

Alzheimer's Disease: The Long Gray Hallway

BAPTIST CENTER FOR GLOBAL CONCERNS

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A Current Moral Issue

Ever increasing numbers of older Americans begin a slow walk down “the long gray hallway” years before their symptoms are diagnosed as Alzheimer’s Disease (AD). Alzheimer’s, a significant cause of dementia among older people, “is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks of daily living.” Recent estimates indicate that about 5.5 million Americans have AD (estimated to reach 14 million by 2060), and these numbers will likely grow, unless the disease can be effectively treated or prevented, because the risk of AD increases with age and the American population is aging. Treatment

can slow the progression of the disease and help individuals and their families to manage it, but there remains no cure.

The causes of Alzheimer's disease are not yet fully identified, but it is known to develop because of a complex series of events that occur in the brain over a long period of time. The likely causes include genetic, environmental, and lifestyle factors. People differ in their genetic make-up and lifestyle, so the significance of these factors for preventing or delaying Alzheimer's differs from person to person. The *time* from diagnosis to death varies—as little as 3 years if the person is older than 90 when diagnosed to as long as 9 or more years if the person is diagnosed at age 65. A person's gender, the presence of other health problems, and the severity of cognitive problems at diagnosis are other factors that affect how long a person will live with AD.

AD creates significant financial implications because total costs of care for individuals with the disease (by all payers) will range from \$277 billion (which does not include unpaid caregiving) this year to more than \$1.1 trillion by 2050. The disease is also important because those afflicted with Alzheimer's experience deep physical, psychological, emotional, and even spiritual travail due to its ravages. The disease can strip a person of his or her dignity and exacts a heavy toll on families that cannot be measured simply in monetary terms. These implications raise ethical concerns related to values like sanctity of life (SL) and justice.

An Ethical Intersection

Some current philosophical perspectives recast historical norms regarding sanctity of life (SL) and personhood, thus categorizing those with dementia (e.g. AD) as having *lives not worth living* (e.g. utilitarianism). In this model, a life worth living is one in which a person has “developed presently exercisable *psychological abilities* [*italics mine*] for understanding, choice, and rational communication” and “actually exercis[es] such abilities in the enjoyment of an acceptable quality of life.” Such a view not only affects those who suffer

with AD but also impacts numerous other persons across a spectrum from the unborn to the comatose to those facing end-of-life illnesses.

On the other hand, SL traditionally holds that human beings possess inherent worth and nothing can remove this value. In such a view, consideration of human worth and dignity would also include emotional, relational, creative and spiritual capacities even if rationality were in decline or absent. *Practically*, ethical treatment of individuals requires truthful and sensitive diagnostic disclosure of probable AD as well as referrals to available resources (e.g. counseling & support group interventions).

People often fear AD because it cripples the capacity to make judgments, solve problems, remember past and present events, conduct business, maintain relationships, experience emotions, recognize oneself, and control bodily functions. Any one of these circumstances can adversely impact human dignity and quality-of-life (QL) perceptions in a patient and his or her family. QL judgments are subjective in nature and the onset of AD can exacerbate negative judgments (cf. some AD sufferers who seek a right-to-die). A supportive environment, social resources, and end-of-life palliative care can offset feelings of despair (cf. attitudes that may contribute to despair such as *vitalism*, the view that bodily life is to be sustained at all costs; cf. also medical paternalism and burdensome medical treatment at end-of-life). QL judgments (cf. those based upon a utilitarian calculus) may lead to subtle pressure to rid society of unproductive members. Such judgments are hurtful and hold implications for justice.

Implications for a Christian Ethic

Contrary to the belief that those who lack “empowering cognitive capacities” are nonpersons, those with AD, while *weakened* by their condition, *remain worthy* of care and respect. Several steps will improve a Christian end-of-life response to *those with AD and their families*.

Christian caregivers seek to *eliminate the stigma* often associated with Alzheimer's (e.g. a "life not worth living" or assigning less value & social status). *Sensitive truth telling* about an AD diagnosis should be the norm because it provides a person with AD the time to plan for "optimal life experiences" in the remaining years of intact capacities and to prepare for end-of-life decisions with family members (e.g. advance directives and durable power of attorney documents). *Respect for competency and autonomy* means that persons suffering from AD should be allowed to exercise those capacities for the specific tasks and choices they retain. AD leads to a progressive reduction in a broad range of capacities, so patients, their families, and churches should develop and sustain caring structures and resources throughout the various stages of the disease (Matthew 25:36).

A diagnosis of AD alone does not indicate incompetency, therefore, it is especially distressing to people with dementia to have their wishes overridden in areas in which they are still competent. However, it remains obligatory to protect a person with dementia from seriously harmful consequences. *Functional devaluation*, albeit unintentional, often occurs within churches where there may be a theology of care, but poor provision of a "hospitable milieu" of care for AD sufferers and their families. Sadly, most church ministries are oriented toward those with cognitive and productive capabilities. The Lord *who knows and remembers* His creation, calls His church to active care for AD sufferers and their families.

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