Assessment of Health State Utilities Associated With Being a Caregiver pr-eu2024) for a list of all Lilly conter for a Person With Alzheimer's **Disease With Mild Cognitive Impairment or Dementia**

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OBJECTIVE

The purpose of this study was to estimate health state utilities associated with being a caregiver for a person with mild cognitive impairment (MCI) or dementia associated with AD.

CONCLUSION

- Utilities followed expected patterns. Greater caregiving responsibility was associated with lower utilities. Mean utilities were lower for health states describing caring for a spouse/partner compared to health states describing caring for a parent with the same disease severity.
- Utilities for the US and UK samples were remarkably consistent, with no significant differences in utility between the two countries.
- This study adds to the existing literature on caregiver utilities. Methodological aspects of this study can inform future research on caregiver utility estimation.
- The utilities estimated in this study may be useful in models examining and comparing cost-effectiveness of treatments for MCI or dementia associated with AD.

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STUDY DESIGN

- Six health state vignettes were drafted as described below in the Health State Development section (see example health state in **Figure 1**, and a complete list of health states in **Table 1**).
- These health states were valued in time trade-off (TTO) utility interviews conducted from October 2023 to February 2024 with samples of general population respondents in the UK and US.

| Τ | | | | |
|------------------------|--|--|--|--|
| Your Spouse or Partner | • You live with your spouse. • It sometimes seems like something is not right with their thinking and memory . | | | |
| Behavioral Impact | You sometimes notice that the following things occur: They forget and lose things more often than they used to. They lose their train of thought. They ask the same question repeatedly or engage in repetitive conversations. | | | |
| Emotional Impact | They are sometimes frustrated by their problems with memory and thinking. Sometimes, they seem anxious or depressed about their thinking abilities. Your spouse does not have as much confidence in their abilities as they used to. | | | |
| Functional Impact | • Their ability to perform their typical daily tasks is not impaired, but subtle changes are noticeable to close family members. • They show less interest in activities they used to do. • They avoid some activities, such as driving in unfamiliar areas or at night. • They sometimes get lost in places they know well. • They sometimes forget appointments and social events. • They have some difficulty organizing some tasks, like cooking a complete meal. • They have made some lifestyle adjustments to compensate for the memory changes. For example, they write things down to ensure that they don't forget them. | | | |
| Your Role | • You do not have any daily caregiving responsibilities. • You take on more organizational responsibility than you used to, like planning things for both of you. | | | |
| Impact on You | You sometimes try to minimize your spouse's symptoms in public by helping them remember things and answering questions for them. You watch their behavior to try to better understand what the problem is and what the future might bring. | | | |
| Emotional Impact | You sometimes feel irritated because of repetitive conversations with your spouse. You worry about whether they can independently manage daily activities like shopping. You worry about the future of your spouse's condition and your relationship with them. | | | |
| Healthcare | • Because of what you have noticed, you have started searching on the internet for information on memory disorders. • You have made appointments with healthcare providers to assess your spouse's condition. | | | |

BACKGROUND

- Alzheimer's disease (AD) is the most common cause of dementia, accounting for 60% to 70% of cases.^{1,2}
- Patients with AD dementia often require caregivers, a role which typically falls to a family member. Caregiving for people with AD dementia has been found to be associated with increased stress,^{3,4} anxiety,⁴⁻⁶ depression,⁴⁻⁶ worsened mental functioning,⁴ and lower quality of life.⁷ However, the burden of caregiving may be reduced by interventions targeting psychiatric symptoms, behavioral disturbances, and quality of life in persons with AD dementia.⁸

METHODS

Participants

General population participants were required to meet the following criteria: (1) \geq 18 years of age; (2) able to understand the assessment procedures; (3) able and willing to give informed consent; (4) able to complete the protocol requirements; and (5) a UK or US resident.

Health State Development

- Health state descriptions were developed based on literature review and multiple rounds of telephone interviews with five clinicians (3 neurologists and 2 psychiatrists in the UK and US with an average of 17.6 years of
- Participants completed health state valuation tasks and then provided feedback on health states and interview procedures. Almost all participants had no difficulty understanding the health states or the TTO task.
- Minor edits were made to the health states for clarity based on participant feedback.
- Because there is no consensus regarding methods for valuing caregiver health states, several TTO approaches were explored in the pilot study. Interviewers gathered feedback from participants about their understanding and comprehension of each approach, which was reviewed to inform the methods used in the main valuation study, including the upper anchor

Although the burden of caregiving for a person with AD dementia has previously been quantified,⁸⁻¹² the effect caregiving has on an individual's utility has rarely been studied.^{13,14}

Table 1: Health State Utilities

lealth State Description Letter

- Caregiving for parent with MCI due to AD Α
- Caregiving for parent with mild dementia due to AD В
- Caregiving for parent with moderate dementia due to AD С
- Caregiving for spouse/partner with MCI due to AD D
- E Caregiving for spouse/partner with mild dementia due to AD
- Caregiving for spouse/partner with moderate dementia due to AD

experience working clinically with MCI/AD demented patients).

- Health states were reviewed and refined in focus groups with members of Alzheimer Europe's European Working Group of People with Dementia and European Dementia Carers.
- Two of these focus groups were conducted, one with caregivers of parents with AD (n=4, all women, average age 59 years old) and another with caregivers of spouses/partners with AD (n=6, three women, average age 64 years old).

Pilot Study

Prior to the main study, a pilot study was conducted to finalize the interview procedures and health state descriptions (N = 25; mean age = 41.2 years; 56% women).

of the scale.

Procedures

- Participants first ranked the health states in order of preference. Then, they valued the health states in a TTO task. After completing the TTO portion of the interview, the participants also completed a demographic and clinical information form.
- After reviewing the performance of the various upper anchors attempted in the pilot study, the upper anchor of the utility scale was defined as an absence of emotional and logistical caregiver burden because the family member does not have MCI or dementia.

Table 2: Demographic Characteristics

| Characteristics | UK Sample (N=304) | US Sample (N=202) |
|---|-------------------|--------------------|
| Age (years), (mean, SD) | 46.7 (15.7) | 46.4 (16.2) |
| Gender (n, %) | | |
| Male | 139 (45.7%) | 100 (49.5%) |
| Female | 164 (53.9%) | 96 (47.5%) |
| Nonbinary | 1 (0.3%) | 6 (3.0%) |
| Ethnic Background (n, %) | | |
| Hispanic or Latino | | 19 (9.4%) |
| Not Hispanic or Latino | | 182 (90.1%) |
| Missing | | 1 (0.5%) |
| Racial Background (n, %) | | |
| Asian/Asian British <u>/Asian American</u> | 24 (7.9%) | <u>27 (13.4%)</u> |
| Black/African/Caribbean/Black British <u>/African American</u> | 8 (2.6%) | <u>33 (16.3%)</u> |
| Mixed/Multiple ethnic groups | 12 (3.9%) | <u>7 (3.5%)</u> |
| White | 249 (81.9%) | <u>123 (60.9%)</u> |
| Other | 11 (3.6%) | <u>12 (5.9%)</u> |
| Marital Status (n, %) | | |
| Single | 101 (33.2%) | 83 (41.1%) |
| Married | 97 (31.9%) | 66 (32.7%) |
| Other | 106 (34.9%) | 53 (26.2%) |
| Employment Status (n, %) | | |
| Full-time work | 116 (38.2%) | 91 (45.0%) |
| Part-time work | 76 (25.0%) | 44 (21.8%) |
| Other | 112 (36.8%) | 67 (33.2%) |
| Education Level (n, %) | | |
| No university degree | 93 (30.6%) | 59 (29.2%) |
| University degree | 211 (69.4%) | 143 (70.8%) |
| Participant had a family member with MCI diagnosis | 53 (17.4%) | 49 (24.3%) |
| Participant had a family member with AD diagnosis | 75 (24.7%) | 54 (26.7%) |
| Participant had experience as a caregiver for a person with dementia due to MCI or AD | 60 (19.7%) | 55 (27.2%) |

Sample Description

Results

• A total of 304 participants from four locations in the UK (Edinburgh [n=59], Leeds [n=72], London [n=116], and Bath [n=57]) and 202 participants from two locations in the US (Bethesda, MD, [n=108] and Chicago, IL [n=94]) completed the TTO utility elicitation.

Health State Rankings

- In the UK, health state A (parent with MCI) was ranked first by 65.8% of the sample. Health state D (spouse with MCI) was ranked highest by 31.3% of the sample. Health states C (parent with moderate AD) and F (spouse with moderate AD) were most commonly ranked lowest by 26.6% and 70.7% of the participants, respectively.
- In the US, health state A (parent with MCI) was ranked first by 55.0% of the sample. Health state D (spouse with MCI) was ranked highest by 38.6% of the sample. Health states C (parent with moderate AD) and F (spouse with moderate AD) were most commonly ranked lowest (35.6% and 59.9% of the sample, respectively).

Health State Utilities

Mean (SD) utilities are presented in **Figure 2**. In both countries, all health state comparisons across severity levels (e.g., mild vs. moderate AD) were significant (p<0.0001). In the UK, utilities for all parent health states were significantly higher than corresponding spouse/partner health states (p<0.0001). In the US, utilities for parent mild and moderate AD

dementia were significantly higher than corresponding spouse/partner health states (p<0.05), but there was no significant difference between parent and spouse MCI health states (p=0.08). There were no significant differences in utilities between samples in the UK and US.



Figure 2: Mean Health State Utilities (N=304 in UK, N=202 in US)

Abbreviations: AD = Alzheimer's dementia; MCI = mild cognitive impairment; SD = standard deviation; UK = United Kingdom; US = United States

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Limitations

- Utilities are derived from general population preferences for hypothetical health state vignettes, rather than the experiences of actual caregivers. Comparability between these values and those derived from caregivers is unknown.
- Assessment of caregiver utilities is still an emerging field with no consensus on the preferred methodology for utility elicitation. Further research is required to provide more confidence in these methods.

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