

Unique Needs and Challenges Experienced by Young People With Stroke

An International Qualitative Analysis

Marika Demers, PhD, Marina Charalambous, PhD, Li Khim Kwah, PhD, Shamala Thilarajah, PhD, Danira Bazadona, MD, PhD, Sherita Chapman, MD, Ahmed Nasreldain, MD, PhD, Laetitia Yperzeele, MD, PhD, Dinah Amoah, MPH, Carolee Winstein, PhD, Julie Bernhardt, PhD, and Urvashy Gopaul, PhD

Correspondence

Dr. Demers
marika.demers@umontreal.ca

Neurology: Clinical Practice 2025;15:e200406. doi:10.1212/CPJ.0000000000200406

Abstract

Background and Objectives

Stroke in young adults has a lifelong impact on activities of daily life, including driving, leisure, and community-based activities; social participation; and reduced productivity. The needs of young people with stroke (YPwS) are likely to vary across different countries, and the development of age-adapted information and interventions is therefore critical in addressing those needs. This study aims to (1) identify the unmet needs of people with stroke aged 18 to 55 years across countries with varied income levels and cultural backgrounds and (2) determine their preferred means to access knowledge and information about stroke in the young.

Methods

This international needs analysis used a phenomenologic qualitative design to gain in-depth perspectives about the experiences of YPwS. Participants were recruited from 9 countries of varied socioeconomic status. We interviewed 44 participants with stroke (men: 22; women: 21; transman: 1; mean age: 44.2 ± 8.5 years) living in the community (range of time since stroke: 0.5–10 years). The semistructured interview focused on lived stroke experience, unmet needs, helpful strategies to meet individual needs, hopes, and dreams. The interview was recorded, conducted in the participants' native language, and transcribed verbatim. Data were analyzed using inductive thematic analysis.

Results

Four main themes emerged from the interviews: (1) heterogeneity of unmet needs specific to YPwS, (2) invisible disability, (3) lack of age-specific stroke information, and (4) call for accessible information resources available in different formats. The results highlighted the need to provide long-term and contextually tailored support to YPwS, aligned with their recovery goals and age-specific needs. Initiatives such as peer-support groups, self-management or peer-mentoring programs, information resources in various formats, and participation in research projects could help address the unique needs of this population.

Discussion

Our results emphasize the importance of raising awareness of stroke in the young and the unique challenges of this population. Future research could focus on the development of stroke care pathways specific to YPwS.

University of Southern California (MD, CW), Los Angeles; Université de Montréal (MD); CRIR-Institut universitaire sur la réadaptation en déficience physique de Montréal (IURDPM) (MD), CIUSSS du Centre-Sud-de-l'île-de-Montréal, Quebec, Canada; Cyprus University of Technology (MC), Limassol, Cyprus; University of Fribourg (MC), Switzerland; Singapore Institute of Technology (LKK); Singapore General Hospital (ST); University Hospital Centre Zagreb (DB), Croatia; University of Virginia (SC); Richmond VA Medical Center (SC); Assiut University (AN), Egypt; Antwerp University Hospital (LY), Belgium; University of Tasmania (DA), Hobart (TAS); The Florey Institute of Neuroscience and Mental Health (JB), Heidelberg, Victoria, Australia; and The KITE Research Institute-Toronto Rehabilitation Institute (UG), University Health Network, Ontario, Canada.

Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the full text of this article at [Neurology.org/cp](https://www.neurology.org/cp).

Introduction

Although stroke in young people is less frequent than in older populations, it has a major impact on the individual and society.¹ Approximately 10%–20% of stroke occurs in young people aged 18–50 years, with the incidence of stroke in young people rising globally.^{2,3} Stroke is life changing at any age, yet additional challenges are faced by young people with stroke (YPwS) because of their age-related life demands and roles.⁴ According to the World Health Organization International Classification of Functioning, Disability and Health (ICF) Core Set for stroke,⁵ YpwS experience chronic limitations and restrictions in the activity and participation domains, resulting in low rates of return to work in the first 12 months after stroke, social isolation, high rates of depression, and poor quality of life.^{6–8} When compared with older people, YpwS are more likely to be engaged in vocational and social activities such as being employed, parenting young children, and relying on work-related income to ensure their financial security and that of their family. In addition, YpwS are more likely to have an active lifestyle contingent upon high physical and cognitive functioning. This creates unique challenges and needs for their rehabilitation and community reintegration.

Stroke in the young often affects everyday activities. Examples include driving, leisure and community-based activities, social participation, and productivity.^{4,9–11} Financial burden is frequently reported in YPWs because of limited access to government benefits, entitlements, or significant out-of-pocket health care costs associated with one's disability.^{6,12,13} A qualitative analysis of social media platforms found that steps along the care pathway for young adults were problematic, such as receiving the initial diagnosis or sometimes misdiagnosis, returning home, and achieving long-term recovery with inadequate community support.¹⁴ These results highlight the complexity of stroke recovery for this population.

Previous studies identified unmet needs that are specific to this age group.^{4,15–17} Despite global efforts to improve stroke care quality, increasing evidence demonstrates that younger adults lack information and age-adapted interventions after stroke, and that the care they receive is incongruent with their age-related needs.^{4,9,18,19} To date, most research to understand the perspectives of YPWs was conducted with young White people with stroke from high-income countries. For example, in a cross-sectional survey of how to address YPWs's unmet needs, only 5% of participants were from countries outside the Anglosphere.²⁰ Little is known about the specific needs of YPWs in low- and middle-income countries (LMICs).²¹ Contextual factors such as access to and skills of rehabilitation therapists and organizational structure are likely to vary across geographical locations, socioeconomic status, and societal cultures, thus exploring cross-country variation would be valuable.

This study addresses the need to provide long-term stroke care programs that are contextually tailored and person centered in varied socioeconomic contexts, aligned with the call to action by Bernhardt et al.²² Knowledge of how stroke affects young people across different countries and how to address these unique needs can inform the design of new models of stroke care and community-based programs to maximize community participation of YPWs. This study aims to (1) identify the unmet needs of people with stroke aged 18–55 years across countries with varied income levels and varied cultural backgrounds and (2) determine the preferred means to access knowledge and information about stroke in the young.

Methods

Study Design

This international needs analysis uses a phenomenologic qualitative design.²³ Unlike other research designs that may prioritize quantitative data or preconceived hypotheses, phenomenology allows researchers to delve deeply into the lived experiences of YPWs, providing rich insights into the unique challenges, coping strategies, and needs. This study design was aligned with the Consolidated Criteria for Reporting Qualitative Studies 32-item checklist.²⁴

Participants

Participants were recruited from Belgium, Canada, Croatia, Cyprus, Egypt, Ghana, Mauritius, Singapore, and the United States. Because this work was conducted in the context of a pilot project from the Future Leaders program (World Stroke Organization), we purposefully recruited participants through the team's respective countries, recognizing an unbalance between high and LMICs. Participants were recruited through stroke support organizations, research flyers, stroke organization newsletters, social media advertisements, direct contact with stroke survivors or their families, and snowball sampling. The inclusion criteria were stroke diagnosis (ischemic or hemorrhagic stroke or venous infarction), age 18–55 years (as per recommendations of the Stroke Recovery and Rehabilitation Roundtable²⁵), and discharged from hospital (>4 months after stroke, no upper limit). For feasibility reasons (i.e., obtain informed consent and recall their experience since their stroke), we excluded people with severe cognitive impairments. Participants with other neurologic conditions were also excluded to distinguish the effects of stroke from those of other conditions. Aphasia-friendly resources and communication strategies were incorporated for people with aphasia to allow consistent involvement in the study. We recruited approximately 5 participants per country.

Standard Protocol Approvals, Registrations, and Patient Consents

The procedures followed were in accordance with the ethical standards of the revised Declaration of Helsinki. Institutional

review board approvals were obtained at all participating sites. All participants were fully informed of the procedures involved and provided written informed consent.

Procedures

Participants took part in a 30-minute individual semi-structured interview (audio or video recorded). The interviews were conducted face to face (i.e., in a clinic or a university setting), over the phone, or virtually using the Zoom platform (Zoom Video Communications, Inc., San Jose, CA), depending on pandemic guidelines, participant preferences, and internet access in respective countries. For remote interviews, guidance was offered for those with limited familiarity with technology. A preinterview questionnaire was administered to capture clinical, cultural, and sociodemographic information, and each semi-structured interview followed a detailed interview guide (eMethods). It included open-ended questions about lived stroke experience, unmet needs, strategies to meet individual needs, hopes, and dreams. The interview guide was first developed in English and translated in each country's native language by native speakers. It was also piloted with 3 YPwS and refined before initiating data collection. Each interview was led by a member of the research team (man or woman), all medical or rehabilitation professionals, fluent in the country's native language. Some interviewers had a previous professional/clinical relationship with participants. All facilitators were trained in qualitative methods and communication strategies for people with aphasia. The facilitator took field notes and summarized the main ideas to ensure they accurately reflect the opinions expressed by the participants (i.e., member checking²⁶).

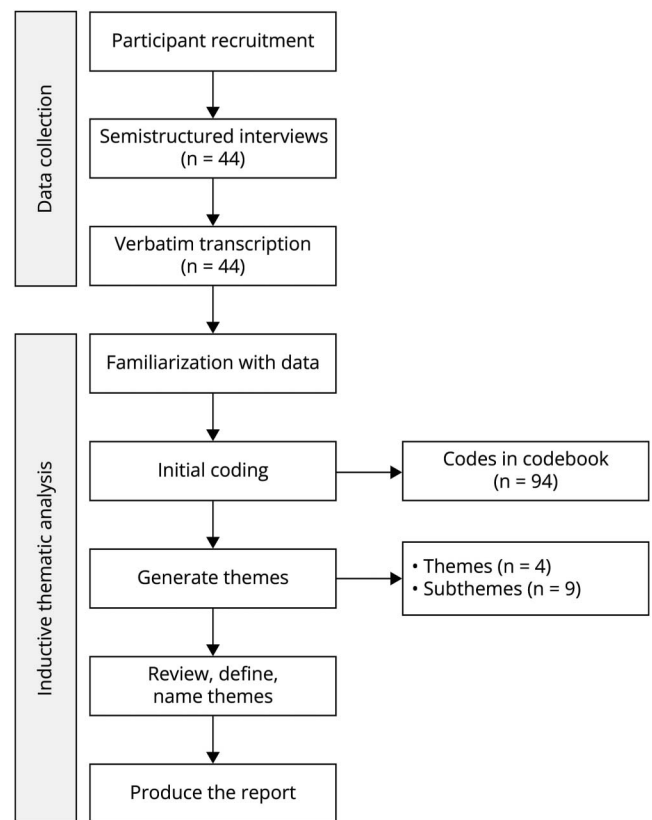
Data Analysis

Each recording was transcribed verbatim and translated in English if the interview was conducted in another language. Transcripts were analyzed independently by 2 researchers using the Braun and Clarke 6-step framework²⁷ for a mixed inductive and deductive approach to thematic analysis within and across countries (see Figure 1 for flow diagram of data collection and analysis). NVivo software (QSR International, Burlington, MA) was used for interpreting meaning from the context of textual data. Consensus was reached by the 2 coders through discussion. Data saturation, which was defined as no new code emerging, was reached across the whole sample. An audit trail was kept on the rationale behind the codes and themes. Once the thematic analysis was completed, individual codes and subthemes were mapped onto the ICF Core Set for stroke⁵ to classify the unmet needs associated with the functioning and disablement and contextual factors for YPwS.

Data Availability

Anonymized data not published within this article will be made available by request from any qualified investigator.

Figure 1 Flowchart of the Thematic Analysis



Results

The sample comprised 44 YPwS from 9 countries (6 high-income, 1 upper middle-income, and 2 lower middle-income countries based on the World Bank²⁸) across 4 continents. The mean (SD) age was 44.2 (8.5) years. Participants were on average 3.3 (2.9) years after stroke and had mild disability (median modified Rankin Scale: 1). Table 1 displays participant characteristics. Our participants represent a heterogeneous cross-section of YPwS both in terms of disability and socioeconomic characteristics. None of the participants dropped out from the study. Four main themes and 9 subthemes emerged from the analysis: (1) heterogeneity of unmet needs specific to YPwS, (2) invisible disability, (3) lack of age-specific stroke information resources, and (4) call for accessible information resources available in different formats.

Theme 1: Heterogeneity of Unmet Needs Specific to YPwS

Impact on Daily Activities and Independence

Each young person with stroke had a unique lived stroke experience, perception of their recovery, and hopes for the future. Multiple unmet needs specific to this population were identified across all domains of the ICF (Figure 2). Most of the participants (41/44; 93.2%) described that they were

Table 1 Participant Characteristics

Measure	% or mean \pm SD
Gender	
Man	50.0
Woman	47.7
Transgender	2.3
Age (y)	44.2 \pm 8.5
Country income levels^a	
Low- and middle-income country	29.5
High-income country	70.5
Time since stroke (y)	3.3 \pm 2.9 (range 0.5–10)
Stroke type^b	
Ischemic	45.5
Hemorrhagic	40.9
Venous infarction	4.5
Unknown	11.4
Hemisphere affected	
Left	44.7
Right	55.3
Modified Rankin Scale (score/5)	
Median	1
Interquartile range	1–3
Education (y) ^c	13.6 \pm 3.6 (range: 0–20)
Living situation	
Alone	2.3
With partner	22.7
With partner and children	27.3
With other family members	47.7
Marital status	
Single	29.7
Married or common-law	59.5
Divorced	10.8

^a Classification according to the World Bank.

^b Self-reported when the data were not available from the medical chart; more than 1 type possible.

^c Self-reported, calculated from primary school.

unable to return to their active lifestyle, such as driving, playing sports, traveling, or going out with their friends. Recovery of impairments was often perceived to enable greater independence, such as working or financial independence. Work or study, social relationships, and family

were central to the needs of YPwS. Indicative quotes that reflect a range of experiences are shown below.

“All the little things suddenly became the biggest.” (USA; 41–55 years old)

“Because I was so active and due to the stroke, there are massive changes in my life. I used to have a boat, a cottage, and an outdoor life. I had to give up a lot of things.” (Canada; 41–55 years old)

“I cannot see everything on the left-hand side of the world. That affects my ability to do day-to-day things.” (Mauritius, 26–40 years old)

Social Relationships and Family

The impact of stroke extended to the family and loved ones. Strained relationships, conflicts, disruption of family dynamics, and challenges with childcare were frequently reported. Family members often had to take on more responsibilities to compensate for the lack of independence of the YPwS. Although family support was beneficial, the willingness of family members to provide help and support frequently decreased in the long term. YPwS without children (who either decided not to have children or plan to have children in the future) raised a doubt as to whether they would be able to assume parental responsibilities. YPwS identified having trouble to relate to their peers; many felt socially isolated since their stroke because of difficulties in resuming daily activities or trouble with engaging in conversations. Establishing new relationships and having intimate relationships were significant concerns. Three participants from Egypt described they felt shameful about their disability and preferred to be left alone than to have others see their disabilities.

“I am lonely. All my friends disappeared.” (Cyprus; 41–55 years old)

“It did bring a lot of problems into my relationship, because (my husband) says that I have changed.” (Belgium; 26–40 years old)

“The inability to perform all these things alone made me embarrassed to be among other people. I prefer to stay alone. I don’t want the others to see me.” (Egypt; 26–40 years old)

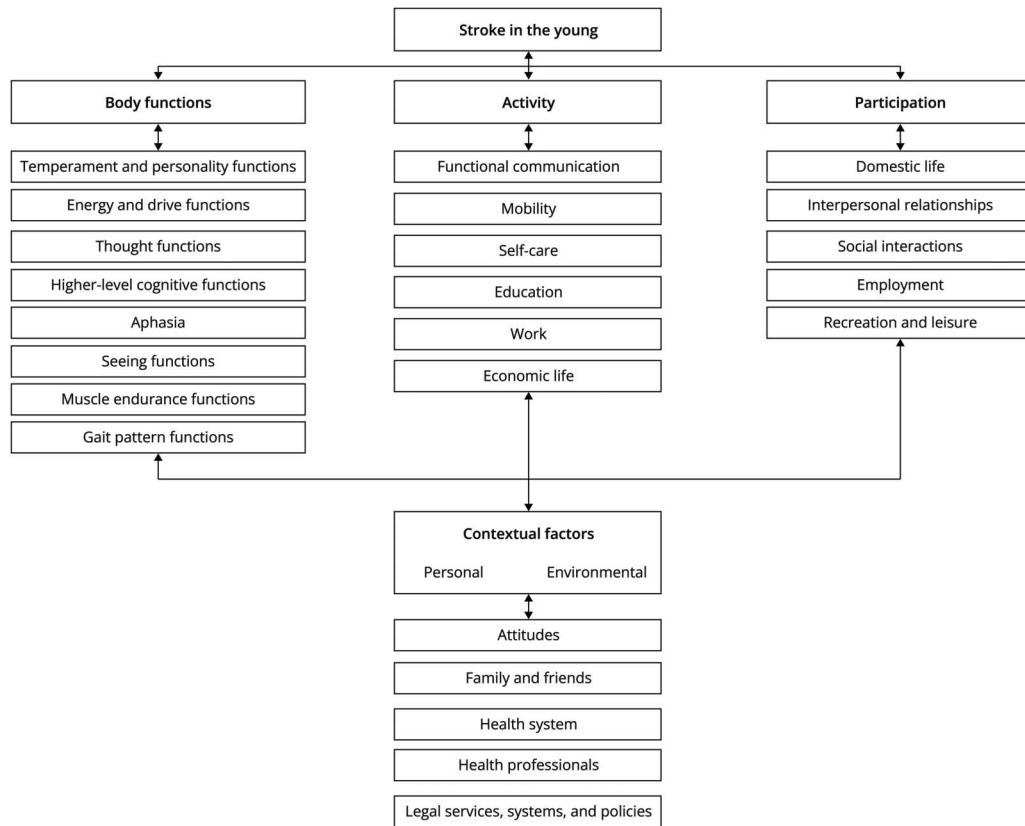
Financial Burden

Regardless of the country participants lived in, financial burden was high, described by many of our participants (72.7%). Loss of income due to unemployment; limited access to government benefits; and health care costs for additional therapies, medication, or equipment were frequently cited. The out-of-pocket cost of mental health services or lack of reimbursement was reported in Belgium and Canada. By contrast, in LMICs, challenges to access rehabilitation care, out-of-pocket costs, and transport to outpatient rehabilitation clinics were the main issues raised with financial stability.

“Financially, it is quite difficult because I have to take a taxi every time we go for physiotherapy sessions. Money for food is another concern.” (Ghana; 41–55 years old)

“I need better medical service, need better physiotherapy. I do not have enough money, so I used to get the public hospitals medical service, which of course is not good like private hospitals medical service. They offer us cheap, weak medications and non-effective physiotherapy.” (Egypt; 26–40 years old)

Figure 2 Needs of Young People With Stroke Classified Using the International Classification of Functioning, Disability and Health Core Set for Stroke



Employment and Productivity

Working was valued by YPwS, but 76.5% were unemployed at the time of the interview. Work was not only a way to be financially independent or taking care of their family but also to feel accomplished and maintain their social network. For 20.5% of participants, return to work was unsuccessful because of the high job demands, a lack of flexibility of the employer or their coworkers, or their disability. Lack of accessibility of the workplace and stigma toward disability were also raised as barriers to reintegration into the workplace. Since their stroke, 3 participants reoriented their careers and returned to school. Accommodations to support students with disability were helpful to support YPwS in their studies.

“I don’t think mentally, I can work in my old job. My mind isn’t working enough to do what I was doing before. So, I don’t think I would be going back to work.” (Canada; 41–55 years old)

“(When I started working) fulltime, that’s where I hit the wall very hard. That turned out not to be feasible. I seriously crossed my limits.” (Belgium; 41–55 years old)

“I suppose the main thing I was struggling with for a long time was finding employment again. And then even after finding employment, adapting to the working environment, that was a bit tough.” (Singapore; 26–40 years old)

“As a father of big family like my family, stopping my work is a fatal thing.” (Egypt; 41–55 years old)

Theme 2: Invisible Disability

Invisible disability, which is defined here as any physical, cognitive, or psychological impairments that are not immediately apparent,^{29,30} was highly prevalent for YPwS. Examples included cognitive dysfunction, persistent fatigue, and emotional regulation. Psychological distress was reported by 93.2% of participants, exacerbated by social isolation and daily challenges experienced. Anxiety, fear of something else happening, or frustration with the uncertainty of recovery were common among our participants, whereas 6.8% of participants experienced apathy. Invisible disability affected daily functioning, especially activities requiring both high physical and cognitive abilities, ability to work and maintain meaningful social relationships. 22.7% of YPwS reported that the general population’s lack of awareness of “invisible signs of stroke” led to unrealistic expectations of performance at work. Invisible disability was also a major barrier to returning to or maintaining work.

“It is hard to do tasks. I have some paperwork, I gotta do. It’s sitting there for a month and a half because I can’t seem to get started on it.” (Canada; 41–55 years old)

“The consequences, the invisible consequences or the complications I had, turned my life upside down a bit” (Belgium; 41–55 years old)
“Physically, from the outside, I’m the same (as before my stroke). I look the same, but everything else is different. From my role in everything, basic everyday things to mood, I am not the same and I don’t know how to explain it to (people around me).” (Croatia; 41–55 years old)

Identity Loss

A total of 22.7% of participants reported a loss of identity since their stroke, identifying themselves as disabled first. Disruption of daily activities, challenges to undertake their family responsibilities, and challenges in returning to work contributed to this identity loss.

“Besides the obvious physical deficits, I think the deeper impact that I had was a loss of identity.” (Singapore; 26–40 years old)

“Since my stroke, I stay at home. I feel that I am permanently handicapped, and I will not be healthy again.” (Egypt; 26–40 years old)

Lack of Support for Emotive and Cognitive Impairments

In high-income countries, participants highlighted the lack of support for mental health or neuropsychological resources for cognitive impairments or psychological distress. After discharge from rehabilitation services, participants were faced with challenges to accomplish daily activities, meet family responsibilities, or resume work because of invisible impairments that were not addressed during the rehabilitation process. Many participants reported seeking additional resources and services after months of struggles because they lacked awareness of available resources to support them.

“From the moment you are physically a bit okay, you are literally pushed aside, you are dismissed while you notice that so many things are not yet possible.” (Belgium; 41–55 years old)

Theme 3: Lack of Age-Specific Stroke Information Resources

Across all 9 countries, participants lacked age-specific information resources at the time of their stroke or in the chronic phase of stroke recovery. Four main educational content priorities were identified by YPwS (see Table 2). The most important information priority was to learn about the impact of stroke, persistent impairments, and the recovery process. Misconceptions about stroke and recovery were raised in LMICs. Globally, many YPwS initially believed they would recover in a few weeks. However, they were faced with issues when they returned home or back to work. Participants wished they had access to a roadmap to help them navigate care and resources because they lack education about what services or governmental program were available in their region.

Lack of Public’s Awareness About Stroke in the Young

Because of their age, 20.5% of YPwS did not recognize they had a stroke, which delayed their admission to the hospital. Information about primary and secondary stroke prevention, how to recognize stroke signs, and etiology were judged important.

Participants felt that family members, loved ones, and the public should receive education about stroke in general, invisible disability, and how to support YPwS. All YPwS identified using their own strategies to overcome the lack of resources available. Examples included self-management programs, peer-support groups, seeking support from their social environment, and participation in research projects.

Theme 4: Call for Accessible Information Resources Available in Different Formats

YPwS preferred to receive tailored resources available in various formats (e.g., flyer, website, peer-support, podcast, or video). However, information resources, when available, were not consistently offered and not centralized in one location. Similarly, the available information resources were difficult to understand or not appropriate for those with cognitive, perceptual, or language impairments or low literacy. Short, easy-to-understand, and aphasia-friendly information were judged ideal. In addition to traditional methods of education (i.e., pamphlets or websites), social media, in the form of blogs, social network sites (e.g., Facebook and Instagram), and short videos (e.g., YouTube and TikTok), were useful in the provision of age-specific information. In LMICs, participants offered to provide stroke education in faith-based organizations or on the radio to facilitate the dissemination of stroke-relevant information, when access to internet was limited.

“Reading after stroke is challenging. ... A video would help. A short one. Not very long and complicated.” (Cyprus, 26–40 years old)

“Oral information is fleeting information. It doesn’t stick.” (Belgium; 41–55 years old)

“Unfortunately, I am illiterate. I cannot read or write. I did not have any information about stroke or its symptoms or how to be treated effectively.” (Egypt; 26–40 years old)

Value of Peer Support to Complement Education From Health Care Professionals

Participants valued peer support for questions, for encouragements, and to gain understanding of the journey through recovery, yet it was inconsistently offered. Challenges were raised for stroke support groups tailored to older people with stroke because participants felt they could not relate or identify generational gaps. Health care professionals were perceived to have a considerable impact on the delivery of information, especially tailored information to their condition and situation.

“Getting support from other people to understand my struggle and understand where my deficits lie and pick up on those low points.” (Mauritius; 26–40 years old)

“Part of my problem being so young was that there was a tiny amount of people in the same boat as me. ... [Being in contact with someone who had a similar stroke at a similar age] helps you see the future, hear people’s stories and also, it makes you feel better.” (Canada; 41–55 years old)

Discussion

This international needs analysis identified diverse unmet needs specific to YPwS by illustrating their significant

Table 2 Educational Content Priorities for Young People With Stroke

Educational priority	Quotes	Number of participants
(1) Impact of stroke, persistent impairments, and the recovery process	<p>26–40 years old (Mauritius): “I would have wanted to understand what I got. I was only hearing the word stroke, but nobody explained to me what it was.”</p> <p>41–55 years old (Singapore): “I wish, I know that there is such thing as golden period for recovery...yeah because, once you pass the time already, even if you want to go back, cannot go back. Now every rehab center that I go to tell me the same thing there’s no chance for you to recover.”</p> <p>41–55 years old (Ghana): “I think I would have wished to know how the recovery would be like and how long it would take.”</p>	31
(2) Stroke prevention, recognition of stroke signs, and etiology	<p>41–55 years old (Ghana): “I am someone who likes taking medicines so if the health care professionals had told me to report back for a refill after the blood pressure medications got finished, maybe this condition would not have occurred.”</p> <p>41–55 years old (USA): “I should have taken care of myself better.”</p> <p>41–55 years old (Croatia): “I knew that the recovery would be long time because unfortunately I’ve arrived in hospital too late. [My family] didn’t take me to hospital right away because they didn’t know what was happening to me.”</p> <p>26–40 years old (Egypt): “I would like to know why I got this stroke. I am afraid from getting it again.”</p>	25
(3) Education to the public and family members	<p>41–55 years old (USA): “I think my family was at a lost because they didn’t really know who to talk to. Information was not readily available to them. Like pamphlets or anything to take home about how to take care of a stroke survivor or who to call.”</p> <p>41–55 years old (Belgium): “You do really get nasty remarks from people sometimes. ... You can’t see what the problems are from the outside.”</p> <p>26–40 years old (Singapore): “What would be useful is sort of like a handbook, at least a pamphlet of information for at least the caregiver especially. ‘This is what might happen, and this is who to ask for advice’ and things like that.”</p> <p>41–55 years old (Croatia): “My needs are, well they are more personal now, to have more understanding from my family maybe. [...] I think my family should also be educated on how to give us support. I think they are not aware of how much their support means to us.”</p>	19
(4) Roadmap to navigate care and resources	<p>41–55 years old (USA): “I wish I had known more about the [health care system]. There is a lot of people out there that are not educated about the system and the insurance. They don’t know the process.”</p> <p>41–55 years old (Canada): “Someone could really have a physiotherapy recovery roadmap saying now what you should be doing is going for long walks, swimming pools, whatever should be next.”</p> <p>41–55 years old (Belgium): “I’m still trying to figure that [employment] out for myself, because I experienced it very much as a lack of what to expect in terms of work possibilities.”</p>	15

challenges in all domains of the ICF including returning to work or school, parenting, social isolation, financial burden, invisible disability stigma, and difficulty navigating the care pathway. These unique needs hindered lifelong community reintegration. Unfortunately, there is a lack of limited age-specific resources and services, especially in languages other than English. Video-based resources could help overcome literacy challenges. Having concise and accessible resources is a first step in addressing the needs of YPwS. The distinct contribution of this work lies in its comprehensive exploration of unmet needs among YPwS across diverse cultural and income backgrounds. By uncovering themes such as invisible disability and the demand for age-specific stroke information, this research underscores the necessity for tailored support initiatives that transcend cultural barriers, offering valuable insights for global health care strategies aims to enhance the well-being of YPwS.

Similar to the findings from Wolfenden and Grace,¹³ our participants experienced vulnerabilities. This vulnerability was exacerbated by invisible disability, affecting participation, social relationships, and productivity. Invisible disability after stroke is frequently reported as a source of frustration.^{18,31} It may also lead to difficulty with psychological adaptation³² and feelings of being an outsider.¹⁸ Unfortunately, society tends to judge people with invisible disability according to conventional standards about what constitutes acceptable behavior.³¹ This is aligned with one of the 4 educational priorities identified by our participants to educate the public and family members about stroke and invisible disability. Comprehensive screening for invisible impairments and follow-up assessment of participation during community reintegration could be beneficial to tailor treatment.²⁷⁻²⁹ Similar to the poststroke checklist developed by the Global Stroke Community Advisory Panel and endorsed by the World Stroke Organisation,^{33,34} our team has commenced work on a similar checklist that targets the needs of YPwS that are often present but not explicitly identified (e.g., contraception, pregnancy and parenting, return to work, driving, participation in leisure and social activities, return to physical activity or sports, and finances). YPwS raised concerns related to intimate relationships and parenting, similar to those raised by nondisabled age-matched peers.³⁵ In the literature, intimate relationships are particularly vulnerable for YPwS, especially for those who are single, living with their parents, or in parenting roles.³⁵ More sensitization about the various forms of invisible disability is needed in the society at large and in the workplace. For example, stroke educational campaigns were shown to be effective to improve public's knowledge and awareness.³⁶ Learning from initiatives performed in people with Alzheimer disease and stroke, storytelling in videos, books, or podcasts might be effective to educate the general public.^{37,38} Social media platforms hold promise as tools for YPwS; they offer avenues for peer support, educational resources, and empowerment through shared experiences, ultimately fostering resilience and facilitating rehabilitation

efforts. As examples, YPwS in Australia and the United Kingdom have set up foundations to share their stories, raise funds to meet unmet needs, and develop resources for other YPwS.^{39,40} These commendable initiatives support the public's education about invisible disability associated with stroke in the young. Health care professionals can be made aware of these resources and signpost other YPwS to relevant resources, although more of such solutions will be needed in LMICs.

Unemployment is a frequent adverse outcome in YPwS. In a cohort study, nearly 47% of the sample did not return to work 5 years after stroke.¹⁰ This has important financial implications to the individual, their family, and society. YPwS have significant financial burden associated with stroke disability.^{6,13} Revenues from employment are often a necessity.¹² Both income from the same household may be affected because family members may need to change their work capacity to support the YPwS or take more family responsibility.^{12,41} On a societal level, chronic productivity losses and decreased participation in work and community activities contribute to the economic burden of stroke.⁴² Moreover, returning to work after stroke is of substantial importance for psychological well-being and life satisfaction.⁴³

Consistent with work performed in high-income countries,^{4,15-17} our results emphasize the need to provide long-term and contextually tailored support to YPwS. This study highlights the lack of information about stroke etiology, recovery, and prevention specific to YPwS. As a result, they may access online resources to gather health-related information. An online repository of information resources tailored to YPwS can be a practical solution to facilitate access to quality information. Navigating the health care system was challenging. A roadmap of the local resources and services could be a solution to explore. Multimodal information resources were preferred to access knowledge and information, both within and outside the traditional health care setting. This is consistent with the results from an online survey in which YPwS identified face to face contact with a health care professional, a succinct list of tips and peer support as preferred methods to meet unmet needs.²⁰ Because impairments after stroke are heterogeneous, accessible information in different formats could be useful to meet the needs of a diverse group of YPwS. Work performed by nonprofit organizations, such as Different Strokes,⁴⁴ the Stroke Foundation,⁴⁵ and the Heart and Stroke foundation,⁴⁶ can also address some unmet needs.

The unmet needs to YPwS highlighted in this study can serve to lobby governing or regulatory bodies for changes in service provision. The findings can be useful in shaping the content of universities for training programs for rehabilitation professionals worldwide. Initiatives such as peer-support groups or peer-mentoring programs, participation in research projects, and self-management programs were empowering to

TAKE-HOME POINTS

- Young people with stroke (YPwS) experience multifaceted challenges, including difficulties in returning to work or school, navigating social relationships, and coping with invisible disability stigma, which collectively hinder lifelong community reintegration.
- The study underscores the scarcity of age-specific resources and services, particularly in languages other than English, emphasizing the need for accessible and concise information tailored to the unique needs of YPwS.
- The vulnerability experienced by YPwS, exacerbated by invisible disability, underscores the importance of comprehensive screening and tailored treatment approaches to address their specific impairments and facilitate psychological adaptation and participation in society.
- Long-term contextually tailored support should be provided to enhance employment opportunities and mitigate economic burdens of stroke in the young.
- The study advocates for the development of multi-modal information resources to facilitate access to quality information and support services for YPwS.

our participants. These could be low-hanging fruits to improve stroke care in the young. Future research directions could include the codesign of accessible information resources with YPwS to meet the 4 educational priorities identified, but efficacy should be tested. In the codesign of these resources, concise, easy-to-use, and aphasia-friendly resources, available in different formats and languages should be kept in mind. Future work should explore how the resources are integrated in stroke care pathways, to ensure that all YPwS access the information they need to promote their community and reintegration. Finally, country- and region-specific needs should be identified to improve local stroke care pathways.

This study does not allow for country-specific recommendations to be made because of the qualitative study design and small sample of participants in each country. Nonetheless, perspectives from participants from different geographical regions and varied socioeconomic and cultural backgrounds constitute a strength of this study. It is possible that details and nuances may have been lost in the translation of the interview guide and the verbatim. However, we performed frequent checks with each interviewer to mitigate the impact of the translation. It is acknowledged that a response bias may have occurred. A short interview

(30 minutes) may not have allowed participants enough time to become comfortable with the interviewer and share more sensitive personal challenges. The single time point study also limits our ability to draw conclusions on how needs change over the course of recovery. Because some of the interviews were carried out using an online platform, opportunities to use a variety of conversation support techniques to promote communication access were limited for those with aphasia. Instead, the interviewers often repeated words or phrases to verify the interviewee's understanding, incorporated closed questions, used simplified language, and clarified the subtle meanings of participant gestures or facial expressions.

Our results underline the importance of raising awareness of stroke in the young and the unique challenges of this population. Traditionally, stroke care is offered regardless of the age of the person. However, YPwS have unique needs and may not receive the optimal care for their recovery. Stroke care delivery should be congruent with YPwS recovery goals and age-specific needs.

Acknowledgment

We acknowledge the contributions of Isaac Kwarkye for his assistance with participants' recruitment, Marie-Louise Bird and Susanna Aba Abraham for their assistance with the IRB process in Ghana, Nitishah Naugah for her assistance with translation and transcription of interviews, and of Nijasri Suwanwela and Ahmed Elkady for their guidance in developing the study protocol.

Study Funding

This project was funded by the Future Stroke Leaders project grant from the World Stroke Organization.

Disclosure

The authors report no relevant disclosures. Full disclosure form information provided by the authors is available with the full text of this article at [Neurology.org/cp](https://www.neurology.org/cp).

Publication History

Received by *Neurology: Clinical Practice* December 13, 2023. Accepted in final form September 17, 2024. Submitted and externally peer-reviewed. The handling editor was Editor Luca Bartolini, MD, FAAN, FAES.

Appendix Authors

Name	Location	Contribution
Marika Demers, PhD	University of Southern California, Los Angeles, Université de Montréal, CRIR-Institut universitaire sur la réadaptation en déficience physique de Montréal (IURDPM), CIUSSS du Centre-Sud-de-l'Île-de-Montréal, QC, Canada	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data

Continued

Appendix (continued)

Name	Location	Contribution
Marina Charalambous, PhD	Cyprus University of Technology, Limassol, University of Fribourg, Switzerland	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data
Li Khim Kwah, PhD	Singapore Institute of Technology	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data
Shamala Thilarajah, PhD	Singapore General Hospital	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data
Danira Bazadona, MD, PhD	University Hospital Centre Zagreb, Croatia	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; analysis or interpretation of data
Sherita Chapman, MD	University of Virginia, Richmond VA Medical Center	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design
Ahmed Nasreldein, MD, PhD	Assiut University, Egypt	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; analysis or interpretation of data
Laetitia Yperzeele, MD, PhD	Antwerp University Hospital, Belgium	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data
Dinah Amoah, MPH	University of Tasmania, Hobart (TAS), Australia	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; analysis or interpretation of data

Appendix (continued)

Name	Location	Contribution
Carolee Winstein, PhD	University of Southern California, Los Angeles	Drafting/revision of the manuscript for content, including medical writing for content
Julie Bernhardt, PhD	The Florey Institute of Neuroscience and Mental Health, Heidelberg, Vic, Australia	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design
Urvashy Gopaul, PhD	The KITE Research Institute-Toronto Rehabilitation Institute, University Health Network, ON, Canada	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data

References

- Griffiths D, Sturm J. Epidemiology and etiology of young stroke. *Stroke Res Treat*. 2011;2011:209370-209379. doi:10.4061/2011/209370
- Béjot Y, Delpont B, Giroud M. Rising stroke incidence in young adults: more epidemiological evidence, more questions to be answered. *J Am Heart Assoc*. 2016;5(5):e003661. doi:10.1161/JAHA.116.003661
- Boot E, Ekker MS, Putaala J, Kittner S, De Leeuw FE, Tuladhar AM. Ischaemic stroke in young adults: a global perspective. *J Neurol Neurosurg Psychiatry*. 2020;91(4):411-417. doi:10.1136/jnnp-2019-322424
- Shiple J, Luker J, Thijs V, Bernhardt J. How can stroke care be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia. *Disabil Rehabil*. 2020;42(12):1697-1704. doi:10.1080/09638288.2018.1534278
- World Health Organization. *Towards a Common Language for Functionary, Disability and Health: ICF Beginner's Guide*: WHO; 2002.
- Walters R, Collier JM, Braighi Carvalho L, et al. Exploring post acute rehabilitation service use and outcomes for working age stroke survivors (<65 years) in Australia, UK and South East Asia: data from the international AVERT trial. *BMJ Open*. 2020;10(6):e035850. doi:10.1136/bmjopen-2019-035850
- Maaijwee NAMM, Rutten-Jacobs LCA, Schaapsmeeders P, van Dijk EJ, de Leeuw FE. Ischaemic stroke in young adults: risk factors and long-term consequences. *Nat Rev Neurol*. 2014;10(6):315-325. doi:10.1038/nrneurol.2014.72
- Amaricai E, Poenaru DV. The post-stroke depression and its impact on functioning in young and adult stroke patients of a rehabilitation unit. *J Ment Health*. 2016;25(2):137-141. doi:10.3109/09638237.2015.1022251
- Wolf TJ, Brey JK, Baum C, Connor LT. Activity participation differences between younger and older individuals with stroke. *Brain Impairment*. 2012;13(1):16-23. doi:10.1017/BrImp.2012.1
- Aarnio K, Rodriguez-Pardo J, Siegerink B, et al. Return to work after ischemic stroke in young adults: a registry-based follow-up study. *Neurology*. 2018;91(20):e1909-e1917. doi:10.1212/WNL.00000000000006510
- Alaszewski A, Alaszewski H, Potter J, Penhale B. Working after a stroke: survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment. *Disabil Rehabil*. 2007;29(24):1858-1869. doi:10.1080/09638280601143356
- Essue BM, Hackett ML, Li Q, Glozier N, Lindley R, Jan S. How are household economic circumstances affected after a stroke? The psychosocial outcomes in Stroke (POISE) study. *Stroke*. 2012;43(11):3110-3113. doi:10.1161/STROKEAHA.112.666453
- Wolfenden B, Grace M. Vulnerability and post-stroke experiences of working-age survivors during recovery. *SAGE Open*. 2015;5(4):2158244015612877. doi:10.1177/2158244015612877
- Holloway A, Chandler C, Aviles Reinso L, et al. Young Adults Rehabilitation Needs and Experiences following Stroke (YARNS): a review of digital accounts to inform the development of age-appropriate support and rehabilitation. *J Adv Nurs*. 2022;78(3):869-882. doi:10.1111/jan.15076
- Shiple J, Luker J, Thijs V, Bernhardt J. The personal and social experiences of community-dwelling younger adults after stroke in Australia: a qualitative interview study. *BMJ Open*. 2018;8(12):e023525. doi:10.1136/bmjopen-2018-023525
- Abrahamson V, Wilson PM. How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Serv Res*. 2019;19(1):480. doi:10.1186/s12913-019-4210-2
- Teasell RW, McRae MP, Finestone HM. Social issues in the rehabilitation of younger stroke patients. *Arch Phys Med Rehabil*. 2000;81(2):205-209. doi:10.1016/S0003-9993(00)90142-4

18. Röding J, Lindström B, Malm J, Öhman A. Frustrated and invisible—younger stroke patients' experiences of the rehabilitation process. *Disabil Rehabil.* 2003;25(15):867-874. doi:10.1080/0963828031000122276
19. Sadler E, Daniel K, Wolfe CDA, McKeivitt C. Navigating stroke care: the experiences of younger stroke survivors. *Disabil Rehabil.* 2014;36(22):1911-1917. doi:10.3109/09638288.2014.882416
20. Keating J, Borschmann K, Johns H, Churilov L, Bernhardt J. Young stroke survivors' preferred methods of meeting their unique needs: shaping better care. *Neurology.* 2021;96(13):e1701-e1710. doi:10.1212/WNL.00000000000011647
21. Opoku S, Eliason C, Akpalu A. Why me?: a qualitative study on the experiences of young stroke survivors in the accra metropolis of Ghana, West Africa. *J Patient Exp.* 2020;7(6):1788-1796. doi:10.1177/2374373520967505
22. Bernhardt J, Urimumbeni G, Gandhi DBC, Eng JJ. Stroke rehabilitation in low-income and middle-income countries: a call to action. *Lancet.* 2020;396(10260):1452-1462. doi:10.1016/S0140-6736(20)31313-1
23. Wojnar DM, Swanson KM. Phenomenology: an exploration. *J Holist Nurs.* 2007;25(3):172-185. doi:10.1177/0898010106295172
24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357. doi:10.1093/intqhc/mzm042
25. Kwakkel G, Lannin NA, Borschmann K, et al. Standardized measurement of sensorimotor recovery in stroke trials: consensus-based core recommendations from the Stroke Recovery and Rehabilitation Roundtable. *Int J Stroke.* 2017;12(5):451-461. doi:10.1177/1747493017711813
26. Doyle S. Member checking with older women: a framework for negotiating meaning. *Health Care Women Int.* 2007;28(10):888-908. doi:10.1080/07399330701615325
27. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
28. WDI—the World by Income and Region. Accessed May 6, 2024. datatopics.worldbank.org/world-development-indicators/the-world-by-income-and-region.html
29. Terrill AL, Schwartz JK, Belagaje SR. Best practices for the interdisciplinary rehabilitation team: a review of mental health issues in mild stroke survivors. *Stroke Treat.* 2018;2018:6187328. doi:10.1155/2018/6187328
30. Johansson B, Rönnbäck L. Mental fatigue and cognitive impairment after an almost neurological recovered stroke. *ISRN Psychiatry.* 2012;2012:686425. doi:10.5402/2012/686425
31. Stone SD. Reactions to invisible disability: the experiences of young women survivors of hemorrhagic stroke. *Disabil Rehabil.* 2005;27(6):293-304. doi:10.1080/09638280400008990
32. Murray C, Harrison B. The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disabil Rehabil.* 2004;26(13):808-816. doi:10.1080/09638280410001696746
33. Philp I, Brainin M, Walker MF, et al. Development of a poststroke checklist to standardize follow-up care for stroke survivors. *J Stroke Cerebrovasc Dis.* 2013;22(7):e173-e180. doi:10.1016/j.jstrokecerebrovasdis.2012.10.016
34. Ward AB, Chen C, Norrving B, et al. Evaluation of the post stroke checklist: a pilot study in the United Kingdom and Singapore. *Int Journal Stroke.* 2014;9(suppl A100):76-84. doi:10.1111/ij.s.12291
35. Martinsen R, Kirkevold M, Sveen U. Younger stroke survivors' experiences of family life in a long-term perspective: a narrative hermeneutic phenomenological study. *Nurs Res Pract.* 2012;2012:e948791. doi:10.1155/2012/948791
36. Rasura M, Baldereschi M, Di Carlo A, et al. Effectiveness of public stroke educational interventions: a review. *Eur J Neurol.* 2014;21(1):11-20. doi:10.1111/ene.12266
37. Gray JB. The power of storytelling: using narrative in the healthcare context. *J Commun Healthc.* 2009;2(3):258-273. doi:10.1179/cih.2009.2.3.258
38. Alawafi R, Rosewilliam S, Soundy A. An integrative review considering the impact of storytelling and sharing interventions in stroke. *Behav Sci (Basel).* 2021;11(6):88. doi:10.3390/bs11060088
39. SameYou. *SameYou*. Accessed May 16, 2024. sameyou.org/
40. Genyus network. Genyus Foundation. *Eliminate Isolation for Stroke and Brain Injury Survivors*. Accessed May 16, 2024. drct-genyusnetwork.prod.supporterhub.net/donations/supporter-army
41. Banks P, Pearson C. Parallel lives: younger stroke survivors and their partners coping with crisis. *Sex Relationship Ther.* 2004;19(4):413-429. doi:10.1080/14681990412331298009
42. Brown DL, Boden-Albala B, Langa KM, et al. Projected costs of ischemic stroke in the United States. *Neurology.* 2006;67(8):1390-1395. doi:10.1212/01.wnl.0000237024.16438.20
43. Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *J Rehabil Med.* 2003;35(3):127-131. doi:10.1080/16501970310010475
44. Different Strokes. *Different Strokes | Stroke Charity Helping Younger Stroke Survivors*. 2023. Accessed February 16, 2023. differentstrokes.co.uk/
45. Stroke Foundation. *Young Stroke Survivors*. *Stroke Foundation Young Stroke Project*. 2021. Accessed August 16, 2021. strokefoundation.org.au/How-you-can-help/Get%20involved/young-stroke-project
46. Heart and Stroke Foundation. *Different Strokes: Stroke Recovery Across the Ages*. Heart and Stroke Foundation. 2017:15.

How to cite this article: Demers M, Charalambous M, Kwah LK, et al. Unique needs and challenges experienced by young people with stroke: an international qualitative analysis. *Neurol Clin Pract.* 2025;15(1):e200406. doi: 10.1212/CPJ.0000000000200406