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ORIGINAL ARTICLE

Adjusting to life after pediatric stroke: A qualitative study

Claire M. Champigny[1,2] | **Samantha J. Feldman**[1,2] | **Robyn Westmacott**[1,3] | **Magdalena Wojtowicz**[2] | **Casey Aurin**[2] | **Nomazulu Dlamini**[3] | **Peter Dirks**[4] | **Mary Desrocher**[1,2]

[1]Department of Psychology, the Hospital for Sick Children, Toronto, Canada

[2]Department of Psychology, York University, Toronto, Canada

[3]Division of Neurology, the Hospital for Sick Children, Toronto, Canada

[4]Division of Neurosurgery, the Hospital for Sick Children, Toronto, Canada

Correspondence
Claire Champigny, the Hospital for Sick Children, Department of Psychology, 555 University Avenue, Toronto ON M5G 1X8, Canada.
Email: claire.champigny@sickkids.ca

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Abstract

Aim: To examine adjustment after stroke in adolescence from the perspective of affected young people.

Method: Fourteen participants (10 female) aged 13 to 25 years with a history of ischemic or hemorrhagic stroke in adolescence participated in one-on-one semi-structured interviews at the Hospital for Sick Children, Toronto, Canada. Interviews were audio-recorded and transcribed verbatim. Two independent coders conducted a reflexive thematic analysis.

Results: Five themes were identified as representative of adjustment after stroke: (1) 'Processing the story'; (2) 'Loss and challenges'; (3) 'I've changed'; (4) 'Keys to recovery'; and (5) 'Adjustment and acceptance'.

Interpretation: This qualitative study provides medical professionals with a personal, patient-driven lens through which to better understand the challenges of adjusting to life after pediatric stroke. Findings highlight the need to provide mental health support to patients to assist them in processing their stroke and adapting to long-lasting sequelae.

Pediatric stroke is an important cause of acquired brain injury in young people.[1] Contrary to popular belief, young people do not recover from stroke better than adults: mortality rates and functional outcomes are similar.[2] Most young people with stroke experience long-term neurological deficits.[1,3–5] Motor and physical impairments are especially common, affecting 50% to 80% of survivors.[3,6] Neurocognitive deficits occur in up to 75% of survivors[7–10] and can affect a range of domains such as processing speed, working memory, and executive functioning,[11–15] contributing to lower academic achievement.[16,17] Pediatric stroke also adversely affects social, emotional, and behavioral functioning,[18,19] and is associated with increased rates of psychopathology such as attention-deficit/hyperactivity disorder[20,21] as well as anxiety, depression, and post-traumatic stress disorder.[12,22,23]

Qualitative health research has been increasingly recognized as a valuable methodology in neurology, aiming to shed light on patients' lived experiences including trajectories associated with recovery and rehabilitation.[24] Findings from qualitative studies can benefit healthcare practitioners conceptually by giving insight into 'what it is "like" to live, play, learn with, or receive care for a specific condition'.[24] Four studies have investigated the lived experiences of caregivers affected by pediatric stroke, with findings indicating that caregivers felt emotionally distressed and unprepared for the burdens associated with stroke sequelae.[25–28] To guide healthcare practitioners in supporting their patients, scientists have indicated the need to hear from affected young people directly about adjustment after stroke.[25,26] To our knowledge, the present study is the first to examine the lived experience of young people with pediatric stroke from their own perspective.

METHOD

Participants

A systematic search of medical records identified patients at the Hospital for Sick Children (Toronto, Canada) who met inclusion criteria for this study. Inclusion criteria consisted

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This original article is commented on by Hanes on pages 1272–1273 of this issue.

of stroke occurring in adolescence (i.e. approximately ages 10–18 years), age at the time of interview between 13 and 25 years (i.e. old enough to reflect on past experiences), at least 6 months post-stroke, and proficiency in English. Exclusion criteria included unstable medical condition and a diagnosis of moderate to profound intellectual disability. A random selection of eligible participants was contacted between January and June 2021.

The study was approved by the Research Ethics Board of The Hospital for Sick Children.

Procedure and materials

An author (CMC) wrote the interview script, informed by the scientific literature and clinical experience (Appendix S1). A survivor of pediatric stroke consulted and provided feedback on the script.

Once informed written consent was obtained, participants took part in a semi-structured interview with CMC at the Hospital for Sick Children or through Zoom for Healthcare.[29] Interviews were audio-recorded and lasted approximately 45 minutes. Open-ended questions queried stroke recovery and adjustment. After 14 interviews, data saturation was met (i.e. no new codes appeared and clear patterns had emerged) and recruitment ended. Interviews were transcribed verbatim and reviewed for accuracy.

Participants or caregivers completed a demographics and history questionnaire querying demographic information as well as medical, developmental, and family history.

Data analysis

A reflexive thematic analysis was conducted, closely following the steps outlined by Braun and Clarke[30,31] for a descriptive phenomenological approach.[32] Authors CMC and SJF reviewed transcripts for familiarization with the data, then created a living codebook that was continually revised in line with emerging patterns in the data, using the software ATLAS.ti.[33] CMC and SJF coded the interviews independently and met weekly to compare codes. Discrepancies were minor and resolved through discussion. CMC grouped codes into broader subthemes, then defined overarching themes. Results were reviewed with SJF, RW, and MD to ensure consensus, and Karen Fergus provided consultation to ensure methodological rigor.

The authors who wrote the interview script (CMC), conducted the interviews (CMC), and coded the transcripts (CMC and SJF) recognize that it is unavoidable for personal and professional histories to shape their work; that 'we cannot escape our predicament as researchers, being reflexive, culture-bound subjects interpreting a self-interpreting referent.'[34] Self-reflection on our past experiences and underlying a priori expectations aimed to reduce personal bias during the processes of conducting this study.

What this paper adds

- Processing the onset event is a key component of adjustment to stroke.
- Feelings of anxiety, sadness, frustration, and self-consciousness impede adjustment to stroke.
- Young people may feel overwhelmed academically owing to neurocognitive deficits.
- Sequelae may rid young people of hobbies and passions, and alter plans for the future.
- To adjust to stroke, survivors draw on resilience, patience, determination, and social support.

RESULTS

Clinical information was collected from medical records and the demographics and history questionnaire (Table 1). Participants were 13 to 25 years old (mean age 17 years). Age at stroke onset ranged from 9 to 16 years (mean age 12 years). Time since stroke ranged from 9 months to 14 years (mean time 5 years), which provided richness to the data as some participants had just begun adjusting to their stroke while others had reflected on their experiences for over a decade.

Following reflexive thematic analysis, five overarching themes were identified as representative of adjustment after stroke. Anonymized quotations illustrate themes and subthemes.

Theme 1: 'Processing the story'

Participants remembered struggling to process the stroke onset, and this processing was described as a necessary step to begin adjusting to life after stroke. Three subthemes encompassed their experience.

Something's wrong

When describing the stroke onset event including acute symptoms (Table 1), participants vividly remembered when they realized something was wrong. Confusion and fear were prominent emotions during the onset, reported by 11 out of 14 participants. Six participants underestimated symptom severity until the pain became unbearable or unexpected symptoms appeared (e.g. loss of motor function).

> I remember screaming really, really loud … I kept turning right and left to find a way so that the pain would stop. (age 15 years).

> It felt like a really, really bad sting of pain. … And then I tried to move but the right [side] of my body was not moving at all. … And then my

TABLE 1 Clinical characteristics of the sample (*n* = 14).

Clinical characteristics	*n*
Mean age at time of interview, in years (SD)	17 years 5 months (3 years 8 months)
Mean age at time of stroke (SD)	12 years 0 months (2 years 0 months)
Mean time since stroke (SD)	5 years 5 months (4 years 6 months)
Stroke type, *n*	
Ischemic	7
Hemorrhagic	7
Stroke etiology[a], *n*	
Aneurysm	2
Arteriovenous malformation	7
Moyamoya disease	1
Sickle cell disease	1
None/unknown	4
Psychiatric conditions, *n*	
Attention-deficit/hyperactivity disorder	1
Anxiety disorder	2
Autism spectrum disorder	1
Depressive disorder	3
Intellectual disability	1
Learning disorder	2
Obsessive–compulsive disorder	1
Post-traumatic stress disorder	1
Sleep disorder	1
None	6
Prefer not to say	2
Symptoms at onset, *n*	
Headache, migraine	7
Lethargy, sudden fatigue	6
Loss of consciousness, coma	6
Motor difficulties	8
Nausea, vertigo	8
Speech difficulties	6
Sensory difficulties	6
Vomiting	7
Other[b]	7
No symptoms	0

[a] Numbers add up to 15 because one participant reported two etiologies.

[b] In the blank space provided next to 'Other', participants/parents wrote the following responses: loss of vision (*n* = 2), earache (*n* = 1), dizziness (*n* = 1), seizure (*n* = 1), while sedated at the hospital (*n* = 1), would not wake up from sleep (*n* = 1).

> speech got slurred, and that's when I felt like, I really panicked. … That's when I knew something was really wrong. (age 21 years).

> I started feeling violently ill, and I thought I was dreaming. … It felt like it was the most tired I've ever felt in my life. … I kept dropping the water bottle in my left hand and I was so confused at what was happening. It was scaring me. (age 17 years).

> It feels like my soul's been knocked out. (age 14 years).

Piecing together what happened

Participants described varying degrees of memory loss surrounding the event and confusion after waking up in hospital. They attempted to piece together what had happened by trying to recall the event, asking people who were present about it, and processing information from their hospital care team.

> [I was] really confused, 'cause obviously I didn't really know why I was in the hospital and then I was hooked up to all these tubes and stuff. (age 16 years).

> I didn't really know how to take it in or how to understand what happened to me. … Mostly my mom told when it happened … later on, throughout life. Like, 'oh this happened, and this happened,' so I was kind of putting in the pieces and stuff. (age 24 years).

Feeling and sharing the story

Participants described strong emotions and feelings of surrealness when reminiscing about the stroke onset. Most participants felt that these emotions attenuated over time as they became habituated to recounting their story to others. Six had outstanding questions even years later. The primary reasons for sharing their story with others were that stroke was an important part of their identity and that it felt good to talk about it. Two participants shared their story with broader audiences to raise awareness about pediatric stroke. Two other participants preferred to keep their stories private.

> It's like a surreal experience that takes a long time to really hit you. (age 15 years).

> Sometimes Mom will say a story and I won't even remember it and that really frustrates me. 'Cause it's like, that was me, that happened to me, and I can't even remember it. (age 16 years).

> I like to bring awareness to it and tell people my story because I like people to know what

> happened to me. 'Cause I feel like that's a very important thing in my life. (age 17 years).

> There's obviously emotions attached to it, but it was much harder the first time telling somebody than now because, I don't know, I've said it quite a few times. (age 14 years).

Theme 2: 'Loss and challenges'

Participants expressed several losses and challenges affecting their day-to-day tasks and plans for the future. Five subthemes were identified.

Letting go

Many hobbies and passions that participants were involved in before their stroke were no longer feasible due to neurocognitive and motor sequelae, such as reading, drawing, and playing sports. Participants described with sorrow having to reluctantly 'let go' of these activities, as well as of some ideas and plans for the future, such as learning to drive.

> Before my stroke, I was an athlete. I did everything … So, it was really, really hard to get, to understand that I couldn't do those things anymore. (age 25 years).

> I was a huge reader, I loved reading … But now it's a struggle … It's really exhausting. (age 15 years).

> I used to do a lot of art and drawing before my stroke … Now I'm left-handed and now suddenly I have to switch over. I learned how to draw and everything, but it didn't feel the same. (age 21 years).

> Eyesight has been affected, which has affected things that were really important to me, like getting my driver's licence … So that was a big thing for me … that I wouldn't be able to get that. (age 15 years).

> I had to rethink my limits … [to] be like a police person, or like physical jobs … I was like 'Oh I can't do that anymore'. (age 25 years).

Challenges with day-to-day

Participants struggled with day-to-day tasks that used to require little effort but were now difficult owing to motor issues, such as manipulating small objects and using public transit. They emphasized the patience and dedication needed to adjust to or overcome these challenges. Two female participants expressed frustration with how difficult it had become to tie up their hair owing to impaired fine motor control.

> … Little challenges, that was new to me. Trying to learn how to hold a pen or hold an object with my right hand. (age 24 years).

> [I have] to rely a lot on my parents and family members and friends to have to get me places 'cause I can't get anywhere by myself. (age 15 years).

Feeling left behind

Participants' statements reflected a common experience of feeling left behind, overwhelmed, and slower than their peers, especially in academic studies. Four participants felt unable to keep up with their classes owing to their neurocognitive deficits, and this was compounded by having missed classes during their inpatient stay.

> I feel like I'm just always playing catch up … I really just feel like I'm behind. (age 18 years).

> At school it's like the kids are like the rabbit, they're like, okay, they're going faster and faster, and I felt like the turtle going … You know? (age 24 years).

What could have been

Six of the 14 participants identified a tendency to contemplate an alternative reality in which they had not suffered a stroke. They mourned their ideas of what they felt could have been their life.

> I have this habit of looking back, like what if I didn't have my stroke … I would've continued swimming … I would've become a lifeguard or instructor. (age 15 years).

> If I didn't have a stroke and my hand was functioning normal, then I would've gone into [the] baking industry. (age 21 years).

> If I didn't have this, would I be further from where I am right now? (age 24 years).

Worries about the future

Nine out of 14 participants shared worries and anxiety about their future owing to impaired abilities and decreased independence.

> I think I'm not ready yet to be on my own. And I do worry about that sometimes, what that would look like … The fear of what the future will look like. (age 18 years).

> I might not be able to get some job because of my disability. They could say, 'oh, this job is focused on memory, and if you have memory loss, I don't think we can hire you.' (age 13 years).

> Maybe because of the stroke, my marks [*sic*] in school goes down a bit, so that I can't go to the university that I wanna go. (age 16 years).

> [The stroke] definitely changed the way I thought about driving … It was in the back of my mind that, 'what if I can't drive when I am of age?' (age 25 years).

Theme 3: 'I've changed'

Nearly all participants described changes in their emotions, behavior, and self-confidence, often associated with mental health concerns. Two subthemes illustrated these changes in self-perception.

Anxiety, anger, and sadness

New-found anxiety, anger, and sadness were endorsed by 9 out of 14 participants. For five participants, these changes were substantial and associated with depression and/or an anxiety disorder.

> I'll be doing something, and the stroke will, like I'll be reminded of it – like my right hand for example, I'll be reminded of it – and then I'll get really angry and like, why me, why did it have to happen to me? (age 16 years).

> There was definitely a part of me that was mad about it … I think it's where the depression also came. I was mad at myself. (age 24 years).

> I felt anxious all the time. I was always scared of another stroke happening. (age 21 years).

Self-consciousness

A common experience – endorsed by eight participants – was increased self-consciousness, often related to motor impairments. Four participants noticed a shift in their behavior as they became uncharacteristically quiet.

> I was talkative but now I'm like, shy and anonymous. Because I don't wanna say something like, weird. (age 16 years).

> My right arm … it kind of just looks like it's like there, like I can't even use it … I'm so worried about people looking at that. (age 16 years).

> People in the hallway were like, 'Oh what happened to you? Why do you limp? Why do you walk like that?' … I wanted to live a normal life, like not have to worry about putting all the AFO [ankle foot orthosis] … or taking a special needs bus to school. (age 21 years).

Theme 4: 'Keys to recovery'

Recovery looked different from one person to the next, but support and hard work were consistently reported as crucial components for success. Three subthemes summarized the common experiences.

A strong support system

Family and friends were identified as valuable sources of support by all 14 participants. Teachers and principals played important roles in transitioning back to school. Five participants brought up fond memories of hospital staff who had made a lasting impact through their kindness. Three young people reported that faith or faith leaders contributed to their recovery.

> If I was by myself doing it, there's no way I would find that strength, but to see everyone cheering me on, on the sidelines, I was like, 'okay I can do this, I can get through this.' (age 16 years).

> [The school and rehab team] had a whole afternoon meeting about transition and like, what I needed and everything … I felt safe. (age 25 years).

> My classmates were really, really understanding and caring, like I remember they used to compliment my hand splints [laughs]. (age 21 years).

Determination and hard work

Seven participants reported that recovery involved intensive rehabilitation on a daily basis even years after stroke. The importance of determination, hard work, and a positive attitude were discussed.

> I knew I needed to gain strength in my right hand, so I just kept writing with my right hand … I was like, 'okay, just do everything with your right hand.' (age 24 years).

> I'm using the elliptical every day, so I'm working out just to get my strength back. Still not there, but I've improved. (age 18 years).

Finding your community

Three participants met peers who had undergone a similar medical experience (e.g. acquired brain injury, neurological condition); for them, finding a community that made them feel understood played an important role in their emotional adjustment to stroke. Communities described included adaptive sports teams and support groups.

> I have a lot of friends from parasport now, who I wouldn't have met otherwise … A lot of the advocacy, like self-advocacy I got, or I have now, stems from watching my teammates or someone in the community go through it. (age 25 years).

> We had a teen lounge … Just being able to, after therapy, go there and complain about brain injuries and stuff that affected us, I mean, that made a world of a difference … To have those friends that understood what I was going through. (age 15 years).

Theme 5: 'Adjustment and acceptance'

Participants expressed how they had adjusted to their new reality and accepted their stroke. They identified feelings of strength, resilience, and gratitude. Four subthemes reflected their insights.

Adapting, one step at a time

Participants found an array of strategies to compensate for and adapt to motor and cognitive impairments, with practice, patience, and determination.

> Learning how to adapt to do everything with one hand … [is] the hardest thing … like to put on my socks, zip up my coat and stuff. I still haven't learned how to tie my shoes yet. (age 17 years).

> It took me years to figure out how to put my hair up in a ponytail. (age 25 years).

> I have to go my own pace and try to understand it slowly, step by step. So, it's just kind of, go slow and take your time on the basic things. (age 24 years).

Gratitude

Seven of 14 participants described feeling grateful that they had survived their stroke and contemplated how the consequences could have been worse.

> I feel like it's made me a better person 'cause I am more thankful for little things … I try to make the most of my life with how it is. (age 17 years).

> I know it sounds weird, but after everything, I feel much more appreciative … I'm alive! There's a huge chance, toss of a coin, that I couldn't have been, right? (age 15 years).

Resilience

For 13 out of 14 participants, their experience unearthed a resilience they did not know they had. Three also felt the stroke had increased their pain tolerance.

> If I can go through that, then I can go through anything. (age 21 years).

> It did make me stronger for sure … [If] I have to get a needle for any reason or blood tests or anything, I remember how I've been literally through any worse pain. (age 15 years).

> It changed me in a positive way because I overcame it and that's a really big accomplishment. I survived it. (age 14 years).

This is me

Stroke changed many aspects of participants' lives and bodies. They described how they came to terms with who they were today.

> There's no before and after. It's just me. (age 25 years).

> It was weird at first, but then I just kind of accepted this is a part of my body now. (age 13 years).

> My stroke is part of my identity. Obviously, every day I'm trying to get better and better,

> but I don't hide from it. I'm okay, yeah. I had a stroke, this is who I am today. (age 21 years).

Advice for peers with stroke

Participants were asked what advice they would have for a peer newly diagnosed with stroke. Their responses were organized into categories: (1) work hard and stay motivated; (2) expect changes; (3) surround yourself with supportive people; (4) do things you enjoy; and (5) take it day by day. A selection of quotes was compiled (Table 2).

DISCUSSION

This qualitative study investigated adjustment after stroke in adolescence from the perspective of affected young people. Participants shared insights about the painful and confusing stroke onset, the burden of short- and long-term sequelae, and the strategies they devised to adjust to their new reality. Matters important to them revolved around difficulties keeping up with school, loss of hobbies and abilities, worries about a less independent future, and shifts in behavior because of low self-confidence. Despite feeling alone in their experience, many participants drew on an array of sources of support and personal characteristics to help in their recovery, rehabilitation, and acceptance of stroke. This study identified positive outcomes and shone light on changes in self-perception, which had not been examined in this population yet. New-found resilience and gratitude were consistent outcomes that emerged within this sample.

This study has limitations. Although a pediatric stroke survivor was consulted on the interview script, the researchers did not adopt a participatory action approach, which would have benefitted the project.[24] Second, it is possible that the virtual nature of some interviews limited rapport and disclosure compared with in-person interviews; however, benefits of virtual interviews include that young people living remotely could still participate. Third, the interviewer was involved in the neuropsychological assessment of two participants, which may have biased their disclosure. To reduce this possibility, she explained during informed consent that discussions in the interview, as well as study participation or decline thereof, would not affect clinical care. Another constraint was that we required participants to be proficient in English; families for whom English was a second language were probably underrepresented. Next, in line with self-selection bias – a common drawback in research – it was possible that young people who agreed to being interviewed were less likely to have severe adverse outcomes than young people who declined. Lastly, our participants ranged in age and time since stroke, which may have limited the internal validity of the sample. Overall, the experiences of these participants did not represent the experiences of all young people with stroke; nonetheless, we believe that the results begin to suggest patterns and themes that illustrate common threads in the lived experiences of this population.

Findings have important implications for clinical practice. Many young people struggled with the toll that the stroke onset and long-term recovery took on them and felt ill-prepared, especially for the emotional challenges. These findings emphasize a need to expand the psychological resources offered to families upon discharge and follow-up. We recommend that

TABLE 2 Advice from participants to young people recently diagnosed with stroke.

Work hard and stay motivated
'Say yes to every single thing the therapists are telling you to do … They know how to help you.'
'Stay strong and motivated.'
'Push yourself to the limit and do the best you can. And yes, sometimes it's going to be hard, and yes you could fail at some things, but it's natural because you can't succeed unless you fail once in a while.'
'I would say that even if it's hard or it gets boring, to do the physio … because with each time you do it, it will get easier.'
Expect changes
'You're gonna face some difficulties and not be able to do things other kids can do, but that's okay … You're you and you don't have to be like everyone else.'
'It might change your health, and sports, if you play any sports, or like any physical stuff, it might change. Also, your emotions might change more too.'
'You're gonna come out a new person and you're gonna be stronger … You won't be the person you were before, and that's not a bad thing.'
Surround yourself with supportive people
'If you have the right, good support system, everyone cheering you on, like you'll be able to push through.'
'Make sure that there's a lot of people around you that love you.'
'Find [your] own community … find someone to go through it together.'
'Find someone you can talk to, who will really care about you … And if it's not a person in your life, you can go to a psychiatrist or a psychologist who will actually care for you … If you feel overwhelmed, you know, talk to someone about it, don't just take it on as a burden.'
'Make sure to tell people who need to know, like the school or something like that, because they can help. Because if they don't know, they can't do anything.'
Do things you enjoy
'Find new things to enjoy. I've played sitting volleyball … and then I started golf. So just, you gotta find new things to love and keep yourself entertained.'
'Just try to make sure you still do everything that you enjoyed doing before your stroke to make it a little more normalized.'
'Comedy can be a really big relief … I watch funny stuff. That really, really helps me.'
Take it day by day
'Don't worry so much about the future, just worry about the moment.'
'Have patience. It might seem really, really frustrating at times, but if you have patience and try different things, it will … work out.'
'Take a day off … You need that mental break. Your emotional recovery is really important, as much as your physical recovery … You'll have moments where you'll have pitfalls and you'll feel really emotional as to what happened.'
'Just take your time. It takes time to recover … You'll feel slow, but you'll eventually get there.'

tertiary care centers discuss the potential repercussions of stroke with families, regularly assess psychiatric risk at follow-up appointments, and refer for mental health services pre-emptively. In line with these suggestions, we also recommend that clinicians share with their patients with stroke the advice given by our participants (see Appendix S2 for family-friendly handout). In addition, many young people felt that their peers could not understand their experience, and a few had benefitted from meeting others with similar medical experiences. It is recommended that support groups be offered as part of clinical care to connect families affected by stroke.

Future research should adopt a participatory action approach, thereby including young people with stroke in the study design, data collection, analyses, and interpretation. The involvement of stakeholders increases a project's real-world impact through concrete changes within the healthcare system[35] and allows stakeholders to feel empowered through their engagement.[36] Participatory action research is especially recommended in the context of qualitative research examining childhood neurodisability.[37] Another key direction for future study is the examination of predictors of psychological adjustment after stroke, as this line of research can help determine which young people are most at risk for psychopathology. Furthermore, investigation of therapy modalities is key to providing effective support for this population. In line with participants' reflections about the relief found in meeting others who went through similar experiences, we recommend that researchers consider developing group therapy programs for this population. Lastly, the literature on stroke in adulthood suggests that resilience plays an important role in prognosis and adjustment.[38] Investigating predictors and correlates of resilience in the pediatric stroke population is warranted to inform the development of psychological support services for affected young people.

CONCLUSION

To our knowledge, this is the first study to examine the lived experience of young people with pediatric stroke from their own perspective. The qualitative design gave participants the space to discuss topics of their choosing. These conversations provided researchers with a unique and personal lens through which to learn about living with pediatric stroke. Participants shared insights about the burden of the stroke onset and sequelae, changes in self-perception, coping strategies, and adjustment post-stroke. Some topics converged with those from other studies on outcome after pediatric stroke, such as worries about academics and symptoms of anxiety, while other topics were novel, such as concerns about the future, feelings of resilience and gratitude, and shifts in components of identity. Findings highlight the need to provide mental health support to patients and to assist them in understanding and processing their stroke. As a first step, it is our hope that printouts of the advice given by our participants (Appendix S2) will be shared clinically to help young people with stroke anticipate what to expect for their recovery, learn strategies to cope with sequelae, feel less alone in their experience, and draw on their resilience to adjust to their new reality.

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CONFLICT OF INTEREST STATEMENT

The authors have stated they had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

Owing to the nature of this research, the data are not available for sharing. Interview transcripts contain information that could compromise confidentiality.

ORCID

Claire M. Champigny https://orcid.org/0000-0002-6660-040X
Robyn Westmacott https://orcid.org/0000-0003-1154-5471
Nomazulu Dlamini https://orcid.org/0000-0001-5927-3132
Mary Desrocher https://orcid.org/0000-0002-3551-8737

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SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Interview script.

Appendix S2: Handout: tips and advice for young people with stroke

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