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A scoping review of research investigating patient and carer psychoeducation needs regarding post-stroke cognition.

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-084681
Article Type:	Original research
Date Submitted by the Author:	25-Jan-2024
Complete List of Authors:	Hobden, Georgina; University of Oxford, Department of Experimental Psychology Tabone, Faye; University of Oxford, Nuffield Department of Clinical Neurosciences Demeyere, Nele; University of Oxford, Nuffield Department of Clinical Neurosciences
Keywords:	Stroke < NEUROLOGY, Rehabilitation medicine < INTERNAL MEDICINE, Patient-Centered Care, Psychosocial Intervention, Family





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12	Abstract word count: 295
13	Manuscript word count: 4 111
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ABSTRACT

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Objectives To search the literature systematically to map and identify gaps in research investigating patient 28 29 and family member psychoeducation needs regarding post-stroke cognition. 30 Design Scoping review conducted in line with Joanna Briggs Institute (JBI) recommendations and 31 32 PRISMA-ScR checklist. **Methods** 33 34 MEDLINE, PsycINFO, Embase, CINAHL and Scopus were searched for peer-reviewed

studies which were conducted in a high-income country, describing cognition-related 35 psychoeducation needs in stroke survivors and/or family members aged ≥ 18 years ($\geq 50\%$ of 36 37 the study population). Two reviewers independently screened titles, abstracts, then full text 38 articles. One reviewer extracted pre-defined data. Data were verified by a second reviewer. Synthesis involved descriptive statistics and a pragmatic thematic analysis. 39

40 **Results**

Searches identified 8,115 articles, of which 30 were included. Articles were published between 41 1996-2023. Studies were conducted in Australia (n=7), USA (n=6), UK (n=5), Canada (n=3), 42 New Zealand (n=3), Ireland (n=2), Netherlands (n=2), South Korea (n=1) Sweden (n=1). Most 43 44 studies (n=21) used an exclusively qualitative approach but 6 combined qualitative/quantitative 45 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. 46 Research was conducted with stroke survivors only (n=7), family members only (n=12) and 47 48 both stroke survivors/family members (n=11). Qualitative analysis suggested participants wanted psychoeducation about cognitive impairment, including recovery expectations, 49 50 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 (e.g., memory, attention, executive function).

Conclusions

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

71 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, whilst there is currently no method for reliably predicting long-term post-stroke cognitive outcomes 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 diagnoses (20) and previous research has found a beneficial impact of psychoeducation on self-efficacy and knowledge among those with minor stroke (14).

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Nevertheless, stroke survivors and their family members have reported substantial unmet psychoeducation needs regarding cognition (21) and, 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 poststroke 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 wellbeing - 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. The ultimate goal of the research is to inform, alongside other primary research (28,31), the design of a complex intervention focused on monitoring and psychoeducation to support cognition after stroke. The specific questions addressed by this review are:

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1 2		
3 4	121	1. What research methods and designs have been used in previous studies describing
5 6	122	stroke survivor and family member information needs regarding cognition?
7 8 9	123	
10 11	124	2. What timepoints after stroke have been investigated in previous studies?
12 13	125	
14 15 16	126	3. What are the characteristics of stroke survivors and family members included in
17 18	127	previous studies?
19 20	128	
21 22	129	4. What psychoeducation needs related to post-stroke cognition have been reported in
23 24 25	130	previous studies?
26 27	131	
28 29 30 31 32	132	5. What factors have been suggested to impact psychoeducation needs in previous
	133	studies?
33 34	134	
35 36	135	6. What key gaps exist within the current evidence base?
37 38	136	
39 40 41	137	
42 43	138	METHODS
44 45	139	Review protocol
46 47 48	140	The review was conducted in accordance with the Johanna Briggs Institute (JBI) methodology
49 50	141	for scoping reviews (32) and the Preferred Reporting Items for Systematic Reviews and Meta-
51 52	142	Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist. The protocol for this
53 54 55	143	review underwent a rigorous peer-review process for publication (33) and has been made
56 57	144	openly available (https://osf.io/fmz9t). Any divergences from the protocol are justified and
58 59 60	145	provided in Supplementary Materials.

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146 **Patient and Public Involvement**

Patients were involved in developing the funding proposal for the fellowship of which this 147 148 research forms a part. Patients were consulted on the importance of the research question and 149 the approach through a survey with the Stroke Association's Voices in Research (43 respondents) and three smaller focus groups. With regards to the present study, they 150 emphasised the importance of including family member/carer perspectives where possible. 151

153 Search strategy

152

154 The search strategy was developed in consultation with an expert librarian at the University of Oxford (Supplementary Materials). A systematic search was conducted in five electronic 155 databases on August 25th, 2023: MEDLINE (PubMed), PsycINFO (Ovid), Embase (Elsevier), 156 157 CINAHL (Ebsco), and Scopus (Elsevier). Grey literature databases were not searched as the 158 aim of the review is to inform an evidence-based intervention, so we sought articles that had been through rigorous peer-review. The search strategy was limited to English, but it was not 159 160 limited by year.

- 161
- **Inclusion criteria** 162

The inclusion criteria were based on the JBI Population/Concept/Context (PCC) framework 163 (32). Articles were eligible for inclusion in this review if they met the following criteria: 164

60

- 166 **Participants**
- 167 Stroke survivors and/or family members of stroke survivors. Stroke survivors were defined as a person who has experienced a clinically diagnosed stroke of any type. 168 169 Family members were defined as a person who identifies as related to a stroke survivor 170 by blood, marriage, or with other familial involvement. 59

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1 2		
2 3 4	171	• Stroke survivors and/or family members of stroke survivors comprising at least 50% of
5 6 7	172	the study population, in line with cut-offs used in previous scoping reviews (Fletcher
7 8 9	173	et al., 2022; Theou et al., 2018).
10 11	174	• Stroke survivors and family members aged 18 years and over.
12 13	175	
14 15 16	176	Concept
17 18	177	• Self-reported information needs regarding post-stroke cognition. Information needs
19 20 21	178	were defined as a desire to obtain information to satisfy a conscious (or unconscious)
21 22 23	179	need (34). Cognition is defined as thinking skills related to any of the following
24 25	180	domains: memory, language, attention, executive function, praxis, number processing
26 27	181	(22).
28 29 30	182	
31 32	183	Context
33 34	184	• Studies conducted in the United Kingdom and other high-income countries, defined
35 36	185	using the most recent World Bank country classifications (2022).
37 38	186	• Participants based either in a clinical setting or the community.
39 40	187	
41 42 43	188	Types of sources
44 45	189	We included published peer-reviewed articles that used quantitative, qualitative, or mixed
46 47	190	methods designs. Review articles, peer-reviewed commentaries and opinion pieces were
48 49	191	excluded.
50 51 52	192	
53 54	193	Study selection process
55 56	194	Identified records were collated and uploaded into EndNote v.X9 (Clarivate Analytics, PA,
57 58	195	USA). SR-Accelerator Deduplicator (35) removed duplicates. GH and FT independently
59 60	196	screened records against eligibility criteria by title, abstract, then full-text after conducting a

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197 pilot screening round. They recorded reasons for exclusion for articles excluded at the full-text 198 stage. Differences in inclusion/exclusion decisions were settled by discussion among the 199 research team. Reference lists of the included articles were hand searched to identify further 200 relevant records.

202 Data extraction

A data extraction tool was developed prior to extracting data and refined iteratively throughout the process. GH used the final version of the tool (Supplementary Materials) to extract data from the included articles. FT reviewed extracted data for accuracy.

207 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 the codebook approach outlined by(36), was used to code and classify specific cognition-related psychoeducation needs identified within the included articles and factors potentially impacting them (Research Questions 4 and 5).

- ' 216
- 217 RESULTS

218 Selection of evidence sources

The database searches retrieved 8,112 records. This was reduced to 6,726 records afterdeduplication. 27 records were selected for inclusion after screening. A further 3 records were

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2 3	221	identified from reference lists. This resulted in a total of 30 articles being selected for inclusion
4 5 6	222	in the scoping review. Figure 1 documents the selection process.
7 8	223	
9 10 11	224	[Figure 1]
12 13	225	
14 15 16	226	The included articles were published between 1996 and 2023. Most studies ($n = 20$) were
16 17 18	227	published between 2001-2020, with 14 published in the last ten years (2013-2023). Studies
19 20	228	were conducted in Australia ($n = 7$), United States of America ($n = 6$), United Kingdom ($n =$
21 22 22	229	5), Canada ($n = 3$), New Zealand ($n = 3$), Ireland ($n = 2$), the Netherlands ($n = 2$), South Korea
23 24 25	230	(n = 1) and Sweden $(n = 1)$. Each included article was numbered. Table 1 presents numbers
26 27	231	corresponding to each article and a summary of extracted data. The following section presents
28 29	232	a textual synthesis of extracted data with articles referenced by number.
30 31 32	233	
33 34	234	[Table 1]
35 36	235	
37 38	226	
39	236	1. What research methods have been used?
40 41	236 237	1. What research methods have been used?Twenty-one articles used an exclusively qualitative approach to data collection and analysis
40 41 42 43	236 237 238	 1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles
40 41 42 43 44 45	236 237 238 239	 1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most
40 41 42 43 44 45 46 47 48	236 237 238 239 240	 1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews
40 41 42 43 44 45 46 47 48 49 50	236 237 238 239 240 241	 1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews [2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted
40 41 42 43 44 45 46 47 48 49 50 51 52	236 237 238 239 240 241 242	1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews [2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted focus groups [1, 4, 14, 15, 26]. Participant sample sizes in qualitative studies varied
40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55	236 237 238 239 240 241 242 243	1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews [2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted focus groups [1, 4, 14, 15, 26]. Participant sample sizes in qualitative studies varied substantially. Two articles presented a case study involving a single family member [10, 16].

participants with aphasia [25, 30]. Focus group sizes varied between two-four participants [15]and six-ten participants [26].

Articles that used qualitative data collection methods employed different analytic approaches and frameworks. Eight articles used a version of thematic analysis [1, 2, 8, 17, 18, 24, 27, 29], eight articles used a version of content analysis [4, 12, 14, 16, 23, 25, 26, 30], two used the constant comparative method [7, 19]. Other approaches were narrative analysis [10] and a modified referenced five-step process [3]. One article described an approach that resembled thematic analysis but did not label it as such [6]. Two articles did not describe how semi-structured interview data were analysed [9, 13]. 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 [1, 3, 4, 6, 7, 8, 10, 13, 14, 15, 16, 18, 19, 21, 22, 25, 26, 27, 29, 30].

Five of the included articles used surveys or questionnaires [11, 20, 21, 22, 28]. All of these articles used custom measures rather than validated standard questionnaires. Questionnaires were administered remotely in three studies [11, 20, 28] and face-to-face in the other two studies [21, 22]. Face-to-face administrations were audio-recorded and analysed qualitatively to complement quantitative questionnaire data [21, 22].

264

265 2. What timepoints after stroke have been investigated?

Ten articles explicitly stated their investigation pertained to the first six-months after stroke (acute/subacute stage) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29]. Specific timepoints investigated included stroke onset/first days after stroke [1, 3, 10, 21, 22], first week after stroke [21], two-

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weeks after stroke [9], first month after stroke [21], first three-months after stroke [8], and fourmonths after stroke [16].

Three articles explicitly stated their investigation pertained to the period at least six-months after stroke (chronic stage) [9, 16, 21]. Specific timepoints investigated were six-months [9, 21], seven-months [16], eleven-months [16], twelve-months [21], more than twelve-months [21], and two-years after stroke [9].

Eight articles investigated information needs at multiple timepoints after stroke [1, 3, 9, 16, 21,
22, 24, 29]. However, many articles did not specify the timepoint under investigation [2, 5, 6,
7, 11, 12, 13, 14, 15, 17, 18, 19, 20, 23, 25, 27, 28, 30] and some articles used ambiguous
terminology. Temporally ambiguous terms used to describe the timepoint under investigation
included initial rehabilitation [1], rehabilitation [3], up to one-month after discharge [29],
starting to recover [22], preparing to leave hospital [22], just returned home [22], settled at
home [22], and chronic phase (defined as stroke survivor's return home) [1, 3].

) 2

3. What are the characteristics of participants?

Seven studies recruited stroke survivors only [4, 8, 14, 17, 21, 25, 30] and eleven articles included both stroke survivors and family members [5, 9, 11, 13, 18, 20, 23, 26, 27, 28, 29]. Some studies did not report the mean age of stroke survivor participants [4, 11, 18, 29] or the mean time since stroke [4, 5, 8, 9, 11, 13, 18, 21, 26, 29]. The mean age of stroke survivors was less than 70 years in all studies that reported this variable [8, 13, 14, 17, 20, 21, 23, 25, 26, 27, 28, 30]. The mean time since stroke for stroke survivor participants was between eleven months [14] and seven years [17] but these studies did not describe how stroke date was established (e.g., self-report, medical records).

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With regards to the cognitive status of stroke survivors, 18 articles focused on stroke survivors with or family members of stroke survivors with aphasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. Other cognitive impairment (including dementia) was listed as part of the inclusion/exclusion criteria in eight studies [2, 8, 17, 19, 21, 22, 25, 30], whilst the other ten articles did not report whether stroke survivors had cognitive impairments affecting domains other than language [1, 6, 7, 10, 12, 15, 16, 23, 24, 27].

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 [4]. One article assessed cognitive functioning in non-language domains using Raven's Coloured Progressive Matrices (RCPM: Raven, Court, & Raven, 1995) [14]. Only one article reported in detail the cognitive status of stroke survivors in domains other than language [3]. 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) [3].

Twelve studies recruited family members but not stroke survivors [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Two of these articles were case studies involving only one family member [10, 16]. Most family members were described as spouses/partners/significant others (n = 134across these twelve articles) [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Some articles also included children (n = 37) [1, 2, 7, 12, 16, 19, 24], parents (n = 6) [1, 2, 3, 12], and siblings (n = 6) [3, 12]. Other family members were relatives-in-law (n = 4) [7, 12], aunts/uncles (n = 3) [7], and grandchildren (n = 2) [7]. Two studies included one friend alongside other family member participants [2,19] and one study included three friends [7]. One study included ex-family members (n = 3) as well as current family members (n = 45) [12].

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We note that different terminology was used to describe stroke survivors in the articles, including stroke survivors [5, 9, 11, 14, 18, 21, 26, 28], patients [8,13, 29], individuals/people/participants with aphasia due to stroke [17, 15, 23, 25, 27, 30], and individuals with communication-debilitating illness or injury due to stroke [7]. The following terms were used to refer to family member participants: family members [1, 12, 13, 15, 16, 20, 22, 23, 28], significant others [2, 7, 10], carers [3, 6, 29], caregivers [9, 11, 26], informal carers [18], relatives [27], communication partners [19], and care partners [24].

4. What psychoeducation needs have been reported?

Participants across the included studies reported psychoeducation needs regarding cognitive difficulties after stroke [1, 2, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 27, 28, 29, 30]. This most often referred to aphasia [1, 2, 6, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 28, 29, 30] but participants also described a need for psychoeducation about memory problems [9, 18, 29], concentration problems [9, 28], and general cognitive changes [13, 20].

Participants in one study wanted information about the cognitive assessment process [26]. A more commonly reported need was for information about future outcomes, including overall prognosis and the rehabilitation timeline [2, 7, 10, 12, 22, 24, 27, 30]. This information need was more commonly reported in studies that included family members [2, 7, 10, 12, 22, 24, 27], compared to stroke survivors [27, 30], though this may be explained by the generally greater level of detail provided by these studies.

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Participants in seven studies described a need for information about treatment/therapy for cognitive problems [1, 2, 3, 4, 12, 16, 22, 30]. Specific needs were for information about treatment progress [3, 4, 12], how to maximise treatment outcomes [1, 2], treatment efficacy [2], treatment rationale [3], and supplementary treatments (e.g., music therapy) [3]. Ten articles described a need for information about available services and/or resources [1, 3, 6, 12, 15, 16, 17, 22, 23, 30]. The specific type of service/resource was not always clear, but articles mentioned support groups [1, 3, 22], support for carers and patients [3], and psychosocial support and counselling [1]. Five articles mentioned the importance of receiving information that helps to maintain hope and optimism [1, 3, 12, 16, 19]. 5. What factors impact psychoeducation needs? Cognition-related psychoeducation needs were reported in articles investigating both the acute/sub-acute stage [1, 3, 8, 9, 10, 16, 21, 22, 24, 29] and chronic stage after stroke [9, 16, 21], 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 [9, 21]. Hanger et al. [9] reported that only 4 out of 60 (7%) participants asked questions about poor memory/concentration in the first two-weeks after stroke, whereas 25 out of 111 (32%) asked these questions two-years after stroke.

366 Similarly, whereas 3 out of 60 (5%) participants asked questions about communication
367 difficulties in the first two-weeks after stroke, 7 out of 72 (10%) participants asked these

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questions two-years after stroke [9]. Rose et al. [21] simila found that only 9% of stroke survivors considered it helpful to receive written stroke and sia information on the day of admission but 91% of participants considered this inform n helpful more than twelve-months after stroke. Results from Rose et al. (2010) sugge nat information needs around aphasia may peak before this, however, as 97% of stroke ivors considered it helpful to receive written stroke and aphasia information six-months at stroke.

Only one article provided insight into how the content of co ion-related information needs evolves over time [22]. Family members in this study conside some information more useful to receive in the first days after stroke and other information useful once they were settled at home. For example, 93.8% considered it useful to receive rmation about what aphasia is in the first days after stroke, compared to 75% who consid this information useful once settled at home. On the other hand, only 52.3% of participation onsidered it useful to receive information about support groups for people with aphasia he first days after stroke but 90.4% considered this information useful once settled at hor

There were no obvious differences in the information needs orted in articles that included stroke survivors only versus family members only but res from one article tentatively suggest that information needs may vary depending on the ific relationship of the family member to the stroke survivor [2]. Cheng et al. [2] reported t non-partners tended to want information about aphasia prognosis, regardless of whether prognosis was 'good or bad'. However, partners tended to favour information about habilitation over prognostic information and they felt that the delivery of prognostic info tion should be dictated by the preference of the stroke survivor.

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at key gaps exist across the included articles?

jority of articles focused on stroke survivors with or family members of stroke survivors hasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. Psychoeducation elated to other cognitive domains (e.g., memory, attention, executive function) were mentioned. Figure 2 shows the number of times cognitive terms included in the search y were used in included articles. Furthermore, most studies investigating aphasia did not cognitive status in other domains, making it difficult to determine whether non-language ve impairments were also present within the sample.

[Figure 2]

ely few studies considered psychoeducation needs at multiple timepoints after stroke 16, 21, 22, 24, 29] and only two of these articles [9, 21] investigated how the prevalence ntent of cognitive-related information needs evolve over time.

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apped and identified gaps in 30 published articles investigating self-reported education needs of stroke survivors and family members regarding cognition. Both survivors and family members reported cognition-related psychoeducation needs and rere present at all timepoints investigated, although the prevalence and specific content in some articles over time. Participants wanted information about expected cognitive ry, treatment/therapy options, services/resources available, and hopeful information. ince stroke and family member relationship may affect prevalence and content of on-related psychoeducation needs, but very few studies investigated multiple ints. Furthermore, very few articles addressed non-language cognitive domains

Stroke survivors and family members in the included articles expressed a need for

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

information about cognitive impairment diagnosis (37-42), prognosis (43-50), treatment (43,46,47,50–54), and available services (46,47,50–52,54–58). Whilst these needs were apparent throughout the post-stroke period, two articles found cognition-related psychoeducation needs became more prevalent over time (37,59), 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 (60). Clinical reviews are recommended by United Kingdom clinical guidelines at six-months, twelve-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 six-months reviews received by only 36.9% of stroke survivors in 2022/2023, a reduction from 2021/2022 when reviews were received by 40.7% (61). 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 (43-51,54-59,62-64), with very few articles considering other commonly affected cognitive domains (e.g., memory, attention, executive function, number processing, praxis) and only one study reporting the prevalence of non-language cognitive impairments in their stroke survivor sample (52). Understanding psychoeducation needs related to other domains is crucial as non-language impairments may be even more prevalent than language impairments (24) and domain-specific impairments vary

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substantially in their underlying aetiologies and likely trajectories (5,19,26,65). Future research
should also aim to include stroke survivor samples with cognitive profiles that better reflect
the clinical reality (i.e., 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, we acknowledge 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 reliable patient-centred picture.

Overall, as stroke mortality rates continue to decline and the number of stroke survivors experiencing cognitive impairment correspondingly rises (66), it is critical to consider how to prepare stroke survivors and their family members to cope with cognitive changes and to integrate this into a cognitive care pathway for stroke (13). Psychoeducation is a key element of post-stroke care that plays an essential role in helping stroke survivors manage and monitor their symptoms (67). This scoping review demonstrates that stroke survivors and their family members are generally keen to receive psychoeducation about cognition throughout the post-

1 2		
2 3 4	467	stroke care continuum, but further research is required to strengthen our understanding of these
5 6	468	psychoeducation needs and how best to meet them in clinical practice.
/ 8 9	469	
10 11	470	
12 13	471	
14 15 16	472	
17 18	473	FUNDING STATEMENT
19 20	474	Georgina Hobden is supported by an Economic and Social Research Council (ESRC) grant
21 22 23	475	(ES/P000649/1). Nele Demeyere (Advanced Fellowship NIHR302224) is funded by the
23 24 25	476	National Institute for Health Research (NIHR). The views expressed in this publication are
26 27	477	those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of
$\begin{array}{c} 28\\ 29\\ 30\\ 31\\ 32\\ 33\\ 34\\ 35\\ 36\\ 37\\ 38\\ 39\\ 40\\ 41\\ 42\\ 43\\ 44\\ 45\\ 46\\ 47\\ 48\\ 49\\ 50\\ 51\\ 52\\ 53\\ 54\\ 55\\ 56\\ 57\\ 58\\ 59\\ 60\\ \end{array}$	478	Health and Social Care."

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FIGURES AND TABLES

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

Figure 2. Word cloud and table showing the frequency with which cognition-related words from the systematic search strategy were mentioned in the included articles. The word cloud was created using Word It Out software.

Note. Words included in the search strategy with an asterisk (e.g., cogniti*) were searched in full text articles using their stem but they are represented in the figure as full words (e.g., cognition) to increase interpretability.

 BMJ Open Table 1. Summary of extracted data from included articles. Where the article had multiple aims, all study afters are presented with the aim most relevant to this scoping review highlighted in italics. Terminology and results are quoted verbatim from included articles where they align sufficiently with the table headings, leading to variation in terminology used across the table. Psychoed represented in the order listed within the articles.

12 13 14	Reference number	Authors, Year, Country	Study aims	Study methodology	Participant sample	Participant demographics	Onto Timepoint(s) ຄົວ investigated ຊຸມ	Cognition-related psychoeducation need(s) identified
15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	[1]	Avent et al., 2005, USA	To identify information needed by family members at different phases after onset of aphasia.	Qualitative methods. Focus groups, analysis using five-stage framework approach.	16 family members.	Age: Not reported. Gender: 15 female, 1 male. Relationship: 12 spouses, 2 children, 1 parent, 1 long-term partner. Average time since stroke: 5.5 years (range: 1.10-13).	Onset of aphasia (hospitalisation) at Initial rehabilitation Chronic phases Bining , Al training , and similar techn	 General information. Specific time-based aphasia information. Information about psychosocial support and counselling. Hopeful information. Information about coexisting behavioural and medical conditions, including depression, impaired judgement, fatigue, personality changes. Information about aspects of treatment. Information about maximising communicative effectiveness. Information about long-range planning (e.g., life expectancy and health maintenance). Information about travel. Information about support groups. Information about support groups. Information about alternative therapies. Information about support groups. Information about support grains. Information about support groups.
31 32 33 34 35 36 37 38	[2]	Cheng et al., 2022, Australia Davidson &	To explore the perspectives of significant others of people with aphasia on receiving information about prognosis.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis. Qualitative methods.	7 significant others. 4 carers.	Age: 64.71 years (range: 35-76). Gender: 5 female, 2 male. Relationship: 3 partners, 2 parents, 1 child, 1 friend. Time since stroke: 7.29 months (range: 3-12). Age: 65.5 years (range: 59-70).	3-12 months poo	 Information on expected outcomes (impairment-level improvement and process of recovery). Information to help family member recover. Information on how to maximise the outcome of recovery (optimal practice stimuli and techniques). Information on treatment efficacy. Information about practical aspects of recovery (arranging suitable accommodation, planning supports for daily activities). Information about aphasia Information about the rehabilitation timeline.
39 40		Wallace, 2022, USA	needs of carers of right hemisphere stroke			Gender: 3 female, 1 male.	Rehabilitation. Chronic.	 Information about symptoms. Information about the roles of medical professionals.
41 42 43				For peer revi	ew only - http://bm	jopen.bmj.com/site/about/gui	delines.xhtml	

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		survivors at different phases after stroke.	Semi-structured interviews, analysis using phenomenological approach using a modified five-step process.		Relationship: 2 spouses, 1 brother, 1 parent. Time since stroke: 6.11 years (range: 3- 10.5).	4681 on 15 January Ense ncluding for uses r	 Information about treatment rationales. Information about treatment progress. Information about techniques and compensatory strategies. Information on support for carers and patients (e.g., support groups). Information on home practice activities. Information on supplementary treatments (e.g., vision, music, water therapies). Hopeful information.
[4]	Davoody et al., 2016, Sweden	To explore stroke survivors' information needs after discharge in order inform the development of an eHealth service.	Qualitative methods. Focus groups, content analysis.	12 stroke survivors.	Age: Mean not reported (range: 30-85 years). Sex: 7 female, 5 male. Time since stroke: Not reported.	After discharge. J 2025. Downlo elated to text	 Simple description of invisible difficulties (e.g., chronic fatigue, cognitive impairments, and personality changes) to share with family and friends. Information to track recovery (motor and cognitive) progress.
[5]	De Simoni et al., 2016, UK	To describe the characteristics of participants of an online stroke forum, <i>their</i> <i>reasons for posting in the</i> <i>forum</i> , and whether the responses addressed these needs.	Qualitative and quantitative methods. Descriptive statistical analysis of forum user population, thematic analysis of posts from representative subsample of forum users.	2,348 forum users overall. 59 representative users selected for subsample thematic analysis, representing 26 stroke survivors and 33 stroke survivors mentioned by third party.	Subsample age: Not reported. Subsample gender: 27 female, 30 male, 2 NA. Subsample time since stroke: Not reported.	verieur (ABES) . and data mining, Al t	 Information about stroke physical symptoms (communication impairments, cognition). Information on potential for recovery (timeline, age influence, recovery of functioning, reading, memory, communication). Information on invisible stroke impairments
[6]	Denman, 1998, UK	To identify needs of spouses caring for someone with communication difficulties due to stroke and to identify solutions they felt would alleviate the difficulties described.	Qualitative methods. Semi-structured interviews, identification of common themes.	9 carers.	Age: Not reported. Gender: 6 female, 3 male. Relationship: 9 spouses. Time since stroke: At least 12 months (mean and range not reported).	Not specified. http://www.orginal.com/orgi	 Information about symptoms and their recovery (e.g., aphasia). Information about financial entitlements. Information about services available locally.
[7]	Donovan-Kicken & Bute, 2008, USA	To investigate sources of uncertainty for significant others of patients with communication- debilitating illness (CDI) or injury and how uncertainty is managed.	Qualitative methods. Semi-structured interviews, analysis using constant comparative technique.	31 significant others of individuals with CDIs, including 18 significant others of individuals with CDI due to stroke. Other CDIs were brain injury ($n = 3$), brain tumour ($n = 3$), autism ($n = 2$), Alzheimer's disease ($n = 2$), AIDS ($n = 1$), dementia ($n = 1$), throat cancer ($n = 1$).	Age: 42.6 years (range: 25-75). Gender: 23 female, 8 male. Relationship: 18 children, 2 spouses, 3 close friends, 2 grandchildren, 3 aunts/uncles, 1 child-in-law. Time since CDI: 4.2 years (range: 6 months-12 hears). <i>Note.</i> Demographic details for stroke subsample not available.	ar technologies.	 Information about diagnosis. Information about the extent of damage caused by illness or injury. Information about cause of CDI. Information about long-term prognosis (possibility for and extent of physical and mental recovery). Information about quality of life.
[8]	Grohn et al., 2012, Australia	To describe the experience of the first 3 months after stroke in order to identify factors	Qualitative methods. Semi-structured interviews, thematic analysis.	15 stroke survivors.	Age: 66.3 years (range: 47-90). Gender: 7 female, 8 male. Time since stroke: Not reported.	First 3-months after stroke.	 Information from other people with aphasia about how they make adjustments. Information on completing activities of daily living (write shopping list, cheques, use a computer)
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		which facilitate successfully living with				right, includi	
[9]	Hanger et al., 1998, New Zealand	aphasia after stroke. To identify what type of questions are asked by stroke survivors and their caregivers and how the nature of questions asked changes with increasing time after stroke.	Qualitative and quantitative methods. Longitudinal, semi-structured interviews conducted at three timepoints (two-weeks, six- months, two-years after stroke), descriptive and inferential statistical analyses.	Subsample 1 (two- weeks after stroke): 60 participants. Subsample 2 (six- months after stroke): 111 participants. Subsample 3 (two- years after stroke): 72 participants. <i>Note.</i> Number of stroke survivors versus caregivers not reported.	Subsample 1. Age: 71.5 years (range: 42-99). Gender: 26 female, 34 male. Time since stroke: Not reported. Subsample 2. Age: 72.3 years (range: 23-100). Gender: 48 female, 63 male. Time since stroke: Not reported. Subsample 3. Age: 71.8 years (range: 24-101). Gender: 35 female, 37 male. Time since stroke: Not reported. Note. Demographic details for stroke survivors versus caregivers not reported.	Two-weeks after stroke. Six-months after stroke. Two-years after to text and data mi	 Information about communication difficulties. Information about memory problems. Information about poor memory/concentration.
[10]	Hersh & Armstrong, 2021, Australia	To explore how the wife of a man with aphasia managed his discharge from hospital in the acute stage after stroke.	Qualitative methods. Single case study, narrative analysis of semi-structured interview collected as part of a large multisite study, systemic functional linguistics analysis of two complaint letters.	1 significant other.	Age: 63 years. Gender: Female. Relationship: Spouse. Time since stroke: 4 years.	Stroke onset ang Stroke onset ang S following days. 9, Al training, a	 Information about aphasia, including definition of term. Information about what might happen in the future.
[11]	Hinojosa et al., 2012, USA	To identify information needs of stroke caregivers with regard to managing recovery process at home; to explore whether and how information needs vary by race, ethnicity and place; to explore how the information needs are associated with caregiver characteristics (depression, coping, social support etc.).	Quantitative methods. Survey, descriptive and inferential statistical analyses.	276 stroke survivor- caregiver dyads.	Caregivers: Age: 59.36 years (range not reported). Gender: Not reported. Relationship: Not reported. <i>Note.</i> Stroke survivor demographics not reported.	Not specified. Not similar technologies.	 Information about knowing how to help others communicate w patient due to speech.
[12]	Howe et al., 2012, New Zealand	To identify rehabilitation goals of family members of stroke survivors with aphasia.	Qualitative methods. Semi-structured interviews, content analysis.	48 family members.	Age: 60.92 years (range: 24-83). Gender: 36 female, 12 male. Relationship: 28 spouses or de facto partners, 7 children, 5 siblings, 2 parents, 6 other relatives (e.g., sister-in- law). Time since stroke: Not reported.	Not specified.	 Information about aphasia. Information about future recovery prospects. Information about available services. Information about therapy. Information about progress. Information that is hopeful and positive.
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[13] Oh et al., 2017, South Korea	To develop a home- based, online cognitive rehabilitation program that can be easily and repeatedly implemented and integrates cognitive training into daily activities.	Mixed methods. Three stage process involving analysis, design, and development. Analysis stage involved literature reviews and two- phase participant needs assessment (Phase 1: cognitive assessment; Phase 2: semi- structured interviews). Design stage involved feedback on intervention design from expert panel. Development stage involved validity testing with questionnaire measures.	Analysis Stage Phase 1 (cognitive assessment): 60 stroke patients. Analysis Stage Phase 2 (semi-structured interviews): 5 stroke patients. 5 family members. Design Stage: Number of panel members not reported. Development Stage: 4 patients. 6 family members. 10 healthcare professionals.	 Analysis Stage Phase 1: Gender: 12 female, 48 male. Age: 61.4 years (range not reported). Time since stroke: Not reported. Analysis Stage Phase 2: Gender: Not reported. Age: 69 years (range not reported). Relationship: Not reported. N.B. Subsample demographics for patients versus family members not reported. Design Stage: No demographic details reported. Development Stage: No demographic details reported. 	Not specified. Not specified. Not specified.	 Information on cognitive impairment. Information on rehabilitation.
[14] Kerr et al., 2010, UK	To determine what information stroke survivors would like to see on a website about living with stroke; to determine how to structure the information; to identify differences between stroke survivors with and without aphasia.	Qualitative and quantitative methods. Focus groups, modified card sorting task, content analysis of focus groups, descriptive statistical analysis of modified card sorting task.	12 stroke survivors.	Age: 67.8 years (range: 45-86). Gender: 7 female, 5 male. Time since stroke: 11 months (range: 6- 15).	Not specified. S) . Not specified. Al training, and s	Information about aphasia/communication problems.
[15] Le Dorze & Signori, 2010, Canada	To explore needs of family members of people with aphasia and barriers/facilitators to meeting these needs.	Qualitative methods. Focus groups, custom analytic approach.	11 family members, including 10 family members of individuals with aphasia due to stroke and 1 family member of an individual with aphasia due to brain tumour resection.	Age: 60.5 years (range: 51-68). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since aphasia onset: 6.66 years (range: 3-15).	Not specified. imilar technologies.	 Information about aphasia. Information about available resources.
[16] Le Dorze et al., 2009, Canada	To describe a daughter's adaptation process to her father's stroke and aphasia.	Qualitative methods. Longitudinal, single case study, semi-structured interviews (four-months, seven-months, and eleven-months after stroke), content analysis.	1 family member.	Age: 31 years. Gender: Female. Relationship: Daughter. Time since stroke: 4-11 months.	Four-months after stroke. Seven-months after stroke. Eleven-months after stroke	 Information about aphasia. Information about services and resources available. Information about therapy. Information about other people who have suffered from aphasia maintain hope and optimism.
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[17]	Manning et al., 2022, Ireland	To explore the perspectives of working- aged adults with post- stroke aphasia toward what has or would help them in living well with aphasia.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	14 individuals with aphasia as a result of stroke.	Age: 51 years (range: 33-62). Gender: 6 female, 8 male. Time since stroke: 7 years (range: 14 months-14 years).	ht, in cluding for us	 Information about aphasia. Information about services available. Information relevant to younger people with aphasia. Information to help relatives understand aphasia.
[18]	Merriman et al., 2019, Ireland	To examine the perspectives and preferences of stroke survivors, carers, and healthcare professionals to inform the design of a cognitive rehabilitation intervention.	Qualitative methods. Semi-structured interviews, thematic analysis.	14 stroke survivors. 11 informal carers. 19 healthcare professionals.	Stroke survivors: Age: Mean not reported (range: 35-40 to 80-85). Gender: 8 female, 6 male. Time since stroke: Mean not reported (range: <1 year–17 years). Informal carers: Age: Mean not reported (range: 40-45 to 80-85). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since stroke: Mean not reported (range: <1 year–17 years). Note. Age was reported categorically.	Jary 2025. Downloaded from http:// es related to text and data mining, J Not specified.	 Information about consequences of stroke. Information about rehabilitation. Information on purpose of activities instructed to undertake. Information about impact of stroke on memory.
[19]	Paul & Sanders, 2010, USA	To explore education experiences and needs of communication partners of individuals with aphasia.	Qualitative methods. Semi-structured interviews, constant comparative analysis.	9 communication partners.	Age: 58 years (range: 37-78). Gender: 7 female, 2 male. Relationship: 5 spouses/significant others, 3 children, 1 friend. Time since stroke: 11 months (0.5-24).	Al training, a	 Information that fosters hope for improvement. Information on how to support transition to independence. Information that is tailored to needs of dyad. Information about employment, disability, and return to work. Information about communicating with the person with aphasi
[20]	Rochette et al., 2008, Canada	To identify information on the internet regarding rehabilitation intended for those who have experiences a stroke and their families and to assess the usability of a newly created website on stroke rehabilitation for laypersons.	Quantitative methods. Questionnaire.	4 stroke survivors. 3 family members.	Stroke survivors: Age: 53.5 years (range: 47-68). Gender: Not reported. Time since stroke: 11 years (range: 4-19 years). Family members: Age: 49 years (range: 42-62). Gender: Not reported. Relationship: 1 spouse, 2 children. Time since stroke: 113.67 months (range: 2 months–28 years).	Not specified. Not specified.	Information about cognitive changes.
[21]	Rose et al., 2010, Australia	To determine whether stroke survivors with aphasia consider it important to receive written stroke and aphasia information; to examine preferences for timing and modality of	Qualitative and quantitative methods. Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content	40 stroke survivors.	Age: 65.9 years (range: 32-84). Gender: 16 female, 24 male. Time since stroke: Not reported.	Admission. Gen Day after stroke. Within first week after gen stroke. Within first month after stroke. Six-months after gen stroke. Gen	Information about aphasia.
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[22] Rose et al., 2019, Australia	this information provision. To explore family members' experiences and preferences for	analysis of audio-recorded interviews. Qualitative and quantitative methods.	65 family members.	Age: Not reported. Gender: 48 female, 17 male. Relationship: 53 spouses/partners, 12	Twelve-months after of to stroke. More than twelve months after stroke. First days after stroke of through to settled at home.	 Information about what aphasia is. Information about causes of aphasia. Information about purpose of communication assessment. 		
	receiving aphasia information.	Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.		NA. Time since stroke: 3.7 years (range: 1- 16).	uary 2023. Downloaded from no inseignement Superieur (ABES) es related to text and data mini	 Information about communication progress to expect. Information about communication progress to expect. Information about aphasia therapy. Personal experience stories from people with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about aphasia associations. Information about aphasia research (ways to be informed about or involved in research). 		
[23] Rotherham et al., 2015, New Zealand	To explore the benefits for adults with aphasia of all the groups they had chosen to participate in post-stroke.	Qualitative methods. Semi-structured interview, content analysis.	10 people with aphasia. 6 family members.	People with aphasia: Age: 69 years (range: 51-83). Gender: 2 female, 8 male. Time since stroke: 55.1 months (range: 7 months-8 years). Family members: Age: 63 years (range: 51-78). Gender: 6 female, 0 male. Relationship: 6 spouses/partners. Time since stroke: Not reported.	Not specified. and simila	 Information about aphasia. Information about shared experiences of others with aphasia. Information about strategies. Information about resources. 		
[24] Shafer et al., 2022, USA	To explore how care partners of stroke survivors with aphasia accessed information and adapted to the caregiver role at different stages of recovery during COVID-19 pandemic.	Qualitative methods. Longitudinal, semi-structured interviews at up to five stages post-stroke (event, stabilisation, one-two weeks after stroke, one-month after stroke, six-months after stroke), thematic analysis using codebook approach.	Stage 1/2 (event/stabilisation: 13 care partners. Stage 3 (one-two weeks after stroke): 11 care partners. Stage 4 (one-month after stroke): 9 care partners. Stage 5 (six-months after stroke):	Age: 64.18 years (range: 49-75). Gender: 9 female, 4 male. Relationship: 7 spouses, 5 children, 1 relative. Time since stroke: Not reported. <i>Note.</i> Demographic details for subsamples at each interview stage are not provided.	Stroke onset thrægd une to six-months after stroke.	 Information about aphasia. Information about recovery prospects. Information about how to help during rehabilitation. 		
			7 care partners.			3.		
Page 3	5 of 39					BMJ Open	njopen-202 by copyri	
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1 2 3 — 4	[25]	Tomkins et al., 2013, Australia	To explore the factors influencing the satisfaction and	Qualitative methods. Semi-structured interviews,	50 people with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range	24-08 ght, in 468 Not specified. Cludin Not specified. I or	Information about aphasia.
5 6 7			dissatisfaction of people with aphasia with regards to their health care.	content analysis.		not reported).	i 15 Jan E ig for us	
3 9 10 11 12 13 14 15 16	[26]	Tyson et al., 2014, UK	To investigate stroke survivors' and caregivers' experiences and views of rehabilitation assessment process.	Qualitative methods. Focus groups, content analysis.	17 stroke survivors. 6 caregivers.	Stroke survivors: Age: 58 years (range: 19-84). Gender: 6 female, 11 male. Time since stroke: Not reported. Caregivers: Age: Not reported. Gender: 4 female, 2 male. Relationship: 5 spouses/partners, 1 parent. Time since stroke: Not reported.	Within the first sessed related to text and data after stroke.	Information about psychological assessments (cognition and mood).
17 18 19 20 21 22 23 24 25	[27]	van Rijssen et al., 2023, Netherlands	To explore the experiences, needs, and wishes of people with aphasia and their relatives to inform development of communication training for healthcare professionals.	Qualitative methods. Semi-structured interviews, thematic analysis.	20 people with aphasia. 12 relatives.	People with aphasia: Age: 59 years (range: 46-93). Gender: 11 female, 9 male. Time since stroke: 82.5 months (range: 9 months–31 years). Relatives: Age: 67 years (range: 39-96). Gender: 5 female, 7 male. Relationship: 10 spouses/partners, 2 children. Time since stroke: 105.25 months (range: 9 months–31 years).	Not specified. (ABES) . Al training, and s	 Information about aphasia. Information about emotional consequences of living with someone with aphasia. Information about what to expect for the future.
26 27 28 29 30 31 32 33 34 35 36 37	[28]	van Veenendaal et al., 1996, Netherlands	To investigate informational needs of stroke survivors and their family members.	Quantitative methods. Questionnaires, descriptive statistical analysis.	35 stroke survivors. 39 family members. 43 health professionals.	Stroke survivors: Age: 61 years (range: 36-79). Gender: Not reported. Time since stroke: 18 months (range not reported). Family members: Age: 62 years (range: 36-84). Gender: Not reported. Relationship: Not reported. Time since stroke: 16 months (range not reported). Health professionals: Age: 41 years (range not reported). Gender: Not reported.	Not specified. Not specified.	 Information about talking difficulties. Information about problems with concentration.
38 39 40				For peer revi	ew only - http://bm	Professional role: 11 nurses, 10 physiotherapists, 9 social workers, 13 not reported. njopen.bmj.com/site/about/guic	delines.xhtml	3 [,]

1 by copyright, inclustion During hospitalization **BMJ** Open Page 36 of 39 Qualitative methods. Stage 1 (during Note. Demographics for subsamples of • Information about significance of symptoms (including memory loss Up to one-mont after hospitalisation): participants included at each stage not and speech difficulties). discharge. õ Semi-structured interviews at 6 patients. reported. Demographics for carers not -• Information about how symptoms (including memory loss and speech 15 January : Enseig ہے fer uses re Two-twelve more three time-points after stroke 1 carer. reported. difficulties) should be managed. (during hospitalisation, after discharge. Information about how long symptoms (including memory loss and up to one-month after Stage 2 (up to one-Demographics for stroke survivors speech difficulties) might last. discharge, two-twelve months month after discharge): interviewed/referred to during seignem s related after discharge), thematic 5 patients. interviews (n = 21): 2025.

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Not specified.

Age: Mean not reported (range: 50-85).

Age: 63.9 years (range not reported).

Time since stroke: 54.9 months (range

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Gender: 10 female. 11 male.

Gender: 26 female, 24 male.

not reported).

Time since stroke: Not reported.

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[30]

Wiles et al., 1998,

Worrall et al..

2011,

Australia

UK

To identify information

needs of stroke patients

and their informal carers

analysis.

to ICF.

Qualitative methods.

Semi-structured interviews,

content analysis, coding of

subsample of goals according

3 carers.

months after

discharge):

8 patients. 8 carers.

aphasia.

Stage 3 (two-twelve

50 participants with

at various stages after

To describe the goals of

stroke and to code the

goals according to the

Functioning, Disability

International

Classification of

and Health (ICF).

people with aphasia after

stroke.

Information about terms used to describe communication difficulties.

· Information about prognosis and what to expect at different stages

· Information about how to explain difficulties to friends or people in

Information about aphasia.

Information about aphasia services.

• Information about aphasia therapy.

after stroke.

community.



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

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executive function	Word	Frequency
neuropsychology	Aphasia	2180
memory language	Cognition	316
	Language	257
oppoio	Memory	88
	Attention	63
	Executive function	24
	Dementia	23
neglect cognition	Neglect	6
attention	Thinking	5
dementia	Neuropsychology	2

Figure 2. Word cloud and table showing the frequency with which cognition-related words from the systematic search strategy were mentioned in the included articles. The word cloud was created using Word It Out software.

159x65mm (144 x 144 DPI)

Supplementary Materials

Divergences from protocol.

The scoping review protocol stated "Data will be analyzed using a grounded theory approach based on the principles of textual narrative synthesis, in line with the procedure outlined by Lucas et al." (Hobden & Demeyere, 2023, p.3). However, after further consideration of JBI guidelines supporting the use of qualitative analysis only when it is descriptive in nature, we opted to employ a pragmatic approach to thematic analysis, broadly resembling qualitative content analysis procedures but diverging in epistemological and ontological assumptions (Braun & Clarke, 2021). In line with qualitative content analysis, a structured coding framework was used to develop and document the analysis but (post)positivist and atheoretical assumptions often espoused by proponents of content analysis were not endorsed, so we consider our method more closely aligned to the codebook approach outlined by (Braun & Clarke, 2021) than more traditional content analysis methods (Forman & Damschroder, 2007). Nevertheless, in line with guidance from (Peters et al., 2020), the goal of the qualitative analysis was purely descriptive in nature.

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Supplementary Table 1. Final search strategy with example search conducted on MEDLINE (PubMed) on 7th July, 2023. After approval of the search strategy from peer-reviewers, the search strategy was used to conduct a systematic search in five electronic databases on August 25th, 2023: MEDLINE (PubMed), PsycINFO (Ovid), Embase (Elsevier), CINAHL (Ebsco), and Scopus (Elsevier).

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

Supplementary Table 2. Final tool used to extract data from included articles.

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47	Author,	Title	Research design	Research	Timepoint(s)	Population(s)	Participant	Relevant
48	Year,		(e.g., cross-	methods (e.g.,	since stroke	investigated	demographics	findings
49	Country		sectional,	survey, semi-	investigated			
50			longitudinal)	structured				
51				interviews)				
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A scoping review of research investigating patient and carer psychoeducation needs regarding post-stroke cognition.

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-084681.R1
Article Type:	Original research
Date Submitted by the Author:	19-Jul-2024
Complete List of Authors:	Hobden, Georgina; University of Oxford, Department of Experimental Psychology Tabone, Faye; University of Oxford, Nuffield Department of Clinical Neurosciences Demeyere, Nele; University of Oxford, Nuffield Department of Clinical Neurosciences
Primary Subject Heading :	Patient-centred medicine
Secondary Subject Heading:	Neurology
Keywords:	Stroke < NEUROLOGY, Rehabilitation medicine < INTERNAL MEDICINE, Patient-Centered Care, Psychosocial Intervention, Family





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2	psychoeducation needs regarding post-stroke cognition.
3	Georgina Hobden, MSc ¹ , Faye Tabone, MSc ^{1,2} MSc, & Nele Demeyere, PhD ²
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	Email: Georgina.hobden@psy.ox.ac.uk
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26	ABSTRACT
27	Objectives
28	To search the literature systematically to map and identify gaps in research investigating patient
29	and family member psychoeducation needs regarding post-stroke cognition.
30	Design
31	Scoping review conducted in line with Joanna Briggs Institute (JBI) recommendations and
32	PRISMA-ScR checklist.
33	Methods
34	MEDLINE, PsycINFO, Embase, CINAHL and Scopus were searched on August 25th, 2023 for
35	peer-reviewed studies which were conducted in a high-income country, describing cognition-
36	related psychoeducation needs in stroke survivors and/or family members aged ≥ 18 years
37	(\geq 50% of the study population). Two reviewers independently screened titles, abstracts, then
38	full text articles. One reviewer extracted pre-defined data. Data were verified by a second
39	reviewer. Synthesis involved descriptive statistics and a pragmatic thematic analysis.
40	Results
41	Searches identified 8,115 articles, of which 30 were included. Articles were published between
42	1996-2023. Studies were conducted in Australia ($n=7$), USA ($n=6$), UK ($n=5$), Canada ($n=3$),
43	New Zealand ($n=3$), Ireland ($n=2$), Netherlands ($n=2$), South Korea ($n=1$) Sweden ($n=1$). Most

een =3), lost 44 studies (n=21) used an exclusively qualitative approach but 6 combined qualitative/quantitative 45 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. 46 Research was conducted with stroke survivors only (n=7), family members only (n=12) and 47 both stroke survivors/family members (n=11). Qualitative analysis suggested participants 48 49 wanted psychoeducation about cognitive impairment, including recovery expectations, treatment/therapy options, and signposting to services/resources available. Hopeful 50

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> 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 (e.g., 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 (e.g., memory, attention, executive function impairments) is required. TF 7 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 articles may not have been included.

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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, whilst there is currently no method for reliably predicting long-term post-stroke cognitive outcomes 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 diagnoses (20) and previous research has found a beneficial impact of psychoeducation on self-efficacy and knowledge among those with minor stroke (14).

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Nevertheless, stroke survivors and their family members have reported substantial unmet psychoeducation needs regarding cognition (21) and, 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 poststroke 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 wellbeing - 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. The ultimate goal of the research is to inform, alongside other primary research (28,31), the design of a complex intervention focused on monitoring and psychoeducation to support cognition after stroke. The specific questions addressed by this review are:

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2 3	128	1. What research methods and designs have been used in previous studies describing
4 5	120	stroke survivor and family member information needs regarding cognition?
6 7	129	stoke survivor and ranning memoer information needs regarding cognition?
8 9	130	
10 11	131	2. What timepoints after stroke have been investigated in previous studies?
12 13	132	
14 15 16	133	3. What are the characteristics of stroke survivors and family members included in
10 17 18	134	previous studies?
19 20	135	
21 22	136	4. What psychoeducation needs related to post-stroke cognition have been reported in
23 24 25	137	previous studies?
26 27	138	
28 29	139	5. What factors have been suggested to impact psychoeducation needs in previous
30 31 32	140	studies?
33 34	141	
35 36	142	6. What key gaps exist within the current evidence base?
37 38	143	
39 40 41	144	
42 43	145	METHODS
44 45	146	Review protocol
46 47 48	147	The review was conducted in accordance with the Johanna Briggs Institute (JBI) methodology
49 50	148	for scoping reviews (32) and the Preferred Reporting Items for Systematic Reviews and Meta-
51 52	149	Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist. The protocol for this
53 54	150	review underwent a rigorous peer-review process for publication (33) and has been made
55 56 57	151	openly available (https://osf.io/fmz9t). Any divergences from the protocol are justified and
58 59 60	152	provided in Supplementary File 1.

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153 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. With regards to the present study, they emphasised the importance of including family member/carer perspectives where possible.

160 Search strategy

159

161 The search strategy was developed in consultation with an expert librarian at the University of Oxford and was peer reviewed. The final approved search strategy (Supplementary File 2) was 162 adapted to search additional electronic databases using the Polyglot tool provided by 163 164 Systematic Review Accelerator software (https://sr-accelerator.com/). Systematic searches were conducted in five electronic databases on August 25th, 2023: MEDLINE (PubMed), 165 PsycINFO (Ovid), Embase (Elsevier), CINAHL (Ebsco), and Scopus (Elsevier). Search 166 167 strategies developed using the Polyglot tool are presented in Supplementary File 3. Grey literature databases were not searched as the aim of the review is to inform an evidence-based 168 intervention, so we sought articles that had been through rigorous peer-review. The search 169 strategy was limited to English, but it was not limited by year. 170

171

172 Inclusion criteria

173 The inclusion criteria were based on the JBI Population/Concept/Context (PCC) framework174 (32). Articles were eligible for inclusion in this review if they met the following criteria:

i 175

59 60 176 Participants

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2 3	177	• Stroke survivors and/or family members of stroke survivors. Stroke survivors were
4 5 6 7 8 9	177	Shoke survivors and/or family memoers of subke survivors. Subke survivors were
	178	defined as a person who has experienced a clinically diagnosed stroke of any type.
	179	Family members were defined as a person who identifies as related to a stroke survivor
10 11	180	by blood, marriage, or with other familial involvement.
12 13	181	• Stroke survivors and/or family members of stroke survivors comprising at least 50% of
14 15 16	182	the study population, in line with cut-offs used in previous scoping reviews (Fletcher
17 18	183	et al., 2022; Theou et al., 2018).
19 20	184	• Stroke survivors and family members aged 18 years and over.
21 22 22	185	
23 24 25 26 27 28 29	186	Concept
	187	• Self-reported information needs regarding post-stroke cognition. Information needs
	188	were defined as a desire to obtain information to satisfy a conscious (or unconscious)
30 31 32	189	need (34). Cognition is defined as thinking skills related to any of the following
33 34	190	domains: memory, language, attention, executive function, praxis, number processing
35 36	191	(22).
37 38 39	192	
40 41	193	Context
42 43	194	• Studies conducted in the United Kingdom and other high-income countries, defined
44 45	195	using the most recent World Bank country classifications (2022).
46 47	196	• Participants based either in a clinical setting or the community.
48 40	197	
50 51	198	Types of sources
52 53 54	199	We included published peer-reviewed articles that used quantitative, qualitative, or mixed
54 55 56 57 58	200	methods designs. Review articles, peer-reviewed commentaries and opinion pieces were
	201	excluded.
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203 Study selection process

Identified records were collated and uploaded into EndNote v.X9 (Clarivate Analytics, PA, USA). SR-Accelerator Deduplicator (35) removed duplicates. GH and FT independently screened records against eligibility criteria by title, abstract, 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.

212 Data extraction

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

217 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).

7 222

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 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 Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

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articles (i.e., 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 (i.e., inductive analysis). The research team discussed and agreed 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 (i.e., clinical neuropsychology, clinical psychology), experiences (e.g., working on hyperacute stroke units and in community brain injury rehabilitation settings), and values (e.g., 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

250 Selection of evidence sources

251 The database searches retrieved 8,112 records. This was reduced to 6,726 records after
252 deduplication. 27 records were selected for inclusion after screening. A further 3 records were

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2 3 4	253	identified from reference lists. This resulted in a total of 30 articles being selected for inclusion
5 6	254	in the scoping review. Figure 1 documents the selection process.
7 8	255	
9 10 11	256	[Figure 1]
12 13	257	
14 15	258	The included articles were published between 1996 and 2023. Most studies ($N = 20$) were
16 17 18	259	published between 2001-2020, with 14 published in the last ten years (2013-2023). Studies
19 20	260	were conducted in Australia ($N = 7$), United States of America ($N = 6$), United Kingdom ($N =$
21 22	261	5), Canada ($N=3$), New Zealand ($N=3$), Ireland ($N=2$), the Netherlands ($N=2$), South Korea
23 24 25	262	(N=1) and Sweden $(N=1)$. Each included article was numbered to facilitate concise reporting.
25 26 27	263	A summary of extracted data and numbers corresponding to each article are presented in
28 29	264	Supplementary File 5.
30 31 32	265	
32 33 34	266	1. What research methods have been used?
35 36	267	Twenty-one articles used an exclusively qualitative approach to data collection and analysis
37 38 20	268	[1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles
39 40 41	269	used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most
42 43	270	studies that used a qualitative data collection approach conducted semi-structured interviews
44 45	271	[2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted
46 47 48	272	focus groups [1, 4, 14, 15, 26]. Participant sample sizes in qualitative studies varied
49 50	273	substantially. Two articles presented a case study involving a single family member [10, 16].
51 52	274	The maximum sample size among the articles using exclusively qualitative methods was 50
53 54 55	275	participants with aphasia [25, 30]. Focus group sizes varied between two-four participants [15]
56 57	276	and six-ten participants [26].
58 59	277	

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Articles that used qualitative data collection methods employed different analytic approaches and frameworks. Eight articles used a version of thematic analysis [1, 2, 8, 17, 18, 24, 27, 29], eight articles used a version of content analysis [4, 12, 14, 16, 23, 25, 26, 30], two used the constant comparative method [7, 19]. Other approaches were narrative analysis [10] and a modified referenced five-step process [3]. One article described an approach that resembled thematic analysis but did not label it as such [6]. Two articles did not describe how semi-structured interview data were analysed [9, 13]. 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 [1, 3, 4, 6, 7, 8, 10, 13, 14, 15, 16, 18, 19, 21, 22, 25, 26, 27, 29, 30].

Five of the included articles used surveys or questionnaires [11, 20, 21, 22, 28]. All of these articles used custom measures rather than validated standard questionnaires. Questionnaires were administered remotely in three studies [11, 20, 28] and face-to-face in the other two studies [21, 22]. Face-to-face administrations were audio-recorded and analysed qualitatively to complement quantitative questionnaire data [21, 22].

295 2. What timepoints after stroke have been investigated?

Ten articles explicitly stated their investigation pertained to the first six-months after stroke (acute/subacute stage) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29]. Specific timepoints investigated included stroke onset/first days after stroke [1, 3, 10, 21, 22], first week after stroke [21], twoweeks after stroke [9], first month after stroke [21], first three-months after stroke [8], and fourmonths after stroke [16].

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Three articles explicitly stated their investigation pertained to the period at least six-months after stroke (chronic stage) [9, 16, 21]. Specific timepoints investigated were six-months [9, 21], seven-months [16], eleven-months [16], twelve-months [21], more than twelve-months [21], and two-years after stroke [9].

Eight articles investigated informat needs at multiple timepoints after stroke [1, 3, 9, 16, 21, 22, 24, 29]. However, eighteen arti did not specify the timepoint under investigation [2, 5, 6, 7, 11, 12, 13, 14, 15, 17, 18, 19 23, 25, 27, 28, 30] and some articles used ambiguous terminology. Temporally ambiguo rms used to describe the timepoint under investigation included initial rehabilitation [1], abilitation [3], up to one-month after discharge [29], starting to recover [22], preparing eave hospital [22], just returned home [22], settled at home [22], and chronic phase (defi as stroke survivor's return home) [1, 3].

3. What are the characteristics of participants?

Seven studies recruited stroke sur rs only [4, 8, 14, 17, 21, 25, 30] and eleven articles ily members [5, 9, 11, 13, 18, 20, 23, 26, 27, 28, 29]. included both stroke survivors and Four studies did not report the mea e of stroke survivor participants [4, 11, 18, 29] and ten nce stroke [4, 5, 8, 9, 11, 13, 18, 21, 26, 29]. The mean studies did not report the mean tim age of stroke survivors was less th) years in the twelve studies that reported this variable [8, 13, 14, 17, 20, 21, 23, 25, 26, 8, 30]. The mean time since stroke for stroke survivor participants was between eleven n ns [14] and seven years [17] but these studies did not describe how stroke date was estab ed (e.g., self-report, medical records).

4 324

With regards to the cognitive status of stroke survivors, 18 articles focused on stroke survivors with or family members of stroke survivors with aphasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

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21, 22, 23, 24, 25, 27, 30]. Other cognitive impairment (including dementia) was listed as part of the inclusion/exclusion criteria in eight studies [2, 8, 17, 19, 21, 22, 25, 30], whilst the other ten articles did not report whether stroke survivors had cognitive impairments affecting domains other than language [1, 6, 7, 10, 12, 15, 16, 23, 24, 27].

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 [4]. One article assessed cognitive functioning in non-language domains using Raven's Coloured Progressive Matrices (RCPM: Raven, Court, & Raven, 1995) [14]. Only one article reported in detail the cognitive status of stroke survivors in domains other than language [3]. 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) [3].

Twelve studies recruited family members but not stroke survivors [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Two of these articles were case studies involving only one family member [10, 16]. Most family members were described as spouses/partners/significant others (n = 134across these twelve articles) [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Some articles also included adult children caring for the stroke survivor (n = 37) [1, 2, 7, 12, 16, 19, 24], parents (n = 6) [1, 2, 3, 12], and siblings (n = 6) [3, 12]. Other family members were relatives-in-law (n = 4) [7, 12], aunts/uncles (n = 3) [7], and grandchildren (n = 2) [7]. Two studies included one friend alongside other family member participants [2,19] and one study included three friends [7]. One study included ex-family members (n = 3) as well as current family members (n = 45)[12].

 We note that different terminology was used to describe stroke survivors in the articles, including stroke survivors [5, 9, 11, 14, 18, 21, 26, 28], patients [8,13, 29], individuals/people/participants with aphasia due to stroke [17, 15, 23, 25, 27, 30], and individuals with communication-debilitating illness or injury due to stroke [7]. The following terms were used to refer to family member participants: family members [1, 12, 13, 15, 16, 20, 22, 23, 28], significant others [2, 7, 10], carers [3, 6, 29], caregivers [9, 11, 26], informal carers [18], relatives [27], communication partners [19], and care partners [24]. 4. What psychoeducation needs have been reported?

Participants across the included studies reported psychoeducation needs regarding cognitive
difficulties after stroke [1, 2, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24,
25, 27, 28, 29, 30]. Psychoeducation needs mentioned within the articles were most often
described in the context of aphasia [1, 2, 6, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17, 19, 21, 22, 23,
24, 25, 27, 28, 29, 30] but participants also described a need for psychoeducation about memory

problems [9, 18, 29], concentration problems [9, 28], and general cognitive changes [13, 20].

When describing psychoeducation needs related to aphasia, participants reported a desire for general information, including definitions and information about symptoms [1, 5, 6, 7, 9, 10, 12, 14, 15, 16, 17, 21, 22, 23, 24, 25, 27, 28, 29, 30], and participants in two studies wanted information about psychological comorbidities [1,2]. With regards to recovering from aphasia, participants wanted information about what to expect in the future [1, 2, 5, 6, 7, 10, 12, 22, 24, 27, 29, 30], treatments for aphasia and their efficacy [1, 2, 12, 16, 30], as well as ways to maximise recovery [2]. The following information about living with aphasia was also sought: compensatory strategies [8, 22, 23, 29], maximising communicative effectiveness [1,11,22], available support and services [1, 6, 12, 15, 16, 17, 22, 23, 30], psychosocial support and

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counselling [1], support for family members [2,17], support groups [1, 22], employment [1,

19], financial aid [1, 6], and information to help maintain hope and optimism [1, 12, 16, 19].

Though far fewer studies considered non-language cognitive impairments, participants in these studies similarly described a need for general information about symptoms and definitions [3, 4, 5, 9, 13, 20, 28, 29]. Some participants also wanted information about recovering, including what to expect in the future [3, 5, 29], treatments and rehabilitation available [3, 13, 18], and information to track recovery progress [3, 4]. Finally, in terms of living with cognitive impairments, some participants wanted information about compensatory strategies [3, 29], support for family members [3], and information to help maintain hope and optimism [3]. Themes and subthemes are summarised in Table 1.

[Table 1]

390 5. What factors impact psychoeducation needs?

Cognition-related psychoeducation needs were reported in articles investigating both the acute/sub-acute stage (i.e., less than six-months since stroke) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29] and chronic stage after stroke (i.e., more than or equal to six-months after stroke) [9, 16, 21], 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 [9, 21]. Hanger et al. [9] reported that only 4 out of 60 (7%) participants asked questions about poor memory/concentration in the first two-weeks after stroke, whereas 25 out of 111 (32%) asked these questions two-years after stroke. Page 19 of 47

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Similarly, whereas 3 out of 60 (5%) participants asked questions about communication difficulties in the first two-weeks after stroke, 7 out of 72 (10%) participants asked these questions two-years after stroke [9]. Rose et al. [21] 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 twelvemonths after stroke. Results from Rose et al. (2010) 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 six-months after stroke.

Only one article provided insight into how the content of cognition-related information needs evolves over time [22]. 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 to 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 versus 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 [2]. Cheng et al. [2] reported 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 Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

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information and they felt that the delivery of prognostic information should be dictated by the preference of the stroke survivor.

6. 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 [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. Psychoeducation needs related to other cognitive domains (e.g., memory, attention, executive function) were rarely mentioned. Figure 2 shows the number of times cognitive terms included 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.

[Figure 2]

Relatively few studies considered psychoeducation needs at multiple timepoints after stroke [1, 3, 9, 16, 21, 22, 24, 29] and only two of these articles [9, 21] investigated how the prevalence and content of cognitive-related information needs evolve over time.

DISCUSSION

We 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.

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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. Furthermore, very few articles addressed non-language cognitive domains commonly affected by stroke (e.g., 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 (39-44), prognosis (45-52), treatment (45,48,49,52–56), and available services (48,49,52–54,56–60). Whilst these needs were apparent throughout the post-stroke period, two articles found cognition-related psychoeducation needs became more prevalent over time (39,61), 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 (62). Clinical reviews are recommended by United Kingdom clinical guidelines at six-months, twelve-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 six-months reviews received by only 36.9% of stroke survivors in 2022/2023, a reduction from 2021/2022 when reviews were received by 40.7% (63). 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 (45–53,56–61,64–66), with very few articles
considering other commonly affected cognitive domains (e.g., memory, attention, executive
function, number processing, praxis) and only one study reporting the prevalence of non-

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Ianguage cognitive impairments in their stroke survivor sample (54). Understanding psychoeducation needs related to other domains is crucial as non-language impairments may be even more prevalent than language impairments (24) and domain-specific impairments vary substantially in their underlying aetiologies and likely trajectories (5,19,26,67). Future research should also aim to include stroke survivor samples with cognitive profiles that better reflect the clinical reality (i.e., 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, we acknowledge 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 reliable patient-centred picture.

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> 495 Overall, as stroke mortality rates continue to decline and the number of stroke survivors 496 experiencing cognitive impairment correspondingly rises (68), it is critical to consider how to 497 prepare stroke survivors and their family members to cope with cognitive changes and to 498 integrate this insight into a cognitive care pathway for stroke (13) and self-management 499 approaches that often involve psychoeducation as a key component. This scoping review

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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.

- - **FUNDING STATEMENT**

Georgina Hobden is supported by an Economic and Social Research Council (ESRC) grant (ES/P000649/1). Nele Demeyere (Advanced Fellowship NIHR302224) is funded by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of Health and Social Care."

CONTRIBUTORSHIP

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.

COMPETING INTERESTS

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2 3	525	There are no competing interests for any author
4 5	526	
6 7	520	
8 9	527	ETHICS APPROVAL STATEMENT
10 11	528	This study involves review of existing literature so did not require ethical approval.
12 13	529	
14 15	530	DATA SHARING STATEMENT
16 17 18	531	All data relevant to the study are included in the article or uploaded as supplementary
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FIGURES AND TABLES

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

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 (e.g., cogniti*) were searched in full text articles using their stem but they are represented in the figure as full words (e.g., cognition) for interpretability.

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Table 1. Surticles incranslation	ummary of theme cluded in the scop al value.	e structure developed t ing review. Note that	o capture cognition-related psychoed themes were developed to resemble d	ucation needs and on omain summaries and on summaries and summaries and summaries and s	fluencing factors mentioned in order to enhance their actionable
Domain		Theme	Subtheme	Articles 5	3 0
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topics		Descussing from	Psychological comorbidities		
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			Psychosocial support and counselling		ž
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			Employment, return to work, and job	[1, 19]	14,
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1 2 3 4 5 6	Domain-general psychoeducation topics	Recovering from cognitive impairment	What to expect in the future Treatments and rehabilitation available Information to track recovery progress	[3, 5, 29] [3, 13, 18] [3, 4]	4-084681 on 15 J ht, including for	
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10 11			Information to maintain hope	[3]	1025. ated	
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Frequency with which cognition words used in the ^{34 of 47} systematic search strategy were mentioned in articles





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Supplementary Materials

Supplementary File 1. Divergences from peer-reviewed protocol.

The scoping review protocol stated "Data will be analyzed using a grounded theory approach based on the principles of textual narrative synthesis, in line with the procedure outlined by Lucas et al." (Hobden & Demeyere, 2023, p.3). However, after further consideration of JBI guidelines supporting the use of qualitative analysis only when it is descriptive in nature, we opted to employ a pragmatic approach to thematic analysis, broadly resembling qualitative content analysis procedures but diverging in epistemological and ontological assumptions (Braun & Clarke, 2021). In line with qualitative content analysis, a structured coding framework was used to develop and document the analysis but (post)positivist and atheoretical assumptions often espoused by proponents of content analysis were not endorsed, so we consider our method more closely aligned to the codebook approach outlined by (Braun & Clarke, 2021) than more traditional content analysis methods (Forman & Damschroder, 2007). Nevertheless, in line with guidance from (Peters et al., 2020), the goal of the qualitative analysis was purely descriptive in nature.

Supplementary File 2. Example search conducted on MEDLINE (PubMed) on 7th July, 2023. Note that this search strategy was developed in consultation with an expert university librarian and was peer-reviewed.

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

Supplementary File 3. Search strategies used to search the following electronic databases on 25th August, 2023: PsycINFO, Embase, CINAHL and Scopus. Note that these search strategies were developed from the above peer-reviewed search strategy using the Polyglot tool provided by Systematic Review Accelerator software (<u>https://sr-accelerator.com/</u>).

PsycInfo (Ovid)

Search	Query
#1	exp Stroke/ OR stroke*.ti,ab. OR "cerebral infarct*".ti,ab. OR "cerebrovascular infarct*".ti,ab. OR "cerebrovascular accident*".ti,ab.

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#2	exp Patients/ OR exp Caregivers/ OR patient*.ti,ab. OR survivor*.ti,ab. OR victim*.ti,ab. OR caregiver*.ti,ab. OR famil*.ti,ab.
#3	exp Education/ OR "information need*".ti,ab. OR "education need*".ti,ab. OR "knowledge need*".ti,ab. OR psychoeducation*.ti,ab.
#4	exp Cognition/ OR exp Memory/ OR exp "Executive Function"/ OR cogniti*.ti,ab. OR thinking.ti,ab. OR memory.ti,ab. OR attention.ti,ab. OR "executive function*".ti,ab. OR
	aphasia*.ti,ab. OR dementia*.ti,ab. OR language.ti,ab. OR neglect.ti,ab. OR neuropsych*.ti,ab.
#5	aphasia*.ti,ab. OR dementia*.ti,ab. OR language.ti,ab. OR neglect.ti,ab. OR neuropsych*.ti,ab. #1 AND #2 AND #3 AND #4

Embase

Embase	0
Search	Query
#1	Stroke/exp OR stroke*:ti,ab OR 'cerebral infarct*':ti,ab OR 'cerebrovascular infarct*':ti,ab OR 'cerebrovascular accident*':ti,ab
#2	Patients/exp OR Caregivers/exp OR patient*:ti,ab OR survivor*:ti,ab OR victim*:ti,ab OR caregiver*:ti,ab OR famil*:ti,ab
#3	Education/exp OR 'information need*':ti,ab OR 'education need*':ti,ab OR 'knowledge need*':ti,ab OR psychoeducation*:ti,ab
#4	Cognition/exp OR Memory/exp OR 'Executive Function'/exp OR cogniti*:ti,ab OR thinking:ti,ab OR memory:ti,ab OR attention:ti,ab OR 'executive function*':ti,ab OR aphasia*:ti,ab OR dementia*:ti,ab OR language:ti,ab OR neglect:ti,ab OR neuropsych*:ti,ab
#5	#1 AND #2 AND #3 AND #4

CINAHL

Search	Query
#1	(MH Stroke+) OR (TI stroke* OR AB stroke*) OR (TI "cerebral infarct*" OR AB "cerebral infarct*") OR (TI "cerebrovascular infarct*" OR AB "cerebrovascular infarct*") OR (TI "cerebrovascular accident*" OR AB "cerebrovascular accident*")

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#5	#1 AND #2 AND #3 AND #4
#4	(MH Cognition+) OR (MH Memory+) OR (MH "Executive Function+") OR (TI cogniti* OR AB cogniti*) OR (TI thinking OR AB thinking) OR (TI memory OR AB memory) OR (TI attention OR AB attention) OR (TI "executive function*" OR AB "executive function*") OR (TI aphasia* OR AB aphasia*) OR (TI dementia* OR AB dementia*) OR (TI language OR AB language) OR (TI neglect OR AB neglect) OR (TI neuropsych* OR AB neuropsych*)
#3	(MH Education+) OR (TI "information need*" OR AB "information need*") OR (TI "education need*" OR AB "education need*") OR (TI "knowledge need*" OR AB "knowledge need*") OR (TI psychoeducation* OR AB psychoeducation*)
#2	(MH Patients+) OR (MH Caregivers+) OR (TI patient* OR AB patient*) OR (TI survivor* OR AB survivor*) OR (TI victim* OR AB victim*) OR (TI carer* OR AB carer*) OR (TI caregiver*) OR (TI famil* OR AB famil*)

Scopus

Search	Query
#1	INDEXTERMS(Stroke) OR TITLE-ABS(stroke*) OR TITLE-ABS("cerebral infarct*") OR TITLE-ABS("cerebrovascular infarct*") OR TITLE-ABS("cerebrovascular accident*")
#2	INDEXTERMS(Patients) OR INDEXTERMS(Caregivers) OR TITLE- ABS(patient*) OR TITLE-ABS(survivor*) OR TITLE-ABS(victim*) OR TITLE- ABS(carer*) OR TITLE-ABS(caregiver*) OR TITLE-ABS(famil*)
#3	INDEXTERMS(Education) OR TITLE-ABS("information need*") OR TITLE-ABS("education need*") OR TITLE-ABS("knowledge need*") OR TITLE-ABS(psychoeducation*)
#4	INDEXTERMS(Cognition) OR INDEXTERMS(Memory) OR INDEXTERMS("Executive Function") OR TITLE-ABS(cogniti*) OR TITLE-ABS(thinking) OR TITLE-ABS(memory) OR TITLE-ABS(attention) OR TITLE-ABS("executive function*") OR TITLE-ABS(aphasia*) OR TITLE-ABS(dementia*) OR TITLE-ABS(language) OR TITLE-ABS(neglect) OR TITLE- ABS(neuropsych*)
#5	#1 AND #2 AND #3 AND #4

Supplementary File 4.	Final tool used to extract data from included articles.

5 6 7 8 9 10	Author, Year, Country	Title	Research design (e.g., cross- sectional, longitudinal)	Research methods (e.g., survey, semi- structured interviews)	Timepoint(s) since stroke investigated	Population(s) investigated	Participant demographics	Relevant findings
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4 5 6 7 8	Supplement the aim most	t ary File 5. Summ t relevant to this so	ary of extracted data	a from included ghted in italics.	articles. Where the article I Terminology and results ar	had multiple ain gain gain gain gain gain gain gain	section of the sectio		
9 10 11 12 13 14	align sufficio order listed v	ently with the tabl within the articles.	e headings, leading	to variation in t	erminology used across the	eignoe eignoe table. Psychol tont Support text support	Solucation needs are presented in the		
15 Reference 15 number 16	e Authors, Year, Country	Study aims	Study methodology	Participant sample	Participant demographics	Timepoint(s)	Cognition-related psychoeducation need(s) identified		
17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32	Avent et al., 2005, USA	To identify information needed by family members at different phases after onset of aphasia.	Qualitative methods. Focus groups, analysis using five-stage framework approach.	16 family members.	Age: Not reported. Gender: 15 female, 1 male. Relationship: 12 spouses, 2 children, 1 parent, 1 long-term partner. Average time since stroke: 5.5 years (range: 1.10-13).	ABES Onset of aphasiaining (hospitalisation) Initial rehabilitation Chronic phases of aphasia.	 General information. Specific time-based aphasia information. Information about psychosocial support and counselling. Hopeful information. Information about coexisting behavioural and medical conditions, including depression, impaired judgement, fatigue, personality changes. Information about aspects of treatment. Information about maximising communicative effectiveness. Information about long-range planning (e.g., life expectancy and health maintenance). Information about financial aid. Information about independent living arrangements. Information about support groups. Information about alternative therapies. Information about job retraining. Information on recovery trajectory 		
33 [2] 34	Cheng et al., 2022, Australia	To explore the perspectives of significant others of people with aphasia on receiving information about prognosis.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	7 significant others.	Age: 64.71 years (range: 35-76). Gender: 5 female, 2 male. Relationship: 3 partners, 2 parents, 1 child, 1 friend. Time since stroke: 7.29 months (range: 3-12).	3-12 months post- stroke.	 Information on expected outcomes (impairment-level improvement and process of recovery). Information to help family member recover. Information on how to maximise the outcome of recovery (optimal practice stimuli and techniques). Information on treatment efficacy. Information about practical aspects of recovery (arranging suitable accommodation, planning supports for daily activities). Information about cognitive comorbidities. 		
41 42 43 44 45 46			For peer revi	iew only - http://bn	njopen.bmj.com/site/about/gu	idelines.xhtml			

					BMJ Open	jopen-2024-0 by copyright,	Page 42
[3]	Davidson & Wallace, 2022, USA	To explore information needs of carers of right hemisphere stroke survivors at different phases after stroke.	Qualitative methods. Semi-structured interviews, analysis using phenomenological approach using a modified five-step process.	4 carers.	Age: 65.5 years (range: 59-70). Gender: 3 female, 1 male. Relationship: 2 spouses, 1 brother, 1 parent. Time since stroke: 6.11 years (range: 3- 10.5).	Onset. Rehabilitation. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic.	 Information about the rehabilitation timeline. Information about symptoms. Information about the roles of medical professionals. Information about treatment rationales. Information about treatment progress. Information about techniques and compensatory strategies. Information on support for carers and patients (e.g., support groups) Information on home practice activities. Information on supplementary treatments (e.g., vision, music, water therapies). Hopeful information.
[4]	Davoody et al., 2016, Sweden	To explore stroke survivors' information needs after discharge in order inform the development of an eHealth service.	Qualitative methods. Focus groups, content analysis.	12 stroke survivors.	Age: Mean not reported (range: 30-85 years). Sex: 7 female, 5 male. Time since stroke: Not reported.	After discharge. to text superieur tand da	 Simple description of invisible difficulties (e.g., chronic fatigue, cognitive impairments, and personality changes) to share with family and friends. Information to track recovery (motor and cognitive) progress.
[5]	De Simoni et al., 2016, UK	To describe the characteristics of participants of an online stroke forum, <i>their</i> <i>reasons for posting in the</i> <i>forum</i> , and whether the responses addressed these needs.	Qualitative and quantitative methods. Descriptive statistical analysis of forum user population, thematic analysis of posts from representative subsample of forum users.	2,348 forum users overall. 59 representative users selected for subsample thematic analysis, representing 26 stroke survivors and 33 stroke survivors mentioned by third party.	Subsample age: Not reported. Subsample gender: 27 female, 30 male, 2 NA. Subsample time since stroke: Not reported.	(ABES) . tra mining, AI trainin	 Information about stroke physical symptoms (communication impairments, cognition). Information on potential for recovery (timeline, age influence, recovery of functioning, reading, memory, communication). Information on invisible stroke impairments
[6]	Denman, 1998, UK	To identify needs of spouses caring for someone with communication difficulties due to stroke and to identify solutions they felt would alleviate the difficulties described.	Qualitative methods. Semi-structured interviews, identification of common themes.	9 carers.	Age: Not reported. Gender: 6 female, 3 male. Relationship: 9 spouses. Time since stroke: At least 12 months (mean and range not reported).	g, and similar tech	 Information about symptoms and their recovery (e.g., aphasia). Information about financial entitlements. Information about services available locally.
[7]	Donovan-Kicken & Bute, 2008, USA	To investigate sources of uncertainty for significant others of patients with communication- debilitating illness (CDI) or injury and how uncertainty is managed.	Qualitative methods. Semi-structured interviews, analysis using constant comparative technique.	31 significant others of individuals with CDIs, including 18 significant others of individuals with CDI due to stroke. Other CDIs were brain injury ($n = 3$), brain tumour ($n = 3$), atrain tumour ($n = 3$), atrain ($n = 2$), Alzheimer's disease ($n = 2$), AIDS (n = 1), dementia ($n = 1$), throat cancer ($n = 1$).	Age: 42.6 years (range: 25-75). Gender: 23 female, 8 male. Relationship: 18 children, 2 spouses, 3 close friends, 2 grandchildren, 3 aunts/uncles, 1 child-in-law. Time since CDI: 4.2 years (range: 6 months-12 hears). <i>Note</i> . Demographic details for stroke subsample not available.	Not specified. 14, 2025 at Agence Bibliog	 Information about diagnosis. Information about the extent of damage caused by illness or injury. Information about cause of CDI. Information about long-term prognosis (possibility for and extent of physical and mental recovery). Information about quality of life.
			For peer revi	ew only - http://bm	jopen.bmj.com/site/about/gui	raphique idelines.xhtml de	

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[8] Grohn et al., 2012, Australia	To describe the experience of the first 3 months after stroke in order to identify factors which facilitate successfully living with	Qualitative methods. Semi-structured interviews, thematic analysis.	15 stroke survivors.	Age: 66.3 years (range: 47-90). Gender: 7 female, 8 male. Time since stroke: Not reported.	it, in 484681 on 15 Ja First 3-months after stroke. Ing for 1	 Information from other people with aphasia about how they n adjustments. Information on completing activities of daily living (write shop list, cheques, use a computer)
[9] Hanger et al., 1998, New Zealand	aphasia after stroke. To identify what type of questions are asked by stroke survivors and their caregivers and how the nature of questions asked changes with increasing time after stroke.	Qualitative and quantitative methods. Longitudinal, semi-structured interviews conducted at three timepoints (two-weeks, six- months, two-years after stroke), descriptive and inferential statistical analyses.	Subsample 1 (two- weeks after stroke): 60 participants. Subsample 2 (six- months after stroke): 111 participants. Subsample 3 (two- years after stroke): 72 participants. Note. Number of stroke survivors versus caregivers not reported.	Subsample 1. Age: 71.5 years (range: 42-99). Gender: 26 female, 34 male. Time since stroke: Not reported. Subsample 2. Age: 72.3 years (range: 23-100). Gender: 48 female, 63 male. Time since stroke: Not reported. Subsample 3. Age: 71.8 years (range: 24-101). Gender: 35 female, 37 male. Time since stroke: Not reported. <i>Note.</i> Demographic details for stroke survivors versus caregivers not reported.	Inuary 2025. Downloaded from http://bm Enseignement Superieur (ABES) . Six-months afted to text and data mining, AI Two-years after to text and data mining, AI	 Information about communication difficulties. Information about memory problems. Information about poor memory/concentration.
[10] Hersh & Armstrong, 2021, Australia	To explore how the wife of a man with aphasia managed his discharge from hospital in the acute stage after stroke.	Qualitative methods. Single case study, narrative analysis of semi-structured interview collected as part of a large multisite study, systemic functional linguistics analysis of two complaint letters.	1 significant other.	Age: 63 years. Gender: Female. Relationship: Spouse. Time since stroke: 4 years.	Stroke onset and following days. ining, and simil	 Information about aphasia, including definition of term. Information about what might happen in the future.
[11] Hinojosa et al., 2012, USA	To identify information needs of stroke caregivers with regard to managing recovery process at home; to explore whether and how information needs vary by race, ethnicity and place; to explore how the information needs are associated with caregiver characteristics (depression, coping, social support etc.).	Quantitative methods. Survey, descriptive and inferential statistical analyses.	276 stroke survivor- caregiver dyads.	Caregivers: Age: 59.36 years (range not reported). Gender: Not reported. Relationship: Not reported. <i>Note.</i> Stroke survivor demographics not reported.	n June 14, 2025 at Agence E ar technologies.	 Information about knowing how to help others communicate patient due to speech.
[12] Howe et al., 2012, New Zealand	To identify rehabilitation goals of family members	Qualitative methods.	48 family members.	Age: 60.92 years (range: 24-83). Gender: 36 female, 12 male.	Not specified.	 Information about aphasia. Information about future recovery prospects. Information about available services.

121 Of et al., 2027, South Tomas Of detenia university with sphese. Send structured interviews. Send tomas Send structured interviews. Send tomas Send structured interviews. Send tomas Send structured interviews. Send tomas Not specified. Information about thesisy. Send tomas Information about thesisy. Send tomas 121 On et al., 2027, South Tomas To develop a nome- base cally also transmission about thesisy. Send tomas Mode methods. The signed senders about to a to early also transmission about thesisy. Send tomas Not specified. Not specified. Information on cogetity impacts and spinos 121 On et al., 2027, South Tomas To develop a nome- base cally also transmission about thesisy. Send transmission about thesisy. The signed senders and spinos assessments. Sender Tomas Not specified. Not specified. Information on cogetity impacts and spinos assessments. Sender Tomas Not specified. Information on cogetity impacts and spinos assessments. Sender Tomas Not specified. Information about aphasis/communication problems. Sender Tomas Access Strapp Theora 7: Cogetity Spinos Not specified. Information about aphasis/communication problems. Sender Tomas 124 For et al., 2020, Not specified. To develop a nome- senders Cogetity Spinos Not specified. Tomas Not specified. Information about aphasis/communication problems. Senders Tomas Not specified. Tomas Information about aphasis/communication problems. Senders Tomasprob. Towas 124					BMJ Open	y cop	Р
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 B. Die et J. 2017, Such Kortzo B. Such Kortzo Such Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Such Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo C. Strake Super Kortzo Kere et al., 2010, Super Kortzo Strake Super Kortzo Kere et al., 2010, Super Kortzo Strake Super Kortzo Kere et al., 2010, Super Kortzo Strake Super Kortzo Kere et al., 2010, Super Kortzo Strake Super Kortzo 		of stroke survivors with aphasia.	Semi-structured interviews, content analysis.		Relationship: 28 spouses or de facto partners, 7 children, 5 siblings, 2 parents, 6 other relatives (e.g., sister-in- law). Time since stroke: Not reported.	ncluding for	 Information about therapy. Information about progress. Information that is hopeful and positive.
 [14] Kerr et al., 2010, UK Information stroke ara website about living sirvivors would like to see on a website about living how to structure the information; to determine how to structure the information about aphasia. Information about therapy. 	[13] Oh et al., 2017, South Korea	To develop a home- based, online cognitive rehabilitation program that can be easily and repeatedly implemented and integrates cognitive training into daily activities.	Mixed methods. Three stage process involving analysis, design, and development. Analysis stage involved literature reviews and two- phase participant needs assessment (Phase 1: cognitive assessment; Phase 2: semi- structured interviews). Design stage involved feedback on intervention design from expert panel. Development stage involved validity testing with questionnaire measures.	Analysis Stage Phase 1 (cognitive assessment): 60 stroke patients. Analysis Stage Phase 2 (semi-structured interviews): 5 stroke patients. 5 family members. Design Stage: Number of panel members not reported. Development Stage: 4 patients. 6 family members. 10 healthcare professionals.	Analysis Stage Phase 1: Gender: 12 female, 48 male. Age: 61.4 years (range not reported). Time since stroke: Not reported. Analysis Stage Phase 2: Gender: Not reported. Age: 69 years (range not reported). Relationship: Not reported. N.B. Subsample demographics for patients versus family members not reported. Design Stage: No demographic details reported. Development Stage: No demographic details reported.	Enseignement Superieur (ABES) . uses related to text and data mining, AI tra	 Information on cognitive impairment. Information on rehabilitation.
 [15] Le Dorze & Signori, 2010, Canada [16] Le Dorze et al., 2009, Canada [16] Le Dorze et al., 2009	[14] Kerr et al., 2010, UK	To determine what information stroke survivors would like to see on a website about living with stroke; to determine how to structure the information; to identify differences between stroke survivors with and without aphasia.	Qualitative and quantitative methods. Focus groups, modified card sorting task, content analysis of focus groups, descriptive statistical analysis of modified card sorting task.	12 stroke survivors.	Age: 67.8 years (range: 45-86). Gender: 7 female, 5 male. Time since stroke: 11 months (range: 6- 15).	aining, and similar tec	 Information about aphasia/communication problems.
[16] Le Dorze et al., To describe a daughter's Qualitative methods. 1 family member. Age: 31 years. Four-months after • Information about aphasia. 2009, adaptation process to her Gender: Female. stroke. • Information about services and resources available. Canada father's stroke and aphasia. Longitudinal, single case study, semi-structured interviews Relationship: Daughter. Seven-months after stroke: 4-11 months. Seven-months after • Information about therapy.	[15] Le Dorze & Signori, 2010, Canada	To explore needs of family members of people with aphasia and barriers/facilitators to meeting these needs.	Qualitative methods. Focus groups, custom analytic approach.	11 family members, including 10 family members of individuals with aphasia due to stroke and 1 family member of an individual with aphasia due to brain tumour resection.	Age: 60.5 years (range: 51-68). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since aphasia onset: 6.66 years (range: 3-15).	Not specified. hnologies.	 Information about aphasia. Information about available resources.
	16] Le Dorze et al., 2009, Canada	To describe a daughter's adaptation process to her father's stroke and aphasia.	Qualitative methods. Longitudinal, single case study, semi-structured interviews	1 family member.	Age: 31 years. Gender: Female. Relationship: Daughter. Time since stroke: 4-11 months.	Four-months after Stroke.	 Information about aphasia. Information about services and resources available. Information about therapy.

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			(four-months, seven-months, and eleven-months after stroke), content analysis.			Jht, in 4-084 , in 4-084 Here 4-087 Eleven-months 4067 Stroke din on	 Information about other people who have suffered from aphas maintain hope and optimism.
[17]	Manning et al., 2022, Ireland	To explore the perspectives of working- aged adults with post- stroke aphasia toward what has or would help them in living well with aphasia.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	14 individuals with aphasia as a result of stroke.	Age: 51 years (range: 33-62). Gender: 6 female, 8 male. Time since stroke: 7 years (range: 14 months-14 years).	g for uses relate Not specified.	 Information about aphasia. Information about services available. Information relevant to younger people with aphasia. Information to help relatives understand aphasia.
[18]	Merriman et al., 2019, Ireland	To examine the perspectives and preferences of stroke survivors, carers, and healthcare professionals to inform the design of a cognitive rehabilitation intervention.	Qualitative methods. Semi-structured interviews, thematic analysis.	14 stroke survivors. 11 informal carers. 19 healthcare professionals.	Stroke survivors: Age: Mean not reported (range: 35-40 to 80-85). Gender: 8 female, 6 male. Time since stroke: Mean not reported (range: <1 year–17 years). Informal carers: Age: Mean not reported (range: 40-45 to 80-85). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since stroke: Mean not reported (range: <1 year–17 years). Note. Age was reported categorically.	b. Downloaded from http://bmjopen d to text and data mining, Al trainir Not specified.	 Information about consequences of stroke. Information about rehabilitation. Information on purpose of activities instructed to undertake. Information about impact of stroke on memory.
[19]	Paul & Sanders, 2010, USA	To explore education experiences and needs of communication partners of individuals with aphasia.	Qualitative methods. Semi-structured interviews, constant comparative analysis.	9 communication partners.	Age: 58 years (range: 37-78). Gender: 7 female, 2 male. Relationship: 5 spouses/significant others, 3 children, 1 friend. Time since stroke: 11 months (0.5-24).	Not specified. and simil	 Information that fosters hope for improvement. Information on how to support transition to independence. Information that is tailored to needs of dyad. Information about employment, disability, and return to work. Information about communicating with the person with aphasi
[20]	Rochette et al., 2008, Canada	To identify information on the internet regarding rehabilitation intended for those who have experiences a stroke and their families and to assess the usability of a newly created website on stroke rehabilitation for laypersons.	Quantitative methods. Questionnaire.	4 stroke survivors. 3 family members.	Stroke survivors: Age: 53.5 years (range: 47-68). Gender: Not reported. Time since stroke: 11 years (range: 4-19 years). Family members: Age: 49 years (range: 42-62). Gender: Not reported. Relationship: 1 spouse, 2 children. Time since stroke: 113.67 months (range: 2 months–28 years).	ar technologies.	Information about cognitive changes.
[21]	Rose et al., 2010, Australia	To determine whether stroke survivors with aphasia consider it important to receive	Qualitative and quantitative methods.	40 stroke survivors.	Age: 65.9 years (range: 32-84). Gender: 16 female, 24 male. Time since stroke: Not reported.	Admission. Day after stroke. Within first week after stroke.	Information about aphasia.
		aphasia consider it important to receive	For peer revie	ew only - http://bn	Time since stroke: Not reported. njopen.bmj.com/site/about/gui	Within first week after og stroke.	

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		written stroke and aphasia information; to examine preferences for timing and modality of this information provision.	Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.			right, in 15 Januar Within first mortual after stroke. Six-months after stroke. Twelve-months offer stroke. More than twelve	
[22]	Rose et al., 2019, Australia	To explore family members' experiences and preferences for receiving aphasia information.	Qualitative and quantitative methods. Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.	65 family members.	Age: Not reported. Gender: 48 female, 17 male. Relationship: 53 spouses/partners, 12 NA. Time since stroke: 3.7 years (range: 1- 16).	store from http://bmj store from http://bmj home. Superieur (ABES) . Al tr	 Information about what aphasia is. Information about causes of aphasia. Information about purpose of communication assessment. Information about communication progress to expect. Information about coping strategies and living successfully with aphasia. Information about aphasia therapy. Personal experience stories from people with aphasia. Information about support groups for people with aphasia. Information about support groups for people with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about aphasia associations. Information about aphasia research (ways to be informed about or involved in research).
[23]	Rotherham et al., 2015, New Zealand	To explore the benefits for adults with aphasia of all the groups they had chosen to participate in post-stroke.	Qualitative methods. Semi-structured interview, content analysis.	10 people with aphasia. 6 family members.	People with aphasia: Age: 69 years (range: 51-83). Gender: 2 female, 8 male. Time since stroke: 55.1 months (range: 7 months–8 years). Family members: Age: 63 years (range: 51-78). Gender: 6 female, 0 male. Relationship: 6 spouses/partners. Time since stroke: Not reported.	Not specified. Not specified.	 Information about aphasia. Information about shared experiences of others with aphasia. Information about strategies. Information about resources.
[24]	Shafer et al., 2022, USA	To explore how care partners of stroke survivors with aphasia accessed information and adapted to the caregiver role at different stages of recovery during COVID-19 pandemic.	Qualitative methods. Longitudinal, semi-structured interviews at up to five stages post-stroke (event, stabilisation, one-two weeks after stroke, one-month after stroke, six-months after stroke), thematic analysis using codebook approach.	Stage 1/2 (event/stabilisation: 13 care partners. Stage 3 (one-two weeks after stroke): 11 care partners. Stage 4 (one-month after stroke): 9 care partners.	Age: 64.18 years (range: 49-75). Gender: 9 female, 4 male. Relationship: 7 spouses, 5 children, 1 relative. Time since stroke: Not reported. <i>Note.</i> Demographic details for subsamples at each interview stage are not provided.	Stroke onset through 1, 2015 six-months aftererok 2025 at Agence Bibliogra	 Information about aphasia. Information about recovery prospects. Information about how to help during rehabilitation.
			For peer revie	ew only - http://bm	ijopen.bmj.com/site/about/gui	delines.xhtml	

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			Stage 5 (six-months after stroke): 7 care partners.		4-084681 on yht, includin	
[25] Tomkins et al., 2013, Australia	To explore the factors influencing the satisfaction and dissatisfaction of people with aphasia with regards to their health care.	Qualitative methods. Semi-structured interviews, content analysis.	50 people with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	g for uses relat	Information about aphasia.
[26] Tyson et al., 2014, UK	To investigate stroke survivors' and caregivers' experiences and views of rehabilitation assessment process.	Qualitative methods. Focus groups, content analysis.	17 stroke survivors. 6 caregivers.	Stroke survivors: Age: 58 years (range: 19-84). Gender: 6 female, 11 male. Time since stroke: Not reported. Caregivers: Age: Not reported. Gender: 4 female, 2 male. Relationship: 5 spouses/partners, 1 parent. Time since stroke: Not reported.	Within the first Superieur (ABES) after stroke.	Information about psychological assessments (cognition and mo
[27] van Rijssen et al., 2023, Netherlands	To explore the experiences, needs, and wishes of people with aphasia and their relatives to inform development of communication training for healthcare professionals.	Qualitative methods. Semi-structured interviews, thematic analysis.	20 people with aphasia. 12 relatives.	People with aphasia: Age: 59 years (range: 46-93). Gender: 11 female, 9 male. Time since stroke: 82.5 months (range: 9 months–31 years). Relatives: Age: 67 years (range: 39-96). Gender: 5 female, 7 male. Relationship: 10 spouses/partners, 2 children. Time since stroke: 105.25 months (range: 9 months–31 years).	Not specified. Al training, and similar t	 Information about aphasia. Information about emotional consequences of living with some with aphasia. Information about what to expect for the future.
[28] van Veenendaal et al., 1996, Netherlands	To investigate informational needs of stroke survivors and their family members.	Quantitative methods. Questionnaires, descriptive statistical analysis.	35 stroke survivors. 39 family members. 43 health professionals.	Stroke survivors: Age: 61 years (range: 36-79). Gender: Not reported. Time since stroke: 18 months (range not reported). Family members: Age: 62 years (range: 36-84). Gender: Not reported. Relationship: Not reported. Time since stroke: 16 months (range not reported).	Not specified. Bechnologies.	 Information about talking difficulties. Information about problems with concentration.

1						BMJ Open	njopen-2024-i 1 by copyrigh	Page 48 of 47
2 3 - 4 5						Gender: Not reported. Professional role: 11 nurses, 10 physiotherapists, 9 social workers, 13 not reported.	084681 on 1: , including 1	
6 7 8 9 10 11 12 13 14 15 16 17	[29]	Wiles et al., 1998, UK	To identify information needs of stroke patients and their informal carers at various stages after stroke.	Qualitative methods. Semi-structured interviews at three time-points after stroke (during hospitalisation, up to one-month after discharge, two-twelve months after discharge), thematic analysis.	Stage 1 (during hospitalisation): 6 patients. 1 carer. Stage 2 (up to one- month after discharge): 5 patients. 3 carers. Stage 3 (two-twelve months after discharge): 8 patients. 8 carers.	 Note. Demographics for subsamples of participants included at each stage not reported. Demographics for carers not reported. Demographics for stroke survivors interviewed/referred to during interviews (n = 21): Age: Mean not reported (range: 50-85). Gender: 10 female, 11 male. Time since stroke: Not reported. 	o During hospitalisation During hospitalisation Up to one-monts of the service of the service discharge. Superieur (AB after discharge. to text and data n data n	 Information about significance of symptoms (including memory loss and speech difficulties). Information about how symptoms (including memory loss and speech difficulties) should be managed. Information about how long symptoms (including memory loss and speech difficulties) might last.
18 19 20 21 22 23 24	[30]	Worrall et al., 2011, Australia	To describe the goals of people with aphasia after stroke and to code the goals according to the International Classification of Functioning, Disability and Health (ICF).	Qualitative methods. Semi-structured interviews, content analysis, coding of subsample of goals according to ICF.	50 participants with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	Not specified. Not specified. Al training, 2	 Information about terms used to describe communication difficulties. Information about aphasia. Information about prognosis and what to expect at different stages after stroke. Information about aphasia services. Information about how to explain difficulties to friends or people in community. Information about aphasia therapy.
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A scoping review of research investigating patient and carer psychoeducation needs regarding post-stroke cognition.

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-084681.R2
Article Type:	Original research
Date Submitted by the Author:	07-Oct-2024
Complete List of Authors:	Hobden, Georgina; University of Oxford, Department of Experimental Psychology Tabone, Faye; University of Oxford, Nuffield Department of Clinical Neurosciences Demeyere, Nele; University of Oxford, Nuffield Department of Clinical Neurosciences
Primary Subject Heading :	Patient-centred medicine
Secondary Subject Heading:	Neurology
Keywords:	Stroke < NEUROLOGY, Rehabilitation medicine < INTERNAL MEDICINE, Patient-Centered Care, Psychosocial Intervention, Family





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1	A scoping review of research investigating patient and carer
2	psychoeducation needs regarding post-stroke cognition.
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26	ABSTRACT
27	Objectives
28	To search the literature systematically to map and identify gaps in research investigating patient
29	and family member psychoeducation needs regarding post-stroke cognition.
30	Design
31	Scoping review conducted in line with Joanna Briggs Institute (JBI) recommendations and
32	PRISMA-ScR checklist.
33	Methods
34	MEDLINE, PsycINFO, Embase, CINAHL and Scopus were searched on August 25th, 2023 for
35	peer-reviewed studies which were conducted in a high-income country, describing cognition-
36	related psychoeducation needs in stroke survivors and/or family members aged ≥ 18 years
37	(\geq 50% of the study population). Two reviewers independently screened titles, abstracts, then
38	full text articles. One reviewer extracted pre-defined data. Data were verified by a second
39	reviewer. Synthesis involved descriptive statistics and a pragmatic thematic analysis.
40	Results
41	Searches identified 8,115 articles, of which 30 were included. Articles were published between
42	1996-2023. Studies were conducted in Australia ($n=7$), USA ($n=6$), UK ($n=5$), Canada ($n=3$),
43	New Zealand ($n=3$), Ireland ($n=2$), Netherlands ($n=2$), South Korea ($n=1$) Sweden ($n=1$). Most

een =3), lost 44 studies (n=21) used an exclusively qualitative approach but 6 combined qualitative/quantitative 45 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. 46 Research was conducted with stroke survivors only (n=7), family members only (n=12) and 47 both stroke survivors/family members (n=11). Qualitative analysis suggested participants 48 49 wanted psychoeducation about cognitive impairment, including recovery expectations, treatment/therapy options, and signposting to services/resources available. Hopeful 50

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> 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 (e.g., 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 (e.g., memory, attention, executive function impairments) is required. TF 7 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 articles may not have been included.

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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 characteristics³. 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 dementia⁶. 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 outcomes¹¹. Specifically, whilst there is currently no method for reliably predicting long-term post-stroke cognitive outcomes on an individual level¹², a recent systematic review and meta-analysis identified baseline cognitive impairment as the strongest risk factor for longer term cognitive impairment after stroke¹¹. This highlights the importance of acute cognitive screening to flag and support patients at risk of poor long term outcomes¹³.

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 stroke¹⁴.

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Nevertheless, stroke survivors and their family members have reported substantial unmet psychoeducation needs regarding cognition²¹ and, although clinical guidelines highlight the importance of psychoeducation generally⁹, 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 wellbeing – 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. The ultimate goal of the research is to inform, alongside other primary research^{28,31}, the design of a complex intervention focused on monitoring and psychoeducation to support cognition after stroke. The specific questions addressed by this review are:

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3 4	127	1. What research methods and designs have been used in previous studies describing
5 6	128	stroke survivor and family member information needs regarding cognition?
7 8 9	129	
10 11	130	2. What timepoints after stroke have been investigated in previous studies?
12 13	131	
14 15 16	132	3. What are the characteristics of stroke survivors and family members included in
10 17 18	133	previous studies?
19 20	134	
21 22 23	135	4. What psychoeducation needs related to post-stroke cognition have been reported in
24 25	136	previous studies?
26 27	137	
28 29 30	138	5. What factors have been suggested to impact psychoeducation needs in previous
30 31 32	139	studies?
33 34	140	
35 36 27	141	6. What key gaps exist within the current evidence base?
37 38 30	142	
39 40 41	143	
42 43	144	METHODS
44 45 46	145	Review protocol
40 47 48	146	The review was conducted in accordance with the Johanna Briggs Institute (JBI) methodology
49 50	147	for scoping reviews ³² and the Preferred Reporting Items for Systematic Reviews and Meta-
51 52	148	Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist. The protocol for this
55 54 55	149	review underwent a rigorous peer-review process for publication ³³ and has been made openly
56 57	150	available (https://osf.io/fmz9t). Any divergences from the protocol are justified and provided
58 59 60	151	in Supplementary File 1.

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152 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. With regards to the present study, they emphasised the importance of including family member/carer perspectives where possible.

158

159 Search strategy

160 The search strategy was developed in consultation with an expert librarian at the University of 161 Oxford. The final approved search strategy (Supplementary File 2) was adapted to search additional electronic databases using the Polyglot tool provided by Systematic Review 162 163 Accelerator software (https://sr-accelerator.com/). Systematic searches were conducted in five electronic databases on August 25th, 2023: MEDLINE (PubMed), PsycINFO (Ovid), Embase 164 (Elsevier), CINAHL (Ebsco), and Scopus (Elsevier). Search strategies developed using the 165 166 Polyglot tool are presented in Supplementary File 3. Grey literature databases were not searched as the aim of the review is to inform an evidence-based intervention, so we sought 167 articles that had been through rigorous peer-review. The search strategy was limited to English, 168 but it was not limited by year. 169

170

171 Inclusion criteria

172 The inclusion criteria were based on the JBI Population/Concept/Context (PCC) framework³².

173 Articles were eligible for inclusion in this review if they met the following criteria:

4 174

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175 Participants

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3 4	176	• Stroke survivors and/or family members of stroke survivors. Stroke survivors were
5 6	177	defined as a person who has experienced a clinically diagnosed stroke of any type.
7 8	178	Family members were defined as a person who identifies as related to a stroke survivor
9 10 11	179	by blood, marriage, or with other familial involvement.
12 13	180	• Stroke survivors and/or family members of stroke survivors comprising at least 50% of
14 15 16	181	the study population, in line with cut-offs used in previous scoping reviews .
17 18	182	• Stroke survivors and family members aged 18 years and over.
19 20 21	183	
21 22 23	184	Concept
24 25	185	• Self-reported information needs regarding post-stroke cognition. Information needs
26 27	186	were defined as a desire to obtain information to satisfy a conscious (or unconscious)
28 29 30	187	need [34]. Cognition is defined as thinking skills related to any of the following
31 32	188	domains: memory, language, attention, executive function, praxis, number processing
33 34	189	[22].
35 36	190	
37 38 39	191	Context
40 41	192	• Studies conducted in the United Kingdom and other high-income countries, defined
42 43	193	using the most recent World Bank country classifications (2022).
44	194	• Participants based either in a clinical setting or the community.
43 46 47	195	
48 49	196	Types of sources
50 51 52	197	We included published peer-reviewed articles that used quantitative, qualitative, or mixed
52 53 54	198	methods designs. Review articles, peer-reviewed commentaries and opinion pieces were
55 56	199	excluded.
57 58	200	
59 60	201	Study selection process

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Identified records were collated and uploaded into EndNote v.X9 (Clarivate Analytics, PA, USA). SR-Accelerator Deduplicator³⁵ removed duplicates. GH and FT independently screened records against eligibility criteria by title, abstract, 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. GH used the final version of the tool (Supplementary File 4) to extract data from the included articles. 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 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 (i.e., text describing psychoeducation needs and factors impacting them) at a semantic Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

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level. The template was revised iteratively throughout the coding process to ensure themes were firmly rooted in the data (i.e., inductive analysis). The research team discussed and agreed 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 guidance³², themes resembled domain summaries, rather than broader interpretive units of meaning.

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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 one³⁸. Indeed, the research team recognised that the final themes would inevitably be shaped by their own expertise (i.e., clinical neuropsychology, clinical psychology), experiences (e.g., working on hyperacute stroke units and in community brain injury rehabilitation settings), and values (e.g., 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.

247 RESULTS

248 Selection of evidence sources

The database searches retrieved 8,112 records. This was reduced to 6,726 records afterdeduplication. 27 records were selected for inclusion after screening. A further 3 records were

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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. [Figure 1] The included articles were published between 1996 and 2023. Most studies (N = 20) were published between 2001-2020, with 14 published in the last ten years (2013-2023). Studies were conducted in Australia (N = 7), United States of America (N = 6), United Kingdom (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 Supplementary File 5. 1. What research methods have been used? Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews [2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted focus groups [1, 4, 14, 15, 26]. Participant sample sizes in qualitative studies varied substantially. Two articles presented a case study involving a single family member [10, 16]. The maximum sample size among the articles using exclusively qualitative methods was 50 participants with aphasia [25, 30]. Focus group sizes varied between two-four participants [15] and six-ten participants [26].

Articles that used qualitative data collection methods employed different analytic approaches and frameworks. Eight articles used a version of thematic analysis [1, 2, 8, 17, 18, 24, 27, 29], eight articles used a version of content analysis [4, 12, 14, 16, 23, 25, 26, 30], two used the constant comparative method [7, 19]. Other approaches were narrative analysis [10] and a modified referenced five-step process [3]. One article described an approach that resembled thematic analysis but did not label it as such [6]. Two articles did not describe how semi-structured interview data were analysed [9, 13]. 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 [1, 3, 4, 6, 7, 8, 10, 13, 14, 15, 16, 18, 19, 21, 22, 25, 26, 27, 29, 30].

Five of the included articles used surveys or questionnaires [11, 20, 21, 22, 28]. All of these articles used custom measures rather than validated standard questionnaires. Questionnaires were administered remotely in three studies [11, 20, 28] and face-to-face in the other two studies [21, 22]. Face-to-face administrations were audio-recorded and analysed qualitatively to complement quantitative questionnaire data [21, 22].

293 2. What timepoints after stroke have been investigated?

Ten articles explicitly stated their investigation pertained to the first six-months after stroke (acute/subacute stage) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29]. Specific timepoints investigated included stroke onset/first days after stroke [1, 3, 10, 21, 22], first week after stroke [21], twoweeks after stroke [9], first month after stroke [21], first three-months after stroke [8], and fourmonths after stroke [16].

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Three articles explicitly stated their investigation pertained to the period at least six-months after stroke (chronic stage) [9, 16, 21]. Specific timepoints investigated were six-months [9, 21], seven-months [16], eleven-months [16], twelve-months [21], more than twelve-months [21], and two-years after stroke [9].

Eight articles investigated information needs at multiple timepoints after stroke [1 0, 16, 21, 22, 24, 29]. However, eighteen articles did not specify the timepoint under invest on [2, 5, 6, 7, 11, 12, 13, 14, 15, 17, 18, 19, 20, 23, 25, 27, 28, 30] and some articles use biguous terminology. Temporally ambiguous terms used to describe the timepoint under stigation included initial rehabilitation [1], rehabilitation [3], up to one-month after dis ge [29], starting to recover [22], preparing to leave hospital [22], just returned home [2 ettled at home [22], and chronic phase (defined as stroke survivor's return home) [1, 3].

3. What are the characteristics of participants?

Seven studies recruited stroke survivors only [4, 8, 14, 17, 21, 25, 30] and el articles included both stroke survivors and family members [5, 9, 11, 13, 18, 20, 23, 26 28, 29]. Four studies did not report the mean age of stroke survivor participants [4, 11, 18 and ten studies did not report the mean time since stroke [4, 5, 8, 9, 11, 13, 18, 21, 26, 2] he mean age of stroke survivors was less than 70 years in the twelve studies that reported variable [8, 13, 14, 17, 20, 21, 23, 25, 26, 27, 28, 30]. The mean time since stroke for str survivor participants was between eleven months [14] and seven years [17] but these st did not describe how stroke date was established (e.g., self-report, medical records).

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With regards to the cognitive status of stroke survivors, 18 articles focused on stroke survivors
with or family members of stroke survivors with aphasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 10]

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21, 22, 23, 24, 25, 27, 30]. Other cognitive impairment (including dementia) was listed as part of the inclusion/exclusion criteria in eight studies [2, 8, 17, 19, 21, 22, 25, 30], whilst the other ten articles did not report whether stroke survivors had cognitive impairments affecting domains other than language [1, 6, 7, 10, 12, 15, 16, 23, 24, 27].

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 [4]. One article assessed cognitive functioning in non-language domains using Raven's Coloured Progressive Matrices (RCPM: Raven, Court, & Raven, 1995) [14]. Only one article reported in detail the cognitive status of stroke survivors in domains other than language [3]. 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) [3].

Twelve studies recruited family members but not stroke survivors [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Two of these articles were case studies involving only one family member [10, 16]. Most family members were described as spouses/partners/significant others (n = 134across these twelve articles) [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Some articles also included offspring caring for the stroke survivor (n = 37) [1, 2, 7, 12, 16, 19, 24], parents (n = 6) [1, 2, 3, 12], and siblings (n = 6) [3, 12]. Other family members were relatives-in-law (n = 4) [7, 12], aunts/uncles (n = 3) [7], and grandchildren (n = 2) [7]. Two studies included one friend alongside other family member participants [2,19] and one study included three friends [7]. One study included ex-family members (n = 3) as well as current family members (n = 45)[12].
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We note that different terminology was used to describe stroke survivors in the articles, including stroke survivors [5, 9, 11, 14, 18, 21, 26, 28], patients [8,13, 29], individuals/people/participants with aphasia due to stroke [17, 15, 23, 25, 27, 30], and individuals with communication-debilitating illness or injury due to stroke [7]. The following terms were used to refer to family member participants: family members [1, 12, 13, 15, 16, 20, 22, 23, 28], significant others [2, 7, 10], carers [3, 6, 29], caregivers [9, 11, 26], informal carers [18], relatives [27], communication partners [19], and care partners [24].

357 4. What psychoeducation needs have been reported?

Participants across the included studies reported psychoeducation needs regarding cognitive
difficulties after stroke [1, 2, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24,
25, 27, 28, 29, 30]. Psychoeducation needs mentioned within the articles were most often
described in the context of aphasia [1, 2, 6, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17, 19, 21, 22, 23,
24, 25, 27, 28, 29, 30] but participants also described a need for psychoeducation about memory
problems [9, 18, 29], concentration problems [9, 28], and general cognitive changes [13, 20].

When describing psychoeducation needs related to aphasia, participants reported a desire for general information, including definitions and information about symptoms [1, 5, 6, 7, 9, 10, 12, 14, 15, 16, 17, 21, 22, 23, 24, 25, 27, 28, 29, 30], and participants in two studies wanted information about psychological comorbidities [1,2]. With regards to recovering from aphasia, participants wanted information about what to expect in the future [1, 2, 5, 6, 7, 10, 12, 22, 24, 27, 29, 30], treatments for aphasia and their efficacy [1, 2, 12, 16, 30], as well as ways to maximise recovery [2]. The following information about living with aphasia was also sought: compensatory strategies [8, 22, 23, 29], maximising communicative effectiveness [1,11,22], available support and services [1, 6, 12, 15, 16, 17, 22, 23, 30], psychosocial support and

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counselling [1], support for family members [2,17], support groups [1, 22], employment [1,

19], financial aid [1, 6], and information to help maintain hope and optimism [1, 12, 16, 19].

Though far fewer studies considered non-language cognitive impairments, participants in these studies similarly described a need for general information about symptoms and definitions [3, 4, 5, 9, 13, 20, 28, 29]. Some participants also wanted information about recovering, including what to expect in the future [3, 5, 29], treatments and rehabilitation available [3, 13, 18], and information to track recovery progress [3, 4]. Finally, in terms of living with cognitive impairments, some participants wanted information about compensatory strategies [3, 29], support for family members [3], and information to help maintain hope and optimism [3]. Themes and subthemes are summarised in Table 1.

[Table 1]

388 5. What factors impact psychoeducation needs?

Cognition-related psychoeducation needs were reported in articles investigating both the acute/sub-acute stage (i.e., less than six-months since stroke) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29] and chronic stage after stroke (i.e., more than or equal to six-months after stroke) [9, 16, 21], 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 [9, 21]. Hanger et al. [9] reported that only 4 out of 60 (7%) participants asked questions about poor memory/concentration in the first two-weeks after stroke, whereas 25 out of 111 (32%) asked these questions two-years after stroke. Page 19 of 47

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Similarly, whereas 3 out of 60 (5%) participants asked questions about communication difficulties in the first two-weeks after stroke, 7 out of 72 (10%) participants asked these questions two-years after stroke [9]. Rose et al. [21] 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 twelvemonths after stroke. Results from Rose et al. (2010) 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 six-months after stroke.

Only one article provided insight into how the content of cognition-related information needs evolves over time [22]. 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 to 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 versus 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 [2]. Cheng et al. [2] reported 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 Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

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423 information and they felt that the delivery of prognostic information should be dictated by the424 preference of the stroke survivor.

426 6. 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 [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. Psychoeducation needs related to other cognitive domains (e.g., memory, attention, executive function) were rarely mentioned. Figure 2 shows the number of times cognitive terms included 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.

[Figure 2]

Relatively few studies considered psychoeducation needs at multiple timepoints after stroke
[1, 3, 9, 16, 21, 22, 24, 29] and only two of these articles [9, 21] investigated how the prevalence
and content of cognitive-related information needs evolve over time.

DISCUSSION

We 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. Page 21 of 47

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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. Furthermore, very few articles addressed non-language cognitive domains commonly affected by stroke (e.g., 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 [39–44], prognosis [45–52], treatment [45,48,49,52–56], and available services [48,49,52–54,56–60]. Whilst these needs were apparent throughout the post-stroke period, two articles found cognition-related psychoeducation needs became more prevalent over time^{39,61}, 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 period⁶². Clinical reviews are recommended by United Kingdom clinical guidelines at six-months, twelve-months and then annually and these reviews are crucial to ensure cognition-related psychoeducation needs are identified and addressed⁹. However, data from the Stroke Sentinel National Audit Programme (SSNAP) suggest completion of these reviews is currently inadequate, with six-months reviews received by only 36.9% of stroke survivors in 2022/2023, a reduction from 2021/2022 when reviews were received by 40.7%.⁶³ 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 (e.g., memory, attention, executive function, number processing,
praxis) and only one study reporting the prevalence of non-language cognitive impairments in

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their stroke survivor sample.⁵⁴ Understanding psychoeducation needs related to other domains
is crucial as non-language impairments may be even more prevalent than language impairments
²⁴ and domain-specific impairments vary substantially in their underlying aetiologies and likely
trajectories^{5,19,26,67}. Future research should also aim to include stroke survivor samples with
cognitive profiles that better reflect the clinical reality (i.e., 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, we acknowledge 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 reliable patient-centred picture.

493 Overall, as stroke mortality rates continue to decline and the number of stroke survivors
494 experiencing cognitive impairment correspondingly rises⁶⁸, it is critical to consider how to
495 prepare stroke survivors and their family members to cope with cognitive changes and to
496 integrate this insight into a cognitive care pathway for stroke¹³ and self-management
497 approaches that often involve psychoeducation as a key component. This scoping review

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498 demonstrates that stroke survivors and their family members are generally keen to receive 499 psychoeducation about cognition throughout the post-stroke care continuum, but further 500 research is required to strengthen our understanding of these psychoeducation needs and how 501 best to meet them in clinical practice.

- ² 502
 - 503 FUNDING STATEMENT

504 Georgina Hobden is supported by an Economic and Social Research Council (ESRC) grant 505 (ES/P000649/1). Nele Demeyere (Advanced Fellowship NIHR302224) is funded by the 506 National Institute for Health Research (NIHR). The views expressed in this publication are 507 those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of 508 Health and Social Care."

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510 CONTRIBUTORSHIP

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.

522 COMPETING INTERESTS

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2 3	523	There are no competing interests for any author.
4 5 6	524	
7 8	525	ETHICS APPROVAL STATEMENT
9 10 11	526	This study involves review of existing literature so did not require ethical approval.
12 13	527	
14 15	528	DATA SHARING STATEMENT
16 17 18	529	All data relevant to the study are included in the article or uploaded as supplementary
19 20	530	information.
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FIGURES AND TABLES

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

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 (e.g., cogniti*) were searched in full text articles using their stem but they are represented in the figure as full words (e.g., cognition) for interpretability.

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Table 1. Surticles incranslation	ummary of theme cluded in the scop al value.	e structure developed t ing review. Note that	o capture cognition-related psychoed themes were developed to resemble d	ucation needs and on omain summaries and on summaries and summaries and summaries and s	fluencing factors mentioned in order to enhance their actionable
Domain		Theme	Subtheme	Articles 5	3 0
Aphasia	psychoeducation	General information	Symptoms and definitions	[1, 5, 6, 7, 9, 10, 12, 44]	1 1 1 1 1 1 1 1 1 1
topics		Descussing from	Psychological comorbidities		
		arbasia	Treatment and its office as		
		apilasia	Maximiaing recovery	[1, 2, 12, 10, 50] Ģ ►	://bn
		Living with onbasis	Componentary strategies	[²] trai	лјор
		Living with aphasia	Maximicing communicative effectiveness	[0, 22, 23, 27] n [1 11 22] g	en
			Available support and services	[1,6,12,15,16,17 P 2	<u>3</u> .
			Psychosocial support and counselling		ž
			Family member support		on (
			Support groups	[1, 22] tech	- Une
			Employment, return to work, and job	[1, 19]	14,
			retraining	gies	2025
			Financial aid	[1, 6]	at b
			Information to maintain hope	[1, 12, 16, 19]	genc
		General information	Symptoms and definitions	[3, 4, 5, 9, 13, 20, 28, 2	e Bibliograph
		For peer rev	iew only - http://bmjopen.bmj.com/site/ab	out/guidelines.xhtml	ique de 3

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1 2 3 4 5 6	Domain-general psychoeducation topics	Recovering from cognitive impairment	What to expect in the future Treatments and rehabilitation available Information to track recovery progress	[3, 5, 29] [3, 13, 18] [3, 4]	4-084681 on 15 J ht, including for	
7 8		Living with cognitive	Compensatory strategies	[3, 29]	lanu: En	
9		impairment	Support for family members	[3]	ary 2 seig srelg	
10 11			Information to maintain hope	[3]	1025. ated	
12 13 14 15	Influencing factors	Time since stroke	Psychoeducation needs become more prevalent over time	[9, 21]	Downloade ent Superiei to text and	
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43 44 45 46		For peer rev	view only - http://bmjopen.bmj.com/site/ab	oout/guidelines.xhtr	ml e	32

Frequency with which cognition words used in the ^{34 of 47} systematic search strategy were mentioned in articles





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Supplementary Materials

Supplementary File 1. Divergences from peer-reviewed protocol.

The scoping review protocol stated "Data will be analyzed using a grounded theory approach based on the principles of textual narrative synthesis, in line with the procedure outlined by Lucas et al." (Hobden & Demeyere, 2023, p.3). However, after further consideration of JBI guidelines supporting the use of qualitative analysis only when it is descriptive in nature, we opted to employ a pragmatic approach to thematic analysis, broadly resembling qualitative content analysis procedures but diverging in epistemological and ontological assumptions (Braun & Clarke, 2021). In line with qualitative content analysis, a structured coding framework was used to develop and document the analysis but (post)positivist and atheoretical assumptions often espoused by proponents of content analysis were not endorsed, so we consider our method more closely aligned to the codebook approach outlined by (Braun & Clarke, 2021) than more traditional content analysis methods (Forman & Damschroder, 2007). Nevertheless, in line with guidance from (Peters et al., 2020), the goal of the qualitative analysis was purely descriptive in nature.

Supplementary File 2. Example search conducted on MEDLINE (PubMed) on 7th July, 2023. Note that this search strategy was developed in consultation with an expert university librarian and was peer-reviewed.

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

Supplementary File 3. Search strategies used to search the following electronic databases on 25th August, 2023: PsycINFO, Embase, CINAHL and Scopus. Note that these search strategies were developed from the above peer-reviewed search strategy using the Polyglot tool provided by Systematic Review Accelerator software (<u>https://sr-accelerator.com/</u>).

PsycInfo (Ovid)

Search	Query
#1	exp Stroke/ OR stroke*.ti,ab. OR "cerebral infarct*".ti,ab. OR "cerebrovascular infarct*".ti,ab. OR "cerebrovascular accident*".ti,ab.

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#2	exp Patients/ OR exp Caregivers/ OR patient*.ti,ab. OR survivor*.ti,ab. OR victim*.ti,ab. OR caregiver*.ti,ab. OR famil*.ti,ab.
#3	exp Education/ OR "information need*".ti,ab. OR "education need*".ti,ab. OR "knowledge need*".ti,ab. OR psychoeducation*.ti,ab.
#4	exp Cognition/ OR exp Memory/ OR exp "Executive Function"/ OR cogniti*.ti,ab. OR thinking.ti,ab. OR memory.ti,ab. OR attention.ti,ab. OR "executive function*".ti,ab. OR
	aphasia*.ti,ab. OR dementia*.ti,ab. OR language.ti,ab. OR neglect.ti,ab. OR neuropsych*.ti,ab.
#5	aphasia*.ti,ab. OR dementia*.ti,ab. OR language.ti,ab. OR neglect.ti,ab. OR neuropsych*.ti,ab. #1 AND #2 AND #3 AND #4

Embase

Embase	0
Search	Query
#1	Stroke/exp OR stroke*:ti,ab OR 'cerebral infarct*':ti,ab OR 'cerebrovascular infarct*':ti,ab OR 'cerebrovascular accident*':ti,ab
#2	Patients/exp OR Caregivers/exp OR patient*:ti,ab OR survivor*:ti,ab OR victim*:ti,ab OR caregiver*:ti,ab OR famil*:ti,ab
#3	Education/exp OR 'information need*':ti,ab OR 'education need*':ti,ab OR 'knowledge need*':ti,ab OR psychoeducation*:ti,ab
#4	Cognition/exp OR Memory/exp OR 'Executive Function'/exp OR cogniti*:ti,ab OR thinking:ti,ab OR memory:ti,ab OR attention:ti,ab OR 'executive function*':ti,ab OR aphasia*:ti,ab OR dementia*:ti,ab OR language:ti,ab OR neglect:ti,ab OR neuropsych*:ti,ab
#5	#1 AND #2 AND #3 AND #4

CINAHL

Search	Query
#1	(MH Stroke+) OR (TI stroke* OR AB stroke*) OR (TI "cerebral infarct*" OR AB "cerebral infarct*") OR (TI "cerebrovascular infarct*" OR AB "cerebrovascular infarct*") OR (TI "cerebrovascular accident*" OR AB "cerebrovascular accident*")

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Seenus	
#5	#1 AND #2 AND #3 AND #4
#4	(MH Cognition+) OR (MH Memory+) OR (MH "Executive Function+") OR (TI cogniti* OR AB cogniti*) OR (TI thinking OR AB thinking) OR (TI memory OR AB memory) OR (TI attention OR AB attention) OR (TI "executive function*" OR AB "executive function*") OR (TI aphasia* OR AB aphasia*) OR (TI dementia* OR AB dementia*) OR (TI language OR AB language) OR (TI neglect OR AB neglect) OR (TI neuropsych* OR AB neuropsych*)
#3	(MH Education+) OR (TI "information need*" OR AB "information need*") OR (TI "education need*" OR AB "education need*") OR (TI "knowledge need*" OR AB "knowledge need*") OR (TI psychoeducation* OR AB psychoeducation*)
#2	(MH Patients+) OR (MH Caregivers+) OR (TI patient* OR AB patient*) OR (TI survivor* OR AB survivor*) OR (TI victim* OR AB victim*) OR (TI carer* OR AB carer*) OR (TI caregiver*) OR (TI famil* OR AB famil*)

Scopus

Search	Query
#1	INDEXTERMS(Stroke) OR TITLE-ABS(stroke*) OR TITLE-ABS("cerebral infarct*") OR TITLE-ABS("cerebrovascular infarct*") OR TITLE-ABS("cerebrovascular accident*")
#2	INDEXTERMS(Patients) OR INDEXTERMS(Caregivers) OR TITLE- ABS(patient*) OR TITLE-ABS(survivor*) OR TITLE-ABS(victim*) OR TITLE- ABS(carer*) OR TITLE-ABS(caregiver*) OR TITLE-ABS(famil*)
#3	INDEXTERMS(Education) OR TITLE-ABS("information need*") OR TITLE-ABS("education need*") OR TITLE-ABS("knowledge need*") OR TITLE-ABS(psychoeducation*)
#4	INDEXTERMS(Cognition) OR INDEXTERMS(Memory) OR INDEXTERMS("Executive Function") OR TITLE-ABS(cogniti*) OR TITLE-ABS(thinking) OR TITLE-ABS(memory) OR TITLE-ABS(attention) OR TITLE-ABS("executive function*") OR TITLE-ABS(aphasia*) OR TITLE-ABS(dementia*) OR TITLE-ABS(language) OR TITLE-ABS(neglect) OR TITLE- ABS(neuropsych*)
#5	#1 AND #2 AND #3 AND #4

Supplementary File 4.	Final tool used to extract data from included articles.

5 6 7 8 9 10	Author, Year, Country	Title	Research design (e.g., cross- sectional, longitudinal)	Research methods (e.g., survey, semi- structured interviews)	Timepoint(s) since stroke investigated	Population(s) investigated	Participant demographics	Relevant findings
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9 10 11 12 13 14	align sufficio order listed v	ently with the tabl within the articles.	e headings, leading	to variation in t	erminology used across the	e table. Psychology to to t	glucation needs are presented in the
15 Reference 15 number 16	e Authors, Year, Country	Study aims	Study methodology	Participant sample	Participant demographics	Timepoint(s)	Cognition-related psychoeducation need(s) identified
17 [1] 18 [1] 19 20 21 22 23 24 25 26 27 28 29 30 31 32	Avent et al., 2005, USA	To identify information needed by family members at different phases after onset of aphasia.	Qualitative methods. Focus groups, analysis using five-stage framework approach.	16 family members.	Age: Not reported. Gender: 15 female, 1 male. Relationship: 12 spouses, 2 children, 1 parent, 1 long-term partner. Average time since stroke: 5.5 years (range: 1.10-13).	Onset of aphasianing (hospitalisation) Initial rehabilitation Chronic phases of aphasia.	 General information. Specific time-based aphasia information. Information about psychosocial support and counselling. Hopeful information. Information about coexisting behavioural and medical conditions, including depression, impaired judgement, fatigue, personality changes. Information about aspects of treatment. Information about to access available resources. Information about long-range planning (e.g., life expectancy and health maintenance). Information about travel. Information about travel. Information about independent living arrangements. Information about support groups. Information about support groups. Information about support groups. Information about job retraining. Information on recovery trajectory
33 [2] 34	Cheng et al., 2022, Australia	To explore the perspectives of significant others of people with aphasia on receiving information about prognosis.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	7 significant others.	Age: 64.71 years (range: 35-76). Gender: 5 female, 2 male. Relationship: 3 partners, 2 parents, 1 child, 1 friend. Time since stroke: 7.29 months (range: 3-12).	3-12 months post- stroke.	 Information on expected outcomes (impairment-level improvement and process of recovery). Information to help family member recover. Information on how to maximise the outcome of recovery (optimal practice stimuli and techniques). Information on treatment efficacy. Information about practical aspects of recovery (arranging suitable accommodation, planning supports for daily activities). Information about aphasia Information about cognitive comorbidities.
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[3]	Davidson & Wallace, 2022, USA	To explore information needs of carers of right hemisphere stroke survivors at different phases after stroke.	Qualitative methods. Semi-structured interviews, analysis using phenomenological approach using a modified five-step process.	4 carers.	Age: 65.5 years (range: 59-70). Gender: 3 female, 1 male. Relationship: 2 spouses, 1 brother, 1 parent. Time since stroke: 6.11 years (range: 3- 10.5).	Onset. Rehabilitation. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic. Chronic.	 Information about the rehabilitation timeline. Information about symptoms. Information about the roles of medical professionals. Information about treatment rationales. Information about treatment progress. Information about techniques and compensatory strategies. Information on support for carers and patients (e.g., support groups) Information on home practice activities. Information on supplementary treatments (e.g., vision, music, water therapies). Hopeful information.
[4]	Davoody et al., 2016, Sweden	To explore stroke survivors' information needs after discharge in order inform the development of an eHealth service.	Qualitative methods. Focus groups, content analysis.	12 stroke survivors.	Age: Mean not reported (range: 30-85 years). Sex: 7 female, 5 male. Time since stroke: Not reported.	After discharge. to text and da and da	 Simple description of invisible difficulties (e.g., chronic fatigue, cognitive impairments, and personality changes) to share with family and friends. Information to track recovery (motor and cognitive) progress.
[5]	De Simoni et al., 2016, UK	To describe the characteristics of participants of an online stroke forum, <i>their</i> <i>reasons for posting in the</i> <i>forum</i> , and whether the responses addressed these needs.	Qualitative and quantitative methods. Descriptive statistical analysis of forum user population, thematic analysis of posts from representative subsample of forum users.	2,348 forum users overall. 59 representative users selected for subsample thematic analysis, representing 26 stroke survivors and 33 stroke survivors mentioned by third party.	Subsample age: Not reported. Subsample gender: 27 female, 30 male, 2 NA. Subsample time since stroke: Not reported.	Not specified. (ABES) . It a mining, AI trainin	 Information about stroke physical symptoms (communication impairments, cognition). Information on potential for recovery (timeline, age influence, recovery of functioning, reading, memory, communication). Information on invisible stroke impairments
[6]	Denman, 1998, UK	To identify needs of spouses caring for someone with communication difficulties due to stroke and to identify solutions they felt would alleviate the difficulties described.	Qualitative methods. Semi-structured interviews, identification of common themes.	9 carers.	Age: Not reported. Gender: 6 female, 3 male. Relationship: 9 spouses. Time since stroke: At least 12 months (mean and range not reported).	Not specified. g, and similar tech	 Information about symptoms and their recovery (e.g., aphasia). Information about financial entitlements. Information about services available locally.
[7]	Donovan-Kicken & Bute, 2008, USA	To investigate sources of uncertainty for significant others of patients with communication- debilitating illness (CDI) or injury and how uncertainty is managed.	Qualitative methods. Semi-structured interviews, analysis using constant comparative technique.	31 significant others of individuals with CDIs, including 18 significant others of individuals with CDI due to stroke. Other CDIs were brain injury ($n = 3$), brain tumour ($n = 3$), autism ($n = 2$), Alzheimer's disease ($n = 2$), AlDS (n = 1), dementia ($n = 1$), throat cancer ($n = 1$).	Age: 42.6 years (range: 25-75). Gender: 23 female, 8 male. Relationship: 18 children, 2 spouses, 3 close friends, 2 grandchildren, 3 aunts/uncles, 1 child-in-law. Time since CDI: 4.2 years (range: 6 months-12 hears). <i>Note</i> . Demographic details for stroke subsample not available.	Not specified. Not specified. Not specified.	 Information about diagnosis. Information about the extent of damage caused by illness or injury. Information about cause of CDI. Information about long-term prognosis (possibility for and extent o physical and mental recovery). Information about quality of life.
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[8] Grohn et al., 2012, Australia	To describe the experience of the first 3 months after stroke in order to identify factors which facilitate successfully living with	Qualitative methods. Semi-structured interviews, thematic analysis.	15 stroke survivors.	Age: 66.3 years (range: 47-90). Gender: 7 female, 8 male. Time since stroke: Not reported.	it, in 484681 on 15 Ja First 3-months after stroke. Ing for 1	 Information from other people with aphasia about how they n adjustments. Information on completing activities of daily living (write shop list, cheques, use a computer)
[9] Hanger et al., 1998, New Zealand	aphasia after stroke. To identify what type of questions are asked by stroke survivors and their caregivers and how the nature of questions asked changes with increasing time after stroke.	Qualitative and quantitative methods. Longitudinal, semi-structured interviews conducted at three timepoints (two-weeks, six- months, two-years after stroke), descriptive and inferential statistical analyses.	Subsample 1 (two- weeks after stroke): 60 participants. Subsample 2 (six- months after stroke): 111 participants. Subsample 3 (two- years after stroke): 72 participants. Note. Number of stroke survivors versus caregivers not reported.	Subsample 1. Age: 71.5 years (range: 42-99). Gender: 26 female, 34 male. Time since stroke: Not reported. Subsample 2. Age: 72.3 years (range: 23-100). Gender: 48 female, 63 male. Time since stroke: Not reported. Subsample 3. Age: 71.8 years (range: 24-101). Gender: 35 female, 37 male. Time since stroke: Not reported. <i>Note.</i> Demographic details for stroke survivors versus caregivers not reported.	Inuary 2025. Downloaded from http://bm Enseignement Superieur (ABES) . Six-months afted to text and data mining, AI Two-years after to text and data mining, AI	 Information about communication difficulties. Information about memory problems. Information about poor memory/concentration.
[10] Hersh & Armstrong, 2021, Australia	To explore how the wife of a man with aphasia managed his discharge from hospital in the acute stage after stroke.	Qualitative methods. Single case study, narrative analysis of semi-structured interview collected as part of a large multisite study, systemic functional linguistics analysis of two complaint letters.	1 significant other.	Age: 63 years. Gender: Female. Relationship: Spouse. Time since stroke: 4 years.	Stroke onset and following days. ining, and simil	 Information about aphasia, including definition of term. Information about what might happen in the future.
[11] Hinojosa et al., 2012, USA	To identify information needs of stroke caregivers with regard to managing recovery process at home; to explore whether and how information needs vary by race, ethnicity and place; to explore how the information needs are associated with caregiver characteristics (depression, coping, social support etc.).	Quantitative methods. Survey, descriptive and inferential statistical analyses.	276 stroke survivor- caregiver dyads.	Caregivers: Age: 59.36 years (range not reported). Gender: Not reported. Relationship: Not reported. <i>Note.</i> Stroke survivor demographics not reported.	n June 14, 2025 at Agence E ar technologies.	 Information about knowing how to help others communicate patient due to speech.
[12] Howe et al., 2012, New Zealand	To identify rehabilitation goals of family members	Qualitative methods.	48 family members.	Age: 60.92 years (range: 24-83). Gender: 36 female, 12 male.	Not specified.	 Information about aphasia. Information about future recovery prospects. Information about available services.

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		of stroke survivors with aphasia.	Semi-structured interviews, content analysis.		Relationship: 28 spouses or de facto partners, 7 children, 5 siblings, 2 parents, 6 other relatives (e.g., sister-in- law). Time since stroke: Not reported.	cluding for	 Information about therapy. Information about progress. Information that is hopeful and positive.
13]	Oh et al., 2017, South Korea	To develop a home- based, online cognitive rehabilitation program that can be easily and repeatedly implemented and integrates cognitive training into daily activities.	Mixed methods. Three stage process involving analysis, design, and development. Analysis stage involved literature reviews and two- phase participant needs assessment (Phase 1: cognitive assessment; Phase 2: semi- structured interviews). Design stage involved feedback on intervention design from expert panel. Development stage involved validity testing with questionnaire measures.	Analysis Stage Phase 1 (cognitive assessment): 60 stroke patients. Analysis Stage Phase 2 (semi-structured interviews): 5 stroke patients. 5 family members. Design Stage: Number of panel members not reported. Development Stage: 4 patients. 6 family members. 10 healthcare professionals.	Analysis Stage Phase 1: Gender: 12 female, 48 male. Age: 61.4 years (range not reported). Time since stroke: Not reported. Analysis Stage Phase 2: Gender: Not reported. Age: 69 years (range not reported). Relationship: Not reported. N.B. Subsample demographics for patients versus family members not reported. Design Stage: No demographic details reported. Development Stage: No demographic details reported.	Not specified. Not specified.	 Information on cognitive impairment. Information on rehabilitation.
14]	Kerr et al., 2010, UK	To determine what information stroke survivors would like to see on a website about living with stroke; to determine how to structure the information; to identify differences between stroke survivors with and without aphasia.	Qualitative and quantitative methods. Focus groups, modified card sorting task, content analysis of focus groups, descriptive statistical analysis of modified card sorting task.	12 stroke survivors.	Age: 67.8 years (range: 45-86). Gender: 7 female, 5 male. Time since stroke: 11 months (range: 6- 15).	Not specified.	 Information about aphasia/communication problems.
15]	Le Dorze & Signori, 2010, Canada	To explore needs of family members of people with aphasia and barriers/facilitators to meeting these needs.	Qualitative methods. Focus groups, custom analytic approach.	11 family members, including 10 family members of individuals with aphasia due to stroke and 1 family member of an individual with aphasia due to brain tumour resection.	Age: 60.5 years (range: 51-68). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since aphasia onset: 6.66 years (range: 3-15).	Not specified. hnologies,	 Information about aphasia. Information about available resources.
16]	Le Dorze et al., 2009, Canada	To describe a daughter's adaptation process to her father's stroke and aphasia.	Qualitative methods. Longitudinal, single case study, semi-structured interviews	1 family member.	Age: 31 years. Gender: Female. Relationship: Daughter. Time since stroke: 4-11 months.	Four-months after stroke. Seven-months after of the stroke.	 Information about aphasia. Information about services and resources available. Information about therapy.
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			(four-months, seven-months, and eleven-months after stroke), content analysis.			Jht, in 4-084 , in 4-084 Here 4-087 Eleven-months 4067 Stroke din on	 Information about other people who have suffered from aphas maintain hope and optimism.
[17]	Manning et al., 2022, Ireland	To explore the perspectives of working- aged adults with post- stroke aphasia toward what has or would help them in living well with aphasia.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	14 individuals with aphasia as a result of stroke.	Age: 51 years (range: 33-62). Gender: 6 female, 8 male. Time since stroke: 7 years (range: 14 months-14 years).	g for uses relate Not specified.	 Information about aphasia. Information about services available. Information relevant to younger people with aphasia. Information to help relatives understand aphasia.
[18]	Merriman et al., 2019, Ireland	To examine the perspectives and preferences of stroke survivors, carers, and healthcare professionals to inform the design of a cognitive rehabilitation intervention.	Qualitative methods. Semi-structured interviews, thematic analysis.	14 stroke survivors. 11 informal carers. 19 healthcare professionals.	Stroke survivors: Age: Mean not reported (range: 35-40 to 80-85). Gender: 8 female, 6 male. Time since stroke: Mean not reported (range: <1 year–17 years). Informal carers: Age: Mean not reported (range: 40-45 to 80-85). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since stroke: Mean not reported (range: <1 year–17 years). Note. Age was reported categorically.	b. Downloaded from http://bmjopen d to text and data mining, Al trainir Not specified.	 Information about consequences of stroke. Information about rehabilitation. Information on purpose of activities instructed to undertake. Information about impact of stroke on memory.
[19]	Paul & Sanders, 2010, USA	To explore education experiences and needs of communication partners of individuals with aphasia.	Qualitative methods. Semi-structured interviews, constant comparative analysis.	9 communication partners.	Age: 58 years (range: 37-78). Gender: 7 female, 2 male. Relationship: 5 spouses/significant others, 3 children, 1 friend. Time since stroke: 11 months (0.5-24).	Not specified. and simil	 Information that fosters hope for improvement. Information on how to support transition to independence. Information that is tailored to needs of dyad. Information about employment, disability, and return to work. Information about communicating with the person with aphasi
[20]	Rochette et al., 2008, Canada	To identify information on the internet regarding rehabilitation intended for those who have experiences a stroke and their families and to assess the usability of a newly created website on stroke rehabilitation for laypersons.	Quantitative methods. Questionnaire.	4 stroke survivors. 3 family members.	Stroke survivors: Age: 53.5 years (range: 47-68). Gender: Not reported. Time since stroke: 11 years (range: 4-19 years). Family members: Age: 49 years (range: 42-62). Gender: Not reported. Relationship: 1 spouse, 2 children. Time since stroke: 113.67 months (range: 2 months–28 years).	ar technologies.	Information about cognitive changes.
[21]	Rose et al., 2010, Australia	To determine whether stroke survivors with aphasia consider it important to receive	Qualitative and quantitative methods.	40 stroke survivors.	Age: 65.9 years (range: 32-84). Gender: 16 female, 24 male. Time since stroke: Not reported.	Admission. Day after stroke. Within first week after stroke.	Information about aphasia.
		aphasia consider it important to receive	For peer revie	ew only - http://bn	Time since stroke: Not reported. njopen.bmj.com/site/about/gui	Within first week after og stroke.	

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		written stroke and aphasia information; to examine preferences for timing and modality of this information provision.	Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.			right, in 15 Januar Within first mortual after stroke. Six-months after stroke. Twelve-months offer stroke. More than twelve	
[22]	Rose et al., 2019, Australia	To explore family members' experiences and preferences for receiving aphasia information.	Qualitative and quantitative methods. Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.	65 family members.	Age: Not reported. Gender: 48 female, 17 male. Relationship: 53 spouses/partners, 12 NA. Time since stroke: 3.7 years (range: 1- 16).	store from http://bmj store from http://bmj home. Superieur (ABES) . Al tr	 Information about what aphasia is. Information about causes of aphasia. Information about purpose of communication assessment. Information about communication progress to expect. Information about coping strategies and living successfully with aphasia. Information about aphasia therapy. Personal experience stories from people with aphasia. Information about support groups for people with aphasia. Information about support groups for people with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about support groups for people living with aphasia. Information about aphasia associations. Information about aphasia research (ways to be informed about or involved in research).
[23]	Rotherham et al., 2015, New Zealand	To explore the benefits for adults with aphasia of all the groups they had chosen to participate in post-stroke.	Qualitative methods. Semi-structured interview, content analysis.	10 people with aphasia. 6 family members.	People with aphasia: Age: 69 years (range: 51-83). Gender: 2 female, 8 male. Time since stroke: 55.1 months (range: 7 months–8 years). Family members: Age: 63 years (range: 51-78). Gender: 6 female, 0 male. Relationship: 6 spouses/partners. Time since stroke: Not reported.	Not specified. Not specified.	 Information about aphasia. Information about shared experiences of others with aphasia. Information about strategies. Information about resources.
[24]	Shafer et al., 2022, USA	To explore how care partners of stroke survivors with aphasia accessed information and adapted to the caregiver role at different stages of recovery during COVID-19 pandemic.	Qualitative methods. Longitudinal, semi-structured interviews at up to five stages post-stroke (event, stabilisation, one-two weeks after stroke, one-month after stroke, six-months after stroke), thematic analysis using codebook approach.	Stage 1/2 (event/stabilisation: 13 care partners. Stage 3 (one-two weeks after stroke): 11 care partners. Stage 4 (one-month after stroke): 9 care partners.	Age: 64.18 years (range: 49-75). Gender: 9 female, 4 male. Relationship: 7 spouses, 5 children, 1 relative. Time since stroke: Not reported. <i>Note.</i> Demographic details for subsamples at each interview stage are not provided.	Stroke onset through 1, 2015 six-months aftererok 2025 at Agence Bibliogra	 Information about aphasia. Information about recovery prospects. Information about how to help during rehabilitation.
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			Stage 5 (six-months after stroke): 7 care partners.		4-084671 on yht, includin	
[25] Tomkins et al., 2013, Australia	To explore the factors influencing the satisfaction and dissatisfaction of people with aphasia with regards to their health care.	Qualitative methods. Semi-structured interviews, content analysis.	50 people with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	g for uses relat Not specified.	Information about aphasia.
[26] Tyson et al., 2014, UK	To investigate stroke survivors' and caregivers' experiences and views of rehabilitation assessment process.	Qualitative methods. Focus groups, content analysis.	17 stroke survivors. 6 caregivers.	Stroke survivors: Age: 58 years (range: 19-84). Gender: 6 female, 11 male. Time since stroke: Not reported. Caregivers: Age: Not reported. Gender: 4 female, 2 male. Relationship: 5 spouses/partners, 1 parent. Time since stroke: Not reported.	Within the first Superieur (ABES) after stroke.	 Information about psychological assessments (cognition and module of the system) of the system of the
[27] van Rijssen et al., 2023, Netherlands	To explore the experiences, needs, and wishes of people with aphasia and their relatives to inform development of communication training for healthcare professionals.	Qualitative methods. Semi-structured interviews, thematic analysis.	20 people with aphasia. 12 relatives.	People with aphasia: Age: 59 years (range: 46-93). Gender: 11 female, 9 male. Time since stroke: 82.5 months (range: 9 months–31 years). Relatives: Age: 67 years (range: 39-96). Gender: 5 female, 7 male. Relationship: 10 spouses/partners, 2 children. Time since stroke: 105.25 months (range: 9 months–31 years).	Not specified. Al training, and similar to	 Information about aphasia. Information about emotional consequences of living with some with aphasia. Information about what to expect for the future.
[28] van Veenendaal et al., 1996, Netherlands	To investigate informational needs of stroke survivors and their family members.	Quantitative methods. Questionnaires, descriptive statistical analysis.	35 stroke survivors. 39 family members. 43 health professionals.	Stroke survivors: Age: 61 years (range: 36-79). Gender: Not reported. Time since stroke: 18 months (range not reported). Family members: Age: 62 years (range: 36-84). Gender: Not reported. Relationship: Not reported. Time since stroke: 16 months (range not reported). Health professionals:	Not specified. Bechnologies.	 Information about talking difficulties. Information about problems with concentration.

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2 3 — 4 5						Gender: Not reported. Professional role: 11 nurses, 10 physiotherapists, 9 social workers, 13 not reported.	084681 on 1: , including 1	
6 7 8 9 10 11 12 13 14 15 16 17	[29]	Wiles et al., 1998, UK	To identify information needs of stroke patients and their informal carers at various stages after stroke.	Qualitative methods. Semi-structured interviews at three time-points after stroke (during hospitalisation, up to one-month after discharge, two-twelve months after discharge), thematic analysis.	Stage 1 (during hospitalisation): 6 patients. 1 carer. Stage 2 (up to one- month after discharge): 5 patients. 3 carers. Stage 3 (two-twelve months after discharge): 8 patients. 8 carers.	 Note. Demographics for subsamples of participants included at each stage not reported. Demographics for carers not reported. Demographics for stroke survivors interviewed/referred to during interviews (n = 21): Age: Mean not reported (range: 50-85). Gender: 10 female, 11 male. Time since stroke: Not reported. 	o Juring hospitalisation During hospitalisation Up to one-monts of the self discharge. Scheft Two-twelve monts of the self after discharge. after discharge. Two-twelve monts of the self after discharge. A self to text and data n	 Information about significance of symptoms (including memory loss and speech difficulties). Information about how symptoms (including memory loss and speech difficulties) should be managed. Information about how long symptoms (including memory loss and speech difficulties) might last.
18 19 20 21 22 23 24	[30]	Worrall et al., 2011, Australia	To describe the goals of people with aphasia after stroke and to code the goals according to the International Classification of Functioning, Disability and Health (ICF).	Qualitative methods. Semi-structured interviews, content analysis, coding of subsample of goals according to ICF.	50 participants with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	n http://bmjopen.bm nining, Al training, a	 Information about terms used to describe communication difficulties. Information about aphasia. Information about prognosis and what to expect at different stages after stroke. Information about aphasia services. Information about how to explain difficulties to friends or people in community. Information about aphasia therapy.
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