

## ETHICS CASE

### Should Dementia Be Accepted as a Disability to Help Restore Hope during Cognitive Decline?

Commentary by Nathaniel M. Robbins, MD, and James L. Bernat, MD

#### Abstract

Dementia is a common condition that impacts the patient, the family, and society. Currently, a diagnosis of dementia evokes hopelessness in the afflicted, and society provides few resources or systematic support for caregivers or for demented patients. In this commentary, we discuss the origins of hopelessness in dementia, the World Health Organization's six-stage framework of dementia care, and barriers to "normalizing" the experience of dementia in order to provide beneficent and humane care for patients with dementia. We also offer recommendations for clinicians who care for patients who feel that a life with dementia is not worth living.

#### Case

As a fourth-year psychiatry resident, Dr. Daniel is spending elective time with a geriatric psychiatrist, Dr. Woods, while rotating through a memory diagnostic clinic within the department of psychiatry at the hospital. The first evaluation in which Dr. Daniel participated was for an 82-year-old man, Mr. Farnal, with a history of coronary artery disease. He had a myocardial infarction about five years ago and several transient ischemic attacks over the past several years, although he has no appreciable residual deficits. He was referred to the memory clinic by his primary care physician for further evaluation due to his concerns about worsening memory over the past two to three years.

Mr. Farnal has lived by himself since his wife passed away about five years ago due to metastatic breast cancer. They had no children. He retired from his position as a professor eight years ago and many of his connections to friends at the university have lapsed, particularly over the last couple of years. On the initial evaluation, he denied any previous psychiatric history and scored a 1 out of 15 on the geriatric depression scale (scoring a point only for indicating that he didn't feel like he had much energy). He scored 18 out of 30 on the Montreal Cognitive Assessment (MOCA), for which a score of at least 26 indicates normal cognition [1]. Based on the initial assessment done by Drs. Woods and Daniel, dementia signs seemed to justify referral for further evaluation with behavioral neurology, formal neuropsychology testing, and MRI. These test results

corroborated that dementia was probable, most likely due to vascular dementia as well as a comorbid Alzheimer dementia. Drs. Daniel and Woods communicated to Mr. Farnal that his symptoms, though mild, were likely to progress and that it would likely become increasingly difficult for him to function independently.

Although not surprised by the diagnosis, Mr. Farnal was devastated. He reported that he took care of his father, who had lived with dementia many years before his death, and he also reported that this experience suggested to him that life with dementia becomes less and less worth living. As a fiercely independent individual, Mr. Farnal expressed that he did not see himself living in a nursing home or having an aide to help him. He again denied symptoms of depression and denied any active thoughts or plans of killing himself, but he strongly indicated that a life of worsening dementia was not one that he wanted to live. Drs. Woods and Daniels wondered how to respond to him.

### **Commentary**

Mr. Farnal believes that a life with progressive dementia is “not worth living”—at least for him. He has no remaining family and few things to which to look forward. He is not acting impulsively or as a consequence of depression but instead making a deliberative, evaluative assessment based on his personal experience that a life with dementia is devoid of meaning, which is an important distinction when considering a patient’s degree of autonomy [2].

Mr. Farnal’s case highlights the hopelessness faced by people with dementia. In this commentary, we discuss the origins of this hopelessness and ways in which society can work towards normalizing the experience of dementia, thereby restoring hope. We then discuss barriers to achieving this normalization and the ethical issues surrounding the implementation of social policy aimed at normalization. Finally, we offer practical guidance for physicians charged with caring for patients like Mr. Farnal.

### **Origins of Hopelessness in Dementia**

On a personal level, progressive dementia represents the inexorable loss of autonomy and arguably one’s most important possession—the mind. There is currently no cure or substantially effective treatment [3]. According to some, the best outcome a person with dementia can expect is good quality of life during decline, followed by a dignified death, characterized as good palliative care towards the end of life. Unfortunately, these outcomes are the exception rather than the rule in modern dementia care [4].

Through supporting his father in his dementing illness, Mr. Farnal has had firsthand experience with the accompanying loss of autonomy and functional decline. He has little hope that his own experience will be better. In this context, despite his cognitive impairment, Mr. Farnal likely retains the capacity to make a decision about ending his life, although deeper questioning might be required to more accurately assess his [decision-](#)

[making capacity](#) [5, 6]. Mr. Farnal bases his decision that life is not worth living on his perception that there is no intrinsic value to the life of a patient with dementia residing in a nursing home or with an aide. Loss of his spouse undoubtedly contributes to this feeling. To alter this perception, Drs. Woods and Daniels would need to identify sources of meaning and hope in Mr. Farnal's future—sources that might change his calculus despite his inevitable cognitive decline in the future. Identifying sources of hope might be difficult because modern societies have few systems in place to support people with dementia and their [family caregivers](#) [7, 8].

This task of building hope is made more difficult because social stigma against patients with dementia remains prevalent. Such patients are generally viewed as burdensome to their caregivers and society, contributing little of positive value. This situation contrasts with that of other chronic illnesses. Cancer patients, for example, are honored for their resilience—they are survivors [9]. There are also numerous cancer support groups and survival advocacy groups [10]. This level of social support contrasts with the limited availability of social support resources for people with dementia—at least, beyond the early stage of the disease [11]. Patients with other brain diseases, such as those with lifelong intellectual disability, may be trained to join the workforce. No such vocational programs exist that we know of for persons with dementia. As a result, Drs. Woods and Daniels have few inspirational words of hope for Mr. Farnal.

### **Normalization of Dementia: Goals and Barriers**

An estimated 8.8 percent of the United States population over age 64 has dementia [12]. For society to provide beneficent care for this population, it is imperative to develop strategies to normalize the experience of dementia. The World Health Organization (WHO) promotes a framework in which societies progress through six stages of dementia acceptance [7]. Stage I is ignoring the problem. By Stage VI, dementia achieves “normalization,” in which the diagnosis is accepted as a disability and patients are included in society as much as possible. To achieve this stage, society must find a way to bestow meaning and value on the lives of people with dementia, despite their functional limitations, by creating “dementia-friendly communities” [13]. If Drs. Woods and Daniels could direct Mr. Farnal to successful social programs—and direct others like him who wish to remain employed to work participation programs that bestow at least some degree of autonomy—Mr. Farnal and other patients with dementia might be able to feel hope despite their future of inevitable functional decline.

Unfortunately, several barriers impede the achievement of the WHO goal of dementia normalization. First, social stigma is prevalent. For example, there is widespread belief among clinicians that dementia care is futile because available treatments do not alter the course and prognosis [14]. Efforts at palliation might be limited by clinicians' perception that demented patients remember neither their suffering *nor* their successful palliation, so what is the point? If nothing can be done to reverse the course of illness,

nothing *needs* to be done. This spirit of nihilism accompanied by physicians' personal fear of loss of intellect can lead to depersonalization of the patient with dementia. Medical professionals subconsciously relate loss of intellect with loss of personhood and consequently use a variety of pejorative, cynical, and insulting names for patients with dementia [15].

This depersonalization of patients with dementia contrasts starkly with attitudes toward other progressively ill patients such as those cancer patients whose behavior is not perceived to have contributed to their disease [16]. It seems that society continues to distinguish between chronic progressive diseases of the body and the mind and currently provides insufficient public education and policy initiatives to normalize the experience of dementia and remove its stigma. To cope with his diagnosis, Mr. Farnal needs to feel that patients with dementia are treated well in society. His caregivers need to be able to highlight public figures with dementia who have retained their humanity and personhood and were permitted to serve valuable roles in society despite their disabled state.

There are also economic barriers to normalizing the experience of dementia. Factors that improve quality of life for patients with dementia include improving relationships with family and other people; enhancing control over one's own life; and, importantly, contributing to the community [17]. As patients with dementia deteriorate intellectually, greater resources are required to create opportunities for them to contribute to society and retain their autonomy—both essential elements to maintaining hope and a decent quality of life. Family caregivers cannot be relied upon to provide comprehensive dementia care—at least not without substantially improved social support systems [8]. Patients with dementia are not financially productive and will never provide an economic return on investment, so nonprofit entities will be required to fund these opportunities. Even if care is provided in a fee-for-service setting, government- and community-run facilities will be required to support the nonmedical aspects of beneficent care—such as [socialization](#), job training, transportation, and other services required to preserve the autonomy of patients with dementia—and also to empower them to maintain relationships and contribute to the community.

Countries other than the US, whose nationalized health care systems place greater emphasis on public health and preventative services, may find it easier to construct a comprehensive system for dementia care. Indeed, the WHO currently ranks the US only in Stage IV of the dementia acceptance framework, in which various established civil society organizations (e.g., the Alzheimer's Association) raise awareness about and advocate for patients with dementia. The few countries in Stage V (e.g., Australia, England, France, Norway, South Korea, and Sweden) have developed nationwide policies and dementia plan strategies, standards of dementia care, stronger legal frameworks, and access to financial support [7]. In Stage VI, patients with dementia are incorporated

into society as much as possible in dementia-friendly communities and by other means. Unfortunately, Stage VI has not yet been achieved anywhere in the world.

### **Ethical Issues Surrounding Normalization of Dementia**

Although beyond the scope of this commentary, we briefly note ethical questions that arise from the WHO public health framework recommendations. Most people agree that high-quality dementia care is a worthwhile goal. First, it is the *beneficent* thing to do. Second, dementia is a disease of the elderly, and most elderly people have spent a lifetime contributing to society. Accordingly, it seems *just* that they are cared for by society in their old age dependency.

Unfortunately, good dementia care as outlined in Stage VI is expensive. In reality, implementing a nationwide policy of comprehensive dementia care could potentially bankrupt the US health care system unless the funding for this care could be provided through savings in other areas (e.g., by eliminating waste and unnecessary medical services) [18, 19]. There is a very real trade-off between care for dementia patients and care for the rest of society. A utilitarian viewpoint might argue against comprehensive dementia care, because channeling resources to care for younger and more productive members of society might improve average or overall happiness or utility. Accordingly, the principles of justice and beneficence that support comprehensive dementia care might be at odds with a guiding utilitarian framework.

### **Advice for Mr. Farnal's Physicians**

Although dementia has not been accepted yet as a disability in any country according to the WHO's dementia report [7] and no comprehensive dementia plan exists in US society, Mr. Farnal's physicians still have a number of good responses to his stated position that "a life of worsening dementia was not one that he wanted to live." First, they can direct him to the resources that currently exist for patients with dementia: community-care advocacy organizations and support groups that work to empower such patients to maintain their autonomy and contribute to society [11]. Through these resources and with time, Mr. Farnal may learn to accept his decline and find comfort in his remaining days. Second, if Mr. Farnal persists in his desire to end his life, his physicians can discuss lawful options to hasten death and encourage dignified dying. For example, Mr. Farnal has the right to refuse life-sustaining treatments, hospitalization, or institutionalization. Third, his physicians can work to raise dementia public awareness in Mr. Farnal's community by running support groups, promoting popular books (e.g., *The Corrections* [20], *The People in the Trees* [21]) and movies (e.g., *Still Alice* [22]) with dementia identity and care themes, and educating patients and caregivers about dementia and its prognosis. Humans are social beings, and if Mr. Farnal can find a community of like individuals, he might feel less lonely and hopeless as the disease progresses. Fourth, his physicians can examine their own biases toward caring for patients with dementia and try to revise any stereotypic assumptions they may have

about care (e.g., that continued treatment is futile). Finally, Mr. Farnal's physicians can help him identify positive things in life that could give him pleasure as his function declines and encourage him to make those things a larger part of his life. For example, animal lovers may seek dementia care facilities with dogs, or opera enthusiasts may seek facilities with music programs. These small pleasures may be sufficient to improve quality of life and provide enough hope for Mr. Farnal to find his diminished life worth living. Ultimately, broader changes are needed to improve society's ability to accept people with dementia. Until this acceptance is achieved, it will be very difficult for Mr. Farnal's physicians to instill in him hope sufficient to embrace his new life with dementia.

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