

# Information needs of stroke survivors and their family members regarding post-stroke cognition: a scoping review protocol

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## ABSTRACT

**Objective:** The aim of this review is to map current evidence describing the information needs of stroke survivors and family members regarding cognition.

**Introduction:** Managing cognitive changes is the most frequently reported unmet need among stroke survivors; hence, there is an urgent need to improve support for post-stroke cognitive impairment. While there is evidence that psychoeducation may help stroke survivors and their family members develop awareness about cognitive impairment and self-management strategies, it is unclear what information stroke survivors and their family members want to receive and how their needs change over time.

**Inclusion criteria:** This review will consider peer-reviewed articles describing information needs relating to the following cognitive domains: memory, language, attention, executive function, praxis, and number processing. Stroke survivors and/or their family members must comprise at least 50% of the study population and must be aged at least 18 years. Quantitative, qualitative, and mixed methods studies will be included.

**Methods:** The review will be conducted in line with the JBI methodology for scoping reviews. A full literature search will be conducted in MEDLINE (PubMed), PsycINFO (Ovid), Embase, CINAHL (EBSCOhost), and Scopus using a search strategy developed in consultation with an expert university librarian. Articles will be screened by title, abstract, and full text; then, data will be extracted by 2 independent reviewers. The reference lists of included articles will be hand-searched for additional material. Data analysis and reporting will involve qualitative (textual narrative synthesis) and quantitative (descriptive statistics) methods.

**Keywords:** caregivers; cognition; information needs; stroke

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## Introduction

Stroke affects up to 15 million people worldwide each year.<sup>1</sup> Nearly all stroke survivors experience changes in their cognitive functioning (memory, language, attention, executive function, praxis, and number processing) in the early stages after stroke.<sup>2,3</sup> These changes have been linked to reduced quality of life<sup>4</sup> and increased risk of depression.<sup>5,6</sup> Over the longer term, post-stroke cognitive outcomes are variable. Although a proportion of stroke survivors recover from early stage impairments, the majority

will retain a stable impairment or experience further cognitive decline and/or post-stroke dementia.<sup>7–10</sup>

In the United Kingdom (UK), national clinical guidelines highlight the importance of screening for cognitive impairment in the early stages after stroke,<sup>11</sup> but there is a lack of clear guidance for providing cognitive care beyond this point.<sup>12</sup> Consequently, 45% of stroke survivors feel abandoned when they leave hospital,<sup>13</sup> and managing cognitive changes after stroke is the most frequently reported unmet need.<sup>14</sup> To address this gap, the James Lind Alliance Priority Setting Partnership,<sup>15</sup> the NHS England Demand Signaling Report,<sup>16</sup> and the most recent National Clinical Guidelines for Stroke<sup>11</sup> have highlighted the need to improve long-term rehabilitation

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services for stroke, with cognition being identified as a particular research priority.<sup>15</sup>

While there is a lack of high-quality evidence to support pharmacological<sup>17</sup> and non-pharmacological interventions for cognitive impairment after stroke (Cochrane reviews on memory,<sup>18</sup> executive function,<sup>19</sup> and spatial neglect<sup>20</sup>), there is evidence that psychoeducation (ie, information provision) may help stroke survivors and their family members develop awareness about cognitive impairment and self-management strategies.<sup>21</sup> Nevertheless, while prior research suggests stroke survivors have information needs related to psychological changes after stroke,<sup>22</sup> it is unclear what information stroke survivors want to receive about cognition specifically. It is also important to develop a clearer understanding of family members' information needs. This is because family members often take on caring responsibilities once stroke survivors are discharged from inpatient services, but their information needs may differ from those of stroke survivors.<sup>22</sup> Furthermore, as information needs may change over time after stroke<sup>2</sup>, understanding whether and how psychoeducation needs linked to memory, language, attention, executive function, praxis, and number processing evolve is crucial if psychoeducational interventions are to target the appropriate post-stroke stage.

The objective of this review is to scope and identify gaps within the existing literature describing the information needs of stroke survivors and their family members regarding cognition in high-income countries. Importantly, the goal of the review is not to generate a single conclusive outcome through synthesis of current literature, but rather to map the existing evidence base to inform future research, culminating in the development of a UK-based complex intervention for people with stroke. A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and *JB* Evidence Synthesis was conducted and no current or in-progress scoping reviews or systematic reviews on the topic were identified.

## Review questions

- i) What research methods and designs have been used in previous studies describing stroke survivor and family member information needs regarding cognition?
- ii) What timepoints after stroke have been investigated in prior studies describing stroke

survivor and family member information needs regarding cognition?

- iii) What are the characteristics of participants included in prior studies describing stroke survivor and family member information needs regarding cognition?
- iv) What information needs related to post-stroke cognition have been reported in prior studies describing stroke survivor and family member information needs regarding cognition?
- v) What factors have been reported or suggested to affect information needs in prior studies describing stroke survivor and family member information needs regarding cognition?
- vi) What key gaps exist within the current evidence base?

## Inclusion criteria

### Participants

The review will consider articles that include stroke survivors and/or family members of stroke survivors. For the purposes of the review, a stroke survivor is defined as a person who has experienced a clinically diagnosed stroke of any type. A family member is defined as a person who identifies as related to a stroke survivor by blood, marriage, or through other familial involvement. The stroke survivors and/or family members will have to comprise at least 50% of the study population, in line with cut-offs used in prior scoping reviews,<sup>23,24</sup> and will have to be aged 18 years or over. The participants may be at any stage post-stroke.

### Concept

This review will consider studies that explore information needs regarding post-stroke cognition. Information needs are defined as the desire to obtain information to satisfy a conscious (or unconscious) need.<sup>25</sup> Cognition is defined as thinking skills related to any of the following domains: memory, language, attention, executive function, praxis, and number processing.<sup>3</sup>

### Context

This review will consider studies conducted in the United Kingdom and other high-income countries, defined using the most recent World Bank country classifications.<sup>26</sup> While the aim of this scoping review is to inform UK-centric guidelines and service improvement, we wish to include all potentially

informative studies conducted in geographic regions with a similar burden of stroke.<sup>27</sup> Participants may be based either in a clinical setting or in the community.

### *Types of sources*

This scoping review will consider published, peer-reviewed articles using quantitative, qualitative, or mixed methods study designs.

## **Methods**

This review will be conducted in line with the JBI methodology for scoping reviews<sup>27</sup> and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).<sup>28</sup>

### *Search strategy*

An initial search of MEDLINE (PubMed) and PsycINFO (Ovid) will be conducted under the supervision of a university librarian with expertise in literature reviews. Words contained in the title and abstract of retrieved papers will be reviewed, alongside index terms used to describe articles, to identify terms to include in the full search strategy. The full search strategy will be developed in consultation with the librarian and adapted to each of the included databases.

We will search the following databases: MEDLINE (PubMed), PsycINFO (Ovid), Embase, CIN-AHL (EBSCOhost), and Scopus. Gray literature databases will not be searched as we intend to only include articles that have been through a rigorous peer-review process, given the ultimate aim of this review is to inform future research by developing an evidence-based complex intervention. The search strategy will be limited to articles published in English, but will not be limited by date. Articles written in languages other than English will not be included because of budgetary and time constraints that prohibit translation. See Appendix I for a draft search strategy.

### *Source of evidence selection*

Following the search, all identified records will be collated, uploaded into EndNote v.X9 (Clarivate Analytics, PA, USA), and deduplicated. Two independent reviewers will conduct an initial pilot on 10 articles to test the screening process. This will ensure

consistency in the application of the inclusion and exclusion criteria during screening. After the pilot test, all retrieved articles will be screened independently by the reviewers by title, abstract, and then full text. Full texts of the final selected articles will be assessed in detail against the inclusion and exclusion criteria and reasons for exclusion of papers at this point will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers will be resolved by a third member of the research team. The reference lists of articles selected for inclusion in the review will be screened for additional records. The results of the search will be reported in full in the final scoping review and presented in a PRISMA flow diagram.

### *Data extraction*

Data will be extracted from the included articles by 2 members of the research team using a data extraction tool (Appendix II). The data extraction tool will be iteratively modified and revised as necessary during the data extraction process. Modifications will be detailed in the final scoping review. Two members of the research team will use the final version of the data extraction tool to retrieve data from all included articles. Extracted data will be discussed throughout the data extraction process (at least once per month) to ensure accuracy of data used in the final analysis. Authors of included articles may be contacted once to request missing or additional data, where required.

### *Data analysis and presentation*

Data will be reported using the PRISMA-ScR checklist. Data will be analyzed using a grounded theory approach based on the principles of textual narrative synthesis,<sup>29–31</sup> in line with the procedure outlined by Lucas *et al.*<sup>29</sup> One member of the research team will use the extracted data to produce a study commentary for each included article, referring back to the full text for additional detail where necessary. Articles will be grouped by the following factors: research method, research design, timepoint investigated, and study population. We will develop subgroup syntheses by synthesizing study commentaries from each article included in the subgroups. We will use subgroup syntheses to identify similarities and differences across the included articles in order to address the key research questions. The final textual narrative synthesis will address each research question. Tables will

provide numerical summaries of the included studies. The tables will also address the key research questions by listing the number of studies that used different research methods/designs, investigated different time-points, and included different study populations. This will facilitate identification of gaps in the literature.

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## Author contributions

GH conceived the framework for this review protocol and prepared the manuscript for submission. ND helped conceive the framework for the review protocol and critically reviewed and edited the manuscript.

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## Appendix I: Search strategy

### MEDLINE (PubMed)

Search conducted: July 7, 2023.

Search	Query	Records retrieved
#1	"Stroke" [MeSH] OR stroke*[tiab] OR "cerebral infarct*" [tiab] OR "cerebrovascular infarct*" [tiab] OR "cerebrovascular accident*" [tiab]	369,044
#2	"Patients" [MeSH] OR "Caregivers" [MeSH] OR patient*[tiab] OR survivor*[tiab] OR victim*[tiab] OR carer*[tiab] OR caregiver*[tiab]	8,296,534
#3	"Education" [MeSH] OR "information need*" [tiab] OR "education need*" [tiab] OR "knowledge need*" [tiab]	907,499
#4	"Cognition" [MeSH] OR "Memory" [MeSH] OR "Executive Function" [MeSH] OR cogniti*[tiab] OR thinking [tiab] OR memory [tiab] OR attention [tiab] OR "executive function*" [tiab] OR aphasia*[tiab] OR dementia*[tiab] OR language [tiab] OR neglect [tiab] OR neuropsych*[tiab]	1,719,882
#5	#1 AND #2 AND #3 AND #4	434

**Appendix II: Draft data extraction instrument**

Author, year, country	Title	Research design (eg, cross-sectional, longitudinal)	Research methods (eg, survey, semi-structured interviews)	Timepoint(s) since stroke investigated	Population (s) investigated	Participant demographics	Relevant findings