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

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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.

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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

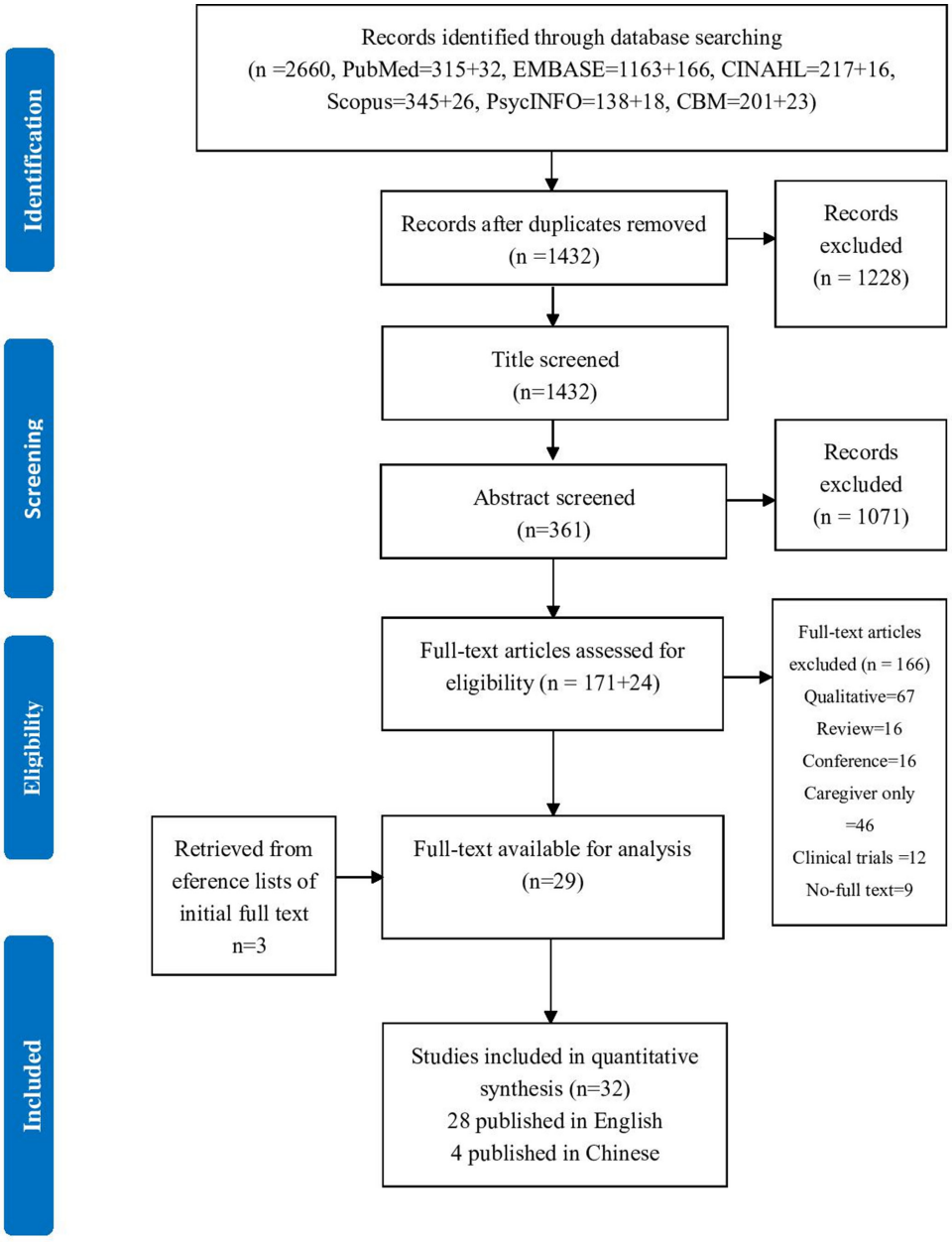

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow of this systematic review.

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	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
				5 years		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	>1 year, 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	42	72 (8.1)	8–60 months	PSC	11 categories of unmet needs were identified
	Singapore	100	61 (10.9)	9–36 months		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

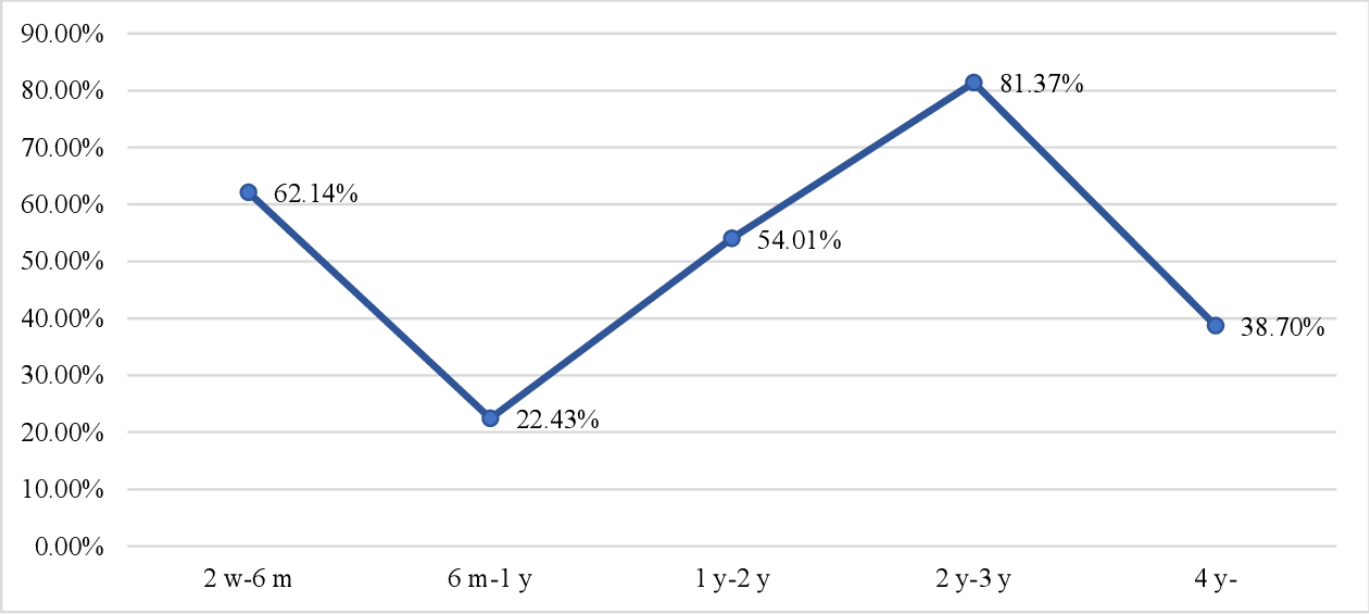

Figure 2 Pooled prevalence of unmet needs after stroke.

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

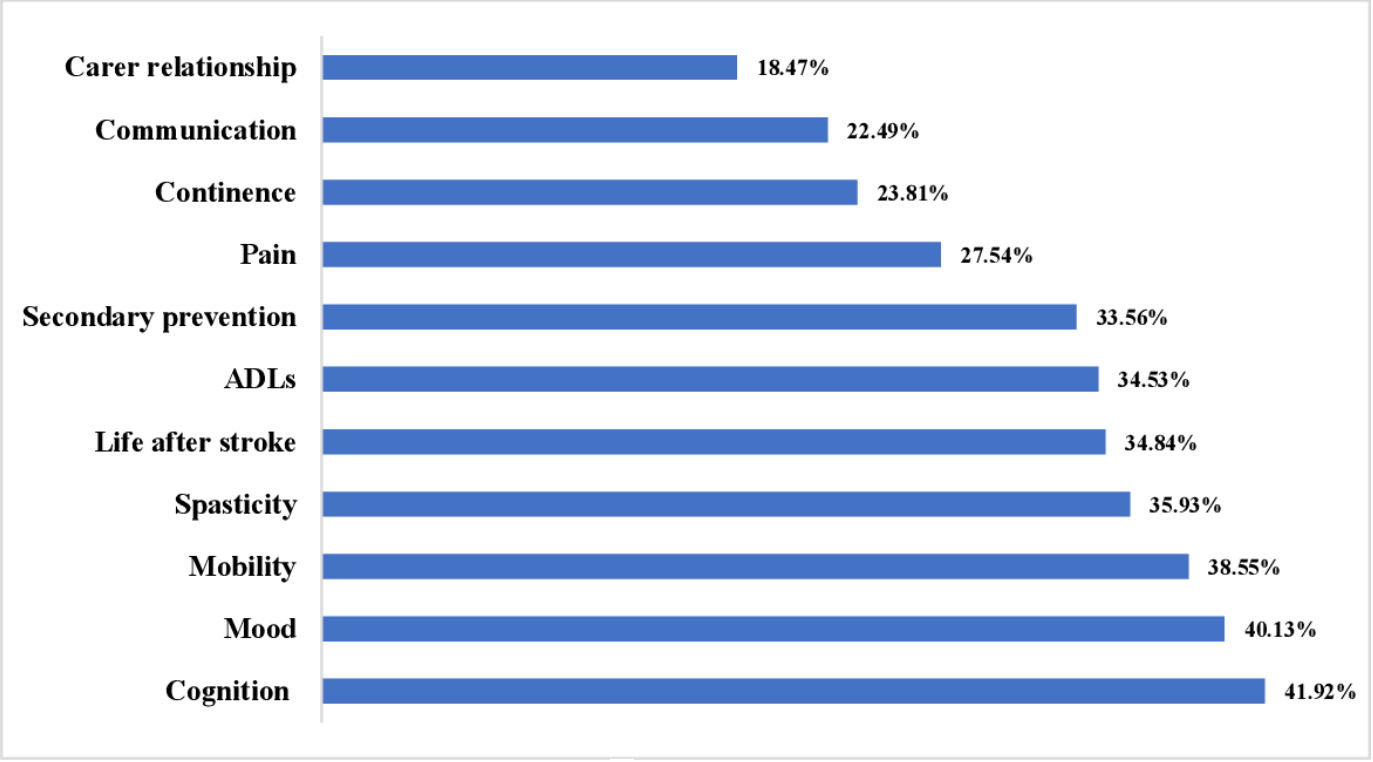

Figure 3 Unmet needs identified according to post-stroke checklist. ADLs, activities of daily living.

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.

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