BMJ Open

Unmet care needs of community-dwelling stroke survivors: a systematic review of quantitative studies

Bei-lei Lin [1,2] Yong-xia Mei,[1] Wen-na Wang,[1] Shan-shan Wang,[1,3] Ying-shuang Li,[4] Meng-ya Xu,[5] Zhen-xiang Zhang,[1] Yao Tong[6]

¹Nursing and Health School, Zhengzhou University, Zhengzhou, China
²Academy of Medical Sciences, Zhengzhou University, Zhengzhou, China
³The Hong Kong Polytechnic University, Hong Kong, China
⁴The First Affiliated Hospital of Zhengzhou University, Zhengzhou, China
⁵The Second Affiliated Hospital of Zhengzhou University, Zhengzhou, China
⁶School of Information Engineering, Zhengzhou University, Zhengzhou, China

Correspondence to
Professor Zhen-xiang Zhang;
zhangzx6666@126.com

ABSTRACT

Objectives Understanding the unmet needs of community-dwelling stroke survivors is essential for further intervention. This systematic review was performed to summarise their unmet needs from a quantitative viewpoint.

Design Systematic review using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Data sources A comprehensive search of six databases was conducted from inception to February 2020: PubMed, EMBASE, CINAHL, PsycINFO, SCOPUS and CBM. The methodological quality of the studies was assessed. Unmet needs were categorised, and a pooled analysis of the main outcomes was conducted.

Eligibility criteria for selecting studies We included quantitative studies focused on the unmet needs of stroke survivors who live at homes rather than in any other institutionalised organisation.

Results In total, 32 of 2660 studies were included, and 1980 unmet needs were identified. The prevalence of patients with unmet needs ranged from 15.08% to 97.59%, with a median of 67.20%; the median number of unmet needs per patient ranged from 2 to 8 (0–31). The prevalence of unmet needs was high at 6 months post-stroke (62.14%) and 2 years post-stroke (81.37%). After categorisation, the main concerns among these patients were revealed to be information support, physical function and mental health; a few studies reported unmet needs related to leisure exercise, return to work and so on. Additionally, differences in the measurement tools used across studies affect what unmet needs participants report.

Conclusions Sufficient, accurate, individualised and dynamic information support is a priority among community-dwelling stroke survivors. Physical function and mental health are also the most significant concerns for re-achieving social participation. It is essential to design and disseminate standard, effective and time-saving tools to assess unmet needs.

Trial registration number CRD42018112181.

Strengths and limitations of this study

► We searched across English and Chinese databases; a total of 50 341 stroke survivors were included.
► Study selection, quality assessment and data extraction were performed by reviewers independently of each other.
► Heterogeneity among studies may affect the findings' dissemination; healthy policy and cultural differences should be considered in the analysis process.
► The impact of recruitment procedures on the results has not been thoroughly analysed because of lack of adequate evidence.
► Different tools focus on similar but varied domains or problems; they may affect the integration of the results.

INTRODUCTION

Stroke is a leading cause of death and disability globally, particularly in low-income and middle-income countries, and this burden is increasing.[1] According to the Global Burden of Disease Study 2017, there was a significant increase in the stroke incidence rate, and it demonstrated differences in the rise of stroke geographically.[2] Analysis from different countries illustrated that the average hospital length of stay ranged from 3 to 15.7 days.[3–6] A smaller number of patients, that is, those with severe stroke, stayed in the hospital for 28 days or even longer.[3 6] Moreover, due to the long-lasting disability and social impact caused by stroke, the lives of survivors and their families are strongly affected by the long-term consequences of stroke, including physical disability, cognitive disorders, difficulty in concentration, memory problems or even severe psychological problems.[7–9] Such issues significantly affect their ability to perform daily life activities or cope with long-term care needs. Therefore, active rehabilitation and conventional follow-up early after stroke are needed and recommended.[10 11] However, studies have shown that most patients who had a stroke felt abandoned by health organisations or professionals when returning to the community.[12–15] In an Australian cross-sectional survey among 765 patients who had a stroke 2 years after stroke, 84% had one

or more needs that were not fully met.[16] Even 15 years after stroke, 63.1% of the survivors still had various levels of disability.[9] Even in some developed countries with a conventional and compulsive health and social care review at 6 months and 1 year after stroke,[17][18] respondents still had unmet needs since they stayed at home, because only 3 in 10 stroke survivors received a six-month follow-up review.[19]

Unmet needs have been defined as 'a need for something or help from someone (that would help overcome some of the effects of stroke and the resulting difficulties) that is not being met'.[16][20] Large-scale studies have investigated the long-term care needs of stroke survivors or their family members, including rehabilitation needs,[21][22] learning needs,[23] educational needs[24][25] and medication-related needs.[26] In addition, systematic reviews have been conducted to synthesise stroke survivors' and caregivers' experiences with primary care and community health,[13][27] the long-term needs of stroke survivors with communication difficulties,[28][29] the experience of engaging in an occupation[30] and social participation.[31] Most of the reviews that focused on qualitative studies concluded that stroke survivors and their caregivers feel abandoned because they have become marginalised by community health services. A smaller number of reviews focusing on survey studies or mixed-methods studies have synthesised the evidence under different categories or themes but failed to include studies from developed countries to generate locally relevant evidence.

In summary, systematic reviews[7][28][32–34] of the experiences or needs of stroke survivors have been performed, and data have been searched until 2018.[34][35] However, new evidence keeps emerging, and data from developing countries should be synthesised as well. In addition, stroke survivors' needs change over time, with previous investigations of long-term care needs ranging from 2 weeks[17] to more than 5 years.[36][37] Therefore, it is essential to identify the primary unmet needs and track the changing trends to understand stroke survivors' unmet needs at different stages after stroke. This consideration will enable researchers to map the stroke survivors' unmet needs in different health policies and cultural contexts to generate evidence on stroke survivors' multidimensional needs.

METHODS
Protocol and registration
The review protocol was registered and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.[38][39] Both quantitative studies and quantitative data from mixed-methods studies were searched initially, but only quantitative data were included and analysed in this review.

Search and study selection
The databases were searched from inception. The literature search was conducted from October to December 2018. We later updated the search in February 2020 to retrieve and screen relevant publications until the completion of the systematic review in accordance with the protocol (see online supplemental files 1 and 2).[38] Studies on unmet needs that were investigated using samples that completely or partly included stroke survivors were also included. We included studies that recruited community-dwelling participants aged 18 years or over with a clinical diagnosis of stroke. Studies were limited to those published in English or Chinese with English abstracts and conducted among human subjects only; articles published in conferences were excluded. If the two reviewers had different opinions, a third reviewer joined the discussion to resolve the disagreement. All search results were imported into EndNote V.17.0, and duplications were removed both automatically and manually. Two reviewers independently assessed the titles, abstracts and keywords of all selected research. The first step was to remove irrelevant studies by evaluating the titles, followed by the abstracts, and finally, the main text of the study.

Quality assessment
We performed a critical quality assessment to identify the characteristics, validity, strength and limitations of the included studies rather than rating the evidence level or appraising the quality of studies as exclusion criteria. Seven of the 14 criteria based on the National Heart, Lung, and Blood Institute's 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' were used.[40] As guidance, the questions are designed to help researchers focus on the key concepts for evaluating the internal validity. They are not intended to create a list to arrive at a summary judgement of quality. One reviewer performed the quality assessment for all selected studies, and a second reviewer checked this assessment.

Data extraction and synthesis
The primary reviewer extracted data and entered them into a table; the second reviewer checked the accuracy and other details independently. If the information obtained from the included articles was unclear, we searched the relevant articles or contacted the authors to ask for precise data. To assess the main research interest (unmet needs), we extracted original data, including types, numbers, scores, proportions or frequency of needs reported in quantitative studies. Data from mixed-methods studies were summarised by exclusively focusing on quantitative results. Then, we categorised data into two types: unmet or met. To further categorise unmet needs, we developed a word cloud using NVivo V.11.0 software. We also referred to Maslow's Hierarchy of Needs[41] and the WHO's The International Classification of Functioning, Disability and Health (ICF)[42] to analyse the unmet needs from physical, psychological and social perspectives. If multiple needs could not be assigned to the above domains, an 'other' domain was developed.

According to the statistician's suggestions, we attempted to calculate a weighted average needs prevalence to facilitate data integration and comparisons between different studies. Additionally, to further analyse needs relevant to physiological aspects, we extracted data from 7 of the 32 studies using post-stroke checklist (PSC) to identify unmet needs, and weighted mean prevalence values were calculated. We did not intend to analyse the unmet needs of different subgroups because of the heterogeneity, but we stratified the data by discharge times and measures for simplicity.

Patient and public involvement

There was no patient involvement.

RESULTS
Study selection

Figure 1 presents a flow diagram of the search, screening and selection process. The search strategy of the original review identified 2660 records. After removing duplicates, the titles and abstracts of 1432 records were screened.

Study characteristics

A total of 29 full-text papers met the inclusion criteria, and 3 were identified by screening reference lists. Seven were conducted in the UK, five in Sweden, four in China and three in the Netherlands. The details were listed in table 1 (detailed unmet needs were shown in online supplemental file 3). The data from one paper[43] containing findings from two countries were analysed separately but as one record; two records[44 45] that reported different
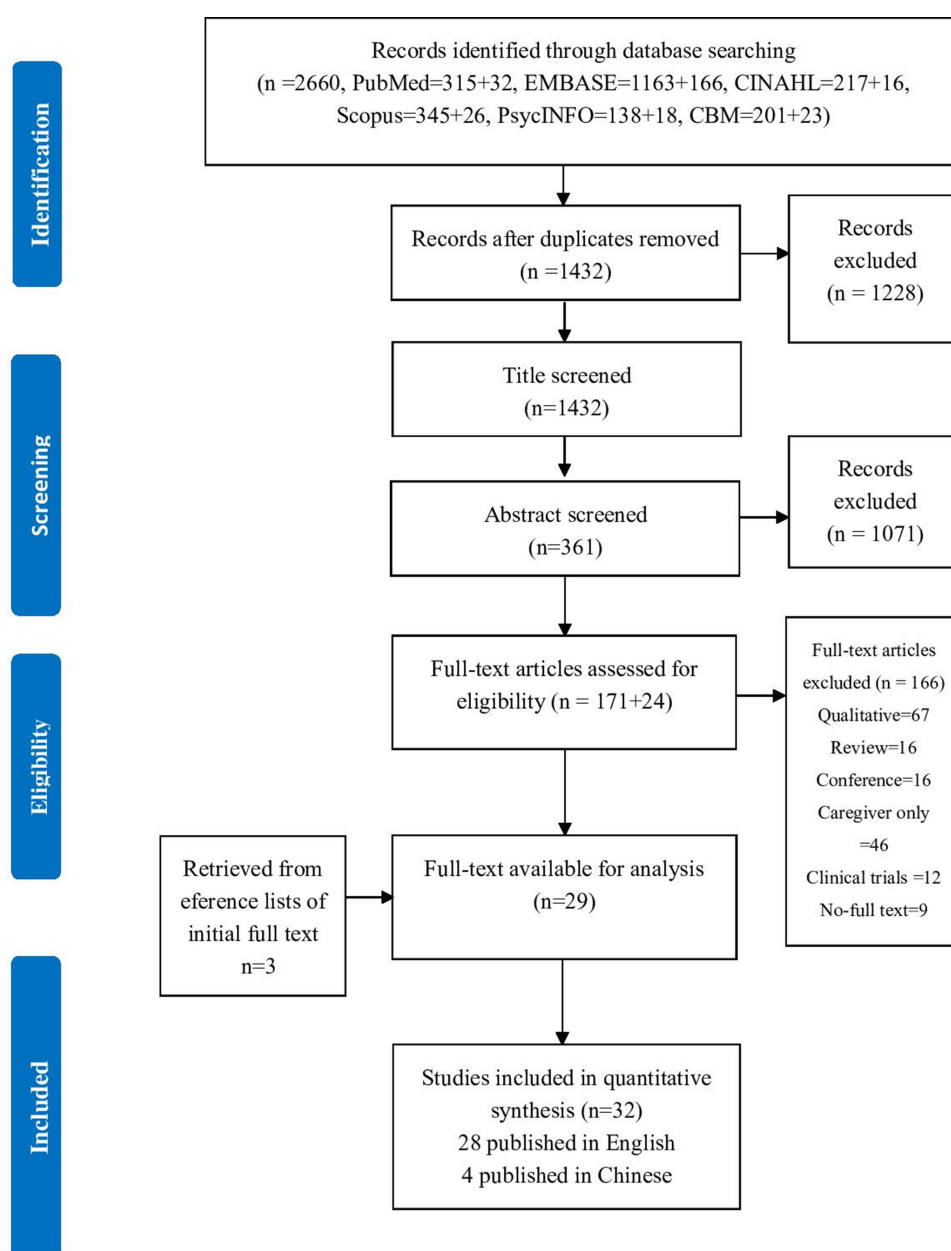

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow of this systematic review.

Table 1 Characteristics and unmet needs of the included studies (n=32)

Study	Country	Sample size	Age (year)	Time since stroke	Measures	Total unmet needs (main results)
Tistad et al[68]	Sweden	175	68 (14)	1 year	One item	33% reported unfulfilled rehabilitation needs
Ullberg et al[69]	Sweden	37 383	75.3/71.5	1 year	One item	21.5% reported unmet rehabilitation needs
Lee and Cho et al[50]	South Korea	1099	77.2 (6.7)	NR	One item	53.07% reported unmet home care rehabilitation needs
Vyas et al[49]	Canada	5976	>40	NR	One item	15.08% reported unmet healthcare needs
Lehnerer et al[44]	Germany	57	69.3 (9.8)	2–3 years	Nikolaus score	97 unmet needs were identified
Scholte et al[36]	The Netherlands	382 / 224	≤69 186 / >69 196	6 months / 5 years	SRUQ	31% perceived at least one unmet care need / 45% perceived a demand for more types of care / 8 categories of unmet needs were identified / 20% perceived at least one unmet need / 3 categories of unmet needs were identified
Jerome et al[4]	France	61	64 (8.5)	1–2 years, mean 17 months	SRUQ	54.1% needed more help / 41% reported depression / 4 categories of unmet needs were identified
Lundgren Nilsson et al[60]	Sweden	68	53	2 years	A checklist	15 categories of unmet needs were identified
Boter et al[46]	The Netherlands	166	64	<6 months	A checklist	97.59% reported problems / 1419 unmet needs were identified / Median number of unmet needs was 8 (5–11) / 9 categories of unmet needs were identified
Kersten et al[58]	UK	315	55	>1year, mean 3 years	SNAQ	70% reported unmet needs / Median number of unmet needs was 2 (0–6) / 8 categories of unmet needs were identified
Low et al[59]	UK	135	52	Mean 3 years	SNAQ	88% reported unmet needs / Median number of unmet needs was 5 (2–10) / 5 categories of unmet needs were identified
Boerboom et al[48]	The Netherlands	67	52.5 (10.7)	4 years	SNAQ	67.2% had at least one unmet need / Mean number of unmet needs was 3.5 / Median number of unmet needs was 2 (0–6) / 23.9% reported depression / 43.3% had mild cognitive impairment / 67.2% were unemployed / 11 categories of unmet needs were identified
Ward et al[43]	UK / Singapore	42 / 100	72 (8.1) / 61 (10.9)	8–60 months / 9–36 months	PSC	11 categories of unmet needs were identified / 11 categories of unmet needs were identified

Continued

Table 1 Continued

Study	Country	Sample size	Age (year)	Time since stroke	Measures	Total unmet needs (main results)
Crow[17]	UK	21	72	2 weeks	PSC	52% participants identified unmet needs Median number of unmet needs was 3 (1–6) 48% participants needed referral to local neurorehabilitation teams 12 categories of unmet needs were identified
Iosa et al[70]	Italy	64	69.17 (12.39)	Mean 38.4 months	PSC	11 categories of unmet needs were identified
De Bartolo et al[71]	Italy	53	65.76 (13.50)	3.3 months–21 years	PSC	11 categories of unmet needs were identified
Hotter et al[45]	Germany	57	69.3 (9.8)	2–3 years	PSC	95% reported at least one unmet need 5 categories of unmet needs were identified
Kjörk et al[72]	Sweden	46	70 (41–85)	Mean 3 months	PSC	87% had problems Median number of problems per patient was 4 30% needed information about secondary prevention 11 categories of unmet needs were identified
McKevitt et al[20]	UK	799	69.9 (12.3) 66.3 (13.0)	1 year	LCNQ	49% reported unmet needs Median number of unmet needs was 3 (1–13) 12 categories of unmet needs were identified
Rothwell et al[47]	UK	137	72.6 (40–93)	6 months	GM-SAT	92% had unmet needs Mean number of unmet needs was 3 (0–14) 464 unmet needs were identified 13 categories of unmet needs were identified
Groeneveld et al[73]	Dutch	78	61.7 (13.8)	5–8 years	LUNS	67.9% indicated having at least one unmet need Median number of unmet needs was 3.5 (2.0–5.0; 1.0–14.0) 21 categories of unmet needs were identified
Ytterberg et al[37]	Sweden	110	63	>6 years	LUNS	11 categories of unmet needs were identified
Pierce et al[74]	USA	24	56	NR	SRSQ	12 categories of unmet needs were identified
Bai et al[61]	China	346	60	NR	SRSQ	12 categories of unmet needs were identified
Jiang and Liu[62]	China	110	67.47 (12.02)	7 (1–12) months	SRSQ	3 categories of unmet needs were identified
Zhang and Liu[63]	China	177	67.3 (10.8)	>1 year	SRSQ	3 categories of unmet needs were identified
Gao et al[51]	China	127	62.61	NR	SRSQ	5 categories of unmet needs were identified
Walsh et al[75]	Ireland	196	61.9 (13.9) 24–89	3 months–19 years	SRSQ	78% had unmet health needs Median number of unmet needs was 3 (1–5) 19 categories of unmet needs were identified

Continued

Table 1 Continued

Study	Country	Sample size	Age (year)	Time since stroke	Measures	Total unmet needs (main results)
Andrew et al[16]	Australia	765	68	Mean 2 years	SRSQ	84% reported unmet needs Median number of unmet needs was 4 of 20 18 categories of unmet needs were identified
Kamalakannan et al[64]	India	50	58.9 (10.5)	<6 weeks	SRSQ	82% reported unmet needs 12 categories of unmet needs were identified
Olaiya et al[3]	Australia	335	73	>2 years	SRSQ	87.6% reported at least one unmet need 5 categories of unmet needs were identified
Jamison et al[26]	UK	596	72.7	7.7 months	SRSQ	44.5% reported unmet needs, including medication-related needs 6 categories of unmet needs were identified

SRSQ is being designed by research group for assessment.
GM-SAT, Greater Manchester Stroke Assessment Tool; LCNQ, Long-term Care Needs Questionnaire; LUNS, longer term unmet needs after stroke; NR, not reported; PSC, post-stroke checklist; SNAQ, Southampton Needs Assessment Questionnaire ; SRSQ, Self-Reported Structured Questionnaire; SRUQ, Self-Reported Unstructured Questionnaire.

types of unmet needs from one study were included as two records.

Quality assessment

No studies were excluded because the questions in this tool are designed to help researchers focus on the key concepts for evaluating the internal validity of a study but not intended to create a list that arrives at a summary judgement of quality (table 2).

MAIN FINDINGS
Prevalence of total unmet needs

In total, more than 1980 unmet needs were reported in 23 articles[44 46 47]; precise data from two studies were obtained by emailing the authors.[45 48] The weighted mean of unmet needs was 25.31%. In addition, the median prevalence of unmet needs was 67.20% (15.08%–97.59%), and the median number of unmet needs per patient ranged from 2 to 8 (0–31). Weighted mean unmet needs were calculated according to different times since stroke; 20 articles were analysed, the results showed that the unmet needs were more prevalent in the first 6 months and at 2–3 years after stroke (figure 2). The prevalence rates of unmet needs reported by the remaining three studies without precise or mean times were 15.08%,[49] 53.07%[50] and 78%, separately.[51]

Prevalence of categorised unmet needs

To categorise unmet needs, we first referred to the studies[41 42] and divided the needs into physiological needs (physical function, mental function), safety needs (personal security and financial security), love and belongingness needs (family relationship, social life), esteem needs (respect, self-efficacy, self-care), self-actualisation (job support, support services, individualised mentorship), and needs related to activity and participation (self-care and domestic life, mobility). Second, 292 unmet needs were extracted and imputed into NVivo V.11.0 software. A word frequency query was performed, and the results were displayed as a word cloud to demonstrate the frequencies of words (see online supplemental file 4). The results showed that the commonly reported terms (the larger font size) included information, mobility, cognition, secondary prevention, rehabilitation, social and communication. Finally, nine categories were identified, including information needs, rehabilitation needs, physical function needs, mental health needs, safety needs, love and belongingness needs, esteem and self-actualisation needs, needs related to activity and participation, and other needs.

The main unmet needs are listed in table 3. Information needs were the most commonly reported, with an estimated prevalence ranging from 7.7% to 96.85% and a median of 57.00%. Rehabilitation needs ranked second. For physical function, the main problems included physical problems, fatigue and spasticity. In terms of mental health, the most commonly reported unmet needs

Table 2 Quality assessment of studies (n=32)

Study	Q1	Q2	Q3	Q4	Q5	Q11	Q13
Tistad et al[68]	+	+	+	+	−	NA	−
Ullberg et al[69]	+	+	+	+	−	NA	NA
Lee and Cho [50]	+	+	+	+	−	+	+
Vyas et al[49]	+	+	+	+	+	NA	+
Lehnerer et al[44]	+	+	NA	+	−	+	NA
Scholte et al[36]	+	+	+	+	−	+	−
Jerome et al[4]	+	+	+	+	−	+	+
Lundgren Nilsson et al[60]	+	+	+	+	−	+	+
Boter et al[46]	+	+	+	+	−	−	+
Kersten et al[58]	+	+	−	+	+	+	−
Low et al[59]	+	+	+	+	−	+	−
Boerboom et al[48]	+	+	+	+	+	+	+
Ward et al[43]	+	+	NR	+	−	+	NA
Crow[17]	+	+	NR	+	−	+	NA
Iosa et al[70]	+	+	NR	+	+	+	NR
De Bartolo et al[71]	+	+	NR	+	−	+	NA
Hotter et al[45]	+	+	NA	+	−	+	NA
Kjörk et al[72]	+	+	NA	+	+	+	NA
Mckevitt et al[20]	+	+	+	+	+	+	NA
Rothwell et al[47]	+	+	NR	+	−	+	NA
[73]	+	+	+	+	+	+	NA
Ytterberg et al[37]	+	+	−	+	+	+	−
Pierce et al[74]	+	+	+	+	−	−	+
Bai et al[61]	+	+	+	+	−	−	NA
Jiang and Liu[62]	+	+	+	+	−	−	NA
Zhang and Liu[63]	+	+	+	+	−	+	NA
Gao et al[51]	+	+	+	+	−	−	NA
Walsh et al[75]	+	+	+	+	+	+	NA
Andrew et al[16]	+	+	−	+	+	+	NA
Kamalakannan et al[64]	+	+	+	+	−	−	NA
Olaiya et al[3]	+	+	+	+	−	+	NA
Jamison et al[26]	+	+	−	+	+	+	NA

Q1. Was the research question or objective in this paper clearly stated?
Q2. Was the study population clearly specified and defined?
Q3. Was the participation rate of eligible persons at least 50%?
Q4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
Q5. Was a sample size justification, power description, or variance and effect estimates provided?
Q11. Were the outcome measures (dependent variables) clearly defined, valid, reliable and implemented consistently across all study participants?
Q13. Was loss to follow-up after baseline 20% or less?
NA, not applicable; NR, not reported.

included cognition, mood and stress. Self-care and participation were also highly concerning. Compared with the other categories, fewer needs related to love, belongingness and self-actualisation were reported by community-dwelling stroke survivors.

The combined results from studies using the PSC showed that the most frequently reported unmet needs were cognition (41.92%), followed by mood (40.13%) and mobility (38.55%); unmet needs related to caregiver relationships, communication and continence were the
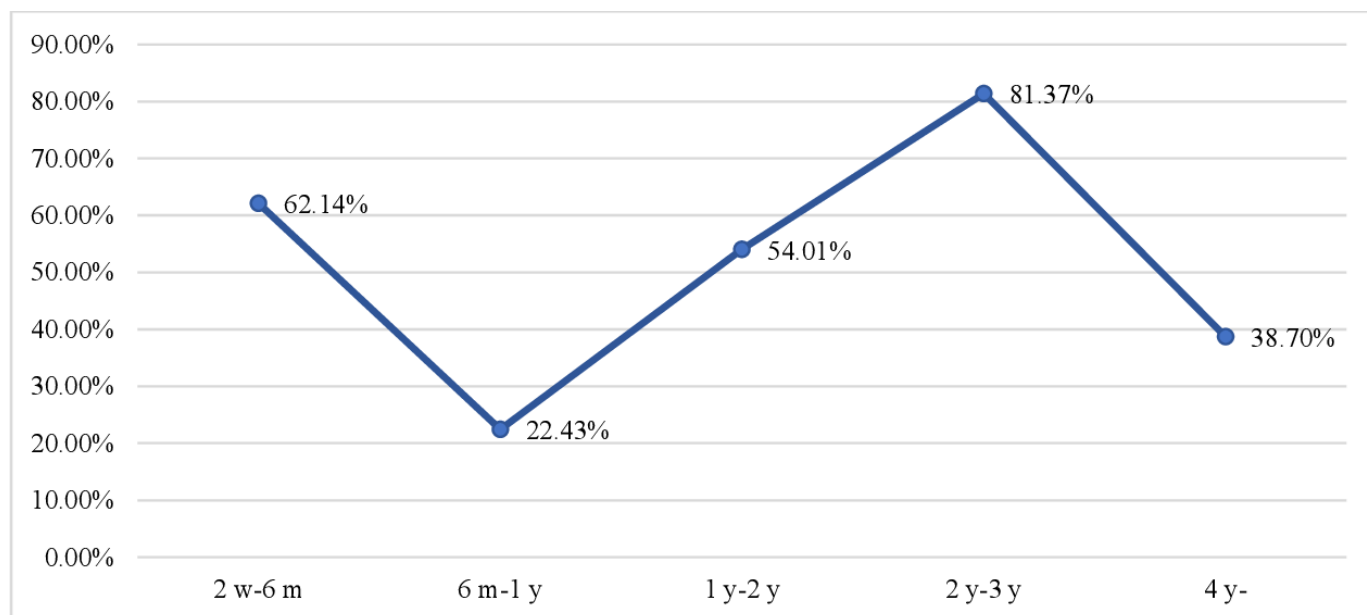
Figure 2 Pooled prevalence of unmet needs after stroke.

least frequently reported (18.47%, 22.49% and 23.81%, respectively) (figure 3).

DISCUSSION
Principal findings
Unmet needs are relevant because they are associated with a reduced quality of life for both patients and caregivers.[52] This systematic review demonstrates that substantial proportions of stroke survivors in the home live with unmet needs related to their disease and its consequences, even if the needs varied widely. The highest rate of unmet needs was reported by Boter *et al* from the Netherlands. Specifically, 97.59% of the participants reported problems within 6 months, and a total of 1419 unmet needs were identified.[46] The lowest rate of unmet needs was reported by Vyas *et al*[49] in Canada in 2019; they found that approximately 15.8% of patients who had a stroke had unmet health needs. Considering stroke survivors' need changed significantly over time.[28] Data from a national survey with 799 participants reported that 49% of patients had unmet needs at 1 year after stroke.[20] Still, Rothwell *et al*'s[47] study indicated that 92% had unmet needs 6 months after stroke. We tried to explore the effect of time points on unmet needs in a particular region, but the different participants and instruments made it impossible, even the seven studies from the UK. Therefore, we tried to recalculate and synthesise the data from 20 studies.

Interestingly, the results showed that 62.14% of stroke survivors have at least one type of unmet need within 6 months after stroke. Thus, prevalence decreased sharply to 22.43% after 6 months. It continually increased up to 81.37% at 2 years after stroke. This result could definitely strengthen the importance of long-term care of stroke survivors; and stratified attention should be given to stroke survivors at different stages. However,

the imbalance between the supply of resources and demands for services may be affected by many factors, such as national health policies, availability of services, place of residence, patients' choices and so on.[35] In addition, the participants' characteristics within each study were different; the recruitment criteria and procedures may affect the unmet needs reported by patients.[20 46 47 49] Therefore, given the substantial heterogeneity between articles, the credibility and accuracy of the combined results need to be verified and adjusted with a more rigorously designed study.

With respect to different types of needs, in accordance with the present results,[23 53] sufficient information remains the primary demand among stroke survivors. According to the healthcare professionals, all patients and their caregivers were provided sufficient information guidance in the hospital and before discharge.[54] However, stroke survivors and their caregivers still feel abandoned and marginalised by healthcare services due to unmet information needs and insufficient rehabilitation.[12–15] They claimed that the language and information was too difficult to process at the time of their diagnosis.[53 55] In addition to the language being too difficult to understand, the cognitive inconsistency between these two populations is also the cause of unmet needs.[35] A qualitative study conducted by Turner *et al* revealed that patients emphasised the importance of understanding their diagnosis and individualised support regarding stroke risk. At the same time, healthcare professionals prioritised medical investigation and secondary prevention medication.[56] Moreover, some stroke survivors question their healthcare professionals' quality and competence, highlighting the challenge of moving from illness towards health and well-being and expressing a need to meet experienced and knowledgeable 'helpers' to discuss their changed lives after stroke.[57]

Table 3 Pooled unmet needs of community-dwelling stroke survivors

Category	Extracted unmet needs	N	Minimum (%)	Maximum (%)	Median (%)
1	Information needs	11	7.70	96.85	57.00
2	Rehabilitation needs	12	8.00	78.03	50.33
3	Physical problems	8	8.00	92.00	49.80
6	Self-care needs	4	31.06	63.01	49.45
3	Fatigue	5	34.30	75.00	47.00
4	Memory/concentration	12	21.80	78.00	44.00
4	Cognition	11	10.00	75.60	43.40
4	Mood/emotion needs	21	15.40	73.20	41.00
9	Secondary prevention	10	9.30	77.00	40.30
5	Social life or participation	7	8.96	68.13	37.57
3	Spasticity	7	14.70	56.60	35.00
8	Mobility	18	6.00	77.75	33.00
8	Transportation	5	5.00	53.00	32.00
5	Fall	6	21.00	71.00	32.00
3	Swallowing	3	11.56	44.00	31.00
8	ADL	8	5.00	51.20	29.02
3	Communication/speaking	12	4.76	58.00	28.00
9	Medication	4	2.90	49.80	27.90
3	Vision/sight	5	18.00	64.00	27.00
8	Continence/constipation	12	4.76	52.00	25.05
6	Life after stroke	6	14.26	70.70	24.62
3	Pain	10	14.10	54.00	22.65
5	Finance needs	8	5.97	70.90	22.50
6	Social services	4	13.43	20.90	20.90
6	Relationship within family	7	3.80	32.08	20.00
7	Work	3	10.45	60.00	18.00
7	Home adaption/help	6	5.00	39.00	15.50
9	Behaviour	6	3.00	49.00	12.80
7	Housing	3	10.30	66.70	11.94
6	Environmental factors	3	2.60	42.70	10.30
9	Acupuncture or massage	2	27.75	44.09	–
7	Personal care	2	17.00	50.00	–
8	Leisure time/exercise	2	62.00	64.00	–
5	Nutrition	2	4.40	63.00	–
7	Intellectual fulfilment	2	17.00	34.00	–
3	Reading difficulty	2	12.00	34.00	–

N=numbers of studies. 1=information needs; 2=rehabilitation needs; 3=physical function needs; 4=mental health needs; 5=safety needs; 6=love and belongingness needs; 7=esteem and self-actualisation needs; 8=activity and participation; 9=other needs.
ADL, activity of daily living.

Therefore, consideration must be given to the time, way, frequency and role when providing information support to patients.

Referring to other needs, according to Maslow's Hierarchy of Needs and the ICF, the results demonstrate that community-dwelling stroke survivors' priorities are mainly limited to physical functions and mental health; minimal attention has been paid to their higher level needs. The latest narrative review also demonstrated that physical and other stroke-related problems were their prioritised needs, which was the least reported among 105 studies.[35] This may be correlated with participants' age and social role. In this review, two studies[58 59] assessed the unmet needs related to intellectual fulfilment among younger
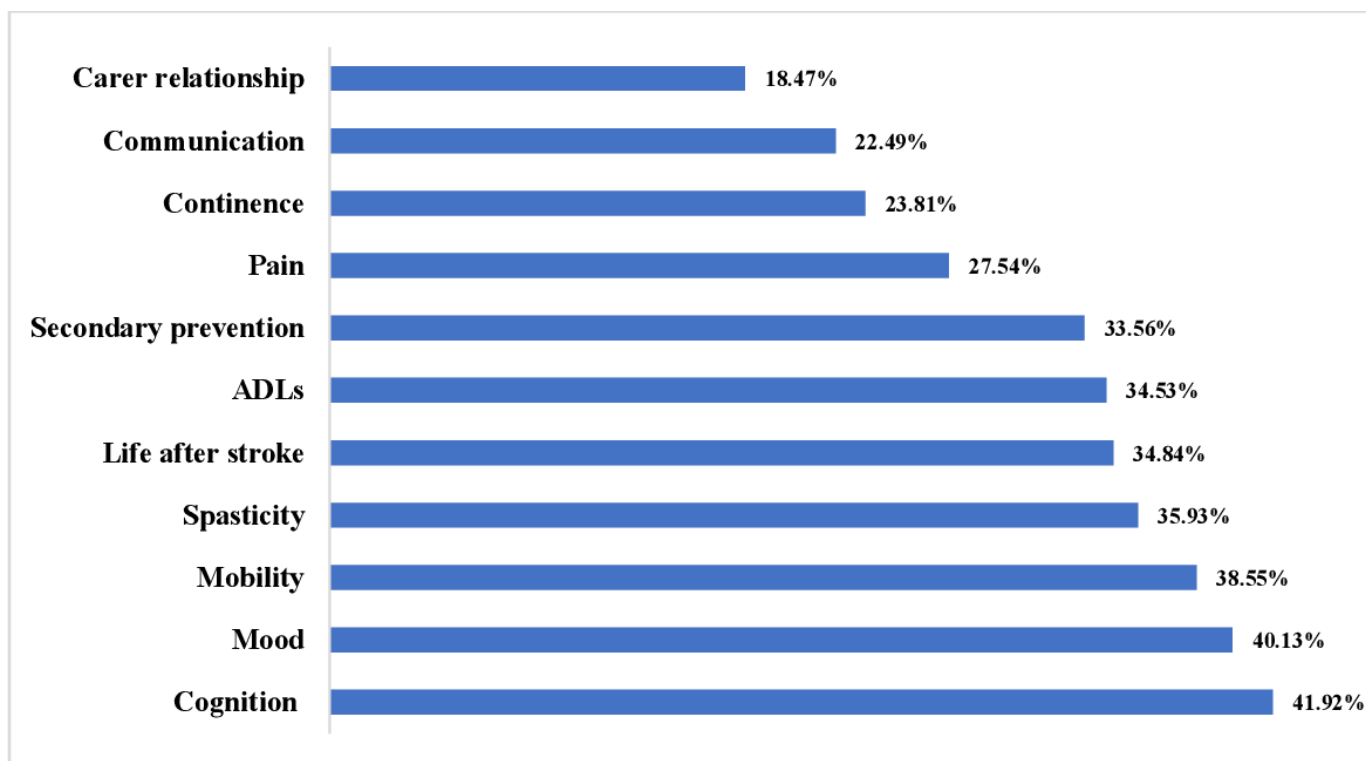
Figure 3 Unmet needs identified according to post-stroke checklist. ADLs, activities of daily living.

stroke survivors, and it was the second most common demand. However, even with the same measures, 34% of young patients who had a stroke from a voluntary sample reported intellectual fulfilment unmet needs,[59] and the prevalence was 17% in another study.[58] Through further analysis, we found the patients were recruited from different places, it is possible that more participation in stroke organisations could help to trigger awareness of home care needs. A qualitative study[57] of young stroke survivors also revealed that follow-up programmes must consider their particular challenges as young and midlife stroke survivors. This review also illustrated that 4 of the 32 studies[16 48 59 60] conducted in developed countries reported needs related to going back to work, and three of them concerned patients under 55 years. Five studies[50 51 61–63] conducted in Asia did not report self-fulfilment needs, as the average age of participants was over 60 years. However, another study from India found that 33.4% of the patients who had a stroke (mean age was 58.9 years) needed rehabilitation guidance for work.[64] On one hand, this difference may be affected by age and measures. On the other hand, it may reflect the health priorities among different countries. Thus, this finding clearly indicates that age, economic and cultural aspects should be considered when implementing interventions for community-dwelling stroke survivors.

Another issue that needs attention is social and leisure activity restrictions among community-dwelling stroke survivors in both developed and developing countries. Promoting participation in leisure activities post-stroke is a priority area and benefit for cognitive rehabilitation,

given that older adults who have had a stroke often experience significant restrictions in leisure participation.[65] Two studies in Sweden[60] and Australia[16] reported unmet needs related to leisure exercise. The prevalence was high, and 62%–64% of the participants needed help to guide them to perform and participate in leisure exercise. Moreover, this systematic review demonstrates that patients' self-reported relationships with family members' relevant needs (3.8%~32.08%, median 20%) were much lower than other aspects, such as self-mobility needs, which is consistent with the latest review.[35] However, findings from caregivers revealed that they were concerned about and needed more help to cope with relationship problems, communication problems and care burden.[32 66 67] Although this review only analysed stroke survivors' needs, the findings suggest that the inconsistency between patients' and caregivers' needs should be considered. Moreover, the limited evidence from this review shows the imbalance between the supply of resources and demands for service. The prevalence of unmet needs changes over time after stroke and varies between countries, which should be a matter of further concern in the future.

Strengths and weaknesses
The study protocol was robust and underwent peer review, and a statistician guided the analysis process. We chose to use the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies for quality appraisal. We systematically reviewed the unmet needs of community-dwelling stroke survivors in quantitative perspectives

from inception to February 2020. In addition, articles published in Chinese were first included for review as well. We tried to synthesise the latest and most comprehensive data as much as possible. We also recalculated the prevalence of unmet needs and map it according to follow-up time; it might provide new evidence for further intervention to some extent. However, heterogeneity should be considered in the comprehensive analysis of demand. Culture and service differences may account for a large proportion of the variance in the reporting of unmet care needs. In particular, the difference between instruments is a significant factor influencing the consistency within studies. Additionally, the different cohorts or recruitment procedures in the included studies likely resulted in large differences in unmet needs between studies, which might affect comparisons between studies or make the meta-analysis impossible. To compensate for this limitation, we provided the original results extracted from each study as a supplement for further review.

Implications and future research

This review is a useful resource for researchers and multidisciplinary clinicians seeking to develop targeted interventions or evaluate the effectiveness of post-stroke management for community-dwelling stroke survivors. Information needs may persist up to 4 years or more after stroke, requiring professionals to consider repeating information delivery. Specifically, stroke survivors need targeted information or other support that is consistent with their status and demand. In addition, lending from Maslow's Hierarchy of Needs and the WHO's ICF model needs relevant to self-fulfilment and relationship should be emphasised, especially in developing countries. Although the health management policy and the model of care adopted by a particular government affect the services made available to the community of patients who had a stroke, standardised items for needs assessment should be considered and implemented regularly, thereby optimising independence and enhancing quality of life of stroke survivors. Thus, on one hand, such research must consider the characteristics of the population being studied. On the other hand, an appropriate tool such as PSC should be developed for comprehensive and consistent assessment, to contribute to sustainable and dynamic stroke care delivery, and encourage optimal use of available resources.

CONCLUSIONS

The findings indicate the importance of information, especially individualised, accurate and sufficient information, for community-dwelling stroke survivors' long-term rehabilitation. The estimated prevalence of unmet needs after stroke is high among these survivors, but there is considerable heterogeneity in the types and frequencies of specific unmet needs. Moreover, the inconsistency of measurements is common, and a comprehensive, time-saving and targeted tool should be developed and standardised. Therefore, a standard checklist or questionnaire is necessary to promote active follow-up and reduce the marginalisation experienced by stroke survivors in primary care stroke reviews. More importantly, generalised follow-up review guides for stroke survivors must be widely established for healthcare professionals worldwide.

ORCID iD
Bei-lei Lin http://orcid.org/0000-0002-6502-7402

REFERENCES

1. Benjamin EJ, Muntner P, Alonso A, *et al*. Heart disease and stroke Statistics-2019 update: a report from the American heart association. *Circulation* 2019;139:e56–28.
2. Krishnamurthi RV, Ikeda T, Feigin VL. Global, regional and Country-Specific burden of ischaemic stroke, intracerebral haemorrhage and subarachnoid haemorrhage: a systematic analysis of the global burden of disease study 2017. *Neuroepidemiology* 2020;54:171–9.
3. Olaiya MT, Cadilhac DA, Kim J, *et al*. Long-Term unmet needs and associated factors in stroke or TIA survivors. *Neurology* 2017;89:68–75.
4. Jerome D, Dehail P, Daviet J-C, *et al*. Stroke in the under-75S: expectations, concerns and needs. *Ann Phys Rehabil Med* 2009;52:525–37.
5. Forster A. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *Clinical rehabilitation* 2013;27:1020–8.
6. Yagi M, Yasunaga H, Matsui H. Impact of rehabilitation on outcomes in patients with ischemic stroke: a nationwide retrospective cohort study in Japan. *Stroke* 2017;48:740–6.

7 Jaracz K, Grabowska-Fudala B, Górna K, *et al*. Consequences of stroke in the light of objective and subjective indices: a review of recent literature. *Neurol Neurochir Pol* 2014;48:280–6.

8 Kamwesiga JT, Tham K, Guidetti S. Experiences of using mobile phones in everyday life among persons with stroke and their families in Uganda – a qualitative study. *Disabil Rehabil* 2017;39:438–49.

9 Crichton SL, Bray BD, McKevitt C, *et al*. Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health. *J Neurol Neurosurg Psychiatry* 2016;87:1091–8.

10 Lindsay P, Furie KL, Davis SM, *et al*. World stroke organization global stroke services guidelines and action plan. *International Journal of Stroke* 2014;9:4–13.

11 Dworzynski K, Ritchie G, Playford ED. Stroke rehabilitation: long-term rehabilitation after stroke. *Clin Med* 2015;15:461–4.

12 Lutz BJ, Ellen Young M, Cox KJ, *et al*. The crisis of stroke: experiences of patients and their family caregivers. *Top Stroke Rehabil* 2011;18:786–97.

13 Pindus DM, Mullis R, Lim L, *et al*. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS One* 2018;13:e0192533.

14 Martin BJ, Yip B, Hearty M, *et al*. Outcome, functional recovery and unmet needs following acute stroke. experience of patient follow up at 6 to 9 months in a newly established stroke service. *Scott Med J* 2002;47:136–7.

15 Kjörk EK, Carlsson G, Å L-N. Follow-Up needs after stroke-can post-stroke checklist be part of the solution? *Neurorehabilitation and neural repair* 2018;32:406.

16 Andrew NE, Kilkenny M, Naylor R, *et al*. Understanding long-term unmet needs in Australian survivors of stroke. *International Journal of Stroke* 2014;9:106–12.

17 Crow J. A 2-week stroke review identifies unmet needs in patients discharged home from a hyperacute stroke unit. *British Journal of Neuroscience Nursing* 2018;14:29–35.

18 Physicians. RCo. *National clinical guidelines for stroke. In: Party ISW, (ed)*. London: Royal College of Physicians, 2016.

19 Stroke Association. State of the nation: stroke statistics; 2018. https://www.stroke.org.uk/sites/default/files/stroke_association_annual_report_2018_0.pdf

20 McKevitt C, Fudge N, Redfern J, *et al*. Self-Reported long-term needs after stroke. *Stroke* 2011;42:1398–403.

21 Ekstam L, Johansson U, Guidetti S, *et al*. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. *BMJ Open* 2015;5:e006784.

22 Lincoln NB, Gladman JRF, Berman P, *et al*. Rehabilitation needs of community stroke patients. *Disabil Rehabil* 1998;20:457–63.

23 Johnson J, Pearson V, McDivitt L. Stroke Rehabilitation: Assessing Stroke Survivors' Long-Term Learning Needs. *Rehabilitation Nursing* 1997;22:243–8.

24 Poulin V, Carbonneau H, Provencher V, *et al*. Participation in leisure activities to maintain cognitive health: perceived educational needs of older adults with stroke. *Loisir et Société / Society and Leisure* 2019;42:4–23.

25 Bernikier D, Sautreau R, Kammoun B, *et al*. Educational needs of post-stroke patients and their caregivers. *Ann Phys Rehabil Med* 2013;56:e144.

26 Jamison J, Ayerbe L, Di Tanna GL, *et al*. Evaluating practical support stroke survivors get with medicines and unmet needs in primary care: a survey. *BMJ Open* 2018;8:e019874.

27 Lloyd A, Bannigan K, Sugavanam T, *et al*. Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation: a systematic review of qualitative evidence. *JBI Database System Rev Implement Rep* 2018;16:1418–53.

28 Wray F, Clarke D. Longer-Term needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *BMJ Open* 2017;7:e017944.

29 Wray F, Clarke D, Forster A. The needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *International Journal of Stroke* 2016;11:49.

30 Williams S, Murray C. The experience of engaging in occupation following stroke: a qualitative meta-synthesis. *British Journal of Occupational Therapy* 2013;76:370–8.

31 Woodman P, Riazi A, Pereira C, *et al*. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil* 2014;36:2031–43.

32 Hafsteinsdóttir TB, Vergunst M, Lindeman E, *et al*. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Educ Couns* 2011;85:14–25.

33 Lee N, Aries A, Hunter S. The long-term needs of stroke survivors: a systematic review. *International Journal of Stroke* 2014;9:42.

34 Chen T, Zhang B, Deng Y, *et al*. Long-Term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open* 2019;9:e028137.

35 Zawawi NSM, Aziz NA, Fisher R, *et al*. The unmet needs of stroke survivors and stroke caregivers: a systematic narrative review. *J Stroke Cerebrovasc Dis* 2020;29:104875.

36 op Reimer WJ, Scholte de Haan RJ, Rijnders PT, *et al*. Unmet care demands as perceived by stroke patients: deficits in health care? *Qual Health Care* 1999;8:30–5.

37 Ytterberg C, Kristensen HK, Tistad M, *et al*. Factors related to Met needs for rehabilitation 6 years after stroke. *PLoS One* 2020;15:e0227867.

38 Lin B, Ding C, Mei Y, *et al*. Unmet care needs of community-dwelling stroke survivors: a protocol for systematic review and theme analysis of quantitative and qualitative studies. *BMJ Open* 2019;9:e029160.

39 Moher D, Shamseer L, Clarke M, *et al*. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015;4:1.

40 National Heart L, Blood Institue. Study quality assessment tools, 2018. Available: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

41 Hale AJ, Ricotta DN, Freed J, *et al*. Adapting maslow's hierarchy of needs as a framework for resident wellness. *Teach Learn Med* 2019;31:109–18.

42 Abdi S, Spann A, Borilovic J, *et al*. Understanding the care and support needs of older people: a scoping review and categorisation using the who International classification of functioning, disability and health framework (ICF). *BMC Geriatr* 2019;19:195.

43 Ward AB, Chen C, Norrving B, *et al*. Evaluation of the post stroke checklist: a pilot study in the United Kingdom and Singapore. *Int J Stroke* 2014;9 Suppl A100:76–84.

44 Lehnerer S, Hotter B, Padberg I, *et al*. Social work support and unmet social needs in life after stroke: a cross-sectional exploratory study. *BMC Neurol* 2019;19.

45 Hotter B, Padberg I, Liebenau A, *et al*. Identifying unmet needs in long-term stroke care using in-depth assessment and the post-stroke checklist - the managing aftercare for stroke (MAS-I) study. *Eur Stroke J* 2018;3:237–45.

46 Boter H, Rinkel GJE, de Haan RJ. Outreach nurse support after stroke: a descriptive study on patients' and carers' needs, and applied nursing interventions. *Clin Rehabil* 2004;18:156–63.

47 Rothwell K, Boaden R, Bamford D, *et al*. Feasibility of assessing the needs of stroke patients after six months using the GM-SAT. *Clin Rehabil* 2013;27:264–71.

48 Boerboom W, Heijenbrok-Kal MH, van Kooten F, *et al*. Unmet needs, community integration and employment status four years after subarachnoid haemorrhage. *J Rehabil Med* 2016;48:529–34.

49 Vyas MV, Fang J, Kapral MK. Temporal trends in the unmet health care needs of Canadian stroke survivors. *Can. J. Neurol. Sci.* 2020;47:176–82.

50 Lee K, Cho E. Activities of daily living and rehabilitation needs for older adults with a stroke: a comparison of home care and nursing home care. *Jpn J Nurs Sci* 2017;14:103–11.

51 Gao CH, Wang W, Liu YL. Needs of rehabilitation of stroke patients: investigation in Wugang community. *Chinese Journal Of Rehabilitation Theory And Practice* 2012;18:289–90.

52 Andrew NE, Kilkenny MF, Lannin NA, *et al*. Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? *Qual Life Res* 2016;25:2053–62.

53 Rodgers H, Bond S, Curless R. Inadequacies in the provision of information to stroke patients and their families. *Age Ageing* 2001;30:129–33.

54 Kjörk EK, Gunnel C, Lundgren-Nilsson Åsa, *et al*. Experiences, needs, and preferences for follow-up after stroke perceived by people with stroke and healthcare professionals: a focus group study. *PLoS One* 2019;14:e0223338.

55 Turner GM, Mullis R, Lim L, *et al*. Using a checklist to facilitate management of long-term care needs after stroke: insights from focus groups and a feasibility study. *BMC Fam Pract* 2019;20.

56 Turner GM, McMullan C, Atkins L, *et al*. Tia and minor stroke: a qualitative study of long-term impact and experiences of follow-up care. *BMC Fam Pract* 2019;20.

57 Martinsen R, Kirkevold M, Sveen U. Young and midlife stroke survivors' experiences with the health services and long-term follow-up needs. *Journal of Neuroscience Nursing* 2015;47:27–35.

58 Kersten P, Low JTS, Ashburn A, *et al*. The unmet needs of young people who have had a stroke: results of a national UK survey. *Disabil Rehabil* 2002;24:860–6.

59 Low JTS, Kersten P, Ashburn A, *et al*. A study to evaluate the Met and unmet needs of members belonging to young stroke groups affiliated with the stroke association. *Disabil Rehabil* 2003;25:1052–6.

60 Lundgren Nilsson Åsa, Aniansson A, Grimby G. Rehabilitation needs and disability in community living stroke survivors two years after stroke. *Top Stroke Rehabil* 2000;6:30–47.

61 Bai GF, Liu T, FY HE. A survey of rehabilitation needs of stroke patients in Shijiazhuang City for community chronic disease management. *Chinese Journal Of Rehabilitation Medicine* 2010;25:677–9.

62 Jiang H, Liu BY. Rehabilitation status and education needs in community stroke patients. *Chinese Nursing Management* 2011;11:66–8.

63 Zhang ZX, Liu LM. Nursing needs and influencing factors of stroke patients in community. *Chinese Journal of Gerontology* 2012;32:4250–2.

64 Kamalakannan S, Gudlavalleti Venkata M, Prost A, *et al*. Rehabilitation needs of stroke survivors after discharge from hospital in India. *Arch Phys Med Rehabil* 2016;97:1526–32.

65 Desrosiers J, Bourbonnais D, Noreau L, *et al*. Participation after stroke compared to normal aging. *Journal of Rehabilitation Medicine* 2005;37:353–7.

66 Wagachchige Muthucumarana M, Samarasinghe K, Elgán C. Caring for stroke survivors: experiences of family caregivers in Sri Lanka – a qualitative study. *Top Stroke Rehabil* 2018;16:1–6.

67 López-Espuela F, González-Gil T, Amarilla-Donoso J, *et al*. Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study. *PLoS One* 2018;13:e0195190.

68 Tistad M, Tham K, von Koch L, *et al*. Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. *BMJ Neurology* 2012;12:40.

69 Ullberg T, Zia E, Petersson J. Perceived unmet rehabilitation needs 1 year after stroke: an observational study from the Swedish stroke register. *Stroke* 2016;47:539–41.

70 Iosa M, Lupo A, Morone G, *et al*. Post soft care: Italian implementation of a post-stroke checklist software for primary care and identification of unmet needs in community-dwelling patients. *Neurological Sciences* 2018;39:135–9.

71 De Bartolo D, Morone G, Lupo A. From paper to informatics: the post soft Care-App, an easy-to-use and fast tool to help therapists identify unmet needs in stroke patients. *Funct Neurol* 2018;33:200–5.

72 Kjörk EK, Carlsson G, Sunnerhagen KS, *et al*. Experiences using the poststroke checklist in Sweden with a focus on feasibility and relevance: a mixed-method design. *BMJ Open* 2019;9:e028218.

73 Groeneveld IF, Arwert HJ, Goossens PH, *et al*. The longer-term unmet needs after stroke questionnaire: cross-cultural adaptation, reliability, and concurrent validity in a Dutch population. *Journal of Stroke and Cerebrovascular Diseases* 2018;27:267–75.

74 Pierce LL, Finn MG, Steiner V. Families dealing with stroke desire information about self-care needs. *Rehabilitation Nursing* 2004;29:14–17.

75 Walsh ME, Galvin R, Loughnane C, *et al*. Community re-integration and long-term need in the first five years after stroke: results from a national survey. *Disabil Rehabil* 2015;37:1834–8.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

BMJ Open

Unmet care needs of community-dwelling stroke survivors: a protocol for systematic review and theme analysis of quantitative and qualitative studies

Beilei Lin,[1] Chunge Ding,[1] Yongxia Mei,[1] Panpan Wang,[1] Fayang Ma,[2] Zhen-Xiang Zhang[1]

¹Clinical 1 Teaching and Research Office, Nursing School, Zhengzhou University, Zhengzhou, Henan, China
²China-US (Henan) Hormel Cancer Institute, Zhengzhou University, Zhengzhou, Henan, China

Correspondence to
Professor Zhen-Xiang Zhang; zhangzx6666@126.com

ABSTRACT

Introduction Stroke is a leading cause of disability worldwide. The average hospital length of stay ranges from 3 to 28 days, and after discharge home the stroke survivors will live with physical, cognitive, even psychological disorders for the rest of their lives. It is essential to review the unmet needs of stroke survivors.

Methods and analysis A systematic review of previous quantitative and qualitative studies reporting the unmet needs of stroke survivors in their homes will be conducted. The following six databases will be searched from inception to December 2018 for relevant articles: PubMed, EMBASE, CINAHL, PsycINFO, SCOPUS and China Biology Medicine. We will include studies limited to human and published in English or Chinese, and the patients with stroke should discharge home rather than any other professional organisations including nursing homes or community rehabilitation units and so on. Data of quantitative research will be standardised for comparison, thematic analysis will be used for qualitative data and a narrative synthesis and pooled analysis of the main outcomes will be reported.

Ethics and dissemination This review will be submitted to an international professional journal, and the detailed search strategies and analysis flowchart will be openly included as supplements. This study does not require ethical approval as no patient's identifiable data will be used. Our findings will give a new look at the aspect of stroke survivors' unmet needs in their long-term recovery stage, especially the trajectories of unmet needs at different timepoints. What is more, this review will demonstrate the long-term unmet needs of stroke survivors from different countries, will compare any variations between high-income and low-income regions, and the geographical differences of needs will be mapped if necessary. We will endeavour to provide as much information as possible to healthcare professionals and public health policy makers in order to promote further medical reform.

Trial registration number CRD42018112181.

INTRODUCTION

Stroke is the third leading cause of death and the second leading cause of disability worldwide.[1] According to the study of the Global

Strengths and limitations of this study

► In contrast to other published reviews, this systematic review will be the first to synthesise in an organised way both qualitative and quantitative studies regarding the unmet needs of stroke survivors at home in their community.

► This review will search articles published both in English and Chinese, with our group taking the lead in systematically adding the Chinese research database and making this large body of data available to a non-Chinese speaking audience.

► We will describe the trajectories of stroke survivors' long-term unmet needs expecting that this will provide targeted intervention points to community health professionals and organisations.

► A possible limitation of this study is that this research of self-reported unmet needs may lead to an overly one-sided outcome, and may introduce selection and report bias, and we will not search the grey literature that may increase the risk of selection bias.

► Simultaneous integration of qualitative and quantitative findings may affect the comprehensiveness of the complex unmet needs of stroke survivors. However, standardised methods to be performed in this review have been used and evaluated in the process of other published systematic reviews.

Burden of Disease, the number of people with stroke increased by 68% between 1990 and 2010.[2] In some developed countries, stroke is the leading cause of disability, with an estimate that about 24%–74% of stroke survivors need long-term care. Moreover, some are even totally dependent on their caregivers because of their low level of ability with the activities of daily life.[3 4] Even worse, in some developing countries, over the past two decades, the intensity of the care burden of stroke has continued to increase, now comprising 75.2% of deaths and 81.0% of stroke-related disability-adjusted life years

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

(DALY).[5] It indicates that the global stroke epidemiology is changing rapidly. Although the age-standardised mortality and prevalence have declined,[1] the total number of people who live with stroke or die from stroke is increasing, especially with a serious trend towards younger adults, aged from 20 to 64 years.[6] Similarly, in China, the age-standardised mortality has tended to decline; but the total number of deaths shows a slow upward trend. Stroke is also the leading cause of death among rural residents and the third leading cause in urban areas.[7] In China, the DALY is much higher than that in developed countries. Compared with the UK or the USA, the proportional contribution of ischaemic stroke-related DALY due to stroke increased from 1016.10 to 1186.22 between the year 2005 and 2016.[1]

In this context, the global outlook for the total disease burden from stroke is a bit more humbling, for while there was a significant decline in developed countries, there have been obvious growth trends within low-income countries.[8] However, because of variations in limited medical resources, the average hospital length of stay ranged from 3 to 15.7 days, and showed great disparities between different countries.[9–13] A smaller number of patients, those with severe stroke, stayed in the hospital for 28 days or even longer.[9–13] The limited professional resources combined with high disability rate exacerbate the shortage of services needed. It is estimated that about 70% of stroke survivors lived with several different disorders. In sub-Saharan Africa, 82.3% (103/130) of the patients with stroke died by 7 years post-stroke, and the most significant predictive factor was functional ability.[14] For many survivors and their families, their lives are strongly affected by the long-term consequences of stroke, including physical disability, cognitive disorders and with difficulty in concentration, memory problems or even serious psychological problems. After 15 years follow-up, 63.1% of the survivors still had various levels of disability, with the prevalence of cognitive impairment at 30.0%, depression 39.1% and 34.9% with anxiety.[15] So, there remains a huge number of disabled people surviving in their home with stroke and its consequences. This will significantly affect their ability to carry out daily life or to cope with long-term care needs.

Unmet needs were defined as 'a need of something or help from someone (that would help overcome some of the effects of stroke and resulting difficulties) that is not being met'.[16 17] Various studies have investigated how long-term care needs were followed, including surveys of physical care needs, emotional needs, rehabilitation needs, educational needs, learning needs and so on[18–22]; and unmet needs of stroke survivors both in low-income and high-income countries have been surveyed.[9 12 16 23–27] Results showed that even in developed countries, the unmet needs still existed. According to the national survey of stroke needs in the UK, 49% reported unmet needs, and among those patients reporting unmet needs, 54% of them reported an unmet need for information[16]; for stroke survivors living in Australia, 84%–87%

of responders reported unmet needs in at least one aspect, in particular secondary prevention.[9 17]

A number of systematic reviews have summarised stroke survivors' or caregivers' experiences of primary care and community health,[28 29] the long-term needs of community dwelling stroke survivors with communication difficulties,[30 31] their social participation experiences[32] and the survivors' experience in trying to return to their work occupations.[33] Most of the reviews only focused on qualitative studies[30 33–37] concerning the views or experiences of long-term care, and concluded that stroke survivors and their caregivers feel abandoned because they have become marginalised by community health services or because they do not have the knowledge or skills to cope with long-term disabilities caused by stroke. Lee *et al* reviewed the most frequent long-term problems and coping strategies experienced by stroke survivors with search terms 'stroke', 'long-term', 'support', and 22 problems categorised into eight themes were identified.[38] However, according to the survey about perceptions of professionals and patients, the support needed by stroke survivors recognised by nurses or physicians is significantly different from the views from the patients' perspective.[39] So, we should not only pay attention to what healthcare providers see as the experiences or perceptions of stroke survivors', but also to these survivors' self-reported needs.

In conclusion, while systematic reviews of the experiences or needs of stroke survivors have been carried out, the unmet needs of community-dwelling stroke survivors need further targeting and intervention. In addition to the previous survey measurements, it appears that a new systematic review process will integrate a broader understanding of stroke survivors' unmet needs.[16 40 41] In addition, stroke survivors' needs change over time following their discharge from the hospital, with previous investigations of long-term care needs ranging from 2 weeks to more than 5 years.[42 43] Since new definitions of stroke recovery timepoints have been established and agreed on,[44] it is essential to review the unmet needs of patients with stroke at different stages. In the meantime, with the sharp shortage of community nurses or general practitioners,[45] it is ever more essential to identify and track the changing trends to understand stroke survivors' unmet needs at different stages, and to map the stroke survivors' unmet needs by means of systematic review from both a qualitative and a quantitative perspective.

METHODS AND ANALYSES
Patient and public involvement
This is a protocol of systematic review, and only published data will be analysed and synthesised; no new patient or public data will be involved in this study.

Study design
We will conduct a systematic review of studies reporting the unmet care needs of stroke survivors discharged from the hospital to home or any other place without

professional care provided. Both qualitative, quantitative and mixed methods of research will be included and analysed. This systematic review protocol will conform to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) Protocol and will be reported in accordance with the PRISMA statement.[46]

ELIGIBILITY CRITERIA
Type of studies
Eligible studies include qualitative, quantitative and mixed method research focused on unmet needs of stroke survivors live at homes rather than in any other institutionalised organisations.

Participants
We will include studies which recruited participants with a clinical diagnosis of stroke aged 18 years or over, regardless of ischaemic stroke, haemorrhagic stroke or transient ischaemic attack, as long as they were resident in a community setting and lived at home lonely or with others. We will include studies whether the unmet needs were investigated directly from stroke survivors or partly from them. We will exclude studies with subarachnoid haemorrhage, unless a subgroup of patients with stroke could be identified as separate results.

Issue of interest
The interest of this review are the unmet needs, perception and experience of patients with stroke after they discharge home. We will include studies focused on patients' needs outside the hospital, if some patients lived in institutions and others not, these studies will be included only if it is impossible to extract data separately.

Outcomes
The main outcome of this review is to evaluate the unmet needs of community-dwelling stroke survivors, including not only their self-reported needs, but also the challenges or problems they encountered. In the meantime, their satisfaction or suggestions to their local medical departments will be analysed for further discussion. Their social support needs may be classified as physical, psychological, emotional and informational, but with any other identified needs as well. We will include unmet needs self-reported by stroke survivors themselves or by their caregivers only if the survivors have difficulties in finishing the questionnaire without help. If the study shows factors influencing unmet needs, these can be analysed and summarised for further discussion.

Search strategies
"Stroke" terms based on a Cochrane review have been developed.[47 48] For "needs" and '"care needs", terms were based on a systematic review of unmet needs of people living with advanced cancer[49 50] or chronic liver disease,[51] "community" or "home" terms were based on systematic review of community-dwelling older people.[52] In addition, the search terms refer to a review protocol of unmet

needs of caregivers of stroke survivors.[53] The first step is to develop a search strategy on the PubMed database and to adapt it in accordance with other databases. The search strategy includes medical subject headings and free-text terms using applicable controlled vocabulary. The following electronic databases will be searched: PubMed, EMBASE, CINAHL(EBSCO), PsycINFO (EBSCO), SCOPUS and China Biology Medicine). Reference lists of included studies and relevant systematic reviews will be searched to identify additional studies for potential inclusion in this systematic review. Databases will be searched from October to December 2018, and the search strategy will be conducted monthly across databases to retrieve and screen relevant publications until completion of systematic review; furthermore, we aim to search all relevant studies, so there will no precise start date, generally from inception to December 2018.

The search terms for PubMed can be found in online supplement.

Screening the studies
All search results will be imported into Endnote 17.0 and we will remove duplications both automatically and manually. Two reviewers will independently assess the titles, abstracts and keywords of all selected research. The first step is to remove irrelevant studies by title, then by abstract and finally according to the main text of study. Studies will be limited to those published in English or Chinese and conducted among human subjects only; articles published in other languages, but with only their abstracts in English, will be excluded. If two reviewers have different opinions, a third reviewer will join in to resolve the disagreement.

Assessment of risk of bias and quality of included studies
We will undertake critical quality assessment to identify the characteristics, validity, strength and limitations of the included studies, rather than rating the evidence level or appraising quality of studies as exclusion criteria. In the meantime, the critical appraisal involves considering the risk of potential for selection bias, information bias, measurement bias and so on. Two reviewers will assess the methodological quality and bias of all studies, and, if any disagreement arises, a third reviewer will join in discussion.

Qualitative studies
To be eligible for inclusion in this review, studies must have used qualitative methods for data collection and data analysis. The Joanna Briggs Institute (JBI) critical appraisal instrument for qualitative research[54] will be used to assess the methodology quality and determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis, it is a 10-item tool that conducts comprehensive and critical appraisal of each research synthesis selected. It can help us to assess the congruity between research methodology and

research questions, data collecting methods, study design, data analysis and reporting quality and so on.

Quantitative studies

The 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' was developed by the National Heart, Lung, and Blood Institute (NIH).[55] It is a tool that we can use for quality assessment and contains 14 questions including research objective, study participation rate, sample size, independent and dependent variables, exposure measures and assessment, blinding of outcome assessors and the follow-up rate and so on.

Mix-method studies

We will justify the quality of mixed method studies by using the JBI critical appraisal instrument for research on qualitative components and the methodological assessment developed by NIH where appropriate, regarding quantitative components. The Mixed Methods Appraisal Tool[56] will be applied as a framework for quality appraisal and which has previously been used in a systematic review of unmet needs of patients with cancer conducted by Moghaddam.[50]

Data extraction

The main reviewer will extract data and establish a tabled file; the second reviewer will check the accuracy and other details independently. They will each discuss half of the findings, if any discrepancy exists or a final consensus cannot be reached, a third reviewer will check the records and join in the discussion to reach agreement. Qualitative data will be integrated in a systematic way, and quantitative results will be analysed and summarised. The main content extracted from the articles may include publication year, countries, research settings, sample characteristics, study methodology, primary outcomes and measurements and especially the unmet care needs and proportion of various needs. If the information provided in the main published articles is unclear, relevant articles will be searched or we will contact the author for online supplementary materials. All records will be kept during the full extracting process.

DATA ANALYSIS

Qualitative studies

Qualitative data will be thematically analysed by means of the qualitative meta-synthesis method that can systematically triangulate, and reintegrate the primary findings. We will integrate the content and analyse the theme based on the following questions: (1) What is the community-dwelling stroke survivors' health status and experience when they live at home? (2) What are their perceptions or concerns of the public health service or home care resource that available for them? (3) What needs of their daily life did they most mention? Specific codes or themes for unmet needs domains will be synthesised. Two

reviewers will discuss these items and if they cannot reach a consensus, a group discussion should occur.

Quantitative studies

For the quantitative studies reporting the unmet care needs of stroke survivors, we will categorise their unmet needs into physical, psychological, social aspects and so on, and then pool the proportions of different needs, and there will also be an examination of the influencing factors. If the multiple needs cannot be assigned into the above domains, an 'other aspect' will be developed. To facilitate comparison among different studies, we will try to refer to methods used by Lambert *et al*.[49] An average needs prevalence will be counted, with the result recalculated into a 100-point system, so that the average needs reported across studies can be compared. If there is any inconsistency, a third reviewer will join in the discussion.

Mix-method studies

Data of mix-method studies will be synthesised according to the above-mentioned methods of qualitative and quantitative studies. We have no plan to analyse the unmet needs of different subgroups if possible, but may just simply summarise, stratified by age, gender, discharge time or country.

Data combined strategies

For any critical differences, we will report the results of qualitative studies and quantitative studies separately in the results section with reference to previously published studies.[57 58] First, to answer the main research interest (unmet needs), we will extract original data including types, numbers, scores, proportions or frequency of needs reported in quantitative studies, then we will categorise all kinds of data into two types, unmet or met, finally we will report all unmet needs and the frequency mentioned by subjects stratified by discharge time and country. Second, to answer another question (perception or experience), we will use a thematic analysis and develop with an inductive approach, the target findings will be imported and structured by the analysis programme NVivo V.11.0. The main reviewer will extract original theme reported in qualitative studies, finish the free line-by-line coding to add new themes if they emerge during the process of analysis. A second reviewer will review the provisional thematic schema. Finally, for the mixed method research, quantitative and qualitative data will be extracted separately follow the procedures above.

DISCUSSION

This will be the first study to systematically review the unmet needs of community-dwelling stroke survivors by means of mix-methods including both qualitative and quantitative studies. It is also the first time that a database from China will be included. Evidence from this review will provide a view with a global scope of unmet needs of patients with stroke, and it will give recommendations for public health

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

policy makers or professionals to address their patients' needs. Stroke leads with the highest disability rate of any chronic disease However, limited medical resources have reduced the length of hospital stay of patients with stroke, especially in developing countries, and there is such a shortage of community public health resources that they cannot be allocated with priority to stroke survivors. A significant fraction of stroke survivors and caregivers feel being abandoned by their local community. So, if we can systematically analyse or summarise their unmet needs, it will promote a better distribution of medical resources, and subsequently improve the outcomes and quality of life community-dwelling patients with stroke.

Ethics and dissemination

This study will search the published papers and analyse the main research outcomes according to the PRISMA statement and checklist. So, there is no problem with protection of the subjects' privacy or rights, no patients and the public will not be involved in the design or planning of the study. At the conclusion of the study, we would like to publish this review in a peer-reviewed journal so the findings can be widely disseminated to provide a complete and comprehensive perspective for future research and reform conducted by governmental or non-governmental organisations.

REFERENCES

1. Feigin VL, Norrving B, Mensah GA. Global Burden of Stroke. *Circ Res* 2017;120:439–48.
2. Krishnamurthi RV, Feigin VL, Forouzanfar MH, *et al*. Global and regional burden of first-ever ischaemic and haemorrhagic stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet Glob Health* 2013;1:e259–e281.
3. Miller EL, Murray L, Richards L, *et al*. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. *Stroke* 2010;41:2402–48.
4. Jamison J, Ayerbe L, Di Tanna GL, *et al*. Evaluating practical support stroke survivors get with medicines and unmet needs in primary care: a survey. *BMJ Open* 2018;8:e019874.
5. Feigin VL, Krishnamurthi RV, Parmar P, *et al*. Update on the Global Burden of Ischemic and Hemorrhagic Stroke in 1990-2013: The GBD 2013 Study. *Neuroepidemiology* 2015;45:161–76.
6. Krishnamurthi RV, Moran AE, Feigin VL, *et al*. Stroke Prevalence, Mortality and Disability-Adjusted Life Years in Adults Aged 20-64 Years in 1990-2013: Data from the Global Burden of Disease 2013 Study. *Neuroepidemiology* 2015;45:190–202.
7. Wang W, Jiang B, Sun H, *et al*. Prevalence, Incidence, and Mortality of Stroke in China: Results from a Nationwide Population-Based Survey of 480 687 Adults. *Circulation* 2017;135:759–71.
8. Kim AS, Cahill E, Cheng NT. Global Stroke Belt: Geographic Variation in Stroke Burden Worldwide. *Stroke* 2015;46:3564–70.
9. Olaiya MT, Cadilhac DA, Kim J, *et al*. Long-term unmet needs and associated factors in stroke or TIA survivors: An observational study. *Neurology* 2017;89:68–75.
10. Jerome D, Dehail P, Daviet JC, *et al*. Stroke in under-75-year-olds: expectations, concerns and needs. *Ann Phys Rehabil Med* 2009;52:525–37.
11. Forster A. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *Clin Rehabil* 2013;27:1020–8.
12. Boerboom W, Heijenbrok-Kal MH, van Kooten F, *et al*. Unmet needs, community integration and employment status four years after subarachnoid haemorrhage. *J Rehabil Med* 2016;48:529–34.
13. Yagi M, Yasunaga H, Matsui H, *et al*. Impact of Rehabilitation on Outcomes in Patients With Ischemic Stroke: A Nationwide Retrospective Cohort Study in Japan. *Stroke* 2017;48:740–6.
14. Walker RW, Wakefield K, Gray WK, *et al*. Case-fatality and disability in the Tanzanian Stroke Incidence Project cohort. *Acta Neurol Scand* 2016;133:49–54.
15. Crichton SL, Bray BD, McKevitt C, *et al*. Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health. *J Neurol Neurosurg Psychiatry* 2016;87:1091–8.
16. McKevitt C, Fudge N, Redfern J, *et al*. Self-reported long-term needs after stroke. *Stroke* 2011;42:1398–403.
17. Andrew NE, Kilkenny M, Naylor R, *et al*. Understanding long-term unmet needs in Australian survivors of stroke. *Int J Stroke* 2014;9 Suppl A100:106–12.
18. Allgeier C, Kämmerle-Hofrichte I, Braun S, *et al*. [Determining the support needs of patients who live at home following a stroke]. *Pflege* 2005;18:373–80.
19. Andrew NE, *et al*. Differences in long-term unmet needs between younger and older stroke survivors. *Cerebrovascular Diseases* 2013;35:791.
20. Bernikier D, Sautreau R, Kammoun B, *et al*. Educational needs of post-stroke patients and their caregivers. *Ann Phys Rehabil Med* 2013;56:e144.
21. Brandriet LM, Lyons M, Bentley J. Perceived needs of poststroke elders following termination of home health services. *Nurs Health Care* 1994;15:11.
22. Yoon S, *et al*. Post stroke culturally-sensitive care needs: Comparison of functioning and disability and contextual factors among hispanic and non-hispanic urban dwellers. *Cerebrovascular Diseases* 2012;33:485–6.
23. Johnson J, Pearson V, McDivitt L. Stroke rehabilitation: assessing stroke survivors' long-term learning needs. *Rehabil Nurs* 1997;22:243–8.
24. Ward A, Payne KA, Caro JJ, *et al*. Care needs and economic consequences after acute ischemic stroke: the Erlangen Stroke Project. *Eur J Neurol* 2005;12:264–7.
25. Ullberg T, Zia E, Petersson J, *et al*. Perceived unmet rehabilitation needs 1 year after stroke: An observational study from the swedish stroke register. *Stroke* 2016;47:539–41.
26. Iosa M, Lupo A, Morone G, *et al*. Post soft care: Italian implementation of a post-stroke checklist software for primary care and identification of unmet needs in community-dwelling patients. *Neurol Sci* 2018;39:135–9.
27. Magaard G, Wester P, Levi R, *et al*. Identifying unmet rehabilitation needs in patients after stroke with a graphic rehab-compass™. *J Stroke Cerebrovasc Dis* 2018;27:3224–35.
28. Pindus D, *et al*. The experiences ofand need for primary careand community health services in informal carers of stroke survivors - A systematic qualitative review. *European Stroke Journal* 2016;1:570–1.
29. Pindus DM, Mullis R, Lim L, *et al*. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS One* 2018;13.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Open access

30. Wray F, Clarke D, Forster A. The needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies. *International Journal of Stroke* 2016;11:49.

31. Wray F, Clarke D. Longer-term needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *BMJ Open* 2017;7:e017944.

32. Woodman P, Riazi A, Pereira C, *et al*. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil* 2014;36:2031–43.

33. Williams S, Murray C. The experience of engaging in occupation following stroke: A qualitative meta-synthesis. *British Journal of Occupational Therapy* 2013;76:370–8.

34. Kamel AA, Bond E, Froelicher ES. Stroke patients' caregivers: Their experiences and needs: A qualitative literature review. *Jordan Medical Journal* 2009;43:341–50.

35. Quinn K, Murray C, Malone C. Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disabil Rehabil* 2014;36:185–98.

36. Pindus D, *et al*. Stroke survivors' experiences of and need for primary care and community health services - A systematic review of the qualitative literature. *European Stroke Journal* 2016;1:570.

37. Lloyd A, Bannigan K, Sugavanam T, *et al*. Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation: a systematic review of qualitative evidence. *JBI Database System Rev Implement Rep* 2018;16:1418–53.

38. Lee N, Aries A, Hunter S. The long-term needs of stroke survivors: A systematic review. *International Journal of Stroke* 2014;9:42.

39. Vincent C, Deaudelin I, Robichaud L, *et al*. Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC Geriatr* 2007;7:20.

40. Andrew NE, *et al*. Long-term unmet needs of community dwelling stroke survivors and carers in Australia. *Cerebrovascular Diseases* 2013;35:792.

41. De Bartolo D, Morone G, Lupo A, *et al*. From paper to informatics: the Post Soft Care-App, an easy-to-use and fast tool to help therapists identify unmet needs in stroke patients. *Funct Neurol* 2018;33:200–5.

42. Walsh ME, Galvin R, Loughnane C, *et al*. Community re-integration and long-term need in the first five years after stroke: results from a national survey. *Disabil Rehabil* 2015;37:1834–8.

43. Crow J. A 2-week stroke review identifies unmet needs in patients discharged home from a hyperacute stroke unit. *British Journal of Neuroscience Nursing* 2018;14:29–35.

44. Bernhardt J, Hayward KS, Kwakkel G, *et al*. Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. *Int J Stroke* 2017;12:444–50.

45. Dugani S, Afari H, Hirschhorn LR, *et al*. Prevalence and factors associated with burnout among frontline primary health care providers in low- and middle-income countries: A systematic review. *Gates Open Res* 2018;2:4.

46. Moher D, Shamseer L, Clarke M, *et al*. *Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement*. *Syst Rev* 2015;4:1.

47. Cheng D, Qu Z, Huang J, *et al*. Motivational interviewing for improving recovery after stroke. *Cochrane Database Syst Rev* 2015;6:Cd011398.

48. Bridgwood B, Lager KE, Mistri AK, *et al*. Interventions for improving modifiable risk factor control in the secondary prevention of stroke. *Cochrane Database Syst Rev* 2018;5:Cd009103.

49. Lambert SD, Harrison JD, Smith E, *et al*. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support Palliat Care* 2012;2:224–30.

50. Moghaddam N, Coxon H, Nabarro S, *et al*. Unmet care needs in people living with advanced cancer: a systematic review. *Support Care Cancer* 2016;24:3609–22.

51. Valery PC, Powell E, Moses N, *et al*. Systematic review: unmet supportive care needs in people diagnosed with chronic liver disease. *BMJ Open* 2015;5:e007451.

52. Menz HB, Auhl M, Spink MJ. Foot problems as a risk factor for falls in community-dwelling older people: A systematic review and meta-analysis. *Maturitas* 2018;118:7–14.

53. Denham AMJ, Baker AL, Spratt N, *et al*. The unmet needs of informal carers of stroke survivors: a protocol for a systematic review of quantitative and qualitative studies. *BMJ Open* 2018;8:e019571.

54. . Institute, T.J.B. JBI critical appraisal instrument for qualitative research. 2017. (cited 4 Dec 2018); Available from: https://wiki.joannabriggs.org/display/MANUAL/2.6.6+Assessment+of+methodological+quality.

55. National Heart, L., and Blood Institue. Study quality assessment tools. 2018 (cited 29 Nov 2018).

56. Souto RQ, Khanassov V, Hong QN, *et al*. Systematic mixed studies reviews: updating results on the reliability and efficiency of the Mixed Methods Appraisal Tool. *Int J Nurs Stud* 2015;52:500–1.

57. Gardner T, Refshauge K, Smith L, *et al*. Physiotherapists' beliefs and attitudes influence clinical practice in chronic low back pain: a systematic review of quantitative and qualitative studies. *J Physiother* 2017;63:132–43.

58. van den Berg MMJ, Dancet EAF, Erlikh T, *et al*. Patient-centered early pregnancy care: a systematic review of quantitative and qualitative studies on the perspectives of women and their partners. *Hum Reprod Update* 2018;24:106–18.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance
placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Supplement 2

PUBMED SEARCH Strategies

The first-round search before December, 2018.

Search	Query	Items found	Time
#15	#14 Filters: **English**	315	23:48:32
#14	#13 Filters: **Humans**	352	23:42:15
#13	#5 AND # 9 AND #12	389	23:42:09
#12	#10 OR #11	482836	23:41:17
#11	Search **(need*[Title] OR demand*[Title] OR requirement*[Title] OR wish*[Title] OR experience[Title] OR challenge*[Title])**	442378	23:40:28
#10	Search **(Health Services Needs and Demand[MeSH Terms])**		
#9	#6 OR #7 OR #8	925190	23:36:16
#8	Search **(Community[Title/Abstract] OR Home[Title/Abstract] OR Outpatient*[Title/Abstract])**	728095	23:35:31
#7	Search **Outpatients[MeSH Terms]**	13862	23:33:14
#6	Search **((Community Health Services[MeSH Terms]) OR Home Health Nursing[MeSH Terms]) OR Home Nursing[MeSH Terms]**	283066	23:25:43
#5	#1 OR #2 OR #3 OR #4	270387	23:23:40
#4	Search **((cerebral[Title] OR cerebellar[Title] OR brain*[Title] OR vertebrobasilar[Title])) AND (accident*[Title] OR hemorrhag*[Title])**	8234	23:23:14
#3	Search **((cerebral[Title] OR cerebellar[Title] OR brain*[Title] OR vertebrobasilar[Title])) AND (infarct*[Title] OR ischemi*[Title] OR thrombo*[Title] OR apoplexy[Title] OR emboli*[Title])**	38477	23:21:52
#2	Search **(((((cva*[Title] OR stroke*[Title] OR poststroke*[Title] OR post-stroke*[Title] OR post stroke*[Title] OR transient ischemic attack*[Title] OR TIA*[Title] OR ministroke*[Title] OR mini stroke*[Title] OR SAH[Title])))))**	96618	23:19:45

Search	Query	Items found	Time
#1	Search ((((Stroke[MeSH Terms]) OR Basal Ganglia Hemorrhage[MeSH Terms]) OR Brain Ischemia[MeSH Terms]) OR (Intracranial Embolism and Thrombosis[MeSH Terms])) OR Intracranial Hemorrhages[MeSH Terms]	230804	23:09:26

The second-round search on February 28th, 2020

Search	Add to builder	Query	Items found	Time
#17	Add	Search ((((((need*[Title] OR demand*[Title] OR requirement*[Title] OR wish*[Title] OR experience[Title] OR challenge*[Title]))) OR ((Health Services Needs and Demand[MeSH Terms])))) AND (((((Community[Title/Abstract] OR Home[Title/Abstract] OR Outpatient*[Title/Abstract])) OR Outpatients[MeSH Terms]) OR (((Community Health Services[MeSH Terms]) OR Home Health Nursing[MeSH Terms]) OR Home Nursing[MeSH Terms]))) AND (((((((cerebral[Title] OR cerebellar[Title] OR brain*[Title] OR vertebrobasilar[Title])) AND (accident*[Title] OR hemorrhag*[Title])) OR (((cerebral[Title] OR cerebellar[Title] OR brain*[Title] OR vertebrobasilar[Title])) AND (infarct*[Title] OR ischemi*[Title] OR thrombo*[Title] OR apoplexy[Title] OR emboli*[Title]))) OR ((((((cva*[Title] OR stroke*[Title] OR poststroke*[Title] OR post-stroke*[Title] OR post stroke*[Title] OR transient ischemic attack*[Title] OR TIA*[Title] OR ministroke*[Title] OR mini stroke*[Title] OR SAH[Title]))))))) OR (((((Stroke[MeSH Terms]) OR Basal Ganglia Hemorrhage[MeSH Terms]) OR Brain Ischemia[MeSH Terms]) OR (Intracranial Embolism and Thrombosis[MeSH Terms])) OR Intracranial Hemorrhages[MeSH Terms])) Filters: **Humans; English**	347	03:14:3

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Supplement 3

Details of unmet needs extracted from included studies

No.	Year-First Author	Country	Sample size	Age	Time science stroke	Measures	Unmet needs (category)	UM-total
1	2012-Tistad M	Sweden	175	68(14)	1 year	Single item	33% unfulfilled rehabilitation needs	
2	2016-Ullberg T	Sweden	37383	75.3/71.5	1 year	Single item	21.5% unmet rehabilitation needs	
3	2017- Lee K	South Korea	1099	77.2(6.7)	NG	Sing item	53.07% Home care rehabilitation needs	Transformed data
4	2019-Vyas MV	Canada	5976	40-	NG	Single item	15.08% The unmet health care needs were	
5	2019-Lehnerer S	Germany	57	69.3(9.8)	2-3y	Nikolaus-score	43% social unmet needs	Totally 97 unmet needs
6	1999-Scholte Op Reimer WJM	Netherlands	382 224	<=69 186 >69 196	6 months	Semi-structured questionnaire	1) 8% Psychosocial support 2) 8% Physical therapy 3) 7% Home adaption 4) 6% Outdoor mobility 5) 5% ADL care 6) 5% Home help 7) 5% Aids 8) 0% Nursing care	31% perceived at least one unmet care needs 45% perceived a demand for more types of care
					5 years		1) 12% Home help 2) 1% Sociocultural care 3) 1% Day care	20% perceived at least one unmet need
7	2009-Jerome D	France	61	64(8.5)	1-2 years Mean 17 months	Non-structured questionnaire	1) 47% Family help 2) 45.9% External human help 3) 37% Instrumental device 4) 10% Information	54.1% need more help 41% depression
8	2000-Nilsson AL	Sweden	68	53	2 years	A checklist with	1) 66% Special support and service	

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance
placed on this supplemental material which has been supplied by the author(s)

BMJ Open

						15 areas	2) 62% Leisure/spare time 3) 49% Diet/weight/exercise 4) 44% Social function 5) 41% Support to caregivers 6) 38% Self-care 7) 32% Housing 8) 32% Transportation 9) 29% Consultation with specialists 10) 28% Communication 11) 24% Mobility outdoors 12) 21% Economic counseling 13) 18% Work/education 14) 10% Cognitive function 15) 10% Mobility indoors	
9	2004-Boter H	Netherlands	166	64	< 6 months	A checklist with wide range	1) 92% Physical problems 2) 60% Emotional problems 3) 48% Cognitive problem 4) 40% Disease prevention 5) 31% Mobility 6) 23% Handicap 7) 22% services 8) 16% IADL 9) 3% Behavior problems	97.59% reported problems totally 1419, Median number was 8 (5-11)
10	2002-Kersten P	UK	315	55	>1 year mean 3 years	Southampton Needs Assessment Questionnaire	1) 45% Information needs (cause21, prevent19 treatment14, recovery13) 2) 24% Assistances with finance	Median number was 2 (0-6) 70% report unmet needs

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

						(SNAQ)	3) 19% Social activities 4) 17% Intellectual fulfilment 5) 16% Adaptations 6) 16% Vehicles 7) 15% Social life 8) 15% Physiotherapy	
11	2003-Low JT	UK	135	52	Mean 3 years	SNAQ	1) 57% Information needs (cause34, prevention23 getting back to work19, recovery 20) 2) 34% Intellectual fulfillment 3) 33% Physiotherapy 4) 33% Help with finance 5) 33% Assistance with non-care activities	88% reported unmet needs
12	2016-Boerboom W **(email contact)**	Netherlands	67	52.5(10.7)	4 years	SNAQ	1) 67.2% Total unmet needs 2) 59.7% Information need 3) 20.9% Formal social services 4) 19.4% Mobility 5) 14.93% Voluntary Organizations 6) 13.43% Formal Health Services 7) 11.94% Housing 8) 11.94% Family 9) 10.45% Working or Training 10) 8.96% Social activities 11) 5.97% Finances	67.2% had one or more unmet needs. Mean number of um was 3.5/ median of 2 (0-6) 23.9% depression 43.3% had mild cognitive impairment 67.2% were unemployed
13	2014-Ward AB	UK	42	72(8.1)	8-60m	Post stroke checklist (PSC)	1) 75.6% Cognition	

							2) 73.2% Mood	
							3) 70.7% Life after stroke	
							4) 65.9% Spasticity	
							5) 63.4% Absence of Secondary prevention	
							6) 56.1% Mobility	
							7) 51.2% ADLs	
							8) 43.9% Communication	
							9) 41.5% Continence	
							10) 39.0% Pain	
							11) 29.3% Carer relationship	
			Singapore	100	61(10.9)	9-36m	PSC	1) 24.0% Cognition	
								2) 21.3% Mood
								3) 21.3% Pain
								4) 17.3% Mobility
								5) 16.7% Life after stroke
								6) 14.7% Spasticity
								7) 12.0% ADLS
								8) 11.3% Continence
								9) 10.0% Carer Relationship
								10) 9.3% Absence of secondary prevention
								11) 7.3% Communication
14	2018-Crow J	UK	21	72	2 weeks	PSC 12 items	1) 28.57% mood	52% participants identified unmet needs
							2) 23.80% secondary prevention	Median number 3
							3) 19.04% cognitive impairments	
							4) 19.04% ADLs	

						5) 14.26% Pain 6) 14.26%Mobility 7) 14.26%Life after stroke 8) 19.04%Spasticity 9) 9.52% relationships with family 10) 4.76% Communication 11) 4.76% Incontinence 12) 4.76% Sexuality	(1-6) 48% participants needed referral to local neurorehabilitation teams.
15	2018-Iosa M	Italy	64	69.17(12.39)	3.5m-15 years 38.4(30.4)m	PSC	1) 53.1% Mobility 2) 50% Mood 3) 43.7% ADL 4) 42.2% Spasticity 5) 40.6% Absence of Secondary prevention 6) 37.5% Pain 7) 34.4% Cognition 8) 28.1% Continence 9) 26.6% Communication 10) 26.6% Life after stroke, sex 11) 21.9% Carer relationship	
16	2018-De Bartolo D	Italy	53	65.76(13.50)	3.3m-21 years	PSC	1) 56.6% Increased spasticity 2) 45.28% Secondary prevention 3) 45.28% Mobility 4) 47.17% Reduced independence in ADL 5) 45.28% Reduced mobility 6) 43.40% Cognition 7) 41.51% Mood	on phone

						8) 32.08% Carer relationship 9) 33.96% Communication 10) 30.19% Continence 11) 22.64% Life after stroke, sex	
17	2018-Hotter B **(email contact)**	Germany	57	69.3(9.8)	2-3y	PSC	1) 61% Cognitive deficits 2) 35% Spasticity 3) 20% Depression 4) 18% Social needs 5) 14% Medication compliance	95% report at least one unmet need
18	2019- Kjörk EK	Sweden	46	70(41-85)	3m (1-84)	PSC	1) 61% Life after stroke 2) 56% Cognition 3) 41% Mood 4) 39% ADL 5) 30% Secondary prevention 6) 33% Mobility 7) 26% Communication 8) 24% Spasticity 9) 24% Pain 10) 20% Relationship with family 11) 17% Incontinence	87% have problems Median 4 problems/patients 30% need information about secondary prevention
19	2011-Mckevitt C	UK	799	69.9(12.3) 66.3(13.0)	1 year	Questionnaire of Long-term care needs	1) 59% Memory problem unmet 2) 54% Information needs cause, prevention re 3) 43% Concentration problem 4) 43% Fatigue problem 5) 39% Emotional problem needs unmet	Definition of Unmet needs 51% reported no unmet needs Median number of

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

						6) 34% Reading difficulty 7) 28% Speaking difficulty 8) 26% Sight problems 9) 25% Mobility problem 10) 21% Falls 11) 21% Incontinence problems 12) 15% Pain problems	unmet needs was 3 (1-13)
20	2013- Rothwell K	UK	137	72.6(40-93)	6 months	Greater Manchester Stroke Assessment Tool GM-SAT	1) 34.3% Fatigue 2) 25.5% memory, concentration and attention 3) 21.9% Secondary prevention non-lifestyle 4) 19.0% Depression. 5) 18.2% Benefits and finances 6) 13.1% Exercise 7) 7.3% Smoking 8) 6.6% Diet 9) 4.4% Nutrition 10) 5.1% Alcohol 11) 2.9% Medication management 12) 1.5% Foot care 13) 0.7% Will-Walking	92% has unmet needs Mean number of unmet needs was 3 (0-14) Totally 464 unmet needs
21	2018-Groeneveld IF	Dutch	78 (resp 53.8%)	61.7(13.8)	5-8 years	the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool	1) 46.2% Information on stroke 2) 21.8% Fear of falling 3) 21.8% Help with concentration/ memory 4) 19.2% Difficulties walking 5) 16.7% Help with applying for benefits	median number of unmet needs was 3.5 (2.0-5.0; 1.0-14.0) 67.9% indicated

						6) 16.7% Medication/blood checkup 7) 15.4% Help with mood 8) 14.1% Pain 9) 14.1% Bladder or bowel problems 10) 12.8% Advice on diet 11) 11.5% Information on holidays 12) 11.5% Information on public transport 13) 10.3% Help in household 14) 10.3% Need for aids/adaptations inside 15) 10.3% Help with personal care 16) 10.3% Advice on daily occupations 17) 7.7% Information on moving to another home 18) 5.1% Help with managing money 19) 3.8% Advice on physical relationship 20) 2.6% Need for aids/adaptations outsides 21) 2.6% Information on driving	having 1 or more unmet needs
22	2020- Ytterberg C	Sweden	110	63	>6 years	Stroke Survivor Needs Survey Questionnaire (SSNSQ)	1) 47% Fatigue problem 2) 45% Mobility problem 3) 35% Concentration problems 4) 30% Falls 5) 29% Emotion problem 6) 29% Memory problems 7) 22% Incontinence problem 8) 22% Speaking difficulties 9) 19% Pain	Rehabilitation needs

							10) 18% Sight difficulties	
							11) 12% Reading difficulties	
23	2004-Pierce LL	USA	24	56	NG	Questionnaire of self-care needs	1) 71% Preventing falls 2) 63% Maintaining adequate nutrition 3) 63% Staying active 4) 58% Managing stress 5) 50% Dealing with emotional and mood changes 6) 46% Managing roles 7) 46% Learning activities to increase dexterity, memory 8) 42% Preventing constipation or elimination 9) 42% Understanding stroke diseases 10) 38% Dealing with communication problems 11) 38% Dealing with behavior 12) 29% Learning about exercise	
24	2010-Bai GF	China	346	60	All	Questionnaire	1) 83.82% Information 2) 78.03% Community rehabilitation 3) 39.02% Psychological care needs 4) 37.57% Social participation skills 5) 23.99% Transform help 6) 77.75% Mobility 7) 63.01% Self-care needs 8) 42.77% Walking instrument 9) 34.97% Cognitive 10) 30.55% Tableware modification	

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

						11) 27.75% Acupuncture	
						12) 11.56% Swallowing	
25	2011-Jiang H	China	110	67.47(12.02)	7 (1-12) m	Questionnaire	1) 70.9% Mobility 2) 60.9% Self-care ability training needs 3) 47.59% Rehabilitation needs	
26	2012-Zhang ZX	China	177	67.3(10.8)	>1 year	Questionnaire	1) 72.73% Information 2) 64.19% Rehabilitation needs 3) 68.13% Social support	
27	2012-Gao CH	China	127	62.61	All	Questionnaire	1) 96.85% Information 2) 75.59% Community rehabilitation 3) 77.17% Physical therapy 4) 44.09% Acupuncture or massage 5) 25.19% Psychological care needs	
28	2015-Walsh ME	Ireland	196	61.9(13.9) 24-89	3m-19years	Questionnaire	1) 77% information about secondary prevention 2) 68% Information about cause 3) 68% information about diet 4) 66.7% help with housing tasks 5) 53% Emotions 6) 52% fatigue 7) 50% need help with personal care 8) 48% concentration 9) 48% writing 10) 45% bladder/bowel 11) 45% memory 12) 40% reading 13) 39% arm function	78% having unmet health needs median number of unmet needs was 3 (1-5)

							14) 34% falling 15) 32% speech 16) 32% mobility 17) 31% swallowing 18) 27% sight 19) 25% pain	
29	2014-Andrew NE	Australia	765	68	2 years M	Questionnaire	1) 84% Health domain 2) 60% Work domain 3) 52% Support domain 4) 38% Financial domain 5) 34% Living domain	84% reported needs not be fully met median number of needs was 4 of 20)
							1) 78% Concentration 2) 77% Memory 3) 75% Fatigue 4) 73% Emotions 5) 75% Cognition 6) 69% Reading 7) 64% Vision 8) 58% Speech 9) 54% Pain 10) 53% Transport 11) 52% Incontinence 12) 46% Falls 13) 46% Mobility 14) 44% Swallowing	

							15) 64% Leisure needs 16) 39% Home help 17) 19% home adaptation 18) 17% Personal care	
30	2016-Kamalakannan S	India	50	58.9(10.5)	<6 weeks	Questionnaire	1) 82.0% Information needs 2) 70.9% Financial needs 3) 63.6% Physical symptoms 4) 59.1% Rehabilitation services 5) 58.3% Community support 6) 52.4% Psychological needs 7) 50.0% Transfers and mobility 8) 46.7% Social/recreational needs 9) 33.4% Employment needs 10) 31.6% Self-care needs 11) 24.0% Social interaction 12) 23.1% Home management	82% unmet needs
31	2017- Olaiya MT	Australia	335	73 M	>2 year	Questionnaire self-administered	1) 72.5% Secondary prevention 2) 60.6% Body function 3) 50.6% Post-acute care 4) 50.0% Activities and participation 5) 42.7% Environmental factors	87.6% reported at least one unmet need
32	2018-Jamison J	UK	596	72.7	7.7m	Questionnaire	1) 49.8% Prescriptions and collection of medicines 2) 36.4% Reminding to take medicines 3) 34.1% Checking that medicines have been	44.5% reported unmet needs at least one aspect of taking medication

						taken	
						4) 20.2% Swallowing medicines	
						5) 27.9% Getting medicines out of the box or packet	
						6) 34.7% Missing taking their medicines.	