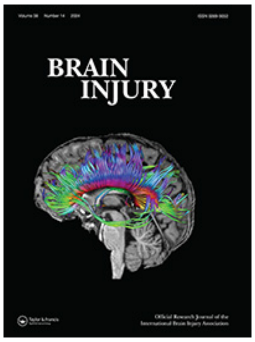

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Looking beyond body structure and function: a scoping review of non-impairment impacts of stroke on adolescents

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ABSTRACT
Background: Much of the childhood stroke literature has not distinguished impacts for adolescents from those of younger children. Research has also focused on body impairments. With adolescence being a unique period, this scoping review aimed to identify the impacts of childhood stroke on activity, participation, and quality of life for adolescents 13–18 years, and identify how these impacts were determined.
Method: This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Data pertaining to non-impairment impacts of childhood stroke for adolescents, participant and study characteristics, and measurement instruments were extracted.
Results: Following screening, 79 articles were included, and 33 measurement instruments identified. Only 6 studies reported separate data for adolescents, identifying difficulties with daily activities, social and academic impacts, and reduced quality of life. Impacts of post-stroke communication difficulties on daily activities and schooling were also noted. Measurement instruments developed specifically for adolescents with stroke are lacking.
Interpretation: The review identified limited research reporting non-impairment impacts of childhood stroke for adolescents. Further research specific to this population and the development of measurement instruments for adolescents who have experienced childhood stroke is required to support future research and clinicians working with this population.

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KEYWORDS
Childhood stroke; adolescence; impacts; scoping review; activity; participation; quality of life

Introduction

Childhood stroke is defined as stroke occurring between 28 days after birth and 18 years of age (1). Krishnamurthi et al. (2) reported the global prevalence of childhood stroke to be 1.3 to 13 cases per 100,000 children. Adolescent males aged 15–19 years have been found to have the highest prevalence and mortality rates amongst the childhood stroke population (2). A range of chronic impairments have been associated with childhood stroke, including those in the cognitive (3–5), motor (6–8), language (9), and psychological (10,11) domains. Given these wide range of impairments, it is integral that the impacts of stroke on adolescents are investigated.

Adolescence is defined as the transitionary period between childhood and adulthood and is marked by a series of rapid and abundant changes (12). During this period, adolescents may strive for independence, reevaluating relationships with their parents and spending increased time with their friends and romantic partners (13,14). They are also faced with increased educational demands in high school (15) and may begin to engage in paid employment outside of school (16). Given these increased social, educational, and vocational demands, research that identifies the impacts of childhood stroke on adolescents is required to ensure that this population can be best supported in navigating this important developmental period.

There is currently limited research on adolescent-specific impacts of stroke. In the past decade, two reviews on the outcomes of childhood stroke for both adolescents and younger children have been published (17,18). Both reviews used the International Classification of Functioning, Disability and Health (ICF) (19) to categorize literature. Greenham et al. (17) described the outcomes of childhood stroke, while Gordon (18) focused on the impacts of both neonatal (i.e., stroke occurring from birth to before 28 days after birth (20)) and childhood stroke, beyond impairments of body structure and function. In the ICF, ‘body structure and function’ describes anatomical parts and physiological functioning (21), with any loss of parts or functioning known as ‘impairments.’ The impacts described in Greenham et al. (17) and Gordon (18) related to the ‘activity’ and ‘participation’ domains of the ICF, which respectively detail an individual’s ability to execute tasks and be involved in life situations (21). Both reviews identified that literature mainly focused on impairments, particularly cognitive, executive function, and motor outcomes. Research on the activity and participation domains, on the other hand, was emerging but limited. Greenham et al. (17) found that activity limitations and participation restrictions after childhood stroke often occurred in the context of decreased motor function, self-care skills, and communication.

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Several studies have also reported academic and social impacts of childhood stroke (5,22–26). However, data for adolescents and younger children has rarely been separated in these studies and findings specific to adolescents not reported. In the academic domain, students aged 6–20 years were found to have difficulties with math calculation, spelling, and reading (5,22,23), while issues with working memory, planning, initiation, and longer-term memory hindered engagement in schoolwork (22). Rivella et al. (24) conducted a systemic review of social functioning post-childhood stroke, noting decreased social acceptance, adjustment, interaction, and prosocial behavior, and increased peer problems in children and adolescents. Lo et al. (25) further reported that patients with childhood stroke presented with reduced conative theory of mind (ToM), which affected their ability to recognize the social cues and intentions of other people. Given the physical, emotional, and psychosocial difficulties children and adolescents experienced after stroke, along with activity limitations, O'Keeffe et al. (26) determined that they were more likely to rate their quality of life (QoL) lower than peers without stroke (26). An association between post-stroke communication difficulties and reduced wellbeing was also noted in this population (24).

It is evident from the findings of current literature that patients may experience various impacts of childhood stroke. However, most studies to date have recruited both children and adolescent participants and reported findings relevant to both age groups, without separating specific findings for each group. Some studies also recruited young adults in their samples (23). Thus, findings specific to adolescents are lacking in the current knowledge base. Given that adolescents are faced with different developmental, social, and educational needs from younger children and young adults, it is important that adolescent-specific impacts are identified. Thus, this scoping review aimed to identify the non-impairment impacts of childhood stroke specific to adolescents. The objectives of this study were to review published literature to identify 1) non-impairment impacts reported by adolescents or their significant others (e.g., parents, teachers) and 2) the instruments used to measure these impacts. The age range of 13–18 years was also selected for this review, as electronic databases such as Pubmed and Cumulative Index of Nursing and Allied Health Literature (CINAHL) considered adolescents to be between this range. A search was conducted on Pubmed, CINAHL, Cochrane Database of Systematic Reviews and JBI Evidence Synthesis prior to the commencement of the review to determine whether previous scoping reviews with similar objectives were published, with no such reviews identified.

Materials and methods

Study design

Due to the broad nature of the research question and limited evidence available in childhood stroke and adolescence, a scoping review methodology was selected to explore the nature and extent of research evidence available in the area, and to identify evidence gaps (28,29). This review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (30). The methodological framework proposed by Arksey and O'Malley (28) and expanded upon by Levac et al. (29) was referred to during data collection and analysis, while the guidelines by Peters et al. (31) were also adhered to during the reporting process. The study was conducted in five stages, which are detailed below. There is no registered protocol for this project.

Stage 1: identifying the research question

This review aimed to identify the non-impairment-based impacts of childhood stroke for adolescents. *Non-impairment impacts* were described as impacts beyond body structure and function on the WHO's (19) International Classification of Functioning, Disability and Health (ICF). *Childhood stroke* was defined as stroke occurring from 28 days after birth to before 18 years of age (1). *Adolescents* were individuals ranging between 13 and 18 years of age. *Measurement Instruments (MIs)* were defined as outcome measures that allowed for quantification of symptoms or impacts (32).

Stage 2: identifying relevant studies

In accordance with Arksey and O'Malley's (28) recommendations, a librarian was consulted when developing the search strategy. Primary searches were run in July 2021 and May 2024 in the following five electronic databases: PubMed, CINAHL, Embase, American Psychological Association (APA) PsycInfo and Web of Science. Variations of the terms 'stroke' and 'adolescent' were input into each database, along with terms describing non-impairment-based impacts. An example search strategy is presented in Table 1 and the remaining search strategies are included in supplementary appendix 1. In addition, secondary searches were also conducted in July 2021 and May 2024 using Google Scholar and the reference lists of included studies.

Stage 3: study selection

Search results were imported into the Covidence systematic review platform, Veritas Health Innovation, Melbourne, Australia (available at www.covidence.org). Two members

Table 1. PubMed search terms.

Search number	Search terms
1	(stroke [MeSH Terms]) OR ('cerebrovascular accident') OR ('cerebrovascular disease')
2	(adolescen*) OR (teen*) OR (youth) OR ('young person') OR ('young people') OR ('young adult') OR (child*) OR (pediatric)
3	('quality of life') OR ('activity') OR (participat*) OR (involve*)
4	1 AND 2 AND 3

of the research team independently screened the title and abstracts of all identified articles according to the inclusion and exclusion criteria. If disagreement occurred between the two reviewers, a third member reviewed the title and abstract and provided a deciding vote. Two researchers (DL and MW) then independently completed full-text screening of 20% of the articles included at the title and abstract, reaching 98% agreement. The remaining articles were screened in full by DL.

Studies were included according to the following criteria:

1. Participants were adolescents aged between 13 and 18 years with a diagnosis of childhood stroke, or their significant others (i.e., family members, carers, or teachers). Due to the limited research in this area, stroke studies with participants outside of the specified age range were also included if the study included participants aged between 13 and 18 years. Studies that did not report a participant age range were included if they reported either a mean participant age between 13 and 18 years, and/or a stroke onset age range or range of time post-stroke at assessment that included participants between 13 and 18 years.
2. Studies reported non-impairment-based impacts on adolescents resultant from stroke in any area of the brain.
3. Impacts were reported by the adolescents themselves or their significant others.
4. Studies were peer-reviewed research articles published in English with quantitative, qualitative, or mixed-methods data.

The following exclusion criteria was applied:

1. Reviews, conference abstracts, book chapters, or study protocols were excluded from analysis.
2. Adolescent participants had a diagnosis of cerebral palsy.

Stage 4: charting the data

Data related to participant characteristics, study design and aims, publication year, and definitions and terminology used for childhood stroke were extracted from each included study. Key findings of non-impairment impacts, MIs used, and impacts related to communication difficulties were also extracted. All extracted data were compiled into a Microsoft Excel spreadsheet.

Stage 5: collating, summarizing, and reporting the results

Frequency counts were used to analyze extracted data. Counts were applied to participant and study characteristics and definitions and terminology of childhood stroke used in studies. Frequency counts were also employed to analyze and report the non-impairment impacts of stroke and the MIs used to identify these impacts.

Results

A total of 8650 articles were identified from database searching, with 6044 articles screened at the title and abstract level following removal of duplicates ($n = 2606$) (see Figure 1). Screening yielded 79 studies which met the inclusion criteria, with no additional studies identified from secondary searches. Characteristics of the included studies are presented in Table 2 and supplementary appendix 2.

Study characteristics

Included studies were published between 1994 and 2023. Studies most frequently employed a cohort design ($n = 49$, 62%). Twenty-seven of the 79 studies (34%) provided definitions for childhood stroke (see supplementary appendix 3). All 27 studies with definitions stated that childhood stroke occurred beyond the neonatal period, but variations were noted for the start and ending ages. Starting ages included 29 days, 30 days or 1 month. While most studies ($n = 25$) considered 18 years as the upper age-limit for childhood stroke, two studies stated this to be 16 years (39,40). Terminology used within the studies also differed, with studies using 'childhood' ($n = 21$, 78%), 'pediatric' ($n = 4$, 15%), and 'non-/beyond neonatal' ($n = 2$, 7%) to describe stroke occurring within this period of development. Five (19%) studies used 'pediatric stroke' as an umbrella term to cover both neonatal stroke and childhood stroke (20,41–44).

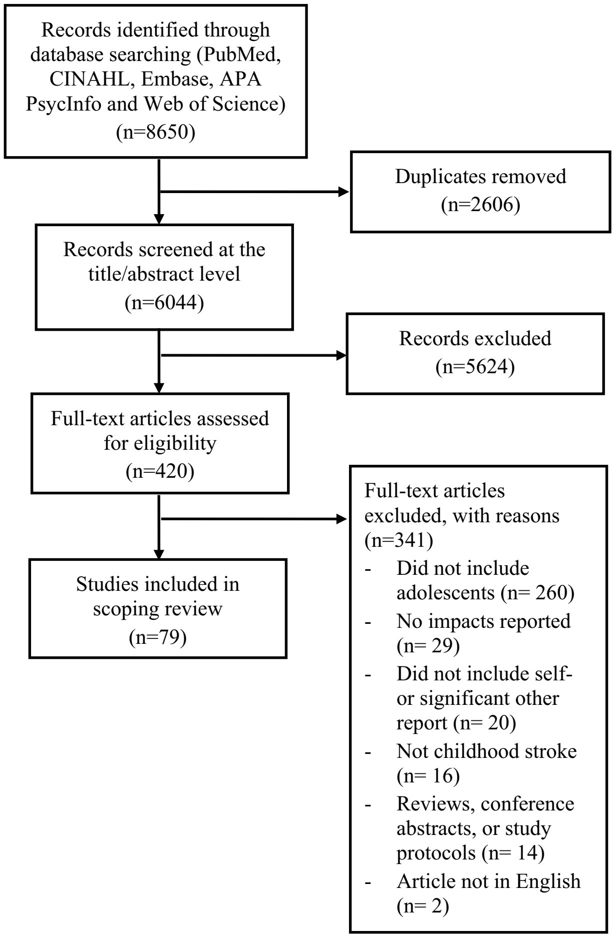

Figure 1. PRISMA flow diagram of the study screening process.

Table 2. General characteristics of included studies ($n = 79$).

Characteristic	n	%
Publication year		
<2000	3	4
2000-2010	22	28
>2010	54	68
Study design		
Cohort study	49	62
Case-control study	13	16
Cross-sectional study	10	13
Case study/series	3	4
Qualitative study	4	5
Country of participant recruitment[1]		
United States of America	15	19
Australia	13	16
Canada	10	13
Netherlands	9	11
Germany	7	9
Switzerland	7	9
United Kingdom	7	9
France	5	6
India	2	3
Sweden	2	3
Austria	1	1
Brazil	1	1
China	1	1
Estonia	1	1
Mongolia	1	1
Spain	1	1
Participant recruitment sources ($n = 78$)[2]		
Hospital	65	83
Stroke registry	10	13
Specialist or private rehabilitation services	3	4
Nursing home	1	1
Aged care assessment team lists	1	1
Newsletter/newspaper advertisement	1	1
Health region	1	1
Brain injury etiologies investigated by studies		
Childhood stroke only (n, %)[3]	33	42
Childhood and neonatal[4] stroke (n, %)	24	30
Childhood and adult[5] stroke (n, %)	18	23
Childhood stroke and other brain injuries (e.g., traumatic brain injury, brain tumor)	4	5

1. Three studies recruited participants from two countries (33–35).
2. Two studies recruited participants from more than one source (36,37). One study (38) did not report recruitment source/s.
3. Stroke occurring from 28 days after birth to before 18 years of age (1).
4. Stroke occurring from birth to 28 days after birth (20).
5. Stroke occurring after 18 years of age (1).

Participant characteristics

Forty-seven studies (59%) reported the age range of participants, while the other 32 studies (41%) provided a mean age between 13 and 18 years, or an age range of stroke onset and/or a range of time post-stroke at assessment that included participants between 13 and 18 years. Of the 47 studies that reported a participant age range, only four studies solely included adolescent participants aged between 13 and 18 years with childhood stroke. Thirty-three (41%) of the 79 studies exclusively included participants with childhood stroke, while the forty-two studies (54%) included participants who had experienced stroke as either a neonate or adult in addition to participants with childhood stroke. The remaining four studies (5%) included participants with other brain injuries, such as traumatic brain injury or brain tumor, alongside participants with childhood stroke. Stroke etiology was also reported in some studies, with examples including Moyamoya disease (38,45–47), sickle cell disease (45,47), arteriovenous malformation (48), congenital heart disease (49,50), and cancer (46).

Non-impairment impacts of childhood stroke

Studies reporting sole or separated data for adolescent participants

Amongst the 79 included studies, six studies (8%) reported data that could be attributed specifically to adolescents who had experienced stroke or their significant others. Four of these studies included solely adolescent participants between 13 and 18 years of age with childhood stroke (38,51–53). The other two studies included younger children with childhood or neonatal stroke (46,54), but data was able to be separated for adolescent participants who had experienced childhood stroke. Four of the six studies also included participants who acquired stroke during adolescence (51–54). The key findings from these six studies are reported in the following section.

Activity limitations. Amongst the six studies that reported data specific to adolescents post-stroke, two studies (33%) reported findings relevant to activity limitations. Ploughman et al. (53) conducted a case study of a patient who experienced stroke at 16 years. The authors stated that the adolescent experienced difficulties completing activities of daily living (ADLs) one-month post-stroke due to impairments in his right arm and hand. These difficulties, as reported by the adolescent's family, included the adolescent being unable to incorporate his right hand into everyday bilateral tasks, such as stabilizing a jar while opening the lid. Additionally, parents of two adolescents who acquired stroke at 13 and 15 years were interviewed in the research by McKevitt et al. (54). These parents reported a reduction in participation in their adolescents' daily activities due to emotional or behavioral issues, which were difficult to locate professional support for.

Social impacts. One study (17%) discussed social impacts for adolescents post-childhood stroke (52). Five adolescents participated in this study. Two adolescents experienced stroke at 15 years, while the remaining three participants experienced their stroke at 10 or 11 years of age. When discussing their social endeavors in an interview, the adolescents noted that they felt connected, active, and satisfied (52). However, their parents did not share these sentiments when completing the Vineland Adaptive Behavior Scales (VABS)- 1st edition (55). They reported concerns about the adolescents' socialization, specifically that they seemed to be more withdrawn following stroke and sought out fewer encounters with peers (52).

Academic impacts. The three (50%) studies reporting on performance at school post-stroke (38,51,52) presented contrasting findings. Some stakeholders reported adolescents returning to positive participation experiences in schooling. For example, the adolescent and his mother in the case study by Godfrey et al. (51) reported a return to pre-stroke school participation levels 7 months post-stroke at 17 years. Self-report from five adolescents in O'Toole et al. (52) similarly revealed that they felt they were able to cope with the impacts of their stroke and return to school, despite some participants requiring special education or in-class modifications. However, teachers who participated in the research by Godfrey and colleagues (51) reported that their adolescent student exhibited persisting behavioral changes, such as disinhibition and disorganization, which impacted on his academic performance. In a case study (38), a mother also discussed the difficulties her son (aged 15 years at the time of writing) encountered academically post-stroke due to his language difficulties. Her son was 10 years old when the stroke occurred. Upon his return to the mainstream education system, the mother found herself constantly advocating for his needs, as he was often mistaken as lacking intellect. During high school, she reported that her son felt he was unable to access learning in the mainstream classroom, as classes moved too quickly for his level of comprehension, and he was unable to take notes. Given these difficulties, at 15 years of age, the adolescent transitioned into a school for students with language-based learning disabilities, where staff were trained to provide specific teaching support.

Quality of life. One study (17%) reported QoL impacts for adolescents post-childhood stroke. Cnossen et al. (46) utilized the Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL) Adult's Quality of Life Questionnaire (TAAQOL) (56) with adolescents aged 16–18 years (*n* = 75% of 66). These adolescents acquired their stroke between 1 month and 17 years of age. They reported a reduced QoL compared to normative data, due to impairments with fine motor and cognition.

Studies reporting data for adolescent participants combined with other age groups

Apart from the six studies that reported adolescent-specific findings, the remaining studies (*n* = 73; 92%) included in this review presented findings for combined cohorts of adolescents, younger children and/or adults. Some studies also included participants with childhood stroke and other brain injuries (e.g (57,58)). The key findings from these 73 studies are reported in the following section.

Activity limitations. Activity limitations due to stroke was explored in six (8%) studies. Champigny et al. (45) interviewed 14 participants aged 13 to 25 on their experiences of adjusting to life after stroke during adolescence. Stroke onset for these participants ranged from 9 to 16 years. One of the subthemes in the study described the sorrow participants felt of having to 'let go' (p. 1360) of hobbies they previously enjoyed, which included reading, art, and drawing, due to their fatigue and motor impairments. Participants also had to revise their future plans like getting a driver's license. Another subtheme in the study also identified that participants adapted to their activity limitations 'one step at a time' (p. 1362), developing strategies for tasks such as putting on their socks, zipping up their coat, and tying their hair in a ponytail.

The remaining studies utilized parent report to investigate activity limitations. Report from young people aged under 18 years was also obtained alongside parents in Gordon et al. (59). Using their self-developed activity limitation measure, Gordon et al. (60) found that activity limitations were most frequently present in the areas of education and self-care skills for children and adolescents aged 5 to 15 years, while parents in Christerson and Stromberg (61) reported that activity limitations affected their child's participation in school and family life. Lambregts et al. (62) similarly noted that 50% of their sample (56 of 112 participants) experienced participation restrictions due to limitations with completing home and community activities. When reflecting on unmet needs after stroke, 31 out of 44 survey respondents in Gordon et al. (59) stated difficulties with participating in leisure activities either alone or with friends. Decreased ability to complete daily activities was also correlated with poorer motor abilities from stroke (39,60,63,64).

Social impacts. Impacts of childhood stroke on social participation was reported in 19 (26%) studies. Neonatal and/or childhood stroke was linked to increased social difficulties in children and adolescents, as determined by self-report questionnaires. These difficulties included poorer social adjustment and participation (20,33) and reduced prosocial behavior in children and adolescents aged 5 to 15 years (65). Parents of children and adolescents aged 0 to 19 years with brain injury (e.g., stroke, TBI) also shared in focus groups that their children experienced negative impacts in their ability to make friends and socialize in the community (66). Cognitive function at 12 months post-stroke and parent mental health were found to impact social skills, such as cooperation, empathy, engagement, and self-control (65,67). Simon-Martinez et al. (64), however, found that children and adolescents with childhood stroke aged 12 to 15 years (*n* = 13) demonstrated similar levels of participation at home and in the community as their peers. The researchers hypothesized that peers in home and community settings were potentially more understanding of the child and adolescents' needs post-stroke, whereas bullying was more likely to occur at school.

Academic impacts. Outcomes related to academic and educational needs were reported in ten (14%) studies. Using parent report from the Child and Adolescent Scale of Participation (CASP), Greenham et al. (34) and Lambregts et al. (62) both reported that communication difficulties were associated with participation restrictions at school in participants aged 6 and above. The adolescents and young adults in Champigny et al. (45) reported 'feeling left behind' (p. 1360), stating that they felt overwhelmed and slower than peers in their academic studies. Participants felt that cognitive deficits after stroke and missing class while staying in hospital impacted their studies. In another study, Champigny et al. (68) completed academic testing and noted that students aged 8–18 years (*n* = 29) with childhood stroke scored lower than their peers in mathematics and reading, and significantly lower in sentence comprehension and spelling. De Montferrand et al. (41) reported that 66 of 184 participants in their study presented with academic delays several months or years post-stroke. These students required educational adaptations or modifications, as did 50% of the students aged 6–17 years (*n* = 30) who had experienced childhood stroke in Hawks et al. (48). Both Champigny et al. (68) and Hawks et al. (48) also identified that difficulties with language domains, such as receptive and expressive language, reading, and spelling, were linked to the need for educational modifications at school. Only 27% of students (*n* = 29) in Champigny et al. (68) were enrolled in mainstream schooling without requiring any adaptations. The remaining students (73%) attended mainstream schooling too but required support such as Individualized Education Plans, extra help, or access to a teacher aide. Despite these supports, the study showed that students who had experienced stroke shared similar levels of satisfaction to their peers toward the school environment, peer

Table 3. Measurement instruments used in included studies (*n* = 79).

Measurement instruments (MIs)	Number of studies that used the MI n (%)	Age range of participants MI was used with
Activity and participation		
Vineland Adaptive Behavior Scales- 1st and 2nd editions (55,89)[1,3]	11 (14)	0 to 15 years (44) 0 to 16 years (67) 0 to 18 years (91,92) 2 to 18 years (76) 3 to 15 years (20,65,88) 4 to 20 years (63) 9 to 36 years (49) 13 to 18 years (52)
Strengths and Difficulties Questionnaire (93)	6 (8)	1 to 17 years (67) 3 to 15 years (65,88) 6 to 18 years (47,94) 10 to 16 years (95)
Child and Adolescent Scale of Participation (96)	4 (5)	5 to 15 years (97) 5 to 22 years (98) 6 to 15 years (34) 6 to 22 years (62)
Participation and Environment Measure for Children and Youth (99)	4 (5)	3 to 15 years (20,88) 4 to 20 years (63) 5 years and older (64)
Child Behavior Checklist (90)[1]	3 (4)	6 to 15 years (33) 11 to 21 years (100) 17 years (51)
Social Skills Improvement System Rating Scales- Problem Behaviors and Social Skills subscales (101)	3 (4)	0 to 18 years (92) 3 to 15 years (20,65)
Behavior Assessment System for Children (102)	3 (4)	0 to 18 years (103) 11.9 years (mean), 3.32 years (standard deviation) (104)
ABILHAND-Kids (105)	2 (3)	13 to 18 years (52) 5 years and older (64)
Friendship Quality Questionnaire (106)	2 (3)	6 to 23 years (39)
Relational Provisions Loneliness Questionnaire (107)	2 (3)	6 to 15 years (33,34)
Activity Index (108)[3]	1 (1)	16 to 70 years (58)
Apathy Evaluation Scale (109)	1 (1)	17 to 95 years (110)
European Brain Injury Questionnaire (111)[3]	1 (1)	17 to 80 years (37)
Harter Self-Perception Profile for Children: Social Competence subscale (112)	1 (1)	6 to 15 years (33)
Network of Relationships Inventory (113)	1 (1)	6 to 15 years (33)
Nottingham Extended Activities of Daily Living (114)[3]	1 (1)	16 to 70 years (58)
Social Support Questionnaire (115)[3]	1 (1)	16 to 70 years (58)
Walker-McConnell Scale of Social Competence and School Adjustment: Adolescent version (116)	1 (1)	10 to 16 years (95)
Quality of life		
Pediatric Quality of Life Inventory (82)	15 (19)	1 to 19 years (70) 2 to 15 years (43) 2 to 17 years (73) 2 to 18 years (42,72,117,118) 3 to 15 years (20,88) 4 to 20 years (63) 5 to 22 years (77) 6 to 18 years (47) 6 to 21 years (119) 6 to 22 years (57) 7 to 25 years (84)
Child Health Questionnaire (120)	5 (6)	0 to 19 years (79) 1 to 34 years (121) 2 to 20 years (40) 5 to 15 years (60) 5 to 26 years (61)
KIDSCREEN-27/52 (69)	4 (5)	0 to 15 years (83) 6 to 21 years (35) 8 to 17 years (68) 11 to 21 years (100)
12-/36- Item Short Form Health Survey (122)	3 (4)	0 to >64 years (123) 1 to 34 years (121) 17 to 96 years (124)
KINDL-R (125)	2 (3)	4 to 21 years (75) 8 to 38 years (50)
Aachener Life Quality Inventory (126)[3]	1 (1)	17 to 76 years (80)
Assessment of Quality of Life Instrument (127)[3]	1 (1)	2 to 97 years (36)
Centre for Health Promotion's Quality of Life Profile (128)	1 (1)	2 to 18 years (76)
Life Satisfaction Questionnaire 9 (129)[3]	1 (1)	17 to 70 years (86)
Marburger Inventory (ILK-MARSYS) (130)	1 (1)	11 to 21 years (100)

(*Continued*)

Table 3. (Continued).

Measurement instruments (MIs)	Number of studies that used the MI n (%)	Age range of participants MI was used with
Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL)- Children, Adult, and Parent Forms (56,131)[1,2]	1 (1)	1 to 18 years (46)
Pediatric Stroke Quality of Life Measure (118)	1 (1)	2 to 18 years (118)
Satisfaction with Life Scale (132)[3]	1 (1)	9 to 36 years (49)
Sickness Impact Profile (133)[3]	1 (1)	16 to 45 years (134)
Stroke-Adapted Sickness Impact Profile (135)	1 (1)	14 to 60 years (87)

1. Measurement instruments (MIs) were used in studies that reported impacts of childhood stroke specific to adolescents.
2. The TNO-AZL Adult Form was used with adolescents aged 16 to 18 years in Cnossen et al. (46).
3. These MIs were used to collect information from participants who had communication difficulties.

support, and social acceptance, as identified through self-report on the KIDSCREEN-52 (69). The researchers discussed that this satisfaction may be attributed to resilience or a positive outlook on life (68). On the other hand, Gordon et al. (59) described the education needs of children and adolescents post-stroke as being unmet, with more than 30% of 44 participants reporting inadequate support with completing school activities and learning.

Due to their impairments post-stroke, it was also noted that not all children and adolescents who had experienced childhood stroke were able to attend mainstream schools. For example, five of 21 (24%) students (age range 6–21 years) in the study by Everts et al. (35) attended ‘special schools’ for children with language or physical disabilities. Seven of 35 (20%) students aged 4–19 years in Bulder et al. (70) also attended special schooling due to learning disabilities, while 40% of students aged 15 years and younger ($n = 128$) in Yvon et al. (71), received special education.

Quality of life. A total of 38 (52%) studies reported on quality of life (QoL) post-childhood stroke. Thirty-seven studies ($n = 37$, 97%) utilized child and adolescent self-report and/or parent report to obtain their findings on QoL, while the remaining study (3%) (47) collated reports from teachers in addition to children/adolescents and their parents. Contrasting findings on the impact of stroke on QoL were identified, with studies reporting either reduced QoL (e.g (36,40,46,47,72–75)., or QoL on par with normative data (e.g (49,57,76–81). Contrasting views on QoL impacts were also identified between children and adolescents and their parents. Using the Pediatric Quality of Life Inventory (PedsQL) (82), 22 children, adolescents, and young adults aged 6 to 22 with stroke and other brain injuries rated their QoL to be similar to healthy reference populations, while their parents reported reduced QoL due to poor psychosocial health (57). Ten studies (26%) also investigated factors associated with QoL in adolescents, children, and adults post-stroke (aged 3–97 years) (36,50,74,75,83–88). Reduced QoL was associated with higher levels of cognitive and neurological impairments (74,75,83), fatigue (88), epilepsy (50), and hemorrhage size in hemorrhagic stroke (84). On the other hand, factors such as long-term regular exercise (85), active problem solving-focused coping styles (86), and adequate physical function and independence with ADLs (36,87) contributed to increased QoL.

Table 4. Respondent(s) for studies that used one or more measurement instruments ($n = 88$).

Respondent/s	Number (n)	Percentage (%)
Parent only	37	42
Participant with stroke and parent	28	32
Participant with stroke only	17	19
Participant with stroke, parent, and teacher	3	3
Teacher only	2	2
Parent and teacher	1	1

Measurement instruments

Thirty-three MIs assessing stroke impacts were used across the 79 studies a total of 88 times (see Table 3). The MIs were most frequently used to obtain report only from parent/s ($n = 37$, 42%) (see Table 4). The most frequently used MI was the PedsQL (82) ($n = 15$, 19%), followed by the Vineland Adaptive Behavior Scales- 1st or 2nd edition (55,89) ($n = 11$, 14%). Self-developed MIs were also used to investigate activity limitation (60), self-reported needs (59), and QoL (81). McKevitt et al. (54) and Williams et al. (66) used qualitative methods, including interviews and focus groups, to explore the experiences of parents of children and adolescents with childhood stroke. Champigny et al. (45) also used semi-structured interviews to identify adolescent experiences of adjusting to life after stroke.

Three different MIs, completed either by adolescents and/or their parents, were identified in three studies that reported separated data for adolescents aged 13–18 years with childhood stroke. These MIs included the TAAQOL (56), Vineland Adaptive Behavior Scales (VABS)- 1st edition (55), and Child Behavior Checklist (CBCL) (90), which were used in Cnossen et al. (46), O’Toole et al. (52), and Godfrey et al. (51) respectively. All three studies obtained data using parent report, while adolescents in Cnossen et al. (46) and Godfrey et al. (51) also completed the TAAQOL (56) and CBCL (90).

Discussion

While literature on childhood stroke has been described within prior reviews (17,18), to the authors’ knowledge, a review of the literature focusing on non-impairment impacts of stroke in an adolescent population has not been completed to date. Given the unique changes adolescents experience during this developmental period, this review identified impacts specific to adolescents following stroke and the MIs used to determine them.

Amongst the 27 studies that provided definitions for childhood stroke, most studies ($n = 21$, 78%) used this term to describe stroke occurring between 28 days after birth and before 18 years of age. The use of this terminology was in line with recent stroke management guidelines (1,136,137), demonstrating emerging consistency in the labeling of childhood stroke between research and clinical documents. However, use of other terminology, such as 'pediatric' and 'non-/beyond' stroke, instead of childhood stroke remained apparent in this review. According to medical guidelines, 'pediatric stroke' is defined as encompassing both neonatal and childhood stroke (1). Moreover, it was also noted that more than half of the studies ($n = 52$, 66%) included in the present review did not specify a definition or age range for what was considered as 'childhood stroke' in their research. Thus, further consistency with the use of 'childhood stroke' in research is required to ensure that findings can be clearly differentiated between the various types of pediatric stroke (e.g., childhood stroke vs. neonatal stroke). Consistency in terminology and definitions will also assist in ensuring that research findings relevant to childhood stroke can be clearly interpreted by clinicians and translated into clinical practice.

Non-impairment impacts of childhood stroke for adolescents

Activity, social, and academic impacts were identified across studies that reported adolescent-specific findings and those that recruited adolescents alongside younger children and/or adults. Firstly, activity limitations were reported in two adolescent-specific studies and six studies that included adolescents with other age groups. An association between motor impairments and decreased ability to complete daily activities was reported across both groups of studies, demonstrating that adolescents with post-stroke motor difficulties were likely to experience activity limitations. Additionally, while Champigny et al. (45) interviewed both adolescents and young adults, their study revealed that adolescents were susceptible to experiencing sorrow and negative emotions after stroke due to their activity limitations. These emotions especially occurred when adolescents had to cease partaking in hobbies they previously enjoyed or revise their future plans, such as learning to drive.

Another 20 studies reported social impacts, with only one of these studies investigating solely adolescents. Through patient- or parent-report, the 19 studies that included adolescents with children identified that both age groups had difficulties with social adjustment, social participation, and prosocial behaviors, which affected their ability to form friendships. Parents in the adolescent-only study (52) also noted concerns for their child's socialization, reporting that they seemed to be more withdrawn and sought out fewer peer encounters after stroke. This report contrasted with the adolescents' reports, who stated that they were satisfied with their social endeavors and felt connected. The authors discussed that this discrepancy between adolescent- and parent-report was potentially due to reduced insight from the adolescents, particularly toward the more subtle aspects of their functioning.

For academic impacts, three studies focused specifically on adolescents while ten combined findings from adolescents and children. The latter studies demonstrated that patients with childhood stroke experienced impacts such as reduced academic performance, the need for academic modifications, or special school attendance. Despite these impacts, Champigny et al. (68) reported that their participants aged 8 to 18 years were satisfied with their school environment. The adolescents in O'Toole et al. (52) similarly felt they were able to cope with the impacts of their stroke at school. Champigny et al. (68) hypothesized that children and adolescents with stroke were possibly more resilient and had a more positive outlook on life, which aided their ability to cope at school. Alternatively, the presence of communication difficulties may impact adolescents' ability to return to school or achieve academic success in mainstream environments. The adolescent in Dow-Richards (38) experienced difficulties with understanding and keeping up in mainstream classes due to his language impairments, which led to him transferring to a special, language-based school. Similarly, Greenham et al. (34) and Lambregts et al. (62) linked communication difficulties with school participation restrictions, which was apparent in both primary and secondary students. However, findings relevant to communication difficulties identified in this review were notably brief. With literature demonstrating the increasing importance of peer friendships (14) and educational demands during adolescence (15), it is vital that more in-depth research be conducted to identify supports for adolescents who experience communication difficulties after stroke.

Lastly, QoL was the most researched domain within this review, with 39 articles reporting related data. One of these studies (46) recorded adolescent-specific findings, noting that QoL was reduced for adolescents post-stroke. Inconsistent findings were reported within the other 38 studies that included adolescents, children and/or adults. Some studies reported reduced QoL, while others identified results on par with population norms. As the participants in these studies spanned a wide age range (i.e., ranging from young children to older adults), it is likely that the there are other factors and circumstances unique to certain age groups that may influence the QoL of stroke patients but not their counterparts of other ages. However, there were some consistent findings noted between Cnossen et al. (46), which reported adolescent-specific findings, and other studies that focused on QoL in adolescents and other age groups (74,75,83). All four of these studies determined an association between cognitive impairments and decreased QoL, showing the vulnerability adolescents with cognitive deficits may have in achieving positive QoL and general wellbeing (33-35, 38-45, 51-53).

Measurement instruments

Most studies used standardized questionnaires or rating scales to collect data from children or adolescents with childhood stroke and their significant others, such as their parents/caregivers and teachers. This reflected the prominence of quantitative studies included in this review. However, it was noted that all of the MIs identified were used with other age groups (i.e., younger children and/or adults) in addition to adolescents. Greenham et al. (17) similarly noted that many standardized measures used in childhood stroke research were validated for children with other medical conditions, such as cerebral palsy and head trauma. These measures were often not sensitive or specific enough to identify focal and mild deficits of childhood stroke. Hence, further development of standardized MIs validated for use with adolescents with childhood stroke, particularly in the areas of activity limitations and participation restrictions, is required. Additionally, supports for adolescents with communication difficulties should be considered when developing MIs, given the impact of communication on daily activities and education.

Limitations

Limitations of the literature base

Several knowledge gaps were noted within the current literature base. One of these gaps included limited insight into the specific impacts adolescents with childhood stroke experienced. All four studies that recruited solely adolescents included very small numbers of participants, with three studies being single participant case-studies and the remaining study including five participants. The limited number of participants meant that the conclusions that could be drawn from these studies were limited. The findings across these studies were also unable to be synthesized, as different MIs were used. Additionally, most of the studies included in this review also incorporated findings that were relevant to other populations, such as younger children, adults, and participants with neonatal stroke and brain injuries of other etiologies. Thus, with heterogeneity within the study participants, findings could not be fully attributed to adolescents with childhood stroke. Moreover, this review also revealed that in-depth descriptions of the impacts of childhood stroke for adolescents are lacking. While one study (45) interviewed young people on their experiences with stroke during adolescence, the majority of studies in this review relied on standardized questionnaires or rating scales to collect information from adolescents, which did not allow for in-depth insight and analysis into their experiences. Lastly, it should be acknowledged that the studies included in this review spanned several decades, with a few studies published prior to 2000 (see Table 2). With societal norms and stroke care having changed over the years (138), it is likely that the impacts experienced by adolescents today may be different from those experienced by adolescents in previous decades (45).

Limitations of the review

Limitations related to the design of this review should also be acknowledged. It is important to acknowledge that studies with participants outside of the specified age range and participants with other brain injuries were included. Given the limited amount of research that has been completed in adolescent stroke, this inclusion was chosen to avoid the potential omission of articles that contained important findings. Other scoping reviews focused on the adolescent population have also encountered similar issues. Clarke et al. (139) in their review related to interpersonal trust in adolescents with mental illness stated that studies with young children or adult participants were included in their review to avoid 'important insights' (p.192) relevant to adolescents, while the review on volunteerism in adolescents by Hernantes et al. (140) adopted a wide age range for adolescence in their study inclusion criteria, as there was a lack of consensus in the literature for an accepted age range. A lack of consensus on terminology for the adolescent period was also noted in literature pertaining to this developmental period, with terminology such as 'young people' and 'youth' used in other studies (141,142). To emphasize the respective experiences and outcomes of different age groups, future research should consider separating their participants into groups according to age (e.g., children vs. adolescents) and injury type (e.g., stroke vs. traumatic brain injury) and reporting specific findings and observations for each group in addition to overall findings of combined data. Further, it should be acknowledged that the experiences of adolescents living with or without another health condition (e.g., Moyamoya disease, cancer) alongside their stroke were not compared in this review. The differences in impacts of childhood stroke in the absence or presence of other chronic health conditions may be important to identify in future research. A final limitation of this review was that a quality appraisal of the included studies was not undertaken as it was deemed outside the purview of a scoping review. Prior to conducting a systematic review with an evaluation of study quality, the current findings have identified the need to extend the body of literature specific to adolescents following stroke. There is a need for larger scale research studies, specifically with adolescent participants, which extend beyond a single-case design and identify participant comorbidities. In addition, reduced heterogeneity in the outcome measures used, definitions of childhood stroke, and years defining adolescence would more easily allow for synthesis and comparisons across studies.

Clinical implications

Clinical implications can be drawn from the impacts of childhood stroke identified in this review. Firstly, the findings highlight that adolescents can potentially experience impacts in a variety of areas, including activity limitations, social and academic impacts, and reduced quality of life. Health professionals should consider these areas when working with adolescents with childhood stroke, such as when collecting information about impacts and administering therapy. However, contrasting findings found in the literature, such as in academic impacts, demonstrates that management for this population should be individualized and tailored to the needs of each adolescent. Additionally, contrasting views between stakeholders emphasize that health professionals should consult with adolescents, parents, and teachers when collecting information and collaborate with all parties for therapy goal setting. Sanders (14) advises that clinicians should spend time with adolescents and their parents both together and separately to help adolescents achieve confidence in voicing their concerns and making decisions about health-related issues independently.

Conclusion

After experiencing childhood stroke, it is essential to recognize that the needs of adolescents differ from younger children. Thus, this review aimed to identify non-impairment impacts of childhood stroke for adolescents. Findings from included studies revealed that adolescents experienced activity limitations, social and academic impacts, and decreased levels of QoL. Most studies used quantitative methods and caregiver report to identify non-impairment stroke impacts for adolescents. Hence, more research that captures in-depth, lived experiences from adolescents with childhood stroke is needed. Research into the impacts of post-stroke communication difficulties experienced by adolescents is also required. This review further highlighted the need for MIs specific to the adolescent phase of development, to capture activity, participation, and QoL impacts after stroke.

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