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**A Small Qualitative Peer Research Project Exploring the
Return-to-Work Experiences of Young Stroke Survivors**

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Abstract

This case study focuses on a small qualitative study that explored experiences of young higher functioning survivors of stroke in re-establishing identity and resuming employment. It was peer research as the student researcher who carried out the project is a young stroke survivor herself. The research falls within the tradition of critical social research and is underpinned by critical social work theory. In keeping with these approaches, the research was grounded in people's everyday experiences and had a strong political intention to contribute to change to improve the lives of young stroke survivors. In-depth, semi-structured interviews were conducted with five young stroke survivors. Barbara disclosed her stroke to participants during pre-interview screening and project discussion, generally in response to the question as to why she chose to research in the area of young stroke. This had the effect of building an easy rapport between researcher and participant. This Social Work Honors research project was slightly ahead of the current drive for diversity and innovation within the research sector. However, this peer research demonstrates the benefit of health diversity in researchers as well as participants. It illustrates engagement and comfort in discussing health-related challenges. The combination of applied professional and academic expertise along with unique experiential expertise is both striking and dramatic, potentially contributing to research innovation within the medical and health sciences sectors. Since completing the research, Barbara has continued to work for greater recognition of the rehabilitation needs of young stroke survivors.

Learning Outcomes

By the end of this case, students should be able to

- Define the term “peer research” and discuss what this entailed in the study of young stroke survivors
- Comment on the political intention of critical social research to bring about change to make life better for disadvantaged groups, drawing on the study of young stroke survivors as an example of this intention
- Discuss how qualitative research can be used to contribute to understanding people's lived experiences in relation to health and wellbeing

... the intertwining of ability and disability is both striking and dramatic.

Titchkosky (2003, p. 528)

Barbara Wolfenden's Honors research was inspired by her own experience of young stroke. It could be seen as insider research although Barbara describes it as “peer research.” Both of these terms refer to research that is carried out by people who share characteristics with the research participants. As Lushey and Munro (2015) indicate, these approaches reduce power differentials between researchers and participants, contributing to the quality of engagement and empathy with research participants. This encourages participants to express their views fully and frankly, thus enhancing the quality of the data included in the research. Barbara was conscious of reducing power imbalances during all contact with her research participants, endeavoring to cater empathically for their post-stroke needs such as memory loss, anxiety, pain, delayed processing, fatigue, and/or needing to take breaks during conversation. Sharing the

interview questions ahead of time, and allowing participants to consider and prepare their thoughts and responses if they wanted, was part of this process. Barbara let participants know that she too had experienced the challenges of young stroke. She wanted to imbue a sense of bottom-up research rather than top-down, as this was very much her own position in undertaking this research project to improve the plight of young stroke survivors. As far as possible she wanted to establish a sense of shared power by openly valuing participants' expert knowledge relating to their own experiences and encouraging them to contribute to co-creation of knowledge. Barbara chose to position herself as a researcher from within the young stroke community, researching for and with fellow community members. Participants appreciated this, as evident in the rich data they provided and the vulnerabilities they openly shared, with assurances of anonymity. Barbara used intuition and reflexivity not only in designing the project but also in informing her participants of the project, disclosing her own stroke survivor status, conducting in-depth one-to-one interviews, analyzing, and interpreting meaning from the data.

The research explored experiences of young higher functioning survivors of stroke in re-establishing identity and resuming employment. This small qualitative study, which took an iterative-inductive approach, falls within the tradition of critical social research (Henn, Weinstein, & Foard, 2009) and is underpinned by critical social work theory (Fook, 2012). In keeping with these approaches, the research was grounded in people's everyday experiences and had a strong political intention to contribute to change to improve the lives of young stroke survivors. Barbara was keen to raise political consciousness regarding post-stroke needs of young survivors, in ways that would encourage their self-determination and self-efficacy in pursuit of life-stage endeavors. She wanted her work to inform future stroke rehabilitation policy and practice, and the research was planned and carried out with these aims in mind. Since completing the research, Barbara has continued to work with organizations and individuals to ensure that the findings of this small-scale honors research project have been incorporated into policies, practices, and further research. This project not only provided her with a solid research foundation, but it heightened her appreciation of the tenacity of young stroke survivors to overcome challenges in recovery and develop their own stroke expertise. Subsequently she was further encouraged to undertake a PhD in young stroke.

To survive stroke and reclaim life requires determination, operating beyond sheer exhaustion, frustration, and pain. Post-stroke, determination grows from an underlying belief in the self. It is often shrouded by significant self-doubt, anxiety, frustration, and yet it glimmers through as hope against the odds. Hope fuels self-efficacy through gritty determination to make gains in recovery (Dorsett, 2010; Jones, Mandy, & Partridge, 2009; Kvigne, Kirkevold, & Gjengedal, 2004), sometimes exceeding prognosis and expectation (Allatt & Stokes, 2011; Gee, 2016; Levin, 2016; Reed, 2009). Barbara relied heavily on hope in overcoming significant difficulty and persevering in recovery while pursuing outcomes meaningful to her. Mentors, including Dr Marty Grace who supervised Barbara's Honors research, supported her to develop self-confidence and channel her determination, frustration, and ability into research and advocacy, thus supporting Barbara as she developed skills and new purpose in her life. This was an empowering experience, in stark contrast to her initial experience of returning to employment post-stroke. Barbara's Bachelor of Social Work Honors research focused on experiences of young stroke survivors in re-establishing identity and returning to work.

One of the first tasks in the research was to focus on the topic and define key terms. Barbara's thesis commenced with definitions of key terms and an explanation of the topic and focus of the study. The introduction and literature review gave background, demonstrating disadvantage and rehabilitation needs specific to young survivors of stroke. These sections clearly indicated the importance of the topic, why it is worth studying, and its relevance to social work.

Key Terms in the Research, and the Importance of the Study

Stroke can occur without warning. It is indicative of cerebrovascular disease (Senes, 2006), caused by thrombosis, embolism or hemorrhage in the brain (*Macquarie Dictionary*, 2005), and blocking blood supply or causing bleeding in the brain. Consequences include chronic illness and the potential to alter drastically the lives of survivors and their families (Wolf, Baum, & Connor, 2009). Stroke is considered a condition of aging (Kersten, Low, Ashburn, George, & McLellan, 2002; Lawrence, 2010; Low, Kersten, Ashburn, George, & McLellan, 2003; Senes, 2006), despite 30% of all stroke survivors in Australia being aged below 65 years (National Stroke Foundation [NSF], 2013). The term "young stroke survivor" is used to encompass those below the age of 65 years as specified by the World Stroke Organization (WSO; 2015). The stereotype of a stroke survivor is challenged by the younger group and their distinctive needs in recovery (Morris, 2011). In this research, differentiation is similarly made between stroke survivors of working and retirement life-stages.

Rehabilitation is crucial to re-establishing life following stroke. Ideally, according to the NSF (2010, p. 30), rehabilitation is a process that is "proactive, person-centred and goal-oriented," aiming to maintain and improve function with a view to attaining physical, psychosocial, and financial independence. An interdisciplinary team is beneficial. Rehabilitation involves maximizing self-determination and supporting community reintegration. However, "the availability and quality of stroke care in Australia varies" (NSF, 2010, p. 30). Current research indicates that rehabilitation is predominantly medical in approach and deficit focused, overlooking significant psychosocial aspects important to recovery (Guise, McKinlay, & Widdicombe, 2010; Maaijwee, Rutten-Jacobs, Schaapsmeeders, van Dijk, & de Leeuw, 2014; Radford & Walker, 2008). Research has found young stroke survivors to have significantly higher unmet needs than those aged more than 65 years (Andrew et al., 2014). Morris (2011) recognizes a lack of specific psychological intervention for young survivors. While acknowledging the importance of existing stroke services to meet their needs, he encourages development of separate services dedicated to this group. However, Lawrence and Kinn (2012) do not think specialized services are necessary for young stroke survivors if all stroke survivors are offered truly individualized rehabilitation. This, however, does not seem to be happening adequately to meet needs, and young stroke survivors continue to call for their own stream of rehabilitation as witnessed by Barbara at the Young Stroke event launching Brain Injury Awareness Week on August 15, 2016, at the Melbourne Brain Centre (the livestream can be obtained through the Stroke Foundation Facebook page).

Impairment resulting from stroke involves a wide variety of physical and/or cognitive factors, frequently affecting identity. Survivors experience recovery across years (Kersten et al., 2002), beyond hospital discharge and/or rehabilitation. We now know that brain plasticity is lifelong (Doidge, 2007). Hope and optimism are beneficial within the recovery process (Anderson & Marlett, 2004; Dorsett, 2010). Recovery

goals of this group include meaningful age-related activities and responsibilities (Banks & Pearson, 2004; Jones, Mandy, & Partridge, 2008; Morris, 2011; Wolf et al., 2009). These encompass challenges of daily living and interaction, restoring continuity in life and re-establishing identity (Guise et al., 2010), all of which take time and effort. Wolf et al. (2009) found that approximately 50% of all stroke survivors experience mild stroke and are likely to want to participate as completely as possible in life. Young higher functioning survivors not only develop the ability to manage self-care but resume significant responsibility within family, community, employment, and/or study. This rarely happens easily and often requires determination to pursue such recovery goals despite minimal or no rehabilitation and some unmet needs, including financial need (Andrew et al., 2014; Essue et al., 2012). It also involves the moderating effect of the survivor's lived environment (Hammel et al., 2015; Wolfenden, Carey, & Douglas, 2015)

Recovery involving identity is complex. Survivors require communication and information provision to support identity (Anderson & Marlett, 2004). Biographical disruption, the disjuncture in the life-course caused by chronic illness (Germov, 2009), is a challenge to be resolved in stroke recovery. The young survivor of stroke needs to discern which roles and aspects of self can be retained and which life threads may need to be restored or replaced (Ellis-Hill, Payne, & Ward, 2008). This is frequently achieved through daily interaction and development of personal narratives, in pursuit of recovery goals (Anderson & Marlett, 2004; Ellis-Hill et al., 2008).

Some young higher functioning survivors of stroke identify returning to work as a significant goal for recovery. In this research, "work" incorporates part-time or full-time paid employment. It has been found to contribute to re-establishing social identity, self-image, life satisfaction, and general wellbeing, through independence and employment-related income (Banks & Pearson, 2003; Gilworth, Eyres, Carey, & Tennant, 2008; Koch, Egbert, Coeling, & Ayers, 2005; Medin, Barajas, & Ekberg, 2006; Stuart, 2004; Treger, Shames, Giaquinto, & Ring, 2007). Nevertheless, consideration of employment following stroke may result in anxiety and depression. This may occur for those planning to return to work and for those who fear they will be unable to do so (Alaszewski, Alaszewski, Potter, & Penhale, 2007; McGurk, 2009; Medin et al., 2006; Morris, 2011; Teasell, McRae, & Finestone, 2000; Treger et al., 2007). Furthermore, ambiguities occur for young higher functioning survivors who re-engage in employment as before and yet are changed by their experience of stroke (Lawrence, 2010).

This research is relevant to social work and social policy because social workers will often be positioned to assist individuals, as well as advocating for social policy change and service development. Operating within a Human Rights framework and committed to social justice (AASW, 2010), social work can assist young survivors of stroke at the personal, social, and structural levels within their recovery.

The Literature Review

Barbara conducted a thorough search for existing literature on her topic. She read the articles and identified themes in the published research. She then collated and synthesized the findings of previous research and wrote her literature review under the headings of "The stroke experience and rehabilitation for younger survivors," "Theoretical approaches to stroke rehabilitation," "Theory relating to identity," "The need for identity to be included within integrated rehabilitation," and "The goal of resuming employment following

stroke.” In conclusion to her literature review, she wrote,

The literature identifies return to employment as a goal of young higher functioning survivors of stroke. Some of this group are frustrated at not having this need adequately addressed and supported through vocational rehabilitation and necessary supports. Many still take the challenge on in a self-efficacious manner with varied outcomes. Identity is challenged by stroke, and time is required to recover and make necessary adjustments. Return to employment both requires and contributes to re-establishment of identity. Rehabilitation has an important role to play in resuming employment and the associated reconstruction and/or preservation of identity.

Both identity and resumption of employment have received some attention in the literature. Interest in researching work after stroke largely developed over the past decade. There is limited research considering re-establishment of identity for, specifically, young higher functioning stroke survivors, although some research addresses identity in relation to acquired brain injury, chronic illness, and disability (Ellis-Hill et al., 2008; Gracey et al., 2008; Kurz, Saint-Louis, Burke, & Stineman, 2008; White & Johnstone, 2000). There is minimal literature available regarding identity continuity (Haslam et al., 2008; Sani, 2008). I did not find research primarily examining identity and return to employment in an inter-connected way. My research focuses on experiences of young higher functioning stroke survivors in re-establishing identity and resuming employment. The purpose of my research is to explore and document experiences and perspectives of this group. This research, through contributing to increased understanding of their experiences, will have implications for stroke rehabilitation policy and practice.

The literature review informed the focus of the research, and Barbara concluded her literature review with a clear statement about the need for her research, and its significance.

Data Gathering

As part of the preparation for her research, Barbara approached the National Stroke Foundation and asked whether they would be willing to publicize her research project for the purpose of recruiting participants. They agreed, and the research was advertised in an online forum and in a newsletter. Barbara's Honors research was designed as a small-scale project that could be completed in approximately 12 months. Her aim was to develop an in-depth understanding of the experiences of a small number of people, and she aimed to conduct approximately five in-depth, semi-structured interviews. We estimated that this would generate approximately 50,000 words of transcripts, at the upper limit of what an Honors student could reasonably be expected to manage. Seven people responded to the call for participants, and each volunteer was contacted to ascertain they met the criteria for inclusion in the research. They were either notified of their selection or if ineligible, thanked for their expression of interest. One volunteer did not meet the criteria and was excluded from the research.

Each eligible participant was sent information about the research, a consent form, and a copy of the interview questions via email prior to arranging an interview. One participant who met the research criteria and eligibility withdrew from the research prior to signing the consent form, stating that reflecting on the interview questions was becoming too stressful.

The five remaining participants experienced stroke between the Years 2001 and 2009, aged between 27 and 44 years at the time of stroke. Each participant met the specified research criteria that they had returned to employment. Three participants continuously sustained their position within employment. All participants experienced significant residual effects following stroke, some of which persist.

Five eligible participants were contacted to arrange an interview time and meeting place convenient to them. They were given the opportunity to ask any questions regarding the research prior to interview. The researcher met with four participants in their homes, and one participant at her workplace. Data were gathered through semi-structured in-depth interviews (Liamputtong, 2013). Interview questions addressed work and other commitments prior to stroke, the perceived benefit of stroke rehabilitation to recovery goals, the experience of returning to employment, and perceived impact of stroke on identity, including any suggestions to make these processes easier. The duration of the interviews varied between 60 and 120 min. Interviews were digitally recorded and transcribed.

Barbara disclosed her stroke to participants during pre-interview screening and project discussion, generally in response to the question as to why she chose to research in the area of young stroke. Barbara also felt strongly about reducing any researcher–participant power imbalance; however, she avoided discussing her own experience and instead refocused on the purpose of the research interview. This had the effect of building an easy rapport between researcher and participant, with adequate understanding and trust for participants to feel comfortable not only in sharing their expertise but also in volunteering experiences of vulnerability in stroke recovery, providing rich data.

Data Analysis

At the time of interview, participants were offered the opportunity to check the transcript of their interview. All participants declined this offer but expressed interest in reading the completed thesis. Following transcription, the interviews were analyzed thematically. The approach to thematic analysis was similar to that described by Liamputtong (2013) as qualitative thematic analysis. The process began with open coding. Barbara read over the transcripts and coded them extensively according to the topics the participants discussed, the experiences they described, their feelings and opinions that were expressed in the interviews. The process of coding the transcripts and then consolidating and grouping the codes was quite laborious and time-consuming. However, eventually we were able to identify descriptive themes on the basis of the detailed coding of the transcripts. At this stage, Barbara listened once again to the audio recordings of the interviews and made notes about what the participants said in relation to each theme. Four groups or categories of themes were identified through this process: (a) Rehabilitation and recovery, (b) Vulnerability, (c) Returning to employment and study, and (d) Identity. We gave names to each of the themes. As an example, the category of “Vulnerability” encompassed the themes of (a) Energy levels, (b) Factors contributing to vulnerability, (c) The young stroke survivor and health professionals, (d) Involvement with Centrelink/national social security service, and (e) Factors indicative of vulnerability and the need for support. The category “Identity” held the following themes: (a) Peer support, (b) The impact of stroke within the identity of young higher functioning survivors of stroke, and (c) Identity continuity. Barbara collated the material from each transcript in relation to each theme, read over each theme, and wrote about what was

said. She was careful to ensure that all of the participants' views and experiences were represented in the report of her findings, at the same time as analyzing the meaning of the findings in relation to the research questions guiding the project. Both Barbara as the student researcher and Marty as the research supervisor were vigilant in making sure that the research findings reflected the participant interviews, not Barbara's pre-existing views based on her own experience. Although many of the themes identified in the research were no surprise to Barbara, the theme of vulnerability was not anticipated. Similarly unexpected was that each of the five participants unequivocally expressed moving beyond disrupted identity to then experience a sense of identity continuity. This necessitated a late hunt for the literature on the topic to add to the literature review and support the findings. As there was very little literature on identity continuity following acquired disability or stroke, Barbara approached some authors addressing identity to assist in this search. This change in the research, in response to the findings, illustrates the iterative-inductive approach of the research.

Ethical Considerations

This research was approved by the Victoria University Human Research Ethics Committee. Procedures ensuring informed consent, protection from harm, privacy, anonymity, and confidentiality were followed. Participants were fully informed regarding the purpose of the project and the interview process prior to signing the consent form.

Barbara sent the interview questions to the participants approximately 2 weeks ahead of interview. As we understood the potential for participants to experience vulnerability or anxiety in discussing stroke-related experiences, adequate time was allowed for participants to process the questions and determine their level of comfort with being interviewed. To manage cognitive challenges resulting from stroke, participants were enabled to prepare thoughts and responses prior to interview if required. Some participants took this opportunity, whereas others responded spontaneously.

Findings

At the beginning of her findings and discussion chapter, Barbara introduced the research participants with short vignettes. Here is an example:

Phoebe

Phoebe, who is married with two children, experienced stroke 12 months prior to interview, aged 44 years. She holds a degree in urban planning and was working three days per week in this field. When admitted to the acute stroke ward in a large public hospital she was not expected to live. She was given Tissue Plasminogen Activator (tPA) to break up the blood clot causing stroke. To the amazement of the Stroke Registrar, within 24 hours, she was able to get up and walk a short distance. Phoebe transferred to a public rehabilitation facility for three weeks. She was much younger than other inpatients. She experienced optimal rehabilitation, but observed that this was not the case for everyone.

Following discharge, Phoebe received in-home support services to assist with home duties and

childcare. She remained an outpatient for another eight to nine months, while gradually re-engaging in her professional work role.

Phoebe remained optimistic and determined. She returned to professional employment, supported by an occupational therapist and neuropsychologist. Initially she attempted to increase work hours too quickly. She dropped them back and gradually built her hours to her pre-stroke capacity. Across seven months Phoebe committed energy to “a really, really, really big, long, hard slog” fulfilling her pre-stroke work role and work hours.

On every level. I was set up to succeed. It was a supported journey. (Phoebe)

Following the vignettes, the findings of thematic analysis of interviews were presented in two parts. The first addressed identity re-establishment, with themes of vulnerability, biographical disruption, and identity continuity; the second explored links between identity re-establishment and resumption of employment. Barbara wove her discussion of the findings into the presentation of the findings, making links with the literature as each theme was presented. This chapter concluded with 13 recommendations.

Conclusion

From a critical social work perspective, this research challenged stereotypes and assumptions in relation to young stroke survivors while working toward a politically transformative and empowering outcome for this group. It addressed the application of power and knowledge within relationships pertaining to stroke rehabilitation, revealing aspects of disempowerment and social injustice for young survivors. The research aimed to address psychosocial aspects of recovery inadequately covered by a medical model of stroke care (White & Johnstone, 2000; Wolf et al., 2009) with a view to informing service development.

This Honors research project was slightly ahead of the current drive for diversity and innovation within the research sector. However, this peer research demonstrates well, the benefit of health diversity in researchers as well as participants. It facilitates engagement and comfort in discussing health-related challenges, and thus results in rich data. If we conclude by reflecting on our opening quote: “... the intertwining of ability and disability is both striking and dramatic” (Titchkosky, 2003, p. 528), we may consider that the combination of applied professional and academic expertise along with unique experiential expertise is both striking and dramatic, potentially contributing to research innovation within the medical and health sciences sectors.

Exercises and Discussion Questions

1. What is the meaning of the term “peer research”?
2. What are the distinguishing features of critical social research?
3. What are the advantages and disadvantages of a researcher disclosing to participants that they have personal experience of the research topic?
4. As a critical social researcher, Barbara tried to ensure that her research has an impact and contributes to making a difference in people’s lives. She has published her research findings and has contributed to the development of resources for young stroke survivors. (The two papers relating to this research

project are listed under section “Further Readings”). What else could she do to make sure that her research contributes to making life better for young stroke survivors?

Further Reading

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Web Resources

Return to Work resources from Different Strokes Organization—UK: <http://www.differentstrokes.co.uk/index.php/foryou>

Stroke Foundation and resources for both stroke survivors, and professionals—Australia: <https://strokefoundation.com.au/>

Young Stroke Organization—located in the USA: <http://youngstroke.org/>

World Stroke Organization (WSO): <http://www.world-stroke.org/>

Global Stroke Bill of Rights provided by WSO: http://www.worldstrokecampaign.org/images/global_stroke_bill_of_rights/English_GlobalBORights_web.pdf

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