Living with Dementia: Mental Health and Mortality Effects on Spouses

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Alzheimer's disease and related dementias (ADRD) affect nearly 50 million people worldwide, a number expected to rise substantially in the coming decades, imposing pressure on health care systems, public budgets, and families (OECD 2020; Alzheimer's Association 2024). ADRD is among the most costly diseases in high-income countries, primarily because of the demanding, inflexible, and round-the-clock long-term care patients require (Chandra et al. 2023). Indirect costs are at least as large as direct medical expenses, yet they are typically calculated from forgone wages associated with family caregiving alone, while a comprehensive assessment must also incorporate spillovers onto the broader well-being of family members. The family member most continuously exposed is the patient's spouse, who shares a household with the affected individual, is often the primary caregiver, and is aging alongside the patient. Population-level evidence on the health consequences of this exposure remains limited.

In this paper, we provide population-level estimates of the mental health and mortality consequences of having a spouse with ADRD. Our analysis uses Danish administrative registers covering the full population from 1995 through 2018, linking patients to spouses and combining vital statistics, health care encounters, prescriptions, and cause-of-death records. We follow spouses over a 17-year window spanning 10 years before to 5 years after the patient's death and use the year of death as the index year in a matched event-study design. As in our companion work on adult children, identification rests on the progressive nature of ADRD, in which the years preceding death are marked by increasing disability and dependence. Because symptom onset does not reliably correspond to diagnosis (Nicholas et al. 2021), we center the design on death, which is precisely measured.

We construct 17,025 matched triplets, each consisting of an ADRD patient and spouse together with two counterfactual patient–spouse pairs. Matching is on spouse birth year, gender, and education and on patient birth year, with household wealth used as a propensity score tie-breaker. In the first counterfactual, the matched patient never developed ADRD and did not die in the index year, and is assigned a placebo death year drawn from the matched ADRD patient. In the second, the matched patient died of causes unrelated to ADRD in the index year. Comparing ADRD spouses with placebo spouses recovers the effect of a spouse dying with dementia, and comparing non-ADRD spouses with

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placebo spouses recovers the effect of a spouse dying without dementia. The difference between the two comparisons isolates the component specific to ADRD rather than to spousal illness and bereavement more generally.

We find that mental health care use among treated spouses is indistinguishable from the counterfactual trend until approximately eight years before the patient's death, at which point it begins to rise and continues to climb through the year of death. The increases are large. Relative to placebo spouses, the share of spouses with a mental health visit approximately triples, rising from 2.5 to 7.5 percent among men and from 3.75 to 11 percent among women, while psychiatric medication use increases by roughly 50 percent. Spouses whose partners died of other causes exhibit no comparable pre-death trend. Expressed relative to the outcome mean, the difference between ADRD and non-ADRD spouses in mental health visits is 33 percent for men and 21 percent for women eight to five years before death, rising to 82 and 68 percent over the final four years; differences in psychiatric medication use follow a similar trajectory but are smaller, reaching 12 and 10 percent.

The gap between ADRD and non-ADRD spouses closes in the year of death and remains closed thereafter. We interpret this pattern as evidence that the mental health burden reflects sustained exposure to the disease rather than bereavement: once the patient dies, spouses of ADRD patients resemble spouses bereaved for other reasons. Part of the measured increase in the years preceding death reflects dementia-related diagnostic encounters for the spouse, which we examine separately.

We also find that spouses of ADRD patients face elevated mortality as the patient's disease progresses, with the largest effects among men, and that the excess is concentrated in dementia-related and neurological causes rather than in cardiovascular or other stress-mediated pathways. This is consistent with a caregiving burden channel, but also with shared environmental risk or assortative mating, and we are investigating these explanations in ongoing work. Differential mortality also complicates inference, since attrition is substantial: by the index year approximately 50 percent of male and 22 percent of female spouses have died, rising to 75 and 50 percent five years later. Because spouses in worse mental health die earlier, this selection biases the estimated effects toward zero. We address it by constructing a balanced panel that drops a matched set whenever any member dies, by applying Lee (2009) bounds that trim excess survivors from the placebo matches, and by restricting the sample to spouses alive ten years before the patient's death. All three produce estimates close to the main results, which lie near the Lee lower bound, and we therefore interpret our estimates as conservative.

We observe only muted heterogeneity by spouse age at death, household wealth, and number of children, indicating that the mental health burden is broadly distributed rather than concentrated among disadvantaged households. The most notable heterogeneity is by the patient's use of a nursing home, a proxy for disease severity and care intensity: effects are markedly larger when the patient is institutionalized, so the burden scales with disease severity rather than being relieved by the transition to formal care.

Our study builds on three strands of literature. First, we contribute to research on the health consequences of dementia for family members, which documents elevated psychological distress among dementia caregivers relative to other caregivers and to non-caregivers (Pinquart and Sörensen 2003). This work is largely survey-based, relying on samples too small for precise population estimates or for following families across the full disease trajectory. Second, we complement a literature in economics that uses administrative data to study family spillovers of health shocks (Fadlon and Nielsen 2021). These studies typically examine unanticipated events such as heart attacks or sudden death, whereas ADRD progresses gradually, motivating a design centered on a well-measured event. Third, we contribute to work on the degree to which a comprehensive formal care system mitigates the family costs of chronic disease (Løken et al. 2017).

Denmark maintains one of the most extensive public long-term care systems in the world (OECD 2020), and in companion work we show that this system largely insulates adult children from the labor market and physical health consequences of parental dementia while leaving mental health spillovers

intact. The present results indicate that spouses, who are more directly and continuously exposed, bear both mental health and mortality costs even in this setting. We therefore read our estimates as a lower bound on the spousal costs of ADRD where families shoulder more of the care burden directly.

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