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 who has physical or health conditions, or is elderly.\(^\text{1}\)
- Informal caregivers experience impaired quality of life (QoL), increased psychological distress, lower health utility scores, elevated rates of absenteeism and presenteeism, and employment loss associated with the strain of caregiving.\(^\text{2,3}\)
- In addition, the informal caregiver population is reported to have higher mental health and non-mortality prevalence of psychiatric disorders, particularly clinical depression and anxiety disorders.\(^\text{4}\)

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.\(^\text{5}\)
- PTSD has one of the highest economic burdens among mental disorders.\(^\text{6}\)
- To our knowledge, there have been no studies exploring the economic burden of PTSD specifically in the informal caregiving population.

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

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.\(^\text{7}\)
- Davis et al. reported an annual PTSD-attributed cost per patient of $18,649 for insured, Medicare, commercially insured, and uninsured groups in 2018 (adjusted to $19,953.80 in 2020 USD).\(^\text{11}\)
- Hanova et al. reported mean per-patient annual direct costs of $18,753 and $10,960 for Medicaid (n=1,114) and privately insured (n=7,200) populations, respectively (2018 USD; adjusted to $26,761.51 and $15,630.04 in 2020 USD).\(^\text{12}\)

Evaluating the economic burden of PTSD in the target population

A simple model was constructed using the data described above, resulting in an annual PTSD-attributed cost of $80 billion USD to 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.

<table>
<thead>
<tr>
<th>Number of at-risk informal caregivers in the US (50% of the AARP and NAC 2020 estimate) (53 million, based on the 12-month caregiver/hospitalization rate (48%))</th>
<th>Estimated annual excess cost of PTSD in target population (2020 USD)</th>
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<tbody>
<tr>
<td>$0.15 x 26,500,000,000</td>
<td>$20,767 = $82,548,825,000</td>
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Prevalence of PTSD in informal caregivers (15% conservative estimate based on review of the literature) | Annual per-patient cost of PTSD (rounded mean of the three civilian cost estimates identified by Davis et al. 2012 and Hanova et al. 2011, adjusted to 2020 USD) |
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Discussion

- The initial model presented here is based on several assumptions that are yet to be refined; however, the magnitude of the figure highlights the importance of further study to develop policy and practice.
- In the absence of economic data specific to the informal caregiver population, contextualization of this group in the larger 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.

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 understudied diagnosis, we hope to support the implementation of educational and screening programs targeted at recognizing and treating mental health disorders in this population.

Table 1. Select diagnostic criteria for PTSD from the DSM-5.\(^\text{6-9}\)

<table>
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<th>Diagnostic Criteria (^\text{a})</th>
<th>PTSD prevalence in caregivers(^\text{b})</th>
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<td>Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways:</td>
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<td>- Directly experiencing a traumatic event(s)</td>
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<td>- Witnessing, in persons (the event) as it occurred to others.</td>
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Adapted from the American Psychiatric Association as cited in the Center for Substance Abuse Treatment.\(^\text{10}\)

DSM-V Diagnostic and Statistical Manual of Mental Disorders.\(^\text{11}\)

Funding for this work was provided by: Evidera, PPD’s Evidence, Value, and Access business unit; Bethesda, MD, USA.

References

- Ivanova et al. JAMA Internal Medicine. 2015;175(12):1820-1827.
- Cucinotta et al. JAMA Internal Medicine. 2015;175(12):1836-1841.
- Kehoe LA, et al. JAMA Psychiatry. 2022;83(3).
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