

**DIALOGUE TO ACTION:
INCLUDING PUBLIC EXPECTATIONS
IN HEALTHCARE ETHICS**

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Introduction

Dialogue to Action is a pilot program that establishes a link between hospital ethics committees (HECs) and the public they serve to consider how ethics committees should define their role within hospitals. It is directed by the Division of Medical Ethics at the University of Utah and LDS Hospital, and partially funded by a grant from the Utah Humanities Council.

The impetus for this project stems from several concerns. The first is that despite the proliferation of HECs, members of the public may only be vaguely aware of them, the kinds of issues they can help resolve, how to access them, and how they may serve as a patient resource. The second concern is that even those serving on the growing number of HECs are confused about their committees' roles and what their future functions should be, especially with the increased presence of managed care in the healthcare system and the resolution of many early questions for bioethicists, such as the acceptability of withdrawing care. A third concern that gave rise to the project is the perception at many institutions, including ours, that the HEC is removed from real cases and patient concerns. HECs are seen as existing in an abstract realm of policy, theory, and self-education rather than in the more concrete realm of patients, families, and their hospital experiences.

This said, it may be that HECs are ready for a "shift in perspective" that would allow them to view ethical issues in a broader, more comprehensive way (1). To this end, we decided to explore the kinds of care that dying patients and their families received — if and how they participated in medical decisionmaking, where they waited, what they found helpful, and what they would change if they could — and thought

that the best way to learn about these issues would be to talk with the people who had experienced them. By making this project participatory we hoped to create an environment in which our HEC could focus its efforts where they are most needed and avoid the presumptuous position of assuming what is important to patients and their families during their hospital stays.

With these ideas in mind, our goal for Dialogue to Action is to make HECs, and ours in particular, more responsive to the public's needs and concerns. We want to know what the public expects from hospital care, whether or not those expectations are being met, and how ethics committees might help if they're not.

Our first step toward this goal was to establish a forum for discussion between the public (as represented by families of patients who had died in our hospital) and healthcare workers about the assumptions that underlie modern medicine and how they play out during hospital stays. The second step was to share the comments that we gathered from such a dialogue with other HEC members from the Intermountain region so that they, too, could respond more directly to the needs of patients and their families.

To bring members of the public and health care providers together we conducted the first of two planned programs in Salt Lake City, Utah, at LDS Hospital. Members of LDS Hospital's ethics committee met with a facilitator in one room while members of the public met with a different facilitator in another. Both groups' discussion were framed by structured questions. At the end of the first hour, members of LDS Hospital's ethics committees joined the family members to learn about their hospital experiences and to share comments from their own discussion. The program content will be addressed at length below.

Methods

Recruitment

During late December 1994, Health Information Services at LDS Hospital generated a list of patients from the greater Salt Lake City area who had died in the hospital between August 1993 and July 1994. We chose July as our end parameter to make sure that the families we contacted would be at least five months away from their loved one's death. From this first list of all the patients who had died at the hospital,

Dialogue to Action

we selected 131 patients by identifying the hospital units that the patients occupied when they died. We selected all of the patients from the hospital's Intensive Care Units (ICUs) and oncology units before considering the more heterogeneous medicine wards. Our primary rationale for this selection was that we knew that most deaths occurred on these units and we hoped to have more than one representative family from them.

Based on our consultation with others experienced with focus group discussions in a medical setting, we decided that 12 people would serve as the target size of our group. We were told to anticipate at least a 10 percent no-show rate, and we recruited our participants accordingly.

To determine the name, address, and phone number of the 131 patients' "next of kin," which included relatives and significant others, we reviewed the patients' charts. From the death certificates we identified 155 names, addresses, and phone numbers. (Some patients had listed more than one next-of-kin or emergency contact person.) We sent a brief, introductory letter that invited them, and a support person of their choice, to a dinner and discussion. The letter explained that the discussion would center on the care that they and their dying patients experienced at the hospital and the ways in which HECs might help make that care as compassionate and appropriate as possible. We described our program and what we hoped to accomplish with it, and told them to expect a call from us within the next week.

After the ten days had passed, we called everyone who had been sent a letter. When 17 letter recipients, representing as many patients, had accepted our invitation for the evening discussion, we decided that we had enough participants, especially if each was accompanied by a support person. We continued our calls, however, and told the other "next of kin" contacts that we couldn't include any more participants in the session mentioned in their letter. Those who were unable to attend on 17 January 1995 because of our space limitation or their own schedules were asked if they would like to participate in the future.

We also sent a short letter to the 32 members of the HEC that explained the evening's agenda to them and invited them to participate in the discussion.

Format

The "next of kin" met for dinner in the Administration Board Room from 6:00-7:30 p.m. The session was facilitated by Leslie P. Francis, Ph.D., J.D., a member of the Division of Medical Ethics, Professor of Law, Professor of Philosophy, and Adjunct Associate Professor of Internal Medicine. After giving a brief overview of the evening, she asked the relatives and friends to introduce themselves. Then, she asked the group the following questions.

1. How were you, and especially your family member, involved in the major decisions made during his or her illness?
2. What do you think a hospital ethics committee is?
3. Given what has been said about medical decisionmaking and ethics committees, what do you expect an ethics committee to do?

After the participants offered their answers to the second question, Professor Francis took a few moments to explain the *purpose* of HECs and the expertise of the people who serve on them. Specifically, she told them that HECs are groups of 12 to 15 volunteers from multiple professions and perspectives, such as medicine, nursing, social work, law, administration, and religion. She explained that the HEC is expected to [1] assist with conflicts between patients/physicians/families; [2] educate hospital staff; and [3] develop and review hospital policies and guidelines. She also mentioned that the committee assumes an advocacy role, as part of its mission, to ensure that the wishes of patients and, when applicable, their families, are respected with regard to medical care decisions.

While the public participants met in the Administrative Board Room, another facilitator (JAJ), addressed similar questions to members of the HEC in the Administrative Conference Room. Ethics committee members were also asked three questions.

1. What do you think the public knows about ethics committees?
2. During the care of critically ill patients, what kinds of issues arise that could benefit from committee involvement and/or policy change?
3. How are we addressing these kinds of issues?

Dialogue to Action

Comments were recorded during both sessions and the public session was taped for transcription. Evaluation sheets were provided to all participants.

Results

Participation in our program, from both the public and the HEC, was beyond our expectations. The level of interest voluntarily expressed by those unable to attend surprised us, as well. By phone we reached 81 of the 155 people to whom we sent letters. Of these, 46 (57 percent) were willing to participate in our program. Seventeen agreed to attend the 17 January 1995 program with at least one support person, which gave us a total of 26 people. Twenty-nine letter recipients were willing to participate in a future program if we planned one. Of those 26 members of the public and their support person(s) who agreed over the phone to attend, 23 of them did, they represented 11 patients. Two of the three "next of kin" and support people who didn't attend phoned to explain that their absence was due to winter weather conditions.

We made repeated phone calls at different times of the day but were unable to reach 74 of the 155 letter recipients, largely because of disconnected lines and wrong numbers.

Our group of patients' family members and friends was diverse. Participants ranged from a Hispanic mother and daughter who had lost a son/brother in his mid-twenties to injuries sustained in a car accident to an elderly Caucasian couple who had lost a close friend after long-term medical illness. We had several older attendants who had lost a spouse, adult children who had lost parents, and a young woman with children who had lost her husband. They represented different religious denominations, socio-economic levels, and ethnic backgrounds. Some family members said they had a "good" hospital experience while others were still angry and confused about the treatment their family member received.

Eleven of the hospital's thirty-three ethics committee members agreed to participate in the evening so that they could listen and respond directly to the public's comments and questions. Nine of the eleven actually attended.

While each family's experiences differed, several themes emerged

during the discussion. The most consistent theme that ran through their comments was the extraordinary value that they placed on being involved with decisionmaking. They expressed a tremendous amount of gratitude toward those care providers — mostly nurses and social workers, but some physicians too — who took the time to educate them about their loved one's condition, not only the availability but the wisdom of various treatment options. It seemed that while participants wanted to know the diagnosis, prognosis, and treatment options, they also wanted to have the implications of each explained and interpreted. Merely being told that their loved one had metastatic breast cancer or an ischemic bowel, for example, wasn't valuable to them. What was valuable to participants was how this disease would affect them and what it would mean in their own lives and in the lives of their hospitalized family members. Similarly, those who knew that their loved one's condition was terminal and deteriorating weren't content with just knowing that. They wanted more information about what they could expect on a day-to-day basis during the dying process.

Once they had a better sense of the medical situation, those participants who indicated that they had a positive experience said that they felt empowered to be involved in subsequent decisions and, in most cases, they were. Those participants who had a less positive experience drew a distinction, however, between being informed about, or *told of*, the medical decisions that were made, and being more actively *involved in* those decisions.

Participants also valued being with their loved ones as much as possible. Whether it was in the Emergency Department trauma room or the ICUs they wanted to be able to touch and hold their family members. They also wanted to have as many family members as possible with the patients during all stages of the hospital stay, especially as the patients neared death.

The third theme that emerged from the stories was perhaps the most poignant: a sense of isolation and disorientation that most families felt. Several of them said that, as they faced value-laden decisions, such as the withdrawal of care, they felt like they were the only ones who had ever been faced with the enormity of such a decision. They reported feeling utterly alone and not knowing how to proceed. When they were faced with weighty decisions, family members said they had desperately

Dialogue to Action

wanted information about what other families in similar situations had decided to do.

While they groped for information to help them make decisions for their loved ones, participants said that they also wanted to know what was morally right and acceptable for them to do. They were searching for paradigms to help guide them through their worlds that had been placed in flux by the serious illness of their loved ones. To this end, several of them indicated that they wanted to know what their respective religions' positions were on issues like withdrawing care or deciding against aggressive treatment.

Family members almost unanimously indicated that they would have contacted the HEC for help and clarification with their decisionmaking for their loved ones if they had known of its existence. The fact that they didn't, confirmed the HECs worst prediction about answers to the question — "What do you think the public knows about ethics committees?" To be sure, our participants weren't a representative, random sample of the public. Nevertheless, our participants suggested that the public, particularly those who are in the hospital as patients, know very little, if anything, about HECs. Committee members thought that those who had at least heard of HECs still might have misconceptions about them and think that they only address end-of-life issues.

Committee members thought that HECs could provide patients with information about specific aspects of hospital policy, such as the suspension of DNR orders during surgery. They also thought that committees could be involved in decisions about third-party carrier issues, preferably on a policy, rather than individual patient, level.

Discussion

Traditionally, the focus of medicine and the ethical considerations about it have had little to do with notions of family, particularly the members of a family after a patient dies. Much of the institution of medicine is centered, and in most instances rightly so, on patients, their illnesses, and their hospital experiences. It is entirely unclear if, and to what extent, family needs ought to be considered in hospital planning and medical practice and, moreover, who, exactly, ought to be responsible for such considerations. Families certainly aren't peripheral to patient care

when patients are incompetent, but it becomes less clear to what extent medical practice should be concerned with them when patients are competent.

From a purely administrative, public relations, and health-care-as-business perspective, it may not be unreasonable, and indeed may even be prudent, to consider the kinds of experiences that family members have in our hospitals, and the kinds of impressions that they carry with them into the community. However, there seems to be a more intrinsic reason to consider families from a medical perspective. Much has been made of the need to make medicine "more humane" and to move in concentric circles out from identified infection or malignancy so that the patient is seen as a *person* rather than a disease to be cured or a problem to be solved. In this effort to step back from the view of patients as diseases that one might find under a microscope, to see diagnoses and treatment options in relation to the patients they affect, and to take patients' *context* — social, economic, educational, religious — into account, it seems perfectly reasonable to see some patients in relation to the social network of their family and close friends, just as their disease is seen in relation to them.

At the very least, we thought that it was important for our HEC to grapple with these ideas and to determine if they were important to our ever-evolving ideas about patient care. By talking with family members about their needs — those that were met and unmet during their loved ones' deaths—we hoped to provide the HEC both with the framework and content for a discussion about what is important in patient care, the ways that medical decisions are made, how and where they are made, and who in the hospital is or should be responsible for addressing these issues.

The stories that participants related and the recurrent themes that emerged from them were intensely powerful, educational, and, in terms of the honesty and emotion with which they were told, very real. They can be read on multiple levels. In an atemporal way, they speak to the need to humanize medicine and how it is "delivered" in a system that is becoming increasingly mechanized in the name of cost reduction and efficiency. The very facticity of the stories, and the number of people willing to come and share them, reflects the importance of providing family members, and when possible patients, a forum to voice their evaluation of, and suggestions for, medical care. Family members, one step

Dialogue to Action

removed from the patient-physician interaction and the institutional structure built around it, have pointed observations. Yet at the same time that participants' stories were describing events that were "outside" of them, they reflected a great deal of internal resilience on the part of the "story tellers."

Finally, the ways that participants described themselves as understanding their own stories are consistent with studies that suggest that the more involved and informed families and patients are, the more comfortable they are with their care (2)(3).

When we asked participants how they and their family member had been involved in patient care and treatment decisions we heard two general reactions. Either participants had a good experience, in which case they at least felt involved in making medical decisions, or they had a bad experience, which usually meant that they had not been consulted about their opinions, or when they were, felt that their opinions were disregarded. With both reactions, the key elements were communication and information. In a synergistic way, these components work together to make family members, as well as patients, empowered within the medical decisionmaking process.

Good communication between patients, family members, and healthcare providers provides a sense of involvement and establishes a context in which a patient and/or family can make decisions. Family members thought that HECs could encourage physicians and nurses to provide more information about available treatment options. Because they felt that it was difficult to process new information while a physician or other healthcare worker is in the room, some family members even thought that the HEC could oversee the production of literature that explains different ways of reasoning through medical decisions, reviews relevant hospital policy, and provides some descriptive information about what most people decide to do in certain cases. Such a document would be something that the family and patient could refer when the healthcare worker was absent.

One family indicated that they had a positive hospital experience because they felt that their physician communicated well with them about the care that their loved one received, the various alternatives available, and even about the existence of the hospital's ethics committee. However, after listening to the experiences of others, they felt their

experience was unique. They suggested that HECs, with soft guidance through both policy and education, can help create a hospital system that would enable physicians to learn to communicate better, which in turn would keep families informed and involved.

Several families, however, felt that the notion of "involvement" was a cruel charade. They not only felt shut out of the "information loop" and stranded because of poor communication, they also felt isolated from their loved ones, from the healthcare workers, and from other families who might have had similar experiences.

Because of the lack of communication, and, therefore, information available to her, one daughter's hospital experience was one of frustration. Her mother had a DNR order when she was admitted to the Emergency Room, but it was overridden during surgery. Her mother emerged from the Operating Room on a ventilator. Completely outside of the decisionmaking in this cases, the daughter felt she had no choice but to accept the surgeon's explanation for why her mother's DNR order was ignored. The situation was even more stressful and disturbing because she was unable to obtain a clear answer from him about how long her mother would be dependent on mechanical life support. She subsequently found herself in the very position she and her mother had hoped to avoid with the DNR order. In retrospect, she wished that more information had been provided initially about the risk of cardiac arrest or pleural fluids during surgery and how DNR orders are customarily suspended during surgery. If they had known these "customary" procedures with regard to DNR orders, she and her mother might have made different decisions, or at least been more explicit about the nature of the DNR order.

But when *families* are in the position to make decisions, one family aptly noted that their desire to be the ones making care decisions doesn't mean that they want physicians, nurses, or their opinions to disappear. Family members' desire for involvement in decisionmaking doesn't mean that they want to be abandoned to *their* decision. One family in particular remembered wanting more support as they made the decision to discontinue life-sustaining treatment for their father. Specifically, they wanted to know if what they had decided was ethically acceptable for them to do.

Who is there that you could have turned to?...When we made the decision to take my father off life

Dialogue to Action

support...we felt, in a way, like we were doing it blind. We didn't realize what taking him off life support meant having never dealt with the issue. And when we realized that it literally meant taking everything away from him and then he didn't die, and they said it could be *weeks* before he died...we felt like we were killing him and no one addressed this issue with us. And it wasn't until we pressed the issue: 'Is he suffering?' — that they finally said, 'We can give him morphine,' which did allow him to slip faster and die... I mean we really thought we were in the dark. And that was very frightening.

The family also wished they had been given more support after the decision had been made. As it was, once they made the decision to stop the ventilator, feeding, and hydration, they said they never saw their physician. "*Nobody came back.*" Ethics committees could examine what might be motivating the physician's avoidance and then consider what alternatives would be available, if necessary, to prevent a family from feeling abandoned by their loved one's physician, who, while not actively caring for them, exists as what social psychologists call "social anchors."

The notion of abandonment seemed to resonate with several families in another direction in terms of how close they wanted to be to their loved ones. Even if *they* felt abandoned, and perhaps because of it, families didn't want their loved one's to feel abandoned. Family members wanted to be with their loved ones as they died. Yet, before death seemed imminent and when medical interventions were still being explored, family members wanted to offer what they could: support, love and presence. During resuscitative attempts and line placements, for example, they wanted to hold their loved ones' hands, or just be in the room.

One mother whose son was brought to the ER following a car accident and who was allegedly declared Dead-On-Arrival (DOA) wanted the HEC to explore not only why seemingly futile treatment is initiated and continued, but also why family members are denied access to their loved ones at that time. Months after her son's death and her hospital exposure she didn't understand why hospital staff decided to "bloat" her son with 21 pints of blood and proceed surgically after telling her that he

was DOA. She said she understood that physicians and nurses "wish to save everybody" but she thought there should be a mechanism to limit treatment. Her requests for the cessation of aggressive treatment were apparently ignored. She grieved about being outside of this decisionmaking process, but even more so about being kept from her son during the attempts that were made to save his life.

I knew he was dying and I would have given anything to sit with him, which I was not allowed to do.... And that is what I wanted to do.... [T]hey wouldn't let me go in there. And I didn't *care* what he looked like. They were try'n' to tell me that the plastic surgeon had to go in and do.... There was nothing wrong with his face. I understand that they want to clean him up. I understand that they wanted to make him presentable. But I've seen him in a hell-of-a-lot of different ways and I didn't care. I just wanted to be with him while he died. I just wanted him to know that his mother was there at the last minute. You can't always be with him. You can't always be there. But I felt at that time I had an opportunity to [be there].

Perhaps for many of the same reasons and sentiments expressed by this mother, several other public participants told us that they had taken vigorous steps to make sure that as many family members as possible were with their loved ones as they died. One gentleman who had been at home when his wife had a cardiac arrest asked the nurse to keep her alive until he and his children were able to reach the hospital.

Family members thought that HECs, because of their broad representation, are well-suited to examine why physicians and nurses may be uncomfortable with a family's presence in general or during some procedures. They hoped that the HEC would initiate a dialogue in their hospitals to include families as much as possible — through communication, through physical presence during some procedures — in patient care, especially when the patient is deteriorating.

In response, HEC members suggested that prohibiting family members from being with their loved ones probably stemmed from physician and nurse discomfort at "being on display", as well as from the

Dialogue to Action

assumption that it would be an undesirable experience for family members. Emergency staff, for example, may hesitate to permit family involvement because of their fear that family members would interfere with medical care. No data exist to support these claims, and, in fact, one study suggests that with careful selection and preparation, family members can be present during some procedures without disrupting medical care (4). Ethics committee members acknowledged that our hospital policy allows visitation, but that hospital staff, based on their own biases and emotional comfort levels, may sometimes enforce their own limitations on family visits.

Despite the variety of participants' experiences and their internalization of them, the most broadly-held position was that they would have used the resources that the HEC could provide if they knew more about them. One woman expressed a desire for some kind of guidance, and said she would want the ethics committee

to mediate, or to give some precedents, or "this is what is often done" so [families] don't feel like [they're] the first [ones] to have done this and [they're] doing it alone and making that decision. I would have liked to have had someone say: 'Under these circumstances this is something that happens often, and this is a choice that you can make, or, you can choose this.' But just that reassurance that it was an ethical decision and that it was something that was acceptable and something that was done all the time.

Other participants wanted HECs to be more proactive throughout the hospital rather than waiting for "traditional" ethics problems — such as conflict over withdrawal of treatment — to come to them. For example, they wanted the HEC to take a step back from medical culture and examine some of the unquestioned and common practices mentioned above — such as suspending DNR orders during surgery and some radiological procedures, keeping families from their loved ones during resuscitation attempts and other procedures in the Emergency Room, on the medical wards, or until the patient has been "cleaned up." They also wanted to have the HEC review protocols and oversee education to make

sure that treatment was not continued when it was medically futile. In this regard, they seemed to see HECs as having a more general role than simply serving to resolve conflicts. They saw the HEC in a role of examining hospital medicine from a variety of different perspectives in order to make it, and those who practice it, more aware of how those perspectives intersect.

Participants saw the HEC as a group of people who could facilitate better communication between physicians and patients as well as between co-workers. They also saw the HEC as an interested and educated group of people who could provide patients and families with medical information and "answers" to questions about everything from religious positions on certain issues to what happens when someone dies. On another level, they clearly saw the committee as a group that could better educate physicians, nurses, and other clinical staff about the kinds of ethical issues that might arise in the course of patient care, such as the acknowledgement of a mistake or the futility of care. In short, our participants strongly suggested that the HEC develop a more effective mechanism within the hospital to educate hospital staff, as well as patients, about the committee in general and how to access it.

Because we limited the number of participants in our focus group to encourage discussion, one ought not to generalize from the information we collected and the patterns we observed. Our sample group was also limited because it was not necessarily representative of the hospital population; indeed, those who attended our program from this group were self-selected. However, based on the amount of corroboration that spontaneously occurred between participants as they told their stories, as well as our own experiences, the points above, while not collected in a systematic and entirely representative manner, are at least common enough to warrant further attention and consideration.

Conclusion

Based on our evaluations, informal comments after our discussion session, and subsequent HEC meetings, it is clear that the public participants as well as the HEC members, found the Dialogue to Action program valuable, and the issues raised during it worth further exploration. The public participants appreciated the opportunity to share

Dialogue to Action

their opinions, experiences, and suggestions for improvement with the healthcare workers on the HEC because they perceived committee members as willing to initiate changes in the hospital based on their experiences. Members of the HEC were clearly affected by the stories they heard and were subsequently motivated to identify those aspects of patient and family care that could be improved, e.g., the public's knowledge of HECs, patient and family access to information about ethical and medical decisionmaking, and communication between healthcare workers, patients, and families.

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