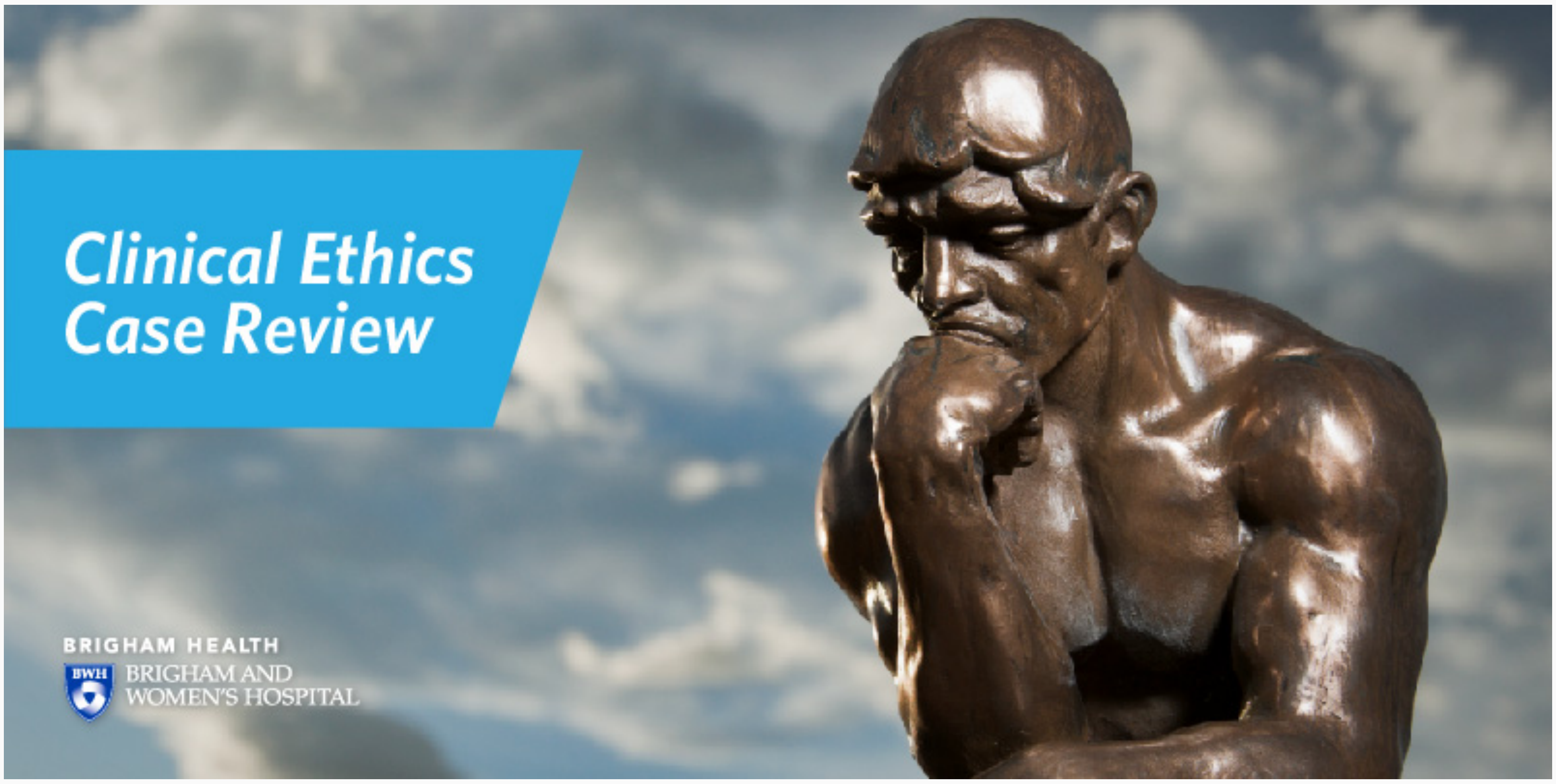

Brigham Clinical Ethics Case Review *is published by the Brigham's Office of Clinical Ethics. Each issue highlights a Brigham case that posed an ethical challenge for a patient, family members and/or caregivers, leading to an ethics consultation and Brigham Ethics Committee discussion. Please note that because cases are based on actual ethics consultations, some details may have been altered to protect patient privacy and confidentiality.*

"All That Matters Is Being Home"

Reconciling Risk Avoidance and Autonomy Promotion in Discharge Planning

This issue of *Brigham Clinical Ethics Case Review* highlights a case in which the care team struggled to decide on a discharge plan for an elderly patient with advanced dementia who was vocal about his desire to go home, but kept turning away the supports he needed to make home discharge a safe option.

The Case

The patient was an elderly man with cardiac disease and advanced dementia, among other health problems. His wife also had dementia, but not as severe. They lived at home by themselves. The patient was forgetful about taking medications for his heart condition, causing him to experience repeated episodes of angina (chest pain caused when the heart doesn't get enough blood flow from the coronary arteries). Whenever this occurred, his wife would call 911 and he would be taken by ambulance to the Brigham and Women's Emergency Department (ED) and admitted to the cardiology service. Once stabilized, the patient always expressed a strong desire to go directly home rather than to a rehabilitation facility or other supported environment. His wife agreed with this plan wholeheartedly. As they frequently said, the most important thing to them was being together in their own home.

Over the course of several admissions, the care team tried to honor this wish by arranging for visiting nurses or home-based palliative care, but each time the patient and his wife refused to allow clinicians into the house. Their family members endorsed home care based on the patient's consistent requests and previously stated preferences; however, they were minimally involved in the couple's daily lives and didn't take any steps to optimize the discharge plan.

By the time of the patient's most recent hospital stay, his mental status and physical condition had become markedly worse. Though verbally interactive and quite vocal, he was now determined to lack decisional capacity, particularly with respect to understanding the risks and benefits of different treatment options. His nursing care needs had become more extensive, involving recurrent re-orientation, management of anxiety, and prompting for medications and activities of daily living. Not getting this care would place the patient at risk of accelerated clinical decline and a potentially fatal event at home.

The patient was once again emphatic about wanting to go home, insisting that all that mattered was being there with his wife. The treatment team had serious concerns about the patient's safety in that setting, and felt the better option was discharge to a rehabilitation facility. Yet, they didn't feel comfortable overriding the patient's persistent and deeply held wishes. The team requested an ethics consultation to help address their uneasiness about this situation.

Discussion

In considering discharge options for older adults who adamantly oppose medical team recommendations, the principles of beneficence (doing good and protecting from harm) and autonomy (self-determination) often come into conflict. Clinicians feel torn between taking a “risk avoidance” approach to protect patients from harm, and an “autonomy promotion” approach to honor patients’ personal values and goals (Moats and Doble 2006). As neither is ideal in this situation, clinicians may experience moral distress stemming from uncertainty about the right thing to do.

In the risk avoidance approach, the main goal is to situate the patient in an environment that fosters recovery and protects the patient from physical injury. Home discharge is assessed primarily in terms of safety. Decisional control rests with the provider, leaving the patient and family largely out of the process. While risk avoidance may benefit the patient in a biomedical sense, it can take an emotional toll if it involves significant changes to which the patient is opposed. For older people who invest significant meaning in their homes as the locus of cherished memories and comforting routines, being relocated makes them particularly susceptible to emotional distress (Moats and Doble 2006).

Autonomy promotion allows for more patient input in the decision-making process. It contends that adults with decisional capacity have the right to make health care decisions in accordance with their own values and goals, even if those decisions place them at higher risk of undesirable medical outcomes. Nevertheless, it can be difficult for clinicians to accept decisions in favor of plans that they consider unsafe. In addition to concerns for patient well-being, they may worry about legal repercussions if the patient sustains an injury. They may also question the wisdom of prioritizing short-term interests over long-term goals. For example, if respecting a patient’s immediate wishes increases the risk of serious injury, his or her chance of maintaining autonomy in the future may be compromised (Moats and Doble 2006).

Rather than choosing one approach over the other, the literature suggests adopting a more balanced style of discharge planning — one grounded in “mutual respect, shared power and negotiation.” This model emphasizes the interdependence among patients and others, including family members, health care professionals, and the greater community. Finding an acceptable level of risk calls for a negotiated interaction which considers patients’ strengths and limitations, personal values, and available resources. The extent of both professional and family input depends on the patient’s cognitive status and the amount of support that the family will need (and be willing) to provide. For example, if the patient has significant cognitive impairment and/or the discharge plan is highly dependent on family support, then family and caregiver participation will need to be greater (Moats and Doble 2006). The patient’s loss of decisional capacity does not, however, mean his or her wishes should be disregarded; rather, discharge decisions should reflect the patient's previously articulated values and goals to the degree they can be safely and reasonably honored.

During the ethics consultation, the ethicists invited the patient's family and multidisciplinary care team to share their perspectives. The patient's wife spoke eloquently about wanting to take the patient home. She described her deep love for him and their life together, insisting that she was able to care for him and did not want the intrusion of someone coming into their home. The care team emphasized the couple's need to accept help in the home if they were to remain there. They expressed their concern that going directly home from the hospital could undermine the patient's goal of remaining at home over the long-term. Family members acknowledged that possibility but recalled how consistent the patient had been about preferring to be home, even when he still had decisional capacity and could appreciate the risks.

In the end, the participants reached a negotiated compromise. The care team agreed that, while 24-hour care was recommended, it would be acceptable to allow home discharge on condition that the family provide for some home care and arrange to be there when the caregivers arrived to ensure the patient accepted them. The family agreed to this plan and met with Brigham Care Coordination to explore home care options. There was also consensus that an acute care plan should be entered into the patient's electronic medical record to allow ED staff quick access to his history and, as agreed by family and caregivers, to provide instructions regarding future hospitalizations and goals of care.

Supporting Literature

Carrese, J. "Refusal of Care: Patients' Well-being and Physicians' Ethical Obligations." JAMA 2006:296(6);691-695.

Cummings, S and Cockerham, C. "Ethical Dilemmas in Discharge Planning for Patients with Alzheimer's Disease." Health Soc Work 1997:22(2);101-108.

Moats, G and Doble, S. "Discharge Planning with Older Adults: Toward a negotiated model of decision making." Can J Occup Ther 2006:73(5);303-311.

We welcome your feedback about Brigham Clinical Ethics Case Review. *Please email your questions and/or comments to* **BWHEthicsService@partners.org**. *The Ethics Service is available 24/7 by pager to all Brigham clinicians without a physician order, as well as any Brigham patient or family member. To learn more about ethics consults, visit the* **Office of Clinical Ethics** *website. This newsletter is primarily intended for internal distribution to the Brigham community. If you'd like to use this content for another purpose, please contact the* **Office of Clinical Ethics**.

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