

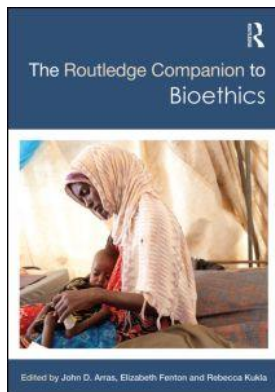
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Part VII

END-OF-LIFE AND LONG-TERM CARE

This section highlights two sets of related issues: First, the ethical issues posed by chronic illness and our individual, familial, and social responses to it; second, the traditional bioethical problems of defining death, forgoing life-sustaining treatments, and active euthanasia. In keeping with the overall orientation of this volume, justice issues are presented front and center whenever appropriate.

We begin with Bruce Jennings' chapter on the challenges of Alzheimer's disease, a chronic and degenerative brain disorder that gradually erodes memory and effaces the patient's capacity for self-control as well as their sense of personal identity and selfhood. Whereas a popular conception of Alzheimer's tends to focus exclusively on the burdens to self, caregivers, and society, Jennings proposes an alternative approach, based upon capability theories, which emphasizes the patient's remaining capacities for human flourishing. And in place of a dominant philosophy of caring that emphasizes merely physical comforts, discomforts, and protection against harm, he advocates for a more person-centered approach that attempts to salvage and support whatever remains of the patient's identity, sense of agency, and previously held values.

In a world in which more and more people will live longer due to the successes of contemporary medicine and public health, more and more people will suffer from diseases like Alzheimer's, cancer, and other chronic, debilitating conditions. Who will provide care for all these people? The traditional response has been the provision of care within large, extended families, but in developed countries today family caregivers are often squeezed between the demands of looking after loved ones, young and old, and by the demands of outside jobs that support their families. A widespread solution to this problem has been to hire caregivers driven from their home countries by poverty and lack of opportunity. At the level of social policy, this migration of caregivers from poor to developed countries represents a troubling brain drain, especially with regard to the thousands of physicians and nurses trained at great expense in their home countries. By actively soliciting such health care workers to attend to the needs of patients and families in developed countries, well-off nations play an active role in undermining the provision of health services to some of the most needy people on earth. This is clearly an injustice of the first order that demands worldwide recognition of the problem and concerted efforts to stem the tide of the brain drain.

On a more personal level, what do the families of patients in developed states owe to those who undertake the hardships of leaving their home countries to care for their loved ones in private households, nursing homes, and hospitals? Lisa Eckenweiler fills a large gap in the existing bioethical literature by confronting this question directly as a problem of justice. She concludes that those who utilize the services of these migrant care providers owe them recognition, solidarity, and “preventive foresight” in anticipating looming problems on both the personal and policy levels.

Whether we die from a chronic, debilitating disease like Alzheimer’s, or from accident or old age, we all die. But what is death anyway, and how do we know that a human being has died? Traditionally, before the advent of mechanical ventilators and the modern intensive care unit, this question was not particularly difficult to answer. A person was dead when their breathing and heartbeat had permanently stopped, period. But the development of technologies to keep the heart beating and blood flowing by mechanical means, coupled with the advent of organ transplantation, called for a serious rethinking of the very nature of death and the criteria and clinical tests for determining that someone has died. A conception of death as “whole brain death” involving the destruction of the entire brain—including both the brain stem and the neocortex—quickly emerged as the accepted standard in both medicine and law, but recent developments in intensive care medicine have called this longstanding consensus into question. Winston Chiong provides a helpful history of this long-running controversy, and offers his own philosophical and policy solution that rejects standard approaches based on a quest for a set of air tight necessary and sufficient conditions for death. Instead, Chiong proposes a more flexible account that would view death as a “cluster concept” composed of a variety of human functions that normally go together but that can be disaggregated in some circumstances that call for nuanced policy judgments based upon the nature of the decision at hand, such as transplantation, the continuation of treatment, or burial.

A focal point in bioethical debates about the definition of death and the ethics for forgoing life-sustaining treatments has been the permanent vegetative state (PVS). In this condition, the patient’s higher brain functions and capacity for conscious awareness have been permanently destroyed by cardiac arrest or traumatic brain injury, but the brain stem remains intact, thus leaving the patient in a state of “wakeful unresponsiveness.” Some advocates of a “higher brain” conception of death claim that patients who are permanently vegetative should be considered dead, and several of the salient cases in the ethics and law of forgoing treatment have centered on such patients (e.g., Quinlan, Cruzan, Schiavo). If the moral and legal valence of PVS were insufficiently controversial, we now have evidence from functional neuroimaging tests (fMRI) that many patients formerly diagnosed as persistently or permanently vegetative actually exhibit some degree of motor, spatial, and linguistic neural activities. In other words, such patients are actually conscious to some degree (“minimally conscious”), and up to 40 percent of patients diagnosed as in PVS by standard behavioral measures may have been misdiagnosed according to these new techniques. Joseph Fins underscores the clinical and ethical complexities of such developments emanating from the neuroscience laboratory and charts their implications for clinical ethics.

The ethics of forgoing life-sustaining treatments, always controversial, has become even more heated with the advent of the disability critique of bioethical orthodoxy. The standard bioethical approach to forgoing such treatments has consisted of two steps: First, discern what the patient wants or would have wanted; second, in the absence of such subjective information, choose so as to advance the patient’s best interests.

Advocates for individuals who are disabled often claim that what might seem at first glance to be an autonomous wish to die might instead be a not fully autonomous response to negative social judgments, and that the quality of life of these individuals, judged from their own perspective, might be much higher than physicians might think. Although they concede that some versions of this disability critique might be exaggerated and problematically paternalistic, Leslie Frances and Anita Silvers maintain that our standard bioethical assumptions bearing on decisions to die need to be rethought in light of the circumstances of the disabled within societies that often marginalize their voice and denigrate their quality of life.

Beyond the ethics of treatment refusal and termination, there are the far more controversial practices of physician-assisted dying and active euthanasia—i.e., assisting patients' attempts to terminate their own lives (e.g., by prescribing a lethal dose) or actively killing patients unable to accomplish death on their own. Whether or not one ultimately approves or disapproves of such practices, there is at least a strong autonomy-based moral and legal argument for them: viz., death is sought by virtue of the patient's own choice. Even more controversial, then, are cases of active euthanasia without any appeal to the patient's wishes or values. Here death is sought on the sole ground of mercy, to end a patient's suffering. And within this category by far the most controversial cases involve newborn children freighted with lethal and painful conditions. Focusing on the Dutch "Groningen Protocol" for regulating infanticide for children, Marian Verkerk and Hilde Lindemann explore the darker side of the neonatal intensive care unit that now salvages many children who would have mercifully died in previous decades, but now live on only to experience unbearable suffering.

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ALZHEIMER'S DISEASE

Quality of Life and the Goals of Care

Bruce Jennings

Introduction

There are approximately one hundred forms of dementing illness, but Alzheimer's disease (AD) is the most prevalent type, accounting for over 60 percent of all cases. The risk of symptomatic AD increases with age. Today it affects an estimated 5.4 million people in the U.S. and 432,000 in the U.K. Worldwide, the prevalence of all forms of dementia is over 24 million people. In 2050 there will be an estimated 11–16 million people with AD in the U.S., and the cost of their care will exceed \$1.1 trillion (Alzheimer's Association 2012: 13–21; Nuffield Council on Bioethics 2009: 4–6).

AD is a progressive and degenerative brain disorder that gradually undermines cognitive function and emotional control. The disease lends itself to the mapping of various stages of impairment and dysfunction, although the manifestation of behavioral symptoms varies significantly among individuals. In addition to the loss of short-term memory and disorientation in relation to everyday activities, AD also progressively manifests changes in the individual's personality; the onset of psychiatric conditions such as depression, paranoia, hallucinations; the erosion of executive functions regarding such things as personal hygiene, apparel, and social etiquette; and loss of self-control in the presence of strong feelings such as anger, frustration, or fear. Fine motor function, judgment, and physical response time may also be affected during the course of the disease.

In bioethics and moral philosophy, neither the ethics of dementia care, nor indeed more generally the ethics of cognitive impairment and chronic long-term care, have been a central focus of research or analysis (Nussbaum 2006; Kittay 1999; Kittay and Carlson 2010). This is surprising given the social impact of AD. Even today there are relatively few extended treatments of the ethical aspects of AD and dementia (Post 1995; Agich 2003; Hughes and Baldwin 2006; Hughes et al. 2006; Nuffield Council on Bioethics 2009). In the broader culture, the background presence of dementia is evident, but it is not often openly or seriously discussed; it remains shrouded in fear, shame, and taboo. Alzheimer's leads us to think about a condition that is profoundly at odds with a culture enamored with open horizons, independence, youth, physical vitality, and cognitive acuity.

Broadly defined, the ethical challenge of AD is twofold. It puts self-identity, personhood, and the value of continued living in question. And it puts what we owe to one

another in question. Careful thinking about AD forces one to confront the *imperative for care*—that is, to face up to our common human need, fragility, vulnerability, and dependency on others. It also presents the ethical challenge of the *imperative to care*—to face up to moral responsibility or obligation in recognizing and responding to the needful vulnerability of others, despite the involuntary limits—or in any case, the “transformation”—that giving care to someone with AD brings about in one’s life and future.

If the message of impairment that goes with AD is that our bodies and our brains are vulnerable, the message of care is that we are also fragile in ourselves and our minds (MacIntyre 1999). We cannot flourish humanly solely on our own, or on our own terms. We cannot *be* alone because we cannot subsist without being cared about and cared for. Moreover, we cannot *become* alone because we cannot realize our human potential without caring for, being cared about, and, especially, without caring with. Human flourishing happens in the space of interrelationships of mutual accommodation with others.

Care as a Structure of Meaning

AD creates circumstances in which particular decisions involve ethical dilemmas and require the application of general principles and values in order to resolve them. However, AD care is not simply a series of individual treatment or care decisions. It is a pattern of decisions, treatment plans, and caregiving practices that take on a certain shape and tend in a certain direction over a long period of time. Therefore, what a bioethics perspective can bring to Alzheimer’s is not simply well formulated moral rules or principles, but in addition a careful understanding of the appropriate metaphors, resonance, sensibility, and moral imagination required by the challenge of AD. The bioethics of dementia requires careful attention to the task of interpretation so that beneath the surface, or between the lines, of the memory loss, confusion, disorientation and the other symptoms of AD, can be seen a remaining person who is experiencing a life of a certain quality and still capable of a certain kind and degree of communication and relationship with others.

Considered as a pattern of interaction, Alzheimer’s care must be discerning and interpretative, and it must also be intentional and directed toward certain ethical and humane goals. The structure of long-term relationships between persons living with AD and those who care for and protect them has an impact on the quality of life and experience of the individual. That structure of interactions forms a kind of social environment or ecology, which, like the physical and architectural environment of the patient with AD, has a direct influence on the person’s impairment and its manifestation and consequences. A social and physical environment can greatly reinforce and exacerbate the impairment caused by the progressive neurological damage and loss of function; a particular pattern and place of caregiving can be a disabling condition in the context of AD. By the same token, the environment within which care is given can be an enabling and sustaining influence. The social dimension of AD care may not be enough to overcome the neuro-physical and chemical aspects of the disease, for which at the moment there is no effective cure or medical treatment. However with the right goals, resources, and techniques, social care can stave off the loss of personhood and meaningful living for a considerable period of time (Kitwood 1993, 1997; Kitwood and Breden 1992; Killick and Allan 2001; Jennings 2010). Stated somewhat differently, if the brain cannot

be restored through cure, that does not mean that the mind cannot be preserved and healed for a time through care. As Steven Sabat and Rom Harré argue:

... if [in dementia] there is a loss of the capacity to present an appropriate self, in many cases the fundamental cause is to be found not in the neurofibrillary tangles and senile plaques in the brains of sufferers, but in the character of the social interactions and their interpretation that follow in the wake of the symptoms.

(Sabat and Harré 1992: 460)

Alzheimer's creates the need for the conservation of mind and self in the face of the deterioration and disintegration of the brain (Harré 1998; Harré and Gillett 1994). So in an important sense AD care is a form of reminding. It is reminding in the ordinary sense of recalling to mind something that has been forgotten; in AD care a person's memory of past abilities and experiences can be nurtured and used therapeutically, and the loss of short-term memory and behavioral control can (to some extent) be mitigated and compensated for.

Alzheimer's care is reminding in another sense of reconstructing the subject, the person. It is a rediscovering and refashioning of relationality and specific modes of communicating and interacting with others (Killick and Allan 2001). Reminding is changing the environment and the external support system that surrounds the person so that *different* abilities do not become *the absence of* abilities. Reminding, as the play on words suggests, is remembering who and where one is, most fundamentally, as a human person (a "subject" who still has the ability to act as distinct from an "object" who is merely acted upon by others); and how one must be treated by family and society. The tragedy of AD is not only that it alters brain function and changes what people do; the deeper tragedy occurs when and if the long-term care and health care systems allow—or even cause—those changes to "objectify" persons, reducing them to the status of mere objects and not subjects, and treat them only in terms of their impaired body and altered behavior, rather than working with them to re-remember themselves and to be re-remembered among those with whom they are living.

The Imagined Reality of Alzheimer's

Alzheimer's has an objective, scientific and physical reality, a social reality, and what might be called an imagined reality. The imagined reality consists of paradigms, icons, and images concerning dementia. These are the lenses and filters through which we most habitually perceive and create assumptions, attitudes, and reactions to AD. Among the most important facets of this imagined reality are beliefs that have to do with the loss of mind, self, and personhood due to the neurological impairment AD involves and with the lack of continuity of self-identity over time. Work in bioethics should critically reexamine this imagined reality and the social construction of AD.

In the face of AD, family members (and other caregivers) have to fashion new patterns and new structures of meaning for themselves. This is shown clearly in the literature of various memoirs, autobiographical accounts, and "pathographies" of AD (Bayley 1999; Bernlef 1988; DeBaggio 2002, 2003; Cooney 2003; Davidson 1997; McGowin 2003; Mitchell 2002). At least in the early stages of dementia, individuals with AD who are aware of their own symptoms and changes must do this, too. Still sensitive to the cues and reactions of others around them, persons living with dementia may assimilate and

take such patterns of response into their own work of reminding and healing. They also carry with them into the course of their disease expectations about dementia previously drawn from the culture and perhaps their own experience with a parent or loved one. They, like others with disability, will have to refashion such expectations to preserve their self-identity and esteem from the negative interpretation that encroaches upon them (Davidson 1997; Bayley 1999).

There are three aspects of the imagined reality of AD and the conventional patterns of response to it that should be examined carefully before the issues of quality of life and the goals of care can be addressed. Careful analysis and reflection may lead us to reject or drastically modify each of these factors in the imagined reality of AD.

The first aspect is the assumption that the impairment of brain must of necessity erase the ability to make meaning, what can be called *communicative ability*, and thereby erode one's membership in the human moral community, a membership status that involves being understood by yourself and others as a subject rather than an object. The absence of amyloid plaques and neurological tangles does not guarantee, in and of itself, a normal self; similarly the presence of these abnormalities in the brain need not, in and of itself, preclude the continued exercise of communicative ability or erase one's status as a person or subject.

The second widely held view that should be examined critically is the notion that quality of life for persons with moderate to severe cognitive and behavioral impairments from dementia involves primarily security, comfort, and the fulfillment of immediate, experiential interests. This is the hedonic (comfort and safety) notion of quality of life. An alternative conception of quality of life, to be discussed below, holds that the preservation and restoration of capacities for human flourishing and self-realization, appropriate within the context of AD, are the ethically warranted goals of care.

And, third, the notion that the proper stance of the family (or others with the legal and moral authority to make decisions on behalf of the patient with AD) *vis-à-vis* a person with moderate to severe dementia is one of "guardianship," the purpose of which is to protect the best interests of the person with dementia as defined by their hedonic and experiential quality of life. An alternative conception, which I refer to as "trusteeship," is that the ethically (and legally) appropriate standard for caregivers entrusts them with pursuing the conditions necessary for the preservation of capacity and personhood of the individual receiving care.

Quality of Life

The phrase, "quality of life," is almost always controversial. The basic idea behind the concept of quality of life is that some characteristics of the person and his or her surrounding environment are better than others from the point of view of the human good or human flourishing (Nehamas 1998; Nussbaum and Sen 1993). Yet, despite its difficulty and frequent lack of clarity, the concept of quality of life seems to be an indispensable one. It is especially pertinent to the situation and care of persons with dementia and is very commonly brought up in this context. Therefore, a consideration of the various meanings the concept of quality of life has and the controversies surrounding it are central to a consideration of the goals of dementia care.

What are we talking about when we invoke a person's "quality of life"? There are two common notions that are often conflated and should be clearly distinguished, especially when dementia is the focus of discussion; the first is useful, the second pernicious.

Quality of Life as a Goal of Care

One common meaning of quality of life defines it as a goal of care. The moral point of our dealings with another (whether the situation be health care or some other form of relationship) is to sustain and improve the quality of life. In this sense, quality of life becomes a benchmark to guide human activity and a norm of assessment and evaluation. But notice that the evaluation here is directed primarily at the caregiver and the caregiving process, not at the recipient of care, who partakes of the quality of life achieved but is not judged by it. Moreover, quality of life can be thought of as an interaction between the person and his or her surrounding circumstances, including other people. Thus understood as a goal or outcome of care, an improved quality of life may be a change (for the better) in the person's symptoms or perceptions; or it may be a change in the person's relationship with his or her environment. Medical cure, symptom relief, psychological happiness, or social empowerment may all be goals of care as comprehended by the concept of quality of life.

Quality of Life as the Moral Worth of a Life

The term quality of life is sometimes also used to refer to the moral worth or value of a person and his or her life. Pushed to its logical extreme, this understanding of the quality of life takes us to the infamous Nazi concept of "life unworthy of life" (*lebensunwertes Leben*), which was used to rationalize everything from active euthanasia of those with disabilities to the genocidal death camps (Lifton 1986; Cohen 1983). To say that a person has no quality of life or a very low quality of life is to say that prolonging this person's life has no moral significance, either to the person himself or to society.

In my own view, it is a mistake to use quality of life as a measure of the moral worth of human beings. The notion of the moral worth of a life is logically quite distinct from the notion of quality of life. An account of moral worth is based on an underlying account of humanness or the human person; an account, that is, of what it is to be human. The concept of quality of life, however, is based on an account of a person's inherent capacities and external circumstances. Quality of life may legitimately reveal what is required in order to *become (more fully) human*, but it cannot completely define the value of *being human*.

Let us now consider the main philosophical theories of quality of life. In the history of philosophy there are many such accounts. Most of the theories that are pertinent to dementia and dementia care fall into two categories (Brock 1993; McCormick 1978; Parfit 1984: 493–502; Scanlon 1993): Hedonic theories and capability theories.

Hedonic Theories

These accounts identify quality of life with the individual's awareness, consciousness, or experience. Happiness or pleasure, however those terms are precisely to be defined, are the *sine qua non* of quality of life. This allows for considerable individual variation in assessing good quality of life because different things make different people happy, but it also allows for some kind of common metric (at least on the negative side) because there are seemingly universal negative states of pain or suffering or unhappiness that all (normal) persons avoid.

An interesting question is whether the kind of happiness (or pleasure) that makes for a good quality of life is a direct, unmediated sensation, or instead a more complex psychic

state that results from some act of self-interpretation. If it is the former, then it would seem to follow that a person locked in a cell with an electrode implanted in a pleasure center of the brain would be experiencing the highest quality of life. That conclusion must be mistaken and counts against the theory. However, if the pleasure or happiness the theory requires involves some form of cognitive mediation and secondary interpretation, then persons who have serious cognitive deficits will be automatically judged to have a poor quality of life by definition, and that view seems unduly biased against non-intellectual goods in life.

Capability Theories

This type of philosophical theory attempts to base our understanding of the good life on an account of those functions, capacities, and excellences that are most fully and constitutively human. To the extent that we attain and master those capacities, and to the extent that we avoid those conditions that would stunt or undermine those capacities, we flourish as human beings. Theories of this type also usually have a developmental component built into them, for those most fully human capacities are ones that are not mastered at birth or automatically expressed by instinct, but must be developed and nurtured by education, interaction with others, and practice over the course of a lifetime. To the extent, then, that the individual continues to grow and develop throughout his or her life, quality of life on the capability view is enhanced by that growth.

Accounts of these important capacities differ among philosophers, but as a generalization we can say that they usually emphasize the following elements: (1) The human capacity to take part fully in social relationships of intimacy, friendship, and cooperation; (2) the capacity to use reason and to develop and follow a life plan of self-fulfillment and self-realization; (3) the capacity for independence and self-reliance; and (4) the human need for an appropriate social and cultural environment that provides the individual with various types of resources necessary to meet both basic and secondary needs (Nussbaum 2011).

In mainstream medical and legal approaches to AD care, the most commonly adopted philosophical perspective is the hedonic (Cantor 2005). It may seem that only this type of theory is compatible with the radically diminished cognitive capacity in dementia, but this may be a serious conceptual bias. The relative strengths and weaknesses of these two types of philosophical theory have not been explicitly discussed in the medical literature, and the hedonic approach has been adopted without sufficient critical analysis.

There is nothing in the capability theory of quality of life that necessarily makes it inapplicable to the situation of AD. When applying capability theory to this context, for example, the question becomes how to supplement and perpetuate those capacities that we value as expressive of our humanity. When one of the bodily (neurologic) preconditions for the exercise of these capacities is damaged, caregivers could try to find a social, environmental functional equivalent for it. If a speech disorder manifests itself in a person's dementia, caregivers could try to compensate with resources for non-verbal communication, for it is in the communication itself that important ethical goals of dementia care—such as respect for the person and the preservation of agency and capability—are met, not in the particular medium of communication (Killick and Allan 2001). If short-term memory loss is a problem, environmental cues, interior renovations, and the like could be used to facilitate a daily round of social relationships that do not require a robust memory.

Although capability theories often stress high-level cognitive skills in their accounts of quality of life, relational and communicative factors that remain present in dementia, virtually until its end stage, can easily be shifted to the center of attention. Making sense together, remembering a distant past and self, making judgments and expressing evaluations, even though non-verbally through emotional responses and bodily, kinetic gestures—these are some of the constituent elements or capabilities of a quality life, whatever the degree of one's other abilities at short-term memory processing and reasoning.

Those without the impairments of dementia do these and other things in many different ways with an audience of others or with an audience of various "selves" or perspectives within their own minds. Those with the impairments of dementia do them differently, more tenuously, and need different kinds of audiences and help, but they do them, sometimes for a remarkably long time into the progress of the disease. Life lived with and in spite of dementia, then, even well into its later stages, can be appreciated and understood by drawing on conceptions of human agency and flourishing; and it need not be assessed only in the most directly sensate, hedonic terms (Albert and Logsdon 2000; Burgener 1998; Lawton 1995; Russell 1996).

The Goals of Care and the Obligations of Caregivers

AD involves memory impairment, cognitive impairment, loss of emotional and behavioral control, and loss of "executive function," or the person's sense of what conduct is socially appropriate. Consequently, caregiving often involves restraining or deflecting the willful behavior of the affected person, sometimes by physical and coercive means. Who then should superintend the person with dementia? What norms of conduct should govern dementia care and the exercise of power and authority it involves so that protective measures do not become abusive and excessive? The ethical boundaries within which dementia caregivers operate are related to one's views on the goals of care and the quality of life that should be preserved for the person.

There are two contrasting frameworks within which ethics and the law have tried to address these issues. The first is the *guardian model*; the second is what may be called the *trustee model* (Jennings 2001).

The guardian model is concerned primarily with the health, safety, comfort, and hedonic quality of life of the incompetent person. The trustee model is more broadly concerned with sustaining and preserving the person's capacities and abilities in ways appropriate to the developmental course of the disease. The guardianship model is grounded on a duty of protection. The trustee model, by contrast, is principally grounded on a duty to promote, preserve, and sustain the agency and the dignity of the person being cared for. Its aim is environmental adaptation in order to accommodate ongoing impairments to agency and to preserve remaining capacities for agency by the person living with AD.

How well does the model of guardianship fit the circumstances of AD? The guardian model is close to the everyday look and feel of Alzheimer care in homes and families, where most persons with mild to moderate AD still reside. It is even closer to the attitude toward caregiving prevalent in nursing homes. However, the guardian model has some problems and limitations when applied to the circumstances of risky behavior in AD care.

One problem is the tendency of the guardian model to treat decision-making capacity as an all or nothing proposition. A guardian is not appointed at all unless a person is

determined to be legally incompetent, and once that is done the guardian assumes the entire decision-making function and is not bound by the person's current preferences. (A person without competence is considered to be a person whose "preferences"—if he or she can be said to have preferences at all—do not legally matter.) The directing goal of the guardian's decision-making is the best interests of the ward. In clinical settings matters are not usually so formal and legalistic, but it is not uncommon for the patient to fade into invisibility as a person if a determination of incapacity is made. Unfortunately, this is particularly likely in the case of persons with AD, even in its early stages.

In the field of bioethics, the all or nothing approach of the guardian model is not endorsed as the best practice of surrogate decision-making (Buchanan and Brock 1990). On the contrary, decision-making capacity is understood as constituting a spectrum of ability; the patient may be significantly involved in some decisions where he or she has a definite preference and excluded or overridden in others. This style of caregiving, which fits the trustee model more closely than the guardian model, is done not primarily for reasons of expedience, tranquility, and humane patient control, but for the explicitly ethical goals of preserving agency and respecting the person being cared for.

In the early stages of AD's long course of decline, patients are situated on the margins of decision-making capacity and personal judgment, not clearly in the realm of either autonomy or incompetence. Here caregiving involves small coercions, the little skirmishes through which the management of risky or inappropriate behavior is conducted. The decisions of a person with AD in its early stages are shaky, fallible, and debatable. Clearly, this is a matter of degree, for this kind of fallibility characterizes the situation of all of us some of the time. But during early AD the tension escalates, and conflicts between the person with early AD and family and caregivers inevitably arise.

In the ethics of AD care we must therefore consider the complex dynamics of justified "paternalism" in the context of marginal capacity. Paternalism has been defined as any case where one person acts to diminish another person's freedom or violates their rights (e.g., to be informed), to the end that the other person's good may be secured (Kleinig 1984; De Marneffe 2006; Conly 2012; Coons and Weber 2013). Paternalism thus is often an issue for ethical analysis in health and long-term care settings. Many philosophers have argued that paternalism can be justified under certain conditions. Feinberg (1986), for example, considers the proportionality between the importance of the liberty lost and that of the harm to the self that is prevented. G. Dworkin (1988, 2010) emphasizes the future-oriented nature of the person's interests being served by the paternalistic intervention. Paternalism is justified now if it serves greater freedom or autonomy later and if the person whose freedom was limited can ultimately acknowledge that benefit.

Such arguments are generally persuasive, but they do not perfectly fit the situation of controlling behavior in early AD. For one thing, analyses of paternalism of this kind do not shed much light on the problem of assessing relative risk; instead, they tend to assume that as a starting point. This is a flaw in the guardian model generally. Once relative risk has been assessed, and the risk has been found to be immediate and serious, then the duties to protect the incompetent against harm to self and the duties of promoting a loved one's best interests clearly apply. But in mild dementia the risk assessment stage is difficult. If we look at risk narrowly, then forgoing all kinds of activities is almost always the most reasonable thing to do. As one's capacities erode, one constricts one's repertoire of behavior accordingly, like closing concentric circles. But if we take the psycho-social costs of restricting freedom and curtailing activity seriously, then excessive caution may not be in the best interest of the person with dementia. Such overly

cautious guardianship may indeed prove harmful to the ward. Even at the level of physical health and wellbeing, such a course of caretaking for persons with AD leads to an earlier sedentary existence, more rapid loss of cognitive skills, and increased morbidity and mortality. This is one instance in which the goals of guardianship (understood as protection against harm) and trusteeship (understood as sustaining agency and capacity) are most clearly at odds.

Most of the inappropriate or dangerous behavior that patients with early AD wish to engage in grows out of their desire to sustain some part of themselves that they, perhaps inchoately, feel is being lost. This interpretation of early stage AD behavior is attested to in both first person and family member memoirs of the experience of the disease (DeBaggio 2001; Davidson 1997) and in more social scientific and clinical observational accounts (Kitwood 1997). If this is the case, then we take too narrow a view of the moral reality of the situation presented by dementia when we focus exclusively on coercion and the limitation of behavior. Curtailing behavior is only an early step in a morally justified response to the problem. What persons living with early and mid-stage AD need is more than protective restraint; they need help in effecting a transition from one set of behavioral skills to another. They need an environment (both physical and human) that provides them with alternative ways of sustaining their sense of self other than those past activities that have now become inappropriate or dangerous. Here a sheer clash of wills is *not* always inevitable, and there is room for accommodation and adjustment.

Persons with AD can be led to move the focus of their attention and intention from one object to another and from one activity to another. Cooking is not the only way to validate your identity as someone who cares for her family, and driving is not the only way to sustain your sense of independence and self-reliance. Creativity in caregiving is required to find viable and acceptable substitutes; finding a morally desirable outcome is sometimes difficult, but it is not impossible. Often some minor risk is not the principal evil to be avoided; the devastating ripple effects of continuous conflicts and clashes of will can be much more destructive.

In the care and superintendence of persons with AD, the trustee model emphasizes the preservation and restoration of capacities for human communicative relations and an honoring of the identity of the person with dementia as the principal goals of care. Work in the bioethics of Alzheimer's care should assist the broader health care system in reconceptualizing the concept of best interests so that it is not exclusively defined by the hedonic conception of quality of life and its preoccupation with security, comfort, and the fulfillment of immediate, experiential interests. The focus of trusteeship is the person, the subject, the self as an active being in the world of meaning and relationships with others. Trustees view progressive dementia not so much as a declining state in which capacity, agency, and personhood are lost, but as a state of transitions and transformations. Without romanticizing the devastating aspects of AD, trustees stress difference rather than loss, and look for whatever value and meaning can be found in those states of being and capacities for agency that do remain available to the self prior to the end stage of the disease (Burgener 1998).

The goal of trusteeship is to sustain the person's human flourishing and quality of life in ways suggested by capability theory. For trusteeship, providing comfort, pleasant sensation, and experience is not enough. The challenge is to create a caregiving environment or social ecology, containing the necessary caregiving skills and practices that meet the goals of preserving the communicative and relational capacity of the individual with dementia, and acknowledging that this individual remains someone to whom respect,

dignity, and care, not just custodial comfort and safety, are owed. The problems posed by the symptoms of AD are attributed to the pathology of the patient's brain, but that is not sufficient because these problems are often exacerbated by the care-taking environment and the (usually well-intentioned) behavior of the caregivers. An ethical response to AD requires that the caregiving system accommodate these symptoms in creative ways and that it compensate for them as much and for as long as possible.

Alzheimer's and End-of-Life Care

If the hedonic conception of quality of life is too narrow in the early and middle stages of dementia, it also gives the wrong kind of guidance in the late stages.

One aspect of end-of-life dementia care that has provoked an important debate in bioethics has to do with the use of advance medical directives, standards of surrogate decision-making, and the use of life-sustaining technologies such as artificial nutrition and hydration through the use of percutaneous endoscopic gastrostomy (PEG) feeding tubes (Finucane and Bynum 1996; Grant et al. 1998; Finucane et al. 1999; Rudberg et al. 2000; Gillick 2000; Post 2001). Individuals who have lost decision-making capacity must have medical treatment decisions made by a designated representative or surrogate, and the standard view in bioethics is that individuals' prior wishes and instructions, when they exist, should guide the surrogate in making these decisions. In other words, end-of-life treatment decisions should be made on the basis of the patient's advance directive or on the basis of what the surrogate decision-maker infers would be the patient's express preference if he or she were able to make the decision (the so-called substituted judgment standard).

The hedonic conception of quality of life casts substantial doubt on the currently prevailing ethical and legal approach to end-of-life care in dementia in cases where prolonging life through technological means, such as PEG tube feeding, may be hedonically acceptable as in the patient's best interests, but where it would be forgone if the patient's advance directive were followed. Challenging the standard view, Dresser and others (1986; Dresser and Robinson 1989) have argued that a contemporaneous best interest standard, rather than an advance directive or substituted judgment approach, should be used in decision-making about forgoing life-sustaining treatments. Best interests on this view should be defined by assessing the quality of life of the patient with advanced dementia in hedonic terms. Counter-arguments by R. Dworkin (1993), Post (1995), and Jaworska (1999), among others, appeal to interests and senses of personhood that go beyond hedonic quality of life as reasons why we should honor a person's advance directive or longstanding wishes and values. R. Dworkin, for instance, makes a distinction between what he calls "experiential interests" and "critical interests," the former being those things that a person experiences as enhancing their good and the latter those things that rationally, objectively do enhance a person's good whether he or she is aware of it or not. A person with dementia may have lost all experiential interest in her previous values, beliefs, and instructions—because she has forgotten them or can no longer understand what they mean—but it does not follow that her critical interests in these things has been lost, or that their significance for the person's quality of life has been erased. And it is on the basis of a person's critical interests that both quality of life and the obligations of caregivers toward the person must be assessed; experiential interests (or hedonic quality of life) alone are important, but ethically insufficient to be the determining factor in end-of-life treatment decisions.

Conclusion

If it does nothing else, critical work in bioethics on quality of life and the goals of care in AD should increase our awareness of new possibilities for family, professional, and community caring for persons with dementia. Bioethics should teach our society how to read dementia properly. In AD there is a kind of personhood that seems devoid of relationality and is therefore limited to the protection of comfort and safety, not because it really is, but only because we do not know how to interpret it.

Related Topics

Chapter 21, "Autonomy," Catriona Mackenzie
 Chapter 22, "Capacity and Competence," Jessica Berg and Katherine Shaw Makielski
 Chapter 34, "Family Caregivers, Long-Term Care, and Global Justice," Lisa Eckenwiler

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