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BEFORE GUARDIANSHIP: ABUSE OF PATIENT RIGHTS BEHIND CLOSED DOORS

*Peter J. Strauss**

I expect my remarks to be somewhat controversial, so I will begin with an explanation of my point of view and fundamental approach. I am a practicing attorney. I have specialized in the problems of aging for about twelve years and have concentrated on advising healthy clients about the need to plan for the possibility of illness or incapacity by establishing a system for financial management, such as durable powers of attorney and living trusts, and advance directives for health care decision-making, such as living wills and health care proxies. I also counsel families when crisis intervention is necessary because of the severe illness of a family member. I have been involved in many guardianship proceedings, representing both petitioners and protectees, and as court-appointed guardian ad litem.

My experience in advising several thousand families in crisis has led me to believe that the impaired client's needs are best served through some form of adversarial process. For example, I was retained by the daughter of an eighty-three year old widower (Mr. G) who was clearly suffering from an illness that caused significant dementia. He lived alone, refused all supportive care, was threatened with eviction because he would not pay legitimate rent increases, and maintained his small apartment in such a high degree of filth that the board of health cited him for code violations. On behalf of the daughter, I brought a guardianship proceeding with the hope that a court-appointed guardian would intervene to provide appropriate care for Mr. G and to protect his interests. The court-appointed guardian ad litem, a person designated by statute the task of protecting Mr. G's interests, agreed that a guardian should be appointed. I arrived at the trial expecting a brief and uneventful hearing. Mr. G, however, had retained his own attorney who vigorously contested the petition, making me wish I had brought one of my litigation partners to the trial. Meanwhile, Mr. G roamed the courtroom shouting and screaming at the spectators and the court officers.

The judge called counsel into chambers and stated that while it was

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quite clear that Mr. G was impaired, he did not think I had established Mr. G's incapacity by sufficient evidence and inquired whether Mr. G's lawyer had any suggestions for a settlement. He did. The lawyer found a person who Mr. G knew from his church, who was trusted by Mr. G, and to whom Mr. G was willing to give funds to be used to pay his back rent, clean up the apartment, and hire part-time home care aides. Mr. G agreed to this settlement because he felt he had won; he had resisted the unwanted intervention of his daughter and the courts. Mr. G accepted this limited intervention only because at some level he perceived the risk of a greater loss of autonomy. The solution fashioned for Mr. G met his needs in part and worked. He was thereafter agreeable to increased supportive services, without further loss of control, as his needs increased. I strongly believe this outcome could have occurred only through an adversarial process.

One of the flaws in the guardianship systems in this country is that in most cases the lawyer appointed by the court to represent the interests of the protectee is really an advisor to the court, charged with informing the court as to what appears to be in the best interest of the protectee, rather than with advocating the expressed wishes of the protectee. Many advocates for reform of guardianship laws (including, for example, the American Bar Association Commission on Legal Problems of the Elderly (CLPE)) have called for the protectee to be represented by an advocate who will vigorously speak for the protectee's views. The CLPE organized a National Guardianship Symposium in 1988 that recommended thirty-three reform measures, including a proposal that protectees should be represented by counsel throughout the guardianship process.

Concerning this issue, Nancy Coleman, Executive Director of the CLPE, and Jeanne Dooley have written as follows:

Those opposed to "slow and contentious court proceedings" point to the proposed ward's medical or social best interests, which they allege would be advanced by prompt diagnosis and treatment. On the other side, a finding of incapacity and subsequent appointment of a guardian involve extremely important personal and property rights. On balance, the conferees, like most legislatures and courts, concluded that the medical considerations are outweighed by the even more serious legal concerns. Thus, an adversarial hearing best reflects the proper balance between the need for care and treatment

and the loss of rights.¹

Nevertheless, guardianship law reform has been slow to adopt the advocacy approach. While the recently enacted Florida guardianship statute establishes a relatively vigorous adversary structure, the proposed New York guardianship statute takes a middle ground approach, calling for an attorney/advocate only where the protectee requests one or when the court-appointed investigator believes it to be necessary to protect the rights of the protectee.

It is extremely difficult to budge the managers of our legal system from their fear that increased cost, administrative delay, and stress on the court system would result if all guardianship proceedings were made adversarial in nature. Why require this in all cases, they argue, when there are few situations that require the adversarial approach? Imperfect as the guardianship system may be in this regard, at least there is a mechanism for questioning decisions regarding an impaired older adult and the opposition of the protectee can be aired and considered. This is not the case when, say, nursing home placement decisions are made in the absence of a guardianship proceeding or when an impaired senior citizen is being discharged from a hospital. Consider the following examples:

Charles lives with his second wife, Betty, in a one bedroom apartment. He is a middle level Alzheimer's victim and a home health aide attends him daily for twelve hours. Betty can no longer cope with Charles' behavior and the cramped quarters. She has difficulty sleeping and is becoming increasingly angry about her plight. The couple's assets are modest. Charles can be maintained in their residence with home care, but, understandably, Betty has decided to have Charles admitted to a nursing home against his wishes. Other family members support this decision. Who speaks for Charles?

Mary and Robert were married for forty years when Mary suffered a severe stroke. Following months of hospitalization and rehabilitation the hospital discharge planners and Robert decided it was in Mary's best interests to be placed in a nursing home even though Mary expressed a desire to return home and her physician felt she could be maintained safely at home with home care. Who speaks for

¹ Nancy Coleman & Jeanne Dooley, *Making the Guardianship System Work*, GENERATIONS, Supp. 1990, at 47, 48.

Mary?

I do not want to be misunderstood. The decisions to place Charles and Mary in nursing homes may have been the right decisions.

Most elderly people express a desire to remain in their familiar surroundings and receive care from those they love. It is important, however, to realize that 24-hour care of an elderly loved one can be an onerous responsibility. The potential for abuse and neglect is great. Elderly family members rarely will admit that this is happening, because of their dependency and the natural bond linking the parent and child.²

The question of whether the ultimate decision is the "correct" one is not my primary concern. The issue that most concerns me is that in these situations—the pre-guardianship cases—there is no person who clearly speaks for the impaired person. The caregiver in these cases often has control over the financial affairs of the family, either because assets are in joint bank accounts or because assets have been placed in the sole name of the "healthy" spouse. Thus, guardianship is neither necessary nor sought. The caregiver has the power to make the placement.

In the hospital setting, the discharge planner is not charged with the duty of advocating the wishes of the patient but only with establishing an appropriate and medically sound care plan. In fact, the hospital discharge planner may be in a position where he or she has a conflict of interest, the needs and economic interest of the institution being weighed against the needs and wishes of the patient, with the result that the discharge planner—perhaps the only possible advocate of the wishes of the patient—may be prevented by institutional pressures from taking action on the patient's behalf.

In the home setting the problem is even more serious. When the caregiver spouse makes the difficult decision for placement and has control of the family's assets, the decision is usually implemented without outside objection or interference. Unless the impaired patient is vocal, or difficult enough to cause the nursing home or its other residents harm, a facility will not decline an admission only because the rights and wishes of the

² Patricia A. Young, *Home-Care Characteristics That Shape the Exercise of Autonomy*, GENERATIONS, Supp. 1990, at 17, 18, 19.

patient may have been violated.

In his introductory article to the June, 1988 issue of *The Gerontologist*, Brian F. Hofland wrote that "the due-process and equal-protection rights of frail and impaired older adults are often abridged in the policies and admission agreements of nursing homes and compromised in discharge-planning and guardianship procedures."³ Nevertheless, most of the attention to the issue of autonomy, i.e., control of decision-making by the individual, focuses on the conflict between autonomy and paternalism because of the tendency to define the best interests of the patient in accordance with the values, goals, and experience of those seeking to furnish assistance to the impaired older adult.

As Bart J. Collopy wrote,

When an elderly person makes decisions or acts in ways that seem harmful, caregivers face what may be conflicting commitments: to respect the person's autonomy, on the one hand, and to promote the person's well-being, on the other. The choice between autonomy and well-being, between freedom and best interest, is nettled with dilemma, since it requires not simply choosing right from wrong, but choosing right from right, choosing one value over another. The risks entailed in such choice raise what are perhaps the most elemental questions in the ethics of long term care.⁴

The focus on the issue of autonomy versus paternalism is appropriate where the best interest of the patient is the primary concern of all parties. The direction of the law is clearly to give preference and weight to the expressed wishes of the patient over the often rational desire and attempts by the caregiver to intervene. Systems can, and are, being developed to insure that the patient's wishes are protected, and when it is *only* the interests of the patient that are involved, this approach is morally, ethically, and legally sound.

This value system breaks down when interests *other* than those of the patient exist, such as an interest of the hospital in discharging a patient because its third party payments expire, or in the case of a patient at

³ Brian F. Hofland, *Autonomy in Long-Term-Care: Background Issues and a Programmatic Response*, 28 GERONTOLOGIST 3, 4 (June Supp. 1988).

⁴ Bart J. Collopy, *Ethical Dimensions of Autonomy in Long-Term-Care*, GENERATIONS, Supp. 1990, at 9, 9.

home when the interests and needs of the caregiver conflict with the wishes and (in some cases) the best interests of the patient.

In a perceptive article, Nancy N. Dubler discusses the doctrine of informed consent and patient autonomy.⁵ She notes, in comparing institutional decision-making standards with those to be applied in the home care setting, that

In home care, by contrast, many individuals other than the patient/client possess moral interests that demand respect, and autonomy of the patient/client is but one factor among many real moral claims. All of these parties, and their various interests, must be accounted for in fashioning an ethically acceptable and practically feasible home-care plan. This is especially true as home-care plans often encompass many social services as well as medical elements and, in fact, may be relatively nonmedical in scope. In this process the concept of "accommodation," rather than the solitary principle of autonomy, should determine an ethically appropriate arrangement. Because persons other than the patient have a weighty, focused, and direct stake in home care, there can be no solitary decision making based solely on autonomy; considerations of autonomy, unmodified by consideration of the needs and plans of others, can result in a selfish rather than a defensible choice.⁶

Patient autonomy must be balanced against several other factors, Dubler states, including "the competing interests and obligations of family, neighbors, and community whose functioning and whose lives may be altered by the presence of the client in the home."⁷ I agree with Dubler's conclusion: "Because of the real moral claims of the various parties, in the context of home care it makes far more sense to talk about *accommodation* rather than *autonomy*. Accommodation requires mediating between the patient's desires and (1) the reality of available services and (2) the real and weighty competing interests of others."⁸

The cases of Charles and Mary are typical of the thousands of cases

⁵ Nancy N. Dubler, *Autonomy and Accommodation: Mediating Individual Choice in the Home Setting*, GENERATIONS, Supp. 1990, at 29, 29.

⁶ *Id.*

⁷ *Id.*

⁸ *Id.* at 31.

involving an impaired senior citizen (frequently, these cases involve younger, disabled people living at home) where the trauma of the illness has turned a loving, caring situation into a horror of medical and economic problems causing anger, frustration, and suffering on the part of the caregiver who can, understandably, no longer give priority to the needs and wishes of the patient.

The problem with an accommodation approach is the concept that these now conflicting interests should be mediated. The concept is flawed because, except in rare cases, the impaired patient has no voice and no representative. The answer to the question, "Who speaks for Charles?" is that, too often, no one does.

The issue is complicated because it is often unclear who the professional involved in the case represents. In a 1986 article, Dubler and I asked, "Who is the client?"

When the relative of a disabled elderly patient seeks legal advice on behalf of the patient, the ethical question shifts from competence to who is the client? If the lawyer concludes that the patient's incapacity forces a family member to make decisions, a number of questions arise.

1. What is the attorney's obligation to assure adequate legal representation for the disabled elderly patient?
2. Does the obligation to ensure legal representation exist only when the needs of patient and family clearly conflict?
3. Is it appropriate to transfer the patient's assets to a family member to create future Medicaid eligibility for the patient? Suppose the transfers would limit certain future care options for the patient, but would clearly protect the family from future poverty? Who should decide if there is a conflict, and who should resolve it?
4. In evaluating who is the client, should the lawyer's decision be affected by the patient's medical condition, such as the existence of fluctuating paranoid ideation symptoms or other transitory mental impairment?⁹

⁹ Peter J. Strauss & Nancy N. Dubler, *Ethical Issues in Decision Making*, *COMPLEAT LAW.*, Fall 1986, at 14, 14.

These questions should be asked by all professionals who work in home care crisis situations. Physicians, social workers, visiting nurses, or community leaders who counsel the patient and the caregiver face the dilemma of determining who they represent. The National Association of Private Geriatric Care Managers (NAPGCM) addressed this problem when it adopted a code of standards and practices. Standard 1 is on point:

While the "primary client" usually is the older person whose care needs have instigated the referral to a private geriatric care manager, all others affected by her/his care needs should be considered part of the "client system."

Rationale

In the area of private geriatric care management, the care needs of the older person often have significant consequences for others. The private geriatric care manager's goal is to assist the individual members of the client system to understand fully the issues under consideration and arrive at a solution which allows maximum decision making autonomy for the person receiving care and for the other persons involved with or affected by these care needs.

Guidelines

- 1) The "primary client" may not be the person who makes the initial contact or the person responsible for payment for services rendered.
- 2) Members of the "client system" may include:
 - the older person
 - a family member within or outside of the older person's household
 - a paid caregiver
 - friends, neighbors or community agencies
 - a third party with fiduciary responsibilities
 - other professionals, such as a physician, a nurse from a home health care agency, an attorney etc.
 - the private geriatric care manager . . .
- 3) In the event of conflicting needs within the client system, the goal of professional intervention should be to strive for resolution through a process of review and dis-

cussion among the parties, facilitated by the private geriatric care manager.

- 4) The private geriatric care manager should request assistance of appropriate peers, as needed, to help the client system find an acceptable solution to the conflict it faces.¹⁰

Working with private care managers throughout the country, it has been my experience that this standard does, in fact, govern their practice. The presence of a professional whose intervention is guided by the approach called for by the NAPGCM standard constitutes the kind of mediation system advocated by Dubler. Allegiance to this type of approach significantly minimizes possible abuses. When alternatives are explored, public and private resources identified, counseling and respite care made available to the caregiver, and adequate in-home care services instituted, continued treatment at home may be possible and institutionalization can be deferred or possibly made unnecessary. I believe it is critical to find ways to make these services available to all families where home care is becoming difficult. Programs of counseling and intervention could be based in a variety of institutions: Area Agencies on Aging, local not-for-profit organizations, corporate employee assistance programs, or community advocacy groups. Funding is obviously the key to broadening the availability of such programs; I propose that Medicare and Medicaid regulations be amended to provide coverage for such services. Further, I propose that federal and state regulations regarding Medicare Supplemental Insurance and long term care insurance policies be amended to require reasonable coverage for social workers, care managers, and not-for-profit organizations who offer programs of counseling and intervention.

The nursing home and home health care industries should play a greater role in dealing with these problems. Nursing homes and home health care agencies have been a major beneficiary of Medicare and Medicaid and ought to take on a greater financial role in supporting counseling and mediation programs.

Attorneys and physicians need to become better educated about the crit-

¹⁰ NATIONAL ASSOCIATION OF PRIVATE GERIATRIC CARE MANAGERS, STANDARDS AND PRACTICES Standard 1 (1990).

ical role they play in working with the patient and caregiver. The professional can be the key to the caregiver's acceptance of appropriate intervention.

It has been suggested that advance directives can serve to protect the rights of the patient when unwanted placement decisions are proposed. I do not see the advance directive as an effective tool to protect the patient's choice in placement decision-making since in most cases the holder of the patient's proxy will be the spouse, the person who has the greatest conflict of interest at the time placement is proposed.

In the final analysis, placement decisions often are made because there are no funds to provide adequate in-home services and insufficient alternatives to nursing home placement. Many nursing home residents can be cared for at home or in other kinds of non-institutional settings. We need to develop new forms of alternative living facilities as well as new resources to support caregivers. Until this happens, understandable but often unnecessary nursing home placements will occur and the wishes and rights of patients will continue to be neglected.

I began this Article by stressing my belief in the adversarial system as the best way to protect autonomy and patient choice. Applied to decision-making in the home care setting, a pure adversarial system will not work. Something in between that and the current total absence of protection of the patient's rights must be developed. A meaningful counseling and mediation system can work, but, except for a few cases where funds and programs are in place, the necessary system does not exist.

SUGGESTED READING

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