Who Is the Patient? A Family Case Study of a Recurrent Dilemma in Family Practice

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This article presents a family case study of a recurrent dilemma in family medicine. The ethical dilemma involves what role the physician should play in mediating a conflict in a family when the health needs and wishes of the individual patient do not parallel those of the other family members. Who is the patient, the individual or the family? It is the authors' conviction that in meeting the needs of the presenting patient, the family context is of great importance. To this end, the authors delineate a framework for analyzing ethical conflicts of this nature, utilizing key ethical principles in combination with a systems perspective to aid in the clarification of such choices. The principles examined include autonomy, nonmaleficence, and justice. Also taken into account are the relevant facts, values, and the biases of the physician. Exploration of these factors allows the physician a comprehensive and logical approach for resolving such conflicts. Such a framework, however, can only provide guidance; it does not guarantee easy or uniformly acceptable alternatives to difficult issues.

Family physicians frequently care for all members of the families in their practices. Ideally, caring for all family members provides a comprehensive framework in which to treat individuals. These physicians have the opportunity to see a family at various stages of its life cycle and at times of well-being as well as crisis, and they come to know the strengths, stresses, and styles of coping used by individual patients within their families and communities.

In this context difficulties may arise when family members make a request contrary to the physician's values or when the family and the physician are in agreement but differ with hospital policy and practices. A dilemma may also occur when the health needs and wishes of different family members conflict and the physician is asked to act as a mediator, or harder still, to choose sides.

Whether the individual patient or the family unit is the appropriate focus of care is not a question usually attended to directly in family medicine. It is the authors' conviction that the family physician cares for and acts as advocate for the individual patient, but does so in a context of the awareness of the family and how the health or disease of each member influences the others. Yet in conflictual situations, where an individual patient's needs and wishes do not parallel those of his family, the

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physician may feel caught in the middle. Who is his patient, the individual or the family? Sider and Clements[1] discuss the ethical issues involved in the decision to treat an individual or couple in therapy. They point out that each time there is dysfunction within an individual, adaptation is also required at the marital or family unit level. To think in general systems terms, one must conceptualize issues not only at the level at which one enters a system (eg, the problems of the individual patient) but also at the higher levels that are impinged upon (couple or family). Conflicts arise when the good of one level may not be the good of another level, and in fact may even be destructive to the stability of the system.

The latter dilemma was experienced recently by a family physician on the residency faculty of a large urban teaching hospital. An elderly female patient developed congestive heart failure and was hospitalized. Her married son took this opportunity to raise the issue of nursing home placement following her current inpatient treatment. This decision was strongly resisted by the patient. Such a precipitate transition from one life stage to another (independent elderly to dependent elderly) demanded adjustment on the part of the entire family. The physician was called upon to help the family in this difficult time.

This case presents a common dilemma in family practice. An analysis of such a case may best proceed from a consideration of (1) salient facts, (2) values, (3) ethical principles, and (4) possible biases of the physician that may unduly prejudice the outcome.

A Family Case Study

Mrs. F. was a 75-year-old widowed woman who had been Dr. S.'s patient for two years. She lived in her own apartment with her 50-year-old son, Steve, who was mentally retarded since birth. Mrs. F. had multiple chronic illnesses, including rheumatoid arthritis and severe osteoporosis. She was unable to live alone; similarly her son's retardation prevented his living alone. Together they could manage with the help of a 45-year-old married second son, James, who did shopping and laundry and provided transportation. James himself had an autistic child and was very involved in community and political activities for the mentally retarded.

In December 1979 Mrs. F. became severely ill with respiratory symptoms and congestive heart failure and was hospitalized. At this juncture, James insisted that his mother be placed in a nursing home and that his brother be removed to a day-care facility. He strongly felt the need to anticipate his mother's demise and to ease as much as possible his brother's transition to residential care. Mrs. F. was adamantly opposed to these changes.

Dr. S. was caught between the wishes of his patient, Mrs. F., and her married son, James. James criticized his mother's attempt to control him, while Mrs. F. opposed any attempt to alter her current living arrangements with her son Steve. Dr. S. felt caught between their opposing wishes, but felt that his primary responsibility was toward Mrs. F., whom he identified as his original patient.

Dr. S. faced several unavoidable decisions in the immediate management of Mrs. F. The problem involved making a choice with as clear an awareness as possible of the comparative worth of the alternatives. Decisions were necessary in the following areas:

1. Should he get involved at all?
2. If he does, should his involvement be purely medical?
3. If his intervention is more than medical, how directive should his role be?
4. Should he transmit his own values, or should he help the family define and reconcile their own values?
5. Should he treat the family or simply Mrs. F.? It is assumed at this point in the care of Mrs. F. that some choice must be made. Inactivity is itself a choice that will have its effects.

A conflict in values may arise when it is difficult to reach a unanimously acceptable resolution. The ethical problem, simply stated, became "whose values should take precedence?"

Values

In common language the term *value* means that which a person prizes, prefers, and chooses from among other alternatives. At the turning point in the case of Mrs. F., the individuals involved had to

consider how to effect a future that was most preferable. The important values influencing their decision were as follows:

1. Mrs. F.'s strongest preference would be to remain at home with her mentally retarded son. (It is well-documented in the geriatric literature that changes are especially difficult for the aging.[2,3] A forced move to a nursing home might well exacerbate Mrs. F.'s illness and hasten her demise.[4-9]) From her point of view, the status quo was clearly best.

2. The retarded son, Steve, has lived with his mother for his entire life. They are interdependent and function adequately together. Steven has relied on his mother for simple living skills, which he still lacks. Her demise would leave Steve without the necessary time or skills to make a smooth transition to a new life in a community facility.

3. The married son, James, has carried the responsibility of overseeing both his brother (Steve) and his mother for some years. It is probable that his responsibilities would increase in parallel with his mother's invalidism. To complicate things further, James's own responsibilities have increased with the demands of his own autistic child. The competing demands of his mother and brother have caused tensions in his marriage. From his point of view, the time has come to put his mother in a nursing home and his brother in a day-care facility.

4. Both Mrs. F. and her son James have the financial means to pay for nursing home and day care. Good facilities of both types exist in this city.

5. The family dynamics have significantly shifted as a result of Mrs. F.'s last illness. She had been a powerful influence in the family and able to act forcefully in her own behalf. With her increased disability, it was no longer possible for Mrs. F. to be autonomous in the same way as before. She now finds her son's plan less possible to reject.

Biases

In such a confusing case, with conflicting values, the physician may be tempted to impose his own value on the situation to bring resolution to the issue. This might be done unconsciously, growing out of the need for closure, or it might be done consciously, stemming from confidence in the correctness of one's own position. In this case, Dr. S. was conscious of his bias toward the mother (Mrs. F.), who had been his long-term patient.

Ethical Principles

Among the key ethical principles involved in this case are (1) the autonomy of the individuals involved, (2) nonmaleficence (which action would do least harm), and (3) justice—the fair distribution of burdens and benefits, awarding to each what each deserves or can legitimately claim.

The principle of autonomy acknowledges the rights of individuals to their own views and actions. It respects each person's perspective and value judgments. When well, Mrs. F. was able to command the respect of her family and to live in accord with her own wishes. Although her illness did not diminish her desire for autonomy (her beliefs were clear and as strong as ever), it did diminish the ability of Mrs. F. to act independently. Her married son took a diametrically opposite view from his mother as to the best course of action. He had the advantage of much greater freedom of action. Mental retardation rendered the elder son incapable of exercising his autonomy. Dr. S. would have preferred to respect the autonomy of his patient without compromising the rights of the other family members, which, of course, was impossible. This example is an all too common situation in primary care medicine in which the physician must choose among competing interests of family members in his practice.

The principle of nonmaleficence (do no harm) applies here as well in considering the possible effect of alternative solutions. One implication of this principle is that physicians should not only avoid causing harm directly, but also be sensitive to the indirect effects of their clinical choices. (This elaboration of the principle of nonmaleficence is dealt with in detail by Frankena.[9]) By supporting the status quo, Dr. S. would prevent emotional harm to Mrs. F. by protecting her from the loss of (1) her home, (2) control over her life, and (3) the companionship of her retarded son. On the other hand, by agreeing to the institutionalization of both Mrs. F. and her retarded son, Dr. S. could reasonably expect to alleviate the continuing

stress on the other son's marriage by relieving him of the burden of caring for his mother. Dr. S. could also expect that a well-planned transition time in an institution would help the retarded son gain the skills needed to exist without his mother. Finally, Mrs. F. would be likely to receive better medical care in a nursing home than at her own home. In cases where the principle of "do no harm" is not applicable to all individuals concerned, how then should the physician proceed?

Having considered the principles of autonomy and nonmaleficence, the remaining major principle to be considered is that of justice, defined in ethical analyses as the fair distribution of burdens and benefits. It is useful to review the alternative courses of action discussed above in these terms. In cases where more than one person stands to lose or gain by an action, one can review the total system, in this case the family, to determine how to achieve the greatest good for that family unit. This approach to the distribution of burdens and benefits is referred to by ethical analysts as the principle of comparative justice. The complementary principle of noncomparative justice operates when fairness to one individual is judged by a standard that is independent of the claims of others. Physicians frequently must make the choice between comparative and noncomparative justice, often without being aware of the principles involved. Historically, physicians' loyalties lie exclusively with the individual patient. Family medicine, on the other hand, attempts to treat the entire family. Hence, the dilemma of choice between the two types of justice is particularly acute for family physicians.

Discussion

Resolution of this case demands attention to several key factors. With regard to the physician's role, in a case where the major participants are capable of voicing their own concerns and wishes, a strong paternalistic role seems inappropriate. The clearest ethical choice in this case is for the physician to act as an advocate for the family as a whole. This would involve helping family members clarify their individual values, mediating disputes between family members, supporting family members during a difficult life transition, and making sure that one's own biases do not override the decisions of the family.

A consideration of values is outlined in the Potter Box (Figure 1). The authors choose the second option as the most valued outcome: "using the present crisis as a natural transition to create a new family structure that recognizes the growing dependency of the mother and the need for emancipation of both sons." This choice is sustained by the facts as identified earlier, eg, the mother's failing health, the son's change in position, and so on, and seems to encompass the greatest number of values for all concerned. It is important to point out that in such cases some disappointment is inevitable.

Of the four major ethical principles, the overriding principles in this case are those of justice and nonmaleficence. In such cases where there are conflicting needs and interests, the physician must attempt to balance the needs and interests of all parties, while attempting also to minimize harm to any one. Attention to the "family system" provides a context for resolving such conflicts.

In summary, family medicine espouses the treatment of the entire family but without clarifying how or when to concentrate one's loyalties on the patient, couple, or entire family system. This article has provided a framework that allows analysis of conflictual cases utilizing key ethical principles in combination with a systems perspective to aid in the clarification of such choices. This framework for analysis was extremely helpful to the physician in this case. In spite of acting as carefully as possible, however, Dr. S. lost the confidence of the patient, Mrs. F. Dr. S.'s encouragement toward honesty notwithstanding, the younger son, James, and his wife lied to the retarded brother. This action was beyond the control of Dr. S. and was also deemed unethical by the authors. Thus, even utilizing this framework does not guarantee nonproblematic resolution of difficult issues. Much work remains to be done to develop methods of helping families make optimal use of the insights provided by this model.

Resolution (What Actually Occurred)

Following the work that Dr. S. had done with the family. Mrs. F. was placed in a nursing home.

Relevant Facts	Biases Involved
1. Mother desires to remain at home 2. Married son wants mother in nursing home and retarded brother in community facility 3. Married son no longer willing to help mother and brother in daily care 4. Mother cannot care for herself at home alone 5. Finances are available for facility care 6. Quality or length of life for mother could decrease in nursing home	1. Physician biased toward mother (Mrs. F.) as opposed to the family system 2. Possible bias in favor of home vs institutional care
Values Considered	**Ethical Principles That Apply**
1. Keeping the current equilibrium of the family system 2. Using the present crisis as a natural transition to create a new family structure that recognizes the growing dependency of the mother and the need for emancipation of both sons 3. Value conflict between individual vs family system	1. Autonomy: Issue for mother and married son (mentally retarded son not deemed competent to exercise autonomy in same way) 2. Nonmaleficence (which would do least harm) • Retarded son would be least harmed if he can gain skills and time for a transition away from mother • Marital strife caused by the burden of care would be alleviated by institutional help for the mother and the retarded son • Mother would get better medical care; possibly her emotional needs would not be so well met in a nursing home (loss of control) 3. Justice: Greatest good for greatest number without undue burden for any competing individual needs: • Mother wants to remain at home; it is felt by married son that the retarded son would do better in a community facility; married son considers the present burden on him and his family unfair; least infringement on individual rights if look at system

Figure 1. Potter Box used to summarize the facts, biases, values, and ethical principles relevant to this case

After that time, Mrs. F. refused to see Dr. S. for her health care, as she felt he had betrayed her by siding with her family and refusing to support her individual wishes. Without consulting Dr. S., James and his wife lied to Steve (the retarded son) and told him that his mother had just died. Steve was then placed in a day-care facility and was reported to have made the transition well.

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