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Ethical Decision Making in a Rural Health Care Facility

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THESIS
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I. OVERVIEW OF THE HISTORY OF INSTITUTIONAL ETHICS COMMITTEES

In 1976, the New Jersey Supreme Court ruled in favor of removing the respirator, which was considered a life-sustaining treatment, from a comatose 19-year-old Karen Ann Quinlan. Because she was in a "persistent vegetative state," her prognosis was uncertain. Surprisingly, after the removal of the respirator, Quinlan, who was never declared totally brain dead, persisted in her comatose state until June 11, 1985.

The ruling in the Quinlan case had a far-reaching impact on the ethical decision-making processes of hospitals. In their ruling, the court recommended an alternative to judicial involvement. The New Jersey Supreme Court proposed that an "ethics committee" monitor Ms. Quinlan's prognosis and the probability of her regaining consciousness. It is interesting to note that the New Jersey Supreme Court's original mandate did not actually refer to an ethics committee but to a "Prognosis Committee" which was physician-governed. This committee was directed to confirm the diagnosis of Quinlan's comatose state, but not to make any ethical or social evaluations.

The Quinlan decision prompted the formation of ethics committees in several hospitals in the state of New Jersey. At about the same time, there was a surge of interest in some of the nation's 6,800 acute care hospitals in exploring the complex bioethical issues
relevant to the hospital care of very sick patients and ways of addressing these issues through ethics committees.

A few years after the Quinlan case, interest in forming ethics committees gradually diminished until 1982 when the Infant Doe case occurred. This case involved a Down’s Syndrome baby boy born in Bloomington, Indiana with an esophageal atresia. Some of the doctors caring for the infant recommended surgical repair while others believed that treating the baby would not improve the quality of his life. The parents decided not to treat the baby, which lead to a series of heated debates in court. Eventually, the boy died by starvation. The Indiana courts at all levels ruled that the parents could elect nontreatment for the baby as long as the physicians recommended it. Not surprisingly, this case received widespread negative publicity.

In the spring of 1983, a 550 page report called Deciding to Forego Life-Sustaining Treatment was issued by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Biobehavioral Research. The report concluded that there were issues arising with respect to the treatment of incompetent patients as well as the seriously ill newborns. The commissioners recommended that hospitals "should explore and evaluate various formal and informal administrative arrangements for review and consultation such as ethics
committees, particularly for decisions that have life or death consequences for incompetent patients." Establishing hospital ethics committees seemed like a reasonable way of promoting effective decision-making through education, development of guidelines, and case review. The Commission, however, realized that ethics committees may raise as many issues as they solved.

In the fall of 1983, the Baby Jane Doe case gained attention in New York. In this case, the parents of an infant with spina bifida and hydrocephaly elected conservative treatment as opposed to the more aggressive surgical treatment. An attorney unknown to the parents decided to challenge their decision in court. The attorney, over the objection of the parents, obtained a court order requiring surgery for the baby. The appellate court, however, overturned this ruling. This case underscores the point that physicians and parents may face legal challenges when they choose treatments which involve the withholding of life-prolonging measures.

As a result of the Baby Doe cases, the American Academy of Pediatrics and the U.S. Department of Health and Human Services in the Baby Doe regulations recommended that hospitals caring for newborns, especially those with neonatal intensive care units, should have an Infant Care Review Committee (ICRC). Even, the conservative Surgeon General Everett Koop expressed his desire to integrate
"materials on the role of ICRCs in decision-making for handicapped newborns" in medical schools, nursing schools, and social service programs.  

This recommendation seems to support the idea that hospitals should have an ethics committee. To further promote this idea, some state legislatures passed resolutions advocating the formation of ethics committees in hospitals. In fact, medical societies, hospital associations, and insurance companies have also endorsed resolutions favoring the formation of hospital based ethics committees. 

Even though Ethics Committees, as a movement emerged slowly, they first appeared as recognizable entities in the mid-1970's. It was actually in the early 1980's that they became an object of interest. A 1981 survey of U.S. hospitals by Stuart Youngner of Case Western Reserve University School of Medicine estimated that only one percent of the hospitals who were registered with the American Hospital Association (AHA) had ethics committees. That figure, however, has been challenged because it includes decision-making ethics committees only as opposed to committees who see their role in consultation as advisory and not binding. 

The increased prevalence of ethics committees became apparent in 1983, when an AHA survey reported that 25% of U.S. hospitals had committees, and another 25% said they
planned to establish them. In 1986, the most recent AHA survey noted that "perhaps as high as 60% of hospitals have committees." Even nursing homes and dialysis centers are establishing ethics committees. While the number of participating hospitals is uncertain, the movement toward hospital based ethics committees has proceeded at a rapid pace and will continue to do so.

In the June 1986 Hastings Center Report, two professors of philosophy, J.M. Gibson and T.K. Kushner, published an update on the status of Hospital Ethics Committees, which are also known as "Institutional Ethics Committees" (IEC's), so that other forms of health care institutions besides hospitals will not be excluded. This report confirmed earlier national surveys which documented a continuous and rapid increase in the number of IECs functioning in American health care institutions.

As support for these IEC's increased, the California Medical Association Council advised that all acute care hospitals in California "establish and support an ethics committee". A movement that started in a very small way has become a large and important one, and promises to be even more significant in the future. It bears directly on the resolution of difficult moral dilemmas and on the quality of care provided to the patient.

Advocates of ethics committees believe that they manage to broaden the base of decision-making and
consultation, thus enhancing the possibility that a wide range of interests and values will be considered when ethical decisions are made. Others believe that ethics committees are a means of evading difficult moral choices, or are mechanisms of decision-making that improperly remove decision-making responsibility from physicians.

Despite this diversity of viewpoints, the support for ethics committees continues to develop. There is reason to believe that ethics committees are here to stay. Maryland recently became the first state to legally mandate ethics committees for every hospital in that state, and other states are expected to follow suit. In fact, it is now rumored that the Joint Committee on Accreditation of Hospitals (JCAH) may force hospitals to have ethics committees as part of its accreditation process.

II. THESIS QUESTION

Despite the development of considerable interest in the committees, and the expansion of their roles, there remains a great deal of uncertainty as to how they should operate and more importantly, what should be the scope of their work. Of particular interest here is the question whether ethics committees are a preferred method of ethical decision-making for all institutions, or whether there may be more appropriate models under some circumstances. The purpose of this paper is to look at some of these issues, particularly the role, if any, of ethics committees within
a rural health care facility.

Although it is beyond the scope of this paper to answer the question on a national scale, the intent here is to examine this question with respect to one rural health care Facility F, (the health care institution chosen for this investigation), and provide some discussion as to what its implication may be on a larger scale.

Worth noting is that while the overall percentage of hospital based ethics committees may be has as high as 60% based on the American Hospitals Association survey, Gibson and Kushner's study currently under analysis still shows that smaller institutions, that is hospitals with less than 200 beds, are not establishing ethics committees at the same rate as larger institutions. Why have rural facilities' ethics committees not grown in the same proportion as the institution as a whole and perhaps, more importantly, should they?

III. HOW ETHICS COMMITTEES FUNCTION

In order to answer the above question, it is first necessary to examine more closely what committees actually do and how do they define their activities. Most ethics committees perform three functions: (1) Education, (2) Policy and Guideline Development, and (3) Case Consultation. Most committees start with self-education. After self-education, comes the educating of the hospital
staff, and then the education of the community. Finally, with experience and confidence, the committee will typically begin to develop policy for the hospital. At this point, case consultation can be undertaken by those committees whose members are well prepared.

**Education:**

The function of education can be divided into three types: (1) self-education of the committee, (2) education of the hospital, and (3) education of the community. In most cases, a hospital which decides to establish a committee will start with self-education, later progressing to community-wide education.

Self-education often is started by studying landmark cases like Baby Doe or Quinlan in order to become aware of the more common bioethical issues encountered in hospitals so that a baseline knowledge can be established. Many hospitals use case studies to educate their ethics committee members. This method seems to be effective. Once committee members and hospital staff members have been educated, the more established ethics committees hold workshops for the public on issues like surrogates making decisions for the incompetent patient or the Durable Power of Attorney.

**Policy and Guideline Development:**

Frequently, one of the first policies many committees develop is the DNR (Do Not Resuscitate) order. Current
committees are finding further policies necessary such as foregoing life support treatments and the very controversial issue of withholding or withdrawing nutrition and hydration.

An important question that is being asked is "Do Committees make a distinction between writing Policies or writing Guidelines and if so what are they actually engaged in?" Policies suggest mandatory adherence within the institution, whereas guidelines may be only recommendation by the Committee.

Consultation:

The function of consultation is similar to the medical consultation where the doctor brings in an expert for advice. In the ethics situation, the physician, nurse, or staff person seeks a consultation when the family and the healthcare provider cannot agree on the treatment modalities. At first, the consultations are formal and the committee meets as a group to discuss the case. As the committee gains more experience, the method of consultation becomes more informal and the members who have more experience become available for counsel. Therefore, consultations serve as another way of educating hospital staff.

For consultation purposes, an ethics committee can be set up in three different ways: (1) optional/optional, (2) mandatory/optional, or (3) mandatory/mandatory. In the
optional/optional committee, physicians are allowed to seek the advice of the committee on a voluntary basis and also have the option of choosing whether to follow the advice. In the mandatory/optional case, physicians are required to consult the committee but would not have to follow its advice. The mandatory/mandatory committee requires that the physician not only consult them but requires them to follow their counsel as well.

Structural Organization of an Ethics Committee:

Ethics committees can be divided into three categories: (1) single-issue or consult-only committees, (2) education and policy-making committees, and (3) committees that do consultation as well as develop institutional policies and educational programs. Ethics committees which fall in the first category may have started off as a policy-making committee, but quit after deciding that each case is so different that setting policy would not be practical.

Committees that engage in education and policy-making stress the importance of education more than policy-making. Some of these committees do not engage in consultation because the hospital already has an effective counseling service and thus they wish not to duplicate those services. These hospitals believe in working with the family, patient, and hospital staff when a particularly difficult case arises--one that is not covered under institutional
guidelines.

The committees that engage in all three activities (education, policy-making, and consultation) usually have established solid educational and policy-making roles. The consultation aspect of the committees are usually advisory in role only. A review of literature, however, reveals that physicians have started to become more dependent on the committees’ advice, especially concerning difficult cases because of the committee member’s ethical and legal expertise.

IV. POSSIBLE ADVANTAGES OF ETHICS COMMITTEES

Proponents of ethics committees have suggested several possible benefits. First, ethics committees provide a systematic method of approaching the complicated bioethical dilemmas within the hospitals and long-term care institutions. In other words, ethics committees help with the decision-making process concerning ethical aspects of clinical care. By having knowledgeable health care professionals discussing in an open forum the possible ethical and medical ramifications of each treatment option, a more reasonable decision will be rendered.

Both the President’s Commission and the U.S. Department of Health and Human Services (HHS) have acknowledged this first benefit. The President’s Commission stressed the importance of good decision-making practices and that having ethics committees may be a way to
encourage good decision-making practices within health care institutions. HHS stated in their final Infant Doe regulations that ethics committees "can be very valuable ... in bringing about informed, enlightened, and fair decision making regarding these difficult issues."^8

A second benefit closely related to the first is that ethics committees "can serve as a link between societal values and the actual developments occurring in the institutions that care for and treat the particular patients whose cases manifest these dilemmas."^9 Similarly, they can serve as a conduit for new information such as court decisions, federal regulations, etc. to institutional administrators and staff. Thus, an ethics committee can serve as a vehicle to ensure that the rights of the individuals and societal interests are protected.

A third possible benefit of ethics committees is that they can assist health care institutions determine which ethical issues suggest that an agreement may exist and those where no agreement appears possible, at least for now. For instance, currently the idea that the death of a brain means death of the individual is accepted in 36 states through legislation including California. Ethics committees can help medical staff members, patients, and their families to understand and accept this standard of death. Another area where agreement is starting to develop is the do-not-resuscitate (DNR) policies. Again, ethics
committees can serve the important role of educating the medical staff and the community about when DNR orders are appropriate and when they are not.

Fourth, ethics committees provide an open discussion for specific ethical issues which might be problematic for the staff. For common ethical issues, the committee can assist in developing policies and guidelines for the institution, e.g., allocation of medical resources, do-not-resuscitate orders, and brain death. Having clear written policies and guidelines instills trust and confidence within the medical staff. An institution that has incoherent policies might produce conflict among the medical staff.

In prospective consultations, ethics committees can be helpful by ensuring that all the relevant information has been gathered for the decision makers. They will be able to identify the various ethical issues that are involved and clarify the conflict of interest. Ethics committees can also arbitrate disagreements, perhaps avoiding unnecessary litigation. However, should the need arise, ethics committees can recommend the involvement of the judicial system.

In retrospective review of cases, an ethics committee can see if appropriate decisions were made and to determine which cases involved bad decisions so that in the future better decisions can be rendered.
Finally, if there is a lawsuit brought against a health care institution, having an ethics committee may demonstrate to the courts that the contested case has received careful review by a staff of professionals.

V. POSSIBLE DISADVANTAGES OF ETHICS COMMITTEES

With the number of ethics committees increasing geometrically, it is imperative to examine the possible adverse effects they may generate. Unfortunately, this issue has not been addressed with the same thoroughness in the literature as the benefits they offer. One of the main concerns that opponents of ethics committees have expressed is the disruption of the sensitive doctor-patient relationship. They believe that ethics committees might actually impede the establishment of such a relationship by having the decision making process moved "from the office or bedside to the conference room or executive suite". Instead of doctors—who have direct contact with the patient—making the treatment decisions, a committee, which has no direct relationship with the patient, will be making the treatment decisions. This disruption is most likely to occur when there is a disagreement between the committee members and the physician or the family members.

Another concern is that the committee may not be promoting the best interest of the patient, but may be directed by the interest of the institution or the doctor.
For example, the committee may arrive at a particular decision to protect the hospital from liability. Thus, opponents of ethics committees believe that what was once an important part of the doctor-patient relationship will be replaced by an anonymous decision-making body which may not be concerned with the patient's feelings. The purpose of having a committee in the first place is to provide decisions that are in the best interest of the patient. Strict vigilance is necessary to avoid such co-optation of the members of the committee.

Ethics committees may also become involved in a lawsuit because of their actions or inactions. Thus, there is concern among some physicians, nurses, and other health care practitioners that they will be charged with medical negligence or homicide if, after withholding treatment, the patient dies. Should this occur, then everyone on the ethics committee might be held responsible and thus accused of conspiracy to commit homicide.

Members of ethics committees have expressed their concern that the committees might become dominated by a particular profession, individual, or medical subspecialty resulting in just another "rubber stamp" committee. Nonetheless, ethics committees recognize the importance of physician representation on these committees while being on guard against domination by any one individual or profession.\textsuperscript{11}
There may be a tendency for the committee to reach a consensus which is ethically questionable. For instance, during the 1960's when kidney dialysis technology was in its infancy, hospital committees had to choose suitable candidates for the dialysis machine from among the many patients with chronic renal failure. When it was revealed that the patient's "social worth" was considered, decisions by the committees were deemed as unfair.

Another pitfall that may befall ethics committees is what Bernard Lo calls "groupthink". Here the committee, which is supposed to represent diverse opinions, may in fact be forced to reach an agreement too quickly by underestimating risks, failing to consider alternatives, or failing to look for additional information.12

"Groupthink" may occur if the committee is not careful. First, the committee may reach a decision too quickly by not considering the patient's wishes. Informed consent is supposed to remedy that situation, but often patients are not sufficiently involved in their own care. Second, committees may get second hand information and not evaluate it critically. In other words, the committee members may be presented with conclusions and inferences which describe a patient as being "terminal" or that a patient may not want "heroic measures" to be used to save his or her life. Thus, it may be prudent for committee members to seek more information because such phrases are
unclear and can be misleading.

Mark Siegler, director of the Center for Clinical Medical Ethics at the University of Chicago Pritzker School of Medicine, made the point that the removal of the attending physician from the decision-making process and giving that responsibility to the IECs is unethical. To emphasize his point he quotes from Christine Cassel, a professor in the Department of Geriatrics and Medicine at Mount Sinai Medical Center in New York:

The coming together of many different perspectives and areas of expertise may provide the "crucible" in which the best (i.e., most humane and most just) decisions are made. But a committee can also provide the setting in which immoral decisions can be made for which no one has ultimate responsibility. This is most likely to occur in a setting where most persons on the committee are relatively removed from the clinical setting, where conflict of interest with administrative needs exists, and where the group dynamic is bureaucratized. Such a committee is no longer a crucible for the tempering of apparently conflicting values, but rather a bureau whose primary value is not the anguish of moral dilemma but the efficiency of decision making, abiding by rules and adhering to regulations and legal proscriptions.13

Other problems which may be encountered with an ethics committee include the following: (1) A particular decision rendered by the committee may be forced upon the patient or the family which may not be agreeable to them; (2) The responsibility of the decision-making becomes so diffuse because too many people who are not directly caring for the patient become involved; (3) Decisions made by the
committee may be seen as infringing upon the patient’s choices and the doctor’s responsibility to care for the patient; (4) Violation of the patient’s confidentiality; (5) Domination by members who subscribe to a particular religious belief which would limit the patient’s options; (6) The probability that the committee may allow membership to only those who subscribe to a particular point of view; (7) Fear that the committee might become a "cost containing committee" rather than a patient advocate; and finally (8) The question of legal status of an ethics committee. (Of course there are some states that have recommended the use of these committees.)

VI. FACILITY F AS A RURAL HEALTH FACILITY

Before examining Facility F and its method of moral decision making, it is first necessary to understand what it means to describe such a facility as "rural." Like any complex concept, there are several ways to explain a facility being located in a "rural sector."

There are at least four different ways a rural sector can be defined. According to the U.S. Census Bureau, size is the criteria used in determining what is considered rural and what is not. An "urban center" has at least 2,500 persons or more within a town boundary and persons in a "rural area" consists of everyone else; a "metropolitan area" has a county of 58,000 or more people and a "non-
metropolitan" county is any other county.

The World Health Organization defines a rural sector in terms of distance and travel time. They consider an area rural if at least thirty minutes are required for travel to a densely populated area. A third method defines a rural sector as an area that has a population density of less than 500 people per square mile. Finally, a fourth approach uses sociological characteristics. For example, a rural community may be considered more conservative and independent than an urban community. Since Facility F is located outside the town border, and at least thirty minutes by car from a relatively densely populated area, it is defined as rural.

Facility F is an outpatient clinic that serves about 15,000 patients per year. It is operated as a non-profit corporation which consists of four clinics. Funding comes from the federal government which is administered by the state. Each clinic is represented by two persons on the board of directors which oversees the operation of the four clinics. Each facility has a clinic administrator, one fulltime physician and registered nurse, two fulltime physician's assistants, and two fulltime nurse's aid.

A clear picture of one rural health facility would be impossible without a description of the kinds of people who use them. In the case of Facility F, the patients are mainly the farmworkers of Hispanic origin. In his study of
farmerworkers in Tulare county, Richard Mines describes the
groups of workers such as those seen in the clinic. Mines
classifies the Mexican Farmworkers into three different
groups.¹⁵ The first group he calls the Newcomer Families;
they are the Mexican nationals whose families have recently
crossed the border in search of agricultural wage labor in
California. When they begin to earn more of their income
in California, the type 1 household begins to settle here
as well and eventually moves into non-agricultural work.

Type 1 households in most cases have to depend
completely on farm work for their income. Because these
families have only recently joined the farm labor force,
they will be dependent on it as their primary source of
income for several generations until they have established
themselves as type 2 households (see below). The type 1
group almost never has more than two generations under the
same roof—which means that there are no grandparents
present. But, there is a high proportion of infants and
children because the heads of these households are only
recently beginning a family. This group also has a very
high fertility rate which makes perinatal health care an
extremely important issue for them.

The type 2 group are called the Settler Families who
have been living across the border for a few generations. A
good portion of their income comes from non-agricultural
work. In this group, only the male head of the household
is involved with farmwork and his wife and children are involved with part-time work or full-time work in other occupations. Consequently, this group often has a higher income level which creates a higher standard of living as well. These people might own homes, have at least one car, and in effect have a permanent residence.

In contrast to the younger type 1 families, type 2 families have members who are much older, due to the higher proportion of elderly, retired farmworkers. This group also has a much lower fertility rate. The higher percentage of elderly in this group makes health problems related to old age an important issue for them. Their main health complaints seem to be orthopedic in nature, due to their lifetime of hard, manual labor.

Lone Males constitute the third and final type. The common characteristic of members of this group is that they have nuclear families back in Mexico and that they have crossed the border to work in order to supplement the income of their families back home. These families consist of parents and younger siblings if the man is single; they consist of a wife and some children if he is married. The Lone Males generally come from a poor peasant background with very little knowledge of how to survive after they have crossed the border. These men often find work in the fields and orchards without asking what the pay rate is and usually live in very poor housing conditions which might
even lack beds.

The Lone Males' health concerns include poor diet and the effects of substandard housing. Their health concerns are aggravated by the fact that they have no visas—which makes them reluctant to seek health care when needed. They also suffer a great deal of loneliness, depression, and alcoholism, which may result from their separation from loved ones. They also have a higher rate of venereal disease than the general population or the other two groups.

VII. ETHICAL POLICIES AND PROBLEMS AT FACILITY F

To understand the kinds of ethical issues this rural health care facility encounters, as well as how decisions are reached, I conducted a series of interviews with the following administration and staff: the associate director, who is second in charge of all four clinics, the clinic administrator, the medical director, a physician's assistant, and a registered nurse. I conducted my interview at a small rural health care facility which has no ethics committee.

Facility F is typical of rural health care facilities in that it has no ethics committee and has no plans to establish one. Like typical rural facilities, this clinic does not have facilities for dialysis, organ transplant, artificial transplantation, in vitro fertilization, or level III neonatal intensive care. As a consequence, many
of the ethical issues which arise from having advanced medical technology are not the focus of their concern. Here most of the ethical questions have to do with the doctor-relationship.

In response to the need for guidance in this area, this clinic has established written policies for informed consent, reporting negligent practices, and determination of incompetence. They also have a Patient's Bill of Rights. The informed consent form is the one used by the California Hospital's Association which gives "[consent] to treatment when they enter the facility but not to individual procedures." (medical director) Determination of incompetence is judged by periodic chart audits, but a more formalized system was being developed at the time of the interview. There is a policy for dealing with negligent practice, but how it is handled was not explained. The document called the Patient's Bill of Rights was the one developed by the federal government.

In contrast, they did not have any guidelines for the following: determination of death, orders not to resuscitate, termination of treatment, foregoing fluids and nutrition, or allocation of resources.

Ethical issues like termination of treatment or determination of brain death do not arise because Facility F does not handle acute care cases. According to one of the staff persons, the policy for emergency cases is to
stabilize them and then transfer them to the county hospital. Because the clinic is so small and since it does not have an intensive care unit, they "don't want to take care of critically ill patients".

The absence of any policy regarding allocation of resources appears particularly surprising, given that when asked as to the kinds of ethical issues seen most frequently, all the interviewees responded that treating indigent patients was the most frequently seen and also the most problematic ethical issue at Facility F. Because the federal government subsidizes the clinic, it is subject to various economic guidelines. Each person who uses the clinic must be placed into a certain payment category based on a sliding fee program according to that person's income.

One of the more difficult situations is when a person comes in and only qualifies under the 100% payment category—which means he or she has to pay the complete bill because he or she makes too much money. In reality, most of the families who are placed in the 100% payment category cannot afford to pay the total cost of their health care bill. At the same time, the federal government prohibits the clinic from denying care to patients based on their income. This creates a critical dilemma for the clinic. By treating these people, the facility loses money. However, from an ethical perspective, how can the facility deny care to those who need it?
Due to the severe cutbacks of federal funds in recent years, the clinic has been asking all patients for a minimal fee of $24. This problem is reflected in the following response from one of the interviewees:

If a patient does not have the means to pay, are you going to deny service? We have dealt with that in the light of the regulation of the federal government. One is that the federal government wants us to be productive—to see an X number of patients so we can get Y number of dollars. Forcing us to come up with 50% of the cost to run the centers. We were charging the medical indigents nothing, but 6 years ago we started charging—calling it a donation. If a patient has to be seen in an emergency situation, then the patient is not asked to pay.

One person expressed frustration when working up a patient and a plan, "but not [being] able to realize that plan because of financial problems." Other issues with ethical components have to do with the frustrations of working with a patient's cultural differences. Often, they are not able to understand the reasons for treatment and why they are sick. Another issue expressed is the serious problem of trying to educate the patients about prevention.

VIII. HOW ETHICAL ISSUES ARE HANDLED AT STUDY FACILITY F

In small clinics where there are no ethics committees, how are ethical issues handled? In the clinic where I conducted my study, most cases were handled on an individual basis between the care-giver and the patient and family members. Respondants indicated that the process of
ethical decision making always involved the family and the provider who was caring for that patient. The family and the patient played a big role in deciding which treatment plan to follow. One respondent stated, "...we tell them that they are the ones who are going to make the decision in each step of the plan.... if they don't want to continue with the plan, we have to present options for them and also explain the risks and benefits. We have to keep them informed and tell them that they are the boss in the end because it doesn't do us any good if we go ahead with a plan and have them not comply with it."

Another person responded as follows: "We try to make everybody (family, patient, and provider) work together in harmony and doing that makes it easier for the patient. They always have the decision of making the choice of what happens to them...If they ask for our opinion, we try to let them know the consequences of each [option] and after that they decide for themselves."

When asked if there has ever been any discussion about forming an ethics committee, they all stated no. The main reason as to why such a discussion has never occurred was because the clinic does not deal with acute cases where decisions like termination of treatment might occur.

Most agreed that having an ethics committee is not necessary because the clinic does not deal with critical care patients and most ethical issues can be dealt with on
an individual basis by the health care provider, patient, and family. One respondent stated that the advantage of not having an ethics committee is that he "has a freer hand to do and make [his] own decisions on an individual basis with [his] own biases. If we had an ethics committee who told you what to do then that would be a disadvantage for me personally."

One respondent stated that a disadvantage of not having an ethics committee is that if an ethical issue does arise, then the facility will not have a defined mechanism to handle the problem.

IX. NETWORKING

The Random House Dictionary definition of networking is "an association of individuals having a common interest, formed to provide mutual assistance, helpful information, or the like." Networking among hospital ethics committees where groups are formed to trade information, offer assistance on problems of mutual concern and even in some cases provide case consultation, are a rapidly growing phenomenon around the country. Since the movement to form networks of committees is so new, information on who these networks are, where they are, and what they are doing is scarce. However, descriptions of networks that have been identified provide an illustration of the range and depth of issues addressed by networks and suggest a possible
function not yet explored of networks—as support and resource groups for small institutions which do not have their own ethics committees like Facility F.

To illustrate the range and depth of issues addressed by networks which have been identified, a brief description of their activities will follow.

Minnesota:

The Minnesota Network for Institutional Ethics Committees, one of the first ethics network systems, was established in 1982. The Minnesota Hospital Association has been providing financial backing since 1984. This particular network publishes a quarterly newsletter called the "Ethics News" which currently has over 800 subscribers and is continually growing. In fact, since 1987, the publishers of the newsletter have begun to charge a nominal fee of $15 per year because of its increased subscriptions.

An interesting trend was established when the Minnesota Supreme Court and the probate court cited the conclusions of an inter-hospital ethics committee formed by three Twin city hospitals, all members of the Network, concerning the withdrawal of respirator support from a permanently comatose patient. The courts agreed with the committee that withdrawal of life support under such circumstances was appropriate. Other activities in which the Network has been involved include developing a method of activating consults at other hospitals, forming a
booklet on limited treatment guidelines, and serving as a clearing house for educational resources like movies and speakers.

**California:**

Two networks have been established in California. For example, the *Orange County Bioethics Network* through the Center for Bioethics at St. Joseph Hospital, has about fifteen committees from that area working together and they have had three meetings since they started in March of 1987. The first meeting focused on educating the committee members through self-education and education for the staff as well. The agenda for the second meeting was on policy writing and the third meeting consisted of a mock case review. The *Orange County Bioethics Network* is one of the newest in the country, but activities of the group have spread and requests for information on developing guidelines and how to establish committees is soaring.

The second network to be established in California is the *Bay Area Network* which had its first meeting in October 1987. This network is being sponsored by the joint forces of the Hastings Center and the San Francisco Medical Society’s Bioethics Committee. Currently there are plans to establish an information exchanging process among all the ethics committees in California.
New Mexico:

In New Mexico, the cities of Albuquerque and Santa Fe have a network of hospital ethics committees which have successfully worked on ways to deal with the issue of getting informed consent from the elderly patients who are admitted to the hospital, but who have no family or next of kin. The Network was concerned that these patients, who are often mentally incompetent, may be getting treated without much of their wishes or preferences being considered.

Due to this concern, the "Treatment Guardianship Program for Hospitalized Elderly Patients" was started on September 1, 1987. This program identifies mentally incompetent elderly patients who have no medical decision maker and assigns treatment guardians who serves the patient during the patient's stay in the hospital. These volunteer guardians serve as patient advocates by monitoring the process of treatment decision making.

These volunteers are mostly from the community and are elderly themselves. They participate in a course which covers ethical, legal, medical, and psycho social issues. They are also trained in procedures which help identify patient wishes through building a value-history. When the patient's value-history is taken, it is given to the care taker to be placed in the patient's permanent record to assure the patient's autonomy and substituted judgment
are preserved.

Arizona:

In the spring of 1987, a meeting was organized among the members of the Arizona Humanities Council, the University Medical Center at the University of Arizona, the Arizona State College of Nursing, and two hospitals from Phoenix to discuss the possibility of forming a Bioethics Network. In one study, Katherine Coe, a Phd. candidate from the Arizona State University College of Nursing, demonstrated that out of the 63 acute care hospitals in that state only 7 had ethics committees. The hope of the Arizona Bioethics Network is the promotion of ethics committees in hospitals in Arizona.

Wisconsin:

The state Wisconsin has recently established two Bioethics Network. At the state level is the Wisconsin Ethics Committee Network which has about 45 committees participating. Currently, the Network is planning to meet quarterly in different parts of the state to make the meetings accessible to members. The Network is also working on educational activities and policy development.

The other network in Wisconsin is the Catholic Hospital Association of Wisconsin (CHAW). Although CHAW Network is still new, one meeting has already taken place with a representative from the Minnesota Network to help them organize.
Vermont/New Hampshire:

The Vermont/New Hampshire Network was initiated during the mid 1980's when workshops on Ethics Committees were held and representatives from hospitals of both states were invited to attend. These workshops were organized by Charles Culver and sponsored by the main teaching hospital at Dartmouth University. The workshops have prompted many of the participants to start ethics committees at their respective institutions. To keep the Network going Dr. Culver keeps in touch with Committee Chairs and visits hospitals.

Denise Niemura, a primary care physician, and Chair of the Ethics Committee at North County Hospital in Newport Vermont, has recently finished a study concerning problems encountered by ethics committees in small rural facilities. She says that out of the sixteen hospitals in Vermont, twelve of them have less than 100 beds and that lack of finances makes it impossible to have an ethicist. She feels that many of the ethics committee members are not familiar with concepts and theories of ethics, but should be. Dr. Niemura feels that the Network is a way of correcting this problem. Thus, it seems that networking, though a relatively new phenomenon, is slowly becoming popular.
X. BENEFITS OF NETWORKING FOR FACILITIES WITHOUT ETHICS COMMITTEES

A question that was posed at the beginning of this thesis was whether all health care institutions need an ethics committee. The Youngner study in 1981 suggested that smaller facilities like those with less than 200 beds were less likely to have an ethics committee. In fact, an ongoing investigation being done by Gibson and Kushner reaffirms that ethics committees at hospitals with more than 200 beds are growing at a disproportionate pace compared to smaller institutions.

While no literature is yet available as to why facilities of less than 200 beds are slow in forming committees, some of the possible reasons may be similar to the views expressed by my interviewees at Facility F when they were asked if an ethics committee would benefit their patients. Some of the staff and administration at Facility F did not believe an ethics committee was needed for the following reasons: (1) the fact that the clinic did not handle any acute care cases precluded the necessity for a committee to assist in ethical decision-making; and (2) the staff has a strong commitment to an open doctor-patient relationship and the existence of an ethics committee may prove to be an impediment in this relationship.

Even though Facility F rejected the idea of establishing an ethics committee, it was evident from the
interviews that the activities in which ethics committees are traditionally involved, were also areas of concern for Facility F. For example:
(1) **Education:** Staff at Facility F stated that one of their biggest problems is educating patients about preventive care.
(2) **Policy and Guideline Development:** Although the staff at Facility F identified ethical dilemmas connected with indigent patients as the most serious problem currently facing the clinic, they have no policies or guidelines to deal with this issue.
(3) **Consultation:** Staff at Facility F state that at present they do require consult services because they do not handle any acute care cases which might present with difficult ethical issues. They do, however, raise the question about how problems might be handled when future problems arise.

Even if Facility F continues to reject the idea of an in-house ethics committee for the reasons expressed in the interviews, it does not mean that they could not benefit by joining a Network of committees. In regards to the first problem, networking will allow the staff at Facility F to learn about creative methods of community education which have been successful at other institutions. The problem of care for the indigent patient seems to be an issue for many ethics committees as pointed out by Gibson and Kushner in their research. Through networking, Facility F could be
exposed to policies and guidelines which other institutions have developed on a variety of issues including the indigent patient. Finally, with respect to the issue of Facility F's concern about possible future problems and case consultation, the staff at Facility F could request help in case consultation from another institution's committee or from a committee composed of members of other committees.

Perhaps the greatest benefit to be gained by network association is the forum it offer for committees to share their problems and receive support from those who have common concerns. Health care professionals operating in isolation and attempting to make ethical decisions are unnecessarily separated from an important source of information and help.

XI. CONCLUSION

In this research, the history of ethics committees has been highlighted and the current growth of ethics committees across the nation has been explored. However, with the increased rate of ethics committees being formed, the question that needs to be asked is: "What is the role of ethics committees, if any, in the decision-making process for small rural health care facilities?" In fact, research shows that the number of ethics committees in rural institutions are lagging behind the larger urban
facilities.\textsuperscript{20} Despite the slower growth of ethics committees in rural facilities, this does not preclude those rural institutions which are facing ethical dilemmas to have those issues addressed within an ethics committee structure.

Although smaller facilities may not be able to establish a committee due to limited resources, or may choose not to form one because of concern the doctor-patient relationship may be altered, this does not mean that rural facilities cannot benefit from the expertise and experience that committee members can offer. Small rural facilities can become part of the growing movement of ethics committee networks where individual committees and institutions join together for purposes of mutual support, education, assistance in establishing policies, and case consultation. Becoming part of such an organization would seem to be a solution for the needs of small facilities while at the same time not sacrificing the direct lines of communication and decision-making that the rural facility values. Networking may prove to be the needed bridge between isolation and improved services for patients in rural areas.
FOOTNOTES


5. Ibid.


9. Ibid.


11. Results from a pilot study done at the Hastings Center conference on Ethics Committees in October 1986 (which is part of a larger national survey currently being conducted by Kushner and Gibson), show that committees have
been successful in creating a multi-disciplinary membership. Although physicians as a group make up the largest number of members, they constitute less than one-third of the membership on a typical committee; nurses makeup the next largest group comprising over one-fourth of the membership and then the next largest group consists of the social workers and clergy.

Despite the fact that the committees are not physician dominated, there is really no information about the dynamics of the committee. Is there free exchange of ideas among the committee members or is there tensions which inhibit this free exchange of ideas? How does gender related tensions hinder interactions? Do all members feel free to participate without fear of embarrassment?


16. Identity and the position of the interviewees will not be revealed due to an agreement between the participants and the interviewer.


Gibson and Kushner: research in progress.
APPENDIX

1. What is the bed capacity of your hospital?

2. What is your institution’s affiliation?
   __not for profit  __teaching not for profit
   __for profit     __religious not for profit
   __other_level III neonatal intensive care

3. Does your institution have any of the following capabilities?
   __dialysis
   __organ transplant
   __level III neonatal intensive care
   __in vitro fertilization
   __artificial transplantation
   __other procedures that would present ethical problems

4. Has your institution developed guidelines or policies on any of the following? If yes, who developed them?
   __brain death (determination of death)
   __orders not to resuscitate (DNR)
   __termination of treatment (foregoing treatment, withholding treatment, supportive-care-only plans)
   __foregoing fluids and nutrition
   __treating unwilling patients
   __Patient's Bill of Rights and Responsibilities
   __informed consent
   __reporting negligent practice
   __determination of incompetence
   __allocation of resources
   __other

5. Were objections to any of the guidelines raised?

6. If objections were raised, what were they?

7. If objections were raised, which of the following groups raised them?
   __board of trustees
   __medical staff
   __administration
   __attorneys
   __other

8a. What are the kinds of ethical issues seen most frequently? (Concerning patient care)

8b. Do you see a change in the types of ethical issues you find problematic? (For example, at one time were you more concerned with termination of treatment whereas now you are more concerned with indigent care.)

9. Which are the most problematic for your clinic?
10. What is the structure of making ethical decision within the clinic? ___doctors alone ___team ___family

11. What role does the family or patient have in decision making?

12. Has there been any discussion about having an ethics committee? If yes, what is the discussion? If no, why not?

13. What are the advantages and disadvantages of the clinic continuing with its present policy of not having an ethics committee?
REFERENCES


President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to Forego Life-Sustaining Treatment. March 1983.

