

BMJ Open Protocol for scoping review study to map out the existing research in relation to post-traumatic stress symptoms among caregivers of individuals with neurodevelopmental, psychiatric and neurocognitive disorders

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ABSTRACT

Introduction The challenges of providing caregiving that impacts the caregiver have been attributed to high levels of intensity and physical strain, burden and distress. This is likely to include emotional and psychological distress as manifested in post-traumatic stress symptoms (PTSS). As this is a new area of investigation among caregivers of individuals with neurodevelopmental, neurocognitive and psychiatric disorders, the extent of the literature for PTSS in these groups of caregivers is limited and unclear. This scoping review aims to map the existing research focusing on key concepts and identifying gaps in relation to PTSS among these caregivers.

Methods and analysis The scoping review will be guided by Arksey and O'Malley's proposed 5-stage framework. A search for published and unpublished grey literature between years 2005 to 2020 in the electronic databases of CINAHL, SCOPUS, PsychInfo, OVID PubMed and ProQuest Dissertation, and Thesis Global electronic databases was conducted using keywords to identify relevant studies. Articles will be limited to the English language. Endnote 20 software will be used to eliminate duplicates, and results will be exported into Abstrackr for the review screening process consisting of two stages: title and abstract reviews and full-text reviews. Selection process of eligible studies will follow the recommendations in the Preferred Reporting Items of Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist. A data chart will be used to capture relevant information from all included studies, and results will be presented in tabular form and in a narrative report.

Ethics and dissemination This scoping review consists of reviewing and collecting data from publicly available materials and hence does not require ethics approval. The scoping review results will be disseminated via publications in peer-reviewed journals and conference presentations. The results will also guide the design of a mixed method research study to examine the extent of trauma symptomatology and potentially traumatising experiences, and how they relate to the mental health of caregivers of adults with intellectual and developmental disability from different cultural backgrounds.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The scoping review will follow Arksey and O'Malley's established framework for conducting scoping reviews.
- ⇒ The search strategy is broad as it includes CINAHL, SCOPUS, PsychInfo, OVID PubMed, ProQuest Dissertation and Thesis Global electronic databases for peer-reviewed literature, and grey literature.
- ⇒ The search population is broad as it aims to capture post-traumatic stress symptoms among caregivers of individuals with neurodevelopmental, psychiatric and neurocognitive disorders.
- ⇒ As the quality of the studies selected for the scoping review will not be assessed, the statistical reliability of data extracted from selected studies cannot be commented on.

BACKGROUND

Caregiving is the act of providing care to someone in need and is a universal role that involves the provision of care to a person whose needs might include physical and mental health support.¹ This can include regularly looking after a sick child, an elderly person, or a disabled individual. An informal caregiver is an unpaid individual providing assisted care to others in activities of daily living and/or medical tasks.² These informal caregivers can include a spouse, family member, friend or neighbour. When caregiving is taken on by a family member, this informal caregiving becomes the backbone of the health and social care delivery for the individual. As these informal caregivers are a family member of the care recipient, some aspects of their lives might be affected. For example, situations can arise where working caregivers suffer work-related difficulties due to their dual roles, or when the caregivers

eventually relinquish their employment which leads to a loss of income.² The impact of this can result in health-care and social burden on the existing health and social system.³

Caregiving challenges, caregiver burden and mental well-being

Aside from social and financial support needs, many caregiving challenges have been described and studied across all care recipient populations. The challenges of providing caregiving have been attributed to the high levels of intensity and physical strain required in the provision of long-term care.⁴ These challenges have also been attributed to the amount of burden, distress, and role strain that care begets the caregiver,^{5,6} as well as the skills required to master care tasks.⁷ General health is also reported to deteriorate for caregivers, with findings that the longer caregivers have been providing care, the more likely they are to report fair to poor health.² Other studies have echoed similar findings related to the duration of caregiving, with evidence indicating that the distress experienced by caregivers continues, and worsens as responsibilities increase and/or change.^{8,9}

Caregiver burden has been studied extensively in different caregiving groups. This includes caregiving to persons with dementia,^{10–13} individuals with psychiatric conditions,^{14,15} and individuals with neurodevelopmental disorders.^{16–18} Furthermore, studies have found that caregivers exhibited greater levels of self-reported stress and psychological distress than the general population.¹⁹ This distress included depression and anxiety, as well as a sense of helplessness and fear.^{20,21}

Within existing research among caregivers of individuals with neurodevelopmental disorders, it has been highlighted that caregiver burden is a significant predictor of mental health problems.²² A recent study conducted by Grootsholten *et al.*¹⁶ comparing caregivers of adults with ASD, and caregivers of adults suffering from depression and schizophrenia, found that more tension and emotional distress was experienced by the caregivers of adults with ASD. This was found to be related to the more intense and emotional bond between caregiver and the adult with ASD, the differences in expectations of the adult individual with ASD, as well as the high levels of worry about the adult with ASD.

Caregiver burden might also include being exposed to stressful or distressing events within the caregiving relationship and as such caregivers may be vulnerable to developing symptoms of post-traumatic stress.

Post-traumatic stress symptoms (PTSS), and model of PTSD

The American Psychiatric Association²³ describes symptoms of post-traumatic stress to include intrusive re-experiencing aspects of a traumatic event, avoidance of reminders or emotional numbing, and increased physiological arousal or hypervigilance following exposure to a traumatic event. Post-traumatic stress has typically been researched among military veterans^{24–26} or victims

of interpersonal violence.^{27,28} There are examples of post-traumatic stress research in relation to medical illnesses. Stuber *et al.*²⁹ used a post-traumatic stress model to understand the long-term psychological sequelae for parents caring for their children with cancer. The model provides the framework in which ongoing distress such as intrusive thoughts, arousal and avoidance can be conceptualised and treated. The authors described practical implications of the model in providing support for these parents. Corresponding to this, Ehlers and Clark's³⁰ cognitive model of PTSD explains that PTSS becomes persistent when individuals process the traumatic event in a way which leads to a sense of serious, current threat. This sense of threat is a combined consequence of negative appraisal of the trauma and/or its sequelae, and incomplete memory processing. As such, it can be postulated that if caregivers experience an incident that involves aggression and/or a threat to safety, the caregiver might develop a perception of the caregiving relationship as unsafe, and might engage in maladaptive rumination and use maladaptive coping strategies as a consequence.

In recent years, research has started to consider the impact of trauma on, and the prevalence of PTSS among caregivers. For example, three studies have focused on trauma and PTSS among caregivers of individuals with psychosis,^{31–33} while in the IDD population, two recent studies investigating PTSS among caregivers have been conducted.^{34,35} Dementia, a neurocognitive disorder, has major impact on caregivers who provide prolonged care.³⁶ The Behavioural and Psychological Symptoms of Dementia, as well as the progressive disabilities of adaptive living skills have negative impact on these caregivers, inducing a rise of emotional and affective disorders.^{37,38} For these reasons, being involved in caregiving of patients with neurocognitive disorder can be considered a risk factor for being exposed to a traumatic event. Given that PTSS is a precursor to PTSD, all experiences of PTSS are of interest in this review, where both PTSS and PTSD will be included in this review.

Therefore, the study of PTSS is relevant to all caregivers of individuals with neurodevelopmental, neurocognitive and psychiatric disorders given that caregivers are vulnerable to psychological distress and caregiving for any of these groups might include being victim to or witnessing very stressful events.^{31–38} As this is a new area of investigation among caregivers of individuals with neurodevelopmental, neurocognitive and psychiatric disorders, the extent of the literature for PTSS in these group of caregivers is limited and unknown. Hence, this scoping review aims to map the existing evidence to identify key concepts and gaps in research in relation to PTSS among adult caregivers of children and / or adults with neurodevelopmental, neurocognitive and psychiatric disorders.

Study objectives

The objective of this scoping review is to systematically scope the literature following the Preferred Reporting Items of Systematic Reviews and Meta-Analyses Extension

for Scoping Reviews (PRISMA-ScR) guidelines to understand the nature of PTSS among adult caregivers, to reveal key concepts examined, and to identify gaps in the existing research.³⁹

The results from this scoping review will guide the next phase of a mixed method research design study to examine the extent of trauma symptomatology and nature of potentially traumatising experiences, and how they relate to the mental health of caregivers of adult children with intellectual and developmental disability (IDD) from different cultural backgrounds. The review also has the potential to raise awareness of the mental healthcare needs of caregivers of individuals with neurodevelopmental, neurocognitive and psychiatric disorders and provide evidence to inform mental healthcare professionals to better address the needs of these caregivers.

METHODOLOGY

A preliminary search of Medline, the Cochrane Database of Systematic Reviews and *JBI Evidence Synthesis* was conducted and no current or underway systematic reviews or scoping reviews on the topic were identified.

Patient and public involvement

No patients were involved in this study.

Scoping review

This protocol is for a systematic scoping review of literature reporting on PTSS among adult caregivers of children and/or adults with neurodevelopmental, psychiatric and neurocognitive disorders. A scoping review method was selected as it aims to outline different types of evidence on the area of interest and identify gaps for further research. The scoping review will be guided by Arksey and O'Malley's³⁹ proposed 5-stage framework that includes: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising, and reporting the results. This framework will serve as a guide for synthesising the literature and determining the key concepts and identify gaps in the existing literature. Quality appraisal will not be done as the review aims to map all research activities in this field.

Stage 1: identifying the research question

Through consultation with the research team, the overall main research question developed is: what is known about the prevalence, causes and other factors associated with traumatic stress symptoms among caregivers of individuals with psychiatric, neurodevelopmental or neurocognitive disorders?

The study will use the PICO (table 1) format to aid in clarifying the research question, and help determine search concepts and context of study that is most appropriate to answer the research question.

Types of sources

This scoping review will consider both experimental and quasi-experimental study designs including randomised controlled trials, non-randomised controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research.

Stage 2: identifying relevant studies

A search was conducted for published and unpublished grey literature on the research area in the following electronic databases: CINAHL, SCOPUS, PsychInfo, OVID PubMed, ProQuest Dissertation and Thesis Global in September 2020. The search strategy, including all identified keywords and index terms, was adapted for each included database and/or information source. Hand searching of all reference lists of included studies was also conducted to identify additional studies of relevance.

Search terms were determined with input from the research team. The search strategy was developed in consultation with an experienced research librarian, and was revised pending input from the research team. The search strategy is shown in online supplemental appendix 1. Terms were searched as both keywords in

Table 1 PICO framework for eligibility of study

| Criteria | Determinants |
|--------------------|---|
| P—Population | ▶ Participants of the study involve caregivers who provide care to individuals with neurodevelopmental, psychiatric or neurocognitive disorders. |
| I—Interest/Concept | ▶ The article explores/investigates/examine post-traumatic stress symptoms (PTSS), trauma symptoms, or PTSD, in these caregivers. ▶ The article reports qualitative or quantitative primary data about PTSS, trauma symptoms, and PTSD in these caregivers |
| Co—Context | ▶ Caregivers must be providing caregiving to individuals with neurocognitive, psychiatric or neurodevelopmental disorders. |

the title and/or abstract and subject headings as per the requirement of each database. Studies published between years 2005 and 2020 were included as the scoping review focuses on recent research findings as this is a new area of investigation among caregivers. Moreover, to the best of the research team knowledge, very few studies have been conducted prior to this period. All search results will be uploaded into Endnote V.20 software, and duplicates identified and removed. Subsequently, they will be exported into Abstrackr for the review screening process at Stage 3.

Stage 3: study selection

The review screening process will consist of two stages of screening: (1) a title and abstract review and (2) full-text review. In the first stage of screening, 2 reviewers (a clinical psychologist with 13 years of experience and a psychiatrist with 6 years of experience) will independently screen the title and abstract of the first 100 search results using the abstract screening tool (online supplemental appendix 2) to ensure that the inclusion criteria are robust to capture all relevant articles. Any conflicting ratings will be discussed by the two reviewers until a consensus can be reached and the abstract screening tool will be revised as necessary. Subsequently, all remaining search results will be dual screened using the revised abstract screening tool. Articles that are deemed relevant by both of the reviewers will be included in the full-text review. Articles with conflicting ratings will be discussed until a consensus can be reached, if necessary, a third reviewer (a clinical psychologist) will provide further input.

For studies to be included, articles must be in the English language. These studies must meet the following criteria: informal/unpaid primary caregivers who provide majority of the care to children and/or adults with neurodevelopmental, psychiatric or neurocognitive disorders; the article explores/investigates/examines PTSS, trauma symptoms, or PTSD, in these caregivers; the article reports qualitative or quantitative primary data about PTSS, trauma symptoms, and PTSD in these caregivers.

Studies will be excluded if they have any of the following characteristics: not in the English language, caregivers who are professionals/paid caregivers; articles that review secondary data from other research related to PTSS, trauma symptoms or PTSD in caregivers, articles that focus exclusively on post-traumatic growth in caregivers; and caregiving provided to individuals with medical illnesses, or premature infants.

In the second stage of the screening, the two investigators will then each independently assess the full-text articles to determine if they meet the inclusion/exclusion criteria. Any full-text articles with conflicting ratings will be reviewed a second time and further disagreements about study eligibility at the full-text review stage will be resolved through discussion with a third investigator/research team until full consensus is obtained. The selection process of eligible studies will follow the recommendations in the PRISMA-ScR checklist.

Stage 4: extracting and charting the data

A data chart form will be used to electronically capture relevant information from all the included studies. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

The extracted data will include the following fields: author and date, title of study, publication, aim of study, study setting, study population, sampling method, study design, including any measures used, data analysis, most relevant findings and recommendations. Data abstraction will be conducted by extracting data from all included studies. The data will be compiled into a single excel spreadsheet in Microsoft Excel for validation and coding.

Stage 5: collating, summarising and reporting the results

The data will be presented in tabular form and a narrative report will be produced to summarise the extracted data around the key concepts and identified gaps in the research field. These results will be described in relation to the research question and in the context of the overall study purpose. As a scoping review can be used to map the concepts underpinning a research area, the findings from the scoping review will provide an overview of the research rather than an assessment of the quality of the individual studies.

Dissemination and ethics

As the scoping review methodology consists of reviewing and collecting data from publicly available materials, this study does not require ethics approval. Results of the scoping review will be disseminated via publication in a peer-reviewed journal and presentations at scientific conferences. Results from the scoping review will also guide the design of a mixed-method research study to examine the extent of trauma symptomatology and nature of potentially traumatising experiences, and how they relate to the mental health of caregivers of adult children with IDD from different cultural backgrounds.

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