

# Trajectories of Spousal Caregiving prior to Widowhood across European Countries

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## Short Abstract (150 words)

Although pre-widowhood caregiving is consequential for surviving spouses' wellbeing before and following spousal death, no studies have documented longitudinal pre-widowhood caregiving experiences. This study addresses three research questions: What pre-widowhood trajectories of spousal caregiving exist in Europe? How do they differ across countries? How are they associated with surviving spouses' mental health before and after bereavement? Data from the Survey of Health, Ageing and Retirement in Europe (SHARE) are used to create and analyze sequences with information on spousal caregiving for up to 10 years prior to spousal death. Five distinct patterns are found that differ by whether personal care is given to the spouse, whether care is long- or short-term, and whether in-home care is provided. Surviving spouses in Western and Southern Europe are more likely to profit from in-home care, while surviving spouses in Eastern Europe are more likely to provide prolonged personal care.

## Introduction

Gerontological and public health research in the United States suggests that nearly all to-be widows and widowers provide care for their dying spouses prior to bereavement, and that a majority provide care alone (Ornstein et al., 2019). Numerous studies have focused on the impact of caregiving for surviving spouses as they transition from caregiving to widowhood (Baumbach et al., 2024) Spousal care givers are thought to be at a higher risk of mental and physical health decline (Williams et al., 2008), increased social isolation (Bolano & Arpino, 2020), and even cognitive deterioration (Wu-Chung et al., 2022) prior to spousal death compared to to-be widows and widowers without caregiving obligations. Chronic stress related to caregiving in the pre-widowhood phase has been argued to be linked not only with a slower recovery from grief and depressive symptoms following bereavement (Keene & Prokos, 2008; Van Hout et al., 2020), but with a higher mortality risk (Elwert & Christakis, 2008, 2011).

Although pre-widowhood caregiving has been shown to be consequential for surviving spouses' wellbeing both prior to and following spousal death, few studies have attempted to document pre-widowhood caregiving experiences at a population level (see Ornstein et al., 2019 for the United States). Most research that seeks to document spousal caregiving experiences is based on qualitative or mixed-methods studies with small samples (see DiGiacomo et al., 2013; Gibson et al., 2019; Groh & Saunders, 2020; Bijnsdorp et al., 2022 for examples). These studies have improved our understanding of the emotionally and physically burdensome caregiving

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load that spouses' often bear in the months and years leading up to spousal death, the consequences of that burden, and the mechanisms linking the two. However, we lack a population-level description of pre-widowhood caregiving experiences that would allow research to draw conclusions on both a national and cross-national scale.

In this study, address three research questions: First, what pre-widowhood trajectories of spousal caregiving exist in a sample of European countries? I draw on longitudinal data from the Survey of Health, Ageing and Retirement in Europe to create and analyze sequences with information on spousal caregiving for up to 10 years prior to spousal death. Second, how do trajectories of spousal caregiving prior to widowhood differ across European countries. This sheds light on whether compositional and institutional variation across countries translates into cross-national differences. Finally, how are trajectories spousal caregiving prior to widowhood associated with surviving spouses' mental health before and after bereavement.

## **Data and Methods**

I drew on SHARE data from the Survey of Health, Ageing, and Retirement in Europe (Börsch-Supan et al., 2013) to address my research questions. SHARE is a cross-national household panel study that collects information on health, socio-economic status and social and family networks of individuals aged 50 or older on a biennial basis.

The first wave of SHARE was collected in 2004 with representative samples of individuals in 11 European countries and Israel. The third wave of SHARE, also called SHARELIFE, consisted of a life history module rather than the regular questionnaire from the first and second wave. In the life history modules of SHARELIFE, retrospective information on respondents' work, family, residential, and health histories as well as information about childhood was collected. The 4th, 5th, 6th, 8th and 9th waves returned to the regular questionnaires from the first two waves that collected various prospective information and saw the addition of numerous countries. The 7th wave, collected in 2017, was a dual wave: Respondents and countries who did not participate in the third wave (SHARELIFE) were given the retrospective life history questionnaires rather than the regular prospective interview. Only respondents who had participated in the third wave were given the regular questionnaire.

Our aim was to assess the caregiving experiences of spousal loss on a sample of persons who were observed to experience a spousal death. I first restricted our country sample to those who participated in at least five waves, excluding wave 3. This ensures that our potential window of observation was long enough to observe transitions into widowhood. Note that Greece and Luxemburg were additionally excluded from the sample due to small sample sizes. Our sample included individuals from Austria, Germany, Sweden, the Netherlands, Spain, Italy, France, Denmark, Switzerland, Belgium, Israel, the Czech Republic, Poland, Slovenia, and Estonia.

Sequences were created based on respondents' responses on whether they provided regular personal care for their spouse, children, grandchildren, relatives, and non-relatives in the previous 12 months. Regular care is defined as daily or nearly daily care for at least three months. Examples of personal care include help with dressing, bathing or showering, eating,

getting in or out of bed, or using the toilet. Additional information from spouses was included on whether in-home or nursing care was received. Based on this information, we created a variable observed at every regular observation that indicates whether the respondent (1) gave no personal care to their spouse, (2) gave personal care to their spouse, (3) gave personal care to their spouse as well as to others, (4) gave personal care to their spouse receiving in-home care, (5) gave no personal care to their spouse who receiving in-home care, and (6) had a spouse in nursing home care.

We omitted respondents with fewer than three observations and used forwards and backwards filling to create sequences with annual states from 10 years prior to spousal death to the year of spousal death. An optimal matching distance matrix with constant substitution costs of 2 and insertion costs of 1 (OM 1&2) was calculated and applied to a partitioning around the medoids (PAM) clustering algorithm (Gabadinho et al., 2011). I extracted a five-cluster solution with a moderately high average silhouette width value of 0.56, indicating an acceptable structing of the data (Kaufman, Leonard, 1990).

To assess the first research question, I visualize the results of the cluster analysis to display different trajectories of pre-widowhood spousal caregiving. In a second step, I assess cross-national differences in the probability to belong to each cluster. Finally, I estimate the association between cluster membership and mental health both before and after widowhood.

## Results

Figure 1 displays the results of the sequence and cluster analysis as sequence density plots. I find two patterns that are characterized by relative stability over 10 years. While the “No Personal Care” cluster is defined by the lack of spousal caregiving and any care receiving on behalf of the spouse, the “Long-term Personal Care” is characterized by a relatively early transition into spousal caregiving without any considerable home or nursing care.

Two other clusters show a relatively early care take-up on the part of the dying spouse, although with a differing amount of involvement of behalf of the surviving spouse. In the “Transition to In-Home Care” cluster, dying spouses receive in-home care without the surviving spouse providing additional care. In contrast, in-home care is often proceeded and accompanied by personal care by the surviving spouse in the “Transition to Personal and In-Home Care” cluster. A final cluster labelled “Transition to Personal Care” is comprised of to-be widows and widowers who provide personal care to their spouses in the final two or three years of life. Interestingly, we find no patterns characterized by giving personal care to more than the spouse or to prolonged nursing home care.

Figure 2 displays the probability of spousal caregiving cluster membership by country. I find that across all countries the most common pre-widowhood trajectory of care is defined by the lack of personal caregiving by the spouse. Roughly 80 percent of Dutch pre-widowhood trajectories fall into the “No Personal Care” pattern, compared to somewhat less the 60 percent of French and Belgian trajectories. These two latter countries are however overrepresented in the “Transition to In-Home Care” pattern. This indicates that to-be widowed spouses in France

and Belgium may profit from strong in-home care systems. Surviving spouses in other countries in Western and to a lesser extent Southern Europe also seem to be more likely than their counterparts in Eastern Europe to profit from in-home care. In contrast, surviving spouses in Eastern Europe are more likely to either provided prolonged personal care or to a lesser extent provide personal care shortly prior to spousal death.

Figure 1: Sequence Density Plots of Spousal Caregiving prior to Widowhood

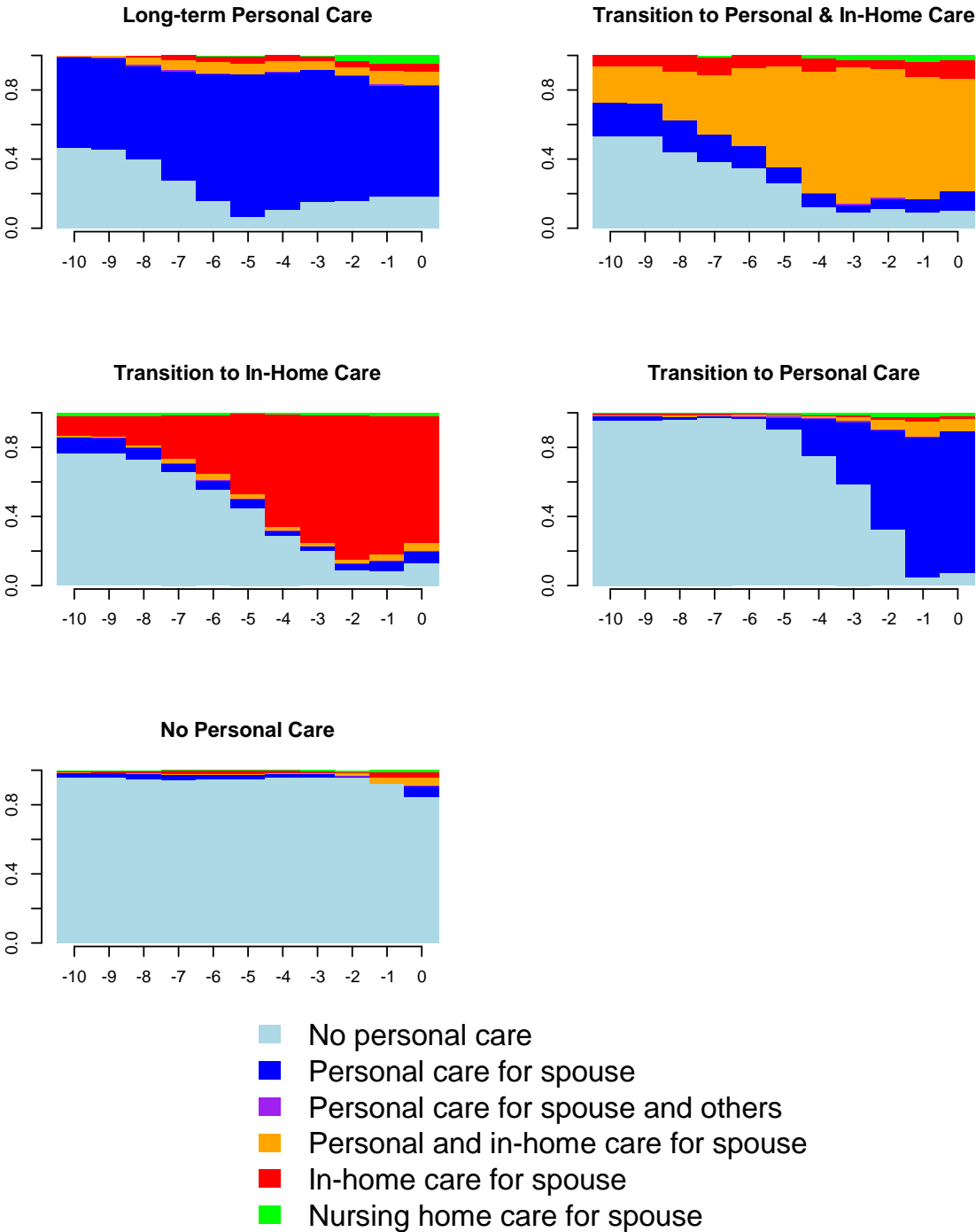
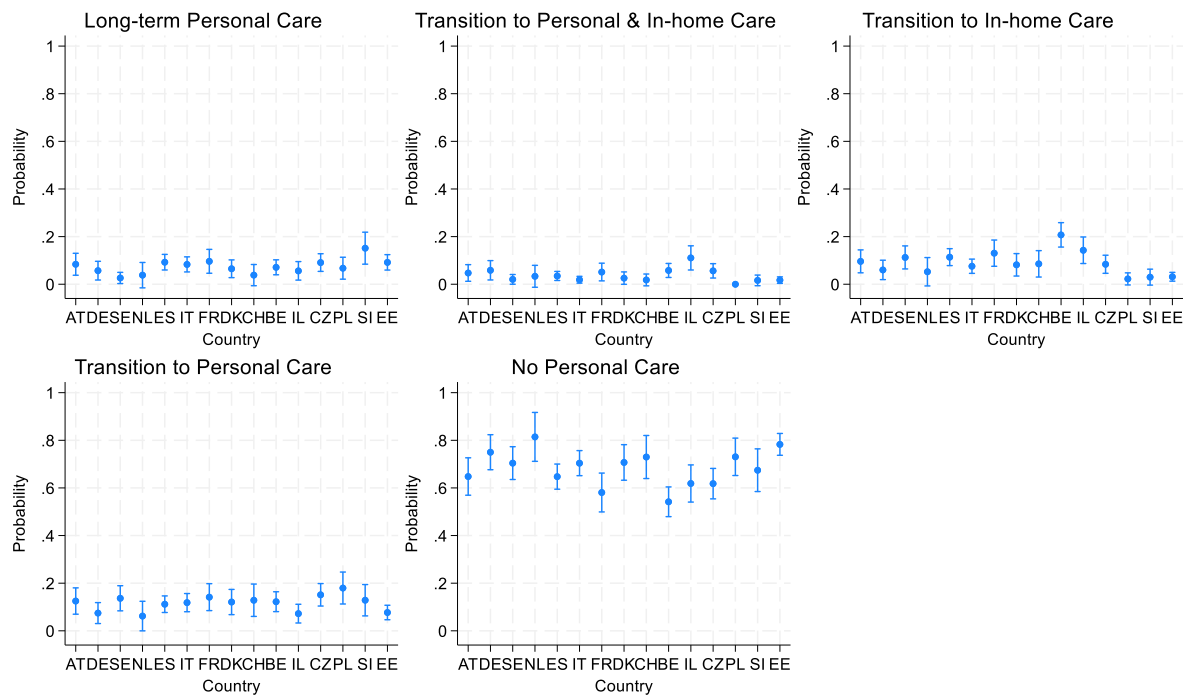


Figure 2: Probability of Spousal Caregiving Patterns prior to Widowhood across Countries



## Discussion

This is the first study to document trajectories of spousal caregiving prior to widowhood across a number of European countries. In the next steps, I will further refine my sequence alphabet to better reflect surviving spouses' caregiving experiences. For example, in further analyses I will incorporate informal care to spouses, such as practical household help or help with paperwork, and others. Due to the strict definition of personal care, my sequences likely give a conservative impression of to-be-widows' and widowers' caregiving activities. In addition, data from end-of-life interviews will be used to add an additional observation point to each caregiving sequence.

Moreover, I will seek to better understand cross-national differences and how they arise. For example, existing research on caregiving within the welfare state literature will enable me to draw hypothesis on which country differences are most likely to emerge. In addition, multinomial logistic regression models adjusted for important compositional factors, such as age, gender and income, will deliver a better understanding of how cross-national variation in trajectories of spousal caregiving prior to widowhood emerge. Finally, I will estimate the association between my patterns or pre-widowhood spousal caregiving and mental health before and after spousal death. This will enable me to contribute to the literature on spousal caregiving and adjustment to widowhood.

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