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CLINICAL BURDEN AND HEALTH-RELATED QUALITY OF LIFE IN CAREGIVERS OF CANCER PATIENTS: RESULTS FROM LINKING ELECTRONIC HEALTH RECORDS TO PATIENT-REPORTED OUTCOMES

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BACKGROUND

- Caregiving is an underestimated burden with long-term emotional, physical, and financial consequences.[1-3]
- In the US, family caregiving, which is primarily informal and unpaid, represents over 85% of in-home adult caregivers.[4] In Europe, over one-third of the adult population has provided care for a family member, close friend, or neighbor.[3]
- The economic burden of mental illness is estimated at greater than 4% of the gross domestic products across 28 European countries, without considering the impact to caregivers.[5]
- The impact of caregiving on mental health has both negative (e.g., depression and anxiety from loss) and positive (e.g., satisfaction, meaning, growth) effects. Caring for cancer patients is associated with higher prevalence of depression (42%) and anxiety (47%).[6]

OBJECTIVE

- To examine depression and anxiety presence and health-related quality of life (HRQoL) in cancer caregivers in the US using self-reported survey data and clinical data from electronic health records (EHRs).

METHODS

Data Sources

- Survey Data
  - Self-reported data were from the 2015-2018 US National Health and Wellness Survey (NHWS), a self-administered, internet-based general health survey of US adults (aged 18 years or older).
  - Respondents were recruited from an internet panel using a stratified random sampling framework to ensure the demographic composition (with respect to age, gender, and race/ethnicity) was representative of the adult population based on the US Census.
- EHR Data
  - Clinical data were from Veradigm, a large US ambulatory EHR database consisting of patient-level historical data from 2012 to 2018 for over 50 million unique patients.
- Direct linking of patients in the NHWS and EHR was performed by comparing Protected Health Information (PHI) and Personal Identifiable Information (PII) in a HIPAA-compliant matching algorithm.

Study Population

- The study consisted NHWS respondents between 2015 and 2018 with clinical records in the EHR (**Figure 1**).
- Cancer caregivers were compared with non-caregivers and caregivers of other conditions (e.g., Alzheimer's disease, stroke, and schizophrenia) who were classified based on the questions:
  - "Are you currently caring for an adult relative with any of the following conditions?"
  - "Are you the custodial parent or legal guardian of a child with any of the following conditions?"

Measures

- Demographic characteristics obtained from the NHWS included age, gender, race/ethnicity, marital status, education, employment status, insurance status, and household income.
- Health characteristics obtained from the NHWS included the Charlson Comorbidity Index (CCI), body mass index (BMI), alcohol use, and smoking status.
- Outcomes
  - Depression
    - Presence of depression was estimated using self-reported physician diagnoses from the NHWS and ICD-9 and ICD-10 codes in the EHR.
    - Depression severity was evaluated using the Patient Health Questionnaire 9-item (PHQ-9) (self-reported, NHWS) with scores categorized: none/minimal (0-4), mild (5-9), moderate (10-14), severe (≥ 15).[7]
  - Anxiety
    - Presence of anxiety was estimated using self-reported physician diagnoses from the NHWS and ICD-9 and ICD-10 codes in the EHR.
    - Anxiety severity was evaluated using the Generalized Anxiety Disorder 7-item (GAD-7) (self-reported, NHWS) with scores categorized: minimal (0-4), mild (5-9), moderate (10-14), severe (≥ 15).[8]
  - HRQoL was measured using the Short Form 36-Item Health Survey (SF-36v2) (self-reported, NHWS),[9] which includes:
    - Physical Component Summary (PCS) and Mental Component Summary (MCS) scores
    - Eight domain scores (bodily pain, general health, mental health, physical functioning, physical role limitations, emotional role limitations, social functioning, and vitality)
  - Health status was measured using the Short Form 6-Dimension (SF-6D) utilities index on a 0 to 1 scale (self-reported, NHWS), with higher scores indicating better health status.

Statistical Analysis

- Presence of depression and anxiety were estimated using self-reported physician diagnoses and ICD-9 and ICD-10 codes in the EHR.
- Bivariate analyses were performed using analysis of variance (ANOVA) and Chi-squared tests to compare 1) caregivers of cancer patients vs. caregivers of patients with other conditions and 2) caregivers of cancer patients vs. non-caregivers.

RESULTS

Sample Characteristics

- A total of 14,309 NHWS respondents met all study inclusion criteria and were included in the analysis (**Figure 1**). The mean age was 51.4 years and 64.4% were female.
- The study cohort comprised 243 (1.7%) cancer caregivers, 2,700 (18.9%) caregivers of patients with other conditions, and 11,366 (79.4%) non-caregivers (**Table 1**).
- Compared with non-caregivers:
  - Cancer caregivers were younger ($p < .001$), more likely to be female ($p = .028$), and more likely to currently smoke ($p < .001$) (**Table 1**).
  - Cancer caregivers had greater comorbidity burden as measured by the CCI ($p = .011$) (**Table 1**).
- Cancer caregivers were also less likely to be married compared with other caregivers ($p < .001$) (**Table 1**).

Figure 1. Study Sample Cohort Creation

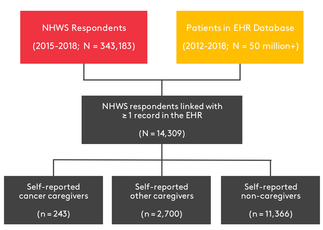


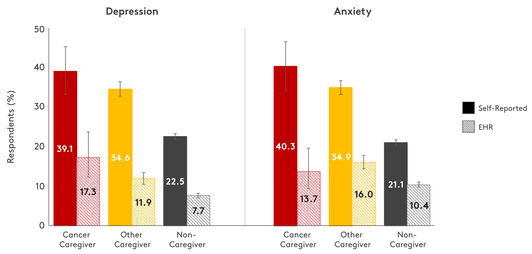
Table 1. Demographic and Health Characteristics for Cancer Caregivers, Other Caregivers, and Non-Caregivers

				Cancer Caregiver *p* -value	
	Cancer Caregiver (n = 243)	Other Caregiver (n = 2,700)	Non-Caregiver (n = 11,366)	Vs. Other Caregiver	Vs. Non-Caregiver
Age, mean (SD)	46.2 (17.2)	47.5 (14.3)	52.5 (17.6)	.173	< .001
Age Group				.022	< .001
18-44	114 (46.9%)	1200 (44.4%)	3717 (32.7%)		
45-64	84 (34.6%)	1138 (42.1%)	4189 (36.9%)		
65+	45 (18.5%)	362 (13.4%)	3460 (30.4%)		
Gender				.178	.028
Male	75 (30.9%)	725 (26.9%)	4294 (37.8%)		
Female	168 (69.1%)	1975 (73.1%)	7072 (62.2%)		
Race/Ethnicity				.471	.844
Non-Hispanic White	190 (78.2%)	2017 (74.7%)	8959 (78.8%)		
Non-Hispanic Black	15 (6.2%)	243 (9.0%)	808 (7.1%)		
Hispanic	17 (7.0%)	187 (6.9%)	676 (5.9%)		
Other	21 (8.6%)	253 (9.4%)	923 (8.1%)		
Marital Status				< .001	.659
Married/living with partner	137 (56.4%)	1853 (68.6%)	6599 (58.1%)		
Not married (e.g., single, divorced, etc.)	106 (43.6%)	847 (31.4%)	4743 (41.7%)		
Declined to answer	0 (0.0%)	0 (0.0%)	24 (0.2%)		
Education Level				.916	.280
College degree or higher	101 (41.6%)	1148 (42.5%)	5277 (46.4%)		
No college degree	142 (58.4%)	1551 (57.4%)	6078 (53.5%)		
Declined to answer	0 (0.0%)	1 (0.0%)	11 (0.1%)		
Employment Status				.919	.261
Employed full-time	109 (44.9%)	1220 (45.2%)	4572 (40.2%)		
Employed part-time	25 (10.3%)	256 (9.5%)	1097 (9.7%)		
Unemployed	109 (44.9%)	1224 (45.3%)	5697 (50.1%)		
Household Income				.188	.033
Less than $75,000	159 (65.4%)	1605 (59.4%)	6732 (59.2%)		
$75,000 or more	76 (31.3%)	986 (36.5%)	3832 (33.7%)		
Declined to answer	8 (3.3%)	109 (4.0%)	802 (7.1%)		
Insurance Status				.326	.331
Insured	221 (90.9%)	2523 (93.4%)	10537 (92.7%)		
Uninsured	19 (7.8%)	155 (5.7%)	645 (5.7%)		
Not sure	3 (1.2%)	22 (0.8%)	184 (1.6%)		
Smoking Status				.372	.001
Never smoker	135 (55.6%)	1536 (56.9%)	6590 (58.0%)		
Current smoker	49 (20.2%)	452 (16.7%)	1417 (12.5%)		
Former smoker	59 (24.3%)	712 (26.4%)	3359 (29.6%)		
Alcohol Use				.371	.255
Abstains from alcohol	73 (30.0%)	887 (32.9%)	3810 (33.5%)		
Consumes alcohol	170 (70.0%)	1813 (67.1%)	7556 (66.5%)		
BMI Category				.436	.130
Underweight (< 18.5 kg/m^2)	6 (2.5%)	40 (1.5%)	195 (1.7%)		
Normal (18.5-24.9 kg/m^2)	54 (22.2%)	662 (24.5%)	3291 (29.0%)		
Overweight (25.0-29.9 kg/m^2)	83 (34.2%)	819 (30.3%)	3526 (31.0%)		
Obese (≥ 30.0 kg/m^2)	94 (38.7%)	1119 (41.4%)	3977 (35.0%)		
Declined to answer	6 (2.5%)	60 (2.2%)	377 (3.3%)		
CCI, mean (SD)	0.47 (1.08)	0.37 (0.87)	0.33 (0.84)	.107	.011

Presence of Depression and Anxiety (Figure 2)

- Compared with other caregivers:
  - Cancer caregivers were significantly more likely to have depression based on EHR diagnoses (17.3% vs. 11.9%, $p = .044$) but not based on self-reported diagnoses.
  - The presence of anxiety was not significantly different in cancer caregivers based on EHR or self-reported diagnoses.
- Compared with non-caregivers:
  - Cancer caregivers were significantly more likely to have depression based on self-reported (39.1% vs. 22.5%, $p < .001$) and EHR diagnoses (17.3% vs. 7.7%, $p < .001$).
  - Cancer caregivers were significantly more likely to have anxiety based on self-reported diagnoses (40.3% vs. 21.1%, $p < .001$) but not based on EHR diagnoses.

Figure 2. Presence of Depression and Anxiety among Cancer Caregivers, Other Caregivers, and Non-Caregivers Based on Self-Reported and EHR Diagnoses

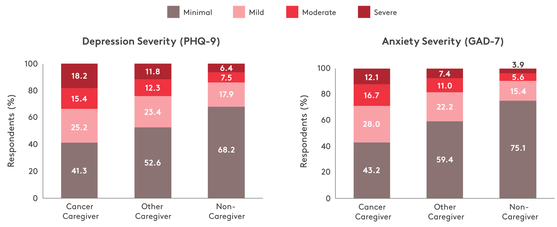


Note: Error bars indicate 95% confidence intervals.

Severity of Depression and Anxiety (Figure 3)

- Compared with other caregivers:
  - Cancer caregivers reported greater severity of depressive symptoms based on the PHQ-9 and were more likely to report mild (25.2% vs. 23.4%), moderate (15.4% vs. 12.3%), and severe (18.2% vs. 11.8%) depression ($p = .031$).
  - Cancer caregivers were more likely to report mild (16.7% vs. 11.0%), moderate (28.0% vs. 22.2%), and severe (12.1% vs. 7.4%) anxiety based on the GAD-7 ($p = .003$).
- Compared with non-caregivers:
  - Cancer caregivers reported greater severity of depressive symptoms based on the PHQ-9 and were more likely to have mild (25.2% vs. 17.9%), moderate (15.4% vs. 7.5%), and severe (18.2% vs. 6.4%) depression ($p < .001$).
  - Cancer caregivers were more likely to report mild (16.7% vs. 5.6%), moderate (28.0% vs. 15.4%), and severe (12.1% vs. 3.9%) anxiety based on the GAD-7 ($p < .001$).

Figure 3. Severity of Depression and Anxiety among Cancer Caregivers, Other Caregivers, and Non-Caregivers



Health-Related Quality of Life (HRQoL) by Caregiver Status

- Cancer caregiving was consistently associated with lower HRQoL.
- Compared with other caregivers:
  - Cancer caregivers had significantly lower PCS (mean = 46.4 vs. 47.8, $p = .047$) and MCS (mean = 43.3 vs. 45.0, $p = .033$) (**Figure 4**).
  - Cancer caregivers had lower HRQoL across six of the eight SF-36v2 domains (all *p*'s < .05, except for vitality and general health) (**Figure 5**).
  - Cancer caregivers also had significantly lower SF-6D health utility scores (mean = 0.65 vs. 0.68, $p = .004$) (**Figure 4**).
- Compared with non-caregivers:
  - Cancer caregivers had significantly lower PCS (mean = 46.4 vs. 49.3, $p < .001$) and MCS (mean = 43.3 vs. 48.6, $p < .001$) (**Figure 4**).
  - Cancer caregivers had lower HRQoL across the eight SF-36v2 domains (all *p*'s < .001) (**Figure 5**).
  - Cancer caregivers also had significantly lower SF-6D health utility scores (mean = 0.65 vs. 0.72, $p < .001$) (**Figure 4**).

Figure 4. Health-Related Quality of Life (HRQoL) and Health State Utilities by Caregiver Status

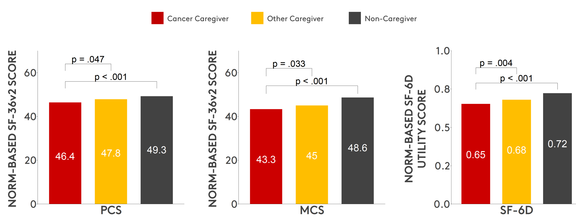
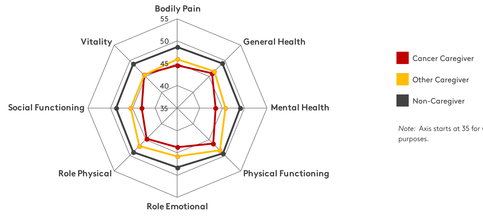


Figure 5. Health-Related Quality of Life (HRQoL) Domains by Caregiver Status



Note: Axis starts at 35 for visualization purposes.

STRENGTHS AND LIMITATIONS

- Self-reported measures in the study, such as diagnosis of depression and anxiety, are subject to potential selection bias and therefore limit the generalizability of the results. In addition, causality between the burden of cancer caregiving and depression and anxiety cannot be definitely established based on the cross-sectional nature of the survey data.
- EHRs often do not reflect a patient's full healthcare history, since patients can visit providers outside of the health system or network. These visits are not captured in the EHR and result in missing data.
- The linkage between self-reported and clinical data in this study enabled a more comprehensive assessment of cancer caregiver burden than if either data source had been used in isolation.

CONCLUSIONS

- Cancer caregivers had significantly poorer HRQoL and more severe depression and anxiety than other caregivers and non-caregivers.
- The presence of both depression and anxiety was lower in EHR compared with self-report, which may suggest that caregivers are suffering from these conditions but are not seeking care.
- Linked patient-reported survey and EHR data provide valuable insights into burden of disease and especially for a population such as caregivers who cannot be directly identified from medical records.

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