Impact on Quality of Life and Productivity Associated with Caregiving for Adults with Depression

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INTRODUCTION

- Depression is the most common cause of disability worldwide, affecting nearly 350 million people, and conferring greater humanistic and societal burden than most other medical and mental health conditions.[1-3]
- In addition to the burden of depression on patients themselves, those caring for such patients may also be impacted.[3]
- Studies have shown that caregivers experience reduced health-related quality of life (HRQoL), loss of economic productivity, and increased psychiatric symptomatology.[4,5]
- Given the prevalence of depression overall, it is important to better understand the burden enacted on caregivers.
- Currently there are few studies of the impact of caregiving for adults with depression in Europe.

OBJECTIVES

- The present study examined the excess burden of caregiving for adult relatives with unipolar depression (CAPUD) compared to caregiving for adult relatives with other chronic diseases (CAPOD) and compared to non-caregivers in the general adult population in Europe.

METHODS

Design

- A retrospective, cross-sectional analysis was performed using data from the 2016 Europe National Health and Wellness Survey (NHWS) (5EU: France, Germany, Italy, Spain, and the United Kingdom [UK]) that included 77,184 adult respondents.

Data Source

- The NHWS is a large, nationally representative, self-administered, cross-sectional, internet-based general health survey of European adults aged 18+ years.
- A stratified random sampling procedure is used to ensure the demographic composition of the NHWS sample is representative of the corresponding adult population in each of the 5EU countries with respect to gender and age.
- The 2016 NHWS protocol and questionnaire were reviewed by Pearl Institutional Review Board (Indianapolis, IN, USA) and granted exemption status.
- The study was conducted in accordance with International Society for Pharmacoepidemiology Guidelines for Good Pharmacoepidemiology Practices and applicable regulatory requirements.

Participants

CAPUD (n=1,380)

- Inclusion criteria: Currently caring for an adult relative with depression.
- Exclusion criteria: Currently caring for an adult relative with bipolar disease or schizophrenia.

CAPOD (n=6,470)

- Inclusion criteria: Currently caring for an adult relative with any of the following conditions: cancer, chronic kidney disease on dialysis, chronic obstructive pulmonary disease (COPD), diabetes (Type I), epilepsy, heart disease (e.g., congestive heart failure), ITP (platelet disorder), macular degeneration, muscular dystrophy, osteoarthritis, and/or stroke.
- Exclusion criteria: Currently caring for an adult relative with unipolar depression.

Non-Caregivers (n=69,334)

- Inclusion criteria: Not caring for an adult relative.
- Exclusion criteria: Declining to respond to whether they were caring for an adult relative or were caregivers of an 'other' chronic disease not included in the CAPUD or CAPOD groups.

Measures

Demographic, Clinical, and Caregiver-Specific Characteristics

- Demographic characteristics:
  - Age, sex, country of residence, marital status, education, household income, and employment status
- Clinical characteristics:
  - Charlson comorbidity index (CCI),[6] body mass index (BMI), exercise (past 30 days), alcohol use, smoking status, anxiety symptoms, depressive symptoms, sleep difficulties

Outcome Measures

- Health-related quality of life (HRQoL):
  - The Medical Outcomes Study 12-Item Short Form Survey Instrument version 2 (SF-12v2)[7] is a 12-item multipurpose, generic health status instrument. Higher scores on the SF-12v2 indicate better HRQoL. The SF-12v2 metrics are normed, such that a score of 50 (standard deviation [SD]= 10) equals the average in the general population. The SF-12v2 was used to calculate the following:
    - Mental component summary score (MCS)
    - Physical component summary score (PCS)
    - 8 separate subdomains (physical functioning, bodily pain, general health, role physical, role emotional, social functioning, vitality, and mental health)
- Health status:
  - The Short Form-6 Dimension (SF-6D) is derived from the SF-12v2. The measure is calibrated between 0 (death) to 1 (perfect health) and is normally distributed.
  - The EuroQoL-5 Dimensions 5-Level (EQ-5D-5L)[8] questionnaire is a self-report measure of health for clinical and economic appraisal. Higher scores on the EQ-5D-5L indicate better HRQoL. The EQ-5D-5L is comprised of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.
- Work Productivity and Activity Impairment-General Health (WPAI-GH)[9]:
  - Using responses from the WPAI-GH, the following indices were derived among those participants who were employed at the time of survey completion:
    - Absenteeism (percentage of time missed work due to health problem in the last 7 days)
    - Presenteeism (percentage of impairment while at work in the last 7 days due to health problem)
    - Overall work productivity loss (percentage of the combination of absenteeism and presenteeism)
    - Activity impairment (percentage of impairment in daily activities in the last 7 days)
- Healthcare resource use (HRU):
  - Frequency of HRU within the past 6 months was reported by respondents for:
    - Healthcare provider visits (HCP)
    - Emergency room (ER) visits
    - Hospitalizations

Statistical Analysis

Descriptive Analyses

- Patient demographic and clinical characteristics were assessed using frequencies and percentages for categorical variables and means and standard deviations (SD) for continuous variables.

Multivariable Analyses

- Groups were compared using generalized linear mixed models (GLMMs) and adjusting for the following covariates: age, sex, marital status, employment, number of children in household, alcohol use, BMI, education, smoking status, exercise in past 30 days, and CCI.
- Differences between groups were examined using adjusted differences (AD) or relative risks (RR) and lower and upper 95% confidence intervals (CIs). Estimated marginal mean scores and standard errors (SE) were also calculated. Tukey post-hoc tests were implemented to compare between estimated marginal mean values.
- All statistical analyses were conducted using R 3.5.2.

RESULTS

Study Sample and Characteristics

- Across the 5EU, a total of 1,380 respondents (1.8%) were identified as CAPUD and 6,470 (8.4%) were identified as CAPOD.
- Group comparisons across sociodemographic and clinical characteristics are presented in **Table 1** and **Table 2**.
- Overall, CAPUD (n=1,380) were younger and a larger proportion was female compared to CAPOD (n=6,470) or non-caregivers (n=69,334) (mean age: 44±16, 48±16, and 49±16, respectively; female: 62%, 58%, and 55%, respectively).
- Comorbidity burden was greater for caregivers than non-caregivers (0.29-0.34 versus 0.19, respectively).
- Anxiety and depression were consistently reported at higher rates among CAPUD than CAPOD and in the non-caregiver population:
  - 31% of respondents in the CAPUD group reported anxiety compared to 19% in the CAPOD group (*p*<0.001) or 13% in non-caregivers (*p*<0.001).
  - 36% of respondents in the CAPUD group reported depression compared to 18% in the CAPOD group (*p*<0.001) or 14% in non-caregivers (*p*<0.001).

Table 1. Sociodemographic Characteristics of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers

	CAPUD (n=1,380)	CAPOD (n=6,470)	Non-Caregivers (n=69,334)	*P*-Value versus CAPUD[a] CAPOD	*P*-Value versus CAPUD[a] Non-Caregivers
Age, years (mean±SD)	43.6±15.5	48.1±16.1	48.5±16.4	<0.001	<0.001
Female	62%	58%	55%	0.007	<0.001
Marital Status					
Married/Living with Partner	62%	66%	62%	0.010	<0.001
Divorced/Separated/Widowed	10%	9%	14%		
Single, Never Married	28%	25%	24%		
Declined to Answer	0%	0%	0%		
College/University Degree or Higher	39%	40%	39%	0.209	0.939
Employed	60%	56%	55%	0.006	<0.001
Number of Adults in the Household	2.4±1.0	2.4±1.0	2.1±0.90	0.708	<0.001
Number of Children in the Household	0.60±0.89	0.52±0.87	0.45±0.82	<0.001	<0.001

Note: CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases; SD=standard deviation
[a]*p*-value tests

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Table 2. Clinical Characteristics of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers
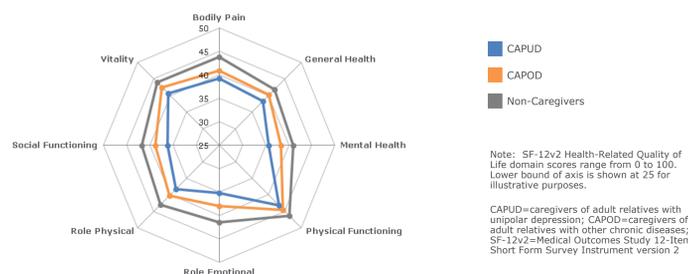
	CAPUD (n=1,380)	CAPOD (n=6,470)	Non-Caregivers (n=69,334)	*P*-Value versus CAPUD[a] CAPOD	*P*-Value versus CAPUD[a] Non-Caregivers
BMI					
Underweight	4%	4%	3%	<0.001	<0.001
Normal Weight	46%	43%	46%		
Overweight	27%	34%	33%		
Obese	23%	20%	18%		
Missing	6%	5%	5%		
Smoking Status					
Current Smoker	30%	28%	24%	0.104	<0.001
Former Smoker	30%	30%	31%		
Never Smoked	40%	42%	45%		
Alcohol Use					
Moderate/High	45%	49%	45%	<0.001	0.002
Low	33%	29%	32%		
None	22%	22%	23%		
Exercise (days in past month)	8.6±4.0	6.9±8.3	7.1±8.6	0.364	0.241
CCI, Categorical					
0	82%	84%	89%	0.136	<0.001
1	9%	8%	6%		
2	6%	6%	4%		
3+	3%	2%	1%		
CCI, Continuous (mean±SD)	0.34±0.92	0.29±0.85	0.19±0.63	0.089	<0.001
Anxiety[b]	31%	19%	13%	<0.001	<0.001
Depression[b]	36%	18%	14%	<0.001	0.001
Sleep Problems[b]	10%	7%	5%	<0.001	<0.001

Note: BMI=body mass index; CCI=Charlson Comorbidity Index; CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases; SD=standard deviation
[a]*p*-value tests
[b]Self-reported physician diagnosed and experienced symptoms over past 12 months

HRQoL and Health Status (Figure 1 and Figure 2)

- Adjusting for covariates, mean HRQoL and health status scores were consistently low for CAPUD followed by CAPOD and then non-caregivers across all domains assessed (all *p*-values <0.001).
  - Estimated marginal mean MCS was 35.0 for CAPUD compared to 37.8 for CAPOD (*p*<0.001) and compared to 40.7 for non-caregivers (*p*<0.001).
  - Estimated marginal mean PCS was 42.5 for CAPUD compared to 43.7 for CAPOD (*p*<0.001) and compared to 45.5 for non-caregivers (*p*<0.001).
  - Estimated marginal mean EQ-5D-5L was 0.63 for CAPUD compared to 0.67 for CAPOD (*p*<0.001) and compared to 0.73 for non-caregivers (*p*<0.001).

Figure 1. Health-Related Quality of Life (HRQoL) (SF-12v2) of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers

Note: SF-12v2 Health-Related Quality of Life domain scores range from 0 to 100. Lower bound of axis is shown at 25 for illustrative purposes.

CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases; SF-12v2=Medical Outcomes Study 12-Item Short Form Survey Instrument version 2

Figure 2. Health Status of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers
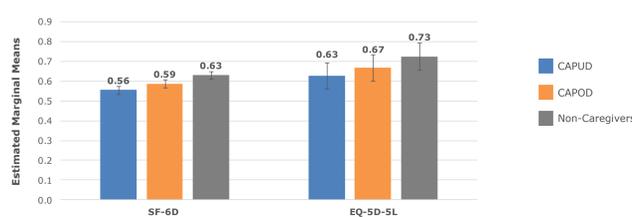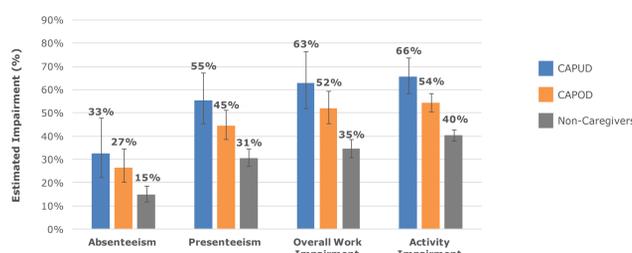

Note: Error bars reflect the 95% confidence intervals of the estimated means derived from regression models.
CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases; EQ-5D-5L=EuroQoL-5 Dimensions 5-Level; SF-6D=Short Form-6 Dimension

WPAI-GH (Figure 3)

- CAPUD reported significantly higher levels of absenteeism, presenteeism, overall work impairment, and activity impairment than the non-caregiver population (all *p*-values <0.001).
- Impairment was consistently greater for caregivers of depression than other chronic diseases.
  - CAPUD reported 63% overall work impairment compared to 52% for CAPOD (*p*=0.080) and compared to 35% for non-caregivers (*p*<0.001).
  - CAPUD reported 66% activity impairment compared to 54% for CAPOD (*p*=0.002) and compared to 40% for non-caregivers (*p*<0.001).

Figure 3. Work Productivity and Activity Impairment (WPAI) of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers
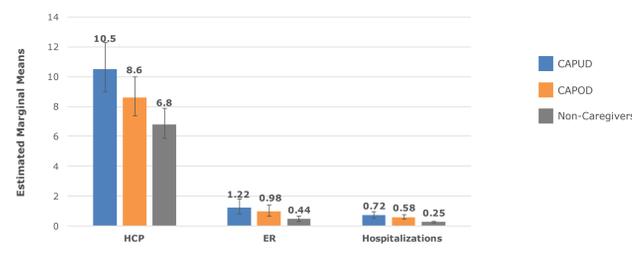

Note: Error bars reflect the 95% confidence intervals of the estimated means derived from regression models.
CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases

HRU (Figure 4)

- Estimated marginal rates for HRU were higher for CAPUD and CAPOD than non-caregivers for HCP visits, ER visits, and hospitalizations (all *p*-values <0.001) when controlling for covariates.
  - CAPUD experienced almost three times more ER visits compared to the non-caregiver population (1.22 versus 0.44 visits in the past 6 months, *p*<0.001) and almost three times more hospitalizations (0.72 versus 0.25, *p*<0.001).
  - CAPUD had over 20 percent more HRU compared to CAPOD. For example, HCP visits in the past 6 months: CAPUD=10.5 versus CAPOD=8.6 (*p*<0.001).

Figure 4. Healthcare Resource Use (HRU) in the Past Six Months of Caregivers of Adult Relatives with Unipolar Depression Compared to Other Caregivers and Non-Caregivers

Note: Error bars reflect the 95% confidence intervals of the estimated means derived from regression models.
CAPUD=caregivers of adult relatives with unipolar depression; CAPOD=caregivers of adult relatives with other chronic diseases; ER=emergency room; HCP=healthcare provider

STRENGTHS AND LIMITATIONS

- The NHWS is a nationally-representative patient-reported outcome survey across five major countries in Europe.
- While the NHWS is broadly representative of the adult population for the corresponding five European countries, these data may not be representative of the entire respective CAPUD or CAPOD populations.
- The NHWS is a cross-sectional study, thus causality cannot be inferred.
- All data in this study are self-reported; therefore, responses are subject to recall bias and cannot be verified by a third party (e.g., medical chart).
- The severity of the disease being cared for within and between groups was unknown. Further, identification of caregivers was limited since, for example, full treatment histories were not available for their affected relatives; therefore, proxy indicators were used. Results are likely an underestimate of the true association.

CONCLUSIONS

- In Europe, there is an incremental burden on caregivers of adult patients with unipolar depression compared to non-caregivers in terms on HRQoL, productivity, and HRU.
- There is an excess burden of caregiving for adult relatives with depression above that of caring for adult relatives with other chronic diseases.
- The current findings show an excess burden for caring for people with depression compared to those with other chronic diseases, similar, although not as severe, to the findings for people with and without treatment-resistant depression.[3]