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Communication, Social Organization and the Redefinition of Death A Case Study in the Institutionalization of an Idea

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Abstract

One of the problems of most interest to students of communication is the analysis and conceptualization of the social processes by which our common notions of what exists, what is important and what is legitimate are shaped. These notions are social and cultural meanings -- values, norms, practices -- the stuff of social and cultural reality, and they are sometimes most manifest and perceptible when they are changing.

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OF AN IDEA

Leslie Ann Rado

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Supervisor of Dissertation

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Graduate Group Chairperson

TO THE MEMORY OF MY GRANDMOTHER

MABEL FLORENCE LEE

Who told me just of often enough,

"Me name is tough, and I lives on Tough Street.
The further down ye go, the tougher it gets, and
I lives in the very last house."

ACKNOWLEDGEMENTS

With no halting prose either claiming or disclaiming the agonies of writing acknowledgements or dissertations -- the agonies of both are widely recognized -- I take this opportunity to express my deep appreciation to those who helped make this effort less agonizing and less solitary than it might have been.

None of this would have been possible without the financial as-sistance awarded me by the Russell Sage Foundation. Special thanks are due Diana Crane who introduced my project and me to the Foundation.

Thanks go secondly to those men who took time from their highly active schedules to participate in this study. Special thanks are ex-tended to those who offered suggestions, sent me their offprints, and allowed me access to their personal files. Their willingness to participate in a social analysis of their efforts and social contacts was clearly essential to the success of this study. Several gave con-tinual access and spent more time helping me than participation in the study demanded: Robert Veatch of the Hastings Center; Alexander Capron of the University of Pennsylvania Law School; Leon Kass, then of the Kennedy Institute of Bioethics and now of the University of Chicago; Don Harper Mills of Los Angeles; Hannibal Hamlin, William Curran, the late Henry Beecher, and E. P. Richardson, all of Harvard University.

It was only through Diana Crane's efforts and helpful advice that I was able to conduct such a successful survey. And I would never have winded my way through any of the complexities and frustrations of network analysis without the assistance of Michael Eeley, Klaus Krippendorf, Charles Kadushin, and especially Geoffrey Greene.

The several people who at one time or another were members of my doctoral committee contributed to the project in different ways. The late Sol Worth offered several helpful criticisms of my plan of attack at the outset of this study. Virginia Ingersoll consistedly encouraged me both on the east and west coasts. Ray Birdwhistell warned me (once more) not to come - a-cropper, a state of being to which I came perilously close over the years. Robert Hornik, who joined by request at the last minute, made several incisive criticisms which helped enlarge the significance of the project. Renée Fox graciously offered the resources of the Sociology Department of the University of Pennsylvania for conducting the survey. Our occasional but always exciting talks guided my sights in conducting this study.

The study became manageable and viable through Diana Crane's excellent advice and her gentle insistence that I keep on the track. We may have exceeded known records for discussing dissertation matters in and from different locales, most of which begin with the letter "P": Philadelphia, Paris, Princeton, Portland, West Lafayette and Boston.

My friend and intellectual guide (not to mention doctoral committee chair), Larry Gross, deserves special mention. Throughout my graduate career at Penn, his timely suggestions (e.g., "Why don't you look into a course offered in Sociology this fall, the sociology of

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CHAPTER 1

INTRODUCTION

One of the problems of most interest to students of communication is the analysis and conceptualization of the social processes by which our common notions of what exists, what is important and what is legitimate are shaped. These notions are social and cultural meanings -- values, norms, practices -- the stuff of social and cultural reality, and they are sometimes most manifest and perceptible when they are changing.

Students of communication will recognize in the paragraph above the suggestions, if not the actual phrasings, of important thinkers who have influenced approaches to communications: George Gerbner (1972a, 1972b, 1972c) and the "cultural indicators" approach to communication; and James Carey (1975, 1978) and Raymond Williams (1974) and the cultural approach to communication. One can also readily discern the influence of an area of sociology known as the sociology of culture or knowledge (see Crane, 1972:129-142; Curtis and Petras, 1970; Kadushin, 1976; Peterson, 1976), especially the influence of Berger and Luckmann's The Social Construction of Reality (1967).

This project[1] began as an effort to integrate these two general areas of study in communication and sociology in a case study of the communication and social organization underlying the development and

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institutionalization of an idea -- the redefinition of death in terms of brain function. The redefinition of death is itself an instance of cultural change; it is also an integral part of a larger process of cultural change, the recent reexamination of death and dying in our society (see Parsons, Fox and Lidz, 1973; Crane, 1975; and Fox, 1974).

The reconceptualization of death in our society has consisted of three areas of major concern: more humane care of the terminally ill; euthanasia and death with dignity; and the redefinition of death in terms of brain, rather than cardio-respiratory function. Each area of concern has been gradually becoming a part of our social structure as each continues a career of institutionalization. By institutionalization I mean the process of arriving at some consensus and legitimation about, for instance, the definition of death, which becomes stabilized within the social structure in the form of what Smelser (1962) calls a "mark" -- an accepted norm, organization or law. The career of each area to date has included the appearance of various marks: several hospices devoted to the humane care of the terminally ill are now in operation; the "right" to die a "natural" death has been formalized into various documents (the Living Will, among them) and state law (the "Natural Death Acts" of California and Oregon, among others); and no less than 22 states (at the time this study was begun, six) have enacted statutes defining death in terms of brain criteria. In all these instances our concepts of death and dying are being transformed; they are in the process of being culturally redefined.

The process of cultural definition of only one of those areas[2] -- the redefinition of death in terms of brain function -- and the

participants in the process -- those who produce, explicate and refine

the definition (the "cultural definers") -- are the primary foci of

study. The "managers" of the institutionalization of "brain death"[3]

themselves, the process of redefinition and the enactment of the rele-

vant policies are at issue: the ways in which redefining death may

have effected clinical practice are not,[4] and neither is the effect of

the definers' work on the public conception of death. If evidence

that the,redefinition of death is indeed an emergent cultural notion is

required, the fact that a number of states (at this time, 22) have en-

acted statues readjusting their definition of death in that regard

should be sufficient.[5]

The Institutionalization of the Redefinition of Death

The institutionalization of cultural definitions (or cultural

change) is a difficult process to manage conceptually (cf. Parsons,

1951). One meaning supplants or supercedes another when the older

meaning becomes inadequate in some regard. For instance, a problem or

anomaly (Kuhn, 1970) arises which the older meaning or set of meanings

cannot contain.

In this case, the use of medical technologies which separated the

function of the three major physiological systems (respirator tech-

nology, resuscitation technology and the electronic monitoring of

brain function, and no less, heart transplantation) provided families

and staff with a rather macabre sight: persons who breathed (with the

aid of a respirator) and whose hearts still beat, but whose brains were

"ruined". The question arose: what can be done about this dehuman-

izing and both emotionally and financially exhausting state of

affairs? In the late '60s a still-beating heart was removed from one person and transplanted to another. Another question arose: How could that be accomplished, if the sign of life was just that -- a still-beating heart? The center of life and character, the treasured subject (true, strong, aching or otherwise) of many a poem, story and song was reduced to a "replaceable muscle" (Ramsey, 1970).

These events were anomalies -- they could not be understood with reference to traditional concepts of death. The strain they provoked stimulated a deep rethinking of what is meant by "life", "death" and "personhood", cultural concepts of profound consequence.

The redefinition of death has been the quietest aspect of the reconceptualization of death. Of the three death and dying topics, it has appeared least often in the popular press and broadcast media, the only exception being the time during which the Karen Quinlan case was being litigated in 1975. Before that case discussions on the topic were located primarily in professional arenas: the courtroom, hospitals, special organizations concerned with bioethics issues, professional journals, conferences and symposia. And after the Quinlan case, the issue has again returned to those arenas. Both before and after the Quinlan case, definition of death discussions included three kinds of participants: physicians, lawyers and theologians or philosophers.

Motives and Goals

This relatively contained topic provided an opportunity to analyze the institutionalization of the idea from first mention to its explication in formal state law, as well as to include several interests.

The primary motivation in choosing the topic was to closely examine a process of cultural change, to try to come to some terms with how it happens that old meanings become inadequate and new ones emerge. Secondly, I wanted to contribute to the study of the ways in which professionals and academics define cultural issues. Little is known about how communication and related social processes (influence, contact, diffusion, interdisciplinary collaboration, participation in symposia, conferences, the mass media and use of the professional journal) are associated with the organization and dynamics of institutionalization. Since many if not most of contemporary societal dilemmas require interdisciplinary competence and collaboration, the more we can learn about the problems and general conduct of interdisciplinary discourse the better. This particular topic provided a context for investigating the extent of interdisciplinary association and communication and the role it played in a process of definition.

In order to analyze the professional communication and social organization of the definers who have managed the redefinition of death, it was necessary to examine the definers' published interpretations of the issue and to assess the degree of consensus among them. And since the issue had been codified into formal state law, there was an opportunity to see how and to what extent professional and academic defining came to bear on local state policy-making. These constitute the goals and motivations of the study. The following section describes the conceptual frames I have adopted toward these ends.

Conceptual Frameworks

Institutionalization and Social Organization

A social movement? What model fits this process of institutional-
ization? Can the redefinition of death be considered a social movement?
If, according to Smelser (1962), there are social movements in the name
of the establishment of a norm, value or generalized belief, then why
not a social movement in the name of a cultural redefinition?

Part of what is meant by "social movement" is a deliberate, some-
what strategic and organized attempt to change an aspect of the social
structure. Moreover, participants in social movements are advocates
who agree (more or less) on the major points of advocacy. It somehow
makes little sense to describe a change in our cultural meanings as
the result of a deliberate, strategic and organized attempt, however
formal or informal, to change them. It just does not seem as if the
speakers in the redefinition process came together and determined to
redefine death in terms of brain function in the same ways the Ku Klux
Klan organized to "protect white racial integrity" or that feminists
have made efforts to change policies and behaviors associated with
rape, female competence and the status of women. Changing or attempt-
ing to change some aspect of social structure (organizations, roles,
practices, norms) is different from cultural redefinition or cultural
problem solving. (Surely feminists have determined cultural meanings,
but did they intend to do so?)

That is not to say there are no advocates among the cultural
definers, not that all advocacy for change of whatever sort fits
into the Procrustean bed of the social movement model. But the

advocacies present in the redefinition process are far too disparate for a social movement. Aside from the objection that it does not seem altogether proper to conceive of a change in cultural meanings as a result of an organized determination to change them, there is simply too much diversity in motivation, goals and interpretation of the issues involved for this process to be considered a social movement.

Social circles, invisible colleges and the like: It is more appropriate to regard this process of institutionalization as a process of fixing a definition rather than as a process of fixing the claims embodied in a social movement. I would adopt an approach from the sociology of knowledge or culture which specifies a concept, idea or style and focuses on the social organization (and, in this study, communication) underlying, and in some sense comprising, the development of the idea. The idea has a career partially constituted by the social organization of those who work with it, explicate it, use it, etc., and that career is not the career of a social movement. What is needed is not a model of the social organization of a kind of social or political advocacy -- what is needed is a model of the social organization associated with the career of an idea.

The best descriptive models for the social structure underlying the institutionalization of the redefinition of death derive from Kadushin's notions of "social circle" (1968; 1975) and Crane's "invisible colleges" (1972). Both models of social organization were designed with the purpose of describing the loose, informal organization that characterizes decision-making and cultural groups and research areas, and can apply as well to cultural defining groups

with their varieties of goals, interests and interpretations.

Two stages of institutionalization: After all the disclaiming of
the social movement model, I propose to do something that social
movement theorists sometimes do -- posit "stages" in the redefinition
of death.

The process of the redefinition of death is composed of two
general, overlapping stages: 1) the defining stage -- stating the
issue; and 2) the policy-making stage -- formalizing the issue in legal
code. The relation between the two and their participants (the
definers and policy-makers), and the organization and dynamics of
each broadly outlines the organization of this study.

Cultural Definers

The major participants in the process of redefining death are
members of three institutions: medicine, law and philosophy/theology.
(Since the advent of the term "bioethics", the term "ethicists" has
become widely used to refer to philosophers and theologians concerned
with death and dying and other bioethical issues, and for the sake of
brevity, I will use it also.) Physicians, lawyers and ethicists have
been the definers of death; they have assessed the appropriateness
of the redefinition of death and its validity in specific medical and
social contexts. They have discussed and sorted what it means -- in terms
of medical and legal practice, moral issues and traditional concepts of
death. They have been directly concerned with reaching consensus on and
clarifying the problems which are entailed in redefining death.

Obviously, however, not all members of these three institutions

have participated in the process of defining, but some did. The
question is, then, why did some enter this particular arena, while
others did not? They certainly have not been allocated the role of
"cultural definer" by their respective institutions. They do not con-
duct their defining work in the same way editors of magazines conduct
theirs -- through the execution of primarily occupational role respon-
sibilities. These definers all have primary occupational commitments
elsewhere. Obviously, none are paid regularly to "define death",
although some (perhaps neurologists or medical lawyers) are paid
regularly to perform tasks which include something like "working on
defining death". In studying the topic, one identifies particular
people, such as Henry Beecher or Paul Ramsey (see Chapter 3) and
organizations such as the Ad Hoc Committee of the Harvard Medical
School to Examine the Definition of Brain Death (the Harvard Committee),
rather than institutions (cultural defining) or institutional roles
(cultural definers). But that is not to say that other social
factors -- for example, particular prominence within certain legal,
medical and philosophical areas -- do not contribute to the making of
cultural definers, but rather the cultural definers do not crank out
definitions by virtue of their positions or roles within a cultural
defining institution. There is simply no such formal institution
(though I suspect that with thorough investigations on several topics,
one would uncover a consistent pattern of allocation of cultural tasks
within institutions). How the definers happened to undertake this
particular task is discussed in Chapter 4.

However they became involved with the issue, it is these

professionals who shape the definition, who are producing it, if you will, rather than merely adopting or simply transmitting it. Opinion leaders (Katz, 1957; Katz and Lazarsfeld, 1955; Menzel and Katz, 1966), as the concept is most often used, serve transmitting and interpreting functions in opinion formation. The opinion leader is a link in a chain of influence from the mass media to the community; he is the first to adopt an opinion given by mass media institutions or decision-making elites. The definition of death did not come out of the blue or as a result of someone's inspiration or some group's determination. It was given in part as a solution to problems raised by life-prolonging technologies and the advent of neurophysiological knowledge and technique. Though a social, cultural and medical fabric was given, some group cut the pattern of the definition of death, subsequently tailored it, and cut again. Opinion leaders and gatekeepers play a major role in cultural definition processes which include transmitting and selecting. However, cultural definers are not primarily relay or selection mechanisms in the process; and adoption and diffusion are not the central processes in this conceptualization of institutionaliza-tion. Production in some sense is at issue; the definers explicate, mold and develop cultural definitions.

Neither the "great man" nor a strictly Durkheimian conception of social and cultural processes is an adequate conception of social or cultural change. The reconceptualization of death has not taken place in a social and cultural vacuum; however, it can't be adequately under-stood as the result of social and cultural drift. One of the major problems I have with sociogenic conceptions of social processes is the

frequent implication that social change occurs in ways similar to natural changes such as continental drift, and tidal and atmospheric fluctuations -- an implication that is unfortunate at best.[7] Persons are products of society, to be sure; and persons maintain, shape and, in some sense, produce society (Berger and Luckman, 1967). "It is against something that the self can emerge" (Goffman, 1961:320); it is also against the activity and consciousness of members of society (persons) that elements of the social and institutional order are both reconstituted and maintained.

There is the social and cultural fabric; there are conventions and rules about how it is to be cut; and there are the fabric-cutters and designers. I am not interested in conceptualizing the fabric-cutters as transmitting and filtering mechanisms in processes that shift and emerge as a function of the drifting social tides of fashion. I am not interested in asking, as Erving Goffman has, "What minimal model of the actor is needed if we are to wind him up, stick him in amongst his fellows, and have an orderly traffic of behavior emerge?" (1967:8). I am interested in conceptualizing a role and function in social defining that accounts for persons doing the winding, the sticking in, the observing, i.e., the cutters and designers of cultural definitions. And in this case they are physicians, lawyers and ethicists.

Communications Processes and Content

Communication channels. Within the professional arenas there are two primary locations for direct and indirect communication on the

topic: 1) informal interpersonal interactions with colleagues at symposia, conferences and committee meetings, in the lunchroom and emergency room, etc.; and 2) more formal communication in settings such as professional journals (Journal of the American Medical Association (JAMA), university law reviews and the like), symposia and conferences. Of particular interest here is the extent to which definers addressed members of other disciplines in both formal and informal settings. In order to reach even the most minimal amount of consensus in a three-way debate, there would have to be some degree of interdisciplinary communication and association.

This study was also designed to consider the definers' participation in non-professional communication settings, such as symposia and panels addressed to the lay public and the mass media. Though public conceptions of death are not considered in this study, I wanted to have some index of the definers' communication with lay audiences.

Thus, there are basically three kinds of communication channels involved in this instance of cultural defining: interpersonal associations; and "places" of professional discourse -- professional journals, symposia and conferences; and settings which include the lay public audiences. The differences in the kinds of channels turn, obviously, on two dimensions: informal-formal communication settings and professional-lay audiences.

Specialized communications. Part of the emphasis of this study focuses on the role of specialized, as opposed to mass, communications in the institutionalization of the definition of death. The professional journals act as a "meetinghouse" for cultural definers and are

vehicles for shaping and spreading definitions as well. They are used
for conducting cross-disciplinary communication and consensus "work"
to some extent. The question is, how were the professional journals
used by the definers and what function did they serve in the process?

Communications content. The content of the journal articles, from
the first suggestions of a need for a concept of "brain death" to the
recommendations, definitions and statutes proposed and the criticisms
and discussions that follow, provide an index of the development of
the issue as well as of the definers' consensus on the issue. The
concept itself has a specific, evolutionary career, and there is simply
no way to understand that career without a close examination of the
public statements in which it is embodied. An analysis of the
definers' articles provides a means to assess the relation of the
social organization and communication of the definers to the evolution
of the concept.

The Basic Conceptual Problem

Lurking behind the goals of the study, the conceptual frameworks
and all, is the spectre of an agonizing conceptual problem: the
relation among social processes (communication, diffusion, etc.),
social structure (social organization and social relatedness) and the
content and development of an idea. Perhaps the easiest of the rela-
tions contained in the triad is that between social structure and the
"content and style" of ideas, and even that relation has recently been
acclaimed as "the most vexing problem in the sociology of knowledge"
(Kadushin, 1976:119).

After a couple of isolated attempts at wrestling with the two-way

relations (social organization and social process, in Chapter 6, and social organization and conceptual approach, in Chapter 7), I close with one final effort at specifying the larger interrelation for this particular case study.

Apologia: The Relations of This Study to Other Research

As already noted, I have taken my bearings from the areas of the sociology of knowledge and culture and communication and culture. The approach taken to the study of those interests is an integration of several approaches and falls squarely under the rubric of none. I know of no study which specifies a group of professionals and academics from three disciplines involved in defining a cultural issue which marks an instance of cultural change and institutionalization. I have borrowed heavily from several scholars and researchers from somewhat different areas insofar as their work has suggested to me the possibilities embodied in this project.

The conceptualization of the cultural definers is taken from the conception of human nature presented by Berger and Luckmann in the Social Construction of Reality (1967). It was in the context of reading their treatment of the social processes of conceptualization and institutionalization by which the social order is maintained and constituted, that I began to wonder how one might conceptualize and study empirically a change in the social or cultural order.

Anyone familiar with the work of George Gerbner and his "cultural indicators" approach (1972a; 1972b; 1972c) will recognize a version of institutional and message analysis adapted to the goals of this study

(rather than to the analysis of mass media institutions and messages).
I like to think that this project is infused in places with something
like the "cultural orientation" Renèe Fox brings to her work in the
ethnography of medicine, in particular Experiment Perilous (1972) and
The Courage to Fail (1974). And the way in which many of the motiva-
tions of this study reached some degree of specification, method and
organization derives primarily from the work of Diana Crane in the
sociology of science, medicine and culture (1970, 1972, 1975, 1976).
Generally, any particular instances of indebtedness or similarities to
other areas of research are discussed in the relevant chapters, as
would be the case in a study of this length and complexity.

Part of the study could be broadly characterized as a study of
the social organization of a particular population and as having
commonalities with the study of the social organization of science
(see Crane, 1969, 1970, 1972; Griffith and Miller, 1970; Nelson and
Pollock, 1970; Mullins et al., 1977; Coleman, Katz and Menzel, 1966;
Brieger, 1976; White et al., 1976; Friedkin, 1978) and intellectuals
(Kadushin, 1974, 1976), as well as other populations. But as I
discuss in Chapter 6, the cultural definers are not quite scientists
or intellectuals in terms of either the contexts or the substance of
their work.

Portions of the design of this research were provoked by dissat-
isfaction with traditional concepts of diffusion (Coleman, Katz and
Menzel, 1966; Katz et al., 1963; Rogers, 1962), influence (Katz and
Lazarsfeld, 1955; Parsons, 1963) and, as is no doubt obvious already,
opinion leaders (Katz and Lazarsfeld, 1955; Menzel and Katz, 1955;

Katz, 1960) and social movements (King, 1956; Smelser, 1962). These
particular conceptual bones are picked in the chapters in which they
arise, primarily this chapter and Chapter 6.

To conclude the apologia whith a suggestive note: For some time I
have been intrigued by a definition of communication anthropologist
Ray Birdwhistell introduced in class (at the University of Pennsylvania)
one day: "Communication is the dynamic aspect of social structure".

Preview

To manage all the goals of this study I had to locate the cultural
definers and ask them about their involvement in redefining death,
their communication activities and their social relations with other
definers. To get some idea of the development of the issue and the
consensus on the issue, I analyzed the articles they wrote that ap-
peared in professional journals. To understand the relation between
the definers and policy-makers, I asked each group questions about
their relations with the other. The details of this research method
and analysis are given in the next chapter, Chapter 2.

Chapter 3, the History of the Redefinition of Death, contains an
introduction to the major characters and events that comprise the
medical, social and conceptual development of the redefining process
(in chronological order). In studies like this one, there are two
simultaneous concerns: the development of the focus of study, in this
case, redefining death; and the social analysis of the process. Of
course, I am not involved in the business of redefining death, but I
cannot see how the reader can understand what I am doing as a

researcher without knowing as much as possible about the issue itself.
The bulk of the chapter is based on primary research (interview data).

Chapter 4 simply introduces the definers as a population.
Included in Chapter 4 are the definers' stories of how they became
involved in the topic to begin with.

Chapter 5 discusses the communication activities of the definers:
their use of professional journals and their objectives in publishing
their articles; their participation in formal professional discussions
and lay discussions on the topic; and the extent of interdisciplinary
communication that occurred.

Chapter 6 analyzes the social cohesion and structure of the
definer population. The findings are given after a brief discussion
of problematic conceptual issues involved in studying networks, com-
munication and social relationships, and the general relation between
social process and structure.

Chapter 7 contains the results of the content analysis of the
definers' articles and an integration of the article data with the
social organization findings to specify the relation of conceptual
approach and social organization.

Chapter 8 is a brief discussion of who the policy-makers are and
the extent of policy-maker/definer interaction.

Chapter 9 is an integration of the findings of Chapters 5-8 into
a discussion of the dynamics involved in the institutionalization of
death in Chapter 9 which responds to the question, What got the issue
going, or in other words, what kinds of social factors had a bearing
on its development?

The concluding chapter provides a summary of Chapters 4-9, an epilogue of the events that have occurred since 1975 regarding the redefinition of death and suggestions both for cultural defining and cultural definers as well as for communication researchers and social scientists who would embark on studies like this one.

ENDNOTES

[1]This study was partially funded by The Russell Sage Foundation.

[2]The Appropriateness of a Case Study: A different approach which fits in no particular tradition and its workings is appropriate to an exploratory or case study which can provide the ground for a comparison in the future. Indeed, one must start somewhere. I originally had suggested that I would compare the development of the idea of "brain death" with the development of one of the other "death and dying" strains of interest -- either care of the dying or euthanasia.

The more involved with the redefinition issue I became, the more inappropriate that plan seemed. First of all, the other two strains of interest have substantively different kinds of careers and do not provide ready comparisons -- both issues have been extensively treated in the mass media and have popular figures and devotees, and entail far more complex historical and political "stories".

Secondly, with the added set of data, this project would have undoubtedly suffered eventually from "the futile prolongation of life", not to begin to mention the probable extent of the author's brain dysfunction.

[3]One of the ethicists' objections to the notion of "brain death" is that it implies that the death of a person can be reduced to the death of an organ. In honor of that objection, I have tried to use the term "brain death" as infrequently as possible and then, in quotes. The consequence is the use of a particularly long phrase "the redefinition of death" or 'death definition", etc. This may be confusing because the focus of the study is the cultural definition of the redefinition of death (instead of "brain death"). I have assumed that the ethical point is worth the inconvenience. The reader may disagree.

[4]In this study, the only aspect of institutionalization examined is the formation of public policy. The intriguing question of how definitions or policies affect actual practice is not considered; the answer requires extensive collection of a different kind of data than that obtained in this study -- in fact, it requires another effort altogether.

[5]Just for the record: A Missouri public opinion firm has assessed its citizens' notions of when a person should be considered dead. Of the resident respondents, 71.3% said "when he has lost consciousness, lung and heart function" (traditional criteria); when he has permanently lost consciousness was the response of 21.7% (cerebral criteria) and only 7% said when the person has lost both

consciousness and lung function -- the criteria basically recom-
mended in the statutes and by medical and legal authority (Charron,
1975:979-1008).

[6]One of the important aspects of social movements is their
political nature. In taking one's bearings from the sociology of
knowledge, one need not fall prey to the assumption sometimes im-
plicitly or explicitly present in research in that area -- that
styles, ideas or concepts develop apart from political pressures or
considerations. I have no intention of ignoring the politics of
this process of institutionalization.

[7]The analogy is as unfortunate politically as individualism
is. As members of our society, we are too accustomed to relegating
the responsibility for important decision-making to vague, anony-
mous forces such as God, the State, the weather and the tides. It's
unfortunate that we are not socialized as decision-makers of impor-
tant issues; and it's just as unfortunate that a good deal of so-
cial and science epistemology does not acknowledge our roles in
constructing the social and cultural order.

CHAPTER 2

CONDUCT: DEFINITIONS, INSTRUMENTS, AND ANALYSES

The details of my modes of attack on the research questions, the instruments used, and the details of general research conduct are given below. Substantive conceptual issues are, of course, discussed in the relevant chapters.

Locating the Definers

One of the major problems in the study of elites, decision-makers, opinion leaders, scientists or other "cultural producers" consists in developing a method for locating them. In this case, a simple method was utilized. Cultural definers are the physicians, lawyers, and ethicists who have written one or more articles which have as their major topic the redefinition of death or the application of various new techniques in determining death, and which are published in professional journals in the United States through 1974.

I located articles with the use of various sources, among them the journal indexes: Index Medicus, The Guide to Legal Periodicals, and The Philosopher's Index. All were searched from 1955-1974. In addition, I utilized bibliographies compiled by various sources: The Hastings Center Bibliography (1975); The National Institute of Neurological Diseases and Stroke Bibliography, Brain Death (Smith and Penry, eds., 1972); and The U.S. Department of Health, Education and Welfare's

Selected Bibliography on Death and Dying. I also had access to the libraries at the Hastings Center in New York and the Kennedy Institute of Bioethics of Georgetown University and to the personal files of several definers. In other words, the most complete bibliography of the kinds of articles defined below may well be in the hands of the present author. In still other words, I have a universe of such articles.

Operational Definitions

Cultural Definers

The professionals, i.e., the physicians, lawyers and ethicists who author articles and documents as defined below. Sociologists, another professional group involved in discussions of death and dying, are not included because, for the most part, they are not concerned with defining death as much as they are with disclosing the social and cultural aspects of death and dying situations. They are not in the business of defining death themselves, though they may be in the business of showing how death is socially defined.

Articles

All articles, documents, reports (including statutes), for which an author(s) or a committee of authors can be specified which have as their major topic the redefinition of death (see below), but omitting "anonymous" editorials and law review notes, as well as letters to the editors of various journals.

Major Topic

All articles which discuss the need for a definition of brain death, the application of electroencaphalography or other neurological techniques (e.g., angiography) to death determination, the appropriateness

of the brain death definition or criteria as represented in major state-
ments of definition (e.g., the Harvard Report), and legal, moral and
religious aspects of the concept of brain death are included. Articles
concerning only technical aspects, clinical aspects or physiological
aspects of cerebral anoxia and the technical details of determining
death according to brain criteria are not included. It is assumed that
those aspects of the technological and physiological discussions which
are relevant to general or specifically moral, legal and medical defini-
tions of death (e.g., that the EEG is not a reliable indicator of
cerebral death in cases of barbiturate poisoning and hypothermia), will
be raised in other discussions. Insofar as I am relying on that assump-
tion, I am trusting cultural definers as editors of their own literatures.

Professional Journals

Periodicals, utilized primarily by professionals and academics,
with total circulation less than 250,000, according to Ulrich's Inter-
national Periodicals Directory, 1973 - 1974, including interdisciplinary
periodicals such as Daedalus (58,000), Science (154,000), The Hastings
Center Studies (later called The Hastings Center Report) (7500) and pro-
fessional periodicals such as The Journal of the American Medical
Association (239,000), The New England Journal of Medicine (140,000),
and various law journals and reviews which are published in the United
States.

Contacting the Definers: the Survey

After fixing the article universe, a cover letter and survey were
sent to 90 senior authors in two waves, followed by a phone call. My
incessant requests to the definers as well as excellent advice on

formulating, printing and distributing the survey and cover letter from Diana Crane resulted in an 83.3% return. The cover letter and question-naire appear in Appendix B.

Mailing Considerations

Deciding to whom I should mail the survey in most cases was straight-forward, but there were exceptions. In the sample were three articles with committee authorship--the Harvard Ad Hoc Committee, the Hastings Task Force (Research Group) on Death and Dying, and the Ad Hoc Committee of the American Electroencephalographic Society. Each of these commit-tees contained authors who had written other articles on the redefinition of death. I sent surveys to the chair and to all authors of other articles. I attempted, with partial success, to schedule interviews with all members of the Harvard Committee. Most of the Hastings Task Force who had worked on the Hastings publications on death definition had also written articles on their own.

If the chair or senior collaborator was deceased, I sent the survey to the second author. In one case, a pair of authors wrote four articles on the topic, and I considered it appropriate to send them both a survey. With the exception of the articles authored by committees mentioned above, articles with one or more authors appear only in the medical literature (usually with one or two senior authors and research associates); ethicists and lawyers, in these articles and in general, tend to write alone. It was often the case that when authors of consid-erable repute collaborated, the second author was the first or sole author of another publication. Several authors wrote more than one

article. My general rule was to include anyone whose name showed up in the literature or in bibliographies more than once.

The Survey: Content

The survey contains questions on what I considered to be the most important aspects of the authors' participation in the redefining process. The survey (see Appendix B) contains sections (in order) concerning (1) the ways in which authors became involved in the issue; (2) their occupations and involvement with either transplantation or dying patients; (3) their social ties with other persons involved in this or closely related issues; (4) their "communication intent" in writing and publishing their articles and the journals they read in keeping up with the discussion; (5) their participation in other public discussions on the issue (symposia, conferences, the mass media); (6) their participation in efforts to pass legislation defining death in terms of brain function; (7) their involvement with other death and dying and bioethical issues; and (8) the place and year of their professional or academic degrees, membership in professional and bioethics organizations and the nature and importance of their religious background. All but the sections on social ties and communication intent are rather straightforward.

Communication intent: Presumably, in participating in the cultural definition of an issue, authors would intend to determine it in some ways and not others. In particular, they would intend to reach certain audiences and accomplish certain objectives in publishing articles in professional journals. I asked questions to this effect to assess their

"communication intent." In addition, I was interested to see to just what extent authors viewed their articles as attempts to shape public policy, as opposed or in addition to, influencing specific readerships. These items on the survey, as well as the definers' participation in other public discussions on the issue (besides publication) are discussed in Chapter 5.

The sociometric section: I included in the survey a section asking them to indicate their ties to other authors and policy-makers. Obviously, any one author could have a variety of social ties established in professional organizations, in hospitals or universities, in interpersonal relationships and ties established through publication. The survey was designed to assess all of these, though the sociometric section focused only on the interpersonal ties of Recognition, Contact, Importance and Professional Friendship. (Recognition and Importance could be ties established through publication as well.) These ties were used because I thought they would be the kinds of ties that would have most to do with how the redefinition of death took shape. The ties, and their similarities and differences, are discussed at length in Chapter 6.

A major goal was to assess the relationship between the definers' social ties and the development of the issue. Unfortunately, I hadn't the foresight to add to the sociometric section a means of assessing the temporal development of relations in the context of the issue's progress. It became clear in interviews that friendships and importance relations developed in the context of working on the issue, but I did not utilize a means for empirically assessing the development of the relations.

At that time, no one had conducted a network or sociometric study which attempted to assess these particular relations--a fact which makes for little means of comparison with other sociometric populations. But it seemed important to use these ties, in part to exemplify the notion that social organization is constituted by a variety of different kinds and aspects of social relations.

The sociometric list: At Crane's suggestion a list of persons which the definers could check was added to the questionnaire, under the assumption that a more representative depiction of the social organization of the definers would emerge than if the definers were asked to name their own friends, discussion partners, etc. I included in the list all authors, all legislators and other policy-makers who had enacted death statutes in the five states, all persons who had been members of any committees which had published articles but who had not published articles themselves, and a few others well-known for their efforts in closely related areas (transplantation, Cardio-Pulmonary Resuscitation--CPR).

The names were organized by disciplinary affiliation into the following areas: ethics--bioethics; law--medical law--legislation; and medicine. Two definers were related to two areas: Leon Kass and Robert Morison, both physicians by training, have become identified with either bioethics (Kass) or general university programs in science and society (Morison). They each had occupational commitment to these areas--these were not just side interests (Kass worked at the Kennedy Institute for Bioethics and now holds a titled professorship of bioethics at the University of Chicago, and Morison was a professor of science and society

at Cornell.) For these reasons I thought that they would be more readily recognized under ethics-bioethics than medicine, so there they were placed.[1]

The open questions--11-14: As a check to see whether the persons most significant in the development of the issues were included, I added an open question in which respondents could name anyone they wanted. I was also interested to see how many persons would mention family or close friends who were not colleagues. Most respondents named local profes- sional cohorts and close colleagues; only a few mentioned personal friends (probably because many of their friends were also professional colleagues) and only a very few (two) mentioned family. Of all that were mentioned, no more than three persons were named as many as three times-- one of those was Pope Pius XII, another was Don Harper Mills. I take that as verification that I had identified the most important persons in comprising the list, although not all of them, for whatever reasons, participated in the study. They were additionally asked to name any books or articles they considered to be particularly important to their interpretation of the issue.

For the most part, no one was omitted from the study whom I judged necessary to include, with one exception. After an initial interview, the most central person to the redefining effort in several respects, Henry Beecher, became too ill to participate further and respond to the final questionnaire.

Respondent accuracy: Of course some respondents probably fudged a bit on their sociometric choices, enlarging their lists of whom they had

contacted and who was a professional friend, and neglecting to mention those who had been important. However, from my knowledge of symposia and conference attendance and bibliographic citations, most choices seemed reasonable. In addition, the persons most peripheral to the effort, such as students, either chose no one or chose only on the basis of what could be bibliographic or publication familiarity, and the persons most central to the effort chose several others on all ties.

The Network Analysis

The following discussion concerns only the method chosen for executing a network analysis. Other conceptual issues involved in the use of concepts of "network," "social ties," and "communication" are discussed below in Chapter 6.

Searching for a computer program (algorithm) which would manage the four large sociometric matrices and uncover a structure of relations without imposing what I consider to be distorting assumptions on the original data was an agonizing process. The matrices were too large to draw a simple sociogram by hand, and the kinds of algorithms available at the time either assumed reflexivity or transitivity (discussed below) or forced mutual exclusivity on the clusters obtained. Neither of these choices was altogether satisfactory.

Some "network" researchers, notably Crane (1972) and Kadushin and Alba (1976), assume transitivity. In tracing research influence among scientists, Crane has argued that often influence is relayed through parties one never meets face to face and that it is important to consider such persons as links in a network of influence (Crane, 1972:42). For

my purposes I am not willing to assume that if A chooses B as important to him in his conceptualization of the issue, and B chooses C, that there is any necessary relation at all between A and C. Such an assumption seems even less tenable considering the other ties--Contact, Recognition and Professional Friendship.

Alba and Kadushin (1976) consider that persons have a symmetrical relation if either mentions the other. "Thus, if individual A stands in a certain relationship to individual B, B will, by assumption, stand in the same relationship to A" (1976:8). Such an assumption obliterates a pattern of choice frequently representative of relations in the real world, i.e., unrequited ones. In assessing social structure it is important to be able to distinguish those who receive attributions but may not return them from those who make them but do not receive them.

Another group of algorithms--hierarchical clustering algorithms (see Johnson, 1967; Brieger, 1976; White et al., 1976)--partition a matrix of binary data into mutually exhaustive clusters. A map of social relations derived from such a program would be highly misleading--most persons have ties with more than one social grouping (cluster, circle, coalition, clique, interaction act, network or whatever). A representative "picture" of the social relations in any population would have to depict overlap. In this study, for instance, one ethicist chose many of the same people other ethicists and other physicians also chose. According to the operations of these algorithms, he would be placed in a cluster along with the group with whom he had the most in common (ethicists) and his commonalities with other groups (physicians) would not be revealed at all; and that is not an accurate map of his social relations.

Not satisfied with either alternative--with either an algorithm which depicted overlap but assumed transitivity or reciprocity or an algorithm which assumed neither transitivity nor reciprocity, but imposed mutual exclusivity on the social groupings that emerge--I chose the latter because (1) I could then use the networks as variables and (2) I could "fill in" overlap through my own analysis of the sociometric information.

Many methods of matrix analysis were considered, among them: "blockmodeling" (Brieger, 1976; White et al., 1976); Alba and Kadushin's "new measure of social proximity" (1976); Krippendorf's "2m strong associative clustering" (1975); and Coleman's "Sociometric Connectedness" method (see Crane, 1972:42). Because of monetary and computer space constraints, a version of Johnson's hierarchical clustering method (1967) adapted for use in the BIOMED P statistical package (1973--BMDP1M) was used. The definers were clustered on the basis of the similarity (correlation) of their choices, rather than on the basis of who chose them. Definers who had the greatest similarity of choices were paired and others were added to the pair on the basis of an amalgamation measure. I chose from the program options the "maximum," or "diameter," method of amalgamation, the strongest in the program. For a definer to be added to a cluster with this method, his choices must be correlated with all members of the cluster--not just any one member of the cluster.

In hierarchical clustering programs it is not customary to include choices of self in the data matrix. However, if the choices of the persons who chose another but did not choose themselves are compared, the vectors representing their respective choices will be dissimilar and the

overall similarity between the two will be lowered. Mutuality, when it occurs, is worth noting, and should add to the similarity of two definers. With this in mind, I arranged the data so that each person chose himself.

To obtain a measure of the relations among clusters, I simply averaged the correlations among the members of each cluster contained in the space on the final matrix where the two clusters intersected.[2] The BIOMED output rearranges the original correlation matrix, making this a relatively simple procedure. I assessed cluster overlap on the basis of the strength of the correlations between members of different clusters. I spent several weeks familiarizing myself with the patterns of choices of each respondent,[3] partially to convince myself that the algorithm was indeed giving a reasonable image of the network of relations among the definers.

Contacting the Definers: the Interviews

In addition to sending all authors a copy of the survey, I arranged interviews with as many as would consent to them (16) on the Eastern seaboard. In addition to the authors, I interviewed several members of the Harvard Ad Hoc Committee, as well as two physicians who were excellent informants on the role of Massachusetts General Hospital and Peter Bent Brigham Hospital (both associated with Harvard University Medical School) in the evolution of the issue. In all cases, I followed the format of the survey, requesting elaboration on their personal intellectual and professional history with the issue, the role of others in developing the issue (particularly those who were deceased at the time of collecting

the data), and details regarding the history and evolution of the issue. All but two permitted me to tape the conversation, and several gave me access to their personal files. The information collected in interviews provides the basis for several portions of Chapter 3.

Managing the Articles: The Content Analysis

After the respondent sample was stabilized at 75 (see Appendix A), each article written by each author was analyzed according to a rather conceptually complex content analytic scheme (Appendix D).

If the author wrote more than one article, the article which was most inclusive of the two or three written was used. Since the data from the questionnaire had to be combined with the data obtained from the content analysis, only one article was finally selected for each author, giving 75 complete author-article data units.

The scheme itself is too complex to be covered substantively apart from the text and is discussed thoroughly in Chapter 7. The general conceptual scheme fit all but a very few articles. It framed each article as a discussion of a problem(s) for which the redefinition of death was considered a solution or as a discussion of problems arising from redefining death.

Reliability

A computer program devised by Klaus Krippendorf (1973) at the University of Pennsylvania was utilized to assess the agreement between two coders on the content analysis scheme for 20 articles randomly selected from the sample. Because the scheme was rather complex, I intensively trained another coder (fellow PhD candidate at the Annenberg School of

Communications, Jo Holtz) in the subtleties and intricacies of the redef-
inition issue and in the general writing styles of physicians, lawyers
and ethicists. We first practiced on ten articles selected for their
complexity, and discussed them and the scheme in detail. Because we were
thoroughly familiar with the scheme and the issues by the time we coded
the 20 randomly selected articles, the reliability obtained for most
items was very high. All but six items had scores of .8 or above, with
most items having scores of .9 or above.

The Cluster Analysis

Sixty-eight items in the scheme are binary items designed to be used
in a clustering analysis to assess which issues or themes are associated
with one another apart from any particular article's content or any par-
ticular author's approach. The analysis was undertaken for two reasons:
(1) to assess the structure of the article sample and the structure of
consensus and (2) to attempt to assess the relation between the clusters
of themes and the social organization of the authors.

For this set of "cluster" data, I used Krippendorf's "Strong Asso-
ciative Clustering of 2m Data" (1975). This program was not convenient
for the analysis of the four sociograms, but it was particularly useful
for the content analysis data. The output lists the frequency with which
each item is mentioned--a handy feature for assessing the themes that
were mentioned most often by the sociometric clusters of authors.

The "2m" method is a hierarchical clustering method like the BIOMED
program, but which, instead of adding items into clusters on the basis of
similarity of pairs of items, forms clusters on the basis of the

cooccurrence of all items in the cluster. In other words, the BIOMED program amalgamates pairs of variables as such; no higher-order cluster based on the cooccurrence of all those pairs at once is obtained as it is in the 2m method. In Krippendorf's algorithm, a cluster of four items is constructed on the basis of what they all have in common, not just on what any two items have in common. He argues that a four-item cluster implies lower-order clusters--four three-variable clusters and six two-variable clusters. One can reason from the higher order to the lower order clusters, but one cannot reason in reverse--from the lower order to the higher order clusters. It is easy to see how conceptually appropriate the "higher order clustering" is for the analysis of sociometric data, if one assumes, as do most social scientists, that a group or network is more or other than a sum of its members or a sum of its dyads. In the same way, one could argue that conceptual approaches present in the articles have an integrity best tapped by this method.

Krippendorf's program does not rearrange the matrix of associations according to the clusters obtained, as the BIOMED program does, and I could not assess the relations among the clusters in the same way I did for the social networks. In this case, I specified the relations among the clusters by tediously noting the association of each item in a cluster to each other item and arranging them according to the strength and number of links from items of one cluster to items of another.

Contacting the Policy-Makers

The Survey

Besides contacting the definers, I sought information from the policy-makers, as well. By writing to each state's legislative council and requesting the name of the sponsor(s) of the bill, I obtained the names of persons who were closely involved in the passage of each bill. I then wrote to the sponsor asking him/her to name five persons who were important in stimulating interest in the issue, drafting the bill or supporting the bill once before the legislature. A cover letter and short version of the author questionnaire was sent to each. The questionnaire sent to the policy-makers included only the sociometric list and questions. I wanted some means of assessing the interaction among policy-makers from different states and among policy-makers and definers. In the cover letter, I alerted the addressee that I would try to arrange a telephone interview. All in all, I interviewed 18/22 policy-makers and received completed questionnaires from as many. The cover letter appears in Appendix C.

The Telephone Interviews

Open, informal interviews were conducted and tape recorded with permission. I asked each "policy-maker":

1. What were local pressures or interests which led to the bill's being passed?

2. What was your role in the process of getting the bill passed?

3. Who, or which group, originally stimulated interest in a "brain death" statute?

4. Who was responsible for the language of the bill?

5. How was the link with the legislature provided or arranged?

6. Who, or which groups, were primary supporters of the bill?

7. Was opposition to the bill voiced? If so, by whom? What was
    the substance of the opposition?

Almost all of the "stories" of the policy developments in the five
states in Chapter 3 derive from these interviews.

Each was then asked standard demographic questions regarding his
(there were no women) education, membership in professional organi-
zations, religious background and importance, and political party
affiliation.

In the process of gathering information, I was astounded by
the lack of formal legislative histories and general information
regarding the formation of legislative policy. Social investigation
of the development of policy is bound to the memories of individual
legislators who have been involved in numerous legislative efforts
and who may have been in office for only one term.

Data Analysis

Needless to say, the questionnaires and the content analysis
scheme produced a good deal of information. Of course, I did not use
all the information collected, nor will I report all of the analyses
performed.

Aside from the network and clustering analyses, I cross-tabulated

many variables with the SPSS "crosstabs" program. Consistently the most

interesting and most inclusive variable is the author's discipline--

throughout the discussion, the primary independent variable. A "second-

ary" independent variable, also an organization variable, is "elite" or

"sociometric star" status, obtained from the network analysis.

Statistics

Since I hadn't a random sample, but had in fact begun with a uni-

verse, I did not consider any statistics other than simple measures of

the strength of the relationship between two variables to be appropriate.

For the 2X2 tables, I used phi^2 a "proportionate reduction in error"

measure" based on the chi square and argued by several sociologists to

be more conceptually appropriate than chi square (Mueller, Schuessler,

and Costner, 1970:244-247; Costner, 1965 and Blalock, 1972:300-302).

For 2X3 tables, I used Cramer's V. Though not popularly used in the

social sciences, it is an adequate measure derived from phi for other

than 2X2 tables (Blalock, 1972:297), and it is certainly less clumsy

than assymetrical measures of association in large tables.

The Rest to Come

It might help the reader if the data sources used in the following

chapters were specified once more. Primary research and the information

collected from interviews with definers and policy-makers provide the

basis of Chapter 3, "The History of the Redefinition of Death." Chap-

ter 4, "The Definers: Who They Are," derives from the survey data, par-

ticularly questions 1-5 and 27-34. Questions 16-24 of the definer survey

provide the data for Chapter 5, "Communication Activities in Cultural

Defining." Chapter 5 includes the discussion of the definers' communi-
cation intent, and their participation in public discussion on the topic.
The chapter on social organization, 6, is based on the sociometric sec-
tion of the definer survey (questions 7-14) and the network analysis.
The content and clustering analyses performed on the articles are dis-
cussed in Chapter 7, "Conceptual Approach: Article Content." "The
Policy-Makers and Definer/Policy-Maker Interaction" was constructed from
the policy-maker survey and interviews. Chapter 9, a discussion of what
facilitated and constrained the institutionalization of the redefinition
of death, is an integration of the findings of the previous chapters.

ENDNOTES

[1] Much to my dismay (after the questionnaire had been mailed), I discovered that I had omitted one important name from the list by accident -- Don Harper Mills. The omission may have made a difference in the sociometric integration of policy-makers and definers, since Mills was highly active as medico-legal editor of JAMA and as a primary consultant on legislation in both Kansas and California. But the omission aside, as they say in sociology, "one person doth not social organization make".

[2] Suggested to me by Robert Norton, Purdue University.

[3] Having recorded all the data from the surveys and having constructed the binary matrix for each tie, I was quite familiar with the choice patterns.

CHAPTER 3

THE HISTORY OF THE REDEFINITION OF DEATH

FROM RESEARCH TO STATUTORY DEFINITION

Interest in defining death in terms of the brain began when it became possible to measure the brain's pathological states with respect to cardiorespiratory function. Until cardiac resuscitation and artificial respiration were possible, with the exception of those suffering certain kinds of coma, persons died all at once, and it was not possible to explicitly determine the differential functioning of the three major systems -- the central nervous system, respiratory system and circulatory system. Comas such as Karen Quinlan is suffering at present, in which spontaneous respiratory and circulatory activity is ongoing, must have presented the first notions of something like "brain death" and these cases were probably characterized as "hopeless", or perhaps "irreversible". But there were few such persons who lived without the benefit of antibiotics and other modern supportive techniques. The concept of the definition of death as dependent on brain function follows the development of technologies for measuring brain function, primarily electroencephalography and angiography, and for reactivating cardiac and respiratory function after failure.

Electroencephalography began in 1929 when German psychiatrist, Hans Berger, first demonstrated the possibility of recording the brain's

electrical activity from electrodes attached to the scalp (Woolsey, 1975). From that time on, the electroencephalogram (EEG) was used as a guide for monitoring changes in brain function due to trauma, pathology and drugs. The EEG is a kind of map or graph of the electrical activity of an organ not otherwise accessible to clinical observation or through the use of radiation.

The earliest experiments of the effects of drugs on the brain, as well as the differential functioning of parts of the brain measured by the EEG, were performed on animals (Beecher and McDonough, 1939; Belleville, 1957; Tentler, 1957). In a classic study using cats, Sugar and Gerard (1938) determined the differential death of the major components of the central nervous system when oxygen was withdrawn. They found that the "lower" brain centers, e.g., the spinal cord, midbrain and medulla, had the longest survival time and the shortest recovery time when resuscitated. The "higher" centers however (the cortex or cerebrum) were the first to lose their function, after about five minutes of oxygen deprivation, and the last to regain it (Alderete et. al., 1968; Belleville, 1957). The brain was quite different from other organs: its cells do not regenerate, and its tissue is much more sensitive to oxygen loss than other body tissues.

Hence the problem: other organs of the body will generate new cells to replace others that have been destroyed, and other organs endure oxygen deficiency and are able to be resuscitated. Not so the cortex, the seat of our symbolic and social competencies and person-alities. And when cardiorespiratory supportive and resuscitative technologies were developed, our society was faced with the bizarre fact

of a disintegrated person or an otherwise functioning body of organs housing a dead brain. This bizarre by-product of an otherwise beneficial advance in life-support technology provided a major stimulus to reevaluating the meaning of life, death and personhood.

The Development of Life-Supporting Technologies and the Role
of the Anesthesiologist in Defining Death

Resuscitation technology developed during the forties and fifties, usually in the context of operating room emergencies. Pharmacological and electrical defibrillation of the heart became increasingly effective over the years (Negovsky, 1961). Cardiologists involved in cardiac resuscitation and emergency coronary care (CPR-ECC) were among the first to ask the questions, "When is a person dead?" and, "When can one stop resuscitative measures?"

Respirator technology grew partially out of efforts to transport supplies at high altitudes in non-pressurized planes during World War II. At that time, it was found that positive pressure could be tolerated by pilots. After the war, drugs which paralyze the respiratory muscles were used during anesthesia and mechanical ventilation in surgery and intensive care wards became the daily function of anesthesiologists. The polio epidemic of the late forties and early fifties increased the need for mechanical respiration to restore respiratory function in those whose respiratory muscles had been paralyzed by the disease. (Informant notes).

During this time, anesthesiologists began to utilize the EEG to monitor and control levels of barbiturate and general anesthesia and

hypothermia (Tentler, 1957; Belleville, 1955). Anesthesiologists were thus in an excellent position to notice and describe the electroencephalographic changes that occurred during anesthesia and interruptions in normal procedure such as cardiac arrest and hypoxia. (Maintaining life-support systems during surgery and frequently in emergency settings is their responsibility.)

Some anesthesiologists have been particularly prominent in the definition of death discussion. The first mention of the use of the EEG to determine prognosis for recovery of cerebral function after sustained oxygen loss in the literature reviewed for this study was made by an anesthesiologist (Belleville, 1955, 1957). Henry K. Beecher, the late Henry Isaiah Dorr Professor of Anesthezia at Harvard University Medical School, and by far the most prominent figure in the American definition of death debate, published one of the first studies on the application of the EEG in studying cortical potentials during anesthesia and under the administration of barbiturates (Beecher, 1938). Another anesthesiologist active in the recent definition debate, Vincent Collins, noted the problem of deciding when a person is dead during resuscitation in a statement to the 1956 meeting of the American Society of Anesthesiologists. And it was the International Congress of Anesthesiologists who posed the three well-known questions regarding anesthesiologists' responsibilities in maintaining life in hopeless cases to Pope Pius XII. The Pope's reply is among the most constantly quoted statements in the literature (see McHugh, 1976; Pius XII, 1958).

One anesthesiologist informant mentioned that he had become interested in the topic of "brain" death through research his laboratory had

executed. He had been engaged in research attempting to quantify sub-
jective responses such as analgesia, nausea and drowsiness, and found
the definition of death a topic to which they might apply their
experience. Anesthesiologists, as well as neurologists and neurosur-
geons, would seem to have substantial interest and experience in the
study of consciousness, a background which would lead to an involvement
with the ways in which death, or even personhood, could be defined. It
was frequently the anesthesiologists who assumed responsibility for
initiating the use of respirators in emergency and operating room
situations. They were prominent figures in the settings in which the
first tragic cases of mindless bodihood emerged (Informant notes).

The Electroencephalograph and the Determination
of "Brain Death"

Along with developments in resuscitation and artificial ventilation
during the fifties, progress was made in utilizing the EEG to identify
particular patterns of rhythms on the graph with disorders. The "flat"
electroencephalograph, indicating an absence of cortical electrical
potential under normal amplification, was linked to various transitory
conditions in normal patients and neurological and psychiatric patients
(Adams, 1957). However, a sustained "flat" EEG was considered to be
indicative of a kind of "cortical death". The conditions under which a
"flat" EEG could not be taken as evidence of "cerebral death", e.g.,
barbiturate influence, hypothermia, were discovered as persons in such
states recovered completely after a sustained period of flat recordings
during the 50's. There still remained considerable confusion regarding

when a flat EEG was a valid prognosis of imminent death and when it was
not (Tentler, 1957; Bental and Leibowitz, 1961).

According to most of the neurological informants, European neurol-
ogists, specifically P. Mollaret, M. Jouvet and H. Fischgold, and
P. Mathis originally, explicated the role of the EEG in diagnosing
specific kinds of coma in 1959. Mollaret gave the name "coma dépassé"
to the phenomenon often witnessed in intensive care wards. Most of the
early discussion of the use of EEG to diagnose coma and other neurologi-
cal conditions was published as various National Electroencephalographic
Society proceedings in the international journal, Electroencephalography
and Clinical Neurophysicology (hereafter, for obvious reasons, abbre-
viated ECN).

Legal Ambiguities and the Definition of Death

Besides the medical developments which began to shake the founda-
tions of the traditional concept of death, questions arose in the early
'50s in legal arenas. Specifically, questions were raised regarding
the execution of wills and estates of two joint tenants whose respective
time of death was at issue. In both cases discussed here, one of two
persons died at the scene of the accident, and the other was in coma for
some days afterward and never again regained consciousness. The ques-
tion for the courts was whether or not both persons could be considered
to have died at the same time. In Thomas v. Anderson,[1] 1950, the court
stated: "death occurs precisely when life ceases and does not occur
until the heart stops breathing and respiration ends. Death is not a
continuing event and is an event that takes place at a precise time"

(Capron and Kass, 1972: 93, n. 23). In this statement, the court empha-
sized a conception of death as an event and not a process. They did
not acknowledge, as some "brain death" advocators in recent years have,
that there may be different levels of death (e.g., "social" death,
"metabolic or cellular" death) and that systems and organs of the body
die at different times. In 1950, before the use of defibrillators and
respirators, nearly everyone died "all at once".

In 1958, a childless couple (the Smiths) who had no other benefac-
tors other than each other, were involved in a serious accident in
which Mr. Smith died at the scene. Mrs. Smith remained unconscious for
17 days before she died[2] and Mr. Smith's lawyer attempted to convince
the court by petitioning,

> That as a matter of modern medical science, your peti-
> tioner...will offer the Court competent proof that the
> (Smiths) lost their power to will at the same instant and
> that their demise as earthly human beings occurred at the
> same time in said automobile accident, neither of them
> ever regaining any consciousness whatsoever.

The Supreme Court of Arkansas would not overturn dismissal of his
petition and refused to acknowledge any sense of death other than that
defined in Black's Law Dictionary. "Death is the cessation of life; the
ceasing to exist; defined by physicians as a total stoppage of the cir-
culation of the blood, and a cessation of the animal and vital functions
consequent thereon, such as respiration, pulsation, etc." The court
held ". . . that one breathing, though unconscious, is not dead." In
the opinion of the court, Mrs. Smith did not die at the same time that
her husband died (Capron and Kass, 1972; Halley and Harvey, 1968).

These court decisions and the legal definition of death in Black's

Law Dictionary formed the legal barrier to physicians' use of a defini-
tion of death as dependent on brain function in the late 60's and 70's.

American EEG Research and Redefining Death

American neurologists and electroencephalographers, principally

Robert Schwab of Harvard Medical School, and Daniel Silverman, Graduate

Hospital, University of Pennsylvania,[3] responded to Fischgold and Mathis

and Mollaret's research in the early '60s and began to collect the data

that provided the basis for the Harvard Committee's 1968 recommenda-

tions and the major reports and studies conducted under the auspices of

the American EEG Society and the National Institute of Neurological

Disease and Stroke (NINDS).

Schwab had watched patients whose brains he suspected were

destroyed lie attached to unsophisticated mechanical respirators for

days on end, and was rather disturbed by the useless prolongation of

these lives. As head of the EEG department at Massachusetts General

Hospital in Boston, he began to collect EEG tracings of some of these

patients and compared them with autopsy and other pathological findings

in the late '50s, obtaining the first evidence of what was later called

"respirator brain" -- a state of necrolysis or liquefaction of brain

tissue noted during autopsy of patients who had been supported on

respirators for a considerable period of time after the death of the

brain.

At the American Electroencephalographic Society's annual meeting

in 1962, Schwab (and Silverman) presented papers summarizing their

findings. Schwab and his collaborators posed the definition of death

problem for the first time in America in the form those arguing for the

definition as a solution to the problem of useless prolongation of irre-

versible coma would use again and again in the late '60s and early '70s.

He explicitly titled the paper, "EEG as an aid in determining death in

the presence of cardiac activity (ethical, legal and medical aspects)",

and began,

> The new cardiac stimulation, other techniques, and compact
> respirators have made it increasingly possible to revive the
> apparently dead. Fortunate cases recover both respiratory and
> higher central nervous system function as well as normal car-
> diac activity. This communication is not involved with these
> patients. The unfortunate situations, where the anoxia was so
> long that destruction to the respiratory centers and higher
> nervous system occurred, but where cardiac function was restored,
> are the subject of this report. In these cases, a human heart-
> lung preparation results that may be viable for many days. For
> hundreds of years death was determined by the absence of a heart
> beat. Therefore, the presence of a pulse, blood pressure, and
> audible heart beat makes it necessary to establish another
> indication of death . . . on such cases the prolongation of
> cardiac circulation serves no purpose, is a tremendous financial
> and emotional stress to the relatives, and a severe demand on
> hospital personnel and equipment. (Schwab, 1963: 15)

He went on to list the neurological and EEG criteria for declaring

death which were decided upon after several cases of establishing death

in Massachusetts General, presumably by the Neurology department (and

perhaps some other departments) and the EEG Lab. It was this research

and data which formed the basis for the Harvard Ad Hoc Committee's

Report in 1968; Schwab was a member of the committee. One informant who

had worked very closely with Schwab at Massachusetts General stated

Schwab never got the credit due him for this groundwork.

One of Schwab's colleagues at Massachusetts General with sensi-

bilities similar to Schwab's, Hannibal Hamlin, wrote the first widely

cited article explicating the general artificial life maintenance problem and suggesting use of the EEG in declaring death; "Life or Death by EEG" was published in JAMA in 1964. The essay was presented first at the 1964 AMA convention, and elicited strong reactions from physicians and press alike. Quoting Pindar's Third Pythian Ode and discussing the cultural meaning of the heart and blood (among other things), Hamlin argued "The sanctity of human life is not generated by cardiac signs of its presence or absence when the brain is already dead . . . Certainly the human spirit that emerges in man's unique individuality is the product of his brain, not his heart" (p. 113).

Early Cadaver Organ Transplantation

During the first half of the '60s, kidney transplantations from cadavers were performed in Europe and at Peter Bent Brigham Hospital in Boston, along with Massachusetts General, part of the Harvard Medical School. Peter Bent Brigham surgeon, Joseph Murray, who was also a member of the Harvard Committee, performed the first successful abdominal kidney transplant from a living twin donor in 1954 (Moore, 1972) and was also the first to perform a successful cadaver transplant with the use of artificial cardio-pulmonary support on patients whose brains had been destroyed from oxygen deprivation.

However, the first real stimulus toward the redefinition of death really came later with the development of cadaver transplant technology and immunology. In other words, it seems that the presence of "human lung preparations" was not enough to pressure medicine and law into acting to resolve problems, but the development of another new medical

technology, transplantation, was.

The first case in which a physician was challenged for using brain criteria for declaring the death of a prospective kidney donor took place in England in 1963 ("The Moment of Death", 1963: 95). The case, Potter, was the first of several to come in the late '60s and '70s regarding potential heart donors. In Potter, a man had been hit on the head in a brawl, taken to the hospital where he stopped breathing, and was placed on a respirator. With the consent of the victim's wife, he was then prepared for the removal of one of his kidneys. After the operation, the victim was disconnected from the respirator and did not breathe spontaneously. A medical witness said that he had virtually died when he first stopped breathing, though legally it would be more correct to say that he had died 24 hours later, after the operation. A neurosurgeon testified that removal of the kidney in no way contributed to his death, but that cranial injuries incurred during the brawl had (Ibid.).

It is important to understand that kidneys which are continually oxygenated with blood circulated with the use of a respirator make for more successful transplants; that is the reason for keeping persons who are otherwise dead on a respirator. The physicians who disconnected the respirator after the kidneys were removed did not obtain or cite evidence that Potter was actually dead according to brain criteria (Ramsey, 1970: 71). The muddle over "virtual" and "legal" death and the lack of a reliable basis on which the declaration of death was made helped to bring the question, "When is a person dead?" into the center of medical-ethical concerns in Europe and England.

The Ciba Symposium: Ethics in Medical Progress

In March, 1966, 21 physicians, five lawyers, one theologian and
one science writer convened in London to participate in a Ciba Founda-
tion Symposium entitled Ethics in Medical Progress: With Special
Reference to Transplantation. Attending the first well-known inter-
disciplinary symposium touching on the topic of death definition were
Harvard's Murray, T. E. Starzl, C. E. Wasmuth, G. E. Schreiner (from
the U.S.) and other prominent transplant surgeons and medico-legal
experts from Britain and Europe. In addition to discussing the medical
and ethical problems of transplantation, issues of informed consent in
human experimentation and the allocation of scarce resources (trans-
plant organs, hemodialysis) were also raised.

Many of the assumptions and emphases made in this symposium for
the first time (to my knowledge) were echoed again and again two to
eight years later. For some reason, the symposium provided a ground-
work and conceptual base for the technical and medical concerns, but
the several trenchant philosophical and ethical concerns raised seemed
to go almost unnoticed for several years. For instance, Starzl, Univer-
sity of Colorado's well-known transplant pioneer, posed the question:

> Such a practice [establishing 'Brain' death for 'storing'
> the kidneys in situ, i.e., in the corpse while the kidneys
> are well-oxygenated] is advantageous for the recipient, who
> can thus be assured of receiving a better kidney, but does
> this pragmatic consideration justify a legal redefinition of
> death, and if so, upon the basis of what infallible evidence?
> (Wolstenholme and O'Conner, 1966:67)

Embodied in his question were relatively implicit mentions of 1) the
tension between recipient benefit and potential danger to the donor;
2) the question of whether or not any practical consideration should

be the basis for a redefinition of death and 3) some recognition of the
confusions and lack of medical consensus with regard to the procedures
of declaring death. The first and last of these concerns were echoed
again and again in the periodical literature for the next eight years.
The second has had a different sort of career as a more subtle consid-
eration for a country and profession with a highly operant technological
imperative (see Chapter 9). The ethical notion that a profound cultural
notion should be redefined without regard at all to pragmatic considera-
tions, such as transplantation, or even without regard for the family
of the irreversibly comatose or for the other patients who could use
them, has been expressed only a very few times in the literature
analyzed for this study.

Other matters discussed during this symposium were:

a) the value of the flat EEG as a criterion with respect to other
clinical criteria for determining death, such as the complete absence
of spontaneous respiration, complete absence of reflexes, complete bilat-
eral mydriasis (excessive pupil dilation), and falling blood pressure;

b) the necessity of dissociating the transplant team from donor
care;

c) the use of angiography to show interrupted blood flow to the
brain as a better sign of death than the EEG;

d) what kind of issue, e.g., theological, ethical, medical, legal,
the definition of death is;

e) the disparity between medical and legal definitions of death;

f) the confusion surrounding the issue which might give rise to
doubts about medical ethics and transplantation among the lay public; and

g) a conceptual distinction which has a rather interesting history and did not catch on in the literature until rather later, namely that the question of when to discontinue extraordinary measures to keep a person alive is different from and should not be confused with the question of at what point a man is dead. Perhaps a major question for this study, and one which may not be answered satisfactorily, is why, given that the Ciba symposium is widely cited, did these same issues need to be stated again and again in the literature written primarily from 1967 to 1974?

The Ciba symposium was the first major statement of the need for a redefinition of death with respect to facilitating organ transplantation and of the major problems and confusions which arise given that need. Ways of expressing the problem at times suggest a very early, perhaps immature, conception of the ethics involved. For instance, one of the participants stated, "I would like to tell you what we consider as death when we have potential donors who have severe cranio-cerebral injuries" (Wolstenholme and O'Conner, 1966: 69, emphasis added). This statement illustrates an instance of heartily defining death for an avowed purpose. It would be shocking to find a similar statement after 1972, after most of the ethical criticisms had been made and the legal dangers had been specified.

The Definition of Death and Euthanasia

In 1967, there were two major problems focusing a need for updating the definition of death -- transplantation and the problem addressed by Schwab and Hamlin, the need to cease the useless

prolongation of dying. At this early point in the redefining process, persons with irreversible coma or brain death were considered to be more "hopeless" than actually "dead" except by a few persons. It was as if one couldn't quite go _that_ far and deny that a beating heart meant life. Even Hamlin, who, I believe, actually considered the bodies which he described as "heart-lung preparations" to be dead, stated "resuscitative devices can maintain the look of life in the face of death" (p. 113) and ". . . some of the nobility in death would be preserved where it has frequently been forfeited through our slavish and superstitious refusal to acknowledge that St. Peter is at the Gate of Charon at the Crossing" (p. 114), when he _might_ have gone further and said "that they can maintain the look of life upon the face of death" or that the Gate had been entered or the River Lethe actually crossed (Ramsey 1970: 86).

Hamlin and others have frequently described that kind of dying as ignoble. Hence the advocacy for "death with dignity". It takes two slight conceptual slips to change the meaning from "cease useless prolongation", or "allow a person to die", to "withdraw treatment" to euthanasia. For the eight years following the publication of Hamlin's article, the issues of the definition of death, withdrawing treatment and euthanasia were thickly intertwined. Persons who were actually _dead_ according to the new criteria were continually referred to as "virtually dead", "irreversibly comatose", or, in other words, "not quite dead", making it easy enough to confuse the definition of death with euthanasia, and several early articles published in 1967 and 1968 did just that.

Three frequently cited articles from that period illustrate some of the confusions. Arguing for a "definition of death based on twentieth century medical facts", psychiatrist Frank Ayd holds: "when the circumstances justify it, the law should recognize that a physician should be permitted to discontinue extraordinary means of sustaining life when clinical death is imminent and inevitable." (1967: 83). Since all death is inevitable and one should be able to live until death is literally upon one and not merely "imminent" or in the offing, suggesting that physicians direct the course of one's dying in this way is to suggest that physicians "hasten" death or commit euthanasia, rather than simply adhere to a new definition.

Law professor George Fletcher, arguing that turning off a respirator is an omission and not an act of homicide, argues similarly:

> The proposals for vesting physicians with greater flexibility in caring for terminal patients are of two strands. The first is a movement toward instituting voluntary euthanasia, which would permit the medically supervised killing of patients who consent to death. These proposals warrant continued discussion and criticism, but they apply only in cases of patients still conscious and able to consent to their own demise. Separate problems adhere to the cases of doomed, unconscious patients who may be kept alive by mechanical means. In the latter area, the movement for reform has stimulated the pursuit of a definition of death that would permit physicians to do what they will with the bodies of hopeless, "legally dead" patients. (1967: 1000-1001, emphasis added).

Surely, the fated, hopeless, or doomed patient, even kept alive by mechanical means, is not the same as a dead patient; and surely, physicians may not do what they will, either to obtain organs for someone else or to cease treating a person because his case is "fated", "doomed", "terminal" or "hopeless". Neither Fletcher, Ayd nor Hamlin

is arguing that such patients are actually dead, but rather that they may be declared or considered dead on the basis of a new definition of death.

In 1968, anesthesiologist Vincent Collins distinguished between letting a patient die and euthanasia, arguing that the latter is essentially murder, whatever the intent. In this chain of articles, Ayd and Fletcher citing Hamlin and Collins quoting Fletcher, all authors are concerned with the quality of life and the dignity of their dying patients. However, Collins comes closest to stating the relationship between the definition problem and the "withdrawing treatment" issue as a matter of not opposing death, or of allowing to die.

> If after some time all measures are obviously not effective and are not reversing the dying process then the measures are failing. . . To persist may produce the appearance of life, but this is most often technical or mechanical life. . . It is the physician's obligation to cease efforts early when they are determined to be ineffective in the total remanimaltion process and objectives. The patient should then be allowed to die. He has this right; he should not be cheated of a peaceful death when the physician is powerless to restore consciousness. A vegetating patient, hopeless and unresponsive, and showing no spontaneous activity, should be allowed to die peacefully. Physicians should make the dying process dignified. (1968: 391)

At any rate, at this stage, death, "hopeless state", "imminent death", "virtual death", "doomed" were all muddled together in most discussions on the topic (Ramsey, 1970:77). Clarification was urgently needed, and it seems that few authors, if any, noted David Daube's comment at the 1966 Ciba Symposium that the question, When is a person dead? is conceptually and analytically distinct from, "When should treatment be withdrawn?

Modern Concern Over Premature Burial

Confusions between "hopeless" and "imminent death" and "death",

as well as the suspicion that the major motivation behind the redefini-

tion effort was to obtain organs for other people, caused the lay person

just concern. Add to this obvious concern a few cases reported in the

mass media which depict recovery from "brain death", and public confu-

sion becomes a problem for the professionals.

The January 15, 1968 issue of Newsweek reported that a leading

Russian theoretical physicist suffered extensive brain damage in a car

accident. According to medical opinion, he was not likely to live and

would be badly brain-damaged if he did. After a coma of sixty days

duration, he regained consciousness and resumed his position as head of

his department of theoretical physics.

In addition, Science News, in 1969, reported a case in which a boy

had been brought to a hospital in Israel with severe brain damage and

who met the five criteria for "brain death" set down by the Council

for the International Organization of Medical Science. The physicians

in charge did not give up and kept the boy on drugs and a respirator.

The boy recovered to normal health.

And on television in the spring of 1970, the "Bold Ones" televised

a drama depicting the recovery of a man with severe brain damage, a

"flat EEG" and all the rest of the makings of "brain death". The

young man miraculously "conquered" the state of brain death -- obvi-

ously a "reversibly ill person, mistakenly thought dead". (Lossing,

1970, emphasis added).

The message seems quite clear: the redefinition of death is so

much hocus-pocus, fraught with indeterminacy and error, a mere means to an end (ending one's life for someone else's benefit), and has little in common with the old and sure ways of determining death. The fact is, of course, that when accepted criteria are met, humans do not "miraculously" or otherwise recover from such a state. However, the fear remains that there may be mistakes -- that in the haste to obtain organs or get rid of burdens, people will be mistakenly declared dead and either will be killed or buried alive.

In 1968, a Kansas City physician published a paper addressing the issue of premature burial and public fear (Arnold, 1967). In "Public Attitudes and the Diagnosis of Death", Arnold discussed the history of attitudes toward premature burial, current attitudes toward the new definition of death and the increasing need for public forums on the issues involved in transplantation and death determination.

The "Replaceable Muscle"

The event which, according to many authors, consummated concern over the definition of death was the first heart transplant conducted by Christian Barnard in December, 1967. Nothing quite points up the need for a new interpretation more vividly than the total usurpation of an old interpretation. The seat of life, personality, love, let alone the object of a great deal of cultural concern for ages, had, as Ramsey put it, become a replaceable muscle. We can imagine some of the first thoughts that the lay public had: Did they kill one person by removing her heart in order to prolong or aid the life of another person? How could anyone call a person with a heart still beating,

dead? And, at any rate, the heart transplants of 1967/1968 (cf. Fox and Swazey, 1974; Ramsey, 1970) brought many other questions to the fore as physicians and other professionals stumbled through various procedures and legalities (see below discussion of Tucker v. Lower and the California statute).

Obviously needed were some authorized guidelines which represented a wide degree of consensus based on empirical findings regarding the death of the brain and the death of the rest of the human organism. The medical professional also needed legal assistance in order to avoid the trouble of situations such as Potter. Legitimation less formal than legal precedent or statute came in 1968 in the form of international committee, symposium and medical school faculty recommendations for guidelines. These reports and documents specifying medical policy represented the consensus of selected and highly regarded physicians and lawyers. In 1967 and 1968 several symposia on the meaning of death and problems in recent medical advances were held and published (cf. World Medical Journal, 14 (5), 1967; North Carolina Medical Journal, November, 1967; Villanova Law Review, 13 (4), 1968).

In the summer of 1968, two statements, now widely accepted on the definition of death and procedures for determining death, appeared. One came from the World Medical Assembly meeting in Sydney, Australia. The Declaration of Sydney affirmed that death is not an event, but a process in which the death of the brain is the most important point, and offered several suggestions regarding procedures for determining when that point has occurred. The Harvard Ad Hoc Committee to Examine the Definition of Brain Death (Harvard Committee) published their statement

"A Definition of Irreversible Coma" in August, 1968. The major American statement of medical policy, hereafter referred to as the Harvard Report, addressed both the problems of futile prolongation of life and trans- plantation, as did the Declaration of Sydney.

The Harvard Committee

Early in 1968, a committee composed of nine physicians, one lawyer with a specialty in legal medicine, one medical historian and one theologian/ethicist, all from Harvard University, began meeting to discuss the problem of death definition. All members of the committee, and especially those in the neurological sciences, are nationally and internationally known members of their respective disciplines. The committee members are/were titled professors and chairmen of their departments. During the several interviews and discussions I had with physicians, three were constantly referred to as either the fathers or grandfathers of American neurology or the neurosciences -- Raymond D. Adams, Derek Denny-Brown and William Sweet. Among them, as well, were the surgeons who had conducted the first kidney transplants. In short, this was a blue-ribbon, high status and clout-bearing committee, and their work became an internationally respected statement of guide- lines -- the Harvard Report. The following discussion of the committee, its development and politics, is based entirely on interviews with seven of the thirteen members.[4]

The committee was organized because of a sense of urgency felt by members of the staff of Massachusetts General Hospital who everyday faced the problems of irreversible coma and artificial life maintenance.

Among those most concerned were Schwab (discussed previously), Adams
and Beecher, each long interested in the problem of defining death in
terms of brain function. Another sense of urgency was felt by those
members of the committee engaged in kidney transplantation at Peter
Bent Brighman Hospital. Neither Massachusetts General nor the Brighman
conducted heart transplantation, though much of the experimental work
on which heart transplantation was based -- kidney transplantation --
was conducted at these hospitals. One surgeon informant confided
"Boston knew better [than to conduct heart transplants], knew that the
effort was doomed to hopeless failure".

At first the committee consisted of Beecher, Adams, Schwab and
William Curran, the medico-legal expert in the group, and later the
committee was dominated by the original four. Beecher was the one
who had originally gone to the dean of the medical school and suggested
that a committee be formed to examine the definition and to make badly
needed recommendations. It was Beecher who issued his own invitations
to join; in many respects, the committee was Beecher's "baby". Schwab
felt that enough empirical data had been gathered to take a strong
position on the issue, and it was thought that a position taken by a
group of Harvard faculty (primarily medical faculty) would be a
respected document, not only in our own country but throughout the world.

Henry Beecher

If one were to interpret the Harvard Medical School's contribution
to the redefinition in terms of a central figure or a "great man",
Henry Beecher would immediately come to mind.[5] Beecher (who died in

1976) was a strong-willed, determined person who was among the very first to stimulate public and professional concern over ethical issues in medicine. In a paper published in NEJM in 1966 (and subsequently relayed by wire services in newspapers all over the country), Beecher was the first to "blow the lid off" the morally objectionable treatment of human subjects in experimental medical procedures. In the furor that followed the publication of "Ethics and Clinical Research", Beecher was ostracized by members of his own profession. He was destroying the profession by "spilling the beans". Even a good friend of his (the editor of a medical journal) suggested that persons would rather receive care from a certain physician (whom Beecher had described in his article as having infected children with hepatitis for experimental purposes) than from a zealot (referring to Beecher, of course). Beecher was quite alone at that time in his public statement. According to one informant, it was Beecher's strength and vision which later directed the Harvard Report.

Beecher's article on human experimentation was one of the primary stimulants to the organization of a conference on the "Ethical Aspects of Experimentation with Human Subjects" by the American Academy of Arts and Sciences (AAAS) and its president at the time, Harvard law professor Paul Freund (Daedalus, 8(2), 1969). The conference took place as a continuing seminar over two years with meetings in November, 1967 and September, 1968. Beecher presented papers in both meetings, one of which, entitled "Ethical Problems Created by the Hopelessly Unconscious Patient", was subsequently published in NEJM (1969). The other paper, "Scarce Resources and Medical Advancement" was published

in the 1969 Daedalus volume.

Beecher had been concerned about the "respirator problem" long before the Harvard Committee was formed. He had been engaged in research on consciousness and pain throughout his career and, according to one informant, had a close colleague who was kept at "functional cadaver status" at Massachusetts General. Both factors seem to have contributed to his involvement with the issue.

The "Ethical Problems . . ." paper was one of the first statements to specify the economic, ethical and social problems raised for others when patients are kept at "functional cadaver status". Beecher's bearing on the issue was taken clearly from a "social need", or "common good", perspective. Redefining death would make organs available for transplantation and would make other scarce resources, such as money and medical equipment, available to those in need. However, in the article, Beecher also warned ". . . . a new definition of death, when there are those who have a vested interest in it, could lead to public questioning and doubt and an unfortunate blurring of the line between this and euthanasia." (p. 1429).

For all the points raised, the paper is riddled with confusions, some of which appeared later in the Harvard Report and some of which were criticized by Rutstein (1969) and Jonas (1969) during the AAAS symposium (1972). For example, throughout the paper, Beecher refers to the "respirator problem" cases as "hopelessly unconscious", "hopelessly injured or damaged" and "hopelessly brain-damaged" -- phrases which would raise doubts in the reader as to whether Beecher is talking about a terminal cancer patient (dying, and not dead), an injured auto

accident victim with brain-damage, a comatose person who <u>just</u> <u>might</u> <u>be</u>
another Rip Van Winkle, the death of an organ, the process of dying
or just plain death. Beecher, however, was very concerned that trans-
plantation not be added to the list of ethically questionable procedures
in recent medical experimentation and thought that many of the potential
ethical problems could be thwarted with a careful examination of the
definition of brain death.

Although Beecher had said that this was an issue that required
the contribution of lawyers, theologians and philosophers, as well as
physicians, how interdisciplinary in function was his committee? I had
been told by another informant not associated with the committee that
Beecher so dominated the group that it was interdisciplinary and
cooperative in name only. According to him, Beecher had waited until
the summer to write the Report and wrote it himself while others were
away, precluding contributions and feedback from the other members.
While Beecher was certainly an overbearing person, or so I've heard,
at least one member of the committee gave Beecher considerable credit
for circulating drafts and prompting his secretary to pursue members
for their comments and criticisms. The report definitely went through
changes, presumably because of criticisms and comments. It is also the
case that two members of the committee, who were not physicians and
who were located on the Cambridge campus, were on leave in the spring
and summer. And, meetings were sometimes held at places and times that
were convenient for physicians at Massachusetts General or the Brighman,
but not as convenient for those on the Cambridge campus. I would con-
clude that the report represents the opinions, values and knowledge of

representatives of several medical areas and a lawyer who had worked closely with the medical school on other occasions. The Report does not represent the thinking and knowledge of one man nor does it really represent the thoughts of the extra-medical members of the committee other than Curran.

With his ethical sensitivity and courage, and with no little political savvy, Beecher organized the committee and the Report. He was not the only contributor, but he was the moving and moral force behind the single most important medical contribution to the redefining process. The following is a summary of the contents of the Report.

The Harvard Report — "A Definition of Irreversible Coma"

As reasons for defining irreversible coma as a new criterion for death, the report included: 1) the respirator problem and the burden resulting therefrom "on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients" and 2) the fact that "obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation" (p. 337).

Acknowledging that more than medical problems are at issue, the committee hoped that the Report would provide a beginning toward better understanding of the legal, moral, ethical and religious issues. Their task, however, was to determine the characteristics of a permanently nonfunctioning brain.

The criteria:

1) <u>Unreceptivity or unresponsitivity</u> - total unawareness to externally applied stimuli and inner need and complete unresponsiveness. . . Even the most intensely painful stimuli evoked no vocal or other response, not even a groan, withdrawal of a limb, or quickening of respiration.

2) <u>No Movements or Breathing</u> - Observations covering a period of at least one hour by physicians is adequate to satisfy the criteria of no spontaneous muscular movements or spontaneous respiration or response to stimuli such as pain, touch, sound, or light.

3) <u>No reflexes</u> - Irreversible coma with abolution of central nervous system activity is evidenced in part by the absence of elicitable reflexes. The pupil will be fixed and dilated and will not respond to a direct source of bright light. . . Ocular movement (to head turning and to irrigation of the ears with ice water) and blinking are absent. There is no evidence of postural activity (decerebrate or other). Swallowing, yawning, vocalization are in abeyance. Corneal and pharyngeal reflexes are absent. . .

4) <u>Flat electroencephalogram</u> - Of great confirmatory value is the flat or isoelectric EEG. We must assume that the electrodes have been properly applied, that the apparatus is functioning normally, and that the personnel in charge is competent. . .

All the above tests shall be repeated at least 24 hours later with no change. The validity of such data as indications of irreversible cerebral damage depends on the exclusion of two conditions: hypothermia (temperature below 90F (32.2C)) or central nervous system depressants, such as barbiturates). (pp. 337-338)

The committee went on to advise that the determination of death be made only by a physician and that death should be declared <u>before</u> the respirator is turned off. "The decision to do this and the responsibility for it are to be taken by the physician-in-charge, in consultation with one or more physicians who have been directly involved in the case. It is unsound and undesirable to force the family to make the decision" (p. 338).

The Report reviewed some of the legal issues, citing <u>Thomas v.</u>

Anderson, Smith v. Smith and the definition of death in Black's Law
Dictionary. Curran (the author of this section) recommends that there
be no statutory change in the law "since the law treats this question
essentially as one of fact to be determined by physicians" (p. 339).
The only circumstances at that time under which Curran would welcome
a statute were: the presence of great controversy or when physicians
cannot agree on the new criteria. The Report then discussed some of
the statements made by Pope Pius XII on his position regarding the use
and maintenance of extraordinary means.

The Harvard group did not recommend the European criteria dis-
cussed during the Ciba Symposium -- neither heavy reliance on the EEG
and falling blood pressure nor cerebral angiography, the injection of a
contrast dye into the arteries to provide an indication of cerebral
blood flow. The secondary status attributed the EEG in the Report is
surprising both in terms of Schwab's and other research on the EEG's
use in diagnosing coma and in the way the Report was subsequently
interpreted in the literature and the popular press: brain death =
flat EEG. Electroencepalography has been viewed with disdain by some
physicians because of the distance of the procedure from ordinary
"pure" clinical neurological assessment. Perhaps the presence of some
of the most prominent "old school" neurologists on the committee
discouraged a lack of primary reliance on the EEG.

The Report has been criticized for being too conservative -- both
in terms of "overlong" time interval required for reapplying the
criteria (24 hours) and in terms of the fact that the criteria refer
to the functioning of the whole brain and not simply the cerebrum or

neocortex. In other words, the Report is no help in alleviating the agony of many cases similar to Karen Quinlan's. At the time of the 1966 American Neurological Association meeting, Schwab stated that his emphasis on lower brain function (as opposed to higher brain function) was a safeguard: if the lower brain centers are destroyed, it can be assumed that the higher centers are also dead (Alderete et al., 1968:20).[6] As late as 1975, a colleague of Schwab's and Adams' told me that he did not feel that a determination of "neocortical death" -- death of the higher centers of the brain only, with spinal reflexes and respiration still intact -- could be made reliably and certainly. Perhaps this first statement of medical policy is appropriately conservative.

Another recommendation contained in the report and of some concern is that the decision to discontinue treatment when a patient fulfills the criteria should be the physician's and not the family's. Such a policy seems to ignore the fact that physicians face less risk if the decision is the family's and not their own. There are also those who argue that decision is not the physician's to make. The committee's decision to state their policy in that manner was based on their experience with the practice of handling such cases at Massachusetts General (Informant notes).

Before the Report, the practice of handling cases of "brain death" at Massachusetts General went something like the following: The physician would go to the family and say that in her opinion, there was no hope, and it was up to the family to decide whether or not they wanted to continue artificial support. She would give the family some

time to adjust to the news and approach them again, saying that there had been no change nor was there likely to be any change, again emphasizing that the decision to discontinue treatment was theirs.   In effect, the physician would lead the family through a learning and accepting process -- a process which took about three days. The staff became concerned that they weren't doing much for the patient, the community or the family and that, in addition, they left the family with the guilt for making the final decision regarding the death of their loved one. They thought that if there were medical agreement that the patient was dead, then the family should be told the patient is dead. Thus the committee decided against "the self-protective placing of the decision in the hands of families - when there wasn't any decision-making which they would do which could do the patient any good" (Informant notes).

At this point in the process of redefining death, 1968, however, it wasn't clear that "brain death", "irreversible coma", "virtual death" or "hopelessly unconscious" meant death in the sense to which most persons are accustomed. And the Report did not clearly state that its recommendation concerned the assessment of death. It would seem that there are many cases (not death) in which declining further treatment or withdrawing treatment is properly and most ethically a matter for the patient and/or the family to decide -- not the physician.

Several ethical and conceptual critiques were levelled at the Report by ethicists and philosophers, although only a couple were published before 1970 (cf. Rutstein, 1969 and Jonas, 1969). Hans Jonas,

Alvin Johnson Professor of Philsophy at the New School of Social Research, criticized both arguments put forth by Beecher during the AAAS symposium and the Report in a paper he delivered as a participant in the same symposium, "Philosophical Reflections on Human Experimentation". In response to a statement made by Beecher ("A strong case can be made that society can ill afford to discard the tissues and organs of the hopelessly unconscious patient; they are greatly needed for study and experimental trial to help those who can be salvaged"), Jonas argued that discarding implies proprietary rights and no one can discard what doesn't belong to him: "Does society then own my body?" (p. 227). As for the Harvard Report, Jonas had no objection to a definition of irreversible coma which allows the cessation of artificially supported life functions in order to _let_ a person die all the way. However, to _keep_ persons from dying all the way and to use the redefinition for transplantation ". . . . oversteps what the definition can warrant" (p. 244). Jonas' essay contains the first arguments "against the stream", i.e., the needs of society for the integrity of the individual person's dying.

Without knowing the exact borderline between life and death, we cannot use the definition for anything other than allowing a person to die and, for that instance, knowing that he is in irreversible coma is enough, according to Jonas.

> For the second purpose (transplantation) we must know the borderline; and to use any definition short of the maximal for penetrating on a _possibly_ penultimate state what only the ultimate state can permit is to arrogate a knowledge which, I think, we cannot possible have. . . When only permanent coma can be gained with the artificial sustaining of functions, by all means, turn off the respirator, the

> stimulator, any sustaining artifice, and let the patient die;
> but let him die all the way. Do not, instead, arrest the
> process and start using him as a mine while, with your own
> help and cunning, he is still kept this side of what may in
> truth be the final life. Who is to say that a shock, a
> final trauma, is not administered to a sensitivity diffusely
> situated elsewhere than in the brain and still vulnerable to
> suffering? a sensibility that we our selves have been keeping
> alive? No fiat of definition can settle this question.
> (Jonas, 1969:244)

In all the literature, it is difficult to find a more passionate protec-

tor of the individual and the sanctity of his body than Jonas. And

there are not many who are more fervent advocates of the rights of

others than Beecher. It is this tension -- the tension between the

individual's right to an uninterfered-with dying and the rights of the

family, the community and other patients, or the "common good" -- which

is the major fulcrum of the definition of death debate. Jonas' critique

was one of the first of several to come which generally questioned the

appropriateness of redefining death and specifically questioned the

morality of redefining death in order to facilitate organ transplants.

Although criticized almost as soon as it was published, the Harvard

Report was easily and widely accepted both in the U.S. and abroad. It

is still, in 1979, the primary reference document of medical policy for

determining death in terms of brain function. Even given the problems,

it was a document of medical legitimation and consensus regarding the

redefinition of death. Interestingly, when Beecher approached the

editor of the New England Journal for publication of the report, he was

told that it was "too controversial". JAMA was a second choice.

<u>1968</u>

In many respects, 1968 was the watershed year for the redefinition
debate, as it was for many other issues and events in our society. The
year of heart transplantation, 1968, is the year which marked the heart's
change of status from the seat of life and personality to a replaceable
muscle and which marked the need for some other locus of death for the
heart donor. The process of redefining death became more complex as
technical and legal difficulties arose, and conceptual and ethical
problems became more apparent.

Flat EEG or Electrocerebral Silence?

By 1968, at least three terms were used interchangeably to refer
to what people thought was one criterion for brain death: "flat EEG",
"isoelectric EEG" and "electrocerebral silence". Regardless of the
secondary status accorded the flat EEG in the Harvard Report, there
was some acceptance of the flat EEG as the primary criterion for deter-
mining death. There were problems: In 1966 a case in which a woman
with a "flat EEG" had eventually recovered with only a mild organic
brain syndrome had been reported (Levin and Kinnell, 1966). In 1968,
Jum Kimura and his colleagues from the University of Iowa Medical
School published an article in which they distinguished between the
flat EEG and the isoelectric EEG, between a very low amount of cerebral
activity at normal machine amplification and no activity at all at
maximum amplification. They suggested the record taken on the woman
who recovered was at normal amplification rather than maximum amplifi-
cation and that resuscitation was probably begun immediately, thereby

assuring some circulation to the brain. They conclude, happily for us all, that "From a technical point of view, therefore, it is important to utilize the highest amplification technically possible for at least part of a record suspected of being isoelectric" (p. 511).

A year earlier, in 1967, the president of the American Electro-encephalographic Society appointed an Ad Hoc Committee to gather information regarding current procedures in utilizing the EEG as one criterion for determining death (Silverman et al., 1968). On the committee were Daniel Silverman, Robert Schwab (both early pioneers in determining death by electroencephalography), Michael Saunders and well-known Columbia neurologist, Richard Masland. They gathered information on such technical matters as the maximum gain setting used in obtaining records, the length of the record and interelectrode distances and resistances. In their report, published in JAMA one month after the Harvard Report, the committee recommended that the term "electrocerebral silence" (ECS) be used and specified guidelines for assessing electrocerebral silence. It was Daniel Silverman who organized another collaborative study, after his death sponsored by the National Institute of Neurological Diseases and Stroke (NINDS). The NINDS research has included the gathering of data on methods for determining death from hospitals throughout the United States.

Medico-Legal Collaboration

As the new definition began to be used more frequently in both heart and kidney transplant situations in 1968, it became clear to some observers that a conflict between legal and medical definitions of death

was imminent. In fact, it was. In 1968, in Virginia, the first trans-
plant case (Tucker v. Lower) in which physicians were accused of causing
death by removing the heart of the donor occurred, although the case did
not come to trial until 1972. Two widely cited authors, law professor
William Harvey and physician-lawyer M. Martin Halley, jointly published
two articles in 1968 and 1969 discussing the conflict, describing
relevant legal precedent and recommending the interdisciplinary collab-
oration of physicians and lawyers in resolving the issues.[7] Halley and
Harvey also recommended a uniform law defining death in terms of brain
function. They proposed a straightforward definition, straightforward
especially in light of the wording of the first statute redefining
death, which was enacted in Halley and Harvey's home state, Kansas, two
years later.

> Death is the irreversible cessation of all of the following.
> (1) total cerebral function, (2) spontaneous function of
> the respiratory system, and (3) spontaneous function of the
> circulatory system (1968:105).

The UAGA

Transplantation became the subject of many a law review article as
law students (the primary contributors and editors of University Law
Reviews) took interest in the topic and its legal complexities. And
most discussions of transplantation contained a paragraph or two on
the redefinition of death. In 1965, the Commission on Uniform State
Laws appointed a committee to design a uniform statute which would
provide each state with a basis for legislation regarding transplanta-
tion (Moore, 1972:226). On July 30, 1968, three years later, the
Uniform Anatomical Gift Act (UAGA) was approved at the National

Conference of the Commissioners on Uniform State Laws. Law professor

Blythe Stason chaired the committee and twin brothers, Alfred and Blair

Sadler, physician and lawyer, respectively, were consultants (Sadler,

Sadler and Stason, 1968).

The act concerns the negotiation of organ exchange with respect to

both living and cadaver donors; among them: the respective authorities

of individuals, minors, and next of kin to donate organs, the conflict

of interest between donor and next of kin, permissible donees and donee

obligations, the mechanism of the gift and the protection of physicians

and others from liability. The commissioners concluded that the defini-

tion of death was a matter for medical determination and decided that

including a definition in the Act would be unwise (1968:2504). Kansas

and Maryland were the first two states to adopt the act late in 1968.

Interestingly, Kansas and Maryland were the first two states to legis-

late a redefinition of death as well, in 1970 and 1972, respectively.

Enter Ethics and the Hastings Center

By early 1969, the redefinition of death was discussed primarily in

the medical and legal arenas. Physicians were concerned primarily with

the problem of irreversible coma and mitigating the financial and

emotional burdens of family and community, with allowing patients to

die with some measure of dignity and with obtaining organs for trans-

plantation. Lawyers were concerned, for the most part, with protecting

physicians and updating legal meanings of death in light of new medical

advances. Authors in both disciplines frequently mentioned the need

for theological or moral consideration of the issues and advocated

interdisciplinary collaboration, although not many actually ventured into the ethical realm. At this point, hardly anyone other than Jonas had challenged the need for the appropriateness of redefining death, though there were notable ethically-oriented discussions published by physicians Gunnar, Biorck, Beecher, Hamlin and Collins (only one of whom, Hamlin, is in the neurological sciences). In 1969, however, ethicist Paul Ramsey addressed the issue in the Lyman Beecher Lectures at Yale, and the Institute of Society, Ethics and the Life Sciences (The Hastings Center) was organized.

"On Updating Procedures for Stating That a Man Had Died"

The Yale University Lyman Beecher lectures, a yearly event since 1882, have been devoted to subjects in theology and designed to be interfaculty in nature. The lectures in 1969, on medical ethics, were sponsored by the Yale School of Medicine and the Yale Divinity School. Eminent Christian ethicist and Yale alumnus, Paul Ramsey of Princeton University, was the lecturer. For four nights, Ramsey lectured and discussed the issues with physicians and theologians.[8]

In 1968, Ramsey was awarded the first grant in medical ethics offered by the Joseph P. Kennedy Foundation and became Visiting Professor of Genetic Ethics at the Medical School of Georgetown University. While in Washington, he conducted most of the research for the Yale lectures. They were published in 1970 by the Yale University Press and entitled The Patient as Person. It is the second chapter of this book which concerns us, perhaps the single most influential, clarifying and systematized discussion of the redefinition debate ("On Updating

Procedures for Stating That a Man Has Died"). While at Georgetown,

Ramsey met and discussed his work and this particular chapter with

Leon Kass, M.D., then biochemist at NIH and later a prominent member

of the Hastings Center and Kennedy Institute for Bioethics (Ramsey,

1970:xix-xxii).

Ramsey's piercing analysis of the issue resolves much of the con-

fusion of multiple terms, conceptual overinclusion and inappropriate-

ness and the general muddledness of the discussions on death definition

published through 1969. As a reader trying to make sense of these

documents myself, I would go so far as to say that Ramsey's working of

the issue is a downright aesthetically pleasurable experience. His

analysis was not final, in that one could say: so the issue stands;

but it provided a greatly needed ethical and conceptual clarification

from which further clarification might proceed and against which the

conceptual evolution of the notion of redefining death could continue.

The following is a summary of his major points.

Not surprisingly, Ramsey begins the chapter with the meaning of

life:

> Life means the functioning of the integrated being or physio-
> logical organism as in some sense a whole. Death means the
> cessation of this functioning. This in turn depends on the
> integrated functioning of certain great organ systems. (p. 59)

Death does not mean the death of the brain, for Ramsey -- the brain is

not the "captain" of the three integrated physiological systems whose

simultaneous functioning constitutes life. The brain is of no higher

status in what constitutes life or death than the heart or lungs. In

this chapter there is no indication that Ramsey sets the "higher"

functions apart from other bodily functions, no effort to claim that these "higher" functions are the sine qua non of personhood.

Ramsey next distinguishes between the concept of death and the procedures for telling that it has occurred, a distinction which, once made, has several implications.

> To enter this discussion it is essential to separate the concept of death from the problem of determining the moment of death. It is also essential to separate the concept of death from the problem of establishing the procedures for stating or pronouncing death on the basis of any one concept. We should not confuse the definition of what death is with the problematics of whether there is a moment when death occurs. Neither should we confuse the definition of what death is with a discussion of the methods by which it shall be determined that death has occurred. (p. 63)

Once the distinction is made, it becomes obvious that one can change while the other does not. In other words, updating criteria does not necessarily mean updating the definition of the concept of death -- the title of Ramsey's chapter implies as much. The distinction also leads one to infer that differential expertise is at issue, that perhaps physicians could be relegated the responsibility for updating criteria and others, perhaps philosophers, theologians, lawyers or the lay public, should have something to do with establishing meanings and definitions. Veatch (1976) raised this same point with regard to the Harvard Committee. He asked if the Committee intended to examine the definition of brain death, then physicians were overrepresented on the Committee; and if they were intending to offer guidelines and procedures for declaring death instead, then what were an ethicist and historian doing on the Committee?

In perhaps his greatest contribution in the chapter, Ramsey

clarifies the kind of intrusion into the meaning of death respirator
technology is. Respirators both obscure signs of death and produce
false signs of life, notably, the still-beating heart. Ramsey suggests
that all the discussion on redefinition is an attempt to dismiss or get
behind the intrusion of the respirator. Difficulty arises in distin-
guishing the dead from the still living when artificial systems drive
the lungs which, in turn, pump the heart, giving "the look of life".

> The trick is to find a way to see behind the look of life
> upon the face of death and to learn to tell the difference
> between a patient who may have only 'technical life' sus-
> tained in him and a patient whose death may as yet be only
> 'virtual', 'suspended' or still successfully held at bay
> even if imminent. (p. 78)

The difficulty is also having to dismiss that primary and culturally
validated sign of life, the still-beating heart:

> The decisive question raised is whether doctors should
> continue to regard signs of "spontaneous" heart life as
> evidence that the patient still lives when these signs are
> still present only because lung life is artificially being
> maintained by respirators that (it can be determined) have
> lost their aim or hope of ever restoring spontaneous
> breathing. Must they wait until the last flicker of a
> failing heart whose dying is being artificially prolonged
> as surely as is the breathing? To the contrary, ought we
> not to say that the seemingly natural heartbeat is also
> being maintained only with the help of artificial pro-
> cedures? (p. 83)

If one holds to a conception of life as the integrated functioning of
the three systems in the whole organism, one is less likely to hesitate
to conclude that the still "spontaneously" beating heart is actually
dead. However, if one holds to an "ensemble of parts" conception of
death in which death is a process of dying by stages and in parts (body
parts), one would perhaps be more likely to say that the heart still
lives. And, as Ramsey and others would argue, we are talking about the

death of the human organism in these discussions -- not the death of
either the heart or the brain.

Ramsey next takes on the respirator in an insightful analysis of
how a technology can be befuddling. He cites Harvard Law Professor
Paul Freund's statement that the Harvard Report seems to be "a set of
guidelines on how to use a respirator".

> It is the respirator that, one step away, is being rebutted
> by these tests, and not brain tests elevated or truly
> spontaneous heart life downgraded in the procedures by which
> we should tell that a man has died. . . It [guidelines for
> brain death] is a way to use a respirator so as to get behind
> its artificial process to discern an unburied body.
> (pp. 93-94, my emphasis)

Ramsey's is the first mention of the fact that the still beating
heart in a patient whose brain is dead is not a "still-beating heart"
in any of the old senses that we are used to, and that guidelines for
declaring death based on brain criteria are ways to dismiss a respira-
tor or ways to get behind the artificial show of life. He makes it
very clear that the quotations that surround the phrases "spontaneously
beating heart", the "life" of patients maintained on a respirator,
should be dropped (p. 84). We are simply being fooled by a machine.

Another conceptual service Ramsey executed for the redefining
process was to reiterate and elaborate Daube's distinction between the
questions "When is a person dead?" and "When should a person be allowed
to die?" Death should not be confused with stopping extraordinary
means. Ramsey additionally suggests that perhaps heart transplant
specialists hve residues of guilt after removing a truly spontaneously
beating heart in order to provide its owner with another, more func-
tional heart. Perhaps physicians fear that they are killing the

patient in making room for the better heart (pp. 100-101).

Death should not be confused with "organ donor eligibility"

(p. 101). Referring to the Declaration of Sydney and the UAGA, Ramsey

asks:

> If in the practical order we need to separate between the
> physician who is responsible for the care of a prospective
> donor, and the physician who is responsible for a prospec-
> tive recipient, we do not need in the intellectual order
> to keep the question of the redefinition of death equally
> discrete from the use of organs for transplantation. . .
> If no person's death should for this purpose be hastened,
> the the definition of death should not for this purpose
> be updated, or the procedures for stating that a man has
> died be revised as a means for affording easier access to
> organs. (p. 103)

Of course, Beecher, as an advocate of updating death in order to obtain

scarce resources, provided Ramsey as well as Jonas with an example of

updating death for an avowed purpose. Ramsey joined Jonas in asserting

the dying patient's right to die all the way. According to Ramsey and

Jonas one does not update either the procedures or the definition of

death in order to obtain organs, beds for others or in order to

relieve either the family or the community of its emotional or finan-

cial burdens.

Part of Ramsey's service in executing this incisive ethical and

conceptual analysis of the issue was in collecting and organizing points

made by others briefly in other publications, drawing out their concep-

tual and ethical implications and stating them more elaborately.

Ethical considerations and conceptual clarity now joined the humane

concern for obtaining organs for dying patients as elements of deep

concern in the redefining process.

The Hastings Research Group on Death and Dying

Later in 1969, a major step toward interdisciplinary collaboration and ethical contribution on the redefinition issue was advanced by the founding of the Institute of Ethics, Society and the Life Sciences in Hastings-on-Hudson, New York, hereafter, for obvious reasons, referred to as the Hastings Center. The Center is a nonprofit research and teaching organization devoted to sustained interdisciplinary and professional investigation and analysis of the social and ethical impact of biomedical advances and technology.

In the early days of its inception, Daniel Callahan, Director of the Center, contacted Paul Ramsey and asked him to join. Ramsey suggested Leon Kass, with whom he had discussed his research at Georgetown, and Kass joined Callahan and Willard Gaylin to organize the Center. It was decided that each of the three would lead a Task Force on behavior control, population and death and dying. Kass chaired the death and dying Task Force (later called the Research Group on Death and Dying) and suggested that the Group take the redefinition issues as its first project (Informant notes). The Research Group grew until it included Eric Cassell, M.D. as co-chairman; Marc Lappe, Ph.D.; Henry Beecher, M.D.; Daniel Callahan, M.D.; Renee Fox, Ph.D.; Michael Horowitz, LLB; Irving Ladimer, SJD; Robert Jay Lifton, M.D.; Robert Stevenson, Ph.D.; and Robert Veatch, Ph.D. (Institute of Society, Ethics and the Life Sciences, 1972:fn). Subsequently, Hans Jonas, Alex Capron and Elizabeth Kubler-Ross joined the Group. Out of this organization came some of the most significant papers on the definition of death in the literature.

The Center opened its offices in 1970 and working papers on death and dying were presented by Kubler-Ross, May, Morison and Beecher at a symposium sponsored by the Center at the American Association for the Advancement of Science meeting in Chicago (Kass, 1970). Two of the most well-known and frequently cited papers in the redefinition literature -- a debate concerning whether death is a process or an event -- were presented by Morison and Kass and later published in Science. Beecher presented a paper in which he responded to Jonas' and Ramsey's criticisms of his position on defining death, transplantation and scarce medical resources. Robert Veatch (student of both Ralph Potter of the Harvard Divinity School and the Harvard Committee and Renee Fox, now of the University of Pennsylvania and the Hastings Research Group, and on this author's dissertation committee), who had been with the Center since its inception, had the opportunity of trying to persuade Beecher of the ethical necessity of separating the definition of death from pragmatic concerns. I gather that a good, heated conceptual round was had by all.

I have been thoroughly impressed with the joys of intellectual discourse reported to me by members of this group in interviews -- it must have been an intriguing and passionate enterprise. Some of the most exciting and most passionate occupations persons can engage in are of this kind, and the participants in this study who belonged to this group would seem to agree.

As far as I can tell from interview notes, the following are some of the group's dynamics, first the tension of personality and conceptual differences. Beecher and Ramsey were both rather dominating

personalities (Ramsey still is) -- one a Boston Brahmin and the other a Southerner -- who took opposing alignments to the issue. I was told that they had conducted informal debates of considerable standing and reputation within the group.

Jonas, Kass and Ramsey took a non-utilitarian and conservative approach to the issue and Beecher and Morison were somewhat more bold and utilitarian. Veatch was in neither camp, quite. Kass, Morison and Beecher were physicians, although by the time I embarked on this venture, they were involved in less medical and more cultural and ethical occupations. Veatch, Jonas and Ramsey are social ethicist, philosopher and Christian ethicist, respectively. These were key members of the group who both published articles and were included in the study. It became clear that a few others in the Group who had not written articles were essential to the discourses which provided the basis for their group publications.

One informant suggested that the cohesive factor in the group was "the willingness to work from very theoretical levels to very practical policy levels and to be open to debate with people with whom they don't agree. . ." I would add to that a cultural and/or philosophical orient- ation to the issues. Aside from those rather inclusive commonalities, the group seemed to function well in terms of their differences. "If we find any particular orientation we recruit the opposite."

Most members thought the discussions influential and beneficial for the most part. Their work was characterized by intellectual sharing and the efforts of "creative" conceptualizing, often against one another. "The Research Group has a much greater influence than its

publication. There's a molding of a thought process which goes on there", as one informant put it. This intense working and thinking experience was not only productive (in terms of actual creative works), but also was socially bonding -- rather strong social relationships were formed. All informants expressed some version of the exciting intellectual climate at the Center during those years, 1969-1973.

The Morison-Kass Debate: Death as Process or Event?

In a somewhat poetic dialogue at the AAAS meeting in Chicago in 1970, Kass and Morison took opposing sides on one of the subtle differentiating issues underlying the redefinition discussion -- whether death is a process or discrete event. One of the significant steps in the clarification of the definition of death debate is the unveiling and elaboration of this distinction. And it is a distinction of no small consequence, as we shall see.

Morison (1971) stated his case, that the notion of death as an event is an example of what Whitehead has called "the fallacy of misplaced concreteness", or of what others (e.g., Berger and Luckmann, 1967) have called "reification". He argued that life in an organism is a totality of complex interactions within the organism and between the organism and the environment, and that "the life of a complex vertebrate like man is not a clearly defined entity with sharp discontinuities at both ends" (p. 96). Taking that position, Morison came to the conclusion that at some point in the process of dying, one may assess the relative worth and death of the dying person. "Just as we recognize that an individual human life is not infinite in duration,

we should now face the fact that its value varies with time and circumstance" (p. 697). And like some others who journey the conceptual path from death as process to the relative value of different lives to the various social costs of the maintenance of those lives, Morison courageously forwards the notion that death perhaps ought to be hastened in some circumstances. "There is simply no hiding place . . . we must shoulder the responsibility of deciding to act in such a way as to hasten the declining trajectories of some lives, while doing our best to slow down the decline of others" (p. 697).

Responding to Morison with as much passion, Kass (1971) argued that "attempts to blur the distinction between a man alive and a man dead are both unsound and dangerous" (p. 698). He called Morison to task on: 1) confusing the question of the definition of death with the question of when life is worth preservering and 2) asserting that defining death is a matter of the useful and the good rather than the true. Integral to Kass' arguments is the concept of "the organism as a whole", derived in part from Jonas', Whitehead's and, possibly, Ramsey's concepts of organism. "Why is the concept of the organism as a whole so difficult to grasp? Is it because we have lost or discarded, in our reductionist biology, all notions of organism, of whole?" (p. 700). And, like Jonas, and Ramsey, Kass argued that the dying person should be allowed to die:

> It is one thing to take one's bearings from the patient and his interests and attitudes, to protect his dignity and his right to a good death against the onslaught of machinery and institutionalized loneliness; it is quite a different thing to take one's bearings from the interests of, or costs and benefits to, relatives or society . . . Life is incommensurable with the cost of maintaining it. . . (p. 701)

In these two publications alone, appearing in 1971, are some of the basic conceptual and ethical tensions underlying the redefinition debate. Under the guise of a seemingly neutral academic question (Is death a process or event?), lies the tension between advocacy of the quality of life and death defined in terms of the social good and advocacy of something like the integrity (but not quite the sanctity) of a person's dying and death defined in terms of considerations which bear on the dying person only. These were the first of four important publications which derived from work and associations at the Hastings Center.

The First Statutory Definition of Death — Kansas, 1970

Of particular interest in the course of designing this study was the history or story of the first statutory definition of death which provided the model for several others. It seemed curious that Kansas, of all states, was the first to enact policy on this issue. The following discussions derive entirely from documents (and letters) given to me for my use and interview notes with the two authors of the statute, one legislator and several members of the faculty at the University of Kansas Medical Center.

Against the advice of the Harvard Report and the Commissioners who authored the UAGA, the state of Kansas enacted the first statutory definition of death in 1970. Since Kansas was the first state to adopt the UAGA, they were somewhat more ready than other states which had previously no heart or cadaver kidney transplant programs to begin work on these developments. Associate Dean of the University of Kansas

Medical Center, Russell Mills, contacted his brother, lawyer-physician

Don Harper Mills of Los Angeles. He mentioned that the Medical Center

was organizing a committee to discuss some of the legal and ethical

issues involved as a prelude to their developing the transplant pro-

grams and asked his brother what legal advice he could offer. The

Medical Center intended to act so that legal problems of the sort that

had developed in other centers, notably Virginia, would be resolved

before the transplantation efforts began. Then Associate Dean of

Clinical Affairs, Dr. Jack Walker (also the major of a small community

outside Kansas City), the Medical Center's "politician-in-residence",

and Russell Mills decided that this would be the Medical School's best

tactic (Informant notes).

Don Harper Mills wrote back, "It is important to arrive at a prac-

tical usable definition not only for the guidance of the transplant

team, but also for evidentiary purposes in court in prosecutions for

criminal homicide and civil wrongful death" (Mills, 1968). Physician

liability was of special concern since most donors were likely to be

trauma victims. Young persons with brains destroyed by accident, crime

or trauma have organs, and especially hearts, in the best condition.

He asked that the Medical Center contact the transplant centers that

were then operating to ask their advice and advised the Center to

conduct legal research into state definitions and legal precedents

concerning death -- especially the decision which had been mentioned

by Halley and Harvey in their 1968 JAMA publication, United Trust v.

Pyke. In that case, death had been defined as ". . . the cessation of

all vital functions without possibility of resuscitation"

(Taylor, 1971:296). Mills also suggested, "It may be necessary for the legislature to create a statutory definition of death. . . " (Mills,1968).

Legal problems had arisen in a transplant center in Houston. The Center consulted with a "group from Houston" and invited a Houston hospital administrator to visit. The Medical Center Committee was advised to get their legal affairs in order, to avoid law suits. Additionally, Mills gave his opinion to the Committee that the Pyke case and the definition used therein was "a rigid preclusion to obtaining organs for transplantation". Moreover, a well-known cardio-vascular surgeon on the Committee flatly stated that he would not participate in any transplantation unless he were protected "statutorily". Physicians thus became convinced that a statute was necessary to protect them.

In a letter to JAMA, one of the principal draftsmen of the bill, physician-lawyer Loren Taylor, stated that the dilemma the Center faced consisted partially of the "cudgel wielded by the insurers of the surgeons by threats of cancellation of professional liability insurance" (Taylor, 1971:296). According to Taylor, it was this threat, the fear and desirability surrounding the practice of organ transplantation and the Pyke decision which ". . . resulted in the Medical Center asking for the development of legislation which would apparently protect the transplanters, if not from malpractice charges, at least from the supposed lesser evil of a murder charge or wrongful death charge" (p. 296).

The Center's Committee first consisted of an eye surgeon (Jared Grantham), internists, a renal surgeon, a cardio-vascular surgeon (William Reid), an anesthesiologist (Taylor), and a neurosurgeon (Charles Brackett Walker) and others, and then enlarged to include

members of the clergy and legislature. Jack Walker contacted persons in the legislature, particularly Glee Smith -- then president pro-tem of the senate and the Kansas Commissioner on Uniform Laws who had worked on the UAGA. Smith was most active in getting the UAGA passed quickly in Kansas.

According to one informant, Walker had decided that perhaps the best way to include a death statute in the Kansas laws was to attach it as an addendum to the UAGA. Smith wanted the UAGA left in its origianl, "clean" form. A separate death statute became a compromise: If Walker would take the statute out of the UAGA, Smith would support the separate bill in the senate. According to another informant, however, the legislature (including Smith) was "thoroughly unimpressed with the need for a statute", and was not sure that Mills' interpretation of Pyke was correct. The definition mentioned by the Kansas Supreme Court could be interpreted as not legally binding. At least one person was of the opinion that Mills had done a disservice to the Center in having interpreted the court's definition as legally binding. "Nobody (else) thinks United Trust v. Pyke was a problem" (Informant notes).

Mills had come only to the first conference the Committee held to offer his views and a tentative version of a statute. He then left never to be heard from by the Committee again (Informant notes). Later, after some Committee deliberation, Loren Taylor wrote the statute. There is some controversy over who the primary or secondary author of the statute as it appeared in its final form was, but it seems to this author that, from copies of the outline and tentative

statute that Mills brought to Kansas with him (which are in my posses-
sion), portions of the final statute were in his original proposal and
that other portions had been reworked and added by Taylor. Both men
have degrees in law and medicine; however, Mills is primarily in the
field of medical jurisprudence and Taylor has been a practicing anes-
thesiologist.

For *some* reason, given that the legislature and Smith were not
impressed with the need for a statute, the passing of the bill occurred
"without groundswell either way". The Medical Center Committee had,
throughout, maintained a low profile and one informant acknowledged a
"subtle process of propaganda was going on in the state". The Commit-
tee encouraged the hospital chaplain to discuss the matter with other
chaplains and enlist their support. When asked how the people of
Kansas had responded to the bill, one informant suggested that the
emotional impact of the heart transplantation efforts all over the
world had been tremendous. "It was like going to the moon - an unbe-
lievable thing - so amazing and exciting. The people of Kansas wanted
to be in the forefront. . . the giving of new hearts - the public
bought that very quickly - and they wanted to have Kansas be first."
The informant acknowledged that Kansas is a conservative state, but
also noted that Kansas had been ahead of the rest of the nation in
legalizing and performing abortions, and that the Medical Center was
practically the only medical school in the midwest performing abortions.

These inconsistencies -- that one informant said that the bill was
passed under relative cover, or at least under low profile, and another
would say that the public wholeheartedly welcomed this issue and

implying almost that heart transplantation is the raison d'etre of the
statute -- are taken directly from telephone interviews, and seem to
represent disparate views regarding the need for and legitimacy of the
first statute. Some were primarily interested in facilitating kidney
transplantation which had not yet been performed at the Medical Center,
others were interested in hopping on the international heart transplant
bandwagon and in gleaning the prestige, excitement and commitment to,
as Ramsey put it, "a most extraordinary therapy" (Ramsey, 1970:99).
Given that at least one state (New York) has had trouble passing a
similar bill when the issue was widely publicized, I suspect that the
issue was passed with a low profile. The statute seems to have been a
mere means to an end to some people and, as such, relatively insignifi-
cant. As one stated, "During the year, we had so many thousands of
pieces of legislation that to recall specifics on one relatively minor
piece like this is difficult".

As it turned out, Kansas never developed a heart transplant pro-
gram and never used the statute for that purpose. And only two inform-
ants (neither of whom live there) seemed to be aware of the furor it
caused elsewhere or of the strong criticisms launched against it
(cf. Kennedy, 1971; Capron and Kass, 1972). One wonders to what extent
the Kansas "group" was aware of the role their statute played in the
debate on the definition of death, which had just really begun when
most of their work on the statute was executed.

The statute as it was adopted (Kan. Stat. Ann. §77-202 (Cum. Supp.
1973)) reads as follows:

>Definition of death. A person will be considered medically
and legally dead, if, in the opinion of a physician, based
on ordinary standards of medical practice, there is the
absence of spontaneous respiratory and cardiac function and,
because of the disease or condition which caused, directly
or indirectly, these functions to cease, or because of the
passage of time since these functions ceased, attempts at
resuscitation are considered hopeless; and, in this event,
death shall have occurred at the time these functions
ceased; or
>
>A person will be considered medically and legally
dead if, in the opinion of a physician, based on ordinary
standards of medical practice, there is the absence of
spontaneous brain function; and if based on ordinary
standards of medical practice, during reasonable attempts
to either maintain or restore spontaneous circulatory or
respiratory function in the absence of aforesaid brain
function, it appears that further attempts at resuscitation
or supportive maintenance will not succeed, death will have
occurred at the time when these conditions first coincide.
Death is to be pronounced before artificial means of
supporting respiratory and circulatory function are
terminated and before any vital organ is removed for
purposes of transplantation.
>
>These alternative definitions of death are to be
utilized for all purposes in this state, including the
trials of civil and criminal cases, any laws to the contrary
notwithstanding.

The first published comments on the statute appeared in the New

England Journal of Medicine written by William Curran of the Harvard

Committee and NEJM's regular medico-legal columnist, British Law

Professor Ian Kennedy, and none other than Don Harper Mills, in 1971.

Curran regarded the "first legislative definition of death in the

history of our nation and of the Common Law world" as useful and skill-

fully drafted as it stands, a turn from his position as legal author

of the Harvard Report in which he recommended no change in the law.

In his criticism of the statute, the first in the literature

(1971), Kennedy argued that the Kansas statute, as a model for other

states "is an unfortunate development" in that 1) it was drafted with

only transplantation in mind when the real problem occurs with terminal and comatose patients and 2) in that the definition implies two types of death -- content which can only confuse the public. "The Act in its present form does not serve to assure the person who may fear that during his last hours on earth, his doctors will be less concerned with his condition than with the person earmarked to receive one of his vital organs" (p. 71). Kennedy noted that the statute makes no mention of requiring two physicians to clear death, a recommendation made by every major professional body. Moreover, the statute contains no provision for separating the role of the physician caring for the donor and that of the physician caring for the recipient. The statute is simply a disaster as far as Kennedy is concerned.

The three articles in NEJM form a chain with Kennedy writing in some, though not major, response to Curran's earlier article and Mills writing an explicit response to Kennedy's article immediately following in the same issue. Mills' article commends the statute (not altogether a surprise), although hardly anyone knew that Mills had been as influential as he had been about what had happened in Kansas and how the issue was conceptualized there. And Mills did not mention his contribution in the article, "The Kansas Statute: Bold and Innovative".

In his letter to his brother (in my possession), Mills did not emphasize transplantation to the exclusion of all other reasons for redefining death -- in fact, he stated that the Kansas Medical Center's decision to act had to be made in the public interest. He also stated in the letter, as in the article, that the statute should be designed to apply to the problems of: the time of death; the issue of when to

stop resuscitation; and the termination of artificial maintenance
(Mills, 1968; 1971). "It may also be assumed that those in the legis-
lature were wise enough to expect benefits for everyone, not just for
doctors".

Thus, two medical jurisprudence experts with positions on the
editorial staff of the two most respected medical journals of general
circulation published in this country, Curran and Mills, definitely
favored the statute. Kennedy, a Briton who at the time was professor
of law at UCLA, provided the only dissenting voice. It is interesting
to note that Kennedy's occupational areas are medical jurisprudence and
legal philosophy. Those with a philosophical eye have been generally
critical of the statute (see the discussion of the Capron-Kass critique
of the statute below).

Maryland Takes the Second Step -- 1972

The Maryland legislature passed a statute defining death nearly
identical to the Kansas statute early in 1972. Kansas and Maryland
had been the first two states to adopt the UAGA, and they were the
first two states to define death statutorily. I assume the motivations
in both states were primarily to "add" to the UAGA the needed guide-
lines for determining death in transplant situations.

Be that as it may, the history and politics of the Maryland stat-
ute are substantively different from those noted above. Passage of
the bill was facilitated by the presence of a physician in the legis-
lature, Johns Hopkins renal internist, Torrey Brown. Another delegate,
Wallace Hutton, introduced and sponsored the bill.

In his general law practice, Hutton frequently handled wills with specifications for the donation of body parts and noted that more often than not, the deceased's wishes were not fulfilled. For Hutton, the whole enterprise -- donating organs and actually having someone in need receiving them -- "became rather meaningless because nothing was going to come out of it". As a practicing nephrologist, Brown was also concerned with organ transplantation. Neither consulted with Loren Taylor, Mills or anyone else from Kansas -- they simply copied the Kansas statute.

The bill was supported by several physicians, among them prominent Johns Hopkins neurosurgeon, A. Earl Walker. (Walker also influenced legislation in New Mexico and directed the NINDS collaborative study on brain death discussed below.) A few Maryland delegates opposed the bill, nicknaming it "the ghoul bill", arguing that it was "anti-Catholic". They even obtained a TV spot to discuss the implications (body-snatching) of the "ghoul bill", but their efforts had little effect. The Catholic Church in the area supported the bill and no one else seemed to take them seriously. Otherwise, the bill passed in Maryland without much incident.

From Whole Brain to Neocortical Death

One of the most frequently mentioned reasons for redefining death is that we should view life in terms of what it means to be a person, rather than in terms of what it means to be a physiological organism. This is the central theme of the debate over "the quality of life" vs. "the sanctity of life". "Unburied corpses" (Ramsey) or "heart-lung

preparations" (Hamlin) which "function" with the aid of a mechanical

respirator are not what we are used to thinking of as persons, although,

as Jonas might insist, many of these bodies look suspiciously like the

persons we love or once loved. In the discussion of what it is that

constitutes personhood, there is considerable agreement that mere

physiological function does not a person make -- hence, at least part of

the reason for redefining death in terms of the brain instead of in

terms of the cardio-respiratory system. In the early seventies, sev-

eral authors (cf. Shalit, 1970; Brierley, 1971; Rizzo, 1973; Korien,

1973; Fletcher, 1974; and Veatch, 1974) suggested that neurological

reflexes governed by the lower brain and spinal cord do not make a

person, either; the Harvard criteria included such reflexes and are

"whole brain" criteria. As early as 1970, an Israeli neurosurgeon

suggested that ". . . the definition of brain death should perhaps be

applied to the death of the cerebrum rather than to the whole central

nervous system" (Shalit, 1970:747).

The distinction between cerebral, or neocortical, death and whole

brain death was made as early as 1928 when Sugar and Gerard determined

that different parts of the brain were differentially responsive to

lack of oxygen and died at different times. At the 1968 American

Neurological Association meeting in which Alderete, Schwab and Richard-

son presented data collected at Harvard, the issue was raised again.

The major medical statement advocating the distinction came in

1971 in Lancet, written by Scottish neurologist, J. B. Brierley. In

the article, Brierley reported the clinical histories of two patients

who breathed spontaneously and who had isoelectric EEG's for five

months following cardiac arrest. The cerebrum was destroyed, Brierley stated, but one patient's pupils responded to stimuli; the other patient responded to a loud voice by opening his eyes toward the end of the five months of coma. He advocated a high reliance on the EEG to determine cerebral death (just about the only method for assessing cerebral function) and suggested confirming the diagnosis with the neurological examination of a biopsy taken from a portion of the cerebrum. In discussing the Harvard whole brain criteria, he stated:

> In essence, it seems that a person who resumes spontaneous respiration after cardiac arrest, yet exhibits an isoelectric EEG, is to be regarded as 'alive', while another surviving the same accident, also with an isoelectric EEG but whose cardiac function depends upon mechanical ventilation, may be regarded as 'dead'. Clearly this distinction between 'alive' and 'dead' attaches cardinal importance to the function of the respiration and none to those higher functions of the nervous system that demarcate man from the lower primates and all other vertebrates and invertebrates (p. 13).

Part of our hesitance to consider persons who breathe spontaneously dead or to consider Karen Quinlan dead, comes deeply from our notions of what it means to be asleep, of the possibility that one might be a Rip Van Winkle and wake from a coma of long duration. Some probably comes simply from the repugnance of suffocating a breathing "person", or taking other definitive action to bring about the complete stoppage of his/her breathing. Withdrawing treatment and mechanical ventilation is one thing, after a person has been declared dead on the basis of accurate, conservative criteria -- having to smother (either through medication or physical action) what we suspect may still be in some sense alive, is another. At this point, our society seems not quite prepared for the latter.

A rather terse criticism of the notion of neocortical death and some of Brierley's assumptions came from the Ad Hoc Committee on Organ Transplantation of the Netherlands Red Cross Society in a letter to Lancet (1971) written by Anne Rot and Adrienne Van Till (the only two women, who, to my knowledge, have published on the topic). They argued that physicians do not agree that severe brain damage, irreversible coma and cortical death are the same as the total absence of the brain's functional capacities. They expressed the fear that such an assumption would lead to there being separate criteria for different states of death; such a practice is "clearly illogical, unethical and unjust" (p. 1099). And even the Harvard Report had done a disservice in citing "emotional, practical, socio-economic and transplantational reasons", other than "purely biological reasons" for declaring irreversible coma. "We believe irreversible coma and cortical death are grounds for stopping treatment and letting the patient die: this is legally and ethically permissible even if the comatose patient is still breathing spontaneously. . . A living body turns into a corpse by biological reasons only - not by declarations, or the signing of certificates" (p. 1100, emphasis added).

A Neurologist Challenges the Redefinition of Death

A prominent neurologist, James Toole, published an article in Perspectives in Biology and Medicine in 1971 challenging the unquestioning acceptance of the need for a redefinition of death. While he acknowledges the reasons which have stimulated a change in the meaning of death, Toole stated that he has

> . . . been worried that unanticipated disastrous consequences
> could follow general acceptance of the concept of brain death.
> For example, most physicians (to say nothing of the nurse and
> layman) cannot make the diagnosis of brain death with confi-
> dence. Even the electroencephalographer is competent only to
> render his opinion about the conditions of brain waves, not
> of the brain itself, for he makes no direct observation of
> the patient (pp. 599-600).

Toole explicitly voiced the discomfort neurologists whom I interviewed felt regarding the use of a technology which mediates the data they would like to observe first-hand. An electroencephalograph is somewhat removed from direct clinical observation. Toole goes on to say that near exclusive reliance on the neurologist's or neurosurgeon's diagnosis in these matters ". . . would place the decision-making responsibility upon specialists who only reluctantly accept it" (p. 600). Toole was the only author I read who mentioned that the brain stem may be dead while the cerebrum is still alive (p. 601), a rather claustrophobic condition, known as the "locked-in syndrome". He is sensitive to some of the objections to the "societal good" line of thinking also expressed by persons like Jonas, Kass and Ramsey.

> We have also seen patients comatose for months or years,
> requiring constant nursing care, expensive support systems,
> occupying scarce hospital beds, and draining the family
> emotionally and financially while the despairing physician
> prolongs this useless life hoping for miraculous recovery.
> Wouldn't it serve a greater good to certify such patients
> dead before this happens? Such logic contains several
> hidden dangers.

One of the dangers he mentioned was overthrowing the patient-centered care long the ethic of physicians for the benefit of family and society or another patient. Toole also noted a danger voiced frequently by conservative ethicists: If we get onto the conceptual and pragmatic slide in which we define human life as that which is not merely

vegetative life, then when do we stop sliding?

> Then what of the senile who populate our rest homes and
> mental institutions? Such patients are also a drain on the
> family and society. They too have a hopeless prognosis and
> have suffered death of portions of their brains. Change
> the legal definition of death a bit more and they too will
> be dead! . . . What harm could come of terminating the lives
> of patients whose brains are almost dead and whose prognosis
> is seemingly hopeless? As the German people discovered
> thirty years ago, it would lead to social disaster if we
> were to accept the proposition that some lives are worth
> less than others, and that the treatment of some patients
> is too arduous or too expensive (pp. 603-604).

As he explains, the Germans underwent an evolution of attitude in

which hopelessness and disability became overburdening. The persons

with such diseases then became worthless; and then, following that

presumption came another -- such persons lives should be terminated

for the societal good. "The physician's major concern became the

family and society, and social tragedy was inevitable. . . In our

society I hear rumblings which suggest that a similar change in social

attitudes may be evolving at a critical speed" (p. 604). Of the few

physicians participating in this study who might be considered to

approach the topic from a bioethical point of view, Toole is the only

one to warn his readers so passionately. At this time in the develop-

ment of the issue, no other hesitance was expressed (to my knowledge),

excepting that of Jonas and Ramsey.

The Hastings Critique of the Kansas Statute

As one informant implied, by mid 1972 it was clear that statutes

defining death would be passed, and that Kansas had provided the model.

Some at Hastings thought that if there were going to be such laws, then

there should be better ones. In probably its most influential paper,

the Hastings Center Research Group, with members Alex Capron and Leon Kass as its principal authors, published a thick critique of the Kansas statute and offered a statutory proposal in the University of Pennsylvania Law Review. Capron is on the faculty there.

Kass and Calahan had met Capron at a conference on genetics and society and invited him to join the Hastings Task Force on genetics. When the Death and Dying Group (actually a much smaller group than that cited previously, worked on this project) began to discuss the definition of death and public policy, Capron was asked to make a presentation of the policy issues. At that time, he was the only one convinced that a change in law, a statutory change in particular, was necessary. Capron gradually convinced the Group that more statutes would be enacted and that the Kansas statute would be the model used until another one was formulated. Also at this time, a case (Tucker v. Lower) came to trial in Virginia in which transplant surgeons were accused of wrongful death in removing the heart of a donor whose brain was damaged in a fall. Virginia was likely to enact a statute based on the case to avoid such problems in the future, and this event clinched Capron's argument (Informant notes).

The article treats the issue with the conceptual, cultural and philosophical sensitivity and clarity characteristic of the publications written by others in the Research Group. Jonas, Ramsey, Veatch, Kass, Morison and even Beecher seem present in the article.

Addressing the issue of public involvement, its substance and means of action, and the question of whether one of those means might take the form of legislation, the authors ask to what extent is the

issue of death definition a medical issue? Arguing that the matter is partially philosophical, they state, "The formulation of a concept of death is neither simply a technical matter nor one susceptible of empirical verification" (p. 94). Involvement in the issue means having to come to terms with the meaning of "living", "organism", and "human", among other fundamental issues, as well as determining which physio-logical functions are salient characteristics" of human life (p. 94). They argue consistently that the issue is of public concern and should be open to public debate. The public's confusion centers on the 1) change of vital signs which traditionally have been "knowable" by laypersons, and which are now knowable only to a special group of persons, in some cases physicians, and 2) the "avowed purpose" behind the change -- transplantation. "Even if the medical profession takes the lead -- as indeed it has -- in promoting new criteria of death, members of the public should at least have the opportunity to review, and either to affirm or reject the standards by which they are to be pronounced dead" (p. 95). Having reviewed the avenues of public involvement and efficacy, the authors chose legislation as the most effective avenue.

Then "what can and should be legislated"? The authors distinguish among four levels of "definitions" any of which, in principle, might be the subject of legislation:

1) "the basic concept or idea . . . . fundamentally a philosophical matter;

2) "the general physiological standards" for recognizing death (the choice of which involves philosophical issues as well as

some medical-technical ones);

3) operational criteria -- further define what is meant by the general physiological standards; and

4) specific tests and procedures -- see if the criteria are fulfilled.

In doing so, they present the first widely-read systematization of the conceptual complexity of defining death. (The same delineation of the concept was made in another of the Research Group's publications, a criticism of the Harvard Report, published somewhat earlier in 1972 and discussed below.) Excluding the two extremes, the most general and the most specific, the question then becomes at which of the two mid-levels does the conceptualization of a statute begin? Operational criteria may change, and law is nearly always too fixed to allow for the change of scientific development; the level chosen is "general physiological standards".

The authors then enumerate general conceptual principles which must be followed in formulating the statute. These are the important underpinnings of a policy statement of such general and profound concern. The definition must concern the death of a human being, not cells or organs (not even brains) or the ". . . cessation of his role as a fully functioning member of his family or community" (p. 105). Ramsey's distinctions between the questions of when a person is dead and when a person should be allowed to die and between concept or definition of death and criteria, find their way into the text, as well as specification that there be no special definition of death for prospective donors and a nod to the notion expressed by Kass in the

process-event debate that some persons are not more dead or differently dead than others. They insist on keeping the transplant issue entirely separate from the question "what is death?". Capron and Kass offer a statutory proposal which reads as follows:

> A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of spontaneous respiratory and circulatory functions. In the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of spontaneous brain functions. Death will have occurred at the time when the relevant functions ceased (p. 111).

The proposed statute refers to the singular death of a person and can be applied uniformly to all persons. It specifies the occasions under which either spontaneous circulatory or respiratory functions on the one hand or brain functions on the other (as the general physiological standards) are to be applied rather than leaves the decision of which to use to a particular physician's discretion. It does not specify a kind of "brain death" but rather states that death may be determined with reference to "brain" standards, if use of the other traditional standards is precluded or "hidden" by artificial means. The statute applies to the cessation of the function of the whole brain. The proposal, unlike the Kansas statute, does not refer to one's being "medically and legally dead" ". . . thus avoiding redundancy and, more importantly, the mistaken implication that the "medical" and "legal" definitions could differ" (p. 115). The proposal does not require that the declaration of death be made before support is discontinued or that the donee care and donor care be separated or that

two physicians make the determination. These requirements, according to the authors, have no place in a statute which defines death -- the first because the time of death is stated generally and the second two because the provision refers to death defined for the purpose of procuring organs.

The proposal was not offered as the final solution to the problems, "but as a catalyst for what we hope will be a robust and well-informed public debate over a new 'definition'" (p. 118). The authors left aside the even more difficult problems concerning the conditions under which medical treatment may be terminated. The question "When to allow to die?" requires separate attention and resolution. Though published in 1972, the proposal was not adopted by any state until 1975, though four more states enacted statutes.

The Hastings Critique of the Harvard Report

Also in 1972, and somewhat earlier than the Capron and Kass proposal, the Research Group published a critique of the Harvard Report, "Refinements in Criteria for the Determination of Death: An Appraisal", in JAMA. Conspicuously present in the Group was Henry Beecher, the primary author of the Harvard Report. The Hastings paper was written, according to one informant, "to mitigate the bad effects of the Harvard Report, which was considered "muddy and illiterate". It was felt that a group of relatively prominent persons would be more influential writing a critique of the Harvard Report than an individual perhaps because the Report was the work of a prominent group of Harvard faculty.

In some ways the Kansas statute critique and the Harvard Report critique are similar in that both point to the conceptual complexities involved in questions such as when or what is death, the problems involved in conceptualizing death as an event or process, or the meaning of living human organism. In this publication, the Research Group specified the formal characteristics or sets of criteria or procedures:

1. The criteria should be clear and distinct and the operational tests . . . should yield vivid and unambiguous results. Tests for presence or absence are to be referred to tests for gradations of function.
2. The tests themselves must be simple, both easily and conveniently performed and interpreted by an ordinary physician (or nurse) and should depend as little as possible on the use of elaborate equipment and machinery and the determination of death should not require special consultation with specialized practitioners.
3. The procedure should include an evaluation of the permanence and irreversibility of the absence of other conditions that may be mistaken for death, e.g., hypothermia, drug intoxication.
4. The determination of death should not rely exclusively on a single criterion or on the assessment of a single function . . .
5. The criteria should not underline, but should be compatible with the continued use of the traditional criteria . . . The revised criteria should be seen as providing an alternative means for recognizing the _same_ phenomena of death.
6. The alternative criteria, when used, should determine the physician's actions in the same ways as the traditional criteria; that is, all individuals who fulfill either set of criteria should be declared dead by the physician as soon as he discovers that they have been fulfilled.
7. Criteria and procedures should be easily communicable -- both to relatives and other laymen as well as to other physicians. They should provide the basis for uniform practice . . . . The criteria and procedures should be acceptable as appropriate by the general public, so as to provide the operational basis for handling the numerous social matters which depend upon whether a person is dead or alive, and so as to preserve the public trust in the ability of the medical profession to determine that death has occurred.

8. The reasonableness and adequacy of the criteria and procedures should be vindicated by experience in their use and by autopsy findings. (p. 49)

The authors regard the Harvard criteria as having met the formal specifications listed above. However, the authors also noted that the Report has generated concern and confusion regarding multiple terms of death, the relation between the definition and transplantation, the appropriateness of the physician's role in changing a definition of death and fears concerning further updatings of the criteria. In conclusion, the authors express hesitancy about "neocortical death" or death of only the cerebral cortex, the function of which can only be determined by EEG. In such cases, a patient breathes spontaneously and has intact lower brain and spinal reflexes -- as does Karen Quinlan. But the authors insist that "It is inconceivable that society or the medical profession would allow the preparation of such persons for burial" (p. 53). They recommend instead that physicians stick to the more comprehensive, clinical, "whole brain" criteria specified in the Harvard Report.

The article was published in JAMA, but that was the Groups' second choice. They went first to NEJM, but were turned down because editors said "It added nothing new" (Informant notes). One wonders how anyone reading the Hastings critique could help recognizing a comprehensive and critical reconceptualization and clarification of the original report. But so go editorial politics.

Tucker v. Lower

This case from Richmond, Virginia[10], probably the most important

to date, illustrates the confusion and indeterminacy of determining

death in transplant situations (for other examples, cf. Ramsey,

1970:70-78 and Veatch, 1972). The case involved a black laborer, Bruce

Tucker, whose heart and kidneys were removed after he suffered irrever-

sible brain damage from a fall and the transplant team at the Medical

College of Virginia in Richmond (Veatch, 1972). Among the team members

was a transplant physician, Lower, who had worked with Schumway in the

late '50s and early '60s performing heart transplants on animals, and

who later came to join Dr. Hume at the Medical College of Virginia.

Dr. Hume had been involved in the first kidney transplant in Boston

and had become director of one of the most active transplant centers

in the world, the Medical College of Virginia (Moore, 1972).

On May 24, 1968 -- in the midst of the heart transplant furor --

Tucker was found, taken to the hospital and subsequently placed on a

respirator because of breathing difficulty. He had severe brain

damage. The state medical examiner, Dr. Abdullah Fatteh, advised

Dr. Hume that permission should be obtained from Tucker's family before

Tucker's organs were removed. One team member notified the police and

asked them to get in touch with the family (Converse, 1975).

At 11:45, the attending physician stated that "prognosis for

recovery is nil and death is imminent" (Veatch, 1972:10). Over an hour

later the staff neurologist was called in for his opinion; on the basis

of one 25 minute EEG tracing, he concluded that there was no evidence

of life or cortical activity (Veatch, 1972). (The Harvard Report

recommends that the entire battery of clinical procedures be repeated in 24 hours before the patient is declared dead, but, at that time, the Report was not yet published.)

At 2 p.m., the police notified the surgeons that they had been unable to reach the next of kin and Tucker was taken to the operating room to prepare for transplantation. At 3:30 the respirator was turned off, and three minutes later an incision was made in the recipient's body; two minutes after that, with the respirator already turned off, Tucker was pronounced dead. An hour later his heart and kidneys were removed (Veatch, 1972).

Interestingly, Tucker's wallet had contained his brother's business card with his place of business clearly marked -- located within 15 blocks of the hospital (Veatch, 1972). Even more interesting, a close friend of Tucker's roamed the corridors of the hospital complex looking for Tucker and inquired at three of the hospital's information desks of his whereabouts, with no success (Converse, 1975).

Tucker's brother charged that the transplant team was engaged in a "systematic and nefarious scheme to use Bruce Tucker's heart and hastened his death by shutting off the mechanical means of support" (Veatch, 1972:10). The suit also held that the transplant was executed without reasonable attempt to notify the victim's relatives or obtain permission for use of his organs. In toto, $1,000,000 in damages were sought; Tucker's brother was represented by State Senator Lawrence Wilder (Converse, 1975).

Coincidentally, four years later when the trial began, a conference of approximately 150 transplant surgeons was being held a few blocks

from the courthouse. Richmond circuit court Justice A. Christian

Compton had decided at first that he would insist on the traditional

definition of death. He argued that the issue was appropriate for

legislation, not the courts. The issue of consent was not raised,

surprisingly, because of a legal technicality. Converse concludes that

the testimony "must have softened" his views, because Compton later

charged the jury:

> . . . you shall determine the time of death in this case by
> using the following definition of the nature of death.
> Death is the cessation of life. It is the ceasing to exist.
> Under the law, death is not continuing, but occurs at a
> precise time. . . . In determining . . . you may consider
> the following elements . . . (among them) the time of
> complete and irretrievable loss of all function of the
> brain. (Converse, p. 424, quoting from the court's report
> in Tucker's Administrator v. Lower)

Those giving testimony for the defendants comprise an impressive

list. William Sweet, chairman of Harvard's department of neurosurgery

and member of the Harvard Committee, testified that he agreed with the

staff neurologist's conclusion that Tucker was dead, and added that

brain criteria were acceptable criteria at the time for determining

death (Fatteh, 1973:33). The surprise witness was Joseph Fletcher,

well-known theologian and euthanasia advocate. Fletcher (associated

with the Hastings Center and long an opponent of Ramsey's in published

debates on issues in medical ethics) was Visiting Professor of Medical

Ethics at the University of Virginia at the time. Converse (1975)

considers Fletcher the most influential witness, and I would tend to

agree that he probably was. His grounds for testifying were challenged

by Wilder, Tucker's lawyer, because he was not a physician -- an inter-

esting statement of the presumed inappropriateness of ethical discourse

and competence in this matter. The theologian prevailed. (On this topic, Fletcher is known for his efforts to establish criteria for humanhood (1974), such as minimal intelligence, self-awareness, and others. Moreover, he advocates defining death in terms of cerebral or neocortical, rather than whole brain, function.)

The jury found in favor of the physician. Compton's instructions became a legal landmark, though not, strictly speaking, a binding precedent in the death debate.

Robert Veatch, of the Hastings Group on Death and Dying, criticized the handling of Tucker's death and the transplant situation, and challenged the widespread assumption that Tucker v. Lower was a "brain death" case (1972).

> In order to accept the jury's decision in this case and accept it as demonstrating that the physicians were justified in the use of brain evidence of death, one would have to accept four highly questionable premises. The first is that the jury did indeed base its decision on a brain-oriented concept of death. Second that a man is really dead when he no longer has any capacity for brain activity. The third is that it was reasonable under 1968 conditions to conclude that the patient had irreversibly lost the capacity for brain activity based on one EEG reading without repetition. Such a conclusion is premature even for the scientific evidence which exists today, some four years later. Finally, one would have to accept that individual medical professionals should be vested with the authority to change public policy on an area as fundamental as life and death. This no one should be willing to tolerate. (Veatch, 1972:13)

Whose Issue is the Definition of Death?

By the end of 1972, several professional groups were grappling for control of the issue. Most physicians had thought all along that the issue was most properly relegated to them, and they continued to do so.

The legal, lay or ethical communities, in other words, had little of any real substance to bring to the topic. After all, medicine had always had its own ethical standards and the law had always left the matter of death to physicians. Death, at least since modern times, was not something the lay public declared or determined anyway, no matter how salient the issue to everyone's existence.

Theologians, ethicists and philosophers, on the other hand, argued: 1) That redefining death entails coming to terms with the meanings of "organism", "life", "personhood" and 2) that physicians are neither competent nor especially trained to dominate the issue. Redefining death is not simply a matter of science and technics or, as philosopher Dallas High argued, "Death is not straightforwardly cashable in empirical terms or in empirical criteria" (1972:454). In their publications, the Hastings Group in particular asserted that the issue should be broadened to include the public. Veatch especially questioned whether notions of medical, and indeed professional expertise in general, were appropriate for this issue of obviously public concern.

Lawyers supported the physician's conclusion that the issue was primarily a medical one, but insisted that there was a significant danger of physician liability in transplant situations if the law were not updated to fit the new neurological criteria. Many advocated legislation. Philosophical and ethical concerns were raised by some.

But regardless of the lack of consensus among those who considered themselves to be responsible for defining the issue, public policy continued to be enacted.

Virginia Responds With a Statute

Approximately eight months after the Tucker decision, a definition

of death was set on legislative course in Virginia (Compton, 1974:535).

The primary stimulus for the bill was the Tucker case and lawyers

representing both the defendents and plaintiff in the case were involved

in the executive process of stimulating and getting the bill passed

(Informant notes; Compton, 1975). The bill's patron was a surgeon,

William Ferguson Reid, who represented Richmond in the state's congress.

Reid himself did not do much more than introduce the bill; two assis-

tant attorneys general and counsel for the defense in Tucker, Theodore

Markow and Bill Crews, did most of the drafting and "pushing" work,

according to informants.

Tucker did not form a precedent, and rather than have the issue

be decided anew each time it arose, Crews decided that a statute was

needed in order to protect physicians. Crews and Markow talked with

physicians at the Medical College of Virginia and leaders of the

medical community looked over the existing death statutes, and were

not satisfied with the Kansas and Maryland statutes. They did consult

with Loren Taylor, one of the draftsmen of the Kansas statute. How-

ever, there was no clamor by physicians after Tucker and physicians

were "lukewarm at best", "less than enthused, almost negative" regard-

ing the bill. Hume originally opposed the bill on the basis that he

thought that it would be too restrictive to physicians; however, Crews

talked with him at length and presumably convinced him of the need for

it. By the time the bill was introduced by Crews' good friend, Dr.

Reid, there was little opposition and little support, but it hobbled

through, nonetheless.

The stimulus for the bill came from the legal community of Richmond, not the medical community -- interesting, since the Medical College of Virginia, in Richmond, had one of the most active transplant programs in the country. One would think the medical community would express some concern over the legal facilitation of transplantation and protection of their surgeons.

Crews drafted the bill; he and Markow "agonized over it, draft after draft", and spent more time than usual on this particular bill. They felt that if there was any little thing wrong with it, the bill would be killed immediately. ". . . but more importantly, we were dealing with people's lives" -- a rare statement of concern about what introducing such a bill means.

The Virginia statute differs in some significant respects from the Kansas and Maryland statutes:

> When person deemed medically and legally dead - A person shall
> be medically and legally dead if, (a) in the opinion of a
> physician duly authorized to practice medicine in this State,
> based on the ordinary standards of medical practice, there
> is the absence of spontaneous respiratory and spontaneous
> cardiac functions and, because of the disease or condition
> which directly or indirectly caused these functions to cease,
> or because of the passage of time since these functions
> ceased, attempts at resuscitation would not, in the opinion
> of such physician, be successful in restoring spontaneous
> life-sustaining functions, and, in such event, death shall
> be deemed to have occurred at the time these functions
> ceased; or (b) in the opinion of a consulting physician, who
> shall be duly licensed and a specialist in the field of
> neurology, neurosurgery, or electroencephalography, when based
> on the ordinary standards of medical practice, there is the
> absence of spontaneous brain functions and spontaneous res-
> piratory functions and, in the opinion of the attending physi-
> cian and such consulting physician, based on the ordinary
> standards of medical practice and considering the absence
> of the aforesaid spontaneous brain functions and spontaneous

respiratory functions and the patient's medical record, fur-
ther attempts to resuscitate or continued supportive
maintenance would not be successful in restoring such
spontaneous functions, and, in such event, death shall be
deemed to have occurred at the time when these conditions
first coincide. Death, as defined in subsection (b) hereof,
shall be pronounced by the attending physician and recorded
in the patient's medical records and attested by the afore-
said consulting physician. (See Compton, p. 533, Va. Code
Ann. §32-364.3:1 (Cum. Supp. 1973))

For one thing, the statute is all of a piece, and not composed of

two paragraphs physically implying two alternative kinds of death.

The statute dictates that death as determined by the absence of brain

functions and respiratory functions will be determined in consultation

with a specialist in the neurological fields and the patient's attend-

ing physician. And, since the statute declares death in the second

instance on the basis of absence of respiratory functions, a concept of

neocortical death would be illegal in Virginia. Thus, the statute is

binding in two important senses -- that there must be consultation with

a neurological specialist and that a definition of death which speci-

fied cerebral death (with respiratory center intact) may at some future

point be a more viable definition than it is at present. Perhaps the

drafters thought that such specifications would ensure that patients

whose death was obscured by artificial means would be declared dead

properly -- according to neurological criteria which refer to the whole

brain. According to Compton (1974) (the judge presiding in Tucker),

the statute was designed to make no reference to transplantation. It

seems (partly because he cites the article) the draftsmen took the

Capron-Kass critique seriously.

Cerebral Angiography

Some investigators, particularly those of the Swedish and German medical schools of thought on this issue, argue that cerebral angiography, a method for determining cerebral blood flow, would facilitate the accurate diagnosis of cerebral death (Shalit, 1970; Korien, 1973; Braunstein et al., 1973). Cerebral angiography is a method which entails injecting a radioisotope into an artery and noting by means of X-ray where the blood flows in the brain. The naive inquirer states, "But if that patient is maintained on a respirator, then of course the blood will circulate through the brain." Not so, as I was told. When the brain is traumatized or destroyed, the tissue becomes swollen, or edemous, and intracranial pressure becomes greater than arterial pressure; blood is blocked by the pressure and does not flow through the brain. It has been known for some time that the brains of patients maintained on respirators were dark and liquid at autopsy -- somewhat like mushroom soup, as one hardened physician described it. Such brains are called "respirator" or "dark" brains.

As stated above, the technique of cerebral angiography is thought to be risky, at least that is the sentiment of physicians here in the United States. Utilizing the technique, among other things, requires that the patient be moved where the equipment is located, something one would be hesitant to do with an already moribund patient (Braunstein et al., 1973). Braunstein and Korien, in nuclear medicine and neurology, respectively, and New York University Hospital developed a safer (in using veins instead of arteries) bedside procedure for performing angiography in hopes of offsetting the major objections

to its use.

However, in 1975 the National Institute of Neurological Diseases and Stroke published the results of a nationwide collaborative study on the determination of death (in which both Korien and Braunstein participated) expressing hesitance about adding angiography to the list of methods for determining death. Coordinator of the study, A. Earl Walker, stated that the injection of the radioactive tracer is invasive and risky and the entire procedure less than 100% accurate. "We have no completely accurate and safe way to determine cerebral blood flow" (Walker, 1975:27). Walker does think that the criterion should be developed as a means for ruling out drug intoxication which electroencephalography cannot distinguish from electrocerebral silence. For whatever other reasons, the method has not yet been well integrated with the procedures for telling that a man has died.

New Mexico Enacts a Statute

Interest in a statutory definition of death began in New Mexico with the joint presence of a transplant program and prominent Johns Hopkins neurosurgeon and Coordinator of the NINDS nationwide study on cerebral death, A. Earl Walker, who became Visiting Professor of the University of New Mexico School of Medicine. Then Dean of the Medical School, Robert Stone, took advantage of Walker's presence to secure a statutory definition to insure their transplant program. In a letter to the President of the New Mexico Legislative Counsel, dated June, 1972, Stone cites a recommendation made in Drug Research that each state establish a statutory definition of death, and states:

I am in agreement with this conclusion and believe that we ought to work towards obtaining such a law in New Mexico in the upcoming sessions of our Legislature . . . . Here in New Mexico we are in a peculiarly fortunate position to take constructive action on this matter. For the past year and a half, Doctor A. Earl Walker, Emeritus Professor and Chairman of the Department of Neurosurgery at Johns Hopkins University School of Medicine, has been a Visiting Professor at the University of New Mexico School of Medicine. Doctor Walker undoubtedly will be available to help us directly and I believe we should move energetically . . . . I intend to write and talk with some members of the Legislature whom we know already will be returning to Santa Fe in order to enlist their support.

Walker became head of the Committee on Cerebral Death of the New Mexico Medical School to examine the issue, and was generally active in stimulating interest in and gathering support for a statutory definition. Walker had been a consultant on the Maryland bill as well. One legislator who became one of three sponsors of the bill and who was a member of the Mental Health Board of the Medical School (as one physician put it, "an intelligent man with no particular axe to grind") escorted the bill through the legislative process. Stone had approached one other legislator and told him that the Medical School faced potential problems with the UAGA and its transplantation research (Informant notes). The major supporters of the bill were those involved with the Medical School, and the bill passed with little dialogue and virtually no opposition in either house. One informant blurted, "I hope you don't ask hard questions, Ma'am -- I'm just a cowboy!" The language of the bill was the responsibility of the state Legislative Council, and is nearly identical to the Kansas statute.

1-2.2.2 Death defined. - A. For all medical, legal and statutory purposes, death of a human being occurs when, and "death," "dead body," "dead person" or any other reference to human death means that:

(1)   based on ordinary standards of medical practice, there is
the absence of spontaneous respiratory and cardiac function
and, because of the disease or condition which caused, dir-
ectly or indirectly, these functions to cease, or because of
the passage of time since these functions ceased, there is no
reasonable possibility of restoring respiratory or cardiac
functions; in this event death occurs at the time respiratory
or cardiac functions ceased; or
(2) in the opinion of a physician, based on ordinary standards
of medical practice:
(a)   because of a known disease or condition there is the
absence of spontaneous brain function; and
(b)   after reasonable attempts to either maintain or restore
spontaneous circulatory or respiratory functions in the absence
of spontaneous brain function, it appears that further attempts
at resuscitation and supportive maintenance have no reasonable
possibility of restoring spontaneous brain function; in this
event death will have occurred.   Death is to be pronounced
pursuant to this paragraph before artificial means of supporting
respiratory or circulatory functions are terminated and before
any vital organ is removed for purposes of transplantation in
compliance with the Uniform Anatomical Gift Act (12-11-6 to
12-11-14).
B.   The alternative definitions of death in paragraphs (1) and
(2) of subsection A of this section are to be utilized for all
purposes in this state, including but not limited to civil and
criminal actions, notwithstanding any other law to the contrary.
(N. Mex. §1-2-2.2, Laws 1973, ch. 168)

Among the four statutes passed from 1970-1973, Kansas and New

Mexico had somewhat similar histories in that the State Medical Schools

stimulated interest in and organized support for the bill.   Maryland

and Virginia's statutes evolved primarily from within the legal com-

munity.   All but Virginia's, according to informants, were instituted

to facilitate transplantation; Virginia's is the only statute of the

four which does not mention transplantation in the text.   Virginia is

also the only state in which a wrongful death case was brought to bear

against a transplant team in which the public interest was dramatically

played out against the medical interest.

The Alaska Statute — What Happened?

In 1974, Alaska passed a death statute quite unlike any of the previous statutes. However, I was unable to obtain any information pertaining to the history of the statute, even with repeated calls to the office of Alaska Senator Mike Gravell (who also attempted to obtain information). Inability to report on the social works of the statute is partially due to the disappearance of bill sponsor Milo Fritz. The statute (§1 ch. 8 SLA 1974) reads as follows:

> A person is considered medically and legally dead if, in the opinion of a medical doctor licensed or exempt from licensing under AS 08.64, based on ordinary standards of medical practice, there is no spontaneous respiratory or cardiac function and there is no expectation of recovery of spontaneous respiratory or cardiac function or, in the case when respiratory and cardiac functions are maintained by artificial means, a person is considered medically and legally dead, if, in the opinion of a medical doctor licensed or exempt from licensing under AS 08.64, based on ordinary standards of medical practice, there is no spontaneous brain function. Death may be pronounced in this circumstance before artificial means of maintaining respiratory and cardiac function are terminated.

The phrase "medically and legally dead" does not add to the statute's conceptual clarity, but aside from that, the statute is a bit more simple than the others. It almost seems as if the author of the statute had adopted some aspects of the Capron and Kass proposal, but I was not able to determine whether that was indeed the case. The statute also omits any mention of transplantation.

Transplant Trouble and the Law in California

In the fall of 1973, two lawyers for the defense in two criminal cases argued that the removal of the decedents' hearts for transplantation by Norman Shumway (who was the head of the only heart

transplantation program in the United States at Stanford University Medical Center) was the cause of death and not the negligent or criminal acts which provided Shumway with excellent donors -- a person shot in the head during a fight in Oakland and a young girl with extensive brain damage incurred in a car accident in Santa Rosa.

Shumway had never before, and has never since, utilized criminal victims for transplantation (Medical World News, 3/22/74). In 1968, Stanford's Medical Director had signed an agreement with the Santa Clara county coroner which stated that transplants would not be performed in the county on homicides -- known or suspected. However, when Shumway heard of the Oakland victim's candidacy as a donor, he removed the victim's heart in Oakland (outside Santa Clara county limits) and flew the heart soaked in a brine solution to Palo Alto by helicopter. The county coroner, needless to say, did not appreciate Shumway's action to skirt their agreement (New York Times, 10/29/73).

The Oakland defense was denied, but the judge in the Santa Rosa case reduced the charge brought against the driver from manslaughter to felonious drunken driving and ruled that it was the removal of the child's heart which caused her death. That opinion was later overturned (San Mateo Times, 5/6/74); but it had done its damage. According to one physician informant, "There was no reluctance of physicians to call people neurologically dead until (these cases) occurred . . . " One of the informants received a letter from the Attorney General's office stating that physicians could be considered criminally involved in murder if they participated in transplantation. The challenges to the redefinition of death and the uncertainty of the new definition's

status ". . . scared hell out of doctors and coroners" in California, according to another prominent surgeon, Folkert Belzer, then chief of the kidney transplant program at the University of California Medical Center at San Francisco (Capron, 1974).

Considerable pressure to assure the public and phsyicians of the definition's legitimate legal status was put on transplant societies, individual transplant surgeons, concerned legislators and medical policy bodies. Belzer, Berne (chief surgeon of the kidney transplant program at the University of Southern California) and Shumway all noted dramatic decreases in organ donations immediately following the announcement of the legal cases. Belzer stated that, in his opinion, the decrease was due to the reluctance of the public and of physicians to get involved in donation or referral lest they be called to court (Medical World News, 3/22/74, p. 15). Each month that the issue remained unresolved lives might have been saved by organ transplantation but were lost. The California Medical Association, following the recommendation of the AMA, recommended that the state follow a simple legal route by leaving the issue to physicians and not the public or any public body such as the legislature (Medical World News, 3/22/74, p. 14).

However, California's Attorney General, Evelle Younger, thought otherwise and held the position that ". . . whether or not legislation is needed is not negotiable . . . " (Abstract from the meeting of the Committee on the Definition of Death, Feb. 15, 1974). A statutory solution was the answer. Younger's representative on the Committee, Deputy Attorney General Joel Moskowitz, said to Capron, as he reports

in an article which appeared in 1974 in the New York Times, that the Committee's major premise is that "the definition of death is a matter for resolution by public bodies, and not merely by the medical profession."

Younger had organized a Task Force on the definition of death in 1968, after he had witnessed the questions raised about the time of Robert Kennedy's death, as then District Attorney of Los Angeles. An informant told me that Kennedy had been briefly considered as an organ donor. (Kennedy had, of course, been shot in the head and had subsequently been maintained artificially.) Understandably, this situation threw the Los Angeles medical community and the coroners into a quandary. Younger had asked his friend and eminent cardiologist, George Griffith, who had attended Kennedy, to chair the Task Force. However, after election to his present post, interest in the issue wained until the 1973 court cases, when Younger again activated the Committee (Informant notes).

As soon as the court cases hit the news, according to one informant, small groups in Los Angeles, San Francisco and at Stanford began talking about doing something and began to take action separately. The big leap forward came with Younger's push and the organization and centralization of his Committee. "It was exactly what we wanted, because, you know, in this business you have a lot of doctors who look like they're self-interested in publishing the thing; and even as it was, that was the case, but we had at least the rest of this committee and members to call on to testify." (The Committee included Griffith, Belzer, Berne, Don Harper Mills (!), physicians from all over the state,

lawyers, medical examiners, a news reporter and a legislator (California A.B. 3560, Fact Sheet, pp. 2-3). Organizations soon supported the movement to adopt a legislative definition once it was legitimated by the Attorney General and his "blue-ribbon" committee.

California legislator, Dixon Arnett, who had been Director of Community Relations at Stanford University when Shumway performed the first heart transplant there, was aware of the legal problems presented by the court cases and the uncertainty of the new definition. Before he heard of Younger's committee, he asked his staff to begin researching the issue and possible solutions. After Younger called a news conference to announce the establishment of the Committee and its goals, Arnett contacted him and suggested that they join forces. Arnett formed the link the Committee needed with the legislature, and it was he who sponsored the bill and who worked very closely with the committee.

Mills and Berne, both on the faculty of the University of Southern California, had discussed the matter and the formation of the Younger committee. Subsequently, Mills wrote to Younger and offered his expertise and experience with the Kansas statute, and Mills joined the Committee (Mills, 1974). At an earlier meeting, Moskowitz reviewed the Capron and Kass article and critique of the Kansas statute and introduced a statutory proposal drawn up by another member of the Committee which was a nearly verbatim copy of the Capron and Kass version (Committee Abstract, Feb. 1974). The Committee considered using the proposal and corresponded with Capron. However, Mills thought that the Capron and Kass proposal, while eliminating much excess baggage in the Kansas statute, "still retains the appearance of different criteria for

determining death based on the presence or absence of artificial main-

tenance (Mills, 1974a, p. 1226). Defining death was something the

lawyers for the California Medical Association would not buy, thinking

that their clients' hands would be tied by the rigidity of a definition.

The most active members of the Younger committee attempted to get around

a definition and, on Mills' advice, oriented the statute to merely

establish that brain death is legal (Informant notes). The California

Health and Safety Code, Section 7155.5, had been amended to suggest that

"a person may be pronounced dead if, based on usual and customary

standards of medical practice, the person has suffered an irreversible

cessation of spontaneous brain function." And the Committee decided

that portion of the amendment was the most suitable wording for a

statutory solution. Once in the legislature, the wording was changed

from a merely "permissive authority" to an instruction that death shall

be pronounced. The statute, Chap. 1524 of the 1974 session, reads as

follows:

> A person shall be pronounced dead if it is determined by a
> physician that the person had suffered a total and irrever-
> sible cessation of brain function. There shall be independent
> confirmation of the death by another physician.
>   Nothing in this chapter shall prohibit a physician from
> using other usual and customary procedures for determining
> death as the exclusive basis for pronouncing a person dead.

When one informant (considered by another to be "our most constant, most

vigilant, most accessible expert") was asked who was responsible for the

language of the bill, he stated, "It was entirely Mills, absolutely . . .

the main character as far as I'm concerned was Don Harper Mills." Mills

was interested in constructing a statutory solution which would just

state a concept of brain death and omit attempts to define brain

death (Mills, 1974b).

After a "long battle" with the California Medical Association, the bill went to the House with organized medical support. Having been told by Berne and Belzer that in the usual 90 days it takes for a bill to take effect, 30-50 kidney transplants would not be performed, Arnett took it to the legislature as an "urgency bill" which would become law as soon as the Governor signed it. The bill passed with a 2/3 quota in the House and Senate (as its urgency status required) and Governor Reagan signed the bill with some haste. One informant mentioned that Reagan's wife is the daughter of a nationally prominent neurosurgeon whom the Younger committee had contacted, and suggested that the connection may have contributed to the bill's speedy enactment.

There was some opposition. Two persons opposed the bill because they each had a relative in the hospital whom they expected to die and couldn't face their families if they voted for the bill. (They must have had some lingering doubt that brain death is death and not a kind of euthanasia or killing.) There was a general "worrying" with the issue and some mumblings such as: "If we've gotten along without one for all this time . . . ." One legislator gave a speech on the floor arguing that the bill presented the first step toward legalizing euthanasia and there was some attempt to attach Catholic disapproval to it. However, after the bill was passed, when asked when the soul leaves the body, one high Catholic official stated, "After the second physician writes on the card that the brain is dead" (Informant notes).

The AMA Stand on the Issue as of 1974

The Connecticut delegation at the American Medical Association House of Delegates annual meeting in June, 1973, asked that the House of Delegates urge a moratorium on state statutory definitions of death, and suggested that in their stead "a guiding and consensual principle" be drawn up by the Judicial Council of the AMA which could clear up the muddle regarding the definition (Report of the Judicial Council of the AMA, 1973). The Report of the Judicial Council states that several critiques of statutory definitions have appeared in the literature (among the references are the Kennedy and Capron and Kass articles). The Judicial Council recommends that the House of Delegates "adopt the position, that, at the present, statutory definition of death is neither desirable or necessary" and they recommend "that State Medical Associations urge their respective legislatures to postpone enactment of legislation defining death by state, ... " (A, p. 2) Describing statutory solutions as "inflexible and even repressive", the Council recommended a general guiding principle which reads as follows: "Death shall be determined by the clinical judgment of the physician using the necessary available and currently accepted criteria". This policy was reaffirmed in December, 1974 (cf. AMA Resolution 18, 1974).

The ABA Recommends a Statute

At about the time California was fixing its statutory statement of death, the Law and Medicine Committee of the American Bar Association, chaired by McCarthy DeMere, adopted a definition strikingly like the California statute designed by Mills. Mills was on DeMere's committee,

and one might conclude that he had been instrumental in shaping the

ABA definition as well. The definition and a dedication which accom-

panies the 1974 ABA report, "Death -- A Current Definition", read as

follows:

> For all legal purposes, a human body with irreversible
> cessation of brain function, according to usual and customary
> standards of medical practice, shall be considered dead.

> Dedication

> Universally to the well being of people who will benefit
> from organ transplants in the best cellular condition and to
> those for whose well being it is to cease all artificial life
> supports after a human body is dead.

Thus the proposal was made for the purposes of obtaining organs

for transplantation and withdrawing life support systems, as was the

Harvard Report. Compare the California statute:

> A person shall be pronounced dead if it is determined by
> a physician that the person has suffered a total and irrever-
> sible cessation of brain function. There shall be independent
> confirmation of the death by another physician.
> Nothing in this chapter shall prohibit a physician from
> using other usual and customary procedures for determining
> death as the exclusive basis for pronouncing a person dead.
> (Emphasis added)

The NINDS Collaborative Study: The State of the Art

of Diagnosing Brain Death in 1975

In 1972, the National Institute for Neurological Diseases and

Stroke undertook a study to examine criteria for brain death determina-

tion and cerebral survival. To my knowledge, the study was suggested

by Daniel Silverman who died before this leg of the research was begun.

Nine centers across the country participated and several of the partic-

ipants in this study were members of the NINDS research group. The

first publications from this research appeared in 1975 (cf. <u>Medical World News</u>, 1/27/75; Walker and Molinari, 1975).

After 503 patients were selected for study who met the following conditions: no respiration and unresponsiveness, several conclusions were drawn. The first of these is that the Harvard criteria (which include the absence of spinal reflexes) are too restrictive "for routine usage" (Walker and Molinar, 1975:11). The 24 hour period is frequently too long and only cephalic reflexes need be used, according to the directors of the study. With the original criteria, apnea and unresponsiveness, the authors added absence of cephalic reflexes, a flat EEG and pupil dilation for 100% accuracy in diagnosing the death of the brain. The diagnosis of a dead brain can be made in an hour but may require repeated examinations over six, 12 or even 24 hours before a final diagnosis can be made. The first two criteria enable physicians to make a prognosis of impending death (but not a dead brain) with 91% accuracy (<u>Medical World News</u>, 1/27/75). One of the greatest problems is ruling out drug intoxication. "Apparently, modest amounts of drugs will modify the reaction to cerebral insult, and may be completely unsuspected, particularly in the case of the comatose patient who is brought in off the street" (Masland, in Walker and Molinary, 1975). Richard Masland, also involved in the study to some extent, and at the time at NIH, pointed out several weaknesses in the study which I think it necessary to include:

> However, there are several important weaknesses of methodology that I think need to be highlighted. The first is that in very few instances did they do their first EEG within the initial 6 hours following the cessation of respiration. Furthermore, there was a

considerable number of patients who were originally referred
to the study, but who, for some reason or another, were not
included in the data.

The possibility exists, then, that there may have been
patients who had a brief period of electrocerebral silence
and fulfilled the other criteria of brain death during the
first 6 hours following respiratory arrest, but who recov-
ered and who were not included in this series.

The second weakness of the study is that it was not
inherent in the protocol that all patients must be kept in
the respirator until circulatory failure occurred. There
were, I think, 140 of the 504 cases who were signed out as
"brain death." That is to say, the respirator was turned
off on the thesis that the brain was dead. Dr. Molinari's
report indicates that the pathology has not proven useful
in determining whether those patients were or were not
actually dead. So, the study had a deficiency in that the
determination of death was partly established on the
criteria which the study was supposed to establish.
(Masland, in Walker and Molinar, 1975:13).

As a lay person, it is curious and somewhat unsettling to read

Masland's critique. One wants to insist that there be 100% accuracy

and no doubt whatsoever in using these criteria and that respirators

not be turned off until the most rigid criteria are met. Masland

continues:

For myself, I have come to several conclusions from
this study. One is that methods must be included for veri-
fying that drug intoxication is not a clouding element in
the picture. The second is that the pressure for organ
transplant increases our hazards very materially because
of the pressure for haste, and that there is no substitute
for a reasonable period of time for observation in order
to be certain that one is not being confounded by an
unexpected issue (p. 14).

Another neurologist, Fred Plum, goes on to say, in the discussion

following Walker and Molinar's presentation, that he, like Masland,

sees no choice other than to treat patients in whom any doubt of diag-

nosis exists. I should say. The detailed report of the study was due

to be published in monograph form in the spring of 1979.

These are the major events, persons, committees and issues consti-
tuting the redefinition of death through 1974. An update (Epilogue)
appears in the concluding chapter. The present chapter is intended for
use as a reference for the remaining discussions.

Endnotes

[1]Thomas v. Anderson, 96 Cal. App. 2d371, 215 P.2d 478 (1950).

[2]Smith v. Smith, 229 Ark. 579, 587, 317 S.W. 2d 275, 279 (1958).

[3]At the time I began to collect my data, both Schwab and Silverman were deceased. All the information presented about them was obtained from informants who had worked closely with them.

[4]The members of the committee who cooperated with this study are Beecher, Curran, Denny-Brown, Farnsworth, Mendelsohn, Murray and Potter. Schwab was deceased. I also interviewed committee associates Francis Moore and E. P. Richardson, both of Harvard Medical School.

[5]In this study respondents from all disciplines chose Beecher _far_ more often than any other person.

[6]There is a phenomenon known as the "locked-in syndrome", in which the cerebrum is intact and the reticular formation and other parts of the lower brain are destroyed.

[7]Interestingly, in their article published in JAMA (1968), Halley and Harvey, like so many other authors, quoted Pope Pius XII, or, I should say, misquoted the Pope. Their mistranslation, which causes a severe misreading of the Pope, was caught in 1975 by European lawyer, Adrienne Van Till-d'Aulnis de Bourouill. In this frequently cited article by Halley and Harvey the translation of the Pope reads, "Human life continues for as long as its vital functions, distinguished from the simple life of the organs, manifest themselves _without_ the help of artificial process." As Van Till points out, the French reads, ". . . que la vie humaine continue aussi longtemps que ses fonctions vitales - à la difference de la simple vie des organes - se manifestent spontanement ou _même à l'aide_ de procedes artificiels" (emphasis mine). The translation should read ". . . that human life continues for as long as its vital functions manifest themselves spontaneously or even with the help of artificial processes" (Van Till, 1975:138). Hardly a small and inconsequential difference!

[8]Among the respondents and participants were both Henry Beecher and Ralph Potter, professor of social ethics from Harvard and a member of the Harvard Committee. Also among the participants was Jay Katz, professor of law and psychiatry at Yale (Ramsey, 1970:xix-xxii).

[9]United Trust v. Pyke, 199 Kan 1, 4, 427 P.2d, 67, 71.

[10]Tucker v. Lower, No. 2831; L. & Eq. Ct. of Richmond, 1972.

[11]Capron (1979) is of the opinion that the California statute still uses two unrelated standards, as does the Kansas statute. Mills argues that the Capron-Kass statute does the same thing. I agree with Capron.

CHAPTER 4:

THE CULTURAL DEFINERS: WHO THEY ARE

This chapter is devoted to placing the cultural definers, i.e.
assessing their occupational, organizational, cultural and geographical
locales, in order to lay a groundwork for later discussion of the roles
these different factors play in the social organization of the sample
and in the conceptual approaches taken to the topic. The information
derives from responses to the questionnaire.

Work and Discipline

Of 75 respondents, 39 (52%) are physicians, 21 (28%) are in law
or law and medicine, and 15 (20%) are ethicists -- philosophers, theo-
logians and clergy. Orienting a rather loose definition of inter-
disciplinarity with the following criteria:

1. academic or professional degrees in two or more disciplines;

2. current occupational commitment substantially different from
   original professional/academic training,

fourteen respondents (19%) are interdisciplinarians. Of these, five
were originally trained in either medicine or theology and now have
occupational commitments in bioethics areas.

Most definers are associated with colleges or universities, only
11 (15%) are not. Thirty six percent of the sample are academic
professors, 33% are medical or clinical professors and 16% are

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administrators or were students at the time they wrote their articles. Of 52 members of various faculties, at least 24 hold such distinguished positions as named professors, chairmen of departments and chiefs of wards and laboratories. Examples of such luminaries include internist Gunnar Biorck of Sweden, who holds positions as Scientific Counsellor to the Royal Board of Health and as the physician to the King of Sweden, and internist J. Russell Elkington, who was for many years editor-in-chief of the Annals of Internal Medicine. Medicolegal experts William Curran and Don Harper Mills write regular columns in JAMA and the New England Journal of Medicine, respectively. These three medical journals are among the largest and most respected of those published in the United States. The respondents are not just professionals and academics, but a blue-ribbon list of men (there are no women) many of whom are nationally prominent in their areas of expertise -- the kinds of persons one might expect to be chosen, or to offer their services, for defining an issue of considerable consequence.

The definers represent many areas of knowledge. Of the physicians, 64% work in the neurological sciences, i.e. neurology, neurosurgery, or electroencephalography. Most of the physicians in the sample who write articles on the definition and criteria of death are those who have the most experience with, and knowledge of, brain function and pathology. Some respondents (18%) are internists and again some have specialties in cardiology and nephrology. Surgeons comprise 7% of the medical definers, and of these, surprisingly, only one has been involved in transplantation. Anesthesiologists also comprise 7% of the physicians.

The rest include one psychiatrist, one medical philosopher, one physician in nuclear medicine and two medical students.

Since the question "When is a person dead?" emerges in several contexts, e.g. in transplantation, stopping treatment or "pulling the plug" and resuscitation, it is surprising that there are so few transplant surgeons and cardiologists in the author sample. Transplant surgeons might not appear as often in the death definition literature as in the transplantation literature, since several seem to regard the former topic as subsidiary to the latter. Cardiologists and emergency physicians are continually faced with decisions regarding when one may stop resuscitating. Why so few of them among the authors? One cardiologist informant, a prominent figure in cardio-pulmonary resuscitation and emergency coronary care (CPR-ECC), mentioned his surprise that so few of his colleagues were on the author list. After talking with him, I added three additional prominent CPR-ECC physicians to the list before mailing the questionnaires, and they were recognized by only few informants, mostly internists. Perhaps the reason that they do not appear in the "brain death" literature and are not recognized by this group is because they seem to be concerned with national and community education regarding CPR-ECC. Perhaps their concerns lie in the pragmatics of heart, kidney and intensive care -- in the doing and vigilance; they leave the legitimating and consensus work to others.

Of those in law and medical law, 33% are law professors and half of the professors also provide counsel for physicians. Twenty-four percent are private practitioners, several of whom are specialists in

medical jurisprudence. The list also includes one judge and one legislator, as well as four students.

Among the 15 ethicists, one third mentioned theology as an area of primary concern, most of whom are also members of the clergy. Four are professors of ethics and two are professors of philosophy. Others mentioned combinations of ethical or bioethical analysis, and philosophy and/or theology as major work areas. Over half of the ethicists work in the interdisciplinary area of Christian social ethics, a pragmatic as well as theoretical area of knowledge devoted to the study of action with respect to the social order (Potter, 1975). Medicine and society, and medical ethics are areas of scholarship to which most of them contribute frequently.

Certain work experinces cut across disciplines to some extent, namely working in some aspects of organ transplantation or with the dying. One third of the respondents stated that they had been involved in transplantation, but only three mentioned direct care for the donor or donee in the transplant exchange or transplantation surgery. Others were neurologists asked to make determinations of death on prospective donors according to the new neurological criteria, and anesthesiologists assisting in the surgery. Besides physicians, a few lawyers and ethicists acted as legal and more advisors to transplant programs.

Almost half of the entire sample had worked with some aspect of care of the dying besides transplantation. Slightly more than half of these also had occupational involvement with transplantation. Almost all of the physicians had worked with dying persons. About one third of the ethicists had been engaged in pastoral care of the dying or

counseling the dying and their families.

Origin of Involvement with Redefining Death

How did the authors become involved with the issue of death definition? - a question of considerable interest since there is no recognized training for cultural defining, or even, more specifically, for redefining death, although there are traditional occupational and experiential avenues which are more likely than others to lead to this particular cultural task. The question is of substantial interest to those concerned with how cultural tasks become relegated to or are assumed by particular members of society. In this chapter, only the respondents' answers to the question are addressed. The larger question of the cultural assumptions which govern the allocation of cultural tasks will be discussed in the concluding chapter.

Most respondents, 83%, stated that their involvement with the subject arose in the context of their work, with 44% additionally mentioning that they were invited to participate on a committee or in a symposium examining the topic, 24% adding that personal interest in the topic was an important original factor, and 10% acknowledging that they were asked to counsel a dying patient and/or her family. For most respondents the topic was indigenous to their occupational concerns.

> As a physician I have been diagnosing death and certifying deaths since 1940. As an anesthesiologist I have been managing cardiac arrest and resuscitating coma patients since 1942. This has been a responsibility of anesthesiologists in modern practices. (MD)

> As a medical student at the George Washington University (I was involved) in the care of a child with brain death at the Children's Hospital. (MD)

> My involvement stemmed from the trial of a law suit, over which I presided as the trial judge. (JD)
>
> As a medical examiner, I authorized the removal of the heart from a victim of head injury, for the purpose of a heart transplant. (MD-JD)
>
> I serve as a moral consultant to many Catholic hospitals in the area. Questions on calling code and life-death decision making led to my reflections and the article. This in turn led to many appearances on committees and symposiums. (ETH)
>
> We investigated criteria of brain death at the Bonn University Dept. of Surgery and joined with Neurologists, Radiologists, Neurosurgeons to define criteria of death for intensive care unit patients and for organ transplantation. (MD)

An ethicist said that the issue arose in the context of his teaching, "in the sense that Euthanasia was a topic in my course. The definition issue arose only with the Harvard Report coincident with my research... and lectures..." and his statement serves as a rather typical example of the ways most ethicists entered the redefinition debate. Most became involved with the topic as one other subject matter to which they might apply their skills and methods, usually in conjunction with other subjects which fall under the heading of morals and medicine or bioethics. Ethicists and theologians had been primarily involved in studying other related topics such as population, human experimentation, technology and human values, expertise and decision-making. Several mentioned that their major occupation, ethical analysis, is a method which can be applied to various ethical dilemmas, the re-definition of death among others. For example, as one ethicist put it, "... I really backed into this whole death area. In general, my real

interest is in theories of expertise and I think the definition of death has absolutely muddled that issue (expertise)."

Obviously, topics such as the care of the dying, ethuanasia, transplantation and abortion are, for ethicists and lawyers conceptually closer, and for physicians, pragmatically closer, to the definition of death topic than others. Persons might come to the topic through an intellectual or professional obligation to examine closely related areas. Almost half of the respondents had been involved in public discussions on other death and dying topics (e.g. in descending order of frequency, euthanasia, care of the dying, suicide), and 53% had been involved with other bioethics topics (e.g. in descending order of frequency, abortion, human experimentation, scarce medical resources, health care delivery, etc.). Perhaps the fact that it is indeed difficult to discuss the issue of death definition without discussing transplantation and euthanasia, and vice-versa, is a major factor in many respondents' involvement with the subject, a factor which might be referred to as conceptual proximity. In addition to ethicists, others who had interest in the ethics or legalities of transplantation, informed consent or human experimentation could easily arrive at the topic of death definition. Physicians whose special areas are the neurological sciences could come to the topic by virtue of their expertise and interest or by their position in a hospital setting, i.e. as the physician in charge of patients who made the best transplantation donors, patients with "brain death". Anesthesiologists and cardiologists come to the issue by frequently being confronted with the question when is death, i.e. when is further artificial ventillation

and resuscitation unnecessary, that is, pragmatic proximity.

In one sense, the ethicist and lawyer have more choice in becoming involved with the issue than physicians. As one law professor stated:

> The topic was a personal interest in that I thought
> it raised fascinating intellectual problems which
> had been neglected by lawyers. (JD)

Physicians, on the other hand, faced with the brute factors of death situations - unburied corpses, patients with cardiac arrest, severely brain-damaged patients whose organs might save other lives - must come in contact with the issue and resolve it in one way or other.

Those who mentioned that personal interest had been a source of involvement, whether mentioned alone or along with work, counseling or invitations to committees/symposia, comprise only 34% of the respondents. The relatively low percentage of interest expressed may be due to the fact that many persons view work and personal interest as inseparable or that work initiated the involvement, and interest followed. At any rate, of those who did mentioned personal interest, a few added relevant past experiences which had contributed to their interest and commitment.

> As an observer of "the Medical Case" (The United States
> v. Brandt et al.) held before the American Military
> Tribunal at Nurenberg in 1946-1947, I had a real interest
> in these discussions. (ETH)

> Exposed to triage evaluation of wartime military
> medicine - 1942-5- then civilian practice - all out
> efforts to support functioning existence of moribund
> patients by artificial tactics and with fatal outcome
> certainly encountered repeatedly; slavish obeisance to
> 'sanctity' of life and 'dignity' of death instead of
> 'love or reverence' and 'nobility' respectively. (MD)

Still others, though very few, mentioned that their involvement in the
issue was related to closer personal relationships.

> Dr. X...has been for years a very close personal friend;
> and he was a former student of mine. It was from that
> personal and intellectual relationship that I was able
> to work with him on the articles which we wrote and
> published. (JD)

> As a member of a Law Review, I was assigned to write an
> article...My wife, who is a registered nurse, had told
> me of the differences between the medical and legal
> definitions of death. This topic was of great interest
> to both myself and the director of the Law Review. (JD)

Several respondents who contributed to University Law Reviews as
student members of the editorial staff and other student authors
stated that they had had an opportunity or requirement to write a
paper and chose this topic. Interest and opportunity were the major
factors leading to their involvement.

Having been asked to participate in a symposium or committee
provided the initial context for 47% of the authors' involvement with
the issue. As mentioned in the previous section, Ramsey, Jonas, Capron
and Potter, and to some extent Curran (asked to join, respectively, the
Lyman Beecher lectures, the American Academy of Arts and Sciences
symposium, the Hastings Death and Dying Research Group, and the
Harvard Ad Hoc Committee) fall into this group. Most persons in the
sample who are or were associated with the Hastings Death and Dying
Research Group joined through invitation, and only a few (e.g. Beecher,
Ramsey and Kass) had had prior experience with the issue of "brain
death". Few respondents (7%) came to the topic only by virtue of
invitation to join a committee or conference. The rest of the persons

who had been invited to join a committee or symposium were also occu-
pationally or personally comitted to the issue.

Organizational Affiliation

Another indication of one's social location is the organizations
in which one is most active. Although a quarter of all respondents
(28%) stated that they were most active in specific professional organ-
izations such as the American Academy of Neurology or the American
College of Legal Medicine or the American Society of Christian Ethics.
Only a few (11%) were most active in general professional organizations
such as the American Medical Association or the American Bar Association,
and 12% were most active in both general and specifc professional organi-
zations. Other mentioned activity in local, state and national bar
associations and medical societies, some additionally mentioning specific
professional organizations. Bioethics organizations such as the Hastings
Center or the Society for Health and Human Values, sometimes along with a
specific or general professional organization was mentioned by 9%.

Although only a few respondents indicated that they were most
active in bioethics organizations, 28% of the respondents belong to
organizations which deal specifically with death and dying or other
bioethical issues. In order of frequency of mentions they are:
1) The Hastings Center in New York; 2) the Kennedy Institute of Bio-
ethics at Georgetown University and the Society of Health and Human
Values in Philadelphia. Other organizations mentioned are the
Euthanasia Education Council in New York City, and the Thanatology
Foundation at Columbia University. Several members of the Hastings

Center in the sample are in prominent positions as staff-members, fellows of the Center, or members of the board of directors.

Academic Affiliation and Geographical Locale

In assessing the respondent's academic affiliation, I am concerned with both the university from which a respondent obtained his terminal degree, and the university in which he taught at the time of writing his article. The latter will be discussed along with geographical locale.

The colleges and universities where respondents obtained their graduate degrees are too numerous for a complete mention. Only those universities which awarded degrees to a minimum of two responents are included in Table 1. From the table, we can see that Ivy League universities are substantively represented in the definer group.

Universities which employed definers at the time of publication of their articles are located most heavily in the Boston-Washington corridor. Ten respondents taught in Ivy universities in this area, six or more in universities in the metropolitan New York area, and another four in the Baltimore-Washington area. The second geographical area of concentration is the Midwest with 15 respondents employed at universities in that region, over half of whom are employed in Kansas and Indiana (four each). California universities contain five respondents and southern universities, seven. The most popular academic centers for the the definers are Boston, New York City, Baltimore-Washington, D.C., Kansas City, Indianapolis and Los Angeles. The geographical locations of the non-academic respondents follow the same geographical patterns.

Table 1. Universities where respondents obtained their terminal degrees.

University	No. of Respondents
Harvard University	8
Yale University	4
Cornell University	3
University of Pennsylvania	3
New York University	2
George Washington University	2
Georgetown University	2
Duke University	2
University of North Carolina	2
University of Chicago	2
University of Minnesota	2
University of Kansas	2
University of Southern California	2
Foreign Universities	14

Cultural Location: Religion, Religiosity

and Professional Generation

Religion and Religiosity

In Table 2 we can see that over half of the definers (53%) are
Protestant; 20% are Jewish and 19% are Catholic. About 4% are other
faiths (Hindu and Islam) and an equal percentage are agnostic and
aetheist. Table 2 reveals the distribution of respondents' religions
with a breaksown by discipline.

The respondents were sorted again on the relative importance of
their religious affiliation. Twenty-nine percent said their religion
was very important to them, and almost as many (26%) said that it was
fairly important. Fewer (17%) assessed the importance of their
religion to be at the mid point on the scale, and 24% judged their
religion to be either hardly or not at all important. As a whole the
definers are religious; over half of them stated that their religion
was more important than not. Some refused to rank the importance of
their religion and included a comment, e.g. "strong belief in God",
philosophically important, clerically or theologically unimportant."

More ethicists (76%) than lawyers or physicians stated that
their religion was either fairly or very important, as we would ex-
pect, given the number of theologians and clergy in the group, and
among the ethicists there are no agnostics or aetheists. Physicians were
next, with 62% of them considering religion rather important to them.
Only one third of the lawyers, however, felt similarly about their
religions. Noting the cooccurrences of religion by religiosity, more
Catholics (85%) than either Protestants (59%) or Jews (29%) indicated

Table 2. Discipline by religious affiliation in rounded percentages.

| Discipline | Religious Affiliation | | | | |
	Catholic	Protestant	Jewish	Other	Agnostic/ Atheist
Physicians N=39	23 (9)	44 (17)	20 (8)	8 (3)	5 (2)
Lawyers N=21	10 (2)	66 (14)	19 (4)	0	5 (1)
Ethicists N=15	20 (3)	60 (9)	20 (3)	0	0
Total N=75	19 (14)	53 (40)	20 (15)	4 (3)	4 (3)

that their religion was important to them.

Professional Generation

Professional age (based on the date of the terminal degree) is more relevant and appropriate a variable in this study than chronological age. Definers of the same professional generation may share some of the same values and interpretations of the redefinition of death, and may know one another better through professional associations. In just these ways professional generation may have a bearing on the social organization of the definers. It is not so important to know how old the definers are as it is to know when they went to school and joined their profession. Almost half are relatively "young," having terminated their study from 1960-1974, and 24% are older members of their professions, receiving their degrees before 1950, and 16% are in the middle of their careers. The ethicists and the physicians have been working in their areas longer than the lawyers, but all three disciplines have about the same percentage of "young" definers (about 25%).

Discipline is the most telling of all the variables discussed, obviously associated with work experience, origin of involvement with the topic, and organizational affiliation. Knowing discipline, one could easily predict a definer's work experience, how he might come to the issue, or the professional organizations in which he is most active. Geographical locale, religiosity and professional age are only slightly associated with discipline in that a few more ethicists and physicians than lawyers live in the Boston-Washington corridor, consider their religion more important or are among the older definers.

In subsequent chapters, we will see that some of these variables interact with others as the focus changes from the definers' social organization to their conceptual approach. Throughout, however, discipline is the variable against which other assumes importance.

CHAPTER 5

COMMUNICATION ACTIVITIES IN CULTURAL DEFINING

Various communication activities and processes constitute the social process of redefining death. I have organized this study to assess the definers' communication with one another, with policy-makers, and with the general public. Their interpersonal communication and the interaction of policy-makers and definers are discussed in later chapters. This chapter concerns the definers' use of various channels in discussing death definition: the professional journal; symposia and conferences; and the mass media. I have oriented the findings in terms of the interdisciplinarity/intradisciplinarity of the activities and of the professional status (lay/professional) of the definer's readerships/audiences.

Redefining death is both an interdisciplinary issue and one which demands larger public debate. Not an infrequent situation, as go the crucial 20th century issues. And insofar as the topic includes medical, legal, and ethical components, one would expect some cross-disciplinary publishing and public discourse, but how much? How often did the persons responsible for delineating and explicating the issue address the lay public? Or, in other words, were the communication activities which underlie this complex process of cultural definition integrated across disciplines within the professional domain or often extended toward the public domain?

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In the treatment of the definers' use of professional journals below, the journals definers read, the incidence of cross-disciplinary publishing and the definers' conception of their readerships and objectives in publishing their articles are given. Also discussed are the definers' activity in other public discussions, such as conferences and symposia and discussions in the mass media -- all important aspects of the communication involved in cultural defining.

The Professional Journal

Reading

Definers were asked which medical, legal, ethical or interdisciplinary journals they read in order to keep up with discussions on redefining death. Most said they read the general medical journals, such as the Journal of the American Medical Association (JAMA), 77%, The New England Journal of Medicine (NEJM), 68%, and the British journal, Lancet, 41%. Thirty-nine percent said they read the University Law Reviews and 29% read the bioethics journal, the Hastings Center Report. A technical medical journal which publishes international association proceedings, Electroencephalography and Clinical Neurophysiology (ECN) was utilized by 28%. Ethical and theological journals and Bar Association journals were read by only 19% and 17% respectively. Of course, the respondents may not have read their journals regularly, or even at all. I have taken their choices as indicative of what they would read, or of which journals they consider most important.

Physicians said they read medical journals almost exclusively. Lawyers and lawyer-physicians indicated primarily their own journals

and the most well-known medical journals (JAMA, NEJM). Ethicists were
the most widely read, with almost half mentioning University Law
Reviews, JAMA and NEJM, and 73% mentioning the Hastings Center Report.

Publications

The list of journals which respondents said they read is rather
shorter than the list of journals in which they published. The latter
ranges from the fairly well known to the local and obscure. They
published in the "big" journals and in specialty medical journals, such
as Neurology and Pediatrics, in general medical journals, such as The
American Family Physicians and Hospital Tribune, in local association,
state and unviersity journals, and in interedisciplinary and theological
journals of small circulation, such as Linacre Quarterly, Soundings,
Tradition, and the Journal of the American Scientific Affiliation.

How many authors published their articles in other disciplines'
journals, perhaps to relay their disciplinary perspective on the issue
to those of another disciplinary persuasion or to express their allign-
ment with another discipline's approach? For the most part, the
definers published in their own journals, although 31% of the group as
a whole published outside their disciplines. Table 3 shows the propor-
tion of each discipline publishing in their own, or another discipline's
journals. The pattern found for journal reading holds for publication.
Ethicists published, as well as said they read, most diversely.
Lawyers published primarily in legal journals, but also published in
medical journals. And physicians published in medical journals almost
exclusively.

Table 3. Interdisciplinry publication: kind of journal in which article was published by discipline of author (in rounded percentages).

Discipline	Kind of Journal			
	Medical	Legal	Interdisciplinary	Ethical
Physicians N=39*	87 (34)	8 (3)	5 (2)	0
Lawyers N=21	38 (8)	62 (13)	0	0
Ethicists N=13**	33 (5)	7 (1)	26 (4)	20 (3)
Total N=73	65 (47)	23 (17)	8 (6)	4 (3)

*Not all respondents answered each question. Deviations from total (N= 75) and disciplines (Physicians, N = 39; Lawyers, N = 21; Ethicists, N = 15) noted by specifying N who responded in each table.

**Two articles written by ethicists appeared in books.

Interested in assessing some of the ways in which the authors may have determined to influence the redefining process in publishing their articles, I asked them a) how they conceptualized their readerships, b) what their purposes were in publishing their articles, and c) what effects they wanted their articles to have.

Audience

Each respondent was asked to indicate the audience to whom his articles was primarily addressed: physicians, the allied medical professions, lawyers, ethicists, theologians, policy-makers, or the lay public. And again, a pattern of interdisciplinary and intradisciplinary communication similar to that discussed above emerges. Physicians stated that they wrote primarily for physicians, and a few wrote to physicians and lawyers. If they intended to reach lawyers, and published almost exclusively in medical journals, they must have assumed that lawyers would use the medical journals. Lawyers stated their intended audience was lawyers and policy-makers primarily, and some had addressed physicians as well. Only one third of the ethicists wrote for other ethicists. The rest stated that they addressed physicians, lawyers, policy-makers and the lay public. Perhaps ethicists couldn't assume that other participants in the process of redefining death would peruse their journals, so they placed their messages elsewhere. At any rate, in each case, the definer's intentions were rather more inclusive than their journals' respective circulations.

Publishing Intent

Definers expressed various objectives in publishing their articles. Only a few authors (27%) stated their publishing intent in terms of reaching a particular readership, either another discipline or readers from a particular locale:

> To stimulate thought on the problem in medical and legal professions. (MD)

> To appraise physicians of the chasm between medical and legal definitions and determinants then existing - to make MDs aware of future problems which might arise, e.g. Quinlan case problems. (JD)

> To cause physicians to think of the legal problems involved. (JD)

> To inform members of the Kansas bar. (JD)

> General practitioners in the field of medicine seem to need a working definition in their small towns. (JD)

> To indicate the need for local consideration of (issues). (MD)

> To establish criteria for use in institutions, the general hospital. (MD)

Most others described their objectives in terms of particular kinds of problems they intended to explicate. Among these, some (11%) were interested in drawing attention to the problems of prolonging life in persons whose brains had died or of transplantation, and suggesting the redefinition of death as a solution:

> To provide guidelines - ethical - moral - scientitic so that ineffective therapy could be discontinued in comatose patients. Not euthanasia, passive or other- wise. (MD)

> To present data suggesting medical disunity about the concept of brain death and to call for a more universal acceptance of the entity. (MD)

> My perception of an impending conflict between medical and legal ethics. (MD)

> Help solve a social, legal, medical, theological problem. (JD)

Others (17%), mostly physicians, wanted to introduce new methods for determining death or to redefine old ones:

> To popularize the concept that brain death can be determined in part by tests of brain circulation and/ or metabolism. (MD)

> To better define the Harvard criteria - to demonstate brain death with spinal reflexes present. (MD)

> To investigate EEG criteria. (MD)

> To stimulate a new approach to clinical death more in tune with contemporary knowledge. (ETH)

Another 17%, ethicists and lawyers all, intended to delineate a specific disciplinary perspective on the issue, or to clarify specific disciplinary issues:

> To outline the philosophical and theological implications of decision-making in the health sciences. (ETH)

> To deal with the philosophical issues. (JD)

> Clarification of the ethical problems at stake. (ETH)

> To clarify the philosophical issues over the concept of death. (ETH)

> Myself to understand the Harvard Report and elucidate it accurately in comparison with supposed outdated determiners of death. (ETH)

Also interested in clarifying the muddles, some others (8%) levelled criticism at particular statements of policy or definition. Again the critics are primarily lawyers and ethicists.

> To clarify an important issue which seemed to me to be mishandled by the others who had dealt with it. (JD)

> Points out errors of court and MDs. (ETH)
>
> To draw attention to what I considered to be a bad piece of legislation and to discuss a problem in a journal with wide international circulation. (JD)
>
> To explain to myself, and others, who might be interested, why it may be fallacious to regard death as a definable thing. (ETH)

And, of course, there were those who wrote to encourage legislation (about 10%):

> To encourage stability in this area of law. (JD)
>
> I wanted to influence legislation to be adopted in other states. (JD)

Not surprisingly, some gave the customary nominal and somewhat banal objectives: "to satisfy a requirement for a class," "to prepare a presentation at an invitational symposium," but none stated what might be the obvious objective: "to further my career." All but these seemed interested in determining some aspects of the institutionalization of the notion of "brain death" -- medical policy, legislative policy, or the conceptualization of the issue.

Intended Effect

In addition to their publishing objectives, I asked them whether they wrote their articles to 1) influence a certain readership, 2) affect social policy, or both. In asking this question and the latter, I wanted to ascertain just to what extent the authors saw themselves as active and moving agents in this process of cultural definition. By intending to influence certain readers, perhaps physicians or the "teacher's" teachers, authors could be intending to affect policy

indirectly. But, in that case, they had the option of checking both alternatives. My purpose was to assess their primary intent. Did they intend their articles to have a delimited effect, and only influence readers, or did they intend to directly influence policy, to have a far-reaching political effect?

Among the 70 who responded to the question, 14% wanted only to affect social policy, 39% wanted only to influence a certain readership and 31% wanted to do both. Sixteen percent were not interested in doing either.

Table 4 gives the breakdown by discipline on this item. All disciplines wanted to influence specific audiences more often than to affect social policy. Since they could have checked both and did not, I assume that many simply did not consider that their contributions, or perhaps even the issue were matters of social policy at all. Only a few authors wanted to just affect social policy; most, who wanted to affect policy, wanted to influence their readerships as well. Otherwise, differences among the disciplines were slight.

From my knowledge of their articles and the information obtained from the interviews, I would say that lawyers and ethicists were clearly more "policy-minded" than physicians. Since many physicians opposed legislation, and many argued that the matter was entirely medical, perhaps to them, medical policy is social policy.

Symposia, Conference and Panel Participation

Aside from reading professional journals and publishing articles, about 73% of all respondents also participated in public discussions

Table 4. Desired effect of articles by discipline of author (in rounded percentages).

Discipline	Affect Social Policy	Influence an Audience	Both	Neither
Physicians N=35	14 (5)	52 (18)	20 (7)	14 (5)
Lawyers N=21	5 (1)	19 (4)	57 (12)	19 (4)
Ethicists N=14	29 (4)	36 (5)	21 (3)	14 (2)
Total N=70	16 (10)	42 (27)	36 (21)	17 (11)

such as symposia, panels and conferences on redefining death. Approximately equal proportions of all three disciples participated in such discussions. They were asked to indicate whether they had addressed audiences of their own professional persuasion, interdisciplinary audiences, or lay audiences in the discussions. And, of course, in addressing lay audiences, definers extended the discussion beyond the professional arenas. Table 5 gives the breakdown by discipline and indicates whether definers addressed only professional or interdisciplinary audience of lay and professional or interdisciplinary audiences. More ethicists than physicians or lawyers addressed lay audiences.

Mass Media Discussions

In giving their views in the mass media, definers assure that their messages are cast as broadly as possible, certainly beyond the professional domain. Although most discussions of the definition of death in the mass media have been relayed to the public via medical journalists and journalists who contacted definers, 43% of the 65 authors who responded to the question had participated in some type of media discussion. Thus, many, though less than half, of the definers contributed to the redefining process in the arenas of public, as well as professional opinion. Nearly equal proportions of each discipline are represented.

Television, newspapers, radio and magazines were used in decreasing frequency; several definers discussed the issue in more than one medium. It makes a difference, of course, in terms of their

Table 5. Symposium, conferences and panel participation: audiences addressed by discipline (in rounded percentages).

Discipline	DNA	Professional Only	Interdisciplinary Only	Lay and Professional, Interdisciplinary
Physicians N=32	28 (9)	16 (5)	19 (6)	38 (12)
Lawyers N=19	31 (6)	16 (3)	11 (2)	42 (8)
Ethicists N=14	21 (3)	0	7 (1)	71 (10)
Total N=65	28 (18)	12 (8)	14 (9)	46 (30)

contribution to the domain of public opinion whether definers discussed the issue in the national or local media. Eleven definers appeared in the national and 24 in local media. From Table 6 it is apparent that more ethicists than either lawyers or physicians discussed their views on the topic in both the national and local media.

The communication activities have been discussed in order of decreasing frequency. All definers published articles, and all but a few said they read some professional journal to keep up with the debate. Fewer (73%) respondents participated in symposia and conferences on "brain death," and even fewer (less than 43%) discussed the issue in the media. (All but one of the latter were among the symposium participants.)

In response to the two questions posed at the beginning of this chapter, I would say that the communication underlying the process of death definition is not integrated across disciplines or extended beyond the professional domain to the extent that perhaps it should be. A rather consistent pattern of inter- and intra-disciplinary and extra-professional communication has emerged with respect to definers' disciplines. In both journal use and publication, a hierarchy of exclusion of other disciplines exists, with physicians at the top oriented almost entirely to members of their own professions; lawyers next, reading, and writing for, lawyers, policy-makers and physicians; and ethicists reading journals from each discipline and directing their articles to each discipline, policy-makers and the public. Moreover, in other discussions, either across or beyond the disciplines, ethicists addressed more different kinds of audiences. Ethicists seem

Table 6. Participation in discussions in local vs. national media by discipline (in rounded percentages).

Discipline	DNA	Local	National	Both
Physicians N=33	55 (18)	27 (9)	9 (3)	9 (3)
Lawyers N=20	62 (13)	27 (6)	11 (1)	0
Ethicists N=13	54 (7)	15 (2)	0	31 (4)
Total N=66	57 (38)	26 (17)	6 (4)	11 (7)

to have done most of the "work" to extend their views beyond their discipline and beyond the professional domain. These patterns are interpreted along with findings relating to social organization and conceptual approach below in Chapter 9.

CHAPTER 6

THE SOCIAL ORGANIZATION AMONG CULTURAL DEFINERS

Cultural definers are not socially isolated individuals; they stand in various social relationships to one another -- interpersonal relationships as well as organizational and disciplinary affiliations. I have already discussed some foci of social organization, namely disciplinary affiliation, organizational membership, university and geographical locale. In this chapter, I will consider the interpersonal communication and other social relationships which authors have with one another in these and other social contexts, toward an analysis of the social organization among this group of respondents. Respondents were asked to check the names of other authors:

1. whose names they <u>recognized</u>

2. with whom they had had <u>contact</u> about the issue

3. whom they considered to be <u>important</u> to their conceptualization of the issue of death definition

4. whom they considered to be <u>professional friends.</u>

It is these four kinds of relations, Recognition, Contact, Importance and Professional Friendship, I will be discussing. Each of these ties has a structure.

Recent sociological and anthropological literature has contained studies of the structure of relations among scientists, rural

sociologists (Crane, 1969, 1970, 1972; Lin, et al., 1970; Griffith and Miller, 1970; Coleman et al., 1966; Brieger, 1976; White et al., 1976; Friedkin, 1978), psychotherapy seekers, intellectuals and community elites (Kadushin, 1966, 1968, 1974; Barton et al., 1973; Laumann et al., 1974; Laumann and Pappi, 1973), members of African and Sicilian towns and communities (Boissevain and Mitchell, 1973; Boissevain, 1974), to name just a few. Such studies focus on the social organiza- tion, or the structure of relations of a given population. The term "network" referring to the structure of relations in a given population - has acquired considerable popularity as a useful concept or metaphor for discussing these structures (Katz and Lazarsfeld, 1955; Coleman et al., 1966; Kadushin, 1975; Alba and Kadushin, 1976; Brieger, 1976; White et al., 1976; Friedkin, 1978). Its use has roots in kinship studies, sociometry, studies of the flow of influence and of the diffusion of innovations and information.

To my knowledge no studies have analyzed the structure of rela- tions among persons from different disciplines who are engaged, some of the time, in defining cultural issues and related public policies of cross-disciplinary significance. The present respondents are not in the "business" of furthering a research area within a shared "paradigm" of relevant problem-solving, of using an innovation intro- duced from outside their communities, or of providing the grease for the works of bureaucracies or particular communities. In other words, they are unlike members of other studied populations in that they are not quite scientists engaged in specialty research, adopters of innovations, intellectuals, or organization or community elites (though

they have some characteristics in common with scientists and intellec-
tuals). Nonetheless, other network analysts and I share at least
one goal -- the analysis of social structure among persons engaged in
certain activities. However that goal is not an end in itself, but
a means for understanding the social organization and patterns of
communication underlying a particular kind of cultural change and
institutionalization.

Assumptions Concerning the Concepts of "Network," "Communication" and "Social Relationship"

Although this chapter is intended as a discussion of findings
rather than a treatise on network theory, some conceptual work needs to
be undertaken in order to make proper sense of the data.

"Network"

With respect to the concept of "network", one assumption that I
make is that the networks among the sample members for each category
of relationship (Recognition, Contact, Importance and Friendship) are a
means of describing the social relationships which held for the
authors on the issue of death definition. The network is a kind of
map of social relations -- it is not a structure one could located as
such, or that one could say existed or exists in fact. "Network" is a
construct for describing the social relationships authors say they
had with one another while they were thinking and writing about "brain"
death. The interpersonal networks discussed below are abstractions
which hold only within well-drawn boundaries -- the boundaries of

discussions about death definition in professional journals. Change

the focus of the relationships to genetic screening, myasthenia gravis,

Christian ethics, torts or football, and each respondent would probably

name different persons for each kind of relation.

I find some conceptual problems generally present in the litera-

ture on networks of scientists and of elites and on diffusion and

influence, and I will attempt to resolve these problems for the pur-

pose of this study. The problems seem to develop from three inter-

related conceptual confusions and ambiguities:

1. a conceptual tendency to nominalize social processes
   such as communication and influence;

2. the reduction of social relationships to particular ties,
   channels or links;

3. confusion about the relationship of communication and
   social relationship and a tendency to identify one with the
   other.

In the following discussion, I am not so much concerned with pointing

fingers at particular authors as I am concerned with explicating a way

of speaking about networks, social relationship and communication which

I find problematic and which characterizes the network literature.

Social Networks and Communication: Structure and Process

It seems relatively clear that "network" is a construct used to

represent a social structure obtained with a sociometric investigative

format. Most effort in network discussions goes toward assessing

and delineating structure with little conceptual or empirical attention

to processes or dynamics. What I would argue are indeed processes,

i.e., communication and influence, are frequently conceptualized as

either contents or kinds of networks. Networks are described as
"communication networks" or "interpersonal networks of communication"
or "networks of influence", and communication and influence are
relegated to the status of kinds of flow or stuffs which rattle
through the channels of a network. It is difficult to tell whether
a phrase such as "interpersonal networks of communication" refers to
a kind of relationship structure, e.g., one composed of channels or
tracks, or assumes that a particular interpersonal network is
characterized by "communication content" as opposed to some other sort
of content.

In their study of the diffusion of a new drug among physicians
in three communities, Coleman, Katz and Menzel suggest, "It may be
useful to think of the structure of social and professional relations
among physicians in a community as a network of communication through
which information, influence and innovation flow" (1966:69). The
"flow" seems to have little to do with communication; communication
is rather a kind of network or set of channels, through which other
"stuffs" flow, e.g., information. For another example, take Kaplan,
quoted in Brieger (1976:117) "...the network of social relationships
in which communication is embedded." Reducing communication to a kind
of network or to a kind of content, such as information or rumor, and
ignoring that communication and influence are processes is a conceptual
error.

The tendency to treat communication as a package, element or thing
which is transmitted through a network or which, as such, characterizes
a network, may be an offshoot of studies of innovation and information

diffusion (cf. Rogers, 1970) in which things, such as innovations, are tracked through sets of "communication channels." Linguistically and conceptually (following Whorf) it is much easier to nominalize processes or make processes into stuffs and structures than to conceptualize process as process. The relationship of event, structure and form to process is a formidable, not to mention awesome, philosophical problem.

Structure and process each are inextricably and dynamically related to the other. Social processes such as communication, influence and diffusion are structured/have structures, and every structure -- organization or network -- has its dynamics and processes. This chapter is an analysis of definer social organization, and I will be talking about the network Importance and Contact as "pictures" or representations of the social organization which derived from those two social processes. I can no better than others discuss process when discussing structure or organization. I have attempted to resolve this problem by discussing the dynamics and processes of the institutionalization of the redefinition of death all in one chapter, Chapter 9.

The Reduction of Social Relationships

Another conceptual muddle in discussions of networks takes the form of identifying ties, or aspects of social relationships, with social relationships. Network analysis invariably entails the abstraction of particular types of social ties as a means of operationalizing the kinds of relatedness under investigation. And,

there is something reductionist about rendering social relationships
into ties, network links, channels or choices. The reduction may be
unavoidable. In most cases, we cannot hope to assess all aspects of
any one social relationship, nor would we want to; we focus on those
aspects which are most relevant to our purposes. But I would argue
that it is important that, after particular ties have been abstracted
for analysis, it be noted that one is no longer talking about social
relationships as such, but about particular aspects or components of
them - lest we begin to treat and think of relationships as little
more than simple linear channels, links or ties. I would not argue
that I am getting at all the aspects or dimensions of respondent social
relatedness in discussing either the four ties, disciplinarity, geo-
graphical locale or organizational membership. And unavoidably, I
will be engaging in a bit of reductionism in discussing choices, ties,
and networks in discussing the empirical findings.[1]

Communication Channel or Social Relationship?

There is a tendency to treat social relationships as channels of
communication or the same as communication, a tendency toward conceptual
error and reduction not unlike that discussed above. The identifica-
tion of communication channel or communication with social relationships
is a problem in the theory of communication and deserves separate
treatment.

There is a sense in which communication as social process enters
in some manner (e.g., via socialization, cultural transmission, the
mechanics of organizations and institutions) into most kinds of social

relatedness at some point. As Birdwhistell has been known to argue: communication is the dynamic aspect of social structure. But we must be able to distinguish communication writ large (in the sense of having been integral at some point to all forms of social relatedness) from particular kinds of contact within relationships or contact which characterizes particular relationships. For instance, Contact and Importance, as ties, assume communication of sort on the issue of brain death in a way which Professional Friendship does not.

Social relationships are not the same as communication or channels of communication, and different social relationships do not entail communication in the same ways. All communication occurs within social relationships of one form or another, but not all social relationships entail communication (e.g., institutional memberships). Social relationships, however, may be potential channels of communication or potentially characterized by communication, and one may say that particular relationships differ with respect to the likelihood of communication. That is at least one of the differences between the two social relationships, disciplinary affiliation and professional friendship.

Obviously, these distinctions are rather slippery, and for the purposes of this study, I will attempt to stick to the following: Content in this study is simply discussions of the topic. The social processes are communication, and kinds of communication, influence and diffusion. Communication and influence are processes which are partially represented by two ties utilized in this study, Contact and Importance, respectively, and will be discussed as ties and as

networks during most of this discussion of social organization. In this chapter, I will "stop" or freeze the processes, to get a sense of the structure. In Chapter 9 I will discuss the dynamics and processes underlying the evolution and institutionalization of the concept.

The Four Ties

Recognition, Contact, Importance and Professional Friendship are not conceptually similar ties which cut through the population in four similar ways. In other words, I cannot simply say that this population is organized with respect to four ties and let it go at that, - without discussing what those ties mean and how they are related.[2]

The four ties can be sorted around three different pegs: a) content boundedness, i.e., whether or not the tie is bound to the definition of death or not; b) whether a respondent's knowledge of another is through direct contact or publication; and c) the likelihood that a choice is reciprocated. Recognition and Friendship are not topic bound; respondents may have chosen on a basis of familarity in any bioethics, medical, legal or personal context. In order to make choices on either Recognition or Importance, a respondent need only have read an article or have seen a name in print a few times - he may not have ever had direct contact with the person chosen. These ties are not likely to contain as many reciprocal choices as the other two, because, obviously some respondents are likely to be more "print notable" or "visible" than others, and a respondent's having seen

another's name in print provides no social basis for the latter's ever having seen the former's name in print. On the other hand, Contact and Friendship, ties entailing direct social contact (as opposed to familiarity only through publication) and at least mutual knowledge of, if not mutual regard, are more likely to be reciprocated than Recognition and Importance.

Recognition

Respondents were directed as follows: "If you recognize any of these names, please check..." A check in this instance may mean that the author has seen the name in print, knows of the person, or has met the person, but would not check his name on any of the other ties.

The meaning of this tie is included in the meaning of the others, i.e., if a respondent checks a person on any other tie, he must also recognize his name. In a later section of this chapter, I distinguish between two senses of Recognition: that which means anytime a person was chosen once on any tie, referring to recognition as included in a choice on Contact, Importance and Friendship; and that which means "only recognizes", i.e., does not have any other ties with. "Recognition" refers to the former sense and "Recognition Only" to the latter. Recognition or Recognition Only may entail either mediated or direct knowledge of another.

Contact

Directions were: "If you contacted, i.e., either talked or corresponded with any of these people while you were formulating the ideas expressed in your article, please check..." Contact, like

Importance, is bound to the topic of brain death. However, I seriously doubt that the specification "while you were formulating the ideas expressed in your article" was followed in every case or even often. Some respondents distinguished between contact before the article and contact after the article, and a few additionally mentioned that they were not sure when the contact was made. A choice on the tie can probably be taken to mean contact at any time on the subject. There is a small likelihood that a few respondents took the directions to mean "initiated contact". Contact means contact of any sort, -- by telephone, post, or person, on the topic. Contact implies direct social knowledge of the other person.

Importance

Directions were: "If any of these people were particularly important, e.g., helpful, provocative, influential, to you in terms of your interpretation of the issues involved in death definition and determination, please check..." Importance is obviously content-bound however, the respondent and important person may have never discussed brain death per se, but may have discussed some other related issue -- perhaps e.g., the philosophy of organism. In addition, "Important" may refer to an attribution made in terms of either direct or mediated communication, i.e., in terms of collaboration, committee work, or publication. Some respondents named Aristotle, Tillich, Whitehead, Heidegger and Niebuhr, or their works, as important, and obviously not all of them have been available recently for an exchange of ideas.

I did not use the concept of influence (instead of importance) partially because I expected that professionals, and particularly prominent physicians, would acknowledge importance, broadly defined, more readily than they would influence. I asked directly, "who was important" rather than "who did you go to for advice" under the assumption that most people can name important and influential persons when asked and that in this study, asking directly would obtain more valid responses than asking obliquely.

Another reason why I used importance rather than influence is that influence frequently implies power, persuasion or inducing compliance or a sameness or commonality of behavior or attitude. (e.g., if Sally influences her friends, and Sally wears ruby red lipstick, then the other girls will wear ruby red as well.) I wanted to tap cognitive importance or influence which a respondent could recognize as having affected his interpretation of the issues.

Importance of this sort can result from a wide variety of subtle (cognitive and social) interactions and processes quite different from persuasion, power or inducing compliance or sameness. For instance, it is frequently against a different, even alien, conceptual apparatus that one sharpens and refines one's own. There is little doubt that an opposing viewpoint is often important, but not influential -- in the sense that one does not come away from it shaping one's arguments in the style of the opposition. For example, Morison ("death as a process") and Kass ("death as an event") were important to one another while formulating their arguments, but I am quite sure that neither

would say that the other <u>influenced</u> him, i.e., swayed him or induced in him conceptual compliance.

Cognitive importance may be an attribution based on a skilled explication of points one had not quite yet formulated, a reinforcement of one's own points, a mentioning of things one hadn't come to terms with before, or a particularly provocative use of a concept from a point of view which deeply conflicts with one's own. Specifying helpfulness, provocation <u>and</u> influence, in short, importance, covered the varieties of cognitive influence without excluding some, which, to a population such as this, may have made all the difference.

In addition to cognitive importance, a respondent may consider an author importance by virtue of his cultural certification (Katz and Lazarsfeld, 1955) and respective authority, his association with a particular medical school faculty, his prominence in the field, etc. In such cases, one comes much closer to traditional notions of influence, power and "high" status. Many respondents probably were using criteria of cultural certification in making their attributions or of what I will hereafter call "status importance."

One other sort of importance is relevant, that which might be called "interaction importance" and which refers to the importance particular personalities and their powerful or understated manners make, i.e., an intellectual or professional charisma. A respondent must have had direct contact with another respondent to have been "taken" in this sense; not so for cognitive or status importance. I have no objective means of distinguishing cognitive, status, and interaction importance (if distinctions could be made reliably by

respondents or even researchers) aside from information obtained in interviews. However, direct or mediated importance can be distinguished empirically by noting the coincidence of importance and contact or friendship. These considerations will be discussed in a later section.

Professional Friendship

Directions were: "If you consider any of these people to be professional friends, i.e., close colleagues or collaborators, please check..." This tie, like contact, of course entails interpersonal knowledge of another author, rather than knowledge through publication or public appearance. And professional friendship, as defined above, need have nothing at all to do with the definition of death; a respondent could have chosen a person on the list, with whom he had never discussed this particular issue. This is the least "cognitive" and most "social" of all the ties. It is also the tie most likely to have been interpreted differently from respondent to respondent. Respondent interpretations might vary from simply "good, old boy" to "friendly colleague" to "friendship which transcends professional association."

A point to consider in interpreting this tie is whether or not one might assume that professional friendship implies importance or a subtle influence through the more or less personally close sharing of cultural or professional values. It has been shown empirically that friends are more likely to influence one another than non-friends (Back, 1952). In this case, I will trust the respondents' judgments. Since they were to judge each person with respect to each tie, they had to

consider whether or not a professional friend was also important in
their formulation of their thesis.

The Structure of Social Ties Among the Definers

Without further conceptual ado, we turn to the findings. There
is one important characteristic of the sociometric matrices which
should be noted at the outset. In this study there are 74 choosers,
or respondents, and an addition 36^3 persons whose names appeared in
the questionnaire but who, for various reasons (e.g., they chose not
to participate in the study, they were decreased, or they were import-
ant persons who did not fit the sample definitions) are not among the
respondent sample. They are called non-respondents. Included among
them are some of the most well known physicians in the neurosciences
and other areas whose work initiated research and consideration of the
redefinition of death, persons such as Robert Schwab, Henry Beecher
(both members of the Harvard Committee, deceased), Daniel Silverman
(the originator of the NINDS collaborative effort, deceased), Reginald
Bickford (a well-known neurologist in this area, who would not parti-
cipate), most members of the Harvard committee, including internation-
ally known neurophysicians Raymond Adams, William Sweet, Derek Denny-
Brown and other well-known physicians Dana Farnsworth, Clifford Barger
and others, who did not fit the sample definitions.[4]

Unlike most sociometric matrices, all matrices in this study
are rectangular with 74 choosers and 110 possible choices. Network
analyses of the choices of all ties has been performed on the basis

of choices given, not choices received.[5] And many respondents chose

non-respondents, so the social organization of the respondents is

based on choices to them as well as choices among the respondent

group.

This section includes a discussion of the overall network

cohesion or connectedness among respondents on each tie, a division

of the entire population (respondents and non-respondents) into

elites (sociometric stars) and non-elites, and a description of the

network structure of the four ties as obtained in the network analysis.

Density and Connectedness

Density is a measure of total cohesiveness of a sociometric

population based on the proportion of actual choices made to all

possible choices.[6] (Crane, 1972; Boissevain and Mitchell, 1973;

Kadushin, 1975) The number of total possible ties can be obtained

by multiplying the numbers of choosers by the number of possible

choices - 1. Table 7 below gives the densities obtained on each type

of tie and on all ties taken together.

The meaning of these densities becomes clearer in comparison with

the densities of other network populations in science, even though

my results are not strictly comparable with those obtained in the

studies of scientists mentioned below. Crane (1972) obtained measures

of connectivity for researchers in mathematics and rural sociology

on several types of ties, most of them much more restrictive than

the ones used in this study (e.g., collaboration, thesis director,

teacher-student relations). If we compare the density of all the ties

Table 7. Overall network densities by type of tie.[7]

	Recognition only	Contact	Importance	Friend-ship	Recogni-tion	Total ties
Density or proportion of possible ties actually occurring	.076	.039	.053	.029	.157	.187

she utilized taken together for each population with the density for the definers on total ties, even though the definers chose on ties as loose and unrestrictive as simple recognition, the densities Crane obtained are much higher than the one I obtained. Brieger (1976) assessed densities on "ever heard of"[8] and "mutal contact" for two groups of scientists,[9] which can be compared to the densities obtained in this study for Recognition and Contact. Mullins and his cohorts (1977) report densities on "ever heard of" and "know well", ties roughly comparable to Recognition and Professional Friendship. And finally, a multidisciplinary population of physical scientists in one elite American university was studied by Friedkin (1978). The only tie measured in his study, as far as I know, is "ongoing substantive discussion of scientific ideas".

Table 8 shows the densities by the kind of tie for each population of scientists and the definers. On all ties except Contact, the networks of cultural definers are much less dense than those of the science specialty researchers. The definers, however, are more interconnected than Friedkin's multidisciplinary physical scientists, all of whom work at the same university. One would imagine that highly specialized science researchers sharing paradigm and specialty would be more visible to one another and interactive than either of the interdisciplinary multiparadigmatic (Hagstrom, 1976) populations. And it seems that sharing a body of literature and a single topic is more socially bonding (for the definers) than sharing the same school and campus (the physical scientists).

Table 8. Network densities and connectivity for social ties by
population studied.

Population	Total ties	Ever heard of (Recognize)	Mutual contact (Contact)	Know well (Friendship)	N
Rural Sociology	.536	...	...	...	221
Mathematics[a]	.379	...	...	...	102
Neural control of food and water intake[b]	...	.47	.07	...	107
Australian antigen	...	.84	...	.16	65
Reverse transcriptase[c]	...	.74	...	.15	105
Physical scientists[d]	.069	...	...	...	128
Cultural definers	.187	.16	.04	.03	74

[a]Crane (1972:147-148)

[b]Brieger (1976:122)

[c]Mullins et al. (1977:555)

[d]Friedkin (1978:1447)

If a looser measure of connectedness is considered -- simply the links either to or from respondents -- the definers are highly interconnected on two ties, Recognition Only and Importance. Using this same measure for all of the ties, all respondents but three are directly linked to at least some of the most well-known members of the population, and these three are no more than one link away from the central members. The definer group is interconnected, though sparsely so.

Elites and Non-Elites

By now, it is probably clear to the reader that the definer population is comprised of those who are highly visible and nationally-known and those who are not as well-known -- students and others known in specialized or local contexts. An initial step toward determining the organization of the definers is to separate them into a binary grouping on this basis. The respondents themselves, however, determine who is well-known by their choices; in other words, the elite are defined as the "sociometric stars" or "centrals" -- those to whom most choices are directed. The elite are those respondents who received at least 11 choices on all ties combined and at least four on either Contact, Importance or Friendship (Elite N = 24). The non-elite are the respondents who did not meet this criterion (Non-elite N = 51). In addition, there are those who, for whatever reasons, did not participate in this study who meet the elite criterion (extras -- non-respondent elite). I will refer to the three groups as elites, non-elites and extras.

Among the definers who participated in the study, the elite are highly visible and well-known, not only among the definers, but also within their disciplines, if not in other intellectual contexts. They are nationally known neurologists, lawyers, philosophers and ethicists. The non-elite, on the other hand, are known primarily within more specific geographical or disciplinary contexts. The elite are the older, more established members of the professions, with two-thirds receiving their professional or academic degrees before 1950, whereas half of the non-elite received theirs after 1960. Of the elite, 42% are physicians, 33% are ethicists and 25% are lawyers. Considering the population as a whole, proportionately more ethicists (52%) are elite than either lawyers (28%) or physicians (26%).

Over half (58%) of the elites live in the Boston-Washington corridor, whereas only 24% of non-elites do. Elites are more likely to have been involved in the Harvard Committee, the Hastings Center Research Group, the NINDS collaborative study committee, or the major symposia on death and closely related issues. The Boston-Washington corridor is the central location of the death definition effort, an area known to be conducive to policy-making and defining enterprises because of its geographical concentration, in-area mobility and intellectual and professional centers and facilities. However, the elite are not just persons who happened to be in the right place. In a very real sense, these men made the committees and contributed to the major steps in the evolution of the redefinition of death.

Who, according to these distinctions among elites, non-elites
and extras gets and gives the choices? We might expect that the elite
and the extras would get most of the choices and that the elite would
give few. On the other hand, we would expect the non-elite respond-
ents to give most of the choices and to choose the elite and the
extras more often than they would choose within their own group.
As a matter of fact, the elite and the extras received more than
75% of all choices, but the elite made more than half of the choices,
that is, a bit more than the non-elite made. In other words, the
elite respondents seem to know and know of more of their cohorts
than the non-elite respondents. This is especially the case on Con-
tact and Friendship. On all ties except Friendship, the elite
respondents received more choices than the extras. And, as previously
discussed, Friendship is the tie which had nothing to do with the
topic of death definition.

As expected, the non-elite give more than half of all the choices
on Importance and directed 77% of their choices toward the elite and
the extras (rather than within their own group). And the elite chose
within their group and the extras two to three times more often than
they chose the non-elite. Interestingly, however, on Contact and
Friendship (the "social" ties) the elite chose the non-elites slightly
more often than the non-elite chose themselves. Without the results
of the network analysis, we can already discern a "center-periphery
pattern" in the structure of the definers in which a central group
of visibles or stars receives a high proportion of all choices both

from within its own group and from the larger group of less visibles. (Brieger, 1976:128) Given the above, one would expect that the density within the elite group would be considerably higher than the density within the group as a whole. And a perusal of Table 9 shows that this is the case. Throughout the rest of the report "elite" refers only to the definer (respondent) elite.

The Network Analysis

After having split the group into elites and non-elites to discuss a binary basis of organization, I now turn to the results of the network analysis which splits the group again into several clusters on the basis of the similarity of each respondent's choice. Those who chose similarly are in the same cluster (the basic unit of organization within the networks). They did not necessarily choose each other, though they have in several cases.

An important characteristic of the data is that the sociometric matrices are not square; there are more choices than there are choosers (respondents). In other words, the social organization portrayed in the networks is based on choices that respondents made to other respondents as well as to non-respondents.

Recognition, defined for the network analysis as excluding choices on all other ties so that there is no overlap, has a structure consequently rather different from the others, and will be discussed after a comparison of the other three. Before their differences are given, first, their commonalities.
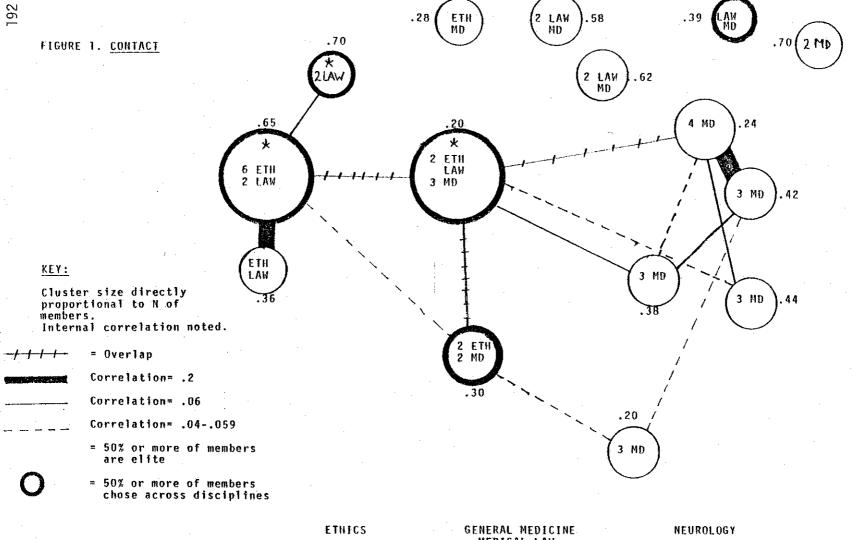
Table 9. Densities within the elite and within the definer

group on all ties

	Density			
	Recognition	Contact	Importance	Friendship
Elite	.440	.197	.152	.127
All definers	.157	.039	.053	.029
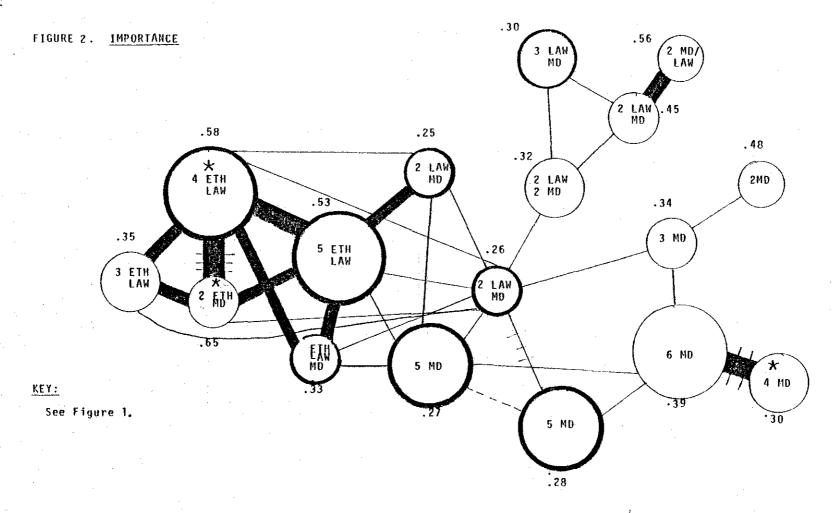
All three networks (see Figures 1-3) consist of three dense, loosely interrelated cluster groupings which reflect particular disciplinary affiliations, i.e., a set of ethics clusters, general medicine clusters and neurology clusters. Most lawyers are associated with either the general medical clusters or distinct medico-legal clusters. The cluster groupings in each network are composed of one or two large, major clusters and two to three small clusters, related to the major clusters. In all three networks, but particularly Friendship, the small or isolated clusters are made up of either collaborators or neighbors. The "isolate" clusters, those containing persons who chose no one and frequently were not chosen, are not given in the sociograms. They are the largest clusters, composed of students and others who are the least known and the most peripheral to the redefining process.

In each network the major ethics and neurology clusters are primarily composed of definers who were on two major working (research and writing) committees -- the Hastings Research Group on Death and Dying and the NINDS collaborative study, respectively. The Hastings clusters are the most dense of the lot, given their size, and contain the most reciprocal choices. In terms of sociometric distance (i.e., those who choose similarly are closest together), the ethics clusters and the neurology clusters are farthest apart with the general medicine and medical-law clusters between.

Although no variable is associated with the social organization of the definers quite so much as disciplinary affiliation, I will discuss four other respondent attributes which characterize the networks' organization to some extent. These are: cross-disciplinary choosing,

FIGURE 1. CONTACT

KEY:

Cluster size directly
proportional to N of
members.
Internal correlation noted.

—/—/—/—/—   = Overlap

�[heavy bar]   Correlation= .2

——————   Correlation= .06

– – – – –   Correlation= .04-.059

= 50% or more of members
are elite

O   = 50% or more of members
chose across disciplines

ETHICS   GENERAL MEDICINE   NEUROLOGY
                MEDICAL LAW

FIGURE 2. IMPORTANCE

KEY:

See Figure 1.

ETHICS   GENERAL MEDICINE   NEUROLOGY
                       MEDICAL LAW

FIGURE 3. PROFESSIONAL FRIENDSHIP

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KEY:

See Figure 1.

ETHICS

GENERAL MEDICINE
MEDICAL LAW

NEUROLOGY

professional generation, present or past geographical proximity and elite status. An attribute is considered to characterize a cluster if it co-occurs within more than 50% of the members of the cluster. Table 10 shows the percentage of total clusters characterized by each attribute in each network.

Only one attribute is related in a general way to the organization of all three networks. Since choices are the bases for clustering, interdisciplinary (as well as intradisciplinary) choosing characterizes all networks to some extent. However, as an attribute, the tendency to choose across disciplines is more associated with some respondents, ethicists, than others, neurologists. In all networks, members of the ethics clusters (primarily ethicists with some lawyers and physicians) chose representatives of both other disciplines. Members of the neurology clusters (physicians and lawyers), if they chose beyond their specialties or discipline at all, chose only members of the one other discipline represented in their clusters, and not ethicists. The general medicine clusters contain respondents who chose in the style of either the ethicists or the neurologists.

Variations in Structure and Attribute Characterization Among the Networks

Contact and Friendship: Contact and Friendship have more in common structurally than either has with Importance. Each has three isolate clusters (clusters in which members choose primarily within and not outside of their cluster) composed of collaborators or neighbors, and each exhibits a center-periphery pattern (cf. Brieger, 1976:128), characterized by strong ties to, and weaker ties from, the major clusters,

Table 10. The percentage of clusters characterized by respondent attribute for three networks.

	Network		
Attribute	Contact	Importance	Friendship
1. Interdisciplinary choosing	39 (5)	47 (8)	27 (4)
2. Proximity	54 (7)	29 (5)	67 (10)
3. Professional generation	39 (5)	24 (4)	47 (7)
4. Elite status	31 (4)	18 (3)	27 (4)
N of clusters	(13)	(17)	(15)

and weak or non-existent ties among the smaller clusters (Mullins et al., 1977:557). Contact is the more integrated across disciplines of the two and contains more interdisciplinary choosers. In other words, definers established more discussion partnerships than friendships with members of other disciplines. On the other hand, most respondents choose their own disciplinary colleagues as friends, making the clusters in that network more discipline-specific than the others and making Friendship the least integrated of the networks. One reason for the difference in interdisciplinary integration between the two networks is that making a choice on Friendship entails no reference to the topic of death definition, so respondents were free to choose any professional buddies on the list whom they knew through professional associations and other disciplinary contexts. Many respondents may have established ties with members of other disciplines only in the context of this topic.

The attribute associated with most clusters in both Contact and Friendship is past or present geographical proximity. That is, neighbors, more than non-neighbors, contacted one another and considered one another professional friends. Secondly, both contain "elite" clusters, reflecting perhaps the elites' participation in many of the same symposia, committees and professional associations.

Contact and Friendship differ with respect to characterization by professional generation. In Friendship, definers of the same professional generation, who may share the same professional "heroes" and values, are clustered together.

Importance: Importance is the most integrated and the most interdisciplinary of all the networks -- in terms of choosing, inter-cluster

connectedness, and cluster membership. Nearly everyone, students and eminent professionals alike, agreed that certain definers were important (e.g., Beecher, Fletcher, Curran, Capron, Ramsey) and many of these notables were chosen by members of all three disciplines. A choice on this tie may involve only "publication" familiarity (as well as some professional humility). Consequently, this network is the most inclusive of the three -- membership is open to anyone who cared to make an attribution.

Since the elite and the non-elite chose the same persons (which was not the case on the other two ties), elite and non-elite are clustered together. No center-periphery pattern is discernible in Importance -- the elite/non-elite structure is within the clusters, not among them.

Neither geographical proximity nor professional generation makes much of a difference in the organization of Importance. The visibility of a few prominent definers who were chosen by many respondents from different disciplines accounts for most of the network organization.

Recognition: Recognition (which excludes choices on all other ties) not only is unlike the other networks, but also is rather uninteresting. Twenty-nine small clusters, most of which are organized according to discipline, constitute Recognition. And because the tie excludes choices on the other ties, persons with wide bibliographic familiarity are clustered together regardless of any rhyme or reason derived from the patterns of the other networks.

In summary: The differences and similarities among the networks are as follows: Recognition, in terms of the analysis of other

networks, is basically unimportant. Contact and Friendship, networks
of "social" relations rather than "publication" and "social" relations,
are composed of neighbors and collaborators, and, in Friendship, members
of the same professional generation and profession. Both Contact and
Friendship exhibit center-periphery patterns unlike Importance, the
most structurally and disciplinarily interrelated of the networks.
Attributes which facilitate the development of discussion partnerships
or professional friendships, such as proximity, collaboration and
professional generation, do not account for the social integration of
Importance. Rather, wide agreement on who is important and the acces-
sibility of the network to persons with "publication" and/or "social"
familiarity with important definers, constitute the major differences
between Importance and the other two networks.

Cooccurrences of the Three Ties

The relationships among the ties in terms of their cooccurrences
on choices to respondents help to further characterize the respondents
in terms of their organization. Are most respondents friends and
discussion contact partners, related through print importance or
charismatic importance, or some combination of these? Respondents
chose others on all three ties more often (116 times) than on any two
ties (Contact and Importance, 41 times; Contact and Friendship, 31
times; and Importance and Friendship, 23 times). And almost all persons
choosing others on all three ties are elites and/or members of
intensive work groups such as the Hastings Research Group, the NINDS

collaborative study, persons involved in the Tucker v. Lower case, or
in the Massachusetts General Hospital environment (out of which
developed the Harvard Report). And recalling the statements made in
interviews discussed in Chapter 3, it seems that the intense innova-
tive collaboration characteristic of committee work on this issue was
a highly socially bonding experience for many respondents. In
addition there seems to be a temporal development of relations with
fellow committee members; I know from the interviews that in some
cases contact led to collaboration and subsequently to attributions
of importance, and finally to the formation of professional friendships.

Since one might expect friends to be more influential or important
than non-friends (Back, 1952; Kadushin, 1975), it is interesting to
note that both other combinations of ties occur more often than the
cooccurrence of Friendship and Importance. Considering that Friendship
as a tie was not bound to the topic of death definition, it may be
that respondents chose friends with whom they had not discussed the
issue, or whom they did not consider important.

I can distinguish between attributions of importance made on
the basis of social vs. publication knowledge of others by noting the
cooccurrence of Importance with either Friendship or Contact.
Importance occurs alone 200 times, and in conjunction with either or
both Friendship and/or Contact 190 times. So, for this population,
attributions of Importance are based almost as often on social contact
as on readership familiarity. All three kinds of Importance noted
previously -- charismatic, status and cognitive importance -- could be
operating in attributions of "social" importance, and all but interaction

or charismatic importance could be operating in attributions of publication importance.

Comparison with Other Network Populations

The definers share some qualities of work, work place, and social organization with both science researchers, particularly those studied by Kadushin (1976), Crane (1972) and Brieger (1976), and those intellectuals studied by Kadushin in The American Intellectual Elite (1974). Before discussing their respective commonalities, I want to point out one substantial and glaring difference between the definers and the other two populations. The substance of their work activity is different: Definers are neither concerned with furthering research within a narrowly defined research specialty, nor with the broad cultural, political and social criticism characteristic of intellectual work. In this instance, they are concerned with the evolution and application of a concept and the establishment of medical and public policy. Given that difference, their work can be characterized as both collaborative and cumulative (after Kadushin) as can the work of scientists. The work of intellectuals is not necessarily either, according to Kadushin (1976:115).

The three groups can be compared as well with respect to their work "places". Definers have direct associations with professional schools, universities, and formal organizations such as hospitals, unlike intellectuals who tend to associate more informally with and in bars, cafés and restaurants (Kadushin, 1976). In this regard, the definers are more like scientists than intellectuals. However, the

definers and intellectuals are not bound to narrow specialties or "invisible colleges" as scientists are. Scientists also work all over the continent, whereas the definers, like intellectuals, seem to have a primary location -- the Boston-Washington corridor. The intellectuals, of course, have New York City (Kadushin, 1974).

With respect to their internal social organization, however, the cultural definers have more in common with science researchers than Kadushin's intellectuals, and particularly with respect to the role of the elite. Kadushin (1976:114-115) states that the elite do not play as prominent a role in the organization of intellectual circles as they do in scientific circles. The "center-periphery" pattern noted in Contact and Friendship is characteristic of science researchers (see Brieger, 1976; Crane, 1972; Mullins et al., 1977). In the present study, the center-periphery patterns are arranged along disciplinary lines, as would be expected for an interdisciplinary population.

The elite are the keystones of the definer social structure. They are the centrals (by definition), the non-elite are the "peripherals". The elite form the links which connect the clusters of the networks. It is their choices which link all of the major disciplinary clusters into a relatively coherent, those loosely connected network. About five times as many elites as non-elites chose across disciplines on Contact and Friendship, and twice as many elites as non-elites chose across disciplines on Importance. Without them, the networks would have been comprised of three discrete sets of cluster groups bound by disciplinary affiliation.

Crane (1972:51) also found that her scientist elite (the High Producers) linked clusters into single, coherent networks, and functioned to tie the research areas together. Crane's elite formed the most dense clusters with the most reciprocal choices in the networks. Both the ethics and neurology cores comprised primarily of elites, are the most dense clusters in the networks and those which contain the most reciprocal choices. Both the elites of this study and of Crane's formed large groups in networks and were comprised of fellow collaborators or committee members. The elite in both studies seem to be what Hagstrom (1976) would call "work groups".

Brieger (1976) found that the elite in his group of neurology researchers evidenced what he calls an "elder statesmen" phenomenon. That is, the elite were highly visible to others but showed low awareness of those others, suggesting that the older elite were freed from keeping up with the contributions of younger researchers. In this study, the elite made the most choices, and chose non-elites slightly more often than non-elites chose themselves on Contact and Friendship. There is some evidence of an "old boy" tendency to attribute importance only to other elite among the definers, but for the most part, the definer elite seem a bit more egalitarian and more widely aware of other definers than Brieger's researchers were.

Summary

So this is what the organization of the definers "looked like" during the institutionalization of the redefinition of death. In the sample there are those who are very well known, definer cosmopolitans,

and those who are not, local and students definers. They have a variety of ties to one another -- affiliations in organization and institutions, geographical propinquity, and relations of contact, importance and friendship which emerged in the process of explicating, refining and diffusing the redefinition. The cosmopolitan elite were most likely to establish relationships which consisted of all three sociometric ties; the locals established all three with their neighbors and collaborators and ties of importance with the cosmopolitans.

With respect to other network populations, the definers are similar both to intellectuals and scientists. As regards their work and the locations of the forums for their work, definers are similar to both. And as regards their internal organization, they are more like science networks than intellectual networks.

It may seem to the reader that after all manner of warnings about nominalizing social processes, that that is just what I have done in discussing the social organization of the definers. I have not been able to find a way to discuss structure without seeming as if I am rectifying the struture or engaging in what Whitehead would call "misplacing concreteness". It is difficult to discuss process while delineating structures, or to talk about an aspect of a social relationship which is based on the occurrence of contact (a process) in other than a structural way -- by referring to the process that the tie refers to as a tie, and the organization of ties/processes as networks. Perhaps other social scientists are more adept at discussing structure/process than I. I can only discuss one while putting the other aside. One way to diminish the dysjunction between the two

would be to assess structural changes through time by administering sociometric surveys at different stages of a process. This research design did not include such an assessment.

<u>Endnotes</u>

[1]By "tie" I mean the aspect of social relation utilized in the analysis. By "network" I mean the social organization of a population "revealed" by subjecting a sociometric matrix of choices on a specified tie to manipulation and analysis. The name of the tie, capitalized, is used to refer to both ties and networks. I will consistently distinguish between the two with the phrases "On ties" and "in networks".

[2]For an instance of treating such different kinds of ties as hospital affiliation, discussion partners and friendship as similar, or at least not different enough to warrant a comparison, see Coleman, et al., 1966:72-78.

[3]Adjustments were made eliminating all respondents who choose no-one on any tie (one respondent) and all non-respondents receiving less than five choices on all ties taken together.

[4]None of these members of the committee wrote articles on death definition or wrote articles which fit the same definitions, and I searched long and hard - I wanted to include them in the respondent sample.

[5]Since all data came from the respondents, I can compare respondents only.

[6]Density, as used here, refers to the number of choices (permutations) and not the number of ties (combinations). As stated previously, I am not assuming that choices made are reciprocated.

[7]"Recognition" overlaps with contact, importance, friendship insofar as the latter include the former. "Recognition," as a tie, refers to the number of times a respondent choise on <u>any</u> tie. "Recognition only" refers to choices made only on recognition and not on the other ties. "Recognition" overlaps with other ties, "recognition only" excludes all other ties.

[8]Actually Brieger used "unawareness" rather than "ever heard of", and Mullins et al. (1977) adapted the complement of "unawareness" for comparison to a tie they used, "ever heard of." I have used the figures reported in Mullins, et al. (1977).

[9]Brieger applied his analysis to researchers in the field of neural control of food and water instake, and Mullins et al., studied two biochemical and genetic specialties, Australia Antigen and Reverse Transcriptase.

CHAPTER 7

CONCEPTUAL APPROACH: ARTICLE CONTENT

After discussing who the definers are, their communication
activities and social organization, I turn now to the conceptual
approaches definers took toward the redefinition of death in their
articles. Doing justice to authors' conceptualizations of an issue
as interdisciplinary and value-laden as the definition of death
requires the analysis of the actual conceptual treatment of the issue.
One cannot simply identify conceptual approach with disciplinary
affiliation and assume that physicians write medical articles, lawyers
write legal articles, and so on. However, as we shall see, for many
definers, conceptual approach is closely related to discipline. The
first section of the chapter acquaints the reader with the structure
of the content analysis scheme and its elements, and the second
section describes the interrelationships of these thematic elements.
The amount of consensus on the various aspects of the issue is noted
throughout. The relationship of conceptual approach and social
organization, a difficult one to determine, concludes the discussion
of article content.

The Content Analysis Scheme

Devising an analytic instrument which helps to make some sense
of 75 articles written by lawyers, physicians and ethicists on a

topic of considerable variety and complexity is not a simple task, and there is no reason to assume that the following schema is the only one, or even the best one which could be constructed. The content analysis instrument (see Appendix D) contains general items referring to the context of the article (date, place of publication, whether or not the article was also a paper delivered at a symposium, etc.). The rest of the instrument contains six conceptually inter-related sections organized around the assumption that most, if not all of the articles were discussions of a solution to some problem -- problems for which the redefinition of death was a solution, problems incurred by redefining death, problems in statutory definitions, etc. Each article contained statements about 1) the etiology of the issue, 2) reasons why death should be redefined in terms of brain function, 3) statements about the sort of issue redefining death is (ethical, public, medical, etc.), 4) a mode of interpretation, 5) several specific issues and concerns and 6) suggested remedies (legislation, further research, etc.).

Each article was sorted on the basis of: 1) its overal concern or purpose, and 2) whether the article was concerned primarily with definition, or procedures for determining death or both. I will describe the major sections of the scheme and discuss the results in terms of general frequencies and the cooccurrence of each variable with the disciplinary affiliation of the authors. Tables including both frequencies and cooccurrences accompany the discussion.

General Concerns

The range of concerns of the articles extends along temporal and disciplinary dimensions. For example, the earliest articles were written by physicians and concerned the use of the EEG in assessing prognosis. Conceptual critiques of medical and legal proposals, of course, must come later than the medical and legal proposals themselves and medical critiques of criteria and suggestion of new methods follow the first statements of methods and procedures. There are eight groupings:

1. The first group, which includes seven articles, consists of the earliest statements on utilizing the EEG in determining death and reports of cases in which "flat EEGs" were followed by recovery or statements criticizing primary reliance on the EEG in determining death.

2. The second group, which includes ten articles, involved discussions of the "prolongation of life" and transplantation problems ("problems in recent medical advances") and medical and bioethical proposals for managing the problems. Hamlin's "Life or Death by EEG", Ayd's "When Is a Person Dead" and the Harvard Report provide examples of articles in this category.

3. Another group of 15 articles constitute the reviews of the problems and proposals and reports of research which support the proposals; some of these inlcude minor modifications of the original statements.

4. Thirteen articles, all published in 1968 or later, address medicolegal issues without specifically discussing statutes or court cases.

5. Eight articles criticize and evaluate (legally, ethically, and conceptually) the Kansas and Virginia statutes and the Tucker v. Lower case.

6. Conceptual and ethical critiques and clarification of particular proposals, such as the Harvard Report, or the general effort to redefine death are the concern of another ten articles. Most of these were written by ethicists.

7. There are four theological critiques, or four articles which treat the issue from a specifically theological point of view.

8. Finally, eight articles concern criticism of either criteria or definition on other groups. Authors in this category promoted the notion of "neocortical death," criticized the use of the EEG, and advocated the acceptance of cerebral angiography as a criterion for determining death.

Definition or Determination of Death

In terms of article purpose, it was important to distinguish between those articles concerned with the definition of death and those concerned primarily with techniques and procedures for the determination of death. Forty percent of the articles dealt primarily with definition, 23% primarily with determination and 37% with both. Most of the determination articles are discussions of research and clinical findings, critiques of criteria and methods, or the early EEG statements. These 17 articles, almost a quarter of the sample, were written entirely from a medical perspective, with a medical audience in mind, and are lodged firmly within a medico-technical framework in a way that

most of the other articles are not. Yet they constitute important steps in the development and evolution of the concept and are essential to the purpose of the study.

Etiology of the Need to Define Death

With striking consistency, most of the articles begin with a discussion of why death should be redefined, for example:

> With the advent of organ transplantation and the development of excellent respiratory support, the determination of death is once again a problem for organized medicine. (Paulson, MD, p. 39)

Most articles (52%) simply include a list of the recent advances in medical technology (transplantation, mechanical respiration, hemo-dialysis, defibbrillation, etc.) or refer generally to the advances. An additional 15% refer to heart transplantation in particular and a few (9%) mention only organ transplantation as the major stimulus. Among the disciplines of the authors, few differences occur.

Reasons Why Death Should Be Redefinied

Apart from the factors which prompted a redefining of death, authors also listed various reasons why redefining death is appropriate or desirable, emphasizing a variety of concerns. These reasons are responses to the question, "Why is it a good idea to define death in terms of brain function?" Table 11 shows the frequency of articles containing each reason and the breakdown by discipline.

The most frequently stated reason for updating the definition of death is to facilitate transplantation. More physicians and lawyers than ethicists cited this reason.

Table 11. Reasons why death should be redefined. Rounded percentages of whole sample and breakdown by discipline mentioning reasons.

Death should be rede-fined in order to:	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V discipline x reason*
1. facilitate general transplantation	57.3 (43)	64.1 (25)	71.4 (15)	20.0 (3)	.38
2. cease useless, futile prolongation of life	53.3 (40)	66.7 (26)	47.6 (10)	26.7 (4)	.31
3. allow persons to die humanely	34.7 (36)	46.2 (18)	14.3 (3)	33.3 (5)	.29
4. mitigate burden (emotional and finan-cial) of family	32 (24)	35.9 (14)	23.8 (5)	20.8 (5)	--
5. update the definition in light of new medical knowledge	26.7 (20)	12.8 (5)	61.9 (13)	13.5 (2)	.50
6. mitigate burden on the community	25.3 (19)	28.2 (11)	23.8 (5)	20.00 (3)	--
7. facilitate heart transplantation	10.7 (8)	10.3 (4)	19 (4)	0	--
8. death should be re-defined in terms of the higher, specifi-cally human functions	28 (21)	30.8 (12)	14.3 (3)	40 (6)	--
9. redefinition is not needed, or redefini-tion presents serious problems	24 (18)	9.7 (3)	19.0 (4)	73.3 (11)	.59

*Cramer's V is an association measure, based on x^2, which indicates the strength of the relation between 2 variables, (in these cases, the difference each theme makes in the distribution). See pp.   for more detailed discussion of the choice of this measure of association.

> Insofar as transplantation of organs is facilitated
> (by redefining death) death may even be viewed as a
> creative act, in the sense that another desperately
> ill individual may be made whole by the gift of an
> organ. (Luchi, MD, p. 284)

Several ethicists took issue with this reason on ethical grounds. Some-what surprisingly, only 11% of the articles mentioned that redefinition was needed to facilitate heart transplantation in particular, although most of the articles were published around 1968-1971 in the midst of and immediately following the heart transplant furor.

Another frequently cited reason for redefining death is in order to cease futile prolongation of life, a reason which contains at least two implications: 1) that the quality, not the presence of life is of upmost importance in defining death, and 2) that it is somewhat grossly inappropriate or immoral to continue treatment on a person who is already dead.

> Death, thus identified (with the brain) will be marked
> by a greater dignity than that which may accompany
> death defined by traditional criteria and following
> prolonged futile attempts at mechanical support...
> (Luchi, MD, p. 284)

This reason is distinguished from the next one, "in order to allow persons to die", primarily in terms of the perspective from which one takes her concern. Mentioning that a person ought to be allowed to die expresses a concern with the dying person -- that his dying ought not to be interfered with. An emphasis on the cessation of useless pro-longation of life derives from the perspective of those concerned with the allocation of care and resources. The distinction is at best rather slippery. From the Table, we see that fewer ethicists than lawyers or physicians stated that redefining death would allow the

cessation of futile treatment. The disciplinary distribution is more even for "to allow a person to die."[2]

As well as the physician's and patient's perspective, the family's emotional and financial burden and the community's burden and resources were mentioned as considerations involved in redefining death with little disciplinary variation. Another reason some authors, about 20, mentioned was that it is fitting to define death in terms of the organ which houses the higher human functions, e.g. rationality, conscious-ness, etc. in terms of the whole brain or the neocortex. Finally, almost one quarter of the articles stated either that the redefinition was not needed, or that the effort was laden with ethical, philosophical and conceptual dilemmas requiring caution and serious consideration. Far more ethicists than members of either of the other disciplines took this position.

> As the German people discovered thirty years ago, it would lead to social disaster if we were to accept the proposition that some lives are worth less than others and that the treatment of some patients is too arduous or too expensive. (Toole, MD, 1971,599).

> Now my point is a very simple one. It is this. We do not know with certainty the borderline between life and death, and a definition cannot substitute for knowledge... In this state of marginal ignorance and doubt, the only course to take is to lean over backward toward the side of possible life. (Jonas, ETH, 1974,138)

Mode of Interpretation

Each author interpreted the issues involved in death definition according to a particular conceptual framework or mode. For the most part, the author's mode of interpretation of the issues coincides with his disciplinary affiliation. Most physicians either interpreted the

issue in a medical mode, discussing the determination of death,
criteria, (62%) or a medical-ethics mode (20%). A few physicians
utilized medico-legal or historical modes. Lawyers and lawyer-physicians
interpret the issue according to a medicolegal mode, and ethicists
treated the issue from philosophical, ethical or theological perspectives.

What Kind of Issue is Redefining Death?

Almost all articles contain some statements about the kind of
issue redefined death is and/or about the sorts of competencies re-
quired for making decisions about the new definition. Table 12 gives
the frequency of each variable in this group.

Less than one third of the sample as a whole, composed almost
entirely by physicians and lawyers, stated that definition and determina-
tion are medical issues, requiring medical competencies. Others (41%)
from all three disciplines said that determination is obviously a
medical issue, but that the definition of death entailed other
considerations and competencies. Once again, it is no surprise which
discipline is associated with which judgment. Physicians assert that
the issue is medical and requires medical competence. Lawyers held the
issue to be a medico-legal one, requiring the collaboration of lawyers
and physicians. Ethicists stated that the issue is bioethical, and
some physicians and lawyers agreed.

> The question of the time of death, however, is not
> eclusively within the realm of medico-legal concern.
> Today, philosophers, theologians, moralists -- in
> fact, almost everyone is concerned with the question,
> 'When is a person dead?'. (Joling, JD, 162)

The substantial differences between ethicists and the other two groups

Table 12. Whose issue is the definition of death? Rounded percentage
of whole sample and breakdown by discipline.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V for Discipline x whose issue
1. Determination and definition are medical issues	30.7 (23)	51.3 (20)	14.3 (3)	0.0 (0)	.47
2. Determination is a medical issue, definition involves other considerations	54.7 (41)	43.6 (17)	71.4 (15)	60 (9)	--
3. Definition is a medico-legal issue	49.3 (37)	33.3 (13)	95.2 (20)	26.7 (4)	.57
4. Definition is a bio-ethical issue	28.0 (21)	25.6 (10)	23.8 (5)	40 (6)	--
5. Definition is a social or public issue	26.7 (20)	15.4 (6)	19.0 (4)	66.7 (10)	.56
6. Definition is a philosophical and ethical issue	21.3 (16)	7.7 (3)	14.3 (3)	66.7 (10)	.45
7. Definition is a theological issue	17.3 (13)	15.4 (6)	9.5 (2)	33.3 (5)	--

hinge on the fact that more ethicists than laywers or physicians con-
sidered redefining death a philosophical and/or public issue. Ethi-
cists frequently argued that the issue entails careful delineation
and clarification of meanings, not simply the application of various
technological competencies or blue-ribbon documents. Another ethicist
emphasis is that the topic demands public and not just professional
debate and discussion. Not many definers stated that the issue involves
theological considerations, and those that did did not specifically
argue that defining death required theological competence, apart from
philosophical or ethical competence.

To go back to the medico-technical framework that "determination,"
rather than "definition", articles are lodged in, we can compare the
two sorts of articles (determination vs. definition or definition and
determination) on some of the variables discussed thus far. Most of
the determination articles were written in a medical mode, and over 3/4
of these authors consider both determination and definition medical
issues, perhaps only because they did not adequately distinguish
between the two topics. Only one fourth of the "definition" articles,
on the other hand, contain statements that definition and determination
are medical issues. Most of these authors stated that determination
requires medical competencies but that definition entails other con-
siderations. Those that discuss only definition are distinguished from
those who discuss both aspects or determination only, in that they most
frequently argue that the issue requires philosophical competence and/
or public debate. Those definers concerned with meanings rather than
methods and applications, more often consider extra-professional

competencies important or necessary to the resolution of the issue.
Perhaps needless to say, most of those writing about definition only
are ethicists.

Consensus?

Thus far, the one thing definers seem to agree upon is that
medical advances and new technologies precipitated the problem to which
the redefinition of death is a solution. There is some consensus
that the determination of death is a medical issue, though not everyone
is willing to agree on that point. Most notably Veatch (1972; 1976)
and others from the Hastings Group, argue that the essential decision
involved in determination, i.e. which criteria, when fulfilled, re-
flect the status of human death, entails philosophical and ethical, not
medical, judgment. As we shall see below, there is little consensus
across disciplines on the issues involved in defining death and
remedies for life-prolonging technology problems.

Kinds of Issues Mentioned

Definers express various concerns and raise issues while dis-
cussing the topic in their articles. Issues mentioned fall into six
categories:

1. those common to variety of perspectives, e.g. clinical,
ethical or legal concern for the treatment of the donor or dying
patient;

2. medical issues, e.g. the use of the EEG as a primary method
for determining death;

3. legal issues, e.g. the need of a time of death for distribution of estates and wills;

4. ethical issues, e.g. one must not meddle with the donor in order to improve the transplant;

5. philosophical issues, e.g. criteria for determining death and a definition or concept of death are not the same things; and

6. theological issues, e.g. the theological meaning of death, or death as when the soul leaves the body.

Bioethical, philosophical and theological issues were distinguished in the following manner. If the issue concerns values and imperatives outside of specific reference to a theology or system of religious thought, I treated it as a bioethical issue. If the issue refers to conceptual confusion, mistakenness or refinement, or to metaphysical or existential meanings in general (e..g the meaning of personhood, death, etc.) I treated it as a philosophical issue. Theological issues are those which refer to theological symbolism, reference to biblical text, or to meanings grounded in specifically religious traditions. My apologies to those who would make finer or different distinctions than I have.

In Table 13, it can be seen that nearly everyone raises common issues, a somewhat tautological point. Two-thirds of the entire sample in the following order of frequency -- medicine, law, ethics -- raise medical issues. Most definers found it somewhat necessary to raise at least a few medical issues just to discuss redefinition. But for the most part, the kinds of issues raised parallel the discipline of the author - lawyers raise legal issues, ethicists and some

Table 13. Kind of issues: Rounded percentage of whole sample and
breakdown by discipline mentioning general kinds of issues.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V discipline x kinds of issues
1. Common issues - issues common to more than one disciplinary perspective	97.3 (73)	97.4 (38)	95.2 (20)	100 (15)	--
2. Medical issues	66.7 (50)	76.9 (30)	61.9 (13)	46.7 (7)	
3. Legal issues	52.0 (39)	38.5 (15)	95.2 (20)	26.7 (4)	.55
4. Bioethical issues	48.0 (36)	48.7 (19)	23.8 (5)	80.0 (12)	.38
5. Philosophical issues	33.3 (25)	15.4 (6)	28.6 (6)	86.7 (13)	.58
6. Theological issues	13.3 (10)	7.7 (3)	0.0 (0)	46.7 (7)	.49

physicians raise bioethical issues, and ethicists raise philosophical

and theological issues.

Common issues: (See Table 14) The most frequently mentioned

"common" issue is concern for the transplant recipient and his need.

In discussions which center around the development of and the need for

organ transplantation, it is the organ recipient who is of most con-

cern. More authors took their bearings in terms of potential good to

the recipient than in terms of potential harm to, or concern for, the

donor (although some authors may not have made a distinction between

the dying patient and the potential donor). However, some authors

urged that the potential donor not have his dying interfered with in

order to obtain organs. "Might not the overenthusiastic heart surgeon

be tempted to declare the donor dead before death occurred in order to

have a viable heart to transplant?" (Appel, MD: 513)

Ethicists frequently oriented their discussions toward the dying

patient as such, not toward the dying patient as potential donor.

Several ethicists and physicians argued that the dying patient ought to

be allowed to die without the imposition of unnecessary treatment,

(or, in somewhat different words, to die a dignified death).

> We must learn to desist from those useless technological
> interventions and institutional practices that deny
> to the dying what we must owe them - a good end. This
> purpose could be accomplished in large measure by
> restoring to medical practice the ethic of allowing a
> a person to die. (Kass, ETH, 1971;701)

In contrast to those who would simply allow a dying person to die,

a few others advocated the active interruption or stopping of some

person's dying.

Table 14. Percent of whole sample and breakdown by discipline mention-
ing theme.

Common Issues	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V associative discipline x theme
1. Concern for trans- plant recipient	49 (37)	51 (20)	57 (12)	33 (5)	--
2. Advocates allowing to die, withdrawing futile treatment	43 (32)	44 (17)	29 (6)	60 (9)	--
3. Concern for protection of donor	36 (27)	33 (13)	38 (8)	40 (6)	--
4. Concern for the dying patient	27 (20)	18 (9)	14 (3)	67 (10)	.45
5. Concern for the threat to, or confusion of, the public	27 (20)	15 (6)	33 (4)	47 (7)	.29
6. Transplantation dis- cussed substantively	27 (20)	18 (8)	52 (11)	13 (2)	.36
7. Euthanasia discussed substantively	23 (17)	13 (5)	19 (4)	53 (8)	.37
8. Allocation of scarce resources	21 (16)	26 (10)	14 (3)	20 (3)	--
9. Death as a process	19 (14)	28 (11)	10 (2)	7 (1)	--
10. Advocates active euthanasia in some circumstances	17 (13)	10 (4)	14 (3)	27 (4)	--
11. Distinction between passive and active euthanasia	17 (13)	15 (6)	14 (3)	27 (4)	.30
12. Death is an event	15 (11)	2.6 (1)	19 (4)	40 (6)	.41

Table 14 continued.

Common Issues	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V associative discipline x theme
13. Abortion discussed substantively	13.3 (10)	5.1 (2)	9.5 (2)	40 (6)	.39
14. Concern for the treatment of senile and retarded	8 (6)	1 (2.6)	0 (0)	33 (5)	.47

> Squirm as we may to avoid the inevitable, it seems time
> to admit to ourselves that there is simply no hiding
> place and that we must shoulder the responsibility of
> deciding to act in such a way as to hasten the declining
> trajectories of some lives, while doing our best to
> slow down the decline of others. (Morison, ETH, 697,
> emphasis mine)

And a few definers, nearly all of them ethicists, asked what, in the

current effort to define death, would keep all manner of social

"undesirables" -- most specifically, the retarded or senile -- from

being declared dead.

> What of the senile who populate our rest homes and
> mental institutions? Such patients are also a drain
> on family and society. They, took, have a hopeless
> prognosis and have suffered death of portions of their
> brains. Change the legal definition of death a bit
> more and they, took, will be dead! (Toole, MD, 603)

Definers of all disciplinary persuasions mentioned the problems

involved in the allocation of scarce resources (organs, respirators,

etc.): who gets the resources and who makes that decision.

Some expressed concern (primarily ethicists) that many discussions

of the redefinition of death would be confusing and threatening to

the public. Notable emphases were: 1) the tendency to refer to two

kinds of death, e.g. "heart death" or "brain death" or "legal death" or

"medical death," and 2) the constant association of transplantation

and the redefinition of death with the implication that anyone's death

can be "redefined" in order to obtain organs for others.

The articles were sorted as well in terms of other related topics

definers discussed in some detail, namely transplantation, euthanasia

and abortion. Nearly one fourth of the authors spend considerable

space discussing transplantation and euthanasia. Lawyers were more

likely to discuss transplantation because it was in the context of

transplantation that they argued physicians could be held liable for wrongful death. Euthanasia was raised by ethicists primarily, perhaps because of their concern with distinguishing the definition of death from notions of euthanasia, and their fear of allowing the definition debate to get onto the slippery conceptual slopes of euthanasia advocacy. Only ten authors discussed abortion, over half of them ethicists.

Death: process or event?: The seemingly simple debate between those who consider death a process ("Death does not occur at a single instant. Death of the cells in various organs can be extended over a period of minutes or hours." (Paulson, MD, 39) and those who consider death an event hides some rather profound disagreements about the interpretation of the issue. If one conceives of dying as a process, then one appropriate question is "at what point is the process irreversible?" Consequently, in determining death one is likely to look for the deaths of particular organs, since organs die differentially. A more subtle result of this assumption is that once the relative indeterminacy of death is granted in arguing that death is a process, questions of who is "less dead" or "more dead" arise as well as questions of the relative worth of persons in this or that stage of dying. However, if one argues that death is an event, one is more concerned with the death of the organism as a whole, not the death of the various organs and cells; and the focus is on just that, the death of the individual.

> Even though one may recognize that tissues and organs
> "die" at different times, this still does not answer
> the question of the death of a person, unless one
> argues misleadingly that the person is the sum of the

> total parts or that the person is a system of cells
> and tissues and nothing more. (High, ETH, 445)

> ....the phenomenon of interest to physicians, legisla-
> tors, and laymen alike is human death, therefore the
> statute should concern the death of a human being, not
> the death of his cells, tissues or organs, and not the
> "death" or cessation of his role as a fully func-
> tioning member of his family or community. (Capron
> and Kass, LAW and ETH, 104)

Authors who view death as an event tended also to argue for

allowing a person to die all the way, to argue for the sanctity of the

body, and generally, to be less likely to participate in debates on

the relative worth of dying persons. As is clear from Table   more

authors consider death a process than an event, and those who do

consider death an event are primarily ethicists.

Medical issues: (See Table 15) Over half of all articles mention

the general criteria for determining death according to brain dysfunctin,

the time interval used for reassessing the status of the patient,

caution about confusing "death" with barbiturate poisoning or

hypothermia, specifics regarding EEG amplications, general methods, etc.

In this regard, more authors showed approval than hesitation over primary

use of the EEG in death determination. One fourth of the sample (a

higher proportion among physicians and lawyers than among ethicists)

expressed concern that in transplant situations, no member of the

transplant team be responsible for the care of or the definition of

the death of the donor.

Since 1970, some authors have distinguished between whole brain

and neocortical death, sometimes arguing that the latter is a more

valid indication of the death of a person than the former, and

Table 15. Percent of whole sample mentioning issues and breakdown by discipline of author.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V for dis- cipline by issue
Medical Issues					
1. The usual specifications of criteria and methods of determinations	53 (40)	69 (27)	48 (10)	20 (3)	.38
2. Encourages primary EEG use	27 (20)	41 (16)	14 (3)	7 (1)	.34
3. Hesitant about EEG use	20 (15)	23 (9)	14 (3)	20 (3)	
4. Concern that no transplant team member care for or declare death of donor	25 (19)	23 (9)	38 (8)	13 (2)	
5. Distinction between whole brain and neocortical or cerebral death	20 (15)	15 (15)	14 (3)	40 (6)	
Legal Issues					
1. Medical liability of concern	31 (23)	18 (7)	76 (16)	0	.63
2. Present legal definition inadequate	28 (21)	13 (7)	62 (13)	7 (1)	.48
3. Need time of death for wills, estates	25 (19)	13 (5)	62 (13)	7 (1)	.52

Table 15 continued.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V for discipline by issue
Bioethical Issues					
1. Persons should be allowed to die humanely	35 (26)	36 (14)	19 (4)	53 (8)	
2. Reference to physician-patient ethics, contract, ethical codes in medicine	31 (23)	26 (10)	24 (5)	53 (8)	
3. The body is sacred, inviolable	16 (12)	8 (3)	5 (1)	53 (8)	.51
4. The definition of death should not be contaminated with pragmatic concerns	8 (6)	0	5 (1)	33 (6)	.47
Philosophical Issues					
1. Existential or metaphysical meanings -- of life, death, personhood	27 (20)	13 (5)	14 (3)	80 (12)	.60
2. Distinction between "when is death" and "when to allow to die"	12 (9)	0	10 (2)	47 (7)	.54
3. Distinction between concept or definition and criteria	12 (9)	36 (1)	14 (3)	33 (5)	.36
4. Identification of death of organ with death of a person reductionist mistaken	8 (6)	3 (1)	5 (1)	27 (4)	.35
5. Value-free or technological approach inappropriate for this issue	8 (6)	3 (1)	0	33 (5)	.47

Table 15 continued.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V for discipline by issue
Theological Issues					
1. Theological meanings or considerations involved in concept of death	11 (8)	3 (1)	10 (2)	53 (8)	.38
2. Death as departure of soul from body	11 (8)	8 (3)	0	33 (5)	.55

sometimes criticizing the Harvard criteria (whole brain criteria) as
being inclusive a method for determining human death.

> With the death of the neocortex, human life is ended
> because the potentiality to reflect consciously is
> eradicated in the organism. (Rizzo, ETH, 23)

> The point is that without the synthesizing function
> of the cerebral cortex (without thought or mind)
> whether before it is present or with its end, the
> person is nonexistent no matter how much the individual's
> brain stem and mid-brain may continue to provide feel-
> ings and regular autonomic physical functions.
> (Fletcher, ETH, 1974, 6)

Assertions about the essential qualities of human beings frequently
accompany the distinction between cerebral and whole brain death,
making this, of all the medical issues, the most morally and conceptually
ponderous. It is not surprising, therefore, that it is the medical
issue most frequently raised by the ethicists. It will remain an
issue for some time to come as more cases like Karen Quinlan's arise.

Legal issues: (Table 15) The legal arguments raised most often
are that the potential medical liability in either transplantation or
withdrawal of treatment situations is of legitimiate concern to
physicians, and that current legal definitions of death (cf. Blacks
Dictionary) are inadequate and do not reflect medical knowledge. Also
at issue in the legal realm is the need for a clearly specified
standard for determining the time of death for estate and heritance
laws.

Bioethical issues: (Table 15) The ethical issues raised most
often, and by all three disciplines, are 1) that persons should be
allowed to die humane or dignified deaths and not have their dying
interfered with and 2) the content of and appeal to the general tenets

physician-patient ethics and general medical ethics (such as the Hippocractic oath and the AMA ethics code). Most authors when discussing the latter mentioned merely that one ought to consult or consider them, or that the general tenets of such systems or codes should still hold in new situations.

A smaller number of definers, mostly ethicists, raised a third bioethical issue, that is that the body is a substantial part of what we mean by "person" or "human being" and, therefore, organ removal for transplantation may undermine the inviolability of the body. Defining death solely in terms of brain function ignores the significance of the rest of the human body.

> The body is as uniquely the body of this brain and no other, as the brain is as uniquely the brain of this body and no other...My identity is the identity of the whole organism, even if the higher functions of personhood are seated in the brain. How else could a man love a woman and not merely her brains? How else could we lose ourselves in the aspect of a face? Be touched by the delicacy of a frame?...the body of the comatose, so long as -- even with the help of art -- it still breathes, pulses, and functions otherwise must still be considered a residual continuance of the subject that loved and was loved, and as such is still unentitled to some of the sacrosanctity accorded to such a subject by the laws of God and men. That sacrosanctity decrees that it must not be used as a mere means. (Jonas, ETH, 1974, 139)

Fourth among the bioethical issues is the notion that the definition of death should not be designed or enforced with reference to pragmatic concerns such as costs, transplantation, or the allocation of scarce resources.

> If no persons' death should _for this purpose_, be hastened, then the definition of death should not _for this purpose_ be updated, or the procedures for stating that a man has died be revised as a means of affording easier access to organs. (Ramsey, ETH, 103)

> We need to recover both an attitude that is more
> accepting of death and a greater concern for the
> human needs of the dying patient. But we should
> not contaminate these concerns with the interests
> of relatives, potential transplant recipients or
> "society". To do so would be both wrong and
> dangerous. (Kass, ETH, 1971, 702)

The contamination of the absolute end to a person's life with a

concern or intent of "meddling with the donor, in order to improve the

transplant" (Wolstenholme and O'Conner, 1966) is a cause of confusion

and fear for the lay public. These warnings by ethicists stand in

opposition to article after article which state that the essential

reason for redefining death is in order to facilitate transplantation.

Philosophical issues: (Table 15) Approximately one fourth of the

definers, mostly ethicists, mentioned that defining death entails

struggling with philosophical conceptions such as life, death, and

the nature of humanness (or personhood).

> What it means to be (as a person) and to cease to be
> (as a person) is not just another example of a problem
> of knowledge. It is at the very center of what is
> real, knowable, and of value. (High, ETH, 455)

> The idea of death is at least partly a philosophical
> question, related to such ideas as "organism",
> "human", and "living." Physicians qua physicians
> are not expert on these philosophical questions, nor
> are they expert on the question of which physiological
> functions decisively identify a "living human
> organism". (Capron, LAW and Kass, ETH, 94)

Secondly, seven ethicists have argued that the question "When is

death?" should be conceptually distinguished from the question "When do

we allow this person to die?" The close conceptual association between

the two questions burdened the redefinition issue for a long time with

issues properly belonging to the realm of euthanasia or caring for the

dying, and seems to have mistakenly encouraged the hope that redefining

death would ease the grotesque problem of "unburied corpses" and

hopelessly comatose persons much more than it has.

> As Professor David Daube has written, 'The question of
> at what moment it is in order to discontinue extra-
> ordinary -- or even ordinary -- measures to keep a
> person alive should not be confused with the question
> at what moment a man is dead" or with the question of
> the procedures by which the presence of life or death
> is to be determined. (Ramsey, ETH, 99)

Some argued that it is important to distinguish between the concept

or definition of death and the criteria or procedures utilized to tell

that a person is dead. Those that did, did so most often to point out

either that the issue is not merely a technical one, or that one needn't

discard all the traditional meanings death has had just because

physicians use new and different criteria to tell when a person had died.

Additionally, objections were raised to the reductionism implied in

the notion of "brain death" - in defining death in terms of a single

organ. These authors argued that what is at issue is the death of

persons, human beings, or the organism as a whole, not the death of

organs.

Finally, among the philosophical points made is the notion that

primarily medical, scientific or technological approaches to the

question of death are conceptually, if not ethically, inappropriate

for the resolution of an essentially moral issue.

> Death is not straightforwardly cashable in empirical
> terms or in empirical criteria. (High, ETH, 454)

> The cowardice of modern secular society shrinks from
> death as an unmitigated evil needs the assurance (or
> fiction) that he is already dead when the decision is
> to be made. The responsibility of a value-laden

> decision is replaced by the mechanis of a value-free
> routine. (Jonas, ETH, 139)

These issues are conceptually interrelated. Distinguishing be-
tween concept and criteria, for instance, allows for the suggestion
that the issue is not reducible to technics but involves grappling with
essential, basic, philosophical meanings of life and death. And the
physician, qua physician, is not necessarily the person to whom
responsibility for redefining death should be relegated. Distinguish-
ing between concept and criteria also allows one to conclude that only
the means or criteria for determining death needs to be updated, and
not the definition or concept of death.

Theological issues: (Table 15) Few definers, excepting ethicists,
mentioned any theological issues. Some mentions were as general as
stating that theological meanings of death should be addressed in the
debate. A few authors in discussing traditional meanings of death
included "the time when the soul leaves the body," and a few ethicists
discussed the issue of death definition in terms of religious texts.
It may be an indication of the extent of secularization in our society
that 85% of the authors, some of whom interpreted the issue philosoph-
ically, conceptually and even ethically, made no mention of religious
or theological tenets or beliefs.

Remedies

Most authors suggested remedies to the problems they discussed.
(See Table 16). Some remedies are not substantially different from
issues raised. For example, several authors considered "allowing
persons to die" a key issue and a key remedy to the central difficulties

Table 16. Remedies: rounded percentage of whole sample and breakdown by discipline mentioning the following remedies.

	Frequency N=75	Medicine N=39	Law N=21	Ethics N=15	Cramer's V (discipline x theme)
1. Redefine death in terms of (whole) brain function	63 (42)	77 (30)	71 (15)	13 (2)	.51
2. Leave the issue entirely to medical practice and/or train physicians in human values, ethics	40 (30)	49 (19)	47 (10)	7 (1)	.34
3. Advocates allowing persons to die	29 (22)	21 (8)	19 (4)	67 (10)	.41
4. Legislation	23 (17)	13 (5)	52 (11)	7 (1)	.45
5. Involve the public in consideration of the issue	20 (15)				--
6. More research, new technologies	16 (12)	21 (8)	9.5 (2)	13.3 (2)	--
7. Leave definition of death to the courts	13 (10)	8 (3)	29 (6)	7 (1)	.28
8. Establish interdisciplinary of lay committees to make decisions	13 (10)	10 (4)	0	40 (6)	.41
9. Respect the sanctity of the human body, use caution with redefinition	12 (9)	5 (2)	0	47 (7)	.54
10. Advocates stopping dying in some instances	11 (8)	10 (4)	5 (1)	20 (3)	--
11. Redefine death in terms of neocortical or cerebral function	8 (6)	10 (4)	0	13 (2)	--

a redefinition of death could mitigate, i.e. undignified dying and futile treatment. Other remedies are indeed different from the issues (e.g. legislation) discussed so far. The remedies suggested focus on two clearly distinguishable issues: 1) who should decide, and 2) what should be done.

Over half (63%) of the group suggested redefining death in terms of brain function, and only a few argued that the definition should be refined to assess only neocortical, and not merely, whole brain function. In other words, all but about 20 definers advocated a redefinition with no hesitancy. On that point, there is considerable consensus, although obviously definers came to that conclusion via different conceptual avenues. And 40% of the definers thought that the redefinition issue should be left entirely in the hands of medical practitioners. Some others (20% - primarily ethicists) advocated restoring the practice of "allowing" terminal patients to die, but only a few (11%) advocated active euthanasia, actively shortening the dying process in some instances. Some physicians and over half the lawyers argued that legislation would be the answer, a few arguing that the issue should be debated in a public forum and before a public body and most others arguing that transplant physicians should be protected by law. Only a few suggested that the courts would be the most appropriate arena for resolving the definition of death debate.

About 20% thought that the issue should be open for general public debate and discussion, since the definition of death is presumably an issue which affects and is of substantial interest to us all. Establishing lay and/or interdisciplinary committees to make

decisions to "pull the plug" or to allocate resources was mentioned by
only 10 definers. Consistent with their stands throughout, most
ethicists argue conservatively for allowing persons to die (rather
than interfering with the dying process), for respecting the sanctity
of the body, and for taking the decision-making and responsibility
out of the hands of the physician.

Consensus?

Most definers agreed that modern technological advances in
medicine have created a problem not easily foreseen, namely, the fact
of unburied corpses whose hearts still beat and who breathe with the
aid of a respirator; and most agreed that redefining death in terms of
brain, rather than heart or respiratory function, was the first step
towards a solution. Other than that, they differ widely with respect
to their major concerns and values, their attributions of responsibility
and competence, and their views on how to solve the many other prac-
tical, legal and moral problems. Some take their bearings from the
point of view of the dying patient, others from the point of view of the
family or the community, and still others from the point of view of
other dying patients esperately in need of new organs. And added to
this particular matrix of concerns are professional orientations which
variously emphasize medical, legal, ethical or philosophical approaches
and definitions. Once could say, at one level, there is some minimal
amount of consensus for a group as diverse as this one, and at another
level, using a finer mesh, one could say that across and even within
disciplines, definers have widely disparate views on the topic, as will
become obvious in the next two sections.

Results of the Clustering Analysis:

The Dying Patient vs. the Common Good
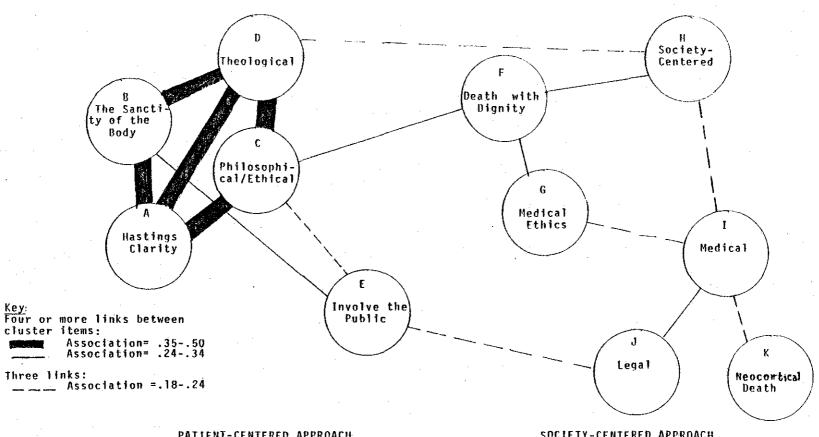
The elements of the content analysis were subjected to an analysis in which all elements appearing most often together (apart from their location in particular articles) were amalgamated. I have called the resulting clusters of themes "conceptual approaches" although that phrase stretches what the clusters of elements or themes are in fact. Each cluster represents consensus on an approach to the topic but is not neatly composed of a reason or two, a statement about what kind of issue redefining death is considered to be, a few central issues and a remedy; but the clusters and their relationships do represent lines of agreement and, as we will see, there are several.

The different clusters and their elements appear in Table 17. Figure 4 is a clustergram representing the relationships among the clusters, and those most strongly associated are closest together. In addition, they have been listed in Table 17 in order of closest association. (That is, clusters A-D are closely related and more closely related to E-G than to H-K, or, in other words, authors who expressed themes present in the first four clusters did not often express themes in the last few.)

Clusters A-D: The Philosophical-Ethical Approach: One Side of the Story

The first four clusters comprise the general philosophical-ethical approach, patient-centered in orientation and containing the conservative "sanctity of life" conceptualization. The first cluster, "Hastings Center clarity" includes many of the points made by members of the Hastings Center Research Group on Death and Dying. Cluster B

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FIGURE 4. RELATIONS AMONG THE DEFINERS'
CONCEPTUAL APPROACHES

Key:
Four or more links between
cluster items:
▮▮▮ Association= .35-.50
＿＿ Association= .24-.34

Three links:
－ － － Association =.18-.24

PATIENT-CENTERED APPROACH   SOCIETY-CENTERED APPROACH

Table 17. Results of the cluster analysis of themes present in definers articles.

Cluster A: Hastings Center clarity

Distinction between "When is death?" and "When to allow to die?"

Distinction between concept or definition and criteria

Identification of death of organ with death of a person is reductionist, mistaken

Definition of death should not be contaminated with pragmatic concerns

Reference to physician-patient ethics, contract or ethical codes in medicine

Concern for the threat to, or confusion of, the public

Cluster B: Sanctity of the body approach

The definition of death is not needed, or presents serious ethical/conceptual problems

Respect the sanctity of the human body, use caution as remedy

The body is sacred, inviolable

Concern for the dying patient

Concern for the treatment of senile and retarded

Death is an event

Death as departure of the soul from the body

Cluster C: Leftovers from A and B

The issue is philosophical/ethical

Existential or metaphysical meanings - of life, death, personhood

Technological or "value-free" approach inappropriate for this issue

Advocates allowing to die as a remedy

Cluster D: Theological orientation

Euthanasia discussed substantively

Distinction between active and passive euthanasia

Abortion discussed substantively

Theological meanings and considerations

Cluster E: Involve the public approach

The issue is a public issue

The issue is theological

Involve the lay public in the issue

Table 17 continued.

Concern for the protection of the donor

Establish interdisciplinary or lay committees to make decisions as remedy

Cluster F: Death with dignity approach

Death should be redefined in order to let persons die humanely

Death should be redefined in order to cease useless or futile prolongation of life

Persons should be allowed to die humanely

Advocates allowing to die or withdrawing futile treatment

Cluster G: General medical ethics approach

Death should be defined in terms of the higher human functions

Death is a process

The issue is bioethical

Concern that no transplant team member care for, or declare death of donor

Cluster H: Society-centered approach

Death should be redefined in order to mitigate burden on the family

Death should be redefined in order to mitigate burden on the community

Allocation of scarce resources

Advocate hastening or stopping dying in some instances

Advocates stopping dying in some instances as remedy

Encourages EEG use

Cluster I: Medical approach

Death should be redefined in order to facilitate transplantation

The issue is medical

Usual specifications of criteria and methods of determination of death

Concern for transplant recipient

Hesitancy about use of EEG

Death should be defined in terms of whole brain function as a remedy

Table 17 continued.

Cluster J: Legal approach

Death should be redefined in order to facilitate heart transplantation

Determination only is a medical issue

The issue is medico-legal

Present legal definitions are inadequate

Need time of death for insurance, wills

Transplantation discussed substantively

Legislation advocated as a remedy

Cluster K: Neocortical death

Distinction between whole brain and neocortical death

More research, new technologies as a remedy

Redefine death in terms of neocortical function as a remedy

representing the "sanctity of the body" approach, although closely related to A, contains fewer philosophical statements and more conservative ethical statements than A. General philosophical issues which are associated with those in A and B, but not strongly enough to be included in those clusters, comprise cluster C. Cluster D implies that authors who discussed euthanasia, also discussed abortion frequently in terms of theological considerations.

Because this general approach is comprised of four clusters, no entire approach is contained in any one cluster, unlike several of the others (see the "medical" or "legal" clusters). For that reason, I have combined the four into an approach complete with reasons, remedies, issues, etc. which appears in Table 18.

Clusters E-G: The Midst

Not as strongly interrelated as the previous four clusters are clusters E-G which are grouped together primarily because they fall between the patient-centered (A-D) and the society-centered approaches (H-I). From the "death with dignity" approach (F), one can easily slip into a society-centered position, a medical position, and even into a patient-centered approach. Several authors found nothing inconsistent about arguing for both the dignity of the dying and for the benefits incurred by others in their dying. The path one takes presumably depends on whether one holds that death should be redefined to allow the dying to die or to withdraw futile treatment and make scarce resources accessible to others. One has the suspicion, however, that respect for humane dying can slip quickly into an enforcement - a notion that one

Table 18. Philosophical-ethical approach (combining clusters A-D).

A. Reasons for a redefinition of death:

1. The redefinition of death is not needed, or presents serious ethical/conceptual problems

B. What sort of issue is the redefinition of death?

1. A philosophical/ethical issue

C. Issues raised/stands taken

Common issues

1. Concern for the threat to, or confusion of, the public

2. Concern for the dying patient

3. Concern for treatment of senile and retarded

4. Death as an event (not a process)

5. Euthanasia discussed substantively

6. Distinction between active and passive euthanasia

7. Abortion discussed substantively

No medical or legal issues

Bioethical issues

1. The definition of death should not be contaminated with pragmatic concerns

2. Reference to physician/patient contract, ethics

3. The body is sacred, inviolable

Philosophical issues

1. Distinction between "When is death?" and "When to allow to die?"

2. Distinction between concept and criteria

3. Identification of death or organ with death of person reductionist mistake

4. Existential or metaphysical meanings of life, death, personhood

5. Value-free or technological/scientific approach in appropriate for an ethical issue

Theological issues

1. Theological meanings and considerations

2. Death as departure of soul from body

Table 18 continued.

D. <u>Remedies</u>

    1. Respect the sanctity of the human body, use caution with redefinition

    2. Advocates allowing to die, withdrawing futile treatment as a remedy

---

perhaps ought to die to make scarce resources available. Perhaps a "right to die" can turn into a duty to do so (cf. Kass, 1972; Veatch, 1976). As mentioned previously, the "involve the public" approach (E) appears in both philosophical-ethical arguments and legal arguments. Of these three clusters, the "medical-ethics" cluster (G) is most closely aligned with F, the "death with dignity" approach and to the "society-centered" and "medical" approaches.

Clusters H-I: The Society-Centered and Medical Approaches: The Other Side of the Story

In Cluster H we find most of the items which comprise a "society-centered" or "common good" approach to redefining death, including attention to the allocation of scarce resources and all other considerations external to the dying patient, except obtaining organs for transplantation. The "medical" cluster (I) focuses on items of concern to physicians as well as the notion that death should be redefined in order to afford easier access to transplant organs and concern for the transplant recipient. Both clusters contain items negatively associated with items in Clusters A-D.

The Remaining Clusters J and K: The "Legal" and "Neocortical" Approaches
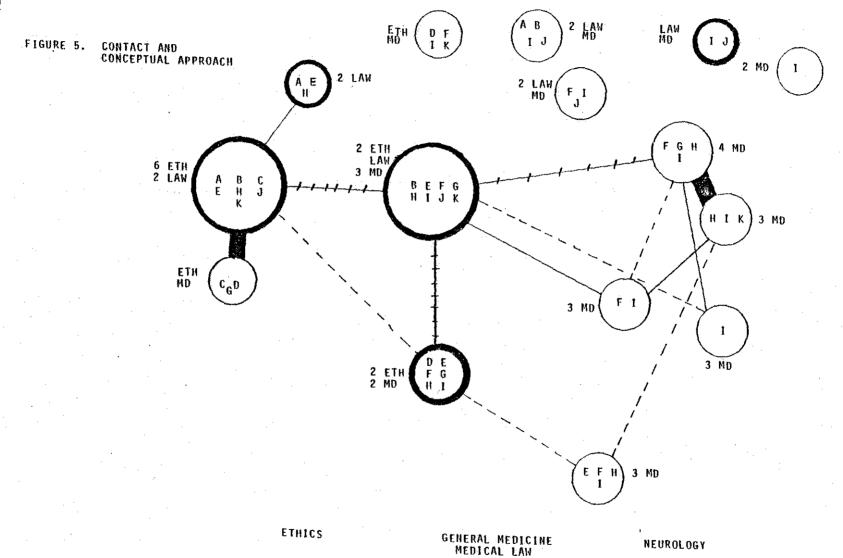
These two clusters have nothing in common other than that both lie to some extent outside the patient centered-society centered dimension. The "neocortical" cluster contains items regarding neocortical as opposed to whole brain death, and is related only minmally to the medical
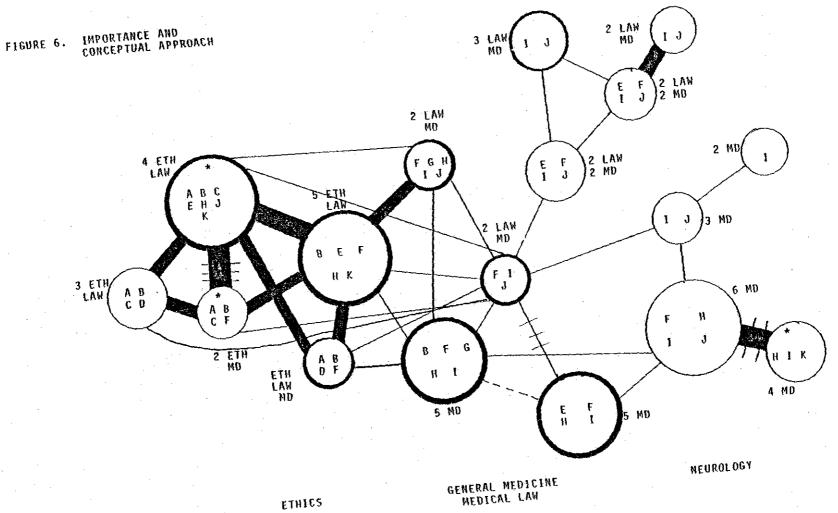
cluster. The "legal" approach, associated with items in both the "involve the public" and the "medical" approaches, reflects lawyers' interest in legislation to protect physicians from liability from wrongful death. Many of the legal issues appear with medical issues because most lawyers echoed physicians' interests but asserted the necessity of updating the legal definition of death through legislation.

It would be mistaken to assert that the clusters do not overlap with one another, or, that the "common good" clusters contain no elements related to those in the "patient-centered" or "sanctity of the body" clusters, or, even more to the point, that authors concerned with the sanctity of the body, for instance, are not also concerned with humane dying or the potential benefits of transplantation. The clusters are both abstractions -- they do not reflect any particular amalgamation of themes found in a specific article -- and fictions of sorts. However, given these hesitations (as well as the current state of dissertation funds and network methodology) this is more or less what the thematic patchwork of the article sample looks like.
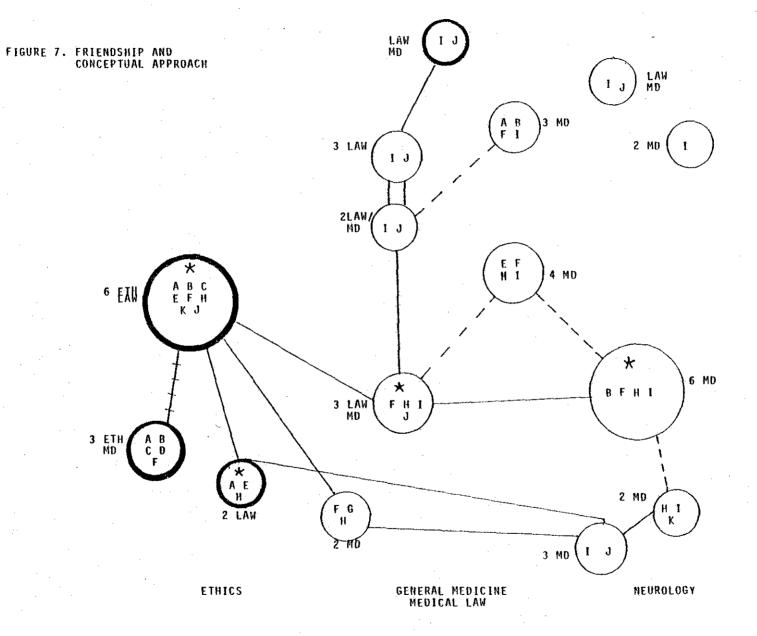
Conceptual Approach and Social Organization

The relationship of the conceptual approaches and the social organization obtained in the last chapter is a difficult one to specify. Posing the problem in terms of a question which asks which is primary or most determining in the relationship practically assures a chicken-and-egg solution. There is no way, apart from applying scarce interview notes on the topic for me to come to grips with the following question: Did respondents approach the issue in a certain way

FIGURE 5. CONTACT AND CONCEPTUAL APPROACH

ETHICS

GENERAL MEDICINE
MEDICAL LAW

NEUROLOGY

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FIGURE 6. IMPORTANCE AND CONCEPTUAL APPROACH

ETHICS

GENERAL MEDICINE
MEDICAL LAW

NEUROLOGY

FIGURE 7. FRIENDSHIP AND
CONCEPTUAL APPROACH

250

LAW
MD

I J

I J   LAW
       MD

3 LAW

I J

A B
F I   3 MD

2 MD   I

2LAW/
MD   I J

*
A B C
E F H
K J

6 LAW

E F
H I   4 MD

3 ETH
MD   A B
      C D
      F

*
F H J

*
B F H I   6 MD

3 LAW
MD

*
A E
H

2 LAW

F G
H

2 MD   I J

3 MD

2 MD

H I
K

ETHICS   GENERAL MEDICINE   NEUROLOGY
                    MEDICAL LAW

because they were members of a specific discipline or group or did they
join the discipline or group because of a basic value or epistemo-
logical orientation which would influence both the choice of a
discipline and the interpretation of the definition of death?
Similarly, one might ask, did respondents approach the issue in a
certain conceptual style because they had been included in a particular
symposium roster because they had a specific approach to the issue?
No doubt some persons of similar conceptual persuasions come together
and some of those who are related by discipline or other organizational
variables express similar persuasions -- a conclusion of questionable
insight and merit.

Conceptual approach and social networks. The most simple
question to manage is, what sorts of conceptual approaches are
associated with the sociometric networks? Many of the people who
utilize the same approaches are clustered together sociometrically.
By now, it is clear which kinds of approaches go with which disciplines,
and in the last chapter, it was stated that the sociometric clusters
are at least somewhat organized according to disciplinary parameters.

Figures 5-7 show the sociometric clustergrams for the three
major ties with the major approaches utilized by the members of each
cluster imposed on the cluster area. The first impression received by
looking at them is that the ethics clusters on the left sides of the
sociometric clustergrams are most closely associated with conceptual
clusters A-D, the patient-centered and ethics approaches. Likewise,
the right sides of each clustergram go together, so that the neurolo-
gists and lawyers are most closely associated with the society-centered,

medical and legal approaches. In the middle of the sociograms, i.e., the "general medicine area", there are a few "involve the public" approaches (E) some "death with dignity" (F) and "medical ethics" (G) approaches, as well as some general medical and legal approaches (I and J, respectively). It is the general physician clusters which link the ethics and neurology-law clusters, and it is the members of those clusters who utilize the approaches which fall into the transitional conceptual space between the patient-centered and society-centered arguments.

On second impression, it is obvious that this matching of thematic and sociometric clusters is a bit oversimple and overgeneral. Clearly, some members of the ethics clusters utilize society-centered approaches and at least a couple of neurologists and general physicians use strong patient-centered, medical ethics, and death with dignity approaches.

When discipline and conceptual approach do not coincide, assessing what factors might be at work in determining either approach or organization is a matter of some speculation. A respondent's intellectual tastes and attractions, his deep value orientations, chance intellectual meetings, exposures and the like, all could be factors which could account for an approach to this issue which is different from one's disciplinary colleagues. And these are factors which I did not include in the questionnaire.

First, how do the different social ties respondents have bear on the relation? In the network, Contact, influence is not at issue, just contact of some kind is. Most of the clusters which contain

persons of varied disciplines and approaches can be readily explained by participation on the same symposium rosters or committees. In other words, social organization accounts for persons with different approaches showing up in the same clusters on Contact.

Differences for Importance are another story. This is the social tie on which respondents chose persons of other disciplinary and conceptual persuasions most often. Importance refers to, by definition and direction to respondents, provocation, aid and influence, and I can assume that at least some of the provocation, aid and influence is conceptual and not social. Many respondents considered authors they had not contacted, or who were not professional friends, important. Participation on research committees and the process of conducting research includes conceptual wrestling, at least some of the time, with conceptual opponents. As one respondent put it, "To a great extent, I believe, people with opposite views to mine have been most instrumental in sharpening my own views." It is not surprising, then, that respondents followed directions and considered persons who were provocative as important, i.e., who took different or opposing approaches.

The directions for both Contact and Importance refer to the redefinition issue in particular, but directions for Professional Friendship do not. And for the most part, persons who chose others with different approaches on the other two ties, chose their own disciplinary colleagues on Friendship. It seems that the longer period of involvement with one's professional colleagues in school and workplaces, at professional meetings and the like determines choices on

Friendship -- not the conceptual or social relations formed while debating the definition of death. Only the Hastings Group chose persons with other approaches (their committee colleagues) on Friendship. And as noted before, the intensity of the conceptual and social involvements on this committee have set this group apart from others in a number of respects.

Social organizational factors (disciplinary membership, participation on committees, in symposia) do shape conceptual approach, no doubt. On the question of conceptual influence or importance in turn shaping the establishment of social ties and organization, I can relay one story which implies that exposure to important conceptualizations of an issue can result in theformation of other social relationships. One informant spent considerable time relating to me the history of his intellectual involvement with defining death. During medical school he had ties with both a professor and a friend who introduced him to the philosophy of biology and organism and Aristotle's, Ethics. These experiences led to a developing interest in the relation of ethics, philosophy and medicine. He actively sought out persons interested in the same relation, particularly, persons who conceptualized the relation similarly. Eventually, they all ended up on a committee together to discuss this issue. Intellectual experience and conceptual style can stimulate the formation of some of social ties, some of them quite strong. We all know that; we've all had similar histories.

Some other respondents named a variety of historically significant thinkers whose work had been significant to them in establishing their conceptual orientation to defining death: Whitehead, Tillich, Arendt,

M. Polyanyi, Neibuhr, Heidegger, Jaspers and Aristotle. More often,
respondents mentioned local, disciplinary colleagues. No doubt
respondents view their own intellectual histories differently, some
placing their involvement squarely in a tradition of intellectual
history, others lodging their in their disciplinary training and daily
professional experience -- one of the several differences between
ethicists and their few lawyer and physician associates and the rest of
the respondent sample.

Conceptual approach and religion: While discussing one cultural
variable writ large, intellectual influence, let's turn to another
cultural variable assessed in the questionnaire: the importance of the
respondents' religions. Do respondents who argue the patient-centered
or philosophical-ethical line differ from those who argue the society-
centered, medical and legal lines according to their religion's
importance? In a word, No.

I take two reasons stated by respondents - that death should be
redefined in order to facilitate transplantation and that death should
not be redefined or that doing so presents serious problems - to be
good predictors of the two orientations, respectively. The first - to
facilitate transplantation - is negatively associated with elements
of the patient-centered approach and substantively associated with
elements of the society-centered approach. The opposite holds true for
the position that redefinition is not needed. Moreover, these two
reasons are conceptually central to both positions.

Collapsing the five point religious importance scale to a three-
point scale, the reasons and religious importance are compared in

Table 19. Little difference between authors who present either reason
in their assessment of the important of their religion hold, except
that fewer who question the need to redefine death feel so-so about
the important of their religions, and more state that their religions
are unimportant.[3]

Conceptual approach, ethicists, and the elite: I can approach
the problem once more by asking who choose authors who have other
approaches? Primarily, it is ethicists and the elite who do, along
with those who had been involved in creative working committees (there
is considerable overlap among the elite, the ethicists, and committee
associates). I would suggest that it is ethicists and/or ethically
oriented physicians and lawyers who do, because it is against the
opposing points of view - the prevailing medico-legal consensus -
that they sharpened their stances.

The same dynamic of opposition seems to have worked for committee
members, especially the members of the Hastings Research Group on
Death and Dying. They set up several public debates in which persons
argued from differing points of view, the most widely known of which
is the Kass-Morison debate published in Science. I was told of other
debates of somewhat longstanding known to the committee members, and
in particular of one, between Paul Ramsey and Henry Beecher. More
fittings representatives of the patient-centered (Kass, Ramsey) and
society-centered (Morison, Beecher) perspectives would be difficult to
find.

The elite also chose others with different conceptual approaches
than their own. Perhaps there is a professional obligation to (or

Table 19. Religion importance by reason to redefine death (in rounded
          percentages.

Reason for redefining death	Religion Importance			
	Important	So-So	Not important	Total
1. Redefine death to facilitate trans- plantation	56 (23)	17 (7)	22 (11)	100 (41)
2. Do not redefine death or serious problems	53 (9)	6 (1)	41 (7)	100 (17)

interest in) taken into account another "well known's" work, whether or not it meshes with one's own. The elite also happen to be those for whom disciple and approach coincide least often. In their various intellectual travels and wanderings, they may have more occasion to be exposed to other points of view than those which tend to be associated with their discipline than the non-elite. In this study, at any rate, the elite are more intellectually cosmopolitan, in terms of both what and whom they know.

Endnotes

[1]Throughout, when quotations supplement the text, the respondent's last name, discipline, and the page on which the quotation is found are all the reference elements given. A bibliography of all respondent articles used in the analysis is given on p.

[2]Most authors who mention "to allow to die" (85%) also mention "to cease useless prolongation". In other words, those concerned with the dying person also express concern that useless prolongation of life be stopped. However, the opposite is not the case: Less than half of those mentioning "cease useless prolongation" also mentioned "allow to die". Several who had the physician's or community's concern in mind (the allocation of resources) did not also explicitly emphasize concern for the patient from his perspective.

[3]I suspect that if I had approached the respondents with a different query about their religious beliefs, in an interview or, in some other than the standard demographic questionnaire format, a different relation might have emerged.

CHAPTER 8

THE POLICY-MAKERS AND DEFINER/POLICY-MAKER INTERACTION

The formation of social policy has been discussed in many contexts,

though not often in terms of interpersonal or of formal communication.

The interpersonal communication which precedes the introduction of a

bill to a state legislature, and the testimony at committee hearings and

the consultation with experts that continue after the bill is introduced

are all important communication activities which underlie the enactment

of policy. In this chapter, I will introduce the policy-makers con-

tacted for this study and describe their occupations and political

affiliations, as well as definer/policy-maker interaction.

The Policy-Makers: Who They Are

I was able to contact drafters or sponsors of brain death statutes

in the five states already discussed. As mentioned previously, after

repeated attempts, I was unable to contact anyone integral to the

passage of the Alaska statute. Eighteen out of 22 persons whom I con-

tacted, responded for interviews and/or to a questionnaire (82%). Half

of the 18 who were major figures involved in successful legislation

efforts are physicians, including two medical school administrators,

two neurosurgeons, two physician legislators and three nephrologists,

or kidney transplant surgeons. Two are lawyer-physicians. Of the

remaining seven, four were legislators and four were connected with the

state attorney general's office as either assistant or deputy attorneys general. Of all those in public office, six are democrats and three are republicans.

Physicians provided the primary impetus and organization for bills in Kansas, Maryland and New Mexico. The bills suggested by the physicians were introduced to the legislative body by legislators with strong connections with local university medical schools. The Virginia statute was drafted and organized from within the attorney general's office by two assistant attorneys general who had counseled the defense in Tucker v. Lower; the bill was introduced to the legislature by a physician legislator who was a friend of one of the drafters. California's statute was the result of a complex collaboration among the state attorney general's office and a committee organized by that office with five active members, including a representative from Attorney General Younger's office, two kidney transplant surgeons, a legislator previously associated with Shumway's transplant program at Stanford University, and a lawyer-physician.

Physicians involved in the legislative efforts provided a few functions--as organizers, expert consultants, or witnesses, or as direct links to their legislatures. Some of the lawyers and legislators became involved because of strong ties to local university medical schools, out of personal interest, or through direct contact with the issue in court cases. Other legislators were identified with the bill simply through normal legislative duty. Some expressed little knowledge of this highly complex and rather profound issue--making statements which are both amusing and alarming: "Recalling specifics on one relatively minor

piece (of legislation) like this is difficult"; "I really didn't do very much on it"; and "You aren't going to ask me any tough questions, are you, ma'am? I'm just a cowboy!"

Definer/Policy-Maker Interaction

A little over one-third of the definers (36%) participated in policy-making activities with regard to redefining death. Most served as expert consultants or witnesses at legislative hearings or committee meetings. Three opposed legislation as private citizens in their communities, and three drafted or authored bills. Only a few who indicated legislative involvement are identified with the enactment of the five statutes included in this study. Others participated in efforts either which did not succeed (Massachusetts, New York) or which were successful between 1974 and the spring of 1976, when the questionnaires were mailed (Georgia, Michigan, West Virginia, Oregon, Louisiana).

Defining death is not exactly one's everyday legislative affair, and one might think that policy-makers would familiarize themselves with the professional literature and/or seek the assistance of those persons or committees who had made the greatest contributions to legitimating and explicating the issue. But how much interaction between definers and policy-makers was there--or, in terms of this study, how socially integrated are the two stages, defining and policy-making, of institutionalization of the definition of death? The two stages, defining and policy-making, were not as socially integrated as they might have been. Sustained collaboration between definers and policy-makers did not occur as often as it should have, given the subtle and intricate nature of the issue. Legislators and even physicians do not necessarily have the

competencies, qua legislators and physicians, to fully define the issue.

Though not one of the imperatives of policy-forming, in each state there were some instances of policy-maker/definer interaction. A few policy-makers, primarily physicians or physician-lawyers, indicated social ties to physician definers. I suspect that the ties were formed in the context of professional associations, rather than in the context of redefining death. Other policy-makers only had ties with their local cohorts. Two participants in the Tucker v. Lower case, the judge and the medical examiner, later wrote articles on the issues involved in the case. William Sweet of the Harvard Committee and Joseph Fletcher, an ethicist definer, each contributed to the decision in that case. Four other definers functioned as policy-makers. Mills co-authored the first statute enacted in Kansas and authored the California statute. Another, chair of the NINDS collaborative study, was head of a committee to establish legislative policy in New Mexico (Walker). The task force established by Evelle Younger in California included three definers, the author of the final version of the California statute among them. In addition, members of Younger's task force contacted a member of the Hastings Center Research Group on Death and Dying (Capron) who had co-authored a statutory alternative to the model Kansas statute (cf. Capron and Kass, 1972) though they did not adopt the alternative.

Though there were these instances, it was not really the case that policy-making was executed with reference either to the professional literature or to contact with the definers. Definers' (usually ethicists') efforts in publishing articles calling, 1) for open public discussion or 2) the careful consideration of ethical and conceptual

problems, had little, if _any_ bearing on policy-making. In three of the five states, policy-making was not accompanied by widespread public debate and discussion. In Kansas and New Mexico the statutes were enacted through the considerable social and political engineering conducted by the states' medical schools. Only in the presence of widely publicized court cases concerning physician liability in transplant situations (Virginia and California) were the bills discussed vociferously in public arenas. In all states, policy-making was accomplished in or with reference to clinical and courtroom settings; in a sense, the legislature's only function was to stamp the pre-determined policy with legal authority. Medical needs and opinion dominated policy-making in all cases, in part because the policy issue was the facilitation of transplantation and legal protection for medical school transplant programs.

In their 1972 critique of the Kansas statute and legislative proposal, Capron and Kass mention several problems which might be incurred if the redefinition of death were to be legislated. Among them: ". . . the possibility that the statutes enacted may reflect primarily the interests of powerful lobbying groups - for example, state medical societies or transplant surgeons" (p. 100). The groups were associated with university medical schools and budding transplant programs, rather than state medical societies, but otherwise their warning characterized legislative efforts through 1974.

CHAPTER 9

THE DYNAMICS OF INSTITUTIONALIZATION

After discussing the social organization of the definers and their varying conceptual approaches to the issue, the question remains -- what facilitated and constrained the process of institutionalization, or what are its dynamics? In this chapter I will discuss the medical and conceptual evolution of the first stage and the evolution of policy in the second stage, and suggest that part of what is meant by institutionalization is diffusion. In addition, I will describe the role of the elite in both stages. Finally, the dynamics of the two stages are compared to assess what factors prohibit the integration of the two stages and consensus.

Stage I: Medical Evolution

Technology

Quite obviously, but not less interestingly, knowledge and meanings change when technological developments prod them. As stated in Chapter 3, the death of the brain could not be recognized until new technologies made it possible to arrest the death of the organism as a whole (with resuscitation and respirators) and to assess brain activity otherwise not discernible by the clinician (with the EEG). The conceptualization of death changed when it became possible to discern separately functioning physiological systems that could not be discerned

previously -- the electrical activity of the brain and the mechanical

substitution for the lungs pumping a heart in a body which also con-

tained what was subsequently found to be a liquefied brain. New facts

about physiology and the brain stimulated the reexamination of the

relation between cardio-respiratory function, brain function and death.

However, the meaning of death was not widely discussed until the use of

these new technologies created new social and moral problems and until

the redefinition of death was conceived as a means for the execution

of still another medical technology -- organ transplantation.

The Significant Statements

The medical contributions to the process of institutionalization

consist of specifying the problems in using respiratory and resuscita-

tive and transplantation technologies, explicating the nature of

irreversible coma and brain death, and delimiting and refining the

criteria for determining that a brain is not functioning. The

significant steps in the medical development are, above all, the

European neurologists' early explications of "coma dépassé" (Fischgold

and Mathis, 1959; Mollaret et al., 1959), Hamlin's address, "Life or

Death by EEG", before the 1964 meeting of the AMA, the Ciba symposium

(1966), the Harvard Report (1968), the Declaration of Sydney (1968)

and the NINDS collaborative study (1975). The single item of most

significance which stands out beyond all others is the Harvard Report.

The medical evolution, like the conceptual evolution, took a path

of increasing differentiation. This is a relatively simple and

obvious point -- that as issues evolve, they become differentiated

from other issues and are increasingly refined. Irreversible coma becomes differentiated from brain death or the death of a person according to whole brain criteria, and "whole brain death" becomes distinguished from neocortical or cerebral death. A "flat EEG" becomes distinguished from an "isoelectric EEG" and the latter is indicative of "electrocerebral silence" not isomorphic with irreversible coma or brain death. But before these distinctions could be made, before refinements and critiques could be made, before alternative criteria could be established, before the phenomenon of cerebral death could be explicated, some general statement of procedures and definition of whole brain death was required: this was the primary function of the Harvard Report. And the Report was not just significant as a statement or explication of the issue against which other steps might be taken, but was also significant as one made by a blue-ribbon committee of Harvard Medical School and University faculty, one which would elicit, as well as represent, widespread legitimacy and consensus in the medical community. What was needed at the time was not just an explication, but one made by a body with reputation and clout and published in a national medical journal with good circulation. This was, I believe, Beecher's vision, and the vision of some of his committee colleagues. After that was accomplished -- the gathering of medical and legal evidence and thought up to that time into an explicit set of notions, practices and recommendations -- others could respond in terms of it: Jonas, Ramsey and the Hastings Group; those who felt the criteria were too strict (the NINDS committee); those who later advocated a cerebral definition of death; those who argued for greater

reliance on angiography; and those who favored legislation.

The Harvard criteria are whole brain criteria, and the effort to draw attention and legitimacy to cerebral death (death only of the cerebral cortex as opposed to the whole brain and spinal reflexes) marks further differentiation in the process of evolution of the medical side of the issue. Brierley's 1971 publication in Lancet seems to have stimulated discussion and controversy regarding the desirability of updating the brain criteria further to declare dead those patients who breathe spontaneously but whose cerebrums are "ruined". Of course, the Karen Quinlan case vividly illustrated the inadequacy of the Harvard criteria for managing cases like hers, as does the fact of patients who are not quite alive but who breathe spontaneously. In the latter '70s one of the issues of most controversy is the desirability or the practical feasibility (in terms of establishing clearly reliable indications of a destroyed cerebrum) of using cerebral death as a primary criterion for determining death (see Korien, 1978).

The Plot Thickens: Conceptual and Ethical Development

Other strains of interest emerged when lawyers and ethicists entered the discussions, enlarging the parameters and thickening the conceptualization of the topic. To trace the evolution of an issue or to discuss the institutionalization of an issue in general entails specifying a path of diffusion. For an issue to evolve and become legitimated, it must spread to different persons or groups of persons. But to trace, even to specify, all the conceptual differentiation and evolution of a topic as complex as this one is a ponderous, if not also

a clumsy task. Therefore, I will trace the diffusion of only two

points: a) that redefining death with an avowed purpose is morally

objectionable and b) that the questions When is death? and When should

a person be allowed to die? are distinct and should be kept separate

in discussion and policy. The first of these assertions is ethical in

kind, the second, conceptual and differentiating.

The Significance of Opposition

Most early discussion of redefining death proceeded with no ques-

tion of the assumption that redefining death was an entirely appropriate

action in response to the problems of prolonging life and transplanta-

tion. Most objections to that assumption came from ethicists and a

couple of lawyers (neurologist James Toole, 1967 and especially 1971,

a glaring exception) -- first, to my knowledge, from theologic lawyer

David Daube during the Ciba symposium in 1964, subsequently from Hans

Jonas at the AAAS meeting in 1968, from Paul Ramsey in the Lyman

Beecher lectures at Yale in 1969 and from other ethicists, especially

those members of the Hastings Research Group on Death and Dying.

Thus, my first generalization regarding "what got the issue going"

is: the issue developed substantially when tension against the medical

consensus was expressed. The two points partially constitute arguments

against that consensus. As Daube first presented them:

> Still, the special interest of transplanters does intro-
> duce an ethical and ultimately legal facet -- the question of,
> one might say, trust . . . it is arguable that precisely
> because of this pronounced interest of transplanters . . . far
> from extending the notion of death, we should, on the contrary,
> be doubly cautious and rather restrict. A redefinition with
> an avowed purpose might well create doubts in the mind of the
> layman; he might fear that there is room here for a transition

from a definition to euthanasia or kakothanasia. (Daube, in Wolstenholme and O'Conner, eds., 1964:191, emphasis added)

Daube introduced another important conceptual step in the evolution of the issue, that "The question of at what moment it is in order to discontinue extraordinary -- or even ordinary -- measures to keep a person alive should not be confused with the question of at what moment a man is dead" (Daube, in Wolstenholme and O'Conner, eds, 1964:190-191). Daube expressed his moral concern in a way very similar to the conservative, patient-centered ethicists writing several years later:

> Discontinuation of such measures is often justifiable even while the patient is conscious. Under the classical defini-tion of death, which should not be lightly discarded, an irreversibly unconscious person whose life depends on a machine is still alive. The doctor may be right to stop the machine and let him die. But until death occurs, interfer-ence with his body is illicit: it is not a corpse.
>   Use of a corpse is also a wide problem . . . I submit that this meeting seriously underrates the feelings of the public concerning the inviolability of the body . . . The feeling is found not only in conspicuously religious countries like the United States but also in nominally atheist ones. How else do you explain the enormous queue which I saw on an ordinary weekday when I was taken to see the body of Lenin? (I had the eerie feeling that there might be a kidney missing.) Even at this meeting we speak of the respect always due to the body, of certain consents needed for its disposal. But why, if the body is nothing? (Daube, in Wolstenholme and O'Conner, eds., 1964:191)

The question to ask (which I have been asking myself now for some time) is why, for all the citations of this volume published in 1966, these particular conceptions were not integrated into the literature and discourse on redefining death until Ramsey cited Daube and expressed the same and other concerns in his examination of the liter-ature in 1970. And even then, as I will discuss below, these points only became integrated into the ethical literature. The possible

responses which might fit the question are a bit obvious. Physicians and lawyers were looking for consensus and legitimation for redefining death in order to develop organ transplantation and did not read, did not consider important, or perhaps even did not fully comprehend Daube's words. And this is the second instance of physicians and lawyers ignoring the ethical literature discussed herein -- the first described in Chapter 5 on the definers' communication activities. Ethicists pick up ethical and conceptual points; lawyers and physicians are concerned with other, more pragmatic matters. In this case, the omission is puzzling. A physician need not ever come across or look for Ramsey's Patient as Person or other ethical works, but the Ciba symposium is a group of essays written by eminent physicians and lawyers. Physicians and lawyers with an interest in the topic would almost have to make an effort to avoid Daube's essay. And one only has to read the literature on the topic from 1966 to 1975 and the managing of the Quinlan case to see what a difference -- in terms of the time and effort spent stumbling over the confusion among the issues of withdrawing treatment, allowing to die and redefining death -- use of Daube's essay would have made.

Is the omission of his essay simply a matter of neglect? It could be the case that points like these have to be explicated again and again and again before they make a dent in the conceptualization of an issue such as this one. Perhaps some conceptual distinctions and ethical concerns are simply too subtle, too fragile and intangible against the prevailing pragmatic and technological ethos governing the definition of contemporary issues. At any rate, the Ciba symposium

did not contribute to the ethical or conceptual development of the issue except in terms of legitimating and providing consensus for transplantation.

The Importance of Interdisciplinary Discussion

My second generalization regarding conceptual development is that the issue evolved primarily in interdisciplinary settings. The Ciba symposium, the AAAS symposium, the Lyman Beecher lectures at Yale and the organization of the Hastings Center are all examples of such settings which provided the context for conceptual and ethical advance.

In The Patient as Person, the publication based on the 1969 Lyman Beecher lectures, Ramsey reiterated and expanded Daube's points, among others. The two points diffused through the social connections made by Ramsey in Georgetown and in the organizing of the Hastings Center. I have every reason to believe that Ramsey had a profound influence on the publications which derived from the work of the Hastings Research Group. Jonas, who first articulated his objections to the redefining effort during the 1967-1968 AAAS symposium, was another particularly influential member of the Group.

In each of the publications of the Group or its members (the Kass-Morison debate on death as process or event, the Group's critique of the Harvard Report, the Capron and Kass critique of the Kansas statute and Veatch's critique of the handling of the Tucker case) one or both of the points originally made by Daube and expanded by Ramsey was stated.[1] These articles were published, moreover, in journals which would be perused by physicians and/or lawyers: Science, JAMA and The

University of Pennsylvania Law Review.

The points of the Hastings Group were not picked up in the profes-
sional literature except by some ethicists. Although one or another of
the Hastings articles was cited by authors of 10 of the 17 articles in
the sample published after 1972, neither of the two points was men-
tioned. The Hastings Group's articles were cited, but none of the
substantive conceptual or ethical issues raised in them were integrated
into other publications.

The conceptual separation of the two questions did not become
clear until there was an actual illustration of the distinction in
1975 -- the Karen Quinlan case. During the case, the definition and
allowing to die issues were confounded until Julius Korien and other
neurologists called on to testify during the case stated very clearly
that Karen was not dead according to the Harvard criteria and that
hers was not a definition of death issue (cf. In the Matter of Karen
Quinlan, 1975). The Quinlan case itself did more to clarify the
distinction between deciding when a person is dead and when to discon-
tinue treatment than the Hastings publications. It seems that the
other ethical point -- that it is morally objectionable to redefine
death for an avowed purpose -- has been lost in the relentless
progression of pragmatism.

The Importance of Committee Organization

In both the medical and conceptual evolution of the issues, organ-
ized creative working groups played a particularly significant role in
and were essential to the issue's development. Some were

interdisciplinary and some were not -- of particular note: the Harvard

Committee, the Hastings Center Research Group and the NINDS collabora-

tive effort. Some of the most important statements and critiques were

products of committee meetings or committee organization.

The members of the committees were particularly well chosen,

whether by determination or fortuity. One could say that the issue

became thicker when certain people came together -- people with profes-

sional eminence and political clout, certain others with eminence and

conceptual, ethical and legal analytic competencies and still others

with eminence and an eye for gathering data.

The medical evolution of the issue was prodded by technological

developments which rendered physiological and neurological functions

visible and determinable, and no less by significant statements of how

to manage the problems incurred by them and transplantation and by

further refinements and research. The assumptions of the medical

authors were straightforward: redefining death in terms of brain

function would solve many of the problems and facilitate organ trans-

plantation to boot; redefining death is for them, of course, a matter

properly relegated to physicians.

The issue became more complex when the medical consensus was

challenged by ethicists and some lawyers. The challenge was profound

indeed and enlarged discussion to a robust debate on the sanctity vs.

the quality of life, death as process or event, individual rights vs.

the common good and egalitarianism vs. professional expertise and

various other arguments, among them the two discussed above.

Organized creative work groups, the concentrated effort of the right people, were the contexts for the production of the significant statements and opposition.

Defining as Diffusion

Technological developments, significant explication, opposition to the prevailing consensus and interdisciplinary discussion are among the social and cultural "prods" in the evolution of the issue. Part of what is meant by the institutionalization or evolution of an issue is diffusion -- for the issue to evolve or for it to become an integrated part of a social structure or cultural system, it must spread. I have already acknowledged this rather simple point by discussing the conceptual evolution in terms of the diffusion of the two arguments. The dynamics of the group include the cultural "prods" mentioned above and vehicles of diffusion. The major vehicles of diffusion are the professional journals and the definers themselves.

The Role of the Professional Journal

The professional journal is the most obvious vehicle of institutionalization of this issue. Policy statements, definitions and objections are more enduring and accessible if made in the professional journals than if made at symposia or conferences. Professional journals are somewhat more enduring than the mass media. All three -- the journals, the mass media and symposia and conferences -- are significant vehicles for the diffusion and the legitimation of this issue. For a discussion relatively confined to professional arenas, the

professional journal is particularly important as it helps to spread the issue to professional domains outside particular geographical locales -- beyond the Boston-Washington corridor, for instance.

Specific journals were used by definers and editors for placing statements of definition (such as the Harvard Report) or critiques (such as Kennedy's critique of the Kansas statute or the Hastings critique of the Harvard Report), namely JAMA and NEJM and the better known law reviews. These respected journals are the ones most likely to be reviewed by science journalists for the mass press. Definers also used what one might call the scholarly or academic press -- Daedalus, Science and the Hastings Center Report -- to spread their treatments of the issue.

No doubt some defining work got done at conferences and symposia, though none of the informants mentioned those situations in that regard. Of course, just their occasion prompts and centralizes concentrated analysis of an issue. But to know just how much was accomplished and in what sorts of contexts and interactions, one would have to attend them. At any rate, the most important conference proceedings and lectures were published immediately, thereby becoming more accessible and a part of the professional literature on the topic.

The Definers: Contribution and Diffusion

As stated at the outset, cultural change is neither a simple nor complex matter of drifting social or cultural forces entirely. Persons, in this case the definers, spread the issue and its significance within and outside the professional arenas. They did the explicating, the

opposing and the contributing to interdisciplinary discussion, all of which kept the issue evolving. Some, however, did more than others.

The elite and the non-elite differ with respect to their contributions to the process of redefining death. The major figures in both the medical and conceptual evolution of the topic were the elite. Many of the elite were members of the major committees which were central to the medical and conceptual eevolution of the issue -- the Harvard Committee, the Hastings Center Research Group on Death and Dying and the NINDS Committee. They authored the major statements of explication, the most important conceptualizations and critiques. In other words, they provided the various conceptual frames through which the issue took shape from 1964 to 1975. I would expect that every social history of an idea has particular persons who are responsible for the dominant conceptualizations of any particular time. (In this instance, of course, they happen also to be those chosen most often on sociometric ties by their colleagues.) The rest of the definers reported research and clinical findings in line with and sometimes a bit at odds with, but always with reference to, the elite's conceptualizations.

Diffusion and Social Networks

Without some means of assessing the development of the clusters and ties and the development of the issue, it is difficult to say whether the networks obtained facilitated the evolution of the issue, merely accompanied it, or resulted from it in part. I am willing to assume on the basis of interview data and my familiarity with the chronology of the issues that the clusters of ties, particularly Contact and

Importance facilitated diffusion. Since the choices definers made for Friendship were not made in consideration of the topic, and since Friendship occurred so often in tandem with either Contact or Importance or both, Friendship was not as important as the other two.

There was an informal division of labor of sorts in this process of institutionalization: the elite provided the major cultural contributions and the non-elite performed what might be called "supporting and relaying work". The elite published their articles in journals of large circulation, such as JAMA, and in eminent journals, such as Science, NEJM, and the Hastings Center Report. The non-elite addressed local readerships in state and university journals and general medical readerships in journals such as Hospital Tribune, American Family Physician, and Pediatrics. Both groups published with about the same frequency in specialty journals such as Neurology and university law reviews.

In public discussions such as symposia, conferences and panels on the topic, similar differences between the two groups hold. Table 20 contrasts elites and non-elites on these variables, and as can be seen, more elite than non-elite addressed national, interdisciplinary and lay audiences and participated in public discussions on death definition outside the professional arenas.

The elite are the prime moving and determining forces in the institutionalization of the redefinition of death. As prominent representatives of their respective professional hierarchies, they explicate and refine the concept, shape and legitimate its cultural career. The non-elite perform an important function by diffusing elite work through

Table 20. Comparison of Elites and Non-elites on Communication
          Behavior Variables (in percentages)

Communication Behavior	Elites	Non-elites	
1. Participation in panels and conferences	91.7 (22)	66.7 (34)	.072
2. Participation in interdisciplinary and lay, as well as professional conferences	79.2 (19)	39.2 (20)	.137
3. Mass media discussions	62.5 (15)	31.4 (16)	.087
4. Discussions in the national media	37.5 (9)	3.9 (2)	.196
N	24	51	

the professional press to local professional groups and to physicians outside the neurological sciences.

I have discussed the social and cultural factors involved in the first stage of the institutionalization of the redefinition of death and the roles the elite and non-elite had in the process. It would be mistaken to conclude that this was an integrated process with medical and conceptual developments contributing equally or with all of the elite equally affecting the development of the issue. There is a politics of cultural defining -- a differential power to define and to affect policy. The differentiation of power is not as much between the elite and non-elite as it is between physicians and lawyers on one hand and ethicists on the other.

The Power to Define

Examples in this chapter have been cited which support the assertion that conceptual and ethical points do not become integrated into the whole redefinition literature, just into the ethical litera-ture. For example, Daube's insistence that the question when is death be distinguished from that of when to allow to die and the subsequent reiteration of that point again and again by the members of the Hastings Group were neglected by physicians and lawyers. Another example is the neglect of the ethical notion that death should be defined apart from pragmatic considerations. The import of that ethical criticism seems to have disappeared -- except for the fact that the California/ABA statute and the Capron-Kass statute make no mention of transplantation.

In Chapter 4, I described patterns of communication in publication,

symposia and mass media discussions -- patterns of exclusion and inclu-
sion of audiences and readerships of different disciplines and the lay
public. A hierarchy of exclusion was drawn, with physicians addressing
primarily other physicians; lawyers addressing lawyers, physicians and
policy-makers; and ethicists addressing each discipline, policy-makers
and the lay public. Whom one addresses and what kinds of literature
or arguments one absorbs or considers relevant is based to some extent
on one's conceptualization of the issue. In addition, I would suggest
that it has something to do with the cultural assumptions regarding
which professional groups should govern which kinds of issues.

First of all, if one argues that the issue is a medical issue,
properly relegated to physicians, rather than lawyers, ethicists, or
the lay public, one might address his message to physicians most often.
And, in fact, the patterns of communication fit each discipline's
general sense of the kind of issue the redefinition of death is. As
seen in Chapter 7, ethicists have a larger conception of the issue than
either physicians or lawyers; for them the issue entails social,
ethical and philosophical considerations, as well as medical or legal
ones.

There is another way in which ethicists regard the topic differ-
ently from most physicians and lawyers which probably affects their
communication activities and intentions. Most physicians and lawyers
tend to accept the desirability of redefining death as a given; the
major questions, then, are of procedure. Some ethicists, on the other
hand, have challenged the assumption that redefining death is an
appropriate response to the problems involved ("unburied corpses",

the need for cadaver organs). In taking an alignment against the prevailing medico-legal consensus, an intent to reach other disciplines and the lay public would seem to be part and parcel of the process.

In any society there are cultural assumptions regarding appropriate expertise and the power to affect decisions on important issues such as the definition of death. And, there seems to be a particularly well-entrenched assumption in our society that the best way of handling this kind of issue is to relegate it to scientific, medical, or technological experts, with the implication that issues like redefining death are matters of medicine, science and technique and not matters of philosophical meanings or ethics. Physicians and lawyers are granted a considerable amount of power to define and decide about important issues in our society. There is little question that philosophers, ethicists and theologians, while they may be considered appropriate consultants, are not vested with the power to affect cultural definitions or major policy decisions. In other words, the hierarchical pattern of exclusion seems to be indicative of a hierarchy of power in the realm of cultural defining. One step in establishing legitimacy in a cultural debate, or of obtaining leverage in the power to define, as it seems several ethicists know, is to speak and become known within and beyond the realm of the "opposition".

In a very real sense, physicians and lawyers do not need to try as hard as ethicists. Both are in line with the prevailing cultural consensus on the power to define the issue and with the mainstream conceptualization. And they have either neglected, excluded, overlooked or misunderstood the ethical literature. Possibly, quite probably,

they feel no need to review it. In effect, they have claimed the issue and the power to define it -- what they say counts. One can imagine that if the cultural assumptions were otherwise, for instance if ethical and philosophical interpretations of societal problems took primacy over pragmatic, economic, scientific or technological ones, the communication patterns might be reversed with ethicists addressing other ethicists because that primacy and the power that accompanies it is given.[2]

The cultural power to define can be seen more readily if we look at the ability to affect action and policy rather than at the omission or neglect of certain authors by others and the communication patterns of those arguing against the medical consensus. The subsequent sections of this chapter concern first, the development of policy in the second stage of the process of institutionalization and secondly, a comparison of the dynamics and politics of the two stages.

Stage II: The Evolution of Policy

Death statutes were enacted primarily because of the threat of physician liability for the death of donors in transplant situations under the old legal definition after such problems arose in Virginia and California, and secondarily, to create standards for annulling physician liability in some cases of resuscitation and termination of life-support systems. In short, these are the dynamics of the development of policy.

The first of these statutes, passed in Kansas in 1970, was met with both approbrium and harsh criticism. And once again, opposition

and criticism proved essential to refinement and development. The first

critique, by philosopher of law Ian Kennedy (1971), objected to the

fact that the statute was drafted with primarily transplantation in

mind and that it implied that there are two kinds of death. Kennedy

utilized the 1966 Ciba volume essays by Daube and Calne who opposed

"meddling with the donor for the purposes of improving the transplant".

The Kennedy critique was important to the Hastings Group (Informant

notes), as they worked on their critique. The statutory proposal con-

tained in the article written by Capron and Kass corrected Kennedy's

objections and embodied corrections of several of their own objections.

The proposal (see page   above) does not imply that there are two kinds

of death, one for transplant donors (brain death) and one for everyone

else (cardio-respiratory death) or that persons could be "medically or

legally" dead. Most importantly, the statute contains no mention of

transplantation. The authors stated repeatedly that mention of trans-

plantation ". . . has no place in a statute on the determination of

death" (Capron and Kass, 1972:117), thus embodying in policy at least

something of the ethicist objection to defining death for an avowed

purpose.

California came closest to adopting the Capron-Kass proposal

before 1975, but did not. Mills, one of the members of Younger's com-

mittee, suggested a simplified bill which the state adopted. The ABA

recommended a similar statute in 1974-1975 (ABA, 1974).

Michigan and four other states finally adopted versions of the

Capron-Kass proposals after 1974, but I have no information regarding

legislators' motivations to deviate from the Kansas or California/ABA

models to adopt the Capron-Kass version, except that the model is par-
ticularly well reasoned, and policy-makers in some states have finally
caught on to that fact.

There is little doubt that the Capron-Kass critique prodded the
California/ABA model; Mills cites its virtues (and what he considers
to be its flaws) in an article he wrote as medico-legal editor of JAMA
in 1974 (p. 1226) and the ABA cites the article as well (ABA, 1974).
Both the California/ABA model and the Capron-Kass model avoid much of
the clumsiness, mistakenness and ambiguity of the Kansas model.
Criticism (differentiation and refinement) spurred the development of
policy as well as definition.

Those who have had the roles most integral in shaping the form
that policy has taken in the various states which passed death legis-
lation through 1974 are among the elite, namely Mills,[3] Capron and
Kass. Two other elite definers influenced the outcome of policy
decisions in three other states, Walker and Fletcher. The elite
determined the form the issue has taken in both stages of the process
of institutionalization of the redefinition of death.

Evolutionary Stages in the Career of an Idea

If one were to specify stages of the progression or evolution of
the redefinition of death, they would be somewhat similar for both
stages. I am always somewhat hesitant about the usefulness of abstract-
ing generalizations of this form from a process of such detailed and
specific history. They are only useful if they are regarded as

tentative, if one can use them as something on which one can hang one's hat temporarily. Integrating the defining and policy-making stages, I can posit eight secondary stages:

1) Emergence - emergence of the problem, anomaly;

2) Explication and Elaboration - stating the problem and elaborating its implications and solutions;

3) Opposition - criticism of the major statements of the problem and emergence of new threads of concern (ethical and legal, in this case);

4) Refinement and Reexplication - the absorption of some of the criticisms and new points of view and restatement of the issue;

5) Making Policy - formal coding into law;

6) Opposition - criticism of policy;

7) Refinement of Policy - the absorption of criticism; and

8) Reexamination of the whole issue - as the topic evolves and becomes differentiated and institutionalized in some forms, new issues arise (in this case, cerebral death, uniform death acts, etc. -- see the Epilogue below).

Defining and Policy-Making Compared

The two major stages of the institutionalization of the redefinition of death are dysjunctive. First, the defining efforts in professional and interdisciplinary settings did not have much to do with the policy enacted in state legislatures. Policy and definition are discussed in both stages, although Stage I consists of defining concepts, delimiting conceptual parameters and offering criticism

toward conceptual refinement and policy alternatives and Stage II

consists of fixing policy. I don't want to imply that policy-makers

selected from the policy alternatives suggested by definers in the

journals; it is clear that most policy-makers contacted in this study

hadn't the vaguest notions of definer work. If they had any notions

at all, they usually concerned the major medical and legal pieces and

perhaps the Capron-Kass critique of the Kansas statute. And if they

were familiar with the Capron-Kass article, it seems clear that they

took the obvious criticisms of the Kansas statute and altogether missed

ethical and conceptual arguments present in the article. Moreover,

interaction among policy-makers and definers left much to be desired;

for the most part, policy-makers did not know the definers or their

work.

Differences in the two stages can be discerned in an examination

of the institutional and political constraints and dynamics character-

istic of each stage. At first glance, the two stages differ with

respect to their respective boundaries. Discussions in the first are

bound primarily by discipline and discussions in the second are bound

by geography, local medical concerns or court cases. Other differences

between the two stages turn on 1) the degree of interdisciplinary

dialogue and 2) the kinds of constraints on discussion by political

considerations and situational exigencies.

The defining process in the first stage was based upon consider-

able social relatedness among the definers and consisted, at least to

some degree, of interdisciplinary collaboration and dialogue. The

policy-fixing enterprise, on the other hand, consisted of the

collaboration of physicians and lawyers toward the enactment of policy based on a single disciplinary perspective. The policy-fixing process lags behind the defining process in terms of both conceptual complexity and ethical concern. I can suggest some reasons for the lag or dysjunction by examining the institutional and political constraints in which discussions in each stage occur.

Though entry is delimited by editorial and political constraints, the professional press, conferences and symposia are settings at least somewhat broad in access which provide relatively flexible structures for the discussion and debate of ideas -- at least in comparison to policy-fixing settings. In the professional press, for instance, there is the time for conceptual clarification and for ethical points to be made, as well as some degree of access to those who would include such issues in discussion.

Change the discussion settings to local clinical and medico-legal situations in which medical technologies are being developed, and lives are being lost for the want of a kidney, or in which physicians are accused of the wrongful death of transplant donors, and discussion is likely to be sharply delimited in terms of the kinds of issues considered legitimate and imperative. The parameters of discussion are governed by urgency as well as by professional domination. Comparatively few institutional or political constraints govern the parameters of discussion in symposia or the professional press. But when discussion enters the policy-fixing arenas, ethical considerations of profound import become lost in the pragmatics of clinical or technological imperatives and the politics of professional dominance.

What Prohibited Consensus?

In both stages there is little consensus regarding 1) what the issue entails and what should be done about it and 2) what sort of policy, if any, should be enacted and for what purposes. Issues as complex as this one are comprised of different levels, and different kinds of concerns which do not facilitate consensus.

Clinical physicians on the one hand, and philosophers or ethicists on the other, work from within what are rather different "occupational worlds" with different parameters, different obligations and different rhythms of time. (They also, I suspect, approach those worlds with different phenomenological screens.) Conceptual and ethical analysis can be slow and imbedded in the history of our most basic meanings and values. In any case, it is removed from situations in which one must take action or put those basic meanings and values to use or effect. Working with the dying in emergency situations where resources are limited and where, most importantly, one must act and be considered liable for one's actions, is another situation and requires another bearing altogether. In the world of action, necessity and use, meanings and action or events are tied together in a way they never are in the conceptual world -- the sheer progression of events and the exigencies of the former govern how meanings are acted upon, if not also how matters mean. It would seem nearly impossible to stop the relentlessness of clinical work for an ethical or conceptual concern which has no immediate effect; whereas, if kidneys or respirators are not found, persons die. The clinician says to the ethicist, "Is it not just the livelihood of persons in terms of which your ethical and

conceptual concerns matter?" And the ethicist can respond, "If some of these ethical concerns are not instituted, culture and human nature may change profoundly for the worse; and in the slow, thick time in which these developments emerge, there is no turning culture back." But that may be in the far distant future. If a kidney or heart is not made available for fear of liability, a person will die imminently. The potential for harm is immediate (if not also somewhat restricted).

Many other problems our society faces can be drawn in exactly these terms -- among them recombinant DNA research, nuclear energy and the problems of environmental pollutants in general. This conflict -- between praxis and theory or between the slow and subtle notions and the urgent and necessary ones -- has riddled thought and action for some time and obviously is not readily resolvable.

These are some of the reasons I would argue why policy has been enacted with regard to some needs and not others, and why it is that physicians and ethicists generally approach the redefinition of death from such different orientations. There are other polarities besides "theory vs. praxis" which prohibit consensus. As discussed earlier, the definers' approaches to the topic turn on three polar concerns: 1) egalitarianism vs. professional or disciplinary dominance in determining the issue; 2) individual rights vs. the common good; and 3) the sanctity of life or the human body vs. the quality of life. The first two characterize the nature of the central conflicts of the twentieth century -- not just the debate over redefining death. The third is inextricably linked with the ability to prolong and resuscitate life. I am aware of the precariousness of interpreting cultural patterns in

terms of dualisms or polarities, yet I would argue that it is just
these three, and that between the physicians' and philosophers' con-
cerns which are difficult to resolve and which prohibit consensus. I
would add to the list unequal access or power to define cultural issues.

Opposition, interdisciplinary discussion and, no less, the elite
themselves who provided the dominant conceptualizations of the issue in
both stages are some of the factors which facilitated the process of
institutionalization. Toward the end of this discussion, I have drawn
attention to some of the situational and political constraints on the
integration of the two stages, and some of the philosophical and value
constraints on definer consensus. My recommendations for facilitating
and better integrating the process of institutionalization follow in
the concluding chapter.

ENDNOTES

[1]Another philosopher, Dallas High, came to conclusions about the redefining effort that are strikingly similar to those of the Hastings Group, though at the time High was not a member either of the Group or the Hastings Center. Included in his citations were both Ramsey and Jonas.

[2]The elite as well as the ethicists (remember that many of the elite are ethicists -- chosen primarily by other ethicists) addressed different audiences. The elite physicians and lawyers may be under a kind of noblesse oblige to familiarize themselves with other elite work -- especially if they are invited to the same conferences. And they are likely to be asked to address lay audiences as well. Their communication patterns may be less a matter of "swimming against the stream" than a matter of the professional obligations which accompany rank and regard.

[3]As mentioned in Chapter 1, I neglected to include D. H. Mills on the questionnaire list. Had I remembered his name, I am certain that he would have met the elite criteria.

CHAPTER 10

CONCLUSION: SUMMARY, EPILOGUE AND RECOMMENDATIONS

In Sum

It has at times occurred to me that reporting this study of insti-
tutionalization is somewhat like telling a "story" -- as thickly as I
can through the styles of various conceptualizations and methods -- a
kind of story complete with actors, settings and communities, dramatic
action, dynamics, goals, politics and a determinate end -- statutory
legislation. The story -- to stretch the analogy still further -- has
two dysjunctive though somewhat overlapping parts: defining and
policy-making.

The actors in the first stage are 75 professionals and academics,
almost all of them university faculty, from the areas of medicine,
law and ethics/philosophy/theology. They came to the issue of redefin-
ing death through various professional and personal avenues -- many
because they worked with the dying, with organ transplantation, and
others because they were concerned with areas of knowledge conceptually
related to redefining death, such as euthanasia and the philosophy of
organism. Some were invited to join committees or to present papers at
symposia, and a few had personal relationships and interests which led
to the topic. They live in all areas of the country and some abroad,
though slightly more live in the Northeast and the Midwest.

Defining and Interdisciplinary Discussion

Definers conducted their defining work in various communication arenas. By definition, all published articles on the topic in professional journals. Almost three-fourths discussed the issue as well in symposia and conferences, and nearly half appeared in the mass media to express their views. I had asked them what they had wanted their articles to accomplish and, according to their various competencies, most intended to do the different tasks required for the evolution of the issue: drawing attention to the problems and suggesting the redefinition of death as a solution; criticizing or redefining either methods or conceptualizations of the issue; pointing out conceptual, ethical or legal problems and advocating solutions. The definers varied, again according to their disciplines, with respect to the kinds of audiences they addressed in each communication arena. Physicians addressed other physicians for the most part. Lawyers addressed other lawyers and policy-makers and physicians. The ethicists most often addressed all disciplines and the lay public in the professional and mass media. Communication among definers cannot be characterized as fully interdisciplinary (with each discipline directing messages to the others), though there was considerable physician-lawyer communication. Instead, a hierarchy of exclusion, with physicians at the top addressing their own colleagues and ethicists at the bottom addressing everyone, describes the communication patterns of definers in public discussion arenas.

Defining and Social Organization

The process of redefining death contains other organizational "settings" besides journals, symposia and the mass media. Apart from their participation in these communication arenas, definers were organized as a variety of overlapping "communities" for each of three social ties -- Contact, Importance and Professional Friendship; "communities" of discipline; elite and non-elite status; committee membership and collaboration; geographical proximity; and professional generation. Some definers seemed to be associated with others because they shared a conceptual approach to the issue apart from their disciplinary affiliations.

Depending on the social tie considered, different "communities" emerge and predominate. If one can imagine three superimpositions of organization for each tie, the social content of organization would change as one turned from tie to tie. On each superimposition are communities of discipline, committee memberships and collaboration. However, definers had contact most often with others who were in the same general locale, of the same professional generation and of the same status (elite or non-elite). They considered professional friends to be those of the same discipline (more often than on any other tie), locale and professional generation. To attribute importance to others, definers need not have had direct contact with them and, for this reason as well as a considerable degree of consensus among definers regarding who was important, that image of social ties was the least shaped by discipline, proximity and professional generation.

And Consensus?

Institutionalization is a story with an end, an end which would indicate at least some degree of consensus about just what it is that should be institutionalized. In this case there was little consensus either across the disciplines or within the social networks. Most definers agreed only on the etiology of the need to redefine death; fewer that redefining death could alleviate some problems (either obtaining organs in the best condition for transplantation or terminating treatment on persons who are dead). Otherwise, definers did not agree on the composition of the issue or who should be relegated the responsibility for managing the issue. One controversy centered on whether the issue is, broadly speaking, a professional or public issue, and within the former, on whether the issue is medical, medico-legal or ethical/philosophical. Physicians and lawyers were in general agreement on most issues, though lawyers differed from some physicians by asserting their right to define and by advocating legislation. Generally, that is, leaving discipline aside to some extent, definers interpreted the issue from a perspective which emphasizes either the quality of life or the sanctity of the human body and from another which emphasizes either the common good or concerns which apply to the dying person only. But regardless of the lack of consensus, policies were enacted.

Defining and the Elite

Not all definers contributed equally or in the same ways to the redefining process. If one looks at the entire samples' statuses and

contributions, two groups clearly emerge. And both groups seem to be aware of the differences -- their sociometric choices confirm the binary grouping into elites and non-elites.

The elite are the definers' definers, the prime movers of the redefinition process from defining to policy. The elite published more articles on the topic and participated more often in public discussions than the non-elite. They were the keystones of the definer social cohesion, having formed the ties which linked the various "communities" together. And it was the elite who most often transcended their professional training in their conceptual approaches to the topic -- the cosmopolitan definers in terms of what and whom they know.

Policy-Making

When the story gets to Stage II, the actors change to policy-makers: those physicians, lawyers and legislators who prompted and developed legislation in Kansas, Maryland, Virginia, New Mexico and California through 1974. There was little overlap between definers and policy-makers, but the few instances there were mattered. Four definers, all among the elite, contributed in substantial ways to the development of legislation in three of these states (Kansas, California and New Mexico). Otherwise there was little general interaction between policy-makers and definers and little familiarity on the part of the policy-makers with the professional literature.

In all cases policy-making was dominated by professional, more specifically, medical and medico-legal interest. Laws were enacted

with primary reference to transplantation and secondary reference to protecting physicians from liability of other wrongful death. Except in those states where cases of physician liability for "wrongful" death causes local furor, the redefinition of death became law with little public discussion.

The Dynamics of Cultural Defining: Facilitation and Constraint

All stories have their dynamics, and in this one, as in so many others, one of the major dynamics was conflict, or opposition -- between lawyers and physicians on the one hand, and the ethicists and ethics-oriented physicians and lawyers on the other. The tension of opposition and of interdisciplinary discussion and collaboration prompted a more complex and conceptually sophisticated issue and more thoughtful policy. Originally the use of new medical technologies stimulated and set up the medical issues and some of the social and ethical ones, but the process of redefining death would not have taken place without timely, explicit and well-placed statements. Someone had to say: This is a problem; this is what that problem looks like, and this is what should be done about it. Most of the first statements were made by physicians.

The development of the issue took a path of increasing differentiation and diffusion. Perhaps that is just what is meant by cultural evolution: differentiation and diffusion. The issue progressed: from whole brain death to cerebral death; from redefining death in order to pull the plug to two different questions (Is she dead? Should she be allowed to die?); and from a simple, direct path of redefining death

to obtain organs for transplantation to many other complex lines of public, ethical and philosophical concern.

However, some voices and arguments were heard more than others. Some opinions and constructions were negotiable as policy, others were not. No such story is without its politics and this one is no exception. Physicians and lawyers with medical concerns had the power to define the issues for policy and the power to be heard by all participants in the redefinition debate. Ethicists, with their interest in ethical social action and in safeguarding the public interest were not heard or read except by other ethicists and a few physicians and lawyers. Strikingly few of their most substantive criticisms and arguments made any difference in the policy arenas.

None of the constraints which prohibit equal contribution by members of all disciplines or consensus are easy to resolve. Reexamining notions of expertise and power and redistributing power in a culture is not an easy task. For whatever reasons, finely drawn, subtle ethical and conceptual arguments do not make the difference that pragmatic arguments and imminence of catastrophe arguments do in our culture. And the polarities that emerge in discussions on redefining death -- the sanctity of the body vs. the quality of life, individual rights vs. the common good and elite or expert control vs. egalitarian control -- are among the most divisive and agonizing in civilization -- as grandiose or overgeneral as that may sound. But policy continues to be enacted, and policy fixes the issue is some form regardless of the lack of consensus. Perhaps eventually the concept will take the shape of the policy, as policy becomes fixed, utilized and reconfirmed.

So the story went as the redefinition of death took shape in definition and policy through 1974.

A Summary of the Social Processes and Organization Associated With the Evolution of the Redefinition of Death

The progression of the idea was facilitated by both specific processes and kinds of social organization. The most obvious social process, simply because it underlies or constitutes the others, is communication. Reading, writing and discussing (Contact), almost all too obvious kinds of communication required for this process of institutionalization, form the basis for the others: influence, diffusion and the kinds of discussion and writing (interdisciplinary discussion, the significant statements and statements of opposition) which stimulated the issue's development. The processes are inseparable from (and in some sense were facilitated by) the organizational loci in which they occurred, namely: the structure of definers' social ties, the committees and symposia, the journals and the mass media.

All the definers participated in some of these processes and loci, though not in the same ways. The elite made the significant statements and significant critiques and used the "big" journals for publication; other definers reviewed and added to the significant statements and critiques and diffused elite work through the smaller and more general professional press.

The process of policy-making, of course, is also composed of reading (not as much as one would like, perhaps), writing (drafting) and discussing (and testifying, consulting) as well. In this stage,

actual and potential legal problems stimulated policy as the use of certain technologies prompted medical and conceptual action. The primary dynamics of policy-making were the exercise of professional power or cultural privilege and criticism or opposition. Power was exercised in policy-making committees, the courtroom and, most importantly, the state legislature. The critiques were placed in the professional press.

Before making any recommendations for the institutionalization of issues like this one, and for studies like this one, I will discuss the most significant events that have happened since 1974 and where the issue stands at present (without, of course, the detailed and quantitative analysis that was conducted on data collected before 1975). These events have a bearing on the conclusions and implications I would draw based on my research through 1974.

Epilogue: The Issue Since 1974

The redefinition of death as an issue and process, has changed, or evolved, in some respects, though it has kept its basic shape.

The year 1975 brought the Karen Quinlan case, two significant court cases in Massachusetts and New York, and the first legislation based on the Capron-Kass model statute and the ABA model statute. In 1976, California enacted the first "Natural Death Act" as a set of guidelines for withholding or withdrawing life support to allow persons to die, legislation basically designed to help answer the second question, Should this person be allowed to die? (For further discussion see Capron, 1978a, 1978b; High, 1978; Hastings Center Bibliography,

1979-1980:26.) (Of course, "definition of death" statutes are designed
to help answer the first question, Is this person dead?)

And since 1975, an effort to enact legislation in New York
defining death in terms of brain function with many new faces and a
couple of the "old definers" directing the effort has failed. In late
1978-1979, National Conference of Commissioners on Uniform State Laws
developed a statute in consultation with several physicians and lawyers.
And in early 1979 the AMA changed its stand against "brain death"
legislation (Mills, 1979; Cranford, 1979a). To this date, 22 states
have enacted death definition legislation (Cranford, 1979a).

Karen Quinlan

The case of Karen Quinlan did almost as much to bring the redefini-
tion and the "allowing to die" issues before the public eye as did the
first heart transplant and the publication of the Living Will (Eutha-
nasia Education Council, 1967) in "Dear Abby" in 1969. So much has
been written on this case in the professional and mass press (the
interested reader may peruse the New York Times or any press reference
source and the Reader's Guide to Periodical Literature from September,
1975 through 1976; the Hastings Center Bibliography, 1979-1980:25-26;
and In the Matter of Karen Quinlan: The Complete Legal Briefs, Court
Proceedings, and Decision in the Superior Court of New Jersey for
thorough saturation on the subject) that I will not discuss the facts
of the case substantively. As stated previously, it was generally held
early on in the case that Quinlan's situation was one which would be
solved as soon as either the New Jersey courts or the legislature

adopted the new brain criteria (see The Evening Bulletin (Philadelphia),
September 9 and 18, 1975). With her case came the widespread knowledge
that application of the Harvard criteria or a brain death statute would
not mitigate such problems. How much damage to her cerebrum had
occurred was indeterminate, though obviously portions of her brain stem
are still intact or she would not continue to breathe on her own today.

Public discussion of the case loosed whatever opinions had been
fixed in the professional press to distinguish cerebral death from
whole brain death, "hopelessly unconscious" or "suffering irreversible
loss of brain function" (partial or whole) from "dead" and "the two
questions". As an illustration, take the following statement made by
the assistant legal counsel for the AMA and paraphrased by a reporter
for the New York Times.

> Miss Anderson said that the brain death statutes were designed
> to facilitate organ transplantation by allowing terminally ill
> donors to be maintained on mechanical respirators after the
> brains, including the respiratory centers, had ceased to
> function. (September 28, 1975:50, emphasis added)

These are just the confusions which some definers had identified for
years since 1968 as those which would rightly befuddle and frighten the
public: redefine death just to obtain organs for other persons and
then terminate the lives of those not yet dead for that purpose.

Members of the original Hastings Research Group had the opportunity
to contribute to the clarity of the case when prosecuting, and defense
attorneys and at least one reporter (see Kron, 1975) contacted them at
the Hastings Center and the Kennedy Institute. One informant later
implied that the trial participants had done their homework, if not
the trial reporters and medical and science journalists.

Although many treatments of the case in the news media served to
muddle the issues, the case itself eventually became a stark illustra-
tion of the distinction between the two questions, Is she dead? and
Should she be allowed to die?, and of the distinction between whole
brain and cerebral death. It became vividly clear that none of the
new whole brain criteria for determining death, including the Harvard
criteria, would help resolve cases like Quinlan or lessen the
emotional and economic costs that accompany them.

The Quinlan case was a turning point in the evolution of the
issue. It stimulated increasing advocacy of cerebral, rather than
whole brain criteria as well as successful efforts to legislate "nat-
ural death acts" or "Living Wills" as attempts to avoid such situations
in the latter '70s.

New Court Cases

Also in 1975, cases arose in The Bronx, New York and Boston,
Massachusetts significant to the evolution of the issue. In New York,
the city's Health and Hospital Corporation ignored the local medical
examiner's office policy that all homicide victims be autopsied before
organs could be removed for transplantation after being pronounced
dead according to brain criteria and removed two kidneys from a homi-
cide victim, R. Daniel Sulsona. The Health and Hospital Corporation
had suffered too many lost opportunities to obtain kidneys under the
medical examiner's policy. The two agencies were pitted against one
another in the Bronx Division of the Supreme Court,[1] and the presiding
judge acknowledged "brain death" as the legal end of human life (New

York Times, March 8, 1975; April 26, 1975). The Court suggested that the state legislature take action to redefine death to mitigate the situation (Veith, 1978). On April 18, 1975, New York medical and legal officials held a news conference to announce their intent to advocate a redefinition of death to include brain criteria (New York Times, April 19, 1975). To this date, 1979, they have not as yet succeeded. (The New York effort is discussed further below.)

As in Virginia, California and New York, a case involving a homicide victim arose in Massachusetts, but in this instance the defense argued that disconnecting the victim's respirator caused death (rather than the accused's action of smashing the victim's head with a baseball bat) whereas in the other states at issue was the removal of organs as a cause of death. One of the key prosecution witnesses in the trial was William Sweet, Chair of the Department of Neurosurgery, Harvard Medical School and member of the Harvard Committee. As mentioned above, Sweet was a key witness in the Tucker v. Lower case as well -- another instance of Harvard's role, by invitation and determination, to legitimate the redefinition. Sweet testified that the victim's brain was "a decomposed, gelatinous mass" and that therefore, the victim had to have been dead for more than two days before the mechanical support was terminated (Boston Globe, May 15, 1975). In 1977, the Massachusetts Supreme Court adopted the concept of death determined with reference to brain criteria (Oregonian, August 28, 1977), to my knowledge the first state to adopt such a definition in its highest court.

Recent Legislation

Since 1974, several states have enacted death statutes based on the Kansas model, the Capron-Kass model and the California/ABA model. Oregon enacted a statute similar to the Kansas statute in 1975, and in 1975, as stated previously, Michigan[2] became the first state to adopt the Capron-Kass model. Subsequently five other states enacted versions based on the Capron-Kass strategy: West Virginia,[3] Louisiana,[4] Iowa,[5] Montana,[6] (Isaacs, 1978) and Texas.[7] Six others, Georgia,[8] Illinois,[9] Oklahoma,[10] Tennessee,[11] Idaho,[12] (Isaacs, 1978) and Wyoming,[13] adopted versions of the California/ABA model. The Capron-Kass model keeps intact the traditional definition based on heart-lung criteria and addresses the situations in which mechanical means obscure those traditional signs. The California/ABA model seems to supercede the traditional definition (cf. Isaacs, 1978:7).

In 1977, North Carolina[14] enacted a bill which combines the death definition statute with a "natural death" statute, an innovation which Capron states (1978a:52) "seems to be a virtual invitation to litigation so many are the problems and ambiguities it creates." As should be all too obvious to the reader by now, it muddles issues which should be kept separate.

The National Conference of Commissioners on Uniform State Laws approved and recommended a "Uniform Brain Death Act" (UBDA) at its annual conference meeting in 1978. The UBDA is in some ways similar to the California and ABA versions, but it very explicitly indicates that only whole brain criteria are to be used with the statute.

> For legal and medical purposes, an individual who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A determination under this section must be made in accordance with reasonable medical standards.

The Act is accompanied by two comments: one stating that the act does not preclude a determination of death according to traditional criteria; and another specifying that "functioning" is a crucial notion, expressing the idea of purposeful, rather than random activity in the brain. Another interesting characteristic of the UBDA is the strong imperative of the second sentence. In April of 1979, Nevada [15] became the first state to enact the UBDA.

There are several differences between the UBDA and the statute recommended by the AMA.

> Section 1. A physician, in the exercise of his professional judgment, may declare an individual dead in accordance with accepted medical standards. Such declaration may be based solely on an irreversible cessation of brain function. (AMA Legislative Department, 1979)

Most statutes are definitive or mandatory and not permissive (Oregon's and Georgia's are exceptions). The UBDA embodies a particularly strong mandatory statement. On the other hand, the American Medical Association recommends a statute which is permissive. One of the drafters/consultants on the UBDA has expressed interest in having the AMA back the UBDA and suggests, understandably, that a permissive statute, such as the AMA's, not only does not make good sense, but also may befuddle the public (Cranford, 1979). A statutory definition of death clearly is no place for indeterminacy. Another obvious difference is the UBDA's insistence on determining death of the entire brain and the conspicuous absence in the AMA model of the word "total" or

"all" in or before the phrase "irreversible cessation of brain function."

Approval from the "pro-life movement" which has provided opposition to legislation in some states is one reason for the emphasis on whole brain criteria in the UBDA, according to consultant Cranford (1979b), but the primary reason is that all accepted sets of criteria refer to the lack of functioning of the entire brain. It is very interesting to note the amount of discretion accorded individual physicians in the AMA model. The reason for the AMA's long-standing policy of opposition to brain death legislation has been the fear that physicians' initiative, medical research and further changes in criteria will all be hampered by such legislation.

New York

An effort begun in 1975 to enact a bill defining death in terms of brain function has to this date not succeeded, but it has produced some interesting collaborations. Several definers live in the New York area and a number of them have been involved to various degrees in the several discussions and publications which have derived from that effort. A couple of members of the original Hastings Research Group and other members of the NINDS collaborative study testified at legislative hearings (one of which I attended as well), and one organized a large conference, "Brain Death: Interrelated Medical and Social Issues", sponsored by the New York Academy of Sciences in 1978 (Korien, 1978). Two recent "state of the issue" articles examining legal, medical and ethical issues, written by physicians, lawyers,

ethicists and theologians involved in that effort, were recently pub-
lished in JAMA (Veith et al., 1978a; 1978b). Some of the more
conservative members of the Hastings Research Group have not partici-
pated in these discussions though they live in the New York area.

One of the problems the pro-legislation group faced in New York
was opposition from various religious groups. In the first of the
two-part article published by the "New York collaborator", and for the
first time in the literature, the theological positions of Orthodox
Jews, Catholics and Protestants are delineated. I take it that the
articles were efforts to legitimate legislation on this matter in
New York and other states.

In New York the public discussions and debates have been sus-
tained and open, and ethicists and theologians have contributed to the
policy effort -- rather a contrast to the way legislation was managed
in all the states included in this study other than California.

As the Issue Stands

Most of my sources for this section come from the New York publi-
cations, including the published Conference proceedings. In a nutshell,
so to speak, the largest issues of debate at this time are 1) cerebral
death vs. whole brain death; 2) whither policy and which model; and
3) greater reliance on cerebral angiography as a criterion for
determining death and revision of the Harvard guidelines in line with
the cerebral criteria. Not an issue of debate, quite, but an issue of
concern seems to be the public's increasing association of the issues
of euthanasia, abortion and death definition.

I was somewhat struck and discouraged to find that many of the same old issues cluttered the New York Academy of Sciences conference. Several articles representing different emphases were included, notably a few on the differential diagnoses of various coma states in the context of distinguishing cerebral death from other states of coma, and others on the use of cerebral angiography in the context of more reliably determining cerebral death. One of the old issues raised was the confusion of cerebral death with whole brain death. The confusion was exacerbated by the relatively recent addition to the "brain death vocabulary" of new terms, all of which refer to cerebral death; "neocortical death" (Brierley, 1971); "persistent vegetative state" (Jennett and Plum, 1972); "the apallic syndrome" (Ingvar et al., 1978); and "cognitive death" (Beresford, 1978). I am particularly enamored of still another phrase, "the ruined brain" (Roelofs, 1978).

Behind the often unclear reference to different states of "ruination" is the more profound problem of being able to determine just what it is that is assessed by either whole brain or cerebral criteria.[16] Some possibilities include "certainly fatal outcome", "death in fact", "irreversible loss of consciousness". In discussing the results of the NINDS collaborative study of 503 cases of what is presumed to be "brain death", one of the major participators in that study states:

> Since pathologic findings did not always confirm brain death, even in patients meeting the more stringent Harvard criteria, the end-point or proof of validity of these criteria remains ill-defined. Prediction of a fatal outcome is not a valid criterion for accuracy of standards designed to determine that death has already occurred. (Molinari, 1978:65)

Indeed, in reading the conference proceedings, one is struck by the befuddlement and indeterminacy of just what is meant by death determined with the use of any brain criteria. I include portions of an exchange between two participants in the discussion period after a paper was given.

> Greenvik: . . . A patient [whose name translated into English as "Guest of Horror"] was certified as brain-dead at an outlying hospital within a few hours after very severe head injuries, and was then referred to us. However, after donation consents were signed by the parents, we found that he did not fulfill the criteria for brain death and was therefore resuscitated and supportive measures were continued. It took us only two weeks to get him sitting up in a wheelchair, eating, talking, and after another two months discharged from the hospital with a rather minimal hemiparesis as the only consequence.
>
> Beresford: Chilling case.
>
> (Korien, ed., 1978:437)

And with the indeterminacy of what it is the criteria mean, the issues of "when is death" and "when should a person be allowed to die" slip and intermingle once again. The notion of cerebral death carries with it hints of euthanasia, passive and active. For in a case such as Karen Quinlan's, although one may be convinced she will never be a person (though she meets none of the Harvard criteria) and is in fact in some sense dead, one may not be willing to smother what life there is, even though what life there is is rather persistently vegetative. At any rate, this is exactly the issue that confronts our society at the present time, the "new generation of problems" in the redefinition of death arena, as one participant (Beresford) put it. A careful delineation of the issues is given by Roelofs (p. 44):

> A decerebrated human being is indeed a pitiful spectacle,

and we may well feel that to be in such a condition is a fate worse than death. But this is not an argument for adopting a new criterion of death. It is perhaps an argument for a rational euthanasia policy.

In many ways the participants in the debate in its more recent emphases are spinning many of the wheels that have been spun in the past. There have been some improvements: new legislation is more sound than the old legislation, and ethicists seem to be gaining some ground in terms of making a difference to this cultural process. Most physicians and lawyers still seem to have missed the subtle conceptual and ethical arguments, but some have picked them up and integrated them into their conceptual approaches. At this point, even with the significant gains, I am left with the concern that again policy will be enacted with insufficiently thorough examination of all the issues.

Conclusions

This extensive study bears on the relation of communication and social organization to the process of institutionalization and, within that relation, on some of the ways in which interdisciplinary discourse and interaction between definers and policy-makers was conducted in the process. The subject of institutionalization, the redefinition of death, is an issue composed of ethical, legal and medical dimensions, an issue of public concern; it is an instance of rather profound cultural change. Interdisciplinary issues of cultural and political import of a similar nature in the areas of ecology, bioethics, technology and society have begun or are in the midst of similar careers

in the second half of this century. Both pragmatic and theoretical

concerns have motivated this particular story, and I will close with

pragmatic and academic recommendations, respectively, for cultural

definers and their modes of conduct and for social scientists and

communication researchers for their efforts in studies such as this one.

Toward More Integrated Cultural Defining

Interdisciplinary collaboration: Most problems and topics of

cultural concern in this period of history are interdisciplinary in

nature and require interdisciplinary collaboration in their solution.

However, few academics and professionals who involved themselves in

defining and solving such problems or who are called upon to do so are

familiar with or competent in interdisciplinary learning and discourse.

Problems -- lack of consensus, professional domination and the resolu-

tion of complex issues -- can be mitigated by interdisciplinary

learning and discussion. Interdisciplinary discussion is discussion in

which definers of different professional and academic interests can

identify and negotiate their competencies, purposes and values.

In the problem area of medical advances, there has been a rela-

tively recent effort (in this decade) at some medical centers (most

notably the University of California at San Francisco and Hershey

Medical Center in Pennsylvania) to train physicians in ethics and human

values. Even more recent cutbacks of financial support for interdis-

ciplinary programs threatens that effort, and yet more physicians and

lawyers need to be trained in ethical and conceptual analysis and the

social sciences -- especially if they are to contribute to the

definition of issues such as "brain death".

For ethicists and philosophers who concern themselves with ethical issues in medical advances to engage in a comparable interchange with physicians, it is not enough, I would suggest, for them to become familiar with the rules of clinical practice or the major tenets of medical science. They should spend time in the clinician's "field" and experience the dynamics of having to make quick life and death decisions or having to adjust the allocation of scarce resources. I think few people understand the dilemmas involved in knowing patients who desperately need replacements for their diseased organs, and at the same time knowing that a "person" with good organs lies in another room in a persistent vegetative state. Ethicists have not typically visited the settings in which the decisions and circumstances that concern them are made.[17] One of my recommendations, then, is for increased sustained interdisciplinary training and discussion for cultural definers. Interdisciplinary organizations and publications -- loci in which interdisciplinary discussion and collaboration can occur -- are absolutely essential to the definition and resolution of most of our pressing cultural issues.

In addition to the need for more sustained interdisciplinary discourse, I would suggest that we should all be trained to some extent in ethical analysis in order to prepare for decision-making and policy-making. There exists a need for the formal, cultural recognition of the ethical and philosophical dimensions of contemporary problems, and what better way to institutionalize that recognition than to add the relevant courses to high school and college curricula?

I would recommend widespread support of organizations like the Hastings Center and the Kennedy Institute for Bioethics whose primary intent is the interdisciplinary discussion of the philosophical and ethical dimensions of contemporary issues in medicine, society and technology. We could learn a great deal more about the dynamics and facilitation of interdisciplinary discussion. Federal support for that is in order. More interdisciplinary and ethical discourse about contemporary issues would affect the politics and quality of cultural definition.

More communication from definers to the lay public: If the process of institutionalization of cultural issues (defining and policy-making) is to be conducted in terms of public debate and the public interest, the communication efforts of both definers and policy-makers should be directed toward those ends. Several definers in this study said that they wanted to address the lay public with the articles they had published in the professional press. However, members of the lay public do not often read university law reviews and the New England Journal of Medicine. If definers wish to reach the lay public or to directly affect their conceptions of the redefinition of death, then they should publish articles in publications which members of the lay public read, periodicals of large circulation (the mass press): Harpers, Ladies Home Journal and the like.[18]

If the redefinition of death is a public and not exclusively professional issue, then the public needs to have ready access to articles on the topic written in a straightforward style. This could be accomplished in two ways. Definers could themselves use the mass

media more extensively, rather than have science and medical journalists relay their work to the public. If, however, definers insist on writing for the "teachers' teachers" or other professionals and academics, then they could encourage writers or journalists to become members of committees and attend conferences. Direct contact with definers might lessen the likelihood of inaccuracy and distortion in reporting complex issues for the mass media.

Increased interaction between definers and policy-makers: The same recommendations for definer-public communication would, of course, hold for definer/policy-maker interaction. Most state legislators are reached more effectively through the mass media than through the professional press.

If the issue is destined to become law or practice, then definers should extend their efforts to the policy arenas, as approximately one-third of those participating in this study did. And one always wishes that policy-makers would do their homework (i.e., read the relevant academic and professional iterature and/or contact definers) as well. It is rather disquieting to know that in two states redefinition of death was treated as if it were just any old legislative issue -- appropriating funds for new highways and the like.

One temptation is to assume that the problems of definer/policy-maker interaction could be solved if the issue were discussed once and discussed well with all interests represented in a national arena with the intent of establishing a uniform law. On second thought, a national, one-time conference could cause more problems than it would solve. It takes time for issues to evolve, time for all the interests

to be stated, for all the mistakes and muddles to be made and subsequently recognized and corrected. A Harvard Report must precede its refinements and clarifications, a Kansas statute is perhaps needed if only to show what improvements would look like. That takes time. I doubt that the redefinition of death could have been done once and well regardless of who contributed to it; perhaps the development and evolution of ideas cannot be compressed in time. The more significant, complex and indeterminate the issues, the more time required.

Other than these somewhat paltry suggestions for better integrating cultural definition, I have none. As for the resolution of the divisive polarities between the sanctity and the quality of life, individual rights and the common good, and egalitarianism vs. professional domination, I can only take a stand on one side or the other. Of course, that is not what I am about here.

Recommendations and Implications for the
Social Scientist

What I am about is studying how cultural definition gets done and what social organization and communication have to do with it. What follows is a set of suggestions for further research.

Improving the basic conceptual issues: Of concern in this study and others in communication and culture, and the sociology of culture is the relation among social organization, social process and the content and style of ideas. It may well be the case that this is a triadic relation much like the dualistic relation between form and matter -- as

Aristotle had it, a relation something like that between two sides of a coin or (even more conceptually agonizing) two sides of a piece of paper. To attempt to manage such complexity along with the specificity and quantity of information required in an empirical study is not the easiest of tasks, but there are things one might do to manage it a bit better than accomplished herein.

The relation of any two of those three elements in any process of institutionalization or cultural change is a precarious locus of study; and any of the relations which includes social processes causes the most frustration. It seems generally clear as talk goes on in the social sciences that discussing structure without nodding to processes is inadequate (too static). In some schools of thought in communication (say, that espoused in the Annenberg School of Communications of the University of Pennsylvania) it is considered equally amiss to discuss social processes like communication without discussing social structures and context. (One might add that it is very difficult to discuss social processes without discussing social form in Standard Average European languages, as Whorf called them). I attempted to "work" the relation between structure and process by using such phrases as "communications arenas", "loci of communication" and by reconciling Contact and Importance as social processes with their structures.

Content and social organization seems a manageable enough focus: How do different forms of social organization affect the content of ideas: One might ask, similarly, how do different kinds of social processes affect the styles of ideas? I would suspect that Importance is a process associated with some kinds of content, perhaps original

work, comprehensive work and, as I defined it, to include provocation, debate and criticism. Contact, as another social process independent of Importance, might be associated with other kinds of content -- review, perhaps, or "spreading the word", "what is happening" kinds of content. However, and this is something I had not foreseen, one would have to know whether the content was established before, along with, or after the social processes and social structures. Juggling the inter-relation of all three elements as it changes through time stretches the imagination indeed.

A means for assessing the development of social relations or changes in them through time is certainly in order. I would also suggest developing a means for coming to terms with the relation of development or change in social relations and change in the content of an issue. That is what I had intended to do, but I did not have the right kind of information nor the right techniques. The specificity required is particularly burdensome for a questionnaire survey format and for subjects' memories -- one ought to rely more extensively on in-depth interviews. Another approach or attack would be to follow an issue as it develops, thus mitigating the problems of memory and the lack of recorded history.

In order to understand the relation of the definers to their defining work (to process, structure and content, that is) more detailed information regarding personal, intellectual and social histories and the ways in which definers got into the topic area would be helpful. The kind of information I have in mind, anecdotes and the like, could only be assessed in interview settings.

Integrating the methods and tools of social history would substantiate conceptual and methodological conduct of studies such as this one. But attempting to reconcile the specificity and concreteness of history with a concern in communication and the sociology of culture for large patterns and relations is one additional task of considerable magnitude.

Interdisciplinary communication and collaboration: Another entire area of study could be developed around interdisciplinary communication devoted to answering questions such as: what facilitates and constrains interdisciplinary communication, and what techniques would allow persons of different training to work on problems together without their becoming generalists and thereby sacrificing their particular competencies or without their sticking to their disciplinary guns and prohibiting consensus and integration? Therapeutic techniques might be relevant tools, and certainly time would have to be spent analyzing each discipline's argument structures and value structures just to be able to identify what needs to be negotiated in an interdisciplinary effort.

A researcher in communications or sociology studying interdisciplinary collaboration would herself be obliged to establish some interdisciplinary competence. To conduct this study I had to spend considerable time familiarizing myself with medical, legal and ethical terms, argument and styles of writing before constructing the survey and content analysis instruments. In my case, that process was eased by having been a philosophy student in college, having grown up in a medical and neurological family and having lived with a lawyer. If

one were to take on completely new areas of knowledge, considerable
time would be involved. That task, however, has not hindered many
studies on the social organization of highly specialized research
areas in the sociology of science.

Policy-making and cultural defining: This aspect of the re-
search effort was greatly hindered by the disturbing lack of detailed
records of the passage of the bills. Of course, it would be cumber-
some to keep histories of each and every legislative issue, but per-
haps it is not too much to ask that ground-breaking and controversial
legislation of national concern be treated differently from general
legislative fare?

Once again, this area of research could be facilitated if one
could attend the "makings of a statute" when the significant steps
are taken. Whether one could know where to go in time is another
question. Would there have been any way to know to go to Kansas in
1970? But perhaps one could attend widely publicized policy-making
situations such as those in New York and California.

The focus of further research: It is important for both the
sociology of knowledge and the "cultural studies" approach to com-
munication to determine whether the patterns found in this study are
idiosyncratic to this issue, these definers and processes or repre-
sentative of the institutionalization of complex, interdisciplinary
and moral definitions of basic human meanings. Of course to conduct
a comparative study, a researcher must specify a definition of com-
parable interdisciplinary and cultural import which has become
formalized in social policy; just any old process of definition will

not do. A comparable process of definition would concern an issue of societal magnitude and deep moral, if not existential concern. Some potential processes of comparison are the professional and interdisciplinary efforts to define the beginning of human life, to define to what use an aborted fetus or "unburied corpse" might be put, or to specify the guidelines and parameters for recombinant DNA research. Robert Hornik (1979) of the University of Pennsylvania has suggested that the interdisciplinary intelligence and educational testing groups associated with the American Psychological Association would provide an appropriate focus of comparative study. There are others, no doubt, but these most readily come to mind.

What follows is a list of the patterns found in this case study and suggestions for comparative research. Though the patterns are organized according to specific areas of concern (e.g., social organization, communication, etc.), I am not thereby implying that isolated patterns could be appropriately abstracted for comparison without due attention to the process as a whole.

Communication: We could ask whether some communication settings are more closely associated with some definitions than others. Do other defining populations utilize professional journals, conferences and the mass media, and in the same proportion and in the same ways this group of definers utilized them?

In this case, most of the redefining of death was done in committee settings and professional journals. And different kinds of journals had different functions in the process: Journals with wide circulation and repute were used for the most significant explication

and policy statements concerning the redefinition of death; other journals were used, in effect, to "pass the word along", or to diffuse the major statements through the local and general (general practice, internal medicine, general law, etc.) professional populations. I suspect that similar patterns of journal use and function would be found in other instances of cultural defining.

In this study, I had no means of comparing the relative contributions of different kinds of communication to the process of institutionalization. Another researcher might ask: How do different communication settings, in particular journals and sumposia, function in cultural defining? What sort of "defining work" is characteristic of each? What gets done in informal workday discussions compared to the informal discussions that accompany symposia and conferences?

One might also ask to what extent other interdisciplinary defining populations actually conduct interdisciplinary discourse in journals or other settings, or to what extent there are structural patterns of exclusion and inclusion similar to those discussed in Chapter 5. In addition, one could assess the extent to which other populations contacted one another, or considered one another either important or professional friends across disciplinary boundaries.

Social organization: Obvious points of comparison for other interdisciplinary defining populations are 1) the density of different kinds of association and social relation and 2) the structure of social networks, i.e. the presence or absence of center-periphery patterns in social networks. Of course, it would help if the same or similar social ties were used.

This defining population is clearly bipartite, that is, comprised of an elite and non-elite group. We might ask if other defining populations fall into such clearly marked binary groupings with respect to either sociometric choice, actual contribution to the defining process, or demographic characteristics. (The elite of this population tend to be professionally elder, alumni of ivy league universities, and residents of the Boston-Washington corridor.) The definers are structured in terms of a clear division of labor in the process of redefining death; perhaps a similar division of labor is characteristic of other cultural defining processes.

Besides the bipartite organization of the group, committee organization is also central to the process of redefining death. Committees served legitimation, critical and creative functions in the process, functions one might expect given the dual nature of the process of institutionalization (defining and policy-making) and given the complex moral, legal and medical nature of the definition. Is committee organization characteristic of interdisciplinary defining processes which eventually result in legislation or other kinds of policy? Do those committees function to legitimate the definition, refine or explicate it? According to Hornik, the APA intelligence and education testing groups and committees seem to function in a similar way.

One more note of interest on the social organization of the definers is the relationship of the definers' disciplinary affiliations to the social networks, communication patterns and coneptual approaches found in the study. Knowing only a definers' discipline, one

could decently predict his sociometric choices, his communication intent, journal use, intended audience and readership, and reasonably well, the content of his article. Membership in a particular discipline may not shape other interdisciplinary defining processes to the to the extent that it did in this case, though one wonders. A task for the sociology of knowledge is to determine just what it means to be a member of a discipline, in terms of the "places" one inhabits, the values one expresses, and the kinds of work characteristic of that membership.

Content: There must exist defining populations who agree on substantial aspects of their definitions -- unlike this one. However, I would guess that whenever members of three institutions with different intellectural histories, values, occupational concerns and methods collaborate to define an important idea, one can expect little consensus, and considerable conflict -- that is, until we can find ways to conduct egalitarian interdisciplinary discourse with compromise and resolution. Until then, it seems those with the big sticks have the greatest likelihood of imposing their definitions of the situation on the lasting cultural forms (e.g. social policy).

In this case, the content of the issue took a particular kind of shape, the shape of three divisive polarities: egalitarianism vs. professional dominance; the sanctity of life or the inviolability of the body vs. the quality of life; and the rights of the dying person and the inviolability of the body vs. the common good. It would be interesting to determine whether or not other defining efforts are characterized by such seemingly irresolvable polarities of concern.

The integration of defining and policy-making: The defining and the policy-making effort in the redefinition of death were not as integrated as one might imagine. Are there issues in which defining and policy-making are integrated, in which many of the same people are prominent in both efforts, and in which definers' work is known to policy-makers and vice-versa? Explicating patterns of definer policy-maker interaction associated with different concepts of definitions is another task which would increase our knowledge of the relation of society to culture and of the politics of defining cultural issues.

The factors which facilitated and constrained the process: The redefinition of death grew by leaps in interdisciplinary discussions. Also important for the evaluation of the issue were the significant explications, the significant statements of what's what and what should be done. The issue took a path of progression in these stages (from Chapter 9):

1. Emergence

2. Explication and elaboration

3. Opposition to the explication

4. Refinement and reexplication

5. Making Policy

6. Opposition to policy

7. Refinement to policy

8. Reexamination of the whole issue from definition to policy

Is the development of other definitions spurred by interdisciplinary discussion and opposition, marked by significant statements or characterized by similar stages?

And of course there are always the questions of the distribution of power: Whose definitions take hold? Who or which groups have particular claims on the issue and of just what do those claims consist? Does the differential power to define have roots in basic cultural assumptions regarding professional and disciplinary dominance for some issues and not others?

Contributing to the resolution of complex moral issues: Many of these conceptual and methodological problems could provide a focus for further research. In addition to the intellectual motivation to resolve these conceptual issues and conquer the research questions, there is an opportunity in this kind of study to contribute to an understanding of how policy regarding complex moral issues develops and how it might better develop. Social scientists study social problems, among other things, and many, if not most, of these problems contain ethical issues; however, the moral and ethical "field" is one not much explored by social scientists. Here, of course, I echo Renée Fox in her consistent advocacy of the social study of moral issues. These are opportunities to contribute to the resolution of contemporary social and ethical dilemmas.

ENDNOTES

[1]The Supreme Court is not New York's highest court. The state has a higher Court of Appeals.

[2]Mich. Comp. Laws Ann. §326.8b, 1975.

[3]W. Va. Code §16-19-1(c), 1975.

[4]La. Rev. Stat. Ann. §9:111, 1976.

[5]Iowa Code Ann. Ch.1, §208, 1976.

[6]Mont. Rev. Code Ann. §69-7201, 1977.

[7]Tex. Civ. Ann. (H.B. 12), 1979.) (incomplete)

[8]Ga. Code Ann. §88-1751.1, 1975.

[9]Il. Ann. Stat. Ch.3, §552(b), 1975.

[10]Okla. Stat. Ann. Ch.63, §552(b), 1975.

[11]Tenn. Code Ann. §53-459, 1976.

[12]1977 Idaho Sess. Laws, Ch.130, 1, 1977.

[13]Wyo. Stat. Ch. 20, §1, WS 35-20-101, 1979.

[14]1977 N. C. Adv. Legis. Serv. Ch.815, §90-320, 1977.

[15]Nev. Rev. Stat. Ch.451, §1, 1979. (possibly incomplete)

[16]This point brought to my attention in a discussion with Robert Veatch, 1979; see Veatch, 1978 and following discussion.

[17]There are notable exceptions, of course -- those ethicists who teach and work with medical students. Another instance of this kind of collaboration occurred several years ago when philosopher Hans Jonas was invited to the University of California Medical Center by three physicians to attempt some reconciliation with Jonas with regard to his objection to redefining death to obtain organs for transplantation (see Jonas, 1969; 1974).

[18]Anthropologist Margaret Mead was known for deliberately publishing social advocacy based on her research in mass magazines such as Redbook and Ladies Home Journal. Communications researcher George Gerbner has discussed his research on television violence on the television program "To Tell the Truth", appropriately enough. If you want to speak to the public or include the public in a debate, then address the public via the appropriate media.

APPENDIX A

RESPONDENT BIBLIOGRAPHY

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RESPONDENT BIBLIOGRAPHY

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APPENDIX B

COVER LETTER AND QUESTIONNAIRE: DEFINERS

UNIVERSITY of PENNSYLVANIA

PHILADELPHIA 19174

Faculty of Arts & Sciences

DEPARTMENT OF SOCIOLOGY
3718 LOCUST WALK   CR

The role of professionals in defining and resolving issues which affect society at large is little understood. We have recently witnessed the collaboration of physicians, lawyers and ethicists (philosophers, theologians and clergy) in resolving the issue of death definition and determination.

Since this is an issue to which you have made a major contribution,* I am writing to ask your cooperation in a study, supported by the Russell Sage Foundation, designed to find out how professionals collaborate with one another in order to resolve such difficult medical, social, ethical and legal issues. I am conducting this study as my doctoral dissertation with the advice of Drs. Renee Fox and Diana Crane, who have published several studies on the social and ethical aspects of medical practice.

My sample consists of a small, carefully chosen group of physicians, lawyers and ethicists who have published articles on death definition and determination in professional journals and who have played a central role in the process of reformulation of these issues. In the early stages of this study, responses have been obtained from Henry Beecher, E. P. Richardson, Ralph Potter, Leon Kass and Alexander Capron. Since the sample is small, your participation is an essential as well as a valuable contribution to this study.

I would be very grateful if you would complete the enclosed questionnaire, which should take no more than twenty minutes of your time. A self-addressed, postpaid envelope is included for your convenience. Although I need to know who fills out these questionnaires, I can assure you that no statements will be attributed to you personally without your permission.

Sincerely,

Leslie Rado
Research Fellow

Enclosure

DEATH: DEFINITION AND DETERMINATION

University of Pennsylvania

Instructions: Please answer the following questions about your involvement with the issue of how death can be defined and determined, particularly with respect to the article(s) mentioned in the covering letter. Most of the questions can be answered simply by checking the appropriate responses. However, when you do not find an appropriate answer, or when you want to add an additional response, please feel free to do so. I realize the questions do not cover all the points that you may wish to discuss or mention, and for that reason a space is left at the end of the questionnaire for any additional remarks you may wish to make. Any information you provide will be helpful.

CHECK AS MANY RESPONSES AS ARE APPROPRIATE.

THE FIRST 5 QUESTIONS CONCERN YOUR GENERAL INVOLVEMENT WITH THE ISSUE OF DEATH DEFINITION AND DETERMINATION.

1. Under what circumstances did you begin your involvement with the definition and determination of death? Check as many of the responses as apply, and if none of them fully describe the events which led to your involvement, please describe them in the space provided.

    _____ a. The issue arose in the context of my work.

    _____ b. I was asked to join a committee to examine the topic.

    _____ c. I was asked to contribute to a symposium on the topic.

    _____ d. I was asked to counsel a dying patient and/or his family.

    _____ e. The topic was a personal interest.

    _____ f. Other circumstances? Please specify below.

2. If you became involved in the issue because you participated in a committee or symposium, please give their titles, locations and dates.

                    TITLE   LOCATION   DATE

    1.

    2.

THE FOLLOWING SEVEN QUESTIONS CONCERN YOUR COMMUNICATION WITH OTHER PROFESSIONALS, INCLUDING LAWYERS, ETHICISTS (BIOETHICISTS, THEOLOGIANS, PHILOSOPHERS AND CLERGY) AND PHYSICIANS WHO HAVE BEEN INVOLVED IN THIS ISSUE.

Questions 7-10 concern your relationship with other professionals who have either written articles on death definition and determination or who have been involved in the formulation of death legislation. Below and on the following page you will find the names of other authors of articles appearing in professional journals and sponsors of death statutes. Next to each name are four columns.

7. If you recognize any of these names, please place a check beside the relevant names in the first column marked "Recognize."

8. If you contacted, i.e., either talked or corresponded with, any of these people while you were formulating the ideas expressed in your article, please place a check beside the relevant names in the second column marked "Contact."

9. If any of these people were particularly important, e.g., helpful, provocative, influential, to you in terms of your interpretation of the issues involved in death definition and determination, please place a check beside the relevant names in the third column marked "Important."

10. If you consider any of these people to be professional friends, i.e., close colleagues or collaborators, please place a check beside the relevant names in the fourth column marked "Friend."

PLEASE RESPOND TO ALL FOUR QUESTIONS FOR EACH INDIVIDUAL ON THE LIST. IN OTHER WORDS, FOR SOMEONE WHOSE NAME YOU RECOGNIZE, WITH WHOM YOU TALKED OR CORRESPONDED, WHOSE IDEAS WERE IMPORTANT TO YOU, AND WHO IS ALSO A PROFESSIONAL FRIEND, YOU WOULD PLACE A CHECK IN ALL FOUR COLUMNS. IF YOU HAVE NEVER CONTACTED A PERSON, BUT HIS WRITINGS ARE IMPORTANT TO YOU, YOU WOULD CHECK THE FIRST COLUMN ("Recognize") AND THE THIRD ("Important"). HOWEVER, IF A NAME MEANS NOTHING TO YOU, DO NOT CHECK ANY OF THE COLUMNS. OF COURSE, YOU SHOULD NOT EXPECT TO KNOW ALL OR EVEN MOST OF THESE NAMES. THE NAMES ARE ARRANGED ALPHABETICALLY BY SPECIALTY AND OCCUPATION.

	1 Recognize	2 Contact	3 Important	4 Friend
ETHICS-BIOETHICS				
1. Bleich, J. Dav.				
2. Carrol, Chas.				
3. Fletcher, Jos.				
4. High, Dallas				
5. Jonas, Hans				
6. Kass, Leon				
7. Kosnik, Ant.				
8. Mendelsohn, Ev. (Hist. of Med.)				
9. Morison, Robt.				
10. Norvell, Wm.				
11. Parsons, Tal.				
12. Potter, Ralph				

	1 Recognize	2 Contact	3 Important	4 Friend
13. Ramm, Bernard				
14. Ramsey, Paul				
15. Rizzo, Robert				
16. Veatch, Robt.				
17. Wasmer, Thom.				
18. Weber, Leon				
LAW-MEDICAL LAW-LEGISLATION				
19. Arnett, Dixon				
20. Bergen, Rich.				
21. Brown, Torrey				
22. Bynd, Rich.				
23. Capron, Alex.				
24. Compton, A.C.				
25. Crews, John				

3. What kind of work were you doing when you became involved in the issue of death definition and determination? Check as many as apply.

_____ a. Electroencephalographic research.
_____ b. Neurological research.
_____ c. Clinical neurology.
_____ d. Neurological surgery.
_____ e. General surgery.
_____ f. Organ transplantation.
_____ g. Anaesthesiology.
_____ h. Internal medicine.
        Specialty: _____
_____ i. CPR-ECC education, management.
_____ j. Community health education.
_____ k. General ethical analysis.

_____ l. Bioethical analysis.
_____ m. Philosophy.
_____ n. Theology.
_____ o. Pastoral counseling.
_____ p. Legal counsel to physicians.
_____ q. Legislative duty.
_____ r. Judicial duty.
_____ s. Developing social policy.
_____ t. College teaching. Specify
        areas: _____
        _____
_____ u. Other. Please specify.

---

4. Were you involved in any way in organ transplantation--either as a principal or auxiliary member of transplant operations, e.g., as an anaesthesiologist, lawyer to physician or donor's family, etc.?

_____ a. Yes.   _____ b. No.

4.1. If yes, what was the nature of your involvement?

4.2. What was the kind of transplant?

_____ a. Heart.   _____ b. Kidney.   _____ c. Other. Please specify.

---

5. Were you involved in the clinical care of dying or irreversibly comatose patients or in the counseling of their families?

_____ a. Yes.   _____ b. No.

5.1. If yes, what was the nature of your involvement?

5.2. What kind of terminally ill patients did you work with most?

_____ a. Terminal renal disease.   _____ d. Terminal cancer.
_____ b. Terminal heart disease.   _____ e. Terminal cerebrovascular
_____ c. Heart attack or arrest.   disease.
                                       _____ f. Other intracranial conditions.

---

6. In what year and month did you begin your involvement with the issue of death definition and determination? If you are not certain, please estimate.

	1 Recognize	2 Contact	3 Important	4 Friend
26. Curran, Wm. J.				
27. Dworkin, Rog.				
28. Fletcher, Geo.				
29. Fritz, Milo				
30. Grant, P. Bob				
31. Green, John C.				
32. Halley, Martin				
33. Hamner, Reg.				
34. Hirsh, Harold				
35. Houts, Marsh.				
36. Hutton, Wall.				
37. Joling, Robt.				
38. Kennedy, Ian				
39. McIntyre, Kev.				
40. Markow, Theo.				
41. Moskowitz, J.				
42. Pearson, John				
43. Reid, Wm. F.				
44. Sadler, Blair				
45. Smith, Glee				
46. Sommer, Theo.				
47. Taylor, H. Merr.				
48. Ward, Walter C.				
49. Wasmuth, Carl				
50. Wilder, Lawr.				
51. Wood, Jerry				
52. Younger, Ev.				
MEDICINE				
53. Acherknecht, E.				
54. Adams, Ray. D.				
55. Alderete, J.F.				
56. Appel, James				
57. Arnold, John D.				
58. Ayd, Frank J.				
59. Barger, Clif.				
60. Becker, Don.P.				
61. Beecher, Henry				
62. Belleville, J.W.				
63. Belzer, Folk.				
64. Berne, Thom.				
65. Bickford, R.G.				
66. Biorck, Gunnar				
67. Borel, David				

	1 Recognize	2 Contact	3 Important	4 Friend
68. Braustein, P.				
69. Brierley, J.B.				
70. Brown, E.B.				
71. Collins, Vinc.				
72. Corbett, L.P.				
73. Corday, Eliot				
74. Crafoord, C.C.				
75. Delmonico, Fran.				
76. DeMere, McCarthy				
77. Denny-Brown, D.				
78. Elam, James O.				
79. Elkington, J.R.				
80. Farnsworth, D.				
81. Fatteh, Abdul.				
82. Fermaglich, Jos.				
83. Folch-Pi, J.				
84. Goodman, Julius				
85. Guttentag, O.E.				
86. Hamlin, Hannibal				
87. Hannah, James				
88. Harp, James				
89. Ivan, Leslie				
90. Jude, James				
91. Kaufer, C.				
92. Kimura, Jun				
93. Korien, Julius				
94. Levin, Philip				
95. Lewis, Howard				
96. Lowrey, John				
97. Luchi, Robert				
98. McCutchen, J.				
99. Masland, Rich.				
100. Merrill, John				
101. Mohandas, Anav.				
102. Moore, Francis				
103. Mollaret, P.				
104. Murray, John				
105. Negovsky, V.A.				
106. Ouaknine, Geo.				
107. Paulson, Geo.				
108. Penin, H.				
109. Riehl, Jean-L.				
110. Rosoff, Sid.				

	1 Recognize	2 Contact	3 Important	4 Friend
111. Sadler, Al.				
112. Saunders,Mich.				
113. Scherlis,Leon.				
114. Schwab, R.S.				
115. Shalit, M. N.				
116. Silverman,Dan.				
117. Smith, Andrew				
118. Solnitsky,Oth.				

	1 Recognize	2 Contact	3 Important	4 Friend
119. Stevenson,Robt				
120. Sweet, William				
121. Taylor,Loren				
122. Tentler, Robt.				
123. Toole, James				
124. Walker,A.Earl				
125. Williamson,Wm.				
126. Winter,Arthur				

11. Are there any persons whose names are not on the list who have been important to you in terms of your interpretation of the issues involved in death definition and determination? If so, please state their names, their specialties (e.g. surgery, law, philosophy), where they work and your relationship to them. They can be personal friends, family, students, colleagues, or any combination of these.

| | NAME | SPECIALTY | EMPLOYMENT | RELATIONSHIP |

1. _____
2. _____
3. _____
4. _____
5. _____

12. Of the persons whose names appear on the list and those whom you have added, who are the three persons most important to you in terms of your interpretation of the issues?
1. _____
2. _____
3. _____

13. Of both those groups, who are the three persons closest to you?
1. _____
2. _____
3. _____

14. Are there any books or articles which were particularly important to you in formulating the views expressed in your article whether or not the author's name appears on the list? Please list the author's name, approximate title, journal or publisher, and the approximate date of publication.

1. _____
2. _____
3. _____
4. _____
5. _____

15. In researching and writing on a topic, most people talk with their colleagues and friends, as well as read books and articles. Which was more important to you in shaping the views expressed in your article(s)? Please check.

_____ a. Talking with colleagues and friends.
_____ b. Reading articles and books.
_____ c. Neither was more important than the other.

THE NEXT 5 QUESTIONS REFER SPECIFICALLY TO THE ARTICLE(S) MENTIONED IN THE COVERING LETTER. IF MORE THAN ONE ARTICLE IS MENTIONED IN THE COVERING LETTER, THEN A COPY OF THE NEXT 5 QUESTIONS IS INCLUDED FOR EACH ARTICLE MENTIONED. THE TITLE OF EACH ARTICLE FOR WHICH QUESTIONS ARE TO BE ANSWERED APPEARS ON THE TOP OF EACH EXTRA PAGE. PLEASE ANSWER THE QUESTIONS ONLY FOR THE ARTICLE WHOSE TITLE APPEARS AT THE TOP OF THE PAGE. IF ONLY ONE ARTICLE IS MENTIONED IN THE COVERING LETTER, PLEASE CONTINUE WITH THAT ARTICLE IN MIND.

16. What was your major objective in writing the article mentioned in the covering letter?

17. Was your objective any of the following? Check as many as apply.
_____ a. To state research results.
_____ b. To explain or clarify the concept of death as dependent on brain function.
_____ c. To explain or clarify criteria or procedures for the determination of death.
_____ d. To suggest a modification or change in the concept of death.
_____ e. To discuss a modification or change in criteria or procedures.
_____ f. To criticize a particular definition of death.
_____ g. To criticize a particular set of criteria.
_____ h. To discuss a particular statute.
_____ i. To discuss a particular court case.

18. Did you write the article in order to do either of the following? Please check.

_____ a. Affect social policy.   _____ b. Influence a certain audience.
           _____ c. Neither.

19. Of the groups listed below, to which audience(s) was your article addressed? Please rank the appropriate responses in order of importance: 1=most important, etc.
_____ a. Physicians.
_____ b. Allied medical professions.
_____ c. Lawyers.
_____ d. Ethicists.
_____ e. Theologians.
_____ f. Policy-makers.
_____ g. The lay public.
_____ h. Other. Please specify.

    19.1. If your audience was a very specific group of persons, e.g., primarily anaesthesiologists or cardiologists or local physicians, please give that information in the space below.

20. Did you read specific journals in order to keep up with discussions on the definition or determination of death? If so, please check all that apply.

_____ a. Yes. _____ b. No.

_____ c. JAMA. _____ i. Bar Association Journals.

_____ d. New England Journal of Medicine _____ j. Ethical or Theological Journals. Please specify.

_____ e. Lancet

_____ f. Electroencephalography and Clinical Neurophysiology.

_____ g. The Hastings Center Report _____ k. Other. Please specify.

_____ h. University Law Reviews.

21. How would you characterize your approach to the problem of death definition and determination? Check all that apply.

_____ a. Medical-research approach. _____ f. Social-ethical approach.

_____ b. Medical-clinical approach. _____ g. Theological approach.

_____ c. Medico-legal approach. _____ h. Counseling (non-legal) approach.

_____ d. Public policy approach. _____ i. Other. Please specify.

_____ e. Bioethical approach.

22. Have you been active in either public discussions (e.g. panel, lectures) or symposia and conferences on the subject of death definition and determination?

_____ a. Yes. _____ b. No.

If yes, which ones? Please check all that apply.

_____ c. Panels and lectures - professional audiences.

_____ d. Panels and lectures - lay audiences.

_____ e. Conferences and symposia - professional audiences, participants.

_____ f. Conferences and symposia - interdisciplinary audiences, participants.

23. Have you discussed these issues in any of the mass media?

_____ a. Yes. _____ b. No.

If yes, in which ones?

_____ c. Newspapers. Please specify. _____ e. Radio (local program).

_____ f. Radio (national program).

_____ d. Magazines, other than _____ g. Television (local program). professional journals. _____ h. Television (national program).

24. Have you been active in efforts to pass legislation defining death as dependent on brain function?

_____ a. Yes. _____ b. No.

If yes, in what state(s)?

24.1. In what capacity?

25. Have you been active in research or public discussion in other death and dying topics? Please state the approximate dates of your activity with these topics, e.g., 1966-70; 1966-, etc.

_____ a. Yes.   _____ b. No.

If yes, which ones?

_____ a. Euthanasia (date:).   _____ c. Suicide (date:).
_____ b. Care of the dying (date:).

---

26. Have you been active in research or public discussion on other bioethics issues?

_____ a. Yes.   _____ b. No.

If yes, which ones? Please state the approximate dates of your activity with these topics.

_____ a. Scarce medical resources,   _____ h. Abortion (date:).
        transplantation, hemo-   _____ i. Behavior control (date:).
        dialysis (date:).   _____ j. Medical ethics education
_____ b. Genetics, fertilization   (date:).
        and birth (date:).   _____ k. Ethical theory (date:).
_____ c. Population and birth control   _____ l. Values, ethics and technology
        (date:).   (date:).
_____ d. Experimentation and consent   _____ m. Other. Please specify.
        (date:).
_____ e. Health care delivery
        (date:).

---

27. Please state the date, institution and kind of your professional or academic degrees.

       DATE   INSTITUTION   DEGREE

       _____
       _____
       _____

---

28. When you were obtaining your degree, did you have a special research interest or thesis which was related to the issues of death definition and determination, death and dying or other bioethics issues?

_____ a. Yes.   _____ b. No.

28.1. If yes, what was it?

28.2. If yes, what was the name of the person(s) who supervised your research?

       1. _____
       2. _____
       3. _____

---

29. In what professional organizations are you most active?
       1. _____
       2. _____
       3. _____

30. Are you a member of any organization which deals specifically with death and dying or bioethical issues?

_____ a. Yes.   _____ b. No.

If yes, which ones? 1. _____

                     2. _____

---

31. When you were writing the article(s) mentioned in the covering letter, were you associated with a college or university?

    _____ a. Yes.   _____ b. No.

    31.1. If so, in what capacity?

    31.2. With what institution?

33. What is your religious background?

    _____ a. Catholic.
    _____ b. Jewish - orthodox.
    _____ c. Jewish - conservative.
    _____ d. Jewish - reformed.
    _____ e. Protestant. Please specify denomination, e.g. Methodist
    _____ f. Other. Please specify.

---

32. Are you currently associated with a college or university?

    _____ a. Yes.   _____ b. No.

    32.1. If so, in what capacity?

    32.2. With what institution?

34. In general, how important would you say your religion is to you?

    _____ a. Extremely important.
    _____ b. Fairly important.
    _____ c. Important/unimportant.
    _____ d. Fairly unimportant.
    _____ e. Not at all important.

---

35. IF YOU HAVE ANY ADDITIONAL COMMENTS OR REMARKS, PLEASE WRITE THEM BELOW AND ON THE BACK OF THIS PAGE. THANK YOU VERY MUCH FOR YOUR COOPERATION.

APPENDIX C

COVER LETTER: POLICY-MAKERS

UNIVERSITY of PENNSYLVANIA

PHILADELPHIA 19174

Faculty of Arts & Sciences

DEPARTMENT OF SOCIOLOGY
3718 LOCUST WALK   CR

As you know, the process of social change as it involves legislation is little understood. We have recently witnessed the collaboration of physicians, lawyers, ethicists and legislators in resolving and passing legislation on the issue of death definition and determination. Since 1970, when the Kansas legislature passed the first bill defining death in terms of the absence of brain function, ten states have enacted similar statues. The drafting of all the statutes has entailed the examination and definition of several important medical, legal and ethical issues.

I am writing to ask your cooperation in a study, sponsored by the Russell Sage Foundation, designed to find out how professionals and legislators collaborate with one another toward the institutionalization of the definition of death as dependent on brain function. Since few states have detailed legislative histories, I have obtained your name by writing to the drafter/sponsor of the statute enacted in your state, asking him/her to name five persons who were important in stimulating interest in the issue, drafting the statute and getting the bill passed in the legislature. Obviously, mine is a shotgun procedure, and the information I have to go on is scanty at best. Consequently, I hope you understand that your participation is an essential as well as an extremely valuable contribution to this study.

I would be very grateful if you would complete the enclosed questionnaire which will take no more than ten minutes of your time at most. I have provided a self-addressed, stamped envelope for your convenience. In the near future, I will phone your office to arrange a short interview by phone, of approximately ten minutes in duration, which will include some general questions about your role in instituting death definition legislation in your state and the local pressures which led to an interest in the bill. Thank you very much for your cooperation.

Sincerely,

Leslie Ann Rado
Research Fellow

Enclosure

APPENDIX D

CONTENT ANALYSIS SCHEME

CONTENT ANALYSIS SCHEME

I. Author and Publication

1. Article Id. # _____

2. Institutional affiliation of author

   1. medicine   3. medicine and law

   2. law   4. ethics, bioethics, theology

3. Date of publication   Month _____ Year _____

4. Journal

   1. JAMA   7. State or Univ. Med. J.

   2. New England J. Med.   8. Univ. Law Reviews

   3. Linacre Quarterly   9. Law Journal

   4. General Medical, e.g., Hosp.   10. Interdisciplinary J.,
      Trib., G.P.   e.g., Daedalus,
                                                 Science, Hastings
   5. Specific Neurological   Center Report

   6. Specific other, e.g.,   11. Theological Journals
      anesthesiology
                                             12. Book   13. Other

5. Contribution to panel or symposium?   1. yes _____
   (not journal symposia)
                                             2. no _____

II. Article Content

6. Primary purpose of article

   1. Early reporting of potential use of EEG to determine
      death, includes research reports

2. <u>Drawing attention to and proposal to help solve</u> the advanced medical technology problem, includes major reports

3. <u>Review</u> of advanced medical technology problem and proposed solutions, includes "how to determine death" and "this is what has been done" articles, may include minor modifications of major reports

4. <u>Criticism</u> of a major criterion used in determination, includes presentation of alternative criteria or methods, includes research and clinical findings

5. <u>Research or clinical findings</u> reports which support criteria and methods of determination of major proposals

6. <u>Criticism of major proposal</u> (e.g., Harvard Report <u>or a defin-ition</u>, including statutes. Also includes major modifications or refinements, e.g., suggestion of concept of neocortical or cerebral death vs. whole brain death

7. <u>Discussion of medico-legal issues</u>, particular court cases and statutes, includes proposal to solve problems

8. <u>Discussion, critique, clarification of the conceptual and/or ethical issues</u> involved in redefinition of death and/or general life prolongation situation

9. 6 & 8   10. 6, 7 & 8   11. 4 & 6   12. 3 & 5

13. Presentation of <u>alternate criterion</u> - blood flow, e.g., angio-graphy

14. 7 & 8   15. 4 & 7   16. 3 & 8

7. Discussion of definition (concept of death) or determination (criteria)?

   1. Definition   3. Both

   2. Determination

8. Stated etiology of the need to redefine death in terms of brain function

   1. The usual, i.e., resuscitation technology (defibrillators) life-prolonging technology (respirators, hemodialysis, anti-biotics), and general transplantation or simple "advances in medical technology"

   2. Heart transplantation primarily or heart transplantation pro-vides primary impetus

35. Theological issues mentioned

COMMON ISSUES MENTIONED

36. Is death a process or event?

37. Death as process - stand taken (e.g., death is the gradual dying of parts of the body)

38. Death as event - stand taken (e.g., death of the organism as a whole)

39. Two definitions of death - heart or brain death, legal or medical death - unacceptable, confusing

40. Concern for transplant recipient (transplantation as a gift and/or moral imperative)

41. Allocation of scarce medical resources should be considered and weighed

42. Concern for dying patient (death should be declared only with reference to the dying patient, not to potential social good)

43. Concern for donor (should not meedle with the donor in order to improve transplant)

44. Confusion or threat to public with respect to potential declaration errors, wrongful death, premature burial

45. Fear of inhumane treatment of the senile, retarded or infirm

46. Hesitant about primary use of EEG in determination

47. In favor of primary EEG use

48. Euthanasia discussed

49. Distinction made passive and active euthanasia

50. Withdrawing treatment ok: the "quality of life" ethic, stopping dying, not allowing to die all the way

51. Allowing to die ok - euthanasia not so good - let die all the way

52. Transplantation, e.g., UAGA, donor ethics discussed

53. Care of the dying - other than allowing to die or death with dignity

54. Abortion and definition of life and death

MEDICAL ISSUES MENTIONED

55. The usual criterion and method specifications, e.g., time interval, how to do it, confusion with barbiturate coma and hypothermia, EEG amplification, etc.

56. No transplant team member should declare a donor dead

57. Attending MD should consult with neurologist or neurosurgeon

58. Different levels of brain death: whole brain vs. neocortical or cerebral death (usually states that whole brain is not refined enough for a definition or criteria)

59. 24 hour interval specified in Harvard Report is too long

MEDICO-LEGAL ISSUES MENTIONED

60. Medical liability in declaring death is valid concern

61. Medical liability is not such a valid concern

62. Need time of death for insurance and will purposes

63. Legislation would freeze medical community and progress

64. Legislation would endanger donor or dying

65. Present legal definition is inqadequate or not specified

BIOETHICAL ISSUES SPECIFICALLY MENTIONED

66. Dying should be allowed to die humanely and/or with "dignity"

67. The body as well as the person is sacred: the body as inviolable

68. General ethics of the MD-patient contract, Hippocratic Oath, AMA ethical code

69. A concept or definition of death should be considered apart from any practical considerations such as transplantation or costs to society

CONCEPTUAL/PHIOLOSOPHICAL ISSUES SPECIFICALLY MENTIONED

70. Identification of death of person (or life) with death (or life) of organism - reductionism

71. Identifying criteria with concept; concept ≠ criteria

72. Confusing "When to declare death?" with "When to allow to die?"

73. A value-laden issue (death) treated by value-free routine (medicine, technology) - inappropriate

74. The meaning of life or death largely, but not theologically, writ

THEOLOGICAL ISSUES SPECIFICALLY MENTIONED

75. Death and relationship of soul to body; death as the soul leaving the body

76. Meaning of death (or life) interpreted within context of religious traditions or texts (life is divine, God's gift)

REMEDIES

77. Legislation

78. Let the courts decide if and when there is a problem

79. Leave entirely to medical practice

80. Increased research, new technologies

81. Advocates "passive" euthanasia and withdrawing treatment, i.e., stopping dying - more radical

82. advocates allowing to die vs. 81. - more conservative

83. Respect human body, hesitate with redefinition of death and proceed with caution

84. Involve public and individuals in consideration of death and their own deaths

85. Establish a committee of non-MD's or interdisciplinary to declare death, consider cases

86. Use concept of "brain death"

87. Use concept of neocortical death

88. Legislation undesirable, not needed

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