Honoring patients’ wishes becomes difficult when doing so threatens their well-being. In this article, the case of a hospitalized elderly woman is presented. The patient, ready for discharge, insists on returning home, yet she is bedbound and lacks adequate social support and financial resources to manage safely. The medical team, troubled by this situation, requests an ethics consultation. The article discusses several issues related to the difficult ethical problem posed by this case, including a brief historical review of the patient’s role in decision making, current thinking about patients’ rights vis-à-vis patients’ well-being, assessing patients’ capacity to make sound decisions, consideration of physician values, and, finally, responding to patients’ refusal of care.

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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.” 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.” A similar study published in 1961 demonstrated that 90% of physicians did not inform patients of their diagnosis of cancer.

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, patient autonomy became established as a dominant principle in bioethics. 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. 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 . . . .” 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. 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.

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. 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. 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 abilities 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. 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.

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. 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 long-standing, 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 while others do not.

**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
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

Responding to Refusal of Care
There are many possible responses to a patient who refuses treatment recommendations. In particularly frustrating 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 psychosocial 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.

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 senior’s 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-
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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