

Refusal of Care: Patients' Well-being and Physicians' Ethical Obligations

"But Doctor, I Want to Go Home"

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CASE PRESENTATION

Mrs A, a chronically debilitated and bedbound 86-year-old woman, was admitted to the hospital with an acute change of mental status. At baseline, the patient was alert and oriented but required assistance with all activities of daily living except feeding herself. Her medical history included critical aortic stenosis (0.53 cm²), atrial fibrillation, hypertension, depression, and a left hip fracture 18 months prior to the current admission. The patient had declined surgery for both the aortic stenosis and the hip fracture.

The patient, widowed in the 1970s, had no children and lived by herself. For 18 months prior to this hospitalization she had paid for an around-the-clock caregiver, but in recent months the caregiver's hours had been reduced to 6 hours a day (9 AM to 3 PM) because of financial limitations. During the evening and overnight, Mrs A was by herself. To pay for caregivers, the patient had taken a reverse mortgage on her home, sold most of her belongings, and used credit cards to their limits. She received medical care through the Johns Hopkins Elder House Call Program (EHCP), a physician home visit system in which patients are evaluated and cared for in their living

environments. She also had an emergency notification system (Lifeline Systems, Framingham, Mass).

Her nephew, who was 71 years old and retired, was her designated health care agent and the main family member involved in her care. He visited periodically to check on Mrs A, but these visits and his ability to provide assistance were limited by frequent travel.

About 8 months prior to admission, a meeting was convened to share concerns with the patient about her safety. Participants included a social worker from Adult Protective Services (APS), her nephew, her EHCP physician (also her primary care physician), and an occupational therapist. The APS social worker was involved in this case for 2 years and had tried, along with Mrs A's nephew, to arrange for her to move into an assisted-living facility (to be financed through a Medicaid waiver), but

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the patient declined. Occupational therapists had worked with the patient for more than a month to see if she could become more independent, hoping to improve the safety of her home situation, but she remained chiefly bedbound. The patient was told by the assembled multidisciplinary team of professionals that her current arrangement was unsafe and that it placed her at higher risk of developing various medical problems and eventually clinically deteriorating. According to her EHCP

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physician, the patient clearly understood what was at stake: her Mini-Mental State Examination score was 28 of a possible 30, and, more importantly, she had the capacity to understand the risks. The patient's response to being confronted by the professionals was telling them, "You'll have to drag me kicking and screaming out of the house if you want to put me into a nursing home." The EHCP physician and her nephew confirmed that this position was consistent with the patient's previously and repeatedly expressed views on the topic.

Both Mrs A's nephew and the EHCP physician expected Mrs A to do poorly and assumed that she would be hospitalized in a short time. Yet for nearly 8 months she did quite well: she was able to stay at home, did not develop skin breakdown until just before hospitalization, remained well groomed, and was in good spirits. In the months leading up to her hospitalization, she was out of bed for only about an hour per day.

In the emergency department, her vital signs included a blood pressure of 90/30 mm Hg, a heart rate of 122/min, and a temperature of 100.3°F. She presented wearing a hospital gown, was oriented only to person, and was considered delirious. She was unkempt, had extensive dental decay and a small stage 2 ulcer on her buttock, and was lying in stool and urine. She had a white blood cell count of $13 \times 10^3/\mu\text{L}$ and a lactic acid level of 3 mg/dL, and urinalysis showed white blood cells too numerous to count loaded with bacteria. She was diagnosed as having urosepsis and was admitted to the medicine service. She was given intravenous antibiotics and rehydration. By hospital day 2, she was markedly improved, her mental status was considered to be back to baseline, and discharge planning was initiated. The physical and occupational therapy team recommended a short-term, subacute rehabilitation placement.

Mrs A was not interested in rehabilitation and wanted to go directly home as soon as possible; going home and staying at home was her foremost priority. Given their insights on the patient's home

situation, members of the multidisciplinary health care team, including social workers, physical and occupational therapists, physicians, and nurses, were concerned about her safety if she were to go home in her current state. She was told that she would likely become sicker, develop worsening bedsores, and have poorer hygiene. She was told that her chances of quickly returning to the hospital or even of dying at home alone were high. In addition, she was informed that her ability to secure in-home caregiver services would end when her money ran out. Although these concerns were shared with the patient, she remained adamant about going home, stating that she was aware of the potential risks and that she was not going to go anywhere else. The medical team thought she had the capacity to make this decision but, given the gravity of the situation, consulted the psychiatry department for a second opinion. Although the psychiatric consultant concluded that the patient was competent, she noted that the patient "may not fully realize the extent to which her health has deteriorated and her increased need for care." The psychiatric consultant indicated that the patient's depression was adequately treated.

The APS social worker was contacted by a hospital social worker. The APS social worker's view, from a safety perspective, was that the patient should not be at home alone in her current state.

The medical team requested an ethics consultation to address the question, "Does this debilitated, dependent, yet competent patient have the right to return home to an unsafe situation?"

DISCUSSION

A major challenge in this case is reconciling 2 fundamental ethical obligations that appear to be in direct conflict: (1) the duty to promote a patient's well-being and protect the patient from harm and (2) the duty to respect the wishes of a competent patient. Everyone involved in the patient's care was concerned that her well-being would be threatened and that the potential for harm was great if she returned directly home from her hospitalization. At the

same time, all involved were troubled by the prospect of overriding her wishes.

Patient Status in the Medical Encounter: Historical Perspective

Historically, patients have been accorded insufficient weight in the process of medical decision making. In 1847, the inaugural Code of Ethics of the American Medical Association (AMA) stated, "The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them."¹ This statement certainly leaves no doubt about the intended locus of authority in the patient-physician relationship. The patient's role was to be obedient and deferential. Physicians were not to be challenged, and patients were not to offer their "own crude opinions."

More than 100 years later, patients' roles in the patient-physician relationship remained relegated to the background, as evidenced by limited participation in decision making and limited access to important information. An article published in *JAMA* in 1953 documented that 69% of physicians never told or usually did not tell their patients that they had cancer. One of the physician participants in that study offered the following commonly held justification for this practice: "I never tell the patient he or she has cancer no matter how strong or stable they are emotionally: very, very few of them are equal to standing the shock of being told the truth."² A similar study published in 1961 demonstrated that 90% of physicians did not inform patients of their diagnosis of cancer.³

Fortunately, over the past 50 years, much has changed with respect to the patient's role in decision making and their status in the patient-physician relationship. In the context of complex shifts in social norms in the 1960s and 1970s,⁴ patient autonomy became established as a dominant principle in bioethics.⁵ A study published in *JAMA* in 1979 revisited the issue of disclosure of cancer diagnosis and found that 97% of physicians now

preferred to tell patients that they had cancer.⁶ Changes in the patient's status in the patient-physician relationship and involvement in medical decision making paralleled these changes in disclosure of information to patients.

The AMA Principles of Medical Ethics in 1980 (and most recently in 2001) stated that "A physician shall respect the rights of patients. . . ."⁷ Among other rights, patients were acknowledged to have the right of self-determination. But does the right of the patient to decide for themselves extend to the right to make a bad decision?

Patient Rights and Patient Well-being

Patients have the right to define for themselves the values and goals that will determine their medical care. These values and goals inform decision making about specific medical interventions; eg, deciding between alternative treatment approaches. To facilitate this right of patients to be self-determined, physicians should adopt a patient-centered approach, taking care to determine the patient's values and goals of care, as well as eliciting the patient's perspective on their illness.

It is often difficult for physicians and other members of the health care team to accept patients' decisions that depart from a professional's recommended course of action, which is intended, of course, to benefit the patient. Even though such decisions may preclude benefit in a biomedical sense, decisions that are congruent with patients' values and goals may benefit patients in other ways.⁸ Patient choices that endanger their well-being and appear to conflict with their own stated values and goals are especially difficult to accept because they appear to be not only "bad" from the medical perspective but also irrational. It is important for physicians to identify the underlying cause for irrational decision making and approach it appropriately.⁹

Mrs A valued, apparently above all other considerations, being at her home. Accommodating this preference, however, made benefiting her in a medical

sense more difficult and introduced the strong possibility of harm. Many authors have expressed concern that one consequence of overly strict adherence to the principle of patient autonomy is that other important principles (such as the duties to benefit and protect patients) receive insufficient priority. This imbalance might result in an inappropriately limited role for patients' physicians in important medical decisions. The goal, it is argued, should be to strike a proper balance between autonomy and beneficence that would include a healthy respect for patient self-determination without abandonment of the duty to benefit patients.¹⁰ This approach would allow physicians a meaningful role in the patient-physician relationship and in medical decision making, one that includes looking out for the well-being of their patients while avoiding backsliding toward paternalism.

In general, however, patient decisions are honored. This is true even if patient decisions are perceived by their physicians to be "bad" or "irrational," unless there is a threat of harm to a third party, an inadequately treated psychiatric illness, or a concern about capacity.¹¹ Although concerns about patient capacity should not be limited to occasions when physicians consider patient choices to be "bad" or "irrational," it certainly makes sense that such choices would raise these concerns.

Assessing Capacity

Methods of assessing decisional capacity typically identify several essential functional abilities¹² and, in this way, differ from measures of mental status, such as the Mini-Mental State Examination. In some formulations, these abilities are presented hierarchically, proceeding from simpler to more complex tasks.¹³ These abilities include making and communicating a choice; understanding relevant information about the medical situation; appreciating that the relevant information applies to oneself in the situation at hand and, perhaps, in the future as well; and engaging in rational deliberation about treatment options and being able to describe why a particular

choice was made, rather than another, based on one's own values. A bedside tool to evaluate capacity for treatment decisions is available and it has been empirically studied, yet time considerations may limit its widespread application in clinical practice.^{14,15}

Some authors have argued for a flexible standard with respect to decisional capacity: the idea that as the risk of harm increases, the criteria for capacity should accordingly become more stringent.¹⁶ In our case, the stakes were quite high. If Mrs A were to be discharged to home, she would be at risk of serious morbidity or even death. Under these circumstances, some experts would insist on a stricter standard for capacity.

In the present case, the psychiatric consultant concluded that the patient was competent yet, at the same time, raised questions about how well Mrs A appreciated certain factors relevant to the choices she was making. An independent evaluation by the physician member of the ethics consultation team (J.A.C.) raised similar concerns: there was uncertainty about how thoroughly the patient had thought through the ramifications of going home. During that interview, the patient seemed either unwilling or unable to engage in a careful (and adequate) conversation about the risks associated with her proposed course of action.

Yet her strongly expressed desire to go directly home and not to a rehabilitation facility was consistent with longstanding, plainly expressed wishes. This history of a consistently stated preference should be given proper consideration. At the same time, patient preferences may appropriately change as circumstances change. The literature on stability of patient preferences over time, or as health status changes, is mixed; some studies indicate stability of preferences^{17,18} while others do not.^{19,20}

Violation of Physician Values

With regard to the personal beliefs and values of physicians, the ethics manual of the American College of Physicians states that "Physicians and patients

Box. Patient Refusal of Care: Suggested Approach and Considerations

Regard refusal as an opportunity to initiate (or continue) dialogue with the patient

Seek and examine the patient's reasons for refusal

Identify patient-related factors that may be contributing to refusal (eg, religious beliefs, cultural background, psychosocial factors, previous interactions with the health care system, influential personal experiences, preferences of family members or friends)

Determine if refusal of care is consistent with the patient's stated goals for care

Assess the patient's capacity for decision making

Explore whether patient autonomy (refusal of care) and patient welfare can be reconciled

When the clinician's personal or professional values are violated, the clinician is not obligated to participate but must carefully reflect on this decision and assist in transfer of care

may have different concepts of the meaning and resolution of medical problems. . . . Although the physician must address the patient's concerns, he or she is not required to violate fundamental personal values, standards of scientific or ethical practice, or the law. . . ."²¹ Arguably, this is a relevant concern in the current case. One could reason that participation by a physician in a plan that sent this patient home to unsafe circumstances would violate a professional duty to protect the patient from harm.

Physicians are not obligated to violate personal values or standards of practice in respecting patients' rights to make their own choices. However, they may not abandon patients. In the setting of irrevocable patient-physician disagreements, physicians must take whatever measures are necessary to facilitate an effective transition of care to another physician.²² Beyond this, physicians should consider carefully whether their personal or professional values truly are being violated. Even when disagreeing with a requested course of action, physicians should examine the appropriateness of refusal to help patients realize their stated preferences.²³

Responding to Refusal of Care

There are many possible responses to a patient who refuses treatment recommendations. In particularly frustrat-

ing cases, some physicians are tempted to disengage and accept patients' decisions out of resignation or even anger. Although this approach may seem easier for the physician, it may not serve patients' best interests. Alternatively, physicians may reject a patient's refusal and attempt to impose treatment through whatever means available, including pursuit of legal options through the courts. In the state where this patient resided, in the absence of a mental illness associated with dangerousness to self or others, attempts to force placement or treatment against a patient's will could only be pursued if the patient were deemed by a judge to be incompetent. Another response to treatment refusal is to explain the physician's perspective to the patient, attempting to persuade the patient to change their mind while avoiding manipulation or coercion.

The BOX summarizes a suggested approach and considerations for managing refusal of care. When treatment refusal is encountered, physicians should regard such resistance as an opportunity to initiate (or continue) dialogue in an effort to understand the patient's perspective. What factors are contributing to the patient's point of view and influencing their decision making? Have members of the health care team considered and explored religious beliefs, cultural background, various psy-

chosocial factors, previous interactions with the health care system, influential personal experiences, or the preferences of family members or friends? The physician should determine the consistency of the patient's choice vis-à-vis the patient's values and goals. Is the proposed choice compatible with the achievement of those expressed goals? Is it the best choice to achieve those goals? Careful consideration of these issues could lead to better ways of communicating with the patient and, ideally, to better decisions and outcomes.²⁴

In Mrs A's case, her care providers sought to better understand her stated preferences and refusal of recommended care. It did not appear, after careful evaluation, that her desire to go home was explained by denial of the essential facts of her medical status or her social and financial circumstances. Communication with her nephew revealed that Mrs A's attitude toward nursing homes stemmed from a time in her life when she volunteered with a seniors' facility. In doing this, she visited several nursing homes and developed an unfavorable view of them, insisting she never wanted to go to one. Accordingly, her nephew explained, past efforts to have her consider assisted-living options were unsuccessful because the patient believed that if she were leaving her home, she was being sent to a nursing home.

CONCLUSION

The care providers in Mrs A's case struggled greatly to determine the correct course of action. Hospital physicians, Mrs A's primary care physician, nurses, hospital social workers, the APS social worker, and Mrs A's nephew all had serious concerns about her safety and well-being if she were to return home, yet all wanted to honor her wishes. As previously stated, the main problem was that her well-being and her wishes appeared to be in direct conflict with each other. When core values conflict, there may not be one clear correct answer. On the contrary, alternative choices may appear (and be) dia-

metrically opposed, each with advantages and disadvantages from an ethical standpoint. In cases with uncertainty about the right course of action, decisions can be accompanied by doubt and distress.

The ethics committee consultation team also struggled to determine the best course of action in this case. The 4-member multidisciplinary consultation team, with representation from nursing, social work, administration, and the medical staff, met at length on 2 separate occasions to discuss this case. The ethics consultation team, which, at the Johns Hopkins Bayview Medical Center, functions in an advisory capacity, concluded that if the medical team believed the patient had the capacity to make decisions about this issue, then the patient had the right to decide to return home. The consultation team noted that if there was sufficient doubt about her capacity to make such decisions, then the medical team would be justified in taking steps to override her plan to return home.

The ethics consultation team also suggested ways to reconcile the patient's right to self-determination with concerns about her well-being. The team proposed an alternative way of presenting information to the patient that was consistent with her goal of getting home and staying there. Specifically, they suggested communicating to the patient that her care was not complete and that she needed continued treatment in an institutional setting for rehabilitation and skin care to optimize her condition for eventually returning and staying home. Going directly home from the hospital might not be the best choice to meet her long-term goal of staying at home and could possibly undermine that goal.

In addition, by communicating with various parties involved in the patient's care, including the APS social worker, the ethics consultation team learned about the APS strategy of applying for a Medicaid waiver on the patient's behalf and was able to relay this information to the medical team. The hope was that after 30 days

in a skilled nursing facility she would become eligible for the waiver and qualify for 12 hours per day of in-home assistance.

Near the end of Mrs A's hospitalization, a meeting was held that included, among others, the patient, members of her medical team, a social worker, a member of the ethics consultation team, and a case manager from the Medicaid waiver program. The discussion addressed her medical status, the need for ongoing treatment in another institutional setting, and the facts of her current financial situation as they related to her ability to purchase in-home support. An effort was made to present short-term rehabilitation as a genuine alternative to either long-term placement in a nursing home or transfer directly home. In addition, the assembled staff explained to the patient that they would apply on her behalf for a Medicaid waiver to help pay for in-home caregivers when the patient was able to return home. In this way, the final discharge plan attempted to account for her desire to go home, albeit in a delayed time frame, but with the expectation that she would be able to stay at home for a longer period than if immediately discharged from hospital to home, bedbound, and without adequate support. It was at this meeting that the patient agreed to be discharged to a skilled nursing facility for skin care and rehabilitation. The attending physician's final note, referring to the patient, indicated that "her autonomy was preserved while striving for optimal care management."

EPILOGUE

Two days after transfer to the skilled nursing facility, Mrs A developed acute gastrointestinal bleeding and became hemodynamically unstable. She was transferred to a different acute care hospital and was admitted to the intensive care unit. She died a few days later.

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REFERENCES

1. Reich WT, ed. *Encyclopedia of Bioethics*. American Medical Association. *Code of Ethics*. 1847:chap I, article II, §6. Cited by Vol 5. Rev ed. New York, NY: Macmillan Publishing Co; 1995:2641.
2. Fitts WT, Ravdin IS. What Philadelphia physicians tell patients with cancer. *JAMA*. 1953;153:901-904.
3. Oken D. What to tell cancer patients: a study of medical attitudes. *JAMA*. 1961;175:1120-1128.
4. Starr P. *The Social Transformation of American Medicine*. New York, NY: Basic Books; 1982.
5. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 5th ed. New York, NY: Oxford University Press Inc; 2001.
6. Novack DH, Plumer R, Smith RL, Ochitil H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA*. 1979; 241:897-900.
7. Reich WT, ed. *Encyclopedia of Bioethics*. American Medical Association. *Principles of Medical Ethics*. 1980:Preamble, §4. In Vol 5. Rev ed. New York, NY: Macmillan Publishing Co; 1995:2649.
8. Jonsen AR. Blood transfusions and Jehovah's Witnesses. *Crit Care Clin*. 1986;2:91-100.
9. Brock DW, Wartman SA. When competent patients make irrational choices. *N Engl J Med*. 1990;322: 1595-1599.
10. Pellegrino E, Thomasma DC. *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York, NY: Oxford University Press; 1988.
11. Bekelman DB, Carrese JA. A practical model for managing treatment refusal. *J Fam Pract*. 2006;55: 403-407.
12. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics*. 5th ed. New York, NY: McGraw-Hill; 2002:55-56.
13. Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York, NY: Oxford University Press; 1998.
14. Grisso T, Appelbaum PS, Hill-Fotouhi C. The MACCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatr Serv*. 1997; 48:1415-1419.
15. MacArthur Competence Assessment Tool for Treatment (MACCAT-T). <http://www.prrpress.com/books/mact-setfr.html>. Accessed June 22, 2006.
16. Buchanan AE, Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, England: Cambridge University Press; 1989.
17. Carmel S, Mutran EJ. Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments. *Soc Sci Med*. 1999;49:303-311.
18. Rosenfeld KE, Wenger NS, Phillips RS, et al; SUPPORT Investigators. Factors associated with change in resuscitation preference of seriously ill patients: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Arch Intern Med*. 1996; 156:1558-1564.
19. Weissman JS, Haas JS, Fowler FJ Jr, et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. *Med Decis Making*. 1999;19:16-26.
20. McParland E, Likourezos A, Chichin E, Castor T, Paris BEC. Stability of preferences regarding life-sustaining treatment: a two-year prospective study of nursing home residents. *Mt Sinai J Med*. 2003;70:85-92.
21. Snyder L, Leffler C. *Ethics manual*: fifth edition. *Ann Intern Med*. 2005;142:560-582.
22. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med*. 1995;122: 368-374.
23. Jecker NA, Carrese JA, Pearlman RA. Caring for patients in cross-cultural settings. *Hastings Cent Rep*. 1995;25:6-14.
24. Carrese JA, Rhodes LA. Bridging cultural differences in medical practice: the case of discussing negative information with Navajo patients. *J Gen Intern Med*. 2000;15:92-96.