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The Ethics of Palliative Care in Psychiatry

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We first met "Margaret" in the fourth month of her six-month admission to the geriatric psychiatry inpatient unit. Margaret was 54 years old and suffered from advanced dementia. At the time, few traces remained of the formerly demure, mild-mannered woman with sparkling blue eyes and gentle smile. Currently, she inhabited a state of almost constant agitation, with frequent fits of loud screaming and crying, which had prompted her three children to bring her for psychiatric admission.

The onset of Margaret's symptoms had been deceptively insidious. Six years prior, unexplained mistakes on the job had precipitated a leave of absence from work. Episodes of getting lost while driving had resulted in nonrenewal of her driver's license. As her cognitive status declined, her temporary work leave turned into a permanent retirement. Her son "Paul" moved in to live with her, and Paul and her two daughters, "Mary" and "Martha," alternated caring for her. Within a few years, Margaret had gone from living independently and working full-time as a highly valued registered nurse to being nonverbal, profoundly cognitively impaired, and exclusively reliant on her children for self-care.

Eventually, behavioral disturbances of dementia emerged. Shortly after 11 September 2001, she called 911, thinking terrorists were outside her window. She was often distraught for no discernible reason, and suffered bouts of uncontrollable yelling and agitated pacing, and was combative in response to care. One week prior to her index admission, she was admitted to a general hospital for management of unremitting agitation. An exhaustive work-up failed to elucidate potentially reversible causes of acute mental status changes. She spent much of that admission in restraints, and it was recommended that she be transferred to a geriatric psychiatry unit, with possible transition to a long-term care facility. At that point, her children opted to take her home, hoping that the more familiar home environment would decrease her level of distress. However, within a few hours, the children were forced to call 911 due to renewed escalation of behavioral dyscontrol.

Margaret had no prior psychiatric history and an unremarkable medical history. She had been born and raised in Boston, as one of four children of an emotionally detached and occasionally physically abusive mother, and had been sexually abused by an uncle. She had married once, and had three children, but was eventually divorced. Her husband was in recovery from alcohol dependence. Later in life, he developed multiple sclerosis and was confined to a nursing home. Despite adverse circumstances, Margaret was described as a kind and generous person who bestowed unconditional love on her children. She had treasured

her role as mother and nurse. She enjoyed arts and crafts, had many close friends, and was active in her religious community.

On admission, Margaret presented as a medium-built, middle-aged woman with short gray hair, looking considerably older than her chronological age. She sustained minimal eye contact and appeared sedated, in part from receiving intramuscular medications en route to the hospital. Her verbalizations were limited to soft moaning and whimpering. She was largely unable to participate in the intake process and was transferred to the geriatric in-patient unit.

Her six-month hospital course was marked by multiple treatment failures. Numerous medication trials were attempted with antipsychotics, mood stabilizers, antidepressants, and anxiolytics, without noticeable improvement. A course of nine electroconvulsive therapy treatments also proved ineffective. A review of her records revealed daily episodes of extreme agitation marked by unprovoked screaming (often lasting hours, and occasionally audible from outside the building), striking out at staff or other patients, and flinging herself against walls or onto the floor. Restraints were frequently required to ensure safety. In addition, Margaret underwent a profound physical decline, with a 60-pound weight loss due to poor oral intake. She had multiple internal medicine consults to rule out physical causes of pain, and, although her inability to communicate precluded certainty of the absence of physical pain, no findings on physical exams or laboratory studies appeared to indicate a physical cause for her distress.

Throughout her admission, Margaret's children remained actively involved in all aspects of her care. They closely monitored each twist and turn of her treatment course. With each medication change, they experienced renewed hopes that perhaps, this time, an intervention would be found to alleviate their mother's distress. However, despite momentary reprieves in her agitation, Margaret's improvement was never sustained. The children thus experienced the hospitalization as an emotional rollercoaster ride. Nonetheless, they deeply appreciated the treatment team's indefatigable efforts to help Margaret. The staff, in turn, grew unusually fond of Margaret's three remarkable children. Their aplomb and maturity in the face of their mother's plight inspired deep sympathy and admiration, particularly considering their relative young age at the onset of her illness (the youngest was in her late teens, and the oldest in his early twenties).

In light of Margaret's treatment-refractory symptoms and poor overall prognosis, several consultations with expert clinicians were sought for additional treatment recommendations. Suggestions were implemented, including one trial of dronabinol, based on a study demonstrating decreased agitation among patients with severe dementia.¹ Additionally, two consultants recommended a trial of opioid medications. While not customary, the use of opioids was shown in one study to be effective in reducing agitation and distress in patients with advanced dementia.² However, the use of narcotic pain medications for intractable behavioral disturbances of dementia remains controversial. Not surprisingly, members of the care team disagreed on the ethical validity of this treatment intervention. Some considered it unacceptable to assume the risk of falls, respiratory depression, and possible death associated with the use of these medications. Others felt it was morally wrong to withhold a treatment that might relieve Margaret's profound suffering. The disagreement became more pronounced, given the staff's level of attachment to Margaret and her children. In light of the discomfort with this proposal, and the impasse it generated, an ethics consultation was requested with a member of the hospital's ethics committee.

In the fourth month of Margaret's stay, one of us (D.H.B.) performed an ethics consultation. After observing Margaret's behavior at several different times, and conducting discussions with her children and members of her multidisciplinary team, the following note was placed in her chart.

[Summary of history]

I personally examined [Margaret] [twice], at which times I observed her to be agitated and pacing in a restless and uncomfortable fashion. On both occasions she was groaning incoherently and appeared to have receptive and expressive aphasia. At the time of my second visit, she lunged toward me in the hallway and needed to be contained and redirected by a staff member on the unit. She appeared extremely uncomfortable and inconsolable. . . .

[Margaret's] three children have cared for her in their homes. Her divorced husband has multiple sclerosis and is not

involved in her care. There are no other family members who are involved in decision making about her treatment. The children serve as her healthcare proxy and all three have been in basic agreement about important decisions related to her treatment. In light of her ongoing behavioral deterioration and poor prognosis, they have expressed a clear wish that she not be resuscitated if she goes into cardiac arrest and that no major medical interventions (including antibiotics or surgery) be implemented to treat acute illnesses. In addition, they have expressed a clear preference that she be treated with whatever medications are necessary to control her agitation and to reduce the emotional and physical discomfort that are associated with it. They understand that the use of sedating medications (such as opiates) could reduce her level of agitation but also put her at major risk of serious adverse medical events, such as extreme sedation, falls, respiratory depression, aspiration, and death . . . In a meeting with me and members of the treatment team . . . , all three children reiterated this wish and expressed a clear understanding of the risks inherent in using highly sedating medications to treat her extreme and treatment-refractory agitation, behavioral dyscontrol, and emotional distress.

During the meeting . . . , I explained to [Margaret's] three children that I would be available to facilitate discussions between them and the clinical team regarding the difficult treatment decisions that lie ahead. They understand that the use of medications to control her agitation might lead to medical complications that would be difficult to manage on a psychiatric unit. They understand the possibility that she might require hospice care if medications to treat her agitation caused serious medical consequences, such as respiratory depression. Because her agitation is so severe, her suffering is so great, and her prognosis is so grave, they believe strongly that sedating medications must be used at whatever dose is necessary to achieve the intended effect of reducing her agitation, even if the risk of using such medication is high and potentially fatal. They all believe strongly that this sort of intervention would be entirely consistent with their mother's previous wishes. They seek aggressive treatment of her agitation in order to enhance her quality of life but recognize that such treatment could have the unintended effect of causing medical complication and curtailing her life. From an ethical standpoint, the treatment team at this point would be justified in taking more definitive steps toward controlling her agitation and increasing her comfort. Because these steps are likely to include the use of highly sedating and risky medications, the team must assess carefully how to implement this treatment in a safe fashion. Arrangements for transfer to a medical unit, nursing home, or hospice may become necessary if safe and appropriate care cannot be provided on the geriatric psychiatry inpatient unit. . . . I would be happy to remain involved in the case if the treatment team and/or family members feel that ongoing ethics consultation could be helpful.

Following the ethics consult, the treatment team obtained a palliative care consultation. The palliative care specialist agreed that Margaret was suffering intensely and that management of her distress need not differ from the treatment of intractable pain in any other terminal illness. In other words, the use of opiates was not only justified, but in fact, indicated.

Six weeks after the initial start of the deliberations a decision was made to start Margaret on a trial of low-dose methadone. Almost immediately, Margaret exhibited a profound decrease in her level of agitation and distress. In addition, given Margaret's poor prognosis, the palliative care consultant suggested transfer to hospice. Approximately 10 days later, surrounded by family, and free of visible distress, Margaret died.

During her last week at hospice, Margaret had remained on low-dose opioids and had been sedated but not unable to breathe. She was noted to have a low-grade fever and difficulty clearing her oral secretions. The cause of her death was thought to be an aspiration pneumonia, although, as is consistent with hospice philosophy, no chest radiographs were obtained, and the fever was treated symptomatically with antipyretics but no antibiotics. Following her death, a post-mortem brain biopsy revealed dementia of the Alzheimer's type, rather than frontotemporal dementia, as had been previously thought.

Margaret's children recalled her last week as one of relative peace. One daughter described feeling "grateful" that her mother had died in the "cozy" and "welcoming" hospice environment. Despite undeniable sadness, the children also expressed feeling profound relief that their mother was no longer suffering. This reaction is consistent with empirical findings concerning the caregivers' responses to the death of their loved ones with dementia. In a landmark study of caregivers of dementia patients, more than two-thirds experienced their loved one's death as somewhat or very much a relief, and a vast majority believed somewhat or very much that the death had come as a relief to the patient.³

Interestingly, in the aftermath of Margaret's death, the children's reaction differed considerably from that of the psychiatric staff, who primarily experienced a sense of collective failure. This discrepancy seems understandable, given that transfer to hospice is not the usual aftercare plan for psychiatric patients. The general expectable outcome following a psychiatric admission is one of improved symptom control, with eventual discharge, usually within a matter of weeks, to a less restrictive setting. Yet, in part, this is precisely what makes Margaret's case noteworthy. Despite caring for countless patients with advanced dementia, psychiatric units and hospitals are not well-accustomed to confronting the complex ethical decisions surrounding end-of-life care.

In the psychiatric hospital, death is an uncommon event, usually the result of a suicide. Consequently, deaths are viewed as fundamental failures in the system and are associated with high levels of staff anxiety. This is partly due to the increased risk for malpractice litigation, but also to a sense that, unlike families of severely ill medical patients, families of psychiatric patients do not expect their loved ones to die in the psychiatric hospital. Psychiatric hospitals are meant to be places of safety, where patients go to be *prevented* from harming themselves. Hence, embracing a palliative care approach to advanced dementia, which could result in the death of a patient, appears anathema to the mission of psychiatry. Yet, the growing numbers of patients with dementia may cause psychiatric clinicians to be increasingly called upon to treat patients such as Margaret, who are unable to be cared for appropriately at home or in nursing homes.⁴ In the future, psychiatric units and hospitals may become key settings in which to address the complex end-of-life decisions that confront patients with dementia and their families.

Obstacles to the adoption of palliative care for dementia include difficulties conceptualizing dementia as a terminal illness. In other terminal illnesses, such as cancer or end-stage AIDS, the doctrine of double-effect has gained broad acceptance. This principle argues that an otherwise unacceptable outcome — such as death — may be justifiably risked when it occurs secondary to the primary aim of reducing pain and suffering. Patients with dementia who suffer severe and intractable behavioral symptoms, not unlike metastatic cancer patients who have exhausted treatment options, constitute a cohort of patients in whom the magnitude of suffering renders the principle of double-effect ethically applicable.

Yet dementia straddles the fence between a terminal illness and a more gradually progressive but not necessarily fatal condition. Its unpredictable natural history, in which some individuals survive for decades, while others decline precipitously, makes predicting life expectancy challenging at best. This has practical ramifications, such as the under-representation of dementia patients in hospice programs, in which a life expectancy of six months or less is a prerequisite for enrollment. Moreover, at the time of death, it is the medical event immediately preceding the death, rather than the underlying dementia, that is attributed as the ultimate cause of death. In Margaret's case, aspiration pneumonia, rather than end-stage dementia, was cited as the cause of death. While technically accurate, pneumonias and urinary tract infections are frequent complications of dementia, resulting from difficulty in swallowing and urinary incontinence. Thus, it could be argued that the underlying dementia, rather than the superimposed infection, was the ultimate cause of Margaret's death. This distancing of dementia from death contributes to the perception of dementia as a degenerative but not necessarily fatal illness, and may explain the discomfort with the acceptance of palliative care principles for select cases of advanced dementia.

The palliative care approach to dementia is further complicated by difficulties in establishing and implementing clear advanced directives for patients with dementia. Despite concerted efforts in recent years to encourage individuals to specify wishes for end-of-life care, most patients with terminal illnesses lack advance directives. For patients with cognitive impairment, timely establishment of such directives, at a point when the patient still has the capacity to make such decisions, is particularly important. Margaret's story underscores the need for continued public education on the importance of advance directives.

Yet, even when patients have established advance directives, inadvertent obstacles exist to the implementation of such directives. After Margaret's death, for instance, a legal document was found in her medical chart in which she explicitly delineated her wishes for end-of-life care. Margaret had signed this docu-

ment three years prior, in the presence of her son, who was her healthcare proxy. Excerpts from this document read as follows.

In the event that . . . I am no longer able to make cognitive decisions concerning myself, and . . . that there is no reasonable expectation of my recovery . . . to the extent that artificial and so-called "heroic" measures are required to keep me alive, I request that I be allowed to die a dignified death . . . that medication be liberally and mercifully administered to me to alleviate suffering even though this may hasten the moment of death, and that any action may be taken or withheld, as the case may be, so as not to unreasonably prolong my death nor destroy the dignity of my life. I . . . recognize the responsibility it places upon those of you who must carry out my request, but it is my belief that my right to die under these circumstances is just as precious as my right to live, and it is with the intention of relieving you of such responsibilities and of placing them upon myself that this statement is made.

It is notable how clearly and unambiguously this document embraces a treatment model that is entirely consistent with the palliative care approach that was ultimately adopted. Yet, it also is striking that, in and of itself, the existence of this document did not help to guide the treatment course, nor assuage concerns regarding the appropriateness of the use of narcotic medication. It underscores an unfortunate reality about advanced directives, which is that they often go unheeded. Promoting structured dialogue among families, clinicians, and patients regarding end-of-life wishes, before the onset of an acute crisis, would likely promote a more constructive use of advanced directives.

Margaret's advanced directive specified that medications should be used "liberally and mercifully" to "alleviate suffering." But at the heart of this case lies the question, What exactly is meant by *suffering*? Pain and suffering are intrinsically subjective phenomena. Historically, this has resulted in the undercognition and undertreatment of pain across healthcare settings. More recently, the adoption of "zero-tolerance" policies towards pain has resulted in an attempt to reverse this trend. Yet a distinction continues to be drawn between physical and psychological suffering, such that psychological or existential suffering is even more ill-defined, immeasurable, and unquantifiable than physical pain. For instance, we are far from understanding the complex processes that underlie the suffering experienced by someone with a crippling depression or intractable agitation of dementia.

The cognitively impaired patient's inability to communicate further precludes the clinician's understanding of the nature of the patient's pain and suffering. As a result, the notion of a "zero-tolerance" policy for existential suffering in patients with dementia is not met with the same acceptance as its counterpart for physical pain. In Margaret's case, her agitation and continual cries of distress suggested extreme pain and suffering. But the unknowable nature of this pain may have contributed to the discomfort with adopting a palliative care approach.

With the aging of the population and growing numbers of dementia patients, psychiatrists will increasingly be faced with similar problems in the coming years. Up to now, psychiatrists have been understandably reluctant to think of palliative care as a possibility for treatment-refractory agitation in dementia. But patients such as Margaret make it imperative that we entertain this option thoughtfully, that we heed relevant advance directives, and formulate treatment plans in collaboration with family members, clinical ethicists, palliative care clinicians, and specialists in related areas. Margaret and her three courageous children deserved no less.

NOTES

1. L. Volicer et al., "Effects of dronabinol on anorexia and disturbed behavior in patients with Alzheimer's disease," *International Journal of Geriatric Psychiatry* 12, no. 9 (1997): 913-9.

2. P.L. Manfredi et al., "Opioid treatment for agitation in patients with advanced dementia," *International Journal of Geriatric Psychiatry* 18, no. 8 (2003): 700-5.

3. R. Schulz et al., "End-of-Life Care and the Effects of Bereavement on Family Caregivers of Persons with

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Dementia," *New England Journal of Medicine* 349, no. 20 (2003): 1936-42.

4. M.M. Evers et al., "Palliative and Aggressive End-of-Life Care for Patients with Dementia," *Psychiatric Services* 53, no. 5 (2002): 609-13.

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.