DEMENTIA AND END-OF-LIFE DECISION MAKING: A CASE-BASED APPROACH TO THE CLINICAL APPLICATION OF BIOETHICAL PRINCIPLES

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ABSTRACT

People with dementia account for a growing number of patients requiring end-of-life medical care each year in the United States. The clinical application of bioethical principles is rarely more important than in the context of end-of-life decision making, and determining the appropriate clinical treatment plan can be difficult and complex for clinicians, patients, and medical proxies. While the current bioethical literature offers a wealth of information on the principles underlying ethical medical practice, real-world clinical scenarios are often fraught with confusion, complexity, and conflicting understandings of best practices. There is a need for clinical decision-making tools that are both comprehensive yet simple, and broadly-applicable enough to be clinically useful. This thesis explores the cultural factors that necessitate further discussion and understanding of the issues surrounding end-of-life care for people with dementia, uses a clinical case to demonstrate a real-world approach to the ethical complexities surrounding such care, and proposes a basic ethical decision-making algorithm with the potential for broad application by students and clinicians encountering complex ethical scenarios.

DEDICATION

Dedicated to the woman herein named Estelle Givens,

whom I think about often, and whose memory I

hope to honor in my future career.

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I would like to acknowledge Professor Providenza Rocco and Dr. Nora Jones, whose patience and guidance as well as their personal commitments to justice and equity have inspired me to look for new ways to approach clinical scenarios. I would also like to acknowledge Brijae Chivarria and Pamela Summers Trio, who both offered insights, ideas, and constructive criticism as I formulated my thoughts.

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CHAPTER 1: HOW WE APPROACH THE END OF LIFE

Sir William Osler, known by many as "the founder of modern medicine" and a key figure in modernizing and humanizing how physicians approached and related to their patients in the late nineteenth century, famously described pneumonia as "the friend of the aged" (Osler, 1912, p. 75). Practicing, as Osler did, in a context that afforded little ability to prolong life past a certain age and set of circumstances, pneumonia provided the elderly patients Osler served with a death that was both relatively quick and that inflicted minimal suffering. Within the scope of medicine practiced in Osler's lifetime, pneumonia represented a "good" death.

What is a "Good" Death?

Osler's memorable characterization of pneumonia as a "friend" underscores the foundational fact that throughout history, human beings have wished, in general, for a good death. What this means for the individual who is dying is influenced by cultural understandings of death, religious beliefs about what it means to die, the possibilities that medical practitioners are able to provide, and individual fears and desires. Until the last century or so, death in old age (if old age was reached at all) often meant the racking, breathless coughing fits of tuberculosis, the excruciating pain of cancer, the swollen-limbed, wet gasping of heart failure, or a myriad of other prolonged, painful deaths due to the consequences of untreatable disease. These deaths frequently left the dying person to linger in pain for months to years from onset of the disease until its eventual and inevitable conclusion. In contrast, pneumonia's cough, rising fever, and relatively quick slip into delirium and death allowed those who succumbed to it to shuffle off this mortal coil with minimal pain and minimal suffering. Before the advent of antibiotics, enteral feeding, intravenous hydration, or ventilators, pneumonia represented the gentlest side of the proverbial angel of death.

Within the last century, as our medical technologies, treatments, and possibilities have advanced by leaps and bounds, we have inadvertently outstripped our ability to provide ourselves with a "good death." Paradoxically, in our success in keeping death at bay, we have inadvertently given back to the eventual angel a few of its teeth. For any patient currently approaching death in a developed country, the scenario praised by Osler (one where an elderly patient is allowed to slip into fever and death without other medical interventions) is almost entirely outside the realm of possibility, unless there exists extensive prior legal documentation of that person's end-of-life wishes and the specific circumstances in which these wishes might apply. Outside of this circumstance, the idea that any of us should be allowed to succumb to pneumonia in our twilight years is alien, and the further assertion that this allowance might be considered "good" is even more likely to be automatically rejected.

Culturally, we have shifted from an acceptance that death is likely to be unpleasant (and therefore that relatively gentler deaths should be hoped for and embraced) towards a status quo in which pursuing curative treatments, even at high personal cost, is valued and desired (Smith & Sherwin, 2013, p. 4). This is, overall, as it should be – the extension of life, if its quality can also be preserved, is admirable and desirable. However, we have largely embraced these new ideals of what death ought to be and when it ought to come without giving equal acknowledgement to the argument's counterweight – that there may be times when curative measures are likely to be futile, and (worse than futility) that their pursuit may in fact cause greater suffering and an eventual death that would be unlikely to be described by anyone as "good."

In our current medical environment care must be taken that we do not preserve life at the expense of dignity or autonomy – now that we can do more, we must answer the question of when and how we should do more.

The Cultural Gap Between Provider and Patient

Beyond our cultural desire to do more for more's sake, an additional problem faced by clinicians, patients, and their family members in the US is the sharp divide between the attitudes and understandings about measures taken at the end of life on the part of physicians and other medical professionals, and the attitudes and understandings of the rest of the population. In television shows, movies, and other popular media, American culture presents life-preserving measures such as chest compressions, cardioversion, defibrillation, and artificial ventilation as dramatic, yet routine (and usually efficacious) measures. A 2015 study of television portrayals of CPR on two highly-rated and popular medical dramas showed that TV CPR had nearly twice the immediate and long-term survival rate as that of actual CPR (Portanova et al., 2015, p. 150). Beyond this increased survival rate, television depictions of CPR also frequently fail to convey that even if CPR is immediately successful, the long-term outcomes are usually poor, and outcomes are variable among age groups – elderly patients are much less likely to have good overall health outcomes after surviving a round of CPR than their younger counterparts (Harris & Willoughby, 2009, p. 1277).

In reality, the likelihood that CPR will be efficacious and beneficial for elderly patients is low. A 2015 meta-analysis of 14 studies found that for patients aged 70 or older, the pooled overall survival to discharge rate after experiencing an out-of-hospital cardic arrest was a mere 4.1% (van de Glind, p. 5). A 2006 study cited survival rates that rarely exceed 10%, and found that outcomes predominantly point towards a more realistic rate of around 3%-5% survival to discharge (Adams & Snedden, p. 402). Even when the patient population was carefully controlled to include only relatively healthy elderly patients with primary cardiac diseases and no other chronic illnesses, a study by Murphy et al. found that the chance of survival after CPR topped out at just 39% (1994, p. 545). Further, in evaluating elderly patients' perceptions of how likely they would be to benefit from CPR, Adams & Snedden found that "the expectations of elderly patients and actual survival [did] not correlate well," with 81% of respondents believing that the likelihood that they would survive CPR and leave the hospital afterwards was 50% or better, and almost a full quarter of respondents (23%) placing their perceived likelihood of survival and eventual discharge from the hospital at 90% or higher (p. 403). Again, actual rates of survival to discharge in this population are less than 10%, demonstrating the potential vast overestimation of treatment efficacy that may be present in this patient population.

However, studies have also found that patients readily demonstrate willingness to modify their beliefs and perceptions when physicians take time to discuss the actual likely outcomes with them. Murphy et al. found that once elderly patients understood the actual probability of survival after CPR, most changed their minds and said they no longer would want to have CPR performed on them (1994, p. 548). Additionally, broader efforts to improve cultural understanding of the efficacy of end-of-life measures through working with television writers and other producers of popular media have shown some promise (Sachs et al., 2004, p. 1061).

Studies like those discussed above have demonstrated the profound misconceptions patients and their family members may bring with them to the hospital, and the need for physicians to spend time assessing patients' and families' beliefs around end-of-life measures, as well as to dedicate time to discussing these beliefs and providing patients with accurate information. Inaccurate cultural ideas about end-of-life goals and resuscitation decisions mean that the conversations necessary to achieve mutual understanding of the true risks and benefits that are available from CPR and other life-sustaining measures must usually be long and in-depth – prohibitively so in some circumstances, especially if these discussions are first arising in the context of an acute event that requires prompt treatment. Ideally, education on what can be realistically expected from CPR and other life-preserving measures will have begun long before a crisis event, in discussions with primary care physicians at regular appoinments. Unfortunately, this ideal situation is often not the reality.

In efforts to combat this broad cultural gap between the understanding of medical providers and that of the general public, in the past decade or so a broader discussion of these issues has begun to take place in the bioethical literature. Medical professionals who have witnessed the debilitation, suffering, and pain caused by efforts to preserve life when there is very little chance that anything meaningful can be preserved are among the chief contributors to this discussion. Often these physicians are geriatricians or palliative care specialists, but as our population continues to age and and the global elderly population grows larger, we must begin to recognize that the challenges faced by elderly patients are soon likely to in some way affect almost every specialty of medicine.

As healthcare providers, patients, and patients' family members have begun to reflect on their experiences and observations of our relatively recent cultural attitudes towards death, so too has bioethical literature begun to emphasize the importance of quality of life rather than quantity, and to reflect on practices that will best honor the whole person near the end of their life. The landscape of death has changed. In the chapter that follows I will explore an additional muddler of this already less-than-clear portrait of the end of life: dementia. How should we approach the patient who arrives at the end of their life without the capacity to express their own desires and wishes? This question will only become more pressing in the coming decades, and considerable care is needed to approach its complexities.

CHAPTER 2: DEMENTIA AT THE END OF LIFE

As medical breakthroughs have allowed us to live longer, on average, than at any previous time, the disease of dementia has become a more and more frequent condition. 1%-2% of people have dementia at age 65, and up to 30% of people are diagnosed with some form of dementia by age 85 (American Psychiatric Association [hereafter APA], 2013, Neurocognitive Diseases section). Currently, Alzheimer's disease kills more people in the US than breast cancer and prostate cancer combined, and while 50 million people are currently living with dementia globally, by 2050 that number is expected to be 152 million (Patterson, 2018, p. 7). As we continue to live longer lives, and as our population shifts towards a hgher percentage of elderly people than at any other time in human history, we must give thought to what excellent care at the end of life and the pursuit of a good death might mean for a person with dementia. In this chapter I will address what clinical dementia looks like, how it affects a person's ability to advocate for themselves, and how it necessitates additional consideration on the part of clinicians in order to ensure the safeguarding of a patient's autonomy and right to self-determination.

Dementia Defined

Neurologically, the term "dementia" is a non-specific descriptor for several different acquired disease processes (i.e. diseases which are not present from birth and which are not developmental) that cause a primary clinical deficit of impaired cognition and a progressive cognitive decline from a diagnosed person's previous level of function (APA, 2013, Neurocognitive Diseases section). Put simply, these diseases cause damage to brain cells which cannot be reversed, and which was not present from birth (Patterson, 2018, p. 7). Dementia differs from other diseases and disorders that affect the brain (such as delirium or psychotic episodes) in that these other causes of altered mentation may be episodic or reversible. Dementia is defined by its progressive and irreversible nature. The disease course of dementia advances through various stages, which in the late or terminal stages may result in a global cognitive deficit, leaving the person with dementia unable to comprehend their surroundings, to learn new information, to retain communicated information, or to communicate with others themselves.

The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders uses the term Major Neurocognitive Disorder (or Major NCD) to define dementia. To meet diagnostic requirements, two conditions must be met: first, there must be a concern about the patient's cognitive functioning on the part of the individual, a knowledgeable informant, or the clinician. Second, the person being evaluated for dementia must demonstrate performance on an objective assessment (such as a standardized neurocognitive test) which falls below the expected level for that person, or that has been observed to decline over time (APA, 2013, Neurocognitive Diseases section).

Since dementia is a group of several different cognitive disorders, symptom progression is varied in terms of length of time as well as severity, with some patients progressing slowly over a decade or more, and others experiencing stepwise declines over weeks or months. Two-thirds of patients with dementia have Alzheimer's disease. The other one-third is comprised of people with vascular dementia, mixed dementia, Lewy Body Dementia, and Frontotemporal Dementia (Patterson, 2018, p. 6-7). While medical treatment for dementia varies based on the underlying etiology, the only currently available treatments can at best slow progression of the disease. There is currently no treatment for any form of dementia that will reverse the symptoms and allow the patient to retrn to their previous cognitive abilities. The ultimate prognosis for dementia is one of irreversible cognitive decline progressing to eventual complete incomprehension and disability, followed by death.

How Patients and Families Think of Dementia

Dementia, in its proper context, should be considered a terminal illness. However, patients and their families often do not initially make this association (Sachs et al., 2004, p. 1057). Helping patients and their caregivers to understand dementia as a terminal illness can prove difficult, likely due to several distinct reasons: first, dementia often has a prolonged course, with patients surviving through many years of cognitive decline. Second, dementia is a multi-faceted disease that is difficult to fit into a generalizeable prognostic course to which clinicians, patients, and their families can look for guidance and preparation (Sachs et al., p. 1058). Finally, “dementia” is not documented as the true cause of death as often as it should be. Instead, Sachs et al. found that patients with dementia usually have other diseases documented as their cause of death – pneumonia, cerebrovascular disease, cardiorespiratory arrest, and similar diseases other than dementia (p. 1058).

While it’s true that patients with dementia often die from systemic illnesses, these are compounded or created by the symptoms of dementia itself, which can include apraxia, dysphagia, decreased bowel motility, malnutrition, inability to perform hygiene that would prevent infection, etc. In a person without dementia, problems like these may not be severe enough to cause death, while in a person with dementia they can be the cause of significant morbidity and mortality (Sachs et al., 2004, p. 1058).

The aversion to citing dementia as a cause of death extends to medical bodies as well – indeed, Sachs et al. cite the Center for Health Statistics as not having listed Alzheimer's Disease as a rankable cause of death until 1994 (p. 1057), and a 2014 systemic review of population-based cohort studies found that dementia continues to be grossly under-reported on death certificates (Romero et al., p. 213).

Informed Consent

Beyond the public's poor understanding of dementia and the general as well as medical hesitancy to understand it as a disease that can truly cause death rather than merely make it more probable, there are additional individual factors that make it difficult for a person with dementia to receive care than adheres to the same bioethical standard afforded to patients who are cognitively intact. Among these individual factors the most pressing is that of informed consent. Determining a person's ability to provide informed consent is a critical issue in providing ethical care to all patients, and it becomes only more important when a physician provides care for a person with dementia.

Informed consent is a foundational ethical safeguard for patient autonomy, and at least three conditions must be satisfied in order to feel certain it has been obtained: first, the physician must give the patient sufficient information on the procedure or treatment proposed. Second, the patient's consent must be given freely, without coercion or constraint, and free from any threat or intimation of harm from any individual or agency.

Finally, the patient must be competent to provide this consent or refusal (Bernat, 2004, p. 24-25).

It is the third requirement – the patient must be competent to consent or refuse – that is of primary concern in assessing whether a person with dementia is able to provide informed consent. Beyond the simple dichotomy of competent vs. incompetent there lies a middle ground of partial competence which is of great importance when interacing clinically with patients with dementia.

Competence: A Matter of Degrees

As it relates specifically to patients with dementia, competence falls into a spectrum that must be determined by the clinician before any medical decision-making can take place. Ideally, this determination will be re-assessed at each appointment with the patient's primary care privider, but since dementia is a progressive disease, any new clinician should perform their own assessment upon first meeting the patient, rather than relying on past assessments by prior providers, as these may be out-of-date and no longer applicable. It is of great importance to understand that a diagnosis of dementia does not automatically discredit the patient as a person able to provide valid consent. Indeed, persons with dementia may be competent to make some and potentially all of their medical and goals-of-care decisions. This further demonstrates the need for proper clinical assessment, which can be accomplished through a variety of bedside neuropsychological testing modalities, as well as through structured interviews. Bernat places patients into three categories of capacity: full capacity, partial capacity, and no capacity. In the first category are patients who are capable of providing valid consent; in the second are patients who are capable of providing simple consent. Finally, the third category is reserved for patients who are not capable of providing any form of consent (p. 363).

If the patient is established to be fully competent (capable to provide valid consent), the encounter can proceed as it would for any other patient. However, full competence is likely only in very early-stage dementia, and a scenario in which the patient has only partial competence or no competence is much more likely. In a scenario of partial competence, it's important to understand that the patient does retain some ability to provide information about their wishes and to refuse treatment in certain contexts. Bernat offers the following guidelines for which decisions a patient in each consent category is able to make:

> Valid consents and refusals are those that are sufficient alone. Simple consents require the corroboration of a surrogate decision maker but simple refusals are sufficient alone. The severely demented patient can make neither a simple consent nor refusal and requires a surrogate for all decisions (p. 363).

This conception of capacity is often not well understood by clinicians and other hospital practitioners, especially as it relates to patients with impaired or declining cognitive capabilities: in a study of informed consent obtained from hospitalized patients with delirium and/or their surrogates, Auerswald et al. found that procedures were performed on patients from whom no informed consent had been obtained 19% of the time (1997, p. 410). Additionally, Auerswald et al. found that "patients with substantial degrees of cognitive impairment signed consent forms in 27 of 58 (47%) of cases. These findings suggest that consent was obtained and accepted as valid from patients who may not have been capable of participating in the decision-making process" (p. 415).

Although this study focused primarily on patients with delirium, which differs from dementia in the potential for the delirious patient to recover and return to their cognitive baseline at some point in the future, at the time a patient is suffering from delirium their functional status is similar to that of a patient with dementia. Therefore, extrapolating the results of this study and applying them to patients with dementia is appropriate, and emphasizes the importance of mental capacity assessment in patients with altered mental status. However, as this study demonstrates, proper assessment, documentation, and obtaining of informed consent is a more difficult and involved process than it may at first appear, and if proper care is not taken patients may easily be unwittingly deprived of their right to autonomy.

CHAPTER 3: ESTELLE – A CASE STUDY

The real-world complexities that surround decision-making and determining how to best honor the autonomy of a patient with dementia are apparent in the case of Estelle, a woman in her 80s whom I met in the hospital as a medical student assigned to her healthcare team. Estelle had been living for the past three years in a long-term care facility, and had been admitted to the hospital after the nursing home staff had noticed that she was feverish and less verbally responsive than usual. Estelle had been diagnosed with dementia six years prior, and her disease had progressed to meet the diagnostic criteria for a major neurocognitive disorder. Though she had significant cognitive impairment, she remained fully verbal and had the ability to understand her immediate situation and surroundings for a brief period of time if they were explained to her, though these explanations needed to be frequently repeated since her short-term memory was impaired.

In her earlier life Estelle had been a ballet dancer and later a ballet instructor. Her small frame meant that she was now physically quite frail, and her balance was quite poor. She fell often, causing frequent skin tearing. Because of her frequent falls and degenerative bone disease, Estelle was in continuous pain and was prescribed high doses of opiate pain medications. She was no longer able to walk more than a few feet without using a wheelchair.

Upon her admission to the hospital, Estelle was diagnosed with pneumonia, likely caused by progression of her dementia symptoms – a decreasing ability to swallow properly and decreasing mobility provided the opportunity for a lung infection to take hold. Prior to this hospital admission, Estelle had acquired pneumonia twice before, and had been hospitalized for at least a week each time. At both prior hospitalizations, she had been treated aggressively with antibiotics at the consent of her daughter, Marie, who was Estelle's medical proxy. Estelle did not have an advance directive. Per Marie's report and confirmed through information obtained from the nursing home staff, after each hospitalization Estelle had returned to the long-term care facility weaker and in greater pain. Also per Marie, after she returned from the second hospitalization Estelle had begun to make distressing statements and requests of staff members. She had begun to try to refuse her medications, saying "I don't want that. I want to die." Most distressingly, she had begun to ask staff members to kill her when she was alone with them.

After her second hospitalization, which left her almost entirely bedbound and in great pain, she had begun to press her nursing call bell between 5-15 times per day. responding to the nurses' questions about how she needed to be helped with "please kill me." This caused obvious distress both to Marie and to the nursing staff caring for Estelle.

At the time that I met Estelle, it was clear that she was still suffering. On the day of her admission, she continued asking people who entered her room to end her life, at other times spending an hour or more groaning in pain or sobbing quietly. The attending physician heading Estelle's care team, Dr. Steader, felt strongly that this was a case in which Estelle's autonomy and right to self-determination ought to be honored and pursued, and she began a series of meetings with Marie to achieve a consensus decision about what Estelle would have wanted if she had been able to advocate for herself.

Estelle's Case

In the sections that follow I will use Estelle's case to demonstrate how a clinician might determine best next-steps for a hospitalized patient with dementia who is in need of discussions about end-of-life care, as well as decisions about the pursuit of various available treatment options.

Is Estelle's diagnosis accurate?

Ideally, the first step in Estelle's care would have been an independent and detailed determination and/or confirmation of her diagnosis. In reality, Estelle's care looked like many other real-world cases: many of the important assessments were made, but not quite all and some not quite thoroughy enough. Dr. Steader performed a brief examination of Estelle and agreed that she had dementia, but neither she nor the other members of Estelle's team (including me) assessed Estelle's cognitive capabilities with any of the brief bedside neurocognitive testing modalities that are available. Omitting this portion of Estelle's care left open the possibility that Estelle's dementia was actually more or less advanced than the healthcare team members believed, and that Estelle may in reality have retained either more or less capacity to assent to treatments. Thus, any clinician seeing a new patient with a previous diagnosis of dementia should confirm that diagnosis through a personal examination of the patient which includes a brief objective assessment, such as with a standardized neurocognitive test.

The importance of these re-assessments is demonstrated by studies that have shown that the accuracy of dementia diagnoses in patients in nursing homes can be wildly inaccurate. In a study assessing the diagnostic accuracy of nursing home residents with a documented diagnosis of dementia, Mansdorf et al. found that:

> Of those with established diagnoses, only 17 (38.6%) met criteria for dementia, while with those with 'suspected' dementia, only 3 of the 19 referred (15.7%) met criteria. Of those that did not meet criteria but had an established dementia diagnosis in the record, about half met criteria for 'Mild Cognitive Impairment' (MCI), a possible 'predementia' condition that involves memory disturbance, but no other cognitive disability. The remaining half met criteria for an Axis I diagnosis, which, in this sample, included mostly depressive disorder, but also cases of anxiety and noncompliance (p. 271).

The implications of this study are frightening. A diagnosis of dementia may be inaccurately understood by family members, healthcare staff, and medical providers to imply that the person who has been diagnosed is no longer able to consent to or refuse treatments and procedures. Over-diagnosing elderly patients in nursing homes with dementia has disturbing implications for these patients' abilities to make their desires and wishes understood and respected. Thus, the first step in the assessment of any newly hospitalized patient with a prior diagnosis of dementia, especially one coming from a nursing home, should be to establish whether or not the person actually fits the diagnostic criteria for dementia.

Further emphasizing the importance of re-assessment are other studies that have found a significant number of patients to have *inadequate* diagnosing of their cognitive impairments: "More than half of [assisted living facility] residents in this study had CI [cognitive impairment] and a significant percentage was undiagnosed. Even when diagnosed as dementia, CI is significantly undertreated in this setting." (Magsi & Malloy, 2005, p. 295). These studies demonstrate the necessity for physicians to re-assess any new patient who has been previously diagnosed with dementia. Clinicians must consider whether or not the patient's diagnosis of dementia is accurate – if it is, we are led to our next question: what sort of competence to make medical decisions does the person retain?

What capacity to consent does Estelle retain?

As we have seen, Estelle's capacity to consent to or refuse treatments and procedures was not assessed as accurately as it should have been. Nevertheless, Dr. Steader's belief that Estelle no longer had the capacity to consent was likely accurate – Estelle's dementia was advanced enough that she required frequent reminders about where she was and who was speaking to her, and she did not retain awareness of her surroundings for more than five minutes after they were explained. This level of disability indicates that Estelle almost certainly did not have the capacity to understand the full complexities of her medical situation or the risks and benefits of any proposed treatments. Estelle was also very unlikely to have demonstrated greater capacity than she was believed to retain even if she had been given an objective assessment, but the importance of administering objective assessment tests remains. Though a clinician's gut-feeling about a patient's capacity may be correct the majority of the time, autonomy and self-determination are such important principles that we ought not to rely on instinct when assessing them. This is especially important for dementia patients coming from nursing homes, since the physician's determination of the patient's capacity may be already subject to unconscious bias – the physician may believe the patient has a prior diagnosis of dementia, but as we have seen, this prior diagnosis may have been inacurrate.

Does Estelle's team appropriately understand her goals and values?

Dr. Steader began the conversation about Estelle's goals of care by asking Marie general questions about Estelle – her life, her personality, what she enjoyed, and what she was currently able to do. It was during this talk that we learned that Estelle had been a ballerina and ballet instructor. Marie talked about how much it had meant to Estelle to be able to dance, and how painful Marie found it to see her now, with her mobility so severely affected. We also heard more about how painful and confusing it had been for Marie to hear Estelle talk about wanting to die – she believed her mother would only say things like that if she was in nearly-constant pain or mental distress, and she outlined the many different prescription medications they had hoped would ease Estelle's pain, all without the desired effect. Dr. Steader asked if Estelle had ever told Marie anything about what measures she might want taken near the end of her life, and Marie shared that although Estelle had no advance directive, she had told Marie many years ago that she wouldn't want to be kept alive "artificially," which Marie believed meant that she wouldn't want to have a machine breathing for her. Dr. Steader asked if Marie believed Estelle would say the same thing now if she were able, and Marie agreed that she did not think Estelle's opinion would have changed.

Dr. Steader's questions were aimed at learning more about what Estelle valued and found important in order to gain a better understanding of the kind of person Estelle was and had been, and the kind of goals she might have had for herself. Dialoguing in this way with family members is a vital initial part of framing the goals-of-care discussions, and demonstrates to family members that the clinician and healthcare team see their loved one as a person, not only as a patient. Good end-of-life caregivers find ways to work with family members in choosing a treatment plan that will honor the fullness of the life the person being cared for has led, and avoid reducing them to their present circumstance of sickness and frailty.

How does Estelle's daughter understand her condition?

Marie had a lot of questions about Estelle's condition and prognosis. She had seen her mother endure two previous bouts of pneumonia, and had seen how her physical and mental condition had worsened after each episode. She approached this third hospitalization with many questions about what could be done to make this time less distressing and painful for Estelle. She also believed that her mother was no longer enjoying any part of her life, and wanted to know if there were options for better pain control and hope for greater mobility after this hospitalization.

In cases like Estelle's it is of utmost importance to find out how the medical decision-maker understands the patient's condition and prognosis. Medical proxies cannot make informed decisions on behalf of their loved ones without a thorough understanding of the likelihood of all outcomes, both desired and adverse, and the potential risks and benefits of the possible treatments. This discussion should also include the risks and benefits of deciding to pursue no further treatment – such a decision should be presented as an equally valid option, and its appropriateness and risk/benefit profile should be discussed as thoroughly as any other option would be.

Family members may be resistant to the idea that providing no further invasive care is a valid option, and may perceive it as abandonment of their loved one. They may believe the medical team has "given up," and this can lead to poor communication and further barriers to understanding between family, patient, and clinicians. Because of the potential for communication breakdown, physicians should frame this option carefully. It's important for family members to understand that in some instances, not pursuing further treatment may be the most appropriate and least painful option. Sachs et al. provide an example of the radically different personal outcomes that are possible based on which clinical course a medical surrogate elects to pursue:

> Two patients with advanced dementia at similar stages (nonverbal, functionally dependent in all activities of daily living) had radically different courses because of decisions made by the families. When one patient experienced a dramatic decline in oral intake and was found to have his first pneumonia, the patient's wife refused antibiotics and chose hospice care. That patient soon died peacefully at home with hospice care. At a similar juncture, the second patient's family chose hospitalization, intravenous antibiotics, and tube feeding. Over the next 18 months, this patient was hospitalized seven more times for infections and alterations in mental status before her family opted for home hospice care. The second patient also died peacefully at home (p. 1059).

These examples are instructive when it comes to the realities of end-of-life decisions made by families, and make plain how important it is for the physician to make sure the family has an accurate understanding of what choosing aggressive measures might mean for their loved one.

Marie was receptive to Dr. Steader's presentation of the various treatment possibilities available to Estelle. Dr. Steader discussed the possible benefits and risks of several different treatment plans. One plan opted for aggressive treatment of Estelle's pneumonia with antibiotics, and included the addition of any life-sustaining measures that might become necessary in the future (including placement of a feeding tube and use of a ventilator to breathe for Estelle). Another plan opted for treatment with antibiotics, but allowed for further discussion if Estelle progressed to the point where she might need more invasive measures like a feeding tube or artificial ventilation. A third plan involved treatment of Estelle's pain and discomfort, making sure she was as comfortable as possible, and forgoing treatment of her pneumonia with antibiotics.

After talking over these options, Dr. Steader gave Marie her recommendations. Gently, she explained that Estelle's disease had progressed to the point that it seemed as though she was no longer enjoying her life. She explained that given Estelle's pneumonia, her prognosis for an improved quality of life after aggressive treatment was poor, and that instead Estelle would most probably be even more uncomfortable and weaker than she had been before. Dr. Steader framed Estelle's current pneumonia as a consequence of her progressing dementia, a disease for which there is no cure and which would inevitably continue to progress even if Estelle were to survive this hospitalization. After each statement, she waited to hear Marie's questions and she answered them as best she could. Ultimately, Marie chose to provide Estelle with medications for pain relief and other non-invasive treatments aimed at making Estelle comfortable and pain-free.

How will the healthcare team implement the treatment plan?

After establishing the treatment plan with Marie, Dr. Steader again verbally outlined what this treatment plan would most likely mean for Estelle: that without aggressive measures to combat the pneumonia, Estelle would most likely die during this hospitalization, but she would be kept comfortable and pain-free to the best of the team's medical ability. She again verbally confirmed with Marie that Marie believed this was what Estelle would most likely choose for herself.

After deciding on a treatment plan with Marie, Dr. Steader consulted the hospital's palliative care team, who were able to provide Marie with more resources, information on what to expect, and grief support. The palliative care team also offered their recommendations on how best to keep Estelle comfortable.

Over the following days Estelle became weaker and less responsive. However, her hospital pain regimen meant that she no longer moaned or sobbed in pain, and she was not subjected to surgical placement of a feeding tube or intubation for ventilatory support of her breathing. On the fifth day after her admission to the hospital Estelle died from respiratory failure due pneumonia secondary to her diagnosis of dementia.

CHAPTER 4: IMPLEMENTATION AND RECOMMENDATIONS

Estelle's case demonstrates the complexity of the real-world decision making process for a patient experiencing complications of dementia that require discussions about end-of-life care.When meeting a patient like Estelle, who has come to the hospital with a complication of their diagnosis of dementia, where should a clinician begin? Clinical algorithms are used by many clinicians to determine best practices and appropriate next steps for a variety of diseases and medical complications. Here I propose a best-practices outline for use by a clinician encountering an elderly patient with end-of-life complications of dementia.

Recommendations

These steps should be taken in order upon the clinician's first assessment of the patient:

I. Reexamine the diagnosis for accuracy and/or progression in light of the patient's current presentation.

II. Evaluate the patient's current level of competence to provide consent: are they competent, partially competent, or incompetent?

III. Based on the determined competence level, understand what decisions the patient is able to make alone and which require additional consent.

These steps should be taken when preparing for any interactions with the patient's medical decision-maker or proxy:

I. Recognize that there is no substitute for in-depth person-to-person communication between clinicians and medical surrogate decision-makers. Prioritize these interactions and have a general plan for how to approach them.

II. Inquire broadly about the patient before making any clinical recommendations. The initial portion of any meeting with a patient's surrogate should be spent asking questions designed to facilitate better understanding of the patient's personality and preferences.

III. Present all available treatment options and the significant risks and benefits of each (including the option of no treatment at all). Discuss quality-of-life considerations as well as life-preserving possibilities, then make a recommendation and explain your reasoning behind it.

Follow these steps after a treatment plan or goal has been decided upon:

I. Pause: after reaching a decision with the patient and/or their medical decision-maker, take a brief time-out period to confirm that there is no additional information that would be relevant, and that sufficient understanding of the patient and their wishes has been reached.

II. Prepare: although at this stage the likely outcomes of the chosen treatment plan have already been fully explained to the patient and/or their surrogate decision-maker, take a moment to again briefly prepare them for what will follow. This is especially important if the plan involves cessation or refusal of life-prolonging therapies.

III. Provide empathy, support, and guidance as the treatment plan is put into place. Practice person-entered clinical habits that redirect focus and respect toward the patient.

Conclusion

With these steps as guidance, I hope that some of the pitfalls that accompany the complex ethical decision-making surrounding end-of-life care for people with dementia might be avoided. The end of a person's life is a time when it is more important than ever to ensure that clinical practices align with the ethical principles clinicians aspire to uphold. Amid the realities that accompany the ending of a life, there is still a person who can be honored, and dignity that can be maintained. I believe we are still capable of achieving a good death for our patients – and maybe, someday, for ourselves.

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