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# Living with Dementia: Caregiver Perspectives

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# Living with Dementia: Caregiver Perspectives

## **Abstract**

About four million Americans currently live with Alzheimer's disease (AD) or related forms of dementia. Because the disease process impairs language, insight, and judgment, family members become "caregivers." These caregivers, either in part or in full, often make decisions on patients' behalf. This Issue Brief summarizes a series of studies that describe how caregivers make decisions for AD patients, and caregiver perspectives on the quality of life for relatives with AD.

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## ***Living with Dementia: Caregiver Perspectives***

Editor's Note: About four million Americans currently live with Alzheimer's disease (AD) or related forms of dementia. Because the disease process impairs language, insight, and judgment, family members become "caregivers." These caregivers, either in part or in full, often make decisions on patients' behalf. This Issue Brief summarizes a series of studies that describe how caregivers make decisions for AD patients, and caregiver perspectives on the quality of life for relatives with AD.

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## ***Alzheimer's disease and other dementias have profound impacts on families***

Alzheimer's disease is a chronic, progressive, and ultimately fatal illness that is associated with substantial physical and emotional suffering. It currently affects one in 10 people over age 65 and nearly half of those over age 85. Because of the increasing elderly population, the number of Americans with AD is expected to reach 14 million by 2050 if no cure or prevention is found.

- A person with AD lives an average of eight years after initial diagnosis and may live as many as 20 years after the onset of symptoms. People with AD tend to live with their families until the most advanced stages of the disease. Spouses and adult children—typically daughters—usually provide daily care for AD patients not in nursing homes.
- Caregivers experience significant distress and psychological burdens in caring for AD patients. These experiences may influence how caregivers perceive the patient's quality of life, and thus how they make decisions for patients.

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## ***How caregivers rate the quality of their relative's life***

To understand how the caregiving experience affects the decisions caregivers make, Karlawish and colleagues interviewed 40 primary caregivers of AD patients attending a Memory Disorders Clinic.

- Not surprisingly, from the caregiver's perspective, lower ratings of the patient's quality of life were associated with lower ratings of the patient's overall mental health and higher ratings of the severity of the patient's dementia.
  - Nearly half of the caregivers assess the patient's quality of life differently than they believe the patient would. The caregiver's "substituted judgment" of quality of life was lower when they perceived the patient's mental health as poor.
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- The caregiver's own experience of depression and burden was associated with worse ratings of the patient's quality of life. Caregiver distress over losing control of the patient's behavior was most strongly associated with lower quality-of-life judgments.

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### ***Caregivers value AD patient's quality of life more than survival or delaying the move to a nursing home***

Among the same study group of 40 caregivers, Karlawish and colleagues explored caregivers' priorities when deciding on potential treatments for their relatives with AD. The interviewers described a hypothetical AD-slowing drug and asked the caregivers to rank the importance of possible risks and benefits.

- Nearly 70% of caregivers said that they considered delaying nursing home placement more important than extending their relative's life by one year.
- More than half of caregivers identified a benefit more important than both survival or delayed nursing home placement for their relative. These include quality-of-life benefits such as maintaining memory, the ability to communicate with and recognize family, and the ability to perform daily tasks.
- Most caregivers would accept some risk of side effects from the hypothetical drug, ranging from mild gastrointestinal bleeding to the need for blood transfusions. In order to slow AD progression by one year, 66% of caregivers would accept some risk of the patient's death.
- Caregivers who were adult children, more educated and working 20 hours or more per week were more tolerant of risks, as were those with a family history of the disease.

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### ***Caregiver burden, trust in researchers are important factors in deciding whether to enroll an AD patient into a clinical trial***

Advances in the treatment or prevention of AD depend critically on scientific research and clinical trials. Patients with AD and their caregivers face an ethical challenge when deciding whether to enroll in a clinical trial, because AD impairs decision-making ability. To examine how patients and family members make this decision, Karlawish and colleagues interviewed 22 caregivers of patients with mild to moderate AD who were recruited for a 15-month clinical trial of a promising drug. Of these, nine caregiver-patient pairs chose to enroll, eight declined, and five were ineligible for the trial.

- Caregivers who enrolled were all spouses who report having made the decision quickly, often citing the "desperation" they felt in finding help for their relative. Caregivers who did not enroll were typically adult children who made the decision more deliberately and focused on the hassles and burdens, such as traveling to the study site.
  - Caregivers who enrolled reported greater patient involvement in making the decision than did the caregivers who declined to enroll. Six of nine caregivers who enrolled described a decision-making process that included the patient's preferences about enrolling. In contrast, half of the caregivers who did not enroll said that the patient's role was limited to having an awareness of the trial. Five of seven caregivers who did not enroll said that the patient had expressed a desire to enroll.
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- In general, caregivers described a complex weighing of their preferences with the patients' preferences. Most caregivers did not clearly distinguish risks and benefits for themselves from those for the patient. The blending of caregiver and patient interests points to the interdependence of the risks and benefits of research for caregivers and patients.
  - Trust was one of the key motivators to enroll in research. The caregivers cited trust in the researchers, the clinic, the university and the pharmaceutical company that sponsored the research. This trust helped to minimize concerns about potential research risks and helped them cope with their desperation to find an effective treatment.

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### ***Study assesses voting behavior of patients with dementia, and caregiver assistance with voting***

In addition to making decisions about clinical research and treatment, caregivers help their relatives with AD decide on a wide range of activities that dementia may affect. As an example, Karlawish and colleagues assessed the voting behavior of patients with dementia in the 2000 US Presidential Election. They surveyed 75 caregivers of patients attending an Alzheimer's Disease Center. All interviews were conducted within two months of the election.

- Caregivers reported that 48 patients (64%) voted. In contrast, 70 caregivers (93%) reported that they voted. These figures exceed the proportion of voters nationwide (51%) who voted in the election.
- Patients with less severe dementia, and patients with a spouse as caregiver (as opposed to an adult child) were more likely to vote. However, nearly one-quarter of patients who voted had moderate or severe dementia.
- More than 90% of the patients who voted did so at a polling place; the vast majority of them voted alone in the booth. Patients were more likely to vote on their own than to make their own health care decisions.
- Nearly one-quarter of the caregivers reported helping the patient vote; one caregiver cast a vote on behalf of the patient.
- More than three-quarters of caregivers believed that they should not complete ballots for patients unable to make voting decisions; 24% of caregivers felt that a close family member should complete the ballot in that situation.

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### ***POLICY IMPLICATIONS***

These studies offer an important glimpse into the perspectives of caregivers of patients with AD, and some insights into how they make important decisions for and with their affected relatives.

- Caregivers' depression and burden negatively affect their perception of their relative's quality of life and willingness to enroll their relative in a clinical trial. Therefore, clinicians should screen for and address caregiver depression and burden, as well as address problematic patient behaviors that contribute to caregiver burden.

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## **POLICY IMPLICATIONS**

*Continued*

- Caregiver trust in the people and institutions conducting research is crucial to participating in AD research. This points to the importance of human subjects protections and other safeguards that engender and preserve trust in clinical research.
- More research is needed to understand how persons with dementia and their caregivers decide what activities the person can and cannot do, and how well these decisions correspond to measures of competency.

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*This Issue Brief is based on the following articles: J.H.T. Karlawish, D.A. Casarett, B.D. James, K.J. Propert, and D.A. Asch. Do Persons With Dementia Vote? Neurology, April 2002, vol. 58, pp. 1100-1102; J.H.T. Karlawish, D.A. Casarett, J. Klocinski, C.M. Clark. The Relationship Between Caregivers' Global Ratings of Alzheimer's Disease Patients' Quality of Life, Disease Severity, and the Caregiving Experience. Journal of the American Geriatrics Society, August 2001, vol. 49, pp. 1066-1070; J.H.T. Karlawish, D.A. Casarett, J. Klocinski, and P. Sankar. How Do AD Patients and Their Caregivers Decide Whether to Enroll in a Clinical Trial? Neurology, March 2001, vol. 56, pp. 789-792; J.H.T. Karlawish, J.L. Klocinski, J. Merz, C.M. Clark, and D.A. Asch. Caregivers' Preferences for the Treatment of Patients with Alzheimer's Disease. Neurology, October 2000, vol. 55, pp. 1008-1014.*

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## *Issue Brief*



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