NURSING

journal homepage: http://kont.zsf.jcu.cz
DOI: 10.32725/kont.2024.015

KONTAKT / **Journal of nursing and social sciences related to health and illness**

Original research article

How to restart myself? The lived experience of young stroke patients after first ischemic stroke: an interpretative phenomenological analysiss

Šárka Šaňáková [1], Elena Gurková [1], Kristýna Šobrová [1], Juraj Čáp [2], Daniela Bartoníčková [1] *

[1] *Palacký University Olomouc, Faculty of Health Sciences, Department of Nursing, Olomouc, Czech Republic*
[2] *Comenius University in Bratislava, Jessenius Faculty of Medicine in Martin, Department of Nursing, Martin, Slovak Republic*

Abstract

Aims: To gain a rich understanding of young stroke patients' lived experience one year after their first ischemic stroke.

Methods: An interpretative phenomenological analysis design was used to explore the meaning of the lived experience of young stroke patients. Eight stroke survivors, aged 18–50, years took part in semi-structured qualitative interviews.

Results: Stroke was not only perceived as a traumatic event that led to losses and limitations; for many participants, it was a "turning point" or a path of growth with new challenges and opportunities. Ten subthemes and three interconnected group experiential themes were generated: (i) *Stroke as a sudden and unexpected event*; (ii) *Continuity and discontinuity of self*; and (iii) *Social participation*.

Conclusion: This research highlights several issues within current clinical services for young stroke patients one year after their first ischemic stroke. Implications for patient care – guidelines for special rehabilitation and occupational therapy programmes should be primarily concerned with overcoming residual problems after stroke. Practicing instrumental activities of daily living or skills needed for return to work is also important, as well as the existential aspects of recovery.

Keywords: Interpretative phenomenological analysis; Ischemic stroke; Patient experience; Young adult

Introduction

Recent epidemiological data have shown that ischemic stroke (IS) incidence in adults younger than 50 has risen over the past decade (Yahya et al., 2020). The onset of IS at a young age is problematic because the long-term consequences of stroke affect people at an active and socioeconomically challenging time of life (Maaijwee et al., 2014).

According to recent reviews, the prognosis of IS in young stroke patients (YSPs) remains generally unclear, with its aetiology unknown in 30% of cases (Yahya et al., 2020). Evidence on the consequences of IS and its impact on the quality of life from long-term quantitative observational studies is insufficient (Yahya et al., 2020). Reliable information about the prognosis and causes of their condition is crucial for YSPs as IS affects them when it comes to caring for their dependent children and aging parents, leading active social and working lives, or taking decisive career steps (Maaijwee et al., 2014). Therefore, the occurrence of IS at this time may be a traumatic event that abruptly interrupts one's life trajectory.

YSPs have specific medical and psychosocial needs and priorities compared to older adults (Lawrence, 2010). Most previous studies on IS in the young focused mainly on aetiology, risk factors, residual impairments, or functional outcomes (Hanney, 2012). An extensive body of evidence regarding IS's physical and psychosocial sequelae comes from empirical studies in older populations (Holloway et al., 2022).

The existing literature, guidelines, and rehabilitation programs related to IS focus on older rather than YSPs and their unique needs and experiences (Holloway et al., 2022). There is little evidence regarding YSP-reported outcomes and experiences after IS in the short or long term. The disruptive nature of having IS at a younger age, as well as positive attitudinal shifts, have been described in several studies. Although most empirical studies have focused on the adverse sequelae of IS or its pervasive impact on many facets of stroke survivors' lives, including home life, employment, or social life, recent studies have sought to explore possible positive consequences such as re-establishing a new self or relationship help (Hutton and Ownsworth, 2019; Immenschuh, 2003). In these studies, time post onset of stroke was broad, beginning at 3 months and ending at 31 years. Therefore, this study focused on a more homogenous group of patients and defined the assessment time after stroke in the first 12 months after IS. A better understanding of patient-reported experiences can contribute to

---

* **Corresponding author:** Daniela Bartoníčková, Palacký University Olomouc, Faculty of Health Sciences, Department of Nursing, Hněvotínská 976/3, 775 15 Olomouc, Czech Republic; e-mail: daniela.bartonickova@upol.cz

http://doi.org/10.32725/kont.2024.015

Submitted: 2023-09-07 • Accepted: 2024-02-27 • Prepublished online: 2024-03-07
KONTAKT 26/1: 38–44 • EISSN 1804-7122 • ISSN 1212-4117

better age-appropriate rehabilitation, self-management programs, a patient-centered approach to outcomes, and to developing adequate therapeutic interventions.

The present study aimed to better understand the YSPs' lived experience one year after their first IS.

The research question was as follows: How do YSPs make sense of their lived experience one year after their first IS?

Materials and methods

Study design

An interpretative phenomenological analysis (IPA) design was used to explore the meaning of the lived experience of young stroke patients. IPA focuses on the detailed examination of people's lived experiences and how they make sense of them in the context of their personal and social worlds (Smith and Nizza, 2022; Smith et al., 2022).

Sample

Consecutive IS patients (*n* = 158) who were enrolled in the prospective study FRAILTY (Factors Affecting the Quality of Life After Ischemic Stroke in Young Adults; ClinicalTrials.gov. Identifier: NCT04839887, registered on April 09, 2021) during a period between 6/2021 and 12/2021 were screened for participation in this qualitative study. The FRAILTY study explores how initial stroke-related and personal factors and functional outcomes are associated with health-related quality of life in younger and older individuals, at 3, 6, and 12 months after IS. Therefore, only patients during the first 12 months after IS were included. The study sample was selected purposively. YSPs who attended a neurological outpatient clinic of a university hospital cerebrovascular center for regular follow-up examinations within one year after IS were recruited according to the following inclusion criteria: age 18–50 years, IS with a mild residual neurological deficit at the time of enrolment, written informed consent. The exclusion criteria were as follows: transient ischemic attack without progression to IS; cerebral infarction caused by trauma; hemorrhagic stroke; severe cognitive impairment or communication disorder hindering participation in an in-depth interview; a concomitant severe systemic illness potentially affecting the quality of life after IS. Patients with hemorrhagic stroke were excluded as their prognosis and experience could differ from those with IS. The residual neurological deficit at enrolment was assessed using the National Institute of Health Stroke Scale (NIHSS); the modified Rankin scale (mRS) and Barthel Index (BI) were used to assess the functional outcome. An experienced neurologist screened and selected eligible patients (*n* = 13) according to inclusion criteria, the research team contacted eligible patients, and eight participants (three women and five men) consented to participate in the study (Suppl. Table 1). The final number depended on data saturation and the willingness of patients to participate in the study.

Data collection

An in-depth, semi-structured interview was used for data collection. The research team developed the interview guide and consulted with a clinical neurologist. It consisted of broad areas relating to the chronology of the illness trajectory: the onset of IS, hospitalization, the transition from hospital to home, lived experiences relating to daily living before and after IS, therapy/rehabilitation needs, and experiences after IS. The average interview length was 55 minutes, including a final debriefing conversation. KS conducted the interviews in the Czech language. Two participants were interviewed in the consultant's room on the neurology ward, and six were interviewed at home.

Field notes were also used for reflecting on the interview, environment, patient's behavior, and self-reflection of the interviewer.

Data analysis

Data were analysed using the IPA with modified terminology employed in the analysis (Smith et al., 2022). The IPA analytical process has seven phases: reading and re-reading, exploratory noting, constructing experiential statements, searching for connections across experiential statements, naming the personal experiential themes (PET) and consolidating and organizing them in a table, continuing an individual analysis of other cases, and working with personal experiential themes to develop group experiential themes across cases (Smith et al., 2020). An example of PETs is shown in Suppl. Table 3.

Initial data analysis was conducted by the first author (SS) with NVivo assistance. The second author (EG) was involved in each step of the analytical process. The third (KS) and fifth (DB) authors assisted in conceptualizing the study and were involved in developing group experiential themes across cases and interpreting the findings. An independent audit was performed after the analysis by an experienced researcher in IPA (JC). Regarding positionality, three researchers (SS, KS, DB) worked as nurses with patients after stroke, and the other two researchers (EG, JC) were engaged in research on the quality of life and dignity of people with neurological diseases. Three authors are nurses, one author is a nurse and psychotherapist, and the author who did the independent audit is a philosopher and qualitative researcher (Suppl. Table 2).

Ethical considerations

The study was approved by the Ethics Committee of the University Hospital Olomouc and the Faculty of Medicine and Dentistry, Palacký University (6/2021, No. NU22-09-00021). Each participant's informed consent was obtained prior to participation in the study with guaranteed anonymity and confidentiality. The participants' names have been changed to protect confidentiality.

Rigor and reflexivity

The methodological integrity of the study was ensured by implementing Levitt et al. (2018) criteria (JARS-Qual) and COREQ guidelines for reporting qualitative research and independent audits focused on the chain of evidence from initial analysis to the final report (Smith et al., 2020).

Results

The participants' characteristics are presented in Suppl. Table 1. Comparing personal experiential themes and experiential statements of individual cases resulted in three groups of experiential themes and ten subthemes (Suppl. Table 4). These themes were manifested in almost all the interviews and addressed the essence of what YSPs were experiencing.

Theme A: Stroke as a sudden and unexpected event

A.1 Stroke at young age: I never thought I could suffer a stroke at my age

YSPs described varied experiences of having their first IS, dominated by feelings of confusion and fear. The attack usually caught them when they were totally healthy, during their normal daily activities – at work, in a restaurant, while performing their parental duties, *etc.* They all described it as quick and unexpected, like "a bolt from the blue". Due to the stereotypical view of IS as a disease of the elderly, it was difficult for them to accept that they had experienced IS. *"… fear that I could have died. I would never have thought in my life that I, with two young kids, would have a stroke"* (Mary, age 33). Given the clinical features of IS, for some, recollections of the event were hazy, and they instead interpreted accounts from people present at the time of the acute event. Participants tried to explain the cause of their symptoms, which they interpreted in the context of their existing mental representations of diseases at their age. *"I suddenly felt this weakness, like I became light-headed; I thought it was some kind of low blood pressure or something"* (Robert, aged 46). Initially, they tried to minimize or normalize their symptoms, resulting in later seeking medical help. *"So I thought, well, I get frequent headaches, it'll be fine. I didn't know what was going on at all, it didn't seem to me that there was anything wrong"* (Karen, aged 47).

A.2 Timely help and therapy: early recovery

Due to the sudden onset and nature of the symptoms, participants were dependent on the help and response of others. Retrospectively, they realized that timely and prompt responses by others led to early help, effective treatment, and faster recovery. *"I can be caught so quickly, like really early, because otherwise, I can't imagine it"* (Anne, aged 49). On the other hand, their relatives or colleagues were taken aback by the seriousness of the condition, initially not believing it. *"He asked if I was joking or if I was asleep"* (Karen, aged 47). *"At first, he thought I was joking, but I suddenly slumped to the floor"* (Robert, aged 46).

A.3 Vulnerability: fear of recurrence

Participants no longer felt in control of their health. In retrospect, they reflected on what the consequences of the disease would have been if they had been alone in the situation. *"My friend would have already been at work if it had happened to me five minutes later. I can't imagine what the outcome would have been"* (Mary, aged 33). They were more aware of the unpredictability of life. The persistent and pervasive uncertainty in the future and fear of recurrent IS were perceived by most YSPs. A mere recollection of a stroke triggered fear of recurrence. *"I was terribly afraid to fall asleep; I couldn't sleep because I was afraid I wouldn't wake up."* This fear was manifested in various ways, including limitations in daily activities, greater awareness of risk, increased attention to physical symptoms, or seeking ways to provide for the family in the event of a possible death. *"The first thing I did was get insurance. I just started thinking that it could happen again and that it might not turn out the way it did. So I started providing for the kids, making sure they would have money if I weren't here"* (Mary, aged 33).

Theme B. Continuity and discontinuity of self

B.1 Loss of self-fulfilling activities: I cannot do what I could do

YSPs live with its consequences for a relatively long period of their lives. The overall level of physical activity, returning to work, and resuming previous social activities are essential areas that affect their confidence and independence. Returning to work can be perceived as a sign of recovery and the effectiveness of rehabilitation. YSPs wish to return to work if their health permits and their work environment is favorable and supportive. In addition, social and economic trends suggest that many YSPs may increasingly seek work for economic reasons. The YSPs in our sample were accustomed to having multiple social roles, leading rich family and social lives, and working full-time in a variety of positions. For some patients, participation in social life (especially employment) was a means of fulfilment in their lives. "*Throughout my professional life, I had basically not been unemployed for a single day; I had always had more than one job and many hobbies; now I have canceled everything"* (Richard, aged 48). During the first year after the IS, three of the nine interviewees have not returned to work, and two participants work part-time because they can no longer handle full-time work. *"I just get so tired, and I'm not as fit as I used to be"* (Anne, aged 49). Some of them had to change jobs or job responsibilities altogether. *"I planned to quit driving the truck so I did it a year earlier, but I didn't plan it that way"* (Thomas, aged 37). In contrast, a young woman, a divorced mother with two children who has a physically strenuous job as a manual worker, has returned to work very quickly. *"I stayed at home for three weeks, then went straight to work"* (Mary, aged 33). Two other men who had office jobs, working as a project architect and a banker, have also managed to return fully to their previous employment.

After suffering an IS, some participants had to give up their hobbies and interests. Due to fatigue or other IS-related consequences, they can no longer pursue their hobbies. *"I have tried my best to get any kind of exercise… I sort of do not like to remain sitting in the garden, on a chair, or I don't know what, but I am trying to do something; it is not going very well"* (Richard, aged 48). On the other hand, they try to be active and continue previous leisure activities within their limitations. "*… strumming the strings softly is just not possible. But I haven't given up playing anyway, because it's my hobby and it makes me happy. That didn't stop me buying a new guitar"* (Robert, aged 46).

B.2 Loss of my former self: I am no longer who I was

Having IS at a working age led to a sudden change in the patient's previous life and a loss of their essential, self-determining qualities. *"The stroke changed everything, my whole life changed completely"* (Thomas, aged 37). Realizing that they could no longer do some things as they used to or that some things did not go as easily and well as they were used to, led to frustration, feelings of inferiority and anger towards themselves. *"I used to be so action-oriented, and I'm just not good at it now, and I'm angrier at myself"* (Anne, aged 49). *"I feel inferior and useless now, and I can't entirely do things I could do before"* (Robert, aged 46). YSPs reported difficulty continuing their lives in familiar ways and maintaining a sense of self. The change in identity was related to the loss of a fulfilling working life. Their previous working life had been a source of enriching experiences, new challenges, and personal development that gave them meaning, and fulfilment. *"I had been working all my life, and in 80–90% of my working years, I always had more than one job and many hobbies, so I had to cancel that"* (Richard, aged 48).

Fatigue, loss of energy and motivation, and cognitive dysfunction were factors significantly limiting their return to the pre-IS state. Fatigue was one of the most common physical effects of IS in younger people. This "invisible disability" significantly limited them in activities and pursuits to which they were accustomed. *"Essentially fatigue, to the point that as far as my job is concerned, fatigue overwhelms me and I'm not able to do much"* (Richard, aged 48).

B.3 Seeking and understanding the new normal: reconsideration and slowing down

During the recovery process, some patients tried to return to normal and resume the previous life they led before the stroke.

However, their efforts led to additional health complications rather than the restoration of previous functioning. *"I have tried all sorts of rehabilitation. But basically, I haven't succeeded and I'm not back to where I was or even close to it, so I guess I haven't found the right way..."* In contrast, some YSPs reported being able to resume their previous lives. They attributed a significant role to their optimistic mindset and search for strong recovery models through social comparison. *"I was confident that things would return to normal. I actually know of examples of completely incurable comatose people who have recovered"* (Clark, aged 49).

On the other hand, for other individuals, redefining their long-term roles and reprioritizing personal values was a way of maintaining their pre-IS identity. They integrated IS into their life story and achieved a sense of acceptance. IS can also be seen as a milestone or turning point that fundamentally changes one's previous life. *"Absolutely everything has changed, my whole life. I used to drive a truck; my lifestyle was completely different; I didn't care about it"* (Thomas, aged 37). This change in life can also be perceived as a second chance or a warning. *"I try to think about what I'm doing, because I understand it as some kind of warning, the way I used to live before"* (Clark, aged 49). Another young respondent felt much the same way. *"Well, I'm trying to be a better person. I've quit smoking. I'm enjoying life more than before"* (Mary, aged 33). Accepting help from significant others, adjusting to post-IS changes, and being able to point to positive consequences were also described in terms of coping or restoring normality at different stages of the illness trajectory. *"I'm not pushing myself, like the work and the stresses around... and I'm taking things a little bit differently, a little bit more in my stride. All is not lost that is delayed"* (Karen, aged 47).

Theme C. Social Participation

C.1 Following hospital discharge: invisible to the system

The data were collected at the time of COVID-19. While some participants had virtually no rehabilitation, others only had limited rehabilitation. Since rehabilitation is one of the most important components of the recovery process, this situation was difficult for all YSPs. However, they had to adapt to this exceptional situation and at least make do with what was available. They criticized insufficient information about the disease and prognosis in the early stages of IS, which exacerbated their vulnerability, feelings of insecurity, and anxiety. *"They haven't actually figured out anything, they haven't found out what the cause was. Well, that was the most challenging thing for me, that I didn't know anything"* (Karen, aged 47). Many felt their needs were overlooked and not adequately met because their residual deficit was only mild. *"They told me: Hey, you look great, this is not how people look after a stroke, so they kind of kicked me out and that was it"* (Bill, aged 46). They also lacked information about the options for and availability of rehabilitation after discharge. Some were left to seek services themselves. *"I wasn't offered rehab, but I did some activities on my own, I arranged everything. I tried all sorts of rehabilitation"* (Richard, aged 48). On the other hand, the information and support they did not get from health professionals were provided by their peers who had similar problems. They found the recovery experiences of older patients with more severe neurological deficits inspiring. *"And I actually learn that mostly from the people around me. Yeah, not so much from the doctors, but from the people I was with afterward. When they told me how they were, and when I saw what shape they were in now, it gave me such a kick"* (Karen, aged 47).

C.2 Regaining the role in the family: I do not trust myself

Participants were concerned about being unable to look after the home and family members as they used to. A single mother, who had worked as a hairdresser and could no longer handle her job due to functional limitations after her IS, was most upset by difficulties running her household. *"I can't cook, I can't – I'm just not self-sufficient; these are some problems, but otherwise, everything is as it used to be. Everything is becoming routine now, like everyday life. But I can't do things at home. And I can't do my work; I can't manage that"* (Karen, aged 47). Women more frequently wondered who would take care of their loved ones. This is not only about the impact on fulfilling existing social roles (especially in the family), but also on one's own expectations and the impact on future social roles. A patient who is already a grandmother confided that she was worried about not being able to babysit her young granddaughter. *"I don't really believe that I would actually be able to look after the baby or babysit it"* (Anne, aged 49). A divorced mother said that she needed to recover as quickly as possible to be able to look after her two children because her mother was unfit to do so instead. *"What didn't really help me was the psychological support of my mother. Because when I was in the hospital, she was supposed to look after my younger son, but she was drinking alcohol, you know. So I needed to get over that as quickly as possible"* (Mary, aged 33).

C.3 My family pushes me forward: I am not left to stagnate

The participants spent more time at home with their families, and this helped them become closer to one another. Partnerships and parenting became more profound and more vital as a result of the illness. The strongest motivation was the awareness of parental responsibilities, the desire to be there for the children, and the responsibility for their care. *"The children helped me a lot because when I was with them, I didn't have time to think about what had happened"* (Mary, aged 33). *"My child actually pushed me forward, so to be self-sufficient I kept hoping. My child kept pushing me to get through it"* (Karen, aged 47). Patients also received support from their spouse or partner. *"My husband kept prodding me, telling me to do things and hurry up. Family support is important as they do not let you stagnate completely. It's about resuming the life one had lived before"* (Anne, aged 49).

Discussion

The present study utilized IPA to explore how YSPs experience and perceive the significance of IS at 12 months after its onset. The study outcomes are interconnected group experiential themes reflecting patients' accounts of what the condition, so atypical for their generation, meant for them and how it affected their lives.

Stroke as a sudden and unexpected event

IS suddenly interrupted the expected life trajectory of YSPs. Findings from the current study support previous findings (Hanney, 2012, Holloway et al., 2022) that YSPs perceived themselves as an "invisible group" because of the strong connection between IS and old age. IS is stereotypically associated with older age and this perception appears to have prevented some patients from associating their symptoms with IS. Failure to recognize IS symptoms may result from incomplete or inaccurate mental representations relating to IS. However, only two participants tended to normalize their symptoms. In addition, in contrast to previous findings (Röding et al., 2003; Stone, 2007) which point to YSPs feeling prematurely old or aged, the effect of aging due to IS was not observed in this study. Similarly, the participants did not ask the typical "why me?" question reported by other authors (Immenschuh, 2003; Kuluski et al., 2014). On the other hand, the answer to the "why me?" question also implies an answer to another question characteristic for all participants in the present study, one that is apparently inseparable from the former: How can I prevent a second stroke? The study sample consisted of YSPs without severe residual deficits and with a favorable prognosis. Most participants presented biomedical causality: the cause was identified, and patients underwent the therapy and/or adjusted their lifestyle. A considerable proportion of participants experienced timely diagnosis, and thus more effective therapy, faster recovery, and a less severe disability. The significance of the stroke was greatly influenced by aspects such as understanding its cause, timeliness of therapy, recovery time, the severity of functional impairment, and concerns about possible recurrence.

Continuity and discontinuity of self

YSPs struggle with self-identity after IS. A common theme among the participants' accounts was how IS disrupts their ontological security (Alaszewski et al., 2006; Giddens, 1991), sense of continuity, and predictability in life. This is associated with greater vulnerability experienced by participants as reported by Wolfenden and Grace (2015). In this study, activities they used to take for granted or carry out with certain predictability now require much more effort, are demanding, or even risky. Working-age people's hectic and varied lives were interrupted by a disease that is so atypical and unexpected at their age, so-called biographical disruption (Bury, 1982). Suddenly, the participants found themselves in an unpredictable world, aware of an uncertain future and potentially at risk of another IS. Fear of recurrence, or knowing that the stroke attack may occur again, was a theme reflected by nearly all participants.

Fear of recurrence is closely related to a subtheme concerning reconsidering one's long-term roles, change of priorities, or personal life. YSPs' vulnerability is also related to the third theme, social participation, namely the absence of psychosocial support after discharge from the hospital and financial vulnerability (Wolfenden and Grace, 2015).

The present study has shown that most YSPs attempted to adapt to their post-IS life and incorporate its consequences into their identity. Despite being frustrated by persisting fatigue, many participants apparently more or less accepted their IS and its impact on their lives, and thus maintained a sense of continuity in their life trajectory. For them, the first year post-IS represents a process of negotiation between IS consequences and a desire to continue their previous life. Virtually all participants mentioned a loss of or being frustrated by a loss of particular abilities, such as performance or multitasking, that had been key to their identity. The process of losing one's former self and finding a new self was reflected by a considerable proportion of qualitative studies involving YSPs after IS (Hutton and Ownsworth, 2019; Kuluski et al., 2014; Leahy et al., 2016; Wolfenden and Grace, 2015). IS at a young age can be described as an unexpected transition (unpredictable and stressful life events) in an adult's life (Tønseth, 2018). Some participants reported changes after IS as triggers (turning points), giving their lives a new meaning and direction.

One of the factors that determine the impact of IS on YSPs' sense of self is the centrality of the stroke; that is how crucial the role of the stroke is in the life of young patients. While lower levels of centrality are linked to continuity of self, a stronger perception of centrality results in discontinuity of self or its growth. The perception of centrality changes fundamentally over time and in the context of the life situation (Hutton and Ownsworth, 2019). In the present study, for example, it was significantly affected by current life stressors or demands placed on the patients. Experiences with rapid recovery and minimal long-term consequences diminished the role of IS in participants' lives. Self-management interventions after a stroke have been found to reduce disability and post-stroke depression and improve self-efficacy, quality of life, and social participation (Fryer et al., 2016). Self-management interventions or programs become more meaningful for stroke survivors if valued activities and roles are the points of departure of the assessment, goal-setting, and coaching throughout post-stroke care (Satink et al., 2015).

Social participation

IS affects YSPs' independence in social activities, sense of belonging, and work and family roles. Due to the hidden character of post-stroke impairments (fatigue) or mild cognitive deficits, they are invisible to the system when it comes to long-term care. Consistent with previous studies (Holloway et al., 2022), our findings show that patients' perception of recovery was negatively affected by health professionals downplaying their needs, and the absence of patient-oriented health care appropriate to age and milder impairment, particularly psychosocial rehabilitation. Previous studies (Roberts et al., 2020; Turner et al., 2019) have also highlighted that mild stroke services have not sufficiently addressed residual problems post-stroke or individual needs of patients and existential aspects of recovery. A lack of awareness about residual problems post-stroke, inappropriate referral for services, and outcomes assessment across the care continuum was reported. However, the effectiveness of support programs in post-IS social participation has been evidenced by quantitative studies (Brouns et al., 2019). Patients were unfamiliar with structured rehabilitation or occupational therapy programs that focused on overcoming fatigue, returning to work, or workplace interventions to promote patients' functional abilities and professional challenges, resource facilitation, and specialized job services. The absence of support and efforts to help patients with mild impairment provided by formal services was compensated for by informal social support, mainly provided by family members (children and/or partners). Being supported by their families and friends throughout their recovery was of utmost importance for young patients, especially for lone or single parents (Harris Walker et al., 2021). Some YSPs felt motivated by support from older post-IS patients who had been able to overcome even worse consequences. In the present study, YSPs' prominent problem was post-IS fatigue. YSPs tried to overcome their fatigue but often failed. Evidence from the quantitative research shows that compared to their older counterparts, YSPs more frequently described fatigue as one of the worst post-stroke symptoms and experienced a greater impact on cognitive and psychosocial functioning (Parks et al., 2012). Therefore, health professionals should focus on the severity and psychosocial consequences of post-IS fatigue in YSPs.

Limitations

The article is based on the results of a small qualitative study carried out in a single cerebrovascular center in the Czech Republic. The findings contribute to our understanding of experiences reported one year after IS by YSPs with no residual deficit. Given that participants were apparently interviewed at different stages of their rehabilitation and recovery after stroke, longitudinal research on stroke adaptation should follow.

Conclusion

The current research has contributed to understanding the meaning and experience of mild stroke, through its novel exploration of strokes amongst YSPs.

Despite a less severe residual deficit following IS, the unexpectedness and potential threat of recurrence of the condition considerably affected the continuity of self and character of social participation, contributing to greater vulnerability. The length of recovery and current demands placed on the participants influenced the perception of the centrality of IS in young adults' lives. The first year after IS was characterized by a process of negotiation between IS consequences and a desire to continue their previous life. The continuity of one's former self was associated with the overall perception of recovery affected by fatigue and a lack of support from healthcare services. On the other hand, surviving IS was not always a traumatic event linked to losses and limitations, as many participants saw it as a "turning point" or a path of growth with new challenges and opportunities.

The absence of patient-oriented, age- and mild impairment-appropriate healthcare affects the overall perception of recovery. It is essential to monitor and improve the awareness of specific consequences of stroke and its impact on the quality of life of young adults or their return to pre-stroke activities; this also applies to patients with minimal or no functional impairment. The findings imply that YSPs missed having professional support post-discharge and would have appreciated additional psychological and emotional support, mainly in their self-management process. Therefore, the findings can contribute to a greater recognition of processes (tasks and skills of YSPs) that are significant for effective self-management of illness needs and tailoring self-management programs in this population.

Funding

This study was funded by the Ministry of Health, Czech Republic (grant AZV MZ CR number NU22-09-00021).

Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

References

1. Alaszewski A, Alaszewski H, Potter J (2006). Risk, Uncertainty and Life Threatening Trauma: Analysing Stroke Survivor's Accounts of Life After Stroke. Forum: Qual Soc Res 7(1): 1–21. DOI: 10.17169/fqs-7.1.53.
2. Brouns R, Valenzuela Espinoza A, Goudman L, Moens M, Verlooy J (2019). Interventions to promote work participation after ischaemic stroke: A systematic review. Clin Neurol Neurosurg 185: 105458. DOI: 10.1016/j.clineuro.2019.105458.
3. Bury M (1982). Chronic illness as biographical disruption. Sociol Health Illn 4(2): 167–182. DOI: 10.1111/1467-9566.ep11339939.
4. Fryer CE, Luker JA, McDonnell MN, Hillier SL (2016). Self management programmes for quality of life in people with stroke. Cochrane Database Syst Rev 2016(8): CD010442. DOI: 10.1002/14651858.CD010442.pub2.
5. Giddens A (1991). Modernity and self-identity: Self and society in the late modern age. Stanford: Stanforfd University Press, 264 p.
6. Hanney J (2012). The experience of mild stroke among young adults and their spouses: an interpretative phenomenological analysis. Kildare: Maynooth University, 125 p.
7. Harris Walker G, Oyesanya TO, Hurley A, Sandhu S, Liu C, Mulla M, Prvu Bettger J (2021). Recovery experiences of younger stroke survivors who are parents: A qualitative content analysis. J Clin Nurs 30(1–2): 126–135. DOI: 10.1111/jocn.15529.
8. Holloway A, Chandler C, Aviles Reinso L, Clarissa C, Putri A, Choi H, et al. (2022). Young Adults Rehabilitation Needs and Experiences following Stroke (YARNS): A review of digital accounts to inform the development of age-appropriate support and rehabilitation. J Adv Nurs 78(3): 869–882. DOI: 10.1111/jan.15076.
9. Hutton L, Ownsworth T (2019). A qualitative investigation of sense of self and continuity in younger adults with stroke. Neuropsycholl Rehabil 29(2): 273–288. DOI: 10.1080/09602011.2017.1292922.
10. Immenschuh U (2003). Being left alone – younger people who have suffered a stroke. PR-Internet Pflege 6(7–8): 426–431.
11. Kuluski K, Dow C, Locock L, Lyons RF, Lasserson D (2014). Life interrupted and life regained? Coping with stroke at a young age. Int J Qual Stud Health Well-being 9: 22252. DOI: 10.3402/qhw.v9.22252.
12. Lawrence M (2010). Young adults' experience of stroke: a qualitative review of the literature. Br J Nurs 19(4): 241–248. DOI: 10.12968/bjon.2010.19.4.46787.
13. Leahy DM, Desmond D, Coughlan T, O´Neill D, Collins DR (2016). Stroke in young women: An interpretative phenomenological analysis. J Health Psychol 21(5): 669–678. DO I:10.1177/1359105314535125.
14. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. Am Psychol 73(1): 26–46. DOI: 10.1037/amp0000151.
15. Maaijwee NA, Rutten-Jacobs LC, Schaapsmeerders P, van Dijk E, de Leeuw FE (2014). Ischaemic stroke in young adults: risk factors and long-term consequences. Nat Rev Neurol 10(6): 315–325. DOI: 10.1038/nrneurol.2014.72.
16. Opoku S, Eliason C, Akpalu A (2020). Why Me?: A Qualitative Study on the Experiences of Young Stroke Survivors in the Accra Metropolis of Ghana, West Africa. J Patient Exp 7(6): 1788–1796. DOI: 10.1177/2374373520967505.
17. Parks NE, Eskes GA, Gubitz GJ, Reidy Y, Christian C, Phillips SJ (2012). Fatigue impact scale demonstrates greater fatigue in younger stroke survivors. Can J Neurol Sci 39(5): 619–625. DOI: 10.1017/s0317167100015353.
18. Roberts PS, Krishnan S, Burns SP, Ouellette D, Pappadis MR (2020). Inconsistent Classification of Mild Stroke and Implications on Health Services Delivery. Arch Physs Med Rehabil 101(7): 1243–1259. DOI: 10.1016/j.apmr.2019.12.013.
19. Röding J, Lindström B, Malm J, Ohman A (2003). Frustrated and invisible--younger stroke patients' experiences of the rehabilitation process. Disabil Rehabil 25(15): 867–874. DOI: 10.1080/0963828031000122276.
20. Satink T, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW (2015). How is self-management perceived by community living people after a stroke? A focus group study. Disabil Rehabil 37(3): 223–230. DOI: 10.3109/09638288.2014.918187.
21. Smith JA, Nizza IE (2022). Essentials of interpretative phenomenological analysis. London: American Psychological Association.
22. Smith JA, Flowers P, Larkin M (2022). Interpretative phenomenological analysis: Theory, method and research. London: Sage Publications, 240 p.
23. Stone SD (2007). Patient concerns posthaemorrhagic stroke: a study of the internet narratives of patients with ruptured arterivenous malformation. J Clin Nurs 16(2): 289–297. DOI: 10.1111/j.1365-2702.2005.01490.x.

24. Tønseth C (2018). Anticipated and Unanticipated Transitions as Triggers for Adult Learning. Creat Educ 09(2): 165–181. DOI: 10.4236/ce.2018.92013.
25. Turner GM, McMullan C, Atkins L, Foy R, Mant J, Calvert M (2019). TIA and minor stroke: a qualitative study of long-term impact and experiences of follow-up care. BMC Fam Pract 20(1): 176. DOI: 10.1186/s12875-019-1057-x.
26. Wolfenden B, Grace M (2015). Vulnerability and Post-Stroke Experiences of Working-Age Survivors During Recovery. Sage Open 5(4): 1–14. DOI: 10.1177/2158244015612877.
27. Yahya T, Jilani MH, Khan SU, Mszar R, Hassan SZ, Blaha MJ, et al. (2020). Stroke in young adults: Current trends, opportunities for prevention and pathways forward. Am J Prev Cardiol 3: 100085. DOI: 10.1016/j.ajpc.2020.100085.