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## Review Title:

# Trauma-informed dementia care: a scoping review protocol

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## **Conflicts of interest**

No conflicts of interest.

## **CRedit author statement**

LB – Conceptualisation, methodology, writing (original draft), project administration

GH – Conceptualisation, writing (review and editing)

FU – Writing (review and editing)

JS – Writing (review and editing)

## **Abstract**

### **Objective**

The aim of this scoping review is to investigate and characterise trauma-informed approaches in dementia care.

### **Introduction**

There is growing recognition of the prevalence of trauma and the impact it can have on feelings of safety and establishing trusting relationships. Organisations (schools, criminal justice, health care, social care) are increasingly adopting trauma-informed practices which seek to reframe complex behaviours as a response to trauma. For individuals living with dementia, increasing care needs may lead to situations that cause distress and changes in behaviour. Applying trauma-informed practices may provide a useful approach for understanding causes and providing solutions for responding to distressed behaviours.

### **Inclusion criteria**

The scoping review will include studies and documents that highlight, discuss, or evaluate trauma-informed practices in relation to individuals with dementia or dementia care settings. All study types across the hierarchy of evidence will be considered for inclusion with no geographical restrictions. The review will also include grey literature sources.

### **Methods**

A search of Embase (Ovid), Medline (Ovid), Emcare (Ovid), HMIC (Ovid) CINAHL (EBSCO), PsycINFO (ProQuest) and the TRIP database will be undertaken. Grey literature sources to be searched include HMIC (Ovid), Google, CADTH, Government websites, The British Library, EThOS, professional magazines and professional websites e.g. British Psychological Society. Titles and abstracts will be screened independently by two or more of the review team against the inclusion criteria. Selected papers will then proceed to full text screening by two of the review team. Data will be extracted using a bespoke data extraction tool. Findings will be presented using a narrative approach, using a combination of tabular and textual descriptions.

**Key words**

Dementia, trauma-informed, health care, social care

## Introduction

Changes in mood and behaviour are common characteristics of dementia. It is estimated that up to 97% of individuals experience at least one or more behaviours during their illness (Kales, Gitlin and Lyketsos, 2015). These behaviours may include agitation, restlessness, repetitive vocalisations, disinhibition and resistiveness to interaction and care interventions. Historically called 'challenging behaviour', 'behaviours that challenge' and behavioural and psychological symptoms of dementia (BPSD), these emphasised the cause being due to brain changes. Hughes, Beatty and Emmett (2021) argue that the title BPSD is not helpful as they are not symptoms (what people complain of) but signs (what is observed), as such the term medicalises behaviour, something that needs to be treated. There is now recognition that behaviours are a way of communicating an unmet need (Handley, Bunn and Goodman, 2019) and are a response to psychosocial factors. The term responsive behaviour is now increasingly used in the literature (Clifford and Doody, 2018), however, there is still some contention that BPSD should continue to be used in a clinical setting, due to the vagueness of terms such as responsive behaviour (Cunningham, Macfarlane and Brodaty, 2019). However, the most important factor is recognising each person with dementia is an individual and that each behaviour is individual to that person (Hughes, Beatty and Emmett, 2021).

The risk of experiencing a traumatic event or multiple events increases with age (Ganzel, 2018; Ricks-Aherne, Wallace and Kusmaul, 2020) and therefore, is an important factor to consider when working with older adults. General population surveys conducted in 24 countries have found that approximately 70% of respondents report experiencing at least one traumatic event (Benjet *et al.*, 2016; Kessler *et al.*, 2017). Trauma is defined as resulting... 'from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being' (Substance Abuse and Mental Health Services Administration [SAMHSA], Trauma and Justice Strategic Initiative, 2012, p. 2). This definition is not limited to the diagnostic criteria of post-traumatic stress disorder (PTSD) and adopts a broader approach that recognises that trauma symptoms that do not meet diagnostic criteria can still have significant impacts on physical and mental health (Ganzel, 2018;

Kusmaul and Anderson, 2018). Moreover, research by Reynolds *et al.* (2016) from a nationally representative survey in the USA concluded that PTSD is a more common disorder in later life than previously recognised and propose the need to tailor assessment, diagnosis and treatment for older adults.

Trauma-informed care/practices/approaches are rooted in trauma theory (Kusmaul and Anderson, 2018). It recognises the impact of trauma on developmental processes and later life outcomes as demonstrated in the Adverse Childhood Experiences (ACEs) study (Felitti, 2002). There is now growing discussion and acknowledgment that trauma-informed care needs to be applied across a range of settings, including mental health (Sweeney *et al.*, 2016), hospice care (Ganzel, 2018), end of life care (Ricks-Aherne, Wallace and Kusmaul, 2020), older adults (Kusmaul and Anderson, 2018), learning disabilities (McNally *et al.*, 2022), forensics (Goldenson, Brodsky and Perlin, 2022) and education (Bosse, Clark and Arnold, 2021; L'Estrange and Howard, 2022). A systematic review by (Han *et al.*, 2021) highlights adoption of trauma-informed interventions in several countries (US, Netherlands, Canada, Australia, UK, Sweden, Chile, Iran, Haiti, South Africa and Germany).

SAMHSA propose a universal precaution (Ricks-Aherne, Wallace and Kusmaul, 2020) where an assumption is made that any individual being cared for may have experienced a traumatic event. The UK National Household survey identified that 47% of individuals experienced at least one ACE (Bellis *et al.*, 2014). In 2022 the UK Government released its working definition of trauma-informed practice, identifying that trauma can affect individuals, groups and communities, the need to increase practitioners' awareness of the negative impacts of trauma and to prevent re-traumatisation. It sets out six principles of trauma-informed practice: safety, trust, choice, collaboration, empowerment and cultural consideration (Office for Health Improvements and Disparities (OHID), 2022). Trauma-informed care seeks to recognise the prevalence of trauma and how it may impact on an individual's behaviours (Office for Health Improvements and Disparities (OHID), 2022). In practice this means understanding that distressed behaviours maybe a trauma response.

Older adults and specifically individuals with dementia are likely to have increasing care needs as well as experiencing multiple losses and changes, as such there is a

risk of trauma reactivation and a trauma response (Ganzel, 2018; O'malley *et al.*, 2023). Individuals with trauma histories may be more likely to be anxious, depressed, distrustful, angry and avoidant (Ganzel, 2018). The United Kingdom (UK) National Audit of Dementia (2019) identified that only 36% of notes detailed factors that caused distress and only 32% outlined actions which could calm or reassure (Hood *et al.*, 2019). However, the potential root causes of distress are not captured in these audits. The management of behaviours may result in the prescribing of sedative medication or enhanced observation 'specialing' (Featherstone *et al.*, 2019). The UK audit found that 17% of people had psychotropic medication prescribed during admission/on discharge, with the most frequently recorded reason as agitation and aggression (Royal College of Psychiatrists, 2020). The Global Health Observatory highlights that routine antipsychotic prescribing records for people with dementia is not recorded in all countries (World Health Organisation (WHO), 2021). Identifying less restrictive and harmful practices is necessary for improving care and safety of people with dementia and to reduce their iatrogenic risks (Akrou, Courret-Gilgen and Perrenoud, 2022).

Furthermore, research has explored ACEs and PTSD as possible risk factors for dementia. A systematic review by (Corney *et al.*, 2022) on the relationship between Adverse Childhood Experiences (ACEs) and Alzheimer's Disease (AD) whilst concluding that ACEs appear to be associated with an increased risk of developing the disease, emphasised a lack of research in the area with findings needing to be interpreted with caution. The review also only focused on AD. A systematic review and meta-analysis by Günak *et al.* (2020) on PTSD and dementia concluded that PTSD is a risk factor for developing all-cause dementia. Therefore, it could be suggested that a universal precaution approach as identified by SAMHSA, needs to be taken with individuals with dementia. Where potential trauma needs to be considered when understanding individual needs and providing health and care interventions.

Individuals with dementia may experience various situations that cause distress, intrusive health and care interventions, relationship changes, loss of cognitive and functional skills and moving into long-term care. Understanding the cause of changes in behaviour in dementia can be challenging for family members and health and social care staff. Knowing the person, their life-history, their likes, and dislikes



are recommended as a way to reduce distress (Kindell *et al.*, 2014), however, Ricks-Aherne, Wallace and Kusmaul (2020) caution that life-history work may have a negative impact for older adults by re-engaging the individual with traumatic memories and propose the need for trauma assessments for people with dementia. Furthermore, due to the reported rates of trauma in the general population and the risk of experiencing trauma increasing with age suggests that this is a vital consideration when caring for someone living with dementia and warrants further investigation. A scoping review is needed to identify the available evidence on this topic, clarify key concepts and identify the characteristics or factors related to trauma-informed approaches in dementia care. The findings of the scoping review will be useful for anyone providing care to people living with dementia and highlight questions for future research.

A preliminary search of JBI Evidence Synthesis, Cochrane Database of Systematic reviews, Cumulative Index to Nursing and Allied Health Literature (EBSCO), Embase (Ovid), Open Science Framework and Figshare on the 18<sup>th</sup> March and 17<sup>th</sup> May 2024 did not identify any current or proposed reviews on the topic.

The aim of this scoping review is to investigate and characterise trauma-informed approaches in dementia care.

## **Review question**

What is currently known about applying trauma-informed approaches in dementia care?

- What are the characteristics of trauma-informed approaches related to dementia care?
- What are the contexts in which trauma-informed approaches have been discussed and applied in dementia care?
- What outcomes have been reported when trauma-informed approaches have been applied in dementia care, including outcomes for the individual, family members and health and social care staff?

## **Inclusion criteria**

### **Participants**

The scoping review will include studies and documents relating to individuals living with dementia, older adults experiencing cognitive impairment (may not have a formal diagnosis of dementia), health and social care staff working in older adults/dementia care and family carers of someone with dementia. All types of dementia and cognitive impairment will be included.

There are no age, gender or geographical restrictions.

### **Concept**

The overarching concept of interest for this scoping review is trauma-informed practices and approaches to care with people living with dementia. It will include studies and documents that highlight, discuss, or evaluate trauma-informed practices in relation to individuals with dementia or dementia care settings. If the concept is discussed in context to related areas of care, for example end of life care, these studies and articles will be included. The scoping review will also identify and map any reported outcomes for individuals with dementia, health and social care staff and family carers.

Literature that does not include dementia/cognitive impairment or trauma will be excluded.

### **Context**

This scoping review will consider dementia care in all health and social care settings (including hospitals, care homes, community services, at home) where care and support is provided by paid staff or family carers. It will look at international evidence in any setting.

### **Types of study to be included**

This scoping review will consider papers from across the hierarchy of evidence. This includes both experimental and quasi-experimental study designs such as randomised controlled trials, non-randomised controlled trials, before and after

studies and interrupted time series studies. Furthermore, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. Qualitative studies will also be considered that focus on qualitative data including, but not limited to phenomenology, grounded theory, action research, ethnography, feminist research and qualitative description. Depending on the research question/s systematic/scoping/realist/narrative reviews that meet the inclusion criteria will also be considered. Relevant text and opinion pieces will also be reviewed for inclusion in this scoping review.

In addition to papers sourced through commercial and academic publishers, grey literature which sits outside these domains will be considered for inclusion including but not exhaustively, Government websites, policy documents, unpublished studies, working papers, theses, dissertations, conference proceedings, discussion forums and blogs (Bonato, 2018).

## **Methods**

### **Search approach**

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters *et al.*, 2020) and reported following the PRISMA extension for scoping reviews (Tricco *et al.*, 2018).

### **Search strategy**

The lead author is an experienced clinical evidence specialist, so to reduce any potential bias the search strategy was peer reviewed by a health librarian/information specialist using PRESS (Peer Review of Electronic Search Strategies) (CADTH, 2016). It was developed using a three-stage approach. First an initial search of Embase (Ovid), CINAHL (EBSCO), PsycINFO (ProQuest) and Google was undertaken to identify relevant papers (published and grey literature) to identify key terms and phrases. For the second step, terms and index terms used to describe the papers were used to develop free text terms and in conjunction with the relevant subject headings created the search strategy. Text terms and subject headings were

combined with Boolean operators OR/AND, to enable within and across concepts to be combined. Text terms will remain constant but subject headings will be adjusted for each included database. The third step will involve an iterative approach to the search strategy, as further terms may be revealed during the screening process. The full search strategy is available in Appendix 1.

For grey literature sources key text terms will be used to identify relevant sources. These will be documented accordingly in the final review.

Only studies published in English will be included as the author does not have the resources for a translation service. There will be no other search filters or limiters applied.

Searches for published papers will be undertaken in the following databases; Embase (Ovid), Medline (Ovid), Emcare (Ovid), AMED (Ovid), HMIC (Ovid), CINAHL (EBSCO), PsycINFO (ProQuest) and the TRIP database.

Sources of grey literature to be searched include HMIC (Ovid) (contains official publications as well as grey literature), Google, CADTH, Government websites, The British Library, EThOS, professional magazines and professional websites e.g. British Psychological Society. All sources searched and those resulting in papers/documents to be included will be documented in the final review.

### **Selection of sources of evidence**

Following the search, all relevant citations from the databases will be uploaded to Refworks (ProQuest, 2024) for removal of duplicates. After de-duplication the remaining citations will be transferred to the systematic review platform Rayyan (Qatar Computing Research Institute, Doha, Qatar) (Ouzzani *et al.*, 2016). Titles and abstracts will be screened independently by two reviewers against the inclusion/exclusion criteria. Any disagreements will be resolved via discussion or by a third reviewer. Papers that meet the inclusion criteria at this stage will be collated into a new review on Rayyan for full-text screening and the corresponding papers uploaded. Full text screening will also be completed independently by two reviewers with disagreements resolved via discussion or a third member of the review team. Reasons for exclusion will be recorded and reported in the final review.

The process of study/source of evidence selection will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping reviews (PRISMA-Scr). A full narrative description will be accompanied by a PRISMA flow chart of the steps, detailing the flow from the search, through source selection, duplicate removal, full-text retrieval, grey literature results and any other additions from third search, data extraction and presentation of the evidence.

### **Data extraction**

Data will be extracted from the included papers in the scoping review by two reviewers independently. A bespoke data extraction tool will be used (see Appendix 2). The data extraction tool will include paper characteristics; author, year of publication, country of origin, aims/purpose, population, sample size (if relevant), methodology and methods, intervention, key findings and any reported outcomes. In addition, it will include data relevant to the research questions how trauma-informed approaches are characterised in dementia care (how trauma-informed dementia care is described, what approaches have been used), the contexts in which trauma-informed approaches have been implemented for people with dementia and any reported outcomes for the individual, family carers and health and social care staff.

Data extraction will be an iterative process. The tool will be piloted by two independent reviewers on a sample of papers (10%) and modified as necessary. This may include concepts not initially identified in the protocol. Any modifications to the data extraction tool will be documented in the final review. Any disagreements between reviewers will be resolved through discussion or via a third reviewer.

If required, authors of papers will be contacted to request clarification of published information or additional data.

### **Data analysis and presentation**

The extracted data will be presented using a narrative approach (Hammersley, 2013; Booth *et al.*, 2022) using a combination of textual descriptions and a tabular format. A bespoke draft presentation table has been created for this review (see Appendix 3). Mapping the data in this way (Hammersley, 2013) will enable frequency counts of

characteristics, concepts and contexts and further examination to identify dominant groups or clusters of characteristics (Rodgers *et al.*, 2009). These groups and clusters will provide a framework for the presentation of textual descriptions of the data and how it relates to the objectives and questions of the scoping review.

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# Appendices

## Appendix 1: Search strategy

Embase <1974 to 2024 May 21>

- 1 (trauma adj2 (informed or focused or focussed or intervention\* or past)).af.  
8301
- 2 (Dementia or Alzheimer\* or "cognitive impairment" or "Pick's Disease" or  
"Posterior Cortical Atrophy" or "Primary Progressive Asphasia").af. 580444
- 3 exp dementia/ 465613
- 4 mild cognitive impairment/ 41320
- 5 2 or 3 or 4 641054
- 6 1 and 5 60

## Appendix 2: Data extraction tool

Citation Details (author, date, title, journal)	Country	Study characteristics (type, participants, setting, aims)	How is trauma-informed care described	Intervention characteristics (context, how is trauma-informed care applied)	Key findings	Outcomes

### Appendix 3: Data presentation table

<b>Study characteristics (type, participants)</b>	<b>Context</b>	<b>How is trauma-informed care defined/ described</b>	<b>Intervention characteristics (how is trauma-informed care applied)</b>	<b>Outcomes</b>	<b>Recommendations for future research</b>