Open access Protocol

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

Jan Mei Lim ,[1,2] Joanna Barlas,[1] Divjyot Kaur[1]

To cite: Lim JM, Barlas J, Kaur D. 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. *BMJ Open* 2022;**12**:e058118. doi:10.1136/bmjopen-2021-058118

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-058118).

Received 08 October 2021
Accepted 18 July 2022

Check for updates

[1]Psychology, James Cook University Australia - Singapore Campus, Singapore
[2]Psychology, Institute of Mental Health, Singapore

Correspondence to
Jan Mei Lim;
gracejanmei@gmail.com

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 A search for published and unpublished grey literature between years 2005 to 2020 in the electronic databases of CINAHL, SCOPUS, PsychInfo, OVID PubMed and ProQuest Dissertation, and Thesis Global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 healthcare 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 Grootscholten *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 Association[23] 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 sequalae 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's[30] 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's[39] 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.

Contributors LJM conceptualised the study and prepared the draft protocol under supervision of JB and DK. LJM prepared the manuscript and both JB and DK reviewed it. All authors read and approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been

ORCID iD

Jan Mei Lim http://orcid.org/0000-0002-6318-7103

REFERENCES

1 Talley RC, Montgomery RJ. Caregiving: A Developmental, Life-Long Perspective. In: *Caregiving across the lifespan: research, practice, policy*. Springer Science & Business Media, 2013: 1–10.
2 American Association of Retired Persons Public Policy Institute. Caregiving in the U.S. NAC and AARP public policy Institute; 2015.
3 Family Caregiver Alliance. Caregiver statistics: health, technology, and caregiving resources, 2020. Family caregiver alliance. Available: https://www.caregiver.org/caregiver-statistics-health-technology-and-caregiving-resources
4 Montgomery RJV, Gonyea JG, Hooyman NR. Caregiving and the experience of subjective and objective burden. *Fam Relat* 1985;34:19–25.
5 Berg-Weger M, Rubio DM, Tebb SS. Living with and caring for older family members: issues related to caregiver well-being. *J Gerontol Soc Work* 2000;33:47–62.
6 Seltzer MM, Li LW. The dynamics of caregiving: transitions during a three-year prospective study. *Gerontologist* 2000;40:165–78.
7 Schumacher KL, Stewart BJ, Archbold PG, *et al*. Family caregiving skill: development of the concept. *Res Nurs Health* 2000;23:191–203.
8 Northouse LL, Mood D, Templin T, *et al*. Couples' patterns of adjustment to colon cancer. *Soc Sci Med* 2000;50:271–84.
9 Raveis VH, Karus DG, Siegel K. Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. *Cancer* 1998;83:1652–63.
10 Adelman RD, Tmanova LL, Delgado D, *et al*. Caregiver burden: a clinical review. *JAMA* 2014;311:1052–60.
11 Alltag S, Conrad I, Riedel-Heller SG. Care burdens for older relatives of dementia patients and their influence on quality of life: a systematic review of the literature. *J Gerontol Geriatr* 2019;52:477–86.
12 Chiao C-Y, Wu H-S, Hsiao C-Y. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev* 2015;62:340–50.
13 Springate BA, Tremont G. Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *Am J Geriatr Psychiatry* 2014;22:294–300.
14 Beentjes TAA, Goossens PJJ, Poslawsky IE. Caregiver burden in bipolar hypomania and mania: a systematic review. *Perspect Psychiatr Care* 2012;48:187–97.
15 Möller-Leimkühler AM, Wiesheu A. Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. *Eur Arch Psychiatry Clin Neurosci* 2012;262:157–66.
16 Grootscholten IAC, van Wijngaarden B, Kan CC. High functioning autism spectrum disorders in adults: consequences for primary caregivers compared to schizophrenia and depression. *J Autism Dev Disord* 2018;48:1920–31.
17 Chou YC, Pu C-Y, Fu L-Y, *et al*. Depressive symptoms in older female carers of adults with intellectual disabilities. *J Intellect Disabil Res* 2010;54:1031–44.
18 Marsack-Topolewski CN, Church HL. Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *Am J Intellect Dev Disabil* 2019;124:145–56.
19 Li Q, Loke AY. A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: a review of the literature. *Eur J Oncol Nurs* 2013a;17:578–87.
20 Nijboer C, Tempelaar R, Triemstra M. The role of social and psychological resources in caregivers of cancer patients. *Cancer* 2001;89:1029–39.
21 Weitzner MA, Moody LN, McMillan SC. Symptom management issues in hospice care. *Am J Hosp Palliat Care* 1997;14:190–5.
22 Gallagher S, Phillips AC, Oliver C, *et al*. Predictors of psychological morbidity in parents of children with intellectual disabilities. *J Pediatr Psychol* 2008;33:1129–36.
23 APA. *Diagnostic and statistical manual of mental disorders (DSM-5®*. American Psychiatric Pub, 2013.
24 Magruder KM, Yeager DE. The prevalence of PTSD across war eras and the effect of deployment on PTSD: A systematic review and meta-analysis. *Psychiatr Ann* 2009;39.
25 Kitchiner NJ, Roberts NP, Wilcox D, *et al*. Systematic review and meta-analyses of psychosocial interventions for veterans of the military. *Eur J Psychotraumatol* 2012;3. doi:10.3402/ejpt.v3i0.19267. [Epub ahead of print: 05 12 2012].
26 Conard PL, Sauls DJ. Deployment and PTSD in the female combat veteran: a systematic review. *Nurs Forum* 2014;49:1–10.
27 Dutton MA, Green BL, Kaltman SI, *et al*. Intimate partner violence, PTSD, and adverse health outcomes. *J Interpers Violence* 2006;21:955–68.
28 Lagdon S, Armour C, Stringer M. Adult experience of mental health outcomes as a result of intimate partner violence victimisation: a systematic review. *Eur J Psychotraumatol* 2014;5. doi:10.3402/ejpt.v5.24794. [Epub ahead of print: 12 09 2014].
29 Stuber ML, Kazak AE, Meeske K, *et al*. Is posttraumatic stress a viable model for understanding responses to childhood cancer? *Child Adolesc Psychiatr Clin N Am* 1998;7:169–82.
30 Ehlers A, Clark DM. A cognitive model of posttraumatic stress disorder. *Behav Res Ther* 2000;38:319–45.
31 Kingston C, Onwumere J, Keen N, *et al*. Posttraumatic stress symptoms (PTSS) in caregivers of people with psychosis and associations with caregiving experiences. *J Trauma Dissociation* 2016;17:307–21.
32 Boye B, Malt UF. Stress response symptoms in relatives of acutely admitted psychotic patients: a pilot study. *Nord J Psychiatry* 2002;56:253–60.
33 Loughland CM, Lawrence G, Allen J, *et al*. Aggression and trauma experiences among carer-relatives of people with psychosis. *Soc Psychiatry Psychiatr Epidemiol* 2009;44:1031–40.
34 Casey LB, Zanksas S, Meindl JN, *et al*. Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study. *Res Autism Spectr Disord* 2012;6:1186–93.
35 Stewart M, Schnabel A, Hallford DJ, *et al*. Challenging child behaviours positively predict symptoms of posttraumatic stress disorder in parents of children with autism spectrum disorder and rare diseases. *Res Autism Spectr Disord* 2020;69:101467.
36 Beinart N, Weinman J, Wade D, *et al*. Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. *Dement Geriatr Cogn Dis Extra* 2012;2:638–48.
37 Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology* 1998;51:S53–60.
38 Burns A. The burden of Alzheimer's disease. *Int J Neuropsychopharmacol* 2000;3:31–8.
39 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.

PICo Worksheet and Search Strategy Proposal

1. Define your question using PICo by identifying: Population, Interest, and Context:

   Question:
   - 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?

   Population:
   - Participants of the study involve caregivers who provide care to individuals with neurodevelopmental, psychiatric or neurocognitive disorders.

   Concept / Interest:
   - The article explores / investigates / examine posttraumatic stress symptoms, trauma symptoms, or PTSD, in these caregivers.
   - The article reports qualitative or quantitative primary data about posttraumatic stress symptoms (PTSS), trauma symptoms, and PTSD in these caregivers

   Context:
   - Caregivers must be providing caregiving to individuals with neurocognitive, psychiatric or neurodevelopmental disorders.

2. Type of study – methodology

   Clinical queries:
   qualitative and quantitative studies (Medline, CINAHL)

3. Type of study – data collection

   List types of data collection instruments:
   Questionnaires, interviews

4. Proposed search strategy for respective database:

   <u>PsychInfo</u>

   1st term:
   - PTSD → 5 terms (posttraumatic stress disorder, posttraumatic stress, stress reactions, traumatic experiences, traumatic neurosis)
     (MAINSUBJECT.EXACT("Traumatic Experiences") OR
     MAINSUBJECT.EXACT("Stress Reactions") OR
     MAINSUBJECT.EXACT("Posttraumatic Stress") OR
     MAINSUBJECT.EXACT("Traumatic Neurosis") OR
     MAINSUBJECT.EXACT.EXPLODE("Posttraumatic Stress Disorder"))

This form is adapted from: Miller, S.A. (2001). *PICO worksheet and search strategy*. US National Center for Dental Hygiene Research.

2nd term:

- Caregiver → 5 terms (caregiver, caregiver burden, caregiving, child care, elder care)
- Parent → "explode" → 6 terms
  MAINSUBJECT.EXACT("Foster Parents") OR
  MAINSUBJECT.EXACT("Caregiver Burden") OR
  MAINSUBJECT.EXACT("Caregivers") OR
  MAINSUBJECT.EXACT("Caregiving") OR
  MAINSUBJECT.EXACT("Adoptive Parents") OR
  MAINSUBJECT.EXACT("Homosexual Parents") OR
  MAINSUBJECT.EXACT("Grandparents") OR
  MAINSUBJECT.EXACT("Child Care") OR
  MAINSUBJECT.EXACT.EXPLODE("Parents") OR
  MAINSUBJECT.EXACT("Elder Care")

SCOPUS

1st term:

- (TITLE-ABS-KEY (caregiv* OR parent OR parents OR mother* OR father*)

2nd term:

- AND TITLE-ABS-KEY (ptsd OR "Posttraumatic Stress" OR "Posttraumatic Growth" OR "Trauma Related Disorders")

3rd term:

- TITLE-ABS-KEY (depression* OR anxiety OR autis* OR asperger* OR "intellectual disability" OR "learning disability" OR "mental retardation" OR "developmental disability" OR "attention deficit" OR adhd OR psychosis OR schizophrenia OR dementia OR bipolar OR "obsessive-compulsive" OR ocd OR "personality disorder" OR "borderline" OR "Mental disorder"))

CINAHL

1st term:

- AND TITLE-ABS-KEY (ptsd OR "Posttraumatic Stress" OR "Posttraumatic Growth" OR "Trauma Related Disorders")

2nd term:

- (TITLE-ABS-KEY (caregiv* OR parent OR parents OR mother* OR father*)

This form is adapted from: Miller, S.A. (2001). *PICO worksheet and search strategy*. US National Center for Dental Hygiene Research.

OVID PubMed

1st search:
- Stress Disorders, Post-Traumatic/

2nd search:
- parenting/ or grandparents/ or exp parents/

3rd search:
- Caregivers/

4th search:
- (caregiv* or parent or parents or mother* or father *).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

5th search:
- (ptsd or “"Posttraumatic Stress" or "Posttraumatic Growth" or "Trauma Related Disorders" or "Trauma Neurosis ").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

6th search:
- 1st search + 5th search (with OR)

7th search:
- 2nd search + 3rd search + 4 search (with OR)

8th search:
- 6th search + 7th search (with AND)

5. List any limits that may apply to your search:

Age: no age limit
Year(s) of publication: 2005-2020
Language(s): English

6. List the databases for that searches will be conducted in:

   1. CINAHL
   2. SCOPUS
   3. PsychInfo
   4. OVID PubMed
   5. GREY Literature (ProQuest Dissertation, Thesis Global)

This form is adapted from: Miller, S.A. (2001). *PICO worksheet and search strategy*. US National Center for Dental Hygiene Research.

Caregiver PTSS Abstract Screening Tool

<table>
<tr><th>To Screen In Article
A “yes” or “unsure” to all of the following:</th><th>To Screen Out Article
A “no” to any of the following:</th></tr>
<tr><td colspan="2">1. Title and abstract is written in the English language.</td></tr>
<tr><td colspan="2">2. Population
- Participants of the study involve caregivers who provide care to individuals with neurodevelopmental, psychiatric or neurocognitive disorders.
- **Note**
- Caregivers include informal caregivers, that includes parents and family members; exclude caregivers that are professionals / paid caregivers</td></tr>
<tr><td colspan="2">3. Concept / Interest
- The article explores / investigates / examine posttraumatic stress symptoms, trauma symptoms, or PTSD, in these caregivers.
- The article reports qualitative or quantitative primary data about posttraumatic stress symptoms (PTSS), trauma symptoms, and PTSD in these caregivers
- **Note**
- This excludes articles that review secondary data from other research related to PTSS, trauma symptoms or PTSD or post-traumatic growth in caregivers</td></tr>
<tr><td colspan="2">4. Context (to include in Full text screening tool)
- Caregivers must be providing caregiving to individuals with neurocognitive, psychiatric or neurodevelopmental disorders.
- **Note**
- This excludes providing caregiving to individuals with medical illnesses, or premature infants.</td></tr>
</table>

Guide on Screening Terms in Articles:

Likely to be Relevant	Unlikely to be Relevant
- Caregivers of patients / children / adults with neurodevelopmental, psychiatric and neurocognitive disorders - PTSS / PTSD / Trauma symptoms / traumatic experiences - Aggressive behaviours - Challenging behaviours - Behaviour problems - Violence / violent behaviours - Aggression - Neurodevelopmental disorders - Developmental disabilities - Intellectual disability - Autism - Psychosis - Schizophrenia - Personality disorder - Dementia	Participants - Patients / children / adults with PTSD / trauma - Patients / children / adults with chronic / acute medical illness - Patients / children / adults with cancer - Patients / children / adults with Motor vehicle accident Context - Physical / sexual abuse - Partner violence Types of articles - Commentaries or opinion articles that do not include primary or secondary data