



Who's the Patient?

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WHO'S THE PATIENT?

MARTHA MINOW*

INTRODUCTION

As entertainment, confusion can be a rich source of comedy. In health care, in contrast, confusion can be a silent danger to crucial policy judgments. In comedy, a classic routine starts with the question, "Who's on first?" asked by a baseball fan who does not know that the first baseman's name is "Who." Similarly, in health care, a classic set of difficulties circle around without addressing the basic question, "who is the patient?" I will suggest today that despite the nearly universal assumption that patients are single bodily individuals, a range of circumstances require clinicians to treat families, household members, sexual partners, and even entire communities as patients. By asking "who's the patient?" I hope to illuminate how contemporary discussions of the doctor-patient relationship wrongly proceed with the assumption that the patient is alone in this relationship and that cases involving families and friends are the unusual, complicated ones. Instead, I suggest that the *normal* case is one involving family and perhaps friends, and the conception of the roles of doctors and nurses must be shaped in this context.

The recognition that families and friends are crucially involved in the doctor-patient relationship is especially challenging to the still-recent arrival of patient autonomy as a central commitment in medical ethics. What can and what should autonomy of the individual patient mean in light of the relationships with others that can be crucial in preventing, diagnosing, treating, and managing health conditions? When cost containment concerns point toward reliance upon—and potential manipulation of—the patient's intimate relationships, newly won commitments to patient autonomy are especially in jeopardy. By highlighting the significance of the patient's relationships with others, I make no argument against respect for patient autonomy; instead I

* Professor, Harvard Law School. This essay was presented as the Rome Lecture at the University of Maryland School of Law, March 23, 1994. I appreciate comments on earlier presentations to the Pew Health Policy Program Annual Meeting, June 7, 1993; the Harvard Program on Ethics and the Professions; and the Harvard Division on Medical Ethics. I would like to thank particularly Emily Schulman, Rebecca Dresser, Michael Hardimann, Howard Hiatt, Robert Singer, Joe Singer, Deborah Stone, Marcia Angell, and Susan Wolf for their help.

argue for reconceiving patient autonomy in light of the patient's relationships with intimate others.

I. PATIENTS IN PRACTICE

Nearly all the theories of medical ethics presume that the central focus of medical ethics is the relationship between the physician and the patient—each treated as a single person. Thanks to recent efforts by David Rothman and others, the “physician”-side of that dyad is receiving clarifying correction. Rothman began his book, *Strangers at the Bedside*, with this comment:

As late as 1969, the philosopher Hans Jonas could assert that “the physician is obligated to the patient and to no one else We may speak of a sacred trust; strictly by its terms, the doctor is, as it were, alone with his patient and God.” But even as he wrote, the image of a physician alone with a patient was being supplanted by one of an examining room so crowded that the physician had difficulty squeezing in and of a patient surrounded by strangers.¹

The rest of Rothman's book discusses the new complexities doctors face due to the growth of medical specialties; the rise of human subjects review committees and hospital ethics committees; various fiscal controls such as Diagnosis Related Groups (DRGs);² and emerging judicial and legislative regulation of health care decisions.³ I believe that Rothman's own argument would be strengthened by paying greater attention to the expanding roles of health care providers, focusing especially on the expanding role of nurses.

More fundamentally, I will argue the patient side of the equation also requires equal attention and explanation. I will briefly describe a range of situations demonstrating the complexity about patients that deserves attention. On one extreme, some clinical practice has always, by necessity, dealt with more than one person or individual as “the patient.” Pregnancy is an obvious instance in which “the patient in the bed” cannot fully be described as a single person. Dramatized

1. DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE* 1 (1991) (quoting Hans Jonas, *Philosophical Reflections on Experimenting with Human Subjects*, 98 *DAEDALUS* 219 (1969)).

2. DRGs were created by the Tax Equity and Fiscal Responsibility Act (TEFRA). AMERICAN COLLEGE OF LEGAL MEDICINE, *LEGAL MEDICINE: LEGAL DYNAMICS OF MEDICAL ENCOUNTERS* 427 (1988). Under this system, Medicare pays hospitals a uniform, fixed payment, which is determined mostly by the patient's diagnosis rather than the care or treatment the patient actually receives. *Id.* Accordingly, the payment remains the same for a particular ailment regardless of whether the patient spends one week or 15 days in the hospital. *Id.*

3. See generally *id.*

today with the use of ultrasound and the possibility of intrauterine treatment, pregnancy presents the medical world with the woman and the fetus whose interests are usually joined, but on occasion may not be.⁴

Contagious diseases present an example in which the "patient" easily includes more than one person. Forty years ago, Michael Balint usefully identified the contrasts among the presenting patient, the key patient, and the treatable patient.⁵ In this light, the health care provider must come to perceive the individual who presents himself or herself at the office as a member of a network of relationships that potentially includes others who may have underlying or treatable conditions. Moreover, public health approaches to managing contagious diseases have long identified the chains of relationships between people that are relevant to both treatment and prevention and make the presenting patient simply the initial contact in what will become a series of patients to be tested and potentially treated.

When genetic testing becomes germane to diagnosing a particular patient's condition, the histories of family members assist the treatment of "the patient in the bed," and family members may also become patients if they subsequently receive testing that reveals a similar condition. Accordingly, both contagious diseases and certain kinds of genetic markers present the health care world with issues that begin with one patient but often lead to the identification and treatment of other patients.

This pattern reveals limitations in conventional rules that seek to promote patient autonomy. For example, rules about confidentiality⁶ and informed consent⁷ have been formed on the assumption that only one patient is involved, when, in reality, a physician may be treating family members who may have exposed one another to a contagious disease, such as HIV, or who may share genetically-linked conditions. To respect the autonomy of each patient while pursuing their health interests, the goals behind confidentiality and informed

4. More than one person must be viewed as "the patient" in the far more unusual situation of Siamese twins.

5. See generally MICHAEL BALINT, *THE DOCTOR, HIS PATIENT AND THE ILLNESS* (1954).

6. Confidentiality refers to patients' right to keep their person and records private unless they consent or the law requires disclosure. Indeed, "[a]ccess to a patient's body and to confidential medical information is limited to the primary health care team specifically rendering care to the patient, and to others with special permission." AMERICAN COLLEGE OF LEGAL MEDICINE, *supra* note 2, at 208.

7. Informed consent involves "informing the patient of the nature of diagnostic and therapeutic procedures, and their advantages and disadvantages, such that the patient may participate in accepting or rejecting procedures." *Id.* at 118.

consent require conversations with patients about their intimate relationships, and the rules on confidentiality and informed consent may even require modification to protect the interests of other patients.

Family members or close associates to a patient may also become patients in the sense of falling within the primary responsibility of the health care provider when the initial patient dies, especially when the family member reacts to the news in an extreme way.⁸ More basically, many health care providers acknowledge and attend to the ways in which the actual incidence of disease and conditions of health status reflect interpersonal relationships. One recent book concluded, "There is now a mass of evidence to indicate that [social] support may be one of the critical factors distinguishing those who remain healthy from those who fall ill."⁹ The psychological sensitivity of the immune system¹⁰ is simply one domain of such evidence. For example, studies confirm that "[f]or women, both psychologic and physical symptom levels were significantly lower among those who had confidants and friends."¹¹ Similarly, family members can often be the cause not only of contagious diseases but also of psychosocial factors affecting non-contagious diseases or disabilities.¹² The interaction of health statuses of spouses is a striking example.¹³ Given these studies, any serious consideration of preventive health care involves family members, friends, and coworkers. Dr. Leon Eisenberg taught us of the importance of family, friends, and coworkers in a patient's decision to seek health care¹⁴ and in a patient's own progress toward wellness.¹⁵ In debates over whether to extend health care benefits to domestic partners of employees, employers also are persuaded by evidence of the

8. ROBERT BUCKMAN, *HOW TO BREAK BAD NEWS: A GUIDE FOR HEALTH CARE PROFESSIONALS* 183 (1992) (noting that the patient's family may become the health care worker's primary responsibility and also noting the difficulty of dealing with the family when a patient dies unexpectedly).

9. MARC PILISUK & SUSAN HILLIER PARKS, *THE HEALING WEB: SOCIAL NETWORKS AND HUMAN SURVIVAL* 29 (1986).

10. *Id.* at 40-41 (noting that social support affects those systems of the body designed to deal with the externalities that cause illness).

11. Leon Eisenberg, *What Makes Persons "Patients" and Patients "Well"?*, 69 AM. J. MED. 277, 282 (1980).

12. David D. Schmidt, *The Family as the Unit of Medical Care*, 7 J. FAM. PRAC. 303 (1979).

13. See Eisenberg, *supra* note 11, at 283 (explaining that research has shown that age-specific mortality rates are two to four times greater for widowers than for married men); Schmidt, *supra* note 12; see also John G. Bruhn, *Effects of Chronic Illness on the Family*, 4 J. FAM. PRAC. 1057, 1057-60 (1977) (discussing the detrimental effects of chronic illness on family members).

14. See Eisenberg, *supra* note 11, at 279 (noting that patients often discuss their health status with family and friends before visiting health care providers).

15. See *id.* at 284.

relevance of the relationship between the health status of and care for household members to the health and well-being of their employees. Thus, the "patient in the bed" may be treated effectively only through careful assessment of the individual's relationships with others and sometimes interventions involving others will be necessary for treatment and for preventive measures.

Probably most familiar to health care providers is the significance of family members and close friends in contributing to decisions about care for those individuals who cannot make decisions for themselves. In this circumstance, the others involved in the decisionmaking are not patients, and their individual preferences and opinions are not viewed as "factors" or "information sources" relevant to treatment. Nevertheless, the intimates of the patient provide norms, values, or information about the patient's own preferences and interests when a treatment decision must be made. The dramatic growth of heroic or extraordinary care¹⁶ involves health care providers in close relationships with the families or friends of partially or fully incompetent patients, whether those patients are children or gravely impaired adults.

When someone besides the ostensible patient provides the source of knowledge about the patient's history, desires, or treatment direction, ethicists and lawyers establish fictions to protect the image of the doctor treating the solitary and autonomous patient. One such fiction is "substituted judgment."¹⁷ Such fancy verbal footwork is a sign that something else may be going on. The health care professionals may sincerely try to preserve the single patient as the primary focus for care. Even if this is their goal, however, it is necessary that the medical team be closely involved with those who are intimately affected by the welfare, care, and aftercare of the patient.¹⁸ Moreover, cross-cultural comparisons of medical practices indicate the great significance of family in many cultures and recommend degrees of involvement and

16. Heroic or extraordinary care involves the use of extreme measures to keep a patient alive when death is imminent. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FORGO LIFE-SUSTAINING TREATMENT 83-87 (1983).

17. Substituted judgment involves the appointment of a surrogate for patients who are not competent to make medical decisions for themselves. To the best of their abilities, these surrogates should make decisions in the same manner as the patient would have. *Id.* at 44-45.

18. See RICHARD SHERLOCK & C. MARY DINGUS, FAMILIES AND THE GRAVELY ILL: ROLES, RULES, AND RIGHTS 147 (1988) (arguing that health care providers must elicit information from the patient's family members to provide the patient the best care).

deference to family members in patient decisions that might be deemed violations of patient autonomy in other contexts.¹⁹

Moving even further away from the idea that anyone but the patient-in-the-bed is the subject of the medical care, family members, or other intimate associates, can be crucial to providing patient care. The patient care provided by intimates affects the cure or healing of stroke victims, orthopedic patients, alcoholics, obese individuals, patients with high risk of heart disease, and candidates for organ transplants.²⁰ Further, decisions about whether to hospitalize, institutionalize, or discharge patients center on the capacity of intimates to provide care and support for the patient. Ruth Macklin writes of the ethical dilemma presented by an eighty-four-year-old hospital patient who desired to be discharged so that he could live with his thirty-five-year-old son even though that son had previously failed to provide his father with proper care and nutrition. The medical staff debated whether to send him home, knowing his health would worsen, or to keep him in the hospital against his will.²¹ Despite the team's view, which was based on the actual effects of family members on a patient's health, Macklin recommended that the medical staff respect the autonomy and preference of the patient.²²

Many clinicians must explicitly address the interaction between family caregivers and recovering patients.²³ For instance, what should happen when an elderly patient is ready to leave the hospital and return home, but returning home and depending on the care of an elderly spouse may jeopardize the health of that spouse as well? Caregiving has predictable negative effects on the physical and emotional health of the caregivers, ranging from depression and stress syndromes, to increased susceptibility to physical health problems.²⁴ At the same time, however, separation of spouses can in some circumstances also impair the well-being of one or both of them.

As these examples suggest, an exclusive focus on the individual patient's health care needs raises two possible dangers: (1) the pa-

19. See Jill Klessig, *Cross-Cultural Medicine A Decade Later: The Effect of Values and Culture on Life-Support Decisions*, 157 W. J. MED. 316 (1992) (explaining that physicians must discuss life-support issues "in a culturally sensitive way"); Jessica H. Muller & Brian Desmond, *Ethical Dilemmas in a Cross-Cultural Context: A Chinese Example*, 157 W. J. MED. 323, 327 (1992) (stating that doctors should be sensitive to the norms of various cultures that may have different concepts of patient autonomy).

20. See Schmidt, *supra* note 12, at 309.

21. RUTH MACKLIN, *MORTAL CHOICES: BIOETHICS IN TODAY'S WORLD* 139 (1987).

22. *Id.*

23. See, e.g., Council on Scientific Affairs, American Medical Association, *Physicians and Family Caregivers: A Model for Partnership*, 269 JAMA 1282 (1992).

24. *Id.* at 1283.

tient's own views about the relationships with and interests of the intimate others may point in a different direction than the medical advice; and (2) what would be good medically for the patient may not be good medically or otherwise for relatives or friends who must care for the patient. Again, the conventional notions of patient autonomy do not adequately illuminate these dangers nor point toward sensitive responses.

Given evidence of the mutual impact people have on one another's health, some scholars advocate a shift to an interactional or systems viewpoint in addressing health care issues.²⁵ They recommend a focus on the effect of social interactions on the onset of disease and its course²⁶ and on providing care for caregivers.²⁷ Thus, the AMA's Council on Scientific Affairs recently recommended that physicians treat the patient and the caregiver "as a single unit of care," while also considering the "caregiver as a partner with the physician" in patient care.²⁸ As a practical matter, consideration of the caregiver would demand reimbursement for physician time spent in educating and counseling caregivers and financial support for further research about the needs of caregivers.²⁹ Along the same line, others urge physicians to use their knowledge of family dynamics "to create strong family support for the ill person."³⁰

Each of these recommendations remains consistent with the assumption that the focus of care is on the individual patient. Pursuant to these recommendations, attention to the family members or friends is deemed relevant in order to enhance the health or treatment of the individual patient. This attention has been described as treating "the family in the patient, rather than the patient in the family."³¹ Yet, it is not beyond debate to propose a shift in this fundamental premise. Indeed, a few years ago, John Hardwig shifted this premise by arguing that the interests of a patient's family should be

25. John H. Weakland, *"Family Somatics"—A Neglected Edge*, FAM. PROCESS 263 (1977) (advocating the focus of health care mainly on family systems to study the handling of human problems).

26. *Id.*

27. See Counsel on Scientific Affairs, *supra* note 23, at 1283.

28. *Id.*

29. *Id.* at 1284.

30. Bruhn, *supra* note 13, at 1060 (noting that communication between the physician and the family builds confidence and is often the most effective treatment available for chronic illness).

31. RONALD J. CHRISTIE & C. BARRY HOFFMASTER, ETHICAL ISSUES IN FAMILY MEDICINE 10 (1986) (quoting Dr. Michael Brennan).

considered alongside the interests of the patient.³² Hardwig stated that "it is sometimes the moral thing to do for a physician to sacrifice the interests of her patient to those of nonpatients—specifically, to those of the other members of the patient's family."³³ He defined family broadly to encompass those who are close to the patient, including friends and companions.³⁴ Hardwig argued that given the longer duration of many illnesses and the high costs of medical care, past assumptions that the patient's interests should always prevail deserve reassessment.³⁵ Hardwig specifically recommended that the interests of family members be treated equally with the interests of the patient.³⁶ Equal treatment of patients and their family members would be more honest and more fair, he maintained, than current theory and practice.³⁷

Although Hardwig argued for equal consideration of family members' interests, his analysis does not entirely depart from the premise of the individual person as the patient. A more fundamental displacement of the individual arises when society itself becomes the unit of analysis, as is the case not only in conceptions of public health, workplace and environmental safety concerns, but also in emerging demands for cost-effectiveness and rationing in health care. Rather than employing all possible treatments for the particular individual patient, proponents of rationing health care urge that only *reasonable* care should be provided to *all* potential patients.³⁸ Critics call this "rationing" and oppose such dilution of the health care provider's central commitment to each particular patient. Some have urged a specific separation between the practitioner who delivers care and the policy-makers who determine allocations of resources.³⁹ Current cost-control programs in various forms of managed care render this idea outmoded, however, and primary care physicians and nurses have indeed

32. John Hardwig, *What About the Family?*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 10 (acknowledging the interests of the family may guide and support "physicians, patients, and families in the throes of agonizing moral decisions").

33. *Id.*

34. *Id.*

35. *Id.* at 6.

36. *Id.* at 7.

37. *See id.* (arguing that "medical and nonmedical interests of the same magnitude deserve equal consideration in making treatment decisions").

38. *See* ALBERT R. JONSEN, *THE NEW MEDICINE AND THE OLD ETHICS* 58 (1990) (arguing that justice requires "the competent practitioner to treat each patient with as full a range of resources as is comparable with the capability of other unknown and unseen patients to receive treatment when their time comes").

39. For an influential statement of this view see Howard H. Hiatt, *Protecting the Medical Commons: Who is Responsible?*, 293 NEW ENG. J. MED. 235-40 (1975).

become gatekeepers by controlling access to medical resources. Done ultimately in the interests of the entire risk-pool—or community, cost-containment expands the notion of the beneficiary beyond the individual patient.⁴⁰

Standard public health and cost-containment rationales subordinate interests of the individual to those of society and jeopardize the basic medical ethics commitment to individual autonomy and well-being. I do not propose to import these arguments for subordinating the interests of the individual patient to the rest of medical ethics. Indeed, I worry that an implicit shift against patient autonomy as an ideal is well underway. Given this shift, can we render patient autonomy meaningful in circumstances in which the “patient-in-the-bed” implicates others in the gathering of information, the treatment decision, the treatment process, or the provision of after-care? This question presupposes the desirability of retaining the commitment to individual patient autonomy, which I will now defend, while arguing for a revision of this conception in light of many patients’ important relationships with intimates.

II. PROBLEMS WITH SHIFTING FROM THE INDIVIDUAL AS PATIENT

The most obvious objection to a shift away from the focus on the individual patient is the danger that individuals will become the means for accomplishing other people’s ends. This shift in focus that may result in other people’s ends being met at the expense of the individual would violate ethical commitments to individual autonomy, integrity, and dignity. As I have suggested, such ethical violations are already often tolerated in the name of public health and cost-containment concerns. Perhaps these violations are tolerated only as exceptions to the rule, or only when tailored to maximize concern for the individual consistent with broader societal objectives. We, or others, could argue that the individual patient implicitly consents to the incursions represented by public health and cost-containment initiatives

40. This view has a long history in the field of public health. For example, concern about the overall health of the community directs primary care providers to refuse a patient’s request for antibiotic medication for a minor illness if expanded use by patients in that context would risk the development of a drug-resistant strain posing greater danger to the community at large. Similarly, vaccination of healthy individuals—carrying with it some slight risk to the individual—is a pillar of public health activity given the greater good to the community arising from universal vaccination. Yet, when the societal and community concerns attend solely to financial rather than health interests, an important and troubling shift has occurred. For a discussion about cost-containment, see generally PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS, *supra* note 16, at 95-100 (discussing the constraints societal interests place on the use of life-sustaining treatment).

because the individual shares in the resulting benefits. When the health care focus on the individual patient shifts not to society but instead to the family or intimate group, conceptual, practical, and moral problems can arise. Making individual autonomy meaningful in light of the intimate relationships of the patient requires work. The dangers of shifting from the individual patient, and the steps needed to strengthen respect for patient autonomy given the facts of patients' relationships must be addressed.

A. *Conceptual, Practical, and Moral Problems with "Family" Medicine*

The interpersonal nature of health and well-being leads some health care providers to advocate a shift from the individual patient to the family as the patient. Yet conceptual confusion arises with efforts to articulate a strong version of "the family" as patient.⁴¹ This formulation implies that the family is a reified entity.⁴² In reality, the family is not an entity, but a collection of individuals who have relationships with one another. Perhaps with this idea in mind, one observer concluded that the meaning of family, in family practice, "refers to the form of relationship established between the physician and the patient," rather than the definition of the patient.⁴³

Alternately, the family as patient could mean simply that the health care provider treats, or is willing to treat, all members of a given family and can draw upon the knowledge base acquired during such treatment when dealing with points of common risk or benefit.⁴⁴ Similarly, a systems-approach, as used in family therapy, may guide the health care provider in tracing the source of medical problems and in developing rehabilitation or treatment plans.⁴⁵ These approaches are ethically suspect, however, if they permit less rigor in protecting the confidences of individual patients, or in guarding against the conflicting interests of the professional who provides treatment for two related patients. Hardwig himself argues that "the idea that the whole family is one patient is too monolithic. The conflicts of interests, be-

41. Ruth Macklin traces the conceptual difficulty to the idea of "treating" the family because treatment in this context is ambiguous. "It can mean 'the performance of therapy,' but it also has a nonmedical sense, meaning 'dealing with' or 'behaving toward.'" MACKLIN, *supra* note 21, at 132.

42. *Id.* at 71; see also Lynn P. Carmichael, *The Family in Medicine, Process or Entity?*, 3 J. FAM. PRAC. 562 (1976) (arguing that the family, as a unit of care, is uninvolved in the practice of general medicine).

43. See Carmichael, *supra* note 42, at 562.

44. See MACKLIN, *supra* note 21, at 68.

45. *Id.*

liefs, and values among family members are often too real and run too deep to treat all members as 'the patient.'"⁴⁶

After acknowledging potential conflicts among family members facing medical care decisions, how should the family doctor behave? Is the family physician the judge of potentially competing claims of family members—claims regarding treatment and care affecting other family members? How may the family physician or nurse-practitioner serve as an advocate for one family member's interests when they diverge from the interests of other family members? Adjudicating this conflict is a difficult task for the health care professional. Experience in the legal system shows it is very difficult for one person to serve as judge without the input of others entrusted with the specific tasks of articulating and advocating competing interests. If the family health care provider is the judge, does each family member need a separate advocate? This proposal is at best impractical and expensive, and, at worst, an ill-conceived extension of the adversarial system.

For reasons of this kind, it seems unwise to articulate the interests that family members and intimates may have in the health status and medical treatment of their loved one as "rights." Indeed, Macklin suggests that such thinking is mistaken. According to Macklin, the emotional concerns and interests of family members should not be confused with "rights."⁴⁷ Instead, what families do have, she maintains, are "anxiety, fear, guilt, anger, hope and sadness. It is these feelings that doctors have to contend with, and that some mistakenly label 'rights.'"⁴⁸

The recent history of family practice illustrates similar difficulties in defining the idea of the "family" as patient. This history demonstrates that departure from the individual patient cannot be sustained ethically or conceptually. Launched in the early 1970s with the claim that the patient should be the family, family practice has increasingly exhibited a renewed commitment to the individual as patient, while acknowledging the individual's family context and emphasizing the whole person rather than the disease.⁴⁹ This return reflects both the difficulties clinicians encountered in practice and general philosophic assaults on the idea of "the family" as the patient.

46. Hardwig, *supra* note 32, at 5.

47. See MACKLIN, *supra* note 21, at 132.

48. *Id.* at 138.

49. See CHRISTIE & HOFFMASTER, *supra* note 31, at 10 (noting that a "different approach distinguishes between treating . . . all members of a family and simply being aware of the influence that family relationships have on the health of a person").

For example, and perhaps ironically, one leading critic charged family medicine with threatening the very commitment to the whole-person medicine. In 1976, Dr. Marshall Marinker charged that family medicine undermines whole-person medicine and threatens the integrity of the person because "the doctor must shift his gaze from the person as an individual to the family as a group."⁵⁰ According to Marinker, this shift in focus to the family "destroys the intimate and entirely personal dialogue of whole-person medicine."⁵¹ Professor Marinker also argues that the family might suffocate an individual and that family medicine might embolden a physician to impose treatment on a person who has not accepted the role of patient, or may even encourage the health care provider to escape from hard work with the individual who needs help.⁵² In response, defenders of family medicine retreat to an emphasis on the individual as the primary focus of care, with family members as residual or marginal beneficiaries of help, insofar as that help would aid the patient.⁵³ In this weaker version, the argument for "the family" as patient is compatible with a continuing focus on the individual, with the family, or other intimates, assuming importance only as the context in which the patient lives.⁵⁴

Even when defending the strong version of the family as patient, family practice advocates reflect ambivalence and confusion about the relative weight to be given to individual patient and family member's interests. The coauthors of a leading book on ethics in family practice offer this as a central example: a seventy-four-year-old Native American woman, who has already had one leg amputated following complications from diabetes, is advised by her doctor that amputation of her second foot is necessary. She refuses, preferring to stay at home, on the reservation, and seek traditional North American remedies. She is also the custodian of two granddaughters who are undergoing turbulent adolescent periods. The physician believes the patient should have the amputation, as this procedure would better preserve her life so that she could care for the granddaughters.⁵⁵ It is plausible to view

50. Marshall Marinker, *The Family in Medicine*, 69 PROCEEDINGS ROYAL SOC'Y OF MED. 115, 123 (Feb. 1976) (arguing that the theory of family medicine threatens the integrity of the person).

51. *Id.*

52. *Id.*

53. See CHRISTIE & HOFFMASTER, *supra* note 31, at 73 (assailing Marinker's construction of "respect for autonomy as an inviolable moral principle").

54. See *id.* at 68 (noting that effective management of a patient's problems may require family intervention).

55. *Id.* at 79-80.

the patient's decision as a statement of her preference to resist medical treatment that had not seemed to help her in the past or as a statement of her acceptance of death.

The coauthors report that, in the actual case, the physician successfully enlisted others to help convince the patient to obtain the amputation.⁵⁶ The patient had the amputation, returned home, cared for the granddaughters, and provided strength, stability and discipline for them for two more years.⁵⁷ The authors conclude:

This felicitous result was due largely to the broader perspective of Mrs. L's family physician. If the focus had been on only the individual patient, no efforts to change her mind probably would have been made. But because the focus was on the entire family, both the interests of Mrs. L. and her granddaughters were considered. Happily, these interests turned out to be compatible.⁵⁸

I suggest that it is not just "happy," but crucial that the interests of the patient and her granddaughters were compatible. If these interests were not compatible, it is hard to believe the authors would have selected this case as a central example. Moreover, implicit in this story is the suggestion that the patient's own understanding of her interests included her commitment to care for her granddaughters.⁵⁹ If family medicine means respecting the patient's own commitment to family members as part of the treatment plan, this approach is entirely compatible with a focus on the individual. This expansion in focus considers the medical and nonmedical interests of the patient, rather than shifting the emphasis to the interests of nonpatients. In other words, the health care provider's goal is to treat the individual patient and respect her autonomy, but that individual's own relationships may modify her autonomy or reflect commitments that the health care provider should, in turn, try to respect and support. This theory of family medicine treats the individual as the patient and thus avoids the danger of compromising that person's autonomy and interests.

In these contexts, it is important to emphasize and preserve the role of the health care provider not as a decision-maker, but as an adviser and helper. Much of this discussion contemplates practice at

56. *Id.* at 81.

57. *Id.*

58. *Id.*

59. *See id.* at 94. The authors note that "[c]onstruing autonomy in terms of facilitating personal growth and development not only is compatible with the underlying philosophy of family medicine; it also contributes to a more complete picture of the physician-patient relationship." *Id.*

the moment when the doctor or nurse explores options with a patient and considers both the impact those options may have on loved ones and the impact loved ones may have on those options. Emphasizing the centrality of the patient's choice supports the autonomy of those patients who wish an option contrary to the wants of an intimate other, and those patients who place the interests of another over their own interests.

B. Moral and Political Dangers in Focusing on Individuals as if They Have No Relationships that Matter

Perhaps paradoxically, a focus on the individual patient informed by research on family and social supports produces another set of moral and political mistakes. In brief, the focus on the individual patient has the potential risk of subordinating the needs of caregivers—who are disproportionately women⁶⁰—to the needs of patients. Such an approach also risks excluding from health care resources ethnic and racial minority groups that have historically been excluded from health care resources.⁶¹ Finally, a focus solely on the individual within the family or social system may end up blaming those without vital supports.

I will briefly discuss each of these points. A patient's social supports should be called what they are: actual people, whether spouses, adults, children, or friends. No doubt the presence of vital and capable people can make a difference in the treatment, recovery, and care of many patients, but who will consider the needs of these caretakers from their point of view, not just the viewpoint of the patient? Not only is there a basic unfairness if the needs of the social supports are not considered, but there may also be a systematic bias. More often than not, these caretakers are women.⁶² The statistics show that the overwhelming majority of caregivers are women in the care of the elderly. A recent estimate indicates that 2.2 million family members and friends provide health care and other instrumental assistance to about 1.3 million frail, elderly individuals.⁶³ Approximately two-thirds of these caregivers are women.⁶⁴ As previously indicated, the impact of such responsibilities on caregivers may result in serious mental and

60. Council on Scientific Affairs, *supra* note 23, at 1282.

61. See Steven P. Wallace & Chin-Yin Lew-Ting, *Getting By at Home: Community-Based Long-term Care of Latino Elders*, 157 W. J. MED. 337 (1992).

62. See Council on Scientific Affairs, *supra* note 23, at 1282.

63. *Id.*

64. *Id.*

physical burdens to those caregivers.⁶⁵ Similar gender-based concerns can also be raised about the care of persons with disabilities, and the care of transplant candidates. If attention to family and social context simply aids the individual patient, and if traditional gender roles persist in identifying women relatives and friends as the obvious caregivers for patients, an inequality in the distribution of caregiving may result. If those women are also juggling other responsibilities—to children or to their jobs—justice would demand broader social support for the caregiving these women provide to patients.

Some patients may have concerns about imposing caregiving responsibilities on their relatives, while other patients prefer not to do so. Still other patients may be willing to impose caregiving responsibilities on their relatives or lack an ability to express a preference. Consider the case of "Evan," described by Dr. Janet Haas in materials developed by the Hastings Center.⁶⁶ Evan is a twenty-six-year-old single man who suffered severe injuries following an automobile accident. After extensive medical treatment that stabilized his condition, the neurosurgeon wants to discharge him.⁶⁷ If Medicaid would pay for his care, Evan might be placed in a rehabilitation hospital, in the hope that he could improve sufficiently to receive private care.⁶⁸ Evan, however, shows no willingness to cooperate with therapy. He manifests some post-traumatic amnesia and shows intermittent agitation.⁶⁹ Through a spelling board he indicates that he wants to go home.⁷⁰ It remains unclear what "home" would mean, since he had been unemployed and essentially homeless prior to the accident.⁷¹

Evan's sister is his closest relative. She raised Evan and several of his other siblings since the time he was eight years old.⁷² She currently works full time as a management trainee. The other obvious candidate to care for Evan is his mother, but she recently took charge of caring for his grandmother, who is seventy-eight-years old and suffers from numerous medical problems.⁷³ Neither the sister nor the mother—nor any other relatives—have offered their homes to Evan.⁷⁴

65. *Id.*

66. CASE STUDIES IN ETHICS AND MEDICAL REHABILITATION 29 (Janet Haas et al., eds., 1988).

67. *Id.*

68. *Id.*

69. *Id.*

70. *Id.*

71. *Id.*

72. *Id.*

73. *Id.*

74. *Id.*

The rehabilitation admission decision depends in part upon the candidate's final placement. The rehabilitation hospital wants to avoid taking a patient it cannot discharge due to lack of a placement. The rehabilitation staff can sensibly defend this position on several grounds. People with head injuries, especially, require therapy designed in conjunction with their ultimate placement because adaptability and generalizing skills from one environment to another may be very difficult. A candidate who seems unlikely to have discharge plans may end up occupying a bed that could better serve another patient. Furthermore, a patient who cannot be discharged by the rehabilitation hospital is also likely to lack finances to reimburse the hospital. As a result, the hospital may end up "eating" the cost of Evan's care.

In this light, Evan's case poses an especially difficult question about whether the medical personnel should encourage Evan's sister or his mother to assume his care. The doctor who prepared the case study recommended admission to the rehabilitation hospital.⁷⁵ He portrayed the problem as one of risking denial of the rehabilitation effort simply because of an undesirable and poor patient.⁷⁶ The physician argued that Evan's desperate lack of nonmedical resources, ranging from an unresponsive family to poverty, and his own unwillingness to cooperate with treatment, should not justify denial of treatment that could help him. This line of argument, however, becomes the rationale for pressuring family members to depart from their stated views and plans. The physician concluded that "[r]ehabilitation personnel must work diligently with Evan's sister and other family members" and educate them about his needs, and draw them "into Evan's plan of treatment."⁷⁷

A contrasting view of this case, offered by two nonmedical commentators, questions this solution as serving society, but not the family or even Evan himself.⁷⁸

It is less costly (or so we believe) to have his family care for him than an institution, and his caretakers would certainly be better off if Evan can be taught to behave predictably and in socially acceptable ways. . . . The hospital staff seem to have identified Evan's sister as the family member most responsible for Evan and most likely to arrange family care for him. . . . Even if we are not willing to pass judgment on the

75. *Id.*

76. *Id.*

77. *Id.* at 34.

78. *Id.* at 36 (commentary of Deborah A. Stone & David R. Pokross).

quality of life Evan might lead given his prognosis, that same prognosis tells us a lot about the quality of life his sister (or other caretaker) might have. She has already once before carried the responsibility of raising somebody else's children. Now her siblings are grown and she has an opportunity for some economic and social advancement in a management training program—an opportunity she would probably have to forfeit if she agreed to take Evan into her home. I believe the choice ought to be hers.⁷⁹

This view contrasts with the temptation for any one treating Evan to play upon a woman's sense of guilt in trying to find a good solution to his treatment problem.⁸⁰ Attention to the patient's interest alone will not guard against the temptation to implicate a woman's conscience. Yet add to this analysis the patient's own preference to avoid therapy and his apparent refusal to receive treatment. His apparent preference should not itself render him incompetent to decide.

Thus, in addition to the rather modest proposal that respecting a patient's autonomy includes respecting their own commitments to others, I offer this bolder argument. Respect for patient autonomy should not entail disregard for the autonomy of others in their lives. This argument gains special significance in light of potential patterns of ethnic bias in the utilization of health care resources.⁸¹

To explore the possibility of ethnic and class bias, two researchers studied the use of health care resources by Latino families.⁸² They found that many such families do not use in-home health-care services even when they are in contact with physicians.⁸³ The authors suggested that "[o]ne reason physician visits may not increase in-home health services use is that many physicians may observe the family providing in-home assistance and assume that such assistance is provided for cultural reasons."⁸⁴ Acknowledging that older Latinos often expect assistance from their families, family involvement in health care decisions, and Spanish-language use in quality care, the researchers emphasized that formal services could also improve the status of the patients and their care-givers and that in-home health care services might be welcomed if offered.⁸⁵ Thus, physicians should not assume

79. *Id.*

80. *Id.*

81. See Wallace & Lew-Ting, *supra* note 61.

82. See *id.*

83. *Id.* at 338-39 (arguing that physicians should not presume that Latino families are taking care of their disabled elders simply because of cultural preference).

84. *Id.* at 343.

85. See *id.*

that Latino families taking care of their disabled elders at home do so simply because of a cultural preference.⁸⁶ Instead, physicians should provide information and advice about the availability of in-home health-care services.⁸⁷ Groups that have had to rely on family and social supports may risk exclusion from health care services because they do not seem to need those services when in fact the patient and health-care providers could well benefit from precisely those services.⁸⁸

Finally, is there any danger that society may blame people who lack adequate social supports if they become ill? Or will society blame people who decline to provide care for their relatives or intimates who become ill? Recognition of the benefits provided by family and intimate caretakers may point in these directions. As Weakland says, "[a]ny positive findings about interaction and disease might well, at least initially, be seen more as accusations that people are making their loved ones sick than as a realistic and helpful recognition of how, even without benefit of ceremony, we are in life together, for better or worse, in sickness and in health."⁸⁹

Danger arises when attention to the individual patient's benefits from care provided by family members or friends overrides any consideration of the needs or interests of those others. Overriding the concerns of family or friends poses an immediate danger because these other individuals have interests as well. More subtly, attention to others matters because the patient may care about the interests of those others. Here is where a refined notion of autonomy would demand deference to the individual's own commitments to others. Addressing interpersonal commitments and political deliberation, one philosopher comments that

when John or Mary accords priority to their John-Mary interest over their interests considered atomistically, they do what is best for themselves as members of an entity they relationally comprise. . . . The couple John-Mary is an internal relation formed by John and Mary. It cannot be decomposed into two radically independent entities, the (atomic) individuals John and Mary, because in this case it is the relation

86. *See id.*

87. *See id.*

88. *See* Marilyn Friedman, *The Practice of Partiality*, 101 *ETHICS* 818, 829 (1991) (relying on people's desires to favor their loved ones may prevent redistribution of resources needed for those who do not have them).

89. Weakland, *supra* note 25, at 272.

itself, not the parties related, that is fundamental for the proposed deliberation.⁹⁰

Where a patient is competent and unambivalent, respecting patient autonomy requires deference to the patient who prefers not to be discharged to the relative's care. More difficult issues arise when the patient is competent but ambivalent. Even in that common circumstance, I propose maintaining respect for the individual patient's autonomy by acknowledging the significance of relationships in the life of that patient, while also respecting the autonomy of those intimate others and not treating them as objects to be manipulated as part of patient care.

Some may fear that respecting the autonomy of the family and friends of patients means abandoning the patient and losing the chance to involve those intimate others significantly in the patient treatment and care. This would be a false and sorry picture of autonomy.⁹¹ Many wives and husbands, lovers and parents, children and aunts, and even friends, will chose earnestly and lovingly to attend to a patient in stages of acute and chronic care, as well as in prevention efforts. Similarly, many patients, when allowed to act autonomously, will choose unselfishly. The crucial role for the health care provider is not to push toward these ends, but instead, to help people recognize and articulate their individual and mutual interests before and during health problems.

Consider an elderly couple with this difficulty. After the husband's stroke, hospitalization has stabilized his condition, but his doctor believes he cannot return to independent living at home and needs the full care offered by a nursing home. A nursing home, however, would exhaust his social security and Medicaid benefits, leaving his wife unable to pay the rent. We quickly imagine how his wife may want him to come home, and that he may want nursing home care. Yet she may tell him to go to the nursing home for his own good, and he may say he is coming home for her good. This version is reminiscent of an O'Henry short story, *The Gift of the Magi*,⁹² in which an

90. ANDREW LEVINE, *THE GENERAL WILL: ROUSSEAU, MARX, COMMUNISM* 30 (1993) (discussing deliberations about "the general will").

91. Analogous debates surround contemporary meanings of sovereignty in international relations. A conventional view of the nation state as a "billiard ball," distinct and opaque, fails to account for the varied forms of interconnection and interdependence nations build with one another. And yet many scholars fear that abandoning the conventional view of sovereignty risks damaging national self-determination—or pushing toward more expressions of selfishness. See Ann-Marie Slaughter Burley, *International Law and International Relations Theory: A Dual Agenda*, 87 AM. J. INT'L LAW 205 (1993).

92. O. HENRY, *The Gift of the Magi*, in *COMPLETE WORKS OF O. HENRY* (1937).

impoverished couple wish to surprise one another with presents. She sells her hair to buy a chain for his pocket watch, while he sells his watch to buy combs for her hair. This story is not only a touching portrait of love's ironies, but also clearly indicates that, in Lyndon B. Johnson's immortal phrase, there was "a failure to communicate." Perhaps health care providers can help a patient and loved one communicate to avoid such ironies. Perhaps even a third alternative is feasible, such as sufficient home health care to permit the patient to return home to his wife.

CONCLUSION

In summary, patient autonomy sounds lovely but can become meaningless unless it is understood in the context of the patient's real and pressing relationships with family members or intimate others. Yet, a shift in focus from the individual to a broader group as "patient" raises conceptual, practical, and moral problems. More defensible is a strengthened focus on the individual as someone whose autonomy includes affirmed membership in families and social groups. Relying on those others to help the individual patient may raise issues of fairness and impose health and emotional burdens on those caregivers. Who will attend to those caregivers as patients and as partners in the health care system?⁹³ Respect for patient autonomy demands respect for the patient's relationships, and also for the autonomy of those with whom the patient shares relationships. Perhaps it is not surprising, then, that my closing question asks about the health and emotional needs of caregivers, or in other words, to return to the Abbott and Costello routine of my introduction, "What's on second?"⁹⁴

93. See Council on Scientific Affairs, *supra* note 23, at 1282 (proposing partnership between physicians and family caregivers).

94. Pressure to treat caregivers, family members, and associates as patients may stem from conceptions and reimbursement schemes that deny help to anyone who is not a patient, or who is not sick. Besides dealing with this problem with more expansive notions of "patient," this society could consider adopting other forms of assistance, such as respite care, day care, and a better social safety net.