

## Reflections on Clinical Ethics

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### Abstract

Moral philosophies have rarely helped as I work with families to make the best decision for their child, for the family and for society. What is the proper role for the physician? I have found over a long career as a pediatric neurologist that “benign” paternalism best fits my role.

During the course of my career as a child neurologist and faculty member of the Johns Hopkins Berman Bioethics Institute, I have developed a familiarity with the various moral philosophies: Utilitarian, Aristotelian, Kantian, but have found that they rarely enter my thinking or language as I make difficult clinical decisions at the bedside. They seem much like the field of biochemistry, useful as background, but rarely of use at the bedside.

I am clearly a Utilitarian clinician striving to produce the greatest good for the greatest number, but that number is always constrained to the individual family and child at hand. The patient’s “good” clearly always has primacy, but I am also concerned about the family and about society’s investment in a single individual. Should I be?

### Here are some cases and conundrums that I have confronted

When presented with a profoundly retarded child with uncontrollable seizures from a malformed half of the brain, should I advocate for surgery to remove that malformation, as I would for a child with more normal development? Or, since the operation would help the seizures but is unlikely to cure the retardation, should I advocate against the operation knowing that the child will be a continuing burden on the family and on society no matter what may be the outcome? Is my role to advocate for any position, or merely to state the facts and allow the parents to decide?

As I encourage a family to allow a minor operation to repair the back of their child with spina bifida who will never walk independently, whether I advocate for or against the operation, I worry that I am being too directive by the language I use and the tone of my voice [1]. Should my discussion be more neutral or more paternalistic? Is survival of a severely handicapped child always a blessing? Will that child’s longer term survival truly increase the “greatest happiness for the greatest number”?

Ethical theory does not help my decision-making. If I struggle with these issues, how can a family, inexperienced in these many subtleties, make an informed decision? Never-the-less, they must decide, and I must ratify their decision. Should parents even consider society’s good as they ponder these decisions?

Similarly, as families of patients in a persistent vegetative state request that “everything be done,” should cost to society be considered? I worry about my role in these decisions. What will provide the greatest happiness for the greatest number? What will be the costs to society?

That is my Utilitarian side. I do not use it in reaching my decisions, but it is back there, pushing me in one direction - or another. It does not alter my commitment to the child, but nags at my conscience. These concerns are not voiced to the family, but to my students and residents as we discuss the process of deciding what to advocate. Should it be my role to advocate any position?

I have been awed by parents who constantly demonstrate love, caring and compassion for the profoundly disabled child who has only minimal interactions with them or with the environment, providing none of the immediate positive feedbacks and rewards most of us as parents have come to expect from our children.

Two books about handicapped children, Stasia’s Gift [2], a family’s tale of life with their child with hydranencephaly (the almost complete absence of brain cortical tissue), and The Power of the Powerless [3] a tale of growing up with a profoundly handicapped brother, have made a deep impression on me, and so I recommend them to my students. So has a statement by Deborah Kent [4] who was born blind.

“When I was growing up people called my parents, ‘Wonderful.’ They were praised for raising me ‘like a normal child.’ As far as I could tell, they were like most other parents in my neighborhood, sometimes wonderful and sometimes very annoying. And from my point of view I wasn’t like a normal child. I was normal.”

On reading this I realized how limited is my own view of what other people consider as an acceptable quality of life and how tolerant we must become. And yet I know, or at least I thought I knew, what I would want for myself or for my child. But is that even pertinent?

An opposite view of what is acceptable quality of life was expressed by two of my patients with spina bifida. Early in my career, while running the birth defects clinic, I had been a vocal advocate for the treatment of all children born with the defect. Several years after I had ceased running the clinic, however, I was asked to write a chapter on the ethics of the management of such children [1]. In preparation, I spoke with two of my “best” patients, each now in their early twenties. They had each had caring parents, were college graduates, and although living at home and wheelchair bound, each was employed at Social Security. I told them of my chapter and asked what I should say. In unison they replied, “Tell them we wished we had never been born.” If this is a prevalent view among those with high level defects, how should I now counsel parents of newborns with the defect?

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Utilitarian principles thus do not completely satisfy my need, and I search on for answers. Kantian ethics mandates that I always treat an individual with respect, never as a means. Respect means we treat individuals only with their consent, but their consent is usually acquiescence, and due to their lack of experience is usually based on the information we as physicians have provided, information that contains all of our spoken and unspoken biases as reflected in the words we have perhaps inadvertently chosen - like "severe" or "intractable". Even our demeanor and the body language we use during discussions convey biases. Respect underlies all my actions, but rarely helps families in the decision-making process.

Families come to me for an opinion, or for a second or third opinion. They want to hear my biases and prejudices, but also should want to know that my opinions are just opinions, hopefully informed, thoughtful, caring opinions. I tell them that these are my opinions - not necessarily facts - and try to explain why I hold them. They may collect "facts" from others, but these are also distorted by the others' biases. Providing my opinions is my form of respect and underlies my ethics. I always respect the autonomous decisions of the family - but only if those decisions are reasonable and within the limits of my paternalistic, philosophic boundaries. Does this represent true autonomy for the family? Should I attempt to be more persuasive? Should I call an ethics committee to meet with them? Should I ask the courts to decide?

Parents and patients have even less knowledge than I of what the future will bring or of how they will cope with it. Can anyone know what it would be like to grow up deaf or retarded or with "severe" disabilities? Even using the term "severe" biases the argument, for does the child know severe? Or, like Deborah Kent, will the child consider blindness "normal?" Does any family know how they would raise such a child, or how they or the child would cope? Do families (or physicians) know what it would be like to be in a persistent vegetative state?

### **The Ezekials [5] offer four models of the physician-patient relationship**

- The paternalistic model in which the physician acts as the patient's guardian, articulating what is best for the patient;
- The informative model in which there is no role for the physician's values and he (or she) only to provide "the facts";
- The interpretive model in which the physician elucidates the patient's values and helps the patient realize these values; and
- The deliberative model in which the physician engages the patient in a discussion of what decision would be best.

They provide a case of a young woman with breast cancer and discuss the decision to do a mastectomy or a lumpectomy, each with or without chemotherapy and irradiation. Here there are rational alternative managements and the patient's preferences are rational alternatives. The authors critique each model and conclude that the deliberative mode in which the physician helps the patient determine the best health-related values is the one which best bridges the gap

between paternalism and autonomy. This approach works well for the case they cite, but less well in situations of substituted consent, such as the cases I have presented. Neither approach incorporates society's interests.

My approach to patients is clearly paternalistic. Being better informed and more experienced about the consequences of their decision, I attempt to guide parents towards my point of view. As a male, I cannot be "maternalistic", but I fail to understand the current cant in which paternalism is considered pejorative, while maternalism is equated with beneficence. Perhaps we should grow beyond the Victorian implications of these terms and claim that caring, compassion and concern, nurturing and protecting can and should be characteristics of both sexes, attributes to be sought and praised.

Perhaps rather than applying the right ethical theory, I should encourage my students to use the varied theories in combination rather than in competition. They should attempt to be virtuous in the Aristotelean sense; to follow the rules and to be aware of their duties and obligations to themselves and to the rights of their patients and their duties and obligations to them in the Kantian ethic. They should be sensitive, caring, and compassionate in the maternalistic sense but guide their patients in a paternalistic fashion and sandpaper their own fingertips, to be more sensitive to the family's cultural background and beliefs. They then can better help the family or individual make their own best decisions.

Most of all they should be attuned to the differences and alternatives to what they - the physician - would have the decision be, and tolerant, within carefully defined limits, of the decisions of others. I might term this "benign paternalism".

Over my career my ethical concerns have changed. Starting as a dogmatic, paternalistic physician, I have with experience and time become less arrogant; less certain I know what is "best", and more concerned about the effects of these treatment decisions on society. My concerns have been deepened by an article by Lamm [6] emphasizing the societal costs of the decisions we make. I believe that I have become more humble and less certain of the ingredients in the decision-making process. Knowledge of ethical principles has not helped me on my journey.

### **References**

1. Freeman JM (2004) On Learning Humility: A Thirty-year Journey. *Hastings Cent Rep* 34: 13-16.
2. Kelley B, Kelley A, Littleton MR (1993) *Stasia's Gift*. Crossway Books.
3. Christopher De Vinck (1951) *The Power of the Powerless: A Brother's Legacy of Love*. Crossroad Books.
4. Deborah Kent (2000) "Somewhere a Mockingbird", in Erick Parens and Adrienne Asch, *Prenatal Genetic Testing and the Disability Rights Critique*. Georgetown University Press, Washington DC.
5. Emanuel EJ, Emanuel LL (1992) Four Models of the Physician - Patient Relationship. *JAMA* 267: 2221-2226.
6. Lamm R (1999) Redrawing the Ethics Map *Hastings Cent Rep* 29: 28- 29.

