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

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ABSTRACT

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

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

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

Trial registration number CRD42018112181.

Strengths and limitations of this study

- In contrast to other published reviews, this systematic review will be the first to synthesise in an organised way both qualitative and quantitative studies regarding the unmet needs of stroke survivors at home in their community.
- This review will search articles published both in English and Chinese, with our group taking the lead in systematically adding the Chinese research database and making this large body of data available to a non-Chinese speaking audience.
- We will describe the trajectories of stroke survivors' long-term unmet needs expecting that this will provide targeted intervention points to community health professionals and organisations.
- A possible limitation of this study is that this research of self-reported unmet needs may lead to an overly one-sided outcome, and may introduce selection and report bias, and we will not search the grey literature that may increase the risk of selection bias.
- Simultaneous integration of qualitative and quantitative findings may affect the comprehensiveness of the complex unmet needs of stroke survivors. However, standardised methods to be performed in this review have been used and evaluated in the process of other published systematic reviews.

INTRODUCTION

Stroke is the third leading cause of death and the second leading cause of disability worldwide.[1] According to the study of the Global Burden of Disease, the number of people with stroke increased by 68% between 1990 and 2010.[2] In some developed countries, stroke is the leading cause of disability, with an estimate that about 24%–74% of stroke survivors need long-term care. Moreover, some are even totally dependent on their caregivers because of their low level of ability with the activities of daily life.[3 4] Even worse, in some developing countries, over the past two decades, the intensity of the care burden of stroke has continued to increase, now comprising 75.2% of deaths and 81.0% of stroke-related disability-adjusted life years

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

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

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

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

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

METHODS AND ANALYSES

Patient and public involvement

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

Study design

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

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

ELIGIBILITY CRITERIA

Type of studies

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

Participants

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

Issue of interest

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

Outcomes

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

Search strategies

"Stroke" terms based on a Cochrane review have been developed.[47 48] For "needs" and '"care needs", terms were based on a systematic review of unmet needs of people living with advanced cancer[49 50] or chronic liver disease,[51] "community" or "home" terms were based on systematic review of community-dwelling older people.[52] In addition, the search terms refer to a review protocol of unmet needs of caregivers of stroke survivors.[53] The first step is to develop a search strategy on the PubMed database and to adapt it in accordance with other databases. The search strategy includes medical subject headings and free-text terms using applicable controlled vocabulary. The following electronic databases will be searched: PubMed, EMBASE, CINAHL(EBSCO), PsycINFO (EBSCO), SCOPUS and China Biology Medicine). Reference lists of included studies and relevant systematic reviews will be searched to identify additional studies for potential inclusion in this systematic review. Databases will be searched from October to December 2018, and the search strategy will be conducted monthly across databases to retrieve and screen relevant publications until completion of systematic review; furthermore, we aim to search all relevant studies, so there will no precise start date, generally from inception to December 2018.

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

Screening the studies

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

Assessment of risk of bias and quality of included studies

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

Qualitative studies

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

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

Quantitative studies

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

Mix-method studies

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

Data extraction

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

DATA ANALYSIS

Qualitative studies

Qualitative data will be thematically analysed by means of the qualitative meta-synthesis method that can systematically triangulate, and reintegrate the primary findings. We will integrate the content and analyse the theme based on the following questions: (1) What is the community-dwelling stroke survivors' health status and experience when they live at home? (2) What are their perceptions or concerns of the public health service or home care resource that available for them? (3) What needs of their daily life did they most mention? Specific codes or themes for unmet needs domains will be synthesised. Two reviewers will discuss these items and if they cannot reach a consensus, a group discussion should occur.

Quantitative studies

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

Mix-method studies

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

Data combined strategies

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

DISCUSSION

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

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

Ethics and dissemination

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

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Author note All authors have agreed on the final version of this protocol. LBL is the main reviewer, DCG is the second and MYX is the third reviewer. Professor ZZX is the corresponding author and chief of the project. WPP will join in the discussion when necessary. MFY did the language modification work for this manuscript.

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