The Shared Burden: When Physicians and Families Decide to Forego Life-Sustaining Treatment

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Family physicians are being called upon to make decisions regarding whether to forego life-sustaining treatment. These decisions are made based on consultation with the family of the patient but are complicated by problematic family interactions. The family physician can manage difficult family reactions and assist the family in making a decision by (1) understanding that there are common reactions to loss and bereavement on the part of family members such as anger, denial, and feelings of helplessness; (2) assessing whether problems arise from chronic family conflicts (marital, parent-child, or previous unresolved mourning) or are situation related (unexpressed feelings, how to tell others, need to feel they have done everything, overwhelming other stresses); and (3) incorporating several specific techniques into their practices such as family conferences, accepting anger, involving anxious members in treatment planning, referral to self-help family groups, reframing the decision in terms of the patient's wishes, and negotiating mutually acceptable solutions when patient or family members disagree.

Recent attention to cases of hopelessly ill patients has brought focus on the role of the physician in the decision to forego life-sustaining treatment. As medical technology has advanced, the professional literature has begun to address the complicated ethical, medical, and legal questions in treatment decisions.[1] Medical schools and residencies are providing seminars to help students and residents grapple with the issue. Most recently, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published the results of extensive research and made recommendations regarding the decision to forego life-sustaining treatment.[2]

The family physician, however, rarely makes these decisions in isolation. He or she must work with the patient's family to come to an acceptable decision. The family physician often finds himself confronted with complicated family reactions that contribute to unsatisfactory resolutions. Currently, there is a growing recognition of the importance of teaching family systems concepts and techniques to family practice residents as a method of enhancing the physician's ability to

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detect and prevent problems arising from family dysfunction.[3,4]

This article attempts to provide a framework for family physicians to understand the family's reactions and presents techniques to facilitate the physician's relationship with the family. While such recommendations cannot resolve all conflicts, the attempt has been to provide some clarification and guidelines to ease the burden of those involved.

The President's Commission for the Study of Ethical Problems in Medicine[2] has recognized this issue in its statement, "When there are several treatment options that are acceptable to all interested parties, and there is no advance directive from the patient, the option actually followed should generally be the one selected by the family." Wanzer et al[1] in 1984 stated that, "In their absence [living will or proxy], the physician must ascertain from family and friends the attitudes and wishes the patient would have expressed had competence been maintained."

Foregoing life-sustaining treatment includes the decision to withhold or withdraw all or some measures that are reasonably expected to prolong life because the benefits no longer seem worth the burden created. A more detailed discussion of the ethical, medical, and legal aspects can be found in *Deciding to Forego Life-Sustaining Treatment*.[2]

The first step in alleviating problems regarding decision making is understanding family reactions to fatal or terminal illness; the second step is an appreciation of underlying family dynamics that result from chronic problems in the family or stress reactions to the current situation; the third step is the incorporation of several practical techniques in the physician's contact with the family.

Common Family Reactions to Fatal or Terminal Illness

Situations in which there has been slow progression of a disease, with considerable pain and debility to the patient leading to loss of consciousness, often bring the family to the point of being grateful for the patient's death and the termination of his suffering. On the other hand, situations such as automobile accidents causing massive injury often produce a family reaction of profound shock, disbelief, and unwillingness to accept the fatality of the situation. The age of the patient also affects the family's reaction. Although grief is felt at the death of an elderly patient, family members comfort themselves by the thought that he had lived a long and full life.[5,6]

Despite such differences, certain commonalities exist in family reactions to the consideration of foregoing life-sustaining treatment. Families often request another medical consultation, misconstrue information the physician gives them, or forget certain things they have been told. The physician may witness what seems to be unreasonable anger at the patient and himself or a stoicism and detachment that appears to be coldness or lack of affection. Family members feel guilty about not having done enough or done the right things and may behave in an overprotective or overindulgent manner. Usually such a response is of a transitory nature and will be decreased as the physician listens and reassures.

Another common reaction by family members is that of overacquisition of knowledge in an attempt to cope using the defense of intellectual mastery. Patient and family members seek out popular literature and medical journals and ask the family physician endless questions until they have satisfied themselves that they know everything there is to know and have done everything there is to be done. For family members accustomed to dealing with life in a cognitive manner, this adaptive coping strategy helps them feel more in control.

Another problematic reaction of the family is overt or covert competition with the hospital staff as a result of the hospital having taken over the family's nurturant role. The hospital becomes the major caretaker by feeding, dressing, and toileting the patient. For family members who were formerly very involved with the care of the patient, the result is a loss of role and function. Competition may result in uncooperative behavior on the part of family members and even sabotage of treatment plans.

Family Dynamics that Interfere with Decision Making

A practical understanding of the family as a sys-

tem of interrelated members who share both a history and future together and who shape each other's thoughts, decisions, and actions can clarify treatment decisions. While it is not recommended that the family physician become a family therapist, a recognition of family interaction patterns enables the physician to retain some emotional distance when necessary, to provide support and reassurance, and in some cases actively to intervene to facilitate the process. As most cases do not present themselves with predefined problem areas, the following brief outline is intended to provide a basis for making a family assessment.

For the purpose of this paper, family dynamics are divided into two categories: (1) longstanding problems, and (2) reactions to the current crisis.

Longstanding Family Problems

Marital Conflict

A history of marital problems will make it difficult for a couple to put aside their ongoing battles to come together about a decision regarding one or another's parent, particularly if they have unresolved feelings regarding in-laws or a history of underinvolvement or overinvolvement with their own family of origin. Marital partners may appear to be emotionally distant, dealing with the situation in isolation from each other or using it to fight longstanding battles between them. In other cases, a history of chronically conflicted marital relations may prevent a spouse from making a decision about husband or wife because of feelings of guilt, hostility, or disappointment.

Parent-Child Conflict

All parent-child relationships are characterized by a certain amount of ambivalence regarding the dimensions of closeness and distance, independence and dependence, and overinvolvement and underinvolvement. In the adult, stored-up feelings of rejection or hostility from or toward a parent-now-patient can produce guilty feelings resulting in overprotectiveness and unrealistic wishes to prolong life. On the other hand, distancing and avoidance behavior may result in some family members prematurely urging the termination of life. In other cases, a history of emotional distance or jealousy and competition between siblings can place the physician in the middle of a family feud in which old battles are simply fought out in a new arena.

When a young child is the patient, the situation is often more complex because of developmental issues, and a thorough explanation of the issues would require more detailed investigation than the space in this article. Briefly, however, unconscious disappointment in and anger at the child can cause overinvolvement and overprotectiveness resulting in rage at the family physician and hospital staff for not doing enough. On the other hand, overwhelming pain or the need to deny attachment can result in parents' wishes to forego life-sustaining treatment earlier than seems medically indicated.

Previous Losses and Unresolved Mourning

In families where there have been other disturbing losses, such as untimely deaths, divorces, or children leaving home, family members may be unable to face the current crisis head on. Memories and feelings from the past may make it difficult to separate this potential death from other losses family members have experienced, and therefore, they may not be doing the anticipatory grief work that would be helpful in their making this decision.

Overwhelming Other Stresses

A family that has been focused on the management of a chronic illness in a child may have its resources taxed to such a degree that they feel too depleted to make a decision about another life-and-death situation. The particular role a patient has played in a family system (eg, caretaker) may make it impossible for the family to face the crisis realistically, contributing to group denial and inability to grieve.[7] In such cases, the physical and mental well-being of relatives should be of concern to the family physician.

Reactions to the Current Situation

Unexpressed Feelings toward the Patient

Families need the time and permission to express gratitude or to apologize to the patient for

behaviors in the past before they can "let go." Family members need the opportunity to reminisce and to find their own way of saying goodbye; once this is done, they feel comfortable and relieved.

What To Tell Others

The family needs to think through for themselves to whom they are going to tell what. They may want to keep their decision private and not get involved in detailed discussions with others, or they may find it helpful to select a few significant persons to talk things out with and share the process of their grief.

Certain family members may find it necessary to discuss their concerns with their clergyman, their own physician if he or she is not the dying family member's physician, or a therapist. They may need a form of permission or absolution from a professional who has been significant in their lives before they are comfortable with their decision.

Need To Feel They Have Done Everything

When the family is involved in prolonged life-sustaining efforts, it is more likely that they will feel they have done enough for the patient. In more acute cases, family members may need to go through a process of certain extra efforts before they can agree to forego treatment. The family physician may find that initially a family requests that excessive treatment be administered, even against the physician's best judgment. It may be useful to follow the family's wishes for a while on a time-limited basis with plans to reevaluate in another family conference at a designated time. Generally, as time passes and the hopelessness of the situation is recognized, family anxiety is decreased and the family feels satisfied with the treatments that have been made.

When a patient or family members continue to disagree about the desirability of treatment, a dilemma is raised for the family physician. Increasing knowledge of family dynamics has shown that the physician cannot treat the patient without the family, and if there is disagreement, the physician has to work with all members. Difficulties in managing family disagreements often have to do with not understanding the dynamics or with poor techniques rather than with irreconciliable differences. Yet, there remain cases in which health needs and wishes of family members are in direct conflict, and certain members will not be pleased with the action taken. The family physician makes use of ethical principles in combination with a family systems perspective to aid in the clarification of such choices.[8] In those cases where agreement cannot be reached, institutional or judicial review should be sought.

The Impact of Other Current Stresses

An appreciation of the timing of certain events may clarify a family's difficulty in handling such decision making. Managing an illness crisis in another family member, a recent job loss, or divorce in the family may contribute to strain that taxes the family members' coping mechanisms. Even positive events such as the impending birth of a child or upcoming wedding in the family may contribute to a family's unwillingness to make a decision at a particular time.

Seeking Meaning as to Why the Patient Is Critically Ill

Families seek meaningful explanations for illness based on sociocultural beliefs, which in turn influence how families cope with the illness crisis. Eliciting from the family the personal and social meaning they attach to the event enables the physician to design management plans that fit with the patient and family's belief system.[9]

Management Approaches for the Family Physician

1. Schedule a conference with significant family members, possibly at the bedside, to listen to their feelings and discuss medical aspects face to face. During this conference, the physician provides information to the family regarding the nature of the patient's illness, its causes, pathophysiology, prognosis, treatment options, and costs of care.

In cases of terminal illness, this conference should be scheduled when the diagnosis is first made; however, in acute health crises (eg, stroke

or accident), the physician will have to schedule the conference as soon as possible following hospitalization.[10,11] Rather than catching individuals in the hall or responding to anxious telephone calls, a conference can facilitate and speed up the process of unifying the family, resolving issues, and arriving at a decision. It is important to remember that family members may not really hear, accept, or retain all information initially imparted to them, but they will integrate it over time, and this process is enhanced when it is done in an open, supportive group fashion.[12]

In terminal cases, the family physician reassures family members that medically everything is being done, suggests that they put aside their differences, and initiates the process of the family saying goodbye. The family interview can be the dramatic turning point in the acceptance-adjustment to the fatality of the illness. Family members are supported in dealing with previously unspoken subjects and experiencing feelings previously thought to be unacceptable.[13]

2. Recognize that some anger toward the physician is normal and view it as part of the family members' grief.[12] Allowing the family to have angry feelings—even toward the patient—and sanctioning these feelings dissipates them in a normal grief reaction. While a certain forbearance is required on the part of the family physician who is taking his best care of the patient, listening to anger and not taking personally the family's emotional responses will ultimately facilitate the decision making. Avoidance of family members or getting into power struggles engenders more hostility and greater barriers to resolving the problem.

3. Discuss with the family how they can maintain maximum personal contact while the patient is in the hospital. By arranging family involvement in a variety of ways (bathing, dressing, or companionship), the family is afforded the opportunity to express care, say their last words, and feel as though they have contributed to making the patient more comfortable. Arrangements must be made in conjunction with nursing staff to avoid conflict and competition.

4. Family contact with others in similar situations has often been found to be more helpful than friends or neighbors in providing support to families through the recognition that they are neither alone nor unique. There are a variety of "self-help" and resource groups that address the needs and pain of family members. Knowledge of community groups and referral of the family can help family members share their feelings and get advice and support that physicians and nurses cannot provide. Examples are organizations for families with members who have Alzheimer's disease, or head trauma, or families who have experienced loss of a spouse or child.

5. If family members are intrusive and overinvolved, help them set limits on themselves and the degree to which they endanger their own health and functioning by suggesting they "take time out." Approaching this from the angle that the patient needs them healthy and strong will help battles that emerge from the need to "get the family out of there." Such an approach recognizes the family's need (often neurotic) to be overinvolved while attempting to solve management problems without getting into struggles with family members.

6. Recognize that practical problems and concrete details regarding the impending death may not have been thought through by the family.[14] Overwhelming details regarding legal matters, wills, social security, and, in some cases, the physical strain of coping with daily living (eg, marketing, cooking, child care, etc) may be addressed in a referral to a social worker or a legal counselor. The family may need to put itself "in order" before it can make a decision to forego treatment.

7. Suggest to the family that they make their decision based not on what they think is best, but on what the patient would have wanted.[2] Relabeling the decision in this way can relieve the family of the emotional burden of being responsible for the decision. In cases in which the patient has not made clear his wishes to the family members, the family physician suggests to the family the use of the standard "substituted judgment."[2] The substituted judgment standard requires that the patient's definition of "well-being" is respected and the patient's interest in self-determination is preserved. However, as the principle is based on interpretation, family members may have difficulty separating the patient's wishes from their own needs, which may result in intrafamilial conflict.

8. Give the family "permission" to allow the patient to die by reassuring them through medical authority that they have done everything that they could. Pointing out that the patient may no longer wish to struggle, death becomes appropriate and not unexpected.

9. In cooperation with the family's wishes, discuss with and enlist the nursing staff in the family physician's plan so there are no overt or covert attempts to undermine plans. Conversely, the nursing staff may have its own plan for care and wish to enlist the physician as its ally. The physician benefits from listening to the nursing staff, who are often more in touch with family members' wishes through day-to-day contact. It is not unusual for conflicts between nurses and physicians to arise resulting in mixed messages to the family and an exacerbation of existing family conflicts.

10. Negotiate mutually acceptable solutions when the patient or family members disagree about further diagnostic and therapeutic interventions, frequently a difficult task for the physician without sufficient time or skills in family mediation. More often it is the physician's discomfort in dealing with the family that deters him from this task. It is important to remember that family members can resolve differences in response to support, guidance, and clarification. Certain families, particularly those suffering from longstanding conflicts,will remain impervious to any physician's efforts. Such cases may require a psychiatric consultation, referral to social service, or request for service from an institutional or legal board.

Implicit in these recommendations is the theme of listening to the family and allowing them to express their thoughts and feelings without the imperative to act on each family suggestion. It is difficult for the physician who is accustomed to prompt decision making to recognize that not all expressions of new ideas or strong emotions by family members call for a new definitive action.

A Family Case Study

Mrs. N. was a 45-year-old white, Jewish mother of two girls, aged 16 and 13 years, currently separated from her husband, with a history of breast cancer that had metastisized widely. She was admitted to the hospital for control of her hypercalcemia. Her calcium level would rise, and the patient would lapse into a coma. Initially, she was treated with saline volume expansion and furosemide diuresis, which lowered her calcium, increased her alertness, but also exposed her to excruciating bone pain. At this point, a decision needed to be reached about the use of steroids or plicamycin to effect a change in what seemed to be chronic hypercalcemia. The dilemma: should she be allowed to lapse into an apparently pain-free coma, or should vigorous treatment permit a more alert state with its accompanying excruciating pain?

Mr. and Mrs. N. had been separated for four years and Mr. N. was living with another woman and her two children. Mrs. N.'s most frequent visitor was her oldest daughter, who took a rather maternal approach with her mother and an accusatory approach with the family physician and nursing staff. Mr. N.'s infrequent visits to his wife were characterized by loud arguments heard down the hall, and he made several calls to the physician demanding that more be done. The youngest daughter never came to visit. The family presented itself as an unpleasant and hostile group whom the physicians and nurses preferred to avoid. However, some important decisions had to be made regarding Mrs. N.'s treatment. She was beginning to give the family physician messages that she wished no further treatment, but she felt her family was too fragmented to approach them with her wishes.

The family physician convened a meeting of the family at Mrs. N.'s bedside to discuss Mrs. N.'s prognosis and future treatment and to answer the family's questions. This meeting was characterized by Mrs. N. accusing Mr. N. of abandoning the family, by Mr. N.'s bringing up old marital conflicts, by the oldest daughter's angry attacks on her father and younger for not helping around the house and for getting into trouble at school. The youngest daughter maintained an angry silence except for stating that she preferred her father's "new" family. The family physician ended the meeting feeling overwhelmed by the lack of resolution but scheduled another meeting in two days. When they left the room, Mr. N. confided to the physician that he "felt bad" about what had happened and was going back into the room to talk to his wife.

The physician took this as a clue to the underlying feelings of sadness, guilt, and fears and used this in his next meeting. Because of the physician's support, direction, and clarification, the second meeting took on a completely different character. The physician helped Mr. N. express his sadness about what has happened to his family

and recollect positive memories of the past when they were together. This acknowledgment enabled Mrs. N. to express her angry feelings toward her illness for having cheated her of a long life and the opportunity to see her daughters mature and her jealousy that some other woman would have this joy. The parents were then able to come together to set limits on the older daughter's overinvolvement and their desire to see her participate in peer activities. They were also able to join together to insist that she plan for college rather than stay around in order to help her mother. The younger daughter remained for the most part, silent, but volunteered to help around the house.

With the help of comments by the physician, all family members shared some of the positive feelings they had about their family's earlier years. Ultimately, the family members were able to accept Mrs. N.'s now openly expressed wishes for no further treatments and to be allowed to die at home. The nursing staff assisted the parents in setting limits on the older daughter's involvement and helped to find ways for the younger daughter to spend time with Mrs. N. to begin to face her death. Mrs. N. returned home, lapsed into a coma, and died in a few weeks.

Had the family physician been deterred by the initial anger of the family, he would have avoided them. Even following his initial interview, he could have concluded that this was an impossible situation which would have an unsatisfactory resolution. By permitting the expression of hostility and conflict, the physician was able to help the family make plans for the future and accept the mother's wishes for no further treatment. Because of his involvement as physician to the family, he maintained contact with the daughters and was able to facilitate the youngest daughter's referral to a therapist, which was indicated by her continued poor school performance.

Summary

Whether to continue treatment for the hopelessly ill has become an important concern for physicians and the hospital staff. As technology advances, ethical and emotional issues arise that are new for the physician, placing him or her in decision-making positions that are often uncomfortable. As difficult as the decisions are for the physician, they are even more so for the family of the patient. At best, they are painful decisions; at worst, they bring out destructive family interactions that frustrate the physician and can lead to nondecisions.

Taken from a family systems perspective, this paper provides a basis for understanding family reactions in such situations and offers concrete techniques for the physician to assist families in coming to a decision to forego life-sustaining treatment. While there are still many issues to be addressed, such recommendations attempt to put family reactions in a predictable and understandable context and provide the family physician with a feeling of effectiveness and a reasonable approach to helping these families.

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