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Exploring the poststroke experiences and unmet needs of South Asian communities in high-income countries: a scoping review protocol

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ABSTRACT

Introduction South Asian groups experience a higher burden of stroke and poorer functional outcomes after stroke than their White counterparts. However, within the stroke literature, there has been little focus on the unique poststroke needs of the South Asian community and opportunities for community-based services to address these needs.

Research question What is the current knowledge base related to the experiences and needs, including unmet needs of people living with stroke and their caregivers from South Asian communities living in high-income countries?

Aims This is a protocol for a review that intends to synthesise existing studies of the poststroke experiences and needs of individuals from South Asian communities to uncover opportunities for community-based resources to address these needs.

Methods and analysis This scoping review methodology will be guided by modified Arksey and O'Malley (2005) and Joanna Briggs Institute frameworks. A search on OVID Medline, OVID Embase, OVID PsycINFO, EBSCO CINAHL, the Cochrane Library, Scopus and Global Index Medicus will be conducted to synthesise existing peer-reviewed literature (all study designs). Grey literature will be searched through detailed hand searching. Literature focusing on the poststroke experiences and needs of South Asian groups impacted by stroke residing in high-income countries will be included. Study descriptors will be extracted (eg, study location, type, methodology). Data will be analysed descriptively and thematically. Team meetings will provide opportunities for peer debriefing, thereby enhancing analytic rigour.

Conclusion and implications Findings will enhance knowledge of the poststroke experiences and needs of South Asian communities living in high-income countries and identify actionable opportunities for community-based resources to address needs.

Ethics and dissemination Ethics approval was not required for this scoping review protocol. Community-based organisations will be consulted to provide insights into the analysis and assist with dissemination. Dissemination of findings will also occur through a publication and academic presentations.

Strengths and limitations of this study

- A comprehensive peer-reviewed search strategy will be used in this review, minimising search errors and enhancing the comprehensiveness of the search.
- The inclusion of grey literature will further enhance the comprehensiveness of this review.
- A team-based analysis will enhance analytical rigour and credibility of findings.
- Terminology to describe the topics of interest are inconsistently used within literature (eg, South Asian, experiences, needs), creating risk for missing relevant articles.
- This review will limit to high-income countries as stroke resources and services are expected to differ among higher-income and lower-income countries.

INTRODUCTION

Stroke is a leading cause of disability worldwide.[1] Over the past decade, stroke severity has increased[2] while the length of hospital stay has been decreasing.[3 4] Long-term impacts, including restrictions in daily, social and leisure activities, are experienced by nearly 50% of people living with stroke.[1 5–7]

Mental health challenges are also common after stroke, including depression, generalised anxiety disorder, post-traumatic stress reaction and involuntary emotional expression disorder.[8 9]

Poststroke experiences and consequent needs are broad, heterogeneous and can vary and transcend across care settings (eg, hospital, rehabilitation and community).[10–14] They can relate to body functioning (eg, emotional, anxiety, communication), activity/

participation (eg, social life, exercise, establishing meaningful roles), environmental factors (eg, financial, social, cultural) and education.[10–14] Unmet poststroke needs (defined as 'a need for something or help from someone that is not being met')[15] can interfere with maximising one's function and participation,[16] and are reported by up to 59% of people living in the community with stroke.[16] Poststroke experiences and needs are often overlooked,[13] but are essential to consider because they can inform priorities for poststroke services.[14] As sociocultural factors, such as ethnicity, cultural beliefs, linguistic and spiritual values, influence poststroke experiences and needs,[14 17–20] a person's poststroke experiences and corresponding needs cannot be understood in isolation of these influential factors.

A large ethnic and cultural group that experiences a high prevalence of stroke is the South Asian community (ie, Afghanistan, Bangladesh, India, Maldives, Nepal, Pakistan and Sri Lanka).[21 22] South Asians comprise one-fifth of the global population.[23] South Asians are among the most common and fastest-growing ethnic groups in many high-income countries, including Canada, the USA and the UK,[23–25] with a higher risk of stroke compared with other ethnicities.[21 26 27] It is worth noting that differences in stroke risk also vary depending on South Asian ethnicity whereby Bangladeshi adults have been found to be more at risk than their Indian and Pakistani counterparts.[28] Despite South Asians having greater stroke risk factors, experiencing a stroke at a younger age (eg, nearly a decade younger than White groups), having poorer functional outcomes after stroke and higher instances of mortality from stroke[29 30] compared with other ethnic groups,[18 21 25 31 32] they are understudied in stroke research.[21 33] Various sociocultural factors influencing post-stroke experiences and needs that are specific to South Asian groups have been identified in the literature. For instance, facilitators of and barriers to stroke management include cultural beliefs/norms regarding dependence on others, stroke and family caregivers' roles and expectations.[34] Here within, we define family caregivers as friends, family members (including non-biological kin) and neighbours who provide unpaid care to individuals who have experienced a stroke.[35] Among South Asians, cultural factors are also shown to influence stroke risk modifiers and stroke management, including beliefs that may interfere with filling prescription medication.[36] Current strategies used to educate, treat and reintegrate people with stroke often do not typically account for sociocultural factors impacting poststroke experiences and needs.[25 37 38]

Studies have called for culturally appropriate and/or tailored health resources to meet the needs of ethnic minorities,[39] and specifically people of South Asian descent living in high-income countries.[33 40] Culturally appropriate intervention content addresses the needs (eg, cultural and linguistic) of the groups that they serve, and in doing so, it is more relevant and effective for these groups.[41] Culturally tailored interventions are specifically adapted to meet the cultural needs and preferences of a culture-sharing group.[39] Although data on the effectiveness of culturally appropriate and tailored programmes is limited with South Asian stroke populations, a few culturally tailored programmes demonstrated increased knowledge of stroke.[33 42] Culturally tailored programmes that were not stroke-specific demonstrated the ability to promote healthier lifestyles, including improving well-being and physical activity levels among South Asian participants.[40] Evidence from culturally tailored programmes implemented within other ethnic groups suggests that culturally tailored programmes can improve quality of life and family and community support and increase knowledge of the disease.[39]

To address poststroke needs, community-based organisations (ie, third sector, non-government organisations) can play a valuable role in supporting the ongoing needs of people living in the community and their family caregivers who support their recovery.[40 43] Several community-based programmes have provided tailored stroke programmes and resources to South Asians living with/at risk of stroke (eg, Stroke Recovery British Columbia's South Asian Virtual Stroke Programme,[44] Fraser Health South Asian Health Institute,[45] South Asian Health Awareness about Stroke.[33] However, it is difficult to ascertain how, or the degree to which, these programmes were informed by the best available evidence. While previous reviews have synthesised available evidence regarding the experiences and needs of people with stroke,[11 12] to our knowledge, none have specifically synthesised evidence related to the poststroke experiences and needs of South Asian groups in high-income countries. Thus, this review intends to synthesise existing studies that have captured the poststroke experiences and needs in any care setting of individuals from South Asian communities living in high-income countries to uncover opportunities for community-based resources to address these needs.

METHODS AND ANALYSIS

Patient and public involvement

Patients or the public were not involved in the design of this scoping review protocol.

Design

Given the broad nature of poststroke experiences and needs where many study designs may be used to explore this topic,[10–14] and the inclusion of grey literature sources, a scoping review was determined most appropriate to meet the objectives of this study. This is a protocol for a scoping review of existing literature on the experiences and needs of people impacted by stroke from South Asian communities. Guided by the modified Arksey and O'Malley[46 47] and Joanna Briggs Institute scoping review frameworks,[48] this review will adhere to the following six stages: (1) identifying the research questions; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising and reporting the results

and (6) consultation. Preliminary literature searching began on 14 October 2021, and we anticipate this review will be completed by Summer 2022. Please see online supplemental material 1 for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

Stage 1: identifying the research questions

This review will uncover consideration for poststroke resources tailored for this group by addressing the following primary research question and two subquestions:

- What is the current knowledge base related to the experiences and needs, including unmet needs, of people living with stroke and their caregivers from South Asian communities living in high-income countries?
  - What is known about the poststroke needs of people living with stroke and their caregivers from South Asian communities living in high-income countries?
  - What clinical recommendations are suggested to meet the poststroke needs of people living with stroke and their caregivers from South Asian communities living in high-income countries?

Stage 2: identifying relevant studies

Peer-reviewed literature will be identified using a comprehensive search strategy developed by an Information Specialist and Health Science Librarian (JM) in consultation with the review team. The search strategy will be peer-reviewed following the Peer Review of Electronic Search Strategies to minimise search errors and enhance the comprehensiveness of the search.[49] Subject headings and text words related to the following concepts will be included in the search: South Asian and stroke. The team will develop and finalise the search strategy in OVID Medline and then translate it to OVID Embase, OVID PsycINFO, EBSCO CINAHL, the Cochrane Library, Scopus and Global Index Medicus. A preliminary search was conducted on OVID Medline on 14 October 2021, to inform the search strategy and inclusion criteria. A copy of the OVID Medline search strategy is in the supplementary materials (please see online supplemental material 2). No language or date limits will be applied. The team will export the search results into Endnote to deduplicate records and then import them into Covidence,[50] an online software program that facilitates the screening of abstracts and full texts. Relevant grey literature will be identified by handsearching relevant grey literature databases, catalogues and search engines (eg, OpenGrey, TripPro, ClinicalTrials.gov, WHO International Clinical Trials Registry Platform). As this is a broad topic area, included studies' references will be searched, in addition to forward citation searching, to identify studies that may have been missed within the search. Forward citation searching will consist of a citation index that cites eligible studies included in the review.[51] Given our population of interest, we will only examine articles with samples of individuals of South Asian descent[22] (any generation) living in a high-income country. Several reasons influenced the decision to limit to high-income countries. First, stroke services, health and social supports, infrastructure and resources differ among high-income and lower-income countries,[52] which may impact poststroke experiences and needs. Second, South Asians are a fast-growing ethnic group in multiple high-income countries, including the USA, UK and Canada.[53–56] Third, implementing culturally appropriate stroke services is a priority among many high-income countries.[57–61] Fourth, differences in poststroke incidence and outcomes between White and ethnic groups are noted in several high-income countries.[32 62–64] Fifth, existing studies have focused their attention on understanding the poststroke experiences of ethnic minorities, including South Asians, living in high-income countries as these groups tend to experience unique ongoing unmet needs, such as informational and educational.[65 66] Ultimately, limiting this review to high-income countries can inform system change such that it better meets the needs of South Asian communities. See table 1 for the full inclusion/exclusion criteria.

Stage 3: study selection

Covidence will remove duplicates and facilitate screening articles. Two reviewers (KMK and HS) will independently screen titles and abstracts and review the full text of the identified studies to determine which studies meet the criteria.

Title and abstract screening

Study titles and abstracts will be screened using the inclusion and exclusion criteria (table 1). The criteria will be pilot-tested on a sample of search results to ensure 'substantial' inter-rater reliability (ie, kappa statistic ≥0.61) among screeners.[67] Any study deemed to meet the inclusion criteria will move on to the full-text review. Additional exclusion criteria may be applied given the iterative nature of scoping reviews.[47]

Any non-English article considered potentially relevant at the title/abstract stage and full-text review will be translated using Google Translate.[68]

Full-text review

The full text of the studies will be reviewed to verify whether the studies meet the inclusion criteria. During the title and abstract screening and full-text review, any disagreements will be resolved through discussion during regular team meetings.

Stage 4: charting the data

A data extraction form will be used to extract data from the articles. After reviewing included studies, the team will meet and determine the exact elements to be extracted systematically. Data will be extracted from the articles, including, but not limited to, study characteristics (eg, country and year of publication), sample characteristics (eg, age, sex, gender, type and severity of the stroke, country of origin, urban/rural environment,

Table 1 Inclusion and exclusion criteria

	Include	Exclude
Condition	At least 50% of the sample includes individuals with stroke Stroke: any type of stroke and any time since stroke occurrence	Less than 50% of the sample comprises individuals with stroke
Population	Sample exclusively includes individuals or caregivers of 'South Asian' descent (any generation): Afghanistan, Bangladesh, India, Maldives, Nepal, Pakistan, Sri Lanka,[22] OR the study intends to compare the experiences/needs of a South Asian group with another group	The study does not exclusively include individuals from the identified South Asian groups OR does not compare the experiences/needs of a South Asian group to another group
Topics of Interest	Poststroke experiences and needs are perceived by people living with stroke or their caregivers in any setting, including community, rehabilitation, acute and primary care. Poststroke needs are broad and heterogeneous and can relate to body functioning (eg, emotional, anxiety, communication), activity/participation (eg, social life, exercise, establishing meaningful roles) and environmental factors (eg, financial, sociocultural care) and education.[10–13]	
Study type	Peer-reviewed and relevant grey literature	
Study design	Primary studies of any design	Reviews, opinion papers, commentaries
Setting	Living in a 'high-income country' as classified by the World Bank:[74] Andorra, Greece, Poland, Antigua and Barbuda, Greenland, Portugal, Aruba, Guam, Puerto Rico, Australia, Hong Kong SAR China, Qatar, Austria, Hungary, San Marino, Bahamas, Iceland, Saudi Arabia, Bahrain, Ireland, Seychelles, Barbados, Isle of Man, Singapore, Belgium, Israel, Sint Maarten (Dutch part), Bermuda, Italy, Slovak Republic, British Virgin Islands, Japan, Slovenia, Brunei Darussalam, Korea Rep., Spain, Canada, Kuwait, St. Kitts and Nevis, Cayman Islands, Latvia, St. Martin (French part), Channel Islands, Liechtenstein, Sweden, Chile, Lithuania, Switzerland, Croatia, Luxembourg, Taiwan China, Curaçao, Macao SAR China, Trinidad and Tobago Cyprus, Malta, Turks and Caicos Islands, Czech Republic, Monaco, United Arab Emirates, Denmark, Nauru, UK, Estonia, Netherlands, USA, Faroe Islands, New Caledonia Uruguay, Finland, New Zealand, Virgin Islands (USA), France, Northern Mariana Islands French Polynesia, Norway, Germany, Oman, Gibraltar, Palau	'Upper-middle-income' and 'low-income' countries as classified by the World Bank:[74] Afghanistan, Guinea-Bissau, Somalia, Burkina Faso, Korea, Dem. People's Rep, South Sudan, Burundi, Liberia, Sudan, Central African Republic, Madagascar, Syrian Arab Republic, Chad, Malawi, Togo, Congo, Dem. Rep, Mali, Uganda, Eritrea, Mozambique, Yemen, Rep. Ethiopia, Niger, Gambia, Rwanda, Guinea, Sierra Leone, Angola, Honduras, Philippines, Algeria, India, Samoa, Bangladesh, Indonesia, São Tomé and Principe, Belize, Iran, Islamic Rep, Senegal, Benin, Kenya, Solomon Islands, Bhutan, Kiribati, Sri Lanka, Bolivia, Kyrgyz Republic, Tanzania, Cabo Verde, Lao PDR, Tajikistan, Cambodia, Lesotho, Timor-Leste, Cameroon, Mauritania, Tunisia, Comoro, Micronesia, Fed. Sts., Ukraine, Congo, Rep., Mongolia, Uzbekistan Côte d'Ivoire, Morocco, Vanuatu, Djibouti, Myanmar, Vietnam, Egypt, Arab Rep., Nepal, West Bank and Gaza, El Salvador, Nicaragua, Zambia, Eswatini, Nigeria, Zimbabwe, Ghana, Pakistan, Haiti, Papua New Guinea

socioeconomic status, ethnicity, cultural or religious identification, whether people are newcomers, generation number), study aims, methodology (eg, data collection method to evaluate perceived experiences and needs,[10] analysis approach), study measures (eg, quality of life, social support), the study findings (eg, quotes, subthemes, themes and concepts, survey results) and limitations.

KMK and HS will test the data extraction form prior to reviewing all articles independently. During pilot testing, team members involved in extraction will use the form to extract data from the same articles and then meet to discuss any discrepancies. Team members will then extract the remaining articles independently once their performance is consistent.

Stage 5: collating, summarising and reporting results

Data analysis will involve a descriptive quantitative (ie, frequency analysis)[69] and qualitative (ie, thematic) analysis. First, we will create an overview of the published literature using numerical and textual descriptive summaries of the study design, context, sample, study aims, methodology, and limitations. Data will be reported following the PRISMA-ScR to ensure comprehensive reporting.[70] Post-stroke experiences and

needs are expected to be captured primarily through qualitative or descriptive studies. A comprehensive thematic synthesis is described below, including identifying actionable opportunities for community-based resources where appropriate.[71] We will also report areas for future direction based on insights deemed understudied or missing. The purpose of this review is to identify the current the knowledge base and as such, a result quality appraisal is not indicated.[72]

Thematic synthesis

The analysis will follow three steps of a thematic synthesis as outlined by Thomas and Harden:[71] (1) line-by-line coding of study findings, (2) descriptive themes (eg, descriptions of the data) and (3) analytical themes (ie, interpretative themes). First, we will upload the result and discussion sections of each article onto NVivo,[73] which is a qualitative data management software. Following the Thomas and Harden framework, two reviewers will independently conduct inductive line-by-line coding of the findings section from each article (ie, 'all of the text labelled as 'results' or 'findings' in study reports,' including quotes, concepts, subthemes and themes[71] and 'discussion'). This strategy will allow us to translate concepts from one study into another.[71] Inductive coding will enable us to create data-driven codes. The line-by-line coding will enable us to translate different concepts presented within various articles to a common language. We will allow themes to emerge inductively, but we expect to identify themes related to perceived access, barriers and stigma based on the preliminary literature review. To enhance rigour, two research team members will independently code data from at least three articles. The codes will be compared and consolidated through discussion to create a codebook. The codebook will be applied to the remaining data by a research team member. In the second stage, two team members will independently create descriptive themes by grouping similar codes and creating labels to classify these groupings. This analysis will also descriptively examine how intersectional experiences and diversity among South Asian groups, including gender, socioeconomic status, ethnicity and generation, have been captured in data collection and analysis within the included studies. The two reviewers will meet to compare their descriptive themes. We will resolve any discrepancies between the descriptive codes through discussion. In the third stage, the descriptive themes will be presented to the research team. The research team will review the descriptive themes while considering implications for community-based resources and other interpretations within the data. These team discussions will inform the development of analytical themes. This approach will allow investigators to arrive at a deeper understanding of the experiences of South Asians with stroke to inform implications for future community-based resources needed to address such needs and improve their experiences.

Stage 6: consultation

The findings of this study are intended to inform opportunities for community-based resources to address the needs of individuals from South Asian communities. As such, we will consult with the following key stakeholders: (1) >two staff members (eg, programme managers, healthcare professionals) from community-based organisations that deliver community interventions, programmes, or resources to individuals with stroke (eg, key stakeholders from March of Dimes Canada and the Heart & Stroke Foundation of Canada) and (2) >two individuals with lived experience of stroke and/or caregivers from the South Asian community. To effectively capture the community-based perspective within the analysis, we will engage the organisations during the data analysis stage. Prior to data extraction, we will invite key stakeholders to review and provide feedback on the data extraction table. During the analysis consultation, we will present preliminary findings to the key stakeholders (eg, a list of considerations for community-based resources based on review findings) and ask them for their views on the data based on their valuable perspectives. The consultation meeting will serve as an opportunity for key stakeholders to 'provide insights beyond those in the literature' and add methodological rigour by validating the findings and informing future direction.[47] Moreover, we will consult with key stakeholders to create impactful end-of-project knowledge dissemination activities.

Limitations

As with all reviews, the current review will have limitations. First, while our search strategy is comprehensive, South Asian groups are diverse (eg, language, religion, ethnicity, country of origin). We recognise that we may miss studies that include the target population but did not use the search terms listed within our search strategy. Second, although we intend to include non-English studies, our search strategy may not entirely capture articles in different languages. Moreover, translation via Google translate is a strategy used to enhance review comprehensiveness, but it may not be precise.[68] Third, the inclusion and exclusion criteria may not be easily applied to all articles during screening. If challenges with the criteria are encountered, we will use an iterative team approach to study selection. We may also refine the inclusion and exclusion criteria for clarity, as recommended for scoping reviews.[47] Moreover, having multiple reviewers review search results and conduct data analysis enhances the review quality and analytic rigour.[47 71] Fourth, we will not formally appraise the quality due to the inclusion of all study designs, methodology and literature (ie, grey and published) as well as the review's intent (ie, to identify the current knowledge base rather than assess the quality of data). Finally, we intend to capture the experiences and needs of South Asian groups living in high-income countries rather than the broader South Asian population.

ETHICS AND DISSEMINATION

The findings of this study will highlight the experiences and needs of South Asians with stroke and their families and may inform supports offered in community, acute and rehabilitative care settings. This research may also identify areas where novel research is needed. We will disseminate these findings to a range of audiences (ie, researchers, lay and public audiences, clinicians, health service administrators) through academic peer-reviewed journal publications and local, national and international conference presentations.

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