



Review article

Young adults' experience of ischemic stroke – a qualitative research synthesis

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Abstract

Aim: To report a synthesis of evidence presented in qualitative studies related to the experience of living with ischemic stroke in young patients.

Design: A research synthesis of qualitative studies. The ENTREQ statement was followed to enhance transparency in reporting the synthesis of qualitative research.

Methods: The electronic databases CINAHL Plus (EBSCO), MEDLINE (OvidSP), PsycInfo (EBSCO), ScienceDirect (Elsevier), SocINDEX (EBSCO), Web of Science Core Collection and ProQuest Science Database were used to gather data for a review of qualitative studies, yielding 5,785 sources. The methodological quality of studies was reviewed using the Critical Appraisal Skills Programme Qualitative Research Checklist. In total, seven sources were included in this literature review, focused on young adults' experience of ischemic stroke.

Results: Stroke at a young age can cause a disruption of three domains: disruption of self and self-identity, social disruption, and disruption of close personal relationships. On the other hand, three analytical themes related to coping strategies or personal challenges have been found: re-establishing a new self, re-establishing a social role, and relationship help.

Conclusion: The findings of our review can provide a deeper insight into understanding the experience of a stroke at a younger age and their age-appropriate needs in the long-term rehabilitation process.

Keywords: Ischemic stroke; Patient experience; Qualitative research; Thematic synthesis; Young adult

Introduction

Ischemic stroke (IS) in young adults affects their sense of self or self-identity, and social roles (Guo et al., 2021; Salter et al., 2008; Satink et al., 2013). Qualitative studies of stroke survivors focus on analysing their needs and those of their families, exploring differences in priorities between patients and health care professionals, and understanding barriers to the delivery of quality long-term post-stroke care. Although the impact and experience of patients after IS appears to be substantially researched, it may be somewhat different for younger patients, in whom the incidence of IS has been increasing in recent years (Ekker et al., 2018). Recent reports on the global burden further document that in younger adults under 50 years of age in the United States, IS accounts for approximately 79,500 cases per year, representing approximately 10% of all IS cases (Benjamin et al., 2017). The incidence in Europe ranges between 3.4–21.7/100,000, with, for example, the gender-specific incidence being more typical for females up to 35 years of age, and for males over 35 years of age (Putaal, 2016).

Several authors have argued that the experiences of young stroke survivors have been neglected in research studies (Holloway et al., 2022). A systematic review of qualitative studies by McKeivitt et al. (2004) has already addressed a wide range of issues related to the impact of stroke on survivors' life trajectories. Moreover, a considerable number of recently published systematic reviews of qualitative studies have focused on specific issues after stroke, such as parenting (Harris and Prvu Bettger, 2018), psychosocial needs (Morris, 2011), returning to work (Daniel et al., 2009), unmet needs (Guo et al., 2021), and rehabilitation needs and experiences (Holloway et al., 2022). However, only a limited number of these reviews specifically addressed young adults after stroke. Despite the discrepancy in terms of the definition of a uniform age limit for young adults – the WHO define the upper age limit as 65 years (Feigin et al., 2017), an upper age limit of 55 years has been more frequently used in recent years (Shipley et al., 2020; Yahya et al., 2020). The only one available review (Lawrence, 2010) described the experiences of young adults. However, it did not explain young adults' internal challenges and personal coping strategies at a deep level. It may be useful to not

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<http://doi.org/10.32725/kont.2023.029>

Submitted: 2023-03-28 • Accepted: 2023-07-28 • Prepublished online: 2023-08-10

KONTAKT 25/3: 225–234 • EISSN 1804-7122 • ISSN 1212-4117

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only explore young people's experiences regarding disruption of life trajectory, but also their strategies for how they cope with the stroke. This can provide a deeper understanding of how self-management can be effectively supported for these patients.

Aim

The aim of the review was to report a synthesis of evidence presented in qualitative studies related to the experience of living with stroke in young patients.

The primary research question, according to PICO (Population, Interest, and Context) format, was as follows: *What are the experiences of adults after stroke at a young age?*

Materials and methods

Design

Thomas and Harden's thematic analysis approach was used for the synthesis of qualitative studies (Thomas and Harden, 2008). The ENTREQ statement (Tong et al., 2012) was followed to enhance transparency in reporting the synthesis of qualitative research.

Data sources and search strategy

At the initial phase of the review, a preliminary search in the MEDLINE (Ovid) and the EBM Reviews – Cochrane Database of Systematic Reviews was carried out by the first author (EG) to find all reviews on this topic, as well as to identify the keywords or thesauri and controlled vocabulary (MeSH) that would be most pertinent to the review question. In addition, four peer-reviewed journals (Disability and Rehabilitation; Journal of Health Psychology; International Journal of Qualitative Studies on Health and Well-Being; Topics in Stroke Rehabilitation) likely to publish qualitative studies of stroke were searched to ensure no articles had been missed during the database searches. Grey literature (e.g., dissertations) was included. Qualitative studies (not limited to designs) published in the English language were considered. In the second step, the following search terms and their combinations were identified to cover the experience of living with stroke according to previously published reviews (McKevitt et al., 2004; Morris, 2011; Salter et al., 2008). The "PICO" mnemonic (Participants, Phenomena of Interest, and Context) was used to identify meaningful inclusion criteria and keywords for this review (Table 1).

Table 1. The "PICO" mnemonic, search terms, and inclusion criteria

	Participants	Phenomena of interest	Context
Inclusion criteria	Does the study involve a population of individuals with ischemic stroke? Studies involving participants with a clinical diagnosis of ischemic stroke (IS) were considered, and participants with a clinical diagnosis of transient ischemic attack (TIA) or exclusively focused on other stroke types than IS were excluded.	Is the study primarily qualitative in nature? Does the study explore the lived experience of ischemic stroke? The phenomenon of interest was the everyday life experience of young adults living long-term health post-stroke consequences.	Does the study involve ischemic stroke survivors (ISs) who had a stroke between the ages of 18–55 years? The definition associated with 'young adults' in studies about strokes can range from 18 to 55 years (Yahya et al., 2020; Shipley et al., 2020). Therefore, only studies with participants who had a stroke between the ages of 18–55 years were included in this review. However, the range between 18–45 years has been the most consistent definition of a young stroke. We used a cut-off of 55 years for the upper age limit to involve a wider range of evidence.
Keywords	('stroke' OR 'cerebrovascular stroke' OR 'cerebrovascular accident' OR 'ischemic stroke' OR 'ischaemic stroke')	('patient experience' OR 'lived experience' OR 'perception' OR 'understanding' OR 'perspective' OR 'opinion' OR 'views' OR 'feelings' OR 'qualitative')	('young' OR 'adult, young' OR 'young adult' OR 'middle-aged adults' OR 'working age' OR 'stroke patient' OR 'post-stroke' OR 'stroke survivor')

The electronic databases CINAHL Plus with Full Text (EBSCO), MEDLINE (OvidSP), PsycInfo (EBSCO), ScienceDirect (Elsevier), SocINDEX (EBSCO), Web of Science Core Collection (Clarivate Analytics), ProQuest Science Database (ProQuest), Open Dissertations (EBSCOhost), and ClinicalTrials.gov were used to gather data for a review of qualitative studies. Selection terms were modified for use in each database. A comprehensive bibliographic search of the literature was conducted from April to May 2022 and was guided by the PRISMA statement (Page et al., 2021). The search was supported by hand-searching reference lists of retrieved articles and searching Google Scholar. The relevant studies were identified based on a search of publications between 2000 and May 2022. For the selection, the article inclusion/exclusion criteria were

specified, relevant search terms were determined, and the search strategies and databases were selected. The search is provided in [Appendix](#).

Screening of studies

The bibliographic search was limited to publications in English and reported original qualitative research (involving both qualitative methods of data collection and analysis) relating to the lived experience of stroke or the impact of stroke at a young age. The search included all papers that met predefined criteria: (a) empirical qualitative studies (not limited to designs); (b) focusing on the lived experience of IS in young age, the age range from 18 to 55 years was applied for "young stroke" in this study; (c) focusing on patient 'experiences or their percep-

tions of post-stroke consequences (Table 1). Mixed-method studies, reviews of qualitative studies, editorials, case studies, discussion papers, expert opinions, and studies focusing on perspectives from people other than patients were excluded. Studies in which researchers focused solely on participants with aphasia were not included. In addition, studies focusing exclusively on the experiences of young adults after hemorrhagic stroke were excluded. However, relevant heterogeneous studies comprising a sample of individuals with IS as well as other stroke types were considered if a substantial part of the sample consisted of young adults with IS. As most strokes in younger adults are ischemic, we decided to include those studies that did not specify the type of stroke.

Retrieval of studies, methodological quality assessment

The data were systematically retrieved by five independent researchers (D.B., E.G., L.Š., P.M., Š.Š.), as presented in the PRISMA flow diagram (Diagram 1; Page et al., 2021). The EndNote program was used in the retrieval of studies and removal of duplicates. Four researchers (D.B., L.Š., P.M., Š.Š.) screened studies using titles, and selected studies were analysed using abstracts based on the pre-specified inclusion/exclusion criteria. Eligibility and data extraction were conducted by two independent groups of researchers (D.B., Š.Š. and L.Š., P.M), and the full texts of selected sources were analysed for final inclusion in the review. The methodological quality of each included study was independently reviewed using the Critical

Appraisal Skills Programme Qualitative Research Checklist (CASP, 2018). A fifth independent researcher (E.G.) evaluated those studies where an agreement could not be reached about their inclusion. Any disagreements were resolved based on the consensus of all reviewers.

Data extraction, analysis, and synthesis of findings

Thematic synthesis (Thomas and Harden, 2008) was adopted in this review and included three stages: the coding of findings (free line-by-line coding), the development of descriptive themes, and the generation of analytical themes. In the first step, the data from primary studies (quotations from participants) were extracted. Every step of data extraction and synthesis was completed by two independent reviewers (E.G., Š.Š.). Descriptive features were created for each theme. The whole process was carried out with the aim of the study and the research question in mind.

Results

Study selection

The search produced 5,531 papers. A subsequent manual search of reference lists of included articles provided 254 additional studies relating to the phenomena of interest, increasing the total number of included papers to 5,785. In total, the search produced 5,785 sources, 4,881 studies were screened using titles, and the abstracts were based on the pre-specified

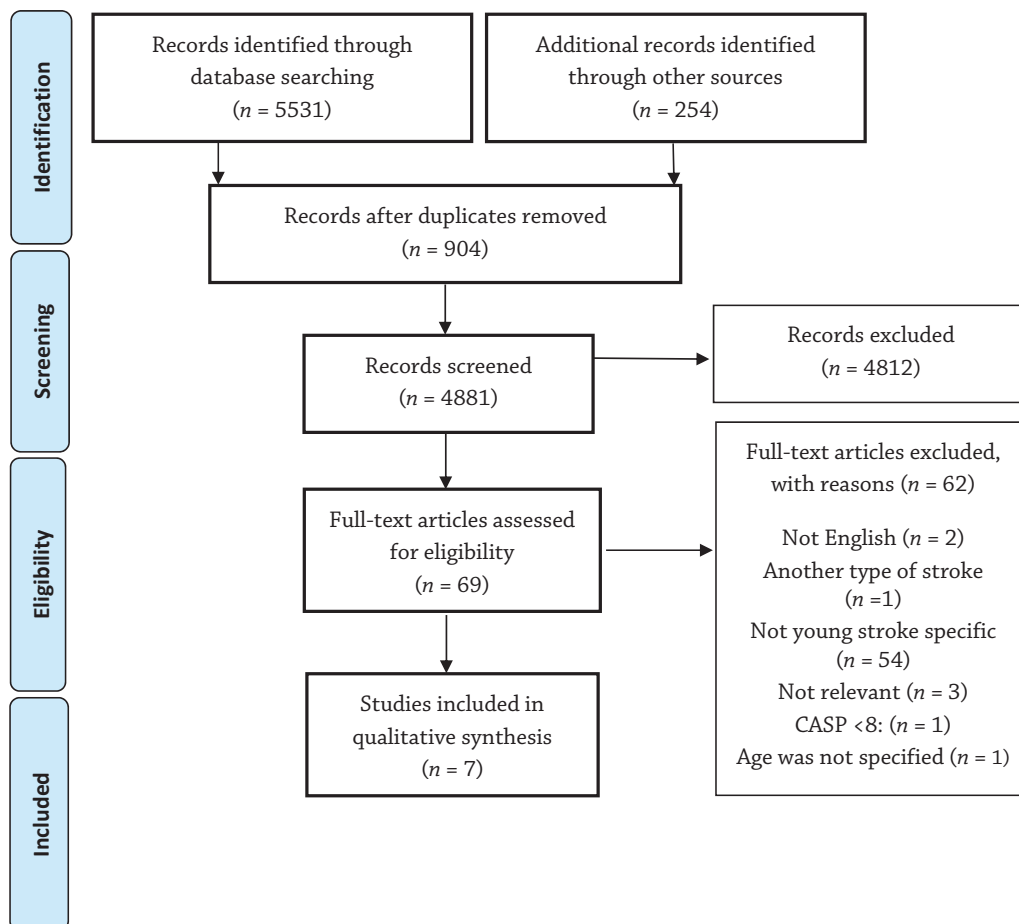


Diagram 1. Flow diagram of the study selection process

inclusion/exclusion criteria. The full texts of 69 sources were studied, and seven studies were finally included in the review. Overall, seven papers met the inclusion criteria and were suitable for evaluation by the quality appraisal tool; 62 papers were excluded. In total, seven studies met the reviewers' inclusion criteria of appraisal scores of eight from ten possible 'yes' answers on the CASP *Qualitative checklist questions*.

Descriptive characteristics of included studies

In total, seven papers were included in this literature review, focused on young adults' experience of stroke. As shown in Table 2, the oldest research study was from 2003. In the period from 2012 to 2017, there were five articles. The latest included research study is from 2020. Two studies included patients with IS and haemorrhagic stroke, and five studies did not specify the type of stroke. Research studies come from different

countries. Most commonly they were from Ireland ($n = 2$) and Australia ($n = 2$). There was one citation from Germany, The United Kingdom, and Ghana. Three studies used a phenomenological approach as their design. Gadamer's philosophical hermeneutics, directed content analysis, a qualitative exploratory design, and a critical interpretive paradigm of social research were applied in one case. The number of participants in the studies ranged from 5 to 17. Participants' ages varied from 18 to 55 years. Time post onset of stroke begins at three months and ended at 31 years. For data collection, semi-structured interviews were most frequent ($n = 5$), followed by in-depth, semi-structured interviews ($n = 2$). The data were analysed by interpretative phenomenological analysis ($n = 3$), content analysis ($n = 2$), hermeneutics ($n = 1$), and thematic analysis ($n = 1$).

Table 2. Study characteristics

Authors, year, country	Aim	Design	Sample	Age range	Time post onset	Data collection	Data analysis	Credibility	CASP
Hanney (2012) Ireland	To explore the experience and psychosocial consequences of stroke among young adults and the impact it has on spouses of stroke survivors	A phenomenological approach	Younger adults with stroke 9 females 4 males	30–49	Average time since stroke was 17 months	Semi-structured interviews	An interpretative phenomenological analysis (IPA)	Not reported	9
Hutton and Ownsworth (2019) Australia	To explore the experience of a sense of self and continuity in younger adults after stroke	A phenomenological approach	Younger adults with stroke 7 females 3 males	18–55	From 6 months to 31 years after the stroke	In-depth, semi-structured interviews	An interpretative phenomenological analysis (IPA)	Reflexivity, participant verification, and an audit of themes and the methods used to explicate them	10
Immenschuh (2003) Germany	To capture the experience of having had a stroke in people under fifty-five during the first year after their stroke	Hermeneutics (Gadamer's philosophical hermeneutics)	Younger adults with stroke 5 females 6 males	18–51	3-, 6-, and 12-months post-stroke	In-depth, semi-structured interviews	Hermeneutics (Gadamer's philosophical hermeneutics)	Reflexivity	10
Kuluski et al. (2014) United Kingdom	To understand the experience of stroke as a disabling life situation among young people and the strategies they use to recover and cope	Directed content analysis	Younger adults with stroke 11 females 6 males	21–53	From 1 to 12 years post-stroke	The semi-structured interviews were drawn from a larger database of stroke survivor interviews	Directed content analysis	The trustworthiness of the data was achieved through prolonged engagement with the data, and through discussion and comparison of codes	9
Leahy et al. (2016) Ireland	To capture the lived experience of stroke from the perspectives of young stroke patients	A phenomenological approach	Young women 12 females	18–47	From 10 to 29 months	Semi-structured interviews	An interpretative phenomenological analysis (IPA)	Not reported	10

Table 2. (continued)

Authors, year, country	Aim	Design	Sample	Age range	Time post onset	Data collection	Data analysis	Credibility	CASP
Opoku et al. (2020) Ghana	To explore the psychosocial impact of stroke on young adults, and identify their coping strategies for surviving their stroke experience	A qualitative exploratory design	Young stroke survivors 2 females 8 males	18–45	Participants had lived with stroke for at least 1 year	Semi-structured interviews	Content analysis	By recruiting only participants who gave consent and those who met the inclusion criteria. Member check by the researcher from participants and throughout the coding and data analysis	10
Wolfenden and Grace (2015) Australia	To explore the experiences of young higher-functioning stroke survivors in re-establishing identity and returning to work	A critical interpretive paradigm of social research	Young higher-functioning stroke survivors 5 women	28–44	1–9 years	Semi-structured interviews	Thematic analysis	The academic supervisor, member checking, and supervisor review of coding and analysis	10

Synthesis of the identified themes

In total, six analytical themes and fifteen descriptive themes emerged from primary codes. Six main analytical themes ex-

pressing the experiences of adults living with stroke at a young age were generated from primary studies included in this literature review (Fig. 1).

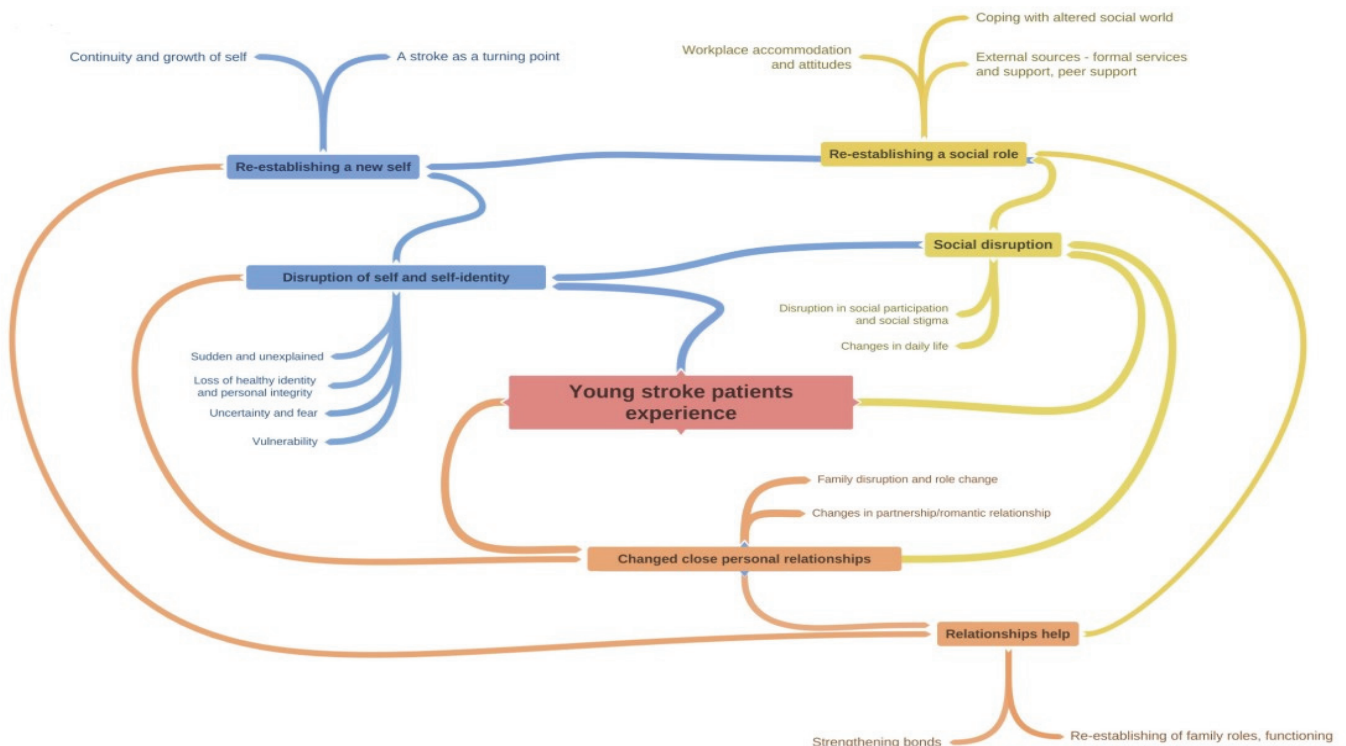


Fig. 1. Summary of analytical and descriptive themes

This figure describes the experience of young adult stroke patients. The inner circle describes the three analytical themes related to the biographical disruption (disruption of self and self-identity, disruption of social life, and disruption of close personal relationships). The outer circle highlights the three analytical themes related to the repair – coping strategies or personal challenges (re-establishing a new self, re-establishing a social role, and relationships help).

Disruption of self and self-identity

The theme 'Disruption of self and self-identity' was synthesized from the following descriptive themes: Sudden and unexplained loss of healthy identity and personal integrity; Uncertainty and fear; Vulnerability (Hanney, 2012; Hutton and Ownsworth, 2019; Immenschuh, 2003; Kuluski et al., 2014; Leahy et al., 2016; Wolfenden and Grace, 2015).

Sudden and unexplained

Having a stroke at a young age was a shock to many individuals, especially if they had previously considered themselves to be in relatively good health (Hanney, 2012; Kuluski et al., 2014) or if they led a life that could be described as normal for younger people in modern society (Immenschuh, 2003, 2004). Because of the stereotypical view of stroke as a condition of the elderly, it was difficult for them to accept the fact that they had experienced stroke: *"I would never have thought that I could get a stroke at my young age"* (Immenschuh, 2003, p. 107). Stroke was *"absolutely unexpected"* and *"came out of the blue"* (Immenschuh, 2003, p. 108). Because of the strong association between stroke and old age, young stroke survivors tended to minimize, or normalize their symptoms, or failed to fully recognize the severity of the symptoms (as a result of incomplete or inaccurate illness representations): *"... I kept thinking 'no, I'm not having a stroke, I'm not having a stroke'. I think when I saw the really old sick people next to me and what they'd been through, and I saw the people who went straight from there to rehab and stuff like that, I was like 'no, I'm different' in my head"* (Hanney, 2012, p. 37). In addition, initially, most of the participants need to explain the stroke and address the question of why they had it: *"... And that question still remains, and I think why on earth, why me of all people? There are some who smoke, who take the pill and have so many other things that are regarded to be risk factors, I don't have any and I get it"* (Immenschuh, 2003, p. 117). A young woman who had a stroke at the age of 34 in the study of Kuluski et al. (2014, p. 6) described the shock of having a stroke *"... A lot of the sort of, 'why me?' started to creep in, particularly because I was so fit, hadn't drunk, hadn't smoked, virtually lived at the gym, blood pressure was always bang on normal."*

Loss of healthy identity and personal integrity

Following the shock of diagnosis, many individuals had serious questions about their identities, particularly regarding the long-term physical and psychosocial consequences of the stroke. Moreover, the healthcare environment (surrounded by older people with the same disease) was considered an important factor in determining what the stroke meant for them (Hanney, 2012; Immenschuh, 2003). Stroke was found to impact the self in diverse ways, with individuals experiencing different levels of disruption of self or a loss of essential, self-defining qualities (Hutton and Ownsworth, 2019). Young stroke survivors often have difficulty continuing their lives in familiar ways and preserving their sense of self after stroke (Hutton and Ownsworth, 2019). Even though a significant proportion of participants did not have long-term stroke symptoms that would be visible to others, some of them described feeling a sudden loss of their former selves or *"bereavement"* (Kuluski et al., 2014, p. 6): *"... it really is like a bereavement, a stroke. I mean, it really was like that woman had died, the one that wore high-heel shoes, walked around and ran a business and had a fantastic memory."* The experience of discontinuity with one's pre-stroke self was described by some as being *"half a person"* (Immenschuh, 2003); or *"a baby with an adult mind"* (Kuluski et al., 2014, p. 6). A young woman described her *"new"* self in contrast to her

pre-stroke self. *"The new [Debora] can't walk without a walking stick, and even then it's very slow. ... The new [Debora] can't be active or get out and do things, she can't drive, so she just can't get up and go and do something. Can't pick up the kids from school... so she's pretty much housebound if there's nobody else around to help"* (Hutton and Ownsworth, 2019, p. 9).

Uncertainty and fear

After suffering a stroke (which was unlikely at their younger age), participants no longer felt in control of their health. They were more aware of the unpredictability of life and their vulnerability and mortality (Immenschuh, 2003). After the stroke, most young adults perceived an ongoing and pervasive uncertainty in the future and fear of stroke recurrence. In addition, the mere memory of a stroke could trigger a fear of recurrence (Immenschuh, 2003). This fear was manifested in a variety of ways, including limitations in daily activities, greater awareness of risk, heightened attention to bodily symptoms or increased symptom surveillance, and self-monitoring: *"I had this fear of I can't go out on my own with the baby, what if it happens again, what if somebody takes the baby, what if somebody thinks I am drunk and they don't help. You know, you hear of these stories"* (Hanney, 2012, p. 39).

Vulnerability

Young survivors of mild to moderate stroke are often discharged quickly, with a lack of recommendations for further recovery that consider their individual needs. A heightened awareness of vulnerability has been identified by stroke survivors in recovery, relating to work resumption, well-being, and administrative systems. Vulnerability after a stroke is often perceived in terms of loss of independence, loss of power, and loss of income (Wolfenden and Grace, 2015). *"It made me really vulnerable because... if my husband left me... I wasn't able to work at all and I wasn't able to care for my children at all. I was completely dependent on another person"* (Wolfenden and Grace, 2015, p. 4). The way healthcare workers communicate and the downplaying of the difficulties of young patients increase vulnerability even more. *"Work identity"* has a strong impact, which is closely related to the question of financial stability. Participants became vulnerable to financial hardship and economic insecurity following their stroke, and attempted to access income support, experiencing considerable anxiety in this process (Wolfenden and Grace, 2015). Some patients are disappointed by the impossibility to access income support despite real need, and highlight the unfairness of it: *"I couldn't get any allowance which was really annoying... All the time when people abuse the system – and they just get it [income support] – it was really annoying that I had to use all my savings. I couldn't get any money"* (Wolfenden and Grace, 2015, p. 10).

Re-establishing a new self

This analytical theme was synthesized from the following descriptive themes: continuity and growth of self, and a stroke as a turning point.

Continuity and growth of self

At different points of their illness trajectory, individuals try to return to their pre-stroke identity and thus restore normality. During the recovery process, several individuals tried to regain their self-coherence by engaging in activities that were important to them prior to the stroke, including re-establishing social roles (Kuluski et al., 2014). However, some aspects of themselves were perceived as unchanged since the IS (Hutton and Ownsworth, 2019). On the other hand, other individuals'

re-definition of their longstanding roles and reprioritization of personal values was a way to maintain their pre-stroke identity. They had integrated the stroke into their life narrative and had achieved a sense of acceptance: “... *I’m a project manager by trade, even though I’m not employed as one. I perceive my situation as a project manager of my own company plus foreman of this half a million-dollar building*” (Hutton and Ownsworth, 2019, p. 9). Some fluctuation between grieving for previous abilities and positive reflecting on new progress was perceived by young adults during the process of recovery: “... *You’re going to feel down in the dumps, you’re going to feel angry, you’re going to feel sad, you’re going to feel frustrated, you’re going to feel absolutely everything under the sun and it’s just, it’s just the process of accepting it and getting better, getting stronger*” (Kuluski et al., 2014, p. 8). Accepting dependency and adapting to the changes after stroke, being able to point to the benefits arising from stroke (such as greater appreciation of family and friends, and increased health awareness) has been described in terms of coping or restoring normality at different points of the illness trajectories (Hanney, 2012; Hutton and Ownsworth, 2019; Immenschuh, 2003; Kuluski et al., 2014).

A stroke as a turning point

The experience of having a stroke was described as “*a turning point*” (Immenschuh, 2003), where young adults reappraise the time before and the time ahead and attempt to implement new insights into their post-stroke lives: “... *You live more consciously. I don’t put myself under pressure any more like ‘you have to do this and that and that and that’, planning half a year ahead. I used to plan what will be in one or one and a half years or so. That’s all passe*” (Immenschuh, 2003, p. 130). In addition, the young adults appeared to have become grateful for “*a second chance*” (Kuluski et al., 2014), and for having survived without having to live with major impairments (Immenschuh, 2003).

Social disruption

Several descriptive themes specify the central theme: changes in daily life; disruption in social participation and social stigma.

Changes in daily life

Residual post-stroke symptoms and impairments at a young age such as physical disability, cognitive impairment, post-stroke fatigue, and depression have a pervasive impact on the daily functioning of young adults. Young stroke survivors perceive a complex set of problems or “invisible dysfunctions” that have contributed to their loss of ability to engage in activities of daily living and their previously held professional responsibilities and roles within the family (Hanney, 2012). This was particularly prominent for individuals who were used to taking on multiple tasks or activities in their social life (Kuluski et al., 2014). The most striking source of frustration was post-stroke fatigue and cognitive impairment (difficulties with memory, concentration, organizational skills, and decision-making). Post-stroke fatigue was described as a “*wave of tiredness*” and a “*train wreck*”: “... *I am wrecked, I am wrecked... it does my head in, it wrecks my head, you know? And that’s probably why I am turning aggressive... I have no interest anymore... I am too tired, my brain is tired*” (Hanney, 2012, p. 42).

Disruption in social participation and social stigma

The onset of stroke in young adults has a pervasive impact on the patterns of their social activities. The invisible effects, such

as fatigue or cognitive impairments, necessitate a change in the nature and extent of socializing (Hanney, 2012). Young stroke patients experienced a disruption of valued tangible activities (e.g., working life/work, driving, leisure time activities) and relational activities (e.g., socializing with friends) that are integral parts of the patient’s self. Therefore, disruption in social participation (including participation in economic life and family responsibilities) may in turn threaten some aspects of identity, such as their sense of belonging, working roles, and independence (Kuluski et al., 2014; Wolfenden and Grace, 2012): “... *It’s the fact that my sport was my life, it was my pleasure, it was my job, financially, everything*” (Kuluski et al., 2014, p. 6). Returning to work (RTW), albeit it temporary or permanent, full- or part-time employment, was a frequent category in all the included studies. The meaning attached to work was a significant element in the decision to return to work. The invisible effects such as fatigue or cognitive impairments were also reported as the main barriers to RTW. Some participants reported loss of enjoyment in socializing (Hanney, 2012) or feelings of vulnerability outside the home (Hanney, 2012). Others distanced from social relationships (Kuluski et al., 2014) because it was a reminder of their former selves (Kuluski et al., 2014). Stroke onset at a younger age is perceived as abnormal and therefore may be considered a stigma (Hanney, 2012; Immenschuh, 2003): “... *people treat me more cautiously, like ‘this woman is crazy somehow or she has a defect, you know, she’s had something with her head’*” (Immenschuh, 2003, p. 190). In addition, the lack of peer learning, support, and comparisons (Leahy et al., 2016), as well as the lack of follow-up services after hospital discharge resulted in patients’ feelings of isolation in dealing with sequels after stroke.

Re-establishing a social role

The studies reported factors that enabled a successful return to work, including employer flexibility, social benefits, and support from family or co-workers.

Workplace accommodation and attitudes

From many studies it emerged that workplace accommodation and attitudes, such as social support of work colleagues, impacted RTW post-stroke: “... *I mean, they were very good to me and I could, when I went back part-time, they let me pick and choose what hours I could manage*” (Kuluski et al., 2014, p. 7).

Coping with an altered social world

During the process of recovery, young stroke survivors identified personal strategies and internal challenges in how to cope with their altered social world. Social comparisons with people they perceived to be in worse situations than themselves were used to motivate themselves: “... *You hear terrible things happen to people all of the time, I know how lucky I am, I got over the feeling sorry for myself, I am just going out to enjoy my life now*” (Hanney, 2012, p. 51). Participants in selected studies were able to point to the benefits that arose from the stroke and reflected positively on their recovery.

External sources – formal services and support, peer support

From analysis of the studies, it emerged that peer support coupled with formal therapeutic and rehabilitation services after a stroke was seen as a facilitator in the re-establishing of social roles (Hanney, 2012). In addition, some participants saw reverting to old hobbies as an important factor (Kuluski et al., 2014).

Changed relationships

This overarching theme captured the significant changes in close personal relationships after stroke – changes in partner/romantic relationships, family disruption and role change.

Changes in partnership/romantic relationship

Dependence on the care of a close partner causes tension in the relationship. *"I don't want to show him that I am not a woman that he loves. I am not a woman because he helps me with everything"* (Hanney, 2012, p. 45). The limitations caused by the effects of stroke alter romantic notions of spending leisure time with a partner and often result in voluntary social isolation. Sometimes the reason is also the fear of confronting their "former self" (Kuluski et al., 2014).

There may be concern about losing the romantic image of a partner if they disclose that they had a stroke at a young age (Kuluski et al., 2014).

Role changes

Many stroke survivors noted changes in family roles. Participants were frustrated at no longer being able to fulfil certain roles. Excessive protection and monitoring of family behaviour is also a problem. This serves to keep the stroke at the fore and may serve as a barrier in moving forward and adjusting to life after the stroke. A woman who had a stroke 18 months after her baby was born *"remembered very little of her [daughter]"* as a small child (Kuluski et al., 2014, p. 5). For other respondents with small children, it was frustrating that they could not enjoy parenting – not being able to read with their children, hug them or pick them up from school etc. In some cases, individuals were encouraged to postpone having children after a stroke. Sometimes there can also be an undesirable exchange of roles in intergenerational care; old parents take care of their adult child after a stroke and sometimes their children as well (Kuluski et al., 2014).

Relationships help

Some of the participants reported the strengthening of relationship bonds after stroke, citing increased appreciation and valued emotional and practical support as reasons (Hanney, 2012).

Strengthening bonds

Shared aspects of recovery and adjustment to life after stroke strengthened bonds and brought couples closer together (Hanney, 2012). Many of the participants described how their partners were shocked and scared in the early stages of the stroke and diagnosis, highlighting the traumatic nature of the stroke for the couple. Sometimes, the partner's fear strengthened the closeness of the relationship. Good communication was highlighted as a key tool for maintaining relationships during the recovery and rehabilitation phases: *"He was there, and I got out of bed, and he hadn't seen my leg gone. And when he saw me limping like that, he went 'Oh God. You better not let anything else happen to you, leaving me with them two lads' and he started crying and he got really upset. And now he just minds me, do you know what I mean, we are closer"* (Hanney, 2012, p. 52). Participants described fairly simple exchanges and interactions as beneficial to their relationships, such as telling their significant other that they are tired or explaining why they don't want to hang out (Hanney, 2012).

Re-establishing family roles

For some, a stroke can confirm their previous roles: the determination to raise their children and therefore take more care

of their health and lifestyle. Increased self-control of behaviour is the result of the belief that without it the family would fall apart. It is for this reason that some are now more aware of their own health problems: *"If I can't function, it is going to break the family down, you know what I mean. So, this is why I have to mind myself, and I am going to watch myself constantly, and if I feel things coming at me, I am going to investigate them"* (Hanney, 2012, p. 46).

Discussion

This literature review aimed to synthesize evidence presented in qualitative studies related to the experience of living with stroke in young patients. The review findings identified key interrelated elements that reflect participants' accounts of what the stroke meant for them and how it affected them as individuals.

The life trajectory of young stroke survivors is disrupted and undermined. Among the impacts on the lives of stroke patients (regardless of age), 'loss' is commonly described as including loss of activities, abilities, personal qualities, and independence, as well as emotional and social losses or changes in self-identity (McKevitt et al., 2004; Salter et al., 2008; Satink et al., 2013). There are also feelings of uncertainty about the trajectory of recovery and possible consequences (McKevitt et al., 2004). In relation to lived experiences, themes relating to change, transition and transformation, loss, insecurity, social isolation, as well as adaptation and reconciliation were described in the meta-synthesis of qualitative research (Salter et al., 2008). The disruptive impact on a patient's concept of self include the need for self-management support, psychological and emotional support, information, as well as social support (Satink et al., 2013).

Because of the rarity of the disease in this age group and the stereotypical image of stroke as a disease of the elderly, young adults consider stroke as a *"disruption of life time and being normal"* (Immenschuh, 2003). In comparison with the previous review by Lawrence (2010), this qualitative review contributes to the existing evidence with a deeper insight into how young stroke survivors cope with stroke and the coping strategies they use to restore normality. Three themes emerged: disorientation, a disrupted sense of self, and altered roles and relationships (Lawrence, 2010). However, Lawrence's synthesis did not indicate how young stroke survivors cope with stroke and what strategies they use to restore normality or pre-stroke status; a gap this thematic synthesis seeks to fill. This study is therefore novel given its intention. The description of the experience was based on some studies on Bury's model of the impact of chronic diseases (biographical disruption, Bury, 1982; Immenschuh, 2003; Kuluski et al., 2014), in addition to his conceptualization of how people cope with the resulting changes (biographical repair). In line with this model, we have identified three analytical themes related to biographical repair: re-establishing a new self, re-establishing a social role, and relationship help. Several studies have also documented these themes.

In the first group of themes, 'disruption of self and self-identity' and 're-establishing a new self', young adults described how they perceived changes in their long-term functional outcomes and persistent disability after stroke, which changed their attitudes about themselves. This review presented a stroke as a 'turning point' (Immenschuh, 2003), or as a journey of re-establishing a new self with the resulting challenges and opportunities (Holloway et al., 2022). Positive atti-

tudinal shifts after stroke have also been described by younger adults, including individuals' re-definition of their longstanding roles and reprioritization of personal values.

The themes of 'social disruption' and 're-establishing of social role' illustrate the number of aspects that negatively or positively influence an individual's day-to-day functioning and social participation. There is strong empirical support in terms of the social consequences after stroke, where young adults are particularly likely to experience difficulties in RTW or workplace re-integration (Daniel et al., 2009, Edwards et al., 2018). Young stroke survivors have impaired psychological needs, and although these overlap with those of older people, some areas are perceived as more important in this specific age group (Morris, 2011). These needs arise from the consequences of stroke, which make them feel 'different' and isolated from their younger peers and 'changed' from their former selves (Morris, 2011). Social consequences are therefore a major concern for working-age adults in relation to their needs. Being seen and treated as people who had had a stroke may be related to feelings of stigma and shame (Immenschuh, 2003). Young adults experienced persistent hidden or invisible post-stroke psychosocial and cognitive impairments, albeit to varying degrees. The issue of the invisibility of impairments and a misinterpretation of the patient's situation emerged from the data. Invisible impairments perceived after stroke could not be well understood in social, community, and work contexts (Wolfenden and Grace, 2015). Young stroke survivors reported that their psycho-emotional and cognitive needs were inadequately addressed in inpatient and outpatient healthcare settings (Shipley et al., 2020).

The third group of themes describes the experience of changes in close personal relationships – in partnership/romantic relationships, parenting, and family functioning. All the studies included in this review described specific constraints in relation to spousal and parental tasks, childrearing plans, and the quality of a future relationship. In addition, young stroke survivors have specific needs related to their developmental stage, including caring not only for their own children but also for the aging parents who look to them for support (Kuluski et al., 2014). On the other hand, the sub-theme 'relationship help' described positive aspects, including strengthening bonds and re-establishing roles in the household. Despite the difficulties in spousal and parenting relationships, some stroke survivors reported feeling a deeper close-

ness and appreciation of their spouse/partner than before the stroke (Hanney, 2012). Support from spouses/partners, the ability to solve post-stroke related problems as a couple, and motivation to continue with parenting tasks and goals, could provide an added impetus in the post-stroke recovery and returning to parenting as a life role.

It was also emphasized that future research should focus on measuring the impact of IS on parenting roles and the interaction of parenting with rehabilitation activities and recovery outcomes (Harris and Prvu Bettger, 2018).

Study limitations

The search was limited to the electronic scientific databases accessible to the authors' institution. Two dissertations were included in this review, as a form of grey literature that is commonly included in systematic reviews. Although seven sources were included, the researchers only directly reported the type of stroke in two. The analysis of included studies was limited, mainly due to the inherent heterogeneity in the subtypes of stroke. Further research focussing directly on IS is needed.

Conclusion

Stroke at a young age can cause disruption in three domains: disruption of self and self-identity, social disruption, and disruption of close personal relationships. However, three analytical themes related to coping strategies or personal challenges have been found: re-establishing a new self, re-establishing a social role, and relationship help. The findings of our review can provide a deeper insight into understanding the experience of a stroke at a younger age and their age-appropriate needs in the long-term rehabilitation process.

Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

Funding

This study was funded by the Ministry of Health, Czech Republic (grant AZV MZ CR number NU22-09-00021). The review was conducted as a part of the research project the FRAILTY study (Factors Affecting the Quality of Life After Ischemic Stroke in Young Adults), registered on ClinicalTrials.gov (NCT04839887).

Zkušenosti mladých dospělých po ischemické cévní mozkové příhodě – syntéza kvalitativních studií

Souhrn

Cíl: Analyzovat a syntetizovat výsledky kvalitativních studií týkajících se životních zkušeností mladých pacientů po prodělané ischemické cévní mozkové příhodě (iCMP).

Design: Syntéza kvalitativních studií. Byl dodržen doporučený postup dle ENTREQ pro zvýšení transparentnosti při předložení syntézy kvalitativních výzkumů.

Metody: Pro vyhledávání kvalitativních studií bylo využito elektronických vědeckých databází CINAHL Plus (EBSCO), MEDLINE (OvidSP), PsycInfo (EBSCO), ScienceDirect (Elsevier), SocINDEX (EBSCO), Web of Science Core Collection a ProQuest, ve kterých bylo dohledáno 5 785 zdrojů. Pro metodologické posouzení kvality studií bylo využito CASP (Critical Appraisal Skills Programme Qualitative Research Checklist). Celkem bylo do literárního review zařazeno 7 kvalitativních studií zaměřených na životní zkušenosti mladých dospělých po iCMP.

Výsledky: Cévní mozková příhoda v mladém věku způsobuje narušení ve třech oblastech: oslabení sebe sama a vlastní identity, sociální narušení a oslabení blízkých osobních vztahů. Na druhou stranu byla nalezena tři analytická témata související s copingovými strategiemi nebo osobními změnami: znovunalezení nového já, znovunalezení sociální role a pomoc ve vztahu.

Závěr: Dohledaná zjištění našeho review mohou přinést hlubší porozumění zkušenostem mladých dospělých po cévní mozkové příhodě a současně jejich věkově přiměřeným potřebám v dlouhodobém rehabilitačním procesu.

Klíčová slova: ischemická cévní mozková příhoda; kvalitativní výzkum; mladý dospělý; tematická syntéza; zkušenosti pacienta

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