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SECOND THOUGHTS

Hospital Ethics Committees, Consultants, and Courts

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Hospital ethics committees grew out of legal controversies regarding the refusal of life-sustaining treatment. We review the fragmented history of hospital ethics committees and argue that though they were born of concerns about legal liability, they do best when they stick to clinical ethics and leave legal questions to a hospital's attorney and the courts. We also underline that procedural mechanisms, including ethics committees and advance directives, have not had a measurable role in improving end-of-life care or reducing end-of-life treatment conflicts.

The Karen Quinlan Case and the Emergence of Institutional Ethics Committees

A famous hospital ethics committee, and the one that began the movement for hospitals to have ethics committees, was instituted by the New Jersey Supreme Court in 1976 in the case of Karen Ann Quinlan [1]. The court determined that Ms. Quinlan, who was in a persistent vegetative state, had a constitutional and common-law right to refuse treatment, even if the refusal would result in her death. Nonetheless, her physicians were unwilling to remove her from a ventilator unless they were reassured that they could not be sued for this action. The court was sympathetic to the physicians and ruled that if a hospital ethics committee agreed with their prognosis—that there was "no reasonable possibility of Karen returning to a cognitive, sapient state" [2]—the physicians would be immune from any legal liability for removing her ventilator at her parents' request. The court had two desires: to help the Quinlans end invasive and unwanted treatment of their daughter and to discourage physicians and hospitals from taking their conflicts with patients outside the hospital for courtroom resolution. The court's ruling, unique among all other state courts that have heard similar cases, permitted hospital ethics committees in New Jersey to grant physicians legal immunity based on a prognosis determination [3].

Similar "right to die" decisions were handed down by courts in other states—but not the immunity-granting authority the New Jersey court bestowed on its ethics committee [4]. Not only did no other state grant ethics committees this authority, but even in New Jersey, the Quinlan-styled "ethics committee" was renamed a "prognosis committee" (because its real charge was to make a prognosis determination) with membership limited to neurologists and neurosurgeons [5]. Nonetheless, some hospitals liked the general idea of using an ethics committee to help resolve conflicts and keep them out of court. Although hospital ethics committees can't grant legal immunity, an expert

committee's agreement that a proposed resolution of a conflict is consistent with good clinical practice means that the likelihood of a successful lawsuit approaches zero. On the other hand, although most ethics committees are advisory only and don't make decisions for physicians, at least some physicians we have worked with feel that it is extremely difficult for them not to take the "advice" of this committee (assuming the committee has experts on clinical ethics, clinical practice, and hospital policies), because it could open them up to a lawsuit if the patient is made worse off by their nonconforming actions. This might inhibit some physicians from seeking help from the ethics committee in the first place—at least those who believe that clinical-ethical decisions should be made in the context of physician-patient relationships and that resort to a committee could do more harm than good. This is because whenever a physician requests a consultation, the working assumption is that expert help is needed and the advice of the expert will be followed (at least if not following the advice cannot be satisfactorily explained by the physician in the health record).

Other Related Committees

Other types of ethics committees had been formed to oversee nontherapeutic activities in hospitals, most notably human subjects research. Research by physicians on their patients (and on nonpatients) had been associated with use and abuse of human subjects as means to an end, because the research context was a nonfiduciary one: research was being done to gain generalizable knowledge to benefit society and there was potential for significant harm to the patient/subject. In the mid-1960s (about a decade and a half before the Quinlan case), Congress recognized that a new and independent mechanism was needed to protect human subjects, which led to the federal government's creation of what is now known as the institutional review board (IRB) in 1974 by the National Research Act [6-8]. Unlike an ethics committee, an IRB is required by federal law and bound by a set of federal regulations that determine the scope of its authority (limited to human subjects research) and set criteria for its deliberations and decisions—specifically, determining that the risks of a proposed experiment are less than the expected benefits and requiring that informed consent is obtained [9].

Around the time of the Quinlan case, another type of ethics committee, the abortion committee, was being abandoned. The abortion committee, required by some hospital policies, was a group of physicians whose concurrence was required before a physician could perform an abortion. In the 1973 opinion of *Doe v. Bolton* (a companion to *Roe v. Wade*), the US Supreme Court decided that this was an unconstitutional interference with the rights of pregnant women and their physicians and that the concurrence of other physicians could not be a requirement for all of physicians' treatment decisions—the state could require medical licensure, but not the concurrence of a committee of physicians, prior to the performance of a medical procedure [10]. Abortion remains the most politically controversial medical procedure, but the *Doe v. Bolton* ruling against committee approval has never been challenged.

In the early 1980s, the American Academy of Pediatrics recommended that all hospitals with neonatal intensive care units establish "infant bioethics committees" to advise on the treatment of infants with severe disabilities. This was in response to, and intended to be a substitute for, the Reagan Administration's "Baby Doe" regulations concerning the nontreatment of newborns with disabilities such as Down syndrome. The administration's rules were ultimately thrown out in court because the courts found that making treatment decisions for newborns with disabilities—and the even more complicated premature newborns—was properly classified not as possible child neglect (a state law issue) but rather as a complicated judgment best left in the hands of a child's parents with the guidance and approval of the child's physician [11]. In our view, no further progress has been made in this area, although hospitals with major neonatal intensive care units continue to have ethics committees to provide advice on request. (We have both served on such committees.)

The Contemporary Institutional Ethics Committee

Post-Quinlan institutional ethics committees (IECs) were initially formed to deal with adults in critical care [4] and focused frequently on do-not-attempt-resuscitation (DNAR) orders—previously known simply as DNR or do-not-resuscitate orders—the right to refuse treatment, determination of death, and organ transplant issues. Often the committees helped a hospital develop written policies and procedures concerning these issues. Subsequently, especially in large safety net hospitals like the one we work in, disputes have become more often centered on conflicts caused by a disagreement between patient or family and the clinical team about demand for treatment judged to be nonbeneficial or even harmful. This is sometimes called the "futility problem," although we think it is mostly a communications problem compounded by unrealistic expectations on the part of a patient's family.

Ethics committees continue to exist and, in our experience, deal mostly with end-of-life conflicts and policies. Nonetheless, the nature, membership, scope, limits of authority, and accountability of institutional ethics committees have still not been well established. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), for example, requires some mechanism for ethics review but doesn't specify what it must entail [12]. By contrast, an IRB derives its authority and mandate from specific federal regulations, which it is required to follow. Although the legal liability rationale for IECs has faded into the background, it is still worth recalling that, at IECs' birth, a committee of the American Hospital Association recommended that IECs all have at least three lawyers as members: one to represent the hospital, one to represent the IEC itself, and an independent lawyer to give the committee neutral advice (William Curran, personal communication). It was also suggested that, since the ethics committee is primarily a procedural mechanism to resolve disputes, a procedural expert (i.e., a lawyer) should act as the committee's chair. Thankfully (in our opinion) this view has not prevailed. Although ethics committees may

well resolve specific disputes, they act best, we think, as substantive policymakers and education resources. They should not act as part of "risk management"—that's the job of the hospital's legal team.

In our experience, it seems fair to conclude that, over the past decade, IECs have been primarily involved in four activities. Three are uncontroversial: education about clinical ethics (which does not require a committee); assistance with developing and implementing policies such as end-of-life care, drafting of DNAR order policies (when it is helpful to have a multidisciplinary committee), and assistance with determinations of brain death; and retrospective review of complicated cases reflecting systemic problems and requiring policy changes. The fourth activity can be controversial because it can seem to be setting the committee up with decision-making authority. This activity involves ethics committees' prospective review of ongoing cases, which requires a consultation mechanism or subcommittee meeting rather than the convening of an entire committee, as the cases are ongoing (i.e., a process similar to consultation liaison psychiatry).

Ethics committees continue to evolve, as do the nature of the cases and conflicts they are asked to help resolve. In our opinion, two main types of conflicts predominate today, both focusing on end-of-life care conflicts. We strongly believe that the vast majority of what are framed as ethical disputes are more accurately understood as problems of communication and group dynamics and can best be addressed by standard conflict resolution processes, including listening to the patient and the patient's family. In our experience, communications problems are much more readily resolved by an ethics consultant leading a discussion with all of the clinical personnel involved in a particular decision, rather than by taking those problems to a committee for discussion. Of course, because ethics committees are not on duty 24 hours a day (though some have members who are on-call for ethics consultation) and, like other hospital committees, meet regularly—once a month being a common schedule, in our experience—only a representative or two of the committee can help in real-time conflict resolution, usually through a mechanism like a "clinical ethics consultation service." The cases to which such a service is most likely to be called for help are those in which there is either no family member available or the family is demanding continued treatment that clinicians no longer believe is indicated or beneficial (just the opposite of the *Quinlan* case, which started it all).

Our experience with ethics consultations and ethics committees in a large urban safety net hospital leads us to conclude that those that are difficult to resolve present no clear-cut answers. As one of us (MG) has put it, "difficult cases are difficult because they are difficult." This seeming tautology can be helpful to both physicians and families in beginning to tackle an ethics problem, the discussion of which can usefully be opened by trying to identify why people are uncomfortable with making treatment decisions. While

almost all ethics committee questions involve end-of-life decisions, those that also involve the poor, disenfranchised, culturally different, and friendless are especially difficult in a culture that both marginalizes these groups and valorizes autonomy. This makes decision making even more challenging in the context of a poor neurological prognosis and when the patients themselves are not competent to make their own decisions (the original *Quinlan* problem, which is still with us).

The movement to get everyone to articulate their directives for end-of-life care, and to appoint a health care agent to make decisions for them when they are unable to make them themselves, is all to the good. Nonetheless, forms and committees will never be able to prevent all clinical controversies at the end of life, because these reflect substantive views on death and how much should be done to delay it. It is at least discouraging that after 40 years of hospital ethics committees, the way we die in hospitals continues to be recognized, both by major medical groups like the Institute of Medicine and popular medical writers such as Atul Gawande, as a major scandal necessitating major overhaul [13, 14]. Ethics committees cannot solve all the problems of death and dying in hospitals, but we think they have a constructive role to play in helping to develop policies and educate clinicians in ways that are likely to promote both patient rights and good health care.

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