Post-Traumatic Stress Disorder (PTSD) in Caregivers: Review of the Existing Evidence and Proposed Framework to Estimate Economic Burden

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Introduction

The burden of informal caregiving

- It is estimated that more than one in five Americans provided informal, unpaid caregiving services in 2020, caring in a non-professional capacity for an adult or child experiencing illness or disability.[1]
- Informal caregivers experience impaired quality of life (QoL), increased physical morbidity, lower health utility scores, elevated rates of absenteeism and presenteeism, and employment loss associated with the strain of caregiving.[2-5]
- In addition, the informal caregiver population is reported to have impaired mental health and a high prevalence of psychiatric disorders, particularly clinical depression and anxiety disorders.[5-6]

Post-traumatic stress disorder (PTSD)

- Given the current diagnostic criteria for PTSD (select criteria are presented in Table 1), caregivers are a population at risk; however, PTSD is likely to be under-reported in this population due to several inter-related factors.[7-11]
- PTSD has one of the highest economic burdens among mental disorders.[12]
- To our knowledge, there have been no studies exploring the economic burden of PTSD specifically in the informal caregiving population.

Table 1. Select diagnostic criteria for PTSD from the DSM-5.[7,13]

Criterion A: Traumatic exposure
Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways: • Directly experiencing the traumatic event(s). • Witnessing, in person, the event(s) as it occurred to others.

Adapted from the American Psychiatric Association as cited by the Center for Substance Abuse Treatment.[7,13]

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; PTSD: post-traumatic stress disorder

Note that the criteria above are not comprehensive and represent only one of several diagnostic criteria and two of four experience qualifications for that criterion.

Objective

- The objective of this ongoing research is to better characterize the economic burden of PTSD in the informal caregiving population in order to facilitate further study on the economic and societal consequences of caregiver PTSD.
- Understanding this burden could help to inform and implement strategies such as education and awareness initiatives and screening programs for early intervention, all of which have been recognized and recommended for at-risk caregiver populations but remain underutilized.[9,11,14-15]

Methods

- Using PubMed searches and a citation-mining approach, we conducted a targeted literature review of existing research on the prevalence of PTSD in informal caregivers as well as the costs associated with PTSD in civilian (non-military) populations.

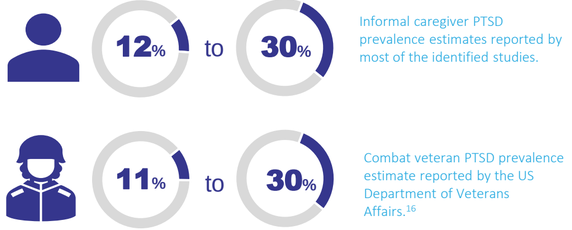
Results

- Prioritizing the most recent studies (published since 2010), we identified 32 publications relevant to these topics:
  - 30 publications reporting the prevalence of PTSD in the target group of informal caregivers
  - Two publications reporting the economic burden of PTSD in civilian populations

PTSD prevalence in caregivers

- The 30 studies we identified included informal caregivers of patients within a variety of clinical situations, including severe mental illness, severe and/or chronic medical issues in both children and adults (including intensive care unit [ICU] and neonatal ICU admissions), dementia, and cancer.
- Across the included studies, PTSD prevalence rates ranged from 3% to 82.9%, varying with patient age, patient diagnosis/clinical situation, and criteria used to define PTSD, among other factors.
- The majority of the studies (17 of 30; 57%) reported prevalence rates between 12% and 30%, closely mirroring the 11% to 30% range reported by the US Department of Veterans Affairs for PTSD among combat veterans (Figure 1).[16]
- Notably, one study found no significant difference in the prevalence of PTSD between a population of informal caregivers and other at-risk groups such as emergency first responders, military veterans, and nurses.[17]

Figure 1. Prevalence of PTSD in caregivers and combat veterans.



PTSD: post-traumatic stress disorder

Results (Cont'd)

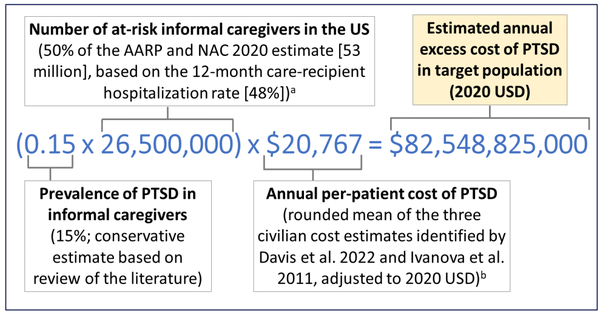
Economic burden of PTSD in civilian populations

- While literature describing costs in non-military populations in the US is limited, we identified two relevant publications:
  - Davis et al. reported an annual PTSD-attributed excess cost per patient of $18,640 for pooled Medicare, Medicaid, commercially-insured, and uninsured groups in 2018 (adjusted to $19,953.90 in 2020 USD).[12]
  - Ivanova et al. reported mean per-patient annual direct costs of $18,753 and $10,960 for Medicaid (n=9,114) and privately insured (n=9,720) populations, respectively (2008 USD; adjusted to $26,726.51 and $15,620.04 in 2020 USD).[18]

Estimating the economic burden of PTSD in the target population

- A simple model was constructed using the data described above, resulting in an annual excess cost estimate of more than $80 billion USD for PTSD in the informal caregiving population in 2020 (Figure 2).

Figure 2. Calculation of annual excess costs attributable to PTSD in the US population of informal caregivers.



AARP: American Association of Retired Persons; NAC: National Alliance for Caregiving; PTSD: post-traumatic stress disorder

[a]While the AARP and NAC report a total of 53 million US caregivers for 2020, this estimate broadly includes anyone "having provided care to an adult or child with special needs at some time in the past 12 months".[1] To derive an estimate more representative of the population at risk for PTSD as described by the DSM-5 diagnostic criteria, we utilized 50% of the total population, informed by the proportion of caregivers whose care recipient was hospitalized over the previous 12 months (48%; reported by the AARP and NAC), for an at-risk population of 26.5 million.[1]

[b]Annual cost estimates were adjusted to 2020 USD using the US Consumer Price Index for medical care.

Discussion

- The initial model presented here is based on several assumptions that are yet to be refined; however, the magnitude of the preliminary cost figure highlights the importance of further study to drive practice and policy.
- In the absence of economic data specific to the informal caregiver population, contextualization of this group in the greater landscape of literature on PTSD is needed.
- While some research suggests that caregivers have similar rates of serious outcomes and similar post-traumatic trajectories to the overall PTSD population, further study is required to investigate whether there are any substantial differences relative to other populations for whom PTSD costs and outcomes have been reported.[19-26]

Conclusions

- There is a growing awareness of the essential role of informal caregivers and the physical, mental, and economic strain they experience.
- The prevalence of PTSD among caregivers is generally found to range from 12% to 30%, mirroring what is seen among military veterans.
- We estimate the excess costs of PTSD in informal caregivers to be >$80 billion annually in the US.
- By characterizing the economic burden of one common yet under-recognized diagnosis, we hope to support the implementation of educational and screening programs targeted at recognizing and treating mental health disorders in this population.

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