

The Impact of Informal Caregiving in Alzheimer’s Disease Dementia: A Health Utility Study in the United Kingdom

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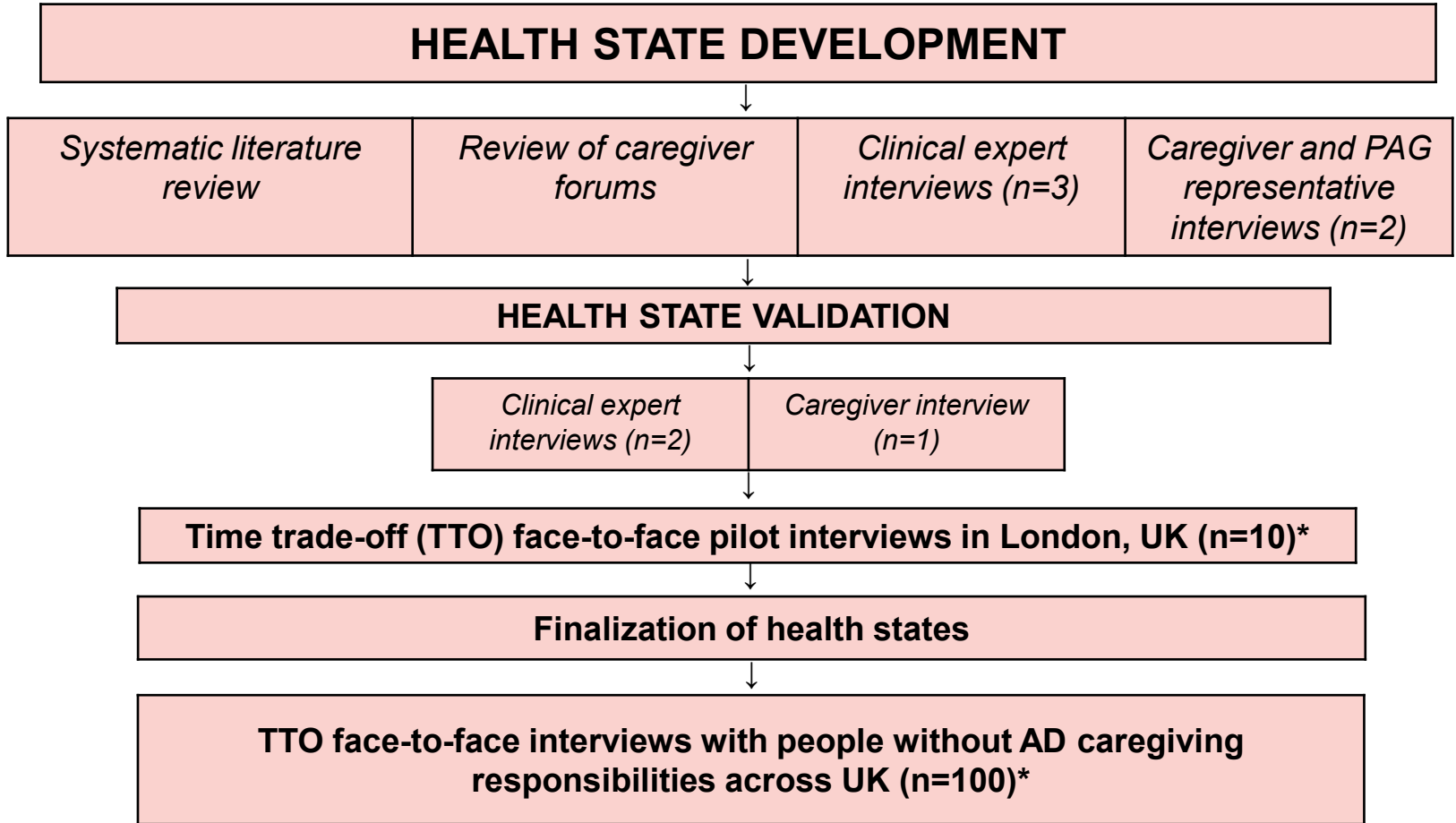
BACKGROUND

- Alzheimer’s disease (AD) dementia is a debilitating neurodegenerative condition which profoundly impacts health related quality of life¹
- Patients with advanced AD dementia may struggle to live without support, which imposes a severe burden on informal (unpaid) care partners, who may be spouses, family members, friends or neighbors^{2,3,4}
- The care partners experience great stress, and as a result, nearly half of care partners meet formal diagnostic criteria for depression and show increased utilization of healthcare resources and psychotropic medications^{5,6}

OBJECTIVE

- The primary objective of this study was to quantify the impact that caring for a patient with AD dementia has on the care partners’ utility in the United Kingdom

STUDY DESIGN



PAG: Patient advocacy group
* Data analyzed based on disease severity (mild, moderate, and severe), care partner-patient relationship (may be spouses, family members, friends or neighbors) and living situation (with the patient or separate from the patient)

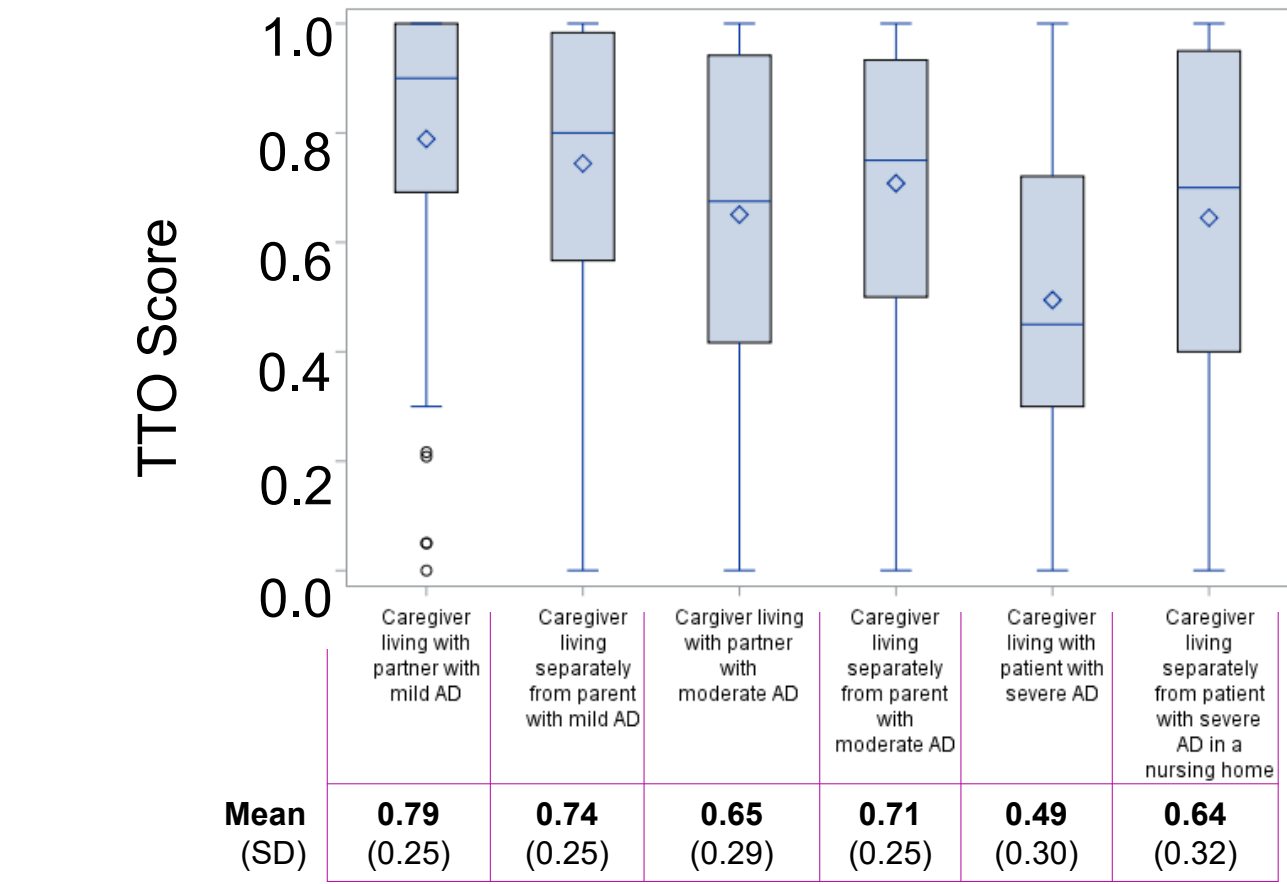
METHODS

Time Trade-off (TTO)

- Utility values (0 to 1) were elicited through TTO face-to-face interviews with members (N=100) of the general public. This method is recommended by National Institute for Health and Care Excellence (NICE) in the absence of appropriate utilities values derived from a generic measure
- In TTO studies, respondents imagine themselves as a person in the described health state
 - This study had the further requirement of respondents imagining themselves as care partners who experience burden due to their relationship with a person diagnosed with AD dementia, in a described health state
 - The reference state, normally defined as unimpaired/perfect health, was considered a state of “no care partner burden” in this study

KEY RESULTS

Utility values for six AD dementia caregiving health states, valued by 109* members of the UK public, using the TTO methodology



* One respondent was removed from the pilot study data because the respondent misunderstood the concept of the study and found the TTO unethical

CONCLUSIONS

- The care partner and patient living status did not appear to have a significant impact on utility of the care partner in the case of mild or moderate disease. However, in the severe stages of AD dementia, institutionalization of the patient was associated with a significantly higher care partner utility than for care partner living with the patient (the lowest reported utility value).
- This study provides an estimate of the impact of caring for a person with AD dementia on care partner disutility, at a variety of severity levels and within various living situations.
- These utility values can be used in cost-effectiveness models as NICE now allows the use of care partner utilities in the base case.⁷

Methods

Statistical Analysis

- Results from the utility interviews were analyzed using SAS (version 9.4)
- TTO scores were recorded in years, months and days (≤10 years)
- These values were decimalized and divided by 10 to give a final utility score (0-1)
Example: if health state for care partner living separately from parent with mild AD dementia elicited a TTO score of 5 years and 6 months, the corresponding utility value would be: 5.5÷10 = 0.55
- TTO utility values were presented as means, standard deviations (SD), medians, interquartile ranges, minimums and maximums for each health state
- Each respondent provided utility values between 0.0 and 1.0 for each health state
- Data from the pilot study were pooled with the general sample since no changes were made to the health states
- Paired t-tests between 2 groups were performed to test statistical significance

Results

- Overall, mean TTO scores decreased with increasing severity of AD dementia when a patient was living with a care partner
 - Care partner living with a patient with AD dementia: mild (0.79; 95% confidence interval [CI]: 0.74 to 0.84), moderate (0.65; 95% CI: 0.60 to 0.71) or severe dementia (0.49; 95% CI: 0.44 to 0.55)
 - Care partner living separately from a patient with AD dementia: mild (0.74; 95% CI: 0.70 to 0.79) or moderate dementia (0.71; 95% CI: 0.66 to 0.76)
 - Care partner living separately from a patient with AD dementia in a nursing home: severe (0.64, 95% CI: 0.58 to 0.71)

Results

- In the whole population, paired t-tests demonstrated a statistically significant difference between most health states (p<0.05) with the exception of:
 - Care partner living with partner with AD with mild dementia versus care partner living separately from parent with AD with mild dementia (p=0.0684)
 - Care partner living separately from parent with AD with mild dementia versus care partner living separately from parent with AD with moderate dementia (p=0.1070)
 - Care partner living with partner with AD with moderate dementia versus care partner living separately from parent with AD with moderate dementia (p=0.0644)
 - Care partner living with partner with AD with moderate dementia versus care partner living separately from patient with AD with severe dementia in a nursing home (p=0.8742)

Key Limitations

- Limitations related to the health state development
 - Limited number of primary sources (i.e., 2 current care partners and 1 former care partner) may have led to a depiction of caregiving that is not fully representative
 - Not all identified AD dementia symptoms and impacts could be included due to the limited length of each health state and the need to limit the number of health states
- Respondents aged over 61 years were underrepresented relative to the UK population
- Proportion of respondents with higher education was higher than the UK average
- TTO typically considers respondents to be in perfect health and to imagine themselves in the health state, whereas in this study respondents were required to imagine themselves as a care partner of a patient

References

1. Bird TD. Alzheimer Disease Overview. In: Adam MP, Ardinger HH, Pagon RA, et al., eds. GeneReviews [Internet]. Seattle (WA): University of Washington, Seattle. 1993-2022.
2. Alzheimer's Association. Alzheimer's disease facts and figures. Alzheimers Dement. 2016;12(4):459-509.
3. Mohamed S, Rosenheck R, Lyketsos CG, et al. Caregiver burden in Alzheimer disease: cross-sectional and longitudinal patient correlates. Am J Geriatr Psychiatry. 2010;18(10):917-27
4. Wimo A, Reed CC, Dodel R, et al. The GERAS Study: a prospective observational study of costs and resource use in community dwellers with Alzheimer's disease in three European countries--study design and baseline findings. J Alzheimers Disease. 2013;36(2):385-99.
5. Sallim AB, Sayampanathan AA, Cuttitan A, Chun-Man Ho R. Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. J Am Med Dir Assoc. 2015;16(12):1034-41.
6. Garzon-Maldonado FJ, Gutierrez-Bedmar M, Garcia-Casares N, Perez-Erazquin F, Gallardo-Tur A, Martinez-Valle Torres MD. Health-related quality of life in caregivers of patients with Alzheimer's disease. Neurologia. 2016;32(8):508-15.
7. National Institute for Health and Care Excellence. NICE health technology evaluations: the manual. 2022. Available at: <https://www.nice.org.uk/process/pmg36/resources/nice-health-technology-evaluations-the-manual-pdf-72286779244741>

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