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Mental Health Effects of Having a Parent with Dementia

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Study Aims: Alzheimer's disease and related dementias (ADRD) impacts close to 50 million people globally, and rates are projected to increase (Knopman et al., 2021). ADRD entails a progressive cognitive decline marked by behavioral and psychiatric symptoms which gradually limit autonomy in everyday activities and self-care tasks, leading to highly demanding, inflexible, and round the clock long-term care needs (Kasper et al., 2015; Nicholas et al., 2021, Frahm-Falkenberg et al., 2016; Chandra et al., 2020). Much of the need for care is met by family members, and this role puts significant strain on the mental health and well-being of family caregivers, especially those with both professional duties and caregiving responsibilities (Bom & Stöckel, 2021). A full accounting of the societal costs of ADRD must include the substantial spill-overs on the economic, mental, and physical health of family members (Freedman & Wolff 2020; Friedman et al. 2015; Choi et al. 2021).

This project will investigate the mental health effects of having a parent with ADRD. These include the direct effects of witnessing a parent experience cognitive decline and dramatic mood and personality changes, the impact of taking on an intensive caregiving role (Schmitz & Westphal 2015; Bom et al., 2019; De Zwart et al., 2017; Coe & Van Houtven 2009), or via other related pressures, including the combination of caregiving and work (Van Houtven et al., 2013; Fahle & McGarry, 2017; Schmitz & Westphal 2017). We link Danish national vital statistics records and tax registries to create a longitudinal panel allowing us to observe health care use (doctors' visits, hospitalizations, prescriptions) and annual labor market outcomes for all adult children of ADRD patients for up to 10 years before and 7 years after an ADRD-related parental death. We use data that spans 1995-2018 to examine two specific aims:

Aim 1: ***How does mental health care utilization of adult children evolve before and after the onset of a parent's ADRD symptoms through their death and the subsequent adjustment period?*** As the mental health effects of experiencing parental ADRD may differ significantly across individuals, influenced by personal, social, and economic factors, the study will uncover which groups are most at risk for adverse mental health outcomes and who may benefit from targeted support and interventions.

Aim 2: ***Which factors influence psychosocial and behavioral responses, as proxied by mental health care utilization, to parental ADRD?*** This aim includes (i) analyzing the comparative mental health impacts of parental death from ADRD and non-ADRD causes, (ii) examining how caregiving, changes in labor supply, and financial distress may contribute to changes in demand for mental health care, (iii) assessing shifts in health-seeking behaviors prompted by increased healthcare interactions and firsthand experience with a chronic, potentially genetically linked disease, and (iv) documenting the specific challenges faced by the 'Sandwich Generation' in managing parenting young children, caring for aging parents, pursuing a career, and the emotional strain of observing a parent's cognitive decline.

Significance and Innovation: Our study contributes to a greater understanding of the substantial, but often difficult to measure mental health consequences of dementia. Family mental health spillovers are an unaccounted-for cost of chronic, progressive illnesses such as ADRD. Rising life expectancy and a rapidly aging population will lead to a growing share of the population living with ADRD, and more working age adults navigating the dual responsibilities of regular employment and informal caregiving. Although Denmark, the setting of our study, has one of the most comprehensive public long-term care systems in the world, this demographic shift comes as the provision of formal long-term care (LTC) services dwindles in generosity, primarily due to the rising costs associated with an aging population and a shortage of LTC professionals (Danish Ministry of Finance et al., 2020). Our findings will point to the challenges of ADRD above and beyond what can be addressed by substantial public spending on LTC and generous workplace leave policies for working caregivers (Rellstab et al. 2020; Anand et al., 2022).

Existing studies of the impact of ADRD on the outcomes of family members have two major methodological limitations. First, many studies rely on surveys to identify ADRD patients and their caregivers, and even the largest, nationally representative surveys of older adults, such as the Health and Retirement Study and National Health and Aging Trends Study in the US and the Survey of Health, Ageing and Retirement in Europe do not include sufficiently large samples to fully examine the impact of having a parent with ADRD. We develop a strategy to move beyond survey-based investigations to identify the children (and eventually other family members) of ADRD patients in administrative data. The administrative data that we use will include the universe of all ADRD-related deaths and is sufficiently powered to identify even small effects among key subgroups. Furthermore, the administrative data also allows us to link parents to all their children, so we can identify the full set of potential caregivers.

Second, empirical studies that estimate family spillovers of disease and disability often focus on sudden, often preventable health shocks such as heart attacks or strokes (Frimmel et al. 2020; Fadlon & Nielsen, 2021; Rellstab et al. 2020), limiting our understanding of the effects of chronic, progressive, incurable disease such as ADRD which are becoming increasingly prevalent and important for policy planning and political priorities

(Larson et al., 2013). Our empirical approach allows us to capture the span of disease progression, including the period between symptom onset, a potential diagnosis, and the death of a parent (Chandra et al., 2020). We also observe a long post-death period, which will fully capture any dynamics that play out following a death. By taking a dynamic approach, we will show how mental health care use evolves with the progression of the disease and demonstrate if and to what extent these consequences extend or resolve *after* the demise of a parent, which is not possible with survey-based samples which center on ADRD patients and do not follow family members after death. In this way we will capture a life course perspective on the potential impacts of ADRD, which are spread out over time.

We will also provide evidence on the distribution of these consequences nationally and within families based on demographic characteristics. If mental health spillovers vary by gender or educational status, then it is important to understand how this generates or exacerbates disparities in health and wellbeing across sociodemographic groups (Marchand et al., 2016). Finally, using population-based administrative registries we can construct counterfactual groups which provides us with the opportunity to unpack the mechanisms underlying mental health trajectories, including the role of the stress of family caregiving, or the stress of experiencing the death of a parent.

Approach: Using linked, population level administrative datasets, we construct a treatment group including all individuals with an ADRD-related death (primary or secondary cause of death) or diagnosis who died between 2003 and 2013 in Denmark and link them to the health records of their children. We track the annual mental health care utilization of these children for up to 10 years before and 7 years after their parent's death, using the year of the death as the event time. To form the control group, we match children whose parents died from ADRD with individuals from the general population. These individuals share essential demographic characteristics, such as birth year, region, gender, and education level, but do not have a parent with a history of ADRD. While one-to-one matching is not a prerequisite for causal identification, it ensures baseline comparability between the two groups and facilitates a clean comparison of unadjusted outcome trends during the study period and enhances the transparency of the event-study design. For each matched control, we assign the treatment pair's event year—the year in which the ADRD parent died—as a 'placebo' event year. This aligns the timelines for both the affected children and their matched counterparts.

The event study approach is based on comparing the mental health care utilization of paired children in the treatment and control over a 17-year observation period, focusing on individuals before and after the death of a parent with ADRD. Using panel data balanced in event-years, this approach will allow us to estimate precise event-year coefficients, adjusted for age and all time-invariant personal characteristics. The comprehensive observation period encompasses three key phases: the disease's initial or non-existent stages, where the familial burden of ADRD is presumed to be minimal; the severe stages, which precede the patient's death and require intensive caregiving due to significant cognitive impairments; and finally, the period following the patient's death. While disease onset, progression and death are not random, this approach aims to capture the varied impact of ADRD on children’s mental healthcare utilization across different stages of the disease.

We will also examine the possible behavioral responses to having a parent with ADRD that may be driving any mental health care effects that we observe. To control for the effect of experiencing a parent’s death, irrespective of ADRD status, we will include a second control group comprised of children who experience a parent’s death in the same year as the treatment groups, but absent an ADRD diagnosis. To test if changes in work behavior, or the combination of work and caregiving, are driving changes in mental health, we will also include measures of labor supply as outcome variables. Additionally, our dataset includes demand for healthcare services unrelated to mental health. This aspect allows us to investigate whether changes in mental health care demand are the primary outcomes affected, rather than confounding general health trends emerging before the parent's death. Moreover, having access to population-level data enables us to identify key subgroups—such as by gender, income, and family structure—and assess if the observed treatment effect heterogeneity aligns with expectations. Although our analysis is descriptive in nature due to the absence of precisely identified exogenous 'shocks,' the length of our observation period centered around a key event, the examination of various key subgroups, and the availability of a wide range of other healthcare use outcomes provide a robust framework to rule out alternative potential explanations for our findings.

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