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Identity Continuity in the Face of Biographical Disruption: 'It's the same me'

Barbara Wolfenden^{1,2} and Marty Grace³

¹ La Trobe University, Melbourne, Victoria, Australia

² Florey Institute of Neuroscience and Mental Health, Melbourne, Victoria, Australia

³ Victoria University, Melbourne, Australia

In Australia, 20% of stroke survivors are aged less than 55 years. These younger survivors value age-appropriate, identity-affirming goals, such as resuming employment. This article reports on a small qualitative research project that explored the experiences of young, higher functioning stroke survivors in re-establishing identity and returning to work. The participants understood identity as both an inner sense of self and as socially and discursively constructed. The research found that the participants actively pursued identity continuity while managing biographical disruption. Resumption of life roles and responsibilities were important for identity re-establishment, but fraught, particularly the return to work. The findings suggest that psychosocial rehabilitation could play a greater role in supporting survivors' resumption of valued life roles, including return to work.

Keywords: stroke, return to work, biographical disruption, identity continuity, psychosocial rehabilitation

Introduction

Stroke is a serious and disruptive event in the lives of survivors and their families. While stroke affects mainly older people, 20% of all survivors in Australia are aged under 55 years (NSF, 2010). Understandably, services are geared predominantly to the older age-group. However, working-age stroke survivors suffer disruptions to their identities and abilities in relation to age-appropriate roles, such as employment. For these young survivors, recovery goals often relate to raising children, mortgage repayments, employment, and marriage or life partnership (Lawrence, 2010; Morris, 2011). According to Ellis-Hill, Payne, and Ward (2008), identity following stroke is particularly fluid, often fractured and undergoes cycles of transition over the longer term. The first cycle begins with post-stroke rehabilitation, and other cycles follow as the individual returns home and endeavours to re-engage in chosen roles and activities.

In the past, biographical disruption has been the main concept informing psychosocial rehabilitation post-stroke. It refers to both the impact of sudden chronic illness on an individual's identity, and how individuals adjust to their condition (Cott, Wiles, & Devitt, 2007; Habibis, 2009). However, *identity continuity* is emerging as a key concept in stroke rehabilitation research (Haslam et al., 2008; Sani, 2008; Sedikides, Wildschut, Gaertner, Routledge, & Arndt, 2008). While both biographical disruption and identity continuity acknowledge the disruption of stroke, the recent work places more emphasis on the subjective experience of the survivor and the desire to achieve continuity, rather than the main focus being on loss and adjustment to loss. The research reported in this article is inspired by this interest in the subjective experiences of stroke survivors. This small qualitative study set out to explore the experiences of young, higher functioning survivors of stroke in returning

Address for correspondence: Professor Marty Grace PhD, MSW, BSW, Social Work Unit, School of Social Sciences and Psychology, Footscray Park Campus, Victoria University, PO Box 14428, Melbourne 8001, Australia. E-mail: marty.grace@vu.edu.au to work, with a particular focus on identity reestablishment. By 'young, higher functioning survivors of stroke' we mean stroke survivors below retirement age who recover adequately to engage in paid employment, higher education and/or the responsibilities of parenting and other care work.

Literature Review

The concept of identity has been understood in various ways, including as an 'internal project of the self', and more recently as interactive, developing socially and discursively (Benwell & Stokoe, 2006, p. 17). Contemporary work recognises identity as fluid, fragmented and relative, always changing and discursively constructed (Benwell & Stokoe, 2006). Within stroke rehabilitation, the concept of biographical disruption emphasises the threads of meaning that persist through life, with serious illness disrupting the predictable course of adult life (Habibis, 2009). The concept of identity continuity also recognises the persistence of threads of meaning, but normalises disruption and re-construction, taking up contemporary ideas about the fluidity of identity, even in the absence of a major disruption such as stroke (Gracey et al., 2008; Haslam et al., 2008; Sedikides et al., 2008). The Life Thread Model employed by Ellis-Hill et al. (2008) suggests that the challenge of identity re-construction post-stroke is like a magnification of normal processes rather than being seen as an abnormal process. According to Ellis-Hill et al. (2008), the combination of the many life threads or stories constitutes a life-story or identity. These stories or threads are influenced by cultural values or norms, and thus 'identity and sense of self . . . are created and constantly recreated between people' (Ellis-Hill et al., 2008, p. 153). These threads or stories contribute to a sense of coherence and stability, establishing continuity between past and future. According to Ellis-Hill et al. (2008), identity re-establishment in stroke recovery involves retaining and restoring some life threads while replacing others, endeavouring to secure quality of life. Haslam et al. (2008) emphasise the social aspects of identity continuity:

Where individuals have a strong sense of social identity and this can be preserved in the context of cognitive and social upheaval, this appears to increase the likelihood of their being able to cope with, and adjust to, change. (Haslam et al., 2008, p. 684)

Mold, McKevitt, and Wolfe (2003) highlighted the serious consequences of an absence of rehabilitation that focuses on re-establishing identity, suggesting that rehabilitation should provide a safe, secure and supportive environment in which to explore and develop a new sense of self post-stroke. If this is not provided, the individual may encounter a sense of recovery being delayed and of not being enabled to learn new ways and adapt to the residual effects of their stroke, or accept their adjusting identity. Other recent work recognises the role of ongoing psychosocial rehabilitation following stroke, including the need to acknowledge and work with the individual self-determination of the stroke survivor (Alaszewski, Alaszewski, Potter, & Penhale, 2007; Medin, Barajas, & Ekberg, 2006); the importance of a client-centred approach, recognising the stroke survivor as holding individual expertise regarding their condition (Cott et al., 2007; Ellis-Hill et al., 2008); and the usefulness of an ecological approach that takes account of social context (Baum, Christiansen, & Bass-Haugen, 2005).

Literature addressing return to work following stroke has grown in the past decade, with some recognition of the value of this endeavour to identity (Alaszewski et al., 2007; Morris, 2011). However, no literature specifically addresses in depth the interactive impacts of returning to work in combination with identity re-establishment after stroke. The research reported in this article explored and documented experiences and perspectives of young, higher functioning survivors of stroke. This research, through contributing to increased understanding of their experiences, provides insights relevant to stroke rehabilitation policy and practice.

Method

This research took a critical interpretivist approach (Sarantakos, 2005). It has a critical political intention to make life better for a disadvantaged group, young stroke survivors. It is interpretivist in that it focuses on experiences of participants, and the meanings they attach to those experiences. The research questions guiding this project were:

- 1. Do younger stroke survivors perceive a change in identity post-stroke, and if so, what meaning do they give this experience?
- 2. What factors are perceived to have influenced identity re-establishment?
- 3. What are the experiences of identity reestablishment and returning to employment for young survivors of stroke?

Recruitment and Sample

A purposive sample of five young, higher functioning stroke survivors was recruited by advertising in the Australian National Stroke Foundation (NSF) *StrokeConnect Forum* (online

discussion site) and the Friends of NSF Newsletter. Participants were provided with the interview questions ahead of interview, prior to giving informed consent for their involvement in the research. In order to ensure that the participants were young, higher functioning stroke survivors who could reflect on their experiences with returning to work following stroke, the following criteria for participation were established: (1) aged between 21 and 55 years; (2) experienced stroke 1-10 years ago; (3) returned to paid employment within 10 years of stroke, although it was not necessary to have sustained employment; and (4) expressed an ability and willingness to reflect on post-stroke experience, including identity and return to work. The research was approved by the Victoria University Ethics Committee. Pseudonyms are used to protect participants' privacy.

Data Collection and Analysis

Semi-structured, in-depth interviews with the five participants included questions about work and commitments prior to stroke, the perceived benefit of stroke rehabilitation to recovery goals, the experience of returning to employment, any perceived impact of stroke on identity and any suggestions to make these processes easier. Interviews were digitally recorded and transcribed verbatim.

Some possible themes were identified following interviews, and more emerged during the coding process, some of which corresponded with the literature. Analytical memos were created during coding, and stories that participants told about their experiences were identified. Each theme was examined, and the report of the findings was prepared based on this analysis of the data.

Findings

In this section we present an introductory vignette in relation to each of the five participants, who were aged between 34 and 44 years at the time of interview. We then go on to discuss the themes that emerged from the interview data, including participants' perceptions and definitions of identity, threats to identity, resumption of life roles and responsibilities, challenges involved in returning to work following stroke, and the idea of one enduring identity. The rich qualitative data add to understanding of identity re-establishment involving the important transition from post-stroke to return-towork.

Phoebe. Phoebe is married with two children. She holds a degree in urban planning and was working three days per week in this field when she experienced stroke. At the time of interview Phoebe

was aged 45 years, having experienced stroke 12 months earlier. She reports that when admitted to hospital she was not expected to live but was given tissue plasminogen activator (tPA) to break up the blood clot causing the stroke. She was transferred to a public rehabilitation facility for 3 weeks. She was significantly younger than other inpatients. Phoebe remained an outpatient for another 8–9 months, while gradually re-engaging in her professional work role supported by an occupational therapist and neuropsychologist. Initially she attempted to increase work hours too quickly. Her hours were subsequently reduced and then gradually built back to her pre-stroke capacity.

Nancy. Nancy is married with two adopted adult children and two young children. She holds a Bachelor of Applied Science and was working in a senior position in a government department, 3 days per week when she experienced the stroke. At the time of interview Nancy was aged 35 years, having experienced stroke 21 months earlier. Nancy reported that initially her stroke was misdiagnosed as inner ear infection; after 3 months of periodic presentation at the Emergency Department of her local hospital, cerebellar stroke was diagnosed, along with a patent foramen ovale (PFO) congenital heart deformity. During these 3 months Nancy continued to work. Following stroke diagnosis Nancy spent 2 weeks in hospital. No rehabilitation was offered on discharge. She and her husband sought rehabilitation professionals through their networks. Nancy undertook 2 months of rehabilitation. At the time of interview Nancy was employed in her pre-stroke role, working pre-stroke hours, and had graduated with a Masters degree that she had commenced prior to the stroke.

Michelle. Michelle was aged 37 years at the time of interview, having experienced stroke 9 years earlier. At the time of her stroke, she was married, pregnant and employed in accounts administration. Michelle reported that when she presented to hospital, her symptoms were considered pregnancy related and she was sent home; 5 hours later she experienced full stroke symptoms and miscarried. She was admitted to a public hospital on a ward with patients she described as 'really old people'. Michelle reported that the blood disorder, antiphospholipid syndrome, was also diagnosed at this time. Michelle spent 1 week in hospital before completing her rehabilitation as an outpatient at two public rehabilitation hospitals for a couple of months. She received physical, but no psychosocial rehabilitation. Michelle experienced financial and housing insecurity, reporting that the Australian national income support agency, Centrelink, would not assist her. Michelle was determined to re-establish independence and carry a baby to term. Almost 10 years later, following a further five miscarriages, Michelle achieved this, and at the time of interview was employed part-time in accounts.

Wendi. Wendi was aged 43 years at the time of interview, having experienced stroke 4 years earlier. She was married and a qualified gym instructor holding a Certificate III in Fitness. She had two jobs, one in customer service and a second in office management. Wendi was home alone when she had her stroke and waited for 36 hours before being found and receiving stroke intervention. Following acute care hospitalization, Wendi was transferred to a public rehabilitation hospital for 7 weeks. She reported lacking psychological support following discharge and subsequently experiencing changes in mood which impacted adversely on her marital relationship, resulting in the end of that relationship. Wendi did not work for 7 months following stroke and reported that Centrelink would not assist her. Instead she exhausted her savings. Her return to work within her customer service role and as an administration assistant was well supported by managers and colleagues. Following stroke and her return to work, Wendi studied Certificate IV in Training and Assessment and at the time of interview was teaching Certificate II level at an institution for technical and further education (TAFE).

Tracey. Tracey was aged 37 years at the time of interview, having experienced stroke 3 years earlier. She holds a Certificate IV in Massage Therapy and a Diploma in Aromatherapy. She was working in the hospitality industry while establishing her own business as a massage and aroma therapist. Tracey reported that her stroke occurred during an allergic reaction to an injection administered by her doctor. She was admitted to a regional hospital and was transferred to a large public rehabilitation hospital where she spent 6 months, before returning as an outpatient to the regional hospital for rehabilitation for another 12 months. Tracey sold her house during rehabilitation and moved in with her parents. She could not return to massage work as she no longer had fine motor movement in her hands, and she also experienced a severe limp, both of which inhibited the delivery of massage. Tracey secured a position as an integration aide at a primary school, but did not have adequate stamina for full-time work, and negotiated part-time hours. She reported that Centrelink demanded compliance with fulltime employment, despite assessment by health professionals stating that Tracey could not yet sustain full-time work. Tracey enrolled in a Bachelor of Education course through distance education, and transferred from general income support (Newstart) to financial support for study (Austudy). At the time of interview Tracey was preparing to undertake the final components of her course, including professional practice placements.

Participant Perceptions of Identity

All participants experienced a fluid, evolving sense of identity following stroke. However, they resisted being defined by their stroke, seeing identity as a sense of self that transcends physical capabilities. For example, Wendi's identity reflects her inner self:

My identity is me as a whole package; you know, my emotional, intellectual, physical; all that is my identity of who I am. (Wendi)

Phoebe did not identify with being disabled, and she was determined to restore her identity as functional despite impairment:

The thought process inside my head was, 'Disability is other people and disability isn't me. I'm not disabled and I'm not going to be disabled'. (Phoebe)

Tracey stated that she gained profound insight regarding her identity *during* the event of stroke. She described her experience:

Like, who am I?... I was something more than this body on the trestle table ... That's probably one reason why I wasn't upset at all by the changes that had come, that's not the sum total of me. That's not how I was identifying myself. (Tracey)

Tracey's identity did not hinge on physicality. She identified with being patient, compassionate and understanding, thus despite physical impairment she said that she had a familiar sense of self to support identity re-establishment in the early stages following stroke.

Identity Threatened

Despite asserting that inner, personal identity transcends the experience of stroke, the participants experienced stroke as threatening to identity at a social level. Four participants reported a sense of being displaced following stroke, or not quite belonging. Phoebe and Michelle experienced this in social situations, or community rehabilitation settings. Nancy and Tracey struggled with rehabilitation programmes that placed them with 'peers' who seemed very different from themselves.

Phoebe experienced insensitive comments at work:

I think that people find it ... especially confronting that young people have strokes because it could be them ... It took me a while, in terms of identity, to learn to let the silly things that other people said just wash past . . . I think I've learnt that the right thing to say is, 'It's great to see you'. (Phoebe)

Michelle's identity involved aspirations of a family and motherhood which was threatened following stroke, miscarriage and blood disorder. She experienced some lack of understanding from friends and family who did not want to hear of her struggles in recovery, despite asking 'How are you?' Nancy did not identify with experiences of older stroke survivors, or those of all young survivors. She expressed closer identification with young, higher functioning survivors who were not significantly disabled. However, it was noted by three participants that peer support specifically addressing the needs of this group was lacking. Nancy stated:

Stroke support groups I'm sure have a really, really important role [but] I steer clear of those things. I don't feel comfortable going because I don't really think I fit the mould. I wouldn't want to make other people feel bad... I feel like I'm a bit 'the exception' that I was so lucky. (Nancy)

Tracey experienced impairment including impaired ambulation, arm and hand weakness, and a language impairment that increased her dependence on parental support, effectively displacing her developmental life-stage. Old school friends were establishing young families, while Tracey was again living with her parents. She lacked appropriate peer support following stroke. Rehabilitation involved walking, water aerobics and hydrotherapy with people predominantly aged over 60 years. Tracey felt awkward recovering while they were not making the same gains. She felt dislocated socially from friends of her own age:

I was hanging out with old people all the time ... they're just talking about what's wrong and not looking on the bright side of things ... my social interactions were actually a bit depressing ... So I've actually stopped going to all of those sort of things. (Tracey)

Resumption of Life Roles and Responsibilities

All five participants identified that resumption of valued life roles and responsibilities contributed to their identity re-establishment. They wanted to reengage with familiar routines and activities, and to reclaim previously valued identities; for example, as worker and friend. What had meaning for each participant was quite personal. They were willing to accept that their capabilities had changed, but determined to reclaim activities that were important to their sense of identity. Nancy shared: I think, for me the getting up and going [to work] in the morning, working in the day, coming home gave me that sense of routine ... There were days when I went in and I forced myself to go even though I didn't want to. My boss would say, 'Maybe you should go home', or whatever. I'd say, 'No, I really have to do this because if I don't, if I'm not going to be able to do this then I won't feel like I'm recovering'. (Nancy)

Tracey wanted to resume walking with a friend:

I've got Nordic walking poles and I walk with them ... So it's just finding the tools to allow me to do what I used to be able to do. (Tracey)

Phoebe revisited competencies achieved earlier in life with the assistance of rehabilitation professionals:

I found a great deal of resilience in being able to do things that I'd always been able to do. So I looked back to things that were really core that I'd particularly done through my teenage years and sought to be able to do them again. One of those things was sewing with a sewing machine. (Phoebe)

The Challenge of Returning to Work Following Stroke

All participants valued employment following stroke, frequently in their pre-stroke positions. All experienced both support and stroke-related challenges in the workplace when they resumed employment during recovery. Michelle explained the amount of energy invested in returning to work:

I used to be able to do the payroll with one eye closed, whereas now . . . I felt like those three hours were weeks, so tired . . . I'm just mentally drained and I'm physically tired . . . Looking back, I'm glad I pushed myself like I did. (Michelle)

Workplace interactions were significant. Phoebe perceived some interactions during her transition back to work as insensitive.

I lost 10 kilos. So I walked into the office where the whole of the left side of my body feels completely different, I'm 100 per cent present in my concentration, 100 per cent of the time my body feels abnormal and I'm so fatigued I can [only] come in here for two hours and of course everybody says, 'You're looking fantastic. You don't look like anything happened to you'. (Phoebe)

Phoebe clarified the impact this comment made on her:

Because for me, people saying you don't look like anything happened to you, completely invalidates just how difficult it is. (Phoebe)

When she shared the significant milestone of progressing beyond a return-to-work plan, to resume her usual work responsibilities and hours, Phoebe was further disappointed by a lack of understanding expressed by colleagues: I was gobsmacked that nobody said congratulations. I took cake in, I circulated a really positive, happy e-mail – it's my stroke anniversary and today's the day I'm fully back at work . . . come and have cake and help me celebrate. Nobody said well done . . . I absolutely knocked myself out to be here, to be doing this job. (Phoebe)

The availability of genuine support and understanding in relation to employment was important to the participants and their re-establishing identity. Phoebe commented:

But I don't think it's very easy to find – apart from among other stroke survivors – any level of understanding of how difficult it is. That impacts on the return-to-work journey when you feel that nobody around you actually has any idea at all just how hard it is for you. (Phoebe)

Three participants experienced financial insecurity following stroke, highlighting the financial importance of return to work. Tracey received income support, the negotiations for which she deemed 'the only obstacle in recovery', with payments cancelled six times throughout rehabilitation. Wendi reported exhausting all her savings during rehabilitation, after receiving a negligible \$A10.92 total income support. Michelle was assessed as ineligible for the disability support pension, and placed on Newstart allowance, requiring her to seek employment. However, due to cognitive challenges early in recovery, she was unable to meet associated compliance measures and follow through on requirements of the job-seeking process.

Centrelink sort of went, 'Well you have to go and get Newstart'. You have to apply for all these jobs, and that was like a major, major thing. Trying to get to interviews and sitting there, having a conversation with someone at an interview process, and not knowing what words to use. (Michelle)

Michelle instead sought financial support through her extended family.

All participants emphasised the importance of an accommodating, flexible and supportive return to employment, building their confidence in recovery within their work roles, despite challenges. Four participants did not receive professional rehabilitative assistance in negotiating this process; they relied on understanding employers. All participants spoke of both managing and understanding the impact of their condition within the work environment. Nancy required support in managing dizziness and balance affecting ambulation, also fatigue, anxiety and panic experienced within the workplace following stroke. She benefited from a personal coach who assisted her to adjust following stroke. Wendi learnt to walk again in rehabilitation. and on her return to work required support in managing fatigue, slower processing, standing up for long periods and fluctuations in mood. She commented that she was overwhelmed by the support and encouragement she received from her work colleagues. Phoebe learned to manage sensory loss, arm orientation in space (proprioception), hypersensitivity to noise and to touch on her left side, and fatigue. Her return-to-work plan, incorporating neuropsychological recommendations, was important in ensuring a manageable daily structure and work environment, enabling concentration. After having overcome aphasia and relearning to walk, Tracey continued to adjust to fatigue, limping and not being able to write with her dominant hand on her return to work and study. She anticipates negotiating roles with colleagues when on camp or excursions involving challenging activities within her future work roles as a teacher. As well as learning to walk without dragging her affected leg, Michelle adjusted to sensory loss in her affected arm, fatigue, slower cognitive processing, short-term memory loss and appearance of vagueness, searching for words needed in communication. Almost 10 years following the stroke, she still felt a little anxious regarding her cognition, in relation to her work.

One Enduring Identity

In discussing the impact of stroke on identity, all participants spoke of having one enduring identity before and after stroke. They exhibited an unequivocally dedicated approach to maintaining subjective identity continuity, a process taking up to 10 years. Phoebe explained that stroke is lifechanging but she has remained 'solid', her stroke experience fluidly absorbed into her identity. She views herself and her identity as continuing on the one life trajectory:

There's no question in my mind that I'm still on the journey to be what I was before . . . An even better $me \ldots A$ me that's learnt from the wisdom of the experience, of course . . . in terms of my identity – yes it was all very confronting and yes at times it's extremely frustrating, but I've not sat and thought I need to make an adjustment and accept the new me as being as good as the old me, because it's the same me. (Phoebe)

Wendi experienced temporary identity change during transition and adjustment following stroke, before establishing identity continuity. She experienced anger and mood fluctuations and felt upset at hurting her mother during this period. She lacked confidence and self-esteem, felt withdrawn and depressed, and gained weight. However, Wendi stated she had lost weight in the weeks prior to interview and attended a health retreat, gaining greater direction in life. She emphasised that she was starting to get back to herself, feeling good about herself and managing the residual effects of stroke. Wendi explained:

I'm feeling more like I used to and I'm more what I was like before... Yeah. So I think, yes I have identity pre-stroke; I've had an identity a bit different poststroke. I've been going on the speed hump to get back to my pre-stroke self and then now I'm nearly there. (Wendi)

Discussion

This research set out to explore the experiences of young, higher functioning stroke survivors with identity re-establishment and return to work. Our participants understood identity as both an inner sense of self, and as a socially and discursively mediated construct. They experienced stroke as a threat to identity at both of these levels. Their responses to these threats could be characterised as holding on to their inner sense of self, while exploring the changes in their social identities, and finding ways to resume valued life roles and assert their social identity continuity. This research supports the findings of previous research that identity following stroke is fluid, undergoing cycles of transition in response to individual challenges, environmental contexts and interactions, and attitudes of both the survivor and others (Ellis-Hill et al., 2008; Haslam et al., 2008). Participants indicated that the journey towards recovery involved overcoming various perceived barriers. These included participation in physical rehabilitation activities geared to older survivors, and lack of referral for psychosocial rehabilitation for younger survivors, particularly those who recover sufficiently to consider resuming employment.

Participants highlighted the time and energy required for activities such as returning to work. They exposed the insecurity involved and the intensive focus required in retrieving, restoring or replacing aspects of identity, while continuing on one's life path, with strategies, compensations and supports to accommodate residual effects of stroke. They clearly evidenced their focus on ability in recovery despite impairment, a process that at times was both experienced and expressed as frustration. Nevertheless, they viewed rehabilitation as transition towards management of impairment, rather than disability, a process noted by Ellis-Hill et al. (2008). These younger, higher functioning participants drew on personal strengths or abilities in managing and overcoming challenges associated with physical and/or cognitive impairment.

They were future-oriented, an aspect reported by Lawrence (2010).

Previous research (Gracey et al., 2008; Haslam et al., 2008) has identified the importance of social identity continuity, and this research confirms the importance of connection and belonging to groups, such as appropriate peer support, work colleagues and family. The research reported here adds a dimension to the idea of identity continuity. Participants spoke of the importance of continuity in intrinsic aspects of the self, such as personal qualities, skills, interests, roles and aspirations. Examples of these aspects include being patient, compassionate and understanding, being able to sew, being interested in walking with friends, being a worker and aspiring to have a baby.

Participants challenged biographical disruption in pursuit of establishing identity continuity. Initially this process started in early recovery as they searched for retained abilities established during earlier developmental stages, things that they knew they could do well previously, such as Phoebe's sewing. Participants appeared to use this technique as a self-imposed assessment, determining where their abilities lay following stroke, and where they may have required assistance - something that they could not determine with any certainty until they tested their ability for themselves. By successfully addressing tasks they were competent at previously, they built confidence, and moved beyond known ability to bigger challenges. The participants clearly showed that despite significant challenge, if their ability is facilitated and impairment managed, life endeavours can be resumed or pursued, such as returning to work.

Limitations

This research specifically involved five younger, higher functioning survivors of stroke. The methodology for this study resulted in the limited collection of information regarding diagnosis and impairments at the time of stroke. The participants were women who experienced, on the whole, reasonably well-supported transitions back into employment and/or study. The research did not capture identity re-establishment and return-to-work experiences of male stroke survivors, individuals who experience lasting aphasia, or individuals who encounter significantly adverse experiences in reengaging with employment. Further research involving a larger, more diverse sample is required to explore fully the broad range of experiences of young stroke survivors in accessing income support, resuming and sustaining employment, impacts on identity and where further support is required.

Implications for Health Professionals

This research adds some fine-grained detail and consumer voices to the findings of previous research in this field. A nuanced understanding of the situation of young stroke survivors who are able to return to work is a useful underpinning for the work of rehabilitation professionals. This research affirms a rehabilitation focus on ability while managing impairment, and similarly suggests a focus on identity continuity while managing biographical disruption. This research supports the importance of specific services focused on the recovery needs of young, higher functioning stroke survivors, both physical and psychosocial, as noted by Morris (2011).

Stroke peer support groups geared to the specific needs of young, higher functioning survivors on their recovery journey were identified as desirable, although not easily found. Current stroke support groups are perceived as not necessarily suitable for the needs of higher functioning survivors. Nevertheless, participants clearly identified a need to belong among peers and individuals who understand the enormity and significance of their specific, intensive, recovery challenges, including resumption of employment and returning to study. This is critical to supporting poststroke adjustment, identity re-establishment, social identity continuity and coherence within a fluid life-story, as similarly reflected in the research of Ellis-Hill et al. (2008) and Haslam et al. (2008).

This research indicates the importance of return-to-work rehabilitation pathways for young, higher functioning stroke survivors. Social identity continuity was supported by successfully resuming and sustaining employment, particularly within pre-stroke workplaces. Belonging to, and being supported by, work-group colleagues and superiors, was found to enhance a sense of recovery, similarly noted by Alaszewski et al. (2007) and Haslam et al. (2008). Recognition of a familiar sense of self was experienced through the work role, contributing to self-perceived identity continuity. Where a return to work was not immediately possible, returning to study emerged as a critical component of the return-to-work pathway.

Conclusion

This article explores identity re-establishment and return to work in young, higher functioning survivors of stroke. Research participants showed that this process involves overcoming significant barriers; resuming valued roles, including returning to work and/or study; and managing impairment while developing and promoting ability. Participants assimilated shifting subjective experiences of normality, as they worked towards minimising and overcoming the effects of biographical disruption resulting from stroke. Each participant achieved and valued identity continuity. The research findings indicate the potential benefits of psychosocial intervention focused on minimising the impact of biographical disruption while facilitating identity re-establishment.

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References

- Alaszewski, A., Alaszewski, H., Potter, J., & Penhale, B. (2007). Working after stroke: survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment. *Disability and Rehabilitation*, 29(24), 1858–1869.
- Baum, C., Christiansen, C., & Bass-Haugen, J. (2005). Person–Environment–Occupation–Performance: a model for planning interventions for individuals and organizations. In C. Christiansen & C. Baum (Eds.), Occupational therapy: performance, participation and wellbeing (pp. 373–392). Thorofare, NJ: Slack Inc.
- Benwell, B., & Stokoe, E. (2006). *Discourse and identity*. Edinburgh: Edinburgh University Press.
- Cott, C., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: preparing clients for life in community post stroke. *Disability and Rehabilitation*, 29(20–21), 1566–1574.
- Ellis-Hill, C., Payne, S., & Ward, C. (2008). Using stroke to explore the Life Thread Model: an alternative approach to understanding rehabilitation following an acquired injury. *Disability and Rehabilitation*, 30(2), 150–159.
- Gracey, F., Palmer, S., Rous, B., Psalia, K., Shaw, K., O'Dell, J., ... Mohamed, S. (2008). 'Feeling part of things': personal construction of self after brain injury. *Neuropsychological Rehabilitation*, 18(5), 627–650.
- Habibis, D. (2009). The illness experience: lay perspectives, disability and chronic illness. In J. Germov

(Ed.), *Second opinion: an introduction to health sociology* (4th ed., pp. 288–306). South Melbourne: Oxford University Press.

- Haslam, C., Holme, A., Haslam, A., Iyer, A., Jetten, J., & Williams, W. (2008). Maintaining group memberships: social identity continuity predicts well being after stroke. *Neurospychological Rehabilitation*, 18(5), 671–691.
- Lawrence, M. (2010). Young adults' experience of stroke: a qualitative review of the literature. *British Journal* of Nursing, 19(4), 241–284.
- Medin, J., Barajas, J., & Ekberg, K. (2006). Stroke patients' experiences of return to work. *Disability and Rehabilitation*, 28(17), 1051–1060.
- Mold, F., McKevitt, C., & Wolfe, C. (2003). A review and commentary of the social factors which influence stroke care: issues of inequality in qualitative literature. *Health and Social Care in the Community*, 11(5), 405–414.

- Morris, R. (2011). The pyschology of stroke in young adults: the roles of service provision and return to work. *Stroke Research and Treatment*, 2011(Article ID 534812), 1–10.
- NSF (Australian National Stroke Foundation). (2010). Facts, figures and statistics. Retrieved from: http://www.strokefoundation.com.au/facts-figuresand-stats
- Sani F. (Ed.) (2008). Self continuity: individual and collective perspectives. New York: Psychology Press, Taylor & Francis Group.
- Sarantakos, S. (2005). *Social research* (3rd ed.). New York: Palgrave Macmillan.
- Sedikides, C., Wildschut, T., Gaertner, L., Routledge, C., & Arndt, J. (2008). Nostalgia as an enabler of self continuity. In F. Sani (Ed.), *Self continuity: individual and collective perspectives* (pp. 227–239). New York: Psychology Press, Taylor & Francis Group.