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**THE UNMET NEEDS OF STROKE SURVIVORS AND STROKE CAREGIVERS:**  
**A SYSTEMATIC NARRATIVE REVIEW**  
 --Manuscript Draft--

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<b>Abstract:</b>	<p><b>Introduction:</b> Facilitating stroke survivors and their caregivers to lead a fulfilling life after stroke requires service providers to think about their different needs. Poor post stroke care may lead to unmet needs in stroke survivors and stroke caregivers. This may compromise them in leading their lives optimally after stroke.</p> <p><b>Objectives &amp; Methodology:</b> This systematic narrative review examines articles published from 1990 to 2017, generated from Ovid, MEDLINE, CINAHL, and PubMed. The search was also supplemented by an examination of reference lists for related articles via Scopus. We included 105 articles.</p> <p><b>Findings:</b> We found that the type of unmet needs in stroke survivors and the contributing factors were substantially different from their caregivers. The unmet needs in stroke survivors ranged from health-related needs to re-integration into the community; while the unmet needs in stroke caregivers ranged from information needs to support in caring for the stroke survivors and caring for themselves. Additionally, the unmet needs in both groups were associated with different factors.</p> <p><b>Conclusion:</b> More research is required to understand the unmet needs of stroke survivors and stroke caregivers to improve the overall post-stroke care services.</p>

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Dr José Biller  
*Editor*  
*Journal of Stroke & Cerebrovascular Disease*

3<sup>rd</sup> April 2020

*Dear Dr Biller*

I am pleased to submit the second revision of our manuscript on systematic narrative review entitled "The Unmet Needs of Stroke Survivors and Caregivers: A Systematic Narrative Review".

We thank you for your consideration to publish our work.

Sincerely,



NOR SHAHRINA MOHD ZAWAWI  
Corresponding Author /  
PhD Student  
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## THE UNMET NEEDS OF STROKE SURVIVORS AND STROKE CAREGIVERS: A SYSTEMATIC NARRATIVE REVIEW

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## **GRANT SUPPORT**

This narrative systematic review was conducted as part of doctorate studies. We thank the University of Nottingham UK for awarding the “Stroke Rehabilitation PhD Studentship: Nottingham UK and Malaysia Collaboration” that allows studies on unmet needs of a stroke population be conducted in Malaysia

## **SHORTENED VERSION OF TITLE**

UNMET NEEDS OF STROKE SURVIVORS AND CAREGIVERS

## **KEYWORDS**

Unmet needs

Stroke

Stroke survivors

Stroke caregivers

Long-term stroke care

**MANUSCRIPT REVISION CHECKLIST (SECOND REVISION)**

**THE UNMET NEEDS OF STROKE SURVIVORS AND STROKE CAREGIVERS:  
A SYSTEMATIC NARRATIVE REVIEW (REF: JSCVD-D-19-01600)**

<b>Reviewer 1</b>		
<b>Comments</b>	<b>Status of action</b>	<b>Remark</b>
Add (Table 5) in the draft with a line	Completed	-
Remove unnecessary old references	Completed	
<b>Reviewer 2</b>		
<b>Comments</b>	<b>Status of action</b>	<b>Remark</b>
Methods: Please specifically clarify how reporting bias was assessed	Completed	
Methods: Please expand as a Random Effects Meta-Analysis can be used in this setting	-	Random effect meta-analysis was not applied in this review as we conducted only narrative review with descriptive analysis in most section. this is in line with our method of article selection, as we include both quantitative and qualitative studies
Review text: check for errors of grammar, syntax and usage	Completed	
References are formatted in a different font than the text	Completed	-

**PREFERRED REPORTING ITEMS FOR SYSTEMATIC REVIEW AND META-ANALYSIS PROTOCOLS  
(PRISMA-P) 2015 CHECKLIST**

SECTION & TOPIC	ITEM NO	CHECKLIST ITEM	REMARK
<b>ADMINISTRATIVE INFORMATION</b>			
Title identification	1a	Identify the report as a protocol of a systematic review.	Completed.
Title update	1b	If the protocol is for an update of a previous systematic, identify as such.	Not applicable
Title registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number.	Completed.
Authors contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding authors.	<b>Completed</b>
Authors contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review.	Completed
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting protocol amendments.	Not applicable
Support: Sources	5a	Indicate sources of financial or other support for the review.	Completed
Support: Sponsor	5b	Provide name for the review funder and/or sponsor.	Completed
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol.	Not applicable
<b>INTRODUCTION</b>			
Rationale	6	Describe the rationale for the review in the context of what is already known.	Completed
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators and outcomes (PICO).	Completed
<b>METHODS</b>			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design setting, time frame) and report characteristics (such as years considered, language, publication status) to be used for eligibility for the review.	Completed
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study	Completed

		authors, trial registers or other grey literature sources) with planned dates of coverage.	
Search strategy	10	Present draft of search strategy to be used at least one electronic database, including planned limits, such that it could be repeated.	Completed
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review.	Completed
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers); through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis).	Completed
Data collection process	11c	Describe planned method of extracting data from reports, such as piloting form, done independently, in duplicate), any processes for obtaining and confirming data from investigators.	Completed
Data items	12	List and define all variable which will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications.	Completed
Outcomes and prioritization	13	List and define all variables for which data will be sought, including prioritization of main and additional outcomes, with rationale.	Completed
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in the data synthesis.	Completed
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesized.	Not applicable
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including planned exploration of consistency (such as $I^2$ , Kendall's $\tau$ )	Not applicable
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	Not applicable
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned.	Completed
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Not applicable
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Not applicable

# THE UNMET NEEDS OF STROKE SURVIVORS AND CAREGIVERS: A SYSTEMATIC NARRATIVE REVIEW

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## ABSTRACT

**Introduction:** Facilitating stroke survivors and their caregivers to lead a fulfilling life after stroke requires service providers to think about their different needs. Poor post stroke care may lead to unmet needs in stroke survivors and stroke caregivers. This may compromise them in leading their lives optimally after stroke.

**Objectives & Methodology:** This systematic narrative review examines articles published from 1990 to 2017, generated from Ovid, MEDLINE, CINAHL, and PubMed. The search was also supplemented by an examination of reference lists for related articles via Scopus. We included 105 articles.

**Findings:** We found that the type of unmet needs in stroke survivors and the contributing factors were substantially different from their caregivers. The unmet needs in stroke survivors ranged from health-related needs to re-integration into the community; while the unmet needs in stroke caregivers ranged from information needs to support in caring for the stroke survivors and caring for themselves. Additionally, the unmet needs in both groups were associated with different factors.

**Conclusion:** More research is required to understand the unmet needs of stroke survivors and stroke caregivers to improve the overall post-stroke care services.

## INTRODUCTION

Stroke has been recognized as a factor that has contributed significantly to the mortality and morbidity in developing and non-developing countries (1). It has been documented that 15 million individuals suffer from stroke globally, in which 5 million patients die from stroke while another 5 million



continue living with disability (2). Analysis from the Global Burden of Disease (GBD) Study 2016 (3) demonstrated differences in the rise of stroke geographically. Specifically, the authors documented higher risk in stroke in East Asia, Central Europe and Eastern Europe. Kim (4) also documented that the burden of stroke is higher in Asia compared to Europe and North America; although the burden is lower in urbanized countries in East Asia such as Japan and Korea compared to those in South Asia like Pakistan and India. These differences may be due to the variations in health policy, national priorities, medical and health advancement; as well as health attitudes and culture.

The advancement in medical care, specifically the provision of acute stroke care in a stroke unit setting, has contributed to a reduction in overall mortality (5, 6). Nevertheless, the overall outcome of stroke survivors remains the same with many survivors continuing to live with some form of disability. This contributes to the significant impact on the socio-economic wealth of the country especially without the provision of comprehensive stroke care, from prevention to care in the community. This suggests the importance of having a systematic, integrated and continuum of stroke care, including rehabilitation and long term care, within the context of the local population, resources and systems (7-9). (to remove ref 8)

The provision of stroke care has evolved from medical and impairment-based interventions to supporting stroke survivors and stroke caregivers live an optimal life. To achieve this would require healthcare providers to adopt a biopsychosocial approach in service provision and decision making. This approach necessitates providers to own skills in identifying patients' multifaceted needs and support them to partnership actively in their own care (10). Additionally, as challenges faced by stroke survivors and stroke caregivers evolve over time, it is essential that these needs are reviewed periodically to ensure appropriate intervention, management and support are delivered (11, 12). Understanding their needs will also allow a patient-centred and culturally sensitive rehabilitation service provision to take place in the health system (13). Additionally, a systematic healthcare needs assessment that is based on balance judgment and agreement between professional defined needs and survivors defined needs is crucial in ensuring quality of care, and subsequently quality of life (14)(to remove). This may also potentially increase the efficacy and efficiency of rehabilitation and other aspects of post-stroke care.

In this review, we focus on articles on the unmet needs from the perspective of stroke survivors and carers upon discharge from hospital; as well as examining the factors associated with the reported needs. We also examined the gaps in understanding the expressed unmet needs of stroke survivors and carers in navigating the continuum of care after discharge from hospital. We anticipate that this review will present knowledge about the unmet needs in different geographical regions and characteristics of stroke survivors and stroke caregivers.

## **METHODS**

### **Study design**

This systematic narrative review was registered with PROSPERO (Registration No: CRD42018086561). It included peer-reviewed, published qualitative and quantitative articles, English language, year of 1990 to 2017, without limiting countries. Additionally, conference abstracts, proceeding and case studies were scanned and included if the topic on unmet needs was discussed.

### **Definitions**

#### *Stroke*

Stroke is defined as “rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (15).

#### *Unmet needs*

“Unmet needs” has been defined differently; i.e. "a problem that was not being addressed or one that was being addressed but insufficiently"(16); or "something or help from someone that would help you now to overcome some of the effects of your stroke and resulting difficulties" (17-20). It has been also described as “expressed needs that are not satisfied by their current service provision” (21) as well as “key long term problems in post stroke care” (22). Overall, the term refers to help that is still needing by stroke survivors or their caregivers in living life fully after stroke.

In this review, “unmet needs” refers to the persistence of problems, expressed by the stroke survivor despite receiving some form of post-stroke care. A similar definition of unmet needs is also extended to stroke caregivers.

### *Stroke survivors*

Survivor is described as “someone who continues to live after an accident, war or illness” (23). In this review, “stroke survivors” refers to people who continue living after discharge from hospital for stroke care, either in a rehabilitation setting or in a community setting.

### *Stroke caregivers*

Lending from Pound & Greenwood (24), “stroke caregivers” refers to people who provide unpaid care and support to the stroke survivors.

## **Study selection criteria**

### *Study population*

Studies of stroke survivors and stroke caregivers aged 18 years and above, living in a community setting or in a rehabilitation setting were included in this review. Their unmet needs were identified from hospital discharge for acute stroke treatment, either following a first or recurrent event of stroke; and were expressed from the perspective of stroke survivors and carers. This review did not include studies on needs in stroke survivors and stroke caregivers conducted within multiple patient populations (e.g. dementia and traumatic brain injury) that did not separate the findings according to specific conditions. Additionally, articles that described normative needs or comparative needs in stroke survivors and stroke caregivers were also disregarded.

## **Search strategy**

The search strategy was designed based on Aziz and colleagues (25) using a combination of key words as listed in Table 1. The selection of the terms were reviewed by an Information Library

Specialist; and were adjusted and tabulated accordingly to allow a systematic, comprehensive, reproducible and low in bias of literature search. The intention of this design was to comprehensively capture published studies or articles to answer the review questions. We conducted our search from December 2017 to February 2018 using databases specific to our search strategy. See Box 1 in Appendix 1 for example of search strategy used for Medline) which include Ovid, MEDLINE, CINAHL, and PubMed; complemented by an examination of reference lists for related articles via Scopus. The searched strategies were adopted based on Information Specialists Sub-Group (ISSG) (26), taking into consideration the inclusion of relevant key words (Medical Subject Heading, MeSH) and Boolean logic terms 'OR' and 'AND'. These key words were also adapted for other databases.

[Insert Table 1]

## Data extraction

All selected publications were stored in Endnote for data extraction. Data were extracted by the main author (Zawawi N.S.M) and presented and discussed at regular co-author meetings. Data collected included author; year; country of study; aim of study; study population (number of participants, age, gender and time since stroke); definition of unmet needs; study design and findings. Where necessary, the authors were contacted to provide additional data or clarification. A list of data extracted is available in Appendix 2.

## Quality assessment

~~The Joanna Briggs Critical Appraisal Tool [https://joannabriggs.org/critical\\_appraisal\\_tools](https://joannabriggs.org/critical_appraisal_tools) was used to assess the methodological quality of the studies.~~ We used the Joanna Briggs critical appraisal [https://joannabriggs.org/critical\\_appraisal\\_tools](https://joannabriggs.org/critical_appraisal_tools) as the guide for the overall bias analysis, and tailored accordingly based on the types of the articles selected for the review. This was carried out prior to the data synthesis. The quality assessment was conducted by the first author (Zawawi N.S.M.) and presented, discussed and verified with co-authors. The information on risk of bias conducted on the extracted literatures guided the strength and limitation of this review.

## Data synthesis

Data synthesis for this review was based on a systematic narrative approach due to the heterogeneity in the included studies, i.e. differences in study design and type of studies. The data synthesis was performed in two stages: (1) reported unmet needs; and (2) factors associated with unmet needs. Two major themes have been identified to categorize the findings i.e. the reported and associated factors of unmet needs from the perspective of stroke survivors; and the reported and associated factors of unmet needs from the perspective of caregivers.

## RESULTS

### *Study selection*

The study selection was conducted based on PRISMA flow guideline (27), as illustrated in Figure 1. A total of 105 studies were selected for synthesis and extraction.

[Insert Figure 1]

### *Study characteristics*

This review includes 32 quantitative studies, 44 qualitative studies, 6 mixed-methods studies, 6 abstracts, 13 review articles and 1 letter to editor (see Figure 1: “Included Studies” section). See the “Data Extraction” appendix for information on study design or type of articles. Specific to the articles on research studies, the majority of the studies were conducted in United Kingdom and Ireland (N=21), followed by Oceania countries (Australia and New Zealand) (N=19); and in the United States of America and Canada (N=16). The other 16 studies were conducted in Europe. Only 8 studies were conducted in Asia. The tools used to capture unmet needs in quantitative studies or quantitative elements of mixed-method studies vary, ~~the unmet needs were captured either~~ through utilization of a specific tool or embedded in questionnaire (see “Data Extraction” appendix for details). The unmet needs were investigated at different times post stroke; within 1 year after stroke, 1 to 5 years after stroke and beyond 5 years after stroke.

## **Synthesis of Results**

The synthesis and presentation of the unmet needs by the stroke survivors was guided by the work of McKeivitt et al. (17), and extended to rehabilitation and care aspects; while the data synthesis for the unmet needs by stroke caregivers was adopted from the work of Tsai, Yip, Tai, & Lou (28).

### ***Reported unmet needs by survivors***

The reported unmet needs by stroke survivors were organized into four categories, i.e. physical and other stroke-related problems, social participation, information as well as rehabilitation and care. As each category has many types of unmet needs, it was further classified into different aspects of unmet needs (Table 2).

Specifically for physical and other stroke-related problems, unmet needs in concentration and memory was reported the most (16-22, 29-31); although in a separate literature, unmet emotional needs were documented the most (31). Additionally, in relation to information needs, survivors highlighted the importance of receiving all information in a written format to help in recalling the information at a later date (32), and to serve as a quick reference (33). Additionally, They also emphasized the presentation of written information; lay-friendly, easy-to-understand and supplemented with graphics (32, 34-36). Consideration also must be given to the way the information is delivered, i.e. in private and by a health professional that is familiar to them (37); as well as ~~presenting it clearly and honestly~~ **clear and honest presentation** (38).

[Insert Table 2]

### ***Factors influencing unmet needs in stroke survivors***

Many articles described the factors associated with reported unmet needs, however, their associations were inconsistent. The differences were likely due to the research design such as the timing of when the unmet needs were captured, the instrument used and the population studied. The reported associated factors are listed below (Table 3).

[Insert Table 3]

### ***Reported unmet needs by stroke caregivers***

The unmet needs by stroke caregivers were broadly organized into two categories, i.e. information and support (Table 4). Caregivers described receiving support during hospitalization, however this was lacking after discharge (100). Additionally, the type of information and support required by caregivers may change throughout the continuum of care; and may be needed for a longer term (35, 61, 101-103).

[Insert Table 4]

### ***Factors influencing unmet needs in stroke caregivers***

The unmet needs in stroke caregivers were found to be associated with factors related to themselves or to the stroke survivors they care for. The associated factors for the reported unmet needs were described in following table (Table 5):

[Insert Table 5]

## **DISCUSSION**

Understanding the unmet needs of stroke survivors and caregivers has received substantial consideration as a way of understanding and improving overall post-stroke care. This narrative review was conducted to explore the unmet needs of stroke survivors and caregivers across communities, with comparisons made between developed nations such as UK, Europe and America and developing nations in Asia. Two key findings were identified from the review. Firstly, the unmet needs of stroke survivors and stroke caregivers extended beyond medical and rehabilitation aspects. Secondly, stroke survivors and stroke caregivers reported different unmet needs. The unmet needs in stroke survivors were related to living after stroke. In contrast, the unmet needs in stroke caregivers were related to supporting stroke survivors, in addition to navigating their own life after stroke.

This review has highlighted the heterogeneous nature of the unmet needs across communities. This finding confirms earlier work by Iosa and colleagues (39) which demonstrated stroke survivors in Singapore (a developing country) have different priorities than stroke survivors in the United Kingdom

and Italy (developed country). In this review, stroke survivors and caregivers in developed countries and developing countries shared a wide range of unmet needs such as information, psychological support, financial support, rehabilitation and secondary prevention. However, as the number of developing countries in this review was significantly lower than developed countries, this generalization should be interpreted with care. Nonetheless, as developed countries and developing countries have a different stroke incidence, ~~their~~ own unique challenges in stroke care provision (126) and ~~adoption of~~ ~~adopt~~ different healthcare policies and priorities, the extent of reported unmet needs may be significantly different. Additionally, there is a prominent need to understand the unmet needs in Asia compared to other continents as the number of stroke survivors in this region who require long term care has increased, partly contributed by the rapidly ageing population (4). A significant gap in knowledge of unmet needs of stroke caregivers and stroke survivors is evident, as demonstrated in this review. The lack of research investigating unmet needs in Asia could be attributed to the lack of awareness of needs of stroke patients beyond hospital care and the lack of provision in providing extended care beyond discharge.

### **Strengths and limitations**

An important strength in this narrative review is the acceptance of articles that reported unmet needs globally. Additionally, this review also included different types of articles. These elements are important when examining different approaches to capture and report unmet needs. This review has suggested that having different tools ~~for stroke survivors and stroke caregivers~~ is essential in understanding ~~the their~~ unmet needs. ~~in-stroke survivors and stroke caregivers~~. These tools should consist of different domains related to medical, rehabilitation, care and life after stroke. Additionally, a wider global inclusion may allow identification and comparison of unmet needs within a specific region or between regions. However, as the number of Asian countries in this review is very small compared to other regions, generalization of information on unmet needs across countries in Asia also warrant extra care in interpretation of findings and further consideration.

This systematic narrative review carries its own limitations. The search strategy focused on care after discharge from hospital, thus the changing needs from acute care to long term care may not be included. Additionally, the heterogeneous research designs, i.e. a mix of qualitative and quantitative



studies, in addition to different sample characteristics, contribute to a considerable challenge in data synthesis. The data extraction and interpretation may also bias the preferences and experiences of the **first** author. Nevertheless, conducting such a review pulls out information from previously conducted research into a comprehensible format (127), and the organization of information retrieved from the literature may serve as a baseline knowledge of the needs reported by stroke survivors and stroke caregivers, indicating that they need more help to adapt with the sudden change in life after stroke.

### **Implications for practice**

Understanding unmet needs in post stroke care should contribute to the development of better targeted stroke care, thereby potentially optimising independence and enhancing quality of life of stroke survivors and their caregivers. Lending from the biopsychosocial model, information about unmet needs may guide professionals to negotiate with stroke survivors and stroke caregivers about their care, and tailor the support they need. Additionally, **regular documentation of ~~documenting~~ unmet needs** in healthcare **~~among a local population~~** through an objective and comprehensive manner **~~on a regular basis~~** is recommended as a mean to determine the **direction and** effectiveness of **changes** in health system **~~changes required~~** (128). Thus, such research must consider the unique characteristics of the studied population, such as cultural and linguistic differences (129) and cultural values and spiritual beliefs (130). This necessitates having an appropriate tool that is tailored to a specific population to ensure information on unmet needs is captured holistically and appropriately. Equal attention must also be given in capturing the unmet needs, specifically in the aspects that are deemed sensitive to the particular population. In addition, as stroke requires a continuum of care, knowledge about unmet needs should be imparted to all medical and non-medical service providers, administrators, policy makers and related support group or organization. This may encourage them to identify priorities for service development in post stroke care, collaborate and address paucity in stroke care from different angles, simultaneously. Finally, sharing the knowledge about unmet needs may reduce fragmentation in stroke care, contribute to a sustainable and dynamic stroke care delivery and encourage optimal use of resources available.

### **CONCLUSION**

This review has demonstrated a wide range of unmet needs in stroke caregivers and stroke survivors living their life after stroke. A great consideration must be given to various aspects if the information of unmet needs is considered to be applied in another countries or settings. This may include the differences in national agenda, health priority, health policy, literacy and support availability. Furthermore, as demonstrated in this review, understanding the unmet needs of stroke survivors and stroke caregivers requires individuals to consider the specific characteristics of the studied population. Thus, it requires a specific tool that is designed carefully, and delivered appropriately, to ensure the captured information on unmet needs of survivors and caregivers represents the authentic views of the population studied.

## **ACKNOWLEDGEMENTS**

This narrative systematic review was conducted as part of doctorate studies. We thank the University of Nottingham UK for awarding the “Stroke Rehabilitation PhD Studentship: Nottingham UK and Malaysia Collaboration” that allows studies on unmet needs of stroke population be conducted in Malaysia

*Author Contributions:* We declare that each author contributed in this systematic narrative review and article writing. Zawawi N.S.M and Aziz N.A. worked on the methodology for literature search. All authors contributed in designing the review. Additionally, Aziz N.A., Walker, M.F., Fisher, R. and Ahmad, K. also facilitated Zawawi N.S.M. in synthesizing the data. The writing of the initial draft was carried out by Zawawi N.S.M. The review of the initial draft and finalizing the articles were conducted together by all authors.

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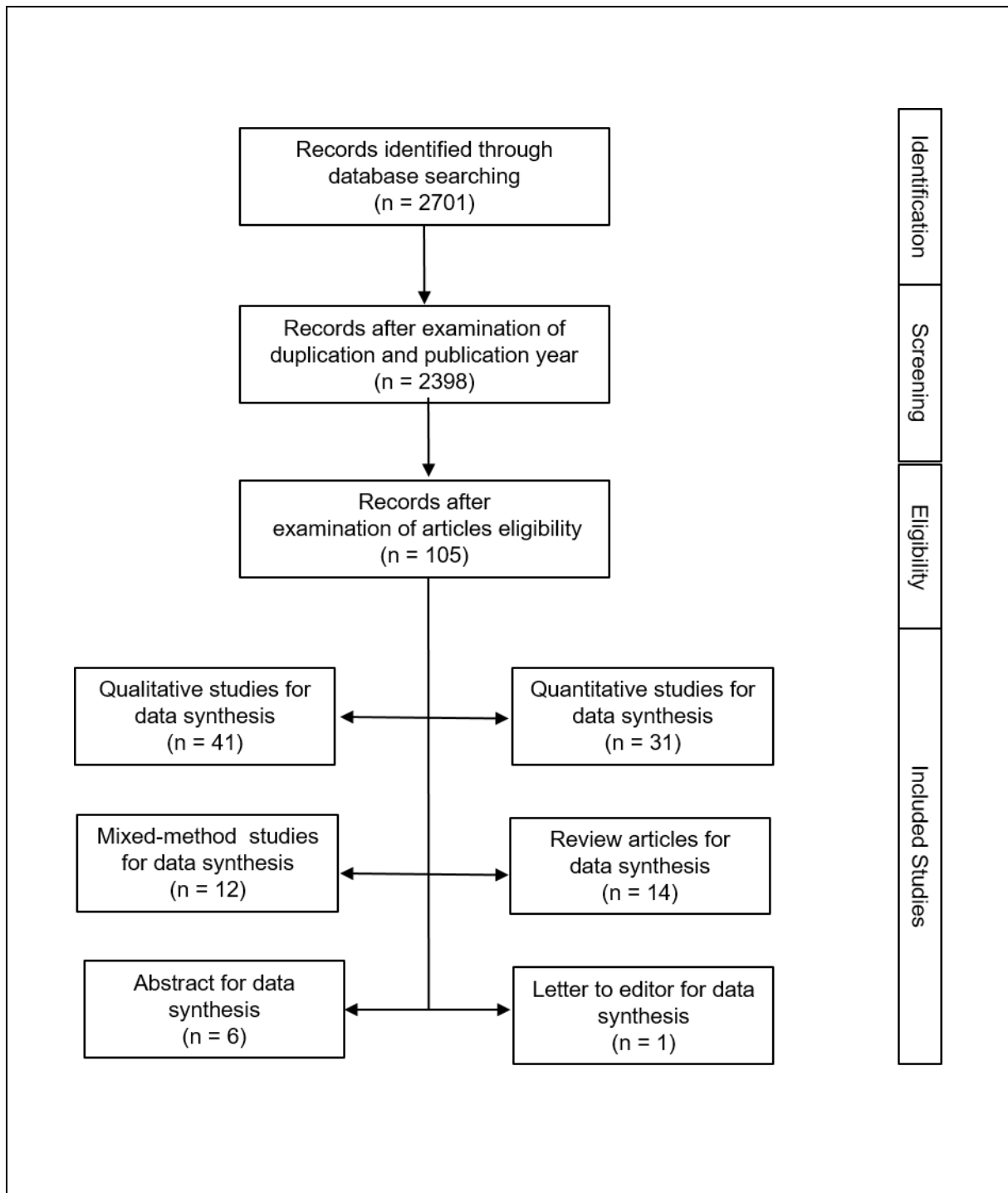
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CATEGORY	KEY WORDS
Population	Stroke, CVA, cerebral stroke,
Intervention	Stroke rehabilitation, long term stroke care, post stroke care, community dwelling.
Comparators	Needs, perspective, experience, opinion.
Outcome	Patients, survivors, caregivers, family, carers.

**Table 1:** The keywords used for search strategy



**Figure 1:** Flow for articles search and selection based on PRISM guideline.

<b>Category: Physical and other stroke-related problems</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Physical functions	A wide range of unmet needs were reported i.e. mobility, pain, fall, fatigue, spasticity, headaches / migraine, bowel control, incontinence, swallowing, sight and speaking, reading, writing, hearing, speech, communication and oral care.	(13, 17, 19, 22, 30, 31, 39-45)
Cognitive functions	These needs consist of concentration and memory, cognition, intellectual fulfilment and attention.	(16-22, 29-31, 42)
Emotion functions	Unmet needs in survivors' emotion, including managing low mood and sense of feeling respected and insecurity in different aspects related to stroke, medical care and life, were documented in 14 articles	(16, 17, 19, 21, 29, 42, 46-48)
<b>Category: Social participation (related to support in living, community re-integration and relationship)</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Support in living	A wide aspects of unmet living support were reported i.e. performing activities daily living and non-care activities, continuing leisure activities, managing emotion, financial-related support, returning to work, transportation and traveling around, managing home and family, aids / adaptation, moving to suitable house and going for holiday. Inadequate professional support to maintain survivors' role in different aspects of living were also reported. Additionally, survivors also received inadequate support from voluntary organization / support group and peers. Unmet support in spiritual need and making will were also reported. In addition, survivors also expressed needing support for their caregivers.	(13, 16-22, 30, 33, 39, 41, 44-46, 49-63)

Community re-integration	Survivors reported having unmet needs in integrating self with community, such as in social activities as well as being able to get around and fulfil communication needs.	(13, 16, 19, 20, 22, 33, 36, 39, 49, 50, 53, 64-66)
Relationship	Survivors reported having unmet needs in keeping their intimate relationships with caregivers, and family relationship.	(16, 17, 21, 22, 30, 39, 43, 67, 68)
<b>Category: Information</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Stroke related information	Survivors reported receiving insufficient stroke-related information i.e. stroke prevention, stroke risk, cause of stroke, stroke recovery and secondary prevention. The information needs may persist up three years after stroke, requiring professionals to consider repeating information delivery. Survivors also needed more information about the impact of stroke, stroke support group and expectations in living after stroke.	(17, 18, 20, 34, 37, 38, 45, 46, 61, 69-72)
Information on post stroke care and rehabilitation.	Specifically, these include inadequate information about stroke care and treatment, managing stroke complication and identifying source for stroke care. Additionally, survivors needing more information about modifying home, care at home as well as long term stroke care. From rehabilitation perspective, survivors reported inadequate information about post-stroke difficulties as well as rehabilitation short-term and long-term goals. They also expressed not having enough information about ways to continue therapy at home.	(16, 34, 37, 38, 41, 66, 71-76)

Information on being productive and continue living after stroke	Survivors reported following unmet information needs related to being productive in living after stroke, i.e. return to work after stroke, and strategies to support survivors at work. Related to living after stroke, survivors reported missing information about driving, using public transport, moving to other house, determining the extent of support they need in daily living and organizing holidays that would suit the needs of stroke survivors. Additionally, they expressed having insufficient information about communication difficulties, for themselves and for the community for communication support. Furthermore, survivors expressed in needing information to resume exercise and physical intimacy	(16, 21, 32, 33, 41, 46, 67, 72, 74, 77-79)
<b>Category: Rehabilitation and care</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Rehabilitation	Survivors reported having unmet rehabilitation needs such as occupational therapy, namely in hand function and work rehabilitation; and physical therapy.	(13, 18, 20, 31, 34, 36, 43, 54, 55, 57, 64, 69, 80-86)
Health-related care	The reported unmet post-stroke care were nursing care, foot care, and medical care (including secondary prevention) as well as managing changes in habit that were related to health and general well-being. Additionally, survivors expressed in needing help in home care, composing will and following appointment dates.	(16, 21, 22, 36, 39, 41, 45, 56, 80, 85, 87, 88)

**Table 2:** The reported unmet needs by stroke survivors.

Associated factors	Description	Papers
Demographic factors	<p><u>Gender:</u> Female survivors were reported having higher unmet needs; although other studies did not find any difference between both genders.</p> <p><u>Age:</u> Younger stroke survivors (i.e. below 65 years old) were found to have higher unmet needs across different categories compared to older age, while older age survivors were described having higher described unmet rehabilitation than the younger survivors. Additionally, age at stroke onset was also found to associate with unmet leisure and work needs. This association however was insignificant in other articles.</p> <p><u>Ethnic:</u> Black survivors were reported to have more unmet needs in self-care than white survivors. However, the unmet needs in mobility and managing household needs were comparable between ethnics.</p> <p><u>Socioeconomic status:</u> The unmet needs were found comparable across socioeconomic status. However, another study demonstrated that unmet needs were higher in survivors with higher sociodemographic status.</p> <p><u>Geography / area of living:</u> survivors living in cities was likely reported unmet needs in everyday living, work, financial and health; whereas survivors living in deprived area reported having higher loss in income and higher need for benefits input. Additionally, survivors living within minority ethnic group were also reported having higher unmet needs.</p>	<p>(13, 17, 41, 89)</p> <p>(17-20, 41, 44, 59, 62, 72, 77, 89-91)</p> <p>(92)</p> <p>(17, 18, 20, 85, 91)</p> <p>(17, 19, 59)</p>
Pre-morbid condition	Survivors with prior history of stroke, diabetes, haemorrhagic stroke and atrial fibrillation were likely having more unmet rehabilitation needs at one year after stroke	(89)



	<p><u>Presence of pain and low perception of health:</u> Unmet rehabilitation needs was found higher in survivors with unmet pain needs and perceived self as having low health.</p> <p><u>Low health-quality of life:</u> Low health-quality of life was also associated with higher unmet living needs, while requiring physical support at 3 to 6 months after stroke were associated with higher unmet health needs.</p> <p><u>Difficulties in activities daily living, community re-integration and communication; and presence of pain:</u> Unmet support needs were found higher in survivors with lower ability to perform activities of daily living, having difficulty in re-integrating self in community and having communication difficulties. Having pain was also found associated with higher unmet support needs.</p>	<p>(91)</p> <p>(40, 61, 87, 96-99)</p>
Mismatch perception	<p>The perception of unmet needs was contributed by the culture and perception of needs in survivors, in addition to between survivors, caregivers and professional.</p> <p>The unmet information needs was also caused by the lack of understanding in health professionals about specific post-stroke disorders. Additionally, it was influenced by the professional perception about the type and extent of information that survivors would need.</p>	<p>(40, 60, 61, 87, 98, 99)</p> <p>(32, 74)</p>

**Table 3:** Factors influencing unmet needs in stroke survivors



Category	Description	Papers
<i>Information</i>	<p>Caregivers reported receiving inadequate information. The missing information can be categorized as following:</p> <ol style="list-style-type: none"> <li>1. Stroke-related information.</li> <li>2. Information about supporting and caring for stroke survivors, including the emotional impact and risk of injury on caregivers as a result of caregiving.</li> <li>3. Living aspects after stroke, such financial assistance, communicating with survivors and resuming physical intimacy.</li> <li>4. Information about stroke rehabilitation / therapy and formal support (medical / non-medical) for survivors.</li> </ol>	<p>(35, 104-107)</p> <p>(35, 66, 72, 76, 103, 105-115)</p> <p>(35, 67, 103, 104, 112, 114, 116, 117)</p> <p>(34, 66, 104, 111, 112, 114, 118)</p>
<i>Support</i>	<p>This aspect is related to formal and informal support received by caregivers. The missing support could be divided into following categories:</p> <ol style="list-style-type: none"> <li>1. Preparing caregivers in stroke caregiving, including caregiving skills and supporting them in transiting to this new role.</li> <li>2. Supporting caregivers in preparing aids and home for stroke patients</li> <li>3. Supporting caregivers in caring and supporting stroke survivors at home.</li> <li>4. Professionals support in involving caregivers to support survivors throughout the rehabilitation process, to make informed decision and to locate additional resources / support.</li> <li>5. Support in sustaining living, such as financial, health and managing family.</li> </ol>	<p>(57, 100-102, 115, 117, 119, 120)</p> <p>(101, 102, 108, 117)</p> <p>(51, 101, 103)</p> <p>(36, 76, 97, 100-103, 111, 116, 119-121)</p> <p>(51, 59, 66, 101, 108, 120, 122, 123)</p>

	6. Supporting caregivers in non-caregiving tasks such as managing home.	(101)
	7. Managing self in caregiving role including emotion.	(36, 44, 51, 61, 102, 106, 111, 115-117, 122-124)

**Table 4:** Reported unmet needs by stroke caregivers.

Associated factors	Description	Papers
<i>Demographic factors</i>	<p><u>Gender</u>: Caregivers' gender was not found to be associated with unmet needs.</p> <p><u>Age</u>: Caregivers at younger age were reported having more unmet needs, although another article reported the unmet needs were higher in older caregivers. However, the unmet needs was also found comparable across age group.</p> <p><u>Ethnic</u>: White ethnic stroke caregivers were reported having more unmet needs than non-white ethnics.</p> <p><u>Geography</u>: The living location influenced the type of unmet needs in caregivers. Caregivers living in mainland expressed greater needs in information about managing behavioural change in survivors, while caregivers living in island needing more information about safety at home.</p>	<p>(97, 101)</p> <p>(51, 59, 72, 97, 101)</p> <p>(101)</p> <p>(104)</p>
<i>Characteristics of stroke survivors</i>	<p><u>Age</u>. Caregivers caring for young stroke survivors (less than 65 years) were reported having higher unmet needs than those taking care of older stroke survivors.</p> <p><u>Physical function</u>. Caregivers caring for survivors with poor physical function at 2 years after stroke was described having higher unmet needs.</p>	<p>(51)</p> <p>(101)</p>
<i>Other factors</i>	<p><u>Presentation</u>: Specifically to unmet information needs, unmet information was contributed by unsuitable presentation such as language used and professional behaviour, information was broad-based and was not tailored to caregivers' needs and supporting materials in suitable written format were not available.</p> <p><u>Caregivers' characteristics</u>: Caregivers with following characteristics were described as having higher unmet needs: no formal education, higher burden, having less</p>	<p>(35, 59, 105, 109, 110, 112)</p> <p>(97, 123, 125)</p>

	<p>social life, having poorer health, unprepared for caregiving.</p> <p>Those who appreciated the benefit in caregiving were also found to have high unmet needs.</p> <p><u>Education and coping mediator:</u> Caregivers with higher education background reported having higher unmet information needs. Caregivers also reported still having high unmet resource needs despite owing positive coping mediators.</p> <p><u>Perception:</u> The perception on caregivers' ability to connect with healthcare providers influenced their perception of unmet support needs. Additionally, mismatch perception between the healthcare providers and caregivers also influenced caregivers' perception on unmet information needs.</p> <p><u>Other:</u> Unmet support needs were also reported to be influenced by accessibility of service and longer rehabilitation.</p>	<p>(72, 101, 125)</p> <p>(60, 111),</p> <p>(111)</p>
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**Table 5:** Factors influencing unmet needs by stroke caregivers.

# THE UNMET NEEDS OF STROKE SURVIVORS AND CAREGIVERS: A SYSTEMATIC NARRATIVE REVIEW

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## ABSTRACT

**Introduction:** Facilitating stroke survivors and their caregivers to lead a fulfilling life after stroke requires service providers to think about their different needs. Poor post stroke care may lead to unmet needs in stroke survivors and stroke caregivers. This may compromise them in leading their lives optimally after stroke.

**Objectives & Methodology:** This systematic narrative review examines articles published from 1990 to 2017, generated from Ovid, MEDLINE, CINAHL, and PubMed. The search was also supplemented by an examination of reference lists for related articles via Scopus. We included 105 articles.

**Findings:** We found that the type of unmet needs in stroke survivors and the contributing factors were substantially different from their caregivers. The unmet needs in stroke survivors ranged from health-related needs to re-integration into the community; while the unmet needs in stroke caregivers ranged from information needs to support in caring for the stroke survivors and caring for themselves. Additionally, the unmet needs in both groups were associated with different factors.

**Conclusion:** More research is required to understand the unmet needs of stroke survivors and stroke caregivers to improve the overall post-stroke care services.

## INTRODUCTION

Stroke has been recognized as a factor that has contributed significantly to the mortality and morbidity in developing and non-developing countries (1). It has been documented that 15 million individuals suffer from stroke globally, in which 5 million patients die from stroke while another 5 million

continue living with disability (2). Analysis from the Global Burden of Disease (GBD) Study 2016 (3) demonstrated differences in the rise of stroke geographically. Specifically, the authors documented higher risk in stroke in East Asia, Central Europe and Eastern Europe. Kim (4) also documented that the burden of stroke is higher in Asia compared to Europe and North America; although the burden is lower in urbanized countries in East Asia such as Japan and Korea compared to those in South Asia like Pakistan and India. These differences may be due to the variations in health policy, national priorities, medical and health advancement; as well as health attitudes and culture.

The advancement in medical care, specifically the provision of acute stroke care in a stroke unit setting, has contributed to a reduction in overall mortality (5, 6). Nevertheless, the overall outcome of stroke survivors remains the same with many survivors continuing to live with some form of disability. This contributes to the significant impact on the socio-economic wealth of the country especially without the provision of comprehensive stroke care, from prevention to care in the community. This suggests the importance of having a systematic, integrated and continuum of stroke care, including rehabilitation and long term care, within the context of the local population, resources and systems (7, 8).

The provision of stroke care has evolved from medical and impairment-based interventions to supporting stroke survivors and stroke caregivers live an optimal life. To achieve this would require healthcare providers to adopt a biopsychosocial approach in service provision and decision making. This approach necessitates providers to own skills in identifying patients' multifaceted needs and support them to partnership actively in their own care (9). Additionally, as challenges faced by stroke survivors and stroke caregivers evolve over time, it is essential that these needs are reviewed periodically to ensure appropriate intervention, management and support are delivered (10). Understanding their needs will also allow a patient-centred and culturally sensitive rehabilitation service provision to take place in the health system (11). Additionally, a systematic healthcare needs assessment, that is based on balance judgment and agreement between professional defined needs and survivors defined needs is crucial in ensuring quality of care, and subsequently quality of life . This may also potentially increase the efficacy and efficiency of rehabilitation and other aspects of post-stroke care.

In this review, we focus on articles on the unmet needs from the perspective of stroke survivors and carers upon discharge from hospital; as well as examining the factors associated with the reported needs. We also examined the gaps in understanding the expressed unmet needs of stroke survivors and carers in navigating the continuum of care after discharge from hospital. We anticipate that this review will present knowledge about the unmet needs in different geographical regions and characteristics of stroke survivors and stroke caregivers.

## **METHODS**

### **Study design**

This systematic narrative review was registered with PROSPERO (Registration No: CRD42018086561). It included peer-reviewed, published qualitative and quantitative articles, English language, year of 1990 to 2017, without limiting countries. Additionally, conference abstracts, proceeding and case studies were scanned and included if the topic on unmet needs was discussed.

### **Definitions**

#### *Stroke*

Stroke is defined as “rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (12).

#### *Unmet needs*

“Unmet needs” has been defined differently; i.e. "a problem that was not being addressed or one that was being addressed but insufficiently"(13); or "something or help from someone that would help you now to overcome some of the effects of your stroke and resulting difficulties" (14-17). It has been also described as “expressed needs that are not satisfied by their current service provision” (18) as well as “key long term problems in post stroke care” (19). Overall, the term refers to help that is still needing by stroke survivors or their caregivers in living life fully after stroke.

In this review, “unmet needs” refers to the persistence of problems, expressed by the stroke survivor despite receiving some form of post-stroke care. A similar definition of unmet needs is also extended to stroke caregivers.

### *Stroke survivors*

Survivor is described as “someone who continues to live after an accident, war or illness” (20). In this review, “stroke survivors” refers to people who continue living after discharge from hospital for stroke care, either in a rehabilitation setting or in a community setting.

### *Stroke caregivers*

Lending from Pound & Greenwood (21), “stroke caregivers” refers to people who provide unpaid care and support to the stroke survivors.

## **Study selection criteria**

### *Study population*

Studies of stroke survivors and stroke caregivers aged 18 years and above, living in a community setting or in a rehabilitation setting were included in this review. Their unmet needs were identified from hospital discharge for acute stroke treatment, either following a first or recurrent event of stroke; and were expressed from the perspective of stroke survivors and carers. This review did not include studies on needs in stroke survivors and stroke caregivers conducted within multiple patient populations (e.g. dementia and traumatic brain injury) that did not separate the findings according to specific conditions. Additionally, articles that described normative needs or comparative needs in stroke survivors and stroke caregivers were also disregarded.

## **Search strategy**

The search strategy was designed based on Aziz and colleagues (22) using a combination of key words as listed in Table 1. The selection of the terms were reviewed by an Information Library Specialist; and were adjusted and tabulated accordingly to allow a systematic, comprehensive, reproducible and low in bias of literature search. The intention of this design was to comprehensively capture published studies or articles to answer the review questions. We conducted our search from



December 2017 to February 2018 using databases specific to our search strategy. See Box 1 in Appendix 1 for example of search strategy used for Medline) which include Ovid, MEDLINE, CINAHL, and PubMed; complemented by an examination of reference lists for related articles via Scopus. The searched strategies were adopted based on Information Specialists Sub-Group (ISSG) (23), taking into consideration the inclusion of relevant key words (Medical Subject Heading, MeSH) and Boolean logic terms 'OR' and 'AND'. These key words were also adapted for other databases.

[Insert Table 1]

### **Data extraction**

All selected publications were stored in Endnote for data extraction. Data were extracted by the main author (Zawawi N.S.M) and presented and discussed at regular co-author meetings. Data collected included author; year; country of study; aim of study; study population (number of participants, age, gender and time since stroke); definition of unmet needs; study design and findings. Where necessary, the authors were contacted to provide additional data or clarification. A list of data extracted is available in Appendix 2.

### **Quality assessment**

We used the Joanna Briggs critical appraisal [https://joannabriggs.org/critical\\_appraisal\\_tools](https://joannabriggs.org/critical_appraisal_tools) as the guide for the overall bias analysis, and tailored accordingly based on the types of the articles selected for the review. This was carried out prior to the data synthesis. The quality assessment was conducted by the first author (Zawawi N.S.M.) and presented, discussed and verified with co-authors. The information on risk of bias conducted on the extracted literatures guided the strength and limitation of this review.

### **Data synthesis**

Data synthesis for this review was based on a systematic narrative approach due to the heterogeneity in the included studies, i.e. differences in study design and type of studies. The data synthesis was performed in two stages: (1) reported unmet needs; and (2) factors associated with unmet needs. Two major themes have been identified to categorize the findings i.e. the reported and

associated factors of unmet needs from the perspective of stroke survivors; and the reported and associated factors of unmet needs from the perspective of caregivers.

## **RESULTS**

### *Study selection*

The study selection was conducted based on PRISMA flow guideline (24), as illustrated in Figure 1. A total of 105 studies were selected for synthesis and extraction.

[Insert Figure 1]

### *Study characteristics*

This review includes 32 quantitative studies, 44 qualitative studies, 6 mixed-methods studies, 6 abstracts, 13 review articles and 1 letter to editor (see Figure 1: “Included Studies” section). See the “Data Extraction” appendix for information on study design or type of articles. Specific to the articles on research studies, the majority of the studies were conducted in United Kingdom and Ireland (N=21), followed by Oceania countries (Australia and New Zealand) (N=19); and in the United States of America and Canada (N=16). The other 16 studies were conducted in Europe. Only 8 studies were conducted in Asia. The tools used to capture unmet needs in quantitative studies or quantitative elements of mixed-method studies vary, either through utilization of a specific tool or embedded in questionnaire (see “Data Extraction” appendix for details). The unmet needs were investigated at different times post stroke; within 1 year after stroke, 1 to 5 years after stroke and beyond 5 years after stroke.

### **Synthesis of Results**

The synthesis and presentation of the unmet needs by the stroke survivors was guided by the work of McKeivitt et al. (14), and extended to rehabilitation and care aspects; while the data synthesis for the unmet needs by stroke caregivers was adopted from the work of Tsai, Yip, Tai, & Lou (25).

### ***Reported unmet needs by survivors***

The reported unmet needs by stroke survivors were organized into four categories, i.e. physical and other stroke-related problems, social participation, information as well as rehabilitation and care. As each category has many types of unmet needs, it was further classified into different aspects of unmet needs (Table 2).

Specifically for physical and other stroke-related problems, unmet needs in concentration and memory was reported the most (13-19, 26-28); although in a separate literature unmet emotional needs were documented the most (28). Additionally, in relation to information needs, survivors highlighted the importance of receiving all information in a written format to help in recalling the information at a later date (29), and to serve as a quick reference (30). They also emphasized the presentation of written information; lay-friendly, easy-to-understand and supplemented with graphics (29, 31-33). Consideration also must be given to the way the information is delivered, i.e. in private and by a health professional that is familiar to them (34); as well as clear and honest presentation (35).

[Insert Table 2]

### ***Factors influencing unmet needs in stroke survivors***

Many articles described the factors associated with reported unmet needs, however, their associations were inconsistent. The differences were likely due to the research design such as the timing of when the unmet needs were captured, the instrument used and the population studied. The reported associated factors are listed below (Table 3).

[Insert Table 3]

### ***Reported unmet needs by stroke caregivers***

The unmet needs by stroke caregivers were broadly organized into two categories, i.e. information and support (Table 4). Caregivers described receiving support during hospitalization, however this was lacking after discharge (97). Additionally, the type of information and support required by caregivers may change throughout the continuum of care; and may be needed for a longer term (32, 58, 98-100)

[Insert Table 4]

### ***Factors influencing unmet needs in stroke caregivers***

The unmet needs in stroke caregivers were found to be associated with factors related to themselves or to the stroke survivors they care for. The associated factors for the reported unmet needs were described in following table (Table 5):

[Insert Table 5]

## **DISCUSSION**

Understanding the unmet needs of stroke survivors and caregivers has received substantial consideration as a way of understanding and improving overall post-stroke care. This narrative review was conducted to explore the unmet needs of stroke survivors and caregivers across communities, with comparisons made between developed nations such as UK, Europe and America and developing nations in Asia. Two key findings were identified from the review. Firstly, the unmet needs of stroke survivors and stroke caregivers extended beyond medical and rehabilitation aspects. Secondly, stroke survivors and stroke caregivers reported different unmet needs. The unmet needs in stroke survivors were related to living after stroke. In contrast, the unmet needs in stroke caregivers were related to supporting stroke survivors, in addition to navigating their own life after stroke.

This review has highlighted the heterogeneous nature of the unmet needs across communities. This finding confirms to earlier work by Iosa and colleagues (36) which demonstrated stroke survivors in Singapore (a developing country) have different priorities than stroke survivors in the United Kingdom and Italy (developed country). In this review, stroke survivors and caregivers in developed countries and developing countries shared a wide range of unmet needs such as information, psychological support, financial support, rehabilitation and secondary prevention. However, as the number of developing countries in this review was significantly lower than developed countries, this generalization should be interpreted with care. Nonetheless, as developed countries and developing countries have a different stroke incidence, own unique challenges in stroke care provision (123) and adopt of different healthcare policies and priorities, the extent of reported unmet needs may be significantly different. Additionally, there is a prominent need to understand the unmet needs in Asia compared to other

continents as the number of stroke survivors in this region who require long term care has increased, partly contributed by the rapidly ageing population (4). A significant gap in knowledge of unmet needs of stroke caregivers and stroke survivors is evident, as demonstrated in this review. The lack of research investigating unmet needs in Asia could be attributed to the lack of awareness of needs of stroke patients beyond hospital care and the lack of provision in providing extended care beyond discharge.

### **Strengths and limitations**

An important strength in this narrative review is the acceptance of articles that reported unmet needs globally. Additionally, this review also included different types of articles. These elements are important when examining different approaches to capture and report unmet needs. This review has suggested that having different tools for stroke survivors and stroke caregivers is essential in understanding their unmet needs. These tools should consist of different domains related to medical, rehabilitation, care and life after stroke. Additionally, a wider global inclusion may allow identification and comparison of unmet needs within a specific region or between regions. However, as the number of Asian countries in this review is very small compared to other regions, generalization of information on unmet needs across countries in Asia also warrant extra care in interpretation of findings and further consideration.

This systematic narrative review carries its own limitations. The search strategy focused on care after discharge from hospital, thus the changing needs from acute care to long term care may not be included. Additionally, the heterogeneous research designs, i.e. a mix of qualitative and quantitative studies, in addition to different sample characteristics, contribute to a considerable challenge in data synthesis. The data extraction and interpretation may also bias the preferences and experiences of the first author. Nevertheless, conducting such a review pulls out information from previously conducted research into a comprehensible format (124), and the organization of information retrieved from the literature may serve as a baseline knowledge of the needs reported by stroke survivors and stroke caregivers indicating that they need more help to adapt with the sudden change in life after stroke.

## **Implications for practice**

Understanding unmet needs in post stroke care should contribute to the development of better targeted stroke care, thereby potentially optimising independence and enhancing quality of life of stroke survivors and their caregivers. Lending from the biopsychosocial model, information about unmet needs may guide professionals to negotiate with stroke survivors and stroke caregivers about their care, and tailor the support they need. Additionally, regular documentation of unmet needs in healthcare through an objective and comprehensive manner is recommended as a mean to determine the direction and effectiveness of changes in health system (125). Thus, such research must consider the unique characteristics of the studied population, such as cultural and linguistic differences (126) and cultural values and spiritual beliefs (127). This necessitates having an appropriate tool that is tailored to a specific population to ensure information on unmet needs is captured holistically and appropriately. Equal attention must also be given in capturing the unmet needs, specifically in the aspects that are deemed sensitive to the particular population. In addition, as stroke requires a continuum of care, knowledge about unmet needs should be imparted to all medical and non-medical service providers, administrators, policy makers and related support group or organization. This may encourage them to identify priorities for service development in post stroke care, collaborate and address paucity in stroke care from different angles, simultaneously. Finally, sharing the knowledge about unmet needs may reduce fragmentation in stroke care, contribute to a sustainable and dynamic stroke care delivery and encourage optimal use of resources available.

## **CONCLUSION**

This review has demonstrated a wide range of unmet needs in stroke caregivers and stroke survivors living their life after stroke. A great consideration must be given to various aspects if the information of unmet needs is considered to be applied in another countries or settings. This may include the differences in national agenda, health priority, health policy, literacy and support availability. Furthermore, as demonstrated in this review, understanding the unmet needs of stroke survivors and stroke caregivers requires individuals to consider the specific characteristics of the studied population. Thus, it requires a specific tool that is designed carefully and delivered appropriately, to ensure the

captured information on unmet needs of survivors and caregivers represents the authentic views of the population studied.

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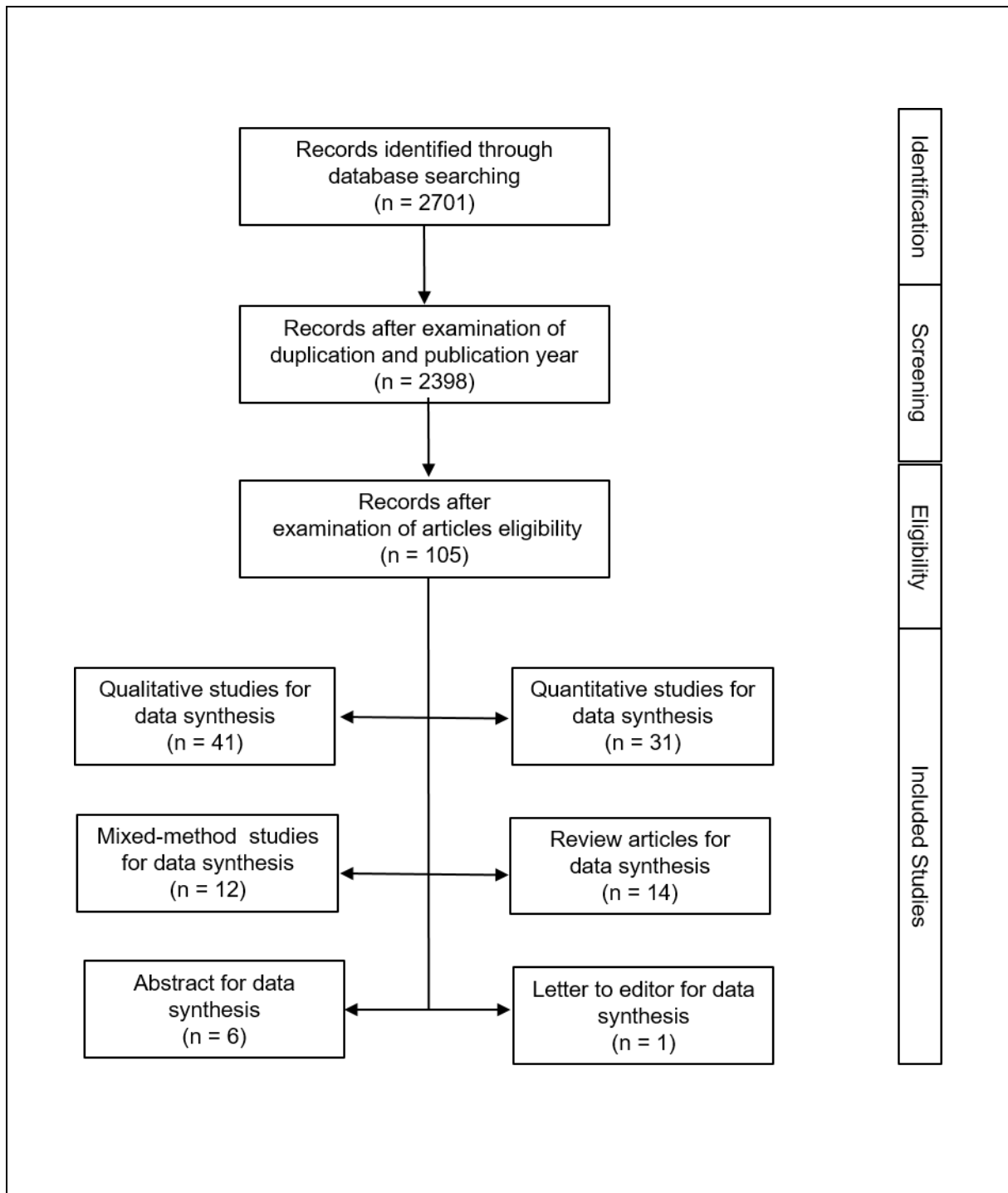
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CATEGORY	KEY WORDS
Population	Stroke, CVA, cerebral stroke,
Intervention	Stroke rehabilitation, long term stroke care, post stroke care, community dwelling.
Comparators	Needs, perspective, experience, opinion.
Outcome	Patients, survivors, caregivers, family, carers.

**Table 1:** The keywords used for search strategy



**Figure 1:** Flow for articles search and selection based on PRISM guideline.

<b>Category: Physical and other stroke-related problems</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Physical functions	A wide range of unmet needs were reported i.e. mobility, pain, fall, fatigue, spasticity, headaches / migraine, bowel control, incontinence, swallowing, sight and speaking, reading, writing, hearing, speech, communication and oral care.	(13, 17, 19, 22, 30, 31, 39-45)
Cognitive functions	These needs consist of concentration and memory, cognition, intellectual fulfilment and attention.	(16-22, 29-31, 42)
Emotion functions	Unmet needs in survivors' emotion, including managing low mood and sense of feeling respected and insecurity in different aspects related to stroke, medical care and life, were documented in 14 articles	(16, 17, 19, 21, 29, 42, 46-48)
<b>Category: Social participation (related to support in living, community re-integration and relationship)</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Support in living	A wide aspects of unmet living support were reported i.e. performing activities daily living and non-care activities, continuing leisure activities, managing emotion, financial-related support, returning to work, transportation and traveling around, managing home and family, aids / adaptation, moving to suitable house and going for holiday. Inadequate professional support to maintain survivors' role in different aspects of living were also reported. Additionally, survivors also received inadequate support from voluntary organization / support group and peers. Unmet support in spiritual need and making will were also reported. In addition, survivors also expressed needing support for their caregivers.	(13, 16-22, 30, 33, 39, 41, 44-46, 49-63)



Community re-integration	Survivors reported having unmet needs in integrating self with community, such as in social activities as well as being able to get around and fulfil communication needs.	(13, 16, 19, 20, 22, 33, 36, 39, 49, 50, 53, 64-66)
Relationship	Survivors reported having unmet needs in keeping their intimate relationships with caregivers, and family relationship.	(16, 17, 21, 22, 30, 39, 43, 67, 68)
<b>Category: Information</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Stroke related information	Survivors reported receiving insufficient stroke-related information i.e. stroke prevention, stroke risk, cause of stroke, stroke recovery and secondary prevention. The information needs may persist up three years after stroke, requiring professionals to consider repeating information delivery. Survivors also needed more information about the impact of stroke, stroke support group and expectations in living after stroke.	(17, 18, 20, 34, 37, 38, 45, 46, 61, 69-72)
Information on post stroke care and rehabilitation.	Specifically, these include inadequate information about stroke care and treatment, managing stroke complication and identifying source for stroke care. Additionally, survivors needing more information about modifying home, care at home as well as long term stroke care. From rehabilitation perspective, survivors reported inadequate information about post-stroke difficulties as well as rehabilitation short-term and long-term goals. They also expressed not having enough information about ways to continue therapy at home.	(16, 34, 37, 38, 41, 66, 71-76)

Information on being productive and continue living after stroke	Survivors reported following unmet information needs related to being productive in living after stroke, i.e. return to work after stroke, and strategies to support survivors at work. Related to living after stroke, survivors reported missing information about driving, using public transport, moving to other house, determining the extent of support they need in daily living and organizing holidays that would suit the needs of stroke survivors. Additionally, they expressed having insufficient information about communication difficulties, for themselves and for the community for communication support. Furthermore, survivors expressed in needing information to resume exercise and physical intimacy	(16, 21, 32, 33, 41, 46, 67, 72, 74, 77-79)
<b>Category: Rehabilitation and care</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Rehabilitation	Survivors reported having unmet rehabilitation needs such as occupational therapy, namely in hand function and work rehabilitation; and physical therapy.	(13, 18, 20, 31, 34, 36, 43, 54, 55, 57, 64, 69, 80-86)
Health-related care	The reported unmet post-stroke care were nursing care, foot care, and medical care (including secondary prevention) as well as managing changes in habit that were related to health and general well-being. Additionally, survivors expressed in needing help in home care, composing will and following appointment dates.	(16, 21, 22, 36, 39, 41, 45, 56, 80, 85, 87, 88)

**Table 2:** The reported unmet needs by stroke survivors.

Associated factors	Description	Papers
Demographic factors	<p><u>Gender:</u> Female survivors were reported having higher unmet needs; although other studies did not find any difference between both genders.</p> <p><u>Age:</u> Younger stroke survivors (i.e. below 65 years old) were found to have higher unmet needs across different categories compared to older age, while older age survivors were described having higher described unmet rehabilitation than the younger survivors. Additionally, age at stroke onset was also found to associate with unmet leisure and work needs. This association however was insignificant in other articles.</p> <p><u>Ethnic:</u> Black survivors were reported to have more unmet needs in self-care than white survivors. However, the unmet needs in mobility and managing household needs were comparable between ethnics.</p> <p><u>Socioeconomic status:</u> The unmet needs were found comparable across socioeconomic status. However, another study demonstrated that unmet needs were higher in survivors with higher sociodemographic status.</p> <p><u>Geography / area of living:</u> survivors living in cities was likely reported unmet needs in everyday living, work, financial and health; whereas survivors living in deprived area reported having higher loss in income and higher need for benefits input. Additionally, survivors living within minority ethnic group were also reported having higher unmet needs.</p>	<p>(13, 17, 41, 89)</p> <p>(17-20, 41, 44, 59, 62, 72, 77, 89-91)</p> <p>(92)</p> <p>(17, 18, 20, 85, 91)</p> <p>(17, 19, 59)</p>
Pre-morbid condition	Survivors with prior history of stroke, diabetes, haemorrhagic stroke and atrial fibrillation were likely having more unmet rehabilitation needs at one year after stroke	(89)



	<p><u>Presence of pain and low perception of health:</u> Unmet rehabilitation needs was found higher in survivors with unmet pain needs and perceived self as having low health.</p> <p><u>Low health-quality of life:</u> Low health-quality of life was also associated with higher unmet living needs, while requiring physical support at 3 to 6 months after stroke were associated with higher unmet health needs.</p> <p><u>Difficulties in activities daily living, community re-integration and communication; and presence of pain:</u> Unmet support needs were found higher in survivors with lower ability to perform activities of daily living, having difficulty in re-integrating self in community and having communication difficulties. Having pain was also found associated with higher unmet support needs.</p>	<p>(91)</p> <p>(40, 61, 87, 96-99)</p>
Mismatch perception	<p>The perception of unmet needs was contributed by the culture and perception of needs in survivors, in addition to between survivors, caregivers and professional.</p> <p>The unmet information needs was also caused by the lack of understanding in health professionals about specific post-stroke disorders. Additionally, it was influenced by the professional perception about the type and extent of information that survivors would need.</p>	<p>(40, 60, 61, 87, 98, 99)</p> <p>(32, 74)</p>

**Table 3:** Factors influencing unmet needs in stroke survivors

Category	Description	Papers
<i>Information</i>	<p>Caregivers reported receiving inadequate information. The missing information can be categorized as following:</p> <ol style="list-style-type: none"> <li>1. Stroke-related information.</li> <li>2. Information about supporting and caring for stroke survivors, including the emotional impact and risk of injury on caregivers as a result of caregiving.</li> <li>3. Living aspects after stroke, such financial assistance, communicating with survivors and resuming physical intimacy.</li> <li>4. Information about stroke rehabilitation / therapy and formal support (medical / non-medical) for survivors.</li> </ol>	<p>(35, 104-107)</p> <p>(35, 66, 72, 76, 103, 105-115)</p> <p>(35, 67, 103, 104, 112, 114, 116, 117)</p> <p>(34, 66, 104, 111, 112, 114, 118)</p>
<i>Support</i>	<p>This aspect is related to formal and informal support received by caregivers. The missing support could be divided into following categories:</p> <ol style="list-style-type: none"> <li>1. Preparing caregivers in stroke caregiving, including caregiving skills and supporting them in transiting to this new role.</li> <li>2. Supporting caregivers in preparing aids and home for stroke patients</li> <li>3. Supporting caregivers in caring and supporting stroke survivors at home.</li> <li>4. Professionals support in involving caregivers to support survivors throughout the rehabilitation process, to make informed decision and to locate additional resources / support.</li> <li>5. Support in sustaining living, such as financial, health and managing family.</li> </ol>	<p>(57, 100-102, 115, 117, 119, 120)</p> <p>(101, 102, 108, 117)</p> <p>(51, 101, 103)</p> <p>(36, 76, 97, 100-103, 111, 116, 119-121)</p> <p>(51, 59, 66, 101, 108, 120, 122, 123)</p>

	6. Supporting caregivers in non-caregiving tasks such as managing home.	(101)
	7. Managing self in caregiving role including emotion.	(36, 44, 51, 61, 102, 106, 111, 115-117, 122-124)

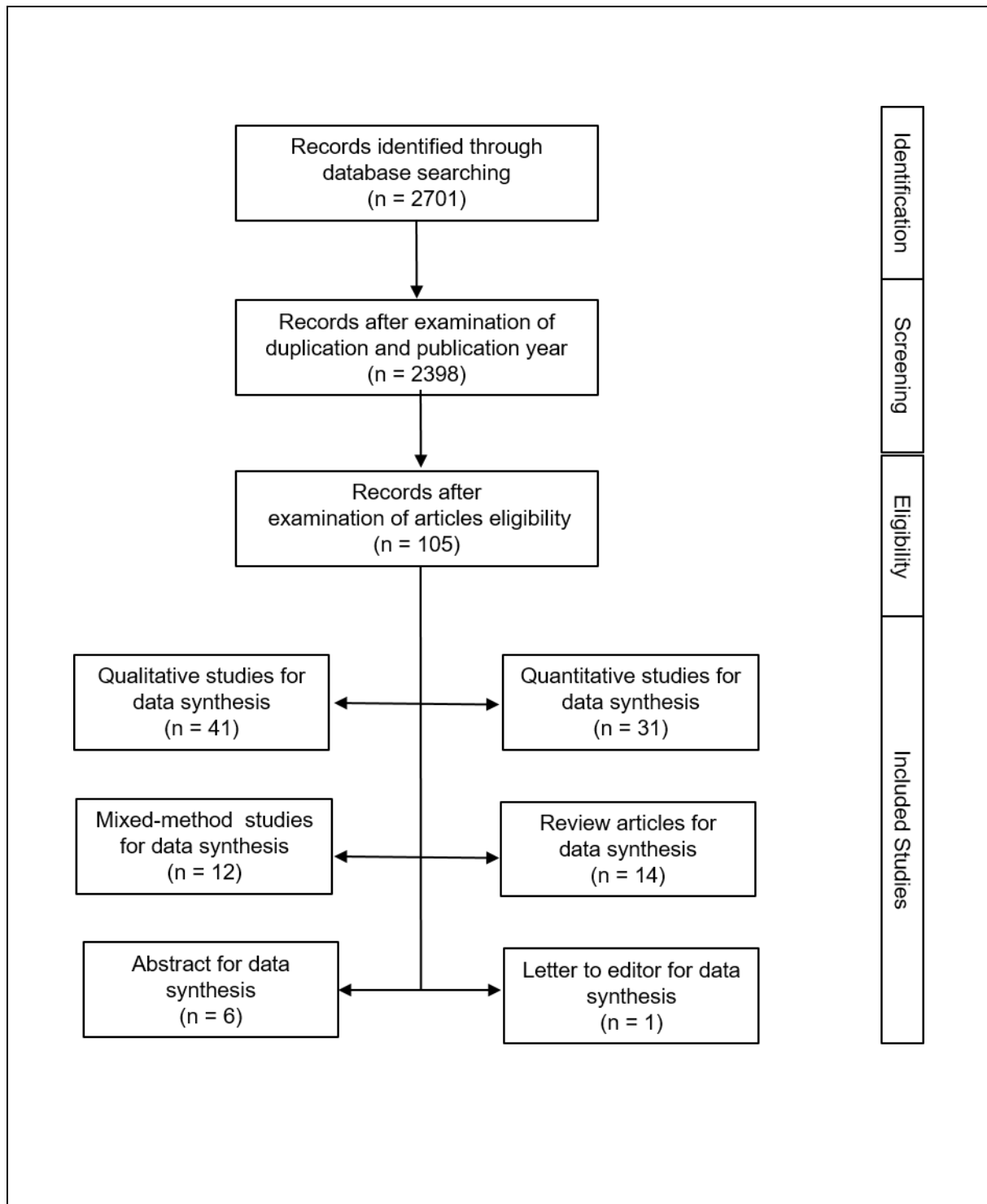
**Table 4:** Reported unmet needs by stroke caregivers.

Associated factors	Description	Papers
<i>Demographic factors</i>	<p><u>Gender</u>: Caregivers' gender was not found to be associated with unmet needs.</p> <p><u>Age</u>: Caregivers at younger age were reported having more unmet needs, although another article reported the unmet needs were higher in older caregivers. However, the unmet needs was also found comparable across age group.</p> <p><u>Ethnic</u>: White ethnic stroke caregivers were reported having more unmet needs than non-white ethnics.</p> <p><u>Geography</u>: The living location influenced the type of unmet needs in caregivers. Caregivers living in mainland expressed greater needs in information about managing behavioural change in survivors, while caregivers living in island needing more information about safety at home.</p>	<p>(97, 101)</p> <p>(51, 59, 72, 97, 101)</p> <p>(101)</p> <p>(104)</p>
<i>Characteristics of stroke survivors</i>	<p><u>Age</u>. Caregivers caring for young stroke survivors (less than 65 years) were reported having higher unmet needs than those taking care of older stroke survivors.</p> <p><u>Physical function</u>. Caregivers caring for survivors with poor physical function at 2 years after stroke was described having higher unmet needs.</p>	<p>(51)</p> <p>(101)</p>
<i>Other factors</i>	<p><u>Presentation</u>: Specifically to unmet information needs, unmet information was contributed by unsuitable presentation such as language used and professional behaviour, information was broad-based and was not tailored to caregivers' needs and supporting materials in suitable written format were not available.</p> <p><u>Caregivers' characteristics</u>: Caregivers with following characteristics were described as having higher unmet needs: no formal education, higher burden, having less</p>	<p>(35, 59, 105, 109, 110, 112)</p> <p>(97, 123, 125)</p>



	<p>social life, having poorer health, unprepared for caregiving. Those who appreciated the benefit in caregiving were also found to have high unmet needs.</p> <p><u>Education and coping mediator:</u> Caregivers with higher education background reported having higher unmet information needs. Caregivers also reported still having high unmet resource needs despite owing positive coping mediators.</p> <p><u>Perception:</u> The perception on caregivers' ability to connect with healthcare providers influenced their perception of unmet support needs. Additionally, mismatch perception between the healthcare providers and caregivers also influenced caregivers' perception on unmet information needs.</p> <p><u>Other:</u> Unmet support needs were also reported to be influenced by accessibility of service and longer rehabilitation.</p>	<p>(72, 101, 125)</p> <p>(60, 111),</p> <p>(111)</p>
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**Table 5:** Factors influencing unmet needs by stroke caregivers.



**Figure 1:** Flow for articles search and selection based on PRISM guideline.

CATEGORY	KEY WORDS
Population	Stroke, CVA, cerebral stroke,
Intervention	Stroke rehabilitation, long term stroke care, post stroke care, community dwelling.
Comparators	Needs, perspective, experience, opinion.
Outcome	Patients, survivors, caregivers, family, carers.

**Table 1:** The keywords used for search strategy

table 2 - unmet needs reported by stroke survivors

<b>Category: Physical and other stroke-related problems</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Physical functions	A wide range of unmet needs were reported i.e. mobility, pain, fall, fatigue, spasticity, headaches / migraine, bowel control, incontinence, swallowing, sight and speaking, reading, writing, hearing, speech, communication and oral care.	(13, 17, 19, 22, 30, 31, 39-45)
Cognitive functions	These needs consist of concentration and memory, cognition, intellectual fulfilment and attention.	(16-22, 29-31, 42)
Emotion functions	Unmet needs in survivors' emotion, including managing low mood and sense of feeling respected and insecurity in different aspects related to stroke, medical care and life, were documented in 14 articles	(16, 17, 19, 21, 29, 42, 46-48)
<b>Category: Social participation (related to support in living, community re-integration and relationship)</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Support in living	A wide aspects of unmet living support were reported i.e. performing activities daily living and non-care activities, continuing leisure activities, managing emotion, financial-related support, returning to work, transportation and traveling around, managing home and family, aids / adaptation, moving to suitable house and going for holiday. Inadequate professional support to maintain survivors' role in different aspects of living were also reported. Additionally, survivors also received inadequate support from voluntary organization / support group and peers. Unmet support in spiritual need and making will were also reported. In addition, survivors also expressed needing support for their caregivers.	(13, 16-22, 30, 33, 39, 41, 44-46, 49-63)

Community re-integration	Survivors reported having unmet needs in integrating self with community, such as in social activities as well as being able to get around and fulfil communication needs.	(13, 16, 19, 20, 22, 33, 36, 39, 49, 50, 53, 64-66)
Relationship	Survivors reported having unmet needs in keeping their intimate relationships with caregivers, and family relationship.	(16, 17, 21, 22, 30, 39, 43, 67, 68)
<b>Category: Information</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Stroke related information	Survivors reported receiving insufficient stroke-related information i.e. stroke prevention, stroke risk, cause of stroke, stroke recovery and secondary prevention. The information needs may persist up three years after stroke, requiring professionals to consider repeating information delivery. Survivors also needed more information about the impact of stroke, stroke support group and expectations in living after stroke.	(17, 18, 20, 34, 37, 38, 45, 46, 61, 69-72)
Information on post stroke care and rehabilitation.	Specifically, these include inadequate information about stroke care and treatment, managing stroke complication and identifying source for stroke care. Additionally, survivors needing more information about modifying home, care at home as well as long term stroke care. From rehabilitation perspective, survivors reported inadequate information about post-stroke difficulties as well as rehabilitation short-term and long-term goals. They also expressed not having enough information about ways to continue therapy at home.	(16, 34, 37, 38, 41, 66, 71-76)

Information on being productive and continue living after stroke	Survivors reported following unmet information needs related to being productive in living after stroke, i.e. return to work after stroke, and strategies to support survivors at work. Related to living after stroke, survivors reported missing information about driving, using public transport, moving to other house, determining the extent of support they need in daily living and organizing holidays that would suit the needs of stroke survivors. Additionally, they expressed having insufficient information about communication difficulties, for themselves and for the community for communication support. Furthermore, survivors expressed in needing information to resume exercise and physical intimacy	(16, 21, 32, 33, 41, 46, 67, 72, 74, 77-79)
<b>Category: Rehabilitation and care</b>		
<b>Aspects of unmet needs</b>	<b>The reported unmet needs</b>	<b>Papers</b>
Rehabilitation	Survivors reported having unmet rehabilitation needs such as occupational therapy, namely in hand function and work rehabilitation; and physical therapy.	(13, 18, 20, 31, 34, 36, 43, 54, 55, 57, 64, 69, 80-86)
Health-related care	The reported unmet post-stroke care were nursing care, foot care, and medical care (including secondary prevention) as well as managing changes in habit that were related to health and general well-being. Additionally, survivors expressed in needing help in home care, composing will and following appointment dates.	(16, 21, 22, 36, 39, 41, 45, 56, 80, 85, 87, 88)

**Table 2:** The reported unmet needs by stroke survivors.

table 3 - factors associated to unmet needs reported by stroke survivors

Associated factors	Description	Papers
Demographic factors	<p><u>Gender:</u> Female survivors were reported having higher unmet needs; although other studies did not find any difference between both genders.</p> <p><u>Age:</u> Younger stroke survivors (i.e. below 65 years old) were found to have higher unmet needs across different categories compared to older age, while older age survivors were described having higher described unmet rehabilitation than the younger survivors. Additionally, age at stroke onset was also found to associate with unmet leisure and work needs. This association however was insignificant in other articles.</p> <p><u>Ethnic:</u> Black survivors were reported to have more unmet needs in self-care than white survivors. However, the unmet needs in mobility and managing household needs were comparable between ethnics.</p> <p><u>Socioeconomic status:</u> The unmet needs were found comparable across socioeconomic status. However, another study demonstrated that unmet needs were higher in survivors with higher sociodemographic status.</p> <p><u>Geography / area of living:</u> survivors living in cities was likely reported unmet needs in everyday living, work, financial and health; whereas survivors living in deprived area reported having higher loss in income and higher need for benefits input. Additionally, survivors living within minority ethnic group were also reported having higher unmet needs.</p>	<p>(13, 17, 41, 89)</p> <p>(17-20, 41, 44, 59, 62, 72, 77, 89-91)</p> <p>(92)</p> <p>(17, 18, 20, 85, 91)</p> <p>(17, 19, 59)</p>
Pre-morbid condition	Survivors with prior history of stroke, diabetes, haemorrhagic stroke and atrial fibrillation were likely having more unmet rehabilitation needs at one year after stroke	(89)

Type of care received	<p>Those receiving care in stroke unit were unlikely having psychological needs, while those receiving thrombolysis were unlikely having physical needs.</p> <p>Survivors who perceived the general practitioners as important in their post stroke care perceived less unmet needs. In contrast, survivors who received stroke service in the community reported having higher unmet needs.</p>	(93)  (41)
Time since stroke	<p>Two articles described that time since stroke was found to have no influence to the perception of unmet needs. However, other articles described that time after stroke influence the presence and type of unmet needs in survivors.</p>	(17-19, 35, 41, 61)
Severity of stroke	<p><i>Survivors with higher dependency and level of disability</i> were reported to have higher unmet needs, however, an article documented that the perception was found comparable in terms of informational need.</p> <p>Unmet rehabilitation needs were associated with the severity of stroke, although one article found it did not contribute to the numbers of unmet needs.</p>	(18-20, 86, 89)  (17, 18, 20, 41, 44, 77, 81, 89, 90, 94, 95)
Problems and conditions following acute care	<p><u><i>Presence of fatigue, emotional and cognitive issues.</i></u></p> <p>Survivors having fatigue, emotional and cognitive issues were reported to have higher unmet needs, although this association was not to be significant in another study. Additionally, survivors having depression were also reported having higher unmet needs.</p> <p><u><i>Ability to return to work:</i></u> Higher unmet needs were found in stroke survivors who were not able to return to work after stroke.</p>	(17, 19, 41, 85)  (20, 50, 77)  (90)



	<p><u>Presence of pain and low perception of health:</u> Unmet rehabilitation needs was found higher in survivors with unmet pain needs and perceived self as having low health. (91)</p> <p><u>Low health-quality of life:</u> Low health-quality of life was also associated with higher unmet living needs, while requiring physical support at 3 to 6 months after stroke were associated with higher unmet health needs. (40, 61, 87, 96-99)</p> <p><u>Difficulties in activities daily living, community re-integration and communication; and presence of pain:</u> Unmet support needs were found higher in survivors with lower ability to perform activities of daily living, having difficulty in re-integrating self in community and having communication difficulties. Having pain was also found associated with higher unmet support needs.</p>	
Mismatch perception	<p>The perception of unmet needs was contributed by the culture and perception of needs in survivors, in addition to between survivors, caregivers and professional.</p> <p>The unmet information needs was also caused by the lack of understanding in health professionals about specific post-stroke disorders. Additionally, it was influenced by the professional perception about the type and extent of information that survivors would need.</p>	(40, 60, 61, 87, 98, 99)  (32, 74)

**Table 3:** Factors influencing unmet needs in stroke survivors.

table 4 - unmet needs reported by stroke caregivers

Category	Description	Papers
<i>Information</i>	<p>Caregivers reported receiving inadequate information. The missing information can be categorized as following:</p> <ol style="list-style-type: none"> <li>1. Stroke-related information.</li> <li>2. Information about supporting and caring for stroke survivors, including the emotional impact and risk of injury on caregivers as a result of caregiving.</li> <li>3. Living aspects after stroke, such financial assistance, communicating with survivors and resuming physical intimacy.</li> <li>4. Information about stroke rehabilitation / therapy and formal support (medical / non-medical) for survivors.</li> </ol>	<p>(35, 104-107)</p> <p>(35, 66, 72, 76, 103, 105-115)</p> <p>(35, 67, 103, 104, 112, 114, 116, 117)</p> <p>(34, 66, 104, 111, 112, 114, 118)</p>
<i>Support</i>	<p>This aspect is related to formal and informal support received by caregivers. The missing support could be divided into following categories:</p> <ol style="list-style-type: none"> <li>1. Preparing caregivers in stroke caregiving, including caregiving skills and supporting them in transiting to this new role.</li> <li>2. Supporting caregivers in preparing aids and home for stroke patients</li> <li>3. Supporting caregivers in caring and supporting stroke survivors at home.</li> <li>4. Professionals support in involving caregivers to support survivors throughout the rehabilitation process, to make informed decision and to locate additional resources / support.</li> <li>5. Support in sustaining living, such as financial, health and managing family.</li> </ol>	<p>(57, 100-102, 115, 117, 119, 120)</p> <p>(101, 102, 108, 117)</p> <p>(51, 101, 103)</p> <p>(36, 76, 97, 100-103, 111, 116, 119-121)</p> <p>(51, 59, 66, 101, 108, 120, 122, 123)</p>

	6. Supporting caregivers in non-caregiving tasks such as managing home.	(101)
	7. Managing self in caregiving role including emotion.	(36, 44, 51, 61, 102, 106, 111, 115-117, 122-124)

**Table 4:** Reported unmet needs by stroke caregivers.

table 5 - factors associated with unmet needs reported by stroke caregivers

Associated factors	Description	Papers
<i>Demographic factors</i>	<p><u>Gender</u>: Caregivers' gender was not found to be associated with unmet needs.</p> <p><u>Age</u>: Caregivers at younger age were reported having more unmet needs, although another article reported the unmet needs were higher in older caregivers. However, the unmet needs was also found comparable across age group.</p> <p><u>Ethnic</u>: White ethnic stroke caregivers were reported having more unmet needs than non-white ethnics.</p> <p><u>Geography</u>: The living location influenced the type of unmet needs in caregivers. Caregivers living in mainland expressed greater needs in information about managing behavioural change in survivors, while caregivers living in island needing more information about safety at home.</p>	<p>(97, 101)</p> <p>(51, 59, 72, 97, 101)</p> <p>(101)</p> <p>(104)</p>
<i>Characteristics of stroke survivors</i>	<p><u>Age</u>. Caregivers caring for young stroke survivors (less than 65 years) were reported having higher unmet needs than those taking care of older stroke survivors.</p> <p><u>Physical function</u>. Caregivers caring for survivors with poor physical function at 2 years after stroke was described having higher unmet needs.</p>	<p>(51)</p> <p>(101)</p>
<i>Other factors</i>	<p><u>Presentation</u>: Specifically to unmet information needs, unmet information was contributed by unsuitable presentation such as language used and professional behaviour, information was broad-based and was not tailored to caregivers' needs and supporting materials in suitable written format were not available.</p> <p><u>Caregivers' characteristics</u>: Caregivers with following characteristics were described as having higher unmet needs: no formal education, higher burden, having less</p>	<p>(35, 59, 105, 109, 110, 112)</p> <p>(97, 123, 125)</p>

	<p>social life, having poorer health, unprepared for caregiving. Those who appreciated the benefit in caregiving were also found to have high unmet needs.</p> <p><u>Education and coping mediator:</u> Caregivers with higher education background reported having higher unmet information needs. Caregivers also reported still having high unmet resource needs despite owing positive coping mediators.</p> <p><u>Perception:</u> The perception on caregivers' ability to connect with healthcare providers influenced their perception of unmet support needs. Additionally, mismatch perception between the healthcare providers and caregivers also influenced caregivers' perception on unmet information needs.</p> <p><u>Other:</u> Unmet support needs were also reported to be influenced by accessibility of service and longer rehabilitation.</p>	<p>(72, 101, 125)</p> <p>(60, 111),</p> <p>(111)</p>
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**Table 5:** Factors influencing unmet needs by stroke caregivers.

1.	stroke.mp
2.	Stroke/
3.	CVA.mp
4.	cerebral stroke.mp
5.	1 or 2 or 3 or 4
6.	stroke rehabilitation.mp
7.	Stroke Rehabilitation/
8.	6 or 7
9.	community dwelling.mp
10.	Independent Living/
11.	post stroke care.mp
12.	long term stroke care.mp
13.	"Quality of Life" / or "Recovery of Function"/
14.	8 or 9 or 10 or 11 or 12 or 13
15.	5 and 14
16.	needs.mp
17.	"Health Services Needs and Demand"/
18.	perception.mp
19.	SOCIAL PERCEPTION/
20.	experience.mp
21.	Patient Satisfaction/ or Social Support/
22.	opinion.mp
23.	Attitude/
24.	16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25.	15 and 24
26.	patient*.mp
27.	Survivors/
28.	stroke survivor*.mp
29.	26 or 27 or 28
30.	Caregiver*.mp
31.	CAREGIVERS/
32.	carer*.mp
33.	family.mp
34.	FAMILY/
35.	30 or 31 or 32 or 33 or 34
36.	29 or 35
37.	25 and 36
38.	limit 37 to (English language and yr="1999-Current")
39.	acute.mp
40.	Coronary Disease/
41.	39 or 40
42.	38 not 41

**Box 1:** Search strategy for Medline

DATA EXTRACTION

Author/year/country	Method	Sample	Data collection on unmet needs	Setting / time after stroke	Data related to unmet needs expressed by stroke survivors / caregivers
Kamalakannan et al. / 2016 / India (11)	Cross-sectional study	50 stroke survivors and 50 stroke caregivers	Mixed method (survey and interview)	Hospital / within 6 weeks after stroke	<p>(1) Stroke survivors reported having unmet needs in rehabilitation for following aspects: information, financial, physical symptoms, rehabilitation services, community support, psychological, transfer &amp; mobility, social/recreational, employment, self-care, social interaction and home management (23.1%).</p> <p>(2) Caregivers reported having unmet needs in rehabilitation for following aspects: information, financial, support for caregivers, community support, physical symptoms, rehabilitation services, psychological, transfer &amp; mobility, social/recreational, employment, self-care, home management and social interaction.</p> <p>(3) Female stroke survivors reported having more unmet needs as they are not usually involved in decision making of their care.</p> <p>(4) Preference in caregiving tasks were documented: Female with personal care and supporting the stroke survivors. Male with mobilization.</p>
Rothwell et al. / 2012 / United Kingdom (13)	Cross-sectional survey	137 stroke survivors	Assessment using Great Manchester Stroke Assessment Tool (GM-SAT)	Stroke survivors' Homes / 5-7 months after discharged from hospital for stroke care	<p>(1) 11 stroke survivors had no unmet need.</p> <p>(2) A total of 464 unmet needs were identified, ranging from 0-14 unmet needs per patient. The unmet need of foot care and will-making were newly discovered. In contrast, having seizure was not considered as unmet needs.</p> <p>(3) More than 20% stroke survivors reported having following unmet needs: secondary prevention lifestyle, memory, concentration and attention; and fatigue (the highest).</p> <p>(4) About 10-20% of stroke survivors reported having following unmet needs: medication compliance, exercise, depression, anxiety, personality changes, benefits and finances.</p> <p>(5) Less than 10% stroke survivors reported having following unmet needs: medication management, alcohol, diet, smoking, hearing, communication, swallowing, nutrition, weight management, pain, headaches / migraines, continence, activities of daily living, mobility, emotionalism, sexual health, sleep pattern, driving, transport &amp; travel, activities &amp; hobbies, employment, house &amp; home, carer/supporter needs and foot-care &amp; will making</p>
McKevitt et al. / 2011 / United Kingdom (14)	Cross-sectional survey	799 stroke survivors	Self-administered survey: UK Stroke Survivors Needs Survey	Community setting / 1 to 5 years after stroke	<p>(1) Unmet information needs: 54% reported wanting more info on cause, prevention and recurrence of stroke. No difference in information unmet needs across age, gender, ethnic, level of disability and time since stroke. However, those in Northern Ireland has significant unmet information needs compared to those in Wales, England and Scotland.</p> <p>(2) Physical and other stroke -related health unmet needs: memory was the highest reported unmet needs (59%) followed by fatigue and concentration (43% each), emotion</p>

					<p>(39%), reading difficulties (34%), speaking difficulties (28%), sight problems (26%), mobility problem (25%), falls and incontinence problems (21% each) and pain (15%).</p> <p>(3) Social participation: black stroke survivors reported higher negative impact in work related activities than white stroke survivors. 42% reported negative change in the relationship and 26% reported negative changes in family relationships. 18% experiencing loss of income and 31% increase in expenses. But only 2% reported in need for money management and 3% needed information related to employment after stroke.</p> <p>(4) Those living in deprived quartile reported a loss in income and in need for benefits advice.</p> <p>(6) Those with communication problem reported need more help in driving and employment; and reported having negative change in work activities, leisure activities, relationships and financial.</p> <p>(7) Number of unmet needs increased with worsening disability and black ethnic. No associations between unmet need and age, gender, cognitive, status or time since stroke.</p>
Low et al / 2003 / United Kingdom (15)	Cross-sectional survey	135 stroke survivors	Self-administered survey: The Southampton Needs Assessment Questionnaires for People With Stroke (SNAQs)	Community setting (stroke survivors received services from the Stroke Association) / minimum of 1 year after stroke	<p>1) The most frequent reported unmet needs were information about stroke, intellectual fulfilment, physiotherapy, help with finances and assistance with non-care activities.</p> <p>(2) Information needs required by the survivor were: cause of stroke, prevention of stroke recurrence, return to work after stroke and stroke recovery.</p> <p>(3) No significant difference in number of unmet needs between age group, time since stroke, level of mobility, employment status and socio-economic status.</p> <p>(4) Specifically to type of unmet needs, those at younger age has significant more unmet needs in family support and intellectual fulfilment. Those with limited mobility has higher unmet needs than those with better mobility. Those who have stroke more than 5 years has more unmet needs for social workers and holidays than those with recent stroke. Those with limited mobility has significant more unmet needs in care arrangements, maintenance with specialized mobility equipment, respite care (for carers), accessibility in physical environment, advise for continence and suitable wheelchair.</p>
Andrew et al. / 2014 / Australia (16)	Cross-sectional survey	765 stroke survivors	Self-administered survey: Australian Stroke Survivor and Carer Needs Survey	Community setting / minimum of 1 year after stroke	<p>1) 96% stroke survivors has one or more unmet needs. The most common reported unmet needs was related to health. Within this category, the cognitive/emotional related unmet need was reported higher than the physical related aspect, namely concentration, memory, cognition, fatigue and emotions.</p> <p>(2) More than 50% stroke survivors reported unmet needs in following domains: work, leisure and support. Financial and living unmet needs were also reported in 38% and 34% stroke survivors, respectively.</p> <p>(4) Young age was likely reported more unmet needs than older age, those living in the cities were more likely to report unmet needs in everyday living, work, financial and some health needs such as speech, increasing number in unmet needs was associated with greater level of disability. Young age also was associated with unmet</p>



					needs in fatigue, cognitive, ADL assistance, emotional, mobility, memory, support, finances and living.
Kersten et al. / 2002 / United Kingdom (17)	Cross-sectional survey	315 stroke survivors	Self-administered survey: The Southampton Needs Assessment Questionnaires for People With Stroke (SNAQs)	Community setting / more than 1 year of stroke	<p>1) The most frequent reported unmet needs were information about strokes, financial needs, assistance with non-care activities, intellectual fulfilment, adaptations, vehicles, social life and physiotherapy.</p> <p>(2) Specifically for information needs, the most reported needs are related to cause of stroke, prevention of stroke recurrence, stroke treatment and stroke recovery.</p> <p>(3) Number of unmet needs different significantly between levels of mobility, specifically respite care, adaptations and accessibility to the physical environment in the community.</p> <p>(4) The number of unmet needs does not differ significantly between age group. However, younger age stroke survivors reported significant needs for intellectual fulfilment, holiday and family support.</p> <p>(5) Those who were able to return to work after stroke reported significantly less unmet needs than those who were not able to work after stroke. The most pressing unmet needs were help with finances, a holiday and a speech-language therapist.</p> <p>(6) Number of unmet needs was not statistically different between people from different social class groups.</p>
Groeneveld et al. / 2018 / The Netherlands (18)	Cross-sectional survey	78 stroke survivors	Self-administered survey: Dutch Longer-term Unmet Needs after Stroke (LUNS)	Community setting / 5 to 8 years after stroke	<p>(1) 67.9% of respondents reported having 1 or more unmet needs. The highest need is on the information on stroke, followed by fear of falling and help with concentration and memory.</p> <p>(2) Needs perceived by stroke survivors were medication or blood check-up, pain, difficulties walking, information on public transport, advice on diet, help with applying benefits, help with bladder or bowel problems, help with mood and information on holidays.</p> <p>(3) 10.3% of stroke survivors indicated unmet needs on following items: needs for aids/adaptation, help in household, information on employment, help with personal care and advice on daily occupations.</p> <p>(4) Following unmet needs was perceived less than 10% of the population: information on driving, information on public transport, information on moving to another house, financial and advice on physical relationship.</p>
Ward et al / 2014 / Singapore (19)	Cross-sectional study	100 stroke survivors	Assessment in long-term stroke problems using Post-Stroke Checklist (PSC)	Clinical setting / 9 to 36 months after stroke	<p>(1) Key long term problems in PSC were regarded as unmet needs.</p> <p>(2) Stroke survivors reported having unmet needs in: (1) absence of secondary prevention, (2) activities of daily living, (3) mobility, (4) spasticity, (5) pain, (6) continence, (7) communication, (8) mood, (9) cognition, (10) life after stroke, and (11) carer relationship.</p> <p>(3) Compared to stroke survivors in UK, the percentage of all reported unmet needs were in Singapore.</p> <p>(4) The highest reported unmet needs for both countries was cognition. The least unmet need for UK stroke survivors was carer relationship while Singapore stroke survivors was communication.</p>

Kristensen et al. / 2016 / Denmark (26)	Cross-sectional survey	63 stroke survivors	Assessment for needs: Self-administered survey using adapted from UK Stroke Survivors Needs Survey	Community setting / within 12 months after completing stroke rehabilitation	(1) Unmet need or need met to some extent were found in following: mobility, falls, incontinence, pain, fatigue, emotion, concentration, memory, speaking, reading, sight. (2) The number of stroke survivors being involved in care and treatment are significantly higher in following areas: incontinence, pain, fatigue, emotion, concentration, memory and speaking. The involvement may contributed to certain extent of met needs in these areas.
LUNS Study team / 2013 / United Kingdom (27)	Cross-sectional survey	529 stroke survivors	Assessment for needs: Self-administered survey - Longer Unmet Needs after Stroke (LUNS) tool	Community setting / 3 or 6 months after stroke	22-items of unmet needs after stroke were validated. They were: physical relationship, managing money, accessible holiday, pain, driving, memory/concentration, information, employment, benefits, daily occupations, bladder/bowel, mood, aids/adaptations outside, diet, personal care, home help, moving house, transport, aids/adaptations inside, falling, mobility and medication/blood pressure.
Walsh et al. / 2014 / Ireland (28)	Cross-sectional survey	196 stroke survivors	Self-administered survey: adapted from UK Stroke Survivors Needs Survey	Community setting / up to 5 years after stroke.	(1) Following unmet needs were reported for more than 40%: emotions, fatigue, concentration, writing, bladder/bowel, memory and reading. (2) Following unmet needs were reported for 30% to 39%: arm function, falling, speech, mobility and swallowing. (3) Following unmet needs were reported for 25A% to 29%: sight and pain
Rose et al. / 2009 / Australia (29)	Cross-sectional interview	39 stroke survivors	Survey interview	Community setting / 2 months to 14 years 9 months after stroke	(1) Participants reported not receiving on insufficient written information on stroke and / or aphasia. A small number were not informed re their stroke diagnosis, had unanswered queries about stroke, and had not learned about aphasia prior to the research. Some participants also demonstrated poor or nil understanding about aphasia. (2) In terms of written material, some perceived it was written in a complex form thus limit their understanding on the information. Some reported only given verbal information which limit their ability to retain information given, while some reported that the presentation of the information was given in different written materials and unsystematic, causing difficulty for them to organize and make sense of their reading. (3) The provision of information on aphasia was mainly by Speech-Language Therapist and very small number from other professionals.
		16 stroke survivors and	Interview	Rehabilitation facility / time	Stroke survivors reported having: (1) inadequate preparation in terms of the practical aspects of activities of daily living and social activities; (2) inadequate information on

Cameron et al. / 2014 / Canada (30)	Cross-sectional interview	15 stroke caregivers		after stroke was not specify	aspects that stroke survivors could be doing independently or must be helped, (3) inadequate written information for quick reference at home. Caregivers reported having inadequate aids, training and confidence to take over the caregiving role at home.
Danzl et al. /2016 / USA (31)	Cross-sectional interview	13 stroke survivors and 12 stroke caregivers	Interview	Community setting or health facility / 1 to 14 years after stroke	Stroke survivors reported having: (1) unmet needs for stroke information, including secondary prevention and managing complications post-stroke (2) unmet needs in information due to lack of comprehensible of written materials, and (3) unmet needs of being heard in rehabilitation . Caregivers reported having inadequate education related to rehabilitation despite taking the role to care for the stroke survivors and were able to accompany stroke survivors to receive services.
Eames et l./ 2003 / Australia (32)	Cross-sectional mixed method study	20 stroke survivors and 14 stroke caregivers	Reading assessment, assessment on written materials and interview	Venue not specify / 2 to 15 years after stroke	(1) 5 stroke survivors and 4 carers reported informational needs were not fully met after discharge i.e. current development in stroke, prevention of stroke recurrence, leisure activities for people with impairments and assistive devices. (2) Participants indicated help from professional to support them in reading and comprehending the information; to provide information in verbal and written forms; to customize information to their needs and to use simple language, especially in those aphasic stroke survivors. (3) 6 aphasic and only 1 non-aphasic stroke survivors indicated need for diagram, figures and pictures to support their reading comprehension
Murray et al. / 2003 (33)	Systematic review	Not applicable	Systematic review on 23 qualitative studies	Venue: Not applicable / 3 months to 6 years after stroke	(1) More than 50% studies reported about insufficient written information. (2) Stroke survivors reported receiving insufficient medical care, rehabilitation need, social services and social reintegration. (3) Among caregivers, expression for more needs in social support, respite care and independence to support caregiving was reported
Garrett & Cowdell / 2005 / United Kingdom (34)	Longitudinal study	16 stroke survivors and 16 stroke caregivers	Interview	Venue was not mentioned / 2, 20 and 90 days after stroke	(1) Stroke survivors reported having unmet information needs about cause of stroke and preventing stroke recurrence. (2) Stroke survivors reported wanting information about long term care, delivered privately - i.e. avoid discussion at bedside and delivered by someone they know.
Roding et al./ 2003 / Sweden (35)	Cross-sectional study	5 stroke survivors	Interview	Homes or health facility / 1 to 1 year and 5 months after stroke	(1) Stroke survivors reported having unmet needs for information on stroke-related topics i.e. cause, consequences, prevention of recurrence; as well as expectations in navigating life after stroke. (2) The information needed to be presented in non-ambiguity way, direct and clear. (3) Not having enough information lead to frustration and sense of passiveness in recovery. (4) In addition unmet rehabilitation needs was also reported in relation to specific needs in everyday living. This aspect was not considered in the rehabilitation process.

losa et. al / 2018 / Italy (36)	Cross-sectional studies	64 stroke survivors	Assessment using Post Stroke Checklist (Italian version)	Telephone interview & face to face: venue was not mentioned / 3 years 5 months to 15 years after stroke	(1) 83% stroke survivors was identified having at least 1 unmet needs. (2) The reported unmet needs were (in hierarchy): mobility, mood, activities of daily living, spasticity, absence of secondary prevention, pain, cognition, continence, communication, life after stroke & sex, carer relationship (3) The identified unmet needs were dissimilar with the identified unmet needs in United Kingdom and Singapore, in terms of frequency of the reported needs
Worthington et al./2017/United Kingdom (37)	Cross-sectional study	22 stroke survivors	Interview	Homes / 6 months after stroke	(1) Stroke survivors reported receiving inadequate input on managing fatigue from the healthcare professionals. (2) For those who received information on fatigue, they perceived that: (1) fatigue was not appropriate for discussion during acute phase, during hospitalization; (2) fatigue was taken lightly by health professionals in which should be accepted as normal by stroke survivors. (3) Fatigue was overlooked by professionals and not necessarily be asked during follow up. (4) Although the content of reading material on fatigue was unclear, having the material was perceived as a reassurance and helpful.
Olaiya et al. / 2017 / Australia (38)	Cross-sectional survey	391 stroke survivors	Self-administered questionnaire	Community setting / 2 years and more after stroke	(1) The questionnaire consisted of 5 domains. 87% stroke survivors reported having unmet need in at least 1 from each of 5 domains. This finding was comparable between ischemic stroke and intracerebral stroke haemorrhage. (2) Health related unmet-needs (post-acute care, secondary prevention and body function) were the most frequently reported (3) Lower unmet needs were associated with those more than 2 years after hospital discharged, aged 65 years or higher, had greater function level and perceived general practitioners (GP) as the most important professionals in their care. (4) Higher unmet needs were related to having depressed, receiving community services after stroke, having higher education and discharged to rehabilitation. (5) No gender difference in reporting unmet needs
Dickerson et al. / 2015 / United Kingdom (39)	Research abstract	Was not mentioned	Multiple methods: interview, literature review & analysis on database	Venue and time since stroke were not mentioned	A total of 25 persisting needs were identified. These included range of emotional, cognitive, physical, practical, social, instrumental, information and support needs
		17 stroke survivors, 12		Venue was not mentioned	(1) Overall, all groups of subjects rated the following domains of unmet needs in stroke survivors differently: personal capabilities, environmental factors and life habits.

Vincent et al. / 2007 / Canada (40)	Cross-sectional study	stroke caregivers (this study also included health care professionals and health care managers)	Focus group and individual interview	/ less than 1 year to more than 9 years after stroke	(2) For personal capabilities, stroke survivors perceived reproduction capabilities (expressing sexuality and viability of information in this idea) as well as motor activity capabilities were their highest unmet needs. However, these were not perceived equally by other groups. (3) In relation to environmental factors, all groups rated the rehabilitation aspects as the highest unmet needs in the stroke survivors. However, in terms of public transport, stroke survivors also perceived this as their significant unmet needs. However, this was not the case for other groups. (4) For life habits, carers and stroke survivors perceived the unmet mobility needs equally. However, stroke survivors rated fitness and interpersonal relationships as the highest unmet needs, while carers perceived mobility as the highest unmet needs in stroke survivors.
Andrew et al. / 2013 / Australia (41)	Research abstract	765 stroke survivors, 387 stroke caregivers	Self-administered survey: The Australian Stroke Survivor and Carer Needs	Community setting / 12 months and more after stroke	(1) Stroke survivors and caregivers reported having different unmet needs. (2) Among stroke survivors, the common reported unmet health needs were concentration, memory, fatigue and emotional problems. Additionally, unmet needs in work and leisure were also reported. Higher unmet needs was seen in younger age (<65 years) and having higher levels of disability. (3) Caregivers reported did not receive sufficient social support and respite care. They also reported experiencing significant changes in their work and leisure activities
Murray, Young & Forster / 2007 (42)	Systematic review	Not applicable	Systematic review of 76 quantitative studies & 1 systematic review paper	Not applicable / 3 months to 10 years after stroke	(1) Stroke survivors reported receiving inadequate information related to community services. They also reported receiving lack of financial help, help in personal care and dental care (2) Caregivers and stroke survivors reported having unmet needs in information related to stroke recurrence and in accessing support services.
Sadler et al./ 2014 / United Kingdom (43)	Cross-sectional study	31 stroke survivors	Interview	Homes / 6 weeks to 28 months after stroke	(1) Stroke survivors reported lack in guidance in physical recovery, support with psychological, emotion and social, as well as professional support. They reported having extreme difficulty in navigating community stroke care. (2) Stroke survivors expressed their expectation that community rehabilitation were delivered beyond physical recovery i.e. addressing needs for support with rehousing, transport, stress management, emotional and interpersonal difficulties. (3) Stroke survivors also expressed inadequate information about stroke recovery and risk of recurrence, emotional support to cope with stroke and help in returning to work to meet their financial needs.
Taule et al. / 2015 / Norway (44)	Cross-sectional study	8 stroke survivors	Interview	Homes or health institution / 6 to 8 months after stroke	Stroke survivors reported unmet needs in emotion related to managing depression and answering uncertainties about life and death, having recurrence in stroke and possible side-effects of medication. The expressed service for psychological support was not offered despite mentioning the need.

Harrison et al./ 2017 / United Kingdom (45)	Cross-sectional study	31 stroke survivors and 28 stroke caregivers	Interview	Homes or workplace / within 1 year after stroke	<p>(1) All stroke survivors described having psychological distress after stroke, with more than 50% having low mood. Some reported being diagnosed as depression.</p> <p>(2) Stroke survivors and caregivers reported being listed in the waiting list for psychological support in the community service. This created perception in stroke survivors that psychological issues are not a valid concern.</p> <p>(3) Some stroke survivors described that this needs were met from support from friends and family members, or by considering that they condition was better than other and thus no help needed.</p> <p>(4) Stroke survivors and caregivers described that having access to information about stroke has served as part of psychological support.</p>
Skolarus, Burke & Freedman / 2014 / USA (46)	Cross-sectional study	892 stroke survivors	Data examination	Venue: Not applicable / Time after stroke was not mentioned	Stroke survivors needed more assistive devices significantly than non-stroke population for self-care activities (eating, bathing/showering, toileting, dressing) and mobility activities (going out, getting around inside, getting out of bed). They also reported higher unmet needs in self-care and mobility compared to the counterparts. This included unavailability of assistance and device to support their needs in both aspects.
Boerboom et al. / 2016 / The Netherlands (47)	Longitudinal study	67 stroke survivors	Mixed methods: Series of questionnaires and interview	Homes / from onset up to 4 years after stroke	<p>(1) More than half stroke survivors having 1 or more unmet needs at 4 years post SAH.</p> <p>(2) Unmet information needs was rated the highest, followed by formal social services and mobility. Other unmet needs were voluntary organizations, formal health services, housing, family, work training, social activities and finances.</p> <p>(3) Only 22 stroke survivors were employed after 4 years post SAH. Total unmet needs was significantly different between those who were employed and those who unemployed.</p> <p>(4) Unmet needs score were significantly associated with community reintegration. Higher unmet needs were associated with a lower community reintegration.</p>
Andrew et. al / 2015 / Australia (48)	Cross-sectional study	Dyads of 369 stroke survivors and 369 stroke caregivers	Data examination (obtained from cross-sectional survey)	Community setting / 12 months and more after stroke	<p>(1) Stroke survivors reported having unmet needs in health, work, leisure, finance and living.</p> <p>(2) Caregivers reported having unmet needs in social support for caregiving role, financial and respite care. They also reported reduction in income and increase in expenses.</p> <p>(3) The unmet needs of stroke survivors cause significant impacts on caregivers across different domains. The number of unmet needs in stroke survivors was significantly associated with caregiver impacts across domains except work.</p> <p>(4) Caregivers to young stroke (Less than 65 years) expressed needing more help for support.</p>
Brunborg & Ytrehus / 2013 / Norway (49)	Cross-sectional study	9 stroke survivors	Interview	Homes or telephone interview / 10	Stroke survivors reported persistence unmet needs in financial support and unable to sustain in job as a result of post-stroke fatigue and concentration issue.

				years after stroke	
Sumathipala et al. / 2011 / United Kingdom (50)	Longitudinal study	35 stroke survivors	Interview	Venue was not specified / 1 to 11 years after stroke	(1) Stroke survivors reported having range of unmet need in financial, information, aids and adaptation, mobilization, health needs, activities of daily living and social participation. The policy / system may influence the unmet needs in rehabilitation. (2) Adopting the International Classification of Functioning, Disability and Health (ICF) may provide a context in understanding the impact of unmet needs in stroke survivors.
Dalvandi et al. / 2010 / Iran (51)	Cross-sectional studies	10 stroke survivors	Interview	Homes or health facility / 3 to 6 months after stroke	(1) Stroke survivors expressed having lack in following supports: (1) socio-economic support including financial, insurance and social support; (2) rehabilitation devices at home; and (3) care and rehabilitation. This reduced their coping mechanism, leading to life disintegration. (2) Caregivers expressed receiving inadequate educational in caring for stroke survivors and supporting the stroke survivors in stroke recovery.
Murgo et al. / 2016 / Australia (52)	Cross-sectional studies	28 stroke survivors	Self-administered questionnaire: The Stroke Specific Quality of Life Scale (needs assessment was added in)	Community setting / within 2 years after stroke	(1) Stroke survivors indicated presence of gaps in rehabilitation service and support group. They indicated in needing support in both aspects. (2) Stroke survivors also indicated still in needing support to complete housework.
Martinsen, Kirkevold & Sveen / 2015 / Norway (53)	Cross-sectional studies	16 stroke survivors	Interview	Community setting, specific facility or workplace / 1 year 5 months to 10 years after stroke	(1) Stroke survivors perceived not receiving medical care for personal medical needs and psychological support despite having follow up with the general practitioners. (2) Stroke survivors also reported receiving insufficient professional help in navigating life after stroke. (3) In terms of rehabilitation, having mismatch between personal needs / situation and the rehabilitation set-up was reported. Stroke survivors emphasized on flexibility in rehabilitation needs to support them in going through the rehabilitation services, to allow them managing their roles / obligations in life simultaneously.
Gutaffasson & Bootle / 2013 / Australia (54)	Cross-sectional studies	5 stroke survivors and 5 stroke caregivers	Interview	Homes / time after stroke was not mentioned	(1) Stroke survivors and caregivers reported receiving inadequate preparation for discharge due to lack of outdoor activities and daily routines in the in-patient rehabilitation's environment. (2) Stroke survivors also reported not knowing who to contact for help, not having help with transport for follow-up appointment and did not receive the expected assistance.
Leahy et al. / 2016 / Ireland (55)	Cross-sectional studies	12 stroke survivors	Interview	Hospital / 10 to 29 months after stroke	(1) Stroke survivors reported having unmet needs in relation to invisible difficulties either physically, cognitively or emotion, leading to a great struggles at work.

					(2) Stroke survivors also reported having unmet needs in peer-support, emotions and information about navigating life after stroke.
Yeung et al. / 2015 / Canada (56)	Cross-sectional study	5 stroke survivors and 13 stroke caregivers	Interview	Telephone interview or in-person (venue was not mentioned) / time after stroke was not mentioned	(1) Stroke survivors and caregiver reported having unmet needs in information due to language barrier. The barrier in language also limited their access in receiving guidance to continue therapy and reduced their ability to benefit from available services, especially among participants at older age and living predominantly within the Chinese community. (2) At rehabilitation stage, following information was not provided: social welfare assistance, financial assistance, governmental assistance and therapy availability in community setting.
Hare et. al / 2006 / United Kingdom (57)	Cross-sectional study	27 stroke survivors and 6 stroke caregiver	Focus group	University, Homes and nursing Homes / 6 weeks to 22 years after stroke	(1) Participants reported receiving lack of information about social support from specific group, as it was deemed "not needed" by the professionals. Additionally, they also perceived lack of support given by the primary healthcare. (2) Caregivers reported lack of support in respite care and managing stroke survivors' incontinence and respite care.
Chenoweth, Gietzelt & Jeon / 2002 (58)	Review article	Not applicable	Not applicable	Not applicable	(1) Stroke survivors and caregivers require emotional and personal support as well as informational support. The type and amount of support differ throughout the time after stroke. (2) Emotional and personal support include support in accessing resources and using aids / adaptation; dealing with perceptions of community and changes in self-identity. (3) Information support would include information pertaining to cause and underlying factors of stroke, risk of recurrence, impact, resources, care and rehabilitation. (4) Emotional support for caregivers was also described as necessary to facilitate the transition and caregiving role, and is associated with readmission rate.
Daniel et al. / 2009 (59)	Systematic review	Not applicable	68 quantitative studies, 9 qualitative studies, 1 mixed method	Not applicable	Unmet financial needs were reported among working-aged stroke survivor. Additionally, unmet need to support family dynamic and assistance in non-caregiving activities as well as social activities were also reported
Sae-Sia / 2000 (60)	Letter to editor - responding to Lui & MacKenzie (Journal pf Advance	Not applicable	Not applicable	Not applicable	Unlike functional impairment, psychosocial and spiritual needs are often been neglected, leading to a wide range of emotional problems



	Nursing, 30, 391-400)				
Corr & Wilmer / 2003 / United Kingdom (61)	Cross-sectional studies (2 studies)	<b>Study 1:</b> 26 stroke survivors. <b>Study 2:</b> 6 stroke survivors	<b>Study 1:</b> Interview & assessments - Canadian Occupational Performance Measure and Role Checklist. Study. <b>Study 2:</b> Interview	Homes / <b>Study 1:</b> 1 to 141 months after stroke; <b>Study 2:</b> 10 to 132 months after stroke	Stroke survivors identified work has been a problem and rated to return to work at high scale. In returning to work, patients reported unmet needs in getting occupational therapy support in planning and returning to work.
Wray & Clarke / 2017 / United Kingdom (62)	Systematic review	Not applicable	32 qualitative studies	Not applicable	(1) Stroke survivors with communication difficulties were reported having negative impact in social network and received lack of support from former friends. (2) Those with unmet communication needs and having ineffective communication strategies also at risk to be isolated socially, losing friendship, being restricted from involving in activities that require some forms of social interaction, as well as losing a degree of independency and self-control in life. (3) The inability to live independently was perceived as unsuccessful living after stroke by those stroke survivors with aphasia
Chen, Dongxia & Bellis / 2015 / Australia (63)	Cross-sectional study	12 stroke survivors and 10 stroke caregivers	Interview	Homes or hospital / Time after stroke was not mentioned	Participants reported having following unmet needs: (1) information in getting and navigating rehabilitation; (2) education in preventing and managing fall; and (3) social support. The inadequate social support contributed to depression symptoms, high sense of burden in caregivers and low quality of life, resulting in social isolation
Schmitz & Finkelstein / 2010 / USA (64)	Cross-sectional study	15 stroke survivors and 14 stroke caregivers	Interview	Hospital / 23 months to 176 months after stroke	(1) Participants did not receive consultation or education related to post-stroke sexuality. Participants assumed that this was due to the sense of discomfort in rehabilitation professionals to discuss such issues, as well as the sensitivity of sexuality topic in nature. (2) Participants emphasized that information of sexual issues post stroke must be tailored made to individually, presented verbally and in written form; and at appropriate timing, for example, at the end of in-patient rehabilitation or before patient is discharged home.
Nilsson et al. / 2017 / Sweden (65)	Cross-sectional study	12 stroke survivors	Interview	Homes, workplace or hospital / 6 years after stroke	(1) Stroke survivors expressed about unmet needs in sexuality. Sexuality was not discussed extensively. (2) Discussion about stroke survivors' concern in sexuality was not held, although professionals might mentioned the side effects of medication on sexuality.

					(3) Sexuality need was described as crucial although the preference in timing of delivery varied among stroke survivors.
Lawrence / 2010 (66)	Review article	Not applicable	4 qualitative studies	Not applicable	Young adult stroke survivors reported receiving inadequate information on cause, risk and prevention of stroke; stroke recovery process and dealing with effects of stroke. They also reported receiving inadequate rehabilitation services and perceived this as a factor that impeded recovery.
Tooth & Hoffman / 2004 / United Kingdom (67)	Cross-sectional study	15 stroke survivors	Questionnaire, face-to-face completion	Homes / Time after stroke was not mentioned	(1) Stroke survivors reported did not receive information related to their concern. (2) The most frequent type of information they reported needing more were related to cause of stroke, treatment and risk factors, as well as stroke support groups. (3) The recipient of information was fragmented and differ between professionals. For example, information related to medical and community support was typically received from doctors. Occupational therapist provided information on returning to home, assistive device, activities after stroke and physical effects of stroke.
White et al. / 2014 / United Kingdom (68)	Cross-sectional study	14 stroke survivors	Interview, supported by quantitative measures	Location was not specify / 18 months to 5 years after stroke	Stroke survivors reported unmet needs in information related to service access, for example availability of ongoing therapy, home modifications, home care or on-going information/education
Hafsteinsdóttir et al. / 2011 (69)	Systematic review	Not applicable	17 quantitative studies, 5 qualitative studies	Not applicable	(1) Inadequate information was perceived by both stroke survivors and family members. Those with high education perceived higher inadequate information. (2) Young stroke (65 years and below) reported unmet information needs related to different range of stroke education, including prevention, treatment, cause and recovery as well as return to work. (3) Stroke survivors also perceived insufficient information in findings sources for help, strategies to carry out activities daily living and reducing risk of recurrence stroke. Among caregivers, lack of information on community services was reported. Lack of information was also associated with difficulty in caregiving
Peoples, Satink & Steultjens / 2011 (70)	Systematic review	Not applicable	12 qualitative studies	Not applicable	Information provision is crucial for stroke survivors' rehabilitation. Inadequate information hinder their active participation in rehabilitation and leading to "passively waiting" behaviour for recovery to take place. In addition, stroke survivors also reported that their rehabilitation was not meeting their personal goals as professionals limited their goals only on physical care and not holistic to their personal needs.
Hinckley, Hasselkus & Ganzfried / 2013 / USA (71)	Cross-sectional study	<b>Survey:</b> 428 respondents <b>Focus group:</b> 10 stroke survivors and	<b>Survey:</b> Online survey <b>Focus group:</b> Interview	Survey: Online, Focus group: Aphasia centres / <b>Focus group:</b>	(1) Responders indicated finding aphasia resources was difficult. The resources referred to anything that would help them to communicate, including awareness among public. However, treatment resources was not included. (2) Some responders indicated the health care professionals (non-SLT) did not demonstrate good understanding about aphasia and were not aware about resources of aphasia.

		9 stroke caregivers		6 months to 20 years after stroke. <b>Survey online:</b> Time since stroke was not included	(3) Stroke survivors with aphasia would like to have more resources about aphasia in a long term, although, some discontinued due to different factors such as finance. The available resources were mainly about speech problems after stroke, but did not necessarily about aphasia.
Worrall et al. / 2011 / Australia (72)	Cross-sectional study	50 stroke survivors	Interview	Homes / Less than 12 months after stroke, and more than 12 months after stroke	Some stroke survivors reported that they did not received information about their communication difficulties. They also were not well educated about aphasia and were not given clear direction about their goals in therapy.
Rodgers, Bond & Curless / 2001 (73)	Review article	Not applicable	Not applicable	Not applicable	(1) Stroke survivors and family members reported receiving inadequate information about every aspects of stroke and support available especially related to emotional impacts. (2) In addition, they expressed unmet need information about the caring aspects, and wanting to be involved in the decision. Lack in this aspects leading to misunderstanding, sense of fear and anxiety which may lead to negative impact on their health status and emotion.
Morris / 2011 (74)	Review article	Not applicable	Not applicable	Not applicable	(1) The most common unmet needs reported by young stroke were information about stroke relevance to them, financial help, non-care activities, intellectual fulfilment, adaptations, vehicles and social contact. (2) Those with limited mobility and unable to return to work after stroke reported having more unmet needs than those who were able to work again. They also reported unmet information needs about returning to work and insufficient understanding about stroke among employers
Liddle et al. / 2009 / Australia (75)	Cross-sectional study	24 stroke survivors	Interview	Homes / 5 months to 16 years after stroke	(1) Stroke survivors reported having lack of information on driving, either at rehabilitation stage or after discharged. Unmet needs in information about safe driving and support to have license to drive were also documented. (2) Stroke survivors received neither information about their ability to drive nor being involved in decision making to drive, even about the necessary to give up driving. Lack of follow up about the driving cessation process. Additionally, lack of options for alternative transport were also reported.
Dalemans et al. / 2010 / The	Cross-sectional study	20 stroke survivors and	Interview (Stroke survivors had	Homes / 1 year 4 months	Stroke survivors described their limitation in social participation due to the poor awareness among community members about aphasia. The community has not knowledge about aphasia and the appropriate strategies to communicate with the

Netherlands (76)		12 stroke caregivers	baseline aphasia assessments 2 weeks prior to interview)	to 11 years after stroke	aphasic stroke survivors. Unmet awareness of aphasia within the community hinder social participation as they have no knowledge about appropriate strategies to facilitate communication in stroke survivors with aphasia.
Chuang et al. / 2007 / Taiwan (77)	Longitudinal study	375 stroke survivors	Telephone survey	Community setting / 1 months, 3 months and 6 months after stroke	(1) The type of unmet needs in nursing care and rehabilitation changed over time. (2) The needs for nursing care was higher at the first month after stroke compared to the 6 months after stroke. (3) The needs for rehabilitation increased throughout time. The unmet needs in rehabilitation increased at 6 months after stroke, compared to the first month.
Duxbury et al. / 2012 / Canada (78)	Longitudinal study	209 stroke survivors	Interview, and quantitative needs & barriers survey (Stroke survivors received functional independence measurement during hospitalization and within a month after discharge)	Homes / within 1 month after discharge from acute stroke care (time after stroke was not mentioned)	(1) Stroke survivors with lower functional ability reported having unmet needs for occupational therapy. They were also more likely in needing for assistive device and less likely to return to work. (2) Improving hand function was frequently reported by those in need for frequent occupational therapy in order to achieve the needs in performing activities of daily living
Tistad et al. / 2012 / Sweden (79)	Longitudinal study	175 stroke survivors	Questionnaire (Clinical assessment of function and impact of stroke prior to discharged from hospital)	Community setting / Assessment on needs and satisfaction was conducted at 12 months after stroke	Unfulfilled rehabilitation needs at 12 months after stroke was predicted by: <ul style="list-style-type: none"> <li>i. the high impact in the Severity in Stroke (SIS) strength domain at 3 months after stroke.</li> <li>ii. the high impact in the SIS hand function domain</li> <li>iii. poor self-perception of recovery</li> </ul>
Doyle, Bennett & Dudgeon / 2014 / USA (80)	Cross-sectional study	16 stroke survivors	Interview	Venue was not mentioned / 6 months to 16 years after stroke	(1) Stroke survivors, namely among those in the outpatient rehabilitation, reported having unmet needs in addressing their arm function. (2) As focus of rehabilitation was mainly for physical activities such as balance and walking, little or no attention given to the sensory impairment of their arm, either in a form of rehabilitation activity or consultation.

Reed et al. / 2010 / United Kingdom (81)	Cross-sectional study	12 stroke survivors	Interview	Homes / 15 to 40 months after stroke	Stroke survivors reported having inadequate resources to support rehabilitation work, including to be engaged in purposeful activities. This aspect is crucial in re-creating a self-image following stroke
Op Reimer et al. / 1999 / The Netherlands (82)	Longitudinal study	<b>First stage:</b> 382 stroke survivors <b>Second stage:</b> 22 stroke survivors	Interview using semi-structured questionnaire	Venue was not mentioned / <b>First stage:</b> 6 months after stroke, <b>Second stage:</b> 5 years after stroke	(1) At 6 months post stroke, 1/3 of stroke survivors perceived having at least one unmet care demands. In contrast, at 5 years after stroke, 1/5 of stroke survivors perceived having at least one unmet care demands (2) The highest unmet demands was physical therapy and the lowest was nursing care. (3) Unmet demands for independent activities of daily living (IADL) was significantly high in younger age, male gender and living alone. (4) Those who were living alone reported having significantly high unmet demands for psychosocial support (5) Those at younger age reported significantly high unmet demands for aids. (6) Compared to those who did not have care demand, stroke survivors with lower sociodemographic, more disabled and having higher rate of dementia required more IADL care. Stroke survivors with higher report of emotional distress required higher psychosocial support.
Tistad et al. / 2013 / Sweden (83)	Longitudinal study	173 after stroke	Interview, questionnaire (stroke survivors had baseline functional assessment at 1 week after stroke)	Homes / Data on needs was collected at 12 months after stroke	(1) About 1/3 of stroke survivors reported having unmet needs for rehabilitation at 12 months after stroke. (2) Increased severity in stroke is associated with higher unmet needs. Having contact with physiotherapist at least once every 3 months contributed to needs met in moderate/severe stroke.
Koh, Barr & George / 2014 / Singapore (84)	Cross-sectional study	68 stroke survivors	Telephone interview	Community setting / Time after stroke was not mentioned	(1) Stroke survivors reported did not received enough help in tracking their rehabilitation appointments. (2) Unmet rehabilitation needs was also due to the goals that were not taking into account their expectation and other comorbidity, and mismatch opinion between service providers about their rehabilitation needs.
Boter, Rinkel & de Haan / 2004 / The Netherlands (85)	Longitudinal study	173 stroke survivors, 148 caregivers	Checklist, data collection through telephone contact and home visit	Homes / 1 to 24 weeks after discharge (time after stroke was not mentioned)	Survivors reported unmet needs for services, specifically for home care. Compared to the initial contact, the reported unmet needs decreased at the final contact.
	Research abstract	35 101 stroke survivors	Data examination	Venue: not applicable / 12	

Ullberg et al. / 2014 / Sweden (86)				months after stroke	(1) Stroke survivors who were ADL dependent, at older age and were institutionalized were reported having unmet needs at 12 months post stroke. Post stroke depression and insufficient pain medication were the most commonly reported. (2) Additionally, unmet needs of rehabilitation was likely to present in female stroke survivors, stroke survivors with recurrent stroke, severe stroke, haemorrhagic stroke, and stroke survivors with underlying diabetes and atrial fibrillation.
Ullberg et al. / 2016 / Sweden (87)	Longitudinal study	37 383 stroke survivors	Self-completed survey (Data on living conditions, risk factors, diagnosis and consciousness level were collected at acute stage)	Community setting / Data on rehabilitation needs was collected at 12 months after stroke	(1) About 1/5 of stroke survivors reported having unmet needs. (2) Unmet needs were significantly more common in those with high dependency in activities of daily living, living in institution, often having pain, receiving insufficient pain medication and self-perceived as having low health. (3) Unmet needs were more frequent in those >85 years and least common among those between 55-69 years. (4) The predictors of the unmet needs upon discharge from acute stroke care were female sex, living alone, having diabetes mellitus, atrial fibrillation and Intracerebral haemorrhage or unspecified stroke; previous history of stroke; current smoking habit and higher stroke severity.
Andrew et al. / 2016 / Australia (88)	Longitudinal study	764 stroke survivors	Data examination	Venue: Not applicable / 90 to 180 days after stroke	(1) Unmet needs in health was significantly associated with pain, living supports, socio-economic status and anxiety / depression. (2) Unmet needs in living was significantly associated with sex and usual activities. (3) Unmet needs in leisure/work was significantly associated with age at stroke onset. (4) Unmet needs in support was significantly associated with pain.
Skolarus et al. / 2017 / USA (89)	Cross-sectional study	432 caregivers	Data examination	Community setting / Time after stroke was not mentioned	Black stroke survivors reported having more unmet self-care needs than white stroke survivors, suggesting racial differences. However, no racial difference in unmet needs for mobility and household needs.
Andrew et. al / 2014 / Australia (90)	Research abstract	173 stroke survivors	Data examination	Venue: Not applicable / 12 months and more after stroke	Unmet needs were reported lower in those receiving recommended care process. Those admitted in stroke unit unlikely reported having unmet psychological needs and those receiving tissue plasminogen activator (tPA) unlikely reported having unmet physical needs.
Barra, Evenson & Valeberg / 2016 / Norway (91)	Cross-sectional study	393 stroke survivors	Self-administered questionnaire	Community setting / 3 months after discharge from stroke unit (time since stroke	A small number of stroke survivors reported having insufficient help from the public healthcare services. This was associated with low function.

				was not mentioned)	
Moreland et al. / 2009 / Canada (92)	Longitudinal study	209 stroke survivors	Interview and self-administered survey (Stroke survivors received functional independence measurement (FIM) during hospitalization)	Homes / Data on needs were collected 1 months after discharge from hospital for acute care. Time since stroke was not mentioned	(1) Overall, stroke survivors reported having persistence needs despite of their FIM score. However, the needs of stroke patients were different between all groups of FIM score from both interview and survey. (2) Stroke survivors with FIM score 41-80 (less able) reported having persistence needs in all domains compared to those with higher score (>80) in all domains. However, the social need was almost comparable between the groups. (3) Those with the lowest range of FIM score (<40) reported having persistence needs mainly in "time to recover", "therapies", "social", "services" ad "emotional". The least needs were "education" and "medical advice". (4) Those with FIM score >80 reported having persistence needs mainly in "education" and "medical advice". The least reported needs were "time to recover", "social", "services" and "emotional"
Clarke et al. / 2002 / Canada (93)	Cross-sectional study	5395 stroke survivors	Data examination	Community setting / Time after stroke was not mentioned	(1) Seniors living with stroke has lower perceived health status and cognitive as well as less social network compared to seniors without stroke. They also required higher help in activities daily living and perceived lower well-being. (2) The dissatisfaction or perceived inadequate among seniors with stroke in receiving support was associated with lower education, lower scores in environmental mastery, positive relations and self-acceptance in well-being dimension. (3) The sense of inadequacy among seniors with stroke in receiving social support also was associated with lower years of education and lower ability in performing independent activities of daily living.
Ekstam et al. / 2015 / Sweden (94)	Longitudinal study	86 stroke survivors, 86 stroke caregivers (86 dyads)	Interview and questionnaire	Homes / Data for present article was collected at 12 months after stroke	(1) Almost 1/3 dyads had disagreement in their perception about sufficiency in rehabilitation needs. (2) At individual level, 25 stroke survivors reported their rehabilitation need were unmet. 29 caregivers perceived the rehabilitation needs were unmet. (3) Dyads reported unmet needs reported having to give up in task and physical demanding activities. (4) Dyads with met needs adopted different strategies to pursue activities despite having limitations in function. (5) Caregivers of dyads who reported having higher unmet needs had higher caregiver burden and reduction in social life. (6) No significant difference between findings was found between age, sex, rehabilitation setting and recipient of informal care to the perception of rehabilitation needs.
Talbot et al. / 2004 / Canada (95)	Cross-sectional study	4 stroke survivors, 5 stroke caregivers	Focus group	Venue was not mentioned / 2 to 8 years after stroke	(1) Domains of rehabilitation needs were nutrition, body condition, personal care, communication, housing, mobility, responsibilities, interpersonal relationships including sexuality (IR), community living, leisure activities, psychological and cognitive.

		(health care providers and administrators were also recruited in this study)			(2) All groups i.e. stroke survivors, carers, healthcare providers (HCP) and healthcare administrators (HCA) perceive unmet rehabilitation needs differently, for most domain. (3) Perception of unmet rehabilitation needs in stroke survivors were IR, community living, psychological and cognitive; (4) Perception of unmet rehabilitation needs in caregivers were body condition, communication, psychological, cognitive.
Shannon, Forster & Hawkins / 2016 / United Kingdom (96)	Cross-sectional study	10 stroke survivors	Interview	Homes / 8 to 12 months after stroke	(1) The self-reported perception of having not having unmet needs, despite of still having existing impairments and limitations, was influenced by following factors: accepting their limitations, shifting their expectations; and comparison made between their current state to those at worse than them. It was also influenced by individual determination, characteristics to be independent, self-view that other people would help the needs more and perception / experience with the potential benefits from the services. (2) A contact with specific service helped in meeting needs
Cameron et al. / 2013 / Canada (97)	Cross-sectional study	24 stroke caregivers (health care providers were also recruited in this study)	Interview	Venue was not mentioned / 1 month to more than 1 year after stroke	(1) Caregivers reported they did not receive on-going support after discharged from hospital. They unmet needs in support following discharge were related to non-caring activities and caring activities. (2) Caregivers also reported having unmet needs in training to be actively supporting stroke survivors in their rehabilitation process.
King & Semik / 2006 / USA (98)	Cross-sectional study	93 stroke caregivers	Interview	Venue was not mentioned / 2 years post discharge from stroke in-patient rehabilitation (time after stroke was not mentioned)	(1) At 2 years after stroke, caregiver reported having unmet needs in supporting stroke survivors, i.e. rehabilitation, adaptations, support and ways to help stroke survivors, transportation, finances. They also reported unmet needs for respite care, legal assistance, family counselling and life planning. (2) Higher unmet needs was associated with caregivers at younger age, white, caring for stroke survivors with lower motor function and holding higher education. (3) Gender, health, first stroke, social status and communication function were not related to unmet needs in caregivers
Lutz & Camicia / 2016 (99)	Review article	Not applicable	Literature review	Not applicable	(1) Unmet needs of caregivers could be categorized into different domains: skills training, communication with providers, resource identification and activation, finances, respites and emotional support. (2) In relation to rehabilitation process, caregivers reported having unmet needs in: information, emotional support for caregivers and stroke survivors, being involved in treatment decisions, and being adequately prepared for survivor's discharged to home.
Mak, Mackenzie &	Longitudinal study	40 stroke caregivers	Scale for caregivers	Rehabilitation & community	(1) Caregivers reported changing in needs before and after discharge. After discharged stroke survivors having higher needs in financial and "witness relatives in



Lui / 2007 / Hong Kong (100)			(Carer Assessment Scale & Cost of Care Index) & open-ended questionnaire	settings / During rehabilitation stay (before discharged) and 2 weeks after discharged.	sick condition" after discharge. However, emotional needs such as "feel tired" and "inner conflict caused by responsibilities" were lower. (2) Unmet needs in supporting stroke survivors' rehabilitation was reported, specifically in managing personal commitment while supporting stroke survivors attending rehabilitation. (3) Caregivers also reported in needing support to care and to support stroke survivors in continuing rehabilitation at home.
Hinojosa & Rittman / 2007 / USA (101)	Cross-sectional study	120 stroke caregivers	Telephone survey of information needs and source of information	Community setting / Time after stroke was not mentioned	(1) Caregivers reported having unmet needs in information and looking for source for information. (2) The unmet need in care-related information included managing safety at home in stroke survivors, including fall; as well as prescriptions / medications. (3) The unmet needs related to stroke information included understanding stroke and risk of recurrence. Small proportion reported having unmet needs in information managing stroke survivors in privacy issues, moving, lifting and functional changes. (4) In relation to social aspect, caregivers reported having unmet needs in information related to managing emotional changes, protecting stroke survivors, getting financial help, managing changes in relationship with stroke survivors and managing changes in stroke survivors' relationship with other family members. (5) The geography of caregivers influenced the type of information required by caregiver. Those living in mainland required higher information in managing stroke survivors' behaviour, while those Puerto Rico needed greater information about safety at home.
Cecil et al. / 2010 / Ireland (102)	Cross-sectional study	10 stroke caregivers	Interview & focus group	Research sites / 8 years after stroke	Caregivers reported having unmet information needs about cause and medical consequences of stroke; and post-stroke care. They emphasized that verbal information must be supplemented in written as quick reference, written in layperson language and understandable format
Saban & Hogan / 2012 / USA (103)	Cross-sectional study	46 stroke caregivers	Self-administered open-ended questionnaire	Community setting / within 1 year after stroke	Caregivers reported having following unmet needs: support, emotions, informal respite care from family members and friends, insufficient information on stroke recovery and caring for stroke survivors, namely in managing medication.
Perry & Middleton / 2011 / Australia (104)	Longitudinal study	32 stroke caregivers	Medical record examination & telephone interview, guided by objective scales for caregivers and	Community setting / 1 & 3 months after discharge from hospital (time after stroke was not mentioned)	(1) Caregivers reported having lack of self-preparation in living with and managing stroke survivors, such as managing personality and mood changes in stroke survivors. (2) Caregivers also reported having insufficient information about stroke-related topics and the impact of caring a stroke survivor, including the psychological involvement.

			open-ended questions.		
Lutz et al. / 2017 / USA (105)	Longitudinal study	40 stroke caregivers	Interview	Rehabilitation setting & community setting / During in-patient rehabilitation and within 6 months after discharged from rehabilitation. (specific time after stroke was not mentioned)	Caregivers reported following unmet needs: unmet needs in information to care for stroke survivors at home, unmet needs in preparing the conducive home environment to facilitate in caring for stroke survivors, and unmet needs in financial for their daily needs and care-related.
Roy et al. / 2015 / New Zealand (106)	Cross-sectional study	19 stroke caregivers (health professionals were involved too)	Face-to-face interview, guided by open and closed ended questionnaire	Venue was not mentioned / 4 months to 4 years and 11 months after stroke	(1) Caregivers described that information presented in unsuitable medium and using medical terms or jargons limited their access to in getting enough information. (2) Caregivers also reported that no information was received after discharge, namely in supporting and caring the stroke survivors
Creasy et al. / 2013 / USA (107)	Longitudinal study	17 stroke caregivers	Interview	In-patient rehabilitation setting and community setting / During rehabilitation and 4 months after discharged (time after stroke was not mentioned)	(1) Caregivers reported that they did not receive information about survivors' discharged plan and the needs of stroke survivors such as level of care and assistance, medical-related needs and rehabilitation. They also received inadequate information about addressing their own emotional needs and were not involved in deciding the care for stroke survivors. (2) Caregivers also described their sense of loss in direction, confusion, anger and hesitance to treatment, as a result of inadequate, unprofessional behaviour and incomprehensible information deliver.
Pesantes et al. / 2017 / Peru (108)	Cross-sectional study	12 stroke caregivers	Interview	Health centres / minimum of 6	Caregivers described having unmet needs in relation to 3 aspects: (1) Related to self, i.e. mental health support

				months after stroke	(2) Related to caring for stroke survivors: information about caring for the stroke survivors, rehabilitation exercise, secondary prevention, access to mental health professionals and monitoring conducting blood pressure. (3) Related to health care service provision: longer rehabilitation sessions, easy access to physical therapy and having access to healthcare providers who were sensitive to their needs and could converse in their primary language.
Cecil et al. / 2012 / United Kingdom (109)	Cross-sectional study	30 stroke caregivers	Interview	Homes / 6 weeks after stroke survivors' discharged from hospital (time after stroke was not mentioned)	(1) Caregivers reported having unmet needs in information about stroke. (2) Having the information was described crucial to support them in understanding the change in life following stroke. (3) They also described the necessity to have the information in written form and to customize the information to their needs.
Hinojosa & Rittman / 2009 / USA (110)	Cross-sectional study	276 stroke caregivers	Telephone survey	Community setting / Time after stroke was not mentioned	(1) Caregivers reported range of caregiving information need. (2) Approximately a quarter of caregivers reported having injury as a result of caregiving. Those who reported having information needs were also likely having caregiving injury, except for information in managing privacy issues such as bathing and cleaning. (3) Specific to type of information, those requiring physical related information in relation to functional changes after stroke, were 4 times likely having caregiving injury. (4) Those in needing social aspects of information, in relation to financial help, stroke-related topics as well as prescription and side effects of medication were 3 times likely having caregiving injury. (5) In terms of caregivers' characteristics, in needing for information, caregiver injury was associated with those having higher education needs, those who provided greater number of activities of daily living and those who used more coping strategies.
Meisel et al. / 2014 / Germany (111)	Research abstract on cross-sectional study	A mixed group of stroke survivors and stroke caregivers (n=257)	Face-to face or telephone interview using semi-structured questionnaire	Venue was not mentioned / Time after stroke was not specify	Stroke survivors and caregivers reported in needing information on self-help group, medical insurance and provision, personal care insurance and provision, outpatient rehabilitation, inpatient rehabilitation, social legislation, pensions and disability benefits. Majority of them required the information within the first year after stroke.
Quinn, Murray & Malone / 2014 / United Kingdom (112)	Meta-synthesis	Not applicable	12 qualitative papers	Not applicable	(1) Caregivers reported having unmet needs in information about preparing self in caregiving role and developing coping strategies, such as in managing the emotional, physical and cognitive impact as a result of caregiving. (2) Insufficient information is associated with sense of helplessness in caregivers.

					(3) Caregivers also reported having unmet emotional support and described themselves feeling overwhelm due to their inability in expressing their emotions and in managing their sense of guilty.
Howe et al. / 2012 / Australia (113)	Cross-sectional study	48 stroke caregivers	Interview	Homes or community setting / 1 month to 195 months after stroke	Caregivers described following goals that they had were not met rehabilitation for aphasia: (1) to be involved in rehabilitation (2) to receive hope and sense of positivity (3) to be connected and to keep the relationship with the aphasic stroke survivors (4) to have information on aphasia (5) to receive support for self-care; mentally, emotionally and physical well-being.
Kerr & Smith / 2001 / Scotland (114)	Cross-sectional study	22 stroke caregivers	Interview	Homes / 1 year after stroke	(1) Carers reported having unmet needs in preparing self for caregiving and in supporting survivors with their physical needs. This included specific aids at home and support from community services. (2) Caregivers also reported having unmet needs in emotion to support them in taking up the caregiving role, as well as unmet needs for information on financial such as information about entitled benefits
Park / 2007 / Korea (115)	Cross-sectional study	119 caregivers	Face-to face interviews, using questionnaire and scale	Day care centre / Time after stroke was not mentioned	Caregiver reported having unmet needs in following area: speech therapy, patient-tailored exercises and physical therapy
McKevitt et al. / 2004 (116)	Systematic review	Not applicable	95 qualitative studies	Not applicable	Caregivers reported that their needs were not considered by professionals. Additionally, they also reported receiving insufficient support to prepare themselves in caregiving role.
Barbic et al. / 2014 / Canada (117)	Cross-sectional study	30 caregivers	Secondary thematic qualitative analysis (telephone interview)	Venue: Not applicable / Time after stroke was not mentioned	Caregivers described receiving insufficient support from family, friends and healthcare providers in transiting their role, namely in managing non-caregiving tasks, financial, information, resources and professional support.
Halle & Dorze / 2014 / Canada (118)	Cross-sectional study	12 caregivers	Interview	Homes or rehabilitation centre / 3 to 36 months after stroke	Caregivers reported having insufficient information to understand about aphasia and to communicate with aphasic survivors effectively. Additionally, they were not involved in the rehabilitation as the service provision was centred only for the patients with aphasic. The available service did not address caregivers' unique needs.
Usha / 2015 / India (119)	Research abstract	40 caregivers		Venue and time after	More than half of caregivers reported having unmet needs in recreation, getting adequate sleep, managing total responsibility, health and financial.

			Semi-structured questionnaire	stroke were not mentioned	.
Sit et al. / 2004 / Hong Kong (120)	Cross-sectional study	102 caregivers	Interview, and quantitative measurements	Homes / 12 weeks after hospital discharge (Time after stroke was not mentioned)	1) Caregivers received inadequate support in getting rehabilitation equipment, financial, transportation, respite care and non-caregiving tasks. (2) Those with no formal education may not be able to understand written information adequately. (3) The most difficult caregiving task was following medical and nursing instructions. (4) Caregivers received less support than what they think
Graven et al. / 2013 / Australia (121)	Cross-sectional study	8 stroke survivors, 6 caregivers	Focus groups, using semi-structured questionnaire	Venue was not mentioned / 5 to 15 months after stroke	Caregivers reported receiving inadequate essential emotion support i.e. respite care and managing their fear of survivors falling during executing daily activities. The fear of fall in survivors limited their ability in supporting survivors in non-therapeutic, leisure and daily activities.
King, Hartke & Houle / 2010 / USA (122)	Cross-sectional studies	235 stroke survivors, 253 caregivers	Quantitative measurements	Rehabilitation setting / time after stroke was not mentioned	Caregivers still reported having high unmet needs despite having positive orientation in coping with the change in life after stroke.

Stroke survivors and stroke caregivers have different types of unmet needs.

The unmet needs are beyond medical and rehabilitation aspects.

The associated factors of unmet needs between the two groups are also different.

A local tool is necessary to capture these unmet needs.

Identification of unmet needs may facilitate improvement in stroke care.

(Note: Each highlight can be no more than 85 characters, including spaces)