Re-examining the Elizabeth Bouvia Case

By Howard Brody, Ph.D., M.D.

In 1987, as part of a study of the impact of illness on individuals' life stories (Stories of Sickness, Yale University Press, ch. 8), I discussed one aspect of the Bouvia case: the reactions of handicapped-advocacy groups to Bouvia's decision to seek death while hospitalized. Here I want to review that discussion very briefly and also ask whether it is deficient.

Suppose that Elizabeth Bouvia had been physically unable to ride the bus in her community. The advocacy groups would without doubt have defended her right to ride public transit and would have called for special devices or equipment to erase the barriers created by the physical problem—even if that had been a very expensive solution. Especially they would have opposed any suggestions that Bouvia should be talked out of wishing to ride the bus; or that perhaps if she rode the bus, that would be setting a bad example for other handicapped individuals or sending a bad image of the handicapped to society at large.

But, with Elizabeth Bouvia asking for aid in ending her life, the handicapped advocacy groups refused to consider any civil-rights implications at all. Instead of upholding Bouvia's freedom to make her own choices (after all, a temporarily-able-bodied person could find many ways to commit suicide on her own, and wouldn't have to ask assistance), the advocacy groups disparaged her decision and (Brody continued on page 7)

Some Handicapper Concerns With Conventional Medical Ethics

By Eric and Judy Gentile

(Judy Gentile is the director of the Office of Programs for Handicapper students. Eric Gentile is the coordinator of Handicapper and Veteran Affairs)

Most value judgments are formed or in great part influenced by each individual's personal experience(s) or lack thereof which is then generalized, or often inappropriately applied to situations beyond their original context, usually with extensive human subjectivity—the foundation for prejudice—pre-judgment.

Most everyone has been, at some point in life, pre-judged by others—some to more of a degree than others and some with more impact on life opportunities than others. The goal of most civil rights legislation is to reduce prejudicial behavior toward people who have experienced the extreme consequences of the devaluing of their “quality of life” or their “worth to society”—on the basis of some natural distinction; e.g., race, religion, gender, age, handicap, etc.

Despite medical and media bias many handicappers have rejected negative prognoses and stigma projected for them—whether it be death, “vegetable” status, disability, etc., to go on to lead full and productive lives. Many, however, can tell of moments of almost succumbing to the powerful influence of negative medical or social opinion regarding their life expectancy or life quality after injury or illness. Add the fact that (Gentile continued on page 2)
most people have had little unbiased experience or exposure to life as a handicapper (one who competes regardless of the effects of major illness, injury, etc.) and are therefore initially biased themselves by the same attitudes of ignorance and prejudice that they now confront. In order to survive, let alone prosper, on acquiring a handicap means learning to overcome these destructive attitudes. Such bias can be reinforced or challenged by family, friends or other support sources.

This places the newly injured/ill individual in a very vulnerable position. Even if the person is alert and allowed to make choices regarding treatment, what information is given to assure an unbiased informed choice? What options are presented? When?

Quality of life is not an issue of physical condition, it is a matter of subjective mental attitudes and spiritual relationships and values.

The mass media and medical journals presented a typical bias in the case of Elizabeth Bouvia. First, the assumption that her depression and her request for “assisted suicide” was totally related to her physical condition. Many individuals that we know, including these authors, could be presented in the same or even “worst scenario” as far as physical condition, yet we chose to live—as life not physical condition is our focus. Bouvia herself had already overcome many obstacles and had achieved success including earning a college degree. She entered a relationship resulting in marriage. So why all of a sudden does Elizabeth experience depression to the point of losing her motivation for life? Her physical condition had not changed. Why was there little if any focus on the fact that she was going through a miscarriage and marriage breakup resulting in the same emotional turmoil that any other woman would experience. Why are we so quick to accept thoughts or acts of suicide as being the result of depression due to disability/handicap? Why do we assume Elizabeth Bouvia’s depression to be linked to disability or handicap BUT DO NOT ASSUME MARILYN MONROE’S DEPRESSION TO HAVE BEEN LINKED TO HER BEAUTY, FAME AND FORTUNE and the physical material value system imposed on her? Jack Kevorkian’s victims have not been “worst-scenario” cases of serious disability or terminal illness, they have been victims of reinforced depression, ignorance and fear of the unknown.

Fifty percent of participants in a survey for the National Mental Health Association stated that they or a family member suffered from depression. Do we, then, offer assisted suicide as a cure for them? ACCORDING TO REPRESENTATIVES OF THE HEMLOCK SOCIETY TESTIFYING TO THE MICHIGAN LEGISLATURE, YES! WOE, THEN, TO ANYONE OVERHEARD COMPLAINING ABOUT LIFE’S DAY TO DAY TRIALS.

Handicappers can readily testify that the biggest barriers we overcome are attitudes imposed on us by assumed disability, tragedy, pity, etc. There is the constant challenge to prove ability and worth, sometimes even to self and always to others. Nowhere is this more true than in the medical area. And nowhere are the potential victims of such attitudes more vulnerable than in a profession where anything short of “physical perfection” or total cure is considered failure.

Understanding the human habilitation and rehabilitation process on the part of the “patient”, the medical staff involved with the patient as well as the family and other support sources is critical to achieving maximum human potential beyond the medical prognosis guessing game.

Whatever one’s faith or lack thereof, anyone with any experience with the medical profession certainly knows that doctors are not all-knowing gods. Medical opinion is frequently wrong—almost always presented in the negative, yet often regarded as gospel or “realistic”.

Judy Gentile’s Own Case Scenario

In 1955, at age 8, I acquired polio. A doctor told my parents that IF I lived more than a year, I’d be no more than a “vegetable” or a “bag of
bones”, unable to breathe or move on my own. Doctor's advice: put her in an institution and take care of your other four healthy children. Mom and dad rejected such advice and found another doctor. Several years later my parents rejected a school psychiatrist's advice: don't let her go to a regular school, she can't physically or emotionally handle it. In 1965, I graduated from public high school with honor. Michigan Rehabilitation Services “diagnosed my condition” as high risk disabled unemployable and unqualified—for college assistance. The MRS doctor confirmed that I would not be able to physically endure the rigors of a campus environment. Yet, I was the first wheelchair user admitted as a freshman to MSU and graduated with honor in 1970. In 1971, I was recruited to direct a new program that I had helped develop. However, my employer was told that he couldn’t hire me because I would not be able to pass a physical exam. Three months later I was hired as the first Director of the Office of Programs for Handicapper Students—(OPHS), a position I still hold twenty years later.

I am a post polio quadriplegic wheelchair user. I currently use supplemental oxygen 24 hours a day and an “iron lung” respirator while sleeping. According to one doctor, I've been “skating on the edge of death for over 30 years”! OK. So, where is my Gold medal?

The Cost Perspective

We would like now to briefly address the question of cost containment; an issue which has become increasingly dominant in both philosophical circles and the mainstream media. The case study (Case Study on page 4) provides an excellent example of exactly the sorts of problem which handicappers face in trying to express their concerns with the public debate as it is being presently conducted.

To begin with there is a disconcerting lack of empirical data concerning Crystal's actual prognosis presented in the case study (or anywhere else in the article from which the case study was excerpted). What little information is presented is slanted in a negative fashion, thereby setting the reader up to view this as a "hopeless" case and to stack the discussion in favor of discontinuing treatment right from the start. This means that when people consider government proposals on how to contend with the numerous public health issues facing the country they will carry with them the vague notion that there are "all those hopeless cases out there which we shouldn't fund" without having a clear idea of what they are agreeing to.

A second point to which we would like to draw attention is that the handicapper community is frequently accused of overreacting whenever we challenge a euthanasia bill or question the morality of withholding treatment from individuals whose quality of life has slipped below some arbitrary line. We see these kinds of proposals as not only invidious in and of themselves, but as beginnings of even more frightening developments. However, when we advance these arguments we are told that we are mis-using the slippery slope argument, that there would be enough safeguards to prevent individuals who had an opportunity for a fulfilling life from becoming expendable ciphers in a quest for a balanced budget.

But notice that Crystal is not even in PVS (whatever that term is supposed to mean), the favorite example of ethicists everywhere of non-cost beneficial treatment. So we move from voluntary euthanasia to involuntary euthanasia on PVS patients, to involuntary euthanasia on "near PVS" patients, continuing onward in the quest for savings which can surely be sought in other areas of society.

The original claim of government assistance programs and insurance programs was to help people who lacked the resources to help themselves, giving priority to those in greatest need. In fact, auto and health insurance companies make their living and huge profits on the fact that some people experience accidents, injuries, or illness, while others do not. One buys into a policy believing that if you need it a helping hand will be there. Now the ethicists claim that the government can save tax dollars and the insurance industry can increase profits even more by killing off those in greatest need--
leaving more resources, supposedly for more people in less need—more likely for more profit and more greed.

As handicappers who are employed, taxpaying, homeowning, spouses, parents, and budget administrators, we are as concerned as any about multiple demands for limited resources. However, when murdering people (whatever the euphemism used in the medical ethic politic of the day) is suggested as a solution for cost control, we are entering very dangerous territory. Of course, genocide as a political method of solving socio-economic problems, is an “easy” solution that has been employed periodically throughout history particularly against the most vulnerable and defenseless victims. Without belaboring this point, let me insist that this society has far from exhausted ways of more efficient resource management in and out of the medical arena and certainly does not need to even consider the “easy-kill” solution to cost-control. If all of us would simply broaden our horizons we could each come up with our own examples of waste.

Here is our partial list:
Government and other administrative waste (Health and Human Services Secretary Sullivan projected annual savings of $20 billion through administrative reforms, notably standardization of record keeping.). $22 million spent each day on snack food. $400 million spent each day on toys. Annual dollars spent on cosmetics and unnecessary/cosmetic surgery. Annual dollars spent on alcohol, tobacco and drugs. Annual cost in crime and health care resulting from alcohol/drugs and the cosmetic ideal. Annual dollars spent on sports and entertainment (including sport and recreation injuries). Annual cost of maintaining prisoners (housing, food, education, legal -counsel, entertainment, “significant other privileges”, etc.). Annual dollars spent on political campaigns and lobbying. Excessive insurance profits. Insurance industry "redlining" — providing coverage primarily for the younger, healthier segments of the population even if at premium prices because they are so active, hence “at risk”. Not to mention the S & L Bank, House Bank, the Social (in-)Security and Post Office scandals.

Does society solve its problems by murdering vulnerable scapegoats? And when these are gone, what will be the excuse for rising costs then? Will new scapegoats be singled out? And, finally when only one human is left on earth, who will the scapegoat be when he looks into his mirror?

Case Study
One day last August Crystal Barbier and Torrance Lobdell were swinging from some willow trees in the Westmont Twin Lakes Park when they both fell into the lake below. Torrance drowned, but Crystal was rescued and rushed to the local hospital. The doctors calculate that before she was revived she was deprived of oxygen for approximately seven minutes, destroying much of her brain.

After eight months it is doubtful whether or not she can see or taste although she can hear and smell. She can not close her mouth or swallow, but she is able to blink. She is tube fed and with the aid of a tube in her throat she can breathe on her own. The doctors have said that it is possible that her condition will never improve. Furthermore, unless she is given constant physical therapy her muscles and joints will stiffen, leaving her immobile and in ever-increasing pain. She requires round the clock nursing care.

Her 27 year old mother, Debra Barbier, has no health insurance for Crystal. The various state, federal and school programs involved will only pay for a part of the total cost of preventing Crystal’s deterioration, a figure which will run upwards of $250,000 a year. Ms. Barbier would have to quit pharmacy school to provide the required services herself and she is unable to afford private care. (Summarized from an April 26, 1992 Chicago Tribune article)
Just Caring: Health Care and the Disabled

By Leonard Fleck, Ph.D.

Do the disabled have a moral right to virtually unlimited access to health care? Does Crystal Barbier have a moral right to $250,000 worth of health care per year to sustain her in a mental state just slightly above that of PVS? If Crystal’s current state becomes her permanent state, such that she would have thirty or forty more years like that at an ongoing cost of $250,000 per year, then would we, as a society, treat her unjustly if we denied her that additional care, the result being her premature death within the next year? The very asking of these questions sounds monstrously insensitive and uncaring. And if we had unlimited resources that we could pour into the health care system, then these would be monstrous questions. But the fact is that health resources are limited while health needs are virtually unlimited. We need to make choices about our health priorities.

My last sentence sounds innocuous enough, until we recall that this is an essay about the just health claims of the disabled. What right do we, the able-bodied, have to impose health priorities (rationing protocols) on the disabled? The obvious answer to that question is that we have no such right, especially when we consider that as a society we have been less than sensitive to the needs of the disabled (which is a generous way of describing matters), and worse, we have actively discriminated against them in jobs, access to educational opportunities, and so on. This brings me to a much more difficult question.

If we assume that the disabled do not have a right to unlimited health care because no one has such a right, then are the disabled morally obligated to establish their own health priorities for themselves within the context of a limited budget? That is, are the disabled morally obligated to fashion their own rationing protocols for themselves? I believe this question requires an affirmative answer, painful as it might be for the disabled themselves. For this is the same pain that the able-bodied must endure in a world of limited health budgets.

There may be a special kind of pain for the disabled in this matter; for, in effect, their perception is that they are being asked to discriminate against their own, that is those who have for a long time been victims of discriminatory treatment. This sounds morally repugnant. Why should those who are among the least well off discriminate against those who are also among the least well off. This way of putting the question is really morally misleading, for the term ‘discriminate’ often carries the implication that the discrimination is unjust. What I want to argue, however, is that there are just forms of discrimination, as when there are only a limited number of ICU beds and twice as many patients who need those beds. Then we need some fair approach to discriminating among all these health claims to determine who has the strongest moral claim to those beds.

Failure to discriminate in the sense that I defend is itself morally problematic. It is well to recall that the most vocal organizations in support of the state of Missouri in the Cruzan case were organizations protecting the rights of the disabled, their claim being that Nancy Cruzan was one of them. Nancy Cruzan, of course, was in a persistent vegetative state (PVS) as a result of an automobile accident; and she was in that state for more than seven years at a cost of more than $900,000 to the Medicaid program in Missouri. If that program provided coverage for all the health care needs of all those below the poverty level, then there might not be anything morally problematic (unjust) about spending that 900,000 for Nancy Cruzan. But the fact is that only 40% of those below the poverty level are covered by Medicaid of Missouri, which is roughly average among the states. When we focus on the fact that that $900,000 could do nothing more than sustain bare biological life in Nancy Cruzan, no conscious life at all, then it seems each and every one of those dollars could have provided substantially more in the way of health benefits for potentially hundreds of poor individuals in.
If the Cruzan case were just an isolated example, we could simply move on. But there are 10,000 individuals in the United States today sustained in PVS at a cost in excess of $1.5 billion. That, however, is only the tip of the iceberg. The larger problem is that only one-third of our Medicaid budget (on average) is devoted to meeting the health needs of the non-elderly, able-bodied poor. The other two-thirds is devoted to meeting the health needs (nursing home needs) of the disabled poor elderly and the disabled non-elderly. For the moment I do not wish to question the legitimacy of these needs or their claims on public budgets. But I must note that these needs have grown astronomically over the past fifteen years, while the capacity or willingness of states to raise taxes has not grown proportionately, the result being that the non-elderly poor have seen themselves squeezed off the Medicaid rolls in one state after another. How should we judge this result from a moral point of view? At the very least it is unseemly that the middle class would play the role of disinterested observers as the disabled battle with the poor for scarce tax dollars.

I need to confess to my readers that when I began to write this essay I did not know how many disabled citizens there are in the United States. I imagined that the figure might be around one or two million. In fact, according to the U.S. census bureau, the actual figure is around 43 million individuals, or about 14.4% of the U.S. population. (The definition that determines who is or is not rightfully included in this group comes from the Americans with Disabilities Act of 1990.) This is an extremely heterogeneous group that includes those who have become disabled as a result of accidents (cars primarily), as a result of disease processes at any stage of life, as a result of genetic disorders that may or may not have been manifest at birth, as a result of dementing disorders, and so on. The cost of caring for different clusters of these individuals varies enormously. One significant statistic is that in 1990 the cost of caring for two million individuals with dementing illnesses was $45 billion out of total health expenditures of $670 billion.

If space permitted there are dozens of other relevant statistics I might cite. But I think I can fairly make my remaining points without those statistics. The assumption in the early part of this essay was that the disabled are a fairly well-defined group, like women or Afro-Americans, and hence, they alone have the moral right to determine for themselves what their health priorities ought to be in the context of limited budgets. That, however, is a false assumption. I will never be a woman or an Afro-American, but there is a very strong likelihood that my future self will be among the disabled. Since I am a poor swimmer, there is a chance that I will be a near drowning victim in a near-PVS state, just like Crystal Barbier. Or I could be seriously and permanently injured in an automobile accident, or I could end up as an elderly demented individual. This would seem to give me some claim to be part of that moral conversation regarding resource allocation for the disabled, for that may be my future self.

I, of course, do not know what the circumstances of that future self might be. But I can imagine myself now making judgments for my future self like this, knowing that resources are limited: If I am like Crystal and there is a high degree of confidence that I will never get beyond that near-PVS state, then my life, a life that I can appreciate, is over, and I should be allowed to die. I would rather that that $250,000 be used to rehabilitate another possible future self of mine that might be in an automobile accident and that could substantially benefit from access to an expensive but effective rehabilitative technology. This strikes me as a reasonable and morally defensible judgment that any of us could make and that captures what the ideal of “just caring” should mean for any of our future possible selves.

This is only one example of the kind of judgments that we must be prepared to discuss in public moral conversations. There are hundreds, perhaps thousands, of such types of trade-offs that we must be prepared to con-
sider as we assess the health needs of the disabled. Invoking the pseudo-moral ideal of the pricelessness of human life and asserting that Nancy Cruzan and Crystal Barbier have as strong a claim to limited health resources as victims of spinal cord injuries effectively blocks the possibility of the kind of moral conversation I recommend. Worse, it provides a pseudo-moral veneer for what are in fact injustices. There are truly amazing rehabilitative technologies that are emerging, and that promise substantial improvements in the quality of the lives of many of the disabled. To fail to deploy such technologies as speedily as possible because $1.5 billion per year is being spent to sustain individuals in PVS is not simply imprudent; it is unjust.

If Crystal Barbier can improve no further, that is tragic. If we then spend $250,000 per year for the next ten years to sustain her in that state, the tragedy will have been compounded with injustice. A society that appeals to pseudo-moral symbols to avoid painful moral conversations risks being both unjust and uncaring.

Brody (continued from page 1)

indirectly applauded her force feeding (which was later ruled a violation of her rights by a higher court).

The lesson I drew from this is that it is quite difficult in today's society to cope with chronic illness and handicap; and many advocacy groups respond by promoting what I called "dogmatic coping." They propose a "good" role for the sick or handicapped, which often emphasizes struggling against odds and a certain degree of social militancy. They then selectively bestow praise and group support on those who play the "good" role and may withhold support or even ostracize those whose life stories unfold in a different way, and who make different life choices in the face of handicap. In extreme cases this can lead to a strange sort of tyranny of the group against the "different" sufferer. (I once cared for a family with a severely afflicted, premature infant, who was kept alive through neonatal intensive care. The parents at one point unsuccessfully petitioned the physicians to stop aggressive care and allow the child to die. For this stance, they were roundly criticized and ostracized by the "parents' support group" in the nursery. Leaving aside the moral question of whether this child should have been saved, it seems clear that this couple had failed to adhere to the unspoken "good parents' role" in that nursery, which was to be abjectly grateful for the fine technological care.)

I concluded that it was in the end better to allow individuals to write their own stories of sickness and handicap, suited to their uniqueness, rather than be pressured to adopt a standard script. My goal was not to condemn the advocacy groups, but rather to point out an unfortunate down side of activities which generally did a great deal of good for patients and the community.

Would I modify my commentary in any way now? Having recently been involved in the ongoing debate over physician-assisted suicide, I would look with more sympathy on one argument raised by the advocacy groups in the Bouvia case—the question of the rationality of a decision to end one's life. I would still defend the notion that the handicapped ought to be allowed to make rational choices for themselves, but I also see the point more strongly, that society may well have a double standard by which to measure "rationality." If another patient's wish to die would be taken as prima facie evidence of mental disturbance, then a handicapped person's wish to die ought not proclaimed to be rational, without further investigation, just because of assumptions that life with a handicap is automatically a life of low quality.

The same point has been made forcefully, regarding physician-assisted suicide, by advocates for the elderly. If a 20-year-old shows up in emergency after a suicide attempt, the cry is,"Protect his stomach and call psychiatry!" If an 80-year-old shows up in emergency in
similar circumstances, it's "Well, of course—what does he have left to live for?" And yet the 80-year-old might have a readily treatable depression. Physicians no less than anyone else in society are subject to these subconscious, pervasive biases.

Having made that point, one must still add that in the original Bouvia case, many commentators urged the need for a full psychiatric assessment. (I still have problems commenting on that case precisely because no such assessment was ever made part of the public record.) It seems wrong to suggest the Bouvia's wish to die was rational simply because she was handicapped. It also seems wrong to say that no rational, handicapped person would ever wish to forego lifesustaining treatment. Listening to individuals and trying to help them tell their own stories about their own circumstances still seems prudent—despite the fact that our society and our culture will inevitably shape the stories we tell, for better or for worse.
Update on Recent Activities of the Center

Publications and Presentations


On June 12, Professor Tomlinson will be delivering a presentation for the Bioethics Network of Ohio entitled,"Health Care: The Future is Managed Care". On September 15 he will be in Grand Rapids presenting his paper, "Resuscitation: Ethical Issues of Nursing Homes" for the Health Care Association of Michigan. In October he will be at the University of Pittsburgh conference on non-heart beating donors, commenting on proposals to revise the concept of "irreversibility" used in criteria of death. In addition, Professor Tomlinson has been nominated to serve on the Board of the Societies for Bioethics Consultation.


On June 17 Professor Fleck will be delivering his paper, "Fetal Tissue Transplants: The Ethical Issues," for the spring lecture series sponsored by Eastern Michi- gan University, at the corporate Education Center in Ypsilanti. He will also be speaking at the national conference of the American Association of Nurse Anesthetists in Denver on August 8.

Howard Brody's article "Ethics, Technology, and the Human Genome Project," was published in the Journal of Clinical Ethics, Winter 1991 (Vol. 2, pp. 278-281). He will be speaking at the Western Association of Gynecologic Oncologists in Durango Colorado on June 20, at the Gunderson Clinic in Wisconsin on July 13 and at the Society for Bioethics Consultation in Chicago, September 10-12.


OTHER NEWS

The "Just Caring" project has been successfully launched with a half-day conference in Traverse City (May 15, 1992). It will be launched with a similar conference at twenty other sites around Michigan in the fall. Leonard Fleck gave the keynote address, "Just Caring: A Problem Framework."

Marion Secundy, a King-Chavez-Parks Visiting scholar and Professor of Community Health at Howard University, will be here from June 21-24.