

BMJ Open Research investigating patient and carer psychoeducation needs regarding post-stroke cognition: a scoping review

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ABSTRACT

Objectives To search the literature systematically in order to map and identify gaps in research investigating patient and family member psychoeducation needs regarding post-stroke cognition.

Design Scoping review conducted in line with Joanna Briggs Institute (JBI) recommendations and PRISMA-ScR checklist.

Methods MEDLINE, PsycINFO, Embase, CINAHL and Scopus were searched on 25 August 2023 for peer-reviewed studies conducted in a high-income country, describing cognition-related psychoeducation needs in stroke survivors and/or family members aged ≥18 years (≥50% of the study population). Two reviewers independently screened titles, abstracts and then full-text articles. One reviewer extracted pre-defined study characteristics and findings. These data were verified by a second reviewer. Synthesis involved descriptive statistics and thematic analysis.

Results Searches identified 8115 articles, of which 30 were included. Articles were published between 1996 and 2023. Studies were conducted in Australia (n=7), USA (n=6), UK (n=5), Canada (n=3), New Zealand (n=3), Ireland (n=2), Netherlands (n=2), South Korea (n=1) and Sweden (n=1). Most studies (n=21) used an exclusively qualitative approach but six combined qualitative and quantitative methods. The post-stroke period under investigation varied, including the acute/subacute stage (n=10) and the chronic stage (n=3), though many articles did not state the timepoint explicitly. Research was conducted with stroke survivors only (n=7), family members only (n=12) and both stroke survivors and family members (n=11). Qualitative analysis suggested participants wanted psychoeducation about cognitive impairment, including recovery expectations, treatment/therapy options and signposting to services/resources available. Hopeful information was important. Factors potentially impacting cognition-related psychoeducation needs were identified as time since stroke and family member relationship. Most articles focused on aphasia with very few studies considering other cognitive domains (eg, memory, attention, executive function).

Conclusions The need for psychoeducation regarding cognition is well evidenced throughout the post-stroke care continuum, though most research has focused on language impairments. Further research investigating other cognitive impairments (eg, impairments in memory, attention and executive function) is required.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study used a robust peer-reviewed search strategy to identify relevant literature from five electronic databases.
- ⇒ Established frameworks for scoping review conduct were followed throughout this study.
- ⇒ Since psychoeducation has a broad definition and grey literature was not searched, some relevant sources of information may not have been included.

INTRODUCTION

The majority of stroke survivors experience cognitive impairment affecting at least one domain in the first weeks after stroke,^{1 2} although exact prevalence estimates vary depending on the nature of assessments used and sample characteristics.³ In the months after stroke, cognitive trajectories vary but post-stroke cognitive impairment persists in a substantial proportion of cases^{4 5} and stroke survivors are at a significantly increased risk of developing vascular and mixed dementia.⁶ Furthermore, stroke survivors consistently report cognitive problems as one of their greatest concerns and unmet needs.^{7 8}

Clinical guidelines recommend cognitive screening as soon as possible after stroke to identify any cognitive impairments^{9 10} and recent evidence suggests early screening may also be helpful for predicting longer-term outcomes.¹¹ Specifically, while there is currently no way to predict long-term post-stroke cognitive outcomes reliably on an individual level,¹² a recent systematic review and meta-analysis identified baseline cognitive impairment as the strongest risk factor for longer-term cognitive impairment after stroke.¹¹ This highlights the importance of acute cognitive screening to flag and support patients at risk of poor long-term outcomes.¹³

After initial cognitive screening, psychoeducation and adjustment often become the focus of cognitive rehabilitation^{14 15} as there is currently no strong evidence to support



interventions that directly improve cognitive outcomes after stroke.^{16–19} Providing information through psychoeducation supports patients (and their family members) to understand and cope with diagnoses²⁰ and previous research has found a beneficial impact of psychoeducation on self-efficacy and knowledge among those with minor stroke.¹⁴

Nevertheless, stroke survivors and their family members have reported substantial unmet psychoeducation needs, including about cognition.²¹ Furthermore, although clinical guidelines highlight the importance of psychoeducation generally,⁹ it remains unclear exactly what information should be provided about cognition. Without clear guidance, healthcare professionals face a substantial challenge in providing cognition-related information, as post-stroke cognitive impairment is a complex syndrome that affects various domains, including memory, language, attention, executive function, number processing and praxis.^{22–23} Furthermore, despite overall high prevalence of post-stroke cognitive impairment over the long term,^{24–25} the underlying aetiologies and longer-term trajectories of domain-specific impairments vary substantially.^{26–27} In addition, information about post-stroke cognition presents risks as well as benefits to patient well-being—for example, discussing increased dementia risk may help some individuals prepare for the future, but others may find the information highly anxiety-provoking.^{28–29}

Successfully navigating this complexity requires a clearer understanding of *what* stroke survivors and their family members want to know about cognition and *when* the need for cognition-related psychoeducation arises and peaks, as stroke survivors and their family members are likely to benefit most if psychoeducation is provided when they are psychologically ready to receive it and able to process it appropriately.³⁰ The aim of this scoping review was therefore to map and identify gaps within existing peer-reviewed articles describing cognition-related psychoeducation needs of stroke survivors and family members. Alongside other primary research,^{28–31} the ultimate goal of the research is to inform the design of a complex intervention focused on monitoring and psychoeducation to support cognition after stroke. The specific questions addressed by this review are:

1. What research methods and designs have been used in previous studies describing stroke survivor and family member information needs regarding cognition?
2. What timepoints after stroke have been investigated in previous studies?
3. What are the characteristics of stroke survivors and family members included in previous studies?
4. What psychoeducation needs related to post-stroke cognition have been reported in previous studies?
5. What factors have been suggested to impact psychoeducation needs in previous studies?
6. What key gaps exist within the current evidence base?

METHODS

Review protocol

The review was conducted in accordance with the Johanna Briggs Institute (JBI) methodology for scoping reviews³² and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist. The protocol for this review underwent a rigorous peer-review process for publication³³ and has been made openly available (<https://osf.io/fmz9t>). Any divergences from the protocol are outlined in online supplemental file 1.

Patient and public involvement

Patients were involved in developing the funding proposal for the fellowship of which this research forms a part. Patients were consulted on the importance of the research question and the approach through a survey with the Stroke Association's Voices in Research (43 respondents) and three smaller focus groups. Of particular relevance to the present study, they emphasised the importance of including family member/carer perspectives where possible.

Search strategy

The search strategy was developed in consultation with an expert librarian at the University of Oxford. The final approved search strategy (online supplemental file 2) was adapted to search additional electronic databases using the Polyglot tool provided by Systematic Review Accelerator software (<https://sr-accelerator.com/>). Systematic searches were conducted in five electronic databases on 25 August 2023: MEDLINE (PubMed), PsycINFO (Ovid), Embase (Elsevier), CINAHL (Ebsco) and Scopus (Elsevier). Search strategies developed using the Polyglot tool are presented in online supplemental file 3. Grey literature was not included; as the aim of the review was to inform an evidence-based intervention, we included articles that had been through rigorous peer-review only. The search strategy was limited to English, but it was not limited by year.

Inclusion criteria

The inclusion criteria were based on the JBI Population/Concept/Context (PCC) framework.³² Articles were eligible for inclusion in this review if they met the following criteria:

Participants

- ▶ Stroke survivors and/or family members of stroke survivors. Stroke survivors were defined as someone who has experienced a clinically diagnosed stroke of any type. Family members were defined as someone who identifies as related to a stroke survivor by blood, marriage or with other familial involvement.
- ▶ Stroke survivors and/or family members of stroke survivors comprising at least 50% of the study population, in line with cut-offs used in previous scoping reviews.

- ▶ Stroke survivors and family members aged 18 years and over.

Concept

- ▶ Self-reported information needs regarding post-stroke cognition. Information needs were defined as a desire to obtain information to satisfy a conscious (or unconscious) need.³⁴ Cognition was defined as thinking skills related to any of the following domains: memory, language, attention, executive function, praxis and number processing.²²

Context

- ▶ Studies conducted in the UK and other high-income countries, defined using the most recent World Bank country classifications (2022).
- ▶ Participants based either in a clinical setting or the community.

Types of sources

We included published peer-reviewed articles that used quantitative, qualitative or mixed methods designs. Review articles, peer-reviewed commentaries and opinion pieces were excluded.

Study selection process

Identified records were collated and uploaded into EndNote v.X9 (Clarivate Analytics, PA, USA). SR-Accelerator Deduplicator³⁵ was used to remove duplicates. Two members of the research team (GH and FT) independently screened records against eligibility criteria by title, abstract and then full-text after conducting a pilot screening round. They recorded reasons for exclusion for articles excluded at the full-text stage. Differences in inclusion/exclusion decisions were settled by discussion among the research team. Reference lists of the included articles were hand searched to identify further relevant records.

Data extraction

A data extraction tool was developed prior to extracting data and refined iteratively throughout the process. One researcher (GH) used the final version of the tool (online supplemental file 4) to extract data from the included articles. Another researcher (FT) reviewed extracted data for accuracy.

Synthesis

Extracted data were synthesised using quantitative and qualitative methods. Descriptive frequency counts were used to characterise the included articles, in terms of key article characteristics (year of publication, location) and factors relevant to the research questions (research methods/designs, characteristics of study population, post-stroke timepoint).

A pragmatic inductive approach to thematic analysis resembling template analysis was used^{36 37} to identify specific cognition-related psychoeducation needs and factors potentially impacting them. First, one member

of the research team (GH) familiarised themselves with the data by reading and rereading the included articles. Then, they developed candidate themes and integrated them into an initial template, which was used to code relevant text from included articles (ie, text describing psychoeducation needs and factors impacting them) at a semantic level. The template was revised iteratively throughout the coding process to ensure themes were firmly rooted in the data (ie, inductive analysis). The research team discussed and agreed on the final template, then one member of the research team applied it to all articles to ensure it adequately captured the data. Any themes or subthemes mentioned within the included articles and corresponding codes were recorded using the data extraction table in the ‘relevant findings’ section and a second member of the research team verified these against the original source articles. To ensure the analysis remained at the descriptive level, as recommended in JBI guidance,³² themes resembled domain summaries rather than broader interpretive units of meaning.

In line with the critical realist positioning of the analysis, the aim was to generate a situated theme structure with translational value rather than a reliable and reproducible one.³⁸ Indeed, the research team recognised that the final themes would inevitably be shaped by their own expertise (ie, clinical neuropsychology, clinical psychology), experiences (eg, working on hyperacute stroke units and in community brain injury rehabilitation settings) and values (eg, importance of addressing cognitive changes after stroke during rehabilitation). Rather than seeing these factors as threats to the reliability of the analysis, however, they were considered an asset that would mitigate the risk of relevant findings from included articles being overlooked.

RESULTS

Selection of evidence sources

The database searches retrieved 8112 records. This was reduced to 6726 records after deduplication. 27 records were selected for inclusion after screening. A further 3 records were identified from reference lists. This resulted in a total of 30 articles being selected for inclusion in the scoping review. [Figure 1](#) documents the selection process.

The included articles were published between 1996 and 2023. Most studies (n=20) were published between 2001 and 2020, with 14 published in the last 10 years (2013–2023). Studies were conducted in Australia (n=7), USA (n=6), UK (n=5), Canada (n=3), New Zealand (n=3), Ireland (n=2), the Netherlands (n=2), South Korea (n=1) and Sweden (n=1). Each included article was numbered to facilitate concise reporting. A summary of extracted data and numbers corresponding to each article are presented in online supplemental file 5.

What research methods have been used?

21 articles used an exclusively qualitative approach to data collection and analysis^{39–57} and six further articles

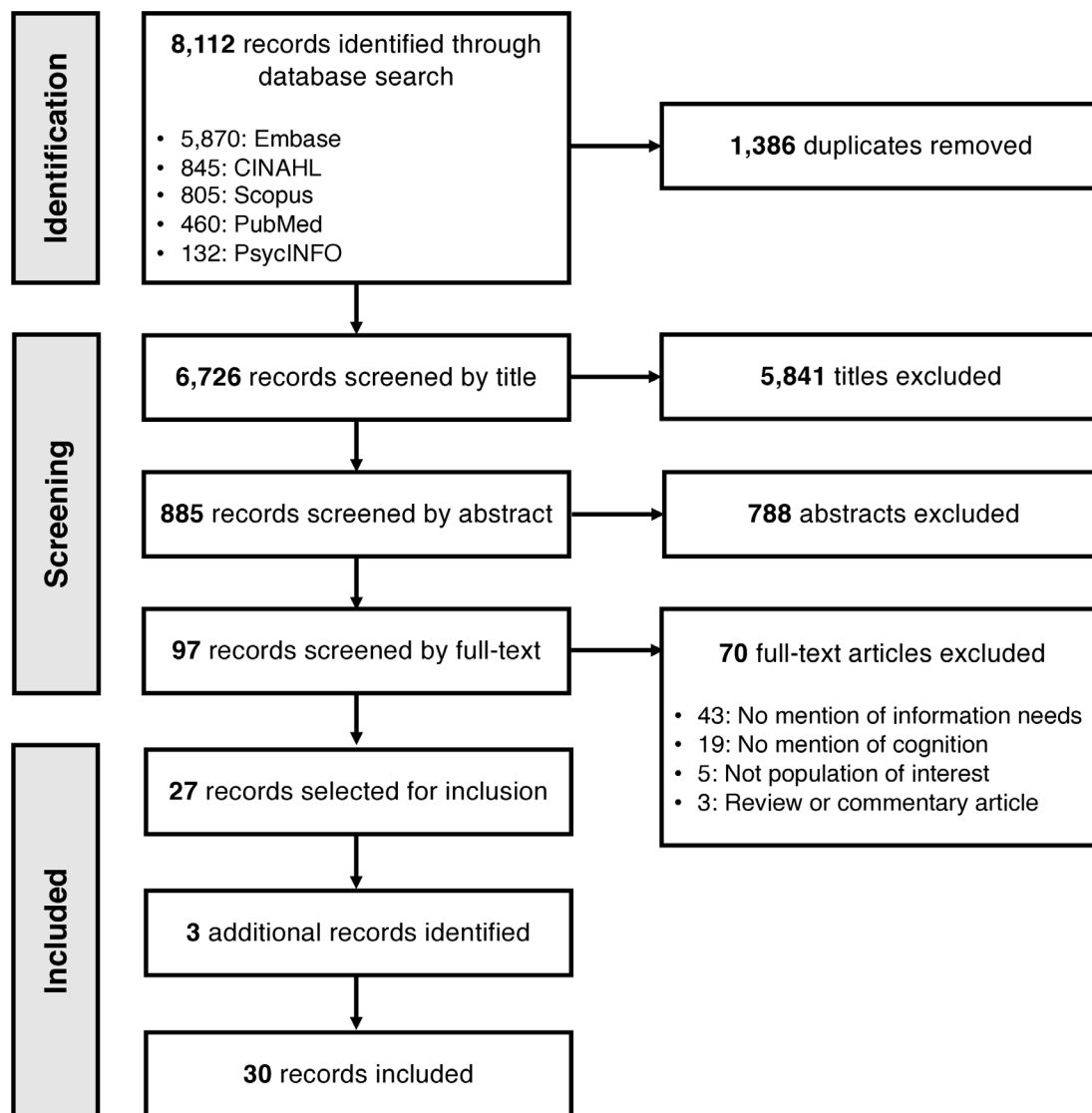


Figure 1 Flow diagram illustrating numbers of articles screened, assessed for eligibility and included in the review.

used qualitative methods combined with quantitative methods.^{58–63} Most studies that used a qualitative data collection approach conducted semi-structured interviews^{40 41 43–45 47–53 55–57 59 60 64 65} but five studies conducted focus groups.^{39 42 46 54 61} Participant sample sizes in qualitative studies varied substantially. Two articles presented case studies involving a single family member.^{47 64} The maximum sample size among the articles using exclusively qualitative methods was 50 participants with aphasia.^{53 57} Focus group sizes varied between 2–4 participants⁴⁶ and 6–10 participants.⁵⁴

Articles that used qualitative data collection methods employed different analytic approaches and frameworks. Eight articles used a version of thematic analysis,^{39 40 45 48 49 52 55 56} eight articles used a version of content analysis^{42 47 51 53 54 57 61 65} and two used the constant comparative method.^{44 50} Other approaches were narrative analysis⁶⁴ and a modified referenced five-step process.⁴¹ One article described an approach that resembled thematic analysis but did not label it as such.⁴³ Two articles did not

describe how semi-structured interview data were analysed.^{59 60} Most studies that used qualitative methods did not mention how they dealt with important qualitative concepts, such as positionality, in their data collection and analysis processes.^{39 41–47 49 50 53–57 60–64}

Five of the included articles used surveys or questionnaires.^{62 63 66–68} All of these articles used custom measures rather than validated standard questionnaires. Questionnaires were administered remotely in three studies^{66–68} and face-to-face in the other two studies.^{62 63} Face-to-face administrations were audio-recorded and analysed qualitatively to complement quantitative questionnaire data.^{62 63}

What timepoints after stroke have been investigated?

10 articles explicitly stated their investigation pertained to the first 6 months after stroke (acute/subacute stage).^{39 41 45 47 52 56 59 62–64} Specific timepoints investigated included stroke onset/first days after stroke,^{39 41 62–64} first week after stroke,⁶² 2 weeks after stroke,⁵⁹ first month

after stroke,⁶² first 3 months after stroke⁴⁵ and 4 months after stroke.⁴⁷

Three articles explicitly stated their investigation pertained to the period at least 6 months after stroke (chronic stage).^{47 59 62} Specific timepoints investigated were 6 months,^{59 62} 7 months,⁴⁷ 11 months,⁴⁷ 12 months,⁶² more than 12 months,⁶² and 2 years after stroke.⁵⁹

Eight articles investigated information needs at multiple timepoints after stroke.^{39 41 47 52 56 59 62 63} However, 18 articles did not specify the timepoint under investigation^{40 43 44 46 48–51 53 55 57 58 60 61 65–68} and some articles used ambiguous terminology. Temporally ambiguous terms used to describe the timepoint under investigation included initial rehabilitation,³⁹ rehabilitation,⁴¹ up to 1 month after discharge,⁵⁶ starting to recover,⁶³ preparing to leave hospital,⁶³ just returned home,⁶³ settled at home⁶³ and chronic phase (defined as stroke survivor's return home).^{39 41}

What are the characteristics of participants?

Seven studies recruited stroke survivors only^{42 45 48 53 57 61 62} and 11 articles included both stroke survivors and family members.^{49 51 54–56 58–60 66–68} Four studies did not report the mean age of stroke survivor participants^{42 49 56 66} and 10 studies did not report the mean time since stroke.^{42 45 49 54 56 58–60 62 66} The mean age of stroke survivors was less than 70 years in the 12 studies that reported this variable.^{45 48 51 53–55 57 60–62 67 68} The mean time since stroke for stroke survivor participants was between 11 months⁶¹ and 7 years⁴⁸ but these studies did not describe how stroke date was established (eg, self-report, medical records).

With regard to the cognitive status of stroke survivors, 18 articles focused on stroke survivors with or family members of stroke survivors with aphasia.^{39 40 43–48 50–53 55 57 62–65} Other cognitive impairment (including dementia) was listed as part of the inclusion/exclusion criteria in eight studies,^{40 45 48 50 53 57 62 63} while the other 10 articles did not report whether stroke survivors had cognitive impairments affecting domains other than language.^{39 43 44 46 47 51 52 55 64 65}

One article described participants as affected by 'mild physical, cognitive, and/or psychosocial disabilities' (p.2) but did not specify the precise nature of these difficulties.⁴² One article assessed cognitive functioning in non-language domains using Raven's Coloured Progressive Matrices (Raven, Court, & Raven, 1995).⁶¹ Only one article reported in detail the cognitive status of stroke survivors in domains other than language.⁴¹ Family members reported that their relative with stroke experienced problems with memory (n=4/4), executive function (n=4/4), attention (n=3/4) and neglect (n=2/4).⁴¹

12 studies recruited family members but not stroke survivors.^{39–41 43 44 46 47 50 52 63–65} Two of these articles were case studies involving only one family member.^{47 64} Most family members were described as spouses/partners/significant others (n=134 across these 12 articles).^{39–41 43 44 46 47 50 52 63–65} Some articles also included offspring caring for the stroke survivor

(n=37),^{39 40 44 47 50 52 65} parents (n=6)^{39–41 65} and siblings (n=6).^{41 65} Other family members were relatives-in-law (n=4),^{44 65} aunts/uncles (n=3)⁴⁴ and grandchildren (n=2).⁴⁴ Two studies included one friend alongside other family member participants^{40 50} and one study included three friends.⁴⁴ One study included ex-family members (n=3) as well as current family members (n=45).⁶⁵

We note that different terminology was used to describe stroke survivors in the articles, including stroke survivors,^{49 54 58 59 61 62 66 68} patients,^{45 56 60} individuals/people/participants with aphasia due to stroke,^{44 46 51 53 55 57} and individuals with communication-debilitating illness or injury due to stroke.⁴⁴ The following terms were used to refer to family member participants: family members,^{39 46 47 51 60 63 65 67 68} significant others,^{40 44 64} carers,^{41 43 56} caregivers,^{54 59 66} informal carers,⁴⁹ relatives,⁵⁵ communication partners⁵⁰ and care partners.⁵²

What psychoeducation needs have been reported?

Participants across the included studies reported psychoeducation needs regarding cognitive difficulties after stroke.^{39 40 43–53 55–57 59–68} Psychoeducation needs mentioned within the articles were most often described in the context of aphasia^{39 40 43–48 50–53 55–57 59 61–66 68} but participants also described a need for psychoeducation about memory problems,^{49 56 59} concentration problems^{59 68} and general cognitive changes.^{60 67}

When describing psychoeducation needs related to aphasia, participants reported a desire for general information, including definitions and information about symptoms,^{39 43 44 46–48 51–53 55–59 61–65 68} and participants in two studies wanted information about psychological comorbidities.^{39 40} With regard to recovering from aphasia, participants wanted information about what to expect in the future,^{39 40 43 44 52 55–58 63–65} treatments for aphasia and their efficacy,^{39 47 57 65 69} as well as ways to maximise recovery.⁶⁹ The following information about living with aphasia was also sought: compensatory strategies,^{45 51 56 63} maximising communicative effectiveness,^{39 63 66} available support and services,^{39 43 46–48 51 57 63 65} psychosocial support and counselling,³⁹ support for family members,^{48 69} support groups,^{39 63} employment,^{39 50} financial aid,^{39 43} and information to help maintain hope and optimism.^{39 47 50 65}

Though far fewer studies considered non-language cognitive impairments, participants in these studies similarly described a need for general information about symptoms and definitions.^{41 42 56 58–60 67 68} Some participants also wanted information about recovering, including what to expect in the future,^{41 56 58} treatments and rehabilitation available,^{41 49 60} and information to track recovery progress.^{41 42} Finally, in terms of living with cognitive impairments, some participants wanted information about compensatory strategies,^{41 56} support for family members,⁴¹ and information to help maintain hope and optimism.⁴¹ Themes and subthemes are summarised in [table 1](#).

**Table 1** Summary of theme structure developed to capture cognition-related psychoeducation needs and influencing factors mentioned in articles included in the scoping review

Domain	Theme	Subtheme	Articles
Aphasia psychoeducation topics	General information	Symptoms and definitions	39 43 44 46–48 51–53 55–59 61–65 68
		Psychological comorbidities	39 40
	Recovering from aphasia	What to expect in the future	39 40 43 44 52 55–58 63–65
		Treatment and its efficacy	39 40 47 57 65
		Maximising recovery	40
	Living with aphasia	Compensatory strategies	45 51 56 63
		Maximising communicative effectiveness	39 63 66
		Available support and services	39 43 46–48 51 57 63 65
		Psychosocial support and counselling	39
		Family member support	40 48
		Support groups	39 63
		Employment, return to work, and job retraining	39 50
		Financial aid	39 43
Information to maintain hope	39 47 50 65		
Domain-general psychoeducation topics	General information	Symptoms and definitions	41 42 56 58–60 67 68
	Recovering from cognitive impairment	What to expect in the future	41 56 58
		Treatments and rehabilitation available	41 49 60
		Information to track recovery progress	41 42
Living with cognitive impairment	Compensatory strategies	41 56	
	Support for family members	41	
	Information to maintain hope	41	
Influencing factors	Time since stroke	Psychoeducation needs become more prevalent over time	59 62

Note that themes were developed to resemble domain summaries in order to enhance their actionable translational value.

What factors impact psychoeducation needs?

Cognition-related psychoeducation needs were reported in articles investigating both the acute/subacute stage (ie, less than 6 months since stroke)^{39 41 45 47 52 56 59 62–64} and chronic stage after stroke (ie, more than or equal to 6 months after stroke),^{47 59 62} but the prevalence and content of these information needs varied depending on the timepoint under investigation.

Two of the articles that investigated cognition-related information needs at multiple timepoints found that prevalence increased over time.^{59 62} Hanger *et al*⁵⁹ reported that only 4 out of 60 (7%) participants asked questions about poor memory/concentration in the first 2 weeks after stroke; whereas, 25 out of 111 (32%) asked these questions 2 years after stroke. Similarly, whereas 3 out of 60 (5%) participants asked questions about communication difficulties in the first 2 weeks after stroke, 7 out of 72 (10%) participants asked these questions 2 years after stroke.⁵⁹ Rose *et al*⁶² similarly found that only 9% of stroke survivors considered it helpful to receive written stroke and aphasia information on the day of admission but 91% of participants considered this information helpful more than 12 months after stroke. Results from Rose *et al*⁶²

suggest that information needs around aphasia may peak before this, however, as 97% of stroke survivors considered it helpful to receive written stroke and aphasia information 6 months after stroke.

Only one article provided insight into how the content of cognition-related information needs evolves over time.⁶³ Family members in this study considered some information more useful to receive in the first days after stroke and other information more useful once they were settled at home. For example, 93.8% considered it useful to receive information about what aphasia is in the first days after stroke, compared with 75% who considered this information useful once settled at home. On the other hand, only 52.3% of participants considered it useful to receive information about support groups for people with aphasia in the first days after stroke but 90.4% considered this information useful once settled at home.

There were no obvious differences in the information needs reported in articles that included stroke survivors only vs family members only but results from one article tentatively suggest that information needs may vary depending on the specific relationship of the family member to the stroke survivor.⁴⁰ Cheng *et al*⁶⁹ reported

Frequency with which cognition words used in the systematic search strategy were mentioned in articles

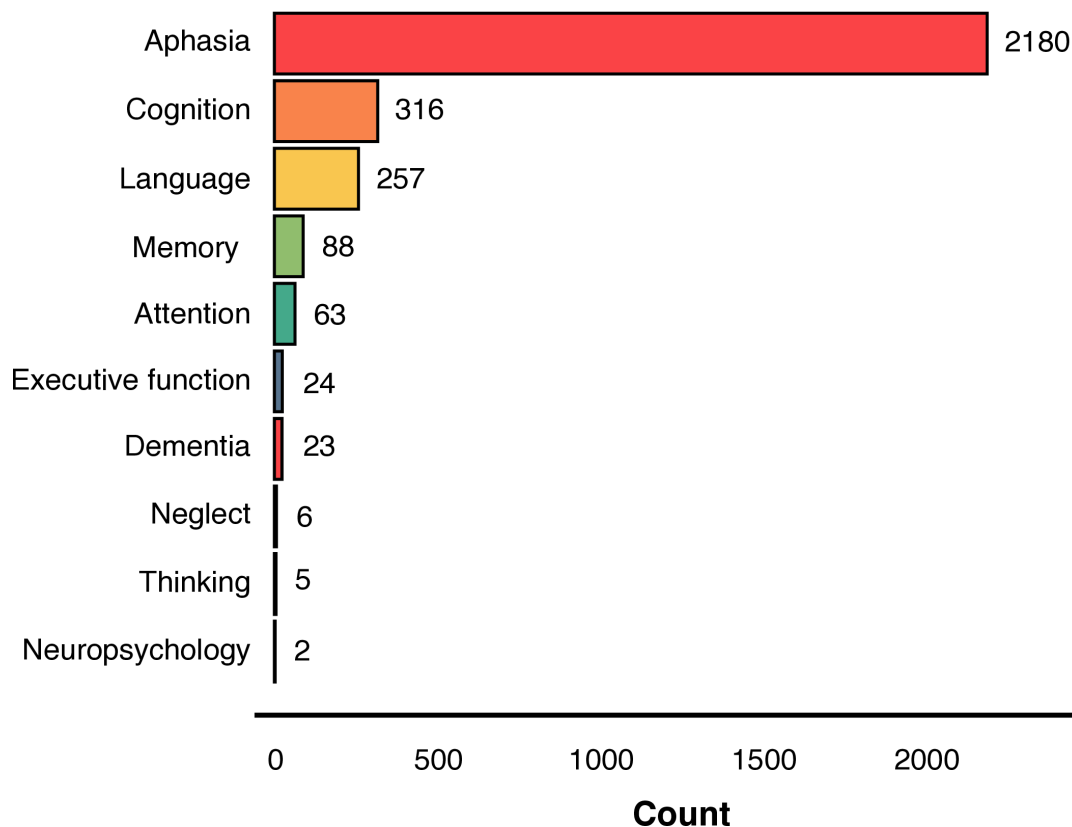


Figure 2 Bar chart showing the frequency with which cognition words used in the systematic search strategy were mentioned within articles included in the scoping review. The frequency counts (x-axis) for individual search terms (y-axis) are presented. Note that words included in the search strategy with an asterisk (eg, cogniti*) were searched in full-text articles using their stem but they are represented in the figure as full words (eg, cognition) for interpretability.

that non-partners tended to want information about aphasia prognosis, regardless of whether the prognosis was ‘good or bad’. However, partners tended to favour information about rehabilitation over prognostic information and they felt that the delivery of prognostic information should be dictated by the preference of the stroke survivor.

What key gaps exist across the included articles?

The majority of articles focused on stroke survivors with or family members of stroke survivors with aphasia.^{39 40 43–48 50–53 55 57 62–65} Psychoeducation needs related to other cognitive domains (eg, memory, attention, executive function) were rarely mentioned. **Figure 2** shows the number of times cognitive terms featured in the search strategy were used in included articles. Furthermore, most studies investigating aphasia did not report cognitive status in other domains, making it difficult to determine whether non-language cognitive impairments were also present within the sample.

Relatively few studies considered psychoeducation needs at multiple timepoints after stroke^{39 41 47 52 56 59 62 63} and only two of these articles^{59 62} investigated how the

prevalence and content of cognition-related information needs evolve over time.

DISCUSSION

This study mapped and identified gaps in 30 published articles investigating self-reported psychoeducation needs of stroke survivors and family members regarding cognition. Both stroke survivors and family members reported cognition-related psychoeducation needs and these were present at all timepoints investigated, although the prevalence and specific content varied in some articles over time. Participants wanted information about expected cognitive recovery, treatment/therapy options, services/resources available, and hopeful information. Time since stroke and family member relationship may affect prevalence and content of cognition-related psychoeducation needs, but very few studies explicitly described how psychoeducation needs vary at different timepoints and across different types of relationships. Furthermore, very few articles addressed non-language cognitive domains



commonly affected by stroke (eg, memory, attention, executive function, number processing, praxis).

Stroke survivors and family members in the included articles expressed a need for information about cognitive impairment diagnosis, prognosis, treatment and available services. While these needs were apparent throughout the post-stroke period, two articles found cognition-related psychoeducation needs became more prevalent over time,^{59 62} which may reflect the early focus on medical management and physical recovery after stroke and emergence of cognitive concerns later in the post-stroke recovery period.⁷⁰ Clinical reviews are recommended by the UK clinical guidelines at 6 months, 12 months and then annually and these reviews are crucial to ensure cognition-related psychoeducation needs are identified and addressed.⁹ However, data from the Stroke Sentinel National Audit Programme (SSNAP) suggest completion of these reviews is currently inadequate, with 6-month reviews received by only 36.9% of stroke survivors in 2022/2023, a reduction from 2021/2022 when reviews were received by 40.7%.⁷¹ Improving cognitive monitoring and psychoeducation may help to address the substantial long-term unmet needs surrounding cognition after stroke.^{7 8}

We identified key gaps in the existing literature. In particular, more than half of the included articles focused exclusively on aphasia, with very few articles considering other commonly affected cognitive domains (eg, memory, attention, executive function, number processing, praxis) and only one study reporting the prevalence of non-language cognitive impairments in their stroke survivor sample.⁴¹ Understanding psychoeducation needs related to other domains is crucial as non-language impairments may be even more prevalent than language impairments²⁴ and domain-specific impairments vary substantially in their underlying aetiologies and likely trajectories.^{5 19 26 72} Future research should also aim to include stroke survivor samples with cognitive profiles that better reflect the clinical reality (ie, patients with impairments across different cognitive domains) to ensure any psychoeducational materials are tailored appropriately.

This scoping review has several potential limitations. First, there was a possible selection bias due to the exclusion of unpublished grey literature. Because this scoping review sits alongside a broader body of qualitative research aiming to develop an evidence-based complex intervention providing psychological support after stroke, we were keen to focus on articles that had been through a rigorous peer-review process. Nevertheless, this decision may have led to omission of informative sources. Second, our decision to include studies with a sample comprising at least 50% stroke survivors or family members may have led to exclusion of additional potentially informative literature—for example, research investigating

psychoeducation needs from the perspective of healthcare professionals. By focusing on self-reported needs of stroke survivors and their family members, we restricted our review to generate a patient-centred picture.

Overall, as stroke mortality rates continue to decline and the number of stroke survivors experiencing cognitive impairment correspondingly rises,⁷³ it is critical to consider how to prepare stroke survivors and their family members to cope with cognitive changes and - ultimately - to integrate this insight into a cognitive care pathway for stroke.¹³ This scoping review demonstrates that stroke survivors and their family members are generally keen to receive psychoeducation about cognition throughout the post-stroke care continuum, but further research is required to strengthen our understanding of these psychoeducation needs and how best to meet them in clinical practice.

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Contributors GH conceptualised the study, formulated the study aims and objectives, determined the study methodology, developed the search strategy, drafted the original protocol and managed the protocol peer-review process, searched databases, screened retrieved records, extracted data from included records, synthesised results, tabulated and visualised results, drafted the manuscript, and edited drafts based on co-author feedback. ND conceptualised the study, formulated the study aims and objectives, advised on study methodology, reviewed and edited the protocol, advised on study inclusion, advised on the data synthesis, and reviewed and edited the final manuscript. FT screen retrieved records, verified extracted data and reviewed the final manuscript. The guarantor of the study (ND) accepts full responsibility for the finished work and the conduct of the study, had access to the data and controlled the decision to publish.

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Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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