

The Prevalence of PTSD Among an Online Sample of US Familial Dementia Caregivers

Genna M. Mashinchi*, Emily C. Hicks, Hannes Heppner

University of Montana, Department of Psychology



*Corresponding author email: genna.mashinchi@umontana.edu

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ABSTRACT

The increased prevalence of dementia has increased the number of caregivers. Familial caregivers can suffer emotionally as a result of caregiving. Despite caregiver organizations campaigning for awareness of caregiver trauma, more research examining PTSD among US familial dementia caregivers is needed. The present study surveyed an online sample of US familial dementia caregivers to gather a prevalence rate of PTSD. We hypothesized that these caregivers experience an equal or greater prevalence of PTSD compared to the general US population, nurses, emergency medical responders, and veterans. An online survey containing the PTSD-Civilian Checklist (PCL-C) was administered to familial dementia caregivers across the US. Data ($n = 23$) revealed that 26.1% of participants surveyed screened positive for PTSD criteria. Consistent with our hypothesis, this percentage is greater than the prevalence rates for the general US population and is similar to the prevalence rates for emergency first responders, nurses, and even US military veterans. These findings can greatly benefit US dementia caregivers by spreading awareness and helping allocate resources to assist those struggling with PTSD.

Keywords: PTSD, dementia, caregiving

1 Introduction

There will be a growing proportion of older US adults in the near future, and because of this, the prevalence rates of adults suffering from cognitive decline due to various forms of dementia will correspondingly increase (Alzheimer's Association, 2022). Due to the increase in cognitive decline, there will be a growing number of adults who will experience difficulties with carrying out crucial everyday tasks or caring for themselves altogether (e.g., shop for groceries, complete household tasks, manage medications, shower, use the restroom; Alzheimer's Association, 2022; FCA 2011; Semenova & Stadlander, 2016). Other individuals, most commonly familial loved ones, often shoulder the responsibility to care for these patients. In 2022, it was estimated that 11 million adults in the US served as unpaid caregivers to an individual with a dementia-related illness (Alzheimer's Association, 2022), and this number is only expected to increase (Alzheimer's Association, 2022).

The required hours needed to care for an individual can increase as the individual progressively declines (Angeles et al., 2021). The demanding and time-consuming nature of caregiving can cause caregivers to experience caregiver burden, which has been defined as "the degree to which a carer's emotional or physical health, social life, or financial status had suffered as a result of caring for their relative," (Zarit et al., 1986, p. 261). More research examining the burden faced by familial caregivers of individuals suffering from dementia is needed. The present study focuses on the rates of post-traumatic stress disorder in an online sample of US familial caregivers.

2 Post-Traumatic Stress Disorder (PTSD)

Post-Traumatic Stress Disorder (PTSD) is an anxiety disorder that develops in some individuals who have experienced a shocking, scary, or dangerous event (National Institute of Mental Health, 2022). Table 1 outlines the criteria for meeting a PTSD diagnosis from the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013). As described in the criteria, depending on the onset and duration of the distress, a caregiver can receive a diagnosis of acute stress disorder (3 days - 1 month) or PTSD (greater than one month). PTSD is associated with maladaptive health outcomes, such as greater generalized anxiety, depression, and substance misuse (National Institute of Mental Health, 2022).

Table 1: Acute Stress Disorder/Post-Traumatic Stress Disorder (PTSD) Criteria from the DSM-5

DSM-5 Acute Stress Disorder/PTSD Criteria
Criterion A: Witnessing a traumatic event (death, threatened death, or serious injury) either through direct exposure, witnessing of the event, learning about it from someone else, or indirect exposure in line of duty (e.g., first responders)
Criterion B: Intrusion symptoms: nightmares, flashbacks, unwanted memories, emotional distress, or physical reactivity as a result of the traumatic event
Criterion C: Avoidance symptoms: avoiding thoughts, feelings, or external reminders of the traumatic event
Criterion D: Negative alterations in cognition or mood: exaggerated self-blame for the trauma, negative affect, feeling isolated, etc.
Criterion E: Alterations in arousal or reactivity: hypervigilance, heightened startled reaction, difficulty sleeping, etc.
Criterion F: Duration: acute stress disorder (3 days - 1 month) or PTSD (greater than one month)
Criterion G: Functional significance: creates distress or impairment in an aspect of life (e.g., occupational, social, etc.)
Criterion H: Exclusions: symptoms are not due to drug use, medication, or another illness

3 PTSD Prevalence Rates

According to the DSM-5, the lifetime risk for PTSD at 75 years of age in the US is 8.7%, while the 12-month prevalence of PTSD in the US is 3.5% (American Psychiatric Association, 2013). PTSD is commonly examined in military veterans, and Copeland et al. (2022) reported a prevalence rate of 30% for this population. Numerous populations have been examined for risk of PTSD, some of which carry out similar tasks and face similar challenges to familial dementia caregivers. Given their similar scope of work in providing care, particularly during emergencies such as falls injuries, or medication management, dementia caregiving can be similar to ambulance first responders and nurses. Ntatamala and Adams (2022) reported a prevalence rate of 30% for ambulance first responders, while Hennein et al. (2021) reported a prevalence rate of 23% for nurses.

4 PTSD among Familial Dementia Caregivers

There is a great deal of research noting the prevalence of anxiety and depression in dementia caregivers (Barrera-Caballero et al., 2021; Han, 2021), particularly during the COVID-19 pandemic in which familial caregivers were often the only source of care (Altieri & Santangelo, 2021; Hwang et al., 2021). Numerous caregiver organizations have campaigned for awareness of caregiver PTSD — a specific anxiety disorder — as evidenced by many blogs and articles featured in online magazines (Concierge Care Services, 2019;

Deneau, 2018; Poareo, 2020). Despite this, as Poareo (2020) noted, there is a need for empirical research examining the presence of PTSD among familial dementia caregivers. The lack of existing research is surprising, as other research examining common stressors caregivers encounter has suggested that, if examined, caregivers would meet criteria for PTSD diagnoses according to the DSM-5 (American Psychiatric Association, 2013). For example, witnessing a traumatic event — defined as death, threatened death, or serious injury — is the first criterion for a PTSD diagnosis (American Psychiatric Association, 2013). Caregivers can witness their care recipients experience a serious injury or threatened death throughout the duration of providing care. This is especially apparent for caregivers of patients with dementia/Alzheimer's disease, in which safety is often compromised by the loss of memory, cognitive abilities, and judgment, such as when a patient forgets how to swallow or walk, touches a hot stove, or wanders away and goes missing (Mayo Clinic Staff, 2022). In addition, caregivers are subject to witnessing the death of their care recipient, which is also included in this criterion.

Due to witnessing these traumatic events, caregivers can initiate further actions or behaviors that meet diagnostic criteria for PTSD. If a traumatic event is witnessed, caregivers can experience unwanted flashbacks and memories of the event and can experience emotional distress or reactivity due to the event (Fauth et al., 2021; Koop & Strang, 2003). As Fauth et al. (2021) and Koop and Strang (2003) noted, this might lead caregivers to avoid these thoughts, memories, or anything that reminds them of the event. Negative emotions and affect, as well as blaming oneself for not being able to prevent the trauma as a caregiver, can also result. With this, a heightened startle reaction, difficulty concentrating, difficulty sleeping, and hypervigilance of the care recipient's whereabouts to avoid another event might also be experienced. This increase in time spent supervising the patient, as well as avoiding the recurrent flashbacks or memories of the traumatic event, can create distress and impair a caregiver's social life, relationships, career, and quality of life (Alzheimer's Association, 2022).

5 Present Study

Although there is extensive research examining the prevalence of anxiety and depression in familial dementia caregivers (Barrera-Caballero et al., 2021; Han, 2021), there is a need for empirical research to examine the prevalence of PTSD, a specific anxiety disorder, in familial dementia caregivers. This is necessary because, as noted above, PTSD is associated with maladaptive health outcomes, such as greater generalized anxiety, depression, and substance misuse (National Institute of Mental Health, 2022). Given this need and the campaigning of many blog posts and articles to conduct more empirical research in this area (Concierge Care Services, 2019; Deneau, 2018; Poareo, 2020), the present study sought to survey an online sample of US familial dementia caregivers and identify a prevalence rate of those with PTSD. Since PTSD can occur any time after one month of the onset of distress, former caregivers were also surveyed to examine if a trend in symptom onset could be identified. We hypothesized that this online sample of US familial dementia caregivers would experience a prevalence rate of PTSD that is equivalent or greater than the general US population, emergency medical responders, and veterans.

6 Methodology

6.1 Participants

A sample of US familial caregivers were contacted through an email list or Facebook support group if they were affiliated with a US Alzheimer's/dementia support group or a larger US caregiving group. In addition, some participants were recruited through the Alzheimer's Association's Trial Match survey, which is a clinical trial software. To be included in the study, participants had to be US residents, over 18 years old, and a caregiver for a dementia-related illness (e.g., Alzheimer's disease, frontotemporal lobe dementia, vascular dementia). Eighty participants signed up for the study by agreeing to the consent form. Participants were excluded if they had more than 5% of data missing from their survey, if they did not care for someone with a dementia-related illness, or if they were not a familial caregiver (e.g., a paid home aide). Data

responses were reviewed by the first author, and 57 participants were excluded because they did not meet these inclusion qualifications.

The final sample was comprised of twenty-three US familial dementia caregivers. Nineteen caregivers completed the demographics questionnaire. The average age of participants was 64 years old ($SD = 5.72$) and ranged from ages 44 to 79. Participants were predominantly female (84.2%), cared for their spouse (94.7%), were caregivers at the time of the study (47.4%), identified as Christian (94.7%), identified as Caucasian (89.4%), and provided care for an average of 4.78 years (range 1 – 15 years). Sixty-eight percent of caregivers performed caregiving duties for more than 40 hours a week (range 2 – 168 hours). Seventy-three percent of participants lived with their care recipient. One participant (5.3%) indicated that they had received a PTSD diagnosis before caregiving, while three (15.8%) participants indicated they had received a PTSD diagnosis after caregiving See Table 2 for full participant data.

Table 2: Participant Demographics

Variable	Percentage	<i>N</i>	<i>M</i>	<i>SD</i>	Min.	Max.
Age		19	64	5.72	44	79
Gender		19				
Female	84.2%	16				
Male	15.8%	3				
Care Recipient		19				
Spouse	94.7%	18				
Other	5.3%	1				
Past or Current Caregiver		19				
Past	47.4%	9				
Current	47.4%	9				
Past and current	5.2%	1				
Years Caregiving		19	4.78	3.46	1	15
Number of Hours Caregiving		19	78.2	66.8	2	168
Less than 40	31.6%	6				
40 or more	68.4%	13				
Living Arrangement recipient		19				
Living with care recipient	73.7%	14				
Other	26.3%	5				
Religious Affiliation		19				
Christian	94.7%	18				
Other	5.3%	1				
Race		19				
Caucasian	89.4%	17				
Asian	5.3%	1				
Latino	5.3%	1				
PTSD Diagnosis Before Caregiving		19				
Yes	5.3%	1				
No	94.7%	18				
PTSD Diagnosis After Caregiving		19				
Yes	15.8%	3				
No	84.2%	16				

Note. *N* = 19.

6.2 Measures

6.2.1 PTSD Checklist - Civilian Version (PCL-C) “Demographic Questions”

The researchers created four free-response items that asked participants to provide more information about the traumatic event that occurred. These items were based on the DSM-5 criteria for PTSD and allowed researchers to determine if the participant fit the timeframe for PTSD (American Psychiatric Association, 2013). These four questions asked the following:

1. Has the loved one that you care for ever been exposed to death, threatened death, actual or threatened serious injury? (If this has happened more than once, please think about the event that has affected you most)
2. When did this event occur?
3. How were you exposed to this event?
4. When did you begin to feel upset about this event?

6.2.2 PTSD Checklist - Civilian Version (PCL-C)

The PTSD Checklist - Civilian Version (PCL-C; Lang & Stein, 2005) is a 17-item, standardized, self-report rating scale designed to capture key PTSD symptoms based on the fourth version of the DSM. Participants are asked to indicate how much they have been bothered by a given symptom over the past month using a 5-point Likert scale, ranging from (1) not at all to (5) extremely. The PCL-C is scored by treating Likert scale responses of a 3, 4, or 5 as symptomatic, and then determining if participants indicated symptomatic responses to each of the following: 1) at least 1 “B” item (Questions 1–5), 2) at least 3 “C” items (Questions 6–12), and 3) at least 2 “D” items (Questions 13–17). The PCL-C has demonstrated acceptable construct validity, test-retest reliability, good internal consistency, convergent validity, and discriminant validity (Wilkins *et al.*, 2011). In the present study, the measure demonstrated strong reliability ($\alpha = .97$).

6.2.3 Demographic Questionnaire

The demographic questionnaire asked participants to indicate the following: their age, gender, race, religious preference, who they are/were caregiving for, how long they had been/were caregiving, what the living arrangements are/were with the care recipient (e.g., live together, patient lives in a facility, etc.), and if they had received a diagnosis of PTSD prior to or after caregiving.

6.3 Procedure

The Institutional Review Board at the University of Montana approved this study prior to data collection. The survey was distributed to various US Alzheimer’s disease/dementia support groups electronically through email lists, Facebook Support Groups, and the Alzheimer’s Association’s TrialMatch — a tool that matches dementia patients or their caregivers with research opportunities

The researchers created and posted the questionnaire on the survey software *Qualtrics*. A link to this questionnaire, along with a brief synopsis and instructions of how to complete the survey, was posted on TrialMatch, a US Facebook Alzheimer’s disease/dementia support group, or was sent to the administrator of the Alzheimer’s disease/dementia support group. The administrator attached the link to this questionnaire, the instructions, and the brief synopsis of the study in one email sent to all individuals on the caregiver email list associated with the support center, which included individuals who had been or were then currently caregivers. If participants were not caregivers at the time of the survey, they were instructed to think back to when they were a caregiver and answer the questions in that frame of mind. Once participants followed the email link, they were taken to the survey on *Qualtrics*. First, they were shown the informed consent form. If participants gave their consent, they were taken to the measures, which were presented in the same order for all participants. After these items, participants were taken to a demographics form. Finally, participants were presented with a debriefing form, were thanked for their participation, and then exited the survey.

7 Data Analysis

After scoring the PCL-C as outlined by the developers of the measure (Lang & Stein, 2005), a ratio was taken. The number of participants who screened positive for PTSD criteria based on the PCL-C was in the numerator, and the number of total participants was in the denominator. A dichotomous endpoint, one-sample study sample size calculator determined that the sample of 23 participants yielded a power of .74 when compared to the general population incidence rate of 8.7% (American Psychiatric Association, 2013). Additionally, chi-square tests were conducted to determine if the prevalence rate found in the present study differed from the rates reported for ambulance first responders, nurses, and US veterans. Since the raw numerical values used to calculate the US prevalence rate were not available, a chi-square analysis could not be conducted for this prevalence rate.

8 Results

8.1 Prevalence Rate of PTSD

Results indicated that 6 out of 23 participants, or 26.1% of participants, screened positive for PTSD criteria. Given that all participants expressed that they were still experiencing symptoms longer than one month after the traumatic event occurred, all participants were considered to meet PTSD criteria, and not acute stress disorder, which is a diagnosis based on the same symptoms of PTSD but is limited to occurring within one month of the traumatic event occurrence (American Psychiatric Association, 2013). See Figure 1 for a visual representation of the findings.

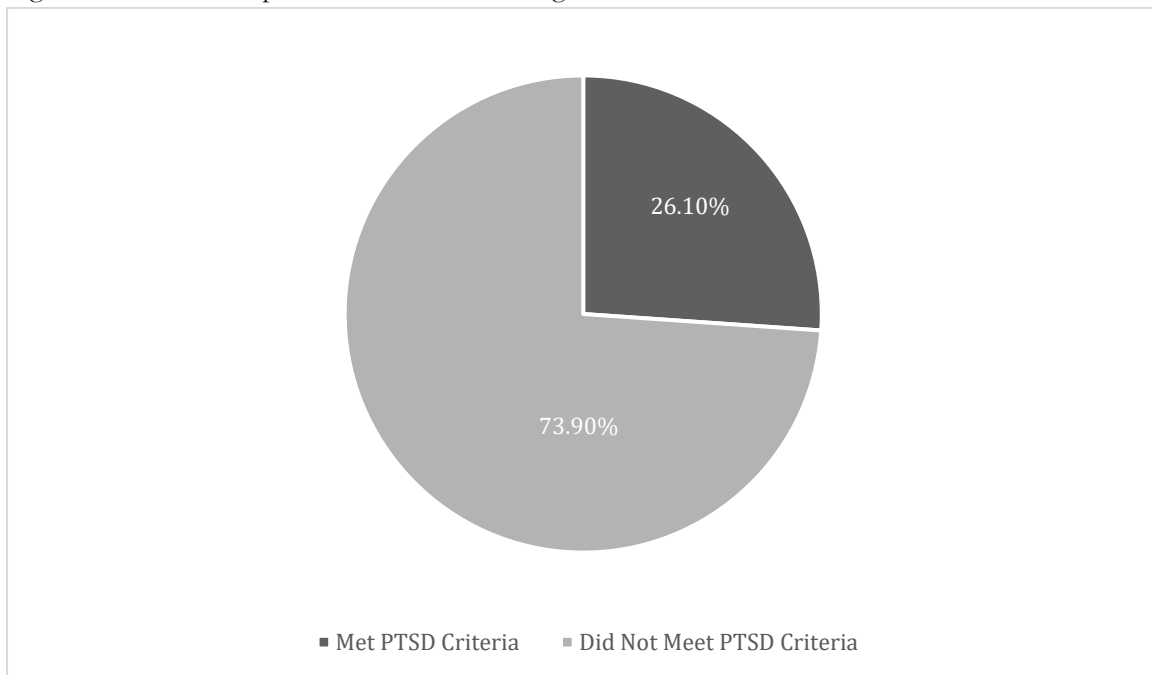


Figure 1: Visual Illustration of the Prevalence of PTSD Among US Familial Dementia Caregivers

8.2 Chi-Square Results

Chi-square analyses were conducted to examine if the prevalence rate in the present study differed from the PTSD rates for ambulance first responders, veterans, and nurses, which were reported in Ntatamala and Adams (2022), Copeland et al. (2022), and Hennein et al. (2021), respectfully. Results revealed that the present study's PTSD prevalence rates for dementia caregivers is not statistically different from the rates of emergency first responders, veterans, or nurses ($ps > .05$).

9 Discussion

Past research has illustrated that the number of individuals needed to provide care to those with various forms of dementia (e.g., Alzheimer's disease, vascular dementia, etc.) is going to increase within the next several years (Alzheimer's Association, 2022). The demanding and time-consuming nature of caregiving can cause caregivers to experience caregiver burden. In fact, there is a great deal of research noting the prevalence of anxiety and depression in dementia caregivers (Barrera-Caballero et al., 2021; Han, 2021), particularly during the COVID-19 pandemic in which familial caregivers were often the only source of care (Altieri & Santangelo, 2021; Hwang et al., 2021). Numerous caregiver organizations have attempted to raise awareness of dementia caregiver PTSD through blog posts and online magazine articles (Concierge Care Services, 2019; Deneau, 2018; Poareo, 2020). However, empirical research examining how these individuals might experience PTSD as a result of caring for an individual that might face serious threat, injury, and an eventual death is needed. Thus, the present study sought to fill this gap and conduct an empirical analysis of the PTSD rate in an online sample of familial US dementia caregivers.

According to the present study's findings, 26.1% of participants met criteria for PTSD as a result of a traumatic event that occurred while caregiving. Consistent with our hypothesis, this percentage is greater than the prevalence rates for the general US population and is on par with the prevalence rates for ambulance personnel, nurses, and even US military veterans. Additionally, three participants reported receiving a diagnosis of PTSD after caregiving, revealing how distressing the caregiving experience can be.

Although there has been greater awareness for the prevalence of PTSD among these specific populations — especially veterans and ambulance first responders — it is clear from these results that more than one in four of the present study's online sample of US familial dementia caregivers suffer from the symptoms of PTSD and have been doing so with little public awareness or policy support for their struggle. The present study allowed preliminary insight into the systemic post-traumatic distress familial dementia caregivers can experience. These results highlight the need for greater awareness regarding the high rates of stress, anxiety, and mental health concerns that familial dementia caregivers are facing. These results can greatly benefit familial dementia caregivers by spreading awareness and helping to allocate resources, such as federal resources for counseling services and respite care. Additionally, these results can encourage healthcare providers to screen patients who they know provide care for someone with dementia for PTSD.

10 Conclusions

There is a need for more literature regarding the post-traumatic stress familial dementia caregivers can experience as a result of witnessing a traumatic event occur to their loved one while caregiving. Past research has acknowledged that dementia caregivers can witness serious threat, injury, or death of their care recipient. Despite caregiving campaigns attempting to spread awareness, more research is needed to investigate this phenomenon of trauma specifically. This is concerning, as the number of familial dementia caregivers is only expected to increase. However, past research has examined the PTSD rates of professions similar to caregiving, such as nursing. The present study sought to examine PTSD rates in an online sample of US familial dementia caregivers. Findings revealed that 26.1% of participants screened positive for a PTSD diagnosis, suggesting that more than 1 in 4 US familial dementia caregivers from this sample might be experiencing PTSD as a result of caregiving. This rate is greater than the rate for the general US population, nurses, veterans, and emergency first responders. As suggested by these results, it is possible that caregivers have long suffered from PTSD, and that the lack of research in this field has left this distress to remain undetected. Recommendations based on these results include increasing awareness of dementia caregiver experience of PTSD symptoms among US familial dementia caregivers and mental health providers. Further, mental health resources should be allocated for familial dementia caregivers. These recommendations can provide assistance and care to those that care for others with dementia.

11 Declarations

11.1 Study Limitations

The greatest limitation of this study was the small convenience sample that completed this study. This can be attributed to the difficulty encountered when trying to contact US familial dementia caregivers. Despite recruiting from Facebook support groups with thousands of members, many caregivers did not wish to be contacted for research surveys illustrating the issue of a convenience sample. The small sample could affect the ability to find results, as indicated by the post hoc power analysis, as well as the ability to generalize the findings. In addition, most of our participants were women (84.2%), which could indicate that male caregivers are not represented in our sample. Further, all participants were residents of the United States, and thus, findings cannot be generalized to other countries.

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11.3 Funding Source

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11.4 Ethical Approval

The present study was considered exempt from review by the Institutional Review Board at the University of Montana.

11.5 Informed Consent

All participants agreed to participate in the study and signed an electronic informed consent form. Data is anonymous.

11.6 Competing Interests

The authors declared that no conflict of interest exists in this publication.

11.7 Publisher's Note

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