

Ethical and Social Issues in Dementia Care

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Bottenberg, F., & Dubljević, V. (2022). Ethical and Social Issues in Dementia Care, in Farrar, T., & Eifert, E. (Eds.): Introduction to Aging, Memory and Dementia for Healthcare and Human Service Professionals. Wiley-Blackwell.

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Abstract:

It is often assumed that “ethics” refers to a pre-established and settled set of professional guidelines or even a “philosophy of life” that outlines a list of values to live by. In fact, ethics refers just as much to the challenging work of thinking about, and with, those sets of guidelines and values. After all, ethical principles don’t just appear in the world—they are the result of people talking about them, refining them, and then codifying them. More than that, every situation we encounter requires us to weigh different ethical principles as we decide what to do. This applies especially in situations where ethical dilemmas are present— situations where we must choose among imperfect options, there being no obvious “win-win” solution. In working with people with dementia, this process of ethical deliberation can become very challenging indeed, given the many personal, social, and logistical variables in play. In this chapter, we will examine some key ethical and social challenges that arise in the context of dementia diagnosis, care support, and social integration. To clarify these challenges, the chapter introduces readers to relevant concepts and frameworks in bioethics and suggests how to work through these challenges using ethical analysis.

Keywords: healthcare | ethics | ethical care | dementia | bioethics

Article:

The Four Pillars of Bioethics

The four principles and pillars of bioethics, which health and human service professionals consult in the case of moral uncertainty or conflict, are (1) respect for **autonomy**, (2)

beneficence,

(3) **non-maleficence**, and (4) **justice** (Beauchamp & Childress, 2013). Respect for autonomy refers to the right of the competent individual to make personal decisions regarding their own medical care, which includes the right to refuse unwanted treatment. The principles of beneficence (do good) and non-maleficence (do no harm) originate from the earliest versions of the Hippocratic

Oath. For instance, these elements guide healthcare professionals in their administration of medical interventions: if there are no other relevant factors to consider, the morally right medical intervention will be the one that is most beneficial to the patient and least harmful. Similarly, human service professionals value enabling their clients to consider both the potential benefits and risks involved in particular decisions or treatments to guide a well-informed decision-making process. While beneficence and non-maleficence are presented in foundational bioethics texts as separate principles, these principles jointly operate as a dyad in clinical and human service work.

Finally, the principle of justice—usually pertaining to the degree to which healthcare resources are fairly distributed among society—is to some extent dictated by the economic environment in which a medical system operates. Notions and theories of justice vary widely across academic and political fields, and we will limit our discussion to the specific cases of injustice as they pertain to living with dementia, while at the same time noting that, at least in the United States, socioeconomic status often determines the degree to which, if at all, healthcare and social service resources are accessible.

Specific ethical issues pertaining to dementia care can easily be encapsulated by the four principles of bioethics, but, as Gilleard and Higgs (2017, p. 461) note, “determining what each principle means and how it should be prioritized in the case of dementia care is the real difficulty.” Even though dementia affects each individual differently, typically dementia as a differential diagnosis is clinically specified in seven stages, each characterized by an anticipated pattern of symptoms associated with increasing cognitive impairment. For example, stage five of seven is characterized by moderate memory loss and difficulty completing simple daily tasks, such as choosing an outfit to wear (Reisberg, Ferris, Anand, de Leon, Schneck, Buttinger, & Borenstien, 1984). A general overview of dementia distinguishes between three broad stages: early, middle or moderate, and late (Alzheimer’s Society, 2020). We follow Gilleard and Higgs (2017, p. 445) in advocating for a stage-like approach to the ethics of dementia, as this provides ethical guidance that is least likely to cause additional suffering and disrespect. This approach requires regular and thoughtful checking-in with people living with dementia and their advocates so that the support received from health and human service professionals can be adjusted to accommodate emerging or worsening symptoms in a timely manner.

Diagnosis Considerations and Stigmatization

Arriving at a confident clinical diagnosis of dementia is about employing sound diagnostic methods and protocols—running through a checklist of cognitive, functional, and biomarker tests that are scientifically established. Bioethical principles such as respect for autonomy, beneficence, and non-maleficence, as outlined in the prior section, also play a role—they help navigate the “when” and “how” surrounding dementia diagnosis.

Turning to the question of “when,” the challenge is balancing respect for the autonomy of someone with dementia with the value of supporting beneficial health and well-being outcomes while preventing or mitigating negative ones. Is the person asking to be tested for Alzheimer’s or a related dementia, or are they in the clinic on a family member’s urging and seem unhappy about the prospect of diagnostic testing? Has the capacity to understand and give informed consent to diagnostic testing been established? And what significance will a positive (or a negative) diagnosis have for treatment options and lifestyle adaptations? How questions such as these are answered not only affect the practical question of “best timing” for diagnostic assessments, they also determine how the various ethical principles at play are prioritized relative to each other.

Similarly, the “how” of dementia diagnosis brings up important ethically loaded questions. Is it always best for an individual to be offered the full array of multiple forms of testing for dementia? For instance, there is substantial expert skepticism in relation to unreflectively using biomarker testing for the purposes of dementia diagnosis (Farrer & Cook, 2021). One reason for this skepticism is that the detection of biomarkers does not correlate with a specific time of symptom onset, nor does it entail that symptoms will ever manifest themselves. If an individual can be diagnosed with dementia based on cognitive or functional assessments, biomarker testing may not be needed and may come saddled with other harms. This example suggests that diagnostic methods themselves are non-neutral and affect the relationship of the diagnosed individual to the diagnosis, as well as the clinician–patient relationship.

Beyond the non-neutrality of diagnostic methods, there is another substantial ethical consideration at play in the context of dementia diagnosis—stigmatization. Dementia is a condition associated with significant prejudice and stigma. There are at least three kinds—structural, social, and self-directed stigma. All of these lead to a range of negative outcomes (Dubljević, 2020b). For instance, structural stigma leads to institutional discrimination that deprives individuals with dementia of effective healthcare, violating the justice principle. If they are labeled as “demented,” their preferences may no longer be taken into account. Social stigma, on the other hand, involves interpersonal victimization or discrimination that may discourage the affected individual from seeking treatment and, once diagnosed, may lead to “social death,” if the individual becomes segregated from the social groups they participated in prior to diagnosis. Self-stigma consists of negative attitudes toward oneself that lead to loss of self-esteem, depression, and poorer health behaviors, such as substance misuse. Self-stigma has also been shown to lead, independently of mood effects, to measurably lowered performance on cognitive and functional testing (Fresson et al., 2017). This effect, known as “diagnosis threat,” is a form of stereotype threat, because it hinges on a person altering their behavior to align with stereotypical expectations placed on a social group they belong to. In this case, people diagnosed with dementia and even those who suspect they may have dementia act out their own capacities or behaviors differently as a result of their expectations of how people with dementia act. Dementia diagnosis threat exists because dementia is so strongly stigmatized in our society. Thus, an ethical imperative we should take seriously involves finding ways to dismantle those types of stigma. This issue is further addressed in the section on social integration later in the chapter.

Assessing Decision-Making Capacity and Moral Agency

Understanding when to place medical decision-making in the hands of a person living with dementia and when to bring in other parties is one of the challenges faced by a staged approach to the ethics of dementia. The notions of capacity (used in legal and medical literature to describe general decisional abilities) and competence (used to describe whether a person has adequate decision-making capacity to make a particular decision—see Tsou & Karlawish, 2014) are complicated by the subjective nature of clinical interviews or patient-report assessment. It is not uncommon for psychiatric clinicians to reach different conclusions following capacity assessments of the same patient (Appelbaum, 2007). Questions of criteria for determination of cognitive capacity (the degree to which an individual is deemed competent to make personal healthcare decisions) are less than clear. In some cases, psychiatric practitioners are able to temporarily restrict medical autonomy entirely by forcing treatment if they determine that individuals are a danger to themselves or others. In such cases, no informed consent process is required, as the

individual has been clinically determined to lack capacity (Appelbaum, 2007). That restriction in medical autonomy is something that most, if not all, people living with dementia will experience. However, the key issue is timing, since premature curbing of autonomy humiliates, offends, and infantilizes people. This is why we will focus on providing guidelines for articulating relevant issues and not on a “one-size-fits-all” solution to establishing capacity and moral agency.

One of the most pressing ethical problems with regards to capacity and agency in the case of dementia pertains to the tradeoff between prior autonomous preferences (i.e., wishes stated before the onset of the disease) and current choices of people living with dementia. Two well-established ethical positions, developed by Ronald Dworkin and Agnieszka Jaworska, respectively, offer guidance in the pressing ethical dilemmas regarding capacity and agency.

Ronald Dworkin (1993) argues that there are two types of interests: “critical” and “experiential.” Critical interests are those relating to what an individual considers good or bad and are fundamental to a person. Experiential interests are those relating to one’s immediate encounters: one’s interest in experiencing pleasure, and avoiding pain, etc. According to Dworkin (1993), persons in the late stages of dementia:

...have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self [...] fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation [...]. They cannot have projects or plans of the kind that leading a critical life requires. They therefore have no contemporary opinion about their own critical interests. (p. 230)

In contrast, Agnieszka Jaworska (1999) defends the view that the immediate interests of an individual, even in cases of dementia, shouldn’t be overridden as long as this individual has the ability to value. She adds that experiential interests are time-specific because one can only care for such interests if the person has them currently. Dworkin and Jaworska both agree that people living with dementia can experience feelings, and therefore have experiential interests, but disagree on the capacity to hold critical interests. Unlike Dworkin, who believes people with dementia have no critical interests, Jaworska argues that they do, and are just not in a state to communicate them. Dworkin argues that people with dementia have no concept of a whole life, which in turn prevents them from generating critical interests. Jaworska responds by saying one doesn’t need to have the concept of a whole life to generate critical interests; one merely needs to have a concept of what one wants and doesn’t want in one’s life. From this, she links the ability to generate critical interests to the ability to value things since the things a person values as good are also the things they want in their life. Further, someone can still have the capacity to value things that are good for them even if they do not remember their history.

Neuroscience provides some data that supports this idea. Alzheimer’s primarily affects the hippocampus (Geula, 1998). The hippocampus is involved in memory consolidation and storage, specializing in the conversion of short-term to long-term memory (Squire & Zola-Morgan, 1991). However, the hippocampus is not needed to execute one’s mental functions (Young & Young, 1997). A person would not be able to add to their life history without the hippocampus, and therefore life would become disjointed, but this does not essentially prevent mental functions. Thus, in case of Alzheimer’s dementia at least, Jaworska argues that if we primarily focus on the person with dementia’s ability to value, and as long as this ability is intact, then one can trust their expressed choices and preferences.

So, are Dworkin and Jaworska's positions completely at odds, and do they thus confuse more than clarify? Not necessarily. Once we take into consideration that Dworkin is focused on late stages of dementia, whereas Jaworska is focused on earlier and mid-stages of Alzheimer's Disease, then we can better appreciate what's really at stake in deciding to respect or limit autonomy of a person with dementia. Before the onset of the disease, people have full autonomy, which includes consistency of choices and actions, mental time travel (i.e., the ability to think about one's past, present, and future), and examination of one's values. Gradual loss of these capacities means that people living with dementia need to learn how to exercise their autonomy effectively with the help of others (e.g., caregivers). In the early to mid-stages of dementia, a person is capable of having some conception of what is important to them, while others can step in to help with the reasoning necessary to translate these ideas into concrete steps that need to be enacted, recovering consistency of action on the person's behalf (Jaworska, 2021). For people in later stages of dementia who have lost most aspects of the capacity for autonomy, caregivers can safely focus on making the person's experiences as pleasurable as possible, keeping them cheerful and free of anxiety.

Obtaining Informed Consent

Once a positive diagnosis of Alzheimer's or another form of dementia has been made, and all relevant parties have been informed of the result, an important next step involves agreeing to a plan for treatment and regularly recurring clinical consultation. This raises the first challenge that clinicians and their clients face together: obtaining informed consent for ongoing professional treatment and support from health and human service providers.

Given the nature of the disease, a positive diagnosis of dementia instantly and unavoidably alters the relationship between clinician and patient. Having established that cognition is impaired to the abnormal degree consistent with dementia onset, the ability of a person with dementia to make sound and stable decisions regarding their own treatment and care are scrutinized to a greater degree than was the case prior to dementia diagnosis. Nonetheless, obtaining informed consent from someone with dementia for ongoing treatment, monitoring, and support, as well as to potentially participate in clinical trials or research, is morally and legally obligated insofar as their capacity to do so seems sufficiently intact. Codes of medical ethics acknowledge that patients have the right to receive information, ask questions and make decisions regarding their own healthcare and participation in biomedical or behavioral research (Berg, 2001; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Additionally, as noted earlier, such codes relate supporting a person's autonomy to respecting them as persons and moral agents.

Earlier in the chapter, we discussed the distinction between decision-making competency and decision capacity. As we noted, establishing that both of these remain intact requires careful assessing by clinicians and should also be supported by evidence communicated by the individual's family. The epistemic challenge for clinicians is to recognize what "sufficiently intact capacity" means in a given consent context. After all, the process of giving consent to treatment is both multi-staged and partly unfolds in the privacy of a person's mind: After reviewing and understanding both the potential benefits and risks of a given treatment, one weighs these pros and cons against each other, and concludes by either accepting or declining that treatment plan and clearly communicating this to other people. That's a lot of cognitive work—which also means

there are several places that the process of decision-making might collapse or be hindered by cognitive impairments.

No general formula or checklist is universally appropriate for determining treatment consent capacity or competency, given the variance of circumstances, symptoms, treatment options, and interpersonal factors involved in any given clinical consultation. That said, there are ways to assess key components of that process (see Figure 1.1), as outlined by Appelbaum (2007).

Assessing Decision-Making Capacity:

The four widely accepted capabilities that constitute decision-making

The Ability to Make and Communicate a Choice	<i>Ask the patient to indicate a choice</i>
The Ability to Understand	<i>Ask the patient to paraphrase back information that has been provided regarding the medical condition and treatment</i>
The Ability to Appreciate	<i>Ask the patient to articulate potential outcomes and consequences associated with treatment or no treatment</i>
The Ability to Reason	<i>The patient should demonstrate awareness of how these facts are relevant to their particular situation</i>
	<i>Ask the patient to provide an explanation of the process or rationale for arriving at the decision</i>
	<i>The patient should be able to demonstrate awareness of various options and at least some ability to compare between them</i>

Figure 1.1 Appelbaum’s Question-focused Capacity Assessment. Note: Adapted from Tsou & Karlawisch 2014, p. 139.

Still, it is worth emphasizing that even these question-focused strategies cannot guarantee a wholly conclusive judgment regarding a person with dementia’s ability to provide informed consent, owing to the fluctuation of symptom expression, even over the course of a single day and due to the variability of the particular decision context. Since common conditions in the elderly, such as depression, insomnia, and anxiety, wreak havoc on a person’s cognitive abilities (American Psychiatric Association, 2013), it is also crucial to separately screen for these possible culprits. If any such conditions are discovered present, treatment to reverse their effects should be prioritized to make it possible to isolate and assess just those deficits caused by progressive dementia.

It is for all of these reasons that clinicians and other service providers should think of consent capacity assessments as iterative and thoughtful, rather than one-time and formulaic. This ethically sensitive process can help establish clinical confidence whether and to what degree capacity or competency to accept or decline treatment or participate in research remain intact in an individual. Should either capacity or competency be judged as impaired, a gradual shift of decision-making responsibility must take place from the person with dementia to other parties involved in the situation, that is, the person’s family members or caregivers who are already serving in the supporter role, as well as the clinician. Why should this shift be seen as gradual? Because in most cases, even if a person’s ability to give rational consent is no longer wholly intact, there remains interest on their part to understand their situation and to be respected as someone whose input matters. Once it comes time to establish a newly diagnosed person’s present ability to deliberate thoughtfully and reliably, particular care should be taken to ensure they are not subject to de-personalizing attitudes and behaviors, for instance, talking to their family member and excluding them from conversation, or referring to them in the third person though they are also

present in the room. These simple interpersonal practices are ways to let people living with dementia know that they remain included and important in communication and decision-making processes—even after specific capacity or broad competency wane. The next section shows how these important ethical considerations can and should guide clinical understanding of person-centered decision-making models.

Relevant Models of Decision-Making

A key ethical, interpersonal, and legal challenge faced by clinicians and other service providers when working with people with dementia involves determining who the appropriate decision-maker should be for issues regarding care and support for a person with dementia. In the previous section, we noted that obtaining informed consent from someone with dementia is obligated insofar as capacity to rationally consent seems sufficiently intact. If an individual's capacity is found wanting, though, how should the process of decision-making proceed—in the case of treatment consent specifically, but also more broadly in respect to the things that we all make decisions about in our everyday lives, from driving, shopping, banking, and housekeeping, to nutrition, exercise, personal hygiene, and socializing? While many decisions made in those domains fall under the category of “personal life,” it's clear that as dementia symptoms worsen, each of these domains increasingly becomes relevant to clinical practice. For instance, if a person with dementia is showing signs of malnutrition, the clinician can ask about their shopping, cooking, and eating habits at home: Who is doing the shopping? What food is in the fridge right now? What do you like to eat these days? Though indirect, these kinds of questions nonetheless can uncover underlying decision-making abilities of people with dementia, in this case pertaining to food habits and nutrition.

At a glance, models for assigning decision-making agency can be grouped into those “by, with, and for patients” (Dildy & Largent, 2021). The models are commonly grouped as autonomous, supported, and surrogate decision-making, respectively, with surrogate decision-making being further divided into substituted judgment, best interests, and substituted interests approaches (Kohn et al., 2013; Tsou & Karlawish, 2014). Each will be briefly introduced in what follows, but it's worth noting at the outset that this particular grouping—by, with, and for—is deliberately placed in that order. Moving from the first to the second model, and from the second to the third, signifies a progressive decrease of decision-making agency by the person with dementia and a correlative increase of agency by family members and care professionals. This sequence mirrors the common progression of dementia, which over time increasingly impacts someone's decision making abilities and makes it necessary to shift decision-making agency to persons other than the one with dementia.

Autonomous Decision-Making

Decision-making models that locate agency exclusively in the individual themselves stand for cases where people with dementia decide on something by or for themselves—adopting this model will work in cases where clinicians detect that both their patients' decision-making competency and their capacity to decide on a particular issue at hand remain sufficiently intact. Here the clinician and the affected person's family members play advisory roles, but should not be making the final decision for them, since this would constitute a violation of the affected person's autonomy and liberty (Miller et al., 2016).

Neurodegenerative illnesses such as dementia pose a peculiar puzzle relating to this model. Just how far into the future should a person's autonomous decisions hold sway? As will be discussed further in the remarks on advance directives later in the chapter, it is controversial to what extent and in what ways someone may make practical or legally binding decisions regarding their possible future self living with dementia. This is controversial because in one sense it's a clear and unimpeded case of autonomous decision-making. In another more existentially complicated sense, it's a case a little like surrogate decision-making for someone with dementia—the person without dementia is making decisions for their not-yet-existing future self living with cognitive impairment. It's not the business of this chapter to get into the metaphysical deep end that this puzzle invites, but interested readers may turn to DeGrazia (1999) and Dresser (1995) for further discussion.

Supported Decision-Making

Decision-making with people with dementia involves shifting some control over the decision-making process and the final decision onto someone other than the diagnosed individual. Normally, it's initially a person's familial caregivers who step into this role, though as the illness progresses and care needs increase, care professionals will also come to inhabit this role. At this stage of the illness, clinicians will likely note changing interpersonal dynamics between the person with dementia and their family members or caregivers. This is because the person who initially was “simply” a caring family member is gradually learning to inhabit the role of supportive caregiver, which is a more demanding and conflicted role precisely because they must step in more actively than before to aid their family member with decision-making, without overly imposing their own desires or dominating that process.

It's worth mentioning that the contrast between autonomous and supported decision-making is not as severe as might seem in calling them distinct categories of decision-making. Taking a step back, we realize that it's natural to perceive many of the decisions we reach to be autonomous ones, but in truth, the advice and support we received from others played valuable roles in helping us make the final call. Indeed, many ethicists have critiqued the view that the natural or primary state of a human individual is to be “absolutely” autonomous; an increasingly popular principle is relational autonomy (Nedelsky, 1989; Osuji, 2018). From this vantage point, shifting from “autonomous” to “supported decision-making” need not be seen as radical at all, or as taking away much agency from the person with dementia— especially if it is done well.

Surrogate Decision-Making

When people other than the person with dementia make decisions for them, we speak of surrogate decision-making. This marks the most radical shift within the sequence of decision-making models being summarized, since it's really only at this juncture that the individual him- or herself no longer makes up the central agency in the decision-making process. Regardless, the radical shift entailed by a move to this model of decision-making means it is also the most likely to be out of line with a person's wishes, both on the level of what is being decided, but also on the level of how something is being decided. Surrogate decision-making becomes necessary precisely because clinical assessment determines the person with dementia no longer has decision-making capacity and/or competency—but that is in part determined by the apparently “unreasonableness” of their decision-making process in the eyes of the clinician or caregivers, an assessment that the person

with dementia is unlikely to simply accept. And in no longer allowing the diagnosed individual to have final say over a particular matter, potentially even going against their expressed will, the person with dementia may also find fault with the decision-making model now in effect, a model that apparently involves demoting their opinion.

There are many cases in which people use deceptive actions to manipulate a person living with dementia, which they think on balance will promote the well-being of the person living with dementia. Since this may be fundamentally disrespectful of the person living with dementia, this is an ethical issue worth addressing. We endorse Jaworska (2021), who argues that, in some of these cases, the apparent dilemma dissolves under closer scrutiny. According to Jaworka (2021, p. 66), “[d]eception is not disrespectful when its aim is to support the deceived person’s autonomy by directly compensating for an autonomy-impeding cognitive impairment.” Jaworska gives an example of a person with dementia who formerly worked as a chef, and likes to think they are in charge of making a meal, while in fact others are in charge and the person with dementia is merely assisting. She claims that “[a]utonomy may be supported in such cases only if the person’s own values would not rule out such deception and only if the person is in fact assisted in realizing their values to the extent possible (as opposed to it merely seeming to the person that their values are realized).” If all of these conditions hold, objections to deception based on the principle of respect for persons no longer apply. Such deception would be morally unproblematic and permissible since it is beneficial to the person and not intended as a form of disrespect. The ethically appropriate solution is thus to assist the individual in retaining meaningful social activities, while delegating decision making to a competent surrogate.

Surrogate decision-making comes in several varieties. Substituted judgment promotes the attempt to choose what the person with dementia would most likely have chosen were they faced with the situation at hand and if they were cognitively unimpaired (Mitchell, 2019). Clearly, the hypothetical thinking involved in this approach will be more appropriate the more intimately and comprehensively the proxy decision-maker knows the affected individual—this model won’t serve a clinician well, presuming he or she lacks that level of detailed knowledge of their patient’s priorities, interests and background. Family caregivers are in a better (though still not ideal) position to act on substituted judgment, given their longtime acquaintance with the person with dementia.

The best-interests approach to surrogate decision-making directs the surrogate decisionmaker to choose that which is “objectively” in the person’s best interest (Berg, 2001, pp. 112– 116). States of physical comfort and safety, or even of feeling connected to others and companionship, are fairly safe bets when it comes to being primary goods for human beings. In a case where these or other goods are competing with each other, a best-interests approach would suggest weighing the pros and cons of sacrificing one for the sake of another—all things considered. Naturally, no one can take a truly objective all-knowing view of what is best for a person. But, in a case where substituted judgment isn’t realistic, gauging what is in a person’s best interest can come to the rescue, given the relative stability of what makes human beings content and what makes them suffer.

Sulmasy and Snyder (2010) have proposed a surrogate decision-making model that integrates substituted judgment and best interests. Substituted judgment stands for respecting the person with dementia by recalling their personality, values and beliefs. Its chief drawback is that it asks the surrogate to make a choice based on elaborate, imaginative hypothesizing of “what would they do were they facing this choice?”—a process that is both stressful and highly prone to miscalculation. The best interests model may seem easier to negotiate, but this comes at the

expense of paying attention to the personal qualities of the person whose life and well-being are, after all, at the center of the choice being faced by the surrogate decisionmaker. The “substituted interests” or “best judgment” hybrid approach begins with the surrogate sharing his or her knowledge of the person’s beliefs and values with the medical or care professionals involved in the particular scenario. Health professionals can offer valuable information about the options that might honor those beliefs and values. By sharing and respecting each other’s experience and knowledge, surrogate decision-makers and health and human service professionals can make decisions collaboratively.

As can be seen from this review of decision-making models, who should have agency to make decisions in a healthcare and human service context depends on several variables, including assessed capacity, availability of family members or close acquaintances to support the person with dementia or act as surrogate decision-makers, and the willingness of clinicians and other health professionals to engage in deliberative work with their clients. It is also worth recalling that decision-making regarding dementia care is emotionally difficult and can give rise to negative feelings between patient, caregiver, or clinician. For instance, in the initial autonomous decision-making condition, the clinician may face hostility from both the person with dementia and their family members for perceived interference or manipulation of the patient’s choices. As the illness progresses, however, those same family members may shift to caregivers and surrogate decision-makers, and then to informants for the clinician as they increasingly rely on professional expertise and support to navigate the challenges of making decisions for their loved one in moderate to late-stage dementia (Tsou & Karlawish, 2014). Clinicians and human service professionals who are cognizant of the nature of these gradual but expected shifts in decision-making agency can prepare themselves for the interpersonal challenges—but also the new care opportunities—that each model respectively affords.

End-of-Life Decision-Making

In the United States, the 1990 Patient Self-Determination Act (PSDA) was enacted in order to ensure that the healthcare system recognizes and honors patients’ written advanced directives, with an immediate result of an increasing number of Do Not Resuscitate (DNR) instructions. Thus, even though the idea was to facilitate early and detailed planning, most advanced directives have amounted to blanket refusals of treatment. Dementia further complicates the picture as people often associate dementia onset with a severe decline in the quality of life. Recently, some have argued that the “cognitive transformation” accompanying dementia diminishes the moral value of advance directives (see Walsh, 2020).

Indisputably, cognitive and capacity considerations related to autonomy fluctuate considerably (Coin & Dubljević, 2021). While individuals without dementia are incapable of completely knowing or anticipating the actual experience of dementia, social and clinical contingencies have the potential to epistemically empower people diagnosed with dementia to produce advance directives deserving of clinician adherence. For example, the most common manifestation of dementia, Alzheimer’s disease, is a neurodegenerative condition that gradually diminishes memory function and leads to severe cognitive impairment and ultimately death. In cases where this is diagnosed early, individuals may complete advance directives for the purposes of binding themselves to a Ulysses contract—a way of dictating medico-legal control over the future self. Because some risk for developing Alzheimer’s disease is genetically inheritable, many people diagnosed with the condition employ family experience in their own advance care planning

(Dubljević, 2020b). Family members often serve as caregivers of loved ones with dementia, and thus are intimately acquainted with the progression of cognitive impairment.

Even for those lacking personal experience with the clinical manifestation of dementia, predicting future preferences may not be as futile as some fear. For instance, it will be recalled that there are seven typical stages of the disease progression. The fact that each of the seven stages—ranging from “very mild decline” to “very severe decline”—are characterized by a clinically predicted progression of symptoms suggests that diagnosed individuals lacking personal experience with dementia may become well-informed via conversation with a clinician. Since decisional capacity in people with dementia is critically affected by the course of disease progression, people may be able to predict their possible preference changes as they progress towards stage seven.

The purpose, or aim, of advance care planning in the context of early diagnosis is to reduce anxiety surrounding the unknown. Walsh (2020) argues that a change in capacity or the transformative experience of dementia may result in preferences that depart from a person’s original advance directive. In doing so, she asks, how can we possibly make an informed choice? The answer is—we cannot, nor do we claim this is possible. The best we can do is acknowledge the unknown, and address the associated uncertainty and anxiety with anticipatory advance care planning. Thus, many individuals initiate advance care planning in anticipation of these preference changes—changes to which they foresee themselves predisposed and may draw on an array of social, clinical, and technological experiences, information, and resources. As such, epistemic inaccessibility and its diminishment of autonomy pre- and post-dementia diagnosis is not as morally problematic as some posit.

For instance, Walsh (2020), focusing on Dworkin’s (1993) preference-based autonomy argument, fails to consider that “preferences”—as they are conceived in her cognitive framework—are not necessarily representative of choice even in the context of late-stage dementia (see Dubljević, 2020a; Jaworska, 1999). Preferences in these late stages are more appropriately conceived simply as actions that consist of autonomic responses to environmental triggers. For example, it is common for people in late-stage dementia to lose their appetites as they near the end of life. People may often express refusal of feeding by turning their head when a staff member approaches their mouth with a spoon. However, because they are unable to articulate their wishes verbally, food is often placed in their mouth anyway, triggering the esophageal reflex and causing the food to be swallowed. The fact that the food was ingested by the person does not connote a preference—no conscious choice to swallow the food was made. Many people with advanced stage dementia are kept alive for months in this state, which has prompted Nevada to pass legislation that authorizes advance directives to direct healthcare providers to not provide food or fluid by mouth in cases of late-stage dementia (Pope, 2019).

Additionally, the circumstances under which an advance directive is completed ought to dictate the moral weight that it affords—individuals frequently incorporate “transformative experiences” into their advance care planning. At its essence, the argument based on the transformative experience fails to acknowledge one of the primary reasons for advance directive completion. For example, it is largely built on the premise that the purpose of the advance directive is to maximize autonomy when one loses the cognitive capacity to do so—this is only partially true. In many cases, advance directives are filled out to avoid uncertainty in the context of terminal, debilitating illness. Recent frameworks for advance directives that authorize voluntarily stopping eating and drinking (VSED) in the context of late-stage dementia have been disseminated in New York (EOLCNY, 2020). The goal of these directives is to allow the natural dying process to occur

when the most basic activities (such as eating) are no longer enjoyable. Understandably, many individuals imagine that a state in which joy from eating is unattainable is one that is not worth living in. The uncertainty of this experience, and the fear it instigates, frequently motivate diagnosed individuals to fill out advance directives. Unfortunately, many long-term care facilities are evaluated by regulators based on their ability to maintain residents' weights and thus many facilities ignore these directives. Thus, it is the social environment and financial reward structures that lead to ignoring advanced directives and not any inherent lack of moral worth.

This reinforces the importance of authoring clear, adequately concise advance directive documents that don't leave much room for interpretation. Ambiguous advance directives continue to cause immense conflict in clinical settings, as treatment teams, family members, and other stakeholders attempt to engage in the notoriously subjective and imperfect process of substituted judgment. For this reason, the quality of the initial advance care planning process must be prioritized. This includes integrating individual life experience, including transformative experiences, into the moral deliberations of such sensitive and personal matters.

Dementia and Social Integration

All patient, clinician, and care partner relationships develop within a larger society; even the strongest ones are influenced by external social forces that may be beneficial or harmful to the overall well-being of the person with dementia. In the following, we first address the harmful forces of ageism, ableism and the tragedy discourse surrounding dementia. Then we consider positive social forces working to de-stigmatize dementia: dementia-friendly approaches to care and advocacy advancements.

Negative Social Forces

It's no secret that we live in an ageist and ableist society, and that these are also not yet widely seen as "problem" prejudices. An ageist attitude or belief is one that assumes that one's worth as a human being and as a member of society fluctuates according to one's age. Ageism is thus not exclusively about dismissing elderly people as less valuable to society or as people—in fact, ageism is also frequently directed toward the young. That said, ageism towards the older members of our society is rampant, as documented by organizations such as AARP, which focuses especially on workplace age-related discrimination (Kita, 2019). Ageism has deep roots in Western culture, despite many of our most respected offices being dominated by persons over the age of 60. The ancient Greek philosopher Aristotle presumably helped cement this tradition, by attempting to rationally establish that middle age is the prime of life, youth the second-best stage, and old age nothing but a miserable and useless phase of wasting away (Anton, 2016).

The idea that older age is necessarily tied to waning abilities and no longer being at one's best ties in to another prevalent and widely tolerated prejudice that affects people living with dementia: ableism. An ableist attitude or belief at its crudest assumes that people with intellectual or physical disabilities are less valuable as human beings, both inherently and societally. Ableism can target anyone who does not perform cognitive or physical tasks the way that the majority of people in their age group can. In the case of people with dementia, ableism has led to historic atrocities committed against this population of especially vulnerable elders.

While overtly brutal and inhumane tactics of control and pacification of those living with dementia are now the stuff of history books, our society is far from having exorcised the underlying

ableism and ageism that ensured their public approval. In recent decades, a “tragedy discourse” has dominated public and private conversations about dementia. The phrase was coined by Reed et al. (2017) to draw attention to the ways that people talk about dementia— both those who haven’t been diagnosed as well as those who have.

Clinicians and other human service professionals, like any other members of society, should be aware of the pervasive and subtle ways this discourse can influence their attitudes toward those with dementia. While there are certainly reasons to view dementia as having a regrettable and difficult prognosis, it is ultimately the attitudes we carry into thinking about dementia— attitudes such as ableism and ageism, fixed by tragedy narratives—that have the greatest impact on the kinds of support and care solutions we can imagine and on the effort we are willing to put into seeing those realized. Clinicians and other human service professionals who work with people with dementia should bear in mind that those attitudes also affect how people diagnosed with the illness view themselves and their outlook. Due to the prevalence of the tragedy narrative of dementia, many people facing diagnosis attempt to internalize that they are a lost cause and on a journey toward increasing indignities and a “living death” (Peel, 2014). We must all combat these perceptions with counter-narratives— an approach that the next section explores.

Positive Social Forces

Dementia-friendly research and approaches to care, as well as improvements in participatory advocacy are all increasing the visibility of dementia and alternatives to the tragedy discourse that is tied to ageism and ableism. As demonstrated by the Americans with Disabilities Act, setting and enforcing protective policies for people with disabilities can help improve the daily lives of people living with impairments, including people living with dementia. Other major forces for positive change, though, are care institutional reform, social community-building, and creatively re-imagining what living with dementia can be like. Increasing numbers of people and organizations are pursuing this re-imagining project (Alzheimer’s Disease International, 2016). The concept of “dementia-friendly community” is sparking new forms of person and relationship-centered memory care, at the institutional level but also at the level of social community-building (Turner & Morken, 2016). The Green House Project, a nonprofit organization working to create non-institutional, humanizing eldercare communities, and award-winning community group Momentia serve as thought-provoking examples of these respective efforts, while also being remarkably distinct of each other in their overall structure, membership and creative direction.

Protective laws and institutional reform enable positive changes surrounding living with dementia. To fight the stigmatizing effect of the tragedy discourse, however, the voices of those living with dementia and their allies must also enter the conversation. Qualitative research on people with disabilities has shown that non-disabled people underestimate the quality of life of people living with disabilities of all kinds, including dementia. This empirical fact has been called the “disability paradox”: many people with serious disabilities (both physical and cognitive) report good or excellent quality of life—while outside observers judge their quality of life as poor (Albrecht & Devlieger, 1999). This finding has also proved true in the case of dementia (Mitchell et al., 2013). The best dementia advocacy groups are those that embrace the disability-rights principle of “Nothing about us, without us!” (Bryden, 2016) and applies this concretely to increase participation and input from people living with dementia.

Conclusion

This chapter has explored several key ethical and social challenges that arise in the context of dementia diagnosis, care support, and social integration. It introduced readers to foundational concepts and frameworks in bioethics and also laid out relevant ethical considerations in reference to dementia diagnosis, obtaining informed consent, end-of-life care, and decision-making models “by, with, and for” individuals with dementia.

The progressive nature of most forms of dementia means that no decisions or actions can be taken as “solving” once and for all the ethical challenges that surface in the context of living with dementia or supporting someone with dementia. As a result, the person living with dementia, as well as their family, social groups, and professional care support team must stay responsive and creative to address factors as they change over time. While this might seem a daunting process to align with abstract bioethical principles and decision-making models, the fundamental value of respecting someone with dementia as a person throughout can serve as a constant and concrete point of reference for all those involved in the care and support of people living with dementia.

It’s well known that “person-centered care” is a prevailing model in dementia care today. This approach counterbalances the reductive biomedical model by placing respect for the autonomy and dignity of people with dementia front and center. As such, it represents a valuable step toward re-humanizing and de-stigmatizing life with dementia. Nonetheless, as our discussion of social forces reveals, we still have a ways to go. Ethically sensitive approaches to diagnosis, treatment and decision-making are likely to increasingly focus not only on the continuing personhood of those diagnosed with dementia, but also on the relationships that enfold their life—because the concern and effort we put into our relationships with each other are important conveyors of the respect we hold for each other as individuals. Health and human service professionals involved in dementia care and support should hold fast to this moral truth as well.

Acknowledgments

The authors would like to thank members of the Neuro-Computational Ethics Research Group at NC State University for their valuable feedback (in alphabetical order by last name): Allen Coin, Elizabeth Eskander, Megan Mulder and Sean Noble. Special thanks to Anirudh Nair for editorial assistance and to Michael Menconi for constructive discussions on the topics of VSED and advanced directives.

References

- Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, 48(8), 977–988. [https://doi.org/10.1016/s0277-9536\(98\)00411-0](https://doi.org/10.1016/s0277-9536(98)00411-0)
- Alzheimer’s Disease International. (2016). Dementia friendly communities – Key principles and global developments. <https://www.alz.co.uk/news/dementia-friendly-communities-keyprinciples-> and-global-developments Alzheimer’s Society. (2020). Stages of Alzheimer’s. <https://alz.org/alzheimers-dementia/stages>
- American Psychiatric Association. (Ed.). (2013). *Diagnostic and statistical manual of mental disorders Dsm-5*.

- Anton, A. L. (2018). Aging in classical philosophy. In G. Scarre (Ed.), *Palgrave handbook of the philosophy of aging*, 115–134. Palgrave Macmillan.
- Appelbaum, P. S. (2007). Assessment of patients' competence to consent to treatment. *New England Journal of Medicine*, 357(18), 1834–1840. <https://doi.org/10.1056/nejmcp074045>
- Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.). Oxford University Press.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979) *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. U.S. Department of Health and Human Services. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-thebelmontreport/index.html>
- Berg, J. W. (2001). *Informed consent: Legal theory and clinical practice*. Oxford University Press.
- Bryden, C. (2016). *Nothing about us, without us!: 20 years of dementia advocacy*. Jessica Kingsley Publishers.
- Coin, A., & Dubljević, V. (2021). Carebots for eldercare: Technology, ethics, and implications. In C.S. Nam & J.B. Lyons (Eds.), *Trust in Human-Robot Interaction*, 553–569. Academic Press. <https://doi.org/10.1016/B978-0-12-819472-0.00024-1>
- DeGrazia, D. (1999). Advance directives, dementia, and 'The Someone Else Problem'. *Bioethics*, 13(5), 373–391. <https://doi.org/10.1111/1467-8519.00166>
- Dildy, K. C., & Largent, E. A. (2021). Directing the End of Life in Dementia. In V. Dubljević & F. Bottenberg (Eds.), *Living with Dementia: Advances in Neuroethics*. Springer, Cham. https://doi.org/10.1007/978-3-030-62073-8_5
- Dresser, R. (1995). Dworkin on dementia: Elegant theory, questionable policy. *The Hastings Center Report*, 25(6), 32–38. <https://doi.org/10.2307/3527839>
- Dubljević, V. (2020a). The principle of autonomy and behavioral variant frontotemporal dementia. *Journal of Bioethical Inquiry*. <https://doi.org/10.1007/s11673-020-09972-z>
- Dubljević, V. (2020b). Disease and wellness across the lifespan: A global perspective on mental health burden of dementia. In D. Stein & I. Singh (Eds.), *Global mental health and neuroethics* (pp. 225–235). Elsevier.
- Dworkin, R. (1993). Life's dominion (pp. 218–237). Alfred A. Knopf.
- End of Life Choices New York (EOLCNY). *Dementia Advance Directive*. (2020). <https://endoflifechoicesny.org/directives/dementia-directive>
- Farrer, T. J., & Cook, S. E. (2021). Diagnosis Threat Related to Disclosure of Alzheimer Disease Biomarkers and a Discussion of the Ethics in Clinical and Research Settings. In V. Dubljević & F. Bottenberg (Eds.), *Living with dementia: Neuroethical issues and international perspectives*, 91–107. Springer, Cham. https://doi.org/10.1007/978-3-030-62073-8_6
- Fresson, M., Dardenne, B., Geurten, M., & Meulemans, T. (2017). Stereotype content of people with acquired brain injury: Warm but incompetent. *Journal of Applied Social Psychology*, 47(10), 539–552. <https://doi.org/10.1111/jasp.12459>

- Geula, C. (1998). Abnormalities of neural circuitry in Alzheimer's disease: Hippocampus and cortical cholinergic innervation. *Neurology*, 51(Issue 1, Suppl. 1), s18–s29. https://doi.org/10.1212/wnl.51.1_suppl_1.s18
- Gilleard, C., & Higgs, P. (2017). Ethical issues in dementia care. In G. Scarre (Ed.), *The Palgrave handbook of the philosophy of aging* (pp. 445–468). Palgrave Macmillan Ltd.
- Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy & Public Affairs*, 28(2), 105–138. <https://doi.org/10.1111/j.1088-4963.1999.00105.x>
- Jaworska, A. (2021). Respect for Autonomy in the Face of Dementia: The Case of Deception. In V. Dubljević & F. Bottenberg (Eds.), *Living with Dementia: Advances in Neuroethics*, 55–68. Springer, Cham. https://doi.org/10.1007/978-3-030-62073-8_4
- Kita, J. (2019, December 30). Age discrimination still thrives in America. AARP. <https://www.aarp.org/work/working-at-50-plus/info-2019/age-discrimination-in-america.html>
- Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2013). Supported decision-making: A viable alternative to guardianship? *Penn State Law Review*, 117(4), 1111–1158. <https://doi.org/10.2139/ssrn.2161115>
- Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, 15(5), 1141–1157. <https://doi.org/10.1177/1471301214555542>
- Mitchell, G. J. (2019). Care of patients with advanced dementia. UpToDate. <https://www.uptodate.com/contents/care-of-patients-with-advanced-dementia>
- Mitchell, G. J., Dupuis, S. L., & Kontos, P. C. (2013). Dementia discourse: From imposed suffering to knowing other-wise. *Journal of Applied Hermeneutics*, 2013(5). <https://doi.org/10.11575/jah.v0i2.53220>
- Nedelsky, J. (1989). Reconceiving autonomy: Sources, thoughts, and possibilities. *Yale Journal of Law and Feminism*, 1, 7–36. <https://digitalcommons.law.yale.edu/yjlf/vol1/iss1/5>
- Osuji, P. I. (2018). Relational autonomy in informed consent (RAIC) as an ethics of care approach to the concept of informed consent. *Medicine, Health Care and Philosophy*, 21(1), 101–111. <https://doi.org/10.1007/s11019-017-9789-7>
- Peel, E. (2014). 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': Representations of dementia in print media and carer discourse. *Sociology of Health & Illness*, 36(6), 885–901. <https://doi.org/10.1111/1467-9566.12122>
- Pope, T. M. (2019, October 6). Avoiding late-stage dementia with advance directives for stopping eating and drinking. KevinMD.com. <https://www.kevinmd.com/blog/2019/10/avoiding-latestage-dementia-with-advance-directives-for-stopping-eating-and-drinking.html>
- Reed, P., Carson, J., & Gibb, Z. (2017). Transcending the tragedy discourse of dementia: An ethical imperative for promoting selfhood, meaningful relationships, and well-being. *AMA Journal of Ethics*, 19(7), 693–703. <https://doi.org/10.1001/journalofethics.2017.19.7.msoc1-1707>

- Reisberg, B., Ferris, S.H., Anand, R., de Leon, M.J., Schneck, M., Buttinger, C., & Borenstien, J. (1984). Functional staging of dementia of the Alzheimer's type. *Annals of the New York Academy of Sciences*, 435, 481–483.
- Squire, L., & Zola-Morgan, S. (1991). The medial temporal lobe memory system. *Science*, 253(5026), 1380–1386. <https://doi.org/10.1126/science.1896849>
- Sulmasy, D. P., & Snyder, L. (2010). Substituted interests and best judgments: An integrated model of surrogate decision making. *JAMA*, 304(17), 1946–1947. <https://doi.org/10.1001/jama.2010.1595>
- Tsou, A. Y., & Karlawish, J. (2014). Dementia. In J. F. Quinn (Ed.), *Ethical, legal, and social issues in dementia* (pp. 137–149). John Wiley & Sons Ltd. <https://doi.org/10.1002/9781118656082.ch10>
- Turner, N., & Morken, L. (2016, March). Better together: A comparative analysis of age-friendly and dementia friendly communities. AARP. <http://www.aarp.org/content/dam/aarp/livablecommunities/documents-2016/Better-Together-Summary-Report.pdf>
- Walsh, E. (2020). Cognitive transformation, dementia, and the moral weight of advance directives. *American Journal of Bioethics*, 20(8), 54–64. <https://doi.org/10.1080/15265161.2020.1781955>
- Young, P., & Young, P. (1997). *Basic clinical neuroanatomy* (p.204). Williams & Wilkins.