2009

The perception of peer support by young stroke survivors

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The Perception of Peer Support by Young Stroke Survivors

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A Report Submitted in Partial Fulfilment of the Requirements for the Award of

Bachelor of Science (Psychology) Honours,

Faculty of Computing, Health and Science,

Edith Cowan University.

Submitted November, 2009

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The Perception of Peer Support by Young Stroke Survivors

Abstract

Social support buffers against the negative effects of significant life events, and peer support is particularly beneficial for individuals experiencing serious health concerns. Stroke is one such event, and often results in a variety of physical and psychological impairments that negatively affect quality of life. Although considered primarily as a condition of the elderly, approximately 20% of strokes occur in people younger than 55. Despite facing significant psychological challenges including negative body image, pressure to return to work, anxiety, isolation, and depression, few younger stroke survivors access peer support services. This study explored young stroke survivors' perceptions of peer support using qualitative semi-structured interviews with eight adults who had a stroke before the age of 35. Thematic content analysis identified that participants had mostly negative perceptions of peer support groups, and were ambivalent about individualised peer support. These results were inconsistent with much of the peer support literature, which suggests that peer support groups are desirable and beneficial for people experiencing significant health concerns. However, these results supported the literature that suggests social comparison can have negative affective results, and the literature about the helper-therapy principle, which describes the benefits for the provider in a peer support relationship.

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Supervisor: Dr Ken Robinson

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The Perception of Peer Support by Young Stroke Survivors

Stroke can be a devastating condition and often results in a number of physical and psychological challenges, such as hemiplegia, speech vision or hearing impairments, loss of independence, anxiety and depression. Close to 20% of strokes occur in a person under the age of 55 (NSF, 2008a), and it has been suggested that younger stroke survivors face a uniquely challenging recovery due to additional difficulties associated with returning to work, family responsibilities and the considerable effect of damaged body image on self esteem (Keppell & Crowe, 2000; Neau et al., 1998; Teasell, McRae & Finestone, 2000; Wolfenden & Grace, 2009). To improve the quality of life for stroke survivors, it is important to increase accessibility and effectiveness of support services (NSF 2008a; NSF, 2008b).

Social support refers to the supportive ways in which people behave in their interactions with each other, and has long been recognised as playing an important role in both psychological and physical wellbeing (Bolger & Amarel, 2006; Cohen & Wills, 1985; Helgeson, 2003; Sarason & Sarason, 2009). Helgeson (2003) suggested that there is a linear relationship between social support and quality of life. When an individual is experiencing a significant health crisis such as stroke, social support from a peer, or a person who has had similar experiences, is thought to be particularly beneficial (Dennis, 2003). This type of support has been linked with a variety of health-related improvements, including recovery from illness and improved ability to withstand stressful situations (Bolger, Zuckerman & Kessler, 2000; Jacobson, 1986; Sarason & Sarason, 2009; Taylor, Sylvestre & Botschner, 1998; Wethington & Kessler, 1986).

The introduction to this thesis is divided into five sections. The first will briefly address the structure and function of social support, and factors affecting the perceived effectiveness of social support. The second section will describe the specific benefits and processes of peer support for people experiencing serious health problems, and participation rates in peer support groups. Third, the incidence and effects of stroke, and the specific experiences of younger stroke survivors will be considered. The fourth section will identify some of the challenges associated with the research of peer support, and the final section of the introduction will integrate the previous sections and provide the rationale for the present study. The remainder of this thesis will describe the present study, then report and interpret the comments that eight young stroke survivors have

made about their perceptions of peer support, and finally integrate these findings with the present body of knowledge.

Social Support

      Structure and function.

Despite the vast body of research devoted to exploring the association between social support and various health outcomes, there is as yet no universally accepted definition of social support, how to assess it, or how to interpret the empirical evidence that has been collected (Helgeson, 2003; Jacobson, 1986; Sarason & Sarason, 2009; Wethington & Kessler, 1986). However, it is commonly acknowledged that social support can be thought of in terms of both its structure and function.

The structure of social support refers to the number, nature and organisation of the social connections that an individual has with other people (Helgeson, 2003). The various sources of social support, including family, friends and peers all contribute in unique and valuable ways to a person's social support network (Taylor et al., 1998). Individuals with a broad range of social support sources have better health and psychological wellbeing than those with fewer social connections (Cohen & Wills, 1985).

The functional qualities of social support are commonly categorised into emotional, instrumental and informational support (Cohen & Wills, 1985; Davidson et al., 1999; Helgeson, 2003; Reinhardt, Boerner & Horowitz, 2006; Thoits, 1995). Emotional support includes listening to, caring for, sympathising with, and reassuring an individual, making her or him feel valued loved and secure, and providing positive feedback about her or his self-worth (Helgeson, 2003; Solomon, 2004). Instrumental support refers to more tangible help, such as financial aid or practical assistance with completing day-to-day tasks (Helgeson, 2003; Jacobson, 1986; Solomon, 2004). Informational support refers to the provision of factual information, advice or guidance, including pragmatic suggestions for alternative coping strategies in stressful situations (Helgeson, 2003; Jacobson, 1986; Solomon, 2004).

Factors affecting perceived social support.

The beneficial effects of social support are influenced by both the actual receipt of support and the recipient's perceptions of the support (Bolger, et al., 2000; Helgeson, 2003; Reinhardt et al., 2006; Wethington & Kessler, 1986). Furthermore, it has been proposed that the perception of social support is more closely related to beneficial health outcomes than the type or amount of support actually received (Reinhardt et al., 2006; Wethington & Kessler, 1986). Each of the three aforementioned functional styles of support is perceived within the context of the type of stressor, the person providing support, and the timing of the support.

Helgeson (2003) noted that if the stressor is controllable, informational type support such as advice about how to modify the situation would be perceived as helpful, whereas if the stressor was uncontrollable, emotional support to facilitate coping with the stressor would be more valuable. Additionally, the source of support affects the perception of its value, for example, informational support is more highly regarded when it comes from a professional such as a nurse or doctor rather than a lay person such as a family member or friend (Helgeson, 2003).

Based on his review of the literature about the relation of social support to several theories of stress, Jacobson (1986) concluded that the timing of social support is also crucial to its perceived effectiveness. He suggested that emotional support is most useful during the early stages of a crisis, informational support is most valuable once the emotional arousal has abated and the individual is trying to make sense of what has happened, and instrumental support is most relevant to the individual as they adjust to the changes that result from the stressor. Thus, for social support to be perceived to be supportive, it must be the right style of support, supplied by the right person, and be provided at the right time.

It is also particularly important that the provision of support is recipient-focused, in that the recipient is given the opportunity to ask for support, and potential providers do not simply assume that they are the appropriate source for a particular type of support at a particular time (Reinhardt et al., 2006). When these guidelines are not met the received support may be perceived as unhelpful, and may have a negative effect on the recipient, such as creating feelings of isolation, indebtedness or incompetence, which may decrease self esteem and self worth (Bolger & Amarel, 2006; Helgeson,

2003; Reinhardt, et al., 2006; Wethington & Kessler, 1986). Indeed, such misdirected support may ultimately be more detrimental to an individual's health than no support at all (Taylor et al., 1998).

Peer Support

When an individual is experiencing a stressful life event, such as a medical diagnosis or severe health concern, the structure of her or his social support network may be affected. Significant health concerns are often associated with intense emotions and experiences, which may isolate the individual from family and friends who cannot understand these changes (Davison, Pennebaker & Dickerson, 2000). In these situations, individuals often report feeling more supported by a peer, or another individual who has had similar experiences and is more likely to be skilful and appropriate in their provision of support (Davison et al., 2000; NSF, 2006; Solomon, 2004). Furthermore, the introduction of a peer to an individual's social support network serves to increase and strengthen that network, and thus improve the individual's wellbeing (Davidson et al., 1999).

Peer support refers to the mutual provision of help and support between individuals who share common experiences (Doull, O'Connor, Welch, Tugwell & Wells, 2005), and peer support programs are widely used to support individuals experiencing significant health concerns such as cancer (Ussher, Kirsten, Butow & Sandoval, 2006), mental illness (Davidson, et al., 1999; Hegelson, 2004; Hodges, 2006), symptomatic HIV disease (Molassiotis et al, 2002), traumatic brain injury (Hibbard et al., 2002) and stroke (Ch'ng, French & McLean, 2008). Peer support occurs in a variety of formats, including coincidental exposure in a hospital setting, telephone help lines, online discussion boards and one-to-one mentoring (Davison et al., 2000; Hibbard et al., 2002; NSF, 2008b), but by far the most popular method of providing peer support is in a group format (Davison, 2000; Helgeson, 2004; Solomon, 2004). Participation in peer support groups has been linked with a decrease in the frequency and duration of hospitalisation, increased social and vocational participation, and a facilitated transition to independent living for people with mental illness (Hodges, 2006). Other benefits include an increased sense of personal control, which decreases depression and anxiety, and increased self efficacy, which improves general wellbeing (Davidson et al., 1999; Dennis, 2003; Hodges, 2006).

How peer support groups work.

Peer support groups vary widely in their processes and specific goals, but can provide all three functional styles of social support; emotional, instrumental and informational (Davidson et al., 1999). Additionally, there are recognised benefits for the providers of peer support (Helgeson, 2003; Solomon, 2004).

Emotional social support is often the primary function of a peer support group and results from the environment of non-judgemental acceptance and empathy cultivated in many support groups (Davidson et al., 1999; Ussher et al., 2006). Peer groups aim to create a sense of community and belonging through the sharing of common life experiences, and often use humour and warmth to reinforce the feelings of cohesion and alliance between members (Ussher et al., 2006). This safe and supportive environment allows individuals to fully explore their emotional reactions to the significant health concern in a way that would not be possible with non-peers (Ussher et al., 2006). Davidson et al. (1999) suggested that the emotional support offered by peer support groups may act as a kind of environmental antidote to the isolation and despair that many people with significant health concerns experience.

Peer support groups also help to normalise and validate an individual's emotional responses to a health concern that may be fairly uncommon within their existing social network (Campbell, Phaneuf & Deane, 2004; Ussher et al., 2006), and to normalise the process of help-seeking (Turner, 1999). This process of normalisation is explained by social comparison theory, which asserts that in times of uncertainty, people seek a sense of normalcy and accuracy by comparing their understanding of the world with other people (Davison et al., 2000; Solomon 2004). Comparison with someone who is perceived to be better off (upward comparison) can provide encouragement, hope and inspiration, whereas comparison with someone who is less well off (downward comparison) may help to put an individual's own experience into perspective, and foster an appreciation for how much worse it could have been (Davison et al., 2000; Solomon, 2004). Much of the literature espouses the benefits of peer support groups for facilitating these effects, and providing access to positive role models (Davison et al., 2000; Solomon, 2004; Ussher et al., 2006). Role models are thought to be beneficial for demonstrating successful recovery within the constraints of

an illness, as opposed to perpetuating expectations for full asymptomatic recovery (Davidson & Roe, 2007).

Buunk, Collins, Taylor, VanYperen and Dakof (1990) conducted individual interviews with members of cancer support groups and found a significant risk of negative affective reactions to both upward and downward social comparison, especially when the individual had low self esteem. They reported that although downward comparison is typically thought to improve self-evaluation and make individuals feel better about themselves, individuals with low self esteem tended to focus on the potential for their own condition to worsen, and therefore tended to feel worse about themselves, rather than better because there were others worse off than them. Buunk et al. (1990) considered that upward comparison may lead an individual to feel that she or he is inferior and thus give rise to negative self evaluation. Yaskowich and Stam (2003) also conducted one-to-one interviews with cancer support group attendees and found that challenges associated with group membership included a reluctance to engage with some of the more difficult issues raised by fellow members, isolation of those with an unfavourable prognosis, and survivor's guilt. Therefore, although a peer support group can be a valuable source of emotional support, its effects may be moderated by the negative consequences of social comparison.

Instrumental support is not traditionally associated with peer support groups, although they do increase the size and strength of an individual's support network, and provide opportunities for an individual who has been socially disconnected as a result of her or his health concern to re-engage in social interactions (Ussher et al., 2006). Additionally, consumer-run services often focus on and advocate empowerment, autonomy and independence, which may facilitate positive identity re-evaluation and prompt individuals to take charge of their own healthcare management (Hodges, 2006; Ussher et al., 2006).

Informational support is often an important feature of peer support groups, and many peers cite the exchange of experiential knowledge as one of the core benefits of attending support groups (Davidson et al., 1999; Solomon, 2004). Peers may share strategies for coping with practical and emotional challenges resulting from the health concern, specific information relating to their health condition, or advice about services and resources they found instrumentally helpful during their recovery (Solomon, 2004).

Davidson et al. (1999) suggested that peers may also share ideological frameworks for making sense of their illness and reconciling their views of the world and of themselves. This may serve as a cognitive antidote to the negative self and world views that can arise from the experience of serious illness (Davidson et al., 1999).

The helper-therapy principle proposes that benefits are derived from helping others (Campbell et al., 2004; Salzer & Shear, 2002; Solomon, 2004). Sarason and Sarason (2009) stated that, "Social support is not simply something done for someone. It occurs within interpersonal transactions that include recipients and providers and their feelings and cognitions" (p. 120). There is often little or no clear distinction between the provider and the recipient within a peer support relationship, as it is by nature a mutual and reciprocal process (Salzer & Shear, 2002), and both members of the dyadic relationship play the role of provider or recipient of support at different times (Pierce, Sarason, Sarason, Joseph & Henderson, 1996). Taylor et al. (1998) argued that support should be conceived of as collaborative social activity that cultivates a shared meaning and understanding of an experience or situation and should therefore be thought of in terms of a relationship that consists of multiple supportive interactions, rather than as a series of discrete instances of supportive behaviour. Thus, within a peer support relationship, each member benefits from the process of giving support as well as receiving support, and it has been argued that giving support can be more beneficial than receiving it (Campbell et al., 2004; Reinhardt, et al., 2006; Salzer & Shear, 2002; Sarason & Sarason, 2009; Solomon, 2004; Taylor et al., 1998). Some of these benefits include increases in self efficacy, self esteem (Davidson et al., 1999; Taylor et al., 1998), self confidence, and life satisfaction, and decreases in depression and fatigue (Schwartz & Sendor, 1999).

Peer support group participation.

Despite the prevalence of peer support groups and the reported benefits of participation in peer support groups, actual attendance rates are often low, for example, Davidson et al.(1999) reported that just one third of people with a diagnosed mental illness attend a peer support group. Davison et al. (2000) found that participation in peer support groups varied as a function of the health concern being addressed, with groups for alcoholism among the most attended, groups for stroke among the least and most cancer support groups in between. Much of the literature about peer support

focuses on the benefits and mechanisms of the more commonly attended groups, and less research explores possible reasons for the lower participation rates (Campbell et al., 2004; Hodges, 2006). A postal survey of the leaders of 66 Australian stroke survivor peer support groups revealed that approximately 4,000 of the 346,000 stroke survivors in Australia attend such groups (NSF, 2006), which means that nearly 99% of stroke survivors do not attend a peer support group. Of those who did participate, the average age was between 61 and 70, although eight per cent of groups reported having at least one member under the age of 30, and two groups were specifically targeted at younger stroke survivors (NSF, 2006).

A Brief Overview of Stroke

Incidence and effects of stroke.

A stroke occurs when part of the brain is deprived of oxygen, which destroys brain cells and results in death or disability (NSF, 2008a). Stroke is Australia's second leading cause of death, and a leading cause of disability, with an estimated 60,000 new or recurrent strokes expected to occur in Australia in 2009 (NSF, 2008a). It is generally considered a condition of the elderly, but approximately 26% of strokes occur between the ages of 45 and 65, and 3-4% occur before the age of 40 (Teasell et al., 2000). These figures suggest that approximately 2,000 Australians under the age of 40 will have a stroke in 2009.

Stroke is a sudden trauma that has a wide variety of potential effects including hemiplegia, speech vision or hearing dysfunctions, and memory and cognitive impairments. Physical impairments such as these have a significant effect on the quality of life of the stroke survivor, and may impact on employment, family life, social connectedness and self image (NSF, 2007). In addition, the loss of independence and autonomy frequently leads to stroke survivors feeling powerless and hopeless (NSF, 2007). The combination of physical impairments and the consequent negative feelings often leads to psychological conditions such as depression, anxiety and suicidal ideation (Ch'ng et al., 2008; NSF, 2007). Many stroke survivors report overwhelming anxiety about having another stroke (Ch'ng et al., 2008; NSF, 2007) and up to 91% of stroke survivors have reported feeling depressed at some point since their stroke. Two thirds experience periodic recurrences of depressive symptoms and 23% of stroke survivors report experiencing symptoms of depression several times a week (NSF, 2007). Factors

that have been identified as predictive of post-stroke depression include the severity of the stroke, the degree of physical impairment (Hackett & Anderson, 2005), negative self image and self esteem, and the inability to return to work (NSF, 2007; Teasell et al., 2000).

Limited Australian research has explored the lived experience of stroke survivors. Ch'ng et al. (2008) conducted a series of focus groups with stroke survivors recruited from peer support groups in Western Australia, to explore the psychological challenges and coping behaviours that promote adjustment after stroke. One of the focus groups was recruited from a young stroke survivor support group, and the study identified that their experiences were notably different from the older participants, including intense feelings of isolation, notable concern about body image and anxiety about future intimate relationships. However, the authors did not expand upon these differences or make age-specific recommendations.

The Experience of Younger Stroke Survivors.

Although some studies have identified that younger stroke survivors face different challenges to older stroke survivors, it should be noted that the term 'young' has been variously defined as under 30 (NSF, 2006), from 16-50 (Teasell et al., 2000), from 15-45 (Neau et al., 1998) younger than 60 (Keppell & Crowe, 2000), or 'working age' (i.e., younger than 65) (Treger, Shames, Giaquinto & Ring, 2007). Based on their retrospective study of 83 young stroke survivors three months after discharge from hospital, Teasell et al. (2000) reported that younger stroke survivors experienced significant relationship stress, with 15% of couples separating, and 38% experiencing conflict within the first three months after the discharge. High rates of depression (47%) and anxiety (66%) were noted, with the most significant causes of anxiety being concerns about returning to work, recovery and childcare. Anxiety about returning to work appears to be salient as less than 10% of stroke survivors were able to return to full time employment (Teasell et al., 2000), and young stroke survivors are particularly vulnerable to depression and anxiety if they don't regain their previous level of function (Ch'ng et al., 2008; Neau et al., 1998; Teasell et al., 2000; Wolfenden & Grace, 2009). Body image is also thought to be particularly important to younger stroke survivors, and a more negative body image after stroke reduces self esteem and self worth (Ch'ng et al., 2008; Keppel and Crowe, 2000).

Given the complex and significant challenges faced by younger stroke survivors during their adjustment to life after stroke, it is reasonable to expect that they would benefit from peer support. The evidence, however, does not seem to support this. The low participation rates in stroke survivor support groups overall seem at odds with perceived benefit. Moreover, as only 5 of the 66 stroke support groups surveyed by the NSF (2007) had any younger members, it appears that young stroke survivors are not seeking support within the existing peer support framework. This inconsistency in perceived benefit of peer support is also evidenced by comments from health professionals involved in the care of younger stroke survivors. They have noted that despite several attempts at establishing a network of support groups for them, many young stroke groups have collapsed due to an apparent lack of interest (D. Blacker, personal communication, 2005; J. Smith, personal communication, 2009; C. Ward, personal communication, 2009). Hence, it would appear that young stroke survivors are not participating in peer support groups and very little is known about how they perceive and experience peer support.

Challenges Associated With Peer Support Research

Much of the research into peer support has focused on those participating in peer support services, and excludes people who do not participate, which may skew the findings towards an uncritical acceptance of the benefits of peer support. Participation rates demonstrate that the majority of people who are thought to benefit most from peer support do not participate in peer support services, so it is important to explore reasons for non-participation.

Another challenge to research in this area is epistemology. Chesler (1991) wrote that much of the psychological literature is positivist, which views the world as quantifiable and measurable, and he suggested it is inappropriate for exploring the nature and processes of support groups. Taylor et al. (1998) also noted that the scientific examination of social support often removes it from its social context and reduces it to a definable service or state, rather than the dynamic process of building and maintaining relationships. The literature has described a variety of beneficial outcomes associated with peer support although little is known about the process by which peer support exerts these effects (Bolger et al., 2000; Bolger & Amarel, 2006; Sarason & Sarason, 2009; Wethington & Kessler, 1986).

Chesler (1991) noted that peer support groups are often reluctant to engage with professional researchers, especially if they are perceived to be associated with those responsible for delivering the service. However, if the researcher is a member of the group being studied, she or he is often afforded greater access to group processes, and has the, "legitimacy and credibility to ask and to be told about intimate organisational details" (Chesler, 1991, p. 764). Chesler (1991) also suggested that involving members of the support groups in the research process would be empowering, and that giving the group members more control over the progression and results of the research would likely yield a more accurate and relevant understanding of their experiences.

The research literature shows the importance of perceived social support for psychological wellbeing, high risk of psychological problems for young stroke survivors, and evidence for the success of peer support groups in ameliorating these problems with other health conditions. Given the methodological limitations faced by researchers in peer support, this study will explore the experiences of young stroke survivors from within their interpretive framework, using a researcher who is a young stroke survivor herself. The exploratory focus was taken to investigate the reasons for their extremely low participation rates in peer support groups, and to identify other ways to support young people who have had a stroke.

Methodology

This study was embedded within a constructionist epistemology, which holds that knowledge and meaning exist as a result of the dynamic relationship between people as they engage with the world (Crotty, 1998). In a constructionist epistemology the participant is acknowledged as the best informant of their own experience, and meaning is constructed between the participant and researcher. This epistemology is suited to the exploration of the perceptions of peer support because meaning is constructed between individuals (Sarason & Sarason, 2009; Taylor et al., 1998).

The present research was couched within an interpretivist theoretical framework, which is based on the primary assumption that the process of making meaning occurs within a framework of historical and cultural interpretations of the world (Crotty, 1998). The construction of meaning about a young stroke survivor's perception of peer support necessarily occurs within a cultural and historical context, and relies upon both the researcher's and the participant's interpretations of that context. Given that both

researcher and participants share the experience of surviving stroke at a young age they are more likely to construct a compatible understanding of the phenomenon (Chesler, 1991).

The methodological design of a study must take into account both the epistemology and the theoretical perspective, to select appropriate methods for the collection and interpretation of data (Crotty, 1998). In the present study, a semi-structured qualitative interview method was chosen to enable both the researcher and respondent to jointly contribute to the direction and depth of the interview, and facilitate the collection of rich and complex accounts of the respondents' experiences (Smith, 1995). The analytical process is described below.

Researcher's Perspective

To ensure that the reported views of the participants are authentic, and to improve the rigour of the present research, the researcher's experience of having a stroke in early adulthood is important. The researcher has a strong background in peer support for young stroke survivors, having attempted to establish a young stroke support group in Western Australia some years ago, and having been involved in the design and testing of other peer support strategies, including online discussion boards and social networking. These experiences gave the researcher an advantage when speaking with the participants because she had empathic understanding of their experiences and established rapport almost immediately. The researcher's unique placement both within and outside of the context of providing peer support to young stroke survivors meant that she was able to engage with the participants' stories both as a peer and as a researcher. The researcher recognizes that this can be both an asset and an obstacle to rigour. The shared experience increases the likelihood that subsequent analysis and interpretation of participants' experiences is accurate and representative, yet there is also a risk that it is the researcher's experience that is represented rather than those of the participants (Chesler, 1991; Kross, Ayduk, & Mischel, 2005).

It is acknowledged that it is usual to present personal reflections in the first person rather than using the passive voice and third person, as it is a more direct form of communication (Liamputtong & Ezzy, 2005). The circumstances of the present research, however, were such that the intensity of the emotional experience and reflection engaged in by the researcher threatened the progress of the research itself.

The researcher found that flashbacks to her own experience were intense, and led to her accessing psychological support to enable her to work through her own experience of the research process (Kross, et al., 2005). As found by Kross and colleagues (2005), the writing of this thesis enabled the researcher to work through her own experiences, and using the third person facilitated the process. This technique also enabled and strengthened the boundaries that respected the authenticity of the participants' responses, while improving the researcher's ability to self-support and maintain clarity and perspective in the research process. The researcher also kept a personal journal, which allowed her to record her own thoughts and experiences to distinguish them from those of the participants, and facilitate self reflection.

Participants and Recruitment

Nine people who have had a stroke were interviewed, although one of the men originally interviewed was not included in the study due to potential intellectual property and confidentiality issues associated with premature disclosure of his academic research. He stipulated during the interview that his transcript would require especially thorough de-identification to prevent potential ramifications in his professional life. Moreover, he was concerned that the material he had disclosed was subject to intellectual copyright. As a result of these two ethical issues, the material from this participant was excluded from the study.

The other eight participants ranged in age from 20 to 37, all had their stroke before their 35th birthday, and the time elapsed since their stroke ranged between 6 months and 16 years (see Table 1). Participant identification in the Table is by number only, to protect their identities. A range of family circumstances was represented: some participants were living with their parents, some with a spouse, and some were parents. Specific details about participants' strokes and impairments were not recorded, but all participants had been discharged from hospital, and most had returned to some form of paid work.

Table 1

Participant Demographics

Participant	Gender	Age in years	Time since stroke
1	M	21	4 years
2	F	20	9 months
3	M	37	3 years
4	M	28	5 years
5	F	29	16 years
6	M	33	6 months
7	F	33	9 months
8	F	21	4 years

Recruitment was carried out with the assistance of the National Stroke Foundation (NSF). It forwarded an email to existing young stroke support groups, and included a short article in the June 2009 edition of the Friends Newsletter, which is published on the NSF website and circulated through NSF mailing lists. An email was also sent to the NSF's contacts in health professions in Western Australia, in an attempt to source participants who were not already affiliated with a young stroke group or the NSF. In addition, the researcher posted a short note on the NSF's Facebook fan page, and approached some of her personal contacts. Four women and one man responded from the Young Victoria Stroke Survivors Group, another two men responded to the article in the Friends newsletter and an additional two men were sourced through the researcher's own contacts in Western Australia.

Ethics

This research was approved by the Edith Cowan University Human Research Ethics Committee. Participants were notified of the potential for some emotional discomfort resulting from the discussion of their personal experiences of stroke, and were informed that they could withdraw from the study at any time without

consequence. Throughout the interview process, the researcher looked for signs of distress, although none were apparent in any of the interviews. Participants were contacted approximately four weeks after the interviews to see if they were experiencing any negative emotional or psychological reactions to the interview process, and no participants reported any distress.

The small size of the population from which this sample was drawn made complete de-identification difficult, given the many personal details disclosed in the interviews. To aid de-identification, participants were requested to provide a pseudonym, and in this paper they will be referred to as: Jess, Mia, Rooklyn, Rose Austin, Leon, Max, and Michael. Detailed demographics are not included in the present report for the same reason. Each participant was provided with a copy of any references to her or him before the paper was submitted, and no participants requested any alterations be made.

The researcher believes that the volume and richness of the transcripts collected in this study warrant further analysis beyond this paper. As such, participants were also asked to consider providing consent for their de-identified transcripts to be retained, pending ethics approval for a further analysis of the data, outside the scope of this thesis.

Materials and Procedure

All participants expressed interest in this research by email, and initial meetings were organised by mobile phone text messages and email. Data collection occurred between the 25th of June and the 30th of July, 2009. Five participants were interviewed in the Melbourne metropolitan area, and three in the Perth metropolitan area. Meeting places included participants' workplaces, public cafes and participants' homes. Interviews lasted between 42 minutes and 3 hours and 35 minutes. A Sony ICD-P210 digital audio recorder was used to record the interviews, and participants were provided with an information letter (Appendix A), and an informed consent form (Appendix B) and a contact details form (Appendix C), which were completed and returned to the researcher.

The researcher began the interview by asking "What do you remember about when your stroke happened?" because Smith (1995) noted that discussing the condition

itself is the best way to begin an interview about such a potentially sensitive topic, and it provided context for subsequent questions. The interview typically moved to the important people in the participant's life at the time of the stroke, and how those relationships changed, before focusing on peers and peer support in particular. See Appendix D for the full interview schedule.

Analysis

Thematic content analysis (TCA) was chosen for the present research because it is a straightforward and efficient technique for processing qualitative data while retaining rich detail about each participant's experiences (Braun & Clarke, 2006). Any qualitative analysis is necessarily an iterative and creative process, but by exploring the data for themes repeated within one transcript and common across multiple participants, the investigator was able to construct an overall picture of the perceptions of peer support by young stroke survivors. The congruity between the researcher and participants' interpretative frameworks increased the likelihood that the researcher accurately interpreted the participants' comments, and identified themes that were representative of the participants' experiences. The researcher's personal journal was used to distinguish between her own responses to the material and the thoughts and feelings of the participants, to ensure that the voices of the participants were authentically represented in the thematic analysis. The measures taken to ensure rigour in the research are described in the next section.

Audio recordings were transcribed verbatim and fully de-identified, and then read several times to gain a broad understanding for the individual participants' stories in their own context, and to begin to search for commonalities across transcripts. The analysis process consisted of four stages. In the first stage, each transcript was annotated with recurring themes, using the participant's own words as headings, to stay as close to the original data as possible. The second stage involved the review of these themes and identification of material directly associated with peers and support groups. This material was subjected to the third stage of analysis, which involved the comparison of sub-themes across participants and identification of commonalities in their experiences of peer support, and preferences for potential peer support services. The final stage comprised identifying material that best represented each theme for the final report. See Appendices E and F for an example of the analytic process.

Rigour

A number of techniques were utilised in this study to confer rigour and consistency of data interpretation. First, owing to the exploratory nature of this study, all interviews were conducted and transcripts analysed before a comprehensive literature review was performed. This ensured that the themes were identified based on an inductive interpretation of the data and the researcher's own perspective, and were therefore more likely to be representative of participants' experiences than that of the extant literature. Coded transcripts were revisited during the third stage of analysis to search for themes that had been identified in subsequent transcripts, and to maintain engagement with the original data.

The potential effect of placing the researcher's own interpretive framework on the thematic analysis was minimised by the use of multiple coding. One participant's full transcription was coded independently by both the primary researcher and the research supervisor, and then the differences in coding were discussed and resolved. A second transcription was then coded independently, to verify that both researchers were using a similar coding framework. This helped to ensure that the researcher's interpretation of the data was similar to the interpretation of a person who did not share the young stroke experience, and vice versa. Subsequent codings for the other transcripts were checked by the research supervisor to provide rigour for the coding process.

Additionally, as indicated earlier, the primary researcher kept a journal of her expectations of and reactions to each interview, as a basis for self reflection, and met with a clinical psychologist on a regular basis to debrief when her reactions to the data were particularly acute. Finally, cross-member checking was employed as all participants were contacted by email and asked to cross-check the drafted results and interpretations section to ensure that they were comfortable with the extent of de-identification, and that their experiences were accurately represented.

Findings and Interpretations

Overview

Participants made a clear distinction between their perceptions of peer support as delivered in a group format compared to a one-to-one individualised relationship, and

between the experience of giving and receiving support in a one-to-one relationship. Participants held negative views about peer support delivered in a group setting, and ambivalent views about individualised support. The findings of the present study will be presented under four main headings: the perceptions of group support, the perceived advantages of receiving individualised support, the perceived disadvantages of receiving individualised support, and the perceptions of giving individualised support.

These young stroke survivors reported limited access to peer support services, and that what they did have was perceived to be unsatisfactory. Although the literature suggests that peer support is desirable and beneficial for people living with serious health concerns (Davison et al., 2000; Dennis, 2003; Hodges, 2006; Solomon, 2004; Ussher et al., 2006), participants were critical of the peer support process and the possibility of it doing more harm than good. They identified the need for training peers, and monitoring the ongoing process of peer support to minimise the risk of harm to either party.   )

Despite these reservations, participants believed that they would have benefited from peer support at some stage in their recovery, had it been provided in the right way, at the right time, and by the right person (Helgeson, 2003; Jacobson, 1986; Reinhardt et al., 2006). A peer was thought to be a person who has "walked the walk" (Max, p. 12), or has "done it all before" (Rooklyn, p. 9). Most thought that a peer should have had a stroke themselves, although Max and Leon suggested that a close friend or family member of a stroke survivor could also be·supportive. Most participants reported that a peer who was similar to them in age and, "stage of life" (Michael, p. 14) would have been more beneficial than one who was much older than them. Several participants thought that a peer should also be similar in terms of the nature and severity of the impairments resulting from their stroke. The most common theme that emerged about young stroke survivors' perceptions of peer support was their desire to help other young stroke survivors.

Perceptions of Peer Support Groups

Most participants were not interested in attending a 'traditional' stroke support group, which they perceived to be comprised exclusively of older people, whom they did not consider to be peers. Rose voiced the sentiments of many participants, that the

difference in age between her and the majority of other stroke survivors would limit
how helpful their support would be:

> I think I, didn't want to hang out with a group of ... not that I didn't want to
> associate with stroke survivors, but the people that I had met, like the local
> stroke support group, are all very, um, well, a lot of them were retired and older
> and ...content with where they're at. (p. 11)

Although Max, Michael and Austin had no ongoing access to a young stroke
survivor support group, the other five participants were aware of at least one in their
area. Only Mia and Jess were actively involved in any young stroke group activities.
Rooklyn and Rose received semi-regular emails from a group, although they were not
actively participating in its events. Rose said that some of the effects of her stroke made
attending a group event difficult, "Like transport, (not) being able to speak, you know,
fatigue and everything, that I guess acted as a huge barrier to me even getting near to
that" (p. 6). Rooklyn found it hard to attend because, "It's just been bad timing too, cos
the kids have a lot of sport stuff and things on the weekend ... and you don't get a lot of
value out of it when you're just watching them (the kids) run around all the time"
(p. 13). Leon had no affiliation with a stroke support group whatsoever. He said that,
"They weren't convenient for me time wise, et cetera, so I never attended one" (p. 35).
Hence, practical issues of convenience were a significant barrier for those participants
who had access to a young stroke group but did not attend, and supported the NSF's
(2008b) assertion that inaccessibility is a major barrier to attending a support group.

Participants also identified a number of other obstacles to participation, which
appeared to be related to maintaining and protecting their own emotional wellbeing.
They reported feeling badly about themselves when they compared themselves to others
who were less fortunate. For example, Rooklyn said:

> The group forum's a bit ... I don't know, it's a bit unnerving for me and I think
> it'd be unnerving for lots of people cos ... like when someone says they're a
> stroke survivor, they could be anything ... have any sort of effects. Difficulty
> with their movement, difficulty with their balance, you know, difficulty
> speaking. And I reckon that, er, group forums would be intimidating for lots of
> people. Because, one, everyone's gonna be looking at you. And you're gonna
> be looking at everyone else, and I ... I just didn't think I could really hack it.

> Yeah, I just think ... like I found it hard to live with the possibility that I could
> have another stroke. (p. 8)

Max had a different emotional reaction:

> I definitely feel guilty that, as I said at our first meeting (of young stroke
> survivors) at the Round Table, I felt guilty sitting there because there were
> people in wheelchairs, and people unable to communicate, you know, verbally
> and whatnot, and here was me, you know, back at work, you know, walking
> pretty well, functioning, umm, so yeah, I felt guilty. (p. 21)

These comments exemplify how social comparison occurs within a peer support
environment, and indicate that these participants were experiencing significant negative
emotional reactions to the process.

Some participants reported that meeting with a group of other stroke survivors
was unlikely to be relevant to or beneficial for them, because they did not all have the
same experience of stroke. Rooklyn reported that significant differences in physical
abilities would limit how beneficial support from other stroke survivors would be for
her:

> You know, you can be ... have quite serious ongoing physical effects. You can
> have, you know, next to none. Umm. It's ... it's just such a huge bunch of
> different people who are gonna face different problems because their ... ongoing
> issues are different. I don't know whether... I wouldn't be able to contribute and
> I wouldn't get benefit from someone who is, has a really different situation from
> me. (p. 11)

One of the central tenets of peer support is that it occurs between people who
have shared experience, and it is that shared experience that allows the normalisation
and validation of an individual's thoughts and feelings, and fosters an environment of
belonging and support (Davison et al., 2000; Ussher et al., 2006). Rooklyn succinctly
described the wide variation in the experience of stroke survivors, and how a lack of
shared experience affects the perceived helpfulness of their support. Hence, support
should come from an appropriate person, and that simply having had a stroke may not
qualify a stroke survivor as an appropriate source of support. Leon made a similar
comment:

I might like Star Trek. It doesn't mean I want to go to a Star Trek convention either. Just because I'm a card carrying member, doesn't mean I wanna hang out with a bunch of people so that, umm ... if we were a sewing club, I call it stitch and bitch, I don't want to (go). Not that I'm not compassionate towards them. My life isn't about that. Umm ... so I don't expect that a peer is gonna, it's gonna be one in a hundred peers that I come across that is gonna impart something (useful) upon me. (p. 35)

Rose, Røøklyn, Mia, Michael and Austin all suggested that a group situation could be a useful way of meeting people with a similar interests and experiences and to "normalise what I'd been through" (Rose, p. 11), consistent with the view that peer group support promotes connectedness with others (Campbell et al., 2004; Davison et al., 2000; Ussher et al., 2006). However, of these participants, only Mia was regularly involved in any group activities, which suggests that there were significant barriers to peer group participation, even though some young stroke survivors valued it as an option.

Mia was a volunteer support group coordinator and provided some insight into the difficulties associated with sustaining the activity of a dedicated young stroke survivor group. She said that the organisation of meetings and group activities often fell to just one or two people, usually volunteers, and that it could become an onerous task. It is possible that burnout or the changing needs of group leaders may have contributed to the dissolution of other dedicated young stroke survivor peer support groups.

In summary, although a few participants were able to suggest some benefits of support group participation, most participants perceived peer support groups negatively. Participants offered three main reasons for their non-participation: practical obstacles, including childcare, difficulties with travel, and time constraints; concern about the negative effects of social comparison, specifically that spending time with someone worse off than them would make them feel bad; and the belief that peers would not offer any relevant or useful support because their experience of stroke was different.

Perceived Advantages of Receiving Individualised Support

Participants were more positive about a one-to-one peer support arrangement, which they considered would provide more individualised attention, be more flexible to access, and probably be less intimidating. For example:

> I like the idea of a mentoring sort of thing. I think it's probably better than a collective group sort of thing. I think the other thing, too, is that everyone's independent reactions and effects and all that, can be so personal. Like, it's so different for everyone, in that ... if you sort of pair people off, or something like that, at least you get ... people with either a similar background, or a similar age, or a similar sort of physical, umm, you know ... mental health issues or whatever, that sort of go off together and ... you know ... share that sort of stuff. (Rooklyn, p. 11)

They expressed a desire to be matched with a similar peer and they described some advantages of such a relationship, including sharing relevant and useful information, feeling more understood and less alone, and feeling inspired by listening to another stroke survivor's story. Rooklyn, Austin and Leon all mentioned how hard it was to find specific information and solutions for practical problems arising from stroke related difficulties. For example, Rooklyn would have liked to ask:

> "Has anyone had this? ... Umm ... someone told me this, or I overheard that ..." or, you know, something along those lines. I dunno ... someone's found a good ... foot massager, because you've got, you know, you can't move your toes, or something ... cos it is hard to find that sort of stuff. (p. 12)

Rooklyn's comment supports the assertion that a central benefit of peer support is access to experiential knowledge, or "specialised information and perspectives that people obtain from living through the experience" (Solomon, 2004, p. 394).

Michael and Jess described a sense of connectedness, a feeling of being understood when they first met a fellow young stroke survivor. Michael said, "So it's just nice to be around people that ... you just know ... it's quite calming that you're just around someone that, you know what they've been through, and they can sort of appreciate (what you've been through)" (p. 28). Jess reported:

Oh well, like, I think he (the peer who visited her in hospital) was um, probably able to like, get like my lifestyle more, or my 'pre stroke' lifestyle. He had his when he was twenty three, so he was sort of able to say, "Yeah, I know when, when they took my licence and I was like at home, or like bored as..." and we used to talk about things like that. And like, all that kind of stuff, whereas for a fifty year old, maybe, it might not be so hard (for them). (p. 12)

Both Max and Rooklyn described a sense of relief that they weren't alone in their experience of stroke when they first met another young stroke survivor, and that they felt inspired for their own recovery. Max said:

It was like, "I'm not the only person in the world that's had a stroke at thirty two". Um, so that in its self is a great relief ... a big pick-me-up. And then, you know, having (the young stroke survivor's) enthusiasm, you know, it couldn't but help overflow into my optimism, make my pessimism into optimism. (p. 25)

Rooklyn said:

I was like ... you know ... at least other young people have sort of gone through this whole thing as well, because I, like I suppose the majority of the population think that, thought before, that stroke things happened to old people and not to, you know, people my age. (The young stroke survivor that I met one-to-one) is pretty inspirational I think and ... I thought, you know what, she's really gone ahead and gives it a good go, and I think early on that was sort of good to see cos, I dunno, I felt a bit hopeless, you know. (p. 8)

These comments reflect how peer support can normalise and validate an individual's reactions to, and experiences of, a serious health condition, and that simply knowing they are not alone can make the individual feel calmed, understood, and relieved. Max and Rooklyn's comments about feeling optimistic and inspired describe positive effects of upward social comparison, demonstrating that young stroke survivors can benefit from social comparison within a peer support relationship.

Thus, participants reported that an individualised, one-to-one style of peer support would be more beneficial than a group because it would be less confronting, more flexible and more appropriate to their situation. An effective peer supporter would be similar in age, 'stage of life', and effects of stroke, and the more similar the peer, the

more effective the peer support would be. Such peer support would provide access to relevant and useful information about stroke-related challenges, as well as helping the young stroke survivor feel more understood, less alone and more inspired. Interestingly, these are very similar to the benefits that much of the literature claims that people experiencing health concerns derive from peer support in a group format (Ch'ng, et al., 2008; Dennis, 2003; Ussher et al., 2006).

Perceived Disadvantages of Receiving Individualised Support

Several potential problems with receiving peer support in a one-to-one format were also identified. Similar to their issues with support groups, participants' biggest concern appeared to be related to maintaining their own emotional wellbeing. Participants believed that a peer with a significantly different stroke outcome would be less helpful, and may cause them to feel worse about their own strokes. Leon summed it up when he said "*My* stroke isn't *your* stroke. And, *my* outcomes aren't *your* outcomes." Austin said:

> I'm having a bad stroke shitty day. I'm feeling bad about having a stupid arm, and feeling bad about having a stupid walk. And then I go and have a coffee at the end of the day, with this guy who's in a wheelchair, with a facial droop. And I'm having a *bad* stroke shitty day and, say, he's having a *good* stroke shitty day and he wants to talk to me about how my life is. And I just *dump* all my crap on him. And then ... say ... that causes him to have a *bad* stroke shitty day, and he .dumps all *his* shit on me. It's like saying, "You know what, what you're going through is nothing right now, because right now I'm in a wheelchair, I've got a facial droop, I'm drowning in my own spit (laughs). You're stupid for thinking that your ... trauma is ... valid." It makes you ... realise that, well it makes you think that ... um ... you're a bit stupid and juvenile for, you know, working yourself up over having a bad arm and a bad leg ... (And) it shits you (if someone has had much better recovery than you). It makes you pissed off. It's like, "How the hell did they cut such a good break when what happened to them is basically identical to what happened to me? Um, what did they do to get there, what do they, um, what do they have that I don't? What part of them is able to overcome this better than I can?" (p. 26)

These comments reflect an acute awareness of the potentially negative consequences of social comparison. They echo Rooklyn and Max' comments about how spending time with a worse-off peer in a group situation would cause them to feel badly about themselves, and highlights the necessity for careful matching of peer supporters for young stroke survivors.

Additionally, some participants reported that a peer could make them feel worse by behaving inappropriately, and offering encouragement, information or friendship in an ill-timed or irrelevant way. Rose typified the assertion that excessive optimism or encouragement from a peer could be harmful if inappropriately delivered when she said:

> I think, um, (the peer who visited me) was too optimistic and ... he spoke in like a forum with all my family. So to me, it felt like his words were like, almost giving my family hope that, you know, that I would recover, and I had to prove myself to do that. So it wasn't, I didn't feel okay to be where I was at. He was, I felt, quite unrealistic because it was almost as if ... he'd forgotten how crap it was to be a survivor. Like now I can see the pros to having had the stroke. Although it's been crap, you know, (I) can see the benefits. But at that point, hearing what he had to say, I was just like, "Seriously?", like there was no relatedness there apart from ... we had stroke. (p. 7)

This quote expresses a number of issues that participants raised about peer support. Rose's peer supporter was providing an inappropriate style of support for her, offering encouragement rather than allowing her to express what sort of support she wanted. The support was not appropriate to her perception of the nature of the stressor, or her stage of adjustment to the stressor, and it was not recipient-focused. This quote also demonstrates how a stroke survivor's needs for support can change over time, and that support that is appropriate for one stage might be inappropriate for another.

Another concern expressed by participants was that a peer is not an appropriate source of medical information and offering unsolicited advice would be unhelpful. For example, Rooklyn suggested that some stroke survivors, "start thinking that they're home school doctors because they've had some experience ... You don't want people taking other people's advice if they're not ... well a medical professional in certain circumstances" (p. 20). This comment demonstrates how support must come from an appropriate source for it to be perceived as supportive. It also appeared to suggest that

Rooklyn would only value medical informational support from a qualified health professional, and that for her, a peer would need to respect that boundary.

Other participants were concerned that a peer might blur the boundaries between the roles of 'supporter' and 'friend'. For example, Jess explained, "I need someone that ... had something happen to them that can support me. Whereas, I think, for him (the peer who visited me in hospital), it was more like coming to visit, like a mate. And I was like, 'Nup.' It got too much at one point." (p. 11)

To summarise, despite the perceived benefits of an individualised service over group peer support, most participants still seemed sensitive to the potential for harm from a peer supporter, and suggested that behaviours such as excessive optimism, offering unsolicited medical advice and confusing the roles of 'peer supporter' and 'friend' would be detrimental to the recipient of individualised peer support.

Perceptions of Giving Individualised Support

Although they perceived difficulties with receiving individualised support, several participants have volunteered to provide peer support to others, and many have also made contact with the NSF to seek to improve "the support network (which) is, ah ... is not flash ... to be honest" (Michael, p. 14) For example, "Because I lost my speech and I knew how hard it was to speak and how frustrating it was, I made sure I spent my time with those people who were finding it hard to speak" (Michael, p. 14). After discharge, Max, Leon and Austin all contacted the hospital wards they had spent time in, offering to speak with other young stroke survivors.

Rose reported that the process of sharing stories was mutually supportive:

I'd be there (to help other young stroke survivors) because I know I never had that. And I know that so much of your own recovery is so dependent on like, your support system and if you don't have that it just hinders everything. And also, it's quite good for me to be able to talk to someone. ... I guess I didn't have that mentor and I didn't have the words or anything to communicate that. So I think in a way it's good for me to be able to vent, too. (p. 9)

This comment is consistent with the helper-therapy principle (Solomon, 2004), because although Rose was 'being there' for a peer, she derived a clear benefit from the

interaction. It also demonstrates the mutual and reciprocal nature of peer support, and how it can be difficult to distinguish between the 'helper' and the 'helped' (Pierce et al., 1996; Taylor et al., 1998).

Participants recommended some sort of training and support for those who provide the service. Rose and Mia both felt that the listening, self-care and delegation skills they had learned in their professional lives helped them to provide appropriate support to other young stroke survivors. Leon and Rooklyn were concerned that the peers who provide the service should be suitable for the job:

> I think for sure there should be some training, and I think you need to vet the ... the wannabe's. "I wanna be your peer". But if you've got an *agenda*, if, if you've, if you've had a bad experience... you need to leave all those other, the *crap* of your life, at the door, and just walk in there with compassion. I think that positive attitude and compassion needs to be at the, sort of, two of the foundations of it. But if you've had bad outcomes and you want to tell that next person about it, then perhaps you're not there for the right reasons. (Leon, p. 42)

> But I think if you frame it around being a more emotive ... umm ... 'Discussion' sort of support ... umm ... You know, you don't want people to put too ... one, too much info out there, about themself cos that's probably, not a smart thing to do. But how you control that ... I dunno, it's pretty ... hard. (Rooklyn, p. 21)

Conversely, Michael was more concerned about the wellbeing of the peer supporters:

> I think the trick with running things (like a peer support service) is ... making sure people don't take on too much as well, ... because what'll happen, they'll burn out. Six months or a year ... they'll be gone. (p. 36)

Hence, although participants were acutely aware of potential harm associated with both giving and receiving one-to-one peer support, many volunteered their time as supporters, and considered that training and support for peer supporters could minimise the potential dangers for young stroke survivors.

Integration and Reflection

The findings of this study are inconsistent with the literature, which suggests that peer support groups are beneficial for people experiencing serious health concerns, and

that they perceive groups to be desirable and helpful (Davison, 2000; Dennis, 2003; Solomon, 2004). Several young stroke survivors reported that peer groups were impractical and potentially harmful, and although individualised peer support was likely to be more practical and more relevant, the peers would have to be closely matched. Although participants were aware that spending time with a fellow young stroke survivor could make them feel bad about themselves, almost all of them were interested in providing peer support to other young stroke survivors.

It is the researcher's opinion that the major contribution of this study is that it allowed young stroke survivors to voice their perceptions and opinion of peer support as it is presently offered in Australia. Three interviews lasted for more than two hours, indicating that young stroke survivors had a lot to say about peer support. Participants appeared to welcome the chance to share their experiences, and many openly expressed their appreciation of the researcher's first hand understanding of some of their lived experiences. The researcher's experience as a young stroke survivor enriched the construction of meaning about the participants' experiences, and enhanced the authenticity of the interpretations made about participants' comments (see Chesler, 1991). It is possible that the unique circumstances of this study, where researcher and participants were able to share common experiences, may have contributed to these results, which seem to be at odds with much of the peer support literature.

In this final section of the thesis, the findings and interpretations will be summarised and integrated with the extant literature under three headings: perceptions of peer support groups, perceptions of receiving individualised support, and perceptions of providing individualised support. Then, the researcher's reflections on the process of this research will be presented, followed by the limitations of this study, its implications and suggestions for future research.

Perceptions of Peer Support Groups

Most stroke survivor peer support groups in Australia are attended by people between the ages of 61 and 70 (NSF, 2006), and most participants in this study reported that a peer would have to be similar in age to them. Therefore, the support offered by the majority of existing stroke survivor support groups would not be considered peer support for the present participants, and would likely be perceived as ineffective or irrelevant. There are a small number of dedicated younger stroke survivor support

groups, but of the five participants who had access to one, only two actually attended its events, which suggested that there may be other barriers to accessing peer support groups. Although the proportion of young stroke survivors who did attend a stroke support group (25%) was much higher in this sample than the 1% reported by NSF (2007), it must be noted that all participants had already contacted either the NSF or an existing young stroke group in some way, and so may not be representative of those young stroke survivors who had not made contact.

Despite this high prevalence of contact with a group, most comments about support groups were negative; although some participants identified benefits of a peer group, including the opportunities to increase their social networks and 'normalise' their experiences. Three main obstacles to peer group participation were identified: the impracticality of the group format, the negative effects of social comparison, and irrelevance of some peers as a source of support.

Participants reported that peer group activities were often impractical to attend, due to difficulties with transport, inconvenient timing, and childcare responsibilities. The three participants from Western Australia had no access to a young stroke support group, because there wasn't one. These reports are consistent with the NSF (2008b) assertion that inaccessibility is a major barrier to peer support group participation.

Participants also spoke about the negative consequences of social comparison. Max and Rooklyn both reported strong emotional reactions to downward social comparison, where they perceived their recovery to be better than another stroke survivor's recovery. Max reported feeling guilty for recovering better, and Rooklyn felt anxious that she might have another stroke, and end up in a similar situation to the worse-off peer. Rooklyn was so sensitive to the possibility of a negative outcome from social comparison that she felt a group situation would be 'unnerving' or 'intimidating'. These findings contrast strongly with predictions from social comparison theory, that downward comparison may result in the individual feeling grateful that her or his circumstances aren't as bad as others' (Solomon, 2004), although Buunk et al. (1990) found that individuals with low self esteem were less likely to benefit from downward social comparisons.

Little mention was made about the effects of spending time with a peer who was better off than them, possibly because participants self-selected into the study, and may

have considered themselves relatively well recovered. All had been discharged from hospital, and most had regained independent living, and these factors probably discouraged upward comparison. Rooklyn and Max' descriptions of feeling optimistic and inspired after an interaction with another young stroke survivor suggests that upward social comparison may be beneficial. The third main obstacle to peer group participation was the perception that the support offered in a group situation would be unhelpful, typified by Rooklyn's statement that spending time with a peer with a significantly different experience of stroke than hers would be of little benefit to either her or to the peer.

These barriers are likely to have contributed to the limited number of active young stroke survivor support groups currently operating. In the course of doing this study, the researcher was made aware that other dedicated young stroke groups had been established in recent years, and collapsed soon after (D. Blacker, personal communication, 2005; J. Smith, personal communication, 2009; C. Ward, personal communication, 2009) . These barriers, in conjunction with comments by one participant who asserted that much of the organisational work involved in maintaining a young stroke group falls to one or two people, suggest that there is considerable scope to improve the effectiveness of the delivery of peer support to younger stroke survivors in a group format. Indeed, given the difficulties experienced by the participants, it may be that a group format is not an appropriate format for young stroke survivor peer support at all.

Perceptions of Receiving Individualised Support

Most participants reported that an individualised peer support system would circumvent the practical and logistical problems associated with attending group events, would likely be less intimidating and more specifically tailored to their needs. Participants spoke about the benefits of receiving individualised peer support in terms of sharing relevant information, collaborative problem solving, feeling more understood, less alone, and more inspired. It should be noted that these are all common expectations of peer support as reported in the peer support group literature (Hodges, 2006; Solomon, 2004; Ussher et al., 2006), although the participants did not make these comments with regard to a peer group.

Participants emphasised the importance of matching in a peer relationship to increase similarity between the peers and reduce the potential for the negative effects of social comparison. This concept of matching was successfully employed in Hibbard et al.'s (2002) study of a peer mentoring program for people with traumatic brain injury. They found that participants who reported most similarity with their mentors also reported the most positive outcomes, including quality of life and ability to cope with depression (Hibbard et al., 2002).

Although participants noted that individualised peer relationships could be more appropriate and supportive than a group situation, they identified a number of issues that may reduce the helpfulness of a one-to-one peer relationship. Social comparison was a significant concern, typified by Austin's hypothetical interaction with a peer that degenerated into an exchange of negative emotion, a particularly descriptive example of the potentially negative effects of downward social comparison. However, Rooklyn and Max identified that upward social comparison may have a positive effect on them, and could leave them feeling optimistic and inspired.

In addition to this, participants were concerned about the appropriateness of the peer as a source of support. They had some experience with a one-to-one peer relationship, usually early in their recovery from stroke, and most reported some negative aspects. It appears that although young stroke survivors appreciated the potential benefits of emotional support from a peer, they were acutely aware of the potential for negative emotional reactions, and were sensitive to the negative emotions of others. Participants attributed the negative effects of these interactions to inexperience and a lack of training on behalf of the peer support provider. Ch'ng et al. (2008) suggested that stroke survivors' support needs change significantly over time, and as Jacobson (1986) noted, the right style of support must be provided for the individual's stage of adjustment to the stressor. Thus, although some young stroke survivors did receive peer support, they did not perceive it to be supportive, because it was the inappropriate type of support, such as informational rather than emotional, or inappropriately timed support, such as prematurely optimistic encouragement.

These findings are consistent with the literature, which suggests that for social support to be perceived as supportive, it must be provided in the right way, at the right time, and by the right person (Helgeson, 2003; Jacobson, 1986; Reinhardt et al., 2006).

Indeed, inappropriate support may be detrimental to the recipient, and cause more damage than if the individual had no support at all (Taylor et al., 1998). This may go some way to explaining young stroke survivors' reticence to attend peer support groups, if they are primarily concerned about being harmed by inappropriate support.

Perceptions of Giving Individualised Support

Despite their generally negative perceptions of group peer support and ambivalent perceptions of individualised peer support, almost all participants expressed an interest in providing individualised support to a fellow young stroke survivor. Mia, Leon and Rose were already involved in a peer relationship with at least one other young stroke survivor, and Max, Michael and Austin had all contacted hospital or rehabilitation wards to express their interest in supporting another young stroke survivor. Although Jess and Rooklyn had not sought to provide this support, both stated that they would be happy to help to support a peer during her or his recovery from stroke.

Participants who were supporting other young stroke survivors provided a number of reasons for their behaviour. Most believed that had they had access to such support earlier in their own recovery, they would have benefited, and that providing this service to others made them feel good about themselves. They also identified the intrinsic reward from helping another person, augmented by the reciprocal nature of the peer support relationship, and that support was more likely to be a mutual exchange than unidirectional advisory service. These sentiments are consistent with the helper-therapy principle, which suggests that the process of supporting another person benefits the supporter as well (Campbell et al., 2004; Salzer & Shear, 2002; Solomon, 2004). The helper-therapy principle is also one of the primary processes responsible for the effectiveness of peer support groups (Campbell et al., 2004; Salzer & Shear, 2002; Solomon, 2004), although participants did not mention it with regard to peer support groups.

Participants identified a number of potential drawbacks to providing individualised peer support, but considered that training and supervision of the peer supporters could reduce the risks to both parties. It is also possible that the strong desire to help other young stroke survivors may be related to the individual's own stage of recovery. It could be that the incidental support gleaned by providing peer support to

others is the best form of support for young stroke survivors who are further along in their adjustment to life after stroke.

Researcher's Reflections

For some participants, meeting the researcher was the first time they had encountered another young stroke survivor, and for all participants, the chance to speak with a peer in an open-ended but supportive situation was uncommon. Some participants seemed to the researcher to be in need of emotional support, and the researcher at times felt challenged by the emotional disclosures made. The researcher also experienced pressure from the family members of some participants, who seemed to view her as an ideal resource for information and advice about how to assist their young stroke survivor in her or his recovery. To help her deal with these challenges, the researcher sought assistance from her own support network.

It should also be noted that the researcher had positive experiences in working with other young stroke survivors. Some participants reported feelings of relief and connectedness, and valued the opportunity to share their personal experiences, which left the researcher feeling instrumental and supportive. Additionally, the researcher valued opportunities to share humorous experiences and other effective coping strategies. The researcher benefited from making connections with people she would likely deal with in the future, and the opportunity to reframe her own experiences of stroke as a young adult by externalising them in her discussions with participants and re-internalising them later with professional assistance. Upon reflection, these experiences closely mirror those positives and negatives reported by the participants in their perceptions of what peer support might be like.

The methodological design of this study was unique, in that the co-construction of meaning between the researcher and participants was facilitated by the similarity of their interpretive frameworks, due to the researcher's experience of stroke in early adulthood. Chesler (1991) suggested that, "Researchers may improve their access and learn more by becoming members of the groups that they study, and then studying themselves" (p. 764). The present study acknowledged the participants' contribution to the construction of meaning, using a researcher who is also a young stroke survivor, and therefore more likely to correctly interpret and represent participants' experiences. It is possible that this approach enabled the young stroke survivors to voice their criticism of

the current peer support framework in a way they might not have with a researcher without this background.

Limitations

The limitations with this study are primarily related to the representativeness of the sample. Although the eight participants were relatively diverse in age, time since stroke, type of stroke, and degree of impairment from stroke, there were no participants who had long term communication difficulties (such as from a severe stroke in the left hemisphere of the brain), which would likely have a significant impact on their perception of peer support. Study of such individuals would represent a considerable challenge to researchers in this field, due to the communication difficulties.

Additionally, all participants had been in contact with the NSF or a support group at some point, which would indicate that they were actively seeking some kind of support, and therefore may not be representative of all young stroke survivors. It is possible that their comments are reflected in this pro-social behaviour, and so the present findings may not be generalisable to the wider young stroke survivor population. Nevertheless, the fact that participants were so clear about the negative aspects of group support suggests that this is an important finding. More research is required with a larger and broader sample, especially targeting those young stroke survivors who are not actively accessing support. It may also be helpful to recruit participants from other states that have dedicated younger stroke survivor support groups, and from those who had joined groups which have since collapsed.

Implications and Future Research

The unique experiences of younger stroke survivors have been explored to some extent in the present study, and future research could specifically investigate their conceptualisations of themselves, especially their body image and vocational identity; their attitudes to other people, including family, friends and health professionals; and their coping strategies for dealing with the challenges of stroke. The wider corpus of data collected in the course of doing the present research could provide further directions for future study. Analysis of these data were beyond the scope of the present study.

There are several further directions for future research. Research could investigate the perceptions that younger stroke survivors have of older stroke survivors, and whether there are any issues of stigma involved in the way they think about and access peer support groups. It may also be that some of the issues reported by younger stroke survivors are reported by older survivors. Moreover, it would be of interest to compare whether young stroke survivors have qualitatively different experiences with respect to peer support than those of young people experiencing other significant health issues, such as mental illness, cancer diagnoses or road accident trauma.

With respect to program support, future research could first investigate ways to provide skilled, careful and appropriate support to young stroke survivors without the added difficulties associated with peers. As long as this support was offered without demand characteristics, and in a sensitive and client-focused way, it may help to identify ways to support young stroke survivors without incurring the costs associated with negative social comparison with peers. Then, the beneficial effects of peer support could be gradually introduced and explored with the guidance of professional supporters. This 'action learning' approach, or cooperative inquiry might be best undertaken using a hermeneutic phenomenological methodology, where the researcher and the participant are on equal footing, have shared control over the making of meaning, and both have continual input into the research process and program implementation and evaluation.

Summary and Conclusions

The beneficial effects of social support for psychological wellbeing are well known, as are the specific benefits of peer support for people experiencing significant health concerns. However, participation rates in peer support groups for health conditions are often quite low, and it is known that barely 1% of stroke survivors access a peer support group (NSF, 2007). Although stroke is primarily considered to be a health condition of the elderly, approximately 20% of strokes occur in individuals younger than 55, and 3-4% in individuals younger than 40 (Teasell et al., 2000). Younger stroke survivors are faced with a unique set of psychological challenges, including pressures to return to work, family responsibilities, and the effect of a damaged body image on self esteem (NSF, 2006). They are known to have an even lower participation rate than stroke survivors as a group (NSF, 2006).

Peer support groups provide emotional, instrumental and informational assistance to members, although little is known about the specific mechanisms and processes by which they act (Davison, 2000; Sarason & Sarason, 2009). The present study found that young stroke survivors have limited access to peer support because most stroke survivors are much older. Moreover, even when the age of a young stroke survivor is matched with a peer, the effects and outcomes of stroke are so varied that it is rare to encounter anyone who has had a similar experience of stroke. The present research demonstrated that there are additional barriers to young stroke survivors participating in peer support: the impracticality of the peer group format, the potential for a significant negative effect of downward social comparison, and perceived irrelevance of a peer's support.

In conclusion, the major finding of this research is that young stroke survivors do not perceive their current peer support options to be supportive. Easy solutions are not apparent, although the literature indicates the importance of peer support for people experiencing significant health concerns. Given the significant psychological challenges that young stroke survivors face, it is important that young stroke survivors have access to a form of peer support that they perceive to be supportive. It is likely that potential solutions may be found through action research and cooperative inquiry.

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Appendix A: Information Letter

HUMAN RESEARCH ETHICS COMMITTEE
For all queries, please contact:
Research Ethics Officer
Edith Cowan University
100 Joondalup Drive
JOONDALUP WA 6027
Phone: ▮
Fax: ▮
Email: ▮

Project title: The perception of peer support by young stroke survivors

Dear Participant,

My name is Kate McGurk and I am researching the experience of surviving a stroke in early adulthood, especially with regard to perception of peer support. I am interested in how relationships with significant others change after a young person survives a stroke, and whether peer support might benefit people in this situation.

I invite you to contribute your experiences to my research. I hope that my findings will help the National Stroke Foundation to develop programs to increase social support for people who survive a trauma in their early adulthood. You may also benefit from the chance to discuss your experiences.

Should you participate, you will be interviewed about your experiences for approximately one hour. Reasonable travel costs will be reimbursed. You will be free to share as much or as little as you feel comfortable with, and may withdraw from the study at any time. Our discussion will be audio recorded and then transcribed.

Four weeks after the first interview, I will telephone you to speak again (by telephone, if you are not in the Perth metropolitan area). In our second discussion I will check that there weren't any negative consequences from the first interview, and ask you to reflect on the themes I identified from the transcript. Your contact details will be strictly confidential, and the transcribed interviews will have any identifying information removed.

It is possible that during the interview we may discuss personal issues that cause you some discomfort. If you feel uncomfortable at any time please let me know, and if necessary I will terminate the interview. I will also ensure that you have access to an appropriate counselling service if you require further support.

This research is being undertaken as part of the requirements of an honours degree in psychology at Edith Cowan University. This study has been approved by the ECU Human Research Ethics Committee, and is funded by the National Stroke Foundation.

If you would like more information about this study, please contact me (mobile: ▮ email: ▮), or my supervisor, Dr Ken Robinson [office: (08) ▮ ; email: ▮. If you have any concerns or complaints about this project and would like to speak to an independent person, you may contact the psychology fourth year co-ordinator Justine Dandy [office: (▮ email: ▮au]If you are interested in participating, please complete a consent form and a contact information form, return them in the reply paid envelope provided, and I will contact you shortly.

Appendix B: Declaration of Informed Consent

HUMAN RESEARCH ETHICS COMMITTEE
For all queries, please contact:
Research Ethics Officer
Edith Cowan University
100 Joondalup Drive
JOONDALUP WA 6027
Phone: █████████
Fax: █████████
Email: █████████

Project title: The perception of peer support by young stroke survivors

I _____ have read the information letter presented

with this consent form and I understand the purpose of this study. I have received

satisfactory answers to my questions regarding participation in this research.

- I agree to participate in the interviews involved in this research and am aware
  that I can withdraw from the study at any time without consequence.

- I agree to provide the researcher with my contact details, provided these
  details will be used only to organise a second meeting, and will be confidential
  at all times.

- I agree that information I provide during the interviews may be used to
  complete a research report, provided I am not identified in any way.

- I agree to have my interviews audio recorded, provided the recordings are
  erased after transcription.

_____   _____

Participant   Date signed

_____   _____

Researcher   Date received

Appendix C: Contact Details Form

HUMAN RESEARCH ETHICS COMMITTEE
For all queries, please contact:
Research Ethics Officer
Edith Cowan University
100 Joondalup Drive
JOONDALUP WA 6027
Phone: █
Fax: █
Email: █

Project title: **The perception of peer support by young stroke survivors**

CONFIDENTIAL

This form will be kept secure and separate from interview recordings and transcriptions. It will be used to arrange meetings and destroyed after the second interview.

Full name	
Gender	
Date of Birth	
Date of stroke	
Mobile phone number	
Home phone number	
Email	
Where you would like to meet	Interview room, ECU, Joondalup (WA) [please tick]
	Public library:

Thank you,
Kate McGurk
Phone: █
Email: █

Appendix D: Interview Schedule Guide

1. What do you remember about when your stroke happened?

2. Describe your social support network before the stroke.

3. In what ways has your social network changed since the stroke?

4. What kind of support did you receive from other people?

5. What kind of support would you have liked from other people?

6. What is the upside to getting support from other young stroke survivors?

7. What is the downside to getting support from other young stroke survivors?

8. What is the upside to giving support to other young stroke survivors?

9. What is the downside to giving support to other young stroke survivors?

10. Describe how easy it was to get support from other young stroke survivors for you. Describe how it worked for you.

11. What suggestions do you have that might make peer support work better for you?

12. Is there anything else you'd like to add or talk about?

Appendix E: Sample Annotation (Stage 1)

Rose, page 9

ROSE: So, because I ... I really know support, like I had so much, like, I've got unbelievable support. I still felt like I had no ... support with the stroke world. Like I knew an acquaintance who worked in stroke but I think, you know, peer support was so crucial. **[peer support was so crucial]**

RESEARCHER: Mm hmm.

ROSE: Um, I think ... um, I dunno, I think every single phase is so different, so, I mean in a way, lots of young stroke survivors have just been handballed to me. Like, I've got like ten that I just regularly touch base with or have coffee with or, you know? **[peer support was so crucial]**

RESEARCHER: Mm hmm.

ROSE: And, one's going back to uni, one's going back to work, one's just starting, um, still doing her rehab. Like it's all totally different, where I was at, at each of those stages. **[every stage I've been through the support has been so different]** So I think for them, well I know for me, not having a ... person to say, "Yep well this is, you know, who you go to if you find finding articles hard", or, "When you go back to work, ask this". I didn't have that so I think that is something I'm quite passionate about enabling others to ... have that mentor, that support. **[every stage I've been through the support has been so different]** Because, I mean, I'm motivated and I'm supported yet I still felt so unsupported in a way. **[peer support was so crucial]**

RESEARCHER: Mm hmm, so then it sounds a bit like you're being the mentor that you never got for these other ten people?

ROSE: Yeah, yep, definitely.

RESEARCHER: So how does that feel? Giving that support, are there any positives and negatives of being on the other side of that?

ROSE: Um ... I think that, um, I know how important it is for me, and all of my close friends go, "Ohh Rose, seriously, you don't need to worry about meeting them". But I know that, you know, for me that is so important. You know I would choose to do that over, um ... and if they need me I'd be there because I know I never had that. And I know that so much of your own recovery is so dependent on like, your support system and if you don't have that it just hinders everything. And also, it's quite good for me to be able to talk to someone. I never had the chance to go, "Oh yeah in rehab this happened, that was crap". I never really had the ability, not that I wasn't supported, but I guess I didn't have that mentor and I didn't have the words or anything to communicate that. So I think in a way it's good for me to be able to vent, too. **[peer support was so crucial]**

RESEARCHER: So you're finding it's more of a two way street rather than them just taking support from you, you're also getting support from them?

ROSE: Yeah. I think um ... um, definitely, once a relationship has started. I wouldn't, you know, on day one just handball all this stuff to them. But yeah, I think in the future, I don't see um, peer support as a ... just ... take thing, I guess a just take thing, and there's some stroke survivors who are at a point that they want support...

[peer support was so crucial]

Appendix F: Sample Themes (Stages 2 to 4)

Rose, page 9

Annotation - peer support was so crucial	Theme
I still felt like I had no ... support with the stroke world. Like I knew an acquaintance who worked in stroke but I think, you know, peer support was so crucial.	No support in the stroke world ?Non-stroke people don't 'get it'
in a way, lots of young stroke survivors have just been handballed to me. Like, I've got like ten that I just regularly touch base with or have coffee with or, you know?	I give others support
I'm motivated and I'm supported yet I still felt so unsupported in a way.	I felt unsupported
I know how important it is for me, and all of my close friends go, "Ohh Rose, seriously, you don't need to worry about meeting them". But I know that, you know, for me that is so important. You know I would choose to do that over, um ... and if they need me I'd be there because I know I never had that. [1]*And I know that so much of your own recovery is so dependent on like, your support system and if you don't have that it just hinders everything. And also, it's quite good for me to be able to talk to someone.* I never had the chance to go, "Oh yeah in rehab this happened, that was crap". I never really had the ability, not that I wasn't supported, but *I guess I didn't have that mentor and I didn't have the words or anything to communicate that. So I think in a way it's good for me to be able to vent, too.*	?Non-stroke people don't 'get it' Getting support aids recovery I didn't get support, so I know how important it is to give it to others Benefits from giving support Support is a two way process I wanted a mentor

[1] Selected quote for findings

I think um ... um, definitely, once a relationship has started. I wouldn't, you know, on day one just handball all this stuff to them. But yeah, I think in the future, I don't see um, peer support as a ... just ... take thing, I guess a just take thing, and there's some stroke survivors who are at a point that they want support	Support occurs within a two- way relationship Timing of support is important
Theme - every stage I've been through the support has been so different	
one's going back to uni, one's going back to work, one's just starting, um, still doing her rehab. Like it's all totally different, where I was at, at each of those stages	Different stages, different needs?
So I think for them, well I know for me, not having a ... person to say, "Yep well this is, you know, who you go to if you find finding articles hard", or, "When you go back to work, ask this". I didn't have that so I think that is something I'm quite passionate about enabling others to ... have that mentor, that support	Passionate about giving support, information, guidance Getting support aids recovery I felt unsupported

Stage 3 (comparison across participants)

Rose was the only participant to explicitly state that peer support was a crucial aspect of the recovery process and that her support needs changed over time