
The Old Man and the Sea: Ethics of Borderline Competency

Like the fisherman in Ernest Hemingway's classic "The Old Man and the Sea," healthcare professionals assisting at-risk individuals with borderline capacity must grapple with difficult ethical questions. This article follows the turbulent history of a patient named Jim suffering from vascular dementia and the challenging process faced by his medical team to respect his autonomy while working to ensure his wellbeing.

by Darryl Rolfson, MD, FRCPC

The Case

Jim is a 77-year-old retired plumber who came to my outpatient clinic for a cognitive assessment. After the first ten minutes, it was obvious that this man had a skill for controlling conversations, and covering up his deficiencies. Yet there was a glimmer of possibility in this man. Whatever the end result, I felt that a complete geriatric and competency assessment would provide this man with real solutions and a meaningful care plan.

Jim, who lived alone, had past problems with disabling congestive heart failure, osteoarthritis, obesity, and alcoholism. His two children and wife refused to participate in his life on the basis of allegations of past abuse. Home Care services also refused to continue to provide any further care, citing past abusive behavior directed to their female staff. No power of attorney or advanced directive had been arranged. Jim claimed total independence in living and was simply looking to have his driving license reinstated.

The patient examination revealed a large, unkempt man who smelled of old urine. His communication style was loud and intrusive. He was quick to express anger, stammered when upset, and easily turned the topic of conversation to his own interest. No clear psychotic ideation was evident and screening cognitive tests were within normal limits. Even his basic knowledge of current world events was accurate. However, there seemed to be a real "disconnect" in his understanding of the functional impact of his own personal health problems. He agreed to be admitted for further evaluation.

After admission, Jim was loud, obnoxious, and impatient. Insisting that his attending doctor had the authority to make things right, he

expected special provisions while complaining of his poor treatment. He frequently threatened to leave, and yet, when given the opportunity, remained to the disappointment of the care team.

The interdisciplinary assessment went smoothly. His primary new diagnoses were vascular dementia with frontal lobe features and urinary urge incontinence. The management of his chronic conditions was optimized, and the importance of assistive devices to minimize falling was reemphasized. He was still deemed to be a moderate fall risk. The team strongly recommended that in the future he would require nursing care (bath assist, continence products and medication monitoring)

Darryl Rolfson, MD, FRCPC
Associate Professor of Medicine,
University of Alberta
Specialist in Geriatric Medicine.

and other support (housekeeping, laundry, meals, transportation, and assistance with money management).

Jim refused to be discharged to anywhere but his own home, despite multiple attempts by myself and other staff to convince him otherwise. His claims that there were renters willing to support him in exchange for reduced

Jim refused discharge to anywhere but his own home, despite multiple attempts by myself and other staff to convince him otherwise.

rent never materialized. Jim did not make any other arrangements for discharge. His competency was best described as borderline. The team was evenly split on whether he should be discharged to his home. None of the discharge options seemed satisfactory:

1. Discharge to his home meant exposing Jim needlessly to unnecessary risk.
2. Certification and direct placement seemed excessively coercive for a man who had strongly valued independence while he was competent and who had been sustaining himself at home, after a fashion.

Principlism

The ethical framework familiar to most physicians is principlism, as described by Beauchamps and Childress.¹ The application of these principles can be very “value-laden,”² and influenced by culture.

How do principles of autonomy, beneficence, non-maleficence, and justice bear on the assessment of decision-making capacity?

Autonomy recognizes that competent individuals should be free to make informed choices within their realm of influence, even if these choices are well outside a social norm. It is assumed that competent individuals are

able to make reasonable choices when given relevant information and when free of coercive influence. Respecting patient autonomy also means respecting the consequences of autonomous choices made by the patient. When a person is clearly incapable, surrogate decision makers should feel more confident in acting on their behalf, regardless of their stated wishes. By default, the substitute decision-maker is sometimes a physician.

Borderline capacity, as in Jim’s case, presents a unique challenge to a substitute decision-maker. The pattern of capacity may follow the gradually changing and multi-domain nature of an evolving dementia. Capacity and autonomy may fade like the setting sun rather than the flip of a light switch. The loss of autonomy, like the decline in cognition tends to be task specific. In contrast, legal standards are rarely flexible enough to account

for the gradual or task specific loss of autonomy. Even with the legal authority to act, substitute decision-makers for individuals of borderline capacity are left straddling this legal breach. They are charged to act according to the dependent adult’s past values and in their best interests. Yet, the dependent adult may retain the ability to participate in a limited yet meaningful way, which is contrary to the best judgment of the decision-maker.

Beneficence and *non-maleficence*. Doing good (beneficence) and avoiding harm (non-maleficence) are by necessity defined by a framework of values. The usual frame of reference for a physician is “what is good or harmful for the patient?” However, other interests can interfere such as the good or harm experienced by the patient’s family, the health care providers, the health organization and even the community at large. These competing interests would normally be considered by a competent, autonomous individual. Substitute decision makers who can show that they are acting as the patient would act, sometimes justify these considerations as well.

The in-patient geriatric assessment and rehabilitation should normally lead to a clear articulation of needs and appropriate settings. Jim’s experience highlights the stalemate that can occur when there are strong differences between patient and care staff in which discharge settings is undesirable. In such a stalemate, care

providers may insist on termination of the acute hospitalization on the basis of futility. Commonly, the patient is given the ultimatum to comply with recommendations for long-term care or make arrangements for their own expressed preference. There is often a reluctance of professionals to assist in the execution of a discharge plan that they believe to be doomed for failure.

There is a more powerful justification for breaching autonomy and acting in the best interests of families, health care providers and communities: beneficence and non-maleficence. This rationale can remain centered on the patient. Due to borderline capacity, a patient may be unable to realize their dependence on caregivers, nor the “burn-out” that these caregivers experience as a result of the performance of their duties. To the extent that this dependence is real, and other care giving options are exhausted, acting in the best interests of caregivers (families, health care providers and communities), in a very real sense, is acting in the best interests of the patient also. Still, even this argument loses momentum if the patient when clearly competent anticipated their upcoming dependence or demise and consistently expressed their desire to be left unassisted.

Justice. When the development of a care and discharge plan involves excessive amounts of time, frustration builds amongst caregivers. After all, caregivers operate with fixed resources. Who has an

obligation to provide care to a patient of borderline capacity when all community-based resources have exceeded their limits? Those who do provide the daily care may ask whether it is fair to distribute their time unevenly to patients, especially the one patient who seems to require excessive time is not compliant with the care offered. Continuing to provide care in such a situation can tax the emotional reserves of caregivers, leaving them spent and less available to other patients who stand to benefit from the caregivers skills.

From the standpoint of a public health organization, how far “out to sea” can care be provided before the line must be cut? Is it ever ethical to settle on a less than optimal discharge plan simply because the time is up? In Jim’s situation, discharge to the community would

have been much less costly to the health organization and would have honored his expressed wishes. However, this would compromise beneficence.

The Home Visit

In the hopes that discharge home with a guardian was an option, we decided to “let out the line” and proceeded with a home visit to better scrutinize his capacity. For

the sake of assessing competency and as a trial of his ability to be discharged, I determined that I would, as much as possible, be a silent observer, leaving the patient to organize his own transportation and refraining from assisting him to enter the home.

Jim’s journey into the house was shocking. Half way up the short walkway, his knees began to buckle. The sinking ground beside the front steps produced a formidable initial barrier that Jim solved by crawling to the top and pulling himself through the door. Once inside, he collapsed into a chair and between rapid breaths, directed us to look around at will. The general state of clutter was apparent in layers, like rings in a tree, with the most recent layers of disorder giving way to deeper evidence of past order, now aban-

Commonly, the patient is given the ultimatum to comply with recommendations for long-term care or make arrangements for their own expressed preference.

doned. Much of the house was inaccessible with the clutter. However, there were clearings and pathways that allowed access to the kitchen, bathroom, bedroom, and laundry room. Reassured, as we casually opened the fridge, the horror of the effects of a month of large amounts of unrefrigerated meat burst upon us. “Oh that,” said Jim, “Do you think that we could give it to the dog pound?”

The Old Man and the Sea

At about this point, I began to feel a little like the fictional fisherman in Ernest Hemingway's "The Old Man and the Sea."³ In the story, this experienced older fisherman was unable to catch a fish for several weeks. As he set out again, each line perfectly placed, he reassured himself that "every day is a new day. It is better to be lucky, but I would rather be exact. Then when luck comes you are ready."³ An enormous marlin took his line that day. The old man held on and exercised all his skill, commitment, and tenacity. The personal cost of failure was too

Capacity assessment is like walking a tightrope which avoids two errors, "allowing incompetent patients to make decisions (which by definition may lead to harm) and preventing competent patients from articulating their treatment choices."⁴

great to yield. He allowed the marlin to pull him out to sea, keeping the tension just right so that the line would not break and yet the marlin would eventually tire. Then, fisherman and marlin bound together in a death grip, journeyed out to the eternal sea, neither flinching over the day, the night and into the next day.

Like the fisherman, teams that assist individuals with borderline capacity who live at risk must grapple with difficult ethical questions:

1. How far out to sea must we go? Frequently, individuals of borderline capacity expose

themselves to excessive risk. How far "out to sea" can a caregiver go before it is ethical to simply "cut the line," either by abandoning their duty or exercising coercion to remove the risk?

2. How does a substitute decision maker act when capacity is borderline? Ethics literature often focuses on high-risk decisions in severe dementia or in patient whose expressed decisions are well outside of common societal values. What is to be done when such decisions are made by individuals known to be eccentric in their life choices,

who now make more risky decisions while of borderline capacity? Even the old man in Hemingway's novel respected the marlin as his equal.

The Sliding Scale

Capacity assessment is like walking a tightrope which avoids two errors, "allowing incompetent patients to make decisions (which by definition may lead to harm) and preventing competent patients from articulating their treatment choices."⁴ Capacity which changes with dementia may be best understood using a sliding scale model,⁵

in which the bar is raised to demonstrate capacity for decisions of higher risk (Figure 1). This model places autonomy (expressed choice) at one end and places beneficence (best interests) at the other. When a surrogate decision maker executes a decision, they "draw the line" somewhere along this continuum. At one end beneficence is valued using a rigid standard of proof of a high level of functioning. At the other, autonomy is valued based on a very liberal standard that accepts expressed preferences at face value.

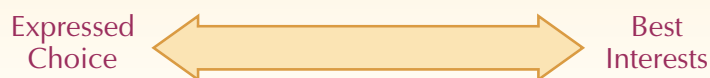
Physicians and psychologists usually apply the standard of competency at different points along this continuum based on the ethical principles (autonomy or beneficence) that are most relevant. Determining the relative weight of these principles often takes into account the anticipated consequences of the decision (*i.e.*, risk) and the presence of competing influences and interests (*i.e.*, interference). Higher levels of risk should prompt a greater duty to achieve beneficence. Higher levels of interference require a greater focus on autonomy.

Returning to Jim

Over the next week in the hospital, Jim retained the details of what was discovered in the home visit and verbalized his plan to address it. He claimed to have made arrangements for the fridge cleanup and private home support. Guardianship and long-term care

Figure 1

The Sliding Scale Model for Capacity Assessment and Ethics



applications were initiated, recognizing that if he was able to follow through with his plans for self-maintenance, the future guardian could modify the care plan as deemed suitable. It seemed that there was finally some closure to the question of placement.

Jim requested one last day pass to supervise the cleanup and this was granted. While waiting for a taxi to pick him up, he fell head first off of his front porch, sustaining what proved to be a permanent head injury, and ironically sealing his fate and simplifying the need for guardianship and institutional care. He remained in hospital for another four months until he was finally transferred to a behavioral unit in long-term care.

Returning to the Old Man

The fisherman also experienced temporary exhilaration when the

marlin finally tired and was drawn in. He similarly saw his success turn into failure when, having gone too far out to sea, his return home was blocked by sharks who destroyed the marlin, leaving only a bony carcass. As he puzzled over where he might have gone wrong, his poignant conclusion was that he “went out too far.”⁶

Process and Outcome: The Meaning of Success

Judged by the standard of outcome, the old fisherman’s circular journey on the sea was a failure. Using the same standard, the image of Jim lying outside his home with a fresh brain injury must also be viewed as a failure. Ironically, this “failure” became a dark success when Jim’s placement became uncomplicated by his borderline capacity. Even family and friends began to emerge

out of the woodwork. An application for private guardianship began and Jim was placed in an appropriate long-term care facility in a reasonable time frame.

Judged by the standard of process, Jim chose to enter and remain in the hospital. He received excellent care and was given every opportunity to prove himself capable of achieving his stated goal to return home. Jim was knowingly permitted to expose himself to the risk of a fall on the basis that he was competent for this short term decision. Many clinicians would have “cut the line” earlier by applying certification or discharging Jim to an inadequate environment. Ultimately, we, like the old fisherman, asked ourselves whether we “went out too far.”

In outcome-based practice, the “end justifies the means.” In process-based practice, the “means justifies the end.” For a substitute decision maker, clinician or lay public, it is challenging to stay true to an ethical process while witnessing the adverse consequences of a dependent adult’s choices. However, holding this ethical line for the sake of process may be preferable to cutting it in the pursuit of desired outcomes.

References:

1. Beauchamps TL, Childress JF. Principles of Biomedical Ethics 4th Ed. Oxford, New York: University Press, 1994.
2. Gordon M, Rosenberg Z. Ethical Challenges in Geriatric and Long-Term
3. Hemmingway, Ernest. The Old Man and the Sea. New York: Scribner Paperback, 1952
4. Fellows LK. Competency and Consent Care. Annals RCPSC September 2001; 34(6):383-7.
5. Drane JF. The many faces of competency. Hastings Cent Rep 1985;15:17-21
6. Hemmingway, Ernest. The Old Man and the Sea. New York: Scribner Paperback, 1952. pp.120.