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Young Adults' Rehabilitation Needs and Experiences following Stroke (YARNS): a review of digital accounts to inform the development of age-appropriate support and rehabilitation.

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CC: Study design, secured funding, editing and writing

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Abstract

Aims: To explore younger adults' experiences of stroke rehabilitation to inform practice, education and future health policy.

Design: Qualitative analysis of digital and other media sources on public platforms.

Methods: Between March and June 2020, the experiences of younger adult stroke survivors aged 18 to 45 at the time of the stroke were collected. Data were gathered from publicly available sources, including social media, and from English speaking users. In total, 117 accounts from 103 participants were identified from films, autobiographical books, blogs, websites, videos, Twitter and Instagram. Data analysis followed narrative and multimodal analysis with a focus on rehabilitation needs.

Results: Younger adult stroke survivors make sense of their experience by reflecting on how stroke has impacted on their lives. Accounts reflected an emotional journey between the past self, the present self and evolving self, as well as associated challenges such as the impact on relationships and careers. The majority of accounts presented transitions as problematic, including the receipt of the initial diagnosis, or sometimes misdiagnosis, to returning home and achieving long-term rehabilitation goals. Specialist stroke nurses were considered essential in the rehabilitation process.

Conclusion: A complex process of recovery follows stroke for younger adult stroke populations. Challenges to the rehabilitation process need to be better understood and the role

of nursing highlighted in future service provision. A series of age-related challenges were highlighted that require attention to improve the care and support offered.

Impact: This article informs clinicians, educators and policymakers of the age-related needs of young adult stroke survivors. Focusing on the individual and the development of age-appropriate person-centred stroke care is important. The study highlights the role of stroke nursing and challenges the current policy focus on older stroke populations as well as arguing for greater awareness of age-appropriate stroke rehabilitation in younger adults following stroke.

- **What problem did the study address?**

Existing literature, guidelines and services tend to focus on older population rather than younger adult stroke survivors and their unique needs and experiences.

- **What were the main findings?**

Young adult stroke survivors presented their experience of stroke as a journey from the past healthy self to a new self with the resultant challenges and opportunities.

Some transitions were identified as especially problematic: obtaining the initial diagnosis, experiences of misdiagnosis, in-patient care, leaving hospital and longer-term rehabilitation needs.

- **Where and on whom will the research have impact?**

The study contributes understanding of age-appropriate rehabilitation needs drawing on younger adults' experiences following stroke.

Key words: stroke, nurses, media, patient perspectives, qualitative approaches, quality of care, rehabilitation, service user perspectives, social media, support.

Introduction

Stroke is one of the leading causes of death and disability globally (Jaromin et al., 2017; World Health Organization, 2020). The impact of the stroke event will depend on the location, extent and severity of the damage in the brain both in the short term and long term but the overall impact on individuals can be devastating (Crichton, Bray, McKeivitt, Rudd & Wolfe, 2016). The degree of recovery or damage and the associated timescales will vary widely between individuals and can affect all aspects of life (physical, cognitive and behavioural) as well as the ability to take part in social, family and work activities (McKeivitt et al., 2011; Murray & Harrison, 2004; Wolfenden & Grace, 2015). While stroke is more common in older populations, younger adults tend to have lower mortality rates meaning that recovery for this group is likely and rehabilitation is of critical importance (Feigin, Norrving & Mensah, 2017; Martinsen, Kirkevold & Sveen, 2015). Existing guidelines and rehabilitation services tend to focus more on older populations rather than younger adult stroke survivors (Leahy, Desmond, Coughlan, O'Neill, & Collins, 2016; Shipley, Luker, Thijs & Bernhardt, 2020). This is despite several global initiatives designed to increase awareness of the issues facing younger adult stroke populations (Johnson, Onuma, Owolabi, & Sachdev, 2016; Stroke Association, 2015; World Stroke Organization, 2021). The current study was part of the Young Adults Rehabilitation experiences and Needs following Stroke (YARNS) project, a study developed in partnership with academics and clinicians with stroke expertise across the four devolved countries of the United Kingdom with the aim of scoping the experiences and needs of younger adults in terms of existing stroke rehabilitation care (The University of Edinburgh, 2020). This paper reports on the experiences of younger adult stroke survivors based on a qualitative analysis of digital and other media sources available on public platforms. As many definitions of age categories may exist, for the purpose of this study the term 'younger adult' covered 18-45 years.

Background

A common form of stroke in younger adults is subarachnoid haemorrhage which may result in sudden death or a life with severe, moderate, mild or no apparent disability (Feigin et al., 2019). However, strokes associated with high blood pressure but also from undetermined aetiology can also occur in younger adults (Smajlović, 2015), adding further challenges in terms of timely diagnosis, and provision of age-appropriate treatment and rehabilitation programmes. Turner-Stokes, Bavikatte, Williams & Sephton (2016) advocate for multidisciplinary rehabilitation approaches that provide efficacy and cost effectiveness, especially in younger adults with stroke due to the long-term nature of neurological disability. Barnes (2003, p. iv3) defines neurorehabilitation as “*a process of education of the disabled person with the ultimate aim of assisting that individual to cope with family, friends, work, and leisure as independently as possible*”. The definition draws attention to rehabilitation as experiential and supports the need to understand younger adult stroke survivors’ experiences. Digital accounts provide insight into expressed needs.

Younger adult stroke survivors’ needs may be considered to have something in common with other younger adult groups who have experienced traumatic neurological injury that also impacts brain function (Dwyer, Heary, Ward & MacNeela, 2019). Kuluski, Dow, Locock, Lyons & Lasserson (2014) highlight the unique nature of stroke for younger adults as a result of the impact that this has on their life trajectories, as well as their personal and social networks. Numerous authors have argued that the experiences and requirements of younger adults have been neglected in the research literature (Kersten, Low, Ashburn, George & McLellan, 2002; Wolfenden & Grace, 2015). Specific considerations relate to communication difficulties post stroke, which may have a significant impact on an individual’s ability to participate in empirical research, making their voices even more likely to be absent in research studies (Pringle, Hendry, McLafferty & Drummond, 2010). These limitations may be magnified further as other common effects, such as cognitive impairment and persistent fatigue, are reported as the most common disabilities in the younger adult group (Palmcrantz, Widén Holmqvist & Sommerfeld, 2012, 2014; Röding, Lindström, Malm & Öhman, 2003). Stone’s (2005) study included 22 young adult women who survived haemorrhagic stroke to explore their experiences regarding invisible disabilities such as cognitive difficulties, persistent fatigue and one-sided weakness. Participants were able to describe the many challenges and frustrations experienced due to the lack of recognition or acknowledgement of their disabilities in the social arena, and how others’ expectations led to demands that further impacted on their ability to negotiate a successful social lives or personal relationships. There are many physical, emotional and psychosocial challenges that impact significantly on younger adults’ lives following stroke

making the provision of adequate care and rehabilitation even more vital to address the nuanced age-specific needs of this group (Morris, 2011; Morris, Jones, Wilcox & Cole, 2012; Sadler, Daniel, Wolfe & McKeivitt, 2017).

Empirical studies that focus on younger adults specifically are limited in the literature, particularly when the definition associated with 'young adults' in studies about stroke can range from 18 to 55 years (Leahy et al., 2016; Rutten-Jacobs et al., 2014; Shipley et al., 2020) and even to just under 65 years old (Dwyer et al., 2019; Morris, 2011). In YARNS project, we followed Smajlović's (2015) age range for younger adults who experienced stroke as between 18 and 45 years, a range also used in other studies (Kersten et al. 2002; Low, Kersen, Ashburn, George & McLellan, 2003).

The study

Aims

This study aimed to explore the care and rehabilitation experiences of younger adult stroke survivors drawing on accounts published on public digital platforms.

Design

A qualitative approach using narrative and multimodal analysis was adopted. The younger adults' experiences were analysed from a range of digital sources in the form of narratives assuming that individuals and groups construct their identities through individual narratives, and that those narratives are strategic, functional and purposeful (Riessman, 2008). The data set included texts, images and videos, to which a multimodal analysis was also employed to integrate the visual material within these stories (Jovanovic & Van Leeuwen, 2018). The use of naturally occurring data, such as stories published on public platforms can have three main advantages: they are person-centered, context rich and provide emic perspective (Kiyimba, Lester, & O'Reilly, 2019). Moreover, the exploration of people's experiences using digital sources is not a new approach as it is increasingly reported in the literature due to their resemblance to other interview-based studies (Thomas, Allison & Latour, 2018) and also by being cost-effective (Chu & Snider, 2013, Yuan, Bare, Johnson & Saberi, 2014).

Sample and participants.

Purposive and snowball sampling strategies were employed (Streubert & Carpenter, 2011). The inclusion criteria were as follows, 1) Accounts had to be from younger adults who had experienced stroke between 18 to 45 years of age, 2) Accounts had to be available in the public domain, 3) They had to be written in English, and 4) They should address rehabilitation or related experiences. Publicly available digital sources such as websites, films, blogs, videos, e-books, Twitter and Instagram posts were searched for the period 2016-2020.

Approximately 90 sources that did not detail the person's age, or were not available in English, were excluded. One book, written by a young adult in 2004 was included as it was considered a key source of its kind. The search followed key terms, including, 'young stroke survivors', 'stroke', 'young', 'experiences', and in terms of social media #stroke, #youngstrokesurvivor. Using these key words, a range of accounts were identified, and data were retrieved via the Internet. Therefore, the accounts emphasised what younger adult stroke survivors had considered important to share, and detailed what information they had made available in a format that they considered appropriate or likely to reach a wide audience. Figure 1 shows a flow diagram of the study and data sampling summary.

Insert Figure 1 about here.

Data collection

Data collection was carried out between March and June 2020 during which time individual accounts from the different digital sources were identified, purchased (if necessary) and retrieved from the internet by four team members (LA, HC, UM, PJ). Individual accounts from blogs and websites were transformed into PDF files, while social media posts were retrieved and converted into Word files to be stored and analysed further. Autobiographical books were also referred to when suggested in the individual accounts and purchased for access. A detailed account of data gathering was carried out as the number of sources soon grew. See supplementary file 1.

Insert link to supplementary file 1 here

The accounts being identified were characterised initially by gender, age, country and type of data source. Ongoing analysis of individual accounts led us to characterise the sample in terms of reported stroke diagnosis, as well as relevant gaps or issues regarding stroke care or rehabilitation provision. However, as the individual accounts were collated from the public domain, and not produced solely for this research study, the character of these data did include some gaps when information was not made available, or not reported, as part of the younger adult's accounts.

Ethical considerations

Ethical guidelines provided by The University of Edinburgh and the Association of Internet Researchers (Franzke, Bechmann, Zimmer, Charles & the Association of Internet Researchers, 2020, The University of Edinburgh, 2019) were followed. Research Ethics Committee approved the study on March 3rd, 2020 (Ref Staff 173). Although no informed consent process was performed due to the data being available in the public domain, awareness of the project was raised through social media accounts (Twitter and Instagram) and via a project website. These sources hosted an open invitation for further contributions to the set of narratives either via anonymous internet link or through contact with the project team for advice, direction (and support, if necessary) as to how additional views could be added to the project. However, no additional accounts were obtained by this method. Where possible, comments were added to participant's social media accounts acknowledging that their experiences had been identified within the project search, and provided a link to the web page should they wish to know more about the project or have their views removed. All data were anonymised for research reports and publications.

Analysis

A combination of narrative and multimodal analysis was used to examine the data set (Jovanovic & Van Leeuwen, 2018; Riessman, 2008) by two researchers (LA and HC), who have experience both as critical care nurses and in the use of qualitative methods. Another two colleagues (UM and PP) also collaborated in the analysis of data, focussing in particular on Twitter and Instagram. The focus of our analysis was on how younger adults constructed their post-stroke & post-rehabilitation identities across different media (Jovanovic & Van Leeuwen, 2018; Riessman, 2008). In addition, regular meetings between the research team members were

carried out to encourage discussion regarding analytic decisions. The main research question guiding the analysis was ‘What are the experiences of younger adult stroke survivors in terms of rehabilitation and recovery?’.

In examining these data using this approach, the richness of younger adult survivor’s experiences emerged from an individual perspective and in a format and style that had made most sense to them. Collective experiences were also identified for this age group.

It was evident from the point of initial analysis that most accounts of stroke were presented as a journey. As a result, a storyline pattern soon became apparent, within which issues such as the purpose, meanings and challenges for younger adults throughout stroke rehabilitation were identified (Riessman, 2008). This preliminary data were discussed within the research team and helped to refine the ongoing analytical process, highlighting further the differences between what was being presented from an individual perspective and the nature of younger adult stroke survivors’ experiences overall.

Accounts from all sources were imported, managed and analysed in the QRS-NVivo 12 software. A research journal was also created to allow follow up on the progress of analysis, as well as to develop insights and foster discussion within the research team. Written narratives were analysed and coded, while images or videos with speech were analysed as combinations and integrated within recurring codes and categories. Regular meetings were carried out with the research team to discuss these emerging ideas, codes and categories. Using this approach, the data set mapped the full range of available accounts, and as well revealing the intended purpose, sometimes more latent message were also identified (Riessman, 2008; Streubert & Carpenter, 2011). Analysis progressed by clustering the codes into categories that represented meaningful events in the rehabilitation journey following the stroke event in younger adults (Mattingly 2012). The categories created were used to capture individual perspectives, as well as an overall account that captured the diverse range of experiences being revealed by these younger adult stroke survivors.

Patient and Public Engagement.

A group of six younger adult stroke survivors and carers from across the UK were consulted during the study, forming the YARNS Advisory Group (The University of Edinburgh, 2020).

This group met online on a monthly basis and provided service-user representation as well as feedback on relevant issues as the study progressed. Initial results were shared online through pre-recordings for the Advisory group to reflect on whether the results being presented resonated with their own experiences. It should be noted that some of these volunteers had experienced aphasia as well as other cognitive impairments, and so we employed digital resources intentionally to facilitate their participation. Sending the pre-recordings with subtitles, as well as some question prompts prior to meetings, and providing them with an opportunity to review the material and reflect on its implications at their own pace was important. During online project meetings their insights and feedback were explored and summarised and then included in the results, highlighting points of resonance from the study with their personal experiences of stroke. As a result, the findings are presented in an integrated way so that the accounts elucidate the experiences of younger adult stroke survivors collectively, whilst also pointing out individual differences where relevant.

Rigour

Rigour in this study followed the criteria offered by Lincoln & Guba (1985). Credibility was developed and tested with the help of the YARNS Project Advisory Group, discussing the findings with members and incorporating their comments and feedback. Dependability was judged in line with triangulation of the different types of data being employed, including written narrative formats, videos and images. Confirmability was encouraged throughout the research process with regular meetings between members of the research team and advisory group where the emerging analysis and findings were presented to arrive at a consensus. The transferability of this study can best be assessed by readers when considering our data and the range of accounts accessed from the public domain. Addressing trustworthiness in this study was relevant and the above quality measures were employed to help strengthen the study outcomes (Streubert & Carpenter, 2011).

Findings

The study gathered 117 accounts from 103 younger adult stroke survivors, mostly from the United Kingdom. See table 1.

From an analysis of these narratives, 20% reported explicit communication difficulties such as aphasia (n=13) and dysarthria (n=8). Whilst the primary purpose of accessing these experiences was to understand stroke and rehabilitation in younger adults, there was also the hope that future effort could be directed towards supporting younger adult survivors, and their families. The overarching theme of 'journey' was identified and this was used to present the findings. Figure 2 presents the stroke recovery journey in a conceptual form.

Insert Figure 2 here

The experiences of younger adult stroke survivors are presented as an emotional journey during which a new and 'evolving sense of self' emerged:

I have written my story to encourage and give hope to anyone who had faced, or is facing adversity (33, Female, Book).

'I'm on the most incredible, emotional, determined & best journey of my life' (40, Female, Charity Website).

The evolving self

The former self

Younger adult stroke survivors commonly focused on their previous lives in order to demonstrate how the stroke event had impacted their identities, often this involved emphasising the emergence of a new sense of self:

Before any of this my life was perfect. I was at college studying 3D design, I had loads of friends and loved going to music festivals. I was just so full of life and potential. (Female, 18, Charity Website).

I've had two lives, my first life ended in the 1990's, when I had a severe stroke at the age of 39 (Male, 39, Video).

Having a stroke at an early age had a significant impact on these people's lives, particularly at an age when most were beginning the transition to independent adulthood. Individuals described how they had felt their lives were at their peak at this time in terms of careers and family life. Photographs were commonly used to demonstrate active, fit and healthy young

adult lives previous to the stroke. Stroke is marked out as a significant life event that impacts their sense of self, as well as confidence, independence and autonomy. Its occurrence is often remembered in great detail using reconstructions of key events.

The onset – and the stigma

The journey of younger adult stroke survivors was defined by the onset of the illness event, which itself depended on the nature of the stroke. An absence of reporting of the type of stroke experienced was identified in 44% of the accounts. Of those younger adults who had provided this information, 26% had suffered ischemic stroke either secondary to patent foramen ovale (PFO) or neck artery defect. Haemorrhagic stroke was reported by 17%, while 13% described other reasons. However, a common finding was the initial response of health professionals:

My GP [General Practitioner] diagnosed me with a bad migraine and sent me home (Male, 23, Charity Website).

One-third of the younger adult's accounts reported either a belated diagnosis, or a misdiagnosis of their stroke (n=31). Statements such as 'only older people get strokes' was reported often. The stigma associated with stroke in younger adults emerged as it was only seen as relevant to older adults. This was also thought to be why some healthcare professional had difficulty in identifying the onset of stroke in these younger adults:

I think, Yes, I was right! I am ill – and they didn't listen to me. I hope the nurse feels really bad – the one in A&E who shouted and accused me of being on drugs! (Female, 35, Book).

Although I was diagnosed as suffering from extreme vertigo the doctors requested an outpatient MRI a few weeks later. This showed that I had suffered a minor stroke and also showed previous cerebellar infarcts (Male, 30, Charity website).

Experiencing these difficulties had motivated them to share their accounts and increase awareness among clinicians and policymakers about the inadequate assessment and identification of stroke in younger adult populations. Younger adult stroke survivors reported not being believed at the time of initial symptoms and would show pictures of MRIs or other scans to validate their experience, and eventual accurate diagnosis:

I was then referred for a trans-oesophageal echocardiogram (T.O.E.) which is a more detailed scan of the heart [..]The TOE confirmed the presence of a patent foramen ovale (PFO). It also confirmed that I have an atrial aneurysm which I understand increases my risk further (Female, 40, Website).

Such accounts were often driven by a strong emotional response and, in this way, stressed the struggles to comprehend, often once in the hospital setting, how and why they had suffered a stroke. Confirmation of the diagnosis of stroke was a milestone moment for these younger adults:

I can vividly remember the moment that I learned it would be at least a year before I was back to my 'normal' self. My heart broke (Female, 21, Website).

This came as a massive shock to me, and I certainly did not fully digest the diagnosis for a while – I thought there must have been a mistake! (Male, 30, Website).

The initial diagnosis was characterised by incredulity and perplexity at having had a stroke at such a young age as well as the long process of rehabilitation and recovery that lay ahead. Feelings of shock and being 'broken', as well as multiple relevant symptoms having been missed, were common in many accounts; a finding that reflects the emotional impact of stroke on young adult survivors as well as their family and wider social networks.

Being supported: the role of the stroke nurse

As impactful as these issues were regarding initial events and emotions associated with their diagnosis, the stroke nurse emerged from these accounts as one of the critical figures in supporting younger adult stroke survivors:

I was met by a wonderful nurse called (name) and from reading his badge he was from the Brain Attack Team. He told me not to worry, that I would be OK and then I went for a CT scan (Female, 42, Charity Website)

My nurse, (name), played a major role in my recovery and rehabilitation; she arranged a cognitive assessment for me at the rehabilitation centre and provided me with all the information and advice I could ask for – and I felt that the doctors had failed to provide (Female, 21, Charity Website)

The stroke nurse was described as a key figure from the initial identification of a stroke, and throughout all information and communication process as well as in the provision of emotional

support throughout the rehabilitation process. The role of expert nursing could also be seen to have impacted positively from the point of suspicion of stroke:

‘The ambulance staff said it wasn’t a stroke, but just then a stroke nurse was going off duty overheard us, and I was seen. She said ‘Lift your leg’. I couldn’t, and when I tried to drink, the water came straight back out of my mouth. Before I knew it I was in a scanner and then on my back for 24 hours.’ (Male, 36, Charity Website)

The role of the multi-disciplinary team in explaining the diagnosis, its potential causes and consequences of the stroke event was also highly relevant for most younger adult stroke survivors. Their willingness to understand what had happened could make the experience a frustrating one, especially when only vague or inadequate information was provided. The majority of these young adults had feared, or had actually experienced, a second neurological event; therefore, having access to accurate information and support was paramount.

Rehabilitation – An ongoing process

The rehabilitation process is acknowledged as one of the most challenging aspects of surviving a stroke event. The analogy of rehabilitation as a journey hints at the uncertain nature of a process that usually identifies short and longer-term goals, as well as expectations and aspirations that may have been threatened by this neurological event. Stroke was also deeply embodied in younger adults through the sequelae of damage to the brain and the emotional consequences of this life-changing experience:

Recovery for me has been a massive journey, even now, six years after, I’m still in recovery (Female, 27, Videos).

Rehab was the key to my recovery (Male, 40, Website).

Physical, cognitive and sensorial difficulties were often intertwined with rehabilitation and the emotional and social consequences that impact at the core of younger adult stroke survivors’ lives. They include numerous changes that altered the physical capabilities of their body, as well as views about life, their intimate network, employment and social networks:

Stroke affected my life dramatically (Male, 28, Video).

As is evidenced in the language used in these narratives, younger adult stroke survivors spoke about rehabilitation as a process of recovery in its widest sense. Some reported struggling with their new physical limitations and focused their efforts on achievable rehabilitation goals and restitution with their past selves. Sharing such experience with other young adult survivors was important:

My advice to others facing a similar experience would be to talk to other stroke survivors in the first few months and to keep a check on the mental side of things. Stroke has a way of forcing you to prioritise your thoughts and your life. (Male, 40, Charity Website)

The hope of regaining some capabilities lost by the stroke characterised the early stages of rehabilitation and the possibility of returning home represented an important bridge to be crossed.

Challenges at home

Home is the most familiar and comfortable place mentioned by younger adult stroke survivors to return to during rehabilitation that helped them to regain a sense of normality in their lives. However, some did struggle when remembering life before the stroke and the challenges that they now faced in their once familiar home environment:

I couldn't wait to get home, but as soon as I did, I had an overwhelming sense of fear and panic (Female, 25, Website).

I found returning home harder than I thought; I felt more anxious and less safe (Female, 23, Website).

Accounts revealed insights into the excitement of first being home and the initial challenges to be faced. All represented major achievements when overcome. However, being at home also implied having to acknowledge the reality of what had happened and the consequences of stroke for their daily lives, family and social network:

I was discharged two days later and that's finally when everything hit me. I was terrified of being back home (Female, 36, Website)

I was discharged after three days and went back home – and then the real effects hit
(Male, 36, Website)

Feelings expressed about this time included fear, panic and anxiousness, which may represent the realisation of how much life had now changed for these young adults:

I was finally discharged, still unable to walk or get any functional use from my left limbs – and “home” was another unknown quantity (Male, 35, Website).

Adequate support, provided by stroke discharge and rehabilitation teams, can have a significant impact on the way that these young adult survivors cope with daily challenges and navigate the phase of adaptation and reintegration following stroke. When professional and social support are present, challenges may be addressed in an environment that feels both comfortable and safe to cope with the rehabilitation of the changed self:

‘Now I’m home. So, this is the new me now!’ (Female, 27, Instagram)

But across all things about me, myself and outlooks all felt a little different (Male, 35, Website).

Often young adult stroke survivors spoke of ‘the new me’, which represents a further transition process and acceptance of a sense of altered selfhood. This new evolving self is one of the main rehabilitation challenges that young adult stroke survivors face. The aftermath of stroke introduces a new set of priorities that can lead to alteration and reconfiguration of life in unexpected ways. However, dealing with this new self is not always easy:

Who am I now? (Female, 34, Film)

Those that know me know that this is my major problem. I'm sorry if my behaviour has ever affected our friendship. I'm working very hard to improve my mood.
#MentalHealth #BrainInjury #Stroke #LifeAfterStroke #SelfHelp #CBT

Community rehabilitation experiences

Community rehabilitation was described as a series of complex interventions taking place at different levels with the GP leading the process and referrals to a range of services, as well as

in-patient rehabilitation centres, private rehabilitation professionals and group support when available:

It was then that my dentist referred me to an excellent GP and things started to improve. I honestly don't know what I would have done if this hadn't happened. This GP changed the direction of my recovery and my life (Female, 28, Website).

I received no physical therapy as I was deemed physically able and not restricted by the occupational therapists, no matter how much I tried to tell them that I wasn't. This assessment was also done before the MRI scan which revealed the stroke. After the MRI confirmed the stroke, I still didn't have any therapy (Male, 23, Website).

Young adult stroke survivors reported feeling well connected to some rehabilitation services in the community, although these could vary according to availability and the resources invested in them. Long waiting lists to access rehabilitation facilities was a recurring problem for these young adults. One way to overcome limited access was through private rehabilitation services, if affordable and available. The majority of accounts reported adequate access to rehabilitation services when physical or speech difficulties were the primary concerns. However, rehabilitation challenges could also include cognitive or other less visible disabilities:

Fatigue is the worst at the moment.. (emoji) It is not like 'I feel tired' sort of feeling but it is a #fatigue that takes over your body and mind (Female, 24, Instagram).

Accepting help from others and not being ashamed to ask for help has been important too (Female, 28, Website).

Transitioning from complete independence to having to rely on others for essential daily activities, including self-care, required a significant resetting of goals and expectations during the rehabilitation process. These data revealed that young adult stroke survivors felt isolated from stroke services where they did not 'fit' as a result of their age. Hence, initiatives such as support groups for younger adults, when available, did provide a useful resource to help cope with challenges and enhanced the perception that emotional support did exist. Sharing experiences with others young adult stroke survivors helped to build a sense of belonging and provided collective support during recovery and rehabilitation:

My first post on the group was a very depressed one – I was offered so much support and reassurance from the group – tips on how to manage the after-effects down to music recommendations that helped to calm anxiety! It's lovely to talk to people going through the same things and getting that reassurance. I never realised how common strokes were, especially in younger people (Female, 25, Website).

Social media also offered platforms where young adults could feel more confident to participate and share their rehabilitation experiences with others, supporting each other during their recovery from stroke:

19 months post stroke and I am 900 metres high reflecting on my journey on the edge. Fight every day to get back what you lost, and it will happen (Male, 36, Twitter)

Smaller and neater! Such a good feeling to see improvements! (Female, 27, Instagram)

Coping with a new self

The sense of personal growth that could also occur as a result of the stroke experience in young adults was grounded in the need to be supported in the ongoing process of recovery and rehabilitation, and was described in emotive ways:

New existence, new dynamic – endless possibility (Female, 34, Film).

I have learnt to accept the new me and so have my family, which is great (Male, 36, Website).

Young adult stroke survivors usually seemed able to embrace their changed selves following rehabilitation and could describe new possibilities for their lives going forward. They described an enhanced sense of personal growth and a resilience that impacted their personal and social lives:

I say life is tough, but I am in a much better, stronger place both physically and mentally now. I have an amazing family (another baby on the way too – my son). I have a great job and I just take it day by day (Male, 27, Website).

I'm so proud to be launching this charity to support fellow Stroke Survivors. Please follow our journey and get involved! (Male, 39, Twitter)

Various associations and charity platforms provided additional supportive spaces through which young adult stroke survivors could engage and help others. The possibility of getting involved and supporting others undergoing rehabilitation following stroke was an essential aspect of their evolving sense of personal growth:

I have been so dedicated since recovering from my stroke to give back and use my able bodied-ness to help others in a worse position than me. (Female,17, Charity Website)

The imperative to strengthen person-centred rehabilitation services for young adult stroke survivors was also emphasised:

The story would end but not the experience/journey (Female, 34, Film).

I have been working with [anonymised institution] to share my experience and make sure that there is “no life half lived”. This is the new me and my new life. Recovery will still happen for years to come (Female, 40, Website).

Discussion

Mapping the digitally available accounts of young adult stroke survivors has provided valuable insights into their experiences and needs throughout the post-stroke journey. Gathering data from the public domain, in such different formats, facilitated the inclusion of young adults with a range of communication difficulties (20%), significantly higher than the 10% reported in some other studies (Graham, Pereira, & Teasell, 2011; Naess, Hammersvik & Skeie, 2009).

Describing the whole stroke experience as a journey helped to facilitate a reflexive perspective and allowed participants to make sense of what had happened and what they considered important to share in public (Beal, 2013; Riessman, 2008). Frank (2013, p.18) asserts that telling stories about illness events are attempts ‘to give a voice to an experience that medicine cannot describe’. Furthermore, this study has highlighted that stroke rehabilitation is a unique and personal experience that evokes powerful emotional impact as a result of how young adult’s lives are changed. This goes beyond focusing only on which rehabilitation services required. Our findings align with the perspective raised by Barnes (2003) about the need to rethink neuro-rehabilitation and to ground it in a person-centred approach.

The complexities underpinning the process of recovery and rehabilitation were highlighted primarily through the impact of stroke and the resultant new sense of self for these young adults. The implications of stroke impacting on the sense of self and identity is not new (Arnaert, Filteau & Sourial, 2006; Arntzen, Hamran & Borg, 2015; Pallesen, 2014) nor is the emphasis on the pre-stroke self (Morris, Oliver, Kroll, Joice & Williams, 2015). However, in this study, although stroke was described as life-changing, these young adults also reflected on rehabilitation as heralding possibilities for a new and evolving sense of self-worth with the regaining of confidence, independence and autonomy.

Arnaert et al. (2006) described the concept of ‘self-healing’ as a turning point in a survivor’s illness experience where suffering and despair can transition into hope for a better future. The relevance of spirituality as a vital source of hope for some is also emphasised. The profound consequences of stroke in young adults’ lives (Murray & Harrison, 2004), reveals a series of unmet physical and emotional needs emerging from the point of diagnosis onwards. Martinsen's et al. (2015) conducted a phenomenological interview study with 16 Norwegian stroke survivors, of whom seven were young adults (21-44 years of age). Their findings echo with our own as they also drew attention to the struggles of stroke survivors to access follow-up services, including flexible rehabilitation input that responded to individual life situations.

The onset of the stroke experience in this study was described as problematic and is an important finding to emphasise. Serious issues regarding early stroke identification and delays in diagnosis were emphasised in 30% of these accounts. Belated confirmation, or the misdiagnosis of stroke were, in part, attributed to the stigma associated with stroke as a condition expected only in older populations. This may be particularly important as a finding for healthcare professionals seeking to improve the diagnostic experience in younger adults. Stigma associated with stroke has been reported widely in the literature (Leahy et al., 2016; Maratos, Huynh, Tan, Lui & Jarus, 2016; Murray & Harrison, 2004), and suggests the need for more awareness on the presentation of stroke symptoms in young adults. There is now the opportunity to co-design education that raises the profile of stroke diagnosis as well as its impact on younger adult groups. It is also important to encourage more young adult stroke survivors’ voices to be heard, especially if age-appropriate stroke services are being developed.

McGuinness et al. (2010) point out that one role of the nurse is to provide a liaison function during stroke rehabilitation and the key role played by expert stroke nurses emerged in these findings. Similarly, Kirkevold, Martinsen, Bronken & Kvigne, (2014) argued that complex interventions, including psychological support, will promote psychosocial health and wellbeing during stroke rehabilitation and our findings concur with this.

Acknowledging how the stroke experience will impact in different and complex ways should be incorporated into recovery plans and discussed openly with young adults, their social networks and health care teams. The way that multidisciplinary teams support this process is one of the questions that needs to be explored further when providing age-appropriate stroke rehabilitation for young adults.

Services must also tackle the rising incidence and the needs of all stroke survivors; our study highlights the particular needs of younger adult groups. The projections for the European Region estimate an increase of 27% between 2017 and 2047 of people living with stroke (Wafa et al., 2020). Health services will need to be adept at developing age appropriate, person-centred models to underpin stroke rehabilitation programmes. There is also the impact of the Covid-19 pandemic to consider as we look to developing agile rehabilitation services for an increasing number of people experiencing stroke in the future (Fifi & Mocco, 2020). The UK Stroke Association has estimated that the incidence of stroke is already occurring about six years younger than normal during the Covid-19 pandemic (Stroke Association 2020). A multi-dimensional approach may be particularly relevant as this study has shown that young adults report unique problems in accessing help. Age-appropriate models of stroke rehabilitation are needed to address the complexities of physical, cognitive, sexual, emotional, social and financial recovery (Cotoi, Batey, Hussein, Janzen & Teasell, 2018; Kuluski et al., 2014; National Institute for Health and Care Excellence (NICE), 2013). The opportunity for a new (and sometimes better) life post-stroke, both in an emotional and physical sense, resonates with the transitions identified in our study between the past, evolving and present self being at the core of rehabilitation for young adults following stroke.

Limitations

The accounts were gathered from public and digital sources available and published during the period of 2016-2020 only. This means that we may have excluded other equally relevant accounts, although we did include an open invitation through the YARNS projects' social

media and website platforms to increase participation. These resources were not used but could offer an alternative source of online recruitment in future research. The sample represents only English-speaking accounts, mostly from the UK, which may locate findings in this specific cultural and health policy context. Moreover, most of the young adult accounts were written by females, which may add a risk of gendered bias. In essence, however, these findings reflect what young adults considered important to share using public digital formats.

Therefore, some caution should be exercised about generalising from these findings, and further research is now recommended to evaluate age-appropriate services for young adult stroke survivors, including the rehabilitation and support needs of this age group.

Conclusion

This study of young adult stroke survivors' experiences using digital accounts provides new insights regarding the need for age-appropriate stroke rehabilitation services. Issues such as the stigma associated with stroke in younger adults, improvements in how stroke services are delivered as well as investment in age-appropriate stroke rehabilitation research programmes are pertinent in light of these findings (Maratos et al., 2016).

Central to empirical research studies in the future will be highlighting the role that the expert stroke nurse plays in supporting young adults who face the challenge of stroke and are seeking to move forward with their life. Building an empirical research base will help to inform clinicians, educators and policymakers of the specific age-related rehabilitation needs of younger adult stroke populations. Adopting a person-centred perspective within age-appropriate stroke care could, in turn, help to encourage innovative practice to benefit younger adult age groups. The study challenges current health policy that focuses primarily on older stroke populations and we call for greater awareness of the profound impact that stroke can also have on younger adults.

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