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FROM THE EDITOR

Dementia, Decision Making, and Quality of Life

Dementia is a highly disabling major neurocognitive disorder. As the cognitive deficits of dementia progress, decision making can become more difficult for people with dementia, requiring surrogate decision makers to become increasingly involved in decision making [1, 2]. Evidence suggests, however, that many people with dementia, even those with more advanced disease, can still articulate their values, preferences, and choices in a reliable manner [2-4]. Indeed, people with dementia maintain a strong desire to remain central in decision-making processes that directly impact their lives [5]. Consequently, it is an ethical priority in the care of people with dementia to maximize the likelihood that they will have opportunities to live lives reflective of their values and maintain active, central roles in decision making.

Decisions that present challenges for people with dementia and surrogate decision makers are not limited to decisions regarding medical care, treatment decisions, or end-of-life preferences but also include decisions regarding everyday concerns, from financial matters to intimate relationships [6]. The theme of this issue reflects this diversity of decisional stakes by focusing on how decisions of all kinds made in various settings (e.g., long-term care, medical offices, and research) can fundamentally impact the autonomy and well-being of people with dementia.

The cases and commentaries included in this issue afford the opportunity for more explicit exploration of the interface of decision making and quality of life for people with dementia. Two of the cases emphasize the sometimes competing demands of autonomy and best interests in supporting the decisions of people with dementia. Considering the case of a woman with advancing dementia who is transitioning from the community to a long-term care facility, Eran Metzger brings into sharper focus competing demands of an institutionalized setting, particularly with respect to [residents' privacy and safety](#). He also offers concrete recommendations for supporting residents' autonomy in tightly regulated and standardized long-term care environments. Nathaniel M. Robbins and James L. Bernat examine the case of a man struggling with hopelessness after being diagnosed with dementia. On the basis of their exploration of some of the origins of hopelessness in dementia as well as barriers to normalizing patients' experiences of dementia as a chronic disease, the authors offer recommendations about how to offer care that focuses on the [best interests](#) of people with dementia and on supporting their quality of life as the disease progresses.

Other cases emphasize the complex family dynamics that are often at play in decision making for people with dementia. In her commentary on a case of a man with advanced dementia whose spouse is struggling to cope with his progressive, end-stage symptoms, Helen Stanton Chapple emphasizes the importance of clinicians' understanding [caregivers' experiences](#) and processes of making meaning from specific treatment decisions (i.e., feeding decisions at the end of life). And Marianna V. Mapes, Barbara O'Brien, and Louise P. King examine the case of a woman with a strong family history of [early-onset Alzheimer's disease](#) who becomes pregnant. Considering the possibility of experiencing a dementing illness while caring for a young child as well as the possibility of the child possessing genetic risk for early-onset disease, the authors examine how concerns regarding future quality of life impact present decision making.

Two articles look more deeply at the linguistic and historical framing of the experience of living with dementia. Peter Reed, Jennifer Carson, and Zebbedia Gibb examine the discourse that permeates the experience of living with dementia, arguing that moving from descriptions of [tragedy and exclusion](#) toward an emphasis on personhood, relationships, and partnerships will enable people with dementia to be actively engaged for as long as possible as primary decision makers about the course of their lives. Jesse F. Ballenger traces the disease's framing as a discrete brain disease in the early nineteenth century to a psychosocial problem of adjustment in the mid-nineteenth century to a major public health crisis today. He argues that [shifts in dementia's framing](#) facilitated pathologization of the experiences of people with dementia for the purpose of maximizing funding for biomedical research, thereby reallocating resources once used for supporting caregivers and optimizing quality of life for people with dementia.

Two contributions discuss efforts to strengthen community ties and supports for people with dementia. Beth Bienvenu and Gay Hanna examine how participation in [community arts projects](#) not only strengthens the autonomy of people with dementia but also offers opportunities to participate in a broad range of social relationships. And in the podcast, Beth Soltzberg offers another perspective on how community-driven initiatives can evolve to resist language that reifies [stigma and isolation](#), such that people with dementia can face fewer barriers to maintaining meaningful connections with their community.

Finally, two articles further examine some of the unique environments in which decisions are made with respect to concerns about cognitive impairment. Laura B. Dunn and Barton W. Palmer examine decision making about participating in [clinical research](#) by elucidating the concept of *therapeutic misconception*, participants' inappropriate assumption that every aspect of a research study is designed to provide direct medical benefit to them. This article reviews the relevant literature and argues that greater understanding of therapeutic misconception in dementia research is needed to ensure protection for participants with dementia who are enrolled in clinical trials, some of them with a surrogate decision maker's consent. And Kimberly Hornbeck, Kevin Walter, and

Matthew Myrvik consider the controversial link between [sports-related concussions](#) sustained at a young age and further development of a neurodegenerative process later in life. They argue for a model of shared decision making that includes children, parents, and clinicians, particularly for decisions about participation in contact sports in which there are concerns about safety and potential long-term detrimental consequences.

It is hoped that the articles in this issue highlight salient aspects of decision making for people with dementia that are relevant to clinicians in providing good care to these people. More importantly, however, it is hoped that these articles can help in humanizing people with dementia, normalizing their experiences of a chronic and disabling condition such that they are not progressively excluded from living lives consistent with their preferences and desires.

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ETHICS CASE

Ethics and Intimate Sexual Activity in Long-Term Care

Commentary by Eran Metzger, MD

Abstract

A case is presented in which the staff of a long-term care facility discovers that the husband of a resident with dementia is engaged in sexual activity with her. The case illustrates a dilemma for long-term care facilities that create a home-like environment with a goal of maximizing residents' autonomy while ensuring their safety. An approach to assessing capacity to consent to intimate sexual activity is described, followed by guidelines that nursing homes can implement to support residents who wish to engage in sexual activity. Recommendations are also offered for supporting long-term care staff and family members of residents who are interested in intimate sexual activity.

Case

As a second-year psychiatry resident, Dr. Brian is working in a long-term care facility during his geriatric psychiatry rotation. The facility is structured to accommodate residents' escalating needs with various levels of care, ranging from independent living to assisted living to nursing home. Dr. Brian is working with a geriatric psychiatrist, Dr. Anderson, whose main role in the long-term care facility is to provide psychiatric consultation.

One afternoon, Drs. Brian and Anderson receive a consultation request regarding Mrs. Shera, an 80-year-old woman living in the nursing home section who has dementia. When reviewing her record, Dr. Brian sees that she was admitted to the long-term care facility about six months ago, after living independently with her husband of 55 years. Over time, it became more difficult for him to manage some of her behavioral issues at home. For instance, when she would take walks through the woods near their house, she would get lost on the paths. Sometimes, the police were called to search for her and take her home. When Mr. Shera tried to limit her excursions, she would become severely irritable, yelling at him and ultimately swinging at him when he tried to keep her from leaving the house. These episodes would last about 5-10 minutes, at which point Mrs. Shera would shut down and then forget what had just happened.

In the nursing home, Mr. Shera visited her as much as he could and she was always happy to see him. Once, a nurse walked into Mrs. Shera's room and found her and her

husband in bed together with some of their clothes removed. After Mr. Shera left, the nurse returned to talk further with Mrs. Shera about what had happened. Mrs. Shera indicated that she loved her husband and that he was a good man, but she wasn't able to answer questions about whether she felt comfortable engaging sexually with him. Troubled that Mrs. Shera's illness compromises her decision-making capacity, the nurse discussed her concerns with Drs. Brian and Anderson. After talking with Mrs. Shera, the nurse and the two physicians still were not clear whether and how it was appropriate for Mr. Shera to engage sexually with Mrs. Shera. They wondered what to do.

Commentary

Mr. and Mrs. Shera's story illustrates only some of the many challenges posed to long-term care facilities (also known as nursing homes) by residents who are engaged in, desire to be engaged in, or do not desire to be engaged in intimate sexual activity. When these situations arise, the treatment team is often faced with issues of capacity and consent, [safety](#), and privacy. The staff could find itself in an ethical dilemma created by trying to both respect residents' autonomy and protect them from harm. The facility might also need to address the varied reactions of different members of the treatment team, as human sexuality is an intensely personal topic and can give rise to conflicting views and embarrassment. The last two decades have witnessed increased scholarly attention to intimate sexual activity in long-term care [1-5]. This is likely a by-product of the resident-centered care movement. What originally started as an effort by a coalition of organizations committed to improving quality of life for nursing home residents led to language in the 1987 Omnibus Budget Reconciliation Act [6] that for the first time mandated by statute that a sector of health care provide "person-centered care" [7]. The intent of this movement has been to make nursing homes feel more like homes and less like medical facilities to their residents by eliciting and supporting their personal preferences, respecting their autonomy, and making changes to the physical plant. The case of the Sheras and other similar cases invite the nursing home to clarify its response to the challenging topic of intimate sexual activity by implementing (1) effective communication approaches with residents and among staff members, (2) assessments of sexual decision-making capacity, and (3) measures that will ensure resident autonomy, safety, and dignity.

Ethical Dilemmas Facing Nursing Homes

While trying to accommodate the individual preferences of their residents, nursing homes must also adhere to federal and state regulations created to ensure safety, comfort, and standardization of care. In some areas of care, regulations leave little room for interpretation. For example, residents who receive medications may not take them on their own volition but must have them ordered by the nursing home's medical clinician, dispensed by a nurse, and administered within a window of the prescribed time [8]. In other areas of care, nursing homes have more discretion—for example, by allowing an individual resident to choose when she will eat her meals and what clothes she will wear.

Absent from nursing home regulations are guidelines on how to assess and accommodate residents' preferences for intimate sexual activity. Federal government regulations instruct nursing homes that they "must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality" [9]. However, such mandates fall far short of providing guidance on how to respond to cases such as that of Mr. and Mrs. Shera and how to determine when intimate sexual activity might enhance or compromise dignity. In the absence of regulatory directives on intimate sexual activity, few facilities have devised their own [5]. Rather, there is a tendency for facilities to fall back on an approach that does not require the additional effort needed to discern residents' preferences in this area and does not challenge the comfort of the staff. This default position, however, runs the risk of compromising residents' quality of life and further impinging on their freedoms within an institutional setting.

Assessing the Capacity to Consent to Sexual Activity

In the Shera case, the team consults psychiatry because of uncertainty about Mrs. Shera's ability to consent to intimate sexual activity. That the psychiatrists, after interviewing Mrs. Shera, should likewise be uncertain should not come as a surprise. While Appelbaum [10] and others [11] have provided clinicians guidance on the assessment of medical decision-making capacity, there is a comparative dearth of information on assessment of capacity to consent to intimate sexual activity [12, 13]. The former focuses on the ability to accept or refuse an administered treatment, based on an appreciation of one's situation and the risks and possible benefits associated with treatment and nontreatment. In contrast to a medical procedure, sexual activity is considered in healthy and autonomous persons to be the expression of innate drives and an important determiner of well-being. In assessing medical decision-making capacity, the medical clinician *defines* the nature of the proposed intervention and who will perform it. In assessing capacity to consent to sexual activity, the clinician must *acquire* knowledge of the nature of the activity and the relationship of the participants. Clearly, a different approach is required for determining sexual decision-making capacity than that for determining medical decision-making capacity.

Lichtenberg and Strzepek have described an approach used in a dementia nursing home unit to assess residents' capacity to consent to intimate sexual activity [14]. Key components of their assessment include determination of residents': (1) awareness of with whom they are having sexual contact and what that person's relationship is to them, (2) ability to articulate the type(s) of intimate sexual activity with which they are comfortable, (3) consistency of behavior with respect to their previously expressed beliefs and preferences, (4) ability to decline unwanted sexual activity, and (5) ability to articulate what their reaction will be if the sexual activity ends. The authors describe a two-step process whereby the multidisciplinary team, after completing the above

assessment, observes residents in their milieu in order to determine if their behavior is consistent with their interview responses.

An emerging literature on sexual capacity in persons with intellectual disability also provides some guidance. Writing about this population, Lyden [15] proposes that assessment of sexual consent capacity address the domains of rationality (“the ability to critically evaluate, to weigh the pros and cons, and to make a knowledgeable decision” [16]), sexual knowledge (“the specific sexual behaviors in question” and “the choice to accept or reject the sexual behaviors in question” [17]), and voluntariness (“aware[ness] that he/she has a choice to perform, or avoid, prospective sexual conduct” [18]). He also recommends that the assessment be performed by someone with whom the person is likely to feel comfortable, ideally someone of the same gender.

Just as the standard for determining medical decision-making capacity is adjusted depending on the nature of the risk of the proposed treatment [19], so, too, the standard for sexual consent capacity might be influenced by the nature of the sexual activity in question. Looking at opposite poles of the continuum, a lower standard of capacity would be applied to assess Mrs. Shera’s capacity to consent to kissing her husband (whom she “is always happy to see”) than would be applied to, for example, her consent to engage in sexual penetration.

Ideally, the clinician could enlist Mr. Shera’s assistance in the assessment. Areas to cover in an interview with Mr. Shera would include the nature of the intimate sexual activity in which he wishes to engage and to what extent this activity is consistent with their prior sexual activity. While a formal neurocognitive examination of Mr. Shera, who is not under the care of the team, would be inappropriate, observing for signs of cognitive impairment would provide additional data that would help the evaluator in her formulation. Can Mr. Shera, for example, articulate awareness and sensitivity to the possibility that his wife’s interest in intimate sexual activity might vary from day to day? Can he articulate how he will assure his wife’s physical safety during sexual activity? Is Mr. Shera aware of Mrs. Shera’s privacy needs? Concerns in any of these areas might prompt the team, with Mr. Shera’s permission, to seek ancillary information on Mr. Shera’s condition from one of the Shera’s children, if they have any.

Just as no medical or psychiatric diagnosis automatically confers incapacity for medical decision making, so, too, should clinicians refrain from inferring that a diagnosis of dementia is *prima facie* evidence of lack of sexual consent capacity. As one author has written, in reference to sexuality and Alzheimer’s disease, “As they say, when you have seen one case, you have only seen one case” [20]. There is increased acceptance in medical ethics that capacity is decision-specific [21]. Inability to make a decision about medical treatment or to manage finances should not be assumed to denote sexual consent incapacity.

Surrogate Decision Makers

The federal 1990 Patient Self-Determination Act increased dramatically the proportion of nursing home residents for whom a [surrogate](#) is identified to make medical decisions if the resident loses medical decision-making capacity [22]. While it might be the surrogate decision maker's responsibility to render a decision about a resident's sexual activity if he or she lacks capacity, this does not obviate the need for a careful capacity assessment that would help guide the surrogate decision maker in arriving at this decision. What if, as could well be the case with the Sheras, the surrogate decision maker is directly involved in the intimate sexual activity in question? Similar situations in which there is a potential conflict of interest for the surrogate decision maker faced with a *medical* decision occur as well. For example, the decision to withdraw medical treatment, in accordance with a resident's advance directives, might be resisted by the surrogate decision maker spouse who wishes to keep his partner alive as long as possible. Alternatively, the decision to embark on a costly treatment regimen recommended for the incapacitated resident could be resisted by the surrogate for whom it might have negative financial consequences. In each of these situations, the clinician has the important role of educating the surrogate on his duty to make decisions in accordance with the substituted judgment standard [23]. When there is concern that the surrogate is unable to do this, the team might need to petition the court for an alternate surrogate.

Working with a family surrogate decision maker—whether it is a spouse, an adult child, or a sibling—to address sexual behavior requires sensitivity to the possibility that the family member will be uncomfortable with the topic [3]. Of family work, one can also say that, "When you have seen one family, you have seen one family." Family members come to this topic with a wide range of backgrounds and comfort levels in discussing intimate sexual activity and, specifically, sexual activity of a relative. The clinician is well advised to give consideration before a family meeting to how a family member's personal, generational, and cultural background can influence the conversation. Some nursing homes have prepared printed educational material for families [4]. Starting the conversation by acknowledging the sensitive nature of the topic can be helpful in mitigating discomfort from the start. Family reactions have run the gamut from acceptance and encouragement of an activity that provides pleasure at the end of life to anger and threats to transfer the resident to another facility or take legal action against the nursing home [3, 5]. The staff member who discusses the issue with the family should also be aware of her own apprehension about distressing the family.

Family members are not the only ones who might experience discomfort over the topic. Nursing home staff members' personal attitudes about intimate sexual activity are similarly shaped by a wide range of individual, cultural, and religious influences, resulting in a similarly wide range of sensitivity to and acceptance of this issue. There is evidence that staff attitudes, too often a deterrent to resident sexual activity in the past, have

evolved in this area [3, 24]. The case of the Sheras involves heterosexual activity by a married couple. A case involving support of less “traditional” sexual activity such as nonheterosexual activity or infidelity is more likely to generate unease among some members of the treatment team [5]. In order for the team to provide consistent implementation of a plan, it is crucial that all members be provided a forum to express their concerns [4]. Allowing a team member who opposes the plan to opt out of caring for the resident might well be preferable to the detrimental effects on team morale caused by a disgruntled clinical caregiver.

Safety

Safety considerations affect not only the decision of whether to permit sexual activity but also, if it is to be permitted, how it can take place with minimum likelihood of harm. Here again, there is no substitute for frank discussion with the involved parties about the nature of the sexual activity involved and the physical and other risks associated with it. Such risks could include risks of falling, infection, and a cardiovascular event [25]. Negotiations might result in an arrangement that strikes a necessary balance between privacy and safety that entails, for example, a staff member periodically checking on the well-being of a resident during sexual activity. Recall that the Shera case comes to the attention of the treatment team after “a nurse walked into Mrs. Shera’s room and found her and her husband in bed together with some of their clothes removed.” Staff members should be coached on how to protect the privacy and dignity of residents engaged in sanctioned sexual activity. Approaches have ranged from the use of “Do Not Disturb” signage to providing a separate room for privacy when a resident does not have a private bedroom [4, 5, 14].

Towards a Resident-Centered Approach to Sexual Intimacy in Long-Term Care

The story of the Sheras will be familiar to clinicians who practice in the long-term care setting and is only one of many scenarios of sexual intimacy that the nursing home staff might confront. In keeping with the ongoing effort to create senior care environments that are respectful of patient autonomy and preferences, long-term care facilities are encouraged to include plans on how to accommodate sexual intimacy. Forrow and colleagues have advanced the concept of preventive ethics, whereby a medical institution engages in activities that can serve to decrease the likelihood of cases evolving into ethical conflicts [26]. Such activities include an emphasis on communicating early about potential conflicts and taking the time to reflect on what institutional factors might give rise to trouble down the road. Nursing homes can implement a number of strategies to help improve their readiness to address an instance of resident intimate sexual activity. Table 1 highlights some central action steps to help a facility prepare in this manner.

Table 1. Action steps for accommodating intimate sexual activity in long-term care [4, 5]

Preparation
Determine statutes and case law on sexual consent for your state. Draft guidelines for your institution's management of resident sexual activity. Establish resources to support resident sexual activity: <ul style="list-style-type: none">• resident sexuality consultation team (analogous to palliative or wound care, infection control)• "intimacy room" for residents who do not have private rooms, appropriate signage• educational materials for staff, families• aids (e.g., lubricants) Hold staff training sessions.
Management
Consult resident sexuality consultant. Conduct sexual consent capacity assessment. Construct individualized plan detailing approaches to maintain safety and privacy. Hold staff support meetings.
Problem-solving resources
Ethics committee consultation State Long-term Care Ombudsman's Office

Summary

Human sexuality and expressions thereof are a sensitive and deeply personal area of human experience. While no amount of preparation can anticipate every possible scenario, the approaches described here are likely to improve clinicians' confidence in responding to intimate sexual situations in a manner that is respectful and consistent with the long-term care facility's mission of creating a safe and life-affirming home.

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Related in the *AMA Journal of Ethics* and *Code of Medical Ethics*

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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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ETHICS CASE

Strategies for Building Trust with the Caregiver of a Patient with End-Stage Dementia

Commentary by Helen Stanton Chapple, PhD, RN, MA, MSN, CT

Abstract

This case describes a patient with advanced dementia and an unrealistic spouse, presenting an apparent dilemma about nutrition for physicians. By eliciting the perspective of the caregiver, the physicians can gain insight and rebuild trust that protects the interests of both the patient and the spouse. Their goal needs to shift from resolving the professional ethical dilemma to affirming the immeasurable contribution of the caregiver, acknowledging her journey, asking for her advice, and enabling the work of making meaning in the time available.

Case

As part of a geriatric medicine elective in his fourth year of medical school, Thomas spends a couple of afternoons a week at a local nursing home seeing patients with the attending geriatrician, Dr. Smith. One of the patients that Thomas sees with Dr. Smith is Mindt, a 78-year-old man with a history of advanced dementia who is recovering from pneumonia. He was diagnosed approximately ten years ago and moved into the nursing home about five years ago when he experienced greater functional and cognitive decline. His wife, Nila, who is in her early 70s, lives in the community and visits him frequently. They had one son who died of a myocardial infarction about 13 years ago. Nila is the health care proxy, but since Mindt didn't clarify his preferences for end-of-life care while he had decision-making capacity, she and his other caregivers are unsure about how to respond when Mindt's dementia progresses to the point at which he has trouble eating. Now that he either won't open his mouth or appears to be choking when she has been trying to feed him, it seems that the time has arrived for a critical end-of-life conversation and decision.

Nila requests a meeting with Dr. Smith to discuss her concerns about her husband's eating. A family meeting is arranged among Nila, Dr. Smith, Thomas, and a nurse and speech-language therapist who both work closely with Mindt. During this meeting, Nila expresses that if Mindt is not eating, he won't be able to keep up his strength, and if he can't keep up his strength, she worries that he won't continue to recover from pneumonia. Dr. Smith explains to Nila that appetite loss and difficulties in eating are part

of the natural progression of end-stage dementia. She further explains how hospice works and suggests hospice as an approach for keeping him as comfortable as possible.

Nila expresses her disagreement with Dr. Smith and clarifies that she wants everything done to prolong Mindt's life. She repeats that she wants to know what can be done to get him to eat more.

Dr. Smith is aware that though some patients with advanced dementia receive a percutaneous endoscopic gastrostomy (PEG) so that nutrition can be provided by a tube, this treatment is not recommended for patients with advanced dementia according to guidelines from the American Geriatrics Society because, among other reasons, it is thought that the benefits do not outweigh the burdens of a patient's discomfort, aspiration, risk of infection, increased oral secretions, tube malfunction, and possible use of restraints [1]. Dr. Smith strives to focus the conversation on preparing for Mindt's death and keeping him comfortable; she feels that bringing up the possibility of tube feeding could lead to his prolonged discomfort. Nila is steadfast, however, about learning more about improving his nutrition. Dr. Smith and Thomas wonder whether to pose the PEG tube as an option.

Commentary

Mindt, with his advanced dementia, and Nila, his diligent caregiver, seem to present a dilemma for the physicians. Asking when and how to advocate for a [comfortable dying process](#) in this context frames the situation in a dualistic way, as if it were a conflict between the interests of a caregiver who is persisting beyond reason, on the one hand, and the interests of the patient whose imminent finitude needs attention, on the other. Dr. Smith wonders whether to broach the topic of an intervention that might burden rather than benefit the patient simply because this desperate caregiver is unable to face her loved one's impending death. Dr. Smith might dread the possibility that Nila's inability to cope might cause her to become uncooperative or even hostile. In such a case, challenging or even removing a surrogate from her role because she is not acting in the best interests of the patient is an available path, but not a first choice [2]. If the resident and the team find that Mindt's and Nila's interests are not as divergent as they first appear, then common ground might prevail.

Context of a Decision about Nutrition

The first step in such a case is to broaden the perspective from the decision in the moment to the context that holds or surrounds it. Mindt has been chronically ill and declining for years. Nila has been his faithful caregiver throughout, but she is also his wife. These two roles have enabled her to witness his painful decline with both unparalleled intimacy and unrelenting unease and sorrow. Anger and resentment may also have been part of the picture at times [3]. Since the death of their son, perhaps Nila has had no one close enough to attest to Mindt's changes in behavior and to the

necessary adjustments and painful decisions she has been forced to make in response. Attending to Mindt's needs most likely has constricted their social universe. All this makes for a very lonely existence for each of them as individuals and for them as a married couple.

Even as long-term caregiving is isolating for family members, it is also unpaid and poorly appreciated in US society [4, 5]. Furthermore, a high burden of care is more common among caregivers of spouses such as Nila than among caregivers who provide care to another relative [6]. While clinicians might be aware of the caregiving situation and its stressful nature, they generally fail to ask caregivers about their own needs [6]. Since his son's death and his own illness, Mindt has represented the sum total of Nila's immediate family. His well-being has been her main goal. When he dies, she will not only feel she has failed at maintaining his health, but also be both bereft and out of a job. It is no wonder that she is resisting the outcome that the team finds inevitable. Persons who have cared for a loved one for long periods might be unwilling to forgo cardiopulmonary resuscitation at the end of life as well [7].

Mindt and Nila's son's death occurred only a few years before Mindt began to show signs of the disease; Nila's continued grief from this major loss might be playing a role in her current reactions, exacerbated by Mindt's decreasing ability to notice or share in her grief. It would be helpful for the team to know the nature of Nila's support system, both then and now. How has Mindt understood his disease and its progression when he was able to process this information? Caregivers should reaffirm that Mindt himself has not expressed an opinion about what should happen under the circumstances they now face. His preferences in either direction do not alter the need to attend to death's approach, however.

Interacting with the Surrogate Decision Maker

As Dr. Smith and Thomas reflect on Nila's position rather than the ethical dilemma facing them, they can change the story they might have been telling themselves about her [8]. If Nila has sensed a willingness on the part of the team to classify Mindt as dying, then her trust might have eroded already. The team needs to make it safe for Nila to talk about her experience with Mindt not only as the clear expert on his needs, but also as a person in her own right who is primarily responsible for his well-being. What has this journey been like for her? The team might offer appreciation for Nila's excellent care, both before and after Mindt's admission to this facility. Surely his decline would have been more precipitous without her ongoing attention. "It must be hard for you to see him like this" is a plausible opening, followed by an invitation for Nila to say more.

The crux of any decision involving [nutrition](#) is a fraught area. Perhaps Nila's recent visits have been centered around mealtimes, especially while Mindt's eating patterns have been changing. His reactions to food may have been a source of struggle for some time,

since both aging and dementia can interfere with taste and smell [9]. Furthermore, meals themselves are ritualistic social occasions. When we feed people, we say, "I love you." When they eat, they say, "I love you back." Even more, eating is also a sign of health and recovery. Although Nila might understand that his disease is ultimately terminal, when Mindt eats, she can be sure that it's "not yet." Mindt's lack of interest in food is therefore layered with meanings that would be very difficult for Nila to face.

The Clinical and Ethical Issues of Nutrition in Dementia

A physical problem beyond the pneumonia must be considered and acted upon in case it is a contributing factor in Mindt's refusal of food. A detailed assessment is critical. Has food refusal happened before? Does he refuse everyone who tries to feed him? Does it happen with every food? As part of the conversation and trust-building with Nila, the team needs to determine how the most recent weeks have been for her. It is equally important to learn more about how this experience fits into her understandings of his disease progression over the last ten years and what it means to her.

While the use of feeding tubes in long-term care varies greatly according to the demographic and other features of the facility [10], it is likely that Nila has observed other residents with these devices. An important part of the context of the discussion is knowledge of the facility's policies on nutrition when patients can no longer manage oral intake [10]. An established relationship with the ethics committee is also helpful in case its support is needed. If the team does not wish to recommend this intervention for Mindt, no one on the team should bring it up for discussion. To do so would imply that placement of a feeding tube would be neutral in terms of its medical impact on Mindt and might prolong his life when the prevailing literature indicates the opposite [11]. Professional groups such as the American Geriatrics Society [1] and the Alzheimer's Association [12] advise against tube feeding because its burdens outweigh its benefits. If Nila asks about it, the team needs to be prepared with a gentle but firm response. It will not accomplish the goals she has articulated so far: to improve Mindt's nutritional status and lengthen his life. Nila will want to recognize that the relational interaction that is so embedded in eating or in hand feeding will be lost with a PEG tube. She will also need reassurance that foregoing such an intervention will not be a discomfort to Mindt [11].

As Nila is able to convey her experiences with Mindt and affirm (or rebuild) her trust in the team, it might be possible to explore additional goals with her. It is likely that Mindt's dementia has made him bedbound, dependent on others for activities of daily living, and that he has difficulty communicating [11]. Palliative care is designed to support patients and families in their journey through any serious illness. It might be a more acceptable choice for Nila if her rejection of hospice arose from her fear of Mindt's death. The case does not mention Mindt's code status. A full discussion on this topic is also important.

If we assume that Nila understands the normal progression of the disease, it appears that she is engaging in false hope. She is avoiding hospice and wants to know more about "improving his nutrition" or getting Mindt "to eat more." Jack Coulehan [13] has offered a perspective for understanding deep hope and false hope that is relevant here. Coulehan characterizes such hope in spite of all odds as possibly "foolish," but not "false" unless it causes harm [14]. Nila's hope that Mindt's physical status will improve at this very terminal stage appears foolish. For Coulehan, deep hope is not dependent on cure or even on patient improvement; rather, it is connected to a human wellspring that is somewhat independent of life circumstance. The team needs more information from Nila to help her tap into her deep hope. The team's obligation to Mindt could be carried out by helping Nila come to terms with changes in, and her expectations for, her relationship with him. What are Nila's goals for her relationship and experiences with Mindt (along with his well-being) now that his disease has progressed this far?

His lack of interest in eating represents one more loss on the journey for the two of them, but opportunities for meaningful interaction remain. The team can help Nila to shift her hopes for Mindt from prolonging his life to short-term, more specific goals, such as signs that he knows she is present with him. Without a feeding tube, perhaps Mindt will take a bite or a sip if he senses that he is not being pressured to do so. Nila can express her caring in concrete ways other than feeding him: touch, such as a hand or foot massage; talking over family photographs (whether or not he can participate); and sharing music. A palliative care consult could assist Nila and the team in exploring these possibilities.

It is tempting for clinicians to urge patients and families to face the fact of dying when death seems imminent, but to do so when they are not ready can jeopardize relationships. Instead, one may solicit their interpretation of what is happening and ask them to frame it in terms of what is most important to them [15]. Hank Dunn has offered helpful vocabulary that might be useful in framing the idea of "letting go" versus "giving up." [16]. In these ways, the team members encourage the family (and each other) to make the most of the time available, placing the inevitable changes in the patient's condition in the context of the family's history together.

The Critical Present

It is possible to anticipate a positive outcome while laying the groundwork for something else [13, 17, 18]. What is key for everyone involved here is to embrace the critical present. The feeding tube is a potentially harmful distraction. This is a moment to turn from investing in an unsecurable future for Mindt and to address the compelling needs of all who labor in the shadow of someone's diminishing vitality. Nila and the team can work to make this time meaningful. By inviting her to talk about her experience and listening with empathy, the team can enable Nila to express what her journey with Mindt has meant to her up to this point and her goals for the two of them in this moment.

Drawing Nila out through thoughtful questions might seem to be time intensive. However, it is key to finding common ground and making meaning in the situation. Repairing frayed trust can reduce misunderstanding and ease future communication, ultimately saving time. Embracing the critical present might not be possible for Nila and the team if the meanings of the past are not honored or at least acknowledged. What happens now needs to rest securely in the context of what has preceded it. From now on, Nila's deep love for and commitment to Mindt cannot make or keep him *well*. But she and the team can and must continue to attend to his *well-being*.

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ETHICS CASE

How Should Clinicians Counsel a Woman with a Strong Family History of Early-Onset Alzheimer's Disease about Her Pregnancy?

Commentary by Marianna V. Mapes, Barbara M. O'Brien, MD, and Louise P. King, MD, JD

Abstract

Counseling patients regarding the benefits, harms, and dilemmas of genetic testing is one of the greatest ethical challenges facing reproductive medicine today. With or without test results, clinicians grapple with how to communicate potential genetic risks as patients weigh their reproductive options. Here, we consider a case of a woman with a strong family history of early-onset Alzheimer's disease (EOAD). She is early in her pregnancy and unsure about learning her own genetic status. We address the ethical ramifications of each of her options, which include genetic testing, genetic counseling, and termination versus continuation of the pregnancy. Our analysis foregrounds clinicians' role in helping to ensure autonomous decision making as the patient reflects on these clinical options in light of her goals and values.

Case

During his third-year OB-GYN clerkship in medical school, Samuel is working with Dr. Bowers seeing patients both in the hospital (on the labor and delivery service) and in the outpatient clinic for routine prenatal visits. For the outpatient visits, he sees patients who present for initial appointments to confirm pregnancy and for appointments just prior to delivery.

About halfway through his clerkship, Samuel and Dr. Bowers see Mrs. Castle and her husband for an initial visit to confirm a pregnancy. Mrs. Castle is a healthy 41-year-old woman with a strong family history for early-onset Alzheimer's dementia. Her father was diagnosed with Alzheimer's dementia at age 45 and died about five years later. Mrs. Castle's older sister, who is in her late 40s, has also been diagnosed with early-onset Alzheimer's dementia and is currently living in long-term care due to complications of the disease.

Mrs. Castle and her husband had tried to conceive for more than a year without success. They had met with a specialist and briefly considered assisted reproductive technology when they put their plans on hold due to Mrs. Castle's sister's illness. The couple thought

carefully about what a pregnancy would mean for Mrs. Castle and her family; they chose not to pursue genetic counseling related to Mrs. Castle's family history of early-onset Alzheimer's dementia. Recently, Mrs. Castle has been more concerned about her own worsening short-term memory. Her husband has also noticed that she seems to have become more irritable and anxious over the last couple of years. They question whether they should continue with the pregnancy.

Dr. Bowers wondered how best to provide support for the patient not only in prenatal care but also in addressing the couple's concerns about parenting in the setting of a strong family history of early-onset Alzheimer's dementia.

Commentary

Dr. Bowers, Mrs. Castle, and her family all face a daunting set of decisions, as Mrs. Castle is early in her pregnancy yet does not know her own genetic status or that of her affected sister. She has received some counseling in the past regarding options related to infertility but is likely not aware of the full ramifications of the multiple decision pathways that are now before her. Dr. Bowers must carefully explore these various options with Mrs. Castle and her family—all in the context of what is likely booked as a 15–30 minute appointment.

Initial Counseling

At the outset of the appointment, ahead of a full discussion, Dr. Bowers is encouraged to proceed with a serum pregnancy test, which we will presume is positive and significant enough to warrant an ultrasound. Mrs. Castle may decline the ultrasound, yet the information afforded would be essential. Her difficulties in conceiving are likely related to her advanced age of 41 years, which puts the pregnancy at increased risk of aneuploidy and miscarriage. Thus, to the extent possible at this early stage, confirming a pregnancy should be the first step. While this process could require multiple appointments, Dr. Bowers, recognizing the time constraints at issue, should expedite this process as best she can.

Assuming a pregnancy that appears to be proceeding normally at approximately 8–10 weeks, we would encourage Dr. Bowers to consult the timeline below and to carefully discuss each of the possible pathways with Mrs. Castle, assuming she wishes to continue her pregnancy (see figure 1). Authors have previously described this very situation as an “existential crisis” for the patient and family [1]. Dr. Bowers might also feel the weight of this existential crisis, given the difficulty of addressing these complex decisions and their far-reaching implications under significant time constraints. A comprehensive discussion of counseling and possible testing is difficult to achieve even ahead of pregnancy in the setting of assisted reproduction, in vitro fertilization (IVF), and preimplantation genetic diagnosis (PGD), which we discuss more fully below. In fact, it might be nearly impossible when a patient is faced with an ongoing pregnancy and no

knowledge of familial genetic risk. Thus, our primary advice to Dr. Bowers is to seek help from an interdisciplinary team. A single clinician, no matter how skilled, is unlikely to be able to provide the counsel and support that Mrs. Castle and her family need as they grapple with these challenging decisions.

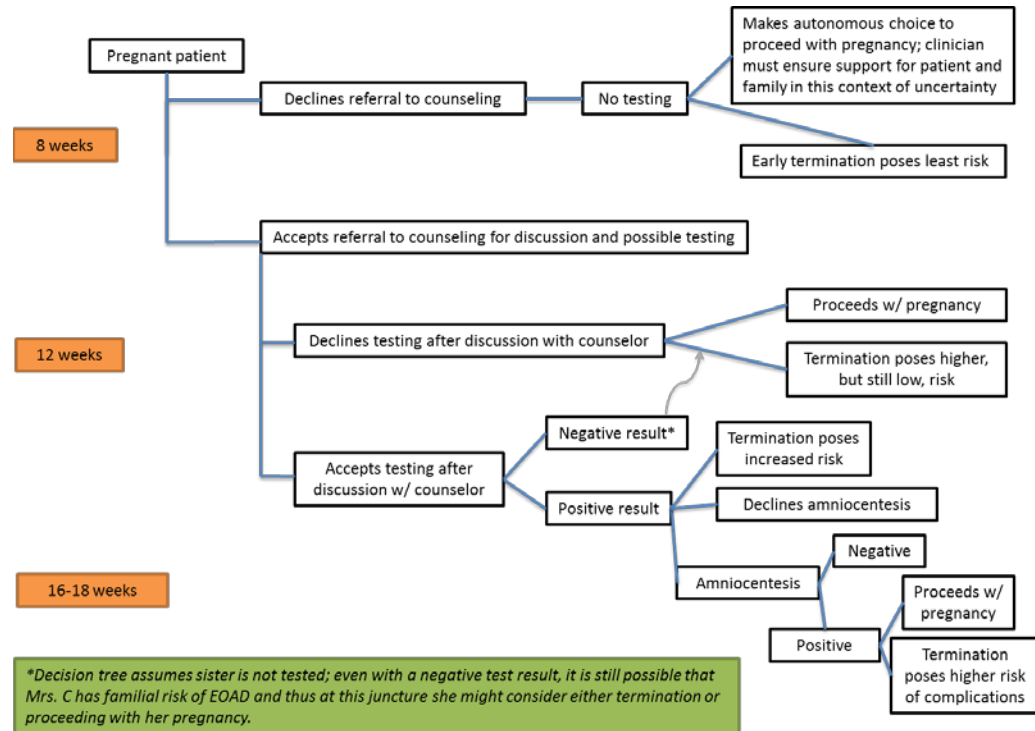


Figure 1. Decision tree and timeline

But first Dr. Bowers should pose to Mrs. Castle a simple question: Does she wish to continue this pregnancy? The likely answer would be yes—she has been trying to conceive for over a year. However, one can imagine a patient who, faced with this existential crisis, would choose at the outset to terminate. Perhaps Mrs. Castle has been avoiding full consideration of what her sister's diagnosis and her own symptoms might mean for herself and a potential child. Confronted starkly with these prospects, she might find that continuing with a pregnancy is simply not possible for her or her family, even without genetic test results. A full discussion of the ethics of abortion is beyond the scope of this paper. Suffice it to say, should Mrs. Castle request termination at any stage of this process (as indicated in figure 1), we will assume her request would be granted.

The next step in our timeline would be to encourage Mrs. Castle and her family, including her sister and her sister's family, to involve genetic counselors and neurologists in her care. To prepare Mrs. Castle for her meetings with these clinicians, Dr. Bowers should discuss the potential downstream consequences of these consults. For example, Dr. Bowers should explain that testing would take weeks, which would push related decisions further along the timeline—and further into Mrs. Castle's pregnancy. Dr.

Bowers should provide a general overview of testing and the options that would arise along each decision pathway. She should also flag the possibility of fetal testing by amniocentesis and the difficulties Mrs. Castle could face in considering this possibility. The details of this discussion are addressed more fully below.

Given the complexities involved, this level of counseling would take hours and might be beyond the scope of what an obstetrician-gynecologist would feel comfortable addressing in a clinic visit. Yet merely referring Mrs. Castle to a genetic counselor without preparing her would not be appropriate. Depending on what consultants are available to Dr. Bowers, involvement of a maternal fetal medicine specialist could be helpful in facilitating her care.

In short, Dr. Bowers should approach this situation as a counseling emergency of sorts, given the timeline, and should involve all those who can assist this family as quickly as possible. What follows is a detailed discussion of the salient points to be addressed in the counseling process.

Overview of Genetic Testing in the Setting of EOAD

Mrs. Castle has a strong family history of Alzheimer's disease (AD), which represents 60-70 percent of dementia cases worldwide [2]. Like other forms of dementia, AD causes progressive deterioration in cognitive, emotional, and social functioning [3].

AD is categorized as early onset (i.e., before age 65) or late onset (LOAD) [4]. The early-onset form of the disease (EOAD) represents 10 percent of all AD cases [5]. Strikingly, the inherited genetic contribution to EOAD is estimated to be 92-100 percent [6]. Strictly speaking, EOAD is not synonymous with autosomal dominant AD, but because autosomal dominant AD is found almost exclusively in families with EOAD, this article will use these terms interchangeably [4].

Genetic testing for EOAD detects any of the three known autosomal dominant mutations in the amyloid precursor protein (*APP*) and presenilins 1 and 2 (*PSEN1* and *PSEN2*) genes [7]. Mutations in the *APP* and *PSEN1* genes are completely penetrant, so people with the mutant allele will develop AD if they live a normal lifespan [4]. A person with either of these mutations has a 50 percent chance of passing the mutant allele on to each child [8]. By contrast, mutations in *PSEN2* are 95 percent penetrant [4]. Although mutations in any of the three known EOAD genes are causative, these mutations only account for 5-10 percent of all cases of EOAD [5]. In short, a person can receive a negative test result for these mutations and remain significantly at risk for developing EOAD.

In addition to mutations in the three EOAD genes, the $\epsilon 4$ allele of the apolipoprotein E (*APOE*) gene increases a person's susceptibility to developing both EOAD and LOAD [4].

However, as predictive *APOE* genotyping is neither recommended nor routinely practiced, it falls beyond the scope of this article [4].

Benefits of Genetic Counseling

Genetic counseling is an interactive process focused on educating the patient about the inheritance, progression, and management of genetic disease [9]. A genetic counselor would discuss Mrs. Castle's eligibility for testing and serve as a neutral source of information and a partner in reflection as she considers the available options in light of their risks and her own values [10].

Per current medical guidelines, people who have symptoms of EOAD, at least one family member with EOAD, and/or a family member with one of the known causative mutations, are eligible for [genetic testing](#) [4]. As Mrs. Castle has two family members with EOAD and is herself apparently symptomatic, she is a candidate for genetic testing. Given the clinical ramifications and emotional burden of genetic testing, the guidelines advise that testing proceed only with neurological evaluation and with genetic counseling both pre- and posttest [4]. Simply put, this process is very time intensive.

To increase the likelihood of obtaining an informative result, the guidelines further recommend that a living, affected family member—in this case, Mrs. Castle's sister—undergo testing for a known causative mutation first [4]. In addition, Mrs. Castle's sister and her family should be advised to consult with a neurologist for possible panel testing to clarify her diagnosis and ascertain whether other factors might be contributing to her dementia. This information stands to benefit the entire family, including Mrs. Castle. Unfortunately, it is not clear that the sister has the capacity to consent to testing, that she would agree to be tested if she had capacity, or that consent could be obtained quickly enough to have any bearing on decisions that Mrs. Castle might make regarding this pregnancy.

It is critical to note here that without first testing Mrs. Castle's sister, a negative test result for Mrs. Castle affords little information about her risks of developing EOAD (see figure 2). Insofar as mutations in the three identified EOAD genes account for only a small percentage of all cases of EOAD, in this scenario, Mrs. Castle could still face a significant risk of developing the disease [5]. Assuming that information about the sister's genetic status is not available, Mrs. Castle must be supported in making a difficult decision about whether to be tested herself so as to make a decision about her pregnancy.

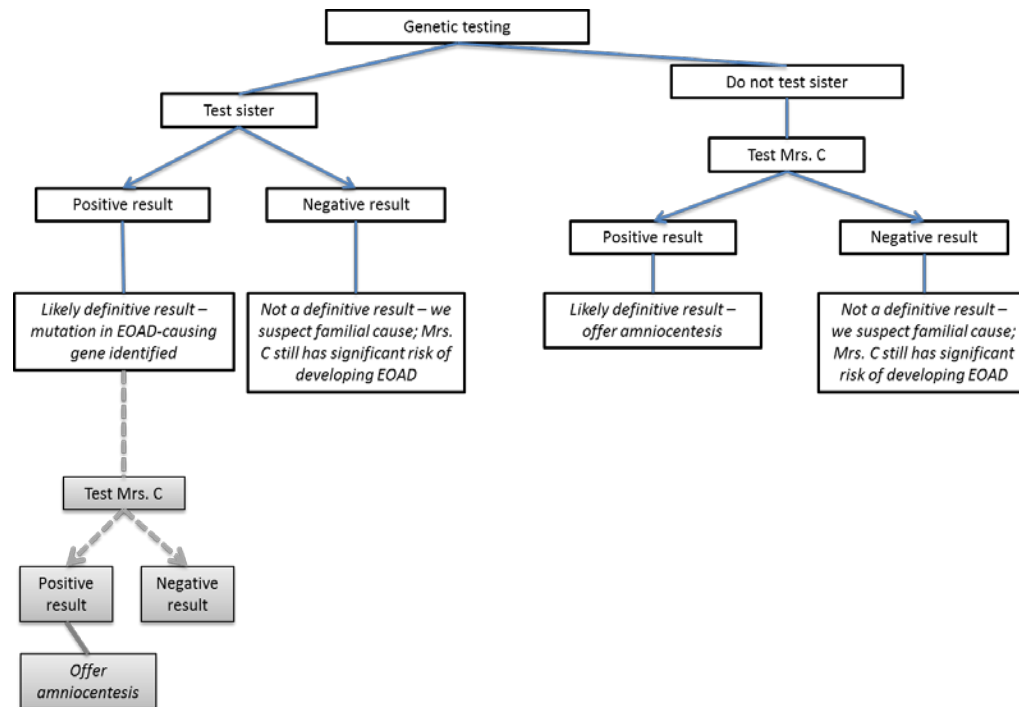


Figure 2. Genetic testing decision tree

Given the pressures involved in these emotional decisions, Dr. Bowers should emphasize ahead of referral that genetic counseling offers significant psychotherapeutic and educational value and does not commit Mrs. Castle to genetic testing [11]. Mrs. Castle should expect genetic counseling to contextualize her risk and provide an informative, nondirective discussion of the implications of the disease. She should also expect that the counselor will review the decisions that she will have to make and again review their possible consequences, as did Dr. Bowers in her initial appointment.

While we might take genetic testing to be a value-neutral mode of providing information, the utilization of test results in clinical decision making could prompt vexing concerns about truly autonomous choice. More specifically, scholars of disability theory raise [ethical concerns](#) that genetic counseling and testing could be implicitly directive in a way that diminishes the value of persons who fall outside constructions of able-bodiedness [12]. One safeguard against this implicit directedness might involve including insights from the lived experiences of persons with the disease. As disease is not strictly physiological but unfolds within a social context, genetic counseling should provide information about both the clinical and social dimensions of living with disease [12–14]. Toward that end, the genetic counselor should discuss with Mrs. Castle that both she and her child, if affected, could live as many as 64 asymptomatic years before the onset of EOAD symptoms, and that the experience of dementia, like that of other conditions, does not *ipso facto* preclude a rich and meaningful human existence [15].

Preconception Testing

As mentioned multiple times in this discussion, the time constraints associated with this case are far from ideal. Mrs. Castle faces both the stress of pregnancy and the prospect of learning powerful information that could affect her own future and that of her fetus. Ideally, the clinical and ethical deliberation concerning genetic testing for Mrs. Castle would have preceded conception. This sequence of events would allow for a more extensive discussion of options, including in vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD) and subsequent transfer of unaffected euploid embryos. Although costly, this option might be available to a patient who wished to transfer unaffected embryos without knowing her own genetic status [1]. Certainly, this option is not without complexities. Clinicians must consider the patient's exercise of autonomy alongside the breadth of parental latitude granted to the patient in making decisions for a future child. The tensions inherent in these decisions are similar to those present in the setting of possible amniocentesis, discussed below. Yet, at the very least, this option affords the family and clinicians time to more meaningfully explore questions related to quality of life that necessarily impact decision making in this context.

Post Counseling

Proceeding along our timeline (see figure 1), following counseling, Mrs. Castle must now decide whether or not to accept testing. Despite the limitations discussed above, even assuming that her sister has not been tested, Mrs. Castle should consider genetic testing for herself. If Mrs. Castle tests positive and wishes to know whether the fetus is affected, she will have to undergo prenatal testing in the second trimester by amniocentesis, discussed further below [16].

Assuming that her symptoms indicate EOAD, Mrs. Castle might decline testing on the grounds that it would reveal what she already believes to be true. Mrs. Castle might surmise that she is likely affected but might wish to remain in a state of ignorance, thereby shielding herself from the knowledge that she might develop a progressive and potentially devastating disease. In this scenario, one could conceive of the possibility of proceeding to amniocentesis to determine if the fetus is affected. However, we would argue that this option should be discouraged. Certainly, this is an area of debate, as some might posit that respect for Mrs. Castle's autonomy demands she be afforded this option. We would argue that the potential for a definitive result here is exceedingly small, as there is no knowledge of the genetic susceptibility in this family. Consequently, Mrs. Castle is in a position to learn either a devastating or a functionally useless result. In the setting of a positive result, she would learn that she and her fetus, along with her sister and other family members, are affected by a mutant allele. Alternatively, in the setting of a negative result, which is much more likely, she would learn very little relevant information.

Should Mrs. Castle instead opt to undergo testing and be found to carry an EOAD-causing mutation, Dr. Bowers and the genetic counselor's first priority would be to work with the other involved health care professionals to continue to tailor care to Mrs. Castle's needs. Even if she received a negative result, in consultation with her neurologist, she could be faced in the short term with a diagnosis of EOAD and thus the counseling that follows testing would still apply. Mrs. Castle will need to consider how best to adapt to her changes in functioning, establish a sound financial plan, and so on. She might also believe that her family has an important role—*beyond* the caregiving roles they are likely to assume—in helping her to grapple with these decisions. Insofar as her priorities, values, and preferences are shaped through these relationships, Mrs. Castle will be best off considering her options through conversation and reflection with those most important to her.

In this interpersonal context, Mrs. Castle will need to think about how to anticipate a *shift*—not necessarily a *downgrade*—in her quality of life with the onset of AD. To be sure, evaluating quality of life is a thorny issue in the context of disease, and Alzheimer's dementia is no exception. Conversations between Mrs. Castle and each of her caregivers should address considerations unique to the experience of dementia and how they should be weighed in her reflections [17]. The declines in cognitive and social functioning that accompany dementia raise significant challenges to our ordinary thinking about a person's future wishes. How might Mrs. Castle plan for the years ahead when her future self is so discontinuous with her current circumstances that extrapolation about her future interests seems impossible? For example, Mrs. Castle might not currently get much enjoyment from watching sitcoms on television or eating an ice cream cone, but it is difficult, if not altogether impossible, to know whether she might take pleasure in these activities after the onset of her dementia. Does she want what is most important to her now to remain an important reference point at a future time when perhaps her interests—and certainly her neurological functioning—have changed considerably? Such questions about the continuity of the self—and the continuity of one's future wishes and judgments about an acceptable quality of life—merit far deeper discussion than we can delve into here. Nevertheless, meaningful reflection on these important and complex questions will undoubtedly suffer under the tight timetable of an existing pregnancy.

Fetal Testing

If she receives a positive test result, Mrs. Castle will then have to quickly decide whether to learn the genetic status of her fetus. Prior to pursuing amniocentesis, Mrs. Castle must consider how she will respond if the test yields a positive result. In this context of [prenatal genetic diagnosis](#), Mrs. Castle's judgments about her future child's quality of life generate even more complex questions. Does Mrs. Castle have the ethical authority to determine that her future child's quality of life would be so diminished by EOAD that it would be in the child's own interest not to exist at all? Or does such a judgment fall

beyond the purview of Mrs. Castle's decision-making authority, especially when it is not clear how the future child might evaluate his or her *own* quality of life as he or she experiences the onset of dementia symptoms as an adult? As Mrs. Castle and her family consider these questions, the involved clinicians should serve as partners in reflection.

In addition to these ethical concerns, Mrs. Castle must consider the slight risk of miscarriage that amniocentesis carries. The procedure-related risk of miscarriage for amniocentesis and chorionic villus sampling (CVS) is approximately 0.1 percent and 0.2 percent, respectively [18]. If Mrs. Castle does not anticipate that the prenatal diagnosis will influence her decision about continuing the pregnancy—that is, if the procedure offers no foreseeable benefit—we find no ethical warrant for posing this risk to the fetus. However, if Mrs. Castle plans to use the prenatal diagnosis in making her decision, we argue that testing might be worth the risk. In such cases, the clinician's role should center on accurately communicating the procedure-related risks and then allowing the patient to determine the course of action most consistent with her and her family's values [19].

Conclusion

The field of genetic diagnosis is expanding rapidly. As evidenced by this case, patients and clinicians will have to engage more and more directly with difficult ethical dilemmas surrounding genetic testing.

In our discussion above, we have laid out the various decisions confronting Mrs. Castle, her family, Dr. Bowers, and the clinicians who will necessarily be involved in her care. From a clinical perspective, we find most daunting the prospect of the first meeting, during which so much information must be conveyed. To proceed with any first step in our decision tree by truly autonomous decision making, Mrs. Castle must understand the downstream implications of each step. Achieving such a level of understanding amidst the anxiety that Mrs. Castle is experiencing seems nearly impossible. Recognizing genuine understanding as an important element of reproductive choice, we emphasize that education of patients about the decisions involved in genetic testing should precede pregnancy. Yet it is unlikely this education could easily be attained for most patients.

Ethical quandaries abound at each node of the decision tree, and, as is frequently the case in reproductive ethics, they center on questions of autonomy and its proper scope. Early involvement of an interdisciplinary team to address these questions is essential in supporting our patients as they make these difficult decisions.

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Related in the *AMA Journal of Ethics* and *Code of Medical Ethics*

[AMA Code of Medical Ethics' Opinion 4.1.2 Genetic Testing for Reproductive Decision Making](#), June 2016

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[Expanded Genetic Testing in Assisted Reproduction: Lessons Learned from Prenatal Testing](#), January 2014
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THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinions on Patient Decision-Making Capacity and Competence and Surrogate Decision Making

Danielle Hahn Chaet, MSB

Editor's Note: The American Medical Association (AMA) Code of Medical Ethics does not directly address dementia, but our [June 2016 issue](#) includes Code guidance on mental health and decision making. Since then, the AMA House of Delegates has adopted a modernized edition of the Code of Medical Ethics; titles, quotations, and links herein are updated.

Although the *Code of Medical Ethics* does not have much to say about mental health per se, the *Code* does consider patient decision-making capacity, mental competence, and surrogate decision making for those who are unable—over the short term or the long term—to make their own health care decisions. These concepts are discussed in opinions 5.3, “Withholding or Withdrawing Life-Sustaining Medical Treatment” [1], 2.1.1, “Informed Consent” [2], and 2.1.2, “Decisions for Adult Patients Who Lack Capacity” [3].

Decision-Making Capacity and Competence

Generally, patients are free to exercise their autonomy in making decisions about their own health care. However, patients can only do so if they are given information about and understand the risks and benefits of a specific treatment and can apply this information to their health. We know that not all patients have capacity (a clinical standard applying to a particular decision at a particular point in time) or competence (a legal standard applying to all decisions at all times) to make these informed choices about their health care [4]. For patients with mental illnesses that can interfere with their insight into their health or with their decision making, physicians have obligations to assess their capacity in order to evaluate their ability to make a particular health care decision at a particular point in time.

Because patients with mental illnesses can be vulnerable—particularly when they are severely chronically disabled by an illness or experiencing an acute exacerbation of an illness—they might not fully understand or be able to integrate information about risks and benefits of possible interventions. Opinion 2.1.2, “Decisions for Adult Patients Who Lack Capacity,” explains that “Even when a medical condition or disorder impairs a patient’s decision-making capacity, the patient may still be able to participate in some aspects of decision making. Physicians should engage patients whose capacity is impaired in decisions involving their own care to the greatest extent possible” [5]. The higher the risk of a particular decision, the more important it is that the patient has

appropriate decision-making capacity. That is, a patient suffering an acute exacerbation of a mental illness at a particular point in time might have capacity to decide what she will eat for breakfast, but she might not have capacity to decide whether to begin a course of psychotropic medications.

More about Surrogate Decision Making

When a patient does not have the capacity to make her own decisions at a particular point in time (or when her decisions are not covered by an advance directive, as noted in Opinion 5.1, “Advance Care Planning” [6]), someone else must do so for her. This person, known as the *surrogate decision maker*, or *proxy*, has either been named by the patient at a time when she had capacity or is a family member or close acquaintance designated by law or statute.

Opinion 2.1.2, “Decisions for Adult Patients Who Lack Capacity,” also applies to patients who are competent but can, at a point in time, lack capacity. This opinion notes that “When a patient lacks decision-making capacity, the physician has an ethical responsibility to ... identify an appropriate surrogate to make decisions on the patient’s behalf” [5]. This person has either been designated by the patient “as surrogate through a durable power of attorney for health care or other mechanism” or is “a family member or other intimate associate, in keeping with applicable law and policy if the patient has not previously designated a surrogate” [5]. Surrogate decision makers should base their decisions on the *substituted judgment* standard; in other words, they should use their knowledge of the patient’s preferences and values to determine as best as possible what the patient would have decided herself. If there is not adequate evidence of the incapacitated or incompetent patient’s preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient’s well-being). Opinion 2.1.2 explains, “Best interest decisions should be based on ...the pain and suffering associated with the intervention,” “the degree of and potential for benefit,” and “impairments that may result from the intervention” [7].

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IN THE LITERATURE

When Does Therapeutic Misconception Affect Surrogates' or Subjects' Decision Making about Whether to Participate in Dementia Research?

Laura B. Dunn, MD, and Barton W. Palmer, PhD

Abstract

"Therapeutic misconception" (TM) refers to inappropriate assumptions and beliefs on the part of research participants regarding key distinctions between the purpose, methods, intended benefits, and potential disadvantages of research compared to those of clinical care. Despite an extensive literature describing TM across varied types of research and populations, minimal work has addressed TM in the context of dementia research. This is a serious gap, for several reasons: people with dementia are at significant risk of diminished capacity; surrogate decision makers are typically asked to provide consent on behalf of the person with dementia; and available treatments for dementia are quite limited. More research is needed on the prevalence, nature, and impact of TM in the context of clinical dementia research.

Introduction

Over 30 years ago, Appelbaum, Roth, and Lidz coined the term "therapeutic misconception" (TM), which they initially defined as the inappropriate assumption by research participants "that decisions about their care are being made solely with their benefit in mind" [1]. For example, citing the work of prior authors, they noted that randomized assignment sacrifices, to a degree, research participants' interests (or right to "personal care") for those of research design in order to advance science for potential future benefit of others. Participants' incorrect assumption that decisions are made to advance their personal therapeutic benefit is the crux of therapeutic misconception and may compromise informed consent. In a seminal article titled "False Hopes and Best Data: Consent to Research and the Therapeutic Misconception," Appelbaum and colleagues [2] provided further descriptive evidence of TM based on interviews with 88 patients with a range of psychiatric disorders, conducted immediately after the participants provided informed consent to participate in one of several clinical studies. The findings indicated that many participants failed to appreciate key distinctions between the purposes, methods, intended benefits, and potential disadvantages of research compared to those of clinical care. For example, a 25-year-old woman with a high school education, who consented to participate in a randomized, placebo-controlled trial of medication for a nonpsychotic psychiatric disorder, stated that she believed "the

placebo would be given only to those subjects who ‘might not need medication’” [3].

In this commentary, we first briefly examine the general importance of considering TM and advances in assessment of TM. We then describe its application to research involving people with dementia.

The Construct of Therapeutic Misconception

A review article on informed consent found that a large proportion of research participants, in medical as well as psychiatric or dementia trials, show poor comprehension of various key aspects of consent-relevant information [4]. However, misunderstanding the intent of a clinical trial as designed to provide individualized therapeutic benefit has special weight and importance beyond evidencing poor general comprehension of disclosed information. Although there is substantial overlap between [research ethics](#) and clinical ethics, they are not synonymous, and the ethical obligations of a researcher to the individual participant are not fully equivalent to those of a clinician to an individual patient. Most notably, clinicians are ethically compelled to act in the best interest of their individual patients. Researchers, by the very nature of research design (such as use of placebo control, fixed dosing, and assessments that are not needed for clinical management) sometimes violate the ethical mandates of personalized clinical care. As Appelbaum notes, “insofar as the justification for a departure from the principle of personal care is premised (at least in part) on the subject’s knowing relinquishment of an entitlement to a physician’s undivided loyalty, a subject’s failure to appreciate that this is occurring renders consent invalid” [5]. Appelbaum and colleagues recommended steps to mitigate the therapeutic misconception through better education of participants about differences between research and clinical care in order to help them better assess the risks and benefits of participating in research [2].

Many articles describing, defining, and debating TM have been published in the years since the emergence of the concept. Empirical studies have painted a detailed portrait of TM as pervasive across nearly all types of research studies and clinical populations [6–10]. The definition of TM has been discussed at length, with attempts at an expert consensus definition [11] as well as further refinement of the concept into several subtypes [6, 12]. A recent article by Lidz and colleagues offered a conceptual basis for TM, in which the authors argued that

TM does not primarily reflect inadequate disclosure or participants’ incompetence. Instead, TM arises from divergent primary cognitive frames. The researchers’ frame places the clinical trial in the context of scientific designs for assessing intervention efficacy. In contrast, most participants have a cognitive frame that is personal and focused primarily on their medical problems [13].

This conclusion implies that efforts to mitigate TM require challenging participants' cognitive frame, i.e., invoking a paradigm shift within participants away from interpreting disclosed information within a clinical-care schema toward interpreting it within a research schema. Finally, the ultimate question of the ethical significance of TM has been thoroughly discussed and debated as well, with some commentators arguing that the laxity of definitions might lead to overheated concerns about TM [14-16].

Attempts to measure TM have also been made, although assessment of the prevalence of TM has been hampered by the absence of a standardized measure of TM. Most recently, Appelbaum and colleagues have developed a psychometrically strong ten-item instrument to screen for TM based on semistructured interviews coded for the presence of several types of TM [12].

Therapeutic Misconception in Dementia Research

Despite the extensive general literature on TM in a broad range of clinical research participants, there has been minimal work specifically examining TM in the context of dementia research. This is a serious gap, for several reasons.

Participants' diminished capacity. First, people with dementia are at significant risk of diminished capacity to consent to research as a result of cognitive impairments, which can impede their ability to understand disclosed information, appreciate the significance of that information for their own situation, reason with the information, and express a decision about participation [17-19]. Studies of capacity to consent to research among people with dementia consistently demonstrate loss of capacity around the time of transitioning from mild to moderate dementia [17-19]. Persons with mild cognitive impairment (MCI) also demonstrate impairments in decisional capacity [20]. Therefore, even in people with MCI or mild dementia, the ability to understand the distinctions between research and clinical care and how these distinctions may affect one's own well-being in a clinical trial may be cognitively out of reach. Of note, in a study of capacity to consent to research among people with mild-to-moderate AD [17], 20 of 37 in the AD group scored 4 or lower (on a 6-point scale) on the "Appreciation" subscale of the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) [21] that arguably most closely targets elements of TM, whereas none of the 15 control participants scored lower than 5. Because the MacCAT-CR Appreciation subscale does not explicitly target TM, these data do not definitely establish that AD is associated with greater risk of TM, but they do at least strongly suggest that possibility, warranting further empirical attention.

Surrogate TM. Second, when people with dementia participate in research, the most common method used by researchers and accepted by institutional review boards (IRBs) for dealing with loss of capacity is the use of "double consent"—i.e., informed consent

provided by a surrogate decision maker (usually the patient's spouse or adult child), alongside the individual patient's assent to participate [22, 23]. Because of a confusing legal landscape surrounding [surrogate consent](#) for dementia research, however, the regulations and guidelines for obtaining surrogate consent remain somewhat ad hoc. The relevant sections of the Code of Federal Regulations do not clearly establish the qualifications for surrogate consent (or the qualifications of a legally authorized representative for research consent) beyond referring to applicable federal, state, or local laws [24]. This lack of clarity leaves each investigator and IRB responsible for ensuring adherence to applicable state laws (which frequently do not directly address the issue) and assuring adequate participant safeguards [25]. As is the case with consent provided by decisionally capable participants, there is no strict requirement that surrogate decision makers prove that they do not hold a therapeutic misconception about the specific research in question. As long as applicable state law recognizes the surrogate as the person legally authorized to provide consent on behalf of the research participant, and as long as the participant does not actively resist participation, the surrogate is allowed and assumed to provide informed consent for the participant.

Implications of limited treatments and surrogates' "informed" consent. Third, the limitations, in terms of both number and effectiveness, of available therapeutic agents for dementia [26] raise important questions. Most importantly, could "false hopes" or even desperation make surrogate decision makers particularly susceptible to TM in the context of clinical trials for dementia research? Also, how can an investigator or an IRB be assured that surrogate decision makers adequately understand the purpose of the research as distinct from clinical care, assess the research-related risks appropriately, and appreciate limitations on direct personal benefit for the individual patient? And, when making a decision on behalf of the patient, how should surrogates weigh risks and benefits? Does TM affect their decision making, even to the point of overriding the patient's preferences? The latter is an empirical question warranting further study.

Studies of Surrogate Decision Making in AD Research

Unfortunately, minimal research has been conducted that can address the questions posed in the above section. In order to better understand the research-related motivations and perspectives of surrogate decision makers of people with dementia, the first author (LBD) and colleagues conducted two studies of surrogate decision making for dementia research. In the first study, Dunn and colleagues interviewed 82 surrogate decision makers for people with any stage of Alzheimer's disease (AD), randomizing them to informed consent for one of three hypothetical protocols that differed in described levels of risks and potential for direct benefit [27]. Among surrogates who stated they would enroll their relative in the study, reasons given included the potential for direct benefit to their relative, altruism, and trust in researchers. Those who stated they would not enroll their relative cited risks, inconvenience, and stage of illness. Dunn and colleagues did not explicitly attempt to measure TM in this study; however, at least

some of the surrogates' statements reflected awareness that while the patient might not benefit directly, other patients might benefit. As one surrogate put it (speaking about the patient's feelings as well), "We both feel her experiments with AD may not help her but can help others" [28].

In another study of surrogate decision making for AD research, Overton and colleagues [29] and Dunn and colleagues [30] interviewed a total of 65 surrogate decision makers (primarily spouses and adult children) for people with AD. Each surrogate was randomly assigned to one of four hypothetical clinical trials for a fictional investigational drug for AD created by crossing two levels of risk and two levels of potential benefit. In-depth interviews assessed potential influences on the surrogates' decision making and willingness to enroll the patient in the protocol, their perceptions of protocol risks and benefits, and their willingness to override the patient's preferences for research participation. The authors were particularly interested in understanding, through in-depth interviews, how surrogates considered, interpreted, and acted upon abstract ethical principles (e.g., substituted judgment, best interests) in different aspects of research decision making, including whether there was an apparent influence of TM on such decisions. Based on qualitative analyses of two subsets of interviews, the authors reported that surrogates translated these ethical principles into specific duties. Substituted judgment was framed as honoring the patient's wishes and values. Best interests took the form of a perceived duty to do their best to maintain the patient's quality of life and avoid burdens or risks. The authors found that surrogates also were trying to discern (e.g., by reading into the patient's behavior) the patient's current preferences about research, either in conjunction with or in contrast to trying to base their decision on the patient's premorbid preferences regarding research.

There is reason for both hope and concern in the above findings. On the one hand, some of the reasons for consent (and refusal) provided by surrogates are very much in accord with ethical standards. One of the quotes above suggests a shared realization by the surrogate and person with AD that the research may have no personal benefit, while emphasizing their shared desire to participate in light of the possibility that the research might lead to help for others with AD in the future. This is indeed the core scientific motivation for the conduct of clinical research. There was also evidence that surrogates were trying to engage their loved ones and consider their current preferences, to the extent possible, in making the decision. This is very much in honor of the principle of autonomy, as an individual's lack of capacity to fully understand and legally consent to a protocol does not mean that he or she no longer has ongoing preferences that should be weighed in the decision. However, there were also some aspects of the findings that did suggest the potential influence of TM, e.g., when surrogates cited direct benefit to the person with AD even though the nature of the trial made such direct benefit unlikely. Together, these findings suggest there can be no "one size fits all" determination or conclusion about the influence (or lack of influence) of TM in surrogate decisions in AD

research.

Conclusion

Empirical research on TM among surrogate decision makers for participants in dementia research is desperately needed to guide policy and practice. What surrogate, patient, protocol, or environmental (e.g., consent method) characteristics foster or diminish TM? What is the nature of TM in dementia research, and how does it specifically manifest in reference to various types of AD research or at various stages of the disease? The answers to such questions are simply not available at present, but it is ethically imperative that the data needed to answer these and related questions be generated. Given the 2017 changes to the Common Rule overseeing research [31], which will be policy for the foreseeable future, such empirical data are needed immediately.

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POLICY FORUM

Should Potential Risk of Chronic Traumatic Encephalopathy Be Discussed with Young Athletes?

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Abstract

As participation in youth sports has risen over the past two decades, so has the incidence of youth sports injuries. A common topic of concern is concussion, or mild traumatic brain injury, in young athletes and whether concussions sustained at a young age could lead to lifelong impairment such as chronic traumatic encephalopathy (CTE). While the pathway from a concussed young athlete to an adult with CTE remains unknown, current research is attempting to provide more clarity. This article discusses how health care professionals can help foster an informed, balanced decision-making process regarding participation in contact sports that involves the parents as well as the children.

Introduction

There are certainly many benefits to participation in youth sports, including improved fitness level, increased self-esteem, and enhanced peer relationships [1, 2]. In recent years, though, there has been increasing concern regarding the safety of contact and collision sports. Much of this concern is owing to the growing body of research and heightened media attention on concussions and potential long-term effects, including the development of chronic traumatic encephalopathy (CTE) later in life. CTE is a progressive neurodegenerative condition associated with neuropsychiatric symptoms, behavioral changes, and cognitive deficits, which, in the classic form reported in boxers, develops one to two decades after retirement, while in the modern form reported in a broader cohort of contact sport athletes, may develop even earlier [3]. Currently, there are no established clinical criteria for the diagnosis of CTE. In this article, we will briefly discuss what is known and unknown about CTE in relation to mild traumatic brain injury and repetitive head trauma and how to ethically address this risk with young athletes and their families when discussing participation in contact sports.

Research on CTE and Related Neurodegenerative Conditions

Currently available research regarding CTE is not definitive. While CTE is associated with tauopathy, the existence of CTE as a distinct neuropathologic condition is not universally accepted [4], as other neurodegenerative conditions are associated with the presence of abnormal tau proteins [5], and abnormal tau protein deposition has been reported to be

part of the normal aging process in the absence of head trauma [5, 6]. As of 2013, there were 158 cases of CTE reported in the published literature [4]. While the authors of these studies propose that both concussive head injury and repetitive subconcussive impacts lead to neuropathologic changes and the subsequent development of neuropsychiatric symptoms, behavioral changes, and cognitive deficits of CTE [4, 7], the sample sizes of these studies are very small and contain an element of selection bias. Additionally, confounding factors such as substance abuse and genetic predisposition to neurodegenerative disease and mental illness were not controlled for. While studies suggest there might be an increased risk of CTE and other neurodegenerative diseases in professional athletes [7, 8], there is little information available regarding the risk to amateur athletes [9]. A cohort study of 438 former high school football players from Minnesota revealed no difference in risk of neurodegenerative disease compared to a control group of 140 classmates who did not play football [10]. Our PubMed search identified no published epidemiological, cross-sectional, longitudinal, or prospective studies related to CTE, making it impossible to determine true incidence and causation.

Neuroimaging

In addition to studies on CTE, multiple studies have demonstrated brain changes on neuroimaging following concussion [11–16], but the long-term implication of these changes is currently unknown. Recently, there has been increased attention to the potential effects of repeated subconcussive head trauma on the brain. While this is most often discussed in relation to [football](#), other contact sports, such as wrestling and soccer, also involve some degree of this type of head impact. A recent study of 25 youth football players found an association between cumulative head impact exposure and microstructural changes in certain white matter tracts over a single season in the absence of concussion [17]. Similarly, a longitudinal study of collegiate football players found white matter changes on diffusion-tensor MRI following one season of play in the absence of concussion; however, these athletes underwent repeat imaging after six months of rest from contact activity, and the white matter changes had returned to baseline [18]. At this time, there is [not enough evidence](#) to correlate changes in white matter to the subsequent development of neurodegenerative disease or functional deficits, especially in young athletes.

Management of Concussion

The diagnosis of concussion is made clinically. Ideally, an athlete suspected of having a concussion is evaluated by a health care professional who is trained and experienced in the diagnosis and management of concussion. Initial management includes cognitive and physical rest [9, 19, 20]. While the athlete remains symptomatic, he or she will often require academic accommodations, such as a modified or reduced schedule, a reduced work load, extensions on assignments, extra time for testing, and additional accommodations to reduce visual and auditory stimuli [21]. Physical rest is also advised, with no return to high-risk or contact activity until the athlete is asymptomatic. Some

athletes require medication for symptom management, such as nonsteroidal anti-inflammatory drugs (NSAIDs) for headaches or antiemetics for nausea, while others can benefit from cognitive behavioral therapy (CBT) for mood disturbance or emotional issues related to their concussion [9, 19, 20]. Treatment of concussion should be individualized, as symptoms can vary widely and preexisting conditions, such as mood disorders, depression, anxiety, attention-deficit hyperactivity disorder (ADHD), learning disorders, and migraines can complicate management and recovery [19, 20, 22]. Prior to full return to sports activity, it is recommended that the athlete complete a [return to play](#) progression, which involves a gradual increase in level of physical exertion prior to returning to any contact activities [23].

Counseling Families and Young Athletes

With all that is unknown regarding concussion and repeated head trauma and the risk of long-term effects, it can be difficult to counsel families seeking guidance related to their child's participation in contact sports. Given the complexity of the discussion and the gravity of the conditions being discussed, an ethical question is raised as to whether or not the child should be involved in this discussion. There is an increasing amount of literature supporting children's involvement in their health care, and inclusion of pediatric patients in decisions affecting their health is supported by the American Academy of Pediatrics [24]. Encouraging young patients to participate in the decision-making process might promote empowerment and improve compliance with medical recommendations [24] and might in addition increase understanding and awareness.

Although minors' involvement in shared decision making remains relatively underresearched, the available data indicate that children prefer to be included and feel it is important to be involved in decisions related to their health care [25, 26]. It has been demonstrated that children as young as nine years old, despite not having the same level of competency as adults, are similarly able to make logical decisions regarding their health [27]. Most adolescents possess a level of cognitive development that allows abstract thinking and the ability to handle complex tasks, making them more capable of informed decision making [28, 29]. Concurrently, adolescence is the time when reward-seeking regions of the brain are developing, which can influence young peoples' choices and lead to risky behavior [30]. This is why the involvement of family and medical professionals remains crucial to decision-making processes regarding the care of children and adolescents, who often value input from their family and treating clinician [31, 32].

Shared decision making regarding sports participation. Health care professionals routinely counsel young patients and their parents about the consequences of activities that could impact long-term health, such as drug and alcohol use, sex, diet, and exercise. Similar to inclusion of pediatric patients in discussions of how smoking can lead to cancer or how obesity can lead to hypertension and heart disease, we recommend that young people be

included in the discussion of concussion and repetitive head trauma and the unknown risk of CTE. This discussion often requires a longer clinic visit. The physician should review the patient's concussion history and risk factors for prolonged recovery with the family. There is evidence to suggest that prior history of concussion, younger age, history of headaches, and history of learning disability might be risk factors for prolonged recovery [9, 19, 20, 22]. Discussion of risk should be age appropriate and individualized, taking into account the child's level of cognitive and emotional development [24]. It is important to be honest about the fact that, despite the available research on concussion and CTE, much remains unknown, including causation, incidence, and risk. Some young athletes and families are more willing to accept this unknown risk than others.

Revisiting the decision. Additionally, it is important to recognize that a young athlete's perspective regarding participation in contact sports can change over time. This can be especially true after he or she sustains a concussion and experiences the effects of concussion symptoms and recovery, including academic and social difficulties. For those who experience prolonged recovery from mild traumatic brain injury or are unfortunate enough to have multiple concussions, the risks of continuing to participate in contact sports activity might outweigh the benefits from a medical perspective as well as from the athlete's and family's perspectives. Young athletes might have similar feelings when it comes to other injuries, such as anterior cruciate ligament (ACL) tears, that are associated with potentially difficult and prolonged recovery processes.

Retirement from sports. There is no evidence-based guideline regarding retirement of a young athlete who has fully recovered from previous concussions. Consideration should be placed on how concussions impact academics, social life, emotional well-being, and normal daily functioning. It is important to discuss the types of sports the child participates in and which sports put him or her at higher risk for sustaining a concussion. At the high school level, football, ice hockey, and lacrosse are among the highest-risk sports for boys, while soccer, lacrosse, and basketball are the highest-risk sports for girls [33]. The decision to remove a young athlete from high-risk activities for a period of time or to retire him or her from contact or collision sports is individualized and should be made collaboratively by a physician experienced in concussion management, the athlete, and the family. In our sports concussion program at Children's Hospital of Wisconsin, we have found that some children and families welcome these discussions and were already thinking about retirement from contact sports but were waiting for the physician to open the discussion. Having these open discussions can also be beneficial in cases in which the athlete and the family, or different family members, might be misinformed about concussion or have differing opinions regarding continued participation in contact sports. Ultimately, the goal is to work together to make the best decision possible for the young athlete based on the available medical information as well as the desires and concerns of the athlete and the family.

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MEDICINE AND SOCIETY

Transcending the Tragedy Discourse of Dementia: An Ethical Imperative for Promoting Selfhood, Meaningful Relationships, and Well-Being

Peter Reed, PhD, MPH, Jennifer Carson, PhD, and Zebbedia Gibb, PhD

Abstract

Supporting people living with dementia in maintaining selfhood, relationships, and well-being requires seeing beyond the common negative focus on disability. Furthermore, prioritizing the person rather than the disease requires rejecting the tragedy discourse, which is the negative lens through which dementia is typically considered. In this paper, we highlight qualitative research on dementia involving people living with dementia as active participants. Recognizing that many people living with dementia remain capable of making decisions that affect their lives, we highlight a research-based approach to support known as “authentic partnerships” that includes people living with dementia as equal partners. We conclude by proposing eight beliefs to mobilize positive change in transcending the tragedy discourse of dementia, thereby opening a space for selfhood, relationships, and well-being.

Introduction

With an estimated 5.4 million people living with Alzheimer’s disease in the United States [1] and almost 50 million worldwide [2], an essential question is the extent to which our society, communities, and health care professionals support people in living well with dementia, rather than focusing exclusively on *managing or treating* a disease. It is the authors’ contention that the dominant view of dementia is grounded in a “tragedy discourse,” which emphasizes the loss of both ability and identity [3, 4], and that this view directly harms people living with dementia above and beyond the effects of the pathology of any disease. In this paper, we first show that the negative impact of the tragedy discourse can be readily understood by listening to people living with dementia talk about their experiences and by considering how they are commonly characterized in the public sphere. We then show that care partners can promote well-being through including and engaging persons living with dementia in decision making. However, we contend that the dominant frame for understanding dementia, the tragedy discourse, promotes stigma and is used as an inappropriate justification for denying persons with dementia opportunities for autonomy and [engagement](#), thus threatening their well-being.

Perspectives of People Living with Dementia

In 2007 and 2008, the lead author on this paper (PR), on behalf of the Alzheimer's Association National Office, led a series of town hall meetings designed to listen to, and directly engage with, people diagnosed with dementia. The methods and full results of these listening sessions were reported by the Alzheimer's Association in its publication, *Voices of Alzheimer's Disease* [5]. In the town hall meetings across the US, along with a virtual town hall opportunity online, a total of 301 people living with dementia offered stories of their personal experiences. Each town hall meeting included the same structured discussion questions, inquiring about experiences across the following eight topics: (1) diagnosis, (2) available treatments and medicines, (3) participation in research, (4) loss of independence and coping with changes in function, (5) changes in roles and relationships (personal and professional), (6) safety issues (e.g., driving, so-called "wandering," and home safety), (7) care and support services, and (8) meaningful activities and social opportunities.

Throughout the town hall meetings, there was surprisingly little discussion of the impact of the disease on personal functioning or abilities. Rather, participants largely focused on poor interactions with physicians during and after the diagnosis process, as well as on the pernicious stigma of the disease and the immediate change in the way they were treated by others in their everyday life postdiagnosis [5]. In other words, participants perceived the social reaction of the medical community and society in general, including friends and family, to dementia as more damaging to their day-to-day well-being than the disease itself. The stigma of being diagnosed and the immediate implications for control and autonomy in everyday decisions (or lack thereof) were of primary concern. In addition, participants expressed the desire to make a difference by advocating for increased awareness of their condition and finding ways to enhance their own quality of life and that of others. Table 1 presents direct quotations from people living with dementia explaining the impact of the disease on their everyday life. The presence of a social impact of dementia beyond the condition's effects on physical and cognitive function was a resounding theme.

Table 1. Direct quotations from participants in the town hall meetings for people living with early-stage dementia [5]

<p>"When people say 'dementia' or 'Alzheimer's,' everybody thinks you're going to die" (p. 7).</p> <p>"My doctor just kind of let me go, because he was of the belief that there was no treatment. He just kind of cut me loose. 'You have dementia and there's nothing that can be done. It's a progressive illness. Goodbye'" (p. 12).</p> <p>"There is a stigma that goes along with the disease. Many people are worried about sharing the fact openly" (p. 7).</p> <p>"People shy away ... like a reaction that might be associated with BO [body odor]" (p. 20).</p> <p>"When I came down with Alzheimer's, my friends weren't my friends anymore. They don't come to talk with me or just to be with me" (p. 21).</p> <p>"People didn't know how to talk to me even though I was the same person I was five minutes before I told them I had it. They just saw this big A on my forehead. They didn't look at me as the same person—I was stupid, or couldn't carry a conversation, or have a single thought of my own, which was very distressing to me" (p. 21).</p> <p>"Something that's really important is to help people understand the level at which we want to be engaged. We still want to have social activities" (p. 24).</p> <p>"We can do all sorts of things until our voices fail us, and then the people who are coming behind us will continue to speak for us" (p. 27).</p> <p>"Just speak out, because if we don't speak out now... nobody is going to speak for us later in life" (p. 27).</p>
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Understanding the Tragedy Discourse of Dementia

The ubiquity of negative characterizations of dementia is not unique to the United States but readily evident in a variety of media and research from around the world. Studies demonstrate that the most common portrayals of people living with dementia center on the difficulties and challenges of living with memory loss, which are often represented in an exclusively negative light [3]. One study that analyzed 350 articles in British newspapers, coupled with individual interviews with care partners of people living with dementia, found frequent use of hyperbolic language that catastrophizes the condition, including language such as "tsunami" or "worse than death" [6]. In a separate analysis of the popular images of dementia in Belgian newspapers, movies, documentaries, literature, and health care communications, Van Gorp and Vercruysse [7] note that the dominant frame promotes the belief that people living with dementia have completely lost their identity. These portrayals of dementia highlight the perceived tragedy of the condition and, as noted, constitute the common lens through which dementia is viewed and discussed by both professionals and the public. Hence we contend that the primary

view of dementia is one embedded in a tragedy discourse that serves to further stigmatize people living with dementia and to position them as something less than full members of our community due to their (mis-)perceived limitations.

The implications of the tragedy discourse are profound, with potentially negative impacts on people living with dementia across multiple dementia support contexts [8]. We contend that the standards of care for people living with dementia are essentially paternalistic in all settings of service, including community-based services such as support groups, education programs, and information and referral; home care; long-term care settings; and acute care for nondementia conditions of people living with dementia (both inpatient and outpatient). This negative lens is, as we have seen, also internalized by people living with dementia. To ascribe differences based solely on the diagnosis of dementia is what Ronch describes as “dementia-ism” [9], a form of both explicit and implicit bias against people living with dementia that serves to discriminate against them in everyday life (and in all health care settings).

How we view a person or group of people influences how we treat them, which might enable or constrain opportunities for a full and enriching life. In this light, why do some advocacy organizations that exist primarily to serve people living with dementia persist in the promotion of negative stereotypes and images, which further stigmatize people living with dementia as an unintended consequence? As Christine Bryden, an author and advocate who is living with dementia explains, “This stereotype tugs at the heartstrings and loosens the purse strings, so [it] is used in seeking funds for research, support and services. It’s a Catch 22, because [organizations] promote our image as non-persons and make the stigma worse” [10]. Yet tragedy and fear are not needed to raise awareness of dementia, as evidenced by Devlin, MacAskill, and Stead’s study [11], which highlights the need for images of dementia that portray the genuine experience of those living with the disease while steering clear of the use of fear in sensationalized messages.

Characterizations of people living with dementia that diminish their value and potential for self-determination—derived from the tragedy discourse—not only misrepresent the complexities of life with dementia but also serve to compromise fundamental principles of bioethics. While we argue that the impact of the tragedy discourse has implications for each of the four well-known moral principles for bioethics put forward by Beauchamp and Childress [12], the most obvious ethical dilemma relates to restricting personal autonomy. A diagnosis of dementia leads clinicians, family, friends, and the community to take a negative view of the capabilities for decision making and independence of people living with dementia [5]. In our experience working with people living with dementia, we have observed a general assumption being made by the public and professionals that the [decision-making capacity](#) of people living with dementia is greatly compromised [13], which might or might not be valid. However, the result of this assumption is a “prescription” for surrogate decision making, or diminished autonomy, in

daily life. We believe that autonomy is a basic fundamental right and critical element of a human's internalized well-being and that it never leaves a person, even if a person faces challenges in expressing it due to dementia. It is the responsibility of clinicians, care partners, and family members to provide the support necessary to ensure that decisions are made in a manner that is aligned with the preferences of a person living with dementia and that the person has the opportunity to contribute to those decisions to the greatest extent possible, even if he or she is severely disabled.

It is our view that a more supportive approach would strive to understand the capabilities of a person diagnosed with dementia through a person-centered assessment that does not include blanket assumptions about his or her limitations, but rather focuses on the person and his or her *retained* abilities. This more individualized approach could better serve to promote and support the autonomy of persons living with dementia, enabling them to live well despite their diagnosis and maintaining their right to self-determination and autonomy in everyday decisions.

A Positive Approach to Inclusion

Internationally, reports published by organizations and initiatives, including Alzheimer's Disease International [14], Dementia Alliance International [15], Partnerships in Dementia Care Alliance [16], and AARP® (formerly the American Association of Retired Persons) [17], demonstrate a growing movement calling for more social and relational understandings of dementia and the transformation of communities to better support people in maintaining well-being, including exercising autonomy to the greatest extent possible. Research demonstrates that people living with dementia retain their selfhood, despite the common assumption that a person's identity is lost in the presence of cognitive changes [18].

The recognition and acceptance of a persistent sense of self among people living with dementia has implications for the approaches of clinicians and other care partners, including those in long-term care communities, in that it can promote patient- or [person-centered care](#) (PCC) [19, 20], which is an important goal of modern medicine. In 2001, a report issued by the Institute of Medicine (now the National Academy of Medicine) included PCC as one of the six essential aims of modern health care [21]. This approach typically calls for the inclusion of the person in all key health care decisions, especially when there is uncertainty regarding effective approaches to care [21]. Despite this emphasis, elders remain less likely to be actively engaged in their own health care [22]. This lack of engagement in decision making is further complicated when a person is living with dementia [23].

However, effective approaches exist to support people living with dementia in being recognized for who they remain as people and to actively engage them in mutually beneficial caring relationships. First, recognizing that identity and selfhood occur in the

social context of relationships, researchers have taken PCC a step further to recommend a reciprocal approach to supporting people living with dementia, known as “relationship-centered care” [24]. A basic tenant of this approach is that optimal care and support can only be achieved when all parties involved in the context of care (i.e., the person living with dementia and his or her family and professional care partners) experience a sense of security, continuity, belonging, purpose, achievement, and significance, which provides a framework for relationship-centered care known as the “Senses Framework” [25]. The increased engagement of people living with dementia could extend beyond the health care context through public acceptance of their retained selfhood and the accompanying opportunity for people living with dementia to continue asserting their individual rights, autonomy, and citizenship (i.e., civic and community engagement) [26].

Recognizing a person’s selfhood within the context of decision making is not necessarily synonymous with his or her *active* engagement, hence the call for “care partnerships,” in which decision making is collaboratively supported to the highest extent possible [27]. Responding to this call, researchers from the University of Waterloo [28] worked in partnership with persons living with dementia to better understand what it takes to work in authentic partnerships across the continuum of dementia care and support. As stated by Dupuis et al. [29], “An ‘authentic partnership’ actively incorporates and values diverse perspectives and includes *all* key stakeholder voices directly (including [those of] people living with dementia) in decision-making. It involves working *with* others, not *for* others.” Drawing on their own partnership experiences and interviews with persons living with dementia and their care partners, they identified three guiding principles and five enablers (see figure 1) that, when supported, help care partners promote empowerment and equality and build collective capacity for shared decision making and social change. The authentic partnerships approach encourages regular collaborative reflection on the principles and enablers of authentic partnerships throughout the partnership process.



Figure 1. A model of authentic partnerships. From Dupuis SL, Gillies J, Carson J, Whyte C, Genoe R, Loiselle L, Sadler L. Moving beyond patient and client approaches: mobilizing "authentic partnerships" in dementia care, support and services. *Dementia (London)*. 2012;11(4):427-452. Copyright © 2012 by The Author(s). Reprinted by permission of Sage Publications, Ltd.

When care partners work in partnership with persons living with dementia, they do more than just protect personhood; they mobilize social citizenship (meaning preserving the same civic and social rights and opportunities afforded to all citizens) by supporting people living with dementia in making contributions to civic dialogue and activities, and thus new possibilities emerge for living well [27].

Transcending the Tragedy Discourse

To conclude this discussion of the social and health care importance of embracing people living with dementia as valid, autonomous, and engaged partners, we offer eight fundamental beliefs (or principles) to help mobilize opportunities to transcend the tragedy discourse. These "mobilizing beliefs" are not intended as instructions for health care professionals but rather as a type of ethical roadmap for restoring fundamental rights, autonomy, and humanity to people living with dementia who have been disenfranchised by a prevalent view that discounts and diminishes their value and potential contributions. The tragedy discourse not only hinders the potential roles and

opportunities of people living with dementia in our communities but also determines the quality of care they receive from health care professionals. Each mobilizing belief is positively framed and offers an aspiration for achieving an alternate lens through which to understand the experience of living with dementia as well as to shape the mindset and actions of professionals and communities (see table 2). Transcending the dominant tragedy discourse of dementia will contribute to an understanding of dementia that is more aligned with respect, dignity, and social justice and in turn will serve to enhance the well-being of the millions of people living with cognitive changes.

Table 2. Eight mobilizing beliefs for transcending the tragedy discourse

<ol style="list-style-type: none"> 1. People are <i>living</i> with dementia. 2. Understanding the experience of living with dementia requires understanding the whole person. 3. Focusing on the whole person offers the opportunity to retain identity and assert autonomy and thus supports fundamental human rights. 4. People living with dementia continue to grow and thrive as individuals when care partners avoid the tendency to medicalize, sterilize, and surveil all aspects of everyday life. 5. People living with dementia are the genuine experts in the experience of dementia; their perspectives, wishes, and preferences should always be respected. 6. People living with dementia can and do communicate and express themselves meaningfully. 7. Truly engaging with each person living with dementia as a legitimate contributor to his or her own experience opens a discourse of possibilities. 8. Supporting engagement, autonomy, and partnership with people living with dementia will promote improvements to their quality of life and well-being.
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MEDICINE AND SOCIETY

Arts Participation: Counterbalancing Forces to the Social Stigma of a Dementia Diagnosis

Beth Bienvenu, PhD, and Gay Hanna, PhD, MFA

Abstract

A diagnosis of dementia profoundly impacts a person in terms of both the functional progression of the disease and the social stigma associated with the diagnosis. A growing body of research demonstrates the effectiveness of innovative programs such as the Alzheimer's Poetry Project, Meet Me at MoMA, and TimeSlips™ in counterbalancing social stigma by building a social and emotional framework for strength-based living for people diagnosed with dementia through arts participation. These programs focus on supporting autonomy and generativity through creative expression to help sustain the social, emotional, and community fabric of people's lives in the face of significant counterbalancing forces (e.g., the disease itself, stigma, and institution-centered approaches to care).

Introduction

The poem springs from the half-spoken words of such patients as the physician sees from day to day.... This, in the end, comes perhaps to be the occupation of the physician after a lifetime of careful listening.

William Carlos Williams [1]

A diagnosis of dementia profoundly impacts a person in terms of both the functional progression of the disease and the social stigma associated with the diagnosis. People become more isolated as the stigma intensifies and often lose any kind of social and emotional framework for strength-based living that focuses on attributes such as hope and capacity for loving relationships [2, 3]. There is a growing body of research demonstrating the effectiveness of [arts participation](#) in both breaking down isolation and reducing social stigma associated with the diagnosis of dementia [4-6]. William Carlos Williams, in the quotation above and in a previous passage explains:

We begin to see that the underlying meaning of all they want to tell us and have always failed to communicate is the poem, the poem which their lives are being lived to realize.... It is actually there, in the life before us, every minute that we are listening.... It is that essence which is hidden

in the very words which are going in at our ears and from which we must recover underlying meaning as realistically as we recover metal out of ore [7].

Innovative arts programs such as the Alzheimer's Poetry Project, Meet Me at MoMA (Museum of Modern Art), and TimeSlips™ have been designed to engage people with memory loss and their caregivers and to recover their lives' underlying meaning through [person-centered care](#). Now being replicated across the country, these evidence-based programs demonstrate that arts participation can connect or reconnect persons with dementia by improving communications, increasing social engagement, and reducing agitation. For example, Philips, Reid-Arndt, and Pak [8] demonstrated that a TimeSlips storytelling intervention increased pleasure and improved communication skills for people with dementia at one-week post-intervention. Other studies have demonstrated the effectiveness of TimeSlips interventions in substantially improving caregiver attitudes towards people with dementia, including those of medical students [9, 10]. Similarly, a study of Meet Me at MoMA interventions found statistically significant and substantial visible mood changes in both the caregiver group and the people with dementia [11]. Moreover, in the same study, people with dementia reported enhanced self-esteem, and caregivers appreciated seeing their family members treated with respect and being able to engage with them in a gracious and beautiful environment [11].

Let us take a closer look at these three evidenced-based programs and examine what makes them successful.

Three Innovative Arts Programs Designed to Engage People with Dementia and Their Caregivers

The Alzheimer's Poetry Project [12], founded by the poet Gary Glazner, trains caregivers worldwide to use poetry as a tool to spark imagination. The project includes special programs, such as memory cafés, which are a series of free arts events for people living with Alzheimer's disease or dementia, their caregivers, family members, and the general public [13]. Glazner also founded Poetry for Life [14], an intergenerational program that builds on the successful Poetry Out Loud school-based poetry recitation competition run by the National Endowment for the Arts [15]. Poetry for Life brings together high school students and people living with Alzheimer's or dementia to enjoy reciting poetry together [14], an activity that reinforces each other's value (see figure 1).



Figure 1. Poetry for Life with Brooklyn Technical High School students at New York Memory Center. Photo: Gary Glazner.

Meet Me at MoMA is a museum-based program of the MoMA Alzheimer's Project within the Museum of Modern Art (MoMA) in New York City [16]. Developed by MoMA's education department, this innovative program takes advantage of the museum's quiet times to bring together trained museum educators and people with dementia and their caregivers to explore great works of art, such as Vincent van Gogh's *Starry Night*, from their collection. Participants engage with their imaginations in a limitless world, interpreting what the art means to them in that moment. Observers might not be able to distinguish between the caregivers and their care partners, as all are engaged in meaningful conversations about each piece of artwork presented (see figure 2). MoMA also developed evidence-based training modules to disseminate this model to museums across the country [17].



Figure 2. Photograph of the Meet Me at MoMA program. Copyright © 2017 The Museum of Modern Art, New York. Photo: Jason Brownrigg.

TimeSlips, founded by MacArthur Fellow Anne Basting, is a creative project that engages groups of people with dementia through storytelling [18]. Online training information enables caregivers to support meaningful exchanges. Each group session is led by a TimeSlips facilitator, who leads the group as it explores a large photograph featuring images intended to encourage storytelling, such as a black and white photo of a baby in a leather handbag, a photo of a person holding a large frog, or a photo of people playing in the rain. As the participants comment on their observations about the photo, a second person documents the remarks and, together with the facilitator, they create a story about the photo. Imagination rules and memories are sparked. No comments made by the participants are excluded. Caregivers and care partners laugh and enjoy the moments of interaction, each beyond the grasp of the progressing disease. Stories can then be submitted to the TimeSlips website, which is building an online community of people with dementia and their caregivers [19]. TimeSlips has made a profound change in person-centered care for people with dementia, expressing respect for their dignity by including their contributions and stories and offering opportunities for them to share their life experiences in ways that honor and accept their present selves without comparison to their prior selves.

What Makes These Programs Successful?

What are the elements of these and other similar arts programs that make them successful and how can facilitators implement them? Although each program engages different arts forms, all have common elements in how they engage people with dementia. Here are several key elements:

- *Introductions.* Every session leader should start by taking time to welcome participants. Saying “hello” to each person and making eye contact are important ways to start the group activity. Introducing both yourself and the activity gives the program a respectful and clear start.
- *Program participation.* Set high expectations for engagement and be prepared to improvise the plan for the activity in order to reach each participant. Accept all contributions and integrate participants’ experiences into a whole using the “yes, and” approach, which accepts each person’s response (“yes”) and adds it to the story being created or told (“and”), rather than offering a negative or corrective response.
- *Program content.* Commit to presenting high-quality arts experiences that are age-appropriate. Although people with dementia lose their cognitive abilities as this disease progresses, activities should be maintained that engage older adult learners by treating their life experience with respect. In our experience, the power of [creative expression](#) is that it lifts people with dementia out of isolation.
- *Environment.* Secure space conducive to engagement. Keep visual and auditory distractions to a minimum so that participants can easily see the facilitator and the art form presented, and so they can hear instructions and others’ responses in the room.
- *Closure.* Every program should end with a celebration of what was accomplished together, such as the sharing of a group poem or story or key discussion points about a piece of visual art. Thanking and saying “goodbye” to each participant, with eye contact and appropriate physical touch, is important.

An Example from a TimeSlips Session

To anchor these concepts, consider this example of storytelling witnessed by one of the authors (GH). It focuses on an art program participant in a TimeSlips activity at a skilled nursing long-term care facility. Let’s call her Carla.

When the nursing assistant rolled Carla into the already-gathered circle of long-term care participants, there were groans and sighs of frustration heard all around. Carla tended to respond to every situation by uncontrollably laughing at everyone and everything, frustrating the other residents. The TimeSlips facilitator introduced herself and then greeted everyone, making eye contact with each participant, including Carla. The facilitator started the program by bringing out a large photograph of a polar bear

with eyeglasses looking towards an open newspaper sprawled out on a sheet of ice surrounded by snow (see figure 3), while the recorder wrote down comments from the participants. The facilitator asked the participants what they thought the bear was doing and why he was there. The answers, comments, and laughter started to whirl around as the participants became engaged in the discussion and the story developed: "He has been dancing and fell down," "His wife just left him and he is sad." All the while, Carla continued to laugh. The facilitator included Carla's laughter in the story as it evolved, saying "and Carla laughed." Soon Carla's laughing quieted as she too became engaged in developing the story with comments instead of laughter. The other participants in the group began to respond to her with respect instead of frustration. By the end of the hour, everyone was fully engaged in imagining a story around this big white bear. The participants seemed to enjoy the process, and the storytelling gave the community assembled on the ward a feeling of belonging and contributing. Carla later told the session recorder that she laughs at things she can't control. The creative process, engagement with others, and guidance from the facilitator provided Carla with a measure of control, respite, and a feeling of inclusion. It offered her a meaningful experience that reduced the stigma of her specific condition among her fellow residents.



Figure 3. Polar bear Father's Day greeting card. Copyright © Avantipress.com.

Transferring Group Facilitator Skills to Clinical Practice

How can the lessons learned from the TimeSlips group contribute to your clinical practice in caring for people with dementia? First and foremost, respect and accept each person

with dementia in the moment of his or her experience with the activity. Try to give positive responses and move the interaction forward, while listening and responding with not only high expectations for participation but also imagination and humor. Verbal critical judgments and corrections have no place in interactions with persons who have dementia. It is crucial that you recognize that the person is still there with you even though the memories and abilities to communicate are fading. Listening and improvising is an important art form in caring for people with dementia. Clinicians might find it helpful to consult the National Center for Creative Aging's online "Creative Caregiving Guide," which features the three aforementioned innovative programs as well as several other programs that utilize music, visual arts, and dance [20].

In conclusion, arts participation in well-designed, person-centered programs that encourage imagination and creativity to be expressed freely can bring joy and counterbalance the stigma of the diagnosis and the progression of the disease [21]. A newly diagnosed Alzheimer's patient said after participating in the TimeSlips program, "*The revelation that I can't remember but I CAN imagine blessed my mind, heart, and soul*" [19], which illustrates the power of imagination and creativity to bring comfort and break down isolation and to cultivate opportunities for self-expression with dignity and respect. Can these benefits of high-quality interaction be achieved throughout the continuum of caregiving? William Carlos Williams seemed to think so.

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HISTORY OF MEDICINE

Framing Confusion: Dementia, Society, and History

Jesse F. Ballenger, PhD, MA

Abstract

This essay will briefly sketch historical changes in the framing of dementia since the late nineteenth century. In broad terms, this period has seen a shift from viewing dementia as a pathological variant of normal aging to viewing it as a distinct disease. Although this broad reframing of dementia was clearly positive in raising awareness and funding for research, it had some negative aspects that should be considered. Caregiving came to seem less important than research aimed at a cure, and the stigma surrounding dementia has, if anything, increased.

Introduction

In his influential article on the social and cultural framing of disease, historian Charles E. Rosenberg argued, "In some ways disease does not exist until we have agreed that it does, by perceiving, naming and responding to it" [1]. Rosenberg was not denying the biological reality of disease but making the case for a historically rigorous perspective that also understands disease as a verbal construct reflecting medicine's intellectual and institutional history. Viewed in this light, disease is also a mediating structure in doctor-patient interactions, an aspect of individual identity and ascribed social role, a focal point for expressing cultural values, and an occasion and arena for public policy debate. Rosenberg's metaphor of a cultural "frame" concisely captures the complex processes involved in how a society defines and deals with a disease. Dementia seems an example of this process par excellence. Everything we know about the natural history of age-associated progressive dementia suggests that it has always been part of human experience, but only since the early twentieth century has dementia been regarded as the product of a disease, and only in the last half of the twentieth century has it been regarded as a major public health issue. This broad reframing of dementia was the result not merely of changing medical concepts but of a broader social transformation of aging.

Framing Dementia as a Brain Disease in Early Twentieth-Century German Psychiatry

In the mid-nineteenth century, psychiatry in Europe and America was seen by many as falling behind other branches of clinical medicine that were rapidly progressing in their ability to define the pathogenesis and etiology of discrete disease entities through pathological and eventually bacteriological research [2]. The discovery by German

psychiatrists in 1857 that general paresis, one of the most common forms of what was then called insanity, was connected to syphilitic infection raised new hopes that clinical-pathological correlations would lead to etiological theories and ultimately therapeutic interventions for other forms of mental illness [3].

In the first decade of the twentieth century, the German psychiatrists Emil Kraepelin and Alois Alzheimer were interested in making dementia the second major mental disorder for which a clear pathological basis had been established. In 1906, Alzheimer presented a brief paper on the case of a 51-year-old woman who developed progressive dementia that, despite her young age, seemed to be identical to senile dementia. In 1910, on the basis of this case and a handful more published by Alzheimer and others, Alzheimer's mentor Emil Kraepelin created the category of Alzheimer's disease in the eighth edition of his influential textbook to distinguish early-onset "presenile" cases occurring before age 65 from the much more common senile dementia occurring at later ages [4].

Subsequent researchers have advanced several different theories about why Kraepelin created this new entity [5]. But what seems clear is that he did not think it made sense to call a condition strongly associated with aging a disease. The pathological processes of deterioration in old age that produced senile dementia were understood to be on the extreme end of "normal," while dementia occurring at earlier ages, as in the case Alzheimer presented, even though ostensibly associated with the same brain pathology and clinical symptoms, seemed to suggest some kind of disease process [5].

Kraepelin's evident reluctance to view age-associated deterioration as a disease helps explain what, from our vantage point today, seems most surprising about the early history of Alzheimer's disease—that it seemed so insignificant to Alzheimer, Kraepelin, and their contemporaries. Alzheimer's initial report drew no enthusiastic reaction from the audience of psychiatrists who heard him give it, nor did its publication in 1907 draw any significant attention [6], and Kraepelin himself devoted only a few pages of a massive textbook to it. After Alzheimer's death in 1915, almost none of the many tributes to him written by his colleagues even mentioned the disease that was named for him [6]. Alzheimer's disease did not seem significant to Alzheimer, Kraepelin, and their contemporaries because they were interested in mental disorders for which a clear pathological basis could be established. Although the pathological basis of dementia was clear, because it could not be disentangled from aging it seemed hard to regard it as a disease. Carving out "Alzheimer's" as a separate disease was helpful, but the condition was too rare to be considered a major breakthrough for psychiatry [5].

Framing Dementia as a Problem in the Adjustment to Aging in the Mid-Twentieth Century

Around the same time as Alzheimer and Kraepelin were researching the neuropathological basis of dementia in Germany, psychiatrists in the United States were

beginning to experience dementia as a growing problem that threatened to overwhelm the state mental hospital system that was the institutional heart of their profession. An unintended result of the creation by state governments of state-funded hospitals through the mid-nineteenth century was that local welfare officials were given a strong financial incentive to classify old people with dementia who could no longer live independently in the community as insane so that they would be institutionalized in the state mental hospitals at the expense of state governments. As a result, beginning in the late nineteenth century and increasingly through the 1950s, aged patients with dementia were becoming one of the most prominent segments of the patient population. Since dementia was regarded as hopelessly incurable, the state hospitals were in danger of being regarded as custodial institutions rather than centers of active treatment [7].

From mid-1930s through the 1950s, a number of American psychiatrists led by David Rothschild responded to the challenge of dementia in the state hospitals by framing dementia as a psychosocial problem rather than a brain disease [8, 9]. Rothschild and his followers argued that the observation of inconsistent correlations between clinical manifestations of dementia and pathological findings could best be accounted for by people's differing ability to compensate for brain damage. Seen this way, age-associated dementia was more than the simple and inevitable outcome of a brain that was deteriorating due to aging and/or disease. It was the interaction between the brain and the psychosocial context in which the aging person was situated. For psychodynamically oriented American psychiatrists, this approach was a more satisfying theory of dementia because it explained the variability often found between the degree of brain pathology found at autopsy and the degree of dementia that had been observed clinically, and it provided a logical basis for trying [therapeutic interventions](#) and preventive strategies [8].

The theory also proved influential beyond psychiatry. To practitioners in the emerging field of social gerontology, the high prevalence of senile mental deterioration as construed by psychiatrists like Rothschild served as an indictment of society's failure to meet the needs of the elderly. The "adjustment" of the individual to the social demands of aging was the key concept for social gerontologists in the 1940s and 1950s [8]. Failure to adjust resulted in senile mental deterioration, but if [policies and programs](#) could be created to keep the increasing numbers of elderly people active and engaged, their mental abilities and independent functioning could be maintained much longer. The community's responsibility for this went beyond altruism, for if the needs of the burgeoning aging population were not met, the result would be a catastrophic increase in senility. As Jerome Kaplan, an advocate for social programs for the elderly, argued in 1953, "with the number of people who are over 65 increasing significantly each year, our society is today finding itself faced with the problem of keeping a large share of its population from joining the living dead—those whose minds are allowed to die before their bodies do" [10].

The framing of dementia as a psychosocial problem was thus a fundamental part of the case aging advocates made for a series of policy changes, such as the creation of the Medicare program [11] and the Older Americans Act of 1965 [12], that helped to transform the experience of aging in America. By the 1970s, many of their goals had been achieved: the economic status of the elderly as a group had been improved, important protections had been won against age discrimination, and negative stereotypes about old age were challenged [13]. In this context, the problem of age-associated dementia became more visible and [tragic](#) because people began to enter old age with a higher set of expectations for remaining active and involved in social life, setting the stage for another dramatic reframing of dementia.

Framing Dementia as a Dread Disease and Major Public Health Crisis in an Aging World

Dementia emerged as a major public issue in the late 1970s through the efforts of a coalition of caregivers and family members struggling to deal with dementia in the context of new expectations for aging, researchers in the neurosciences influenced by the biological revolution in psychiatry, and government officials trying to win funding for research on aging and age-associated conditions. Central to the coalition's strategy was advancing the claim that age-associated dementia should be viewed as the result of disease rather than aging, as part of a more general claim advanced within gerontology and geriatrics that aging itself should not normally be accompanied by disease and disability [5]. Neurologist Robert Katzman was perhaps the most prominent exponent of this claim, arguing in an influential 1976 article that the distinction between what was then called Alzheimer's presenile dementia and senile dementia ought to be dropped and that the unified entity should be called Alzheimer's disease [14].

Combining the categories meant that the problem was large, and with the aging of the baby-boomer generation, it would soon become enormous. Calling the unified category "Alzheimer's" framed it as a specific disease entity with a well-established pathological basis in the brain. Campaigns organized around this reframing of dementia were highly successful. By 1980, Alzheimer's had become a household word and the object of a massive federally funded research initiative [5]. But there were unintended consequences that undermined two other stated goals of Alzheimer's advocates—increasing support for caregivers and lessening the stigma of dementia [5]. To make a compelling case for funding biomedical research aimed at treatment and prevention, advocates always implicitly and sometimes explicitly trafficked in what critics called "apocalyptic demography" [15], arguing that finding an effective treatment or cure was the only way to avoid an avalanche of dementia cases associated with the aging of the baby boomer generation that would overwhelm the health care system [16]. Public policy in the United States largely followed this logic, with the result that while money for biomedical research dramatically increased, relatively little was invested in providing specific supports for caregivers or developing creative approaches to improving the

quality of care for people with dementia [5]. Similarly, in order to make the case that Alzheimer's causes great suffering, advocates represented the losses associated with dementia as so total and irrevocable as to call into question whether people suffering from it could still properly be regarded as people at all, thus greatly deepening the stigmatization of those diagnosed with it and intensifying the anxiety people felt about aging itself [16].

Conclusion

A number of recent developments suggest that a reframing of dementia is underway. A string of highly publicized clinical trial failures of drugs for treating Alzheimer's disease has led critics to question whether research is pursuing a dead end [17], although the pharmaceutical strategy of targeting the beta-amyloid protein that has dominated research for three decades certainly still has strong defenders [18]. Basic research continues to fragment the concept of Alzheimer's disease into subtypes [19], and the nonAlzheimer's dementias have begun to receive more attention [20]. Meanwhile, perhaps the biggest story of the past decade in the dementia field is the surprising finding that the rate of dementia in the United States declined from 11.6 percent to 8.8 percent between 2000 and 2012 [21]. Although the factors behind this phenomenon still must be established, some researchers argue that falling dementia rates are attributable to aging Americans' better control of risk factors and higher average educational level [22, 23]. Finally, in reaction to these kinds of developments, scholars across academic disciplines increasingly have called for a more integrative approach to dementia care that would bring biomedicine into dialogue with public health, social science, bioethics, and the medical humanities [24]; and the policy response in the United States and other countries has broadened to emphasize not just biomedical research but social support and inclusion through the concept of dementia-friendly physical and social environments [25].

It is too soon to precisely define the reframing of dementia that is underway, but it seems clear that the individual and collective experience of people living with dementia and caring for people living with dementia is challenging the conceptual framework that brought attention to dementia as a major public issue.

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IMAGES OF HEALING AND LEARNING

Damnum versus Quaestus

Artwork and captions by Louise O'Boyle, MA

Abstract

Not only is bioethics fundamental to determining or guiding how we live and die, its role as the key interconnecting strand between various disciplines, the public, and decision makers is unique. The works featured here are from a collection entitled "Damnum versus Quaestus" (loss versus gain). They are informed by the lived experience of being with someone (described here as "the patient") as he or she lives through the process of dying.

Judas Kiss II

[Click here to view the video](#)

Media

The soundtrack is a collage of recordings made of a moth as it circled a lamp in my studio.

Caption

Judas Kiss II is a short film intended to capture the terminally ill patient's experience of fear, admiration, pain, life, repulsion, doubt, betrayal, hope, truth, falseness, death, order, cyclicity. The film evokes the myriad emotions and feelings experienced by the terminally ill patient, including confusion, pain, doubt, and suspicion about what is happening to him or her in the hospital—the patient's overwhelming feelings are of being part of an unstoppable tsunami at the end of life and fear about what comes after. This is reflected in the cyclical nature of the imagery and the aching and uncomfortable soundtrack.



Figure 1. *Series Three 06:16:02*, by Louise O'Boyle

Media

Mixed-media sculpture: porcelain, gold luster, polished concrete, resin, wax, soil, medical tubing, human hair, latex, linen, and thread.

Caption

This artwork explores the use/reuse and ownership of material taken from the human body that manifests the patient's experience in sculptural form. It is inspired by lockets worn as jewelry; these miniature vessels can contain for their wearer much more than their physical size would suggest.



Figure 2. *Series One 06:16:03*, by Louise O'Boyle



Figure 3. *Series One 06:16:03*, by Louise O'Boyle

Media

Mixed-media sculpture: porcelain, gold luster, polished concrete, resin, wax, soil, human hair, medical tubing, latex, linen, and thread.

Caption

This artwork explores the patient's experience of disassociation from his or her physical body in sculptural form.



Figure 4. *Series Four 06:16:02*, by Louise O'Boyle



Figure 5. *Series Four 06:16:02*, by Louise O'Boyle



Figure 6. *Series Four 06:16:02*, by Louise O'Boyle

Media

Mixed-media sculpture: porcelain, gold luster, polished concrete, resin, wax, soil, human hair, medical tubing, latex, linen, and thread.

Caption

This artwork physically manifests the patient's experience of being at the end of life.

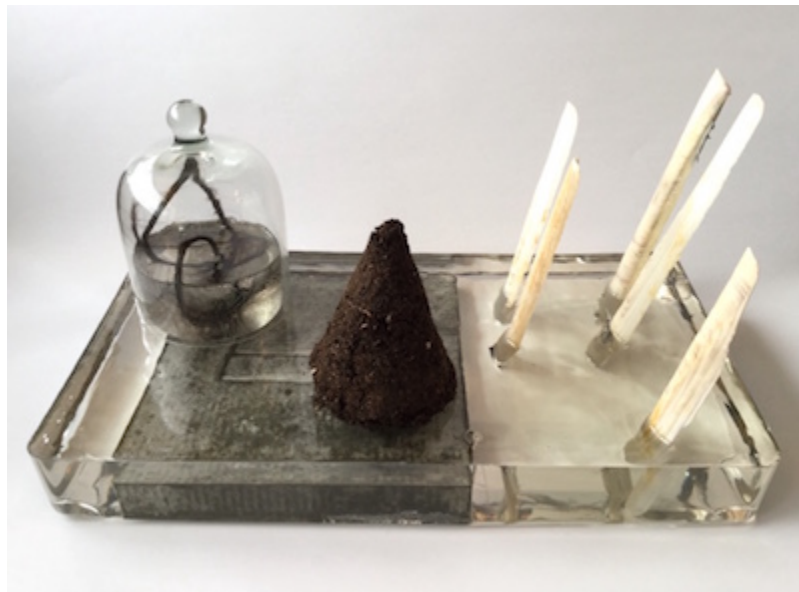


Figure 7. *Series Three 06:16:01*, by Louise O'Boyle



Figure 8. *Series Three 06:16:01*, by Louise O'Boyle



Figure 9. *Series Three 06:16:01*, by Louise O'Boyle

Media

Mixed-media sculpture: glass cloche, soil, resin, and razor shells.

Caption

This artwork depicts the patient's feeling of suspension in time and physical and emotional fragility as he or she nears the end of life.



Figure 10. *Series Four 06:16:03*, by Louise O'Boyle



Figure 11. *Series Four 06:16:03*, by Louise O'Boyle



Figure 12. *Series Four 06:16:03*, by Louise O'Boyle

Media

Mixed-media sculpture: medical tubing, razor shells, polished concrete, resin, leaves, cork, human hair, latex, linen, and thread.

Caption

This artwork explores the balance of interconnecting elements within and around the body—their connection to medical treatments and the physical manifestation of the patient's experience in sculptural form.



Figure 13. *Series Two 06:16:01*, by Louise O'Boyle



Figure 14. *Series Two 06:16:01*, by Louise O'Boyle

Media

Mixed-media sculpture: medical tubing, metal chains, polished concrete, resin, leaves, cork, human hair, latex, linen, and thread.

Caption

This artwork manifests the patient's experience of accepting his or her imminent passing, peace, and desire to move into a new state.



Figure 15. *Series Two 06:16:02*, by Louise O'Boyle



Figure 16. *Series Two 06:16:02*, by Louise O'Boyle

Media

Mixed-media sculpture: medical tubing, metal chains, polished concrete, resin, leaves, cork, human hair, latex, linen, and thread.

Caption

This artwork explores the cyclical nature of living through dying as experienced by the patient.



Figure 17. *Series Three 06:16:03*, by Louise O'Boyle



Figure 18. *Series Three 06:16:03*, by Louise O'Boyle



Figure 19. *Series Three 06:16:03*, by Louise O'Boyle

Media

Mixed-media sculpture: glass cloche, soil, and resin.

Caption

This artwork manifests the patient's experience of reflection on and analysis of his or her past.

Louise O'Boyle, MA, is a lecturer in art and design in the Belfast School of Art at Ulster University in the UK. She earned an arts degree at Manchester Metropolitan University, a master's degree in applied arts at Ulster University, and is currently undertaking doctoral studies in education at Queens University. In tandem with her academic work, she is a practicing artist. Her artwork and research focus on the relationship between the arts, health, and well-being.

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