

### February 2025

# The Ethics Dispatch

"Functioning as our better selves leads to better outcomes for patients and everyone."

-- Tarris (Terry) Rosell, PhD, DMin, HEC-C

# **Hot Topic**

### Bioethics of Dementia Care: Obligatory Beneficence and Difficult Hospital Discharges

This month in the Ethics Dispatch, we continue our exploration of the complex issue of difficult discharges, particularly as they pertain to patients with dementia. The reality of hospital discharges for dementia patients brings to light not only the clinical challenges but also the ethical dilemmas surrounding the care and protection of these vulnerable individuals.

A recent article by Pam Belluck in *The New York Times*, titled "<u>Dementia</u> <u>Cases in the U.S. Will Surge in the Coming Decades</u>," highlights a troubling reality: "...by 2060, new dementia cases per year could double to one million because of the growing population of older Americans" (Belluck, 2025). This projection presents a significant challenge to an already overburdened healthcare system. The article underscores the importance of examining how society addresses dementia care, particularly through the lens of bioethics -specifically, the principles of obligatory beneficence and the difficult decisions involved in hospital discharges.

#### The Growing Burden of Dementia

As Belluck's article points out, this sharp increase in dementia cases represents a massive challenge for the healthcare system. At present, more than six million Americans live with dementia, a number that will continue to rise as the population ages. "Older age is the biggest risk factor for dementia," the article notes, and with "many Americans living longer than previous generations," this prolonged lifespan may lead to an increased need for specialized care. While longer lives are a societal achievement, they come with a complex set of challenges, particularly within the realm of healthcare. In essence, the growth of the aging population is a double-edged sword -- an accomplishment that brings with it an increased need for care that will strain our resources.

The article also draws attention to stark racial disparities in dementia diagnoses. It predicts that "the number of new annual cases among Black people would surge to about 180,000 in 2060 from about 60,000 in 2020." These numbers reflect the disproportionate impact of dementia on Black communities, driven by a combination of factors, including "vascular risk

factors," lower socioeconomic status, and the pervasive effects of "structural racism." Dr. Josef Coresh, quoted in Belluck's article, emphasizes that these factors contribute to a "perfect storm" that leaves some communities more vulnerable to dementia. The principle of obligatory beneficence calls for an ethical obligation to mitigate these disparities, but as the article clearly illustrates, we have yet to fully address these systemic challenges.

#### **Difficult Discharges: Navigating Autonomy and Protection**

Ethical questions surrounding the discharge of dementia patients are particularly complex. As Belluck notes, the task of discharging a patient with dementia is far more challenging than a routine discharge. Dementia patients may lack the capacity to make informed decisions about their own care, raising the question of when the healthcare provider's obligation to protect them should override their autonomy. The principle of autonomy holds that patients have the right to make decisions about their own care, but in the case of dementia, this right becomes more difficult to uphold. This balance between respecting autonomy and ensuring patient safety becomes especially important when considering discharge.

Dr. Kenneth Langa, also quoted by Belluck, emphasizes that the overall number of dementia cases will likely increase, stating, "Even if the rate is significantly lower than that, we're still going to have a big increase in the number of people and the family and societal burden of dementia because of just the growth in the number of older people." Whether the number of cases increases by 750,000 or one million annually, the burden on families and the healthcare system will be substantial. Discharging a dementia patient presents significant challenges, as it requires careful consideration of risks such as "falls or wandering." In such cases, delaying discharge may be necessary to protect the patient, even if it means prolonging their stay in a hospital setting, which carries its own set of challenges. As a result, the ethical question of balancing harm (non-maleficence) with autonomy takes on even more weight.

The ethical complexity intensifies when the patient's family is not adequately prepared to provide the necessary care. As the article mentions, "about 27 percent of the 15,000 participants were Black, primarily from Jackson, Miss.," underscoring the issue of healthcare access. If a dementia patient's family lacks the resources or support to provide adequate home care, the discharge decision becomes even more complicated. The ethical framework of obligatory beneficence suggests that the healthcare system has an obligation to provide resources and support to patients, but, as Belluck's article highlights, such resources are often lacking. In many cases, families are left to navigate this difficult situation without sufficient support, further exacerbating the moral dilemma faced by healthcare professionals.

### **Obligatory Beneficence and Societal Responsibility**

The ethical principle of obligatory beneficence extends beyond individual caregivers and institutions, requiring society at large to take action to prevent and mitigate the effects of dementia. As the article highlights, "the study emphasizes the urgency of trying to prevent or slow the onset of dementia." Prevention efforts are paramount, and the healthcare system must prioritize early intervention. Dr. Josef Coresh suggests several measures to help reduce dementia risk, including improving "cardiovascular health with medication and lifestyle changes," treating "strokes," and encouraging the use of "hearing aids." While these measures may seem simple, their implementation faces significant barriers, particularly when it comes to encouraging behavior change in a population that may be resistant to such interventions.

Moreover, the article draws attention to the racial disparities in dementia onset, noting that "Black participants developed dementia at younger average ages than white participants." These disparities serve as a stark reminder of the broader structural inequalities within the healthcare system. If we are to take the principle of obligatory beneficence seriously, it is imperative that we

address these disparities by ensuring that at-risk populations have access to both preventive care and treatment. Failure to do so will only exacerbate the challenges that an already overburdened healthcare system will face in the coming decades.

#### **Conclusion: Ethical Approaches to the Dementia Crisis**

In conclusion, the ethical implications of dementia care demand that healthcare professionals, as well as society at large, uphold the principle of obligatory beneficence when addressing hospital discharges and long-term care planning. As dementia cases continue to rise, healthcare systems will be faced with an increasing number of difficult discharge decisions.

Belluck's article concludes with a sobering reality: "Whether it's a million people or 750,000 people a year, there's going to be a lot of people, and the longer people live, the more dementia there's going to be." This statement underscores the need for immediate action, as the growing number of dementia patients is an inevitability. However, with increased awareness, policy reforms, and a focus on equitable healthcare, it is possible to avoid a healthcare crisis of unprecedented proportions.

By implementing improved public health measures, targeted interventions, and policies aimed at reducing healthcare disparities, society has the opportunity to rise to the ethical challenges posed by the dementia crisis and ensure that all patients receive the care and support they need, regardless of the number of cases.

Sources: https://www.nytimes.com/2025/01/13/health/dementia-cases-us.html

# **Bioethics in the News**







Trans Youth Are Rattled What the 'moral distress' by Efforts to Ban Gender of doctors tells us about Care. So Are Hospitals The New York Times

eroding trust in health care| The Conversation

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**Case Study:** Ethical Dilemma in Difficult Discharge **Planning** 

### Legal Guardian Insists on Medically Inappropriate **Discharge Location**

Mr. Aldar, an 84-year-old male with dementia, was brought to the hospital after being found unresponsive at his care facility. He is unmarried, has no children, and has a nephew, Tony, who has been involved in his care. However, Tony has shown reluctance to fully engage in his uncle's medical decisions. He believes that he only signed Mr. Aldar into the care facility as a favor to his late mother, Mr. Aldar's sister, and feels his responsibilities end there.

Upon admission to the hospital, the medical team discovered that Mr. Aldar is also suffering from acute kidney failure and will require dialysis. However, the care facility where he was previously living is unable to provide dialysis services, meaning he would need to be transferred to another location that can accommodate his medical needs. After numerous attempts, the medical team finally reached Tony, who insisted that Mr. Aldar should return to his previous care facility. Tony expressed that he would not consent to discharge to any other location. The medical team has explored the possibility of going to court for a new guardian but was advised that this would likely not succeed, as Mr. Aldar already has a legal guardian -- his nephew Tony.

Until the team can identify an appropriate discharge location that meets Mr. Aldar's needs, including dementia care and dialysis, and that Tony approves, Mr. Aldar will remain in the hospital. The ethics committee has been consulted to help navigate the situation and determine the best course of action.

# **Ethical Musings**

### When Does a Person Become a Burden on Others?

According to the dictionary, a burden is a duty, responsibility, or something oppressive or worrisome (<u>https://www.merriam-</u>

webster.com/dictionary/burden). So, when does a person become a burden? When do they shift from being a person to a responsibility, or even worse, something oppressive?

It is common for patients to express that they do not want to be a burden to their families, especially when it comes to long-term medical decisions. Take, for example, a patient recently diagnosed with acute kidney failure. If dialysis is recommended, they might hesitate, not because they are unsure about the treatment, but because they do not drive and will need their children to transport them to and from the clinic. It is an understandable concern. Yet, more often than not, families do not view their loved ones as burdens. They see them as people who need love and care, just as a parent would with their children.

### A Unique Challenge

A four-year-old, for instance, is a significant responsibility. Some might view this as a burden, but it is a burden many are more than willing to bear because of the love they feel for their child. The same goes for patients with chronic or complex conditions that require ongoing attention. It may be overwhelming at times, but many caregivers embrace it out of love. This is not to say it is easy -- caregivers often experience fatigue, stress, and the feeling of being overwhelmed -- but still, they shoulder this burden because they care deeply for their family.

However, conditions like dementia and cognitive decline present a unique challenge. Unlike other illnesses, cognitive diseases can strip away a person's sense of self, not just their physical health. When severe dementia compromises a person's ability to make medical decisions, that "personhood" and/or "self" can begin to fade or at least change significantly. If someone

loses all their memories, are they still the same person? This question delves into deep philosophical territory, and there is no clear answer. It may be one thing to sacrifice for a loved one, but what happens when that person is no longer who they once were? For caregivers, it may feel like they are no longer caring for their loved one, but for a stranger. This sense of loss can make the burden feel even heavier.

### We Will Be Judged

Unlike raising children, where the expectation is growth and eventual independence, dementia brings no such hope. The patient is unlikely to improve -- in fact, they will likely decline. This creates a sense of hopelessness that can leave caregivers feeling morally distressed and emotionally exhausted.

These painful realities can lead some caregivers to wish for greater support or assistance. In an increasing number of cases, no one else is there. Who then takes responsibility? Should the state or federal government step in, or should charitable organizations carry the weight? This is an urgent issue, and one that is only going to become more prevalent as dementia and cognitive disorders affect more people.

Our current medical system, policies, and infrastructure are ill-equipped to address the needs of these patients, and as a nation, we are not prepared for the growing number of individuals who will require care. These patients need care, compassion, and -- above all -- dignity. As the saying goes, "The greatness of a nation can be judged by how it treats its weakest member." Our nation will be judged by how we treat these people. Will we be a nation that values all life, ensuring every person receives the dignity, compassion, and love they deserve? Or will we view a significant portion of our population as a burden to society, one that is unlikely to be managed with love or care?

Sources: Burden Definition & Meaning - Merriam-Webster

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