Title

Moral ordering and the social construction of bioethics

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Publication Date

1991

MORAL ORDERING AND THE SOCIAL CONSTRUCTION OF BIOETHICS

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

SOCIOLOGY

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

Date **University Librarian**

Degree Conferred: 6/16/91

MORAL ORDERING AND THE SOCIAL CONSTRUCTION OF BIOETHICS

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ABSTRACT

As both discipline and practice, bioethics involves the construction of ethical and moral rules. Negotiations over rules, including the making of new rules, and their interpretation, engage common "vocabularies of motive" and legitimizing principles. I have designated the processes of these particular negotiations as moral ordering, the defining, re-defining, constructing, re-constructing and de-constructing of new rules in the area that is interpreted as moral or ethical.

An examination of the forms of moral ordering through an exploration of various discourse turns fundamentally on the concept of legitimacy. Moral ordering, viewed from this perspective, is essentially to be grasped as a struggle between competing discourses. It is essentially the appropriation of legitimacy by one discursive system, which then becomes the dominant or hegemonic model.

In this dissertation I explore some of the processes of moral ordering by examining the emergence of the discipline of bioethics and the practices of eight bioethics committees. The theoretical foundation of the constructions and contexts of bioethics allow me to demonstrate: that bioethics may best be conceptualized as an issue in the sociology of knowledge; that the conditions under which a social problem is constructed or de-constructed has its basis in knowledge and legitimation; that the disciplinary emergence of bioethics was an attempt to deal with developing problems of justice; that decisions in ethics both at the policy level and at the local committee level are based upon a process of moral ordering; and, that in the deliberations of moral ordering in health care, one discipline's knowledges, beliefs, and paradigm prevail.

Bioethics has recently moved into a larger policy arena: community based bioethics committees. These committees, in particular counties and states such as California, Delaware, and Oregon, consider health decisions in larger arenas, making decisions that involve politics, economics, and policy. These committees, along with the hospital bioethics committees, are strategically placed to make health care decisions about justice, in particular, the allocation of resources. It is this potential, which has been unexamined, that prompted my sociological concern with bioethics committees.

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Adele Clarke, Ph.D.
Chair, Dissertation Committee

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MORAL ORDERING AND THE SOCIAL CONSTRUCTION OF BIOETHICS

Patricia Anne R. Flynn

I. CHAPTER ONE: INTRODUCTION

A. INTRODUCTION TO THE DILEMMAS AND THEIR DIMENSIONS

Fifteen years ago Karen Anne Quinlan lay in a "debilitated and allegedly moribund state" at Saint Clair's Hospital in New Jersey (In re Quinlan, 1976:105). Her physicians refused to allow the 22 year-old woman to be removed from the respirator as her family had requested, and the case was taken to court. The New Jersey Supreme Court (In re Quinlan, 1976:115) ruled that:

> there must be a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgments for the well being of their dying patients.

The court considered a distinctive solution: that the hospital should create "an Ethics Committee composed of physicians, social workers, attorneys, and theologians" to help make such difficult decisions. The court quoted a law review article by a pediatrician who had proposed that an ethics committee could provide valuable "input and dialogue" on the ethical issues surrounding withdrawing treatment (In re Quinlan, 1976:115, quoting Teel, 1975:8-9). In its decision, the court encouraged the formation of such a committee.

The fact that a judge, quoting a physician writing in a law review article, subsequently came to recommend an ethics committee to deal with difficult biomedical ethical issues, provides some insight into the complex story discussed in this dissertation. The coalescence of medicine, law, and ethics into what comes to be known as bioethics is framed in a broader context of a societal concern with justice in medicine which had prompted the development of bioethics as a discipline.

Since the 1976 Quinlan decision, over sixty percent of hospitals and an increasing number of nursing homes and other health care institutions have introduced bioethics committees in the hope of resolving difficult ethical problems engendered by modern medicine, technologies, and the politics of health care economics. These committees have no single function or form, but instead perform a variety of tasks, are variously structured, include many different kinds and proportions of people as members, exclude others, and exercise varying degrees of power. They are highly local phenomena. Yet, whatever their structure, composition, and authority, they are involved in significant decisions. These committees confront issues ranging from the appropriateness of withdrawing respirators and feeding tubes from comatose patients to explicit decisions about the allocation of resources.

Bioethics committees are both embedded within and take their intellectual and moral direction from the emergent discipline of bioethics. Bioethics is a theoretical and clinical discipline constructed in the 1960s by professionals from several fields, coalescing an older medical ethics with a theoretical philosophical ethics and law. It was created by new professionals, who became known as bioethicists, who built centers, generated an encyclopedia, literature, and conferences, and took part in developing new clinical practice arenas, the bioethics committees.

The theoretical foundation of the constructions and contexts of bioethics allow me to demonstrate:

- that bioethics may best be conceptualized as an issue in the sociology of knowledge;
- that the conditions under which a social problem is constructed or de-constructed has its basis in knowledge and legitimation;
- that the disciplinary emergence of bioethics was an attempt to deal with developing problems of justice;
- that decisions in ethics both at the policy level and at the local committee level are based upon a process of moral ordering; and,
- that in the deliberations of moral ordering in health care, one discipline's knowledges, beliefs, and paradigm prevail.

Moral ordering involves processes of negotiating, coercing, and otherwise dealing with definitions and re-definitions of that portion of the social order called the moral order. The processes of moral ordering affect issues which are defined by its participants as moral. How the broader society became interested in the specific moral ordering called bioethics and how an interest in justice is involved in the origin and practice of bioethics are a part of the story told in this work. I also describe the wedges which allowed the federal government and other professions to make incursions into the boundaries of medicine in terms of these issues in ethics.

Bioethics has recently moved into a larger policy arena: community based bioethics committees. These committees, in particular counties and states such as Alameda, California and Oregon and Washington, consider health decisions in larger arenas, making allocation decisions that involve politics, economics, and policy. These committees, along with the hospital bioethics committees, are strategically placed to make health care decisions about justice, in particular, the allocation of resources. It is this potential, which has been unexamined, that prompted my sociological concern with bioethics committees in 1986. The findings of my research indicate that my concerns were well placed. The Patient Self-Determination Act, which has recently been before the Senate Finance Committee would have mandated the formation of ethics committees in all states in health care institutions that qualify for Medicare or Medicaid funding (Patient Self-Determination Act 1989). The main aim of the Act would be to require institutions to give adult patients an opportunity to learn about and use advance directives to indicate their wishes about life-sustaining treatment and to appoint surrogates in the event they are unable to make health care decisions for themselves. However, it also gives ethics committees a broad charge. They are to "initiate educational programs on ethical issues in health care, to advise on particular cases, and to serve as a forum for such issues." Largely because of actions against the ethics committee clause by the American Hospital Association and American Medical Association the ethics committee provision was dropped in favor of support for the patient self-determination bill itself (Purdy Interview 1991; Patient Self-Determination 1990). While there is still very little information and empirical research about such committees, we were on the verge of a federal mandate that all hospitals create them.

This dissertation provides some research that will allow a more informed consent or refusal about these and other policy recommendations.

In this dissertation the object of study is the bioethics arena. This arena originated in the United States, and has become international, partly because of the speed of information communication and interaction among principals at conferences. I have chosen to focus on the evolution of bioethics in the United States and use international data primarily to make comparisons to indicate that as Hughes (1971/1984) said, "it might have been otherwise."

Essentially there are three research foci.

- the emergence of bioethics as a discipline;
- the practice of bioethics and its development in hospital bioethics committees; and,
- the implications of bioethics for aging health policy.

(1) BIOETHICS QUA PROBLEM AND EMERGENCE AS A DISCIPLINE.

I examine how bioethics developed from lines of work in philosophical ethics, medicine, and law within several intersecting contexts - the growth of technology, the emergence of a discourse of rights, and the historical erosion of trust in physicians and in medicine as an institution. I examine the constructions, contexts, legitimations, and moral ordering of the new theoretical and clinical discipline **bioethics.**

The data for this historical sociology section of the dissertation included transcripts of early trials and responses to egregious medical experiments, Presidential Commission reports, legal cases and writings, the Bioethics Encyclopedia, and publications of the bioethics institutes. The data are representative of the intersecting social worlds each of which contributed to the construction of bioethics.

(2). BIOETHICS QUA PRACTICE: THE HOSPITAL COMMITTEES.

This sociology of the emergence and foundations of bioethics committees involved a two part analysis. The first part consists of an examination of the literature and cases relating to bioethics committees. These ethical documents and legal and ethical cases form the infrastructure of bioethics. The second part of this analysis consisted of field research in eight bioethics committees.

(3). BIOETHICS QUA POLICY: AGING HEALTH POLICY

In this section I discuss the implications of bioethics for aging health policy. I begin this with a discussion of regnant theories of justice and describe how selecting different versions of justice will affect the aged as well as general health policy. This section includes a sociological analysis of the literature concerning aging and health policy in matters of bioethics and incorporates cases and policies from the committees themselves.

B. METHODOLOGY

1. OVERVIEW OF APPROACH AND METHODS

a. QUALITATIVE METHODOLOGY

The general methodological approach of this research is that of grounded theory as developed by Glazer and Strauss (1967), Glazer (1978); Strauss (1987), Strauss and Corbin (1990); Schatzman and Strauss (1973); and Schatzman (1991). This methodology is effective for both the historical sociological research and the field data on the bioethics committees themselves. My focus was on the emergence of bioethics as both discipline and practice.

In the central focus on the data of the bioethics committees themselves, I use a qualitative approach to the understanding of that social "reality," referred to variously as field research, **verstehen** sociology, interpretive sociology or grounded theory research. The basic canon of this methodology is understanding social worlds through the perspective of the actors in them whether they be physicians and patients (Fox 1959); a class of medical students (Becker, Geer, Hughes, and Strauss 1961); mental patients (Goffman 1961); dying patients (Glazer and Strauss 1965), student nurses (Olesen and Whittaker 1968), cardiac surgeons (Fox and Swazey 1974); pediatricians and nurses (Anspach 1982, 1987, 1988); surgeons (Millman 1977), physicians and patients (Mizrahi 1986), physicians (Bosk 1979; Mueller and Koenig 1988), Institutional Review Boards (Gray 1975; Sackoff-Lambert 1984), or, as in this work, ethics committees.

My focus in this research is on how people come to experience and create a common reality in a particular form, what they do to produce this experience, how they explain its meanings and how a particular reality is constituted, produced, and shared. I sought to go beyond understanding the meanings that the group members may share to examine the assumptions and practices that the members employ to construct a sense of shared or conflictual reality. These assumptions are often unknown to the members as they are prior to, and constitutive of, the meanings with which the typical ethnography deals. It is these assumptions and the taken-for-granted aspects of them that I am concerned with in bioethics. Schutz (1967) argued that the reality commonly experienced in everyday life was but one of a wide variety of realities or provinces of meaning. Each reality was constituted by what Schutz calls its cognitive style or the set of presuppositions and modes of activity that constitute it. Each was equally real and internally consistent, but commonsense reality is considered dominant as it is the realm in which we communicate to one another. Particular practices are examined and rules outlined for understanding how one makes a shared sense of reality out of the flow of everyday life. In the symbolic interaction approach there is an assumption that action depends upon the meanings which people ascribe to their situations (Blumer 1969). The meanings are based on the shared interactions of the participants, and, in this perspective, language plays the key role in shaping social reality. One advantage I had in contrast to other researchers was that I was completely familiar with the medical vocabulary. That is, I was already bilingual. This also meant, of course, that I shared the same **a priori** assumptions as others in medical professions. Knowing this, I consciously and continuously questioned these.

Like any social phenomenon, bioethics is defined by the activities which accomplish it. It is a set of activities, beliefs, attitudes and rituals organized by the notion of knowledge into a more or less coherent flexible whole. The practice includes talk, writings, activities and other work. Put briefly, for this will be considered in greater detail later, bioethics is a socially mediated, reflexively organized phenomenon and "reality" that is socially organized to the degree that it is learned and shared. Studying these socially organized practices can reveal how people collectively produce and explain their experience.

b. DATA COLLECTION IN THE FIELD

i. OBSERVATION OF BIOETHICS COMMITTEES IN THE HOSPITALS

To capture the range of variation of bioethics committee practice I chose to observe several committees rather than remain in one for the duration of the study. In 1986 there were 20 ethics committees in the San Francisco Bay Area in California. I selected six committees representative of institutions in the Bay Area. In 1988, I added two more committees. The types of institutions include a small and a large private hospital, a large research hospital, a Catholic hospital, a small and a large community hospital, a county hospital, and an institution dealing with the aged. The willingness of the committee members to have me observe their committees was explored and no committee refused my visits.

The majority of the committees were observed for a minimum of six days, over a period of one to four years. I observed a total of 40 meetings at eight institutions. The range per hospital was from 3-10 meetings with the average number of meetings four.

My initial negotiations with the committees had been to observe three meetings. In most, this provided sufficient data, but I continued to attend committees to gain a longitudinal view of committee development. I also attended several sub-committee meetings in those hospitals which heard cases in a smaller forum.

I returned to four of the original six committees two years later. Two of these original committees did not exist in the same form as originally but had merged with another hospital's committee. In the four committees that I revisited, I primarily observed the development of the committees and sought to detect whether or not the initial patterns had persisted. This provided me with additional data and a good sense of the longitudinal development of the committees.

In addition to attending bioethics committee meetings, I frequently spent several hours observing at the hospital: interviewing participants, talking to other members of the hospital community and staff, and "hanging out" at the hospital. I spent time in the institutional libraries to see what kind of material on bioethics they had available. I visited the ICUs and CCUs of some of the hospitals to talk with the staff. The fact that I am also a nurse practitioner and had in the past taught several of the nurses in these hospitals made entree into these units uncomplicated.

At the first meeting of each group committee that I attended, I introduced myself, briefly described the research, assured the members of confidentiality, and asked them to introduce themselves so I would know what discipline they were representing. I also indicated that if at any time they wished me to leave, I would. As part of this negotiated entree, I offered to return after the study was finished and share what I had learned from all of the bioethics committee visits. Every bioethics committee was very positive about this and I think that it too added to making entree easy.

My role in the meetings was to listen and observe. I did not participate during the meetings, although several times people asked for my advice on an ethics matter or asked my opinion about a particular case. I would simply state that I could not participate. The committee members seemed to accept my presence and the fact that I was taking notes. I was not allowed to tape the meetings nor to copy any documents relating to past cases, although I was permitted to read these and take notes on them. I took all notes openly.

Once I had attended a few meetings, I was able to begin to focus on certain key aspects of the meeting. Although there were many issues to consider, in light of my purpose, I selected to forego some areas that would certainly have been fruitful, such as the relationships and communications between nurses and physicians, which I will investigate at a later time. I chose to focus instead on committee processes of interactive decision-making.

ii. CONFERENCES

During the four years of the study, I attended several bioethics conferences and lectures given by noted bioethicists and philosophers. Among them were:

American Society on Aging: Summer Series on Aging July 11-15, 1988:
1. Applied Ethics: Professional, Personal and social dilemmas. Martha Holstein
2. Aging and Inter-generational Responsibility: Social Ethics and the Welfare State. Thomas Cole.

Conference on Community, Law, & Moral Reasoning. Jefferson Lectures, University of California at Berkeley. Sept. 30-Oct. 1, 1988.

American Public Health Association's 116th. Annual Meeting. Boston, Nov. 13-17, 1988. Ethics and Technology Section.

The Public and Corporate Ethics Project [PACE] Conference: Limits to Life: Health Care Dilemmas in an Aging Society. A panel discussion with Daniel Callahan and Martha Holstein. Jan. 25, 1989.

Conference at University of California at Irvine. University of California Humanities Research Institute, School of Humanities, College of Medicine and Department of Philosophy UC Irvine. "Life at the Limits: A Conference on the Moral Issues." February 24-25, 1989.

In the first years of the research I attended all of the bioethics grand rounds held at the University of California at San Francisco. These rounds ended shortly after Albert Jonsen, chair of medical ethics left the University.

iii. IN THE LIBRARY

Data here included the documents produced by several bioethics organizations: The Hastings Institute, the Society for Health and Human Values, the Society for Law and Medicine, and the Bioethics Forum of the American Public Health Association. I also drew deeply on the literature of bioethics including The Journal of Medicine and Philosophy, the Journal of the Texas Center for Bioethics, The Hastings Center Report and The Journal of Health and Human Values. I also reviewed the materials in two bioethics newsletters.

I drew upon historical sources from the early literature on eugenics and the Nazi period through the Nuremberg Trial transcripts of the medical trials (Nuremberg Trials 1948-1949).

I had access to and drew on data from American Congressional hearings and letters relating to the construction of institutional review boards and bioethics as well as reading all of the reports of the President's Commissions.

INTERVIEWS

I interviewed 20 people, including bioethics committee chairs, members, medical staff secretaries, and hospital staff who were not ethics committee members. Most were face to face, a few were by telephone and were, with the permission of the person, tape recorded. Included in this group were Daniel Callahan, Phil Lee, officials from HCFA in California and Washington, representatives of the American Medial Association, and officials of the American Hospital Association.

The whole notion of confidentiality is germane to the bioethics committees for the discussions of cases involves confidential material and actual names of patients and physicians were used. In this dissertation I have used data from the committees in such a way that it will be impossible for anyone except perhaps members of the committees to discern what hospital the researcher is referring to. Even this would be difficult since similar themes and discussions took place at several hospitals. This means that instead of identifying a particular hospital and discussing each of its meetings, I use the categorical approach and discuss issues and include data from those committees that dealt with similar themes. In those cases where it is important to make an identification of type of institution I have done so. It is of great importance to me that the committees or their members or discussions **not** be identifiable. Presenting the data in this way has allowed me to reproduce the actual statements made by participants rather than distorting them. I feel that this serves the research goals most effectively while preserving confidentiality.

My principal responsibility to the committees and to the patients whose cases were discussed was confidentiality. This issue was included in the initial statement to the committees. A document about the research was given to each member of each committee and can be found in Appendix B.

C. THEORETICAL FRAMING AND BACKGROUND

1. THE SOCIOLOGY OF KNOWLEDGE AND PRACTICE

The sociologies of knowledge and science form fundamental theoretical bases for this work. These bases are involved in knowledge and truth claims, themselves implicated in any knowledge production or construction. I address both the expression of prior knowledge claims, and the production and reproduction of a specific knowledge claim designated as bioethics which has been created to deal with certain "problems" in medicine, technology and other issues unique to the twentieth century practice of medicine. The perspective of the sociology of knowledge usefully addresses the emergence of new fields of knowledge, such as bioethics, how such fields become legitimated as knowledge, and permits a study of bioethics committees as the locus of practice of that knowledge. I first discuss some issues in the sociology of knowledge, including the social study of science, and sociology of scientific knowledge. The use of scientific knowledge to legitimate biomedicine is vital to the argument for as we will see in Nazi Germany and elsewhere, it was the framing of political ideology in scientific and medical terms that legitimated and made possible a new moral ordering. This leads to a major point of the dissertation: that all knowledge, including bioethics, is socially constructed. What I intend to demonstrate is **how** knowledge has been constructed in the discipline of bioethics and how that knowledge and practice is legitimated through a process of moral ordering.

a. THEORETICAL ISSUES IN THE SOCIOLOGY OF KNOWLEDGE AND PRACTICE: THE SOCIAL CONSTRUCTION OF KNOWLEDGE

> The basic contentions of the argument...are...that reality is socially constructed and that the sociology of knowledge must analyze the processes in which this occurs.
>
> Berger and Luckmann, 1966/1967:1
>
> Men make their own history, but they do not make it just as they please; they do not make it under circumstances chosen by themselves, but under circumstances directly encountered, given and transmitted from the past. The tradition of all the dead generations weighs like a nightmare on the brain of the living.
>
> Karl Marx, 1852/1978:595

Historically, the sociology of knowledge has been characterized by critical questioning of the relations between knowledge and social conditions, ideas and social structure. Explanations of knowledge, epistemological questions once the domain of theology and philosophy, have become secularized and of interest to sociology, for epistemology is clearly a social process. Sociological interest in what may be interpreted as moral or ethical issues contribute profoundly to the intellectual sociohistorical aspects of social worlds and necessitate a sociology of knowledge perspective. The field has many theorists and of these the principal ones that define the field will be considered.

Marx (Marx and Engels 1848/1963) contributed to a sociology of knowledge with his view that peoples' social being determines their thought and consciousness . Marx (Marx and Engels 1848/1963) interpreted moral codes as ideologies just like other ideas: "It is not the consciousness of man that determines his existence - rather it is his social existence that determines his consciousness." Most important for Marx was the individual's relation to the means of production, and he explained peoples' social context in terms of their class position. He argued that if people from one social class embraced the modes of thought suitable to and compelled by another, this led to a false consciousness. False consciousness, in his example, would entail the working class espousing the ideology of the owners of the means of production. Thus, Marx focused on the origins of **false knowledge** in which the revolutionary potential of the working class was concealed from them. That is, he concentrated on the sources of distortion rather than on knowledge itself. For Marx and Engels, economic and class factors were fundamental in the determination of ideas but they excluded science from the possibility of social distortion.

Mannheim (1936) expanded Marx's approach to knowledge to develop a strategy for a sociological analysis of knowledge. His work is often credited as inaugurating the sociological analysis of knowledge systems which were or could be considered as accurate producers of truth. Mannheim extended the analysis of ideas from Marx's concentration on false knowledge to include ideas thought to be true and concluded, as would pragmatist philosophers, that **all** ideas are ideology. Truth, said Mannheim (1936), could only exist within the specific world views of those claiming it. Like Marx, he also excluded science and mathematics from this analysis.

Emile Durkheim (1912/1915) augmented the sociology of knowledge by including morals, values, religious ideas, as well as categories of human thought, space and time. For Durkheim, these kinds of knowledge were, like the idea of society itself, part of the collective representations (representations collective) and the collective conscience (conscience collective) and could not exist apart from social existence. Durkheim saw knowledge, morals, values, and the like as ways of categorizing the world **and** as social facts. The physical world, and scientific knowledge, became for Durkheim a special kind of knowledge which escaped its social context. Thus, like Mannheim and Marx, Durkheim interpreted science as a more evolved body of knowledge which was separate from social organization.

In Sociology and Philosophy, Durkheim (1911/1953) noted that the central questions to ask of moral issues, **choses morales**, are: What are their distinctive characteristics? How is their existence to be explained? And, How are they to be evaluated? Questions of how the existence of moral codes is to be explained have to do with the social construction of moral codes and so formed part of the sociology of knowledge.

SCIENCE AS "TRUTH"

Marx's (Marx and Engels 1848/1963) discussions of science in the Manifesto treated it as privileged and not at the mercy of social and economic domination. Both Durkheim and Mannheim also separated knowledge into scientific knowledge on one hand, and all other knowledge on the other. Followers of the sociology of knowledge tradition such as structural functionalist Robert Merton (1973) and his adherents (e.g. Hagstrom, 1965; Ben-David 1971; and Zuckerman 1977) fully accepted this intellectual separation of science from other knowledge. Their central concern was the manner in which science as a social institution organized and regulated itself. The emphasis was on those who produced the scientific knowledge, their social roles, norms and rewards and for the most part, they ignored the ways in which scientific knowledge was produced and legitimated (Barnes and Dolby 1970; Mulkay 1979; Latour and Woolgar 1979, Latour 1987, 1988) and the content of the knowledge per se in relation to production processes.

In sharp contrast Schutz (1973:250) made no distinction between forms of knowledge but conceptualized all knowledge as constructions produced in human interaction which could not be made into something isolated from social reality:

> A given social structure and its factual 'causal' givenness condition the meaning-structures that prevail in a relative-natural world view - as well as the typical contents of experience and acts that are molded by them.

This social distribution of knowledge involves more than passing on a set of "interpretive meaning structures" (Schutz, 1964:133). It involves transmitting "relevance systems" by reinforcing values, interests, emphases, convictions about what is true and false, and what is worth knowing or negligible (Habermas, 1973a:59). Schutz (1964:133) held that:

> the power of socially approved knowledge is so extended that what the whole in-group approves - ways of thinking and acting, such as mores, folkways, habits - is simply taken for granted; it becomes an element of the relatively natural concept of the world, although the source of such knowledge remains entirely hidden.

It is this socially approved knowledge that forms ways of seeing (Berger 1972). This social approbation of knowledge is also intimately tied to power issues Habermas (1973a:178-186; 193-194; 197) addressed under the rubric of legitimation.

Following Husserl (1913), Schutz (1967:221) further presumed that any phenomenon was socially constructed in that it emanated from and was negotiated within interaction. Continuing and extending the constructionist perspective, Berger and Luckmann (1966/1967) discussed the social construction of knowledge starting from the viewpoint of Schutz and included Durkheim, Weber, and Marx in their formulations about the structural determinants of knowledge and knowledge as a determinant of social structure. For Berger and Luckmann, the phenomenology of Schutz provided the philosophical framework through which the dialectical perspective of Marx, concepts of social reality employed by Durkheim (social facts **sui generis**), and the notion of subjective meanings and understanding (**verstehen**) provided by Weber were integrated. Berger and Luckmann (1966/1967:14-15) redefined the sociology of knowledge through this multi-faceted perspective: "The analysis of the social construction of reality....must concern itself with everything that passes for knowledge" in society. They claimed (1966/1967:33) that the presupposition of phenomenological sociology was the "intersubjectivity of face-to-face relations" which they viewed as the basic unit of social reality both mediated and generalized by our principal sign system: language.

There is a social stock of knowledge, as Schutz (1967) described, which is socially distributed, and which ranges from common sense to expert knowledge. However, neither Schutz, nor Berger and Luckmann discussed the actual mechanisms by which this social stock of knowledge is created or distributed.

Another issue in the sociology of knowledge which is significant to this work is how new knowledge is acquired. New knowledge must originate in experience and Schutz (1973:122) described how experiences must be placed in context to acquire meaning. Meaning is then constituted by relating the concrete experiences to a remembered frame of reference, that is, to a similar and earlier experience. This stock of reference systems can be changed and enriched by adding new elements belonging to the context of knowledge, and this, according to Schutz, is how new knowledge is acquired. This acquisition of new knowledge occurs in a number of contexts, "multiple realities" or "worlds" of everyday life, of work including scientific and medical work, of religious experience, and so on. For Schutz (1973:122), the meanings activated in concrete situations go beyond the here-and-now of the situation and become connected to one's own stock of knowledge. Knowledge then, according to Schutz, is not simply "truth," or merely what is agreed upon but is a social construction rooted in individual experiences within social contexts.

It is clear that our understandings of science, medicine, and bioethics arise within the contexts of the larger societies in which they are embedded. Even the methods through which we apprehend our social worlds themselves arise within the contexts of those same social worlds. For my purposes, in the case of the knowledge termed bioethics, what is needed is a way of looking at the social phenomena which take into account the intentional structures of human consciousness, and one which consequently places a primary significance on the meanings social acts have for the actors who perform them within social contexts and whose reality is built out of their subjective interpretations. That is, people have not simply made their worlds but continuously make and remake them.

b. INTRODUCTION TO THE SOCIOLOGY OF KNOWLEDGE QUESTION: HOW DO WE KNOW? THE EPISTEMOLOGICAL TENSION BETWEEN REALISM/RELATIVISM AND POSITIVISM/CONSTRUCTIONISM

> ...epistemological reflection leads us everywhere to the insight that what the various sciences call the "object" is nothing in itself, fixed once for all, but that it is first determined by some standpoint of knowledge.
>
> Ernst Cassirer 1923/1953:356

At the heart of continuing controversy in the sociology of knowledge is a debate about realism/relativism and positivism/constructionism. This debate forms a foundation for any argument involving truth and reality claims such as those represented in bioethics claims. This discussion reviews some philosophical concepts since historically it has been philosophers who have been most interested in the nature of knowledge and reality and how we know. There has also been a juxtaposition of philosophy and science about the nature of knowledge/reality. Until recently, science had been commonly interpreted as a very special case of knowledge. Philosophers as well as sociologists of knowledge and science had accepted science as a unique sort of knowledge not to be subjected to reflexive sociological analysis. Since the 1960s, beginning with Kuhn (1962) there have been challenges to the idea of science as a privileged way of producing reliable knowledge in a number of disciplines: literary theory, sociology, anthropology, history, and philosophy. There are also an array of intellectual movements engaged in critiques of knowledge claims: post-modernism, representation studies, structuralism, post-structuralism, and relativism (Woolgar 1988:9). The accomplishments and claims of social studies of science have also altered conventional views of science by examining both the institutions and the practices of science.

Woolgar (1988:13) pointed out that a radical approach to the social study of science means that we must "take issue with the concept of 'science'"; moreover, "standard conceptions of 'society' and technology' [must] also come under review." Rather than merely acknowledging that science has aspects that are social but that there is a possible pure science, **science itself** is being redefined as constituitively social (Latour and Woolgar 1979; Latour 1987, 1988; Woolgar 1981, 1988). Currently there are sociologies of scientific knowledge informed by historical and cultural relativism which hold that all knowledge is socially constructed.

Woolgar makes it clear that if one relinquishes the perception of science and society as distinct analytic objects then these conceptions collapse into one another. Latour (1990) takes this further and argues that science and society are co-produced. Not only do we need to practice symmetrical analyses of scientific concepts and practices and sociological concepts and practices. We also need to develop means of understanding co-production processes - not merely "impacts" of science and technology but the very transformations of the social which feed back into conceptions of science and technology (Clarke 1990a,b; 1988; 1985).

These ideas are important to this project because bioethics is immersed in science, technology, medicine, and ethics, all of which make knowledge and truth claims. If knowledge and truth are constructions, then it becomes clear that whoever is able to secure acceptance of their knowledge claims, whoever's knowledge is accepted as legitimate and the ways in which that occurs are key sociological matters for analysis (e.g. Latour 1987).

At each pole of the basic concepts are:

REALISM/POSITIVISM--------------RELATIVISM/CONSTRUCTIVISM

The question addressed by each of the paired concepts realism/relativism and positivism/constructionism concerns the nature of "knowledge" and "reality," and its epistemology; how we "know" that "knowledge" or "reality." Briefly, realism suggests that there is an absolute reality, such as nature, which is simply "out there" to be discovered, and which is true in some perfect sense. This perspective has its roots in the Platonic concept that everything already exists in an ideal sense; we simply have to apprehend it. In contrast, relativists argue that there is no absolute reality or "truth;" rather all reality is relative to something else, such as a culture, place, historical or geographic situation. Positivists, allied with realists, go further in their belief that there is one basic scientific method and it is the only path to "knowledge" or "truth." In contrast, constructionists tend to agree with relativists but emphasize that knowledge is a socially constructed occurrence of reality or "truth." Moreover that there are many scientific methods and they may be highly local, a vivid characteristic of bioethics committees.

Realism implies that successive theories disclose more and more real knowledge; that is, there is one scientific method, and it works. If this were not so, this scientific method could be interpreted as merely one approach with no intrinsic advantage over any other approach. Without a commitment to the legitimacy of the causal forces depicted in theories, Yearley (1984:44) has pointed out, there would be no distinction between a prediction engendered by a scientific theory and one engendered by a rule of thumb. And, in fact, this is one of the claims at issue. Are "scientific" methods superior to any other methods in leading to truth claims? It is the point of the non-positivist sociologists of science that, in fact, "scientific" methods have no inherent superiority. They may seem more reasonable and superior because social constructions can be obdurate (Star 1988; Woolgar 1988) and perhaps because they reflect the dominant ideology.

Advocates of relativism make the assumption that what is sanctioned as "truth" is contingent and therefore historically and culturally based. For example, anti-realists like Feyerabend (1975), say that science is but one family of belief and is equivalent to any other family of belief. For Feyerabend, any knowledge method, any world view or descriptive system is as good as any other belief. Systems of belief, including science, develop within specific social and historical contexts. Rather than seeing scientific products as capturing a different reality, constructivists and anti-realists argue that science, as any other reality, can be understood as constructed in a social, cultural, and historical context (Knorr-Cetina 1981:3) and is a product of the interests and the interpretations of the participants (Knorr-Cetina and Mulkay 1983:8-9).

Theorists of the sociology of knowledge are concerned not only with the social origins and foundations of ideas but with processes of justifying claims to superiority of these ideas, that is, in the legitimation of those ideas. These legitimation claims range from those of sociological theorists like Mannheim (1936) who asserted the cognitive superiority of the intelligentsia, to contemporary sociologists like Therborn (1976/1980; 1980) who have argued for the superiority of historical materialism and the class struggle, with those committed to this as possessing cognitively superior knowledge. There are also important arguments from theorists such as Keller (1985, 1987), Merchant (1980), and Gilligan (1982), who have argued for the difference, if not the superiority, of female ways of knowing.

Knowledge production, whether in science, physics, or bioethics, is a social and political process in which "the facts" and "truth" are negotiated by social worlds and often conflicting communities of professionals in order to protect their interests. This leads to disenchantment (Weber 1922/1978:155) with science or medicine as a culturally privileged activity for gaining "objective knowledge." Within sociology, this has provided validation for recent ethnomethodological, phenomenological and grounded theory studies of scientific activity (Latour and Woolgar, 1979; Knorr-Cetina, 1981; Knorr-Cetina and Mulkay, 1983; Jagtenberg, 1983; Clarke, 1988, 1990a,b) and medical activity (Lock and Gordon 1988; Wright and Treacher 1982; Koenig 1988; Mueller and Koenig 1988; Anspach 1982).

2. LEGITIMATION

a. LEGITIMATION THEORY

I use legitimation theory as a basis for understanding how the new knowledge claims of bioethics have become authenticated. To do this I consider a major debate in legitimation theory which entails the relationship of legitimacy to "truth" and power which involves a concern with both perspective and language.

We owe the concept of legitimation to Weber (1947, 1922/1978), and in its contemporary form to Habermas (1973a). The concept of legitimation originally comes from Weber's concept of the processes through which those who rule justify themselves and their control. For a basis of domination to receive unquestioned obedience, two conditions must be met. First, a basis for authority must be manifest by any person holding authority. If that person cannot unequivocally demonstrate a right to authority, then their legitimacy, and thus their commands, can be contested. Second, a basis of legitimacy can only provide authority in specified areas of competence determined by a prior, socially accepted understanding. That scope of competence must be specified or the validity of a particular order might be challenged as beyond the leader's authority.

According to Weber, there are only three bases for domination that meet these conditions; that is, there are only three bases for authority: formal-legal, traditional, and charismatic. Following Weber (1922/1978), legitimations can be regarded as widely held beliefs through which institutions obtain their justifications and in cases of conflict, a defense against opposition. Legitimacy describes both a state of affairs - the leader is a legitimate leader, and a process - legitimation, and, as discussed above, it has various sources. Legitimation involves both explicit and implicit justifications for the authority of a command on the one hand and the development of a concomitant sense of obligation on the part of the group, on the other. In a subjective sense, and in accordance with Thomas' (1925/1966) renowned insight that: "If men define situations as real, they are real in their consequences," we might say that a member of a social group, or the group itself has legitimation if this legitimation is widely perceived to exist.

Weber's (1922/1978:212) concept of legitimate authority alerts us to the connection between belief in the legitimacy of orders and their potential. The basis of legitimacy reveals "the ultimate grounds of the 'validity' of a domination, in other words...those grounds upon which there are based the claims of obedience made by the master against the 'officials' and of both against the ruled" (1922/1978:953). What is important is the fact that in a given case the particular claim to legitimacy is to a significant degree treated as valid. The concept of legitimation is useful in that it permits a demarcation of types of legitimate authority according to the forms and contents of legitimation.

Habermas drew from Weber and saw authority as primarily coming through the state. He was indebted to Weber's account of the sources and effects of modern bureaucratization and extended Weber's concept of legitimacy to a crisis theory. Habermas gives an account of the potential for a legitimation crisis in advanced capitalist societies. He argues that a number of institutional developments press toward the formation of a legitimacy crisis in which the allegiance, needed by the dominant institutions in order to function effectively, is significantly below that which they are actually receiving.

Weber, says Habermas, was concerned with the ability of an order to establish belief in its legitimacy, but was not concerned with the truth or falsity of the beliefs themselves. What Habermas (1973a:97) found controversial in Weber's account of legitimation is the relation of legitimation to truth. Habermas (1973a:100) demands that the belief in legitimacy be true, and to fail to make that demand is to say that "every legitimate order must be grounded in mystification, manipulation and ideology." Habermas (1973a:97) insists that any belief in legitimacy "is assumed to have an immanent relation to truth...that can be tested and criticized."

This is what Habermas is dealing with in his critical theory. He is attempting to clarify and vindicate rational standards against which beliefs in legitimacy, or illegitimacy, can be tested. But, unlike Weber, Habermas asks not simply whether people believe existing arrangements are legitimate, but whether their beliefs are well grounded. For if they are not, declares Habermas, it prepares the stage for decay and a crisis of the state. A major concern in this project is to demonstrate the implications of these beliefs and truth claims: that legitimacy bears an immanent relation to truth, or that what counts is **belief** that legitimacy is "true" as Weber claims. Again we encounter the issue of whether or not there is a constant truth "out there" to be found or is there a constructed truth or whether there is a some sort of a Kantian in-between.

b. LEGITIMATION, KNOWLEDGE AND POWER

As had the Greeks, Bacon (1906/1952:47) argued that knowledge is the very root of all power: Scientia ex potentia humanum in idem coincident; knowledge and human power come together in one. Discussions of power in social theory tend to separate corresponding to a number of specific conceptual oppositions. Power is conceived of either as a property predicated on the actions of individuals, or as a feature of collectivities. It is seen as the intentional, dispositional capacity of individuals to realize their objectives, or as a structural attribute of social systems. Power is regarded as something possessed or exercised, as being a negative and repressive **or** a positive and productive element in social life.

Marxist views of power have tended to presume its origin in one form or other in the economy, as have certain "liberal" views of power. Power is treated as a possession analogous to a commodity which can be held, taken away, transferred or alienated. This is what Foucault (1980:82) calls the **juridico-discursive** conception of power which analyzes power relations in terms of the language and imagery of the law.

In Marxist conceptions, as power is treated as a function of the economic it is related back to the mode of production, conceived of in the role it plays in the preservation of the social relations of production, and is associated with class domination in the capitalist mode of production. The **raison d'etre** of political power is located in the economy which determines it (Althusser 1971).

Weber's distinctions between domination and authority deal with issues of power, defined as the ability to exercise domination over another and the capacity of agents to impose sanctions for non-compliance with their wishes by others: "the chance of a man or a number of men to realize their own will in a social action even against the resistance of others" (Weber 1922/1978:926). Power has also been conceived of as being legitimate authority circulating in the social system in a manner equivalent to money (Parsons 1951), or as a generalized instrument of communication (Luhmann 1982, 1989).

Foucault (1977:27) maintained that in one sense, power makes individuals what they are as it produces the social reality and the objects of discourse in which the individual is located in terms of his or her particular conception of the articulation between power and knowledge. Power produces both the domain of power and the domain of knowledge for its exercise. Foucault (1977:27) clarifies his concept of the relation of power and knowledge:

> power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful)...there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations.

Knowledge is a condition of possibility for power relations, and it begins to deal with the sociological question of under what conditions knowledge is constructed. Knowledge as a condition of possibility is a knowledge which is not so much true or false, as legitimate or illegitimate in terms of power strategies. Power creates and generates the emergence of new knowledge and bodies of information.

Thus a major theme raised by both Habermas and Foucault involves the relationship of "truth" to power. Foucault (1977:93) maintained that:

> There can be no possible exercise of power without a certain economy of discourses of truth which operates through and on the basis of this association. We are subjected to the production of truth through power and we cannot exercise power except through the production of truth.

Weber (1947), in his description of rational authority provoked the controversy about the "truth-dependency of legitimations" (Habermas 1973:97) at the sociological level. Weber's (1947:953) concept of rational authority represented the legally formed and procedurally regulated type of authority characteristic of modern societies and, he maintained, "the generally observable need of any power...[is]...to justify itself." Habermas (1973:97) pointed out that Weber was describing an "empirical phenomenon " without an "immanent relation to truth." That is, the purpose of "legitimate power" is not related to truth but instead to the justification of power.

This question of omniscience or "truth" has been touched on by Star (1989:22) in her invocation of Strauss's methodological and substantive way around the dilemma which is "to restore the work, the practice." Star (1989:22) points out that what is important "is not that everybody has values, but the egalitarian nature of viewpoints," and goes on to describe her conviction that:

> **every** viewpoint is a part of some picture, but not the whole picture. The implications are that only in the articulation of viewpoints can we understand

> anything about truth; that is, that truth is a fundamentally interactional, social phenomenon.

Star's and Strauss's perspectives are important since the question of "truth" in bioethics is one of the thorniest issues in understanding its constructions and contexts. This again relates to the realism versus relativism debate. Issues are regularly raised which are predicated on assumptions as to whether there a possibility for "truth" or whether all truth is relative and constructed. Much of the argument both in philosophical ethics and bioethics turns on this.

The question of an absolute - truth, knowledge, idea - existing "out there," versus relative - truth, knowledge, ideas - is, as we have seen, at the core of debates in science and knowledge. They are also at the core of debate in medicine and bioethics. Also important is the question of the relationship between legitimation, knowledge, "truth," power and issues of medical control and how these are related to bioethics. I interpret legitimation as a theory embedded in the sociology of knowledge because what is legitimated is knowledge and its production and re-production, application and re-application. That a particular profession can legitimate knowledge is a tribute to the authority (Freidson 1970a,b, 1986) of that profession to legitimate whatever knowledge is contingent upon its own conceptual models and assumptions about reality. This, often via alliances with the state. In medicine, it can thus be seen as, for example, the legitimation of a medical gaze (Foucault, 1972/1973) or a medical model with its basic assumptions and world view.

3. BIOETHICS AND THE SOCIAL CONSTRUCTION OF SOCIAL PROBLEMS

> "...the curious incident of the dog in the nighttime."
> "The dog did nothing in the nighttime."
> "That was the curious incident," remarked Sherlock Holmes.
>
> Sir Arthur Conan Doyle 1894/1967

A consideration of the "social construction of social problems" is critical to this investigation of bioethics. We need to examine how to satisfactorily demonstrate the construction or deconstruction of a phenomenon, such as medical ethics, as a **social problem**. In this section, I ask two questions. First, under what conditions did medical ethics come to be defined as a social problem for which the creation of a new discipline, bioethics, was a plausible solution? Secondly, under what conditions, despite mounting social evidence that ethical problems existed in medicine, was it possible to defer defining them as social problems? This I have called "the curious incident of the non-barking dog."

The implications of social problems theory for bioethics concerns primarily the legitimation of an issue as a problem or the removal of an issue from the aegis of social problem. It is the legitimating and delegitimating of issues as matters to be concerned about or not that is important to my argument at this point.

A fundamental canon of the recent sociology of social problems is that social problems are socially constructed. Drawing on earlier natural history approaches, Blumer (1971:298) initiated the contemporary theoretical dialogue and defined social problems as not simply "objective conditions and social arrangements," but as "products of a process of collective definition." That is, social problems cannot simply be defined as "objective" situations which may be potentially harmful to society. They include another aspect: an interpretation by some participants in a definitional arena that the situation is harmful. How and when an "objective condition" or "social arrangement" become collectively defined as a problem is central to an understanding of the phenomena of legitimation and de-legitimation of "problems" in terms of the sociology of knowledge.

Spector and Kitsuse (1977) held that while the phrase "social problem" was usually taken to refer to a social process of definition and to the actions that thrust the definitional process forward, the definitional venture itself actually constituted the social problem. They did not, however, explain the genesis of that definitional venture. For my purposes, the focus is on the **process** that triggers the "definitional venture." Under what conditions and in what contexts and with what processes is a "definitional venture" initiated? Who initiates the definitional venture and who initiates the **re-definitional** enterprise?

Much is revealed by the ironic twist here on the definition of a social problem, that is, its **non-definition** as a problem. Under what conditions is a phenomenon, such as harmful medical experimentation, which could under particular conditions be construed as a social problem, virtually ignored and considered a non-problem? In this instance, there was a specific **non-definition** for the history involved knowledge that a certain phenomenon existed yet **not defining** it as problematic. At a later date, similar information about the phenomena is used to define it as a problem. For example, Vaux and Schade (1988:12-13) reveal an interesting point about the Beecher (1966) study which detailed experiments of questionable ethics in the United States:

> When one recounts details of such experiments, which were performed during the 1960's in the United States, the reaction of most lay audiences can best be described as one of astonishment verging on horror. We can recall reading some of these articles before the publication of Dr. Beecher's essay, and can remember discussing some of them at journal clubs. In general the ethical dimension of these articles, which was highlighted by Dr. Beecher, was not a serious subject taken up for discussion. One might consider that some investigators were overzealous or perhaps lacked the proper degree of caution. However, the real focus was on whether the proper scientific question had been put to nature, and whether the proper answer had been compelled from her by the design of the experiment. That is, did the experiment represent good science.

Again, how can we explain that the medical activities of some of the physicians of the Third Reich initiated in 1933 were ignored as a social problem until 1945? How were medical experiments in the United States, like the Tuskeegee Syphilis study which began in 1932, disregarded as social problems until 1972? Why were **ostensible** "problems" not so identified? What obstructed the "definitional venture"? Under what conditions was the problem of "unethical" behavior which contributed to the creation of the climate for the emergence of bioethics ultimately defined as a social problem? Who identified it as such? Who legitimated it as a problem? As with the non-barking dog, we can underscore the selective quality of the construction by noting what has been omitted from definition as problematic. Might there be alternative definitions, explanations and interventions that relate to what is labeled a "problem"? If there are, who defines and decides on these alternatives? Hilgartner and Bosk (1988) developed a model of the process through which they believe social problems rise and fall. The process they have described extends the logic of the symbolic interactionist model to view social problems as outcomes of a process of collective definition. Hilgartner and Bosk (1988:54) pointed out that the idea of "importance" and the idea of "problem" must be seen as "essentially contested" concepts. They are expanding Blumer's (1969:300-303) observation that social problems compete for societal attention which is, they assert, a scarce resource (1988:57). Hilgartner and Bosk (1988:55) attempted to discern the dynamics of that competitive process, acknowledging the existence of social problems in relation to other kinds of problems "imbedded within a complex institutionalized system of problem formulation and dissemination." They moved beyond natural history theorists such as Blumer (1969, 1971), and Spector and Kitsuse (1977) to focus upon competition and the role of conflict and power.

Hilgartner and Bosk (1988:57) asserted that there is an objective nature to social problems as well as a definitional one:

> The fates of potential problems are governed not only by their objective natures but by a highly selective process in which they compete with one another for public attention and societal resources.

As with debates about knowledge and truth, the controversy about objectivity and subjectivity re-emerge with "social problems." There is a recurring debate, among those who study social problems, concerning the objective and subjective dimensions of the constructionist formulation (Woolgar and Pawluch, 1985; Hazelrigg, 1985; Schneider, 1985). Ibarra and Kitsuse (1989) describe the controversies which exist in the constructionist approach to social problems. They describe these controversies as emanating from the rejection by Spector and Kitsuse of a positivist conception of "social conditions" and by the absence of "a systematic presentation of the theoretical bases and implications of the constructionist perspective." Ibarra and Kitsuse (1989:9) further identified one of the problems with the constructionist formulation of social problems to be the use of the opposition "putative condition/actual condition" which created "too many incongruities and ambiguities." In order to move beyond this debate, they have recently argued that what is at issue is the need to focus upon an empirically based theory of social problems (1989:2). In a paper intending to clarify many of the problematic issues in the social problem debate, Ibarra and Kitsuse

(1989:4) re-stated some of the terms used to describe social problems and say that in the constructionist view, the term social problem:

> refers to those social interactions in which members' ways of formulating, describing, interpreting, and evaluating a symbolically constructed and morally charged inter-subjective existence are studied and reconstructed.

Ibarra and Kitsuse (1989:9) replaced the older term "putative condition" (Spector and Kitsuse, 1977) with the term "condition category" to suggest new lines of theoretical development. Condition categories are defined as (Ibarra and Kitsuse, 1989:9):

> typifications of socially circumscribed activities and processes -- the society's classifications of its own contents -- used in practical contexts to generate meaningful descriptions and evaluations of social reality. They vary in their level of abstraction and specificity...but they are the terms used by members to establish what the social problem is "about." As parts of a classification system, condition categories are first and foremost units of language.

But how these "**vernacular terms**" are established and explicated in order to trigger the social problems operation remains obscure.

Woolgar and Pawluch (1985) criticized the study of social problems especially as it was outlined by Spector and Kitsuse (1977). At issue were notions of realism versus relativism. Woolgar and Pawluch (1985) argued that the basic "moves" of constructionist analysis comprised "**ontological gerrymandering**" which, in fact, constituted selective realism. Ontological gerrymandering was defined as one way that the tension that is "an expression of the continual play between objective facts and representations of those facts" is managed (Woolgar and Pawluch, 1985:224). Woolgar (1988:98), in fact, in a later publication, asserted that "relativism has not yet been pushed far enough." Woolgar (1988:99) considered proponents of relativism to be maintaining an objectivist ontology and sharing with science the "**ideology of representation**." This "ideology of representation" involves acceding to the notion that objects or meanings pre-exist the surface signs and appearances that give rise to them. For Woolgar, the critique of science would be limited if it did not confront this **a priori** ideology. This seems to be taking deconstruction and reflexivity to the verge of nihilism.

What Woolgar and Pawluch (1985) were arguing in what they called "ontological gerrymandering" involved establishing distinctions between what arguments are or are not open to relativism. Woolgar (1988:99) says:

> The importance of the role of agency is evident in this practice. The susceptibility to relativism of certain kinds of representation (labels, knowledge claims, definitions) is achieved by spotlighting the involvement of agency, and by emphasizing the possibility of arbitrariness, or distortion, of motivated, actively constituted representations. The critical gaze focuses on agencies such as the police and the courts in the case of the sociology of deviance; on the news services in media studies; and on the scientist in the sociology of science.

However, as Woolgar pointed out, the role of the agent who made the decisions about these representations (the police, the scientists) is "hidden, subdued, silent." Woolgar (1988:101) said that the target for deconstruction, must be "the ideology of representation," rather than just 'science' as an organizational phenomenon for:

> science is no more than an especially visible manifestation of the ideology of representation." To make a "distinction between science (as object) and our own disciplines (as resource), we are in danger of mistaking relativistic critiques of science for an adequate appreciation of the more general phenomenon of representation.

The ideology of representation sustains a Cartesian dualism between objects and their representation. While Woolgar (1988:107) granted that the ideology of representation has produced an impressive critique of science and has provided alternative accounts of science, they are ultimately unsatisfactory because:

> By virtue of their inattention to the moral order of representation, most science critics to date have engaged in a form of ontological gerrymandering. The implicit acceptance of this moral order entails the uncritical use of various technologies of representation (notably written) which, as we have suggested, defines the forms of argument accepted as persuasive. An alternative stance, which promises one way of building on the skepticism of the social study of science, is to seek ways of interrogating the moral order of representation in which we are currently locked.

Ball and Lilly (1984) raised a critical question essential to the definitional argument: How do ostensibly rule-breaking conditions and conduct escape collective definition as morally problematic? They have provided an account of how insiders in a "no-tell" motel, a place for sexual assignations, maintained a definition that "nothing unusual is happening" (Schneider, 1984:xv, quoting Emerson 1970).

Becker, speaking of deviance, largely the focus of social problems, considered 'secret' or 'potential' (1963/1973) deviance. These involve situations in which behavior has occurred which might be considered deviant but is not distinguished as deviance or is not visible to those who might define the behavior as such. Schneider (1984:xv) argues that in considering Becker's 'secret deviant' dilemma there is no deviance if there is no one there to so define it. This discussion is reminiscent of the philosophical conundrum of whether there is noise in the forest if a tree falls and no one is there to hear it. Schneider holds (1984:xv):

> If social problems are, as we have argued, definitional activities, and a situation contains no such activities, then no social problem exists. A documentable condition or line of conduct may exist which may be studied in its own right, but a social problem does not.

He goes on to say that the authorization the sociologist has to identify and register potentially problematic conditions is "the viability of such definitions among participants" (1984:xv). But what does this mean? Why is it the sociologist who is authorized to "identify" and "register" potentially problematic conditions? What "viability" among which participants"?

Schneider (1984:215) argued that, "The study of organizational ownership and management of social problems directs attention to how people do this work, to how they handle various kinds of problems and troubles." We can also note and emphasize the connections among the organizational ownership of the problem such as that described by Becker (1963/1973) as "moral entrepreneurs"; the construction of supportive scientific facts and causal explanations; and the attribution of political responsibility to do something about the problematic condition. The validation of this sociology of knowledge approach (Aronson, 1984:215) shows how scientists and experts participate in defining the social problems they purport to analyze.

Aronson (1984) reviewed current work in the sociology of knowledge and contends that these developments provide a strong foundation for the social definitional approach to understanding social problems sociology as well as science. She criticizes the **strong programme** in the sociology of knowledge which makes an absolute separation between knowledge about the world and the world itself. In this account, Aronson (1984) said, all knowledge emerges from social interaction and is socially contingent. It is her view that we should study not only the **content** of such knowledge but also **how** it is created. She points out that both science and social problems involve definitional processes. She asserted that because scientists make interpretive claims to publics outside of the scientific community, these scientific "statesmen" become distinctly involved in social problems development in the whole society, much as Habermas (1981/1984) has described. Just as scientists and sociologists make claims for science as a tool for solving social problems, seeking thereby to contribute to their own power and legitimacy, so too do representatives of medicine.

Aronson (1984:16) contends that one form of interpretive claim, relevant to the sociology of social problems, involves the pronouncement that a social problem exists which a particular scientific specialty is uniquely equipped to solve (see Habermas 1981/1984). She used the example of the "medicalization of deviance" which involved social problems claims making on the part of physicians (see Conrad and Schneider, 1980; Zola, 1972).

My research, about the emergence of the bioethics discipline and committees, demonstrates how the claims making activities of physicians about the existence or non-existence of ethical problems in medicine have legitimized a biomedical perspective, thus contributing to its political and economic security. My argument is that while medicine can develop and define "social problems" this is perhaps not as important as the power of representatives of medicine to deconstruct, or re-interpret, 'problems', to deproblematize domains, and thus ignore potentially defined or definable problems.

Pfohl (1985:228) construed the social construction of social problems as essentially one of power:

> The "social constructionist" perspective has carved out a conceptual space for a radical reading (and writing) of social problems as nothing but the cultural, political, and material effects of the human struggle for the organization of power in (and as) history.

The work of Aronson (1984) and Pfohl (1985) indicate a move from a "theory" of "social problems" to an alternative hypothetical foundation. They based their explanations and analyses of the social construction of social problems in other theoretical bases: theories of the sociology of knowledge in Aronson's work and theories of legitimation and power in Pfohl's. Basing the social construction of social problems in power and legitimation, which progress from the sociology of knowledge, gives work in social problems a more rigorous theoretical base. I locate the construction and de-construction of social problems under the penumbra of the sociology of knowledge and theories of legitimation and power. Extending and re-placing the theoretical interpretation makes possible a more robust theory to explain cases such as the emergence of bioethics.

THEORIES IN THE SOCIOLOGY OF KNOWLEDGE

I

POWER - LEGITIMATION

I

CONSTRUCTION AND DECONSTRUCTION OF SOCIAL PROBLEMS

D. SUBSTANTIVE FRAMING OF THE DISSERTATION

1. SOCIAL SCIENCE APPROACHES-ATTENTION TO BIOETHICAL DECISIONS: THEORETICAL CONSIDERATIONS: A CRITICAL REVIEW

My research represents the first actual field work study in institutional bioethics committees, and so there is no directly comparable literature. There are several lines of approach to research issues germane to this sociological work which include ethical and medical principles in decision making and sociological studies of hypothetical or actual bioethics decisions and cases.

a. ETHICAL AND MEDICAL DECISION MAKING: SOCIOLOGICAL STUDIES OF CASES, HYPOTHETICAL AND ACTUAL

The decisions arrived at in bioethics have been the subject of some research concerning attempts to clarify ethical principles for decision-making and sociological investigations which focus on underlying norms and values involved in ethical decision-making. The largest body of literature that relates to bioethical decisions are written from a position which emphasizes the ethical principles upon which decisions are to be made. This includes work by ethicists, theologians, philosophers, physicians, nurses, lawyers, and sociologists. These works, focusing on ethics, in general deal with how decisions "should" be made.

Sociological analysis can only tell us the ways in which these decisions actually come to be made, not the ways they "should" have been made. Most of the sociologists who discuss life and death decisions write from a structural-functionalist perspective and make certain normative assumptions such as that these decisions are the outcome of consensual norms and values, usually transmitted through professional socialization and education. This view of medicine, which was written about prior to many new medical technologies, described an "active meliorism" allied with values of activism and instrumentalism (Parsons, 1951:466-477). I will review the work of Fox, Crane and other functionalist sociologists here. An interactionist sociological approach deals with the conditions under which events occur and their consequences. This view is represented by Anspach (1982).

Ethical approaches search for principles underlying decisions and seek for principles which will allow decisions to be made. Ethicists do not emphasize decision making processes or contexts within which decision making processes are imbedded. What has been the procedure in bioethics has been to take selected bioethical principles, such as justice, autonomy, beneficence, non-maleficence, veracity and fidelity, and attempt to apply them to solve an ethical dilemma. These principles are further embedded in the major theories of ethics. Teleological ethics or consequentialism holds that the rightness or wrongness of acts are to be judged by looking at their consequences. This includes utilitarian ethics. Deontological ethics or rule based ethics maintain that there are rules that are valid and meaningful apart from their consequences. This includes, for example, the Judeo and Christian decalogue, or ten commandments as well as Kantian ethics. There is also an ethics of virtue, or individual ethics, and a contract ethics. These will be more fully discussed in Chapter VI in my discussion of aging and justice.For the normative sociologist, these ethical principles are interpreted as the consensual norms and values upon which decisions are based. One problem with this approach is that the situation under question is often reduced to its most rudimentary prognostic component. Another difficulty with these perspectives is that there is a preference to examine decisions from the perspective of a single participant. As Anspach (1982) pointed out, a focus on principles vis-a-vis an individual tends to produce a restricted and idealized decision.

Neither bioethical nor normative approaches examine processes of interpersonal influence or power relations or the institutional contexts in which decisions are made (Anspach 1982:98). According to the theoretical bioethics literature, bioethical decisions are purportedly based upon deontological, utilitarian, virtue or contract theories. Normative sociologists do not develop a general theoretical conception of decision-making but rather account for decisions by reference to a set of general societal norms and values which, as Crane (1975) noted, are "undergoing transformation in the wider society."

Diana Crane (1975:206) made a study of decisions to treat critically ill patients, which, she said, went beyond how physicians defined life and death to reflect a "fundamental [cultural] shift" in society's conceptualizations of life and death. She found this cultural shift interesting because she felt it represented a 'transitional' period in which there was a "disparity between formal and informal norms" about treatment decisions. This disparity, says Crane (1975:204) using psychological theory to explain this social phenomenon, might lead physicians, in "reaction-formation," to emphasize "the preservation of life at all costs" in an effort to "control the degree of deviance that exists in their practice." Crane (1975:204) suggested that a transformation of the customary norms might be facilitated by developing medical-ethical "guidelines for the withdrawal of treatment with respect to certain specifically defined conditions" and she suggested procedural guidelines, such as the Harvard definitions of brain death, be constructed. These directives might alter the imperative to always support life but certainly would not provide a general ethical code. Her solution is, again, a medical, not an ethical definition and strategy. Further, if adopted, it would serve to protect the physician, not the patient.

A different sociological approach drawing on an interpretative sociology of knowledge, was used by Anspach (1982:99) in her study of life and death decisions in neonatal intensive care. She found contextual decision-making "ineluctably tied to the set of relationships in which they are imbedded and the social circumstances which surround them." Anspach focused "primarily on the process by which decisions are reached rather than on their normative underpinnings." Anspach attempted to relate situational contingencies to larger conceptions of medical organizations and institutions. She related life and death decisions in the two intensive care units in which she did field research to the social and organizational context in which they took place. Anspach used prognostic conflict as a paradigmatic case to illustrate "how the organization as an ecology of knowledge allocates different information in those who reach life and death decisions." She found that physicians and nurses have different knowledge about infants by virtue of their different experiences. They also have different epistemological strategies based upon their different experiences, nurses basing their judgements upon continuous contact and clues from this, and residents whose limited contact and technologically bases cues conflict in assessments of prognosis. That is, they each have differing and partial views of reality which Anspach sees as "rooted in the cultural and social structure of technology-intensive medical settings." It is the different knowledge based upon organizational features of technological intensive care which Anspach believes both complicates and renders inequitable life and death decisions in these neonatal intensive care units.

Philosopher and ethicist Ruth Macklin (1988), studied a decision made concerning a Jehovah's witness which also drew on a processual approach, and described the somewhat contentious way that a decision was made. This empirical knowledge, describing and providing data about the ways in which decisions are made is rare.

Social science interest in the field of bioethics has in general, as Fox (1989) commented, been modest. However, if broadly interpreted to mean interest in issues now considered bioethical the field is represented by the sociological and social science literature beginning in the mid sixties with Glazer and Strauss' work on dying (1965, 1968), and Sudnow (1967), Parsons, Fox and Lidz (1972), Fox and Swazey, (1974), Fox (1976), Crane (1975), Plough (1981, 1986), Kleinman (1980), Kubler-Ross (1969, 1975), The Presidents Commission (1981, 1983a,b), Wanzer (1984), Anspach, (1982), Koenig (1988), and Mueller and Koenig (1988). It also incorporates the sociological literature on allocation issues.

There is also a long history of sociological concern with how medical decisions in general are made which relate to the activities of bioethics committees. They characteristically are not concerned, as are ethicists, with the issue of ought or should but with what and how. From the early work of Parsons (1951) on the sick role the emphasis on the physician as the decision maker has been examined. Parsons accepted the physician as the appropriate and sole decision maker in medical matters. From the initial diagnosis and labeling of the patient as sick or not, the doctor had a socially important gatekeeping responsibility that contributed to the functioning of the entire social system. For Parsons and Fox, this diagnostic role of the physician was not questioned but accepted as rigorous medical objective fact. Since then, a significant body of data suggests that physician's decisions are based on more than an "objective assessment" of the patient's signs and symptoms (Fox and Swazey 1974; Crane, 1975; Freidson, 1970a,b; Roth, 1963/1986; Glazer and Strauss, 1965, 1968; Sudnow, 1967). These studies make clear the social factors and considerations which contribute to and constitute medical decisions.

Medical decision making is certainly a social process which is affected by a number of contingencies including the personal philosophies of the physician and other health care workers, including the patient (Stacey 1987), the perceptions of the patient's social situation, the evaluation of the patient's social worth, the institutional environment of practice, and the interaction among the actors.

Freidson (1970b) discussed a view of the social construction of illness which interpreted the diagnosis and treatment of illness as a fundamentally social process which was both influenced by physician treatment ideologies and grounded in an historical context. Drawing on Scheff's (1968, 1972) empirical studies, Freidson (1970b), resolved that not only are physicians over-zealous in diagnosing persons as ill, but they are also biased in favor of aggressively treating illness with radical treatment protocols.

Freidson called attention to some of the circumstances in which medical decisions are made but because of his reliance on the secondary data of other sociologists, his analysis remains speculative. His assumption, that the physician's bias is to diagnose illness in any particular case may itself reflect a propensity to universalize from very specific types of conditions such as tuberculosis, mental illness, and tonsillitis, which are idiosyncratic and not representative of conventional medical decision making. However, Freidson's theoretical reasoning suggest some of the ideological and organizational components involved in medical decision making.

Other studies, such as Roth's (1963/1986) ethnographic study of patients in a tuberculosis sanitarium describe decisions to release patients. He found that physician decisions to release patients were grounded only partly on the person's physical condition but also on the patient's ability to strategically negotiate for his or her release at the time of potential discharge. This study reflects the importance of the negotiative relationship between the patient and physician which is missing in many of these other sociological studies.

Two early studies of the treatment of terminally ill patients include rich descriptions of decision making processes and demonstrate that professional decisions to treat terminally ill patients are based, in part, on an evaluation of the patient's "social worth." Glazer and Strauss and Sudnow took into account characteristics of the social situation that influenced treatment and prognosis decisions. Glazer and Strauss (1965), in observational studies of terminally ill patients found that younger and more affluent patients received more attention from staff and more robust efforts at resuscitation. The death of these patients with perceived social value or worth was interpreted as resulting in a significant "social loss" to their families and society. Sudnow (1967) found that patients perceived by staff as able to contribute to society were more likely to be treated actively. Those perceived as having less social worth were less likely to receive aggressive treatment and were less likely to be resuscitated (See also Roth 1963/1986).

Those patients seen as having little social worth were called by different names. Jeffrey (1979) analyzed "deviant" patient categories in the emergency room and concluded that they underscore "normal" sick-role criteria. That is, as in the research by Roth (1963/1986) the less attentive treatment given to "trivia, drunks, overdoses and tramps" is found rational in light of Parson's criteria for the sick role that patients must not be responsible for their illness, must have occupational and family duties from which they can be temporarily relieved, etc. These rules were "Rules broken by rubbish" (Jeffrey 1979:98). "Rubbish" patients define "illegitimate illness" which strengthens the criteria of the normal sick role. "Part of the work done by Casualty staff is the production of deviance as the obverse of the production of legitimate illness" (Jeffrey 1979:106).

Both socially and medically the norms governing medical decision-making have been active and interventionist ones (Fox, 1974). Parsons (1951:466-477) found this "active meliorism" to be compatible with the tradition of American activism and instrumentalism. Choices, especially about life and death matters, could be expected to be decided in favor of life by bringing scientific knowledge and skill to bear on the problem. To treat, when in doubt, has been the finding from Scheff (1968, 1972) whose physicians treating patients with putative tuberculosis said: "when in doubt, treat" to Mueller and Koenig's (1988) resident who said: "If we're still fighting, they're not dying."

Fox (1976:246) described herself as the first sociologist writing about medical research which traversed the "sociological literature on death and on human experimentation." Experiment Perilous (Fox 1959) was a participant observational study of Ward-F-Second, a clinical research unit in a university hospital. In the preface to the second edition (1959/1974:10), she writes that in 1951-1954, when her fieldwork was done:

> no first-hand sociological study of terminal illness, medical experimentation with human subjects, or the psychosocial dynamics of therapeutic innovation had ever been made. Not only was there no precedent for such an inquiry, but its legitimacy was questionable.

Also, Fox, (1976:245-246) described her work on Ward F as the basis of current sociological work:

> some of the medical research and therapeutic developments that took place on Ward-F-Second 25 years ago - notably, very early trials with cardiac surgery, hemodialysis, and organ transplantation - are now in the forefront of bioethical discussion and of the contributions that sociologists are making to it.

Fox and Swazey's Courage to Fail (1974) described dialysis, heart and kidney transplantation and the social milieu in which these occur. Fox and Swazey (1974) described how the values, attitudes, and behavior patterns of researchers in medical experiments were shaped not only by the interaction structures and ambiance of the groups within which the research is conducted, but also by the patterned characteristics of what Fox and Swazey called the process of "therapeutic innovation" (Fox, 1976:248; Fox and Swazey, 1974). Fox and Swazey have described dialysis and transplantation, human experimentation, and therapeutic innovation issues in the social environments in which they have occurred. The work is critical of the medical profession in discussing the artificial heart (1974:149-211) and suggests that there may be:

> some irreducible elements in those situations that cannot easily be changed by enlightened good will, a reformed medical socialization process, or even by new social structural arrangements.

Fox (1984) counseled that a concern with "death with dignity" in the larger society may affect medicine in that there is a perception that physicians are retreating from an "ethic based on the unconditional sanctity of life to one premised on the quality of life." The work of Fox and Swazey focused on these biomedical innovations largely from the point of view of the research physician. The perspectives of patients or their families were, for the most part, absent.

In somewhat dated but critical research, Barber and his colleagues (1973) and Gray (1975) studied how various social control structures and processes affected medical researchers' sensitivity to issues of informed voluntary consent and of the proper fit between benefit and risk, their ethical concern about the subjects, and the ways in which the experiments were planned and carried out. They discussed three major types of control: professional specialization in relation to ethics; patterns of informal interaction in the teams in which the research is carried out; and peer group review of research made mandatory by government and other funding agencies since 1966. They found each of these social control mechanisms deficient.

Barber et al. (1973:188) asserted that:

> medicine is too important to be left to the doctors, science is too important to be left to the biomedical researchers. Because the consequences of professional power are too important to be left to the professionals, outsiders ask the kind of control that comes at least from having the professionals make a reasonable effort to give a reasonable account of what they are doing. Immersed in their own special culture and activities, professionals often not only do not take the initiative in offering such accounts but are resistant to the requests of their clients that accounts be given.

A large scale study by Crane (1975) in an attempt to identify new normative patterns in medical practice indirectly examined how physicians think about life and death decisions. In this inquiry Crane (1975) studied factors which physicians said influenced the active treatment of the critically ill infants with a number of congenital anomalies or birth defects. In her research, based on extensive interviews with physicians in several specialties, and over 3000 questionnaires by specialists, and the records of hospital patients, she was able to provide a good indication of what physicians said that their treatment decisions would be. Her study of how physicians say they would act when confronted with treatment decisions for critically ill patients supports and documents some of the areas of conflict between the traditional and absolutist ethic of the sanctity of life to a relativist ethic which is related to a concept of quality of life. Death, as has been mentioned earlier, has been re-defined in part because of our ability to expand gradations of life and death and our ability along these gradations to keep the person biologically "not dead" by some definition. Crane (1975:204) found that a distinction has evolved from the established medical ethic that urges that treatment "be continued as long as life, defined in physiological terms, can be preserved" and the actual behavior of physicians.

Crane (1975:198) found that physicians responded to the terminally ill patient not simply in terms of physiological definitions of illness but in terms of the extent to which the patient was capable of interacting with others. She found that:

> The treatable patient is one who can interact or has the potential to interact in a meaningful way with others in his environment. The physically damaged salvageable patient whose life can be maintained for a considerable period of time is more likely to be actively treated than the severely brain-damaged patient or the patient who is in the last stages of terminal illness. The brain-damaged patient is also not defined as treatable by many physicians, since he lacks the potential to establish social relationships with others.

In this research, it appeared that social **capacity** rather than social **value** was the most important factor in the physicians' decisions to treat these patients. In other words, the patient's capacity or potential capacity to engage in social interaction was a more important factor in the decision to treat than the person's social status or prestige (Crane, 1975:199-200). The person's social potential or capacity to perform future roles was the salient criterion used by physicians in decisions. This is in contrast to earlier studies by sociologists who maintain that the notable measure used by physicians in reaching life and death decisions are made on the basis of social worth criteria (Glazer and Strauss 1965; Sudnow 1967).

There are two difficulties with Crane's (1975) research. One is theoretical, the other methodological. Like Fox and Swazey, Crane focuses on the physician and eliminates other health workers, patients, or families in considerations of decision-making in life and death situations. A second major problem with Crane's research is methodological in her use of case studies to examine the ways in which physicians ostensibly reach these decisions. Crane's procedure was to mail questionnaires to physicians in 4 medical specialties. The questionnaire included case presentations of hypothetical patients and physicians were asked how actively they should be treated. Crane sought to validate the responses by comparing the hospital case records, but again, the records reflect particular accounts of decisions.

A second large scale survey of how physicians think about life and death decisions was reported by Shaw (et al 1977). This research included a non-random sample of 460 pediatric surgeons and 308 pediatricians. Shaw and his colleagues asked different questions than had Crane but a similar finding, based on physicians reporting, indicated that an ample majority said that they would not actively treat infants with severe congenital anomalies in which the infants could be predicted to have short life expectancies and severe brain damage. The most difficult, and debatable questions involved infants who might live, with treatment, but would have associated mental or physical difficulties.

Hypothetical decisions of the type described by Crane and Shaw and colleagues differ significantly from decisions made in actual situations when the patient is in front of the decision-maker who may have experienced a bond with them. Janis and Mann (1977) discussed the ways in which responses to questionnaires can only be suggestive, not indicative of decisions in actual practice because of the exceptionally distinctive emotional context in which actual "consequential" decisions are made. The questionnaires tap attitudes, and do not determine what the physician will do in actual practice. In fact, to conduct research like this rests upon an assumption that the significant variable in making life and death decisions are the principles of the individual physician involved in the case and locates the decision in the individual conscience of the physician.

Sociologically, moral choices might be seen to inhere in more broadly based norms and values acquired through a process of socialization and internalized or as part of the collective conscience (Durkheim 1912/1915). In actual hospital situations, decisions are made taking into account more than a diagnosis and with more people involved. Most absent in the research cited is any sense of interaction between parents and professionals or amongst professionals. Ideally, decision making might be thought of as a process involving a number of actors negotiating and adding information and experience to the discussion. These studies completely miss that aspect of decision making by focusing solely upon the individual values that are only a part of, not the exclusive feature of, decision making.

The social context in which decisions are made help to define the decisions. Both the different roles and experiences of different actors in the decisions contribute to the different perspectives and constructions of the situations under discussion.

The studies quoted, reflecting a normative approach, do help to reveal some of the values and norms implicated in decision making but they are ineluctably based upon the medical model. The decisions studied involve those in which there is thought to be a clear medical diagnosis and the prognosis of the patient is thought to be known or predictable. The only person studied as decision maker is the physician and he or she is examined a-contextually.

In a recent study of actual physician decisions, medical anthropologists Jessica Muller and Barbara Koenig (1988:359) studied the use of non-curative "life-prolonging" procedures and equipment used to keep actual patients alive "beyond the point at which others present felt that the death of these patients was inevitable." If the cases they studied had been presented in a vignette, the majority of respondents might conceivably have said they would not treat because, in each instance, the medical decision indicated would have been not to treat since treatment was futile.

The vignette versus actual case practice is one of the issues that Carol Gilligan (1982) wrestled with procedurally in her research on abortion decisions. Rather than, as was commonly done, presenting vignettes and asking women if under those circumstances they would or would not have an abortion, she went to offices of gynecologists and clinics where women were in fact pregnant and in the process of making potential abortion decisions. Her research results with their rich ethnographic descriptions provided insight into the decision-making processes involved in actual abortion decisions. The results of the Muller and Koenig (1988), and Gilligan (1982) work also emphasize the importance of analyzing actual decisions as they are being made. I made my decision to study working bioethics committees on the basis of their experiences.

Anspach (1982), in research with decision-making in neo-natal intensive care units has provided such reflection concerning decision-making in the cases of neo-natal infants. Using the analytic tools of both structural and interactionist versions of the sociology of knowledge, she examined the ways in which decisions about life and death were shaped by a particular social context, the social structure of the intensive care nursery. Anspach's (1982:99) work is important to this study for she declined a normative a-contextual approach and used the approach of the sociology of knowledge, assuming that decisions are invariably associated with "the set of relationships in which they are embedded and the social circumstances which surround them." She examined the views and perceptions of several participants in decision making focusing on the processes by which decisions are made and relating the "situational contingencies to larger concepts of medical organizations and institutions." Her goal was to provide a "more explanatory model of decision-making." However, Anspach imputed much of the difference in physician and nurse decision making to the disparate knowledge they each had because of the dissimilar time spent with the infants. In my research in the bioethics committees this factor does not account for differences in physician and nurse knowledge and thus their purported differences, since in these committees all hear the case at the same time. Further, rarely do either physician or nurse know the patient under consideration.

There is as yet, no actual research on bioethics committees by sociologists or other social scientists or medical investigators. The only research involving ethical decision-making that is in any way comparable to my study is Anspach's (1982) ground breaking work involving decisions in two neonatal intensive care units.

b. MEDICAL DECISIONS AND THE CONCEPT OF UNCERTAINTY IN MEDICINE

The problem of uncertainty in medicine is ubiquitous and in clinical bioethics there is significant task uncertainty. This is partially based on the differences between theoretical and clinical bioethics. Theoretical ethics as a discipline can be seen as a 'mature' (Kuhn 1962) discipline since it is based upon conceptually integrated paradigms, standardized problem definitions, exemplary solutions, and binding types of theoretical explanations. In contrast, bioethics as a discipline can be regarded as an immature discipline, with accompanying uncertainty from a philosophical point of view. In bioethics there is also the matter of the pervasive uncertainty inherent in medical practice (Fox 1957, Davis 1963, 1966). Certainty is unfortunately rare. Bosk, (1979, 1980, 1986) recognized the power aspect of uncertainty and argued that professions struggle for control because of their uncertainty in professional knowledge. Decisions are made by physicians with insufficient knowledge and must be made without full knowledge of the facts of the patient's case (Light 1979:1). Bosk (1979) suggested, for example, that the reluctance to impose controls and 'punish' colleagues is related to the recognition of the uncertainties faced by physicians. The focus of medical control is on the individual as opposed to collective control which places emphasis on the individual conscience of the physician as which is seen as an appropriate control by physicians and their organizations such as the AMA. This perspective is based on a virtue ethics which holds that the only way to guarantee ethical behavior is to locate the ethical decision making within an individual of good character and virtue. This individual control disregards group or corporate responsibility (Freidson 1986).

Fox (1957), combines "uncertainty, error, and risk" and in so doing, I believe, dilutes the perception of responsibility that science or medicine take for their actions. She assumes that since there is uncertainty, it is appreciated that there is error and risk. However, much of the error is related more to theoretical issues of knowledge and power than to uncertainty. In some areas, uncertainty exists about when one may say that a person is dead, for an example, but this has less to do with uncertainty as Fox defines it than with competing needs, for example, the need for acquiring a donor organ for transplantation, or the need to avoid legal action. In other areas where uncertainty exists, such as questions about the removal of a respirator, these have become broader questions of responsibility. The results of removing respirators is often uncertain and questions about whether or not it is this the right thing to do at this moment with this patient, uncertainty issues that in the past were resolved by the physician alone, are now potentially resolvable in committee - and responsibility shared with the bioethics committee. Part of the uncertainty in these cases rests upon constructions of the potential quality of life of the patient and is critical to bioethical discussions since they involve social, not exclusively medical decisions.

Although many decisions may be considered "prognosis" decisions the prognosis is virtually always uncertain and decisions are based upon social or ethical factors: is the patient "a person"? What does that entail, what does it mean? When does one cease to become a person - when one enters the status called vegetative? Will the person in whatever condition live or die. Do they have enough possibility of an adequate quality of life to live or die. And who is to say? Since most studies are retrospective we are already only studying those who are clearly dead. Determining an acceptable versus an unacceptable quality of life is an ethical and social decision. Decisions are made, and are made in bioethics committees. They have been studied from two perspectives. One locates the decision maker as the individual making the decision, the physician, or more rarely the nurse. The moral basis for the decision resides in the individual conscience of the person making the decision (Anspach 1982). Another perspective locates the decision in the collective conscience. But what of the anomalies which neither perspective can explain? How does this explain that nurses often reach decisions to terminate life-support before physicians or vice versa. Are there, indeed, systematic differences among different occupational groups?

In contrast to Fox, Atkinson (1984) based his research dealing with uncertainty on ideas from Foucault (1972/1973). Atkinson says that medical training is structured to safeguard, both within medicine and between medical practitioners and the public, the primacy of the physician's personal knowledge of the patient's 'case' based on bedside observation. "Illness," writes Atkinson (1984:103), "is constructed in terms of the exclusive expertise of the medical profession." More important, in any given case, the privileged expertise is that of the primary physician: "He bases his actions and decisions on the unquestionable bedrock - the **certainty** - of direct experience" (Atkinson 1984:101). It is this legitimation of scientific knowledge that is of interest in terms of the legitimation of bioethics. The continued warranting of this expertise is the objective of medical education, in which "first-hand experience must be built up in the development of the practitioner's biography" (Atkinson 1984:100). Such education provides professional socialization for new medical professionals, and it also reaffirms the professed objective reality of the entire process. As Atkinson (1984:98) holds:

> The invisible pedagogy of bedside teaching practices provide a device for the affirmation of the preconstituted nature of illness as an ontological entity.

This knowledge is rooted in a specific cultural and historical social milieu and Atkinson relies upon Foucault's explanation of the emergence of this milieu. Light (1979:30) also believes that the major issue is training for control more than the management of uncertainty. I maintain that the issues of power, legitimacy, and sociology of knowledge are more robust theoretical foundations to explain these issues rather than interpreting them as a **theory** of uncertainty.

How can the sociology of knowledge approach inform the process of making bioethical decisions? The sociology of knowledge links decisions to the social circumstances within which the decisions take place (Anspach 1982). Individuals, as Mannheim (1936) noted, do not have an "objective" view of reality but form their perceptions within their social situations. The social environment structures how the individual will construe the facts of the case as well as what facts will be identified as noticeable, and what they recognize and define as data. How the bioethics committees within its place in the hospital structure shape decisions, how bioethics committees allocate different types of information and structure facts, and how different groups deal with this is of interest.

In most writing on treatment issues and death and dying the question of who should have the authority and responsibility to make these kinds of decisions and how these decisions are made is central. Many of these decisions are "tragic choices" (Calabresi 1969). One assumption of the debate is that there is one choice that is better than the other. This is a philosophical tenet which states that philosophical dilemmas can be solved by applying principles of a philosophical theory and the correct solution will be apparent. However, the real life dilemmas in bioethics are not solved by this approach. The stark fact is often that any decision is difficult because both choices are equally fortuitous or unfortunate.

E. OVERVIEW OF THE ARGUMENT

1. CORE CONCEPT - MORAL ORDERING - HOW IT EVOLVED

In the initial process of observing and analyzing data from 6 committee meetings in six hospitals, I noted a category which I called **legitimation** which included: who had the power to legitimate a case coming to the committee; who was allowed to present a case; what vocabularies and "expert knowledge" were used; who focused the decision/advice; and who selected what literature would be used to 'educate' the committee and to determine hospital policy about bioethics. This category of legitimation served as a broader framing for sub-categories such as professional control/dominance, division of labor and the legitimation of authority and power.

Later in my analyses, a **process** emerged through which these legitimation strategies transpired. The ordering and re-ordering of what were essentially being defined as moral issues suggested the term **moral ordering** to convert the static conception of moral order to a dynamic interactive process.

I had earlier used the concept of **moral ordering** to refer to processes in the large socio-political arena that were defining and re-defining ethics in society. The selection of this category as also central in the ethics committee data evolved over the years 1987 to 1990, as I coded my 1989-1990 data and re-coded my 1987-1988 data. Thus the core process of moral ordering can be viewed as occurring across multiple levels of sociological analysis, from micro to macro.

Let me briefly recount my analytic process regarding this core category. Theoretical formulations guided the data collection in that once the initial core category of **legitimation** was named, the theoretical sampling was then directed to gather more data that would, in fact, confirm or disconfirm **legitimation** as the core category. I knew it was close to what I was seeing, but perhaps a more robust and more original category might emerge.

As I read through and coded committee meeting field notes, I began to feel that what I was witnessing was a form of re-ordering of a fluid moral order which, because of a number of factors, was visible because it reflected somewhat dramatic changes. That is, in the hospitals there had been rather accepted ways of dealing with difficult problems. Now that was changing and paradigmatic of that change were the new bioethics committees themselves.

I had also traced the emergence of bioethics as a discipline in the United States, which represented a changing moral order. The core category for this larger process also seemed to be a **moral ordering**. Here **moral ordering** represented the ways in which the moral and ethical negotiations and power maneuvers were being made and who had the knowledge and power to prevail. It included noting the ways in which the model through which all of these issues were discussed continued to be a medical discourse and vocabulary and how this acted to sustain and re-legitimate medical hegemony. Thus in the socio-historical data this core category worked as well as it did for the ethics committees themselves.

Once the category of moral ordering emerged from the data, everything fell into place. Moral ordering and re-ordering entails the inclusion into the medical model of concepts and vocabularies of ethics, law, and economics at both the wider political levels and local committee levels. There was always some sort of ordering going on and it was about issues that were **labeled** by the participants themselves as 'ethical' or 'moral.' Though the issues were construed as moral ones, conversation and dialogue about them, the language used and solutions found were all primarily framed in the discourse of biomedicine. Less frequently social, economic, or legal resolutions obtained, usually subordinated to medicine.

The second thread holding this dissertation together is the concept of justice. Many of the cases involved issues of justice in the allocation of resources. This often involved dealing with when to stop treating someone linked to when a person could be considered to be dead. These cases required a good deal of negotiation about, for example, new definitions of death and who determines when someone is "dead enough" to stop treating. These types of deliberations also took place in archival materials and in discussions of public policy.

Throughout this dissertation, we will see the following:

- There is a division of labor in moral ordering such that one discipline's knowledge and beliefs can trump another.
- The division of labor remains intact, that is, physicians continue to be primary decision makers and nurses and others fundamentally contribute data.
- The use of the medical model frames bioethics decisions continually in a medical discourse rather than an ethical or social one.
- The power of the medical model informs and dominates decisions without much loss of influence from the participation of "outsiders."
- The hospital bioethics committees, in fact, sustain medical hegemony.
- Legal concerns strongly inform the decisions but are incorporated and reframed as medical decisions.
- Ethical discussions and formulations act primarily to sustain medical ones.

These findings obtained in the initial ethics committees discussions, negotiations, and power plays. They were tested by attending comparable committee meetings in institutions unlike the ones in the original study and by comparing bioethics committees to other medical staff committees and to ethics committees in other arenas.

2. DEFINING MORAL ORDERING

As both discipline and practice, bioethics involves the construction of ethical and moral rules. Negotiations over rules, including the making of new rules, and their interpretation, must engage common "vocabularies of motive" (Mills 1940:906) and legitimizing principles. I have designated the processes of these particular negotiations as **moral ordering**. This refers to the defining, re-defining, constructing, re-constructing and de-constructing of new rules in an area that is interpreted as moral or ethical. Moral ordering is a practice that produces, re-produces and alters a moral order as a component of the social order. Moral ordering is related to what Strauss (1979) described as "negotiated order," the fluid outcomes of social processes in which participants exercise their own power and legitimizing resources as they attempt to interpret, change, or construct rules and activities to their benefit. Strauss and his associates (1963:165) remind us that any order is subject to change:

> Any changes that impinge upon this order - whether something ordinary like a new staff member, a disrupting event, a betrayed contract; or whether unusual, like the introduction of a new technology or a new theory - will call for renegotiation or reappraisal, with consequent changes in the organizational order. Mark the last phrase - a new order, not the reestablishment of an old, a re instituting of a previous equilibrium. This is what we remarked upon earlier as the necessity for continually reconstituting the bases of concerted action, or social order.

Both the large and small scale organizations and interactions are characterized by change and the development of a social order in which members work out shared agreements and understandings in response to everyday contingencies (Strauss, et al. 1964). Strauss (1979) perceives the negotiated order, as dynamic and changing yet contingent upon structural conditions and the more stable elements of social order bounded by larger societal structural contexts. But moral ordering involves more than negotiations for, as Strauss (1978:ix; 262) said, there are power strategies that include coercion, persuasion, manipulation, appeals to rules and education.

People act on the basis of meaningful interactions informed by a variety of considerations in particular situations (Blumer 1969, Weber 1922/1978). This means that the boundaries of medicine and ethics, for example, can be thought of as flexible and negotiable, permeable not solid. Understanding the interaction of internal and external factors might lead to a more interactive theory of social structure as suggested by Dmitri Shalin (1986:26).

Moral ordering is itself a product of the social construction of reality and includes the languages and categories of the issue in question. The origins, nature and consequences of the definition of a given situation are fundamental to understanding its continuity and change, consensus and conflict. The action and practice of individuals in a social world, those in the bioethics discipline and committees in this case, occurs within a communicative process through which meaning is established. This context of meaning can both coerce or facilitate practice.

An examination of the forms of moral ordering through an exploration of various discourse turns fundamentally on the concept of legitimacy made into a dynamic process by Max Weber (1947, 1922/1978). Moral ordering, viewed from this perspective, is essentially to be grasped as a struggle between competing social worlds within their own discourses and what are sometimes called ideologies. It is the struggle to appropriate legitimacy by one discursive system, one world, which can then become the dominant or hegemonic model.

I consider the changing of extant "ethical" rules or the construction of new rules as moral ordering in health care. The processes of moral ordering are explored by examining the emergence of the discipline of bioethics and the practices of bioethics committees. The moral ordering taking place in bioethics discussions and interactions reveals a process through which a fluid order is continuously created and re-created. However, evidence from my research reveals that the biomedical model and vocabulary prevail. The dominant or hegemonic discourse in bioethics is that of biomedicine and individualism.

Moral ordering in health care is but one part of broader moral ordering processes. In bioethics today there is no single normative, accepted, or fixed moral order but instead a moral ordering and re-ordering about who is a person, what is an acceptable or unacceptable quality of life, how is death defined, and when shall we withhold or withdraw treatment. Many of these decisions can certainly be construed as social and ethical and not exclusively medical ones. All are issues which involve considerations of justice. Tensions abound over attempts to balance concerns about individual and concerns about larger groups of people in terms of justice. For example, questions are raised over the justice of spending $1,000,000 on one premature baby when the infant death rate ranks the United States 22nd (DHHS 1990) amongst all nations. Others question the justice of spending $1,000,000 on an artificial heart transplant when life expectancy for certain social groups in our country is only 35 years. Yet others question whether it is fair to expect surgeons to operate without an awareness of the infectious disease status of their patients (Day 1989).

Questions about premature babies and artificial hearts would not have been raised thirty years ago for they derive from our technological ability to do things only dreamt about in the past. Tensions between individual rights and the public's health were largely unquestioned outside of medicine before the language and discourse of rights came to the foreground. In fact, before individual rights were seen as involving issues larger than health alone, public health policy ostensively favored what was defined as the safety of the public over the rights of the individual. From "Typhoid Mary's" incarceration, to legal requirements for notification of partners of those with sexually transmitted diseases, rhetoric about the public's health had been paramount and individual rights overruled. It is clear that what is an accepted moral ordering at one historical moment can be different at another. However, the processes by which moral ordering changes, and how new ideas and discoveries are incorporated into a new moral ordering, remain important and uncritically examined.

II. INDIVIDUAL AND SOCIAL MORALITIES

In describing problems involved in the moral structure of society as he understood it, Durkheim (1912/1915:x) viewed morality as part of the essence of society. He sought to develop a sociology of morality, "a science of morality which would treat moral beliefs and maxims as natural phenomena of which one could seek the causes and the laws" (Durkheim 1912/1915:xv):

> For a century there have been disputes about whether morality should take precedence over science or science should take precedence over morality: the only way to put an end to this antagonism is to make of morality itself a science, alongside the others and in relation to them.

Sociology was, for Durkheim, the study of moral and social factors and he equated moral commitment with social facts and social order to argue that all social norms are ultimately moral. Durkheim (1903/1961:12) also argued that some contracts are more moral than others in discussing moral education and bases that on an underlying assumption of freedom and individuality.

It was Durkheim's (1893/1933:79-80) conviction that the very core of "society" was **le conscience collective**, the collective conscience:

> The totality of beliefs and sentiments common to average citizens of the same society forms a determinate system which has its own life; one may call it the collective or common conscience....It is independent of the particular conditions in which individuals are placed.

The collective conscience defined the moral boundaries of legitimate society. Individuals took their meaning of life in some sense from this collective conscience. How did Durkheim then explain then why individual moralities were so different? According to Durkheim, this was unproblematic in "simple societies" where the collective conscience played a mechanically integrative role. However, in complex societies the existence and role of the collective conscience became problematic. This integration was accomplished in more complex societies through the division of labor. Recognizing this, Durkheim described how each occupational group had its own collective conscience. That is, each had a different professional ethical systems that articulated meaningful values and conduct for members that group. For Durkheim, the key to social order was a dedication to social norms and values and the form of society defined by the type of moral commitment whether voluntary or involuntary. He saw morality as duty (1903/1961:30).

Other sociologists have argued that societies are composed of many different groups which construct meaning along such dimensions as class, region, religion, ethnicity, gender, race, occupation, political commitment, and so on. In these terms, then, morality is continuously negotiated through processes of moral ordering, consequently, the moral and social boundaries of ethical arrangements are continuously shifting and are shaped by the groups participating in any specific ordering situation.

Marx (1844/1978), for example, was aware of the need for a moral connection between people and in his discussion of ideology described a dialectic between two kinds of morality: ideology, the particular values of a society, and, species being, which is achievable through the fulfillment of the self absent ideological domination. This produced a continuing dialectic between species being and the values of civil society.

Weber (1922/1978) regarded a commitment to shared norms and values to be crucial to social order. He said that shared values made possible shared meanings and he made distinctions among a number of values that he felt might be generalizable. Weber (1922/1978:3-30) described different forms of value and value relationships such as formal from substantive rationality as two forms of value and communal from associative relations two types of commitment to those values. These forms of value and commitments to value were critical in his interpretation of the passage to modern society.

Sociologist Anne Warfield Rawls (1990) discussed the distinctions made in classical theory between two forms of social order: primary and secondary, mechanical and organic solidarity, town and country, public and private, communal and associative, gemeinschaft and gessellshaft. Extending classical theory with ideas from Goffman, Anne Rawls (1990:67) held that these distinctions:

> preview the distinction between the morality of the Interaction Order and the contingency of institutional norms found in Goffman.

Rawls (1990:67) described the difference in the distinctions by saying that the classical theorists were trying to explain the transition from traditional to modern forms of life and they did not:

> conceptualize the distinction in terms of forms of organization within a single type of social framework, but rather as competing social forms of the transition from one sort of society to another.

But now, how, within a single type of social framework, is the moral order changed. Under what conditions does the "moral order" in a particular group or social world become vulnerable to change?

The classical theorists, Marx, Weber, Simmel, and Durkheim, regarded the form of social connection between people in a given society to be the essential determinant of the type of social structure (A. Rawls 1990:78). With an alteration in social bonding, they believed that social change at all levels would follow and based this on the notion of some form of social contract. Again, using Goffman, Rawls pointed out how his theory of Interaction Order could return sociology to a concern for morality. That is, although there are formal values, these are contingent in regard to a very different order than the interaction order. The interaction order is a necessary part of the reproduction and definition of the self and the institutional features are carried within. Since for

Goffman and Rawls the individual carries the institutional features of the world within, change comes through interactions

Change comes by interactions among people who test their moral orders against others in the contexts of changing social worlds. But it is this interaction with others in an "Interaction Order" that allows moral ordering to take place. Moral ordering takes place in interaction and the interaction must be founded ultimately on moral guarantees.

Looking at a different unit of analysis, on a larger scale, another way that the moral order is susceptible to change is through the actions of what Howard Becker (1963/1973) called "moral entrepreneurs." Becker described how, in certain periods and places, people arise who are able to advance their interests and values. First, they act to label an issue a social problem. Then, by virtue of their ambition, political power, authority, alliances, proficient use of publicity and ability to neutralize opposition they act to shape social policy through a "moral crusade" (Becker 1963/1973).

In the bioethics arena, one key moral entrepreneur was then Senator Walter Mondale who, in 1968, initiated a moral crusade to examine matters involving science and medicine. In fact, as a consequence of his work to set up an ethics advisory board in the government, Mondale and his allies spurred the emergence of the discipline of bioethics. However, the broader social situation within which Mondale's group operated must be considered, for it was only because wedges existed in the internal control of medicine that Mondale was able to engender support for outside concern with medical ethics.

Attempting to change moral rules can create social change or may be contravened by attempts to restore moral boundaries of the group(s) involved. How this is ultimately decided has to do with claims of expert knowledge, legitimation, power, class, and interest groups. The moral order in a pluralistic "society" is subject to moral ordering where conflict and consensus endure. These multiple perspectives are essentially competing with each other for legitimacy and the meaning of any moral statements are filtered through lenses of those perspectives.

In order to understand a specific applied ethics, such as bioethics, we have to understand its context within the social world and the value structure of that world, both of which are occurring within a socio-historical context. Patterns of ethics can be seen as an integral part of a specific social order. If we consider actions such as removing life-sustaining technology which results in death or in foregoing treatment this behavior may be considered benevolent, deviant, or criminal (e.g. Barber v Superior Court of California 1983). These acts of omission or commission can be interpreted, as some groups have done, as weakening "the social fabric" or leading to a putative slippery slope.

F. OVERVIEW OF THE DISSERTATION

Chapter One explicates the core dimension moral ordering and the methodology used in this study of bioethics. It also takes up issues pertinent to this exploration of bioethics including the sociology of knowledge and practice, legitimation, knowledge and power, and the social construction of social problems. Next, I substantively framed the dissertation research vis-a-vis social science interest in bioethics.

Chapter Two portrays the emergence of bioethics as a discipline in the United States from 1945-1990. I illustrate the construction and deconstruction of ethics in medicine. This process of knowledge construction allows different groups with legitimation power to construct and de-construct the definition of medical ethics as a social problem.

Then I discuss the disciplinary emergence of bioethics from the events of the 1930s from eugenics to euthanasia to the Nuremberg trials, to problems with research ethics in the United States and new technologies. I discuss bioethics and the struggle for control of biomedicine. I examine the theoretical contributions of bioethics.

In Chapter Three, I discuss the institutionalization of bioethics in the United States. This includes a brief description of the centers of bioethics. I analyze the evolution of bioethics committees from their legal and symbolic inauguration in the 1976 Karen Anne Quinlan case to their practice setting in hospitals and other health care arenas.

In Chapter Four, I examine bioethics practice through a study of ethics committees, since these form the most pervasive concrete manifestation and crucible of bioethics. This includes an analysis of the confluence of theory and practice. I discuss two major cases and concepts: moral ordering and its legitimation and, the social construction of 'dead enough.' I discuss major issues of concern related to ethics committees.

In Chapter Five I discuss bioethics and aging. This includes an analysis of constructions of justice. I incorporate this with decisions about withholding and withdrawing treatment and the allocation of "scarce" resources. I discuss a case on allocation and aging: coronary artery bypass surgery.

In Chapter VI, I provide an integrating summary in which I discuss the significance of the findings and their implications for medical sociology and public policy. I include policy recommendations.

CHAPTER TWO

THE EMERGENCE OF BIOETHICS: HISTORICAL BACKGROUND

I. MORAL ORDERING AND THE DISCIPLINARY EMERGENCE OF BIOETHICS: A HISTORICAL SOCIOLOGY OF THE EMERGENCE OF BIOETHICS: CONSTRUCTIONS AND CONTEXTS

INTRODUCTION

Bioethics is dated by most historians of the field to begin with events in the 1960s. However, I maintain that it was under a penumbra of events in the 1930s and 1940s that it emerged, especially the Nuremberg medical trials. These trials bared contradictions between expectable medical practice and ethical standards of European and American culture. The trials themselves initiated wider negotiations about the medical moral order and were requisite for the construction of bioethics. The trials provided a first wedge of entree and allowed the incursion of the state into the internal dynamics of the medical world.

In this chapter I discuss the historical contexts of the period during which I will show that the seeds of the discipline of bioethics were planted. I locate the beginning concerns of groups outside of medicine with medical ethics to the Nuremberg trials including the events leading up to the trials. The movement from eugenics to euthanasia and medical experimentation in Nazi Germany was not inexorable, for the basic philosophy of eugenics and sterilization was also present in a number of other countries and did not move on to mass killings, murders or genocide.

I argue that the killings in Nazi Germany triggered a social concern with ethical issues in medicine through the disclosures made during the Nuremberg Medical Trials. However, I begin with the contexts within which the events leading to the trials occurred, for the dramatic revelations of medical experiments and killing, called "euthanasia," was the last phase of a trajectory that emerged out of a particular Zeitgeist. Portions of that Zeitgeist were also present in, among other Western nations, the United States, Great Britain, and Germany, included theories of Darwin and eugenics, and illustrates, that as Hughes (1977) said, it could have been otherwise.

The problematic of explaining or understanding the actions of a portion of the medical community during World II is a sociological dilemma. There has been a long hiatus between the Nuremberg trials and concern about physicians' actions in the Nazi period. It is only in the past several years that public questions about the behavior of German physicians in World War II have been asked and some answered in two major books about Nazi physicians. One is by physician Robert Lifton (1986) who interviewed a number of Nazi physicians and associates who had been involved in the medically legitimated killing of Jews and others. The second book is an historical account of medicine under the Nazis by historian Robert Proctor (1988), and documents the role played by physicians in the service of the Nazi State. A number of books and papers have also been published in the mid 1980s by German sociologists, historians and others. An important group of these papers are known collectively as the Hamburg reports. Anthropologist Thomas Maretzki (1989:1319) described the Hamburg reports as representing examples of the work begun during the 1980 **Gesundheitstag**, the Congress on German Health in Berlin. Discussions and papers presented at this congress:

> served as a protest against the silence maintained by West German organized medicine with regard to its past role during the Nazi period (tabuisierte Vergangenheit).

The writers of these books, along with other contemporary German authors, discuss broad aspects of research with humans, abuses of medical experimentation in Germany, and racism as a problem central to Nazi policies. Maretzki (1989:1320) significantly noted the link to contemporary bioethics:

> the term "Nuremberg Trials" is widely known today in the English-speaking world as a significant event for medicine worldwide, because it laid the basis and the baseline for attempts to formalize medical ethics.

Contemporary writing about bioethics continues to recall Germany in the early twentieth century in what has come to be called the **Nazi analogy**. Thus the sociological conditions surrounding the medical events in Germany need to be understood in terms of contemporary discussions about perceived similarities and differences which color current understandings of bioethics. Whatever the relationship of Nazi Germany to contemporary bioethics, the perception of a Nazi analogy by some major actors influences the theory and practice of bioethics. The concerns of a number of people in bioethics today, are colored by the events that occurred in Nazi Germany and so need to be understood as background to fears of "slippery slopes" and anxiety about changes in moral ordering by practitioners of medicine. This is one reason to begin this work by reflecting on medicine in Nazi Germany.

A second reason is that revelations at the Nuremberg trials led to the incursion of outsiders, the law in this case, into the ethics of medicine. The wedge provided by the Nuremberg trials into medical ethics is key to the argument of external control of medicine and how that was dealt with to avert control by outsiders and to maintain physician control of bioethics.

The modest questions I deliberate upon in this section are: Under what conditions and with what consequences were the medical events in Nazi Germany constructed and enacted? How did this knowledge, constructed in the image of medicine as medical knowledge, become socially approved (Schutz 1964:133) to the extent that it was not prohibited? How does this knowledge, legitimated by science and medicine, become acceptable to ground practice?

I then consider the relationship this construction of knowledge and power has to current concerns about justice in health care, the significance of these accounts for bioethics, and the implications of the Nazi analogy for contemporary bioethics.

A. FROM EUGENICS TO EUTHANASIA

> Of all the vulgar modes of escaping from the consideration of the effect of social and moral influences on the human mind, the most vulgar is that of attributing the diversities of conduct and character to inherent natural differences.
>
> John Stuart Mill, Principles of Political Economy, Book I 1873

Any ethical system, and the Third Reich was founded upon an ethical system, does not occur in a vacuum, but is created in a particular social universe. Those involved in the events under discussion were actors in and products of their time and their culture. The ideas and actions that occurred in Nazi Germany arose under circumstances similar to those that existed in many parts of the world. This climate included a desire for a more perfect society along with a disregard for the marginal, the liminal and the different. This disdain was the culmination of principles and proposals which had been a part of the prevailing discussion in medicine and science in Europe and the United States and which could be read in scientific and medical journals of the times and for at least 50 years prior to 1933. Analogous deliberations about eugenics had been carried out in the United States, Great Britain and other countries but in the particular context of Germany and due to the efforts of particular actors, Nazi ideology **extended** these political, religious, and social themes that had been part of German, British and American thinking for years.

Even the "euthanasia" and medical experimentation that took place in Germany during World War II did not arise **de novo**. Those foundations too, had been laid during the years prior to 1933. The Nazi **Weltanschauung** was rooted in a series of conservative and reactionary ideas that had appeared throughout Europe and in the United States during the second half of the nineteenth century which rejected Enlightenment thought. These anti-science, anti-rationalist anti-progress ideas led to a longing for an idealized past. Social critics such as Nietzsche (1887; 1905/1953), inveighed against liberal democracy and industrial capitalism, against Marxism and organized labor, and against the culture of modernism. Philosophers filled their work with slogans: "the survival of the fittest," "the will to power," and the virtue of elitism. Hitler was able to move this ultraconservative discussion out of the private intellectual debate of the Second Empire into the beer halls and streets of the turbulent Weimar Republic and in so doing, he transformed it into an ideology of political combat (Lukacs 1989).

The political philosophy of many in Nazi Germany was also based upon Social Darwinist concepts. The implications of Darwin's (1859) observations were attractive to racial theorists as they appeared to offer scientific legitimacy for their ideas and by 1900, theories of Darwinism afforded a rationality for racism. Darwin (1859) had observed that in nature species were engaged in a constant struggle for survival and those best adapted to the environment were the ones who survived. Those inferior in the struggle become extinct or were exiled to less desireable geographic areas.

Darwin concluded that the universal law of nature was the survival of the fittest. This "scientific knowledge" was applied to other human social contexts by racial theorists who felt that, just as the animals in the natural world were engaged in a struggle for dominance, so were humans in the social world.

Darwin's theories had been enthusiastically adopted by racial theorists as they could be used to sanction their own ideas of superior races and to lend a scientific legitimacy to them. Darwin postulated the survival of the fittest; for eugenicists it was a short leap, albeit a leap of questionable logic, to suggest that only the fit **ought** to survive. The ultimate logic of the observation that nature culls the weak and unfit had not been lost on Darwin. In a later publication, The Descent of Man (1871; 136, 632) he discussed his view that human beings, in fact, sabotage nature by not allowing nature to follow its inexorable course:

> We civilized men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws; and our medical men exert their utmost skill to save the life of everyone until the last moment....Thus the weak members of civilized society propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man.

Knowledge of heredity and and Darwinian theories of evolution coalesced in the field of eugenics in 1889. Eugenics is the science of improving the genotype of animals, or humans, by exerting control over breeding. Negative eugenics consists of breeding out undesirable hereditable traits; positive eugenics is selective breeding for desireable traits and improved genetic patterns.

Early discussions about eugenics and euthanasia were held within the context of the social movement of Social Darwinism and the developing "science" of eugenics. The doctrine of social Darwinism became justification for the separation of those considered "inferior," and a warrant for the conquest of **Lebensraum**, a move for "living room" to expand the geographical boundaries of Germany to make room for it's citizens. The Nietzschian "will to power" and the "**Ubermensch**" - superman - became imperatives for domination over civil and political society in Germany.

It was within this broad intellectual, social, political and moral context that German eugenics developed. The early eugenics movement in Great Britain, the United States and Germany had similar foundations based on experience with breeding of livestock which ultimately served as a metaphor for the creation of a healthy state. In Germany, the knowledge constructed by medicine and science became a part of a legitimating process that fit in well with certain political goals of the Nazi state. A dominant cultural idea was to restore, maintain, or purify the established order by not allowing **untermensch** to breed, by allowing those with lives not worth living to die, and by selectively breeding those believed to be genetically favorably endowed. The popularity of these ideas in no way ameliorates the responsibility of those who carried out programs to implement them through sterilization, unethical experiments or euthanasia. However, our understanding of this era may illuminate contemporary concerns about justice practices in contemporary bioethics deliberations in the United States and may explain continuing reference to the Nazi analogy in bioethical discussions.

This was the intellectual climate in the United States, Great Britain, and Germany during the years 1900 to 1930. The sterilization of humans, as a means of stopping the reproduction of the "unfit" first occurred during the first half of the 1900s as a instrument of social policy. Before the Third Reich approved its first sterilization law, sterilizations of the "unfit" were already being performed in the United States in the early 1900s in a deliberate effort to strengthen its gene pool. In fact, it was this fact that lent legitimacy to the German sterilization program. Other nations such as Denmark, Finland, Sweden, and Iceland also had sterilization policies. The issue was hotly debated in England, but no authorization law was ever approved by Parliament. Germany, in an stated attempt to preserve its racial heritage, passed its first sterilization law in 1933 based on a model law written by Harry Laughlin (1929) for potential adoption by states in America.

In the United States, thirty states approved sterilization measures which, in general, authorized sterilization of those thought unfit and likely to pass their "unfitness" on to their children. In the United States the question of the right of the state to sterilize a retarded woman whose own mother and own first child were said to be retarded was raised and the controversy about the morality of sterilization of the unfit reached its zenith in a United States Supreme Court Decision written by Justice Oliver Wendell Holmes (Buck v Bell 274 U.S 200 1927):

> It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes....Three generations of imbeciles are enough.

Proponents of Social Darwinism extended Darwinian evolutionary theory to human races, classes and nations. Haeckel, a famous German biologist and social scientist, believed that "evils" such as consumption and syphilis as well as mental disorders were transmitted by inheritance to descendants. He said that:

> hundreds and thousands of incurables - lunatics, lepers, people with cancer, etc. - are artificially kept alive...without the slightest profit to themselves or the general body.
> ....the progress of modern medical science...possesses and practices more than it used to do the art of prolonging life during lingering, chronic diseases for many years....We are not bound under all circumstances to maintain and prolong life even when it becomes utterly useless.

Gasman (1971) in his work on the scientific origins of national socialism demonstrated that Haeckel believed in strong authoritarian rule, was a follower of Bismark and like him adopted a strong pan-German nationalism. Haeckel's social Darwinism took an extreme form. He believed that the survival of the fittest meant that only a small minority can thrive while the majority decline. This belief provided a base for his advocacy of a ruthless program to eliminate the unfit in Nazi Germany (Gasman 1971). Haeckel was one of the theorists who turned science to the service of ideology. The particular form that Social Darwinism took in Germany was based in Haeckel's Monist League, which in 1906 promoted racial purity, racial imperialism and **Lebensraum** for the Nordic people, and the practice of eugenics. His popular book, published in English as The Riddle of the Universe (1899), sold over 100,000 copies in its first year, ran 10 editions before 1919, and had by 1933 sold half a million copies in Germany alone. It was translated into 25 languages (Gasman 1971:14). This gives some small indication of the worldwide public popularity of these ideas in the early 1930s.

Haeckel proposed that a commission be set up in Germany to determine which of the deformed, insane, and diseased should be allowed to live and which should be condemned to death: "a redemption from evil." He suggested death by a rapid poison (Gasman 1971:95). The idea of **commissions to make decisions about life and death** issues is to recur throughout the twentieth century and generally encompasses ideas of diluting responsibility and accountability.

In 1920, four years before Hitler wrote Mein Kampf, German medical professor and psychiatrist Alfred Hoche and law professor Karl Binding argued, in The Release and Destruction of Lives Not Worth Living, for the principle of "allowable killing" which they thought should be extended to the incurably sick. The medical profession, they held, should participate in health, as well as in facilitating death for certain people for purposes of racial hygiene. The retarded, deformed, terminally ill, and those severely damaged by disease or accident should be put to death. The right to "grant death" should be a natural extension of the responsibilities of the attending physician. Death should be painless and expertly administered by a physician under the protection of the State. Hoche and Binding (1920), (see also Proctor 1988:178), asserted that the right to live must be earned and justified and not assumed.

> Those who are not capable of human feeling - those "ballast lives" and "empty human husks" that fill our psychiatric institutions - can have no sense of the value of life. Theirs is not a life worth living; hence their destruction is not only tolerable but humane.

While the arguments began with the elimination of specified individuals it quickly spread to groups and then categories of people. Hoche and Binding (1920) proposed that mercy killing or euthanasia be applied to those cases in which it was requested by patients, those in which consent was not obtainable as in coma or mental deficiency or psychosis; and where individuals were considered to be a danger or burden to society. This introduced the notion that **killing in the interest of the state could be interpreted as euthanasia**.

The assumptions and consequences of biological explanations for deviant behavior and hereditary theories for feeblemindedness as a cause of poverty, crime, and promiscuity, allowed the state through the medical establishment to appropriate the legal and moral right to institutionalize and sterilize lower class citizens, and devalued groups. Katz and Abel (1984:227-241) use the concept of the "medicalization of repression" for the eugenic sterilization movement in the early twentieth century. Biomedical knowledge, explanations and solutions were enmeshed in political ideologies. The ideologies targeted the lower classes, questioned behavior that challenged the status quo, removed individuals from their socioeconomic environments, and advocated the creation of separate institutions, surveillance, and practices for the targeted individuals, groups, and categories of people (Katz and Abel 1984:241).

The argument was advanced that biology could solve social problems and that knowledge and control over the genetic future, first of individuals and then categories of humans, was the solution to the future destiny of the Volk, the German people. With the sterilization laws in Germany in 1933, the medical construction of the prevalent social prejudices of the day were consolidated.

The concept of **Rassenhygiene**, which can be translated as racial hygiene or race hygiene, was coined by Ploetz (1895), a practicing German physician. "Racial hygiene" according to Ploetz, would eliminate human disease, from schizophrenia and retardation to alcoholism and homosexuality, and other social problems of race, crime, poverty, and gender. As these problems were transformed into medical-biological problems, the racial hygiene movement became attractive to physicians (Proctor 1988:286). Nazi physicians set up schools of public health, institutes for racial hygiene and public health clinics. They mandated the sterilization program: The "Law for the Prevention of Genetically Impaired Progeny" which received assistance from committees: The Tribunals of Hereditary Health and Appeals Courts (Proctor 1988:102). In these tribunals physicians were impaneled as judges in a nationwide court system. Each tribunal had 3 members - a lawyer and 2 physicians - one local physician the other a genetic specialist. Proceedings were secret. The person being considered for sterilization was often not informed until the tribunal was actually in session. She had no due process and no right to present evidence. Requests for legal representation could be denied by the tribunal without explanation.

The sterilization program was based upon the concepts discussed and debated for over fifty years. The program of sterilization, like later euthanasia programs, seemed "reasonable" and "logical" extensions of Social Darwinism. The "scientific principles" invoked were not seen as wild flights of fancy but, judging from the acceptance and lack of public commentary, were accepted as legitimate knowledge in Europe, the United States and Great Britain. This illustrates the legitimation of ideas and actions which can be understood through the approach of a sociology of knowledge. First, scientific or medical knowledge is claimed as expert knowledge and thus remains relatively unquestioned. That knowledge is then used to support practices in the interests of the state. Those promulgating the knowledge gain favored positions and protection from harm.

In all of this, there was a change in an earlier moral order, that is, there was a move from a definition of the role of the physician who had put the well being of individual patients above all else, to a concern with the health of the Volk and serving the state. This move included allowable violence, where social well being was defined as the destruction of the deviant, diseased, and dependent and where doctors were expected to serve the state by killing patients in the name of curing.

Certain assumptions flow from other assumptions, with perhaps an inexorable but faulty logic:

1. The health of the nation depends on the ability of its citizens to work.
2. The health of the nation is necessary for the wealth of the state
3. The medical profession is the appropriate caretaker for matters of health
3. Any decisions to do with what can be defined or re-defined as health should be made by physicians.

In Germany, certain political decisions were constructed as issues of health: the health of the nation, of its citizens, and therefore medical decisions. This interpretation placed the activities and rationale for them squarely in the center of the sociology of knowledge.

THE ROLE OF ECONOMICS IN THE NAZI STATE

Because of the purported "Nazi analogy" in current bioethics debates we need to consider the impact of other factors in the Nazi experience that have certain parallels with contemporary bioethical practice. We cannot ignore the economic arguments for sterilization and euthanasia, for in times of severe economic crisis proposals which seem grotesque in times of abundance may come to seem "reasonable." As the financial crisis in Germany deteriorated and as inflation increased, economic arguments of eugenicists flourished and were more attractive. In an important sense, the fate of Europe's Jews and others were contingent on the evolution of Europe's general crisis. Europe had never recovered from World War I and its people were disillusioned, confused, and filled with distrust (Mayer 1989:7).

The extended World War I had undermined the whole of Europe's economic resilience. The reparations imposed by the Allies on Germany added to the failing stability of Germany's economics. The years of the Weimar Republic were inordinately difficult for Germany. They involved starvation, inflation, and social turmoil leading to economic collapse. Two historians, Yale professor Hajo Holborn (1969), and Princeton professor Arno Mayer (1989:8), believe that the crash of 1929 and its global repercussions revealed that the fiscal consequences of the war had produced a serious structural disorder in the political economy of world capitalism. The consequences of the financial collapse that soon became a worldwide economic collapse were most abrupt and far-reaching in Germany (Mayer 1989:9):

> The fall of the three most awesome dynasties left a legacy of political instability. It also resulted in the map of the Continent being radically redrawn, which inevitably aroused irredentist rancors to be exploited by fascists and their fellow travellers.

The second industrial revolution and organized capitalism had advanced much further in Germany than in any other major European country, and its economy was particularly vulnerable to violent gyrations in the business cycle. Also, Germany's institutions could not overcome the social discontent and political conflicts which were unleashed by massive unemployment, which affected over 30 percent of the work force and nearly 45 percent of all trade union members in 1932 (Mayer 1989:8;

Holborn 1969)). The power elite of big business and agriculture along with the civil and military service in January 1933 turned to Adolph Hitler who was able to rally popular support "for the defense of the established but endangered economic, social, and cultural order" (Mayer 1989:9). Hitler was able to gain the prestige and expertise of the elites at the service of what Hitler characterized as "an eleventh-hour attempt to save Germany from Communism." Germany was in civil and political crisis and the Third Reich by the 1930s was the epicenter of that crisis. Mayer contends that:

> The drive against the Jews originated in this same epicenter. Anti-Semitism had, of course, been one of the cardinal elements of Hitler's syncretic ideology from the very outset. It had also informed much of the political rhetoric of National Socialism....The Jews were used in particular as a vehicle for the attack on the invasive modernity with which the Nazis incited those who felt threatened by it.

But it needed a leader, Hitler, who was able to accrue power to himself and the State:

> the really grave turning point did not come until soon after Hitler was invested with power, when anti-Semitism became official state policy. Following the suppression of all political opposition, particularly the Communist and socialist left, the persecution of the Jews proceeded in tandem with the consolidation of the Nazi regime. German Jews were glaringly and publicly reviled, boycotted, deemancipated, and ostracized. They were also expelled from the professions and expropriated.

This was climaxed with the desecration of almost 200 synagogues, numerous physical assaults, and large scale arrests on 9-10 November 1938 on **Kristallnacht**, Crystal Night. As Germany's national and international troubles grew more stormy Jews were lashed out at.

With the worldwide depression of 1929-1932 and the collapse of the German economy, physicians, who had already endured great financial losses in the years prior to the Nazi rise to power, were severely affected. Proctor (1988:287) pointed out that the collapse of the German economy polarized the medical profession and drove many physicians from the center to the far Left and Right:

> because they felt that Germany's other political parties were not addressing their needs. Physicians found it difficult to identify with either proletarian socialism or the interests of Germany's landed conservative parties. Many found hope in the "third path" of National Socialism.

The numbers of practicing physicians were rising and by 1933 the leading German medical journal warned that if the present situation continued the medical profession would face "a catastrophe" (Proctor 1988:158). As events progressed, physicians had an economic interest in the Nazi movement (Gallagher 1990:194) and professional opportunism (Proctor 1988:288) played an important part in the support for Nazi programs which excluded Jewish doctors from the profession and prohibited them from treating non-Jews.

With a sound economy the influx of Jews into the German medical profession might have been absorbed, but those in academic circles demanded the expulsion of Jews and a quota system during the economic crisis (Foster 1980:12). The elimination of Jewish physicians was one way of reducing the competition for jobs in a climate of marked physician unemployment.

EUTHANASIA, "EUTHANASIA"

> Things fall apart; the center cannot hold;
> Mere anarchy is loosed upon the world,
> The blood-dimmed tide is loosed, and everywhere
> The ceremony of innocence is drowned.
> William Butler Yeats

In Germany, in the Fall of 1933 the Ministry of Justice, as part of the Nazi reform of the German penal code, proposed a law authorizing euthanasia. Two days later, in the United States, on the front page of the New York Times (8 October 1933:1:col.1) the German Ministry of Justice was quoted as proposing that:

> It shall be made possible for physicians to end the tortures of incurable patients, upon request, in the interests of true humanity.

The law as proposed outlined a procedure:

> incurability must be determined by both the attending physician and also **a review committee of two official doctors appointed by the state** [my emphasis].

The State appointed doctors on the review committee were to review the patient's medical history and to examine him or her personally. The New York Times reported that the participation of the expert committee would insure, "**that no life still valuable to the state will be wantonly destroyed.**" This became the basic structure of the euthanasia program instituted six years later, in 1939. The Times reported the full details of the proposal. It did not elicit any published discussion at the time (New York Times Index 1933).

One of the reasons that the Nazi ethic was able to win broad public acceptance was that it was similar to an already understood and accepted ethic. As discussed earlier, certain values involving justice, and eliminating the unfit and incurable were operable in Nazi culture. The change was in the particular German context and in how those values were applied. Haas (1988:191) described how, although people were "uncomfortable" with the euthanasia program, evidently few noticed anything "**morally** wrong" with the concept. The political and religious institutions of the West were "lulled by the formal congruity of the Nazi ethic with their own" (Hass 1988:191). The Nazi theory and practice of "mercy killing" prefigured the killing centers and made them conceivable, plausible, and practicable. The 1933 euthanasia order embodied some of the underlying mainsprings and indeterminate circumstances of the "final solution."

Lifton and others (Proctor 1988; Haas 1984; Gallagher 1990), have documented the participation of German physicians in the "medical experiments" and euthanasia program of the Third Reich. The physician's work began with the sterilization program begun in the summer of 1933 within six months of Hitler's assumption of power. A large number of German doctors, from all evidence (Nuremberg Trial:xx), readily complied with a new law requiring them to identify and surgically sterilize "hereditarily sick" individuals. These "hereditarily sick" were people with diagnoses of congenital feeble-mindedness, schizophrenia, manic depressive insanity, hereditary blindness, hereditary deafness, grave bodily malformation, and hereditary alcoholism. It is estimated that between 200,000 and 350,000 people were sterilized under this program.

The early sterilization program and Nuremberg laws forbidding Jews and non-Jews to marry were in the name of eugenics; the euthanasia program spread from the murder of those with "lives not worth living" to the "medical experiments performed in hospitals and concentration camps, to the aim to eliminate of an entire race of people, the Jews, were premised upon medical and biological ideas. These ideas and the actions leading from them were held by physicians. American psychiatrist Dr. Leo Alexander (1949:44), investigating crimes committed by the German medical profession for the Nuremberg trials, described, how the sponsors and participants in the euthanasia program originated in "small beginnings":

> The beginnings at first were merely a subtle shift of emphasis in the basic attitude of the physicians. It started with the acceptance of an attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude towards the non-rehabilitable sick.

This "subtle shift in emphasis in the basic attitude of the physicians" was a significant emphasis of Alexander's.

The first killing of a retarded and deformed little girl had the imprimatur of the medical establishment in Germany. The program that resulted in the killing of chronic patients began with the institutionalized insane, the severely disabled, the tubercular and the retarded. It was conceived of and carried out by the leading physicians in Germany, professors and psychiatrists of international reputation (Lifton, 1986; Gallagher 1990:5).

The "euthanasia" of physically deformed and mentally defective children was begun in late 1938. The children were killed by physicians with drugs and by starvation. The "treatment" began with neonates and gradually extended to progressively older children. The program came to include retarded, juvenile delinquents, and "minor Jewish-Aryan halfbreeds." The euthanasia program was formally extended to adults in October 1939, a month after the SS began shooting inmates of mental hospitals to "liberate" their beds for the treatment of military casualties. The decree from the Fuhrer which initiated this program expanded the authority of physicians "to the end that patients considered incurable according to the best available human judgement of their state of health can be granted mercy death" (Brandt 1946).

German physicians cooperated with this decree to such an extent that by late 1942 when the program was officially but not actually terminated, an estimated 70,000 adult patients had been gassed and another 20,000 killed by medication and starvation, all under direct medical supervision.

Bouhler and Brandt brought together a corps of euthanasia physicians, some of who chose to operate under false names. Their assignment was to arrange for the "mercy killing" of about 20 percent of the mentally and physically ill patients institutionalized for five years or more. The operation was named T-4 Aktion. Writing about Aktion-4, Wertham (1968:153) quoted Huffeland (1762-1836) as saying:

> If a physician presumes to take into consideration in his work whether a life has value or not, the consequences are boundless and the physician becomes the most dangerous man in the state.

Wertham (1980:614) has drawn attention to support among psychiatrists saying that far from being the result of a direct order from Hitler:

> The reality was very different. There was no law and no such order. The tragedy is that the psychiatrists did not have to have an order. They acted on their own. They were not carrying out a death sentence pronounced by somebody else. They were the legislators who laid down the rules for deciding who was to die; they were the administrators who worked out the procedures, provided the patients and the places, and decided the methods of killing; they pronounced a sentence of life or death in every individual case; they were the executioners who carried the sentences out - without being coerced to do so - surrendered their patients to be killed in other institutions; they supervised and often watched their slow deaths.

Hitler had discussed the question of 'mercy killing' with his medical advisors prior to this order. According to the testimony of Brandt, Hitler had said that "in the event of war he would 'take up and deal with this question of euthanasia'" (1935 to Gerhardt Wagner in Nuremberg Trials 1948-1949). During war time policies like this could be put through more easily and without opposition. Thus, after having conquered Poland, Hitler told Brandt that he would "bring about a definite solution to the problem of euthanasia" (Mitscherlich 1962:234-235).

In the case of baby Houle, the little girl whose parents had asked Hitler for permission to have their child killed on merciful grounds, historian Lucy Dawidowicz (1976:9) asserted:

> Hitler used this particular case to embark on the program he had long had in mind and indeed which he had already sketched out in **Mein Kampf**, a program of radical eugenics which destroyed life that did not meet "Aryan" racial standards.
> The plea on behalf of the child allowed Hitler to insert the thin edge of the wedge. In Mein Kampf Hitler had written that the Volkish state must use the most modern medical means to: declare unfit for propagation all those who are in any way visibly sick, all who have inherited a disease and can therefore pass it on.

The euthanasia program began with individuals, the killing of the little girl, subsequently to other individual deformed children, and next to the killing of adult men and women labeled insane, then to other categories of persons and groups. This well describes what contemporary ethicists point to when discussing what they consider to be an **inexorable** slippery slope.

Telford Taylor, chief counsel for the prosecution at Nuremberg trials was a proponent of the slippery slope theory and said that the first step on the slope took place on the first day of World War II, 1 September 1939 when Hitler instructed Philipp Bouhler, chief of the Chancellery and a **Reichsleiter** of the Nazi Party, and Dr. Karl Brandt, his personal physician, to prepare a plan for the "mercy killing" first of incurably ill and deformed children, then of mentally and physically handicapped adults. From the outset, mindful of adverse reactions in Germany and abroad, Hitler stressed the need for absolute secrecy. These actions were legitimated by tenets of race hygiene. There was an expressed practical and economic aspect of ridding Germany of **Ballastexistenzen**, human ballast, and that was to free hospital beds, physicians and nurses for the war. Leading physicians of the public health services were invited to join the working group to authorize euthanasia. They agreed on a one sentence authorization signed by Hitler (Nuremberg Trials 21 Nov 1946- 20 August 1947. Nat Arch Microfilm Pubs M887, Tape 17. Doc. 630-PS) and dated 1 September 1939 which read:

> Reichsleiter [reich leader] Philip Bouhler and Karl Brandt, M.D., are charged with the responsibility of enlarging the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgement, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death.

Brandt gave this account in his testimony at Nuremberg. He emphasized that this was **not** an order to kill but an authorization to specifically designated physicians to do so, if after the 'most careful diagnosis' they determined that the patient was 'incurably sick'. This was a license to kill, not a directive to do so (also Mitscerlich 1962:265). According to Brandt (Nuremberg Trials), the Nazis did not direct physicians to kill or to perform experiments. They were very clear about this. What Hitler did was to lift the sanctions against such behavior and he did so in the name of science. Gallagher (1990:44) has described how the orders from Hitler gave German physicians license to deal with handicapped people "free from the restraints of law and ethics" when these activities were allowed to proceed in secret.

The role played taken by physicians in the extermination camps has been documented by a handful of writers (Alexander 1949; Wertham 1980; Lifton 1986; Proctor 1988; Haas 1990). Physician functions ranged from the traditional gatekeeper role such as the selection of who should be exterminated, to actually performing the "experiments," and killing those chosen. In the words of Leo Alexander (1949:42), they became "the unofficial executioners, for the sake of convenience, in formality and relative secrecy." They performed what Hughes referred to as "dirty work" (1962/1984:87). But why were professional, moral or religious guides incapable of providing an effective bulwark against the experimentation? The debate about whether one can judge what ought to be on the basis of what is, is a continual argument in philosophy. In history, however, right often does depend on might. Those holding political and economic power have the ability to define what should and therefore what will be. The claims of the powerful are sustained by reason, natural law, inalienable rights, self-evident truth, God's will, destiny or fate, but these legitimations are not unrelated to aspirations for power and its privileges (Rubenstein 1978:67).

Lifton (1986) described the labyrinthine association between medical ideology and the Nazi State. He argued that the principle of the Nazi philosophy, that is, of National Socialism, was itself professedly medical and therapeutic. As I am attempting to chronicle, Lifton analyzed documents and interviews with some of the Nazi physicians to show the goal of the euthanasia program as one of curing Germany of its sickness by purifying, in a medical way, the unfit. The concentration camps were a part of a racial cure, a genetic cure to improve the health and purity of the Aryan race.

Nationalist Socialist doctrine involved the biologic principle of racial purification as a political goal. This made it necessary to use physicians. In fact, Lifton (1986) insists, medicine was not peripheral to the Nazi doctrine that eventuated in mass murders but was an integral and necessary part of it. The Nazis depended upon and needed physicians in three ways: to supervise and take part in the killing, as researchers who conceived of ideological targets of experimentation, and to lend medical legitimacy to the entire program.

The legitimation for the Nazi experiments had rationality as its basic core. Nazi physicians had the power to define social reality and they used it. Any definitional process is simply that, a process, and can leave open various options for solution. Almost without exception the physicians at Nuremberg claimed the legitimacy of their experiments in terms of the advancement of science. This is premised upon the assumption that the advancement of science would have legitimated the torture of humans. For example, historian Jack Boozer (1980:92) asks: "In the medical case, how many of the experiments resulted in research that advanced medical science?" Would it change things if the results of the research were valuable in terms of contributing to medical science? This theme continues to recur. The assumption, which is never challenged, is that the ends of science or medicine justify the means in a classical Machiavellian sense.

Physicians were not used by the Nazi state in their role as clinicians, they were engaged as agents of biological and scientific knowledge by the State to carry out its politics. That is, politics became supposedly impersonal biology and this dispassionate "biological upgrading" was dignified and carried out by respected physicians. Lifton (1986:17-18) has argued that the Nazi State became a **biocracy** which re-labeled heinous killing as a therapeutic mission:

> In the case of the Nazi biocracy, the divine prerogative was that of cure through purification and revitalization of the Aryan race....Among the biological authorities called forth to articulate and implement "scientific racism" - ...doctors inevitably found a unique place. It is they who work at the border of life and death....In connection of all of these killings doctors kept up a medical legitimacy for deaths of Auschwitz prisoners and of outsiders brought there to be killed. They signed false death certificates listing spurious illnesses.

The 23 physicians at the Nuremberg trial denied any guilt for the experiments they admitted performing, but pleaded their innocence on the basis of the standards of medicine. It was the ability to legitimate the ideas upon which the behavior was justified which places legitimation so centrally in this sociology of knowledge. Weber (1976:121) discussed how the power of thought, of rationality, gave us the modern political state. It gave us advanced technology and communication, both of which can be used for good or evil. But it also gave us a new consciousness that "the decisive means for politics is violence." Weber (1958:182) described our life in an iron cage of reason:

> No one knows who will live in this cage in the future, or whether at the end of this tremendous development entirely new prophets will arise, or there will be a great rebirth of old ideals, or, if neither, mechanized petrification, embellished with a sort of convulsive self-importance.

One feature of the experimentation on and killings of patients, was that although there might have been some pathological killers involved, most were 'ordinary' medical professionals: doctors, psychiatrists, professors, scientists, nurses, and technicians. The Nazi ideology eliminated normally present restraints upon the physician and other professionals. The admonition reflected in the Hippocratic oath, to think only of the benefit of the sick, to do no harm, and the withholding of injunctions against murder, and liability that protected the interests of the vulnerable patient were repealed.

Important to our discussion is the secrecy of the euthanasia and experimental programs. One insight about this is provided by Mitscerlich (1962:302) who was very concerned about what the external forms of control in medicine should be. Control is possible, he felt, only when actions are visible and not secret. However, the experiments and activity of the Third Reich were greatly secret and were literally and figuratively behind closed doors.

EUTHANASIA AND THE SOCIOLOGY OF KNOWLEDGE

How can the sociology of knowledge perspective help explain the subtle shift in attitudes among the people of Nazi Germany? Is there any way to help understand how German people were able to move to a conceptual acceptance of euthanasia and extermination? One of the methods was described by Alexander (1949:39) in which ethical dilemmas with built-in presuppositions of social utility were introduced to school children. Mathematical problems such as:

> How many new housing units could be built and how many marriage allowance loans could be given to newly-wed couples for the amount of money it cost the state to care for the crippled, the criminal, and the insane?

This type of knowledge construction established a degree of plausibility for extermination on cost benefit terms. This moved the criteria for the assessment of "lives that were not worth living" to include the non-rehabilitable and those "unfit for work." Indefinite and vague terms such as "non-rehabilitable" allows the term to be extended to cover those in comatose states, with severe physical injuries, and from a racist perspective, non-Aryans. It could easily be extended to be central to the extermination of Jews, Poles, Gypsies, and Soviets, and indeed, was.

Another math problem which assumed a warlike position read:

> A modern bomber can carry 1,800 incendiaries. How long is the path along which it can distribute these bombs if he drops a bomb every second at a speed of 250 kilometers per hour? How far apart are the craters?

It was not just in maths that children were exposed to knowledge that supported the Nazi State, but reading as well. The new books were conservative and nationalistic, some were openly anti-Semetic. Cautionary tales such as Han's Grimm's People Without Space, a book which had envisioned a need, stated by Hitler, for **Lebensraum**, entered the curriculum. Other books such as The Poisonous Mushroom, and Trust no Fox in the Green Meadow and no Jew on His Oath, sought to instill distrust and hatred of Jews into the very youngest children. The introduction to Trust No Fox, sets the tone of the book by contrasting a blond Aryan "who can work and fight" with a repulsive caricature meant to represent a Jew, described as "the greatest scoundrel in the Reich." Later in the text, an Aryan boy is cheerfully playing an accordian while a group, meant to represent Jews, march into exile past a sign that reads ominously: "One-way street" (Boberach 1982; Koch 1988; Flaherty 1989:103).

Alexander (1949:40) described a charge in the discussions at the trials that "legislative regulations providing some orderly method that will ensure especially that the aged feeble-minded are not included in the program." This strategy of shifting the discussion to the limits of the program rather than focusing on discussions of the program itself was an effective means of establishing its plausibility. In this case, the scope for moral concern was focused on particular cases rather than the program as a whole as a way of legitimating euthanasia.

One church member, Bishop Clemens von Galen, stood up against the Nazis and the propaganda waged against church personel. He wrote and gave three consecutive sermons which roused Germany, angered Hitler, and brought von Galen the name of the Lion of Munster. Von Galen read his indictment of Nazi crimes against the church and called for justice: "Justice is the foundation upon which the state is built" (Zahn 1969:84). On learning of the killing of the mentally ill, he gave a sermon which began with a quote from a recent pastoral letter which stated that "never, under any circumstances, was a human being permitted to kill an innocent being, except in war and in legitimate self-defense" (Klee 1988:197). Von Galen said that he believed that the death of those mentally ill who were reported "to have passed away on their own had in fact been deliberately induced." He denounced the ending of the lives of the mentally ill as mass murder. He was concerned that the rationale for doing away with the mentally ill would be expanded to apply to other categories of unproductive members of society.

> Have you, have I the right to live only as long as we are productive....Once you establish and apply this principle that "unproductive" human beings may be killed, then woe to all of us when we grow old and infirm! ...At bottom, to grant common mortals the right to kill "unproductive" fellow humans - even if for the moment only the unfortunate and defenseless mentally ill are targeted - is to license the murder of all unproductive individuals: the incurably sick; the invalids of work and war; and all of us who in our infirm old age will be unproductive (Klee 1988:197).

The Nazi Ministry of Propaganda called the sermon "the strongest attack made against the German political leadership" (Conway 1968:81). He also issued a pastoral letter on the euthanasia program which was distributed through the diocese. In fact, as a result of the publicity attendant upon the Bishop's writings and sermons, Hitler called off the wholesale euthanasia of the T-4 killing program on 24 August 1941 (Portman 1058:107; Zahn 1969:88). The power of one person was dramatically demonstrated, and the intervention of a religious leader shown to be enormously successful. But von Galen was one of very few religious leaders who spoke out against the crimes of the state.

After von Galen's disclosures, the euthanasia program was then moved to the concentration camps. Some of the euthanasia physicians were sent to the camps to help sort out inmates who were physically and psychologically disabled. These euthanasia doctors signed thousands of death warrants and were also involved in testing more effective methods of mass killing for the program of **"merciful release."** About 275,000 people who Hitler termed "useless eaters" were exterminated in this program. Hitler's notion of "useless eaters" was based on a cost benefit utilitarian principle. Useless eaters were defined as those who could not be rehabilitated, who were non-productive had no actual utility and were expensive to support. This notion of social utility has been one of the arguments against using theories of utilitarianism for health care issues. McCullogh (1976:15) has pointed out that:

> If we consider the rationale which gives social utility or economic returns precedent over individual freedom, then we might see how our society could approach the kind of thinking that underlay the Nazi experience. There, racism overrode personal autonomy; here, it might be an economic rationale - the attitude that we won't spend so much per year to keep somebody alive on the slim chance of recovery. The slippery slope then is not the participating act; it is the context in which the act takes place....in the United States...what we have is an economic calculus which would...sacrific[e] individual freedom to the interests of others.

SLIPPERY SLOPE ARGUMENTS

There is a concept of "moral boundaries" which are talked about as reified structures but might prove useful as a concept if thought about as fluid processes. To think of them in structural terms, and then to move beyond what are seen as fixed moral boundaries sets the stage to interpret actions as setting us down a "slippery slope." These "slippery slope" arguments are often heard in arguments in applied ethics and in policy making. The slippery slope argument is also variously known as the tip of the iceberg, the camel's nose in the tent, the thin edge of the wedge argument, the domino theory, and the like. These metaphoric depictions signify the series of gradual yet what are seen as inexorable steps from an acceptable to an unacceptable posture, where it is hard to ascertain the precise point at which the crucial transition is made (Lamb 1988:vii). The slippery slope argument is commonly used to reject a newly proposed moral or legal boundary where the objection is both directed at the proposal and to the putative undesirable consequences which may arise out of it. The logic is flawed in that surely any step down a possible slope does not inevitably lead to the most extreme.

The slippery slope argument is one of the central arguments in bioethics. Opponents of, for example, euthanasia, appeal to the possible long term consequence of the legislation of euthanasia. The argument goes that legalizing euthanasia for humane reasons would lead to a callous disregard for human life and inevitable steps include killing mentally retarded children, those whose care is expensive, the unproductive of all kinds, the aged, senile and socially undesirable. Actions initially seen as innocent and humane would lead to killing for political and racial reasons. Of course this immediately brings up the list of Nazi atrocities as this was the most extreme example of "a slide into moral depravity" (Lamb 1988:10).

The slope argument by itself does not permit nor prohibit action. It must be examined in the contexts in which it occurs with the "potential effects of the proposal on some of our more fundamental moral beliefs" (Lamb 1988:viii). As Kamisar (1958:1031) holds:

> Whether the first step is precarious, is perilous, is worth taking, rests in part on what the second step is likely to be.

Alexander (1949:40) felt that: "It is the first innocent step away from principle that frequently decides a career of crime. Coercion begins in microscopic proportions." The path down the slope for Alexander (1949:45) was one of logical necessity:

> From the attitude of easing patients with chronic diseases away from the doors of the best type of treatment facilities available to the actual dispatching of such patients to the killing centers is a long but nevertheless logical step.

Once you accept certain basic ideas, he contends, then it is logical to move on to others.

However, not all agree with these slope arguments of Alexander and not all see parallel in the Nazi program and contemporary proposals for euthanasia. Kuhse and Singer (1985:95) argue that Alexander:

> has badly misunderstood the Nazi terminology. The misunderstanding vitiates his attempt to use the historical experience of Nazism as an argument against euthanasia as we now understand the term. When the Nazis talked of "a life not worthy to be lived" they meant that life was unworthy because it did not contribute to the health of that mysterious racial entity, the **Volk**. Since our society does not believe in any such entity, there is no real prospect that allowing active euthanasia of severely handicapped new-born infants would lead to Nazi-style atrocities.

However, it is possible that "non-productive" adults may pose a problem.

THE NUREMBERG TRIALS: MEDICAL ETHICS AS A SOCIAL PROBLEM

The events I have been discussing were revealed in testimony at the 1945-1946 Nuremberg Trials. This public forum allowed the Nazi atrocities to become recognized, or prevented the denial of the event, as a social problem, at least for a time. Further, the contemporary emergence of external, that is, non-medical concern about medical ethics can be dated to the Nuremberg Medical trials. I believe that ultimately these trials made it impossible to avoid the disjunction between what was expected in medicine and what members of different social worlds considered ethical. Although there were problems in research ethics prior to World War II, none received the public attention that the Nuremberg Trials received. The trials represent the public and symbolic disclosure associated with the beginning of a loss of confidence and trust in medicine. However, the Nuremberg code seemed to be accepted as a "solution" to these ethical problems and allowed medical experimentation as a problem to disappear such that after the trials there was little public discussion about Nazi medical experiments. After Adolph Eichmann was captured in 1961, there was a resurgence of discussion about the Nazi medical experiments (Arendt 1963). But it would not be until the mid 1980s, 45 years after the Nuremberg trials, that scholars would begin to deal with these issues.

The primary resolution to the revelations of the Nuremberg trials, and the deconstruction of medical ethics as a social problem, was the development of a code of ethics: the Nuremberg Code. The fact that the state became involved in medical research through the Nuremberg Code lay the groundwork for later state incursions into medical research and medical and scientific practice. While it is true that external control influenced the results of the trials, the actual solution - the Nuremberg Code - was written by two American physicians: Alexander and Ivy.

In 1976 Telford Taylor provided additional background on the evolution of the Nuremberg Code:

> ...we began to realize the kind of problems that we would be up against in presenting the case. That led to our getting two well-known American doctors as medical consultants to the prosecution: one, a Boston psychiatrist, Dr. Leo Alexander, and the other, the better-known Dr. Andrew Ivy, who was later involved

> in a controversial cancer cure.... But it was all quite hasty and improvised. If we had been able to do it over again three years later, we would have done it in a much more sophisticated way, that is, with a greater awareness of the implications of the positions we were taking.

The defendants were allowed by the court to examine Ivy "testing in a very illuminating way his ability to distinguish what was done in Illinois prisons and what was done in Germany" (Taylor 1976).

The testimony of Dr. Andrew Ivy, representing the American Medical Association as consultant and expert prosecution witness, was the basis for the draft of the code of ethics which was seen as an appropriate response to the problems of medical experimentation. Consequent attention to what might have seemed a crisis in medical ethics faded. A tribute to the symbolic power of such a code was that most observers felt that the **existence** of a code of ethics was sufficient to prevent such physician behavior as had been demonstrated through the trials.

The Nuremberg code, a ten point statement contained in the Nuremberg Military Tribunal's decision in the trial (United States v Karl Brandt, et al.) accepted the assumption that human experimentation is justified:

> when the results benefit society and when the research is carried out in a way that satisfies certain moral, ethical, and legal concepts among which: voluntary consent, careful experimental designs, highest technical and professional standards regarding equipment, facilities, skills, and scientifically qualified professionals and staff, cessation of the experiment if the subject so requests; **risk benefit analysis should accept no risk that is not exceeded by the "humanitarian importance" of the problem to be solved** (Reich 1978:1764-1765) [my emphasis].

That is, they did not render the experimentation problematic. The focus was primarily upon the need for informed consent. Also the mandate was not for an **a priori** right of persons but upon a risk benefit calculus. Most dramatic in all of these discussions and codes is the absolute assumption that medical research is a necessary and justified activity, even when there is potential damage to the subject. That is, the risk is acceptable if it does not exceed the "'humanitarian importance' of the problem to be solved."

The Nuremberg principles were incorporated in a number of subsequent codes: The World Medical Association's Declaration of Helsinki (1964) revised in Tokyo (1975); The British Medical

Research Council's "Responsibility in Investigations on Human Subjects" (1953; 1963); The American Medical Association's "Ethical Guidelines for Clinical Investigation" (1966), and the German "Richtlinien fur Forschunguntersuchungen am Menschen of the Schweizerische Akademie der medizinischen Wissenschaften" in 1970-1971.

Ivy, the key architect of the Nuremberg Code, was Vice President of the University of Illinois Professional Colleges. When asked to participate in the trials, it is said that he collected many volumes of works that dealt with moral philosophy from Aristotle to Kant and "the legal and constitutional texts explicating the jurisprudential foundations of human rights and freedoms" (Vaux and Schade 1988:6). Ivy was an idealist and wanted a perfect code to guide physicians in their research. It is ironic that he later became involved in work which many feel repudiated canons of appropriate research in his championing of the questionable cancer cure "Kreibiozen." He also became noted for his "safeguard of the University from communism in the McCarthy era" (Vaux and Schade 1988:3). Vaux and Schade (1988:3-4) described the profound influence of Ivy's contributions:

> Ivy's testimony became the architecture for the Nuremberg Code, the derivative Geneva and Helsinki formulations, and the ethicolegal standards that undergird clinical investigations to this day. The Belmont Report and the Guidelines for the Protection of Health and Human Services specifically build upon this foundation. The disclosures and testimony of that trial set in motion an earnest endeavor forever after to establish human experimentation on the three moral pillars of excellent science, humanistic law, and altruistic care.

The assumptions underlying this were clear to Vaux and Schade (1988:4), who said that: "When knowledge becomes possible there is the moral imperative to pursue it. There is a moral and even a theological impulse to discover."

The other American physician at Nuremberg, and the second architect of the Nuremberg Code, was psychiatrist Leo Alexander. Alexander (1966) prepared a memo which he submitted to Taylor and the court on April 15, 1947, and with Ivy's testimony became the basis of the Nuremberg Code. In preparing the memo he relied on what he termed an unequivocal statement in the German literature: Ebermayer (1930) "Der Artze in Recht;" American statutes and court decisions involving the use of new drugs and new medical or surgical techniques (Pratt v Davis 118 Ill.App.

161 (1905); Arthur (1945), "Some liabilities of the physician in the use of drugs"; and the Hippocratic Oath (Alexander 1949).

Alexander (1949), found the trials of those involved in "uncivilized medical experimentation" during World War II focused exclusively on ethical discussion on the protection of human subjects and excluded other issues. Alexander (1949:29-47) reviewed what he learned as one of the United States Army physicians investigating the Aktion T-4 euthanasia program for the Nuremberg trials.

> Physicians have come dangerously close to being mere technicians of rehabilitation. This...attitude has led them to make certain distinctions in the handling of acute and chronic diseases. The patient with the latter carries an obvious stigma as the one less likely to be able to be fully rehabilitated for social usefulness. In an increasingly utilitarian society these patients are being looked down upon with increasing definiteness as unwanted ballast. A certain amount of rather open contempt for the people who cannot be rehabilitated with present knowledge has developed.

At Nuremberg, Caplan (1988:230) said that it had become clear:

> what science and medicine could and would do in the service of the majority. Nazi medical experiments exemplified what crass utilitarian concerns for benefiting the majority within a society could lead to if followed faithfully and systematically.

Alexander pointed out that Brandt's defense was founded upon the moral legitimacy of a state's requiring sacrifices, including death, in the name of its general good. Twenty three years later, Henry K. Beecher (1970) would point to the need to develop codes of ethics requiring informed consent in order to protect individuals against the power of state sanctioned utilitarianism in the United States.

EARLY MEDICAL EXPERIMENTATION: FAUSTIAN BARGAINS AND THE EROSION OF TRUST

I have paid a good deal of attention to the Nazi trial reports of medical experimentation with human subjects. This is because the revelations of inequities and unethical behavior in medical research constitutes the beginning of contemporary interest by outsiders in the profession of medicine and its ethics and, I maintain, began the current erosion of trust in science and medicine which provided the wedges for outside intervention and interest in medical matters involving what are defined as ethical issues. The reports of the trials and of other experimentation allowed these behaviors to become identified as social problems. It was the beginning of external definitions of what constitutes ethics in medical research, what constitutes bioethical knowledge, and how and by whom this new knowledge is constructed.

Both preceding and after the disclosures of the Nazi medical experiments at the Nuremberg medical trials, in which 20 of the 23 defendants were physicians, there was little public discussion in the United States of what we now consider ethical issues in medicine. After the trials the flurry of articles about Nuremberg dealt primarily with the appropriateness of trying enemies for wartime crimes (New York Times Index 1946-1947; Reader's Guide to Periodical Literature 1946-1947; Index Medicus 1946-1947). The trial received little press coverage, and during 1945-1946 there were only 10 articles in the New York Times about the Nazi research. The report that the physicians were indicted, appeared on page 5 of the New York Times. The report of the opening of the trial was only reported on page 9 of the New York Times (NYT 4 November 1945:29). While some were concerned with the fact that a group of physicians, ostensibly dedicated to protecting life, had shown a flagrant disregard for humanity, those in the medical profession, either corporately or individually, in the United States did not respond dramatically. Nor did the medical profession in Germany. After the war most of the physicians who had been involved in the Nazi party returned to their practices and university posts.

We might ask how these experiments could have gone on and how even after the experiments were revealed nothing was done but a handful of men tried and a code written. How can this be explained? It was, according to some, because we constructed the perpetrators as "other:" as the "mad dogs" of Nazi Germany and not physicians like us. But, according to Hanna Arendt (1963) - they were people like us. There exists, she maintained, a banality of evil. It is not just **them** as other, it is **us**. This view was also held by Telford Taylor (1945), counsel for the prosecution who in his opening statement at the trials said that the purpose of the trials were not simply to punish the guilty but that:

> The essential point is to show how the poison of Nazi doctrine had so corrupted men exceptionally qualified to form a moral and professional judgement that they were capable of these acts. It is necessary to demonstrate clearly that it was not a few sadistic criminals who were responsible but that the whole body of organized medicine in Nazi Germany was behind the policy.

This stunning indictment of medicine as not simply a benevolent discipline insinuated doubts as to the trust that physicians had once accepted as their due. Taylor spoke of the perversion of medical ethics by the doctors of Germany during the Nazi years. Added to this was the fact that American scientists too, were no longer seen as purely benevolent as the nation reeled from the revelations of the horrors of Hiroshima and Nagasaki (August 1945).

There is a distinct thread from the events disclosed by the Nuremberg trials and later revelations of experiments in Japan and the United States to the setting up of institutional review boards to oversee research on humans to the development of bioethics committees to provide advice about bioethical matters. One strand of that thread is the protection of humans subjects and patients; another, is the protection of the physician; a third is the provision of legitimation for continuing research and practice. It is this last thread that is surprising for it is rarely questioned that research continue. That is our Faustian bargain.

The disclosures of the Nuremberg trials lay the foundation for a new view of physicians. However, the part played by physicians in other research in other countries must also be considered in an attempt to understand the beginning of an erosion of trust in medicine and its practitioners.

CHAPTER THREE: THE EMERGENCE OF CONTEMPORARY BIOETHICS: TRIGGERING EVENTS

A central concern of this project is the analysis of the creation of the discipline of bioethics in terms of the legitimation of its knowledge and practice through processes of moral ordering. In the preceding section I discussed the events in Nazi Germany which used medicine and science in a process of moral ordering to legitimate policies and behavior that changed the extant moral order. Ultimately, non-medical responses to these events, events now defined as social problems, allowed an external incursion of the state into the domain of medicine via the Nuremberg trials and the subsequent Nuremberg Code (1946).

In this section I continue to establish the conditions, constructions and contexts of the social and historical emergence of bioethics by examining problematic medical research and technological developments in the United States which led to further moral ordering. Responses to these events also allowed an external incursion into the domain of medicine and led to Institutional Review Boards for overseeing medical experimentation, and the President's Commissions for Bioethics. Later problems in clinical medicine made acceptable the creation of local interdisciplinary bioethics committees to similarly deliberate about clinical bioethical decisions. This construction of the discipline and the practice involves an examination of bioethics as it has manifest itself through the interaction of the worlds of medicine, law, philosophy, politics, and religion, and its emergence as a specialization now considered indispensable to the function of bioethics committees.

How bioethics derives its legitimacy is explored in terms of the practice of moral ordering. This is discussed within the theoretical context of the sociology of knowledge and practice. The most influential fields, outside of medicine, have probably been law and moral philosophy as indicated by the fact that the central problems of bioethics have been framed in their vocabularies. However, these disciplines perform remarkably diverse social, intellectual functions. A key issue in this discussion is whether or not external incursions into medical ethics has actually resulted in a loss of control over medical ethics by the profession of medicine as historians David Rothman (1990) and

George Weitz (1990) claim, or whether medicine has maintained its hegemony despite or through bioethics, as I assert.

In the previous chapter, in discussions of physicians in Nazi Germany, it became clear that the disclosures of the Nuremberg trials had the potential to lay the foundation for a new view of physicians (Ivy 1977; Lifton 1986; Miterscherlich and Mielke 1949; Katz 1972; Reiser 1978; Benson and Roth 1988). The part played by physicians in other research must also be considered in an attempt to understand this putative erosion of trust. In a number of cases of research that I will describe, involving practices whose ethical dimensions have been questioned, there is a pattern of behavior involving a diminution of caring for certain lives. The subjects of research of 'questionable ethics' (Beecher 1966) have largely been children, those diagnosed as mentally ill, women, people of color, and elderly patients. To a lesser extent, they have also included prisoners, soldiers, and students. By devaluing and diminishing the lives of these people, researchers were able to justify continuing to pursue research. From the revelations of American research in 1963 at the Brooklyn Jewish Chronic Disease Hospital and Willowbrook both reported in Beecher's (1966) work, to Tuskeegee, and to mind-control experiments on the mentally ill and soldiers, virtually all of the subjects of biomedical research were defined as marginal or were directly under the control of others.

One aspect of these descriptions of unethical research in the United States involves moral ordering. The reasons and justifications proposed so that research could continue involved a moral ordering to allow researchers to continue or begin questionable research. The researchers claimed that if the work were made public, or patients told of the research, they would not be able to do the research. This reluctance to be open about the work, to keep the research secret, implies a realization that were the facts of the research known, others might not find the research so necessary. In many discussions about informed consent and randomized clinical trials, the discussion gets around to the inability of "lay persons" to understand the importance of the research, or the need for randomization of the trials. The difference between "understanding" and accepting is in the way this is framed. This became very clear in the early days of AIDs research, when well educated and medically "savvy" middle to upper class white men decided that mystification and not involving the patient in decisions and withholding treatment without allowing the patient to make decisions to accept risk were not appropriate research methodologies in establishing the efficacy of medicine that might be lifesaving. The posture that only researchers understand research, including the stance that the end of research is knowledge, is an important justification because it allows the means to be ignored and the ends to justify the activity the researcher wants to pursue. Similar rationalizations pertain to clinical treatment issues and these are vital to understand in terms of how people may be treated as means, and ends overvalued, in a utilitarian construction of social worlds.

Stanley Reiser (1978:13) described how the revelations of the experiments conducted by German physicians on prisoners "evoked the greatest moral concern in all of the events of World War II." The experimentation with infection, the action of poisons, surgical procedures, and sterilization had been carried out on thousands of healthy and ill people (Mellanby 1947; Ivy 1947). Reiser (1978:14) described how:

> During and after the trials, efforts were made to modify the attitudes and practices of physicians in clinical research by drawing attention to the ethical principles under which their work might justifiably be pursued.

But if knowledge is seen as the **summum bonum** then one is arguing contra and across philosophies, one saying that the person is the most valued, the other that knowledge is.

Any cautions raised by Nuremberg were apparently abjured during the 1950s by a new wave of excitement about research in the United States along with the abundant infusion of federal dollars. In fact, little concern about research ethics was heard in the 1940s and 1950s. Reiser (1978:16) described this concern as "a stream which became a river in the 1960s and 1970s." The issue of free and informed consent garnered the most discussion and concern which was stimulated by revelations of breaches in medical ethics.

a. AMERICAN MEDICAL EXPERIMENTS 1900-1990

It was soon disclosed that unethical experiments were not confined to Nazi Germany. Even during the Nuremberg Trials, questionable experiments with prisoners in the United States were described and questioned by the German lawyers for the defence (Nuremberg Trials 1948-1949). Later, in the United States several reports of experiments which had disregarded the humanity of the subjects were published. It is important to understand how these well documented acts may have occurred and what they may demonstrate about legitimation of medical research and practice and a perceived need for external concern about medical ethics. I will therefore review several of the more prominent of these experiments to gain a sense in which it is knowledge and its construction that is the goal of research and which justifies it despite its cost in human or ethical terms.

WILLOWBROOK

In 1955, at Willowbrook State Hospital, a New York institution for the severely retarded, a virologist, Dr. Saul Krugman, deliberately exposed children to hepatitis in an attempt to achieve controlled conditions for testing a vaccine. He justified this experiment by claiming that the children were likely to get rampant hepatitis in any case. The basic ethical issue in this case was said to be the lack of informed consent. These experiments were listed in Beecher's key 1966 article as one of his 22 'ethically dubious' experiments but there was little public reaction to it and the "research" continued. Beecher also discussed it in his book Research and the Individual (1970) and was himself surprised that there was so little response to the revelations (Rothman, personal communication 1990). An interesting footnote to Dr. Krugman's career includes the fact that he was later a recipient of the prestigious Lasker award for research.

THE JEWISH CHRONIC DISEASE HOSPITAL CASE

Another very important case, also listed in Beecher's article, that brought medical experimentation to public notice and further established experimentation as a social problem, occurred at the Brooklyn Jewish Chronic Disease Hospital in New York in July, 1963, brought to public attention in 1964. Three doctors, including chief investigator Dr. Chester Southam, with the approval of the director of medicine, injected live cancer cells subcutaneously into 22 chronically ill and debilitated elderly patients without cancer to determine the ability of these patients to reject foreign and live cancer cells. This study was partially funded by the National Institute of Health (Katz 1972). None of the patients had been informed that live cancer cells were being injected into their bodies, nor that the procedure was unrelated to their therapy (Katz 1972:9-65). Other doctors in the hospital were appalled and reported it to board member and attorney William Hyman. This led to an investigation by the board of directors, and the grievance committee of the hospital. Hyman sued to obtain access to the hospital records to learn the extent of the study (Hyman v JCDH 1964). His concern was both with the abuse of the patients and damage to the hospital's reputation, but also with the possible liability of the institution for giving experimental injections without consent. In the proceedings it was found that the study had **not** been presented to the hospital research committee and that the patient's physicians had not been consulted. Three other physicians who had been consulted said that the experiments should not be done as the patients were not able to give informed consent (Katz 1972:60-61).

The Board of Regents of New York heard the charges against the two doctors. In the Board's capacity as the licensing board for the practice of medicine, they suspended the licenses of two physicians for one year, although the execution of the sentences was stayed (Blumgart 1969:257). However, by that act, they "affirmed that medical experimentation represents a public interest to be protected by law" (Blumgart 1969:257).

One contribution of this decision was that the Regents clearly stated that it was the patient, and not the physician, who was to decide the factors relevant to his or her consent to any experiment (Langer 1966):

> There is evidenced in the record...an attitude on the part of some physicians that they can go ahead and do anything which they conclude is good for the patient, or which is of benefit experimentally or educationally and is not harmful to the patient and that the patient's consent is an empty formality. With this we cannot agree.

The regents also recognized and stated that when the physician is acting as experimenter, he or she can have no claim to the doctor patient relationship that would give the right to withhold information if judged to be "in the patient's best interest." The regents said: Deliberate non-disclosure of the material fact is no different from deliberate misrepresentation of such a fact (Langer 1966). Interesting here is the fact that Dr. Southam eventually became president of the American Association for Cancer Research in 1968 (Katz 1972).

These experiments and the philosophies revealed by them again raises the issue of the balance between the general welfare and individual benefit. This is and will become an increasingly divisive issue as resources become more scarce.

THE TUSKEEGEE STUDY: "BAD BLOOD"

Perhaps the most egregious American study was the Tuskeegee syphilis study. At about the time of Dachau and Auschwitz, the United States Public Health Service (USPHS) was recruiting participants for a long term experiment to determine the natural course of untreated syphilis in black men. The first paper about the research was published in 1936 and several papers were published in medical journals during the experiment.

This research did not receive public attention until 40 years later, when reporter Jean Heller published an account of the study on the first page of the New York Times (July 26 1972 1,8). She reported on unethical practices in a long-term study of untreated syphilis in a group of black men in six Southern states. This study began in 1932, when the United States Public Health Service, supported by several foundations, withheld potentially effective treatment from these men to determine the natural course of untreated, latent syphilis in black males. The study consisted of 400 syphilitic men and 200 uninfected controls. At the time, and since 1910, there was a drug, Salvarsan, for the treatment of syphilis, which was indicated. Even after 1945 when penicillin became available as the preferred treatment for syphilis, the men did not receive therapy. In fact, the United States Public Health Service actively sought to prevent treatment on this and several other occasions.

In 1969 an ad hoc committee at the Center for Disease Control reviewed the Tuskeegee study to determine whether or not it should continue. They concluded that such a study should never be repeated but that this study should not be terminated, nor should they now get the consent of the patients. (Levine 1975:52; Gray 1975).

It was not until the July 1972 publicity in the New York Times, when accounts of the study were first published in the national press on the basis of information provided to the press by one of the researchers that this research was seen as a social problem. It was only then that the Department of Health Education and Welfare halted the experiment. At that time 74 of the test subjects were still alive (Brandt 1978:21, 28; Jones 1981). As a result of this publicity, in 1972 an ad hoc advisory panel was formed to investigate the study and make recommendations to the Assistant Secretary of HEW. The panel, with representation from medicine, law, religion, labor, education, health administration and public affairs, held a series of meetings during 1972 and 1973 and issued a report (USDHEW, 1973).

The report, with the chair's abstention, strongly criticized the study. The group resolved that the study was ethically unjustified even at its start in 1932. The finding of unethical conduct was made essentially on the basis of the failure to inform the men of the risks of joining the study or gain their free and voluntary consent to being involved. Again, as at Nuremberg, the focus was on informed consent. But it is reasonable, from an ethical standpoint, that other ethical principles, such as veracity, fidelity, beneficence, non-maleficence and justice might have been seen as equally involved and as important. By keeping the focus on informed consent the solution again became simply to inform the patient.

In addition to not knowing that they were subjects of a life threatening experiment, the men were led to believe that they were being treated (Jones 1980). Further, it was found that the study lacked a written protocol, lacked validity and reliability assurances, and had an overall design of questionable value for a long-term study of this nature. Again, whatever data were gained through this work were useless.

The majority of the committee were strong in their conclusion that withholding penicillin from the untreated group was unethical. It was found that the subjects were not given any "choice" about continuing in the study once penicillin had become readily available. The panel recommended that the study be terminated immediately.

The panel had been asked to determine whether the existing policies of the DHEW about research subjects and patients were adequate and effective and to recommend improvements if they were needed. The bulk of the report (26 pages of 47) discussed this. A subcommittee, headed by Yale law faculty Jay Katz, recommended a comprehensive reconstruction of the system. This began with a proposal that Congress establish by statute a new, permanent body to regulate all federally supported research involving humans. It suggested that this body should regulate all research in the United States. At the local level, the review group would have two parts, the Protocol Review Board, composed mainly of "biomedical professionals" who would examine proposals, and the Subject Advisory Group, composed of professionals and "laymen" who would be concerned primarily with the quality of informed consent. They would aid subjects in their decision-making when requested by the subjects to do so. There was also a suggestion based on a proposal from lawyer Guido Calabresi (1969) that the cases be published and collected, "in much the same way that the decisions of the court are collected" so that the decisions could be studied and analyzed "in learned journals by lawyers, doctors, and historians of science." The result would be better thought out decisions and a "more complex system of controls" (Calabresi, 1969). Katz went on to be a consultant with Senator Kennedy's Subcommittee on Health and helped draft the bill on human experimentation submitted to Congress (1973).

Others involved were researchers and administrators of the National Institutes of Health (NIH 1966) who constructed regulations for local peer review of ethical aspects of all biomedical research funded by them. So, while there were some insiders pushing for changes in ethics such as

Beecher (1966), for the most part insiders have been resistant to changes in ethics and have had power to avoid a larger disruption. The press for change was from outsiders, actors from ethics, philosophy, law, and the humanities, who came to be known as bioethicists (Fox 1976:231-268).

Here again, the role of researcher and primary physician in the same person was discussed. For example, ethicist Paul Ramsey (1971:703-705) argued in the New England Journal of Medicine, that the research role was incompatible with the doctor's healing function and provided an opportunity for a conflict of interest:

> In community and research medicine there is a potentially unresolvable conflict between, on the one hand, an ethics of principles that protect physicians and their primary patients from violation and from moral self-violation and, on the other hand, the ethics of medicine's scientific mission in the conquest of mankind's diseases - i.e. the social requirement upon medicine to do the greatest good for the greatest number of present and future patients altogether.

Sociologist Renee Fox (1960:135) also advised that the persons undertaking research should not be in charge of the patient:

> The physician-friend and the physician-experimenter have different attitudes and interests, and when one doctor tries to combine the two parts there is a risk - quite a big risk sometimes - that the energy of the experimenter will prevail and that the patient will be deprived of the friend to whom he is absolutely entitled.

Ramsey (1971:705) believed that consent was the key. Consent created a covenant between the physician and the patient who became "joint adventurers in medical care and progress." A nice idea, but later experience with Barney Clarke and the artificial heart revealed a joint adventure, but one which did not benefit Clarke.

OTHER SOCIAL PROBLEMS RELATED TO MEDICINE: RESEARCH IN PSYCHIATRY

There were a multiplicity of defined social problems related to medicine and these were at the forefront of bioethical concern in the 1960s and 1970s. These had an additive effect on the general sense of unease with science and medicine. There were a number of issues in psychiatry that were of concern, generally having to do with the control of the behavior of humans. This became a problem in bioethics with the design of technologies for behavior control. This included control of the "brain" through psychosurgery and electrical stimulation of the brain, as well as through the use of drugs. Dramatic revelations, such as Jose Delgado's (1969) experiments at Harvard on the physical control of the mind which centered on rage centers received much publicity and a photograph of Delgado in a bullring with a bull coming towards him in a rage, suddenly stopped by an electrical device imbedded in the bull's brain was a dramatic illustration of the potential power of external control of the mind now possible. Other issues in behavior control included surgical and chemical sterilization used with prisoners and rapists.

Beginning in Europe in the 1930s and in the United States in the 1940s and 1950s, a number of psychiatrists and neurologists and neurosurgeons conducted brain surgery on institutionalized psychiatric patients without their consent and with questionable benefit. The lobotomy operation, had been introduced in 1935 by the Portuguese neurologist Egas Moniz, who would later receive the Nobel Prize for this procedure. Moniz lobotomized 20 psychiatric patients and claimed surgical success, although the results were indifferent and confusing. In the United States the procedure was cautiously received and spread slowly until the end of World War II. Then, without any systematic experiments on animals or humans, or controlled clinical trials, or investigation of those already lobotomized, lobotomy became what can only be called a fad. The lobotomy entrepreneur in the United States, Walter Freeman, invented a transorbital technique using an icepick. This was easily taught and could easily be performed by anyone. Freeman traveled around the country proselytizing for transorbital lobotomies to control the behavior of psychiatric patients. There were powerful economic considerations which, apparently, effectively stifled any reservations people might have held. The fad ended in the 1950s only with the advent of the psychoactive drug Thorazine which controlled behavior chemically.

Brown (1987) pointed out that:

> whatever the glimmer of scientific rationality of the lobotomies, it was the sense of immanent social and economic catastrophe that most surely pushed some psychiatrists to over ride the restraints others felt about pursuing a radical new therapy.

The perceived collective needs of society, not the rights of individual "subhuman" patients, patterned their behavior. In roughly parallel fashion some German doctors in the 1930s doubtlessly felt that there were no alternatives left for the hopeless, institutionalized patients on whom they committed "euthanasia." They believed that these patients could not be cured and that resources in economically devastated interwar Germany would become more strained every day. Thus, they could justify the killings to themselves.

Behavioral control through drugs, techniques such as Delgado's, and lobotomies and electro- and insulin shock were among the early social problems dealt with in the bioethics discipline.

3. BIOETHICS AND THE STRUGGLE FOR CONTROL OF BIOMEDICINE

Both Barber and his colleagues (1973) and Gray (1975) studied how various social control structures and processes affected medical researchers' sensitivity to the social problems of informed, voluntary consent and of the proper balance between benefit and risk, their ethical concern about the subjects and the ways in which the experiments were planned and carried out. They discussed three major types of control: professional specialization in relation to ethics; patterns of informal interaction in the teams in which the research is carried out; and peer group review of research made mandatory by government and other funding agencies since 1966. They found each of these social control mechanisms deficient.

In their key work, Fox and Swazey (1974) described the dialysis and transplantation, human experimentation, and therapeutic innovation issues in the social environments in which they have occurred. Their work (1974:149-211) is critical of the medical profession in discussing the artificial heart. Fox (1976:251) suggested that there may be:

> some irreducible elements in those situations that cannot easily be changed by enlightened good will, a reformed medical socialization process, or even by new social structural arrangements

The seeds for the development of bioethics and the discipline itself were laid in the 1940s and the discipline itself began to emerge in the late 1960s finding a name in 1970. The sixties, in the United States, were a time for a good deal of change. I would like to touch on some of the contextual and structural issues so that concerns about medical ethics and the subsequent vying for control of bioethics is understandable.

THE GENERAL TIMES: THE 60s

Broad cultural changes were taking place over the 30 years when bioethics as a discipline and the committees were beginning. Concerns raised by movements involving civil rights, women's rights, consumer's rights, rights of prisoners and mentally ill, often included health care components. Abortion, contraception, the right to health care information, and access to care were at the forefront of public attention. The American Civil rights movement, the concerns for consumer protection, public hearings involving government officials, are examples of some of American's increased willingness to challenge authority. This change in attitude strongly influenced the role of the physician in American culture as well as the relationships of patient and physician. Heightened media exposure and a growing public fascination with new medical technology brought an increasing sense that physicians were unilaterally making decisions that were as much moral as medical. All of these social problems brought medical matters and bioethical concerns into visibility and public discourse.

Bellah (1976:333) referred to the 1960s as a period characterized by the "erosion of legitimacy:"

> Far more serious than any of the startling events of the decade was the mass erosion of legitimacy of American institutions - business, government, education, churches, the family.

Consider the social milieu of America in the 1960s during the time in which bioethics was developing. Continuing from its inception in the 1950s, the black equality movement and black militancy movement were gathering strength and in the mid sixties the cry of black power filled the college classrooms where I taught. There were daily protests of the war in Vietnam. There was a demand for long neglected women's, homosexuals, and patient's rights.

The country would find three of its most charismatic leaders murdered in the 1963 assassination of President John Kennedy, and the 1968 assassinations of the Reverend Martin Luther King, Jr. and Robert Kennedy.

There was a general questioning of authority. Science was questioned in 1968 because of the new genetic engineering and molecular biology advances. This occurred along with disclosures by people like Rachel Carlson (1962) about Silent Spring and pollution of the environment. A concern with the environment and ecology was symbolized by the first Earth Day in 1969. The book which gave bioethics its name was published by Ralph van Rensaleer Potter (1970), who wrote of an ethic of responsibility for the whole earth, including the people on the earth.

There were several incisive critiques of Medicine and by 1984 Paul Starr would identify medicine as in "crisis." There were concerns about the profits in health care, the commodification of medical care, and medicalization.

Writers on women's health such as Claudia Dreyfus, Ehrenreich and English, flourished and the ground breaking book Our Bodies Ourselves, which hundreds had read in a mimeographed edition was passed from woman to woman. Posters and buttons read "Health Care for People, Not for Profit."

The field of economics became relevant to many in health when economic analysts began to report on the amount of money spent for various procedures, medicines, operations, and the fees paid to hospitals and physicians. A malpractice "crisis" fueled an anti-medicine mood as well as being simultaneously an outgrowth of that mood. The hopes of great things from medicine meant that expectations were increased, such as expectations of parents for a perfect baby.

The doctrine of informed consent, coined in case law in 1957, was brought to the attention of the medical community. This concept was symbolic of the beginning of the intersection of law and medicine where law began to influence medicine. Medicine, law, and ethics were all affected by issues and concerns in the wider society about individual liberties and social equality, made dramatic by increasingly technological, powerful and increasingly impersonal medical care. This was situated in the context of a period of increased legal interest in the right of self-determination and increased philosophical interest in the principle of respect for autonomy and individualism. These were instances of the new rights orientation that the social movements of the last 30 years introduced into society.

The 1970s and 1980s continued the 1960s trend that marked a gradual shift in public attitude toward medicine from one of uncritical acceptance to considerable suspicion. Urgent societal concerns helped reinforce public acceptance of the notion of rights as applied to health care.

Also in 1961, as I mentioned earlier, the capture and trial of Adolph Eichmann re-introduced the revelations of the Nazi atrocities. These, combined with revelations of celebrated cases of abuse of research subjects in the United States, raised suspicions about the general trustworthiness of medical professionals. This, and women's health movement activities highlighting very manipulative experiences with gynecologists (q.v. Ruzek 1976), informed and moved public opinion. The rise of interest in bioethics was a result of social forces in the second half of the twentieth century changing the role and status of American medicine and a reaction to specific legal developments.

Technological advances in medicine such as life support systems changed the terrain of the possible. Very important to the bioethics movement were advances in birth technology, not the least of which were oral contraceptives. The questions raised by contraceptive availability fueled the dissatisfaction of Catholics in America, such as Andre Hellegers who was very disappointed, as were many Catholics, about the Papal decision not to allow Catholic women to use the new birth control pill as contraception. Abortion was not yet legal but there were many efforts on behalf of taking it out of the criminal arena and placing it in the personal and medical one.

A. BIOETHICS AND THE STRUGGLE FOR CONTROL OF BIOMEDICINE

INTERNAL CONTROL OF MEDICINE

Internal control of medical behavior, including research and medical behavior in relation to patients, is primarily based upon education and socialization, oaths, codes of ethics, and professional licensing and regulatory boards. Early oaths and codes said little concerning physician obligations to patients except admonitions to do no harm. That should have averted most of the problems if *the injunction primum non nocere* had been honored.

Prior to World War II there was limited interest in issues dealing with ethics in treatment or research. One early protest was against the improper use of human subjects published by a Soviet physician (V. Smidovich, writing under the pseudonym V. Veresaev 1901/1916) who wrote a critique of clinical and research practices throughout the world (published in Russian in 1901, translated and published in London (1904) as The Confessions of a Physician, and in 1916 published by Knopf in U.S. (Katz 1972:284-291). These codes were written in response to what were described as (Toellner 1981:279):

> The excessively thoughtless and ambitious use of progress-oriented experimentation in the name of humanity [which] aroused public criticism of experimentation in humans and raised all the questions which still dominate current debates about such experiments.

These too were in response to medical experiments. Neisser, the discoverer of gonococcus, in the late 1800s, had given non-syphilitic prostitutes and very young girls injections of a serum obtained from syphilitics, without informing or receiving permission from the women injected. These experiments evoked, perhaps for the first time, a general discussion about the justification of medical experiments on humans. The Prussian Ministry of Culture at the conclusion of this discussion, pronounced an Ordinance (29 dec 1900) that forbid performing medical experiments on those underage and stating that in all cases subjects must give their consent after being accurately advised of the risks involved.

However, during the Weimar Republic further serious incidents and deaths were exposed which had resulted from experimentation, particularly with children. These disclosures evoked fervent discussion between the advocates of academic medicine and its opponents, mostly advocates of natural medicine. The final event was the uncovering of the fact that the director of a prominent hospital, supported by the Council of Health of the city, had experimented with tuberculosis vaccination resulting in the deaths of 14 children. The Minister of the Interior met with the Council of Health 1930 to discuss the trustworthiness of human experimentation. Several medical authorities presented papers leading to the famous guiding principles which the Minister of the Interior sent to the Provisional governments in February 1931. These rigorous Richlinien, regulations and guides were issued to control human experimentation and the use of innovative therapies in medicine.

In its 14 paragraphs, procedures about new types of healing methods were precisely delimited. The inadmissibility of medical experimentation on destitute individuals was defined for the first time. They also dealt with the nature of the appropriate information to give the patient, issues of informed consent and refusal, careful research design, and special protection for vulnerable subjects. They declared that human experimentation was unthinkable without consent and absolutely forbade research with dying subjects. These German regulations had more stringent demands than the later Nuremberg codes would be and remained binding law throughout the period of the third Reich. No other nation had such advanced regulations by 1946. The protection of the patient remained subject to the conscience of the physician (Toellner 1981:280). This was true after the Nuremberg Codes as well.

B. BIOETHICS ESTABLISHED: THEORY

POST WORLD WAR II: MORALS AND MEDICINE

After World War II and the Nuremberg trials, from 1946 to 1966, attention to the institution of medicine and its ethical concerns ebbed, with the exception of a few books. One book, by Episcopal theologian Joseph Fletcher (1954), Morals and Medicine, helped to set the debate and was a key contribution to ethics in this period. Up until the publication of Fletcher's book, textbooks by Catholic moral theologians comprised the primary religious literature on medical ethics (Kelly, 1979). Fletcher's work, provided the exception. His book is the one quoted by most bioethicists as the book that signaled a new direction in ethics. This was, however, preceded by two other classic works which called for a true ethics in medicine, rather than the ethics of etiquette and trade heretofore published. Both of these works were by physicians at the University of California at San Francisco. One by Chauncey Leake, discussed Percival's Ethics and called for a true medical ethics, the other by Otto Guttentag called for a return of ethics to medicine.

Ethicists such as Daniel Callahan consider Fletcher's book a marker for the beginning of contemporary bioethics. It was the single book most cited in the four volume Encyclopedia of Bioethics (Reich 1978). This book may represent the advent of a new knowledge claim; that of a general, civil bioethical knowledge; civil or secular bioethics as opposed to religious bioethical knowledge. It was perhaps, the first book about these issues to deal with ethics from a non-Catholic perspective. Fletcher questioned many of the presumptions of Catholic theology, which had dominated the field of moral medicine, and would continue to do so until the 1960s. In fact, in his introduction to Fletcher's book, psychiatrist Karl Menninger (1954:xiii) noted that with the "exception of Catholic moralists" there was a "blindspot" about the "ethics of health and medicine in almost all ethics literature." Fletcher (1954:16) noted that:

> the Catholic literature on the morals of medical care is both extensive and painstaking in its technical detail, while Protestant and Jewish literature is practically non-existent.

In fact, Catholic physicians had a Federation of Catholic Physicians' Guilds and published the Linacre Quarterly, a Catholic journal which applied Catholic principles to the philosophy and ethics of medical practice.

Fletcher's book (1954), were based upon his Lowell Lectures delivered at Harvard University in 1949. The lectures and the book were organized around five practical problems in the ethics of medical practice from the point of view of the patient. The book (1954:x) was centered around human rights:

- Medical diagnosis: Our right to know the truth;
- Contraception: our right to control parenthood;
- Artificial Insemination: our right to overcome childlessness;
- Sterilization: Our right to foreclose parenthood; and
- Euthanasia: Our right to die.

What Fletcher advocated was radical: that in order for patients to act as morally responsible agents they must have the knowledge and freedom to make those choices. They must be allowed to make an informed consent or refusal predicated upon the physician's obligation to tell them the truth. In fact, Fletcher (1954:33) maintained that in order to be a moral being one must have freedom and knowledge:

> Without their freedom to choose and their right to know the truth, patients are only puppets. And there is no moral quality in a Punch and Judy show.

The two most controversial parts of Fletcher's work were his discussions of reproductive rights based upon the principle of individual choice which was antithetic to Catholic doctrine and his belief that euthanasia was permissible both because the moral status of persons were more important than prolonging life needlessly (1954/1960:191) and because the principles of right based upon "selfhood" and "moral being" favor it (1954/1060:208).

After a flurry of attention to this book, there was virtually no public discussion of medicine and ethics for the next 10 years, 1956 to 1966. Many who had been interested in bioethical concerns turned their interest to the civil rights movement and the ethical issues raised by the Vietnam war.

Then, in a three year period, several events occurred that were critical to a developing wariness of science and medicine. First were the 1966 Beecher revelations of unethical research leading to a public awareness of, and concern about, the propriety of medical experiments. Then, two medical "advances" aroused this interest: the first human heart transplants and genetic engineering.

In an exception to the silent hiatus from 1956-1966 was Harvard anesthesiologist Henry Beecher's (1959:3) monograph, Experimentation in Man. In the introduction, to this monograph, Beecher (1959:3) said that the atrocities disclosed at Nuremberg and modern breakthroughs in biomedical research called for "a long straight look at our current practices." However, this book did not captivate the attention Beecher thought it would. What did gather both public and professional attention, however, was "Ethics and Clinical Research," Beecher's 1966 landmark New England Journal of Medicine article which re-established the public dialogue about medicine and ethics. Beecher (Rothman, personal communication 1990) guaranteed public discussion of the revelations in his article by informing, among others, the New York Times, the Wall Street Journal, Time and Newsweek that the article was being published in the New England Journal of Medicine. In the article he reported on 22 published cases of research which contained dangerous or potentially serious ethical violations in research that had been conducted since World War II that exhibited clear disregard for human rights. The article received widespread commentary in the media both medical and public but disappears. The greatest impact was perhaps felt by the National Institutes of Health who funded the majority of research and whose representatives were asked by key congressman what they were going to do about the matter.

Beecher had documented his work with examples from leading medical schools and university hospitals including the National Institutes of Health. In the article there are no citations to the original publications. These were later revealed in David Rothman's 1987 article "Ethics and Human Experimentation: Henry Beecher Revisited." In discussing the frequency of ethical violations, Beecher (1966) said that a preliminary examination of the matter had been based upon 17 examples which he was able to easily increased to 50. These 50 studies contained references to 186 further likely examples. Beecher (1966:1354) concluded that the data were symptomatic of widespread problems and that he felt he had documented that "unethical or questionably ethical procedures are not uncommon." He also obtained another kind of information, by examining 100 consecutive human studies published in 1964, "in an excellent journal; 12 of these seemed unethical." Aside from issues of informed consent Beecher revealed examples of unethical or questionably ethical studies and cases where known effective treatment was withheld. A few cases will illustrate the kinds of problems described in the article.

It was known that rheumatic fever could usually be prevented by adequate treatment of streptococcal respiratory infections by the parenteral administration of penicillin. Nevertheless, definitive treatment was withheld, and placebos given to a group of 109 men in service, while benzathine penicillin G was given to others. The men were not advised of the experiment and 25 developed rheumatic fever.

Another study was of children undergoing cardiac surgery for congenital heart disease. They were randomized into two groups. In one group a thymectomy - removal of the thymus gland - was done and in both groups full thickness skin homographs from an unrelated adult donor sutured to chest wall. This was purportedly to examine the effect of thymectomy on immunological resistance in children.

Beecher (1966:1354) said that finding these cases published in medical journals was very easy and that "if only one quarter of them is truly unethical, this still indicates the existence of a serious situation." His report received widespread commentary in the media both medical and public but shortly disappeared. The article was said to have "stunned his colleagues into an awareness of the problem" (Barber, 1978:3). However, Barber thought that while Beecher may have "raised the level of consciousness of the medical research world" his analysis was "too individualistic, and focused too much on the individual psychology of the physicians conducting the research." Beecher thought he was dealing with "bad guys." What others have claimed, on the contrary, was that it was a "bad system" that was turning "good guys" into "bad guys" (Lally and Barber 1974; Barber 1976). A similar issue was considered ten years later in a discussion of the responsibility and guilt of those in the DES scandal. Physician researchers Apfel and Fisher (1984:8) in analyzing the responses to the findings regarding DES said:

> The people to whom we described our findings always failed to grasp what we were saying at first. They wanted to know who was responsible for the disaster - who profited by it, either in money or reputation or public honors. They wanted to know who had deceived the public and why. They wanted, in short, the secret inside story of how the scandal occurred. We had to tell them that there was no inside story, no significant heroes and villains; that the scandal is intrinsic to the very structure of modern medicine.

Those at the National Institutes of Health were trying to develop policies regarding research with human beings. Beecher's article contributed to the development of their policy. It was the flagrant violation of any concern for the individuals participating in research without their knowledge or consent and to their danger, which invited external control of medical research and its practitioners. Beecher had drawn attention to another study by Pappworth, a British physician, who was in the process of collecting what would eventually comprise over 500 cases of questionable ethical research. Pappworth's book (1967), Human Guinea Pigs: Experimentation on Man, was critical of the experiments being performed on humans, and of the lack of external controls setting limits on doctors, and of the absence of informed consent by patients. Pappworth attributed the decline in the doctor patient relationship to the wedges that experimentation had driven between "physician friends" and their patients. However, he too assumed that human experimentation was necessary and desireable. Pappworth (1967:200) recommended prior review of research, compulsory reporting of the research during the term of the experiment, and full disclosure to the subject of any danger, minor or major. Unlike Beecher, Pappworth focused his discussions upon rights and principles.

Psychiatrist Jay Katz with Lawyers Alexander Capron and Glass, published a collection of cases about research ethics and law, Experimentation with Human Beings (1972). Katz says he was moved to write this because of his horror over the holocaust. He felt that unless all were made aware of the possible tension between the protection of subjects and the principle of free scientific inquiry, the problems might recur. The writers of literature on ethics and experimentation writing during the 1960s and 1970s drew public and academic attention to problems involving medical ethics by their whistleblowing on concrete examples of abuse of persons by specific researchers. These were central to bringing about regulatory action. The studies drew public attention to medical ethical problems through the use of extensive case studies of outrageous scandals or dubious practices in biomedical research settings.

NEW MEDICAL TECHNOLOGIES: RENAL DIALYSIS, HEART TRANSPLANTS AND R-DNA

The relationship between new technologies and ethical problems in medicine can be illustrated by the cases of renal dialysis, heart transplants and R-DNA.

RENAL DIALYSIS

In 1960 physician Belding Scribner at the University of Washington developed an indwelling shunt to allow a patient to be connected to the dialysis machine for long periods of time and by 1962, long term dialysis was made possible at the Seattle hospital dialysis unit. For each of the dialysis machines there were several potential patients. These allocation problems were brought to public attention in a 1963 Life magazine article entitled "They Decide Who Lives, Who Dies: Medical Miracles and a Moral Burden of a Small Community." In this article, journalist Shana Alexander described an appointed committee of lay men and women, known irreverently as the 'god squad', who determined who would get dialysis, and, in fact, to ascertain who would live and who would die. Before being placed in the pool of potential recipients of dialysis a number of decisions had already been made. These consist of excluding children and those over forty five, residents outside of the state of Washington. In the interviews with the committee members it became clear that the allocations were made on the basis of social worth. Those chosen were predominately male, employed, married, church members, parents, and scout leaders. The choices prompted the comment in a law review article that: "The Pacific Northwest is no place for a Henry David Thoreau with bad kidneys." This very difficult "problem" was eventually dealt with by Congress in 1973 through legislation that made dialysis available to anyone who needed it. As later events revealed, this solution was not realistic - economically, socially, or medically.

Alexander (1962) described the Seattle's Swedish Hospital committee's decision making about selecting the first five patients to participate in the dialysis program. She wrote:

> For the present, someone must choose, which one patient out of 50 shall be permitted to hook up to Seattle's life-giving machines, and which shall be denied.
>
> There is in Seattle a small, little-known group of quite ordinary people who have now made this choice five times, and will make it five more times before this

> year is out. For John Meyers and his fellow patients were not chose by lot. They were not even chosen by physicians. Each was selected individually by an organization named The Admissions and Policies Committee of the Seattle Artificial Kidney Center at Swedish Hospital. Behind this magnificent polysyllabic facade stand seven humble laymen. They are all high-minded, good-hearted citizens, much like the patients themselves, who were selected as a microcosm of society at large.
>
> These citizens are in fact a Life or Death Committee. With no moral or ethical guidelines save their own individual consciences, they must decide, in the words of the ancient Hebrew prayer, 'Who shall live and who shall die'.

The committee met for the first time in the summer of 1961. They included a lawyer, minister, banker, housewife, a state government official, a labor leader, and a surgeon. The prospective patients had been pre-screened by a board of physicians. That is, the medical board had already made "certain rather arbitrary decisions designed to lighten the committee's burden as much as possible" (Alexander 1962).

Doctors recommended a rule to reject automatically all candidates over 45 years of age and children. The doctors believed it would be a mistake to accept children for in so doing they would be "forced to reject heads of families with children of their own."

Two physicians conducted the initial briefing and offered to sit in on all the committee's future meetings in an advisory capacity. The committee members "gratefully accepted" this offer.

> LAWYER: The doctors have told us that they will soon have two more vacancies at the Kidney Center, and they have submitted a list of five candidates for us to choose from.
>
> HOUSEWIFE: Are they all equally sick?
>
> DR. MURRAY [DIRECTOR OF KIDNEY CENTER]: Patients Number One and Number Five can last only a couple more weeks. The others can probably go a bit longer. But for purposes of your selection, all five cases should be considered of equal urgency, because none of them can hold out until another treatment facility becomes available.
>
> LAWYER: Are there any preliminary ideas?
>
> BANKER: Just to get the ball rolling, why don't we start with Number One - the housewife from Walla Walla.
>
> SURGEON: This patient could not commute for treatment from Walla Walla, so she would have to find a way to move her family to Seattle.

BANKER: Exactly my point. It says here that her husband has no funds to make such a move.

LAWYER: Then you are proposing we eliminate this candidate on the grounds that she could not possibly accept treatment if it were offered?

MINISTER: How can we compare a family situation of two children such as this woman in Walla Walla, with a family of six children, such as patient Number Four - the aircraft worker?

STATE OFFICIAL: But are we sure the aircraft worker can be rehabilitated? I note he is already too ill to work, whereas Number Two and Number Five, the chemist and the accountant, are both still able to keep going.

LABOR LEADER: I know from experience that the aircraft company where this man works will do everything possible to rehabilitate a handicapped employee.

HOUSEWIFE: If we are still looking for the men with the highest potential for service to society, then I think we must consider that the chemist and the accountant have the finest educational backgrounds of all the candidates.

SURGEON: How do the rest of you feel about Number Three - the small businessman with three children? I am impressed that his doctor took special pains to mention that this man is active in church work. This is an indication to me of his character and moral strength.

HOUSEWIFE: Which certainly would help him conform to the demands of the treatment....

LAWYER: It would also help him to endure a lingering death...

MINISTER: Perhaps one man is more active in church work than another because he belongs to a more active church.

BANKER: We could rule out the chemist and the accountant on economic grounds. Both do have a substantial net worth...

LAWYER: Both these men have made provisions so that their deaths will not force their families to become a burden on society.

STATE OFFICIAL: But that would seem to be placing a penalty on the very people who have been most provident....

MINISTER: And both these families have three children too.

LABOR LEADER: For the children's sake we've got to reckon with the surviving parent's opportunity to remarry, and a woman with three children has a better chance to find a new husband than a very young widow with six children.

SURGEON: How can we possibly be sure of that?

It is clear from the dialogue, that social worth is guiding the committee. At the end of an hour and a half discussion two patients were chosen: the aircraft worker, and the small businessman, John Meyers. The selection of these two "productive" patients, and the non-selection of those seen as less "worthy" elicited much negative response in newspapers and magazine articles at the time.

Alexander (1962:103) agreed with the committee process, and the:

> acceptance of the principle that all segments of society, not just the medical fraternity, should share the burden of choice as to which patients to treat and which to let die. Otherwise society would be forcing the doctors alone to play God.

But forcing lay people to play God was also problematical as this experience showed. There were no principles to guide either the physicians or the lay members of the committee in making these difficult choices of allocation of scarce resources.

HEART TRANSPLANTS

However, nothing captured the public and media imagination of Americans as did the first human heart transplant in South Africa in 1967. The myths of Dr. Faust and Dr. Frankenstein merged as that first human heart was taken from a 'dead' woman and implanted in a dying grocers chest. Physicians all over the world rushed to duplicate Dr. Barnard's adventure, and indeed, 108 hearts were transplanted in 1968, in what the media labeled the "year of the transplant" (Time Magazine 1968) and what the Journal of the American Medical Association titled its editorial: After 25 Centuries, 1968 Became the Year of the Transplants." (JAMA Editorial 1968:835).

The accomplishment of the heart transplant, symbolizing the artificial creation of life, was noted by the first heart recipient, Louis Washkansky ((NYT Dec. 1967), who on his third postoperative day with his new heart said: "I am the new Frankenstein" (Thus carrying on the tradition of confusing creator with created).

Heart transplants suddenly created new problems, problems such as needing a fresh and still beating donor heart but from a 'dead' person which forced a new definition of death. A Harvard committee chaired by the same Henry Beecher who in 1966 blew the whistle on dubious research ethics was appointed in 1968 to develop a doctrine of "brain death." This definition became authoritative in the United States. By this standard if the brain were dead, then even if the heart were beating the person could be pronounced dead and his or her heart "harvested."

R-DNA

Shortly after the heart transplant breakthrough, Stanford scientists announced the discovery of recombinant DNA techniques (1968). Now there was the potential for life to be humanly created and changed. References to George Orwell's vision of the future unforgettingly depicted in his book 1984, filled the media. Biochemist Arthur Kornberg, synthesized a DNA copy of one simple virus which duplicated the six genes of the original virus including having the exact genetic activity of the parent virus's genes. The potential was seen for social control and engineering of the sort that was reminiscent of the earlier eugenics discussions. But this was far more powerful than simply forbidding some to stop breeding or breeding only the fit. This would permit scientists to create life in a test tube.

POLITICAL ACTION IN RESPONSE TO THE NEW TECHNOLOGIES

The confluence of the power revealed in these two discoveries prompted Walter Mondale, then Senator from Minnesota, to introduce and then present a joint resolution to Congress in February 1968 and later hold testimony from the elite of medicine and science to form an ethics advisory board in the government. To Mondale and others it seemed that a more public ethics had to be imported into medicine. Senator Fred Harris of Oklahoma, who would chair the committee hearings said that

> These matters ought to be talked about in the open by people from various backgrounds with various viewpoints - theological as well as medical, legal as well as sociological and psychological.

The wedges created by public concern over these events described made it possible for then Senator Mondale to demand some sort of accountability. This gave fuel and legitimacy to the new discipline of bioethics.

In 1968, Mondale (Congressional Record, Thursday, February 8, 1968) introduced a Joint Resolution to Establish a Commission on Health, Science and Society

Mondale:

> Mr. President, the current advances in health science and technology are bringing men more and more power in matters of life and death.
>
> **In California, man has created a kind of life. In South Africa, New York, and California, man has taken another step on the path of prolonging life through the substitution of vital organs. And some scientists are predicting that human intervention in genetic processes will one day make it possible to choose which parent a child will resemble.**
>
> These dramatic possibilities, and others perhaps unimagined as yet by most of us, hold great promise for the present and future of mankind. At the same time, they raise profound and complex questions of ethics, law, and public policy -- **what is life and what is death; who shall live and who shall die; how long shall life be preserved and how shall it be altered; who shall make which decisions; how shall society be prepared? [my emphasis]**

Mondale (1968:450) then said that:

> The purpose underlying the Commission's functions is **not to interfere with medical research. Indeed it is to encourage it**, but also to be sure that the moral and social implications of the products of such research are fully and responsibly considered and dealt with. [my emphasis]

Note that Mondale does not question the necessity of research but accepts the biomedical assumption that research should be done. Mondale is simply asking for some controls on research, that the "moral and social implications of the products of such research are fully and responsibly considered and dealt with."

Before the hearings scheduled for Mar 7, 8, 21, 22, 27, 28 by the subcommittee on government research of the committee on government operations Mondale wrote to 200 physicians, deans of schools of medicine, law and theology, social scientists, and public administrators. He received over 150 letters. Of these, 137 supported the commission, and only 13 were against the idea. The replies included those from twenty five heads of medical schools and schools of public health; 18 deans of theology schools and theologians; 16 deans of law schools; 27 physicians and scientists; 51 social scientists, public administrators and the public at large.

The initial committee proposal was to have only scientists and other professionals on the committee. But Hardin, a physician and the Dean of Howard University, wanted a broad array of others included: life scientists, teachers and administrators, health practitioners, public administrators, economists, educators sociologists, and the American public (Hardin in Mondale 1968).

Dean Julius Richmond, M.D. of SUNY Syracuse School of Medicine said:

> Concerning the structure of the commission, I would strongly urge that it not be attached to any existing health agency. Also I would suggest that it not come under the aegis of the National Academy of Sciences or its newly established Board of Medicine in order to give it the freest possible range and try to keep it free of conventional professional political influences.

Mondale then asks a series of questions - remember this is 1968 - twenty three years ago:

> **I. WHAT IS LIFE AND WHAT IS DEATH?**
>
> Heart transplant operations cloud the distinction between life and death, based on the heart beat. The artificial production of a viral core that can replicate itself raises the issue of what besides the ability to reproduce distinguishes life from nonlife.
>
> **II. WHO SHALL LIVE AND WHO SHALL DIE?**
>
> Over 400,000 persons died last year from coronary heart disease. Some could have been saved at least for a time by heart transplant operations. An estimated 7,700 persons died last year for lack of kidney transplant operations.
>
> Theological and moral concerns are manifest in the decision making process. The disparity between demand for transplants and supply of organs, personnel and facilities makes decisions about who shall give and who shall receive the most difficult kind of ethical and moral issue.
>
> **A. THE PHYSICIAN**
>
> The Hippocratic oath instructs the physician to do no harm. But developing medical techniques for prolonged life raises a complex question - do no harm to the potential donor or no harm to the life of the potential recipient?
>
> William A. Nolan, M.D., of the Litchfield Clinic, Litchfield, Minn., wrote to me of some of the ethical problems he and other members of his profession face every day:
>
> "I have been a participant in the weekly surgical conferences at Hennepin General Hospital in Minneapolis for the last six years. Time and time again problems arise relating to tissue transplantation. Under what circumstances can we in good conscience declare an individual dead? Do we use an electroencephalogram, an electrocardiogram, or simple clinical signs to determine the absence of life? How should the relatives of the potential donor be approached? When can the donor be put on a heart-lung bypass? I could go on indefinitely. The point is that confusion reigns even in a center where kidney transplants are frequent. Policies are established but on uncertain grounds."
>
> **B. PATIENT AND FAMILY**
>
> The basic principle guiding choice of donors and recipients is the consent of both parties.
>
> Basic to the ethics and law in this area is the notion that consent be informed and that it be voluntary.

> Discussions have continued for years about what constitutes informed and voluntary consent. The same kinds of questions are raised again by the transplant operations but in a more dramatic context.
>
> C. SOCIETY AT LARGE
>
> How much is a man's life worth?
>
> To ask questions about finance is to see the relationship between social decisions and life and death.
>
> An estimated cost for transplanting a kidney is $5,000, plus follow up care, The cost for hearts may be much more, yet $130 per year could give adequate, routine health care to poor Americans.
>
> A public commitment of $1 billion could buy enough kidney and community dialysis centers to serve the 25,000 or more who will need them in the next decade. Or it could buy comprehensive ambulatory care for more than 1,250,000 poor people.
>
> This is a question of distributive justice. Obviously we need both kinds of health care services. But with limited resources and disagreements about the extent and direction of public commitments, the priorities we establish affect both the quantity of life - who lives and dies - and the quality - just how health people really can be.
>
> D. THE LAW
>
> Legal issues emerge when one examines State statutes dealing with such subjects as donation of human tissues, property rights in dead bodies and mutilation of corpses.
>
> To begin with, what is "death"? As pointed out before, techniques which preserve the function of the heart while other body processes have ceased may make the present medical definition of death obsolete. Law does not provide guidance to the physician faced with the decision as to how long to maintain life artificially through use of a machine. Many writers have called for a redefinition of "death," perhaps based on cessation of brain function.
>
> Then there is the issue of immunity for physicians. Even if a person has donated organ or tissue through a will, there is a legal question of whether the physician could be found guilty of mutilating the corpse if the relatives wanted the body whole for burial.
>
> The dramatic events of recent months have focused attention on the implications of the transplant operations. But the same kinds of questions arise when considering the implications of genetic research, including the DNA - deoxyribonucleic acid - discoveries.

During the hearings, three transplant surgeons testified. Each of them requested increased federal research funds and agreed that a commission was suitable but qualified the power the commission was to have. John Najarian (Hearings on the National Commission 1968:24) agreed that the time for the "aura of mystique" in medicine was past. He agreed to a standardized definition of brain death but warned against the committee interfering with the work of medicine and science. He maintained that if heart transplants were done in university medical centers, some of which have their own review committees, then "you are in the milieu here I think of the best social conscience you can have." Surgeon, Norman Schumway (Hearings on the National Commission 1968:149) agreed that heart transplants could not "fortunately or unfortunately" be done "without public notice and public support."

Henry Beecher was clear that public discourse was needed. Beecher (Hearings on the National Commission 1968:121) contended that a lay presence was needed because "science was not the highest value." He felt, indeed, that science had to be subsumed into other values, into "the order of values."

The testimony of the surgeon who performed the first human heart transplant is interesting. Christiaan Barnard (Hearings on the National Commission 1968:70) testified in opposition of any sort of oversight by a commission, especially one that was not a medical one. He accused Mondale of "seeing ghosts where there are no ghosts." Barnard opposed a new definition of death as well saying that doctors had always certified when a patient is dead and there is no reason, he felt, for a change. In the case of a transplant, this decision is made by a team of doctors. He saw no need for new definitions or for commissions. Decisions of who gets the heart, as who is allocated any resource is nothing new, Barnard said, and these decisions should continue to be made by physicians.

A Minnesota surgeon, the famous Owen Wangensteen (Hearings on the National Commission 1968:98) was utterly opposed to the idea of a commission in which theologians might decide medical matters, and said that medicine would be "manacled by well-intentioned but meddlesome intruders." He held that the people doing the work should make the decisions.

As noted by Mondale in his opening remarks to the commission, transplantation was a key issue, but so also were genetic engineering and behavior control. In the testimony of Arthur Kornberg synthesizer of R-DNA, Senator Abraham Ribicoff (Hearings on the National Commission 1968:41) asked the question that connected Kornberg's work to that in Germany in the 1940s: "Do you see this work of yours leading to the creation of a master race?" Kornberg (Hearings on the National Commission 1968:45) stated that: "I would like to be a part of a 'master race' relieved of some of the scourges that have plagued people for centuries." Kornberg (Hearings on the National

Commission 1968:52) also said that: "This concern [about] our creating little men in test tubes, and a super race, is really not so relevant today."

In terms of the issue of behavior control raised in his introduction to the commission by Mondale, Harvard psychiatrist, Seymour Kety described the use of electrodes to stimulate rage and aggression. The phenomenal implications of the ability to manipulate and control human behavior were frightening to some in congress. While Kety believed that manipulation of the brain "would involve such drastic invasions of privacy, integrity, and inalienable rights of the individual" he also felt that there was no need to worry about this occurring.

The key issue in all of these deliberations were the new technologies. Mondale (Hearings on the National Commission 1968:5-6) said that the race was to keep up with new technologies: "we have been too late, too secret, and too superficial in too many cases." Both Mondale and Ribbicoff referred back to the dropping of the nuclear bomb and the fear of a nuclear holocaust as proof that there is a need to look closely at the implications of what is done.

PROGRESS OF THE COMMISSION

The commission proposal did not pass right away. One reason may have been that Mondale had underestimated the medical opposition to the idea of a commission. Mondale felt that this kind of commission would be a wonderful idea. The physicians felt otherwise. In retrospect one may wonder at Mondale's naivete in thinking that physicians would give up any power of decision making, especially to a body appointed by congress. Also, the proponents of the commission were liberal democrats; the president and administration at the time were Richard Nixon's.

The commission proposal was defeated in 1968. Mondale and Edward Kennedy introduced the resolutions again in 1971 and in 1973 and finally, in 1974 the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was created. The success of Mondale's proposals found strength because of the exposés of unethical research with humans. The

Tuskeegee research reported in 1972 was perhaps the most influential and dramatic. Partly because of the numbers of researchers involved and the length of time of the research, but also because of the subjects of this work.

This and other exposes prompted several congressional hearings and proposed bills. Mondale introduced again the proposal for a national ethics advisory commission, Senator Jacob Javits and Hubert Humphrey introduced again their bill to regulate human experimentation (Congressional Record 24 March 1971:7670), Senator Edward Kennedy's hearings on the "Quality of Health Care: Human Experimentation (Hearings before the Senate Subcommittee on Health 1973:1055). Because the latest scandals created an awareness of a social problem and an awareness that the medical profession had not maintained appropriate professional oversight in research matters, the Kennedy hearings were perhaps more successful than the earlier Mondale hearings. Kennedy, in his opening remarks, confirmed the fact that physicians and researchers had abused their professional powers. He said that there had been a lack of oversight combined with "the most unlimited freedom of action which physicians have in the treatment of their patients." This, maintained Kennedy, had resulted in dangerous practices.

The key cases Kennedy referred to were the misuse of the contraceptive drugs diethylstilbestrol (DES) and Depo-Provera. DES was a drug used to prevent miscarriage and Depo-Provera to treat cancer of the uterus and endometriosis. While neither were approved by the FDA as contraceptives, this was the use to which they had been put. The hearings included testimony about human experimentation involving questionable ethics including experimentation in prisons, psychosurgery and behavior control, genetic engineering, and the marginal status of those experimented upon be it pharmacological, surgical, or whatever form of experiment (Kennedy 1973).

Columbia University sociologist Bernard Barber (Quality of Health Care: Human Experimentation 1973) based his testimony on a large survey he had made and he determined that professional peer review had failed to oversee the ethics of experimentation. He found that science superseded ethical concerns then as in the past.

The work of the Kennedy hearings resulted in a legislative proposal requesting the creation of a National Commission for the Protection of Human Subjects. Kennedy (1973:1264) emphasized the necessity for external control and maintained that the policies developed by the committee would emerge not from the medical profession alone, but from ethicists, theologians, philosophers and others. The Senate accepted Kennedy's proposal as it was written but the House produced a version of the committee that was temporary, rather than permanent. This weakened the body enormously. It was further rendered ineffectual in making it advisory to the secretary of the Department of Health, Education, and Welfare, without any power of enforcement.

This commission opened a role for outsiders in bioethics and the very presence of a commission legitimated the incursion of outsiders. The commission also symbolized an incursion of non medical attention to medical ethics. As the commission was completing its three year charge in 1978, Kennedy was able to reframe the committee into the President's Commission for the Study of Ethical Problems in Medicine.

NIH GUIDELINES FOR HUMAN RESEARCH

Another federal agency, the National Institute of Health clinical center opened in 1963, and the federal government had to face the issue of medical ethics. The NIH 17 November 1963 and its researchers prepared and issued guidelines "Group Consideration of clinical Research Procedures Deviating From Accepted Medical Practice or Involving Unusual Hazard." This document stated that research studies that gave rise to ethical questions were to be reviewed by a committee. The guidelines applied to intramural research at the NIH where a medical review committee reviewed studies involving ethical considerations (Federal Regulation of Human experimentation 1975:13). The primary responsibility for the ethics of research was still on the individual investigator. This document was the first policy established for the protection of human subjects in a United States government health care facility. By 1966 the NIH and the USPHS promulgated guidelines for the protection of rights of human subjects which finally became regulations of the DHEW in 1971 requiring local institutional review by medical and lay panels. These local IRBs initially mandated by the NIH are now completely under the domain of medical researchers and physicians. Some sociological investigation indicates that they primarily serve research priorities.

These papers and guides recommended Institutional Review Boards and or ethical committees as had been described according to paragraphs 1 and 2 of the Helsinki-Tokyo Declaration (1975 in Reich 1978:1771) such as those required by the US Senate (US Senate 1975:30-91 and earlier 1973 and The Belmont Report (1978).

In a survey commissioned by the National Institutes of Health in 1962, and directed by the Law-Medicine Research Institute of Boston University, 86 departments of medicine were asked to respond to a questionnaire which dealt with their use of policies and procedural guides to conducting research (Ladimer and Kennedy 1963). In the 52 responses they found only 9 institutions that had procedural guidelines documents for experimentation committees although 22 had committees examining the questions concerning the use of human subjects (Curran 1969:547, 549). Curran said that at the time there was skepticism toward ethical guidelines for researchers were to be guided by "their own professional judgement and controlled by their own ethical standards as well as those of their institution" (Curran 1969:549). Here again we see the belief in "good people" and their own personal standards as more important than ethical guidelines promulgated from outside the profession.

The idea of a committee to review these issues

was to illuminate the government's legal and ethical obligations for research review. The Livingston report (1964) left the responsibility on the shoulders of the medical community to oversee the ethics of research. The investigators found that few institutions had any research guidelines and in fact typically objected to any kind of oversight. Investigators believed that research matters, including ethical components of the research, be left to the research physicians. However, James Shannon director of NIH 1955-1968 responded to the Livingston report with caution. He felt that in the climate of the times, more was needed:

> To win general acceptance within not only the medical community but also in our society at large, the final statement on principles should probably emerge from a group which includes representatives of the whole ethical, moral and legal interests of society.

By 1966 the NIH and the USPHS promulgated the February 8, 1966 guidelines for the protection of rights of human subjects. Then surgeon general Stewart announced that a "committee of his institutional associates" must approve any extramural research funded by the USPHS. These federal research regulations were incrementally enhanced and amended.

On 1 May 1969, the 1966 guidelines were revised and changes introduced to include a broader group of committee members. The narrow group of biomedical scientists were enlarged to mandate that "the committee must be composed of sufficient members with varying backgrounds to assure complete and equitable review...." And requires that "the membership should possess not only broad specific competence to comprehend the nature of the research, but also other competencies necessary in the judgement as to acceptability of the research in terms of institutional regulation, relevant law, standards of professional practice, and community acceptance (Katz 1972:886-889; Beecher 1970:293-296).

The 1966 USPHS regulations required all institutions to which it made grants to establish boards to review investigations involving humans to safeguard rights and welfare of research subjects and consent and evaluate the risks and benefits. But the question of whether or not investigators follow an approved protocol came up. Some, such as Gray (1975:243-245) and Sackoff-Lambert (1984) wondered if, in fact, investigators follow the approved protocol, and found, that indeed that was problematical. At the end of 1971 the revision of the 1969 guidelines appeared and the **yellow booklet** had requirements for committee membership similar to 1969. The ability to judge the project in relation to community attitudes is explicit.

In 1972 following the disclosure of the Tuskeegee studies and the Willowbrook State School Studies which led to public and professional attention, the DHEW appointed an ad hoc advisory panel to review this study as well as the department's policies and procedures for the protection of human subjects in general. The panel found that research practices were largely regulated by those in biomedicine who conducted the research. The panel noted the need to improve resolution of conflict between "two strongly held values: the dignity and integrity of the individual and the freedom of scientific inquiry" it recommended that Congress establish "a permanent body with the authority to regulate at least all federally supported research involving human subjects" for "society can no longer afford to leave the balancing of individual rights against scientific progress to the scientific community alone....Therefore, we have urged throughout a greater participation by society in the decisions which affect so many human lives." The panel discussed other controversies such as psychosurgery, behavior control and research on prisoners, children and the mentally retarded. Congress responded in 1974 by passing the National Research Act establishing the President's Commission for the Protection of Human Subjects of Biomedical and Behavioral Research [created by federal regulations Public Law 93-348 Title II passed July 12 1974) a National Commission for the protection of Human subjects of Biomedical and Behavioral Research]. The law for the first time required that the majority of a committee dealing with human experimentation be non-researchers.

The main outcome of all of these deliberations has been the construction of the institutional review board or IRB. These are local institutionally supported committees whose purpose is the review and evaluation of proposed research. They comment on the ethics of and safety and appropriateness of human subjects research. Federal regulations mandate that these committees assess human subjects research to guarantee that the rights of the subjects are protected and risks minimized and reasonable in terms of research benefits and that informed consent be obtained. Here again, the fact that research benefits are weighed against other considerations implies an assumption that these putative benefits may, in fact, outweigh other cautions.

These local IRBs initially mandated by the NIH are now completely under the domain of medical researchers and physicians. They form a professional control mechanism which, while combining some centralized government oversight and peer review, is much stronger in terms of peer review and serves to keep government out of decisions except in broad terms. There is a great deal of variety involved in terms of who participates in these committees, how they proceed with research protocol evaluation and ethical judgement. The basic mandate regarding standards for IRBs is about the members: there must be at least five members, include members of each sex, include one non-scientist and one member not involved in the institution (often these two can be one person). Some sociological investigation, Sackoff-Lambert (1984) in particular, indicates that they primarily serve research priorities. Empirical studies of IRBs, while very few, raise questions about their impartiality and competence.

In an ethnographic study, Sackoff-Lambert (1984) observed meetings of a University IRB for 8 months. She found that IRB discussions centered around technical rather than ethical issues. Decision-making was controlled to a great degree by physician-researchers who made up the majority of the board. Professional dominance within the committee was ensured by preliminary proposal review by "expert" members. Lay participation was rare, leading Sackoff-Lambert to conclude that lay representation was symbolic rather than substantive.

The President's Commission (1983) conducted a study in which they visited and evaluated 12 IRBs. They found inadequate procedures for proposal review, an unclear understanding by some IRB members of their roles and responsibilities, and minimal commitment and support by some institutions to IRB activities and goals.

A second President's Commission was enacted in 1978. The publications of these commissions have been extremely powerful, virtually having the force of legal case precedent. In 1983 this second Commission completed its charge. The 1985 Health Research Extension Act to create a more permanent biomedical ethics board and advisory committee was blocked until 1990 when an Ethics Advisory Board was finally appointed.

EXTERNAL CONTROL OF MEDICINE

1. FEDERAL REGULATORY CONTROL OF MEDICINE

a. The Biologics Control Act

Federal control in areas affecting medicine began with the Biologics Control Act of 1902 when President Theodore Roosevelt signed into law:

> An Act to regulate the sale of viruses, serums, toxins, and analogous products in the District of Columbia, to regulate interstate traffic in said articles, and for other purposes.

This was the first federal law involved with drugs and preceded the Pure Food and Drugs Act by four years.

There had been concern about the need for regulation, standardization and quality control of biologics such as diphtheria antitoxin. But, as in our model, and as is generally the pattern in Congressional legislation, it took a tragedy to mobilize popular and professional opinion to stimulate the legislators to act (Kondratas 1982:14). In 1901, in St. Louis a five year old little girl Veronica O'Neill died in the City Hospital from tetanus caused by tetanus-infected antitoxin. The number of children's deaths climbed to thirteen which was widely reported in the press. It also aroused concern among the medical profession. An editorial in the JAMA warned that "anti-vaccinationists, anti-vivisectionists, 'christian scientists' and crotchety persons in general" would use this for "evil purposes" (JAMA 1901:1255).

This represented the highest number of illnesses and deaths yet reported, but there had been other cases of fatal anaphylactic reactions and tetanus in children following the injection of diphtheria antitoxin both in Europe and in the United States. Also, in Camden New Jersey in 1901 almost one hundred cases of post-vaccination tetanus and the deaths of nine children were reported which further contributed to a climate of concern about biologic product safety. Action was clearly needed to sustain confidence in the medical profession. The Biologic Controls Act was the regulation passed. This was followed by the Pure Foods and Drug Act.

There was much research involving drugs but a widely held belief about the value of unregulated scientific research and presumptions about the professional integrity of scientific investigators which led the biomedical community to neglect any formal review of research including peer review within local institutions. This was changed by a series of post 1962 developments. On 10 October 1962 U.S. Congress passed the FDA "Drug Amendments of 1962" which compelled basic changes in federal regulations of the drug industry. The bill was the outcome of three years of debate in Senator Estes Kefauver's subcommittee on Antitrust and Monopoly investigating exorbitant drug costs, price control, competitive markets, and licensing. The revelations of the thalidomide tragedy and infant deformities in Europe and the UK produced by the sedative Thalidomide (Faden and Beauchamp 1986:203) made passage of the bill possible. By 1964 the United States Federal Food, Drug, and Cosmetic Act was passed which requires full and free consent of all subjects of drug trials

Bioethics has become a mix of internal and external control without, I maintain, substantially changing medical hegemony. Those aspects of control which have been inaugurated from outside of medicine have become incorporated into medicine and recast in terms of a medical model and medical knowledge. Since medicine has such a specialized knowledge, any issues that deal with this knowledge chance being engulfed by it. Bosk (1986) noted that social control of a profession's members involve the processes through which the profession generates conformity among its constituents and it is both internally and externally imposed formally or informally. Internal means include professional socialization and training, informal peer influence, codes of ethics and disciplinary procedures related to professional norms, and externally imposed regulations, laws, and requirements for external review. Some critics want more rigorous controls, others feel that government regulation is not effective.

External federal control began with the Biologics Control Act of 1902 and was followed sixty years later by the FDA Drug Amendments of 1962 when the U.S. Congress passed the Kefauver-Harris amendments to the 1938 Food, Drug, and Cosmetic Act. This legislation was largely enacted as a response to revelations of the infant deformities in Europe and the United Kingdom produced by the sedative thalidomide.

In 1972 following the disclosure of the Tuskeegee studies the DHEW appointed an ad hoc advisory panel to review this study as well as the department's policies and procedures for the protection of human subjects in general. The panel found that research practices were largely regulated by those in biomedicine who conducted the research. The panel noted the need to improve resolution of conflict between "two strongly held values: the dignity and integrity of the individual and the freedom of scientific inquiry" and it recommended that Congress establish "a permanent body with the authority to regulate at least all federally supported research involving human subjects" for:

> society can no longer afford to leave the balancing of individual rights against scientific progress to the scientific community alone....Therefore, we have urged throughout a greater participation by society in the decisions which affect so many human lives.

The panel discussed other controversies such as psychosurgery, behavior control and research on prisoners, children and the mentally retarded. Congress responded in 1974 by passing the National Research Act establishing the President's Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

LEGAL CONTRIBUTIONS TO EXTERNAL CONTROL

Not until 1978 was a case involving human subjects research heard and that was by an appellate court in Canada Halushka v University of Saskatchewan (1965). Halushka, a University student allowed testing of a new anaesthetic agent having been assured that it was safe. He suffered cardiac arrest. The court found that he had not been sufficiently informed of the potential risks and awarded damages.

State law protecting human subjects did not exist until 1970s. The most sophisticated and comprehensive state regulations are those of California (Deering 1987). These were enacted in 1978

INTERNAL AND EXTERNAL CONTROL: WEDGES IN THE SYSTEM THAT ALLOWED FOR THE ENTRY OF "OUTSIDERS"

The struggle for control of biomedicine can be framed as a contrapuntal series of events. First a case is revealed which underscores the lack of self-regulation and which is defined as a social problem; <u>Nuremberg</u>, <u>Tuskeegee</u>, <u>Willowbrook</u>. This is followed by media attention and public concern, including State concern by representatives in government: <u>the trials</u>, <u>Mondale in the senate</u>. Then some sort of response and resolution is attempted: <u>a code</u>, <u>a committee</u>. This response is controlled by either medicine, the state, some compromise between the two or a new coalition. If successful, the problem disappears from view and becomes undefined as a social problem. Who defines the problem, how the media is managed, what members of the State become interested, and who defines the solution are all important factors in this process. In the social problems so defined, the events themselves are so dramatic that virtually all of the extant media carried the news once the story had broken. However, there is a long period between the existence of the putative condition or problem in potentia and its emergence and definition as a social problem. What forces keep the problem from being so identified are of interest here. Of all of the numbers of potentially identified and constructed "social problems" the history of them reveals a general ignoring of the issue until enough attention is focused upon the issue so that it is impossible to any longer ignore the issue.

In each case that I will describe, after media expose, the state became interested and either suggested remedies or were able to use public opinion to put into place bills which had previously had little possibility of passing. The events provided the wedge in the hegemonic system that allowed some incursion of state control to challenge medicine. But, in each case involving ethical issues, medicine was ultimately able to reframe the solutions in ways that did not interfere with their general hegemony. They have, for example, been successful in keeping the medical model as the unquestioned base for all of the 'solutions' which in all cases may not be the most appropriate paradigm for dealing with the "problem." In each case the representatives of medicine played a large part in redefining the problem and in creating solutions, in this way sustaining its hegemony in ethical issues. We can take the persistence of biomedical assumptions and use of the medical model in defining death as an example. The initial and subsequent definitions have all been based on quantifying death and using, for example an electroencephalogram (EEG), to identify "death." Quantified techniques are particularly useful as the medical goal in this instance is the diagnosis and prognosis of death. The power to define based upon neurological signs has been carved out by neurologists.

There are two fundamental sources of control of medicine: internal and external. Internal control of medical behavior is based upon medical education, socialization, oaths, codes of ethics, professional licensing and regulatory boards. Early oaths and codes said little about physician obligations to patients except admonishing them to do no harm. That should have averted most of the ethical problems if primum non nocere had been honored.

The major medical professional organization in the United States is the AMA which generated a code of medical ethics in 1847 which has been revised and abbreviated to represent ethical standards such as respect for human dignity, compassion, skilled medical performance, obedience to law, advancement of scientific knowledge (AMA 1982).

Members of the World Medical Association (WMA), saw the Nuremberg trials as a threat to the reputation and integrity of biomedical research also drafted a code to distinguish ethical from unethical research. This code was adopted by the WMA at Helsinki in 1964 and is regarded as the first significant venture in self-regulation internal to medicine itself. Nuremberg has been interpreted as the first code prescribed for medicine externally by a court system, however, since it was written by physicians who represented the American Medical Association, it can be argued that the Nuremberg code represents internal control. In any case, it is an example of medicine retaining control of its own ethics.

THE HISTORY OF INTERNAL CONTROL

Prior to World War II there was limited medical interest in ethics in treatment or research. One early internal voice of protest regarding the improper use of human subjects was published in 1901 by Smidovich, a Soviet physician who wrote a critique of clinical and research practices throughout the world (1901, The Confessions of a Physician, 1916 U.S.).

In Germany in 1901 (Sass 1983), in response to what were described as: "the excessively thoughtless and ambitious use of progress-oriented experimentation in the name of humanity..." a code was written. This was in response to medical experiments by Neisser, discoverer of gonococcus, who, in the late 1800s, had given non-syphilitic prostitutes and very young girls injections of a serum obtained from syphilitics, without informing or receiving permission from them. These experiments evoked a general discussion about the justification of medical experiments on humans. In response, an ordinance was passed (1900) that forbid performing medical experiments on those underage and stated that in all cases subjects must give their consent after being accurately advised of the risks involved.

However, during the Weimar Republic other serious incidents and deaths were exposed resulting from experimentation, particularly with children. The last straw in this instance was that a hospital director had experimented with tuberculosis vaccination resulting in the deaths of 14 children. This was resolved jointly by the minister of the interior and council of health who in 1931 jointly issued "Richtlinien fur neuartige Heilbehandlungen und fur die Vornahme wissenschaftlicher Versuche am Menschen" (Sass 1983), rigorous regulations and guides, in which a statement about the inadmissibility of medical experimentation on destitute individuals was defined for the first time, as were the nature of the appropriate information to give the patient, issues of consent and refusal, careful research design, and special protection for vulnerable subjects. The regulations included a declaration that human experimentation was unthinkable without consent and absolutely forbade research with dying subjects. The question of informed consent (Article 10) was to be based upon respect for the dignity of the patient and following the dictates of humanity (Article 11). No other nation had such advanced regulations by 1946. These German regulations were more stringent than the later Nuremberg (1947) or Helsinki (1964) codes would be, and they remained binding law throughout the period of the Third Reich until 1945 (Sass 1983, 1988). They were legally binding but largely ignored during the Third Reich. As Sass (1983, 1988:52) has pointed out, that such a governmental regulation existed:

> while the Nazis were carrying out human experiments in an irresponsible manner in concentration camps, underlies the irrelevance of legal regulations if they are not enforced by the authorities. It was precisely the human experimentation in Nazi camps - judged worldwide to be cruel, unfair, and immoral - which gave states, professional organizations, and other agencies the incentive to issue laws, regulations, or codes of conduct in order to protect "the principles of respect for persons, beneficence and justice" (Belmont report 1978).

The protection of the patient remained subject to the conscience of the physician before as well as after the Nuremberg Codes. The fact that there are regulations which surely will act to eliminate the most egregious examples of moral atrocity from the domain of human experimentation does not mean that the original moral concerns have been eliminated (Caplan 1988:230).

In each case the state became interested and either suggested remedies or were able to use public opinion to put into place bills which had previously had little possibility of passing. The events provided the wedge in the hegemonic system that allowed some incursion of state control to challenge medicine. But, in each case involving ethical issues, medicine was ultimately able to reframe the solutions in ways that did not interfere with their general hegemony. They have, in fact, been successful in keeping the medical model as the unquestioned base for all of the 'solutions'. In each case the representatives of medicine played a large part in redefining the problem and in creating solutions, in this way sustaining its hegemony in ethical issues. We can take the persistence of biomedical assumptions and use of the medical model in defining death as an example. The initial and subsequent definitions have all been based on quantifying death and using, for example an eeg, to identify "death." Quantified techniques are particularly useful as the medical goal in this instance is the diagnosis and prognosis of death. The power to define based upon neurological signs has been carved out by neurologists. The decision making model has been assumed to be a medical, not primarily social or philosophical one so physicians continue to maintain authority over defining and determining death. A similar situation obtains with defining a person in a "persistent vegetative state" (PVS), in which there is a potential wide and social range, but medicine is assumed to be the profession to determine this.

2. THE INSTITUTIONALIZATION OF BIOETHICS IN THE UNITED STATES

To fully document the institutionalization of bioethics in the United States is beyond the scope of this dissertation. However, I will describe some key components of its institutionalization noting that it is very recent. The principal institutional players are the Hastings Center, The Kennedy Institute of Ethics at Georgetown University, and the Center for Ethics, Medicine, and Public Issues, at Baylor College of Medicine, Texas. The American Society of Law and Medicine provides a strong intellectual and theoretical force but without an institute. The major forces in the institutionalization are from medicine, law, ethics and theology. The arenas include the major centers and their important and potentially influential publications, courses taught in medical schools and universities in bioethics, and the actual work arenas, the courts and the actual institutional bioethics committees. In this chapter I will discuss the centers and their publications. The work done by those in these centers is a part of the sociology of knowledge of bioethics. If the center and its publications is seen as legitimate, then the center will have the power to influence the moral ordering. If the center's work is not legitimated, then its claim to expert knowledge is weakened and it may fail in its mission.

A. CENTERS OF BIOETHICS. CENTERS OF KNOWLEDGE AND "SOCIAL WORLDS."

In the development of the foundations the roles of religion and policy are difficult to tease out. Some of the earliest issues in bioethics, were contraception and birth control, and the treatment or non-treatment of newborn infants. Both of the leading centers of bioethics had these issues as their first concerns.

In 1962-1965 a number of Catholic writers were attached to the Second Vatican Council established by Pope John XXIII. This council, called Vatican Two, was responsible for the modernization and diversity of Catholic moral theology. A small subgroup of 7 members, called the Pontifical Study Commission on Family Population and Birth Problems, studied contraception, a most controversial problem in Catholic medical ethics. They met in 1963, hoping the Pope would allow a more liberal interpretation of contraception which would allow Catholics to use the new birth control pills (Walters 1985). However, John XXIII died and a year later the new pope, Paul VI re-composed the group to include 58 members. Walters (1985:6-7) noted that

> The augmented commission, in which lay members now outnumbered the clergy, was in some respects a precursor to the national and presidential commissions established in the United States in the 1970s.

There were experts from moral theology, reproductive biology, medicine, demography, economics, sociology and pastoral care (Shannon 1970:78). Dr. Andre Hellegers, a Dutch born obstetrician-gynecologist and researcher at Johns Hopkins University, played a major role in the work of the contraception commission (Shannon 1976:84-103). In June of 1966 the group gave its 12 volume report to Pope Paul VI. The majority view of this report was that contraception was not intrinsically evil.

Another Catholic layman interested in the Papal response to the contraceptive commission report was Daniel Callahan, a Georgetown and Harvard trained philosopher associated from 1961-1968 with Commonweal, the leading American Catholic intellectual journal and its editor for several years.

Both Hellegers and Callahan were disturbed by the Papal response to the report. On July 29, 1968 Pope Paul VI released his response to the Papal commission on birth control: He rejected it. Dr. Hellegers, was deeply disappointed by the Pope's decision and wrote an essay about it in 1969 as did Callahan. Hellegers argued that the traditional teaching on contraception was a symbol of a fundamental problem:

> The birth control question is, after all, a test case for the Church's understanding of itself and especially of its understanding of the development of doctrine.
> If there is a tragedy latent in this drama, then it lies in the desperation of good people trying to use old tools to cope with new material. It lies also in the desperation of married couples trying to relate old certainties to new uncertainties...

Nineteen sixty nine was a watershed year, and from 1967-1969 "the institutional foundations for the renaissance of medical ethics were laid" (Walters 1985:8).

In 1969, Callahan began research with a grant from the Population Council on the medical, ethical, and legal aspects of abortion. This was published in 1970 as Abortion: Law, Choice, and

Morality. Later in 1969 Callahan and a psychiatrist-friend Willard Gaylin founded the Institute of Society, Ethics, and the Life Sciences, now the Hastings Center, which was to emerge as one of the "major institutional contributors to the renaissance of medical ethics" (Walters 1985:10).

Andre Hellegers moved to Georgetown University and convinced Paul Ramsey to spend the spring semesters of 1968 and 1969 at Georgetown with support from the Joseph P. Kennedy Jr. Foundation, to do research and writing on medical ethics while in residence in the Georgetown medical school and hospital. This second center, the Kennedy Institute of Ethics was founded by Andre E. Hellegers, who became the first director of the Joseph and Rose Kennedy Institute of Ethics at Georgetown University in 1971 (Walters 1985:8).

During Ramsey's second spring semester of research in medical ethics at Georgetown he prepared the Lyman Beecher Lectures at Yale april 1969. This was published as The Patient as a Person: Explorations in Medical Ethics in 1970. Walters (1985:11) said that:

> Perhaps more than any other single work, The Patient as a Person helped to bring the field of medical ethics to the attention of a broader academic and professional public.

In the 1978 Encyclopedia of bioethics this book by Ramsey was the work most frequently cited (Walters, 1985:11). While it was by a Christian ethicist he discussed secular categories such as the covenant between physicians and patients. He borrowed from Catholic medical ethics textbooks but did not restrict his work by either their authority or structure. He avoided the discussion of abortion and contraception as it would be too parochial. His primary focus was on micro level relationships. He discussed issues such as informed consent, research with human subjects especially with minors, a definition of death, care of the dying, organ donation, transplantation, and the microallocation of scarce resources.

I believe that it was this secularization of medical ethics that made it palatable to a larger public. The pope had disappointed and failed the general desires with the contraception issue, even for Catholics, and the ideology and rhetoric of the Catholic church was unacceptable to non-Catholics, who nonetheless hungered for some meaningful way to approach these difficult problems.

1969 Dan Callahan founded a new research center in Hastings-on-Hudson, New York: The Institute of Society, Ethics, and the Life Sciences, now the Hastings Center.

There were two other contemporary institutional developments. One was the establishing of The Institute of Religion at the Texas Medical Center in 1967 with theologian Kenneth Vaux as its faculty member in ethics. The second was the founding of the Society for Health and Human Values in 1969. The founding members included two chaplains Samuel Banks and E. A. Vastyan and three education officers in protestant denominations Robert Bluford, Robert A Davis and Ronald McNeur.

In 1966 protestant ethicists Arthur Dyck and Ralph Potter at the Harvard center for population studies began offering a graduate seminar on "Religious ethics and population control." The first issue of all of the centers was population control. This did not attract the concern that the heart transplant and DNA revelations would two years later. Perhaps it was because contraceptive issues were mainly of interest to Catholics since protestants and Jews were able to use them if they wished. I believe that part of what made bioethics so interesting to the country was that it was finally not attached to a religious base but found discourse in secular writing and discourse.

In 1967 the first meeting to involve large numbers of future contributors to bioethics was the International Conference on Abortion in Washington D.C. in September 1967. A book based on the conference was published in 1968, The Terrible Choice: The Abortion Dilemma. This was co-sponsored by the Kennedy foundation and Harvard Divinity School. Participants included: Charles Curran, Arthur Dyck, James Gustafson, Andre Hellegers, Richard McCormack, John Noonan, Gene Outka, Ralph Potter, and Paul Ramsey.

A. CENTERS OF BIOETHICS: CENTERS OF KNOWLEDGE AND SOCIAL WORLDS

The first, and probably the most influential center of bioethics was formed in 1969 as The Institute of Society, Ethics and the Life Sciences which became known as The Hastings Center. The co-founders of this institute were long term friends philosopher Daniel Callahan, then the editor of Commonweal, a liberal Catholic publication, and psychiatrist Willard Gaylin. At first, the center was at Callahan's home and the boxes of materials were kept in his bedroom (Callahan 1990, interview). Later, they would move to a mansion at Hastings on the Hudson.

The founding statement of the Institute of Society, Ethics and the Life Sciences reflects some of the issues the two men and their early colleagues were concerned about:

> The Institute was founded in 1969 to fill the need for sustained, professional investigation of the **social impact of the biological revolution**. Remarkable advances were being made in organ transplantation, human experimentation, prenatal diagnosis of genetic disease, prolongation of life and control of human behavior -- and each advance posed specific problems requiring that scientific knowledge be matched with ethical insight.
>
> Physicians, researchers, government officials and others, aware that the discovery of new procedures was outpacing public policy and professional guidelines, asked for more information and more discussion. Scattered articles and random, one-shot conferences did not seem to be the answer.
>
> The Institute's approach was to bring together from many disciplines concerned professionals committed to meeting several times a year over a period of years, with "homework" in between. These 75 fellows, elected by the Board of Directors and assisted by a full- time staff of 12 at the Hastings Center, make up four groups, each concentrating on a specific area: (1) behavior control, (2) population control, (3) genetic engineering and counseling, and (4) death and dying.
>
> This work is supported primarily by a number of foundation grants and, increasingly, by the dues and contributions of Associate Members. (Callahan 1973).

One of the founding group at the Hastings Center was physician Leon Kass (1990:5-6). He writes of how those who gathered to found the "center shared a concern for the human meaning of these and anticipated new biomedical developments." He tells of how only one of the founding fellows made his living teaching philosophy, and would not come if the meeting violated the sabbath. Kass (1990:6) made the point that none of the founding members of the Hastings Center "**came into**" bioethics through either the study or practice of bioethics.

Kass points out that the Hastings center has been and remains a force in bioethics: "For those who practice ethics -- especially biomedical ethics -- Hastings, more than anywhere, is where the action is."

Initially the Hastings center published the Hastings Center Report, which "kept a wide audience informed of developments in this field" but Callahan and colleagues felt "a need to complement the Report with a journal capable of reporting fully on original research and carrying longer, more detailed, and more reflective analyses" And so, in 1973 the first volume of the Hastings Center Report was published. Early emphasis was on behavior control, death and dying, and genetics. The focus on death and dying persists but later articles are more focused on law and medicine as well.

THE CENTER FOR ETHICS, MEDICINE, AND PUBLIC ISSUES, AT BAYLOR COLLEGE OF MEDICINE, TEXAS.

In Houston, Texas, in 1954 the Institute of Religion was formed which later focused its research and writings on bioethics. This became the Center for Ethics, Medicine, and Public Issues, at Baylor College of Medicine, Texas. This center is most notably associated with H. Tristram Engelhardt, Jr. a libertarian philosopher and physician. The publications of the Philosophy and Medicine book series include the following titles:

1. Evaluation and Explanation in the Biomedical Sciences 1975
2. Philosophical Dimensions of the Neuro-Medical Sciences 1976
3. Philosophical Medical Ethics: Its Nature and Significance 1977
4. Mental Health: Philosophical Perspectives 1978
5. Mental Illness: Law and Public Policy 1980
6. Clinical Judgement: A Critical Appraisal 1979
7. Organism, Medicine, and Metaphysics 1978
8. Justice and Health Care 1981
9. The Law-Medicine Relation: A Philosophical Exploration 1981
10. New Knowledge in the Biomedical Sciences 1982
11. Beneficence and Health Care 1982
12. Responsibility in Health Care 1982
13. Abortion and the Status of the Fetus 1983
14. The Clinical Encounter 1983
15. Ethics and Mental Retardation 1984
16. Health, Disease, and Causal Explanations in Medicine 1984

17. Virtue and Medicine: Explorations in the Character of Medicine 1985
18. Medical Ethics in Antiquity: Philosophical Perspectives on Abortion and Euthanasia 1985
19. Ethics and Critical Care Medicine 1985
20. Theology and Bioethics 1985
21. The Price of Health 1986
22. Sexuality and Medicine: Conceptual Roots 1987
23. Sexuality and Medicine: Ethical Viewpoints in Transition 1987
24. Euthanasia and the Newborn: Conflicts Regarding Saving Lives 1987
25. Ethical Dimensions of Geriatric Care 1987
26. On the Nature of Health 1987
27. The Contraceptive Ethos: Reproductive Rights and Responsibilities 1987
28. The Human Use of Human Beings in Research 1988
29. The Physician as Captain of the Ship 1988
30. Health Care Systems: Moral Conflicts in European an American Public Policy 1988
31. Death: Beyond Whole Brain Criteria 1988
32. Moral Theory an Moral Judgements in Medical Ethics 1988
33. Children in Health Care: Moral and Social Issues 1989
34. Catholic Perspectives on Medical Morals: Foundational Issues 1989

This group of publications has a much more explicit medical philosophical core.

SOCIETY FOR HEALTH AND HUMAN VALUES

In 1969 the Society for Health and Human Values was formed by the United Ministries in Higher Education. In 1975 they began publishing the Journal of Medicine and Philosophy.

At Georgetown University, Andre Hellegers had proposed establishing a research institute and the Kennedy Foundation initially offered funding for an institute which became the Joseph and Rose Kennedy, Jr. Foundation for the study of human reproduction and bioethics at Georgetown University. Hellegers sought an ecumenical group during the early years of 1971-1975. Georgetown University announced the creation of an institute that would join biology with ethics in what was being called bioethics. Begun with a $1.3 million grant from the Kennedy foundation the institute aimed to put theologians next to doctors. Obstetrician-Gynecologist Andre Hellegers, was appointed head of the institute. The initial focus was on disabilities, mental retardation, and medical care at birth (Washington Post 2 October 1971:1; 13 October 1971 Can science and ethics meet?). He brought together Catholic theologians Curran, Haering, Richard McCormick, and Warren Reich; Protestant theologians, Roy Branson, Frederick Carney, Stanley Hauerwas, Gene Outka, Ralph Potter, David H. Smith, LeRoy Walters.

By 1975 Hastings and Kennedy centers were providing strong institutional support for bioethics. Hastings with their publications of the Hastings Center Report and periodic bibliography. Also by 1975 the Kennedy bioethics library and information retrieval system were in existence. They had also set up graduate education in conjunction with Georgetown University.

Le Roy Walters of the Kennedy Institute was also editing a comprehensive Encyclopedia of Bioethics:

> When a special encyclopedia - one aiming to be comprehensive in a particular discipline - is the first in its field, its appearance has the potential for marking an important stage in the development of one aspect of human knowledge.

The encyclopedia was the vision of Le Roy Walters and Andre E Hellegers, first director of the Joseph and Rose Kennedy Institute of Ethics at Georgetown University. For it Hellegers sought and obtained a grant from the National Endowment for the Humanities, a federal agency. They provided the principal funding for the project by matching gifts from private sources, including the Joseph P. Kennedy, Jr. Foundation, the Raskob Foundation, The Commonwealth Fund, The Loyola Foundation, Inc. and the David J. Greene Foundation, Inc.

Le Roy Walters, as Senior Research Scholar at the Kennedy Institute during the first year of its existence (1971-1972), conceived the idea of developing a reference work that would gather together what was known about the scientific state of the art and the full range of ethical views and policy options in matters dealing with the life sciences. He developed the basic plan for the project and selected the Editorial Advisory Board, the Associate Editors, and the editorial staff. In the fall of 1972, 22 members of the editorial advisory board met and planned the book. Walters states in his introduction (1978:xv)

> The emergence of bioethics as a field of study is a contemporary phenomenon traceable to several causes. First, the issues of bioethics have captured the contemporary mind because they represent major conflicts in the area of technology and basic human values, those dealing with life, death, and health. Although many bioethical issues have been discussed since ancient times, the introduction of modern biomedical technologies, especially since the 1950s, has intensified some age-old questions and has given rise to perplexing new problems - the prolongation of life, euthanasia, prenatal diagnosis and abortion, human experimentation, genetic interventions and reproductive technologies, behavior

> control and psychosurgery, the definition of death, the right to privacy, allocation of scarce health resources, and dilemmas in the maintenance of environmental health.
>
> Second, there is an intense and widespread interest in bioethics because it offers a stimulating intellectual and moral challenge. In contrast to earlier eras, when ethical world views were held in common and offered a certain security for dealing with moral dilemmas, today the very tools for coping with these problems are themselves subject of considerable controversy. There is an uncertainty about moral values, ethical principles, and their priorities; the contemporary world is experiencing a philosophical upheaval; and many systems of theological thought are questioning traditional assumptions in religious ethics. Bioethics has already had a significant intellectual impact, for it has precipitated a reexamination of basic moral values and methods of applying them to practical ethical problems.
>
> Third, the rapid growth of the field of bioethics has been facilitated by the openness to multi-disciplinary work that characterizes many scholars and academic institutions today, especially in matters dealing with personal and social aspects of human behavior.

Bioethics, like other special fields of learning, has manifested the "explosion of knowledge" characteristic of our era.

B. BIOETHICS COMMITTEES ESTABLISHED: PRACTICE

1. HISTORICAL ANTECEDENTS

Institutional ethics committees are hospital committees whose purpose and charge is to advise, educate, and construct policy in matters related to biomedical ethics. While bioethics committees as we know them are a recent construction, there are historical antecedents to them. The concept of constituting a special committee to consider ethically charged medical problems has occurred before. In Germany during World War II the Nazi medical committees decided on the subjects of sterilization and euthanasia. In the United States in the 1950s, the Catholic medical morals committees were established to deliberate about abortions. There were some other early American sterilization committees in the 1950s and 1960s, which met to determine eligibility for abortions and sterilizations as these could only legally be performed with medical justification. This was true until the 1973 Roe v. Wade Supreme Court decision.

As described earlier, in the 1970s hospitals in Seattle set up a committee to decide which patients should receive the available dialysis machines (Annas 1984:843). Since 1966, the Public Health Service had used committees to ensure that applicants seeking Health Service funds to conduct medical experiments on humans comply with widely recognized ethical standards. Federal legislation enacted in 1974 extended this requirement of "institutional review boards" to a variety of institutions receiving federal funds for human experimentation. The only control over the behavior of the researchers was tied to money and the threat of withdrawal of funds by the federal government which made these requirements (National Research Act 1974; National research act Pub. L. No. 93-348, tit. II 212(a), ~ 88 Stat. 342, 352-53 (1974) (codified as amended at 42 U.S.C. ~ 289 (Supp. III 1985 Robertson, The Law of Institutional Review Boards 26 UCLA L. Rev. 484, 487-88 (1979).

The establishment of IRBs formed a structural and attitudinal prolegomena for bioethics committees. Without the conditions which led to the changes in research ethics and the consequences of these circumstances, there would not be an infrastructure for institutional bioethics committees. The IRBs are mandatory committees and researchers are obligated to bring research project proposals to these hospital committees for approval of their research. The clinical bioethics committees are voluntary committees. I will later argue that it was in order to sustain the voluntary nature of these clinical bioethics committees, that their numbers increased in 1983 from 1% to 60% of hospitals having these committees.

THE JOHNS HOPKINS INFANT

In 1969, a baby with an anomaly of its digestive system was born in Virginia and transferred to Johns Hopkins Hospital where an easily correctable intestinal block was diagnosed (Gustafson 1972-1973:529). The baby also had Down's syndrome and was probably mentally retarded. The parents, after considering the situation, refused consent for surgery and the hospital complied with the refusal. The infant was placed in a corner of the nursery and, unable to eat, died fifteen days later. Three of the physicians involved in withdrawing nutrition and hydration from the infant made a film about the incident including a discussion of the ethical principles involved in the case. The film, funded by the Kennedy family, was shown in October 1971, three years later at a conference funded by the Kennedy Foundation. The press had been invited to the showing of the film and reported on the film pondering the right to life of the infant (New York Timest 15 October 1971:31). During the next few weeks, a 10 minute segment of the film was shown on national television.

Johns Hopkins met the negative publicity by announcing that it had formed a review board compose of a pediatrician, surgeon, psychiatrist, clergyman, and lawyer to advise on difficult cases. As in most issues, the publicity subsided. The hospital review board was an unique response to a difficult public clamor. But the Johns Hopkins case was only one that those outside of medicine were familiar with. This was made public by a critical New England Journal of Medicine article by Raymond Duff and Alexander Campbell on the "Moral and Ethical Dilemmas in the Special Care Nursery." Like Beecher's 1966 article, this paper exposed the secret that the cause of death in a number of cases is the pediatrician's determination to withhold life sustaining treatment. Duff and Campbell named themselves and others. They told of the practices at the Yale-New Haven University Hospital. In the report Duff and Campbell (1973:893) discuss the fact that 43 of 299 (14%) consecutive deaths in the special care nursery between the first of January 1970 and the 30 of June 1972 were because physicians had stopped treatment. Unlike Beecher, Duff and Campbell did not see these deaths as unethical but they did want to have more of a contribution from the parents of the infant in making the decision to stop treatment. They felt that it was proper to stop treatment if both physicians and parents made the decision together. Duff and Campbell believed in the essential goodness and capability of the parents to do so.

2. BIOETHICS COMMITTEES CREATED: FOUNDATION

QUINLAN AND CONTEMPORARY ETHICS COMMITTEES

The beginning of what we know as contemporary institutional ethics committees began fifteen years ago when the twenty-two year old Karen Anne Quinlan lay in a "debilitated and allegedly moribund state" at Saint Clair's Hospital in New Jersey (In re Quinlan, 1976). Karen Quinlan had been brought into a hospital emergency room in a coma whose cause was never demonstrated and from which she never emerged. After several months her parents, believing that she would not recover, sought guidance from priests of the Catholic church who agreed that taking Karen Quinlan off the respirator was a morally correct action since the respirator was "extraordinary" and that taking her off of the machine would be returning her to her "natural state." In pursuit of this, her parents asked her doctors and administrators of St. Clair's hospital to remove her from the respirator that assisted her to breath. Her physicians and the staff of St. Clair's refused to allow her to be removed from the respirator and the case was taken to court. The Quinlan court (In re Quinlan 1976:278-279, 311) ruled that:

> there must be a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgements for the well being of their dying patients.

One of the critical issues, both in the Teel article and in the Quinlan case was that of physician immunity. The decision (In re Quinlan 1976:279) reads:

> We would hesitate, in this imperfect world, to propose as to physicians that type of immunity which from the early common law has surrounded judges and grand jurors....so that they might without fear of personal retaliation perform their judicial duties with independent objectivity.

The Judge goes on to quote an 1872 case in which the Supreme Court (Bradley v Fisher) held:

> [I]t is a general principle of the highest importance to the proper administration of justice that a judicial officer, in exercising the authority vested in him, shall be free to act upon his own convictions, without apprehension of personal consequences to himself.

The New Jersey Supreme court considered a novel solution; that the hospital should create "an Ethics Committee composed of physicians, social workers, attorneys, and theologians" to help make this difficult decision. The court quoted a law review article, by pediatrician Karen Teel (1975:6-9), who had proposed that such a committee could provide valuable "input and dialogue" on the ethical issues surrounding treatment. In its decision the Quinlan court recommended the formation of one version of such committees.

As the judge said in Quinlan (In re Quinlan 1976:312):

> The most appealing factor in the technique suggested by Dr. Teel seems to us to be the diffusion of professional responsibility for decision, comparable in a way to the value of multi-judge courts in finally resolving on appeal difficult questions of law. Moreover, such a system would be protective to the hospital as well as the doctor in screening out, so to speak, a case which might be contaminated by less than worthy motivations of family or physician.

The judge (In re Quinlan 1976:312) made it clear that applying to a court to confirm such decisions is generally inappropriate because:

> not only would that be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome.

The first legal recommendation for the adoption of ethics committees was in this Quinlan decision. While ethics committees had first been discussed in the context of treatment decisions for newborns these were not mentioned in the Quinlan decision. The rationale stated by the judge for his suggestion of an ethics committee was based upon a speech made at a forum on euthanasia in 1974 by pediatric physician Karen Teel (1975). Her suggestion was accompanied by several caveats, rarely discussed or cited. First, the article by Teel was based upon a forum during which several distinguished lawyers and physicians discussed the issue of death. Teel was assigned the topic "The Physician's Dilemma. A Doctor's View: What the Law Should Be." She noted in her introduction that she felt "somewhat presumptuous" in speaking under that title. Her concern was primarily with infants and children who she commonly sees:

> I see medical caretakers, the physicians, the nurses, and others whose whole orientation is assuming the sanctity of life and whose whole efforts are directed at preserving that life with every ounce of potential that can be realized, who then are faced with the reality of a no-win situation. The life can be preserved, but the potential for a meaningful life by any definition is nil; or the life can be preserved only in the most temporary manner and then only at incredible price in terms of human suffering; or the life can be preserved with potential which is impaired but still sufficient to define life as meaningful for both the patient and his family, but

> with the parties usually charged with the right and responsibility for acting to preserve the life choosing not to act. How does one proceed in these situations - by what guidelines, defined by whom, and at what risk.

She discussed the very difficult situation when, for a particular infant, there is no effective treatment and the only expectation for the child is death. The only question to be answered, Teel says, is how and when the baby is to die. Teel (1975:8) portrayed the suffering that the baby would endure and that "parents and family, physicians and nurses all suffer in an agony from their passive participation in this tragedy." She questioned whether the active intervention to "accelerate the dying process" of the baby is "such a horrifying concept that we cannot even discuss it as a possibility?" She wondered if the "waiting and watching for days, the passive participation in the baby's death" was different from active participation. Teel (1975:7) held that it "simply takes longer and means more pain for everyone."

Teel (1975:8) then pointed to what she saw as common problems: First, there is, she said, a need for a system of advocacy for the person in the medical setting which insures that rights are observed and protected. Second, physicians are charged with the responsibility for making ethical decisions which they are not always morally or legally authorized to make and maintained that:

> The physician is thereby assuming a civil and criminal liability that, as often as not, he does not even realize as a factor in his decision. There is little or no dialogue in this whole process.

She suggested that it might be suitable to provide "a regular forum for more input and dialogue in individual situations" to allow the responsibility of these judgements to be shared. Teel then stated the, as it turned out, mistaken belief that:

> Many hospitals have established an Ethics Committee composed of physicians, social workers, attorneys, and theologians, (known irreverently in some circles as the "God Squad"), which serves to review the individual circumstances of ethical dilemma and which has provided much in the way of assistance and safeguards for patients and their medical caretakers.

Her concept of an Ethics Committee was as a multi-disciplinary hospital committee, which would be an advisory, not an enforcing body. Teel's major concern in this paper was to have more open discussion about the distinction of active and passive euthanasia because they exist and they are already being dealt with in one way or another. Not to examine the problem of euthanasia denies its importance and assumes that it is being handled "as it should be already" (Teel 1975:9).

The court in Quinlan (In re Quinlan 1976:312) did not emphasize the multi disciplinary aspect of the proposed ethics committee of Teel but was more certainly focused upon the promoting of:

> the diffusion of professional responsibility for [termination] decisions, comparable in a way to the value of multi-judge courts in finally resolving on appeal difficult questions of law.

In its decision, the Quinlan court altered Teel's proposed decision making committee into a prognosis committee whose charge was to decide the technical question of whether the patient was in a chronic vegetative state, not to decide the ethical issues of the case. If the committee found that the patient was in a chronic vegetative state, the physicians could remove her from the respirator "without any civil or criminal liability." The court aim was to rescue physicians from fears of liability and would take judges out of the business of reviewing decisions to terminate treatment. The decisions, in this judgement, reverted to physicians and to physician prognosis committees.

One result of the trial and the many articles that emerged from the trial proceedings and commentary about the issue of Quinlan was that it forced the issues of who decides when someone may be removed from life sustaining treatment. It brought matters into visibility, matters which had heretofore been secret were now discussed in the daily newspapers. One article by cardiologist Michael Halberstam (1975:23) which appeared on the op-ed page of the New York Times discussed the fact that other Karen Quinlan cases never reach court and he wondered why the case was in court at all: "Each day, hundreds, perhaps thousands, of similar dilemmas present themselves." He felt that while the "decisions are difficult, often agonizing" up until now they had been reached "in hospital corridors, and in waiting rooms, not courts." He described the usual "often unspoken, deliberately ambiguous" steps in caring for patients such as Quinlan.

An editorial by Harvard lawyer, Charles Fried (1976:390) "Terminating Life Support: Out of the Closet" discussed the secrecy aspect of withholding and withdrawing life sustaining treatment and said that life sustaining measures "are in fact regularly withheld or withdrawn is an open secret." Freid claimed that lawyers were not invading the domain of medicine, ut were rather advocates for patients in an effort to right an imbalance of power and establish the principles of patient autonomy.

A discussion in the Rutgers Law Review (Hirsch and Donovan 1977:274) noted the confusion, disagreement and concern evoked by the suggestion of ethics committees:

> would the role...be solely advisory or would its determinations be mandatory? What should be its composition - totally professional or representative of various disciplines? Who should select the members?...And of particular importance, is the requirement of committee concurrence in a termination decision reached by a physician and family or guardian constitutional?

The Quinlan court did not define the role and duties of an ethics committee and by mixing ethics with prognosis further complicated affairs and increased confusion. It was unclear whether the committees would address neurological outcomes or moral values. This initial confusion, we will see, continues in the bioethics committees today.

Once Quinlan was decided, other states brought difficult cases to courts to deal with treatment decisions. In Massachusetts, the case of Superintendent of Belchertown State School v. Saikewicz came to the courts when the superintendent of a school for the retarded asked the court to decide whether or not chemotherapy could be withheld from a mentally retarded adult with leukemia. The court ruled that withholding treatment was justified and said that these decisions had to come to a court. The Massachusetts court disagreed with the idea of an ethics committee:

> We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent.

The court felt that the courts were the proper place to make these decisions and that this would not constitute a "'gratuitous encroachment' on the field of medical expertise." These questions, said the court (Superintendent of Belchertown State School v. Saikewicz 1977), are best decided in the judicial branch who could engage in:

> detached but passionate investigation and decision. This is the responsibility of the courts and is not to be entrusted to any other group purporting to represent the 'morality and conscience of our society' no matter how highly motivated or impressively constituted.

This decision, unlike Quinlan, really did intrude upon physician decision making. Quinlan was very supportive of physicians and did not mandate anything that would impinge upon physician making. Saikewicz actually mandated that life and death decisions were the province of the courts. This court, at least, was unwilling to rely on ad hoc groups or ad hoc procedures to make decisions which it felt were the province of judges, the properly constituted authorities to render such decisions. The editor of the New England Journal of Medicine, Arnold Relman 1978 508 9 pointed out that Quinlan had indeed supported traditional medical ethics as it had assumed hat physicians and patients, or the physician alone, could make life and death decisions. Saikewicz was seen by Relman as representing an all out clash with the authority of the physician. Relman found that the decision left:

> no possible doubt of its total distrust of physicians' judgement in such matters....Physicians must not be allowed to use their own professional judgement, but should be guided instead by government regulations.

The New Jersey's Supreme Court decision was responded to by a number of physicians and was seen by them as an intrusion into their professional dominance and judgement. Articles in Time magazine which included interviews with physicians (27 Oct, 1975:41; 3 Nov. 1975:58) described that physicians felt that lawmakers were taking the judgement away from physicians and putting it in the hands of those not competent to make decisions.

In support of physicians and writing in the Journal of the American Association, bioethicist Richard McCormick (1975:1057) responded to the judgement by stating that if health care decisions were to remain "truly human" they must be controlled primarily within the patient-doctor-family relationship."

After the Quinlan decision, several hospitals set up some sort of bioethics committee. The Massachusetts General Hospital (1976:362) administrators appointed an ad hoc committee to study ways to "manage the hopelessly ill patient." Those appointed to the committee were a psychiatrist, two other physicians, a nursing administrator, a layperson, and a lawyer. The committee recommended a four point classification system ranging from A which would give maximal therapeutic effort without reservation, to D, all therapy can be discontinued. The hospital also organized an optimum care committee to advise where there might be difficulties in "deciding the appropriateness of continuing intensive therapy for critically ill patients." This committee would meet at the request of the attending physician and its recommendation would go to the physician who could then accept or reject the advice. During the six month pilot of this committee requests for consultation had "been rare." The fifteen cases they had heard were basically to clarify misunderstandings, open lines of communication, and:

> above all, maximizing support for the responsible physician who makes the medical decision to intensify, maintain or limit efforts at reversing the illness. 1976 364

Another hospital, Beth Israel (Rapkin et al. 1976:364) in Boston, citing Quinlan drew up guidelines for ordering DNR codes. When a physician believed that a patient was "irreversibly and irreparably ill" with death "immanent," the physician could discuss with an ad hoc committee of physicians, whether death was so certain that resuscitation would be futile. If the committee members were in unanimous agreement then a DNR order would be placed in the patient's chart. If the patient were competent, then an informed consent would be sought, if not the family would be consulted.

Why did the physicians in the Quinlan case refuse to remove the respirator? The court believed that it was because they feared malpractice suits or criminal prosecution. It was self-interest and the fears of sanctions, not medical principles or a commitment to ethics that explains their refusal. The court then took as its mandate to find " a way to free physicians..from possible.." The solution - ethics committees to promote the "diffusion of professional responsibility for [termination] decisions." (In re Quinlan 1976:312).

The Quinlan case brought another group of people into the decision making arena of medicine and legitimated the presence of bioethicists. The case brought to attention the bioethicists and were included in national commissions, in the media. They became part of the medical school faculties to teach bioethics.

THE CASE: KAREN ANN QUINLAN - SLEEPING BEAUTY

Quinlan came to media attention in 1975 as her parents were fighting for legal guardianship so that they might remove her respirator so she could die (NYT Sept. 16 1975; Quinlan and Battelle 1977; Morse 1982:236; Daggert 1975; Oden 1976:12; President's Commission 1981:2).

Karen Ann Quinlan was a previously healthy woman of 22 who lapsed into unconsciousness one night. It soon became clear that she was in a "persistent vegetative state" and would not recover. Recognizing the hopelessness of her condition, her father asked her doctor to disconnect her from the respirator. When the doctor refused, Mr. Quinlan filed suit, asking to be appointed his daughter's guardian so that he could authorize the discontinuance of all "extraordinary means" of sustaining her life. The lower court refused to appoint him guardian, thereby undercutting all other issues in the case and the New Jersey Supreme Court accepted an immediate appeal (In re Quinlan 1976, 1982).

In what is a significant judicial decision, the court granted Mr. Quinlan's request. The lower court had felt that Mr. Quinlan's decision would be distorted by his emotional involvement in his daughter's predicament but the New Jersey Supreme Court found no reason to depart from the ordinary presumption of guardianship by next of kin. In practical terms the decision focused on her bleak prognosis, and held that:

> the focal point of decision should be the prognosis as to the reasonable possibility of return to cognitive and sapient life, as distinguished from the forced continuance of that biological vegetative existence to which Karen seems to be doomed" (In re Quinlan 1976: at 51, 355 A 2d at 671).

The recommendation to was to use the ethics committee to confirm the prognosis of Karen Quinlan who was in coma. This was the first case in the United States in which a court recommended committee decision making in what had previously been the private arena of the physician and patient. The role of the first ethics committee as a body to resolve a medical issue, symbolized its future role to confirm prognosis, which is a medical question, rather than an ethical one. This confusion persists.

At least one lawyer, Robert Burt (1981:145), co-chair of Law and Medicine at Yale University, maintains that Quinlan was an example of physicians unwilling to act on their own. One critical element to be decided in Quinlan was whether Ms. Quinlan needed the respirator to survive. The lower court's opinion rested upon the assumption that turning off the respirator would end her life. Ten years went by since the turning off of her respirator and her death. The basic assumption was that she needed the respirator, when in fact, she did not.

If the medical indications about this were paramount at this point the decision makers might have gone to her bedside and tested the question of whether or not she in fact needed the respirator to breath. However, the court moved on to the next question without testing the essence of the case, a fact that had been testified to by one witness, Dr. Fred Plum, a leading expert on vegetative coma who felt that she did not need the respirator. The case was dealt with as if it were a fictional case, having nothing to do with a real situation. Burt feels that this happens again and again in a court setting; "both the technological reality and, more importantly, the human reality are overlooked." This dealing with actual cases as if they are fictional ones also occurs in many of the bioethics committee deliberations.

Burt (1981:181) described the nature of moral dilemmas as "the problem of too much uncertainty." Moral dilemmas contain so much uncertainty that decisional capacities are themselves crippled. Arnold Relman, then editor of the NEJM agreed with Burt that part of the reason we are in the difficult ethical bind we are in is because of the failure of nerve of the physicians and their failure to accept the responsibility and liability inherent in the practice of medicine and decisions they are faced with. Relman (1976:186) said that:

> we got into this pickle not just because of physicians' excessive concern for immunity, but because of a very important change in society's view of medicine and physicians....We are in an era where doctors' authority are challenged and people are attempting to distinguish between "technical," medical decisions that doctors ought to make and moral ethical decisions that doctors should not make. This is a distinction that you cannot maintain.

In a different approach, at the Yale-New Haven Hospital in deliberations about do not resuscitate decisions they made no provision for the development of committees to review DNR decisions. They considered and rejected the concept of an ethics committee (Levine 1981:24) as mandated in New Jersey by the Quinlan decision. Their judgement was that the health care team that was working with the patient should be presumed to be the most expert "ad hoc prognosis committee" that could be convened under the circumstances.

The New Jersey Supreme Court ruled that treatment could be withdrawn from Karen Quinlan, and other patients in like circumstances, if that were the wish of the guardian, acting on the advice of the treating physician that there was "no reasonable possibility of [the patient] ever emerging...to a cognitive, sapient state," provided that a "hospital ethics committee" concurred with this opinion. The judge's reasons for suggesting that cases such as this come before an ethics committee included:

- the idea that the more open the communications among hospital patients, their families, and the health care team involved in the care of the patient, the more timely and efficient are the resolutions of ethical questions regarding patient care likely to be;
- the more directly ethical questions are recognized, identified, discussed and resolved in the hospital setting, the fewer federal government and judicial interventions are necessary or likely in the processes of medical decision-making about life and death.

Prior to this 1976 decision there had been precedent for mechanisms based on this type of rationale. If, for example, physicians do not define, promote and monitor their own ethical standards of practice, the federally authorized, external regulatory commissions will be appointed to do so. Professional ethics committees, quality control and peer review committees already exist. The institutional ethics committees might be seen as being an extension of quality assurance and peer review committees.

Some of the complex societal issues which are reflected in the operations of these ethics committees include: social views involving a transformation of ideas about death and dying; the presence of technology and the possibility of practitioner's ability to prolong living or dying; the implicit and explicit talk about and action concerning the allocation of scarce resources and rationing medical care. The issue here of age as a standard in rationing care is most important (Callahan 1987). Social views on the acceptability of death include a paradox: on the one hand there is a legal mandate to respect the rights of terminally ill and comatose patients to elect to end their lives in hospital and on the other hand, to override the autonomous choices of legally competent yet suicidal patients to end their lives in hospital.

One issue that began and continues to determine much of bioethics is the status of the person. Is the person, in fact, a person. Who is a person. When is a person dead and thus no longer a person in the sense that one must medically treat him or her? One segment of the history of bioethics reveals the attempts made by one authority or another to institute some definition of what constitutes a person. This definition is filled with the use of metaphor and analogy. The not quite dead person is called a vegetable, or in medical terms, "in a persistent vegetative state." As one comic said, "Yes, I am a vegetable. Today I am a radish, perhaps I will become a broccoli tomorrow." Patients are compared to children, the insane, the sleeping. The problem is in knowing when a person could take on the status of death. Once death as a status was defined, however crudely, then someone was needed to determine if in any particular case an individual should be placed within that status. The physicians were reluctant to continue to make the decision about life and death and so the courts were called in. As the Quinlan court said, they certainly had no expertise to make that kind of determination and it should be left to an ethics committee. This committee would act as a prognosis committee and if the prognosis were grave could put their imprimatur upon the decision to treat the person as if they were a vegetable or as not really alive, or almost dead.

At issue, and what is seldom discussed in the early debates about living or dead; person or non-person, is that one reason this determination was critical was that the organs of some of the soon to be not-a-person, were awaited by another individual's transplant team. Currently, that determination has more to do with economics and resource allocation than any philosophical notion of deadness. Other questions are raised such as, if an 80 year old woman is on a ventilator and is not expected to live a meaningful life, do we need to keep her on that respirator? The decisions about this, by case precedent in Quinlan, maintain that this decision should be made by a bioethics committee. So that now, bioethics committees have the opportunity and are so placed so as to legitimate these recommendations. Much is said in the literature about these committees being purely advisory. However, the way that the advice of bioethics committees is handled and the fear of litigation if one goes against the advice of the committee, is enough to make any bioethics committees decision far more than advisory. The physicians in the hospitals where I studied the bioethics committees felt that they would be bound, morally, if not legally by any decision or "advice" the committees recommended.

Once these decisions were defined and status issues such as personhood, dying, brain dead etc. were defined, albeit crudely, someone was needed to determine if in any particular case an individual should be placed within that status or category. Is this decision, about brain death a medical or legal issue or is it a social issue? For the definition of status and its determination in cases where death was an issue, physicians were not deemed essential in the decision making process. The bioethics committees are in the position of elaborating upon questions of life and death. The bioethics committees initiate discussions such as these into the medical universe of discourse.

Preceding Quinlan there was another case that served as a boundary conceptually: Roe v Wade. Let us think through this. Courts begin with the proposition that a competent adult has the right to refuse treatment even if that refusal of treatment leads to that person's death. This rests on two landmark events. One is the increased acceptance of the courts of the doctrine of informed consent. The second has to do with the privacy issue. In Griswold v Connecticut (1965), the US Supreme Court explicitly first spelled out a constitutional right to privacy. The Supreme Court in this case guaranteeing the right of access to contraception, established an expanded definition of privacy. A better description would be the right to make personal decisions about one's life without interference from the state. The 1973 Roe v Wade abortion decision was based on, and further expanded this right. This was interpreted by the United States Supreme Court in Roe v Wade, as based upon the constitutional right to privacy. Since 1973, courts dealing with non-treatment issues, have discussed the constitutional right to privacy. For example, in the Quinlan case, the court held that the constitutional right to privacy encompasses the right to refuse treatment (In re Quinlan 1976). The Quinlan attorney's (In re Quinlan 1976:1-40) argument centered on the constitutional right of Karen Quinlan and her surrogate to determine her own medical care. The patient, not the doctor was entitled to decide whether or not to pursue treatment Armstrong argued. The courts have said that the right to privacy includes the right to refuse treatment. However, that right is not absolute. There are State interests that have been defined by the courts which include:

1. the preservation of life
2. the protection of innocent third parties
3. the prevention of suicide
4. the maintaining of the ethical integrity of the medical profession.

Anent suicide, the Quinlan court said that as the degree of bodily invasion increases and prognosis dims, the state's interest in preserving that life decreases (1976 at 355 A.2d at 664). The state has an interest in the preservation of the lives of its citizens. However, as the court in Osborne (In re Osborne 1972) observed, the:

> notion that an individual exists for the good of the state is, of course, quite antithetical to our fundamental thesis that the ole of the state is to ensure a maximum of individual freedom of choice and conduct.

However, the hospital and physicians as well as the state attorney general argued differently. They insisted that the courts had no business interfering with physicians' medical judgements. The held the "Removal of the respirator was not supported by accepted medical practice" (In re Quinlan 1976:51). Patients were not permitted to ask the court to compel physicians to violate the Hippocratic oath: "No court...should require a physician to act in derogation of this sacred and time-honored oath" (In re Quinlan 1976:145).

The court affirmed the idea of a constitutionally protected right to privacy overlay the patient physician relationship and held that the right was "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way that it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions." In Quinlan, Judge Muir interpreted the expectations of the social role of the doctor-patient relationship in three ways:

1. the doctor should make certain decisions because he is an expert and thus theoretically has expert knowledge.
2. the physician should do everything to sustain life, as advocate of the patient. There is a higher standard required of physicians.
3. the doctor is assigned role of arbiter in cases of non concurrence when others disagree with his medical judgement.

STATE'S INTERESTS

What is the state's interest in preserving the life of someone who does not want to be treated? The right of physicians to administer medical treatment according to their best judgement is a state interest. This interest usually arises when a court says that a patient is victimizing the health care providers by not allowing them to practice their profession, thus placing them in an awkward situation (see also John F. Kennedy Memorial Hospital v Heston, 1971 at 279 A.2d at 673-674). During the Quinlan trial Ralph Porzio, the lawyer for the two attending physicians said hundreds and thousands of Karen Ann Quinlans would be similarly killed if the Quinlans are successful. Moreover, said Porzio (In re Quinlan 1976) they would be killed according to someone else's definition of a poor quality of life:

> And fresh in our minds are the Nazi atrocities. Fresh in our minds in our minds are the human experimentation. Fresh in our minds are the Nuremberg Codes.

Turning off Karen's respirator was "like turning on the gas chamber" Porzio maintained. During the testimony of the appeal to the NJSC several months after the decision by judge Muir, the role of physicians in deciding matters of life and death was closely scrutinized. The justices continually expressed surprise at the importance placed by physicians on the distinction between disconnecting a respirator and not starting it.

The AMA's official position in 1975-6 was that it was permissible not to put a patient on a respirator but prohibited to take a patient off a respirator once connected. The justices thought the acting and omitting distinction to be "rather flimsy." Neurologist Korein testified that physicians privately used "judicious neglect" to let terminal patients die and that this was an "unwritten standard" in medicine. The justices pressed the physician's attorney about why they couldn't transfer Karen to other physicians and end their relationship with her. They said, that the physicians and the hospital thought the Quinlan's decision was immoral, and that only physicians, not the family, should make such decisions. The NJSC ruled unanimously for the Quinlans. It decided that Mr. Quinlan, would be Karen's legal guardian, that the respirator could be turned off and other support withdrawn; that legal immunity would be granted to physicians and hospital from charges of neglect or homicide; that Karen's constitutional right to privacy could be asserted by her father to allow her to die. The court suggested, but did not require, that any further doubts could be resolved by a hospital ethics committee. The NJSC said that the right to privacy is broad enough to allow families to let their irreversibly unconscious relatives die.

What was the climate in which the Quinlan issue came to court. In terms of the law, there had been one difficult case which had received much publicity; the Edelin case in Mass. Abortion had been legalized by the U.S Supreme Court's Roe v Wade decision in 1973, which said a fetus could not be aborted after "viability." That is, the court held that after viability, the fetus had the legal status of a person. Edelin was in his third year and was chief obstetrics resident at Boston City Hospital. He had performed a late, second-term abortion by hysterotomy at the request of a pregnant teenager and her mother. There was a long and sensational trial which ended with a jury convicting him of criminal negligence. The jury believed that Edelin had not done everything possible to save the fetus, which was viable. He was not convicted of killing the fetus. This verdict was published two weeks before Karen Quinlan became unconscious. In late 1975, Robert Morse, Quinlan's neurologist, had just finished his residency in neurology the previous year. The second physician was Arshad Javed, a graduate of a Pakistani medical school who two years before Karen

Quinlan's admission had completed a fellowship in pulmonary medicine in the United States. Neither physician had much experience in dealing with unconscious brain injured patients or their families.

The Edelin case influenced the Quinlan case. In Edelin, a physician had been convicted of criminal negligence for not aggressively trying to keep alive a fetus defined by law as a person. The Quinlans were asking Morse and Javed to not aggressively treat a persons not defined as brain dead, and asa such, a person, under NJ state law and entitled to protection. Morse and Javed were being asked to disconnect a respirator to kill a non-brain dead person. Since Quinlan was not brain dead under New Jersey law, she had to be treated as any other patient unless some court said otherwise.

Morse was worried about malpractice if the Quinlans changed their minds. Since Karen was an indigent, Mr. Quinlan found Paul Armstrong at a Legal Aid office. The Quinlans portray him as an idealistic young lawyer, but others say that he mismanaged the case. All that was needed, say critics, was to have Mr. Quinlan appointed guardian, then remove her to another hospital where the family's wishes could have been carried out. Instead Armstrong announced Mr. Quinlan's intent to have the respirator disconnected and pushed the issue of letting Karen die, forcing the judge in the lower court, judge Muir to appoint a guardian ad litem other than the Quinlans. The question of guardianship should have been pursued prior to and separately from the question of treatment refusal (Oden 1976). The United States Judicial system has recommended that local, state, and national levels (eg in adjudicating the Quinlan case) abstain from these decisions and let health care professionals wrestle with these ethical dilemmas.

Sociologist Renee Fox (1976), was one of the first sociologists to comment upon and analyze the changes wrought by the new area of bioethics. She wrote of the growing influence of bioethics. Fox (1976:414), however, had some concerns about this emerging discipline and felt that it had too quickly brought what she termed "the wrong set of values to medicine." Since, as Fox felt, bioethicists lacked broad perspective, they were transforming religious questions into ethical ones, rendering a constricted secular feature to discussions that had originally been broader. Fox and

Swazey (1988:688) blamed bioethicists for the intense commitment to individual rights thus minimizing communal and societal considerations:

> In the prevailing ethos of bioethics, the value of individualism is defined in such a way, and emphasized to such a degree, that it is virtually severed from social and religious values concerning relationships between individuals; their responsibilities, commitments, and emotional bonds to one another....In these respects, the individualism of bioethics constitutes an evolution away from older, less secularized and communal forms of American individualism.

Fox and Swazey (1988:670) commented that they did not think it clear that bioethics truly reflected the state of American medical ethics and "whether it can - or ought to - serve as the common framework for American medical morality."

But to see the bioethics movement in a larger framework as Fox suggested was to understand the conditions and consequences of the forces sustaining a move to a concern with bioethics in the general as well as the particular publics. The events revealed at Nuremberg formed a base for later concerns about American unethical medical experimentation. The clear push of concern for informed consent and refusal and concern with the individual rights of persons which came to the forefront of American attention during the sixties and seventies formed a matrix the brought a number of outsiders into medicine. It was the claiming of rights by a number of groups that allowed questioning of medical authority and dominance to even begin. These rights were so strongly felt that judicial and legislative supports for them were provided. In the Quinlan case both the Hastings Center and Georgetown's Kennedy Institute acted as consultants to the Quinlan's lawyer, Paul Armstrong (Quinlan and Quinlan 1977:252-225).

C. PRESIDENT'S COMMISSION: BIOETHICS COMMITTEES AFTER QUINLAN

Interestingly, there was little growth of bioethics committees until the 1983 publication of the President's Commission Report and the 1982-1983 Indiana case of Infant Doe. In 1983 the President's Commission for the study of ethical problems in medicine and biomedical and behavioral research published one of its ten reports Deciding to Forego Life-Sustaining Treatment. This report directed attention to the potential uses of ethics committees. The commission legitimated bioethics committees in concluding that bioethics committees could play a number of roles, expanded from the narrow role of confirming prognoses that the Quinlan court suggested. The Commission exhorted health care professionals and administrators to develop mechanisms for review and consultation in cases raising ethical issues. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, suggested that hospitals form institutional ethics committees in order to situate the making of ethical decisions in hospitals themselves, and to avoid unnecessary involvement by the courts. The President's Commission (1983:4) report, Deciding to Forego Life-Sustaining Treatment, advised that health care institutions:

> have a responsibility to ensure that there are appropriate procedures to enhance patients' competence, to provide for the designation of surrogates, to guarantee that patient's are adequately informed, to overcome the influence of dominant institutional biases, to provide review of decision making, and to refer cases to the courts appropriately.

The President's Commission (1983:6) report, cautioned that there were "enough possibilities for error in the process of decision making for incapacitated persons that at least some decisions made by families and practitioners should be subject to review." To this end the Commission suggested a "surrogate decision maker" to protect the patients interests and ensure the patients well being and self determination the:

> medical staff, along with the trustees and administrators of health care institutions, should explore and evaluate various formal and informal administrative arrangements for review and consultation, such as "ethics committees," particularly for decisions that have life-or-death consequences.

The commission expressly suggested ethics committees as a mechanism for resolving conflicts and to consult on and review decisions with life or death consequences for incompetent patients (Pres Comm. 1983:5).

D. BABY DOE CASES

The third major American event which fostered the burgeoning interest in bioethics committees was the Federal government's 1984 regulations on withholding treatment. These "Infant Doe" regulations did not, in the end, mandate that hospitals form "infant bioethics committees," they encouraged their formation to review decisions not to treat handicapped infants as a safeguard against discrimination (AAP Infant Doe Non-discrimination regs. 1984).

The Health and Human Services regulations was essentially written by the American Academy of Pediatrics, who had made a proposal that institutions caring for handicapped infants in hospitals which participated in Medicare or Medicaid, create infant bioethical review committees (Committee on the Legal and Ethical Aspects of Health Care for Children 1983:203). In the regulations that discuss the Model Infant Review Committee, Health and Human Services (49 FEd. Reg. 1983:1652) describes their perspective of the Infant Care Review Committee to:

> facilitate the development and implementation of standards, policies, and procedures designed to assure that, while respecting reasonable medical judgements, treatment and nourishment not be withheld, solely on the basis of present or anticipated physical or mental impairments, from handicapped infants who, in spite of such impairments, will benefit medically from the treatment or nourishment.

Now, what message does one get here? It is very clear, that treatment is being mandated, even when the benefit will be only a medical benefit, not one that benefits the child or his or her family. It is not one that is in the child's best interest, but one that "treatment and nourishment not be withheld...from handicapped infants...who, in spite of such handicaps, will benefit medically from the treatment or nourishment." That is an odd directive, and one that seems to disregard usual issues taken into account in infant cases. These regulations were struck down by a Supreme Court decision (Bowen v. American Hospital Assn. 1986) but the potential of federally mandated committees was now a impending presence. The baby doe controversies resulted in one of the strongest threats of the incursion of federal government control.

Infant Doe was the fictitious name for the Bloomington baby born with Down syndrome and en esophagus that ended in a blind pouch which prevented his being fed by mouth. A hole in the lower esophagus led to his windpipe allowing air into his esophagus and digestive juices into his windpipe. The dilemma was whether surgeons should be allowed to connect the two ends of the esophagus and close the hole. His parents refused to allow the surgery. Bloomington judges upheld the parents right to forego surgery and the State Supreme Court justices voted not to interfere. Baby Doe died before the US Supreme Court could be asked to act. This all took place in six days. President Reagan was said to be repulsed by this case and instructed Margaret Heckler of the DHHS to act on this.

The Indiana Supreme Court had let stand a trial court decision which had allowed parents of a child with Down Syndrome withhold surgery that the baby needed to correct an intestinal blockage. The criticism of that decision led to the Federal Governments issuing a series of directives and regulations providing for means of investigating allegations of wrongfully withholding life sustaining treatment to children born with handicaps (Section 504 of 1973 Rehabilitation Act). If the hospital was found to have acted wrongfully it could have all of its federal funding including Medicare reimbursement stopped.

The White House intervened and ordered the Office of Civil Rights in DHHS to issue explicit regulations in March 1983 setting forth requirements about treating and instituting a 24 hour toll-free hotline on which to make complaints and which would elicit "Baby Doe squads" to review treatment decisions in individual cases (48 Fed Reg 9630: 1983).

The American Academy of Pediatrics and others succeeded in having the US District Court for the DC prohibit their enforcing on the ground that the regulations had been disseminated without sufficient notice and occasion for comment as is guaranteed in the Administrative Procedure Act (AAP v Heckler 1983). The department next reissued the regulations asking for comments and drew attention to the recommendations of the President's commission report on Deciding to Forego Life Sustaining Treatment (1983). One of the recommendations was that institutional ethics committees would provide better protection for patient's interests than federal intervention or judicial review, especially when a decision is made not to provide life sustaining treatment to a seriously ill newborn. In the reply to the Department, the AAP recommended that the hotline and Baby Doe squads be replaced by a requirement that the governing body of each hospital providing care to children appoint an "infant bioethical review committee," or have joint committees with other hospitals. The revised regulations in 1984 by HHS reserved the Baby Doe hotlines and squad but recommended as well that hospitals appoint "Infant Care Review Committees." They also stated that the fact that a hospital had such a committee be listed as the first recourse for complaints and said that government investigators would give consideration to decisions approved by such committees. Physician Strain (1983) pointed out that this process made ethics committees a focus of dialogue and the idea of ethics committees bnecame sanctioned by many in the medical community in comparison to a few years ago. For physicians and hospitals it seemed clear that unless there were some local arrangements to legitimate controversial bioethical decisions involving adults, it would not be long before the not so invisible hand of government would intervene.

GROWTH OF BIOETHICS COMMITTEES

Prompted by the triune influences of Quinlan, Infant Doe, and the President's Commission report on Deciding to Forego Life-Sustaining Treatment, the number of ethics committees has grown markedly. While in a 1982 survey only one percent of hospitals had ethics committees (Youngner et al. 1983), by 1983, the figure was 26% (Survey 1985) and by 1986, 60 percent of respondents reported that they had instituted such committees (Gibson and Kushner 1986). Currently, statistics from the American Hospital Association and California Medical Association indicate the figure of approximately 60% of hospital having ethics committees to be about the same since rural hospitals do not have the personnel to establish them. A number of prominent medical groups have endorsed Bioethics committees including the American Medical Association, the American Hospital Association, the American Academy of Neurologists, and the American Academy of Pediatrics (Cranford and Van Allen 1985). The structures, functions, powers, and legitimacy of

CHAPTER FOUR: CASE STUDIES OF BIOETHICS COMMITTEES: CONFLUENCE OF THEORY AND PRACTICE.

THE WORK OF BIOETHICS: MORAL ORDERING AT THE BEDSIDE AND IN THE COMMITTEES

A. MORAL ORDERING AND ITS LEGITIMATION

Earlier I discussed the idea that as both discipline and practice, bioethics involves the construction of ethical and moral rules and that the processes of these particular negotiations could be interpreted as moral ordering. This refers to the defining, re-defining, constructing, re-constructing and de-constructing of new rules in an area that is **interpreted** as moral or ethical. Moral ordering is a practice that produces, re-produces and alters a moral order as a component of the social order. Moral ordering includes to what Strauss (1979) described as "negotiated order," the fluid outcomes of social processes in which participants exercise their own power and legitimizing resources as they attempt to interpret, change, or construct rules and activities to their benefit. The moral order is dynamic and changing yet contingent upon structural conditions and the more stable elements of social order bounded by larger societal structural contexts. But moral ordering involves more than negotiations for there are power strategies that include coercion, persuasion, manipulation and appeals to rules and education (Strauss 1979:ix; 262). Actually, what I am doing here, is discussing particular processes involving certain structural conditions in which people deal with what those involved in bioethics define as moral or ethical issues. This involves the social organization of moral work (Addelson 1991).

Moral ordering is itself a product of the social construction of reality and includes specific languages and categories. The origins, nature and consequences of the definition of a given situation are fundamental to understanding its continuity and change, consensus and conflict. The action and practice of individuals in a social world, those in the bioethics discipline and committees in this case, occurs within a communicative process through which meaning is established. This context of meaning can both coerce or facilitate practice.

I found that what I was witnessing was a form of re-ordering of a malleable moral order which, because of a number of factors, was visible because it reflected somewhat dramatic changes. That is, in the hospitals there had been rather accepted ways of dealing with difficult problems. Now that was changing and paradigmatic of that change were the new bioethics committees themselves. Here **moral ordering** represented the ways in which the moral and ethical negotiations and maneuvers were being made and who had the knowledge and power to prevail. It included noting the ways in which the model through which all of these issues were discussed continued to be a medical discourse and vocabulary and how this acted to sustain, legitimate and re-legitimate medical hegemony.

Moral ordering and re-ordering entails the inclusion into the medical model of concepts and vocabularies of ethics, law, and economics at both the wider political levels and local committee levels. There was always some sort of ordering going on and it was about issues that were **labeled,** or not labeled, by the participants themselves as 'ethical' or 'moral.' Though some issues were construed as moral ones, conversation and dialogue about them, the language used and solutions found, were primarily framed in the discourse of biomedicine. Less frequently social, economic, or legal resolutions obtained, usually subordinated to medicine.

I found that:

- There is a division of labor in moral ordering such that one discipline's knowledge and beliefs can trump another.
- The dominant discourse is biomedicine and individualism.
- The division of labor remains intact, that is, physicians continue to be primary decision makers and nurses and others fundamentally contribute data.
- The use of the medical model frames bioethics decisions continually in a medical discourse rather than an ethical or social one.
- The power of the medical model informs and dominates decisions without much loss of influence from the participation of "outsiders."

- The hospital bioethics committees, in fact, sustain medical hegemony.
- Legal concerns strongly inform the decisions but are incorporated and reframed as medical decisions.
- Ethical discussions and formulations act primarily to sustain medical ones.

These findings obtained in the initial ethics committees discussions and negotiations. They were tested by attending comparable committee meetings in institutions unlike the ones in the original study and by comparing bioethics committees to other medical staff committees and to ethics committees in other arenas.

In this section, I examine some of the forms of moral ordering through exploring various discourses which I argue turn fundamentally on the concept of legitimacy (Weber 1947, 1922/1978). Moral ordering is itself a product of the social construction of reality and includes the languages and categories of the issue in question. The origins, nature and consequences of the definition of a given situation are fundamental to understanding its continuity and change, consensus and conflict. The action and practice of individuals in a social world, those in the bioethics discipline and committees in this case, occurs within a communicative process through which meaning is established. This context of meaning can both coerce or facilitate practice.

One key change in contemporary moral ordering involving biomedicine is structural in that there now exists a bioethics committee to advise on "bioethical issues," issues that were at one time the province of the physician alone. This is the new structural condition, my work is to see the extent to which this has or has not changed the moral order of the participants.

In the institution, and in the committees, we can think of there being at least two domains: the clinical domain of medicine, and the moral domain, where social and ethical concerns persist. In the bioethics committees, what has been done, philosophically and ostensibly, is to **add** the social and moral domain. That is, this layer, this domain, has been brought into the hospital to function on a level equal to the clinical domain. The physician and his or her clinical authority has legitimacy, and theoretically at least, the non-clinical moral domain has legitimacy. There is a putative co-equality but since the committee is operating in a clinical realm, to engage the moral dimension is problematic. Primarily, the authority and context are clinical. This makes it difficult, if not impossible, to introduce an ethical or moral dimension in clinical terms. The primary work is clinical and medical and takes precedence. The way the committee members concerns and vocabulary overlay the work is a secondary kind of work.

The bioethics committees in this study have three functions: case analysis and review, both retrospective and current; policy making; and education. While many committees may have mixed success on advising on current cases, they are structurally situated to have a strong role in making decisions in the future. There is now concern in several of the committees concerning explicit allocation decisions, the use of services and technologies for those whose benefit from them is in question, and economic matters. There is a reluctance to engage in overt economically based decisions although discussions of cost and benefit come up frequently. I believe that one of the difficulties in the committee structure is a confusion about the level of decision making. That is, traditionally, both physician and nurse have a covenantal relationship with the patient and that individual patient is the primary concern of the medical staff. The physician or nurse is not concerned about future generations, nor about a patient who might be admitted during the night. The individual medical staff in hospitals do not engage in triage. Their stated concern is with the identified patient with whom they have a covenant. That relationship has never been explicitly changed so that both patients and hospital staff acknowledge that there are times that the sickest patient, or the patient most in need of treatment which would be efficacious is given the treatment which might benefit the patient who is now denied it. As it turns out, the main focus in all of the committees is on death and dying.

Currently these bioethics committees are creating policies surrounding orders not to resuscitate (DNR), and issues of withdrawal and withholding of treatment. Since no one else wants to do this policy work, there is no competition for it. Policy construction is a very influential process, however, the committee members interviewed find it tedious and uninteresting for the most part. What they are really interested in is the cases.

The educational role of the committees consists of educating the committee itself, and educating those in the hospital and community. There is mixed enthusiasm for this task. Some of the committees have engaged in a continuous educational program including retreats, sending people to conferences, and having speakers come to talk about ethical issues.

The role that is seen as most meaningful to the committee members I have interviewed is advising on cases. In this section, the processes of moral ordering are explored by examining the practices of bioethics committees and the interactions of those within them which reveal processes through which the moral order is continuously created and re-created. However, because the structural conditions of the committee processes involve using a medical perspective, vocabulary, and assumptions, most issues are not discussed using an ethical vocabulary, assumptions, or method of analysis.

In bioethics committees there are certain structural characteristics which influence the proceedings, such as: who had the power to legitimate a case coming to the committee; who was allowed to present a case; what vocabularies and "expert knowledge" were used; who focused the decision/advice; and who selected what literature would be used to 'educate' the committee and to determine hospital policy about bioethics. Since, as evidence from my research reveals, the dominant or hegemonic discourse is that of biomedicine and individualism, other perspectives, such as that of ethics, law, or the patient, have to compete for attention. Inasmuch as other voices are unheard, the contest is to those whose voice is predominant.

In the discipline of bioethics today, and reflected in the practices in the committees, there is no single normative, accepted, or fixed moral order but instead a moral ordering and re-ordering about who is a person, what is an acceptable or unacceptable quality of life, how death is defined, and when shall we withhold or withdraw treatment. Many of these decisions are clearly social and ethical and not exclusively medical ones.

I argue that a biomedical perspective is the most influential structural condition of bioethics in the committees. That perspective and its assumptions, vocabulary, and concepts, looms large. In this section I analyze the structural conditions within which bioethics committees exist and the processes involved.

B. BIOMEDICAL DISCOURSE

An integral part of moral ordering involves how people think about issues. In the ethics committee cases I have observed, how people think about issues is primarily biomedical and involves the use of what has come to be called the biomedical model. This perspective forms the thought, vocabulary, and discourse of physicians, nurses, social workers, psychologists, ethicists and others in the health care industry, and increasingly patients and their families who are defined largely if not exclusively in relation to medicine. These biomedical perspectives have become archetypes or patterns through which people discern and explain experience. My fieldwork demonstrates how these perspectives profoundly influence and shape the views and interpretations of individuals and groups in bioethics.

A biomedical viewpoint takes much for granted, makes many assumptions and includes fundamental social and political structures under which bioethics has historically become relevant and ordered. The biomedical view includes a particular discourse which structures thinking as well as perception, both collectively as well as individually.

In the bioethics cases, to hear the discourse, one would think that it was only the body with which we were dealing. Is it an alive body - or brain, or heart? Do we treat the body? Do we feed the body? How do we organize and control bodies within social space? By focusing on the body or body part, such as the brain, negotiations are curtailed. This structural condition of medical language is generally unquestioned and creates a prescribed process and vocabulary of discourse. Because of what is left out, the invisible, it is difficult to make decisions that are based upon anything but "medical facts."

In medical thinking the concept of Occam's razor obtains, that is, the most simple explanation that will explain a situation is accepted as the correct one. This simplification as scientific tenet is in opposition to complex interpretations of events. The complexity of knowledge is often missed by our affinity for wielding Occam's razor. Knowledge is inseparable from human experience as a whole and to simplify or reduce it misses the webs of meaning indispensable to any genuine understanding of it.

In my data, what is interpreted as medically relevant is reflected in what is seen to be of concern and what is discussed from the biomedical view. In an era of so much knowledge, biomedical, moral and social issues become essentially contested concepts (Gallie 1955-1956:167) which vie for attention, and in the clinical world of the hospital, biomedicine and biomedical habits of thought prevail.

In contrast to biomedical and technical interests, social and moral life is characterized by practices which have to do with knowledge that grows out of collective social interaction. Parameters of knowledge are not predefined, but are generated contextually by individuals sharing interpretations of the material world. Inasmuch as the screen of medicine defines a problem as amenable to technical solutions, it tends to depoliticize moral and social issues and removes them from critical scrutiny. This world view of medicine, provides legitimation for actions which may not always be in the patient's best interests.

In a sense, biomedical discourse serves as a screen through which we perceive. This screen becomes a part of the makeup of reality and eventually the screen **becomes** the reality more than simply an artifact of reality. The screen becomes immutable and we are unable to see the extent to which "reality" is in fact a construction of our belief systems. I consider this to be the case with the use of the biomedical model. By this I mean the assumptions in which biomedical knowledge are embedded such as the idea that the body is analogous to a machine, that the body and the mind are separate, and that health and illness are biological states. In biomedical models medical problems are seen as reducible to physiological, cellular, and molecular phenomena, and thus the aim of treatment is to find a mechanism to manipulate these phenomena. To use a biomedical model, I argue, means that we view events through a reified screen and have trouble using another screen which might provide an opportunity to create a different interpretation for events. In fact, since we are largely unaware of the screen, we do not seek another interpretation. This is of concern since these issues and cases being brought to the bioethics committee might legitimately be thought of as ethical questions but are discussed as if they were only medical issues.

Having a committee to discuss bioethical issues implies that ethical issues will be discussed, and will, in fact, be the focus of the discussions. In fact, this is not true. The advice requested, and decisions made, are framed in terms of medicine and not ethics. While the bioethics literature is full of philosophical ruminations about values and ethical principles, these are rarely discussed at the committee meetings. The pattern in several of the meetings I observed that dealt with ethics at all, was to present the case, and then someone would say: "What is the ethical principle?" and another person, often the ethicist, would say, as in a mantra, "autonomy" or "allocation of resources." The incantations of justice, autonomy, beneficence, non-maleficence, veracity and fidelity were heard throughout the committees. In one committee, the chair would press for two ethical principles that were in conflict, so that the response might be, for example: "autonomy" and he would ask "versus?" and someone would sing out "justice."

> Steve, M.D. Chair: How long do you think he will live?
>
> Phil, M.D.: A long time.
>
> Steve, M.D. Chair: **What is the ethical issue?**
>
> Barbara, ethicist: **Allocation of resources.**
>
> Ben: This is a classical situation...we absolutely have to deal with. On cardiac surgical service...[interrupted]
>
> Steve, M.D. Chair: **How about autonomy here?**
>
> Dr.: On whose part?
>
> Bill: What is parental wish - choice?
>
> Ben: This is a classical situation...

Thus endeth the "ethical analysis." This indicates something about the role of the ethicist as outsider. Until the ethicists enter into the world of clinical medicine, they are of little help in solving ethical quandaries for they are literally overwhelmed at the sheer magnitude of the life and death issues being discussed, and being discussed in a language that is inexplicable until learned. The power of ethical reflection would come in its ability to help think through issues to clarify and perhaps make solutions reasonable and possible, or, that ethical principles would provide clear answers about what should be done in a particular instance. Unfortunately, this has not been possible in the ethics committees that I studied. The ethical systems which make it possible to reach specific conclusions are those of an essentially deductive kind. These have well established principles and a long history of highly refined casuistry. The Roman Catholic scholastic tradition and the Jewish responsa tradition are cases in point. However, systems of that kind presuppose a whole variety of cultural conditions and shared world views which simply do not exist in society at large.

The medical model mode of case discussion bases its decisions on diagnosis, prognosis and other medical "facts." The philosophical model bases its discussions on moral goods and marginal cases. The model of casuistry needs knowledge of moral principles, not simply statements that identify an issue as one of "autonomy" or "paternalism" without their foundation. The fact is that many members of bioethics committees learn these terms and use them to argue, without a clear idea of how they are principled terms that carry a whole lot of foundational and fundamental work. Casuist discussions earlier in history were taken part in by those sharing a particular social world. Today in the committees, the many different religions, classes, professions, those to whom loyalty is due, is enormous. It was in committees with a shared world view that the most important discussions can take place.

In the committees, the bioethicists have been more concerned with ethical principles than the processes by which decisions can be reached. Negotiation takes place but it is not negotiations "in a company of equals" (Freidson and Rhea 1963) for there are not equal resources or equal power relationships in the organization or in the bioethics committees meetings. Bioethics is an idealized way of decision making and when imported into the clinical area these ethical principles are not helpful so they go back to the technique of casuistry. But this only works when there is adequate ethical knowledge. A conference with someone like Jesuit-trained Albert Jonsen bears no casuistic resemblance to a committee meeting with no expert bioethicist.

C. ANALYSIS OF THE COMMITTEE DATA: THE INVISIBLE AND THE UNSAID

Poet Adrienne Rich (1978:17) warned us not to confuse "the technology of silence" for absence:

> Silence can be a plan
> rigorously executed...
> Do not confuse it
> with any kind of absence.

For Rich, silence was not simply inadvertent, but a powerful force which could be deliberate. Clearly, for Rich, silence did not mean that something was actually absent. In bioethics deliberations there are many silences involved in making bioethical decisions and the silences here too do not reflect absences. I do not believe that they are deliberately malevolent or premeditated, but rather that the silences exist because of the structural conditions in the committees. In the discussions about dying patients in the committees there are a number of invisibilities, primarily the invisibility of the patient. First, the patient is not present, nor is his or her representative. The patient or family is seldom aware that a deliberation in the bioethics committee is occurring. Facts about the patient are selectively filtered by whoever presents the "case." What is invisible, what is not discussed is a structural property since the discourse is in a traditional format and so is not simply that those using a medical format are overlooking a patients' contextual concern, but it is a fundamental feature of medical language that excludes social world context and morality from serious attention.

In considering the invisible, we might consider the morality of the invisible and note what is excluded. In bioethics discussions there is much that is simply not picked up in the conversation, much that is cut off, many questions and interruptions. The medical discourse often cuts off contextual issues and redirects the focus to technical concerns. But it is not just physicians who do this. All who are using the medical discourse do so. There is a clear separation of the discourse of medicine and the universe of discourse of the patient. The universe of discourse of medicine and the universe of experience of the patient are different, and it is difficult to find that of the patient. Where is the discourse of the patient, the experience of the patient in all of these committee deliberations about what is best for the patient?

Approaches to the world through a particular perspective gives certain form to social worlds and they are invisible, assumed, taken for granted and they construct experience. In using a biomedical perspective to define the field, important areas of moral inquiry are overlooked. Using the conventional field defining model of biomedicine prevents alternative models, such as that of ethics, from opening up new areas for examination. This produces a systematic bias to crucial elements of the constructed reality. Ethics, in a sense, is defined out of existence, except as an appendage to medical reality. Medicine is accepted by the committee members as scientific, rational, and objective; ethics is non-medical, non-rational, and non-objective.

Social class is one element of social context which shapes the content of discourse. Associations of social class are part of the context in which discourse arises and in which decisions are transmitted. In the bioethics committees, social class is not discussed. Also not noted is the fact that virtually every patient discussed is in a marginal social class. Gender, race, and age are also contextual components affecting discourse which are also never discussed openly.

What one might expect, within the committee deliberations, are discussions based upon critical thinking and analysis. That is, through doing ethical decision making work, the committee members would develop a sort of moral expertise through its practice and by using critical thinking about bioethical issues. This is needed because many of the moral problems faced today are novel. There are no deeply established arrangements to guide us. Whether it is right or wrong to keep a person alive for years with no hope of recovery, a person who is barely conscious and perhaps in pain, is novel because the opportunity to do this is so recent in our history that it is not surprising that our arrangements and dispositions about cases like this tend to be ambiguous, vague, contradictory and poorly focused. Without critical thinking, it is inevitable that the discussions should be so.

In this section, I will use the data from the committees to illustrate how I arrived at the concepts through the data. To illustrate the phenomenon of the unsaid and the silence of the patient's life, what follows is an excerpt of a social worker presenting what she might, in another situation, have presented as a narrative of an illness but which here takes on another countenance.

> Anne: Social Worker: This is a 52 year old patient in the CCU, with post anoxic encephalopathy. On 9/19 she was admitted with acute encephalopathy. On 10/9 she arrested and had CPR. She had a consult by outside neurologists. None would say she was brain dead, so the question of brain death persisted.

First, it is noteworthy that the situation is introduced in the ritual ceremony of the medical "case presentation" with such a specifically biomedical vocabulary that anyone not in a medical field would be left out of the discussion. The discourse is precisely biomedical and follows the format of: age, sex, diagnosis, and so forth. Across all of the committees where I did field work, virtually all of the cases are presented in this manner. Moreover, cases were presented in the classic biomedical model regardless of who presented them, doctor, lawyer, nurse, social worker, psychologist or ethicist. But this process, of presenting the medical "facts," and in a Webbian (Jack) sense "just the facts Ma'am," **excludes** a substantial part of the patient's experience and an array of issues which are contextually ambiguous. That which is excluded also affects what may be decided in the bioethics committee deliberations.

To begin a presentation with such a specifically biomedical vocabulary and point of view involves accepting a particular perspective which carries with it many other assumptions, in this case the biomedical model and the assumptions thereof. The assumptions include that the body is a machine; that one can label and then fix the parts with no apparent realization that not everything can be, or would one want to have, fixed. The focus is on the woman's brain, she has "post anoxic encephalopathy" - a swelling of the brain following a decrease in oxygen to the brain; she had acute encephalopathy, her brain was greatly swollen; she arrested, her heart stopped; she had cardiopulmonary resuscitation. The consult with neurologists resulted in none of them saying she was brain dead; the question of brain death persisted; is she brain dead; are there other tests we can use to tell. This entire first portion of the presentation centers upon this woman's brain and its degree of death. Later the focus shifts to her heart and lungs. This illustration also illuminates the consciousness of the participants in the committee meeting. No one said anything about the focus on the woman's brain being perhaps inappropriate. There is a taken-for-grantedness of the entire scene, precisely as medical ritual. The moral ordering about defining this woman as alive or dead is thus far made in one voice, the unquestioned voice of, and perspective of, medicine.

Hearing the report of the "woman with post anoxic encephalopathy," characteristic of most of the ethics committee reports, one is struck by the sheer skeleton it provides of a life. The unsaid looms large. Who is this woman, how did this happen - the encephalopathy, for example - was she sleeping and then woke up, was anyone with her, was she conscious, afraid, anxious, how did she get to the critical care unit. This woman, who is never named, is clearly sick but she, as a person, is profoundly absent from the story.

The difference between disease and illness is critical here. Illness not only indicates what the patient experiences, which in most of these cases is moot since he or she is not responding, but what **others** experience and how they give meaning to the patient's illness. Others include family and friends, physicians and nurses and other health professionals dealing with the person. In this situation, however, the woman is the patient as object; even her status as patient is denied. To be a patient is to be a subject, to suffer, in the original meaning of the term. The difference, in this presentation so far, is focused on the woman as someone with disease: organs with organic lesions, pathophysiological processes. The patient's experience of illness is simply not explored. Perhaps in this case it is because she is non-responsive. But then what of those who might be concerned with the experience and meanings of her illness? The son in the story is described as a litigious man who does not know his mother's wishes, and the mother's significant other who lives with her and who "has the same views as her son" is similarly discounted.

Now, naming this woman as the "person with encephalopathy" may seem like harmless jargon used by busy professionals for the sake of efficiency. But it also becomes a world view, a way in which reality is seen, interpreted, and dealt with. Naming things in this way allows us the illusion that we know and understand them. Medical classification and diagnosis are, in part, a means to control and manage the unknown and perhaps unknowable. But through it, the patient as person is rendered invisible.

The outcomes are unpredictable in all of these situations and are exacerbated by contextual stories that further point out the uncertainty of prognosis. The importance of context may be illustrated by the fact that this situation occurs within a few months of a very unusual story which had much publicity (Cole 1990). The dramatic case of Jackie Cole, an active vigorous woman of forty three, married to a minister, and mother of three grown children suddenly experienced a powerful headache which turned out to be a massive stroke resulting in a seemingly irreversible coma. Her husband, the Reverend Harry Cole, and their children struggled with the question of her "right to die." She had in the past discussed with her family the fact that she did not want to be kept alive if she were ever in such a state and the family decided to follow Jackie Cole's expressed wish. After much discussion, the family asked the physicians to withdraw treatment. The physicians refused and the Coles took the case to court and sought court permission to have her life support systems removed. The court denied their petition and the judge refused to allow treatment to be withdrawn. Six days later Jackie Cole awoke. She had months of rehabilitation ahead of her, but she was alive. The story, on the cover of People magazine and other popular magazines referred to this **Lazarus** story - as if she had risen from the dead. This story, in the media during the time of several of these ethics committee deliberations, provided hope to the families that their child, mother, father, partner, would also experience a miracle. It also made clear the fact that there is considerable uncertainty in who dies and who awakes which influenced everyone concerned. Also, each individual patient may have some sort of personal revival. The "woman with encephalopathy," for example, had recovered from an earlier illness:

> Chris, R.N.: She had an earlier hospitalization, she was in a coma and woke up spontaneously and got well. Now she is demyelinated. So this is her second hospitalization.

This medical formulation, of what might be seen as a social problem, grants the decision symbolic status and renders it immune from change or criticism. However, since the woman had once awakened, might she not do so again? Under the circumstances, it is not irrational for the son and the woman's significant other to hope for another miracle. However, the importance of this is glossed over.

Again, a 1991 film, Reversal of Fortune, depicts Sunny von Bulow, who has been in a coma for eight years yet, in the film, she is the narrator. Sunny von Bulow is laying in bed, in an irretrievable comatose state, narrating the story of her life with Claus von Bulow, accused of attempting to murder her by injecting her with a large dose of insulin. The fact that this woman, all but dead, is clearly aware enough to be the narrator will not escape those who have difficult decisions to make about relatives or friends in similar states. It provides another unusual context for these deliberations about "dead enough."

We have long been concerned with when someone is really dead, the circumstances change but fears of not being dead enough abide. Stories of when someone is "really" dead and of being buried alive are a part of literature and of folklore. An interesting historical anecdote is that of a young boy, Winslow, who had been chronically ill and had awakened on at least two occasions to find himself in a coffin and at the center of a wake. Winslow became a physician and wrote, in a French Medical journal an article in 1740 entitled "The uncertainty of the signs of death and the danger of precipitant interments and dissections (M. Alexander 1980:25). Winslow proposed an operational definition of death: putrefaction. Lacking putrefaction as a standard of death, contemporary physicians have established brain death as the criterion. The issue of whether the brain is "dead enough" to allow physicians to use the body is currently receiving much attention in the matter of anencephalic newborns as a source of organs for transplant. As philosopher Paul Menzel (1990:417) notes, The practical problem here is that we often cannot wait until such infants are legally dead - that is, in most states, fully brain dead. If we wait until then to remove organs, they have deteriorated and we have drastically reduced the prospects for successful transplant." The situation is similar to the heart transplant dilemma. In each, since the need is for not quite dead organs to transplant, the search is for "some ethical way of removing them while the [patient] is still alive" (Menzel 1990:417).

If we say that, for example, the anencephalic infant is dead because their upper brain is dead, that conflicts with existing definitions of death as whole brain death which includes the brain stem. That is the definitional situation in the case of the woman with encephalopathy. Now we might change the definition of death to accommodate the situation of anencephalic infants and say that death exists when the upper brain is dead. That would accommodate cases in which there is only brain stem activity. That might include cases such as Karen Quinlan or our case of the woman with encephalopathy.

In each of these cases, although the person is alive, they are not persons in the sense of having an autonomous capacity for life. The infant has not ever had a life, the adult has had one.

We have seen in several court cases that the legitimate interests in these cases involve those of the person under discussion and those of the state. The state has a constitutional interest in preserving the lives of its citizens. It has been argued by David Blake (1989:8) that the state has an overriding interest in protecting a human life even when that life is filled with pain and suffering - "the life of a person in distress is still a good" and as such, is worth saving. He maintains that the state has a: "prima facie duty to protect the intrinsic value of human life."

D. THE PRACTICE ARENA: STOPPING TREATMENT AND THE SOCIAL CONSTRUCTION OF "DEAD ENOUGH"

In the committee deliberations, questions arise about the **degree of death** of patients. When is any person "dead enough" to stop treatment? Who defines a person as being "dead enough"? Certainly it is not the individual for it is almost always others who impose definitions upon the person. He or she is defined by others. In bioethics committees, this issue arises repeatedly. In each case there is a boundary which is at issue - boundaries constructed between alternate conceptions of the individual and community and between life and death. These boundaries are defined and redefined and serve as symptoms of conflict and redefinition. The redefining is assisted through the use of a hierarchy of language ranging from medical and scientific to lay. The symbolic boundary between self and community, living and dying between alive and dead are negotiated and renegotiated.

A second aspect of these decisions, and one that is also sociologically interesting, is that making these boundary distinctions is in effect making a prognostic assessment. What is the probability that this patient will awake, will live, will die? This is not an unequivocal decision, nor is it a uniquely medical one. These decisions include predictions about the person's future. Decisions to not resuscitate a patient, to "pull the plug" on a respirator, are made only after some sort of estimation is made concerning the degree of death. That is, will the patient live, recover, or die. However, because of the extent of uncertainty present in these deliberations, it is sometimes only a good guess. There is, to begin with, the medical prognosis. In fact, according to the clinical bible <u>Clinical Bioethics</u>, by philosopher, Al Jonsen, lawyer William Winslade, and physician, Mark Siegler, this is **always** the first issue to determine in any case analysis. This involves a prognosis of the patient's trajectory, will they live or die. It only later involves looking at the possible future of the person: if they live will they be paralyzed, able to go home, institutionalized, and so forth. This part of the discussion is not primarily medical. It involves an appraisal of the future and quality of life of the patient and involves value judgements about whether or not this is a desireable quality of life. But desireable to whom, is often not asked.

In many discussions there is agreement upon the prognosis, agreement on the ethical principles at stake, but disagreement about what actions to take based on these. Below is a section of a bioethics committee discussion quoted earlier where the 'deadness' of a patient was being contested. Note how death is defined. The degree of death was an important issue in this patient's biomedical career. If the original neurologists had pronounced her dead, there might have been less difficulty in avoiding treatment for no one is obliged to treat a dead person. But how is brain death determined?

> Anne: Social Worker: ...On 10/9 she arrested and had CPR [cardiopulmonary resuscitation]. She had a consult by outside neurologists. None would say she was brain dead, so the question of brain death persisted. None will, or are able to, describe her as brain dead....The issue is what principle to use? Treatment is ineffective but without justification for termination. Is she brain dead? Are there other tests we can use to tell?

The comment about "other tests" reflects a biomedical mode of looking at death - find a test to document death so that we can proceed. A recurring code category which is explicit here is **measuring the absence of life**. Technologies are deployed to construct death and define and measure the absence of life. One additionally needs to get the "right person" to verify death using those technologies. By saying "none will," the social worker means that the "right people" will not say the patient was brain dead. Those with the power to define, in this situation, from neurology, will not legitimate "dead enough." An interesting footnote to this is that recently clinical neurologists have been suggested by one neurologist to take their place as ethics consultants to be called "neuroethicists" (Cranford 1989:697) in a further effort to document them as "the right people" to grant the imprimatur of death. But this whole presentation keeps the definition of this woman's situation entirely medical. The hierarchical relationship between scientific and moral language, continues to reflect a dominance of science as advanced knowledge and also gives power to those who possess that knowledge. It is this hierarchical relationship of medical knowledge that, I believe, in the committees and in the literature, persuades the non-medical members of the committees to learn and speak, to absorb the perspectives and concepts of medicine into their everyday vocabularies. The non-medical participants become domesticated into the community of the bioethics committees, a medical world.

The bioethics committee discussion continued with arguments from members of the ethics committee disagreeing about what ought to be done in this case.

> Larry, M.D.: What was the **ethical analysis**? If the diagnosis was death, it is a **medical decision**.
>
> Anne, S.W.: It was **futile treatment**; **inefficacy** of treatment. If that decreases does that justify **discontinuing life support**?
>
> Marge, R.N.: We have to use proper **medical judgement**. It is not rational to resuscitate an apneic patient.
>
> Joan, R.N.: It is the option of the hospital and the doctor to approach the son. The **expense** of going through that... [interrupted]
>
> Marge, RN: For all intents and purposes she was **brain dead**. Apneic, but not in a persistent vegetative state.
>
> Chair, M.D.: Just looking at it from **an ethical point of view, not a medical one**, we have to have agreement with the surrogate: the son. There was no DPAHC [durable power of attorney for health care]. There were just conversations back and forth; he [the son] was treated as a surrogate, I think you have to treat him as such, **legally** - and **ethically**.
>
> Lin, Psychologist: The words are interesting; **Liability versus ethics. Ethically, beneficence** for the patient equals doing nothing. **Legally** - there is a conflict between the two....There is a clear **overlap and divergence** of **medical, legal, ethics** in all of this.
>
> Dr. Chair: The fact that the **lawyer is involved and the fact that the son is threatening** definitely altered the profile of the physician of the case.
>
> Dan, M.D.: When Dr. Rex was here he discussed how the criteria for death evolved from organ transplantation. **If two competent physicians say the patient is dead, in the eyes of the law, they are dead**. There is **no ethical requirement to ventilate a corpse**. It is not the family's job to decide.
>
> Don, M.D.: No one agrees on **brain death**. There are little moments of EEG activity, and so brain stem...
>
> Dr. Chair [interrupts] there was **not even brain stem**... [MEETING ENDS]

In this case, some felt that the patient was "dead enough" to stop treating, others felt that there was some question of defining the person "dead enough." Some felt that it could be clearly and medically decided that the person was dead, others felt that there was disagreement in any case. But the definition of the woman as dead enough was continuously perceived as a medical one, regardless of the fact that ethical terms were used. The medical uncertainty about her being dead enough was exacerbated by the son's threat of a lawsuit so that in this case the lack of a firm medical decision allowed a legal discourse to hold precedence, at least temporarily. The woman was continued in treatment and the meeting ended with no closure.

The abrupt cessation of the meeting with no closure points up another problem in the bioethics committees. The time boundedness of the discussions does not always allow for a thoughtful conclusion to be reached.

The original moral order prior to 1960 was that physicians were the primary deciders, over lawyers, over ethics, over patients and their surrogates, over nurses. That is, in most decisions, those at the top of the hierarchy had the ability to trump the decisions of those beneath them. Since patient rights and patient autonomy concepts have become more prevalent, the patient is seen, in ethics and in law, as the appropriate person to make decisions about his or her health care and what happens to his or her body. In the hospital, this change is occurring slowly. In the committees, it is the physicians' decisions in the committees that trumps, unless there is a legal trump as when there is an implicit or explicit threat of a legal suit. In some cases it is nursing that plays that trump, in others, lawyers. In a few cases, it is the physicians themselves who play a legal trump to make the decision.

As in this case, the issue of futility comes up repeatedly. If treatment is futile, even though a person is not "dead" by some assessment, can treatment be stopped? This is currently stated as policy in several directives yet in this case, the futility issue was ignored in favor of seeking a definition of death. The issue of defining futility is of course another area of negotiation.

Then there is another plea from the social worker, expressing the concerns of those on the sub-committee:

Anne: Is she brain dead? Are there other tests we can use to tell?

From this one might assume that the major question in this case is whether or not the patient's brain is dead. "Other tests" would continue the medical definition of death - find a test to document brain death and we can proceed. Again, the code category, **measuring the absence of life**, is evoked.

The discussion continued with arguments from members of the ethics committee disagreeing about what ought to be done in this case. What I want to concentrate on in this analysis is the terminology used.

> Dr. Dan D.: What was the ethical analysis? If the diagnosis was death - it is a medical decision.

This statement captures the logic of several of the "degree of death" discussions in several committees. There is a persistence in viewing these decisions as purely medical ones having to do with death, for example, rather than an issue of futility which could also be framed as a medical decision or as an issue of ethics or law. While questions regarding what the ethical analysis might have been, there is no ethical analysis to be found in the discussion. When Dr. Dan asks "What was the ethical analysis?" he does not wait for a reply, nor does he act as if it matters, for he moves right to his point that "If the diagnosis was death - it is a medical decision."

Closely linked to the definitions and issues of death discussed here are the ways in which both definitions and discourses are constructed. Two things occur in the negotiations about when a patient is "dead enough." One involves the technological and definitional aspects of "death;" the other, is the biomedical discourse - medical language and its boundaries. These implicit or explicit appeals to authority using biomedical perspectives sustain a legitimacy context in many of these discussions. There are also new manifestations of language - the idea of individual autonomy, for example, which essentially decouples the thoughts and commitments of one individual from those of another is one example, the idea of cultural relativism, allowing different beliefs to exist in different situations is another.

Next, at another hospital another patient is discussed using a similar medical vocabulary and concepts. Although it is clear to the physicians that the patient cannot survive without the ventilator, treatment persists because although the patient may be seen as a "throbbing corpse" he is not yet "dead enough." In fact, there was even discussion about treating a future pneumonia with antibiotics.

> Ben, M.D.: This is a man in his early forties who has been in and out of neuro ICU for a good long while. He is ventilator dependent, has a chronic lung condition, retains CO2, and his pulmonary function is difficult. Mental status: some observe that he responds by blinking his eyes. Its a difficult social situation. The family is difficult to deal with. The mother comes in and there is a rocky relationship with her and the staff. **The mother says her son would want "Everything possible done."** He's unweanable from the vent. He can't be placed in a nursing home because he is vent dependent.
>
> ...
>
> Ed, M.D: What is the **legal basis** for a client having us be responsible for his infinite care?
>
> Bill, M.D., Chair: What is his **prognosis**?
>
> Ben, M.D.: Its clear he can't survive without a ventilator. He won't regain neurological function. **He won't improve**. It's not a ventilator mechanical problem - even on a ventilator he retains CO2. At some point he will get pneumonia and not be able to be adequately oxygenated. Now he's at **no code** with the agreement of the mother - mainly on the grounds that the team feels he wouldn't survive.
>
> Ed, M.D.: **He's a throbbing corpse.**
>
> ...
>
> Edna, Social Worker: Admissions is talking about moving this patient. It is getting clear that he was vent dependent. He is HIV+. There is only one facility that would take him in, Foxgrove, that take vent dependent patients. There are virtually no options. The tension started flying when we discussed him.
>
> ...
>
> Ben, M.D.: The crisis will come soon. What will we do? He'll come in again - how aggressively do we treat him? Do we put him on vent, give antibiotics?
>
> Sam, M.D.: Why give antibiotics?
>
> Ben, M.D.: His HIV+ is asymptomatic at this point. Why give antibiotic? I guess the question is, assuming that this life is meaningful, and in the past we have treated, if his condition is OK and can be prolonged by antibiotic, then treat. The natural history is that he will die of infection. Mother says his existence is meaningful and should be extended.
>
> Louise, M.D.: **This is a question of ordinary versus extraordinary support.** Antibiotics are not extraordinary, dialysis is extraordinary. Treat his pneumonia, tune him up. If he codes - no code. **We are dealing in an acute setting with a chronic problem.** In pulmonary at Mt. Children's - the ethics of putting a Cheyne's muscular dystrophy on ventilator **there is no ethical dilemma. We have the technology, we do it.**
>
> Joseph, M.D.: Thank you Dr. Eichmann [referring to Nazi Eichmann].

Another key issue, mentioned here, is the fact that the committee is dealing "in an acute situation with a chronic problem" and there is little discussion of how this factor may influence the decisions made in these committees. This is, however, a major issue and one that continually recurs.

Here is a man, never named, about whom the discussion ranging from possible treatment, whether seen as futile by some or not, is confounded with the mother's appraisal of her son's life as meaningful. The wishes of the mother, by the tone used by the physician, is not really seen as integral to the discussion about how much the physicians are obligated to do. What was not stated until very late in the case, was that the patient was HIV+. What only came out at the very last moment, is that neither the patient or mother were English speaking. That these two important pieces of information were not presented by the physician of the case is puzzling. The social worker brought up the HIV+ issue and, after the meeting ended, in an informal discussion, she brought up the language issue. I believe that this absence of discussion about issues germane to this patient's life reveals the incredibly focused medical language and concepts used in his "case." A narrow professional approach is a possibility when health care personnel are upper middle class and treating "marginal" or lower class patients. In that context, general class relations in society are replicated in the actual medical encounters and the political economy accountable for this enter into the ethics committee meetings silently, like a phantom.

In terms of how this use of the medical model sustains a medical hegemony, we need to see how it is legitimated and, as we have seen, part of that legitimation comes through the structural condition of the medical discourse and language. Languages are fundamentally related to legitimation in that languages can be interpreted as forms of competing discourses. In bioethics, there are discourses of medicine, of philosophy and ethics, of politics, of sociology, of law, and of everyday life. Legitimation, in its discursive forms, can essentially be understood as the mastery of legitimacy by one discursive system which then becomes the dominant or hegemonic language. The dominant or hegemonic language in medical cases, as well as in court cases, is the language of the **individual** - the language of autonomy rather than of community.

Language constructs reality: words create worlds. Reality is constructed through language; and, reality may also exist as social facts. There may be a socially constructed **a priori** realm and a socially constructing process of creation within the structures, mediated by, among other things, language. Language is the **sine qua non** of reality maintenance for it turns the flux of experience into a seemingly coherent and orderly pattern. Language is the most important vehicle of reality construction and maintenance. The use of a biomedical perspective and language is significant both in terms of legitimation and also in terms of the frame of reference for moral ordering.

Language begins the moral ordering and negotiative processes of the committee. Crucially, language allows people to share a representation of a situation which they are not in, or not in at the moment. The language the presenter uses to tell the story of the person creates the situation for the committee. The committee can then express their reactions to this described situation which they can picture together: they can express thoughts, feelings and language tied to rationality, feelings and motivation.

As an example of this, in one situation the same case was presented first by a neurologist, then by a nurse. It is an important case because it is so unusual. It is an instance where one discourse, the medical one, is **explicitly** challenged by a different one, a moral one. After the physician presents the case a nurse consultant enlarges on the situation in a dramatically different way that captures the dilemmas of problems with communication, iatrogenesis, moral issues and the feelings of the nurses, physicians, mother and volunteers. Three people were on the ethics subcommittee consult team of the larger ethics committee: Richard, Steve and Mary. Mary is a nurse, Steve and Richard are physicians. Steve was not present at this meeting.

meeting.

Richard: In March I was asked by Dr. Jon to consider 2 issues on a three month old baby girl: a DNR order; and an order to limit antibiotic Rx. At birth 500/30 gm; Mother Gravida 8 Para 7; Black mother with history of alcohol and cocaine. APGARS 5 and 7 [measures of an infant's vigor at birth]. Respiratory distress syndrome - intubated, mechanical ventilation. All was semi-well until 30 hours after birth. Endotracheal tube obstructed because of secretions. Extubated and became hypoxic. After 1/2 hour became acidulitic, PCO2>6.9. Restarted airway - anoxic encephalopathy. In March

> - 2 1/2 months later, breathing spontaneously - nasoduodenal tube. On 4/8 meeting about DNR. Dr. Jon and Steve and Nurse. Next day there was a meeting with everyone. Nurses came in from home on their day off, as did social service. Social history: The Mother is intermittently visiting. She has a poor attention span. Doesn't have a clue to what was going on.

Then Mary, the nurse consultant, described her participation, illuminating the situation from a perspective strikingly different from the model used by Richard, the neurologist.

> Mary: This was our first baby consult - so all of us on the committee are not experts at this. There seemed to be communication problems. I insisted on seeing this baby. I really got a sense of how nurses are really saints. I scrubbed up in garb - and went in. She's a pretty little thing, blind, deaf, responds like a puppy. Then I got caught up in how nurses are on 12 hours at a time - and there are camps, now people are not talking to each other. Mom - in detox and on phone 2 hours a day with nurses. Not seeing baby. Feelings and frustration. All the kids in this unit are mentally [waves hand]. A roomful of people caring about the little people. All of the reading in the world wouldn't give you this, the feeling, the knowledge you get from being there with the nurses and the little ones. It was Easter weekend and the nurses had filled the crib with animals. They had wrapped her in blankets so she wouldn't be cold and her little face was covered so the light wouldn't be in her eyes. We met one week after Richard took off. She was 4 1/2 weeks - no suck, no gag, breathing, frequent suction and gavage. Foster family are 2 women who take, some awful name - the grave babies, the futile babies.

In Richard's presentation he describes how he was asked by another doctor to consider but two issues: a DNR order; and an order to limit antibiotic treatment. These were clearly being presented as medical issues and had nothing to do, as asked, with ethics. But an order not to resuscitate a baby is more than a medical issue and the fact that this case comes to the committee reflects that. Richard's discussion focuses upon the "case" and the baby's weight at birth, mother's pregnancy history, baby's APGARS, respiratory distress syndrome and treatment of intubation and mechanical ventilation. He describes how, 30 hours after birth the baby's tube "obstructed." Note the passive voice: "All was semi-well until 30 hours after birth. Endotracheal tube obstructed because of secretions. Extubated and became hypoxic. After 1/2 hour became acidulitic, PCO2>6.9. Restarted airway - anoxic encephalopathy." The very clinical medical presentation of this event does not reveal that, in fact, this was an instance of iatrogenesis which is part of the context of this committee discussion, unsaid and invisible. Nor did it reveal that the major "problem" was a conflict between the nurses and the physicians.

In Richard's presentation, the entire social history is that the mother is black with a history of alcohol and cocaine abuse, that she is intermittently visiting, has a poor attention span and doesn't have a clue to what was going on. That these are selected out of a range of social facts which could have been reported is an indication of what I am talking about. The description of the mother in the nurse's account reveals more about the mother as a mother: "Mom - in detox and on phone 2 hours a day with nurses. Not seeing baby. Feelings and frustration."

The "detached concern" (Fox and Lief 1963) assumed by the physician is in contrast to the involved concern in the story told by the nurse. The nurse's discourse reveals the problems in communication, the helpless feelings of the staff, the poignancy of the baby, the distress of the mother, the heroism of the caretakers. Whether the physician felt anything similar is simply not clear from his discourse. The nurse's story is in contradistinction to the neurologist's story and leads to a discussion involving the tension between those caring for the baby continuously and those who drop in to see her once a day. The nurses want the baby "cared" for, not simply to have a DNR order written. This kind of moral ordering discussion, where the predominant model is challenged, had the potential to lead to a new understanding on the part of each of the participants and advanced a different treatment plan.

It would be vastly oversimplified, however, to think that the different discourses could be accounted for by gender (Gilligan 1982) or role alone. The language and discourse from the framework of a biomedical model in the committee meetings is used by men and women in all of the professions. There is no simple breakdown by age or sex, by class or race, by occupation or education. Very few people used a non-medical discourse in any of the meetings I observed.

In this study, few of the examples of predominately moral or non-medical discourse are from physicians. Perhaps one of the reasons physicians do not speak non-medically in the bioethics committees is because of the institutional structural context. That is, when presenting, one adheres to the rules of scientific discourse. That is not clear. Because physicians dominate the discussion in the ethics committees and use a framework of technical medicine it becomes a hidden exercise of power to use the medical model and clinical presentation. Hidden, because it is accepted and unquestioned except for exemplars like this case.

In the committee deliberations, aside from the discourse of medicine there is the discourse of ethics, and of law. The discourse of medicine reflects technical interests and issues from a scientific perspective. In this perspective, the meaning of events is provided through abstract rules that serve to decontextualize events, and which serves to remove them from personal and social contexts. There is also the discourse of the patient which is contextually grounded in the person's experience of everyday life events and problems, but which is, as I have said, notable for its absence.

This concern of balancing individual need and the needs of larger groups are a focus of concern in the committees as well, but in the committees, the focus is felt to be necessarily upon individual rights. The practice anomaly of interpreting individual rights as in such opposition to the rights of others is sometimes so counter-intuitive, that people express a good deal of frustration.

The discourse of medicine, I have said, is a powerful voice, but how is this voice empowered and legitimated in bioethics?

LEGITIMATION AS A COMMUNICATIVE ACTION

In the committees, there is a privacy which means that what is discussed, and the decisions made, are secret and unpublished. The work takes place, in the words of physician ethicist Bernard Lo (1987), "behind closed doors." This privacy allows a disjunction between what people say and what they do. For example, in the bioethics committees, what I observed suggested patterns at variance with the ethical rhetoric. Participants are trapped by the discordance in the words they used to describe the goals and directions of their committees and the actual committee discussions. For example, there is a reiterated language of patient centeredness, yet patients and their families are discussed as the other, sometimes as the enemy, but surely different from us: "the son is litigious," "mother doesn't have a clue," patients are "vegetables." Neither patients as people nor their relatives and friends as a part of a family or as the patient's representatives are a part of discussion contributing to decisions, except in a negative sense. They are not seen as partners in the decision making process but are more generally seen as obstructions to medical decisions. This discourse strongly influences the fact that the medical perspective is maintained and a moral one is disregarded.

There are other structural conditions involved in the acceptance of the biomedical perspective. The actual decisions made can give a glimpse of what people or perspectives prevail in the decisions. In the bioethics committees, for example, we can note who makes the actual decisions about cases, educational matters, and policy. Then, it is important to take into consideration how the power of others prevent concerns from reaching the decision making agenda. In bioethics, this involves the gatekeeper function of the chair. After a discussion of what I call the "invisible cases" at one committee meeting, the invisible being those cases which no one but the chair hears about, one committee decided to change this. The new rule is that every request must be brought to the committee. If the chair makes a decision to **not** hear a case, that will be brought to the committee. For example, the case might be one that needs to go to a different committee, even so, it must be brought to the bioethics committee. This important concern came up in only one of the committees. The chair of this committee was not a physician and the membership was predominantly non-physician.

Another dimension involves the subtle exercise of power, that is, for example, the ability to influence or determine what others want.

> Richard, M.D.: If I'm doing something that's high risk, **I let the patient tell me what he wants** and I write it in the chart. **Pretty much I do what they want.**
>
> Bob, M.D.: **But in reality you negotiate with the patient. If the patient says one thing and you want another, then you negotiate.**
>
> Richard, M.D.: Usually after a 40 min discussion of **talking and negotiating**, if you're reasonable, **they do what you want.**

It is clear, that these physicians believe that given enough time and discussion, patients can be turned to doing what the physician wants. You can recognize that this is so when individuals act contrary to their own interests. There is a often a real contradiction between the interests of those wielding influence and the real interests of those they exclude. An unforgettable instance of this can be found in Dr. Phillip Blaiberg's (1968:65-70) account of his heart transplantation experience. His surgeon, Dr. Christiaan Barnard came into Blaiberg's hospital room:

> "He was haggard and drawn as though he had not slept all night. He no longer resembled the handsome Smuts, to whom I had compared him, but more a martyred Christ....
>
> Professor Barnard spoke in low tones. **"I feel like a pilot who has just crashed,"** he said. **"Now I want you, Dr. Blaiberg, to help me by taking up another plane as soon as possible to get back my confidence."**
>
> Still I did not know what he was driving at. Professor," I said, puzzled, "why are you telling me this? **You know I am prepared to undergo a heart transplant operation at any time you wish."**
>
> "But don't you know that Louis Washkanski is dead?" he asked. "He died this morning, of pneumonia."....Now I knew the reason for his [Dr. Barnard's] distress and agitation.
>
> "Professor Barnard," I said at once, "I want to go through with it now more than ever - not only for my own sake but **for you and your team who put so much into your effort to save Louis Washkanski."....**
>
> "Don't worry," he [Dr. Barnard] said a little more cheerfully now, "everything is going to be fine." [my emphasis]

In this account, by the patient Blaiberg, we see his description and interpretation of the event. In it Dr. Barnard asks his patient Blaiberg for help in getting back the surgeon's confidence which has been lost by the death of the first heart transplant patient, Washkanski. The interaction is with not just the surgeon who resembled Jan Christian Smuts, eminent South African statesman, but now with a "martyred Christ." Christ has just crashed his plane and his patient has died of pneumonia. Not, it is interesting to note, of heart failure. The implication here is that the heart was fine, but the lungs were not strong enough to support the rest of the body. This was in the press at the time: "the operation was a success but the patient died" construction. But Blaiberg is willing to "help" his surgeon, as he requests, by taking up another plane as soon as possible to get back my [Barnard's] confidence."

Blaiberg asks no questions, seems to have no doubts, reports little concern about himself, but his main wish is to help Barnard and his team. Assured of this Barnard cheers up and says: "everything is going to be fine." Now this negotiation is clearly not between equals. The surgeon is characterized as Smuts or Christ. Blaiberg is his helper: the one who will help the crashed pilot take up another plane/transplant another heart and get back the pilot/cardiac surgeon's confidence. The power of the medical aim and the desire to be a part of it and, perhaps, to please the christ figure, makes it clear that this is not negotiation between equals.

E. LEGITIMATION

When I began this research, I wondered how these bioethics committees were functioning and how they found acceptance in the hospitals in which they were centered. That is, how was this knowledge of bioethics and its practice sanctioned and accepted.

In the case of bioethics, while ethicists might seek to claim authority for bioethical matters, and may have some influence in bioethics literature, the base of authority for the committees belongs to the physicians. Traditionally, in matters of health decisions it had been the physician who made these decisions and there was little desire to have a change in this on the part of medical professionals to have a change in who makes what they identify as medical decisions. In fact, they are very concerned about losing their role in medical decision making and are sensitive to incidents where others seem to be intruding upon that role.

> Dr. Ben: ... **The mother comes in and there is a rocky relationship with her and the staff. Mother says her son would want "Everything possible done." ...Very frustrating and difficult patient to take care of....Question of mother as key figure to make decision.**
>
> Doctor Jed: **What is the legal basis for a client having us responsible for his infinite care?**
>
> Dr. Chair: Is there a consensus among attending **that absent the mother they would let him go?**
>
> Dr. Ben: Its a complicated situation.
>
> Dr. Chair: **It's not just the mother practicing medicine without a license?**

...

Dr. Louise: **Is mother his legal guardian? Important legal distinction for relative of adult.**

Dr. Ben: **Mother says his existence is meaningful and should be extended.**

...

Dr. Peds: Two separate issues. What ought we to do. What can we do to get our butt off the line. Beyond mother. It is beyond my imagination to see how we can keep this guy going. If I had a child I would not give the mother option. If mother was not there we would not do this. In doing that we have flipped coin. Ethically sound but deeper and deeper..we've elevated one principle over all others.

Cardiology Doc: Precedent in daily function - patient on pump and heart won't stop, don't go and ask parents.

RN: Yes we do.

Cardiology Doc; Don't ask, just do.

RN: Now we don't do, we ask.

Dr. Louise: If we remove without the consent of the mother, its a set up for murder. Its not just ethical but legal - until this country makes euthanasia legal.

Dr. Sam: I don't think we should regard removal of respirator and euthanasia as the same. That's why I raise the question of not antibiotics.

RN: Aren't you legally obligated to treat?

Dr. Sam: We [i.e. physicians] are an ethical group.

Dr. Ben: **These are not medical decisions. That life is meaningful to that person.**

Dr. Sam: Not valuable enough.

Here the discussion ranges from Dr. Ben who seems ambivalent about treating or stopping treatment for this unnamed man of indeterminate age who is, he says, a "Very frustrating and difficult patient to take care of." But, in the end he says that: "These are not medical decisions. That life is meaningful to that person." Then the discussion ranges to the issue of the mother's intervention and that "absent the mother they would let him go." But for Dr. Sam, the patient's life is "not valuable enough."

In another committee, during a policy discussion, the concern about physicians losing their role in making medical decisions came up. This involved the issue of when physicians can make autonomous decisions and was addressed in a discussion of "futile treatment":

> Sam, M.D. When can a physician on his own make a decision? It sounds like I have to let others do that.
>
> Laura, M.D.: Yes. It needs to be in there somewhere. These guidelines have to be specific. Determining benefits and burdens has to be a physician function. [To Sam] - obviously you and I [both m.d.s] will be in favor of this.
>
> Tom, Pharmacist: Futility - if futile, then it would provide person no benefit.
>
> Laura, M.D.: A physician should have the right to...[interrupted]
>
> Judith, Lawyer: I don't think it should be the doctor. It could be that the doctor says it's futile, do we need everybody to agree?
>
> Anne, Chair: Just when the patient is not competent.
>
> Andrea, Nurse: No. Many times we don't offer because it's futile.
>
> Anne, Chair: Because of medical futility... But there is rationalization and self-justification for doing anything you want. It is all very subjective. We need to discuss this more. Take a stab at writing this into policy. Put in what you think is most appropriate.

The traditional authority of the physician was in this case challenged by the lawyer. It is also pointed out that whoever the person defining a situation as futile, futility is itself socially constructed.

Legitimations can be regarded as widely held beliefs through which institutions obtain their justifications and in cases of conflict, a defense against opposition. Legitimacy describes both a state of affairs - the leader is a legitimate leader, and a process - legitimation, and it has various sources. Legitimation involves both explicit and implicit justifications for the authority of a command on the one hand and the development of a concomitant sense of obligation on the part of the group, on the other. There are a number of ways in which the leader strengthens his or her justification for authority. One way follows medical as well as academic and legal tradition and refers to citing previous cases or literature. In several instances the President's Commission was cited to support a particular case or policy decision. In most cites the case reference was to a legal case become talismanic such as the stories of Quinlan, Cruzan, Cole, Bouvia, or Barber. Frequently cited were articles about issues such as about do not resuscitate (DNR) orders and who is discharged after being resuscitated in intensive care reported in the New England Journal of Medicine. Surprisingly to me, only occasionally an article in the Hastings Report was cited. The New England Journal of Medicine of course, has the authority of medical tradition while the Hastings Center Report does not have this same authority in the medical view. However, it is the chair of the committees who provides reading material to educate the committee members and his or her selections influence what people will read. In three committees, selections from the Hastings Center Report were xeroxed for the committee members when a relevant issue was covered, but there was little discussion of the articles. Virtually no articles from other sources were presented for the committee members.

Other perspectives, in this case than the biomedical one, can be eliminated because of a conceptual or rhetorical domination of the reigning medical model in bioethics in this case. There is a connection between what doctors see, how they interpret the new insights, and how they manage to get those insights accepted. As that discourse becomes hegemonic, other perspectives are silenced. This is what is happening in the committees. In bioethics decisions, who or what profession has the legitimate authority to make decisions: The patient, the family, the staff, the physician of record, the lawyer, the nurse, the ethicist? Generally, in the committee meetings, the physician voice made the decision following the usual division of labor in the hospital. However, there were exceptions, and it is instructive to look at them. In several of the bioethics cases, the family of the patient had made decisions which were different from what one or another staff felt were appropriate. In some cases the family wishes had weight equal to or greater than that of the committee or the physicians; in other cases decisions were based on the legal issues in the sense that the threat of legal suit was explicitly or implicitly a factor. This legitimation of the legal process can overrule medical judgement. It is possibly the only thing that does.

Ben, M.D.: This is a man in his early forties who has been in and out of neuro ICU for a good long while....**The mother says her son would want "Everything possible done."**

...

Louise, M.D.: **Is mother his legal guardian? That's an important legal distinction for a relative of an adult.**

Alfred, M.D.: There are two separate issues. **What ought we to do and what can we do to get our butt off the line.** It's beyond the mother. It is beyond my imagination to see how we can keep this guy going. If I had a child I would not give the mother any option. **If the mother were not there we would stop treating him**. In treating him we have flipped coin. It may be ethically sound but we're going deeper and deeper. We've elevated one principle over all the others.

Louise, M.D.: If we remove the ventilator **without the consent of the mother, we are a set up for murder.** It is **not just ethical but legal. Until this country makes euthanasia legal we have to treat him.**

Sam, M.D.: **I don't think we should regard removal of respirator and euthanasia as the same.**

Nancy, R.N.: Aren't you **legally obligated to treat him?**

Sam, M.D.: **We [i.e. physicians] are an ethical group.**

Here it is clear that absent the mother, the decision would have been easier. The prospect of being accused of murder is on the minds of all in this committee. The ethical principle being elevated above all the others is that of autonomy, what the patient or his surrogate would want done. The issue is of treating a person for whom treatment is seen as futile by most of this committee versus what some of the committee are interpreting as euthanasia. As Alfred, M.D. says, there are two separate issues - "What ought we to do [ethics], and what can we do to get our butt off the line [law]."

It is important to remember that the majority of cases that come to the committees represent cases where there is some sort of non-concordance: the family with physician, the physician with other physicians, the nurse with the physician. If there is concordance at the level of the hospital unit, then there is no need for a bioethics committee intervention or advice. The other main reason for a case coming to the committee is that the physician was doing something that he thought would be safe to get a "second opinion" or "rubber stamp."

In another hospital there is another case in which the threat of a lawsuit influenced the "medical" decision:

> Anne, Social Worker: This is a 52 year old patient in the CCU, with post anoxic encephalopathy....Her primary doc wants to know what support we can offer. **The son is in LA, is proxy, and is opposed to termination of life support. He would sue if she is taken off life support.** There are religious considerations. All of this is going on by phone. MD has questions in terms of life support. Question of what support to offer to this patient. Issue is what principle to use: treatment is ineffective; without justification for termination. Is she brain dead? Are there other tests we can use to tell?
>
> **Are there ways of relating with son leading to different involvement with the son? We reviewed possibility of intervention through the courts.** She came into hospital because she became unconscious, vomiting in the night. **We have no understanding of her wishes. She is living with a significant other and he has the same attitude as her son.**
>
> ...
>
> Barry, M.D., Chair: The other side area is the fact of the CPR issue. **The primary doc, a neurologist, had a conversation with the son who said he wanted "everything done."** The neurologist had a patient care conference in the CCU and made the patient "no CPR." [someone asks with/without dialogue with son. "Probably not."] After ethics committee consult the patient became a full CPR.
>
> **Ted, M.D.: Son wants CPR - he made that decision.**
>
> Barry, M.D., Chair: Appropriate decision. Nothing in progress notes. Method of putting no-CPR requires dialogue with surrogate.
>
> ...
>
> Dr. Durgan: **The patient couldn't represent her own interests. Did the son say his mother had indicated what she had wanted? Was he explicitly following his mothers wishes?**
>
> Cynthia, R.N.: **I'm not sure that no code should have been the issue. The son is speaking to HIS wishes.**
>
> Ted, M.D.: **The man has an attorney and is very litigious. It is not in the Docs or the hospital's interest to get this man more angry.**
>
> MD: Why?
>
> Ted, M.D.: His mother is dying.
>
> Cynthia, R.N.: That is his problem. We have to use proper medical judgement. It is not rational to resuscitate an apneic patient. **We have to use good judgement and not give in to the son.**
>
> Janet, R.N.: It is the option of hospital and doc to approach son. The expense of going through that...

Barry, M.D., Chair: Once you initiate a no-CPR order you need to reflect it in chart and how you got there. Practically, she should be a full code without a lawyer.

Cynthia, R.N.: For all intents and purposes she was brain dead. Apneic but not in a persistent vegetative state.

Barry, M.D., Chair: Just looking at it from an ethical point of view, not a medical one - we have to have agreement with the surrogate: the son. There was no DPAHC. There were conversations back and forth, he was treated as surrogate, **I think you have to treat him as such legally - and ethically. The fact that the lawyer is involved and the fact that the son is threatening; definitely altered the profile of the physician of the case.**

There is clearly confusion about what criteria to use in making a decision about treating or stopping the treatment of this woman. Many issues keep coming up and there is little help from ethical principles, law or medicine. What does act as trump in this case, however, is the threatened lawsuit.

In still another case:

Lisa R.N.: There was a real good AIDS patient this week. The patient was there 1 or 1 and 1/2 weeks, was put on ventilator, he was dying. **The family one minute wanted him to die, then wanted everything done for him.**

Fred M.D.: There is a common thread here. **We are doing everything in light of a hopeless situation. What is obligatory about doing everything?**

Jim, R.N.: There are no concrete guides about intubation of AIDS patients, we don't have that experience. Clinical windows need to be identified and issue of early patient determination of stopping respirator. **We need to know what they want done.** I know we'll get over it [i.e. this reluctance to stop treatment] so we can stop intubation.

Oscar, M.D., Chair: The biggest stumbling block is letting patients die with dignity. **If after the first discussion with the family they say "do everything," family education is not continued. Things are hopeless - do everything on day 1, is not the same on day 28 - enough is enough. In the afternoon educational program with Dr Sonar he talked about the stages the family goes through.**

In this discussion, the Chair is providing educational justification for letting the patient die and legitimating changing decisions on the part of the family and of the staff. Jim, the nurse, points out the changing nature of the moral order in AIDS: "There are no concrete guides about intubation of AIDS patients, we don't have that experience. Clinical windows need to be identified and issue of early patient determination of stopping respirator. We need to know what they want done. I know we'll get over it [i.e. this reluctance to stop treatment] so we can stop intubation." Jim sees the problem as a reluctance to stop treating and believes that this will change, in some part because patient's wishes will be better known in the future.

In another hospital with another patient:

Dorothy, R.N.: We have a young man in the CCU [critical care unit]. A 23 year old sometime coke and alcohol user - a young black man. He was found in the street and had an anoxic injury from which there has been no awakening. I was here as the therapist so went to CCU. There has been no neurologic recovery. A tox [toxicology] screen was negative for cocaine. He has had days of seizures we could barely control. He has a seven year old, mom, two brothers. His wife disappeared into the drug scene when the child was four. They wanted to get an ethics conference about this patient. It was over the Easter holiday. Six days out into discharge on medical unit from the CCU with a different attending, this is the result. How do we treat him? Do we trach, put in feeding tube, send him to a long term care hospital? Needed to be a physician deciding. There was a new young attending - she hadn't done any struggle. Since he had lived for a week she thought she needed to treat. We had to sort out issues with the young attending - about the level of support to give or withdraw. His **Mom was beginning to wonder if they were going to have a miracle.** The young son was warm and breathing - but a vegetable.

John, M.D.: I talked about medicine to support the staff. Its a young staff with no ethics rounds. **They are buying into Mom's: "Lets do everything at all costs."** In St. Jude's long term care hospital, there are 200 people in a vegetative state. The nurse said to the doc: "Think about the quality of life we are blessing him with." Withdraw the IV and it's not an awful death. There is a middle ground - stop O2 - decrease fluids in IV. If he gets an infection, do not treat. The next day we met with the family and sibs. The whole thing fell apart over the holiday weekend. The next day we bring the attending back in. She took leadership in the family conference. She's a new doc, it was not comfortable for her a year ago. Now she had done many withdrawal and withholds. **At least she had the jargon and could talk to the family**. She put the options on the table. In the National Enquirer someone woke up [Jackie Cole] and she was hoping for this miracle. She negotiated another week. If that's what she [mother] thought he wanted. A long term care hospital for ten years - if that's the patient preference. Then the brother lit into his mom - about spending all of her time with her dead child and holding the hand of his dead brother. She is not home taking care of his seven year old which is what she says she wants [i.e. to keep grandson]. She lost her husband, now the son she was having problems with. So we made that decision for one week. As God would have it he died three days later of cardiac arrest and no one was there. Mother's faith was so strong she thought he would not die. So, we had the team changing so everything was all up in the air and Mom's hoping for miracles. This ventilator state is difficult - as is care. Also the implications of Cruzan - what can we do a year from now?

In this discussion the toll taken by **not deciding** to stop treatment on someone who will most probably not regain consciousness or participate in life again is poignant. There are negotiations with the nurse and the physician: "Think about the quality of life we are blessing him with," and with the brother and the argument he makes to the mother: "about spending all of her time with her dead child and holding the hand of his dead brother. She is not home taking care of his seven year old which is what she says she wants [i.e. to keep her grandson]. She lost her husband, now the son she was having problems with" are powerful reminders that treating against all odds may not always be the best decision for the patient and family.

LEGITIMACY OF THE COMMITTEES: WHERE ARE THE CASES?

Other structural conditions and processes have to do with how the committee gets and sustains its authority. Part of what the ethics committees consider an issue in the perceived authority of their committees is "getting cases." The structure and processes that lead to "getting a case" influence the number of cases that each committee hears. How does a case get to the committee? The most obvious basic prerequisites to getting cases is that someone know of the existence of the bioethics committee, that the services of the committee are seen as needed, and that the results of bringing a case to the committee are seen as helpful in some way. In several committees the existence of the committees were unknown to either staff or patients and families. There is a general reluctance on the part of members of these ethics committees to let people know about the existence of the committee.

This key question arose in several committees: Where are the cases?

> Alan, Lawyer: I'm glad about the plans for the education session. [mentioned at the beginning of the meeting] However, I haven't been involved in a case consultation for a long while. That may be because cases are coming to certain members or a subset of the committee. ICUs [intensive care units] may think that they can handle things all in house.
>
> Oscar, M.D., Chair: There has been no curbside consultation. In June we had Dr L's last patient [it is now October - 5 months later].

Mabel, R.N.: In the resuscitation committee, there was a case that should have gone to ethics. It's dependent on the MD referring it. No one here goes out looking. Cases are all over the place.

Oscar, M.D., Chair: Donna, any cases in ICU?

Donna, R.N.: There was a real good AIDS patient this week. The patient was there 1 and 1/2 weeks and put on ventilator, he was dying. The family one minute wanted him to die, then wanted everything done for him.

Phil, M.D.: Can we organize on an emergency basis?

Oscar, M.D., Chair/Mabel, R.N.: Yes

Oscar, M.D., Chair: We can do it with 4 hours notice. Call me and if I am not there call Mabel.

Mabel, R.N.: Yes, very good, case can't wait.

Oscar, M.D., Chair: Maybe its [i.e. that we have had no cases] because there has been no education for the staff in 10 months.

Norman, M.D.: I encourage you not to be interventionist in searching for patients. [here Mabel and Donna looked at one another and rolled their eyes]. The nursing staff is very good about referring problem cases. There was the case of the patient who wanted to stop morphine and go home. They let the patient go, and stop morphine, even though the staff wanted the patient to stay. The living will is good, encourages physician and patient discussion. Also patient directives. Since we're not getting cases, there aren't problems.

Norman, M.D.: Don't look for them. [i.e. problems].

Alan, Lawyer: There's no need to poke around. We need more education and discussion. The committee is alive and well. I hate to see it drop off.

To these committee members, there are clearly different views about the existence of cases and what it means to get or not get a case. In this committee it had been far more than the five months mentioned since they had heard a case and over ten months since they had put on any educational program. There was no information about the ethics committee placed in the patient information packet.

In another committee meeting there was a discussion of evening and weekend coverage by the ethics committee. There are 7 members of this sub-committee from the larger committee. There are two co-chairs (one a physician and one a nurse) and three other medical staff (2 from the nursing department, and 1 from pastoral care or social service). They generally have four people present to consult. The consultant at this bioethics meeting suggests that they just have a nurse and doctor to meet immediately with consult, "Then if they can't resolve it, call in the troops." As committee members, the consultant said:

> Patrick, Consultant, Ethicist: **We reverence the physician-patient relationship - we are not making decisions.** You just need a few people to point out; do we have the information we need, and what are the problem areas. I suggest three as a basic quorum.
>
> Vicki, R.N.: This is what already goes on in oncology. If it is not resolved, sometimes you just need to get out of the environment where its happening.

When the meeting was over several people stood around discussing their concern about getting cases, and a feeling of failure of the committee that there were not any. In most of the committees there have been very few cases and even these are diminishing.

> Loretta, M.D.: **I am worried about cases, where are they?**
>
> PF: This issue is coming up at all of the committees.
>
> Loretta, M.D.: What a relief, **I thought it was my fault that we aren't getting any [cases].**

At the next meeting of this committee there were no discussions of cases during the meeting but afterwards

> Loretta, M.D.: I am hoping for a few cases over the holidays. Will you be around?
>
> PF: Yes, please call me at any time.

In another "Where are the cases?" discussion, in yet another committee, this one with two ethicists:

> Anton, M.D., Chair: How can we make it clear to hospital physicians **the benefits of the bioethics committee.** To let them know that in our use the committee is a process of coming to a decision when there is a conflict of values. All are at risk. **The committee does not interfere with the doctor-patient relationship. It does not increase exposure to malpractice litigation.**
>
> Leo, Ph.D. Psychologist: How is that made clear?
>
> Anton, M.D., Chair: Grand Rounds.

Jane, SW: Grand rounds showed that there were more than two sides to all of that. Was this to get docs to acceptance?

Anton, M.D., Chair Ed: We could change the name from Ethics committee to CLINICAL ETHICS STUDY GROUP.

Joanne, Lawyer: Yes, there was no such thing as a mental health center - but they made it up and it became acceptable.

Ed, M.D.: It would be marketable, the ethics study group. It would not be to tell you how to practice.

Anton M.D., Chair: Does it fit within framework?

Robert M.D.: In the past medical ethics just referred to if your ad was too big.

Ed, M.D.: The ethics committee needs to be independent of other committees. Have a budget of its own. Get people to speak. An administration member should be on the committee.

Anton, M.D. Chair: Sandy is but doesn't attend, she's not here. We need someone not just a letterhead. We need critical thinkers on the committee.

This discussion, similar to those in other committees, make it clear that when people know about the committee, and few do, there seems to be a reluctance to see the "benefits of the bioethics committee." In this discussion, there is even a proposal to change its name so that the committee would be more marketable.

SECRETS AND SILENCE

Later the ethicist comes back to the remark above about putting doctors at risk:

Judy, Ph.D., Ethicist: I am interested in what you said about **'never put the doctors at greater risk'. If we always have to be limited by fear of a suit we couldn't deal with the issues.**

Leo, Ph.D. Psychologist: I think our authority is going to grow by waiting. That line - **reassure** - not limit freedom of consideration.

Judy, Ph.D., Ethicist: **What if the doctor is sued - what about jeopardy**. Perhaps we should keep our discussion off of the chart. What about confidentiality?

Penny, Ph.D. Ethicist: We have to assume that we won't be irresponsible

Anton, M.D., Chair: The point is that our deliberations are sound. I think we should be proud. We use strong reasoning, not controversial. **We are not**

breaking legal precedent. We put down on the chart to see minister or chaplain, or assess competency.

Stan, M.D.: We're the same as any other consultant. If you're right they aren't going to bother you. **If we have good reasons, we are safe generally.**

Anton, M.D., Chair: We need additional documentation of thought processes.

Judy, Ph.D., Ethicist: What about the sacrosanct nature of the minutes. **No lawyer or court can get into the minutes if we have none.** It is unsound to keep sparse minutes. That does harm.

Chair: I think that's putting the cart before the horse. Lets find out about discoverability.

Judy, Ph.D., Ethicist: **If it is a unanimous decision, with good reasons, then the minutes can be made available.** We must make it clear to people coming from outside what we're going to do.

Penny, Ph.D., Ethicist: **Where do we get our authority since we are not accepted by staff?**
[no answer.]

Another interesting issue of silence can be found in committee meetings where the patient's problems were the result of iatrogenesis. This fact does not come up until late in the meeting in each of the cases. It is never really dealt with as iatrogenesis but the topic is skirted in a way that makes it clear that everyone is aware of it, but are too judicious to point it out. This is the baby at Easter case. The neurologist has just presented a five minute medical piece:

Richard M.D.: In March I was asked by Dr. Jon to consider 2 issues on a three month old baby girl 1. A DNR order; 2. Limit antibiotic Rx....All was semi-well until 30 hours after birth. Endotracheal tube obstructed because of secretions....We were going to make a medical decision - we did not want the appearance of a legal issue. The decision was made "in the best interests of the child." We decided, no CPR for arrest. Artificial prolongation of life is futile - wonderful word - don't know what it means. Food comfort etcetera mandatory. No antibiotics don't treat. Two residents said to treat but OK if attending makes decision. One nurse would treat enteral not parenteral but decision not to treat if made by responsible person. "Not treating within a spectrum of responsibility." The nursing staff were concerned with pain and suffering without neurological recovery. CPR inappropriate. Routine nursing care; hydration and nutrition. Attending pediatrician and patient's family -CPS - decide about DNR and antibiotic Rx. DNR ordered. Tracheostomy - if it will make nursing care easier and child more comfortable, then OK. Seen on March 9 - no involvement of ethics committee....At this point I was not giving it an ethical thought just the KISS [keep it simple, stupid] principle. But

> discussed it at length. **I didn't think this needed an ethics committee meeting - it seemed like everything was ok.**

Then Mary, the nurse consultant describes her participation and the issue of iatrogenesis comes up, only when the neurologist questions why the DNR order was not written as he had ordered:

> Mary R.N.: This was the first baby consult. **The DNR was written that day [was supposed to be written Mar 3 not until April 18].**
>
> **Richard M.D.: I thought that had been written before I left.**
>
> **Mary R.N.: The attending was not comfortable writing DNR because of iatrogenesis.** The nurses are concerned about anaesthesia risk.
>
> Richard M.D.: That is an inappropriate concern.
>
> Mary R.N.: **Night nurses say "Dr. Koret [new woman resident] you go home at night" - she finally writes DNR orders.** No one has addressed a game plan. Messages to start to stop, to do, not do....**DNR appropriate. We haven't talked about the issue of iatrogenesis.**
>
> **Richard M.D.: We discussed it at the first meeting - intubation was discussed at length**
>
> **Janet, R.N.: How much did this [i.e. iatrogenesis] influence the medical decision?**
>
> **Richard M.D.: It always has a terrible effect.**
>
> **Janet, R.N.: As I talked to attendings - there was great anxiety about iatrogenesis after prolonged asphyxia.**
>
> **Richard M.D.: That's not going to go away - that's with them for the rest of their lives - I did it 15 years ago. I'll be driving down the road and flashback.**
>
> **Janet, R.N.: But should it change the medical decision?**
>
> **Richard M.D.: It does - that's normative. The pressure of iatrogenesis intensifies your obligation to do more later. If your device has complications then you are obliged to do something. When I'm doing a procedure that's pushing the envelope - we do the operation and in 3-4 days see where its going.**
>
> **Joan M.D., Chair: Figure out what the principle is on the two. Feeding someone who wouldn't eat voluntarily and hard to keep IVs in - NG tube. Resident said: If you do that and she pulls the gastrostomy tube out through the abdomen and gets an infection and ARDS [acute respiratory distress syndrome] - have to ventilate - all obligated to do. Its very common.**
>
> **Richard M.D.: The tube is in, the patient pulls it out - feel obligated to do it.**
>
> **Betsy: Is it appropriate to do?**

Richard M.D.: Whoever is doing it has to be able to sleep at night. The most important thing is to be able to sleep at night at my age.

Joan M.D., Chair: To me. at least, there is an element of proximity and directness of complication. To do a Whipple in a patient needing mechanical op - can't separate Whipple from mechanical ventilator - but, six weeks down the line - renal failure - ? Do we dialyze? This question wouldn't come up if we hadn't done the Whipple. But I wouldn't feel obliged to dialyze.

Jean, Risk Manager: In terms of law, I'm concerned about this cascade of obligation - do one thing and then obliged to do other things. Are we legally obliged to treat patients more intensely because they are in a fix because of something we did? We don't do step one - not 4-7. Undertreat - overtreat.

Lawyer: In a perfect world we have a game plan ahead of time. Look at the burdens and benefits. Don't see avalanche effect.

Joan M.D., Chair: At University Hospital putting a trach in is egregious.

Lawyer: What if it gets plugged? In two weeks, unplug it. More than that, leave it. To me documentation is everything.

Jean: Risk Manager: No two cases are the same. Documentation, I agree is everything about the thinking processes that took place.

Lawyer: I've thought about it before. The possible consequences. As long as the will was there to do the right thing.

A striking feature of this discussion is its highly negotiated character. The participants seem to be negotiating about the facts of the baby's history, but which facts are relevant? The neurologist plays a key role in structuring the account and attempts to close off discussions at several points. For example, he closes off a discussion of the nurse's concern about the anesthesia risk by designating it as an inappropriate concern. He also interrupts the nurse to say that DNR orders were to have been written. In the ritual presentation, medical problems are to be presented before social and family issues can be explored. But sometimes these issues are simply left out. In all of the cases, what is presented reflects a highly selective account of the situation. An intriguing question is what events are included and what excluded in a clinical course that spans several months.

The opening formulation of the problem provides some clue as to how the account is organized. "All was semi-well until 30 hours after birth," and the "Endotracheal tube obstructed," by itself? How, why or any details of this obstruction without an active agent is part of the way that these presentations are structured. Virtually all of the evidence that is selected by the neurologist to support his claims about the nature and progression of the baby's course is measured - by instruments except for APGARs, but they are counted and numeric, and thus supposedly objective.

An iatrogenesis issue came up again, very tangentially, at another hospital, again with an infant.

> Phil, M.D.: The case is an infant who is ventilator and dialysis dependent. Has transected C1 and C2 with, therefore no diaphragmatic function and is quadriplegic. No clinical possibility of recovery. Kidney dysplasia but not a candidate for transplant. Chronic ventilator and dialysis forever.
>
> Steve, M.D. Chair: How long do you think he will live?
>
> Phil, M.D.: A long time.
>
> Steve, M.D. Chair: What is the ethical issue?
>
> Barbara, Ethicist: Allocation of resources.
>
> Ben: This is a classical situation...we absolutely have to deal with. On cardiac surgical service...[interrupted]
>
> Steve, M.D. Chair: How about autonomy here?
>
> Dr.: On whose part?
>
> Bill: What is parental wish - choice?
>
> Phil, M.D.: If child is a quad - mother does not consider that an acceptable quality of life. She has another child at home very ill. Decision was seen as straightforward by the attending but another physician said that "I've never seen them raise this issue with someone who is not brain dead." She is from another part of the country. **Especially since the transection occurred after birth.**

The implication of the comment of the transection occurring after birth was that it had occurred when the resident had intubated, and in so doing, had injured the infant. This was clear to all of the medical participants at the ethics committee meeting yet no one said anything about it. It may also explain the reason why the resident from another part of the country has trouble with the decision to stop treating this infant. Note that this infant has neither name or sex.

WHO CAN ATTEND A CASE.

Another matter involving structural conditions influencing legitimacy is about who may attend a case and this arises in each committee. One aspect of this is whether or not there should be a lay member on the bioethics committee. There has been much discussion in the literature about having a lay person on each committee but this is strongly resisted. In three committees there was an attempt at placing a lay member from the community on the committees. In each case, the individual was an extraordinary person who held most of the values of the medical group. In only one committee were there several lay members and in this particular committee, there were more non-physician members than physician members. The possibility of countenancing patient or family participation is remote. In six of the eight committees that I attended, there had not yet been any information given to hospitalized patients or families about the existence of the bioethics committee. In one committee there was the following discussion:

> Beverly, R.N.: Who can come?
>
> Martin, Chair: Anybody on the treatment team can come.
>
> Samuel, Psychiatrist: Would the presenting doc be offended? I'm concerned about a difference of opinion. It would subject people to different views.
>
> Martin, Chair: The nursing supervisor could represent. There is no problem with the nurse in question being with the doc.
>
> Virginia, Ph.D. Ethicist: The doctor might object.
>
> Samuel, Psychiatrist: If the purpose is to make doctors more comfortable - If helping doctor to make decision and nurse disagrees...
>
> Martin, Chair: Part of what we do is risk management. We want the nurse to come hear or her supervisor represents her.
>
> Beverly, R.N.: As long as the nurse feels heard, represented.
>
> Virginia, Ph.D. Ethicist: I suggest that if the nurse is a problem bring her in. Handle.
>
> Samuel, Psychiatrist: We have to decide if we should help him make a decision. The Baby Doe thing, the nurses blew the whistle. Also the respirator thing in LA stirred up nurses.

> Christine, Social Work: What if the nurse wants to come to the ethics committee and the Doc doesn't?
>
> Martin, Chair: They can come. Not family members though, we haven't thought this through. If there is a discovery of non-concordance with a nurse and doctor, find out who is disagreeing. Lets move along.
>
> Edward, M.D.: The could be a problem if the committee is looking after the patient's best interests. If our opinion diverges from the doctor's - he is not looking after the patient's best interest.

In this remarkable discussion, the question is asked: Who can come? It is clear from the answers that the committee members are talking about nurses - and nurses as problems. The psychiatrist's comment about the nurses blowing the whistle in the Baby Doe cases and the case in Los Angeles reflects the new concern about nurses and it is this implied threat of "blowing the whistle" that allows the nurse's decisions to have weight and in effect have some value as trump.

ETHICS COMMITTEE: ADVICE OR COMMAND?

Concerns about the legal liability of the committee are coming up because of the publicity about the Elizabeth Bouvia case. In this meeting the chair brought up the Bouvia case and the medical staff expert committee from the California Hospital Association paper about this. The chair told the ethics committee that the High Desert hospital's ethics committee had been asked to comment on whether artificial feeding should be continued on Bouvia. He said that there is now a suit against the hospital and the ethics committee accusing them of violating Bouvia's rights. The opinion of the California Medical Association counsel is that ethics committees are traditionally seen as advisory therefore there is no basis for liability. The scope of the ethics committee duties are advisory. They are treated and are insured under the insurance policy of the hospital. There has been a lot of reaction to this case and it may color the kinds of concerns people have at this time; that is, there may be more legalistic than ethical questions being raised because of this suit. The committee continues:

> Martin, M.D. Chair: In the Bouvia case the committee made a decision. Our role is and always has been advisory. We are not making decisions.

Don, M.D.: What if we are asked for advice?

Martin, M.D. Chair: We do not make decisions. We give educational input about ethics and outline different scenarios. We must resist the temptation to have somebody say yes and just take off.

Walt, M.D.: Is the hospital staff aware of the ethics committee, that it is advisory?

This comes up at virtually every meeting. Does the hospital know what we do, about us, how are they informed?

Martin, M.D. Chair: They know through the forums we have had. We had a forum for medical staff last year. A lawyer spoke and told them the committee is advisory. Frequently words go in one ear and out the other. Medical staff are informed, the question is, do they retain it? It is incumbent upon us to reiterate and remind them that we won't make decisions.

Don M.D.: We need to engage in ethical analysis. The committee will eventually be operating as a sub-group. When physicians have the experience of consultation that gets the information around.

Consultation and hearing cases is a problem. In interviews with physicians who have presented cases, they have complained of the judge and jury like proceedings. One committee took on a Perry Mason flavor as the attending physicians questioned the presenting physician. The physician presented a man who is hospitalized and does not want anything done for him. In fact, he wants to be allowed to go home and "wind down" his life.

Stuart, M.D.: This is a 67 year old man with advancing dementia. He has come infrequently to the office and has stayed healthy. On dyazide, no psychotropics. His 37 year marriage to a woman broke up. He began to lie, go crazy, steal. They broke up ten years ago. A few weeks ago Ernie came in, he was not feeling so good. His condition was very deteriorated and going downhill. He has venous insufficiency, had a prostate shutdown. We did a TUR [transurethral surgery to remove prostate]. I sent him home where he has been seen by the nurse. Finally he was re-hospitalized on the psychiatric unit. He has dementia and is very agitated. This is progressive. There is no physiological dehydration. I called the chair of the ethics committee. Then the stepson appeared. He doesn't want anything done. The guy has irreversible dementia. He cannot make a decision about CPR.

Tony, MD: Have you checked his albumin and cholesterol? Is he malnourished? Dry?

Bob, M.D.: Has he had a thorough dementia workup? There may be a reversible caused dementia.

Stuart, M.D.: He is physiologically normal except for venous stasis.

Alex, M.D. Chair: Have you checked for hydrocephalus, odd depression, electrolyte imbalance, occult infection?

Tony, M.D.: No CAT scan?

Bob, M.D.: If you are thinking of doing nothing have you though of treatment and reversibility?

Stuart, M.D.: There is nothing to suggest brain tumor, metabolism or odd emotional state. I would not recommend doing all of this stuff unless you say to.

Alex, M.D. Chair: The committee is advisory only.

Harvey, M.D.: Get out the scalpel. This doesn't become part of the medical record but everything you say here is discoverable.

Stuart, M.D.: He has been on Haldol, now Mellaril.

Frank M.D.: Can he make a competent decision or not?

Alex, M.D. Chair: Are you saying you want to make no attempt to hydrate or nourish him - let him just go down hill? What about his mental status?

Joseph, M.D. Psychiatrist: I did a consultation when patient was on medical observation status.

Alex, M.D. Chair: Can you see forcing nutrition on this patient? If you restrain him can you feed him by tube?

Stuart, M.D.: This man has nothing treatable. He is just winding down his life.

Alex, M.D. Chair: Hospital and physicians are not required to provide food and nutrition for patients. Certain conditions should not be treated. We are advisory - no one is required to do what clinical ethics reports tell you to do. A demented patient, for whom there is nothing to gain and treatment is invasive and the patient doesn't want, we are not required to do. Barber-Nedjl case - two tried for murder.

Tony, M.D.: Seems to me we are talking about removal of food and hydration, just not forcing.

Stuart, M.D.: I consulted this committee to deal with it with before the problem starts.

Alex, M.D. Chair: There is a basic desire to want to feed, hydrate.

Stuart, M.D.: I want advice - moral support.

Tony, M.D.: Over the years he is deteriorating. This is not a medical problem, not acute.

Alex, M.D. Chair: There are certain factors we don't know - he may have been exposed to something chronically [back to medical issue each time]. You're talking about not feeding him and he's going to die. If someone challenges a clinical problem we need to be covered. In the case as described - to put a tube down would be cruel.

Saul, M.D.: What about peripheral alimentation?

Alex, M.D. Chair: He'd not want it. That and IV both represent life support.

Elizabeth R.N.: We are repeatedly poking him to eat and making a difficult life for him.

Alice, R.N.: Is he depressed and cannot make a decision?

Tony M.D.: The first question is have you adequately made a diagnosis of irreversible dementia?

Saul, M.D.: Dementia that is not treatable. Only mental state not being adequately treated.

Alex, M.D. Chair: Has he had CAT scan, EEG?

Tony, M.D.: Has he been checked for alcohol, syphilis, serology.

Stuart, M.D.: This advanced a condition is not treatable.

Saul, M.D.: It's reasonable that its not a toxic effect. Treat for depression, wait 2-3 weeks, if no response then...

Susan, M.D.: What about attempts to feed him?

Elizabeth R.N.: He spits it all out.

Saul, M.D.: Is he not thirsty?

Alice R.N.: What was standard fare?

Stuart, M.D.: Twinkies. Its the twinkies defence again (Laughter).

Alex, M.D. Chair: What do we say to Stuart? How does the committee feel about putting a tube in - that's a difficult question. That's not the direction Stuart wants to go. Can we make a moral commitment and decision if we do not treat? Can we treat and then stop?

Psychiatrist MD: I'm not sure if there is enough time. We might elect to do an antipsychotic trial and if there is no improvement then stop.

Saul, M.D.: There is no evidence of malnutrition. The home setting should be ideal for him.

Alex, M.D. Chair: The best we can do is ask Stuart if in his mind he's had an adequate workup. First do that. Then I recommend antidepressants. I would hate for us to make decisions, offer advice. Decision should be Stuart's and the stepson.

[pt has not been seen, nor his chart]

Stuart, M.D.: I've known this guy for years. He has progressive irreversible dementia. The time has come to let him go.

Saul, M.D.: This could go on for months, he could linger. Do the right thing immediately.

Alex, M.D. Chair: Satisfy diagnostic and therapeutic goals first. Then try antidepressants.

Saul: Stuart says it is dementia, not depression.

Margaret, Social Worker: What part if any does the court play?

Stuart, M.D.: There is just the stepson and he has no legal authority.

Tony, M.D.: The Courts could argue that we had not done enough. The public could say it is an assault if we tube feed.

Alex, M.D. Chair: It is a moral dilemma.

Saul MD: There is more pressure to make a diagnosis and medical decision.

Joseph, M.D.: We're criticized because medicine is less humane because we apply these futile exercises. It is unlikely to find a treatable cause. Put Stuart in perspective. It's a reasonable decision not to do more of a workup.

Tony M.D.: Can antipsychotics help in 2-3 weeks? Put the tube in, then stop. Do it at the beginning. Later you can make a comfortable decision because you have tried.

Stuart, M.D.: We may have to sedate him. We're criticized for that kind of behavior. It makes his last days terrible.

Tony M.D.: In general, the patient deserves early consideration for simple measures.

Stuart, the man's doctor, is talking about his life; the rest of the team seems intent on making a diagnosis, regardless of the moral dilemma which is stated. In the end, the patient was kept in the hospital, placed on psychotropic medications, and a series of invasive tests to determine "treatable" causes for his dementia were performed. This represented the most conservative medical treatment available. The presenting physician told me afterwards that he had actually wanted a simple "rubber stamp" on what he had planned and now he had to make the patient's last days a nightmare:

> I would never, never bring a case to that committee again, and believe me I will let my colleagues know about this. That was a disgrace! Now I have to look for the non-existent god-damned cause for his dementia.

The initial design of this committee was to help with difficult decisions through case consultation in a constructive and non-adversarial manner. From the preceding case of the patient Ernie, one can surmise that the optional advice aspect of the consult has aspects of mandatory decision making. If the bioethics committee tells the physician how to treat his patient, as they did in this case, the physician is clearly not going to return, especially when the decision is in opposition to his best judgement. Most bioethics committees are what Robertson (1984:6) has termed: "optional/optional." That is it is optional to bring a case to the committee, and if the committee makes a recommendation, it is optional that it be followed. However, the institutional legitimacy of the committees, is strong enough that the advice has the force of mandate. These are medical staff committees whose decision may be seen as binding.

REFLECTIONS ABOUT DECISIONS: THE AFTERMATH OF COMMITTEE DECISIONS

In one committee a case was presented and recommendations were made. This is part of the discussion at the meeting after the case presentation:

> Amy, Chair: Any suggestions as a result of the case consult last month?
>
> Stan, M.D.: In the recommendations there are many issues not related to the ethics committee. I think we should put in form of recommendations only those things that really have to do with ethics.
>
> Evelyn, R.N.: Yes, issues such as how we handled the case - how the ethics committee addressed this case. We need to raise those issues directly so we could benefit.
>
> Amy, Chair: What about the patient?
>
> Harry, R.N.: He's still with us, first of all. He is now eating.

Amy, Chair: I guess some of the follow up I heard was some concern about the difficulty especially for team members. The difficulty in the difference between the bioethics committee and the complex reality of this person's life and its decisions. Also perhaps we had jumped too quickly into considering things like the hospice approach and were maybe not aggressive about continuing or initiating treatment. It's a fundamental problem with ethics committees especially when you have a large number of people who don't have the immediate contact with the person, with the patient. Its both an advantage and a disadvantage at the same time. You gain some distance, but at the same time you become too removed from the reality of the persons situation.

Evelyn, RN: It was new to us, unclear. Usually when we bring a case we kind of know, I mean the team usually has an idea of what they want and are looking to the bioethics committee for affirmation. Here we didn't know what we want. The committee wanted to affirm the dilemma the team had. We [the team] wanted the NG [naso-gastric feeding tube] tube removed - we wanted a decision for no ng tube, to affirm that decision. We weren't on sure ground to begin with. So many of the other cases we've known the patient.

Amy, Chair: This raises the whole issue of what the bioethics committee should do or should be. In the fact that it won't always be a panacea by any means. It may be good that it created all this consternation. Perhaps we need to clarify the presentation style that we ask for from the people presenting the case to make sure there are specific questions that they want asked. I personally don't separate out some of these questions. I do think the hospice issue is an ethical one. I also want to re-affirm that I think ethics committees aren't a panacea; they don't always work. Its unclear whether this innovation of ethics committees is actually going to be successful at making any kind of an impact on patient care. Resolving these issues and helping professionals and participants. We're really on the front line in dealing with this. A major point of debate in the ethics community is how much we should do. There is a tendency for people to look to bioethics and principles of philosophy for some kind of dispassionate or easy answers to or solutions to these kinds of questions. They're not there. Questions are not of that realm. The problems encompass all kinds of issues, emotional. **There is no ethics white knight that rides in and says do this and this.** I'm somewhat concerned about the distance of the committee from the patient - that will always be the case. **We need a way of remembering that there's a person there.**

In this discussion, the chair was clear in discussing the bioethics committee that there were problems, and problems that I have been pointing out. The need to establish the centrality of the patient is noted: "We need a way of remembering that there's a patient there." This is the only committee in which this issue was raised: putting the patient in the center of the bioethical decision making process. This is one of the most important points in this entire research, the finding of the absence of the patient in these deliberations.

EDUCATION AND LEGITIMACY

How does the committee get their legitimation for educational matters? Most of the education in the early years of the committees were built around visits from elite ethicists in the bioethics field. Most of the committees in the bay area had invited philosopher ethicist Al Jonsen to speak more than once; philosopher Dan Callahan was invited whenever he was in the area; lawyer Michael Gilfix was invited to a number of the committees. A number of less well known ethicists also spoke at meetings or at day long community events. As the members of the committees gained in knowledge and prestige, they held community meetings about bioethics which involved talks by members of their own bioethics committee.

In those hospitals with medical students and residents, the educational program of the overarching educational institution gave legitimacy to any ethics teaching that was planned. This included courses in bioethics which ranged from several hours to a week long retreat. Other educational programs included guest lectures, programs entailing famous people in bioethics whose profession might be law, nursing, medicine or ethics, and ethics grand rounds. In only one of the institutions I observed did the ethicist have the legitimation of an academic appointment. However, an offer from another university was not matched by his university of residence, and he left (Phillip Lee, personal communication 1990). His place as director of medical ethics was given to a physician.

In general medicine as in bioethics the consulting role ranges from very informal "curbside consultation" to very formal consultation, including a written request to the committee for their advice and a written consult note placed in the patient's chart after the discussion. Legitimacy is also socially bestowed. Hospitals with or without medical schools or resident training have constructed a variety of programs to teach clinical ethics, nonetheless these stand or fall on the acceptance and support of the students, faculty and staff of the institution. There were no institutions in this study that had this kind of socially derived legitimacy in the area of ethics. In no institution was there any mandatory expectation for taking a class, course, or attending ethics rounds or grand rounds. In one three year period, I noted that there was a dramatic decline in the number of medical students taking an elective course in medical ethics.

WHO ARE THE EXPERTS IN ETHICS?

As the chair of one bioethics committee said: "There is no ethics white knight that rides in and says do this and this." Related to legitimation concerns is the notion of expertise. Who is the ethics expert? In large centers with well known ethicists such as Albert Jonsen at Washington University, Ruth Macklin at Albert Einstein, or Anne Davis at the University of California at San Francisco, these individuals have, over the years, proved themselves helpful in clinical bioethics practice. They are able to both clarify the ethical issues and help in the analysis of bioethical concerns. They legitimate themselves and are institutionally legitimated by the perception of them as having expert knowledge in theory and the application of ethical theory to concerns of clinical medicine. They have all published articles and books which further legitimate them as experts in bioethics.

In smaller hospitals or those without a clinical ethicist, the situation is much different. Often one or two of the principals will seek further ethical training and then become the ethics resource for that committee. In some committees this has been a nurse, in others a doctor or psychologist. Very few committees had philosophically trained ethicists. One that did illustrated the vast difficulty of trying to overlay ethical formulas onto clinical medical dilemmas. The ethicist was naive about medicine and the rest of the committee was naive about ethics. In one meeting the ethicist presented a very nice summary of ethical principles but, as in almost all ethics classes I have seen, the way one might fruitfully apply the principles to help solve the problems being presented eluded the members of the committee.

As in most ethics classes in college, the principles are stated - if you are a utilitarian you would do x, if a contractarian you would do y and if a natural theorist z. As is constantly pointed out, in a pluralist society like the United States, where there is no general consensus about either the relevant theories or principles that systematically define ethics, it is a mystery as to how to proceed. How does one begin to select which theory or principle to apply to a clinical case? Here is specialized knowledge, but knowledge for what? Knowledge for whom? One can apply any theory, use any principle to any case. Is this what bioethics is in practice? The application of knowledge or practical reasoning to practical problems may be one goal of bioethics but it rarely occurred in the practice of the committees that I observed. The kind of casuist reasoning and application and discussion of principles, especially, as in most cases, of competing principles, I have only seen done by two very skilled ethicists. But this depended on reasoning, on critical thinking - a methodology, not a theory. The general ethics committee member does not have this skill or understanding. The notion of seeking expert knowledge to solve difficult problems makes certain assumptions - that there is in fact a body of knowledge or that one person's knowledge is any better than anyone else's, as discussed earlier in the sociology of knowledge section. In using this model there is an assumption that this body of knowledge can be applied by deducing conclusions from theories in light of the relevant empirical facts, and that this deduction can be, in fact, must be carried out in an objective, disinterested and value free manner. But is bioethics a body of discipline based knowledge that has any claim to objectivity or superiority? How can a clinical ethicist exact legitimate authority? Who does have legitimate authority in clinical medical decisions? How does this happen in the committees? Do ethical or moral experts have the day, or does the biomedical model of clinical decision making hold the day? Who can claim legitimate moral expertise, or is morality not the issue. Does it rest on traditional medical or nursing decisions and arguments? Who has the legitimate authority to do anything and who can claim it? Does the bioethics committee apply ethics or moral knowledge? What are the potential actions in the practice of clinical bioethics? We look to the ethicist to identify and classify moral issues and problems, and to discover moral problems. The philosopher doing moral ethics ideally would be able to see moral issues that others have missed, anticipate the issues before they actually occur, and properly classify the moral problems which arise in the ordinary ebb and flow of personal and professional life. But from my research, it is not clear that any of this is done in the committees. Inasmuch as most committees do not have either philosophers or bioethicists on staff, these problems of bioethical ambiguity will persist.

CHAPTER FIVE: BIOETHICS AND AGING

I. SOCIAL JUSTICE AND THE AGED.

In this chapter on bioethics and aging, I want to examine a number of issues that involve health care decisions and the aged. I will demonstrate that:

- there is a moral ordering concerning the basis for initiating or stopping medical treatment,
- that the basis for entitlement for health care is undergoing changes, and
- that these changes are moving more and more to a different moral order, specifically concerning the older patient.

Discussions about who are to be treated or not treated are taking place within the institutional contexts of critical care units and hospitals where the decisions are ordinarily made. However, more recently, these discussions are also taking place within the bioethics committees of these hospitals. Since these deliberations take place in hospitals, they are largely private and thus relatively secret. That is, they are not public issues and open to larger debate. Those issues that do become public tend to be cases in which there is legal involvement such as we saw with Quinlan and Cruzan, and which then are commented upon by a large number of people; or moral discussion is evoked by published attempts of moral ordering which then may elicit a good deal of dialogue and public discussion such as Daniel Callahan's 1987 book Setting Limits.

Part of the moral ordering taking place reflects a tension between an individually oriented practice of medicine and a larger community oriented one. The proposed philosophical ethical medical base of decision making is moving from one of patient autonomy and physician beneficence and non-maleficence for each patient to one based upon a utilitarian and cost benefit analysis which may imperil individual patients lives for the aggregate good.

In order to illustrate the various points of view and how they are shifting I would like to spend some time describing the regnant theories of justice and how adopting any one of them changes the decision making Archimedean point. Then, with these theories of justice in mind, I will demonstrate how the move from an individually oriented practitioner client relationship to a larger community concern focus, if done using utilitarian cost benefit analyses or libertarian analysis, will affect the aged if defined as marginal, liminal, or most importantly, a group perceived as non-productive.

I will discuss the unequal impact of decisions based upon specific adopted theories of justice on the elderly and the problems engendered by the lack of public discourse on these decisions. It is the silence, the invisibility of these decisions which, I feel, are crucial. Sociologically, it is important to understand that when the legitimacy of decisions and decision makers is assumed to exist, then decisions made by the decision makers may remain invisible and unquestioned. When decisions are visible, then the assumptions upon which they are based may be open to public debate. It is the unsaid, the invisible, that is of sociological concern, for it allows a perpetuation of power and hegemony that may surely not be in the patient's best interest.

Up until the present, the practitioner client relationship in both medicine and nursing, has been founded upon the covenant to do everything in one's power to help the identified patient and do all that is in the patient's best interest. The covenant was between one patient and one nurse or physician. Patients were treated as they appeared, not using, what is acceptable thus far only in war or in the event of disaster, triage. To change the rules of the game, to now use triage or whoever will best benefit without public discourse, or in many cases without private discourse, is to deny persons rights of informed consent and refusal and treatment options and non-options without their knowledge or consent.

I begin my argument with a discussion of theories of justice and the impact on health care decisions from those holding each theoretical conviction. Then I discuss a case which took place in one bioethics committee which illustrates how a policy change, made with no public discussion affected patients and staff at one hospital, and how the bioethics committee dealt with this. The decisions being made in bioethics committees today, and the potential for their role in making allocation decisions in future, will have a great effect on the aged. I discuss this potential role of the bioethics committees and use the case study to give some sense of how the committees see their role as advocates for the patients.

ALLOCATING ENTITLEMENT BY AGE: GOING GENTLY INTO THAT GOOD NIGHT?

Recent debates segregate the elderly from the rest of society as a group, and portray them as different from us, similar to one another, and so in need, that we are being asked to change the contemporary moral order in health care. That moral order is that autonomy trumps justice. This new position suggests, that autonomy trumps justice unless one is old and without the funds to purchase health care, in which case a version of justice contra autonomous wishes trumps. In this section I will discuss the moral ordering taking place in this new and differential placement of autonomy vis-a-vis justice, and consider the assumptions made by those who would trump the autonomy of those of a "certain age" with arguments of justice. Arguments that are, in fact, increasingly being called upon in determining entitlement to health care for "marginal" groups. The typification of the elderly in this way will constitute a violation of their justice rights if they are the only class affected. As Feinberg (1974:300) has observed: "Injustice consists in treating people differently - more accurately, worse - that they have a right to expect."

Although Daniel Callahan (1987) has sparked the recent passionate debate about annulling entitlement to health care for the aged, there have been other intimations that the aged ought go gently into that good night. The arguments range from those primarily interested with the increased costs posed by an "older and sicker" generation to those concerned that the elderly should accept the natural course of dying (Daniels, 1983, 1985, 1988; Lamm, 1987, 1989; MacIntyre, 1986), and may, in fact, even have a "duty to die" (Battin 1987). While Norman Daniels (1985, 1988) and Margaret Battin (1987) call for a policy of rationing medical care by age, Callahan also tries to sustain rationing independent of arguments for social justice but attempts to convince us that even if there were abundant medical technology and services, we should accept rationing by age for it is the end of a full life that should be embraced. But if, as Christine Cassell (1986:184) concludes, the goals of medicine are, as physicians and nurses have thus far maintained, to promote the patient's interests, then it is morally necessary to turn to that patient to make a decision about treatment rather than use a universal age based criterion.

Callahan (1987) in his concern with justice and autonomy, laments the intense individualism of post-modern society. He longs for a more communitarian state and agrees with Daniel Bell (1976:245) who has interpreted this individualism as a failure of commitment:

> The loss of civitas, that spontaneous willingness to obey the law, to respect the rights of others, to forgo the temptations of private enrichment at the expense of the public weal - in short, to honor the 'city' of which one is a member. Instead, each man goes on his own way, pursuing his private vices, which can be indulged only at the expense of public benefits.

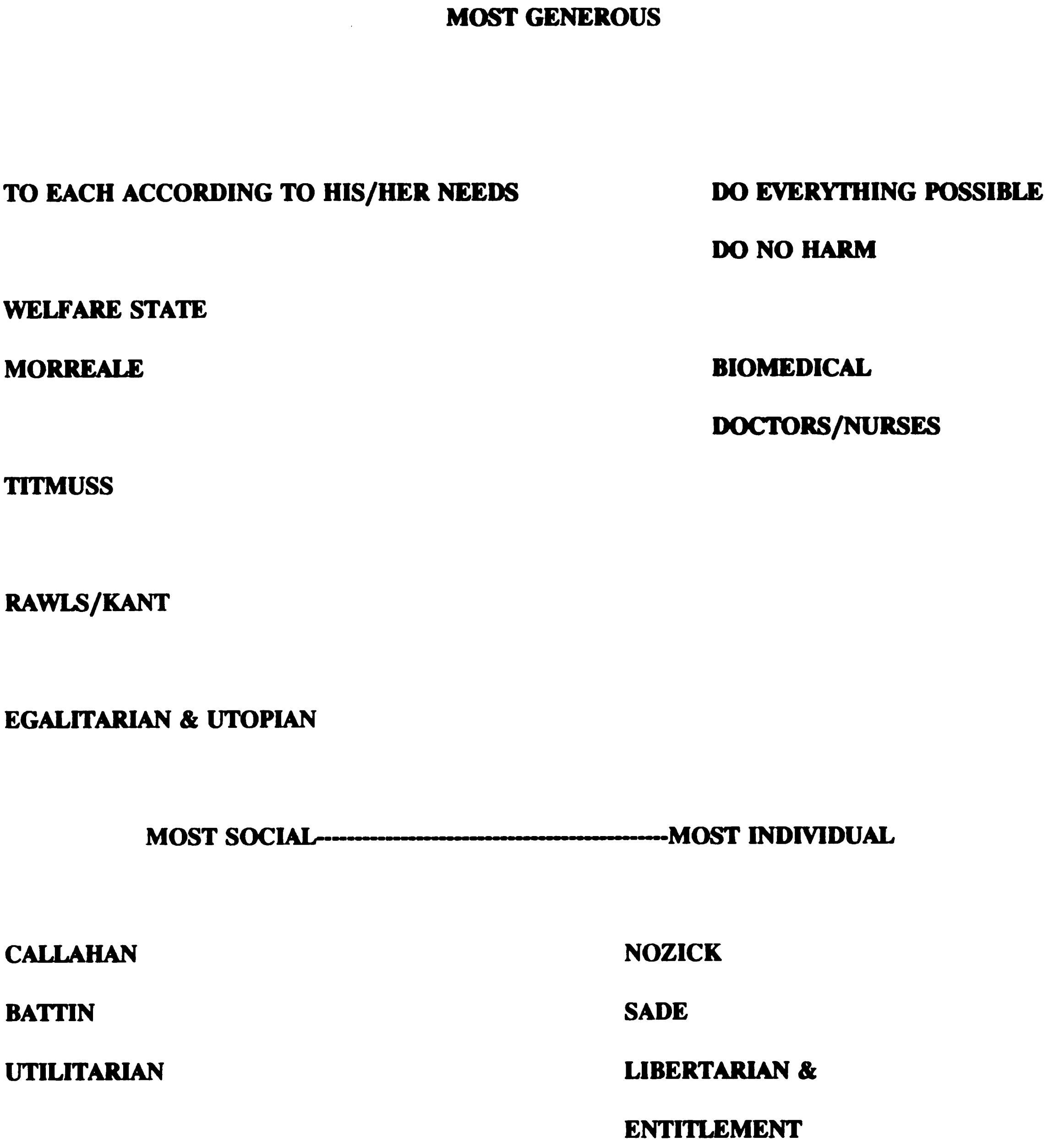
The theme of Bellah and his colleagues (1985) in Habits of the Heart was that even absent a full moral language of public discourse we lead lives of considerable moral depth and our task is to recapture a richer language of moral discourse and public discourse of these matters. The argument Callahan has made in the first sections of his book is important in the quest to reorder public debate. But Callahan (1987:96) believes that our traditional moral language of rights and obligations does not seem to fit the current circumstance of many families and says that "our secular morality...provides few resources for living lives of unchosen obligations.

Callahan (1987) has long been interested in questions of technology and how we understand it, control it, and get it to serve human ends, and this has naturally led him to an interest in general questions about the allocation of resources. Clearly there are severe financial problems with our current health care system and technology has a role in the general elevation of costs. Callahan (1987) is concerned about the direction in which the system is moving and interprets the system as full of contradictions. He finds one contradiction in the care of the aged and the "uncontrolled ambitions to conquer the endless frontier of aging." Callahan (1987) uses health care for the elderly as a paradigm in resource allocation and high technology medicine and asks what might be a fair amount of health care to give to the elderly or what is the reasonable proportion of our health care resources to provide to them. Then, Callahan (1987) asked a most salient question: What are the limits of medicine? This is a most appropriate question to ask of all medicine for all people. But he then abridged the general question to the specific concern of the proper goals of aging and resolved that limits must be set, but set for the aged. The elderly ought not, Callahan believes, beyond a certain age, be entitled to government reimbursement for life-extending medical care, particularly high technology medical care. In fact, the aged ought not **want** to continue living but go gently into that good night without using up all of the available and expensive resources. He declares: "We should always relieve pain and suffering but I do not believe that we are morally obligated to provide everything that medical technology offers by way of life extension" (Callahan 1988:18). This concentrates the question of justice versus autonomy.

MAJOR CONTEMPORARY THEORIES OF JUSTICE AND THEIR RELEVANCE TO HEALTH CARE DECISIONS

I have ordered the major contemporary theories of justice in America today, in terms of their concentration upon the rights of the individual and the aggregate rights of those in the larger community. I have also ordered these theories of justice which, in terms of health care, tend to be more generous to each person in the community, such as a theories of welfare justice, and those which are less generous, such as theories of libertarian justice. The specific aspect of justice we are concerned with in this discussion is distributive justice. Distributive justice encompasses the economic dimension of social justice and deals with the suitable allocation of goods and services within a society. The objective of distributive justice is to assure a proper equitable share to each person and to minimize inconsistent arbitrary discriminations among persons. It is based on the presumption that people are essentially equal and so each have the equal right to health care. Questions about justice in essence are questions about our commitments and responsibilities to one another.

Discussions of justice and autonomy dominate the discourse in bioethics - both in the literature and in the committees. Justice and autonomy are well established principles of ethics. In contemporary bioethical literature in medicine, ethics, and law, there seems to be widespread agreement that it is appropriate to strive for a just distribution of health care resources and services while also sanctioning the autonomy of individual citizens. In fact, traditionally, in health care, autonomy trumps justice. That is, the individual is central to decisions about care, and concerns about societal needs are largely ignored at the clinical level of analysis. Current discussions in the bioethics literature and in the committees point to a expansion of discussions of justice and concerns about social rather than individual needs and preferences at the clinical level of analysis. Most of the concerns capture the tension between autonomy and individualism versus justice and community. It is illuminating to consider of some of the major theories of justice which are involved in these discussions. These theories can be thought of as extending from those most focused on the individual to those most oriented to the larger society. I will illustrate these theoretical concepts with a case from the bioethics committees.



MOST GENEROUS

TO EACH ACCORDING TO HIS/HER NEEDS

WELFARE STATE

MORREALE

TITMUSS

RAWLS/KANT

EGALITARIAN & UTOPIAN

DO EVERYTHING POSSIBLE

DO NO HARM

BIOMEDICAL

DOCTORS/NURSES

MOST SOCIAL---MOST INDIVIDUAL

CALLAHAN

BATTIN

UTILITARIAN

NOZICK

SADE

LIBERTARIAN &
ENTITLEMENT

LEAST GENEROUS

DIMENSIONS OF JUSTICE

A. JUSTICE: THE UTILITARIAN PERSPECTIVE

Generally speaking, utilitarian theories profess that the principle of utility is the ultimate standard of morality and the goal of our action is the greatest balance of good over evil (Frankena, 1973). Utilitarian justice requires that social benefits and burdens be distributed in order to achieve this end. The "good" is interpreted as happiness or satisfaction, but this is independent of any description of what is morally right, since the right is defined as that which maximizes the good. The question of the distribution of health care from the perspective of utilitarian theory is addressed by those who have adopted a "cost-benefit analysis constrained by a decent minimum criterion" (Beauchamp & Faden 1979).

Utilitarian moral philosophy will endorse access to medical care, or universal access to a decent minimum, or a free market approach, depending on which of these is most likely to provide the greatest utility, sum of happiness or well-being for the many. However, it is unlikely that utilitarianism supports extensive equity. Those who are very ill might secure benefit from a great expenditure, but if they could not be rehabilitated, would not benefit if health care was distributed on utilitarian principles. The aged, who might not be benefiting, or who might only receive minimal benefit from care, would not be cared for under the principle of utility. This exclusion of the worst off is unequal, in that it is unfair, and as Veatch (1976) argued, this alone is a reason to reject utilitarian approaches. Another difficulty with utilitarianism may be the most common objection made against it, which is, that its exclusive focus on the aggregate, means that it ignores the fact that some distributions of utility within a population are far less just than others. Justice should prevail, but in this system of the greatest good for the greatest number, some individuals will drop out, generally the poor, the old, and the very needy. The autonomy of the few may suffer for the greater good of the many. This is clearly plausible in the allocation of health care resources. Allocation questions focus on a consideration of how to balance what is needed for all against what an individual person might need. Of particular concern is that the criteria suggested which influence the distribution of resources have implicitly or explicitly been related to age, class, insurance coverage, poverty, nearness to death, and the need for costly interventions. Distribution of resources has also been linked to productivity.

The dilemma here is that it is possible to maximize the average health of the population while maintaining great differentials in health status among individuals. If we let the sickest individuals and those with multiple chronic illnesses die this would decrease overall morbidity and the money could then be spent on other individuals more efficiently. Efficiently, but by what theory of justice is this reconciled? If we recall the utilitarian arguments that supported letting the "useless eaters" of Nazi Germany be killed, the foundational problems of utilitarian justice can be glimpsed. Utilitarians tie social worth so closely to productivity that it is clear that the unproductive, however defined, are at risk.

As a moral theory, utilitarianism leaves something to be desired, say those from other perspectives. A cost benefit analysis disregards the fact that there are other moral values aside from pain and pleasure to be considered, values such as freedom, duty, love, respect, truthfulness, and fidelity. Also, the greatest good for the greatest number is not inextricably linked to what those in a community might consider to be morally right. Clearly the happiness of the majority may be achieved at the expense of the minority. This may disregard the value of the individual, and, not surprisingly, vulnerable individuals are particularly affected.

B. JUSTICE AS FAIRNESS: JOHN RAWLS

Protecting the vulnerable is one aspect of Rawls' (1971, 1987) theory, a theory of justice as fairness. Fairness is a quality which might be built into society's basic institutions by regulating them according to standards to which society's members would agree prior to learning of their individual needs or advantages. The game will be fair, Rawls contends, as long as it is played according to rules agreed to in advance. We are to agree on society's ground rules under a "veil of ignorance" in an experiential vacuum and choose policies which will be the most likely to further our most basic interests.

Rawls discussed this contract-under-ignorance device as well as other general principles of distributive justice. Justice is the first "virtue" of social institutions and for Rawls (1971:3-4), principles of social justice are "a way of assigning rights and duties in the basic institutions of society" and a way to "define the appropriate distribution of the benefits and burdens of social cooperation."

Rawls' principles of justice includes the principle of greatest equal liberty. Each person can be seen as having an equal right to a fully adequate scheme of equal basic liberties which is compatible with a similar scheme of liberties for all. Social and economic inequalities are to satisfy two conditions. First, they must be attached to offices and positions open to all under conditions of fair equality of opportunity; and second, they must be to the greatest benefit to the least advantaged members of society (Rawls 1987:5). That is, all are to have equal rights to the most extensive system of equal basic liberties compatible with a similar system of liberty for all (1971:138). Liberty is considered prior to all other goals, as Rawls (1971:137) says: "Liberty can only be restricted for the sake of liberty."

Second is the "difference principle" or "maximin" principle: inequalities will be tolerated only insofar as they benefit the least well-off. As Rawls (1971:137) comments:

> Social and economic inequalities are to be arranged so that they are both: (a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and (b) attached to offices and positions open to all under conditions of fair equality of opportunity.

Associated with the difference principle is the notion that there is fair equality of opportunity.

Rawls' theory is in opposition to utilitarians who cherish the aggregate good even if it is at the expense of the few. According to Rawls, justice is uncompromising and will tolerate injustice only when necessary to avoid even greater injustice. He holds that, contra utilitarians, the rights of the individual cannot be overthrown by the welfare of the society (1971:3-4). For Rawls, autonomy trumps justice.

Rawls (1982) believed in the greatest individual minimal share of the "social primary goods" but did not regard health as a good that can be distributed. His presumption that "all citizens have physical and psychological capacities within a certain normal range" clearly discriminates against those who are at the outermost limits of health or need (Rawls, 1982). He stated his rationale for this curious exception: "I do this because the first problem of justice concerns the relations between citizens who are normally active and fully cooperating members of society over a complete life" (1982:168). Fundamentally this removes from consideration physically or mentally ill citizens as well as those not "normally active" or those unable to 'fully cooperate', when, for instance they are old, frail, or poor. It is a theory that benefits the productive and healthy.

Rawls' philosophy is deeply indebted to a view of the self as atomistic and a view of society as a derivative construction of solitary selves (Churchill 1987). In it individuals constitute the moral unit of meaning worthy of study. Social relations, as derivative, are of little interest to ethics except as they form an occasion for, or the setting of, individual moral choice. Communal existence, or social relations, are not constitutive of the morally important aspects of persons.

C. NORMAN DANIELS; APPLYING RAWLS' THEORIES TO HEALTH CARE

Norman Daniels (1979a, 1981a, 1983, 1985, 1988) advanced an alternative Rawlsian theory of justice in health care delivery and asserts that health care issues are immanently bound to issues of social justice. He identifies health as a prerequisite to experiencing and enjoying other rights and goods and so holds that health care needs to be justly distributed. That is, the moral significance of poor health goes beyond the unpleasantness of pain and disability. What makes health care a matter of justice is that if one is not healthy, then one has a decreased opportunity to choose among a normal range of life plans (Daniels 1981a). Rawls had said that in terms of distribution of justice, the principle of fair equality of opportunity was to be satisfied before the difference principle is invoked. Daniels established the importance of, for example, access to health care using the opportunity principle and showed that justice requires access to medical care. Justice will be involved with those forms of care with important consequences to opportunity, while other kinds of care may be matters of reasonable spending. Thus, Daniels holds that justice requires access to some, but not all, health services, and these are designated by their relation to opportunity.

Daniels pointed out that one of the major difficulties with health care is the unequal need for it, unlike the general need for food, clothing, and housing. Once a basic need for health care is determined, it may be "extended, modified, or supplemented to accommodate unruly health care needs" (Daniels 1974:189). Daniels agreed that the resolve to provide equal access to all must be found in the society as a whole and not only in the will of, or nature of, doctoring, nursing, and other health services.

In terms of the aged, however, Daniels is close to Callahan. Daniels (1983; 1985; 1988) specifically addressed the issue of equity and aging and asks whether or not the high share required by the elderly is morally appropriate, too much, or too little and on the basis of what reasoning do we determine this. It is clear that he believes the "high share" for the elderly is inappropriate and, like Callahan, argues for an age based approach to entitlement to access to care.

D. LIBERTARIAN THEORIES OF JUSTICE

Libertarianism embraces the view that each individual should be free to pursue his or her own good as he or she sees fit, provided that in doing so there is no interference with a similar pursuit by others (Mill 1859). Libertarians reject the notion of positive rights and instead support negative rights, principally rights of non-interference, but certainly no rights to well-being at others' expense. It is morally irrelevant that an illness may have nothing to do with the personal fault of an individual, according to Nozick (1981), for needs do not give rise to rights. Libertarians who have addressed health care issues state that receiving health care should depend entirely upon the ability to pay. Nozick states that the welfare state infringes upon and, in essence, imposes forced labor on taxpayers by making them involuntarily pay for those not able to pay for their own services. Libertarianism is a theory of minimum obligation, and, as in law, we have no obligation to save a drowning person, so, in health care we have no obligation to provide life-saving goods or services. There are clear limits to our obligations to another, say this group.

One libertarian theorist, Alan Buchanan (1983), offers a suggestion for reconciling libertarian moral theory with government efforts to assure equity in medical care. Libertarians repudiate the prerogative of using government power to enforce a moral right for health care. It makes no difference to them if this right is seen to arise from need, concern for equality of opportunity, or interest in maximizing utility. Buchanan says that there is no reason why one might not feel a strong personal obligation to be benevolent or philanthropic. A quote from Robert Sade (1971:1292), a libertarian physician writing in the New England Journal of Medicine may clarify the position of libertarian doctors:

> The concept of medical care as the patient's right is immoral because it denies the most fundamental of all rights, that of a man to his own life and the freedom of action to support it. Medical care is neither a right nor a privilege: it is a service that is provided by doctors and others to people who wish to purchase it. It is the provision of this service that a doctor depends upon for his livelihood, and is his means of supporting his own life. If the right to health care belongs to the patient, he starts out owning the service of a doctor without the necessity of either earning them or receiving them as a gift from the only man who has the right to give them: the doctor himself.

In this statement Sade emphasizes the libertarian concern that if the government were to assure equal medical care for all, it could only do so by violating the fundamental moral right of the doctor, and would thus infringe upon his or her individual liberty. One difficulty with the libertarian entitlement theory is that many simply do not find it reasonable that people are entitled to stockpile resources and skills desperately needed by others simply because of a desire not to share them.

This essentially conservative view places a great trust in the market system which is geared to profit making and the commodification of health care. Medicine in a market economy is transformed into an exchange of commodities.

E. JUSTICE: THE EGALITARIAN PRINCIPLE

The principles members in a society would need to consider in order to secure an egalitarian health system has been advanced by Morreale (1983:114). He contends that health status cannot be guaranteed since because it is a complex set of values with both public and private characteristics, it cannot be a publicly determined right. However, those in a society can reduce risks of disease and foster positive health concepts and policies, and may indeed have a responsibility to do so.

Social justice in health from an egalitarian point of view requires a material sufficiency ethic, including: a humane, environment-preserving technology; greatly reduced income and wealth disparities; redistribution of wealth through taxation; decentralization of decision-making; community control; and independence and self-reliance (Morreale, 1983:116).

The fair approach, according to this perspective, would be to distribute health care resources on the basis of the principle that everyone has a claim to the health care needed to provide an opportunity for a level of health equal, insofar as possible, to other persons' health. With certain qualifications, if it is to be fairly distributed, health care should be distributed on the basis of need. This is also the basis of the Marxist central doctrine "from each according to his ability, to each according to his need. This has been foundational in utopian theories of justice.

F. TITMUSS AND SOCIAL CHOICES

Lest we imagine that there are no other ways to conceive of justice, let us consider British social theorist, Richard Titmuss (1970), who, using the paradigm of blood transfusion, discussed another way to conceptualize these issues. In The Gift Relationship: From Human Blood to Social Policy (1970), Titmuss studied the provision, in different societies, of human blood for transfusion. Since there is a known requirement for blood in predictable quantities he looked at how that need was met in different societies.

Titmuss concluded that the differences among, say, Great Britain, the United States, and the Soviet Union, could not be attributed simply to administrative and organizational structures of blood supply systems and patterns of medical care services. Titmuss (1970:196) found that different social and political structures and value systems strongly determined which type of donation was characteristic of a particular society and held that:

> Explanations - and admittedly explanations cannot be more than partial - have to be sought in the history, the values and the political ideas of each society.

Titmuss' argument illustrates a different kind of communitarian or universal principle, that social policy is based upon social choices which rest on social values and these values evolve from widely held attitudes. Titmuss argued that the collective choices of individuals in a democracy constitute our social choices. Societies, like individuals, said Titmuss (1974:136) must make choices, and must make them collectively, if they constitute members of a democracy:

> Social policy models...with all their apparent remoteness from reality, can serve a purpose in providing us with an ideological framework which may stimulate us to ask the significant questions and to expose the significant choices.

Titmuss looked at the social relationships involved in blood donation encompassing 'quality of life', implied on the one hand by response to the market and on the other by giving for the general good. He also examined the objectives of social policy, altruism in society, and gift relationships. He demonstrated that the national-collectivist blood transfusion system in Britain was far more efficient than the market system in other societies such as the United States on almost any criterion such as availability, cheapness, purity of blood, economy in its use and so forth. In Britain, donors simply get a cup of tea for their gift, and Titmuss linked this to a broader philosophical principle, the role of altruism in modern society. Altruism is present in many different types of social relationships, including those for social provision. The analysis of social changes, such as an economics which fails to identify such social relations omit a main motive power in human existence. Titmuss (1977:179) wrote that in the last analysis human welfare is an ethical concept and maintained that collectivism, and common access to social services, is a badge of citizenship and the only way of distributing social rights without discrimination and stigma. He argued that this was a point in favor of considering a universalism, with positive discrimination to divert resources to the old, poor, handicapped, and minority groups.

G. JUSTICE AND THE ETHICS OF ACCESS

The report on access of the President's commission for the Study of Ethical Problems in Medicine (1983a) determined that access to health care may be depicted in terms of ethical obligations. The authors concluded that society has an ethical obligation to ensure equitable access to health care for all, and that this societal obligation is balanced by individual obligations.

To speak of equitable access to health care requires that all citizens be able to secure an adequate level of health care without incurring excessive burdens. The commission agreed with libertarians that when equity occurs through the operation of private market forces, there was no need for government involvement. However, unlike libertarians, they acknowledged that the ultimate responsibility for ensuring that society's obligations are met rests with the Federal government. They supported the idea that the cost of achieving equitable access to health care ought to be shared fairly and that efforts to contain rising health care costs are critical. However, they cautioned that efforts to contain rising health care costs should not focus on limiting the attainment of equitable access for the least well-served portion of the public (1983a). The President's Commission concluded that an ethically defensible and practical criterion would be that all persons should have equal access to an adequate level of health care. Defining an "adequate level" includes a consideration of society's resources and other legitimate societal priorities.

It has been suggested that indeed it is not our resources which are scarce, but because of the choices we make there is a relative scarcity of resources (Reinhardt 1985). That is, we have socially constructed scarcity. To say that there are not adequate resources involves accepting a number of assumptions such as: we are spending the appropriate amount of money, time, and goods on health care for the population and that there is a crisis in health care. The construction of a myth of scarcity and of other myths such as the aged are spending an unfair portion of health care resources (Estes 1979; 1986) constitute social constructions, not "reality." Theoretically, we could chose to spend enough to assure that everyone had a minimum level of insurance or of health care. Our extant health care system reflects the choices we are making and we can certainly change the direction of choices that we have made in the past. Those who hold that government intervention is appropriate advocate some sort of universal health insurance so that a basic floor of health care is available. Those advocating a more libertarian view have objected to any kind of universal entitlement. This means that certain treatments or technologies are not available unless the person has money, has insurance or unless the government covers the cost of treatment. This creates a two tier health care system which is inevitable if services exist but only the wealthy or well insured have access to them.

II. AUTONOMY AND ITS RELATION TO JUSTICE

A. AUTONOMY

Another ethical principle involved in considerations of just health care distribution is that of autonomy, often referred to as the principle of self-determination. This principle was expressed by John Stuart Mill in his essay "On Liberty" (1859:10):

> The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant....In that part (of anyone's conduct) which merely concerns himself, his independence is, of right, absolute.

Autonomy involves respect for a person's freedom of action, preferences, and choices. This includes informed consent and refusal; the right of the person to have adequate and truthful information with which to make an informed choice or refusal; and the right of the person to determine what is to become of them. Mill (1859:15) put it thus:

> Neither one person, nor any number of persons, is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it.

This principle was incorporated in case law in 1914 in the case of Schloendorf v. New York Hospital, when Chief Justice Benjamin Cardoza stated:

> Every human being of adult years and sound mind has a right to determine what shall be done with his body.

Ethicists, such as Beauchamp and Childress (1979:56) have defined autonomy as:

> a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself.

Respect for autonomy is a principle rooted in the Western tradition of the importance of individual freedom and choice, both for political life and personal development. The principle of autonomy is associated with several related concepts such as privacy, voluntariness, self-mastery, the freedom to choose, choosing one's own moral position, and accepting responsibility for one's own choices.

There is a problem with the bioethical concern for autonomy and that is the relentless preoccupation with it. Bioethics must encompass more than simply the analysis and protection of autonomy for autonomy is the chief issue only in such instances where there is jeopardy to autonomy through coercion or curtailment of their rights. In matters of policy an autonomy ethic may not be appropriate. It is an atomistic perspective of the moral life that makes difficult developing a social ethic.

A major issue associated with autonomy in health care is the tension between individual choice and the availability of choice, choices made less free because of public policy determinations. As the divergence between what is possible and what is allowed increases, the capacity for autonomous choice decreases. The proposals to annul entitlement to health care by age, for example, is clearly a violation of the autonomy of those affected by this decision: the aged. If justice is invoked, it is not the welfare justice of Tittmuss or the egalitarian justice of Moreal; it is the justice of the utilitarians and of libertarians Nozick and Sade. It is this shift, from decisions based on the patient's autonomous wishes to a utilitarian justice weighing what is best for all and denying services to the unproductive or aged that strikes at the heart of a just health care.

1. CASE DISCUSSION: FOREGOING TREATMENT; PROFOUND DECISIONS

One aspect of allocation is the decision to forego treatment, to withhold or withdraw life sustaining treatment. Many have struggled with the growing concern that it may be inappropriate in all cases to do everything. But how are these decisions being made? In most situations, deciding to stop treatment for a person who is thought to no longer benefit from that treatment also involves an allocation decision. There is generally, say the discussants a more "appropriate use of resources," as the patient in question is now receiving what is termed "futile treatment"

It can be appreciated that futility is a socially constructed state, that is, when futility begins or ends depends on a number of judgements. It unquestionably involves uncertainty. However, even absent futility, there are those who insist that any treatment continue because life is precious in any form and to withhold treatment which then allows the person to die would be a violation of this ideal.

Aware of the social nature of our constructions of futility, each bioethics committee may agree as to what they would accept as indicators of futility and then abide by that defined construct. This would allow a more just rule such as, if treatment is not futile, then all other things being equal, treat. All other things might include the person's desires, the person's "good", and the availability of the resource or service. Obviously if the person needs a kidney transplant and there is no match for one, there is no way to treat. However, if we agree that, however defined, treatment is futile, there is an inordinate difficulty in committees allowing physicians to forego treatment.

For example, there is no difference in withholding or withdrawing treatment according to legal and ethical principles, but people feel a great difference in the two resulting in a practice anomaly. One of the paradoxical issues in the withholding or withdrawing discussion is that there is a distinction between "not starting," and "stopping," a treatment when it is decided that it is futile. That is, when in terms of law, ethics, or medical order one action is "correct" but it is difficult for the practitioner to do. There is no legal or ethical difference between removing an intravenous or nasogastric tube or removing oxygen but people feel it to be immensely different in practice. There is no ethical or legal difference between food or water but there is a perceived difference. In all of these practice anomalies, the symbolic differences are repudiated by law, ethics and medicine.

There are many questions surrounding foregoing life-sustaining treatment decisions for adults and many have struggled with the growing concern that it may be inappropriate to apply technologic capabilities to the fullest extent in all cases and without limitation. It is only recently that there has been an increased awareness of the rights of persons to be treated in accordance with their own decisions and expectations. This means that the use of heroic measures to sustain life can be justified only by fidelity to the person's right to elect or decline the benefits of medical technology and to the dictates of good medical and nursing practice. In the case of a competent person the person determines the course of his or her therapy and may refuse any and all interventions proposed by others as long as their refusals do not seriously harm or impose unfair burdens upon others (Lynn and Childress, 1983; Pres Comm., 1982).

An increased awareness of patients' rights to be treated in accordance with their own decisions and expectation, including prior directives, is a recent development. The use of heroic measures to sustain life can be justified only by fidelity to the patient's right to elect or decline the "benefits" of medical technology. Life sustaining treatment includes all health care interventions that lengthen the patient's life. When these interventions are a matter of choice, a salient question is - who decides? There are two general categories of patients, the competent patient and the patient unable to make his or her own health care decisions. Competence is broadly defined as the capacity to understand and appreciate the nature and consequences of one's actions. However, although the word is much used, technically competence is a legal term and can only be established by a judge.

Patients, competent to determine the course of their therapy, may refuse any and all interventions proposed by others as long as their refusals do not seriously harm or impose unfair burdens on others (Pres. Comm. 1982). The patient's right to make these decisions is clearly stated in a 1891 U.S. Supreme Court decision (Union Pacific Railway v. Botsford 1891) that says:

> No right is held more sacred, or is more carefully guarded, by common law, than the right of every individual to the possession and control of his own person, free

> from all restraint or interference by others, unless by clear and unquestionable authority of law.

More recently a patient's rights to autonomously control his or her body has been embodied in the doctrine of informed consent. In the case of Natanson v. Kline (1960) the judge stated that:

> Anglo American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment. A doctor might well believe that an operation or form of treatment is desireable or necessary, but the law does not permit him to substitute his own judgement for that of the patient by any form of artifice or deception.

Competent patients are at liberty to make their own medical treatment decisions; incompetent individuals are not. Since ethically and legally the competent patient has the right to make this decision, there should be little question about such a patient's refusing treatment. However, cases continue to enter the courts.

DOUBLE AGENTS AND DIRTY WORK.

In order not to treat a patient, someone must give the directive and someone must carry it out. In one bioethics consultation meeting a sub-group of the ethics committee met with a physician who wanted to stop feeding a patient who was in a persistent vegetative state. After 50 minutes of discussion, the chair of the sub-committee turned to the physician and said "It sounds like there is a consensus to remove the tube." The physician said to the nurse, "Can you remove the tube today?" and she said, "You'll have to do that" at which point the physician said "I don't think I'd feel comfortable doing that." The time was up and the recommendation to remove the tube was lost. In several conversations like this, where there was reluctance to complete an act that would lead to the patient's death, I was reminded of Hughes' (1962/1984) concept of "dirty work."

The unwillingness to withdraw treatment, even when the patient is competent and is clearly making her wishes known can be illustrated by the next case (Annas 1987). Kathleen Farrell, a competent 37 year old woman who had been diagnosed with amyotrophic lateral sclerosis, requested that her ventilator be turned off. Her physician refused her request, so her husband sought court authorization to order that treatment be ceased. The court granted his request, but deferred the order until the request could be reviewed by a higher court. Mrs. Farrell died connected to the ventilator before the appeal was heard. The court ruled that treatment could be terminated since the patient clearly wanted it to happen (Annas 1987). A relatively straightforward situation of a competent patient's making her wishes known took a court decision to compel the physician to honor the patient's wishes.

The President's Commission (1983b) established that informed decisions by competent patients regarding choices about life-sustaining treatment should be respected, enhanced, and promoted by health care professionals. However, serious problems often arise in discerning patients' wishes concerning how they view the situation and their desire to be treated or not, because of incomplete knowledge, uncertainty of treatment outcomes, and the diversity of personal values and objectives of both patients and practitioners. In a pluralistic society we cannot impose a single moral vision on either patients or practitioners.

The informed consent doctrine provides a firm basis for the legal and ethical recognition of the competent, terminally ill person's prerogative to resist life-preserving medical treatment. The doctrine of informed consent entitles patients to be informed about the plan and the course of their prospective medical treatment as well allowing patients to withhold consent, when they do not view the prospective treatment to be in their best interest. Fundamentally, informed consent rests on respect for the individual, and for each individual's capacity and right to both define his or her own goals, and to make choices designed to achieve these goals. However, in defining informed consent and its exceptions, the law has tempered this right of self-determination with respect for other values, such as the promotion of well-being in the context of an expert-layperson relationship (Capron 1986:18; Pres. Comm. 1982:17). Nevertheless, the competent patient's wishes must prevail. Although doctors and nurses find it difficult to reject the demands of family members when they differ with the patient, this is clearly required by the respect-for-persons moral principle (Macklin, 1987:54).

THE PATIENT WHO IS INCOMPETENT

What should guide those who must decide for a patient who cannot decide? If the terminally ill patient's ability to make decisions becomes diminished, the treatment team must increasingly rely on the pre-stated or presumed wishes of the person. This became a clear issue in the recent Cruzan case where the decision rested upon her having made a clear statement about her wishes prior to the accident that resulted in her falling into a coma. What might be a way to determine a patient's wishes. A statement, written before the person experiences diminished capacity to make decisions, can be helpful in indicating the patient's preferences about terminal decisions.

It has become clear, especially since Cruzan, that arrangements for surrogate decision making need to be available when patients are unable to make decisions by themselves (Flynn and Davis 1990). When others make decisions they should be those that the patient would have made or, if the patients wishes are not known, the decision must be made in the patient's best interest. Neither caregivers nor family members may seize that opportunity of the patients unresponsiveness to do what they think is best for a patient who has recently and clearly expressed his own wishes about the level of treatment. Although an unconscious person lacks autonomy, if that same person, while conscious, recently exercised autonomy and stated preferences about medical treatment, however the professionals may feel about it, those wishes must be accepted.

Another aid to decision making when the patient cannot participate is a proxy designated in advance by the patient to speak on his or her behalf. In some states this option has been provided by law as part of the state's living will legislation or, as in California, as an amendment to the durable power of attorney statute which extends the authorization to health care decisions. While not a flawless mechanism for projecting a patient's wishes into a period of future incapacity, a proxy designate has the advantage of initiating discussions with patients about their wishes before such decisions are needed.

TREATMENT DISTINCTIONS

Life sustaining measures extend on a continuum from respirators and dialysis, through antibiotics, intravenous glucose and water, to food and drink. A number of treatment distinctions concerning these have been made. One distinction, between omission and commission of a particular act or use or non-use of a particular treatment, is neither always obvious nor obvious to all, especially if judged only by the results. A legal difference between actively doing something and not doing anything has been established, but a vigorous debate about whether or not ethical differences exist is under way.

The matter of actively killing rather than allowing someone to die refers to the moral principle that says that it is not right to kill an innocent human being even when it might result in more good than harm. Those in favor of active euthanasia seek to change this principle, that is they seek, through a process of moral ordering, to change the moral order. In health care today we can ethically justify allowing people to die, but only in certain circumstances. We avoid killing directly but will allow someone to die. In many cases, this depends upon a verbal strategy. For example, if one removes a respirator, one is not said to have killed the patient, but to have allowed the patient to die of his or her underlying disease.

Another distinction, a memento of the moral ordering that took place in 1957, is that of extraordinary or ordinary treatment. This originated in the Roman Catholic tradition as a way of differentiating optional treatment from treatment that was obligatory for medical professionals to offer and for patients to accept (McCartney, 1980; Lynn and Childress, 1987:20). This distinction refers to a treatment as being only customary and unusual. Sometimes this difference relates to the particular circumstances of each patient, so that what is ordinary treatment for one person is extraordinary treatment for another. In clarifying the distinction, Pope Pius XII said that we are normally obliged to use only ordinary means to preserve life, and that a more strict obligation would be too burdensome to most people (Flynn and Davis 1990; McCartney 1980). This, however, does not help distinguish between ordinary and extraordinary.

Treatment criteria can also be categorized in numerous other ways, including simple or complex, natural or artificial, usual or unusual, invasive or non-invasive, reasonable chance of success or futile, proportionate or disproportionate balance of burdens and benefits, inexpensive or costly. An examination of these criteria reveals that most of them are not morally relevant in distinguishing optional from obligatory medical treatments. As Lynn and Childress (1983:21) describe:

> as, for an example, that associated with a rare, complex, artificial, invasive treatment that offers a reasonable chance of nearly painless cure, one would need substantial justification _not_ to provide that treatment to an incompetent patient.

In determining whether or not to provide a treatment to a particular patient, the question becomes whether or not the treatment will provide sufficient advantages to make it worthwhile for the patient to endure the hardships that would attend the therapy. However, one cannot make an _a priori_ decision that a treatment is ordinary or extraordinary, but must examine the particular situation and people involved. In its deliberations, The President's Commission (1983b:84-87) adopted the criteria that treatments are expendable only if they are useless or if the burdens exceed the benefits.

INTENTION

One further distinction in decisions to forego life-sustaining treatments is the differentiation between intended and unintended deaths. Sometimes one option is "doing evil to achieve good" (McCormack and Ramsey 1978). "Evil" consequences of actions are morally permissible provided that: 1) The action itself is good (or indifferent); 2) The intention of the agent is for good; 3) the "evil" effect of the action is not intended; 3) the "evil" and the good effect must be equally immediate causally; 5) there must be a proportionally grave reason for allowing the "evil" to occur (McCormack and Ramsey 1978:7). Thus the doctrine of double effect asserts that is always wrong to intentionally do a bad act for the sake of good consequences that will ensue, but that it may be permissible to do a good act in the knowledge that bad consequences will follow.

An example of the double effect principle might arise when giving morphine to a patient with compromised respiration. The action of giving the morphine is good because it is intended to reduce pain and not to slow or stop respiration. Both pain reduction and the respiratory compromise are equally immediate causally. The proportionally grave reason to allow the "evil" is that the pain reduction is so needed that the benefit outweighs the possible deleterious effect of the morphine (Davis 1987).

The doctrine of double effect holds that killings are wrong only if we intend them. Is the role of intention adequate when determining an act's wrongness or rightness? Some hold that the morality of an action can be distinguished from the blameworthiness of the actor, and that someone can do the right act out of a bad intention. Likewise, one can do the wrong thing out of a good motive. Someone who actually kills for mercy may be an example. Others argue it we know with certainty that an indirect "evil" will result, the good intentions of the actor should not matter (Veatch and Fry 1987:168).

MORAL ANOMALIES: WITHHOLDING OR WITHDRAWING TREATMENT

WITHHOLDING OR WITHDRAWING FOOD AND FLUIDS

While in theory there is no moral difference between withholding a treatment and withdrawing it, health professionals have inordinate difficulty withdrawing treatment once it has begun. The difference between the ease of withholding a treatment and the difficulty of withdrawing it once started provides a psychological explanation of certain actions, but it does not justify them (Lynn and Childress 1987:21). This difficulty may lead to irrational decision processes. For example, if hospital policy states that treatments can be withheld or omitted, but once started not withdrawn, then a distinct motivation to refuse to start procedures exists. This might lead to <u>not</u> treating a patient even when that treatment is warranted at the time. Would it not be better health care policy to begin a treatment, even when there is a reservation about its efficacy and then withdraw it when it is apparent that the treatment is not useful or if it becomes apparent that the patient does not or would not have wanted the treatment to continue, than to deny possibly useful treatment?

This results in another case anomaly. That is, when in terms of law, ethics, or medical order one action is "correct" but it is difficult for the practitioner to do. Again here, one is reminded of Hughes' concept of double agents and dirty work. For example, there is no difference in withholding or withdrawing treatment according to legal and ethical principles, but people feel a great difference in the two resulting in a practice anomaly. There is no legal or ethical difference between removing an intravenous or nasogastric tube or removing oxygen but people feel it to be immensely different in practice. There is no ethical or legal difference between food or water but there is a perceived difference. The President's Commission maintains that neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment (1983:77). Furthermore, unless a special expectation of continued treatment has been created, it ought to be no more significant, morally or legally, to cease a treatment in a patient than not to start the same treatment for that patient" (Capron 1986:22). In all of these practice anomalies, the symbolic differences are repudiated by law, ethics and medicine.

We do not tend to view withholding or withdrawing food and water from a patient with the same objectivity one might have in discontinuing chemotherapy or dialysis treatments. If a competent patient has the right to forgo any life-sustaining treatment, this includes food and water. With incompetent patients, the surrogate's decision should reproduce what the patient would have wanted if competent. If their preferences are not known, the surrogate will assess the benefits and burdens to the patient.

A competent patient's decision regarding whether or not to accept the provision of food and water by medical means such as tube feeding or intravenous alimentation raises questions about the practitioners who must participate in the process. What should guide those who must decide about nutrition for a patient who cannot decide? Standards for other medical decisions are that one should decide as the incompetent person would have decided if he or she were competent, when that is possible to determine, and advance that person's interests in a more generalized sense when individual preferences cannot be known.

A California appellate court found that artificial feeding does not differ from any other life support measure and may be withdrawn when its administration brings no hope of recovery (Barber and Nejdl v Superior Court of the State of California 1983). Some see no reason to apply a different standard of decision making about treatment decisions to feeding and hydration (see for example Lynn and Childress 1983:18). The question for them, becomes: "Is it ever in the patient's interest to become malnourished and dehydrated, rather than to receive treatment?" (Lynn and Childress 1983:18).

When may a procedure that might improve nutrition and hydration for a given patient be foregone?: "Only when the procedure and the resulting improvement in nutrition and hydration do not offer the patient a net benefit over what he or she would otherwise have faced" (Lynn and Childress 1983:19). Some such circumstances are: 1. the procedures that would be required are so unlikely to achieve improved nutritional and fluid levels that they could correctly be considered futile; 2. the improvement in nutritional and fluid balance, although achievable, could be of no benefit to the patient; 3. The burdens of receiving the treatment may outweigh the benefit (Lynn and Childress 1983:19).

When providing food and water to a patient becomes a futile task does it place an intolerable burden on the patient to provide them? When death is imminent, ineffective procedures that attempt to deliver nutrition and hydration may directly cause suffering and offer no benefit for the patient. Such procedures may be tried, but cannot be considered mandatory. In fact, in these cases feeding a person might become a disproportionate burden to that person. Normal nutritional status could be restored but not without a harsh burden for the patient. Treatment often becomes futile in a broad sense since the patient will not actually benefit from the improved nutrition or hydration (Flynn and Davis 1990). There may be no possibility of benefit to those who are thought to be permanently unconsciousness; are in a persistent vegetative state, or are in preterminal coma.

SLIPPERY SLOPE ARGUMENTS

The slippery slope or wedge argument assumes that once allowed in specific circumstances, an action will occur in other circumstances or that once something is allowed to happen it becomes a mandate. There are a number of situations where the slippery slope argument presents problems. This is also known as the wedge argument, once you begin a wedge then it is ever easier to widen and deepen that wedge.

In forgoing food and water, Callahan (1986:61) agrees that discontinuation of feeding under some circumstances is not always morally wrong but "is always repulsive and repugnant" even when in the patient's own good and under legitimate circumstances. Using the slippery slope argument he focuses on the symbolic nature of feeding and the emotions evoked by not feeding. He fears that the symbol of feeding, if not respected, might lead us to a callousness in feeding people generally and the poor in particular. Our commitment to feed the poor will be eroded, the slippery slope argument goes, if we, as a society, tolerate withholding or withdrawing nutrition without revulsion. Is there, though, any logical connection between withholding and withdrawing treatment and allowing the poor to starve? It seems perfectly possible to allow a patient to have an IV line discontinued and still to continue to feed the poor.

Callahan (1986) believes that if our society defines discontinuing of medical nutrition and hydration as a right, it will eventually define this discontinuation as a duty. This slippery slope argument from may to must, from permissible to required may become a more serious problem under economic pressures. Recall the economic arguments in Nazi Germany and the allowability of non-feeding and killing. There does not even need to be a recourse to a slippery slope argument in this scenario. Given the demographic trends in society of more chronically ill, physically marginal, and elderly people, the denial of food and fluid might become the "nontreatment of choice" (Callahan 1983).

Weisbard and Siegler (1986) see a danger that, once the determination to forego food and fluid has been made, even if for humanitarian reasons, death is the desired outcome. They fear that decision makers will become "increasingly less troubled by the choice of means to be employed to achieve that outcome. The line between allowing to die' and 'actively killing' can be elusive, and these writers are skeptical about logical or psychological distinctions between these alternatives proving viable. They believe that if our society is to retain the prohibition of active killing, the "wavering line demarcating permissible 'allowings to die' must exclude death by avoidable starvation" (Weisbard and Siegler 1986:112). Their interest goes beyond a concern for the outcome for a particular patient, and includes a fear for the reverberations of these decisions on family members, health care professionals, and societal values, which survive the patient's death (Weisbard and Siegler 1986:113). These larger concerns draw on the historical data discussed earlier that shows how easily we dis-value the lives of the "unproductive."

The possibility of harm increases when the medical and ethical legitimation of withholding treatments, in this case food and fluids, converges with cost containment strategies that "may well impose significant financial penalties on the prolonged care of the impaired elderly" (Weisbard and Siegler 1986:114). They fear that it would be too easy to move from the "recognition of an individual's 'right to die,' ...to a climate enforcing a socially obligatory 'duty to die', preferably quickly and cheaply" (Weisbard and Siegler 1986:114). Their concerns are not with the patient's self-determination regarding decisions about dying but about the potential use of processes like living wills or Durable Power of Attorney for Health Care as strategies towards cost control. The apprehension is related to the latent tendency to diminish the value of the lives of the "unproductive," those who are old, retarded, institutionalized, or repudiated for any reason, and the feeling that if one withdraws food and fluid in a few selected cases this "bears the seeds of great potential abuse" (Weisbard and Siegler 1986:115).

Childress recognizes a moral presumption in favor of life-sustaining medical treatment in accord with the patient's interests and preferences. This moral presumption must be rebutted before treatment, including food or fluid, can be withheld or withdrawn (1986:76). Many believe that acceptance of the patient's choice to forego treatment reflects concern for individual self-determination, bodily integrity, avoidance of suffering, and empathy with an individual's effort to shape his or her dying process, rather than deprecation of life's values (Flynn 1990). Courts that concur with patients' decisions are impelled by profound respect for individual autonomy, as an integral part of human dignity, and not by any disregard or disdain for the value or sanctity of life (Cantor 1987:4)

There is no obligation to provide useless treatment but there is always an obligation to provide care. Easing of pain, relief of suffering, and supporting and comforting care are necessary and morally required in the presence of incurable and progressive illness. Relief of suffering is a crucial part of the treatment goal. Professionals have the privilege and the responsibility to comfort, always.

Important to consider is the basic moral fabric of the professions including the basic issues of trust and safety. The preservation and maintenance of the ethical integrity of the professions are compelling. There is no obligation to provide useless treatment but there is always an obligation to provide care, regardless of age (Flynn 1990). That should be a fundamental goal: to care for the elderly, as we do for all others. Appropriate care rarely involves the ubiquitously quoted heart transplant, it is far more likely that the need will be for social services, nursing care, or hospice than for high technology. In any case, it is unjust to select one group to cleave from the social body and deny entitlement to health care. As Fried (1976) asserted:

> As long as our society considers inequality of wealth and income...morally acceptable - acceptable in the sense that the system that produces these inequalities is in itself not morally suspect - it is anomalous to carve out a sector like health care and say that <u>there</u> equality must reign.

BIOETHICS COMMITTEES: RATIONING, DENYING ENTITLEMENT AND ALLOCATION DECISIONS

The possible future role of bioethics committees and rationing and allocation decisions was previewed in a hospital bioethics committee meeting. In this meeting, an issue having to do with an already decided policy which denied a certain aspect of health care for the aged, in this case, those receiving Medicare was handled. My prediction has been that bioethics committees would serve to carry out policies of the federal government and, in fact, are so placed that when faced with explicit rationing, first by denying entitlement of health care to the elderly, and then simply denying health care on the basis of age, these committees will not stand as champions of the aged, but instead will carry out a mandate to ration. This was a concern about justice, specifically, distributive justice for the aged.

2. ANGIOPLASTY

The ways in which macro-economic policies affect individuals at a micro-sociological level were dramatically illustrated through the effect of a cost-saving directive from the Health Care Financing Administration (HCFA) upon individual patients and staff of one hospital in my study. The discovery that two deaths following angioplasty at two neighboring hospitals might possibly be related to the lack of on site trained professional staff to perform emergency heart surgery for two elderly patients was the impetus for this case study. The question raised was whether or not the deaths of the two individuals had resulted from a public policy decision, how this effected practice at this hospital, and what was the relation of this knowledge to the responsibility of the bioethics committee. This investigation sought to discover the circumstances under which the policy had been made, the potential impact of the policy, what its consequences were, and the role of the bioethics committee in advocacy or protection of its own patients in the hospital. Here, I explore these decisions and look at the critical areas between public policy which endeavor to maximize cost savings, and the everyday world in which patients live or die and in which very concrete decisions must be made about very real human beings.

The specific policy was Medicare's decision to stop payment for standby services during angioplasty procedures. This was a relatively circumscribed issue and so can easily serve to illustrate the association between public policy macro-sociological issues and micro-sociological issues affecting society, patients and health care providers. We will look at the gaps in policy, in standards of care, and some of the general problems of technology and health and how these are related to bioethics committees.

The policy issue involves the allocation of resources of both personnel and finances and how these resources are allocated. Economics deals with the problems of resource allocation in the face of relative scarcity; politics and ethics also deals with these same issues. In a pluralistic democracy such as the United States there is a diversity of value systems as well as individual and collective preferences and these find political expression in budgets and appropriations that have monetary denominations. Money and its allocation becomes a symbol for basic concerns such as freedom, labor, security, and health. Money expresses directly or indirectly the values we place on the qualities that affect the human condition.

THE POLICY ISSUES: ANGIOPLASTY POLICY AND THE ETHICS COMMITTEE

The specific policy in this case concerns the angioplasty procedure and is related to a broader Health Care Financing Administration policy relating to payment for professionals who may be needed in case of an emergency but who, unless there is an emergency, do not touch the patient. The term stand-by refers to the physician being physically in the room as distinguished from being "on-call" which means that they can be in the room in 10 minutes. In practice this latter is often not possible without being physically in, or next door to, the operating room.

The angioplasty stand-by issue came to notice during an ethics committee meeting in January 1987. The predicament was brought up by the committee chair, an internist with a practice including elderly persons with cardio-pulmonary disease.

> Barney, M.D. Chair: I want to discuss a case: [reads] "Medicare rulings on cardiac surgery and PTCA [percutaneous transluminal coronary angioplasty]: Medicare no longer will cover anesthesia or cardiac surgeons for angioplasty. Blue shield and Blue cross will continue to provide coverage."

This announcement was the first that most of the people in the room had heard of this new non-payment policy, with the exception of the Operating room supervisor who is a nurse, and the administrator of the hospital, both members of this ethics committee. The statement read by the chair condenses the issue: that Medicare will no longer cover anesthesia or cardiac surgeons during angioplasty procedures but private insurance will. This is a clear issue of justice in that one category of patient receives what is currently considered to be the appropriate community standard of care and another does not simply on the basis of their ability to pay. In this instance the payment is tied to Medicare and thus affects the aged population. Entitlement to care is being abridged on the basis of age, as Callahan recommends, but here it is happening without discussion or public debate.

The Operating room supervisor stated:

> Connie, R.N.: There are no longer stand-by services, by the anesthetist or the surgeon. Last week 2 angioplasties were to be done, the non-medicare patient received standby and they left when the second angioplasty started, the medicare patient. This is a duality that needs to be looked at.

The "different levels of care" was a direct result of the policy decision to stop paying for stand-by for Medicare patients. Private insurance continued to pay for stand-by physicians. When a patient came for angioplasty, if he or she were not covered for stand by, the physicians left the room in these cases under discussion.

There are two ways physicians can be on stand-by. The current procedure is to have the physician actually in the room or the next room. Emergency on call means that the physicians are only "on call" and can be anywhere in the hospital or at home if they can be back at the hospital within 10 minutes. The question of the necessity of actually having the physicians "stand-by" in the room was raised by a nurse:

> Jean, R.N.: Emergency on-call - is that sufficient if the patient crashes?

> Connie, R.N. Operating room supervisor: Cedar and St. Bert's Hospitals each eliminated standby and a patient was lost in both instances. The percentage of emergency crashes - on hearts is 5% of the time.

Emergency crashes refers to cases in which an incident occurs which then necessitates open heart surgery to perform coronary by-pass surgery to correct the situation. The issue of risk is a real one and can be substantiated with statistics from around the world. Data from the United Kingdom reported in 1983 show that in 15 UK centers with 678 procedures 5.3% required emergency coronary by-pass graft surgery; in the United States in 1983, 73 centers reported that 6.8% emergency by-pass surgeries were required (Cumberland 1983:97;NHLBI 1983).

Major complications or "crashes" include any of several coronary vascular events, including dissection, occlusion, spasm, embolism, perforation, rupture; or ischemic events such as myocardial infarction, or prolonged angina. A combination of these occurred in 418 or 13.6% of patients (Cumberland 1983:97;NHLBI 1983). Emergency coronary artery by-pass grafts (ECABG) were performed in 6.6% of patients. Indications included coronary dissection 46%; coronary occlusion 20% prolonged Angina Pectoris 14%, coronary spasm 11% (Cowley and Block 1986).

The outcomes in patients with longer stenoses and eccentric stenosis, who are generally older, disclose an emergency surgery rate of 10-15%, a significantly increased risk for needing open heart surgery.

ROLE OF THE ETHICS COMMITTEE

In addition to the economic and medical quandary, and the surgical risks arising from removing stand-by anaesthesia and cardiac surgeons, there are also ethical concerns. In the discussion of this situation in the bioethics committee, a number of issues were enumerated as being important. The members discussed the following dilemmas:

1) Truth telling of physicians.
2) Dual standard of care for non-medicare vs. Medicare patients.
3) Justice of allocation of resources where government implies a certain physician standard of care but will not pay for it anymore.

They discussed the principle of informed consent and said that informed consent was important; that patients must be informed of the risks and the standbys are not there in case of complications; that this option can allow the patient the option of paying cash for the standby. They discussed whether or not Medicare patients are aware of the HCFA change, and decided that they were not aware.

In order to provide informed consent the patient must be advised of the increased risk he or she faces when no standby team is present. In six hospitals where staff were interviewed, each of the angioplasty patients (medicare and non-medicare) had been told that there would be a stand-by anesthesiologist and cardiac surgeon in the room in case anything unexpected were to happen. These standby services were not provided when the patient was under Medicare Part B regulations. In these cases, there was not only a lack of informed consent but also a lack of veracity, another ethical principle. Truth-telling is required of health professionals and in these cases was not realized.

Second, justice requires that there be equality in health care and equity in the ways that goods are distributed. It is clear in this matter that justice in terms of the allocation of resources and in access to the community standard of medical care is inequitable and thus unjust. By economically prohibiting the usual standard of care to Medicare patients a double standard is created of good health care for one level and no care for the other. A clear division of care into two tiers, one for the well insured or well off; another for the uninsured, under-insured, and medicare beneficiaries is apparent. Ethicists hold that all patients with a lethal lesion should have equal access to care and an equal standard of care under the principle of justice. Economics should not be the principal guiding point of care in terms of justice.

Finally, the principle of beneficence, to do good, and non-maleficence, to do no harm, are clearly involved here. In leaving the patient, the anesthetist and cardiac surgeon are not acting in the best interests of their patients, and are, in fact, placing them at significant risk. A further concern, abandonment of the patient might also be raised.

THE PROCESS OF INVESTIGATION AND FINDINGS FROM THIS:

It was extraordinarily difficult to get information from anyone about this stand-by policy. I spoke with four hospital administrators, two operating room supervisors, two internists, four cardiologists, three HCFA officials, Blue Shield of California, and a number of people on ethics committees.

In a telephone interview with a HCFA official in Washington when asked about the origin of the 'no payment for stand-by policy' he said "there is no specific policy written and we have not sent out any memo on this." (Weintraub 1987).

> HCFA: "There is no specific policy about angioplasty [PTCA]. It was a memo, not a policy."
>
> PF: "What was it based on?"
>
> HCFA: "It was based on a policy that came out last spring from Baltimore, that we would not pay for people not directly participating in operations. Then a memo came out about PTCA clarifying the fact that the stand-by person would not be paid.

However, he commented, a surgical standby team which is usually available when PTCA is performed, does not provide an identifiable patient care service unless the patient undergoes bypass surgery. Immediate availability of the cardiac surgeon in, or close to, the operating suite, without performing a specific service, does not constitute a reimbursable physician service (O'Hara February 12, 1987).

In answer to a question about how hospitals and doctors were notified a San Francisco HCFA official, O'Hara (1987 interview) replied:

> O'Hara: This policy was transmitted to physicians via Medicare bulletins which are issued periodically by Medicare carriers, such as Blue Shield of California, which process claims for physician services. Hospitals were not notified of this policy since it relates to reimbursement of physicians, not hospital, services.

It seems that the route of information about a change in procedure which will change the level of risk and increase the need for informed consent was treated in a very cavalier manner. The bulletins which are 'issued periodically' are sent only to physicians accepting Medicare payment. Certainly the hospital administrator, the operating room staff and the patients that are involved need to know. This kind of a policy change with its potentially lethal ramifications was handled in an arbitrary way.

The earliest document from the Medicare Bulletin revising guidelines did not clearly deal with angioplasty but solely with 'stand-by' procedures and so could easily be disregarded by physicians reading the bulletin. In reading through a number of bulletins it was surprising how dense and confusing they were. The original memo distinguishes between 'availability' and 'stand-by' services of physicians:

> Availability applies to situations where a physician is present to perform services to patients generally, should this be required. Availability is not directed toward a specific patient and is not covered under Medicare Part B.
> However, stand-by services which are directed toward a specific patient **may** be covered under specific circumstances. Generally, for stand-by services to be covered, the following criteria must be met:
> **o The physician must be physically present in the operating suite;**
> o The physician's presence **must** be medically necessary;
> o The physician **must** personally monitor the patient's condition and make medical judgments regarding the patient's needs; and
> o The physician **must** be ready to furnish services as necessary.
> [emphasis in original] Medicare Bulletin Feb. 1986

Two things are of interest here: One is the date of this medicare bulletin which is sent out to physicians whose patients are covered under part B of Medicare. It was sent out in February 1986. It did not come up in the ethics committee until January 1987. What was happening during these months? First, the cardiologist who brought this up had continued to tell patients that they would have stand-by anesthesiologists and cardiologists in the room with them in the event that anything went wrong, that is, they crash.

Second, it provided a way to keep the anesthesiologists in the room if they monitor and make medical judgments and the like. At two area hospitals the anesthetists are putting in intravenous lines, which the nurses had previously performed, and so are charging for that, but this still does not reimburse them to the extent that the original stand-by agreement allowed.

In another hospital the cardiac surgeons are now reviewing the patient's chart for which they can be paid a consultation fee of $125.00 an hour. Those patients covered by other insurance pay the stand-by surgeon $500.00 an hour.

A later memo from HCFA was more specific about what they meant by stand-by:

> In terms of surgery if it does not appear that the physician was involved in direct care of the patient there will be no reimbursement. Unless the patient undergoes by-pass surgery the cardiac surgeon will not be paid.

When the source of the policy was discussed, Weintraub said that the memo was sent out through Blue Cross who handles their financial arrangements. Asked about the rationale of the non-payment for stand-by he said: "Because they're not doing anything. They perform no medical service." Simply being there is not a service of the surgeon. "It essentially entails some people hanging around, anyone could say they were 'standing-by'" (Weintraub 1987). This is in fact the rationale. However, Weintraub (1987) then said:

> Weintraub: On the other hand, if it were me, and I'm going to be facing this one day, I would want somebody competent to be right there.

Weintraub asked if the I knew what various California hospitals were doing about the dilemma and I told him that at two hospitals they were having the anesthesiologists put in the I.V. line, which the nurse had done previously, and they could be paid for that. He thought that was good, but he said that he is more concerned about the surgeons who are "doing nothing."

We talked about the two deaths after discontinuance of stand-by, and the fact that hospitals are having to find different ways of providing a standard of care which is the same for all patients. He wondered aloud if hospitals will pay for stand-by and said "I doubt it."

ANALYSIS

An interesting health care paradox is raised by this policy case. First there is a political and methodological public policy issue which is clearly and directly discriminatory in relation to the patients on medicare. The standard of care is that there be stand-by support available during this procedure, and stand-by must be available for all for whom this procedure is performed. A study at Emory University Hospital where they experimented with no stand-by was devastating (Grunzig et. al. 1984). There is no question in the mind of anyone about the need for stand-by. Several physicians and cardiologists have been interviewed about the need for stand-by and they have been appalled that anyone would think of doing angioplasty without stand-by.

If some physicians are willing to do angioplasty without stand-by because of the expense then the standard of care for this procedure needs to be addressed. Aside from the ethical implications, the legal ramifications of this policy and practice are staggering.

To date the investigator has spoken with ten cardiologists and internists all of whom were stunned to find that stand-by was no longer being paid for by Medicare. None of these physicians have heard of this and it is well over a year since this policy has been in effect. It seems as if the only people who know about the policy have been the anesthetists and the stand-by cardiac surgeons.

THE EROSION OF TRUST

This leads to a final note about the climate in which the policy decision was made. One of the issues that came up in my conversation with the Washington HCFA official is the lack of trust in the people doing the standing-by. This may generally be related to a disaffection with physicians, but it is possible that in this case the distrust may also be associated with some of the history of cardiac care in the United States. Included in this history are the promotion of many types of therapy for chest pain which were subsequently relinquished as absolutely without effect. Some of the more interesting remedies include injections of extract of heart muscle, thyroidectomies, use of radioactive iodine, ligation of the internal mammary artery, epicardial abrasion, and injections of cobra venom (Benson 1979:1424; Beecher 1959; 1961; 1966). There have also been questions of unnecessary angioplasty, coronary by-pass surgery, and certain other types of cardiac surgery (CASS 1983:939).

DISCUSSION AND POSSIBLE SOLUTIONS

Angioplasty may be the operation of choice in a number of cases. Those most likely to have good results are otherwise healthy young men with single vessel disease. These are precisely those for whom non-surgical intervention might also prove most effective. Older persons with more severe occlusions of the coronary arteries are at a much higher risk.

The committee understood that angioplasty may prove lifesaving for some of these patients. However, since they are at such great risk for arterial dissection during the angioplasty they are the patients most in need of stand-by services which under the medicare part B policy is now being denied them. This meant that not only was a medical procedure two tiered by ability to pay, it was also two tiered by age. The risk is at least three times greater for the aged and this risk is again increased for those aged on medicare since if they need emergency bypass surgery the anesthesiologist and cardiologist will not be in the room. It became clear that the public policy decision was not made with full informed knowledge of the issues by all of the participants. In this case the policy change was made because of the high cost of stand-by professionals combined with a concern that these people were, in fact, not earning the money expended. HCFA officials in Washington chose to stop payment for these standby surgeons and anesthetists. It has not been possible to determine who actually made this decision but Weintraub presumed that the committee which generally makes these determinations did so in this case and did so because of distrust of the need for the professionals involved to be present in the room when they were not 'working', that is, not actually 'touching the patient' (Weintraub personal communication 1987).

Once this decision was made, the only way it was communicated to anyone was by way of the monthly medicare bulletin, which goes out to physicians and suppliers who accept Medicare patients, from Blue Shield. It was clear that a number of people who needed to know about this change in policy were not advised. The standard of care is an important concern and the decision to discontinue the support of stand-by services results in a different standard of care for Medicare recipients and a dramatic two-tiered level of care in each operating room. This is unacceptable to the staff of these operating rooms, although they elected to do nothing about it. In order to keep a safe standard of care, some other means to finance stand-by will have to be found, and found before patients die. In the two hospitals in this case it was only after the patients died that hospital officials decided to bear the costs of stand-by.

The important thing about this case is that the ethics committee did nothing. In the minutes of the meeting the following was noted:

> Conclusion: The Medicare issue was not referred to the Medical Ethics Committee but discussed as an interesting dilemma only. Member's consensus is that it is vital for the general medical staff to be informed of the issues involved to retain consistency between the hospital and medical staff.

That is, despite the concern about justice and danger to patients, the committee felt that since the matter was not referred to the committee for advice, they would not offer any. The potential to bring this matter before the medical staff or any other body in the hospital was lost. When interviewed about this, some of physicians said that it would violate the purpose of the committee if they were seen as "watchdogs" or "whistle blowers." A nurse simply stated, "We were not asked to comment." The chair maintained that it was simply an "interesting" situation. Why the committee really did not act in this case was puzzling. It would have seemed to be a perfect situation for the bioethics committee to perform an ethically meaningful intervention or bring to notice this situation which they themselves had interpreted as ethically unsound and dangerous. But they were silent.

CHAPTER SIX: SUMMARY AND CONCLUSIONS

A. MAJOR ISSUES AND PROBLEMS IN BIOETHICS COMMITTEES

There are many enthusiastic supporters of bioethics committees. However, there is no compelling evidence that in fulfilling the main purpose of having a committee, to help resolve difficult ethical issues and clinical dilemmas quickly and efficiently, that this is, indeed, the way these committees function. There are some who wonder if this is, in fact, a reasonable goal for these committees.

EXPECTATION OF THE COMMITTEES

The articles, books and interviews of committee participants have often used the analogy of the consultant in discussing bioethics committee consultations. In the medical consultant model, the expert comes in to see a patient with whom there is some question of diagnosis or treatment possibilities. The consultant spends from 30 minutes to an hour, examines the patient and leaves a consultant's note on the patient's chart with the answer to the question that had been asked on the consultation form. Often the consultant and physician do not meet. This consultant model is one that is congenial to the physicians and may prove to be the way of the future. In one committee, this is already what is being done. They have moved from a full committee case analysis to a sub-committee case consult, to having an individual in each critical area that draws cases to consult. The consultants are for the most part physicians, although there are negotiations to have others on the committee participate. These are handled just as any other medical consult. In three other committees, the sub-committee format is used, but anyone may be on the sub-committee. Not all take part.

PERCEIVED BENEFITS OF THE COMMITTEES

The expected benefits of bioethics committees listed by the participants in the bioethics committees I studied include a number of perceived benefits. It was thought that the bioethics committees would:

- Afford an impartial body to hear, assess, and make suggestions about alternatives and options
- Provide a source of knowledge about ethics
- Assure that the patient an family were represented, respected and optimally participate.
- Would function like peer group prior review of research
- Determines that relevant information has been considered
- Identify the ethical issues, spell out conflicting values, interests, duties at stake, not just legal, professional, or medical.
- Facilitate communication and help resolve disagreements
- Provide support for families and patients by confirming ethical complexity and acceptability of some decisions
- recommend that hospital administration seek recourse to courts when needed
- Help would be welcomed by physicians in complex issues
- Serve as protection from criminal charges. Protect from fear of liability
- Financial sanctions in Baby Doe like cases
- Retrospectively decide that correct decisions are made
- Prospectively decide that correct decisions have been made
- Formulate policy
- Educate the committee and the public

In the committees that I observed the function of bioethics that was best served was that of writing policy. This was stated by each committee to be their least favorite work, but the committees developed very powerful policy statements which were ultimately accepted by the medical staffs in each institution. About half of the committees had educational programs that they felt were satisfactory, but again this was not what they wanted to do. The ambition of each committee was to advise on cases. This became more and more difficult as the requests to hear cases diminished on each committee. Even on the most active committee, the cases tended to become reviews of what an individual physician ethicist brought for review, or patient management problems, which might have been addressed by a number of other groups.

The hope that the bioethics committees would identify the ethical issues, spell out conflicting values, interests, duties at stake, not just legal, professional, or medical was also not met. In several meetings at several hospitals the mantra of bioethical principles was heard but without any meaningful discussion of them. For example:

Ed, M.D Chair: What is the ethical principle here?

Barbara, Ethicist: Autonomy.

Barry: Do we have to keep treating her?

The role of the committee as advocate for the patient or family was not observed, in fact, as I have previously described, this was an area of great silence. I cannot of course speak about all bioethics committees. However, I was struck by the fact that the eight committees that I observed, in general, held fairly pragmatic and conservative discussions based on biomedical perspectives. Some of the bioethics sub-committees did serve to clarify communication and management problems and in that sense were very effective in allowing the participants to come to a solution that all could support. But these were not ethics problems but rather specific problems in communication or management. In fact, it is likely that negotiation and mediation skills would be most helpful to learn in order to deal with the basic issues related to non-concordance. I would suggest that negotiation and mediation skills be among the first strategies learned in the bioethics committees.

The term ethics committee itself may be rendered problematical. This is especially since the work of these committees is not confined to ethical issues. Some physicians that I interviewed argue that such committees should address only medical questions. This wish was present when Health and Human Services (HHS) instead of the name "infant bioethics committees" mandated "infant care review committees," and thus clearly removed all reference to ethical decisions.

Others committee members that I interviewed object to the term ethics committee because of its presumed focus on morals and because of the possibility that the committee will impose its values on the medical staff and the patients whom it is supposed to assist. The committees that I visited are not medical committees as in the prognosis committees that the Quinlan court recommended. That court put significant power in the hands of what they called the "hospital ethics committee" (In re Quinlan 1976 at 671). That committee was specifically charged with making a medical determination that confirmed the attending physician's prognosis that Quinlan would not return to a cognitive, sapient state. This is clearly a medical or clinical function, not an ethical one.

Other benefits which proponents of bioethics committees have asserted include the views of Cranford and Doudera (1984), founders of the bioethics committee movement, who see the committees in a most favorable light. They believe that the:

> ethics committees will satisfy the need for a more systematic and principled approach to the contemporary dilemmas of medical/ethical decision making within our hospitals and long term care facilities.

The President's Commission (1983:160-170) emphasized that good decision making practices were a responsibility of the institution and they felt that bioethics committees were one way to encourage institutions and their staffs to develop good decision making practices.

The department of Health and Human Services said in the final Infant Doe Regulations (DHHS 1983) that although it cannot accept such committees as substitute mechanisms for enforcing Section 504, (49 fed reg 1624) they:

> can be very valuable...in bringing about informed, enlightened and fair decision making regarding these difficult issues.

Cranford and Doudera (1984:10) described another benefit of bioethics committees in that aside from "having a group of interested and knowledgeable health care professionals discuss the case in an open forum" the committee can:

> serve as a link between societal values and the actual developments occurring in the institutions that care for and treat the particular patients whose cases manifest these dilemmas.

The President's Commission (1983:5-6) resolved that health care institutions:

> should adopt clear, explicit, and publicly available policies regarding how and by whom decisions are to be made for patients who lack adequate decision-making capacity.

Cranford and Doudera (1984:13) define the function of consultation and case review:

> by having the ethic committee or its individual members available to discuss the ethical and social concerns of interested parties, and by having the committee provide advice to parties who seek it.

The President's Commission (1983b) provided for a broader case review:

> to ensure that the interests of all parties, especially those of the incapacitated person, have been adequately represented, and that the decision reached lies within the range of permissible alternatives.

But these were not the focus of discussion in the bioethics committees that I observed.

PROBLEMS ANTICIPATED OR PERCEIVED IN BIOETHICS COMMITTEES

In my interviews with bioethics committee members and hospital administration and staff, there was some concern that bioethics committees might:

- Bring inappropriate pressure on competent adults to make particular decisions
- Infringe upon a family's role in decision-making
- Infringe on the rights and responsibilities of professionals
- Become dominated by members of one profession
- Undermine physician authority
- Become liable for the committee recommendations
- Become a hospital advocate
- Simply serve as public relations for the hospital
- Act to justify unpopular decisions
- Act as a vehicle for risk management
- Become too powerful
- Have different values from patients
- Violate patient's confidentiality
- Violate the patient's right of due process
- Be burdened by a lack of clinical knowledge of its members
- Diffuse responsibility widely no accountability or authority.
- Make decisions in a time bound manner
- Since acting in private, not have accountability for its decisions

Veatch (1984) analyzed ethical principles that may be adopted by bioethics committees and argued that the variety of tasks may "create real, probably insurmountable problems" for many committees.

PHYSICIAN - NURSE TENSION

One issue that I propose to examine in future research is that of the tension between the views of physicians and nurses. I am preparing a research proposal to examine the patterns of conflict and compromise in physician nurse interaction on the committees. For now, I can say that the view of these two professional often diverge. The divergence is occasionally related to the nurse's knowing the patient and spending time with them and the physicians on the committee not having met the patient or, in the case of the presenting physician, knowing the patient and family in a different way than the nurse knows them. It may also relate to the nurse's "expert knowledge" about the limits of medicine and treating persons with specific conditions. It does not have to do with stopping treatment or continuing treatment per se, for individual nurses and physician will agree or disagree about either, depending on the case.

Cranford and Doudera (1984:10) noted the importance of having the bioethics committees as a:

> multi disciplinary forum is evidenced by the overwhelmingly one-sided comments of nurses on the proposed Infant Doe regulations promulgated July 5, 1983 (49 fed reg at 1623). Of these nurses, 97.5 percent favored the proposed rule. This may be due to their feeling that they have nowhere to go when confronted by ethical dilemmas, and that the regulations provide an arena for action.

This is a key issue and well documented in my data.

COST ISSUES

Should cost be a consideration in health care decision making and if so to what extent or how and when should that discussion take place? Joanne Lynn M.D. (1984) thinks that bioethics committees may provide the necessary responsive forum for resolving this dilemma. A medical policy committee of Blue Cross-Blue Shield of California has recommended that all of its participating hospitals adopt bioethics committees (San Francisco Chronicle 12 February 1983). This may have been in response to allegations that cost containment had been a motivation in the case of Drs. Barber and Nedjl in stopping treatment on Clarence Herbert, a patient at the largest HMO in the United States (Barber and Nejdl v the Superior Court of the State of California 1983). Cranford and Doudera (1984:10) said:

> Allegations of improper concern about cost will impair the trust and confidence that patients and families have in health care professionals, and we need to develop some means for maintaining trust and confidence in the decision-making abilities of doctors and nurses. In addition, we have to ensure that the rights of individuals, as well as societal interests, are protected. Lastly, we must adopt procedures for principled and open decision making. Ethics committees can serve an important role in fulfilling these needs.

But it is the cost issue that repeatedly comes up in the committee deliberations. As long as the traditional contract with the physician and nurse with the patient is not specifically changed, the responsibility is that the health care professional do what is best for the patient. There is a moral ordering taking place in this area, but it is private and secret.

One committee is considering having a second bioethics committee to deal specifically with allocation issues and economics. They plan to prepare some policy papers on this.

> Sam, M.D.: I'm just sitting here and uh - I'm trying to understand how we got to this point - not just him. We have reached a point where so much energy, ethically and thought, to say take me off this - stop doing this. Not in all states but as a nation and this state. We have painted ourselves into a corner. We are so concerned about the slippery slope that we don't take ethical or medical responsibility that we say. "Yes, we'll take a step on the slippery slope." We can't allow decisions to be made by people with emotional interests where there is a 0.5% chance that we're really doing anything for the patient. Our role has changed from allowing a patient to die. We are faced with this in dialysis - the way we are dealing with medical care and allocation of resources.
>
> Ed, M.D.: This situation is disgraceful. That we are spending this level of resources on a person like this. It reflects a terrible tunnel vision. While huge segments of the world and the nation's population are unable to obtain simple care for simple diseases that are curable, we are doing everything in our technical resources for people for whom treatment is futile.
>
> **Bill, M.D. Chair: In the current legal climate we're stuck. Should we form a parallel group that could discuss these issues and take the discussion away from individual care?**
>
> Ben, M.D.: The ethics committee at Mass general discussed DNR orders for the whole hospital.
>
> Bill, M.D.: There are dangers to discussing on particular individual case. Everyone is starting to discuss on larger hospital policy situation.

Ed, M.D.: The hospital has an obligation to the larger society to dispense our facilities equitably. We need to be talking about all of our resources.

Ben, M.D.: It is inevitable. It's going to come.

Bill, M.D.: We could discuss the same issues, with the same people, but not as the ethics committee.

Ed: What a mess.

Bill: As I hear it, the trump card, is watch out you don't get accused of murder. Another group - not ethics committee should discuss. The issues are so burning - another group - call it what you want, to discuss these issues. Costs hospital a bundle.

Joseph, M.D.: It will be. It will grow out of cost containment to multi-disciplinary group.

Bill: It should be ethics based, not money.

Joseph, M.D.: Quality, ethics and money. Three points of a triangle: quality, ethics, money.

Bill: **Ethics should be the engine. should drive it.**

Visiting md: ethics first

Sam, M.D.: Wonder what fuel should be used.

The level of discussion that moves the ethics committee from discussions of individual patients to discussions of broader policy issues is made explicit in this committee. Their solution is to form another committee to deal with more macro issues.

DEATH DEFINITION AND DNR

Cranford and Doudera (1984:11) note that one function that bioethics committees may serve is to:

> help us to distinguish between those ethical dilemmas where a consensus seems to exist and those where no consensus seems achievable, at least in the foreseeable future.

They give as examples the definition of death:

> for example, in this decade we have moved toward a consensus that the death of the brain is the death of the individual....The ethic committee could help educate

> medical staff members and families about this trend and aid them in recognizing and accepting the standard of brain death.

Cranford and Doudera (1984:11) point to another area where consensus is beginning to develop is the:

> appropriateness of written resuscitation and non resuscitation policies. A decade ago, few hospitals had any form of "no-code" or do-not-resuscitate" (DNR) policies in place....A multi disciplinary ethics committee could help health care practitioners feel more secure about the appropriateness of their decisions and help assure patients of their rights.

Where there is no consensus is in the issue of treatment for handicapped newborns and providing fluids and nutrition to the hopelessly ill. Acknowledging areas of agreement and disagreement may prove helpful, but what to do when there is serious and basic disagreement may not be solved in bioethics committee deliberations, and it is the hard questions that find little solution.

B. ENLARGEMENT OF BIOETHICS COMMITTEE INFLUENCE

POLICY IMPLICATIONS OF BIOETHICS AND BIOETHICS COMMITTEES

From the political President's Commissions to local hospital ethics committees to the State and County ethics committees for health care decisions, the committee process has structured much of the debate in bioethics. That these committees are political seems clear. That they are engaging in moral ordering should become clear.

Bioethics decisions have developed as pivotal political themes. Although there has been a move to minimize the role of government in private lives and in delivering a number of services, bioethics increasingly has entered the domain of the political process. The sociopolitical implications of developments in medicine and biomedical technologies have opened the way for political public concern. The President's Commission (1983b:105) discussed the political basis of bioethics decisions and concluded:

> it should be clear that all such decisions finally rest on a political basis and that the entire American electorate has a legitimate stake in both the procedures by which

> the decisions are made, and in the steps that are taken to monitor and control the consequences.

There are several reasons that the whole topic of bioethics decisions have been brought into the public arena. One has been the dramatic value controversies brought about by the technologic challenges to our notions of life and death, of individual need and public cost. Notions of what it is to be a human, when is someone alive, the psychological and pharmacological manipulation of humans, state control, potential harm to future generations, and "playing god," have all become themes in popular discourse. There are medical, legal, ethical and political questions surrounding issues of informed consent and refusal, due process, and privacy. Along with the potential perils there are also great promises engendered by these same technologies and processes. Another factor that adds to politics becoming involved in bioethical decision making is the power of interest which compete to have certain issues solved in a political arena. The lobbying power of special interest is a force to be reckoned with in bioethics. From the group lobbying for care for those needing kidney dialysis to interest such as feminists, the right to life , the right to die , and disease oriented , these all play a powerful role in bioethics.

EXPANDED ROLE OF THE GOVERNMENT

Until the mid 1960s, the American Medical Association had been successful for the most part in keeping government out of financing care for the sick. Leaders in government recognized that support of ventures related to health were favored by the public, they voted more funds for research initially. As medical technology advanced, more and more of what received funding was what Lewis Thomas (1972) called "half-way technology." Patients began to expect more from biomedical technology and their physicians and if they did not get what they expected sued in court more and more. As costs escalated, the government again entered to pay the costs for an increasing amount of care with Medicare and Medicaid. By this time those providing health care in hospitals and those in the profession of medicine were troubled by severe economic problems and by concerns about the fundamental purposes of medicine and how much should be spent to support health care or even life itself. As Raymond Duff (1984:203) pointed out, neither hospitals nor physicians had a:

> tradition of consistently turning to their clients for help in resolving vexing questions...usually they did what bureaucracies do best: continue operations as usual, avoid facing the problems as long as possible, and finally, if nothing else works, appoint a committee to study the problems.

The role of government in public life continues to expand despite a general lack of success in its intervention. As medical costs have escalated the government has assumed a larger proportion of these costs which allows government entree into health care matters. The needs for assessment and evaluation of biomedicine as well as accountability for funding and results of it become more important as costs increase. The need for public debate seems obvious since it is public money that is being spent. Biomedical policy decisions about allocation of funds and other resources are currently being made within a very narrow political context.

LEGISLATIVE PROCESSES

Congress has been slow to recognize and act on policy problems. The process itself depends on negotiations, bargaining and compromising to build majorities at every stage. The policy problems now, of those dealing with bioethics, are quite different from many of the issues being dealt with by those in congress. These issues deal with allocation of money, but also constitute complex ethical and moral components which have traditionally been avoided. The focus has been on immediate problems, not long on range planning partly due to the short term perspective of members of congress. The fragmentation of power in congress and in United State's political system into a committee system has as part of its rationale to distribute labor and minimize workload while maximizing skill but this loses the focus needed to garner focused public concern for a specific issue. Congress passed specific pieces of legislation in the 1970s that dealt with bioethical concerns but it has never produced a comprehensive biomedical policy or assessed the implications of the issues.

While there has been limited congressional action in most areas of bioethics, State legislatures are responsible for legislating matters of the public's health. Few states have established internal mechanisms for dealing with controversial and technological bioethics problems.
The variance across states in terms of capability, will, and generosity, leads to tremendous inequalities and inconsistencies in the quality and content of health legislation.

THE ROLE OF THE COURTS: LEGAL CASES

The role of the courts is to help resolve conflicts that have to do with individual rights and obligations that come before it in a specific case. Case by case adjudication by a number of state and federal courts has added to decisions that are narrowly decided and do not add to the broad public policy need. The court is not in a helpful place to make bioethical decisions. Judges are seldom experts in technologically oriented cases and so depend on expert testimony from "experts" willing to testify on every side of an issue. The judicial process is a passive and retrospective one and too slow to be of help in prospective or current cases.

However, when the courts do speak, they have enormous force, one has only to think of Roe v. Wade (1973). At a symbolic level the courts have a role as catalyst for necessary changes in the system. The law can dramatize injustice and focus attention of legislative and executive attention to areas needing attention.

The most sensitive bioethical issues ultimately will be tested in the Supreme Court. This creates problems because all that the United States Supreme Court can decide is whether an act is constitutional or not. It cannot at all decide on its moral or ethical "rightness." As in the case of Nancy Cruzan, all the Supreme Court could actually decide was whether the State of Missouri could make the decision not to remove Nancy Cruzan's feeding tube. The appropriateness of removing the tube was irrelevant to the supreme court justices for their charge was only the constitutionality of the issue.

AD HOC-ERY

National Commissions and other advisory are temporary and usually created when specific problems reach national attention, that is when an event becomes identified as a social problem or when public officials believe that their creation is politically warranted. Commissions can act as a safety valve to reduce public pressure for immediate legislation until the issue becomes less salient. They can also be used to direct attention to an area of concern and define the boundaries of an issue. The ultimate influence of an ad hoc committee depends on the perceptions of the officials who commissioned it, the composition of its membership, and the response of the policy makers to its findings. The President's Commission, for example, was seen as successful by some, such as Albert Jonsen and Yesley (1980), and not so by George Annas (1980). Findings of commissions are only advisory and not binding at any stage in the policy process. Unlike permanent political institutions, ad hoc bodies have no policy making capability. They simply recommend. Their tenure is specified by statute, usually four years, and thus they cannot provide successive review and evaluation. Commissions give the impression of providing final and comprehensive studies of a problem, but it seems that a permanent body is needed to update the quickly changing definitions and extant issues.

THE PUBLIC

The two major positions involving government involvement in biomedical issues include the concern that government not become involved in matters seen as personal to those believing that some government control is necessary. There are those who disapprove of imposing public controls over biomedical research and use (Fletcher 1974), others (Chorover 1979) are fearful of the potential use of new technologies for "social control." Some ask that the government prohibit certain types of biomedical application (Ramsey 1975). There have been several moratoria on fetal research (Curran 1975) reproductive research, artificial hearts, and in vivo fertilization. There have been calls for government to prohibit biomedical research such as the recombinant DNA research (Cohen

1977) but these are generally challenged as violating free scientific inquiry. One form of governmental action is the establishing of compulsory biomedical policies which are usually defended on public health or economic grounds.

There may be a need for those in the political system as a whole to consider fundamental questions concerning the meaning of human existence, conceptions of justice, and the proper ends of government. We do not have long range national goals with broad community objectives that have the potential to reach at least a minimal consensus with meaningful priorities. We have yet to define realistic goals that reflect the complex moral and political dimensions of the United States nor have we been able to establish a public agenda to meet these goals.

As early as 1973 Amatai Etzioni suggested a two tiered approach which would combine the creation of a permanent national commission "charged with formulating alternative guidelines for public policy" with a "myriad of local review boards" to review individual decisions and deal with specific problems. National commissions with expanded community input and discussions of goals and priorities might be helpful in this. The President's Commission was different from some ad hoc mechanisms as it was given limited jurisdiction over all federal agencies. However, its recommendations were non-binding.

1. CASE STUDY: OREGON HEALTH CARE DECISIONS

A current attempt to introduce some sort of reform into medical care cost structures is Oregon's controversial attempt to rank Medicare funding priorities with immunizations, prenatal care, inpatient psychiatric care, and the diagnosis and treatment of acute illnesses at the top of the list and organ transplants at the bottom. This attempt, whatever one thinks of the ethics of it entails considerations other than chronological age as a basis for health care rationing. In light of the perception of there being a lack of public accountability for issue in health care and to answer the question of how medical decisions can be made accountable to society state and county bioethics committees have been tried.

Oregon, recovering from the early 1980s recession is one of the few states in which voters have approved limits to state revenues and expenditures. In 1983-1984 some 5,000 people attended a series of small group and "town hall" meetings held in Oregon to elicit public views about various ethical dilemmas in health care. The local meetings culminated in a statewide "Citizens Health Care Parliament," which passed thirty-five resolutions addressing the issues raised. The consensus was that "Society must decide what should be the adequate level of health care it will guarantee to all its members" (Crawshaw, et al. 1985:3213; Hines 1986:5-7). Within the framework of a constitutional mandate requiring a balanced budget, the legislature hoped to improve access to basic health care for low income Oregonians in 1987 to 1989 (Welch and Larson 1988:171). In the spring of 1987, the joint ways and means committee of the Oregon legislature was facing a "tragic choice." The division of adult and family services, and administrators of the state Medicaid program met to discuss the options for the next two years. Medicaid could either extend its funding for basic health care to include about 1,500 persons not covered previously, or continue to fund a program of organ transplantation, bone marrow, heart, liver, and pancreas, for a projected 34 patients. The division advocated the basic health care option and the committee concurred with little discussion and no public debate, on 1 June, 1987, the Joint Ways and Means Committee unanimously voted to discontinue coverage for organ transplants. The committee substituted expanded coverage of basic medical services for low income children and pregnant women. Both the Oregon House and senate approved the budget proposal (45-7 and 19 to 3). Governor Neil Goldschmidt signed the bill into law saying:

> We all hate it, but we can't walk away from this issue any more. It goes way beyond transplants. How can we spend every nickel in support of a few people when thousands never see a doctor or eat a decent meal? (Specter 1988:1).

In 1988, the Oregon legislature affirmed that administrative decision that the State's Medicaid program should no longer cover heart, liver, bone marrow, and pancreas transplants. These procedures cost on average $150,000 each for what were projected to be thirty recipients per year. These treatments were considered financially unsustainable, in comparison with the cost of prenatal care for the 1,500 women who could be funded in place of the transplants (Specter 1988; Kitzhaber 1988).

The president of the Oregon Senate was a physician who said: "If we pay for transplants now, we will put a very small Band-aid on a very large iceberg" (Specter 1988). He was subsequently called Dr. Death by the press. The rationing of health care faced by Oregon senators presented a number of moral difficulties. One senator (Specter 1988) said:

> How does one treat the individual who gets tragically cut by a policy that seems best for all. If economic efficiency leads us to choose a particular policy, the conflict lies between individual patient and the socially efficient use of resources.

Initially, there was little media coverage, but in 1987, the cases of two adults who were denied transplants were reported in the news. In November, a seven year old boy with acute lymphocytic leukemia was denied a bone marrow transplant and his death in December elicited nationwide reaction. Headlines in The Washington Post read: "Rising Cost of Medical Treatment Forces Oregon to "Play God." And in The New York Times: Oregon Cut in Transplant Aid Spurs Victim to Turn Actor to Avert Death. The young boy had appeared on television to raise private funds which, in fact, raised three quarters of the funds required by the marrow transplantation facility.

In 1989 the Oregon Legislature passed a number of statutes that expanded access to care by broadening eligibility to Medicaid, created incentives to businesses to provide health insurance, and created an insurance pool to cover those now 'uninsurable' because of preexisting health conditions (Garland and Hasnain 1990:16):

> The law also created a process whereby health care priorities will be established so that Medicaid and state encouraged private coverage can provide the most cost effective and beneficial forms of care for the greatest number of people.

Scores of community leaders received crash training in bioethics and then fanned out to lead discussions in hundreds of small community meetings. Church , local medical and bar associations, senior citizen organizations, parent teacher associations, and high school classes. Discussions took place in places from Rotary lunches to meetings in individual living rooms. An introductory film presented several real life cases and then for a few hours the exchange personal experiences and points of view. Finally participants filled out a questionnaire with a dozen or more specific questions. At the end of the year there was a statewide Parliament where 150-200 representatives from the various discussion tried to synthesize what they have learned and came up with recommendations.

By 1988 more than 10,000 Coloradans had filled out an 8 page 31 question survey. Oregon Health Care Decisions, a nonprofit citizens group, scheduled 13 town hall meetings around the state to find out how Oregonians wanted their tax dollars spent on health care. One of the specific questions: When Medicaid funds are so limited, should priority go to prenatal care or to organ transplants for the poor?

In another state, The New Jersey Citizens Committee on Biomedical Ethics worked with local colleges to develop continuing education courses that explored such dilemmas as how far to go in treating severely impaired newborns or trying to keep very ill old people alive.

In California, California Health Decisions holds regular workshops instructing Californians in using the state's durable power of attorney law allowing them to designate someone to make critical health care decisions for them if they become unconscious or otherwise incompetent. Over 2,100 Orange county men and women attending meetings conducted by California Health Decisions filled out questionnaires on health care spending and bioethical issues.

One question:

> If a close relative is in a coma and not expected to recover, I should have the right to direct the doctors to withhold artificial feeding.
>
> agree 71%　　disagree 13%
> Not sure 14%　　No answer 2%

In a number of states, grass roots are trying to raise public consciousness and begin to develop a community consensus about life and death ethical and economic choices.

It is an attempt to shape health policy and bioethics from the bottom up based on informed public consent. Among the group's recommendations were increased funding for research on disease prevention, better coverage for the medically needy, and allocation of medical resources according to a definition of "adequate health care" developed through widespread public participation. This effort attracted national attention, and in 1985 similar projects were launched in six other states. Leaders of these projects view them as part of a growing movement founded on grass roots involvement in health policy.

2. ALAMEDA HEALTH CARE: RATIONING HEALTH CARE

In 1989 it was reported in the New York Times that (Gross, Jane. March 26:1 NYT):

> The state of Oregon and the county of Alameda in California have become the first governments in the nation to plan explicit rationing of health care for the poor.

For the first time, choices were being made, and lists drawn up, ranking medical procedures from the most effective to the least.

> Oregon has decided, for instance that prenatal care for a woman ranks higher than an organ transplant for a dying child; that the elderly need bunions removed before teenagers are taught the dangers of drug abuse; that having a single physician supervise a patient's care is vital and dental work is not. When the lists are complete, health officials will know exactly where to draw the line when they run our of money (Gross 1989:1).

Dr. John Kitzhaber, president of the Oregon Senate said:

> Although we prefer not to recognize it, we do ration health care in this country. But that rationing is enormously inequitable and not based on any consistent social policy or sound clinical criteria (Gross 1989:1).

In Oakland the first meeting of the Alameda ethic committee met for the first time (San Francisco Chronicle 18 April Tuesday 1989). At the first meeting, the panelists appointed to make recommendations about rationing health care services. Dr. Slaughter, Director of mental health for the West Oakland health center, said:

> Dr. Isaac Slaughter: I don't know if I think its a good idea. It seems to be a foregone conclusion that what we're about is rationing of health care, as if there is no other possibility. I thought we were going to come together to talk about other possibilities.

The ethics committee was constructed so that there was already an assumption of rationing. The charge became how to decide who gets the drastically limited money. The people chosen to be on this committee had their own constituencies and were not citizens deciding behind a veil of ignorance in Rawls' (1971) sense, but were, as one participant told me "sharks put in a pool with one carcass to fight over."

Rather than deal with the politics of getting more money from Sacramento when Alameda has such a drug problem that many of the health problems are related to it: AIDs, infant deaths, injuries from assault weapons" (NYT 3/26 1989), the problems were moved out of the political arena and into an ethical one. It tried to make an economic and political issue a moral one so that economic matters would be prioritized by ethicists and health care workers, rather than solving the problem of insufficient funding by the state.

Five focus were to decide which county residents should benefit from services offered by the department's $290 million budget. Most of the people who use the county medical services are poor. Fifty experts were selected who then met at Fairmont Hospital for a briefing with county health director David Kears and John Galenski, a medical ethicist, and Jesuit priest hired by the county for $6,000.00. There were pickets and critics of the plan outside. The plan was denounced by a coalition of health care advocates on the grounds that it would further short change the poor. The health care advocates, and many who sat on the committee, petitioned for a process for the entire county budget, not just health service funds, which was denied.

The committee of 50 health care professionals and county health officials met to set priorities for county health services (Valley Times 18 april 1989.) They identified, in effect, which programs could be reduced or eliminated when county supervisors draw up next years budget that summer. Their charge was, how best to spend a limited amount of money as noted by Health care director Dave Kears. Committee member Joel Garcia said that the "social ethics" of inadequate health care were what need examination.

In the 1989 Executive summary it was noted that:

> Alameda count adopted a prioritization process similar to that used by the state of Oregon to reflect the manner in which the County health care system is organized and the fact that it provides care, and not just pay for it.
>
> The process called for five focus , representing the primary service components of alcohol and drug, community health services (non-hospital based primary care and public health), mental health, Fairmont hospital acute medical,

> rehabilitation and skilled nursing care, and highland general hospital emergency, trauma and acute medical services.
>
> Participants were selected by respective department heads from a pool of prominent health care advocates, clinicians, and administrators in the community. Every effort was made to ensure representation by sex, ethnicity, area of expertise and geography.
>
> The tasks of each focus group were to list the health care needs of people served by Alameda county, outline the services provided as well as the needs not met, assess better ways to respond to the needs of target populations, and prioritize services and populations, where appropriate. The ten member focus each met twice for all day sessions, with a week between sessions. The committee will explicitly prioritize health services, if the federal government agrees.

In the end, the task could not be achieved. There was little agreement on priorities, but more serious was the inability of the participant to further cut services to the elderly and poor because of a deficient budget. Father Galenski said that the task was hopeless and the committee disbanded. When asked why he had agreed to head this committee when it was so clearly a political maneuver and impossible task, he replied: "I was told how difficult the situation was but I could not believe it."

Here is a case where local government attempted to subvert its responsibility to care for its sick and provide health care by trying to use an ethics committee as did the State legislature in Oregon. The prioritization process was just for Medicaid benefits and so were seen as unfair, unjust and placed too much burden on the poor. The process merely tinkers with a fundamentally defective system that requires complete restructuring said radical critics. Technical critics argued that health care services are too complex to be prioritized with scientific validity.

NEW ROLES FOR ETHICS COMMITTEES

Ethics committees have been voluntary in all states but one up to now. The Patient Self-Determination Act, recently before the Senate Finance Committee would have mandated the formation of ethics committees in all states in health care institutions that qualify for Medicare or Medicaid funding. The main aim of the Act was to require institutions to give adult patients an opportunity to learn about and use advance directives to indicate their wishes about life-sustaining treatment and to appoint surrogates in the event they are unable to make health care decisions for themselves. However, it also gave ethics committees a broad charge. They were to "initiate educational programs on ethical issues in health care, to advise on particular cases, and to serve as a forum for such issues"

How is it that there is a move to mandate ethics committees through federal law? The patient self determination act is especially important since Cruzan.

The bill required an ethics committee in each of the facilities to which it applies. In some states, Virginia eg, only 30% of hospitals have a functioning ethics committee (Fletcher 1990:34) The 1983 President's Commission commended institutional ethics committees as one way of carrying out the imperative to respect the competent patient's choices in a context of "shared decision making." It did not recommend that every hospital have one - in part because of lack of experience with such . Today, in 1991 there is still very little information and empirical research about such committees and yet we were on the verge of a federal mandate that all hospitals create them. Capron (1990:36) holds that ethics committees are still too new to be mandated by law. One state has done so but the results of the experiment and indeed our whole experience with the committees have not been carefully scrutinized. As with the human research committees - IRBS - we are dealing with a system that has been built largely by the enthusiasm of a few prophets, each with his or her own vision of the role, process, and make-up of the ideal committee.

As cost containment strategies and policies continue, Cohen (1989:6) views ethics committees as the "conscience" of their institutions who will have to speak out. This is, in fact, where I see problems. As with the angioplasty case, the conscience of the committees is largely silent.

FROM QUINLAN TO CRUZAN

On 25 June 1990, the United State Supreme Court handed down its opinion in the first case of termination of medical treatment case to come before the court, Cruzan v. Director, Missouri Department of health. In a five to four decision, the court affirmed the Missouri Supreme Court's refusal decision not to accede to Nancy Cruzan's parents' Joe and Joyce Cruzan request to have a gastrostomy tube removed from their daughter Nancy Cruzan, who has been in a persistent vegetative state since an auto accident in 1983.

The United States Supreme Court's ruling in Cruzan has deepened the debate over who shall decide and have the authority to make medical treatment decisions for incompetent patients. The court was not making a decision about what ought to be done for Nancy Cruzan, it simply decided whether Missouri's law, as expressed in the Cruzan case, was permitted by the United States Constitution. That is, it addressed only the authority of the state in the refusal of medical treatment. The case, was decided closely, as had been the vote in the Missouri Supreme Court. Five of the justices voted to uphold the Missouri Supreme Court's order that treatment be continued for Nancy Cruzan; four voted against. The United States Supreme Court held that the regulation of medical treatment decisions for incompetent patients is largely a matter for the states to decide. The United States Supreme Court actually only addressed the authority of state government in the refusal of medical treatment. The majority held that it was likely to consider a wide range of state laws constitutionally valid. The decision upheld the fact that before Cruzan state courts and legislatures were the primary source of law on refusal of treatment.

The United States Supreme Court did not uphold the Missouri Supreme Court's majority opinion entirely. The Missouri opinion had all but denied the competent person's right to refuse medical treatment. The United States Supreme Court justices - eight of the nine - recognized that the Constitution protects the right to refuse medical treatment. The United States Supreme Court's majority opinion written by William Rehnquist states that a competent person has a "constitutionally protected liberty interest in refusing unwanted medical treatment" (Cruzan v. Director, 1990]. This liberty interest, said Rehnquist, has been recognized in prior Supreme Court opinions dating from early in this century. Rehnquist also "assumed" that a competent person has a constitutionally protected right to refuse "lifesaving hydration and nutrition." Rehnquist stated this as an assumption, rather that a holding or rule, because the particular case before the court did not involve a competent patient. In discussing Cruzan's circumstances, Rehnquist stated that the due process clause of the Constitution protects both life and the ability to refuse life-sustaining medical treatment. He analyzed the constitutionality of the Missouri's requirement of clear and convincing evidence in the context of this constitutional interest. In Cruzan, as in a number of other cases heard in the past two years, the United States Supreme Court has recognized as a "liberty interest" a claimed right that previously has been identified as a right to privacy (eg Webster v Reproductive Health Services 1989). This is an important distinction between the older right to privacy much argued against especially after Roe v Wade, and a liberty interest which allows the individual's right to be balanced or weighed against the interests claimed by the state. As in Quinlan, the interest of Karen Quinlan and her parents against the State's interest in preserving life.

In earlier cases involving rights to privacy, the supreme court disclaimed the state restriction unless the state could provide a compelling interest in restricting the behavior - even then, the power of the state could be limited. In more recent cases the right to liberty interest used a different standard. The state's interest must be legitimate and reasonable. That is, if the state has a legitimate interest, it may be successful in defending a state law against a constitutional challenge. One of the key elements of the Cruzan case was the holding of the United States Supreme Court that Missouri's requirement of clear and compelling evidence of the incompetent patient's choice was constitutionally permissible in advancing legitimate states interests.

What is important and what distinguishes the use of the clear and compelling interest standard from other states is that in its requirement of clear and compelling evidence of the formerly competent patient's choice, they excluded alternative grounds for decision making such as substituted judgement or best interests. The United States Supreme Court specifically rejected the argument that the Constitution protects family members' right to make medical treatment decisions

THE ETHICAL FRAMEWORK OF THE CRUZAN DECISION

But what actually was the ethical framework of the Cruzan decision written by Chief Justice Rehnquist, the concurring opinions of Justices Day and Scalia, and the dissenting opinions of

Brennan and Stevens? The opinions allude to preservation of life, state interests, quality of life, substituted judgement, best-interest standard, surrogate decision makers, family and professional roles and responsibilities, sanctity of life, and protection of the weak and vulnerable. However, there was no clear ethical framework to support the discourse which is filled with medical and legal jargon like all of the ethic committee decisions. The Cruzan decision did not clarify the ethical basis for public policy questions surrounding death and dying or feeding and non-feeding. The ruling had significance in terms of the rights of competent patients to control their dying and its classification of tube feeding and other artificial treatment devices as a form of medical treatment. However, it was unclear about the role of proxy decision makers, the bindingness of advance directives, and the status of patients who were never competent. These are issues constantly dealt with in the local bioethics committees, and will continue to remain problematic.

The Cruzan case continues the problem that the local bioethics committees encounter in that it draws a distinction between initially withholding a medical treatment and later withdrawing it. As lawyer Colby put it (1990:5):

> In Missouri, once a family member provides the initial consent to a medical treatment for an unconscious loved one like Nancy Cruzan, the family member at that point forever forfeits all power to undo that consent or to stop treatment. No other state has such a law.

Once treatment is started for an incompetent patient in Missouri, the physician and family lose any role in making the decision. The treatment can only be stopped if it causes pain, which is considered impossible for a person in a persistent vegetative state (PVC), or if the patient left behind clear and convincing evidence of his or her wishes prior to incompetency. The United States Supreme Court only ruled that the United States Constitution does not expressly prohibit Missouri from erecting this procedural barrier.

It is clear, at this point, that neither the bioethics discipline, nor the courts, have any better clues to offer about what to do in cases where there is little concurrence.

V. DISCUSSION

Bioethics committees are both embedded within and take their intellectual and moral direction from the emergent discipline of bioethics. Bioethics is a theoretical and clinical discipline constructed in the 1960s by professionals from several fields, coalescing an older medical ethics with a theoretical philosophical ethics and law. It was created by new professionals, who became known as bioethicists, who built centers, generated an encyclopedia, literature, and conferences, and developed new clinical practice arenas, the bioethics committees.

The theoretical foundation of the constructions and contexts of bioethics allowed me to demonstrate:

- that bioethics is best conceptualized as an issue in the sociology of knowledge,
- that the conditions under which a social problem is constructed or de-constructed has its basis in knowledge and legitimation,
- that the disciplinary emergence of bioethics was an attempt to deal with developing problems of justice,
- that decisions in ethics both at the policy level and at the local committee level are based upon a process of moral ordering, and,
- that in the deliberations of moral ordering in health care, one discipline's knowledge, beliefs, and paradigm prevailed.

Moral ordering involves processes of negotiating, coercing, and otherwise dealing with definitions and re-definitions of that portion of the social order called the moral order. The processes of moral ordering affect issues which are defined by its participants as moral. I showed how the broader society became interested in the specific moral ordering focused on in this work as bioethics and how an interest in justice was involved in the origin and practice of bioethics. I described the wedges which allowed the federal government, and other professions, to make incursions into the boundaries of medicine in terms of these issues in ethics.

I described the move of bioethics into a larger policy arena: community based bioethics committees and showed how these committees, in particular counties and states such as Alameda, California and Oregon and Washington, consider health decisions in larger arenas, making allocation decisions that involve politics, economics, and policy. My concern was that these committees, along with the hospital bioethics committees, since they are strategically placed to make health care decisions about justice, in particular, the allocation of resources deserve attention. It was that potential, until now unexamined, that prompted my sociological concern with bioethics committees in 1986 and which continues today. The findings of my research indicate that my concerns were well placed. The Patient Self-Determination Act, came close to mandating the formation of ethics committees in all states in health care institutions that qualify for Medicare or Medicaid funding (S-1766 Patient Self-Determination Bill, 1989, 1990). The main aim of the Act was to require institutions to give adult patients an opportunity to learn about and use advance directives to indicate their wishes about life-sustaining treatment and to appoint surrogates in the event they were unable to make health care decisions for themselves. However, it would also have given ethics committees a broad charge. They are to "initiate educational programs on ethical issues in health care, to advise on particular cases, and to serve as a forum for such issues." This section of the bill was strongly opposed by the American Medical Association and the American Hospital Association. In a compromise, it was left out of the final bill in return for general support for the patient self-determination bill. It would have been distressing to have had federally mandated bioethics committees in local hospitals when there is still very little information and empirical research about such committees. My research indicates, that there are questions to be raised, and issues to be more broadly discussed before accepting as solutions to ethical dilemmas, institutional bioethics committees. This dissertation provides some research that may raise questions to be answered before mandating these committees and allow a more informed consent or refusal about these and other policy recommendations.

Throughout this dissertation, we saw the following:

- There is a division of labor in moral ordering such that one discipline's knowledge and beliefs can trump another.
- The division of labor will remain intact, that is, physicians will continue to be primary decision makers and nurses and others would fundamentally contribute data.
- The use of the medical model renders bioethics decisions continually framed in a medical discourse rather than an ethical or social one.
- The power of the medical model will inform and dominate decisions without much loss of influence from the participation of "outsiders."
- The committees will, in fact, sustain medical hegemony.
- Legal concerns will strongly inform the decisions but be incorporated as medical decisions.
- Ethical discussions and formulations would act primarily to sustain medical ones.

One basic and essentially unquestioned assumption of bioethics which has emerged in this research is the primacy of the biomedical model. In the emergence of the bioethics discipline, and reflected in the discussions of the hospital bioethics committees, considerations of issues through the lens of a biomedical perspective forms the basis of moral ordering and consequently attempts to solve questions involving medicine and what are essentially social or ethical problems.

I found two major difficulties in the development of the discipline and practice of bioethics. One was the use of the biomedical model to engage in moral ordering to solve what are essentially social problems; the second was contextual. The discursive practices in bioethics occur among multiple worlds and represent at least four intersecting domains: the clinical work worlds of the medical professional, the theoretical worlds of philosophical ethics and law, and the lived world of the patient. The narratives varied in their affinity for technology, principles, legal processes and personal experience. None were incorrect in that they did not fail the test of reason, but they were different and often in conflict.

In bioethics today there is no single normative, accepted, or fixed moral order but instead a moral ordering and re-ordering about who is a person, what is an acceptable or unacceptable quality of life, when is a person dead, and when shall we withhold or withdraw treatment. Many of these decisions are clearly social and ethical and not exclusively medical ones which can be made only by physicians. The narratives of clinical medicine and cure, ethics and justice, law and what is legal, economics and cost, and the desires of the patient, at times intersect, at times do not. Medicine is in a sense the executive branch, "I am in charge, I will do it". There has emerged a judicial branch, of ethics and law, which then comment on what it is that the physician does. But it is always ex post facto. In all of this, I have found the invisibility of the patient to be profound.

The early developments in bioethics began, at least in part, as responses to the unnecessary and dangerous research revealed in the Nuremberg trials, articles revealing dangerous research in the United States (Beecher 1966) and to concerns about conflicts of interest which arose with the human heart transplants. What the discipline of bioethics represents is a body which engages in moral ordering, but it is an ordering primarily based on biomedical assumptions. It has been possible to produce new knowledge - bioethics - and new practice - bioethics committees - and inculcate the vocabularies and <u>selected</u> principles of ethics and law within them into a largely medical discourse. For the most part, however, only that knowledge compatible with the biomedical model has become "bioethics." The knowledge has been produced and re-produced in the image of medicine. In terms of an ethics, by adopting a new discipline - bioethics - and constructing it, the medical profession has protected an incursion by law, ethics and government into their realm by extending its own boundaries to include these other factions now reframed in medical terms and medical models. While government has attempted to define the boundaries of medicine's practice and while there have been incursions made by other outsiders, the medical profession has been successful at reclaiming its authority. This has been done in part by shifting its pliant boundaries to include new contextual categories encompassing law, ethics and increasingly economics. Medicine has absorbed the language of ethics and law into a new "bioethical" vocabulary and process in ethics committees. The amalgam of concepts have been selected to fit within a biomedical model which remains dominant. Because medicine retains control of bioethics, largely because of its clinical nature and practice in which neither philosophical ethics or law have experience, it is medicine's game.

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