's shares with a total value of over \$10 million. Other misleading pieces of information include: Adenovirus was successful as a vector for the OTC gene, but there was no consensus in safety studies involving mice, rhesus monkeys, and baboons: Three monkeys died from an early, stronger version of the vector than Jesse was to receive (they never informed anybody about these deaths), other monkeys were inflicted with severe hepatitis as a result of the same vector that Jesse would receive (Paul was never given this information). There were two dissenting experts who believed that the study was too risky for asymptomatic volunteers, such as Jesse, and their comments were not taken into consideration. No successful data existed on this kind of therapy in humans. Paul Gelsinger and Genovo settled the legal matter out of court [III].

While this case is one that deals with issues of public, research and corporate

policy, I will focus on the role of the physician as the primary care giver. The Hippocratic Oath does not apply to the modern practice of medicine in its entirety; however, it does underline some of its basic principles. “Above all, do no harm”. This principle of nonmaleficence is taken by many health care providers as the most important principle in medicine. The other three major principles that make up the core of medical principles are: beneficence, justice, and patient autonomy. These four principles are a continuum fluid that may agree or disagree in different situations [IV].

Ethical theories can be means-based such as Natural Law and Kantian ethics (deontological), ends-based such as Egoism and Utilitarianism, or have no major principle or prima-facie duty to rule over reasoning in specific situations, such as Virtue Ethics and Feminist ethics (ethics of care). Many other ethical theories have been developed, but they are mainly a more extensive formulation of one of the major ones and try to eliminate existing philosophical problems that may weaken the theory in specific situations (e.g. John Rawls’s theory of justice, and Peter Singer’s animal rights ethics)

Accordingly, the four ethical principles of medicine fall under the major ethical theories can be justified by each one of them; however, philosophical reasoning under a given theory may neglect one of the principles and stress the importance of others. This should not be the case under virtue ethics. It is clear that the physicians in charge of Jesse Gelsinger were thinking in ends-based terms, either egoism (on a personal outcome level) or utilitarian (on an overall outcome for the majority). Given the factual evidence of the financial ties of the physicians with Genovo, Inc., I believe they were practicing egoism. It is clear that they were not considering deontological or means-based ethical principles. Means-based ethical theory is clearly reflected in the patient’s right to autonomy and informed consent, and the principle of

nonmaleficence. Genovo’s scientists were dishonest by withholding information and deliberate deception to achieve a “higher goal” which I have concluded to be ends-based.

Realizing the problems that can arise when there is a misbalance of these principles a possible approach can be proposed to avoid this type of unethical behavior. The ethical virtues [IV] tend to give equal consideration to the four principles mentioned above. They are:

Benevolence	Compassion	Honesty
Charity	Sincerity	Sympathy
Respect	Consideration	Kindness
Thoughtfulness	Loyalty	Fairness

A virtue ethicist, according to Aristotle, one that strives for excellence and balance, will also practice professional virtues:

Rationality	Tenacity (Persistence)
Capability	Patience
Prudence	Skillfulness
Staunchness	Proficiency (Expertise)

A physician, through practice and education, must show a balance of each and every one of these virtues and consider them in his/her decision making process. I believe I have shown that the physicians’ actions were driven not by virtuous behavior but by alternative ideals (ends-based), which I believe compromises and affects the true role of the physician. The virtue ethicist focuses on the moral agent and his/her roles as an ethicist [V]. Moreover, virtue ethics does give other theories a strong consideration. A reasonable utilitarian approach may be used in public policy, but once again, in accordance to virtue. The virtuous individual will willingly understand, obey, and respect these policies. This example can be illustrated by Socrates’ reasoning on the acceptance of his unjust

death sentence for the overall well-being and stability of the republic.

I therefore conclude that the physician's ethical obligations lie in virtuous behavior (or at least according to virtue), and must be focused primarily on patient care and according to legal regulations. I

believe the Genovo scientists did not act according to virtue but according to ends-based reasoning. This type of physician reasoning and behavior, in my opinion, neglects the ethical principles and is therefore unethical and unacceptable.

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Lauren Holguin

Liver Transplantation in Alcoholics: Physicians' Ethical Obligations

Ivan is a 55 year-old white male in need of a liver transplant. He has been an alcoholic since he was 32 years old, and has developed an irreversible advanced liver disease, cirrhosis, which inhibits the liver from performing many of its vital functions. Ivan's physician, Dr. Quandary, believes that Ivan's prolonged alcohol abuse caused his cirrhosis. Without a liver transplant, Ivan will die.

[Ivan's drinking caused a lot of problems for his family, who he verbally abused when he got drunk. This led to his divorce at 38 years of age. By age 47, he began trying to get his problem under control and joined Alcoholics Anonymous. Ivan has had many relapses; some lasted a week, others lasted for several years.] Except for one brief relapse, Ivan had been alcohol-free for one year prior to diagnosis of his liver disease. Though alcoholism frequently causes other health complications, Ivan does not have any other significant medical problems.

Nevertheless, Dr. Quandary and his transplant team have some concerns about accepting Ivan as a patient and placing him on the transplant list because he is an alcoholic. The team knows that Ivan is a recovering alcoholic who has tried to stay off alcohol but is somewhat prone to relapse. As they are the only transplant center in the area, the team knows that if they do not treat Ivan he will not be able to obtain treatment locally. The team also knows that the treatment that would be most beneficial to Ivan is the performance of a liver transplant.

However, providing a liver for Ivan necessarily means that there will be one less liver available for other people on the waiting list. The team is concerned about achieving what is best for society and about using the livers most appropriately. Bearing these goals in mind, the team must decide whether to accept Ivan as a patient and put him on the transplant list.¹

Patients like Ivan seek treatment in hospitals across the United States on a daily basis. Physicians face an ethical dilemma every time they encounter an alcoholic patient in need of a liver transplant. In these cases, the physicians' desire to do what is most beneficial for an individual patient's health (i.e., perform a liver transplant) conflicts with their desire to allocate scarce resources (i.e., donor organs) in a way that is fair and just. Despite the difficulty of this situation, physicians must ultimately make the decision to provide or withhold care for these patients, and they must be able to justify their decision to their patients, their colleagues, and themselves.

To resolve this issue, it is pertinent to ask what qualifies as a "fair" allocation of donor organs: should physicians make donor organs available to all patients in serious need of a transplant, or are there "deserving" and "undeserving" patients? If tempted to take the latter view, physicians should think about what separates an alcoholic from the rest of the patient population requiring a liver transplant. The most frequently cited argument for excluding alcoholics from the transplant list is that "alcoholism is a vice and not a disease, and if alcoholism is a disease it is a disease of self-abuse with a high recidivism rate."ⁱⁱ Essentially, this argument has two parts: first, because alcoholic liver disease results from a self-destructive behavior, these patients should not receive the same consideration as those who suffer from an inherited or otherwise unavoidable disease. Second, alcoholics tend to be prone to relapse, and may continue their self-destructive behavior following transplantation.

A close analysis of this argument exposes several flaws. Viewing alcoholism as a "vice" rather than a disease does not provide a sound basis for denying treatment to alcoholics. This view reflects the

consideration of alcoholism as an immoral practice, a stigma that society has attached to the excess consumption of alcohol for many years. History has repeatedly shown the danger of using social values as a basis for ethical decision-making.ⁱⁱⁱ For instance, German physicians participated in the “euthanasia” of people deemed unworthy of life by the Nazis, including the mentally ill and the handicapped. These horrific events illustrate the danger of relying on social values to justify the morality of a course of action.

The definition of alcoholism as a “disease of self-abuse” also fails to provide a compelling reason for the exclusion of alcoholics from transplant lists. If physicians refused to treat any patient whose condition resulted from poor judgment, countless people with sexually transmitted diseases or life-threatening injuries would go untreated. Admittedly, the resources needed to treat a patient with alcoholic liver disease are not comparable to those utilized in the treatment of a daredevil’s broken leg. The scarcity of organs available for transplantation combined with the vast number of people awaiting donor organs puts pressure on physicians to avoid adding patients to the transplant list. However, physicians should not allow these issues of supply and demand to selectively decrease their tolerance for self-destructive human behavior. Without the attached social stigma, there is no significant moral difference between alcoholism and other dangerous lifestyle choices.

Take, for example, a case in which a 21 year-old bull rider is gored by a bull during a rodeo. The bull’s horn pierces the young man’s liver, and his physician determines that he is now in need of a liver transplant. Many physicians would not hesitate to add this young man to the transplant list, despite the fact that his injury is a direct result of his own choice to engage in a dangerous activity. In this case, the physicians do not worry about providing a donor organ to a person whose lifestyle has caused his own condition. The major difference between the physicians’ response in this case and Dr. Quandary’s

response in the case of Ivan the alcoholic is the social stigma attached to alcoholism.

The high rate of recidivism amongst alcoholics has also been cited as a reason to keep them off transplant lists. This reflects the concern that alcoholics may waste scarce resources by ruining transplanted organs that could have sustained non-alcoholic individuals for a much longer time. To date, scientific studies have shown this fear to be largely unfounded. For example, 111 patients with alcoholic liver disease underwent liver transplantation at the Mayo Clinic Rochester between 1985 and 1999. The mean duration of follow-up was 44.1 ± 3.7 months. Of the 111 patients with alcoholic liver disease, 17 showed objective evidence of alcohol relapse: 2 of these patients had a single episode of alcohol intake, while the remaining 15 returned to chronic usage. Only 1 of these 17 patients caused damage to the transplanted liver as a direct consequence of alcohol relapse.^{iv} Of course, monitoring of the patients who relapsed should continue in order to determine the long-term effects of recidivism in transplant recipients; however, until there is evidence that a significant percentage of alcoholics damage their transplanted organs, recidivism should not be used as a reason to deny liver transplantation to alcoholics.

As demonstrated, the argument against allocating donor organs for alcoholics has several flaws. Conversely, the argument in favor of providing liver transplants for alcoholic patients is strongly supported by historical principles of medical ethics. For clarification of a physician’s ethical obligations, one can refer to the fundamentals presented in the Hippocratic Oath, as well as in more modernized versions of the Oath, such as the Declaration of Geneva.

Students of medicine have taken the Hippocratic Oath for centuries and striven to adhere to its ethical tenets. As translated by Ludwig Edelstein, part of the Oath reads: “I will apply dietetic measures for the benefit of the sick according to my ability and judgment;

I will keep them from harm and injustice.”^v Medical ethicists consider this part of the Oath to be the foundation of the ethical principles of beneficence and justice. According to this statement, physicians have a duty to perform, to the best of their ability, that which is most beneficial to their patient’s health. In the case of alcoholic liver disease, a physician who determines that a liver transplant would be the most beneficial treatment for an alcoholic patient must add that patient to the transplant list. Physicians must also protect their patients from the harmful effects of injustice. Thus, when treating an alcoholic patient, a physician must work to ensure that the patient receives due consideration for all available treatments.

Following the trial of German physicians involved in the “euthanasia” of the mentally ill and handicapped during World War II, the World Medical Association attempted to modernize the basic ethical principles outlined in the Hippocratic Oath. The result of this modernization was the Declaration of Geneva of 1948, which underwent amendment in 1968, 1983, 1994, 2005, and 2006. The most recent version of this pledge, to be taken “at the time of being admitted as a member of the medical profession,” states that physicians must keep the health of their patient as their first consideration.^{vi} Additionally, this pledge

mandates that physicians must “not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between [their] duty and [their] patient.”^{vii} The use of the singular “patient” rather than the plural “patients” emphasizes the physician’s duty to work for the benefit of each individual patient.

In the case of Ivan the alcoholic, Dr. Quandary and his transplant team are hesitant to provide a liver for Ivan because it will necessarily mean that there is one less organ available for others on the waiting list, and they are concerned with doing what is best for society. According to the ethical principles outlined in the Declaration of Geneva, Dr. Quandary’s first concern should be Ivan’s health, and he should not allow anything to interfere with his duty to help his patient.

Based on this analysis of the arguments for and against liver transplantation in patients with alcoholic liver disease, it is clear that physicians have an ethical obligation to provide the most beneficial treatment possible for each of their patients regardless of societal pressures. For Dr. Quandary, this means placing Ivan on the transplant list.

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ⁱ Case scenario adapted from Vanessa Williamson, "Liver Transplant Dilemma: The Alcoholic, Medicaid Patient."

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Tom Pillion
A Fragmented State of Medical Ethics

In writing an essay on medical ethics, it seems appropriate that one begin with a brief consideration of a more fundamental question: what is ethics? Unlike the more theoretical disciplines of metaphysics, logic, and epistemology, ethics is the area of philosophy that is concerned with human action. This does not mean simply questioning and reflecting about human action or debating various opinions about right action. In the words of John Finnis, “one does ethics properly, adequately, reasonably, if and only if one is questioning and reflecting in order to be able to act – i.e. in order to conduct one’s life rightly, reasonably, in the fullest sense well.” (p. 1) In other words, as I write this essay, I ought not be only concerned with having right opinions about human action, I should be reflecting in order to act well, to make good decisions. In regard to medicine, this means reflecting about right human action in order to make good medical decisions. In this sense, medical ethics should be the undertaking of every practicing physician, not just the select few who consider themselves professional “bioethicists.” Leon Kass makes this point when he poses the rhetorical question, “Have our required courses and conferences on medical ethics improved the characters and morals of our rising physicians?” (p. 66)

The real question, however, concerns the meaning of “acting rightly.” What authority decides which actions are good and which are not? In a pluralistic society, one might argue that no such authority exists. Rather, acting rightly only has a subjective meaning, such that right action varies from person to person on the basis of their different beliefs and values. What is right for me may not be what is right for the next person. In medicine, this question of who decides what is right becomes all the more potent and emotionally charged because decisions are often made at some of the most critical moments in a person’s life. In a pluralistic society, where essentially everyone’s

viewpoint is considered equally valid, there seem to be as many “right decisions” as there are physicians and patients involved in those decisions. Naturally, conflicts arise and situations can become complex or confusing. These decisions are often resolved by referral to hospital ethicists or ethics committees. However, as Kass points out, “the discussions there, very different from the ones near the bedside, are generalized, remote, highly influenced by the current fashions of bioethics.” (p. 58) This might include the principles outlined by Beauchamp and Childress: autonomy (respecting the decision-making capacities of autonomous persons), nonmaleficence (avoiding the causation of harm), beneficence (providing benefits and balancing benefits against risks and costs), and justice (distributing benefits, risks, and costs fairly). (p. 12)

These principles may provide a basic framework for approaching ethical problems, but they also allow so much openness to interpretation that we must wonder whether they provide any ethical direction at all. We are still faced with those fundamental ethical questions: who decides the meaning of “benefit” and “harm?” Who determines the limits of autonomy, or is autonomy to be understood without limitation? What is “justice?” (One only needs to read Plato’s *Republic* to appreciate the intricacies of this last question.) The appeal of these principles in a pluralistic society undoubtedly stems from their flexibility, accommodating widely varying points of view. But we cannot help but wonder whether they have then succeeded as ethical principles? Perhaps they have only appeased us by removing the burden of responsibility from the individual physician at the bedside to a group of experts in a conference room, or perhaps there is simply no alternative for individuals in a society who lack a common set of values and beliefs. If the latter is true, however, the end result is not likely to be pluralistic in nature, but rather a

situation where one set of values gets implemented over and above the others.

For example, the care for a terminally ill patient may require only parenteral nutrition, fluids, and pain relief, but who knows how long he will stay alive, occupying an expensive hospital bed. The family may believe that his care should be continued until he dies “naturally”, but the hospital ethics committee may want to withdraw care on the basis of their own philosophical assumptions about “harm”, “justice”, “futility” or some other notion. Or perhaps the physician involved believes that care should be continued on the basis of his own values, but the patient desires that care should be withdrawn. This puts the physician and the patient in a difficult situation, and it raises an important, though often neglected, question, “does patient autonomy trump the autonomy of the physician?” In other words, should the physician violate the dictates of his own conscience because he is expected to adopt the ethical values of someone else, be it the patient or the bioethics committee? Catholic physicians are particularly susceptible to such ethical dilemmas. Take, for example, a teenager who presents to a Catholic obstetrician, requesting contraception or an abortion. The physician must either set aside his own moral convictions in the name of patient autonomy, or the physician must follow his or her conscience at the expense of patient care.

But is it a question of compromising patient care if the physician denies a patient a particular service? Or is it not rather a disagreement about what “patient care” actually consists of; a disagreement about the meaning of “benefit”, “harm”, “justice”, and “autonomy”; a disagreement about the nature of “right action?” Whether at home or at work, we should hope that the physician lives and acts according to his conscience. It should be the very foundation of his concern for a patient’s well-being; that which prompts him to think about the “good” of the patient. One might argue that a physician’s conscience may be telling him to place patient autonomy over

his own beliefs, but this is not possible. Even the physician’s belief in the priority of patient autonomy is, itself, a belief that is prior to patient autonomy. In this way, the physician simply acts according to his own idea about what is “right.” This is not unlike the Catholic physician who refuses to prescribe contraceptives. He or she is acting according to their idea about what is “right.” Why would a physician prescribe contraceptives if he or she believes that they actually harm the patient or the society as a whole? Furthermore, if physicians check their consciences at the door of the examining room, or routinely violate their consciences, what kind of physicians would they be? Why would they feel obliged to adhere to any ethical standards at all? Why should they practice medicine for any reason other than personal gain?

In a pluralistic society, this conflict between differing ethical standards is inevitable. For this reason, patient autonomy must be balanced against the autonomy of the physician in his or her role as “care” provider. We cannot expect that all physicians, as well as all the members of a pluralistic society, will share the same values (in which case it would not be pluralism). However, as our society becomes more fragmented and pluralistic, there is a growing disagreement about the purpose of medicine and the ethical standards that guide it. Perhaps we will end up with a health care system where patients are paired up with physicians who share their value systems. Patients who want contraception will go to physicians who offer that service instead of those who do not offer it. Likewise, Catholic patients who want “Catholic health care”, particularly in regard to obstetrics and gynecology, will go to Catholic hospitals. Of course, neither the population nor the health care system is distributed along such partisan lines. Often times, the only hospital serving the indigent population is a Catholic hospital, where contraception may not be offered. Many people have contended that such scenarios do harm to both the individual and the society because “the poor” cannot escape their poverty without the use of birth control. Likewise, Catholic hospitals that do not offer

“emergency contraception” are accused of harming the young girl who is now forced to carry a pregnancy or get an abortion. These scenarios remind us that the debate about medical ethics is fundamentally a debate about which values should inform our society as a whole. And as long as the society remains fragmented in its values and beliefs, the practice of medicine will also be fragmented, and conflicts between patients and physicians will continue to occur.

Whether society has, or can have, a common set of values upon which medical ethics finds its foundation is beyond the scope

of this paper. But I believe the values that offer the most hope for a common ethic of society, and of medicine, are not purely subjective, but rather are grounded in our nature as human beings. They are values that are universally accessible and identifiable, although only known insofar as they are realized in the actions of individuals. They are values according to which we judge the justness of a society and the wisdom of its leaders. As Kass writes, “only when politics is governed by wisdom about the human soul and man’s place in the larger whole, can art (i.e. the medical art) contribute properly to human flourishing.” (p39, parentheses mine)

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Kristi Pogue
Society and the Right to Healthcare

“...The organization of healthcare into a socially regulated system raises moral questions that would not arise if healthcare remained a more thoroughly private, domestic matter.”ⁱ Indeed, these moral questions have generated much reflection, debate, and activity throughout the world. The most prominent question in today’s news headlines centers upon a “right to healthcare” and “societal obligations” with respect to providing healthcare. Public healthcare is not only a timely topic, but also provides a good source for reflection on our perception of human dignity and its strong connection to individual health. Human dignity and societal values provide a basis for examining the right to healthcare and the level of care that each person should enjoy.

The “right to healthcare” is a fairly new topic with roots less than a century old. This topic has manifested in response to rising wealth in developed countries as well as major technological advances in society. Physician Peter Ubel expounds, “Given the recent plethora of expensive new technologies that offer small benefits at high costs, the need to ration healthcare is a relatively new phenomenon. Perhaps for that reason, people are not used to the idea.”ⁱⁱ His statement promotes the idea that while the technology society has created is good, it promotes a dilemma because it is very costly, and thus not all people will have the money to afford the same treatment. So must we choose between the technology or have unequal distribution of care and treatment? This dilemma has also presented the question of who in society deserves the benefits of new health-related technology, and how much technology do they deserve to keep each individual healthy or at least comfortable? The technology itself is amoral, but the questions it proposes are full of moral dilemmas that do not have easy solutions.

For the first question, do we have to choose between beneficial technology and the

concept of fairness, the answer should seem simple. Technology has made diagnosis faster and more reliable in some cases, thanks to imaging machines. Not only does it help individuals, but it has also affected the society as a whole. Technology has raised the standard of living and the average age in the population. Vaccines and easier vaccine distribution has made certain diseases, like small pox, virtually non-existent in the United States. Overall, the health of society has been unquestionably improved because of technology. In the question of equality versus technology, there is clearly a societal benefit from health-related technology and its advancements, not just improved quality of life for the wealthy in society. While certain inequalities remain, most medical technology has brought so much benefit to society, that its value overreaches the inequality in cost of certain treatments.

While technology has proved to be a constant part of the healthcare field, the questions of inequality loom large in the industry. How and who should care for individuals in our society who cannot afford basic healthcare? To begin addressing this question, it must first be agreed upon that all persons deserve some type of basic healthcare. In the United States, there is a basic right to life, enjoyed by all persons. In one interpretation, this right could be nothing more than protection from being killed, and encompass no other values. However, this narrow perspective would fail to include the idea that all societies will contain weaker members, and they deserve adequate protection within this society by its members. While some people may be weak in health, they might offer other goods to our society. Not only because they are valued members of society, but more importantly, because they are human beings, do they deserve to be cared for by society. Pope John XXIII wrote in the encyclical *Pacem in Terris*, “...every man has the right to life, to bodily integrity, and to the

means which are necessary and suitable for proper development of life,ⁱⁱⁱ and among these necessities he lists medical care. Most people would probably agree that in order to uphold human dignity, institutions, whether political or social, should recognize healthcare as a right fundamental to all persons. While this idea is not unique to Christian communities, the insight can be significant for an entire society. For example, Catholic doctrine looks to the community to support this fundamental right and value of health. Those who can, have a social obligation to help the groups that do not have access to healthcare, as it is essential to the common good of society and it is part of the duty of Christians to help their neighbors. Another approach to this argument also highlights the obligations of individuals to its society. Joseph Boyle argues, "...the inadequacy of government's honoring of the right to healthcare of all under its jurisdiction does not remove the obligation of individuals as members of society to honor that right."^{iv} The obligation to participate in providing healthcare to our society directly corresponds to the inherent right for healthcare and dignity belonging to each person. This approach also recognizes that limits exist by the amount of charity a society can offer. Some nations are not developed industrially and simply do not have the monetary support within their communities to even provide a basic level of healthcare. Does this make their societies less ethical or place added burdens on other societies? Many authors do not see an obligation for wealthier nations to support healthcare in poor countries, unless it is financially possible. Again, the obligation to help human kind is clearly limited by the ability to provide assistance.

The next question addresses the level of healthcare a society is obligated to provide to its members who are unable to pay for care on their own. Perhaps in the past, any sort of care above the minimum may have been considered extraordinary. But now that certain life-saving, or at least quality of life improving technology exists, there is the looming question of who is worthy of this technology.

The status quo seems to make the distinction of who gets certain treatments by who can afford private insurance, and who is unable to pay. But in this distinction arises the notion that the lives of the wealthy are more important than those of the poor. So, our society must decide what kind of treatment encompasses basic care. A good definition of basic care is one closely connected with the immediate values of the society as well as the wealth of that society. Obviously, wealthy societies will be able to have a higher standard for basic treatment than nations without money. Within the United States, and likely most developed countries, we can consider basic healthcare as:

...All legitimate and necessary life-saving medical services, as far as is possible and reasonable, belong to basic healthcare and hence should be made accessible to all. Basic healthcare should also include all forms of protection by preventative medicine, such as vaccinations against infectious diseases, which are realistically speaking dangerous for a certain population, and many other elements to be determined concretely by medical professionals in dialogue with philosophers and theologians.v

Basic care is also determined by the importance of the value of health within a society. Many communities hold a belief in some kind of afterlife, which, while not diminishing the value of this life, reveals an acceptance of immortality. The approach that man is not a God, and he is mortal, places an interest not in preserving health with the intention of approaching immortality, but in maintaining a certain quality of life. But there are societies who might value health in differing degrees. And thus there will be a higher demand for certain procedures to be deemed basic. Overall, basic care is distinguished by extraordinary care.

...Healthcare services are special because of their ability to affect our longevity and our ability to pursue important goals, not all of them are special in this way. Instead, many of them offer small improvements in

people's quality of life in ways that make it hard to distinguish them from a whole lot of other goods and services.^{vi}

An absolute definition of basic healthcare may not be possible as the definition changes with society, and as medical technology becomes more advanced basic care will be redefined in those terms. Essentially there must be a resolved balance between the society's values along with its understanding of basic care and financial capabilities. In the United States, considered to be one of the wealthiest countries in the world, some people may argue that all persons deserve access to treatments that would lead to a "small improvement" in quality of life. However, there are still people in the US whose very basic healthcare needs are not being met. Only when our society is able to

physically and financially meet those needs can we expand upon the definition of basic healthcare.

To summarize, the right to basic healthcare is rooted in the human dignity bestowed upon every human life. In some cases, the basic healthcare needs cannot be met, simply from a lack of financial or physical resources. However, in societies where both the financial and physical resources are available, there is an obligation upon the members to help in meeting those basic healthcare needs, to uphold the dignity of the human race. The values of a society will ultimately dictate a society's understanding of basic healthcare and the most appropriate way to go about providing this care.

ⁱ Joseph Boyle. "Limiting Access to Health Care: A Traditional Roman Catholic Analysis." *Allocating Scarce Medical Resources: Roman Catholic Perspectives* H. Tristram Engelhardt, Jr. and Mark J Cherry, Editors. Washington, DC: Georgetown University Press (2002). p 90.

ⁱⁱ Ubel Peter A.. "Pricing Life: Why It's Time for Health Care Rationing". Cambridge: MIT Press (2000) p xvi.

ⁱⁱⁱ Paul T. Schotsmans. "Equal Care as the Best of Care: A Personalist Approach". *Allocating Scarce Medical Resources: Roman Catholic Perspectives*. p 130.

^{iv} Joseph Boyle. "Right to Health Care and its Limits". *Scarce Medical Resources and Justice*. Massachusetts: Pope John Center (1987). p 19.

^v Josef Seifert. "Toward a Personalistic Ethics of Limiting Access to Medical Treatment". *Allocating Scarce Medical Resources*. p 113

^{vi} Ubel 36

Nina Prabhu

A Case Study of an Ethical Long-Term Care Decision

The ethical decisions involved with treating the elderly with chronic diseases is of great relevance in today's healthcare. As our aging population continues to grow and the average lifespan continues to extend, long-term care decisions will demand more discussion. A specific case I encountered in the VA presented important questions about family dynamics in managing elderly patients, the role of the hospital in caring for those with chronic disease, and the important distinction between beneficence versus non-maleficence.

Mr. M, a 77 year-old man with multiple medical problems, first came to our service in acute respiratory failure with constant secretions from his tracheostomy. After Mr. M was stabilized medically, the greater challenge of appropriate placement began. Mr. M definitely had intensive nursing needs which included frequent suctioning, feeding, turning, and skincare treatments, and he had no rehabilitation potential. He had previously stayed in an extended care living facility. However, upon this discharge his wife was adamant about taking her husband home. His wife, who worked during the day and could not afford any in-house nursing care, was informed of his increased nursing needs and his need for constant care. She insisted that she could care for him despite not being at home all day, and she stated that 911 was only a phone call away. Her main objection to placing her husband in the nursing home was the financial burden. According to the wife, her husband was not service connected enough to be covered for a nursing home, but she could collect some money if she took care of him at home. The wife also maintained that her husband wished to return home, but this could not be corroborated as Mr. M was incapable of verbal communication and he had not designated anyone as his medical power of attorney. The wife ideally wanted her husband to remain at the VA as she felt that he was entitled to that level of care due to his years of service.

The first ethical concept to consider in this case is that of beneficence. From a medical standpoint, the patient definitely has needs best cared for in a nursing home setting. While patient autonomy is paramount, should the patient's family be awarded the same level of autonomy on behalf of the patient? When a medical power of attorney is designated, the named person is legally awarded that same level of autonomy. When no one has been named, the family's level of responsibility for the patient is not clear. Since the patient's wishes could not be ascertained, the family members provided the best indicator of his wishes, as they have knowledge of his previous comments about long-term care. As the next of kin, his family deserves a major role in planning his living situation. However, if the family is denying him adequate healthcare, does it become the physician's duty to ensure he receives it? As the patient's advocate, a physician should ensure that the patient receives the best care available to him.

Since a nursing home was ready to accept Mr. M, denying him this care that could be partially covered by his VA benefits would be unfavorable. Allowing him to be discharged home to a state of likely neglect would be irresponsible of the physician. Yet, if the patient's family could not truly afford the nursing home co-pay, economic hardship cannot be inflicted on them against their will. If physicians make decisions that override those of the family, the physician-patient's family relationship will deteriorate and give doctors inappropriate authority over the family's appropriation of resources. Even if finances were not an issue, placing a patient in a nursing home against a family's wishes disregards the patient's family's autonomy to make decisions. If neglect is witnessed upon a social worker's visit, then the family loses the right to make that decision for the patient.

With respect to the wife's want for her husband to stay in the VA, it would be unethical for the physician to honor that request because of the principle of justice. Since the VA has a limited amount of hospital beds, a chronically ill and medically stable patient must be discharged to provide that bed to a more deserving, acutely ill patient. Hospitals cannot negotiate discharge dates with patients because hospital beds and the medical care allotted to each bed are valuable resources.

As for discharging the patient home, the physician may be inclined to do so with respect to non-maleficence. While the patient may not be helped by that decision, following the patient's wishes according to his family may not be harmful. Provided that social work could evaluate for neglect periodically, the patient's family should be able to attempt caring for him if they so desire. Any appropriate homecare options should be made available to the family, but the decision to finance those options is at the family's sole discretion. Unlike child support payments,

which can legally be extracted from a parent, nursing home payments cannot and should not be demanded of a family. While parents maintain an inherent responsibility for their children by producing them, the spouses and children of the elderly do not bear that sense of creator's responsibility. Also, some families have extreme aversions to nursing homes, and no person should be forced to place a loved one anywhere unless they cannot maintain a certain level of care at home.

Thus, long-term care presents many ethical issues such as justice, patient's family autonomy, and the physician's balancing of beneficence versus non-maleficence. These ethical issues need further consideration as family dynamics play a major role in treating the elderly. Given that this population often may not be able to verbalize their wishes or may be incapable of making their decisions, many long-term care decisions should be carefully reviewed as the roles of the physician and that of the family are not always clearly defined.

Stacey Thomas
The “Me” in Medicine

Like any intimate relationship between two people, the physician-patient relationship involves complex, emotional issues and a delicate interplay of power. The initial meeting holds much hope and uncertainty. With increased interaction and familiarity, both individuals become more forthright in sharing their thoughts and feelings. Each person brings to the relationship his or her individual values and desires, which may serve as a source of unity or conflict. These values and desires may or may not change as the relationship evolves. As challenges demand compromise, both people may struggle to assert their personal ideals and exercise their autonomy. The view of medicine as a service profession suggests that physicians ought to cater to their patients' interests. After all, the customer is always right. Unconditional validation of patients' impressions and beliefs, however, seems to neglect the other duties physicians have to their patients, including nonmalevolence and stewardship. In the pursuit of a meaningful physician-patient relationship, the physician may impact the patient's health-related values and subsequent expression of autonomy.

In their analysis of several models of the physician-patient relationship, Emanuel and Emanuel eventually settle on the *deliberative model* as the preferred paradigm. Under the *deliberative model*, both patient and physician evaluate and discuss the merit of health-related values as they pertain to the patient's clinical condition and goals of treatment. By reviewing factual information, enumerating the available options, and making subsequent moral suggestions, the physician helps the patient to make an educated examination of his or her belief system and to incorporate the recommended values accordingly. The patient ultimately determines which values he or she will pursue, but autonomy in this context is defined by the patient's ability to make informed choices rooted in aptly prioritized values.

The realization of autonomy as delineated by the *deliberative model* relies on two major premises. First, the physician's appraisal and presentation of health-related values must be accurate and complete. In addition, the *deliberative model* presupposes that the physician possesses awareness and insight into all facets of each value. Moral beliefs, however, involve subjectivity by their very nature. No amount of empirical evidence can establish value judgments, medically-oriented or otherwise, as indisputable truth. Furthermore, the physician cannot, in practical terms, present every possible consequence that follows from the adoption of each of the different moral principles, but in failing to provide a thorough evaluation of the various ideologies, the physician fails to meet the conditions for upholding patient autonomy as set forth by the *deliberative model*. The imprecise quality of value systems makes the validity of the physician's interpretations further vulnerable to contestation. Even if the physician unintentionally supplies the patient with false information or omits the costs/benefits of subscribing to particular moral doctrines, the physician undermines the patient's potential to form knowledgeable decisions. On the other hand, the patient's pre-existing health-related values also deserve scrutiny. These beliefs may have developed without the patient's full comprehension of his or her clinical situation and of the ramifications of these values given the specific context. After discussion, the patient may find that his or her predetermined values are inapplicable, less favorable, or even detrimental. Conversely, dialogue could result in the physician's confirmation of the patient's current values. Nevertheless, evaluating the worthiness of each health-related value relies upon a comprehensive understanding of the value's supporting facts and implications. The physician, therefore, has a duty to candidly discuss with the patient all considerations for and against each relevant value.

Communication comprises a crucial element of any successful relationship; hence, a second condition for patient autonomy is the patient's capacity to engage in deliberation. The physician must establish an environment which demonstrates to the patient that he or she is welcome to freely express any issues or opinions. If the physician appears to coerce the patient, then he or she diminishes the patient's involvement in the dialogue. Coercion can manifest in different forms. The physician may refuse to answer the patient's questions or decline to elaborate upon explanations. The physician may also instill guilt in the patient for "doubting" the physician's advice or make the patient feel ashamed for his or her current values. Conversely, the physician also provides a disservice to the patient's exercise of autonomy through complacent affirmation. Assuredly, a thriving physician-patient relationship includes empathy for the patient, but the physician's becoming overly sympathetic can cloud his or her professional judgment and ultimately harms the patient. The physician has an obligation to act as a vigilant participant in the care of his or her patient, and an essential component of that care is the critical evaluation of any treatment decisions made as well as the basis of those decisions. Moreover, the patient must take some of the responsibility for his or her health education. Despite centuries of scientific advancement, physicians still have not mastered mindreading. Although the physician should seek to evaluate the patient's comprehension of the clinical situation, the patient should also take the initiative to relay to the physician any qualms or queries. Additionally, if the patient prevents the physician from explaining his or her assessment of health-related values, the patient's condition, or the available treatment options, then the patient hinders the refinement of his or her own autonomy by impeding the flow of ideas and information. If the patient dismisses alternative values without serious consideration of their merits and without honest communication of his or her objections to the physician, then he or she constrains the development of the physician-

patient relationship and the ability for the physician to effectively respond to the patient's concerns. Furthermore, with dialogue and debate comes the potential for conflict, especially when two people feel very passionately about their respective positions. Intense deliberation could escalate into a heated argument, which would interfere with the patient and physician's objectives as well as the function of their relationship. In order to provide for the patient's autonomous decision-making, communication between physician and patient must be balanced and productive rather than one-sided or belligerent.

The utility of discourse under the *deliberative model* hinges upon a symmetrical relationship between physician and patient, in which both parties are able to understand and question each other. If the patient experiences confusion and cannot grasp the information provided by the physician, then the patient cannot equitably participate in the discussion. The physician's habit of employing esoteric medical jargon often frustrates the patient's efforts to gain a command of the knowledge at hand. Additionally, if the physician cannot comprehend or misinterprets the patient's concerns, then the physician cannot assuage the patient's misgivings and will likely be unsuccessful in persuading the patient to accept the recommended values. Symmetry, particularly in the promotion of moral ideology, however, seems elusive, and in a way, the *deliberative model*, asserts the physician's dominance in the discussion as well as in the relationship. By advocating the physician's role in shaping the patient's health-related beliefs, the *deliberative model* reveals an inextricable element of paternalism despite the increasing emphasis on patient autonomy in modern physician-patient relationships. The fiduciary nature of the relationship, while bolstering physicians' responsibility to their patients, also concedes an imbalance. Patients look to their care providers for answers, and they trust that their physicians, who have cultivated years of experience and expertise, will make the best choices in the management of their health. Overall, the *deliberative model* frames the role

of the physician as a tutor or friend who nurtures the patient's moral self-development through reciprocal discourse, but the paradigm assumes that, even if the physician's goal is to convince the patient to embrace a certain moral path, the superiority of the advocated values become self-evident through open discussion.

The process of prioritizing and revising the patient's value system, however, provides an opportunity for the physician to introduce his or her own beliefs. Particularly in long-standing relationships, the physician may slip into a state of comfort or personal involvement with his or her patient and abstractedly drift from professional standards. Physicians in a close relationship with their patients may be tempted to use their private judgment when faced with the question, "What would you do if you were me?" The response the physician provides to that question, combined with deference the patient may feel toward his or her care provider, may perilously lure the patient into abandoning his or her own beliefs after only cursory consideration. Any regret or other consequence the patient experiences thereafter bears some moral accountability with the physician. Especially in the context of controversial or deeply sensitive issues, physicians may struggle to draw a line between their personal values and professional wisdom. Religious ideology, in particular, often serves as a strong moral compass that pervades all aspects of an individual's life. The patient certainly does not leave his or her spiritual principles at the clinic doorstep, and whether the physician does so or not has been subject to much contention in and of itself. The influence of religious tradition may also

limit the promotion of patient autonomy. According to the *deliberative model*, anything which obstructs the dialogue between physician and patient threatens the patient's capacity for comprehensively educated decision-making. Many theological doctrines oblige a negative moral evaluation or complete omission of a variety of treatment options and information, most notably in the arena of reproductive health. The priority of spiritual wellness in the overall scheme of patient care will differ between physicians and a concrete, widespread, professional standard for its incorporation has yet to be established. Shared moral viewpoints may contribute to growth of the physician-patient relationship. On the other hand, serious discord between the physician's beliefs and the patient's beliefs may create a rift in the physician-patient relationship. Nonetheless, the precariousness of physicians' drawing upon personal judgment suggests that it may jeopardize the cultivation of patients' health-related values and their pursuit of autonomy.

The intricacy the physician-patient relationship demonstrates the need for a judicious balance of restraint and candidness on part of the physician in order to facilitate patient autonomy. Physicians ought to be comfortable with balancing their own concept of autonomy with their obligations to patients. Reciprocal honesty and effective communication between the patient and the physician is fundamental to the support of the patient's ability to understand his or her clinical condition and to make the best, health-related value judgments.

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Joseph D. Walch
The Quality of Life

As a child I always enjoyed going to the doctor. I inhabited a paradisiacal little coastal town and I played and lived just like other children; well, mostly. The doctors would pay so much attention to me and the newspapers would write stories about me and my remarkable abilities and achievements. In school they gave me more time to work on tests and answer questions. Things changed when I became a teenager. On occasion I would walk into poles or park benches. Once I even fell down a flight of stairs. The teachers would sometimes feel very sorry for me and did the best they could. I would simply get up and march on, with the hope that only the teachers saw. I didn't really enjoy participating in athletics with people I didn't know. Socially I felt a little isolated from people, but they told me that all adolescents have that problem; eventually I would grow out of it. They told me that my disease was degenerative.

That sense of 'specialness' wore off momentarily when I was sixteen. I went back to my doctor and was again tested. The room was warm with the light from the window and after dictating the examination with a low voice into his small voice recorder; "extensive damage to the neural fiber layer 360° with bone spicules, massive disc drusen, and macular edema with 4+ exudate," the doctor in a soft but detached melancholy voice asked me if I had ever thought about genetic counseling. I was of age now, and it was about time for me to think about these grownup issues. I should seriously consider the consequences and responsibility of bringing a child into the world. Would I condemn that child to a disease resulting in a lesser quality of life, and was I really capable of safely raising a child? I never went back to that doctor; perhaps out of fear, or out of anger, I can't quite explain why. I came in expecting the doctor to give me something, to add something to me; not to take something out of me. What could have made me feel so empty;

like a hose that has been lifted up to let the water run out both ends.

Years later I spoke to my brother, who is one of the three blind siblings in my family I flew home to visit and we stayed up most of one night talking about those formative years before we all got married. He was also frustrated. As a blind boy in a sighted world he wanted to have the same hopes and dreams as other kids, but every path that the world offered him ended with a barrier that read "blindness." The questions, familiar to those who are weary of considerations would inevitably arise. Why me. If there is a God, why has he abandoned me to a life of futility? "I really could have messed up my life if I didn't cling to hope in those years" he said. Lorin is about 6'3" and has a muscular build. Before becoming a nationally distinguished musician and father of four, he was a physical therapist who worked with Olympic Athletes. Lorin explained it to me like this: "Before I was born, I believe I was given the choice between being blind—but with tremendous opportunity to develop my character, or being sighted and not becoming the kind of man I am today. I believe I chose to live a life with disability because I knew I would develop the higher aspects of my soul. I grasped that hope so tight, even past the point of reason or reasonability. And after a short time wandering in the forest, my path showed itself to me; the path that only I could see, lighted by my enduring hopes and dreams."

The skeptic might say that Lorin was simply falling back on some elaborate defense mechanism. Regardless, my brother reminded me of Victor Hugo's prescient words, who pointed out that:

The wealthy young man has a hundred coarse and brilliant distractions; occupations for the baser side of the soul, and he develops these at the expense of the loftier and more delicate sides. The poor young man goes with the spectacles which God furnishes gratis; he

gazes at the sky, space, the stars, flowers, children, the humanity among which he is suffering, the creation amid which he beams. He gazes so much on humanity that he perceives its soul, he gazes upon creation to such an extent that he beholds God. He dreams, he feels himself great; he dreams on, and feels himself tender. From the egotism of the man who suffers he passes to the adoration of the man who understands.

We all come to this world with two things which allow us to do the real important work of life: spectacles and a body. The doctor's work is on the body, and so I would sit across from the microscope that was situated between me and my eye doctor. He would look at my interesting pathological findings. I no longer mind the fact that there is no cure. I understand that a doctor's livelihood is to preserve and enhance my vision, but when that is not possible what then? Reduce the likelihood that I may spread it to my children? Not have children? Is this just selfishness on the part of the doctor who wants fewer untreatable diseases to deal with?

Doctors come from a privileged aristocracy of wealth and learning—most of which was handed down to them with much tradition and ceremony. I fear that the tradition of transference has allowed doctors to absolve themselves of the responsibility for mistakes they make, and primary among them is this: doctors know not, neither seek to know, sufficient personal grief or tragedy to be able to condescend with the patient in our suffering in a way that gives us hope and joy. The lure of comfort and position is too great for the doctor, who keeps her distance, lest she understand grief! Please don't misunderstand me, the last thing I want is for somebody to feel sorry for me, nor do I wish suffering upon the surgeon, but the quiet suffering that softens hearts is the true mark of a healer. For are we not all bound to molder in the ground? Do we not all have reason to yearn for something greater for ourselves; something greater than we may be at present, or even in the future in spite of the apparent futility of life?

The will to faith, borne from our yearning, is a call to attune our hearts and integrate our character with principles that we devoutly hope, and for which we have reasonable but not certain grounds to believe are true. We are as a balance with weights tethered on each side; sitting in equilibrium to the forces of cynicism and faith. We have both grounds to believe and grounds for doubt, but faith in what? We all create God in our own image, or potential image, and perhaps for the doctor or scientist who works to eliminate pathology, that potential image is a society absent pain, suffering, disability and as a result the absence of the incomparable yearning that results from groping in the dark for some understanding of existence. What will happen when there are no more heroes to save, no more hands hanging low to lift, no more downcast eyes to raise to the light; just everybody with their eyes muddied and hands burdened by mundane materialism.

I am not saying that poverty, disability and suffering alone are good things, but what kind of people will we become when we can no longer contemplate the depth of Shakespeare's tragedies, or the pathos of Dostoevsky? Imperfection and fragmentation is not ideal, but is there not some beauty in fragments, however imperfect; something that is noble in all of our somewhat shattered lives? I have always looked at life through a splotchy, fuzzy visual field, but life has taught me that there is more to my experience than sight. Let us recognize and seek together that solemn yearning within each of us which Wordsworth expressed when he said that, "Unless above himself he can erect himself, how poor a thing is Man!"

That good may be found even in sickness, the Greeks recognized long ago. They understood that there must be opposition in all things, else, how can we recognize the well if we know not the ill. It was Nietzsche who, speaking of Mozart, rejoiced that "the last chord of centuries-old great European tastes . . . still speaks to us," but he warns that "alas some day [even] this will be gone." The

new social-evolution has brought us the selection of more consumption and droning entertainment while the poor of Africa and three out of every four down-syndrome fetuses perish. Society risks becoming a sterile, tone-deaf, monochromatic mix of individuals who merge but never become miscible. Just as our American cities increasingly become, as John Steinbeck put it: “Gopher holes ringed with trash,” so too are our souls becoming as we burrow into ourselves—not really seeking to understand, not full of passion or yearning, reflexively following our base instincts in

pursuit of the frothy pleasures of our private lives.

I may be blind, but I don't need pity or misdirected compassion. I want to be understood as a person who breathes, thinks, suffers, and who yearns deeply; a person who occasionally revels in the joy of her existence. I want to be recognized as a person who is intent on using the good parts from my imperfect genetic list for something good—and hopefully grand.

(Author's note—I wrote this about my wife who has a more severe form of Retinitis Pigmentosa, and who comes from a family with three blind siblings. She reads Braille and walks with a long white cane. She was born and raised in Australia and came to the states to attend University. We have been married since May 2003.)

