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**STROKE IN YOUNGER SURVIVORS:
AN INVESTIGATION INTO THEIR EXPERIENCES AND THE IMPACT OF
PROBLEM SOLVING THERAPY ON POST STROKE DEPRESSION, ANXIETY,
QUALITY OF LIFE AND PROBLEM SOLVING ABILITIES**

**A thesis presented in partial fulfilment of the requirements of the degree of Doctor
of Clinical Psychology**

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ABSTRACT

Stroke affects approximately 6000 New Zealanders every year with approximately 25% of individuals with first ever stroke in New Zealand under 65 years old. Stroke survivors commonly experience post stroke depression, anxiety, and low quality of life, which impacts negatively on the rehabilitation process. Research has also shown that stroke survivors who have higher depression scores demonstrate more ineffective problem solving skills than stroke survivors with lower depression scores. There is limited research into the efficacy of non-pharmacological treatments for the experience of emotional distress following stroke. Research that is available provides promising results for the efficacy of problem solving therapy (PST) for treating post stroke depression in older stroke survivors, however there is no research on this or any form of psychotherapy with younger stroke survivors (18-65).

The current research had two aims. The first was to collect information on problems experienced by younger (18-65) stroke survivors in New Zealand via a short online survey. Quantitative data was analysed using descriptive statistics and demonstrated that younger stroke survivors in New Zealand experience a number of different problems, with the most significant being difficulty with invisible disabilities. The qualitative analysis suggested large variability in how these problems affect the younger stroke survivors, and health professionals working with the younger survivors on their post stroke journey should take this into account.

Using information gathered from the survey the second aim was to evaluate the efficacy of PST for reducing symptoms of depression and anxiety, and increasing effective problem solving skills and quality of life in younger stroke survivors (aged 18-65). Using a group intervention format PST was delivered in six sessions over six weeks.

13 participants were recruited for the PST group, and this was compared with 16 participants who were originally placed on a wait-list control group (between-subject analysis). Once both groups had completed PST, the 28 participants were combined for within-subject analysis.

For the between-subject analysis, measures at baseline (pre-waitlist/pre-baseline) were compared with post-waitlist/post-treatment measures. This demonstrated that PST was no more effective than being on a wait-list control group. However, the within-subject analysis (measures at baseline, at the final therapy session and at three-month follow up) demonstrated significant improvements on depression, anxiety and quality of life measures. Participants also rated the sessions and overall PST as helpful and enjoyable when asked to complete feedback forms.

The main recommendation from this research is that the provision of education sessions post stroke that incorporate the stroke survivor and their families/support persons, would be beneficial. It is suggested that these be run after the acute phase, when stroke survivors are reintegrating back into the community. Information could be provided regarding what common symptoms are (both visible and invisible), how they may manifest, and beneficial ways for the stroke survivors and their family members to respond to these difficulties. It is also recommended that these sessions include speakers who are stroke survivors, and who have been through the post stroke journey. The speakers could talk about what they had experienced, what had been helpful and unhelpful to them, and what resources are accessible in the community. Finally, it is recommended that some form of support group be set up for younger stroke survivors in order to reduce the isolation that younger stroke survivors experience, however it remains unclear what type of support this should be, and future studies should be conducted to further explore this area. These studies could compare PST with social support groups, or

other forms of therapy such as CBT to tease out what is actually beneficial to the younger stroke survivor.

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CHAPTER ONE: OVERVIEW

The ideas for this research evolved from a combination of personal life experience and research that I had conducted at honours level. In 2006 my former partner, then aged 19 years suffered a stroke. Although his recovery was successful, there were significant ups and downs throughout the process. Due to this I have realised the substantial potential that psychological intervention can have on quality of life post stroke.

The focus of my previous research was to examine the effect that the age of the stroke survivor had on the attributions made by the general public on typical behaviours resulting from stroke (fatigue, depression, irritability and social activity). Results showed that when the stroke survivor described was aged 22 years, participants attributed the behaviours more to personality than to age or stroke, whereas when the stroke survivor described was aged 72 years, participants attributed the behaviours more to age than to personality or stroke. It was concluded that the attributions people make for behaviours resulting from a stroke are affected by the age of the stroke survivor (Wainwright, McClure, & McDowall, 2017). This research gave me a deeper understanding of some of the potential difficulties that stroke patients (younger and older) experience. This in combination with my personal experience has motivated me to conduct research into ways to help increase quality of life post stroke for younger stroke patients.

Proposal History

At the end of 2014, I had the opportunity to be involved in a clinic run jointly by the Massey University College of Health, the Massey University Sports and Recreation Centre and the Wellington Hospital Neurology Department for individuals who had experienced cardiovascular disorders. This involved group meetings where my supervisor and I provided psycho-education on the impact of stress, anxiety, anger and depression on cardiac disease. An initial idea for the proposal was to evaluate the benefits of the clinic

for the participants. Although, the clinic was discontinued due to funding issues, the experience provided further experience in running group therapy sessions and generated ideas for the current studies' proposal.

In early 2015, prior to commencing this study, the original proposal aimed to investigate the impact of invisible disability on stroke survivors. The proposal was to investigate differences in depression and anxiety levels in stroke survivors whose symptoms were visible compared to stroke survivors whose symptoms were invisible. An additional aim was to run an intervention group designed to help stroke survivors cope more effectively with the difficulties experienced as a result of their residual symptoms (visible or invisible).

After an extensive literature review, the proposal was adapted to focus on younger stroke survivors. This was a result of the limited research surrounding interventions aimed to increase quality of life for younger stroke survivors and the call for research from the Stroke Foundation of New Zealand regarding this population. Therefore, it was decided to focus on running an intervention study aimed to reduce symptoms of depression and anxiety in younger stroke survivors. The decision was reinforced by the finding that there is limited research on the experiences of younger stroke survivors in New Zealand. This then became a further aim of the research, and subsequently its own study (study one). It was decided that we would create an online survey that investigates the experiences of younger stroke survivors and distribute this nationally with the help of the New Zealand Stroke Foundation.

For part two of the study, a proposal was developed for a randomised control trial evaluating the effectiveness of problem solving therapy (PST) for reducing symptoms of depression and anxiety and increasing effective problem solving skills and quality of life

in younger stroke survivors. The PST group would be compared with a social control group.

As a result of the online survey, we were contacted by younger stroke survivors around New Zealand expressing their interest and gratitude for research into the area of younger stroke survivors. The intervention study was discussed with these younger stroke survivors and a decision made to extend recruitment out of Wellington so that these individuals could be involved in recognition of their clearly expressed need for support in managing their post stroke distress. It was then decided that instead of using a social control group, the research would evaluate the PST group against a wait list control group. That way all participants would receive therapy at some point during the year.

In total, 28 younger stroke survivors across five groups (2 in Wellington and 3 in Tauranga) took part in the therapy sessions. Results were considered from between-subject and within-subject perspectives. For the between-subject analysis, improvements of the wait-list group of 16 between pre-baseline and post-baseline were compared with improvements of the treatment group of 13 between pre-treatment and post-treatment. The two groups were then combined, and after one participant dropped out, 28 completed therapy. Outcome measures for pre-treatment, post-treatment and follow-up were compared for the with-in subject design. Chapters 9-12 will provide further details of the study design for parts 1 and 2.

Organisation of the Thesis

This thesis is divided into 12 chapters. Chapters 2 through 6 provide a thorough review of the current research literature surrounding this topic. These include a general overview of stroke including prevalence and outcomes. The next chapter discusses stroke in younger adults, as this is the salient area of the current research. Chapter 4 covers post stroke depression and anxiety, and the following chapter looks at psychological

interventions into these two disorders. Chapter 6 then outlines and explores problem solving therapy in depth as this is the therapy of choice for this research project. These chapters provide the rationale for the current study.

Chapter 7 highlights the research aims, questions and hypotheses. Chapters 8 and 9 describe justifications for the research methods for studies 1 and 2, providing a rationale for the design and outcome measures chosen. Chapter 10 is the first manuscript produced from this research and is titled “A cross-sectional survey of the experiences of younger stroke survivors in New Zealand: A mixed methods study”. Chapter 11 includes the second manuscript, titled “The efficacy of Problem Solving Therapy to reduce post stroke emotional distress in younger (18-65) stroke survivors”. Finally, chapter 12 includes a discussion of the findings in both studies and the contributions to literature. It will also discuss the limitations of the study, recommendations for future research and conclusions of the study.

In terms of terminology, “younger stroke survivors” refers to individuals who had their stroke between the ages of 18 and 65. The upper limit was chosen for a number of reasons. Firstly, as it is the retirement age in New Zealand, secondly, because there is very little research conducted in individuals under this age and finally because approximately three quarters of all stroke occur in people over the age of 65 both nationally (Tobias, Cheung, Carter, Anderson, & Feigin, 2007) and internationally (U.S. Centers for Disease Control and Prevention, 2012). Thus, 25% of stroke survivors are under the age of 65. It is considered rare for stroke to occur at this age, this is a population who tends to have to fit in with rehabilitation designed for older adults. Research has found that stroke survivors are frustrated with the lack of age adapted rehabilitation (Stone, 2015). Therefore, this research is aimed at improving both the state

of knowledge and the standard of post stroke care for the significant number of stroke survivors who are under age 65.

CHAPTER 2: STROKE

Definition

Stroke can be defined as an acute onset disruption in functioning or a localized necrosis of cerebral tissue. To be defined as a stroke, symptoms must last longer than 24 hours. Symptoms that last less than this are categorized as a transient ischaemic attack (TIA) (Sila & Schoenberg, 2011). Strokes are classified by their pathophysiology. The two major categorizations of stroke are ischemic or hemorrhagic. If the stroke occurs due to an obstruction in blood flow to the brain, then it is termed an ischemic stroke. If an artery or vein ruptures resulting in intracranial bleeding, then a hemorrhagic stroke has transpired. Ischemic stroke is the most common type of stroke, accounting for 80% or more of stroke events, whereas hemorrhagic strokes make up the remaining 20% of stroke events (Morrison, 2014).

Prevalence

In 2010, the worldwide prevalence of stroke was 33 million, with 16.9 million people experiencing their first stroke (Mozaffarian et al., 2015). Stroke is the second leading global cause of death and accounts for 11.13% of total deaths worldwide (Mozaffarian et al., 2015). Approximately one third of stroke survivors will be left with permanent disability (World Health Organization, 2004). In New Zealand, stroke is the third leading cause of death and disability (Dyall, Feigin, Brown, & Roberts, 2008, Ministry of Health, 2009; Stroke Foundation of New Zealand, 2015). The prevalence of stroke has been estimated to be around 60,000 (Ministry of Health, 2008; Stroke Foundation of New Zealand, 2015), and approximately 6000 New Zealanders suffer from a stroke every year (Tobias, Cheung, Carter, Anderson, & Feigin, 2007).

The onset of stroke in New Zealand varies depending on ethnicity and gender. For Māori, the average age of onset is 61 years, for Pacific people it is 64 years and for

European New Zealanders it is over 75 years (Feigin et al., 2006). Women on average suffer a stroke at an older age than men (at approximately 76 years).

Outcomes

Stroke Symptoms. Although Ischemic and Hemorrhagic strokes differ in pathophysiology, the outcomes resulting from both are similar, in that they both eventually result in ischemic injuries (Perna & Temple, 2015). When there is no supply of blood to brain tissue, it quickly deteriorates or dies. This results in paralysis of limbs or organs that are controlled by the affected area of the brain, as well as communication or cognitive deficits (Sila & Schoenberg, 2011). The following sections provide a more in-depth explanation of some of the more common outcomes of stroke. These will be divided into physical symptoms, communication deficits and cognitive difficulties. An additional section also addresses common responses to stroke including emotional distress and reduced quality of life.

Physical symptoms. Hemiplegia (paralysis on one side of the body) and hemiparesis (weakness on one side of the body) are the most common symptoms of stroke and occur on the side of the body that is contralateral to the location of the infarct. These symptoms can affect the facial muscles, arms, hands and legs, and make performing everyday tasks such as dressing, walking, eating and grooming difficult or impossible (Uchino, Pary, & Grotta, 2011). Hemianaesthesia can also occur and is a loss of tactile sensibility on one side of the body.

Further physical symptoms include dysphagia (difficulty swallowing), and incontinence, which can occur if the stroke survivor has difficulty controlling their bladder or bowel movements. Stroke can also result in decreased vision or blindness in half the visual field (hemianopsia) and fatigue, which affects between 40 to 70% of stroke survivors (Uchino et al., 2011). These physical symptoms can significantly impede the

stroke survivors' independence, which consequently reduces their quality of life (Kilbride & Kneafsey, 2010).

Communication deficits. If the left hemisphere is damaged, aphasia is a common symptom affecting approximately one third of stroke survivors in the early stages following stroke (Marshall, Hilari, & Cruice, 2010; Sila & Schoenberg, 2011). There are two types of aphasia: Broca's aphasia (non-fluent) and Wernicke's aphasia (fluent). Broca's aphasia results in a difficulty in communicating orally and with written words. Speech in Broca's aphasia is often hesitant and fragmented and the stroke survivor often has difficulty finding words (Marshall et al., 2010; Sila & Schoenberg, 2011). Wernicke's aphasia (fluent) results in a difficulty in understanding spoken and written language. Here speech is normal in quantity and rate, but includes a lot of errors, including nonsense words and neologisms (Marshall et al., 2010; Sila & Schoenberg, 2011).

Dysarthria and dyspraxia are problems of speech production, rather than language. If they have no other difficulties, stroke survivors with either dysarthria or dyspraxia will be able to read, write and comprehend what other people say, but their own speech will be difficult or impossible to understand. Dysarthria affects motor speech, making articulation and phonation difficult. As a consequence, speech is less intelligible. This disorder affects 20% of stroke survivors (Marshall et al., 2010; Sila & Schoenberg, 2011). Dyspraxia of speech disrupts the co-ordination and sequencing of speech movements. The disorder often only affects planned speech, such as when the individual wants to say something or is asked to talk. Automatic speech, such as counting from one to ten or reciting the days of the week is unaffected (Marshall et al., 2010; McCann, 2006; Sila & Schoenberg, 2011).

Cognitive impairments. Communication and physical difficulties are frequent outcomes of stroke, however in addition there are 6 areas of cognitive functioning that may be affected. These cognitive impairments can be divided into six different domains as outlined in Table 1.

Table 1

Possible cognitive difficulties experienced by stroke survivors, adapted from Knapp (2010) and Uchino et al. (2011)

Cognitive domain	Areas in which difficulties are experienced
Attention	Focused attention Sustained attention Selective attention Divided attention
Memory	Visual memory Auditory memory Working memory Episodic memory Semantic memory Procedural memory Short-term memory Long-term memory
Perception	Visuo-spatial Visuo-perceptual Unilateral neglect Inattention Apraxia Agnosia Prosopagnosia
Executive Function	Decision making Initiation Processing speed Problem solving Planning
Social cognition	Impulsivity Poor understanding of social situations Inability to see someone else's point of view Difficulty being patient and knowing when to talk and when to listen in a conversation

Lesion Location. The outcome of stroke varies greatly depending on which area of the brain is affected. The following table outlines the differences between damage to the left and right sides of the brain.

Table 2

Possible effects of right and left-sided infarct adapted from McCann (2006)

Area of Difficulty	Right – sided stroke	Left – sided stroke
Movement and Mobility	Left hemiplegia and some spatial and perceptual problems	Right hemiplegia
Vision	Hemianopsia in the left visual field of each eye	Hemianopsia the right visual field of each eye
Hemispatial Neglect	Ignoring objects or individuals to the left	Not affected
Behaviour	Impulsivity or inappropriate behaviour	May require frequent instruction and feedback May be slower and more cautious
Memory	Short term memory loss	Increased difficulty in learning new tasks Difficulty in paying attention Difficulty conceptualising and generalising
Language	Not affected	Wernicke’s aphasia Broca’s aphasia
Emotional health	Depression Anxiety	Depression Anxiety

Symptoms can also vary depending on which lobe is affected. The following table outlines the differences between damage to the different lobes of the brain.

Table 3*Possible symptoms related to different lobes of the brain adapted from McCann (2006)*

Area of cerebral cortex	Possible symptoms post stroke
Frontal lobe	Difficulty in persevering with a single thought Inability to plan a sequence of complex movements needed to complete multi-stepped tasks Problem solving difficulties Difficulty with social interaction Changes in social behaviour Personality changes Loss of flexibility in thinking Loss of focus Mood changes Broca's aphasia
Parietal lobe	Apraxia Agnosia Anomia Agraphia Alexia Dyscalculia Difficulty with drawing objects Difficulty in distinguishing left from right Inability to focus visual attention Difficulties with hand eye co-ordination
Occipital lobe	Hemianopsia Difficulty with locating objects in the environment Colour agnosia Word blindness Difficulty in recognising drawn objects Movement agnosia Reading and writing difficulties Hallucinations
Temporal lobe	Prosopagnosia Wernicke's aphasia Selective attention difficulties Difficulty identifying and describing objects Inability to categorise objects Short-term memory loss Long-term memory problems Increased aggression

Common Responses to Stroke. Stroke often comes without warning, and results in admission to hospital and a period of time in an inpatient unit. Stroke can also have a major effect on the survivors social, occupational and day-to-day functioning, especially if they experience physical disability or impairment to their ability to communicate. The following sections will outline different ways in which individuals respond after experiencing a stroke.

Emotional Distress. Experiences of emotional distress such as worry, shock, denial, grief, frustration, irritability or anger, are common post stroke, and are a normal part of emotional and behavioural adjustment (Knapp, 2010). Stroke survivors are often able to work through this distress and find a way to adjust to their new life circumstances. However, for approximately 30% this distress does not resolve and can develop into depression or anxiety (Knapp, 2010; Mellon et al., 2016). Post Stroke Depression (PSD) and Post Stroke Anxiety (PSA) will be discussed in chapter 4, as these are the outcomes of interest for the current study.

Quality of Life. Quality of life is defined as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organisation Quality of Life Group, 1998, p. 551).

A number of studies have shown how quality of life after stroke is significantly impaired (Kim, Warren, Madill, & Hadley, 1999; Mellon et al., 2016) even in survivors with no visible post stroke disability (Lai, Studenski, Duncan, & Perera, 2002). For example, Duncan et al. (1997) compared the health related quality of life (HRQoL) of 304 mild stroke survivors, 184 participants who had experienced a transient ischemic attack and 654 who showed risk factors for but had not suffered a stroke or a transient ischemic

attack. Lowered HRQoL was found for all groups but was lowest in the mild stroke group.

The lowered scores are maintained over time, with Hackett, Duncan, Anderson, Broad and Bonita (2000) reporting lower HRQoL scores in a group of 639 people six years post stroke, than a general population group. Further research has found that on average, HRQoL utility scores of people post stroke range from 0.47 to 0.68 (where 0.0 = death and 1.0 = full health), which is considerably lower than HRQoL utility scores of a healthy reference population, which sit around 0.93 (Sturm et al., 2004). This previous research is supported by a more recent study, which found that quality of life was significantly lower in stroke survivors compared to matched stroke free controls (Haley, Roth, Kissela, Perkins, & Howard, 2011).

Multiple risk factors have been found to be associated with poorer HRQoL in stroke survivors including emotional distress (Mellon et al., 2016), age (older), coping style, gender (female), depression, functional constraints, social support, institutionalization, dependency in activities of daily living (ADL), disability and diabetes (Abubakar & Isezuo, 2012; Gurcay, Bal, & Cakci, 2009). Visser et al. (2015) found that high depression scores had the strongest relationship with low HRQoL scores. Their study also found that stroke survivors who demonstrated a positive problem orientation and therefore robust coping strategies had higher HRQoL scores.

New Zealand Research

Research investigating the experiences of stroke survivors of any age in New Zealand is limited. Glozier, Hackett, Parag and Anderson (2008) investigating the impact of stroke on employment, found that of stroke survivors who worked prior to their stroke only 53% returned to work. In a more recent study, Ahuja et al. (2013) used semi-structured interviews to gather qualitative data for 11 stroke survivors aged between 49

and 72, regarding their post stroke perceptions and experiences. The study reported common problems in the areas of loss of employment, relationship impairment, financial burden, decreased function and family burden, and that stroke survivors coped with the problems through family support, goal setting, and learning and accepting one's limitations.

Similarly, Dyall et al. (2008), investigating the experiences of eight Māori stroke survivors, through semi-structured *kanohi ki te kanohi* (face to face) interviews, reported problems including loss of income, change in family structure, loss of self-esteem, social isolation and withdrawal, loss of mana (prestige), and feeling *whakama* (embarrassed) as the head is *tapu* (sacred). Participants believed that their behaviour post-stroke was similar to mental illness and reported a lack of communication between health care professionals and themselves, and a lack of information and support post-stroke.

In conclusion, stroke affects approximately 6000 New Zealanders every year (Tobias et al., 2007) and around one third of stroke survivors are left with permanent disability. Impairments can affect communication, physical functioning and/or cognitive functioning and vary depending on the location of stroke. Research in New Zealand regarding stroke survivors is limited, however outlines some of the difficulties that stroke survivors in New Zealand experience and demonstrates the unique journey of Māori stroke survivors. The current study endeavours to further investigate the different aspects of stroke survivors' lives that are affected, as well as ways to alleviate negative responses to stroke.

As the focus of the current study is on younger stroke survivors, the following chapter will explore the unique impact that these disabilities have on psychological, social, physical, economic and vocational functioning in the younger stroke survivor age group.

CHAPTER 3: YOUNGER STROKE SURVIVORS

Prevalence

Although stroke can occur at any age, the majority of people understand stroke to be a disease of old age (Groppo et al., 2012). This belief has arisen because stroke risk increases with age, a relationship which is found universally (Feigin, Lawes, Bennett, & Anderson, 2003). As a consequence, stroke is considered as a relatively uncommon event in people younger than 45 years (Groppo et al., 2012). Previous studies have reported the incidence rate of juvenile (15-44 years) stroke to be between 9 to 47 cases per 100,000 people annually (Groppo et al., 2012; Jacobs, Boden-Albala, Lin & Sacco, 2002; Kristensen, et al., 1997; Lee, Hsu, Chen, & Chen, 2002; Rasura, et al., 2006).

Although stroke in young adults is relatively rare, studies have demonstrated that stroke in young adults is becoming increasingly more common and a shift towards an earlier onset is occurring (George, Tong, Kuklina, & Labarthe, 2011; Kersten, Low, Ashburn, George, & McLellan, 2002; Röding, Linderström, Malm, & Öhman, 2003; Rothwell et al., 2005). Approximately 5,000 people of working age suffer a stroke in the United Kingdom every year (Graham, Gillanders, Stuart, & Gouick, 2015). This number will increase with the pattern of older adults continuing to work.

Estimates from the United Kingdom (Kersten et al., 2002), the United States (U.S. Centers for Disease Control and Prevention, 2012), and New Zealand (Tobias et al., 2007) suggest that approximately one quarter of individuals affected by stroke are under the age of 65. Varona, Bermejo, Guerra and Molina (2004) estimated that up to 12% of all stroke incidences occur in patients less than 45 years of age.

Consequences Following Stroke

The likelihood of surviving the initial illness is far greater for younger stroke survivors (Varona et al., 2004). Therefore, the total number of years that a young stroke survivor has to live with the consequences of a stroke (functional and/or cognitive

deficits) is often far greater than the number of years of an older stroke survivor (Rutten-Jacobs et al., 2011). Younger stroke patients also have to deal with the additional psychological task of coping with the peculiarity of suffering an older person's disease at an early age (Stone, 2005).

Although there are similarities, research has shown that young and older stroke survivors report different practical and psychological needs and experiences following stroke. This is because age-normative roles and activities are affected by stroke and younger stroke survivors are at different stages of the life course (Morris, 2011; Stone, 2005). They are often at the stage where they have an active social life, are starting to form families or are already responsible for young children and have active careers (Morris, 2011; Rutten-Jacobs et al., 2011). Individuals affected by stroke during this life stage may find themselves on a completely different path from their anticipated life trajectory. Reported consequences following stroke among this population include family life disruption (Daniel, Wolfe, Busch, & McKeivitt, 2009; Teasell, McRae, & Finestone, 2000), marital breakup (Teasell et al., 2000), family conflict (Teasell et al., 2000), an altered sex life (Daniel et al., 2009; Morris, 2011), employment loss or disruption (Morris, 2011; Teasell et al., 2000), altered finances (Daniel et al., 2009; Kersten et al., 2002), disruption in leisure activities (Daniel et al., 2009), and transportation challenges (Ing, Vento, Nakagawa & Linton, 2014).

Quality of life studies with stroke survivors of all ages have produced inconsistent findings between younger and older stroke survivors (Bays, 2001; Kim et al., 2005). For example, in a long term follow up study, reduced health-related quality of life (HRQoL) in young adult stroke survivors, was associated with dependence, depression, fatigue, being unemployed and being single (Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006). In older stroke survivors reduced quality of life is associated with different

factors such as functional ability, satisfaction with social support, visual impairment, the type of stroke, and seizures (Kim et al., 2005; Mackenzie & Chang, 2002). The following sections will discuss research into the experiences and challenges of younger stroke survivors.

Return to Employment

The enduring impact of stroke on younger adults can leave them reliant on health services for a vast amount of years as they often experience temporary or permanent loss of employment. Singhal et al. (2013) estimated that only 42-53% of young stroke survivors return to employment following their stroke. Of these, 23% need modifications in the workplace. Similar data has also been found in New Zealand. Glozier et al. (2008) used prospective data from the third Auckland Regional Community Stroke (ARCOS) study to determine the percentage of stroke survivors who returned to paid employment. Of the 1423 patients who were registered with first ever stroke, 20% reported that they were in paid employment prior to the event of the stroke with only 53% of these stroke survivors returning to paid employment. Not having a job has been found to be a major source of dissatisfaction for young stroke survivors across numerous studies (e.g., King, 1996; Morris, 2011; Niemi, Laaksonen, Kotila & Waltimo, 1988; Teasell et al., 2000).

Social Interaction

Younger stroke survivors may also experience significant disruptions to their social life (Murray & Harrison, 2004). The following themes have been identified through the use of qualitative research looking at the experiences of younger stroke survivors.

Barriers to social interaction. Murray and Harrison (2004) carried out qualitative in-depth semi-structured interviews with 10 stroke survivors. All participants were younger than 55 except for one 82 year-old. The interview data was analysed using Interpretative Phenomenological Analysis (IPA). The stroke survivors discussed how others interpretation of their physical disabilities inhibited their interaction in the

community. The following participant experiences difficulties with his communication and encountered difficulty with a bus driver.

[The bus driver said] ‘You cannot come on this bus, you are pissed’. [I was] horrified. I asked him three times for his number. In the end I took the number of his bus and reported it to the bus company. I did not want him to get sacked but to chat to him to have a bit more consideration for his passengers. I was not pissed. I told him, ‘I have not had a drink for three years.’ (stroke survivor cited in Murray & Harrison, 2004, p. 812)

Feeling alone and misunderstood. Stone (2014) investigated younger stroke survivors’ desire for peer support through open ended interviews with 28 stroke survivors aged 8 to 49 at the time of their stroke. Transcripts were created and analysed using qualitative methods. Most (22 of 28) participants indicated that they felt alone, isolated and misunderstood following their stroke. Participants talked about how their peers, who hadn’t experienced a stroke, carried on enjoying themselves in social situations, when they had to stay at home on their own.

I can only speak for myself, but I just felt so alone. And so isolated. Um, and that – maybe it was selfish, but – that nobody understood. This big TRAUMA that I’d gone through in me life, you know, and everybody else was out enjoying themselves and I was stuck at home... (stroke survivor cited in Stone, 2014, p. 4)

Desiring Peer Support. Of the younger stroke survivors from the Stone (2014) study, 21 also expressed a desire for face to face peer support. “I kind of felt like I wanted to talk to somebody. Um, somebody that had had it or somebody that knew about it...” (stroke survivor cited in Stone, 2014, p.5).

Forming relationships. Young stroke survivors in the study by Murray and Harrison (2004) discussed their difficulty in forming romantic relationships. This was mainly in relation to their physical disabilities.

... But I think the stroke goes against me. Up to now I haven't been given a chance by anyone else. I feel as though they see the walking stick and that is all they are interested in and not the real person. People don't want to get to know you. They would find a decent bloke, because I am. But the problem is why should a lady want to go out with me if you can go out with someone who does not have a disability? (stroke survivor cited in Murray & Harrison, 2004, p. 812)

Participants also discussed how their pre-existing relationships had ended due to a reduction in their sex life.

In summary, stroke can influence a number of different factors that contribute to social interaction. This is an area that can be influenced post stroke and therefore should be targeted during post stroke rehabilitation.

Family Life

Martinsen, Kirkevold and Sveen (2012) investigated the impact of stroke on family life in younger stroke survivors. The authors carried out in depth interviews with 22 participants who were between the ages of 20 and 61 and in the late recovery phase (six months or more after stroke). The interviews were analysed using a hermeneutic phenomenological approach. Participants discussed how it was difficult to re-enter the family and fulfil their pre-stroke roles. They struggled with the fact that they could not care for others the way they used to and found it harder to devote attention to others and participate in or conduct normal life tasks within the family. They discussed the difficult transition from being an active, independent contributing family member to someone who had to rely on partners, children or their parents for support. Participants also spoke of the

difficulty of becoming a parent or parenting close to the time of stroke onset due to an inability to meet typical parenting expectations. They also discussed how emotional and cognitive changes such as being short tempered created challenges as a parent.

Jones and Morris (2012) investigated the relationships and interactions between parents and survivors post stroke. The study found that younger stroke survivors experienced a sense of loss of worth and identity as a result of losing their independence as a working-age adult and having to rely on their parents. Some of the participants discussed feeling like they were a disappointment to their parents. They also reported experiencing a sense of overprotectiveness from their parents.

Gender roles. A theme that emerged from the study by Murray and Harrison (2004) was that men in particular believed that the disabling effects of their stroke had impacted upon their gender identity. A switch from the role of the caregiver in the family made them feel emasculated. “I get very angry when I cannot do the things that I should be able to do. That my wife has to have so much of my care when I should be taking care of her” (stroke survivor cited in Murray & Harrison, 2004, p. 812).

View of Life

Smout, Koudstaal, Ribbers, Janssen and Passchier (2001) carried out semi structured interviews with eight stroke survivors who were between the ages of 20 and 55 years old and found that most had changed their view of life in response to their stroke. The importance of material possessions had decreased, whereas the importance of health and enjoyment increased. Participants were keen to get the most out of life and had narrowed their perspective of the future to focus more on day to day life, rather than further into the future.

Unmet Needs

Research has found that younger stroke survivors report a number of needs that they feel have not been met such as financial assistance, non-care activities, intellectual fulfilment and help in returning to work (Low, Kersen, Ashburn, George and McLellan, 2003).

Comparing the unmet needs (Southampton Needs Assessment Questionnaire for people with stroke; SNAQS) of two groups of young stroke survivors, one group aged 18-45 and the other aged 46-65, Kersten et al. (2002) found no significant differences in the total number of unmet needs identified between the two age bands. The younger group however reported significantly more unmet needs for family support, intellectual fulfilment and a holiday than the older group.

Van de Port, van den Bos, Voorendt, Kwakkel and Lindeman (2007) investigated the factors that were related to perceived unmet needs in individuals who had had their stroke three years earlier. One third of the 157 participants reported at least one unmet need. The most frequently identified of these were leisure time, work and education. The study found that low motor function, presence of depression and fatigue were all independently related to a greater probability of having perceived unmet needs. Further, being aged over 60 years was associated with fewer reported unmet needs.

In summary, stroke survivors report a number of unmet needs following stroke including financial assistance, non-care activities, intellectual fulfilment, help in returning to work or education and a lack of leisure time. This research should be taken into consideration by health care professionals to ensure that stroke survivors' needs are met post stroke.

Body Image, Self-esteem and Sense of Self

Stroke results in changes to self-concept and low self-esteem, both of which have a negative effect on socialisation in a number of different settings (Keppel & Crowe,

2000; Morris, 2011). Keppel and Crowe (2000) explored the effects of stroke on body image and self-esteem in stroke survivors under 40 years by asking them to rate body image and self-esteem retrospectively (prior to stroke) and currently (after stroke). A decline in body image was found subsequent to their stroke, which was associated with reduction in measures of self-esteem (Keppel & Crowe, 2000). Low self-esteem is a vulnerability factor for depression and low levels of self-esteem has been linked to the development and course of depression in stroke survivors (Keppel & Crowe, 2000).

Younger stroke survivors also experience a loss of self, due to the combination of numerous reductions in physical and cognitive abilities, psychological difficulties and changes in personality (Murray & Harrison, 2004). “It’s hard struggling with the loss of me especially the strong, capable and always care giver me” (cited in Murray & Harrison, 2004, p. 811). Their current personhood felt strange and unfamiliar to them as illustrated by the following quote: “... I am different, not the same person. I have looked in the mirror and said ‘Who the **** are you?’ It looks like me but it isn’t, you know what I mean?” (cited in Murray & Harrison, 2004, p.811).

A more recent study by Lapadatu and Morris (2017) supports the previously mentioned findings regarding identity and self esteem. The authors carried out a cross sectional study that assessed stroke survivors’ perceived identity before and after stroke as well as levels of depression, anxiety, quality of life and self esteem. The results demonstrated that the stroke survivors rated their post stroke identity as more negative than their pre stroke identity. It was also found that larger discrepancies in identify resulted in increased anxiety and depression, and lower self esteem and quality of life.

The above studies demonstrate how the effects of stroke can influence younger stroke survivors’ sense of self, resulting in unfamiliarity and low self-esteem.

Stigmatization

As stated earlier, approximately a third of all stroke patients are left with disability (Tyrrell & Smithard, 2005). Erving Goffman's (1963) concept of stigma states that people who have visible disabilities are perceived by the general public as being different, unusual or bad and as a result may be discredited or stigmatized by the other non-disabled individuals (Joachim & Acorn, 2000; Noonan, Barry, & Davis, 1970). As stroke survivors are often left with physical disabilities, such as hemiplegia they too are at risk of stigmatization from the general public (Kilbride & Kneafsey, 2010).

Due to this stigmatization, people with visible disabilities are less likely to be employed than those with invisible disabilities. For example, Gouvier, Steiner, Jackson, Schlater and Rain (1991) conducted a study with 541 undergraduate participants who were asked to rate four job applicants. Each applicant represented one of four disability types: neurological/visible, neurological/invisible, non-neurological/visible and non-neurological/invisible. Applicants whose disability was highly visible were less favourably viewed than applicants whose disability was invisible. Ravaud, Madiot and Ville (1992) found similar results, indicating discrimination towards individuals with visible disabilities. The authors sent job applications to more than 2,000 French companies. The applications described an individual with or without a disability, and with high or moderate qualifications. Job applications describing able-bodied applicants were more likely to receive a positive response than disabled applicants.

Students in higher education environments also report discrimination. Holloway (2001) reported that students felt marginalised, different and distanced from other students, as a consequence of having to wait outside emergency exits for entry into class and having to sit in the front of the class due to their physical disabilities. Likewise, Hadjidakou, Polycarpou and Hadjilia (2010) found that students with mobility disabilities have fewer options for universities and courses that they can attend, as not all universities

are equipped with the necessary access equipment for people with mobility disabilities, or the universities are too far away from medical facilities and family support.

Problems Arising from Invisible Disabilities

Research suggests that younger stroke survivors are more likely to suffer from a haemorrhagic stroke than older stroke survivors (Hop, Rinkel, Algra & van Gijn, 1998; Jacobs et al., 2002). Haemorrhagic stroke often results in impairments that are not immediately obvious to an observer (Hamedani et al., 2001); therefore, the stroke survivors can be left with only invisible disabilities such as memory impairment, concentration problems or fatigue (Lawrence, 2010; Stone, 2005; Waldman, Cannella, & Perlman, 2009). These invisible disabilities can also have a negative impact on the stroke survivors psychosocial functioning and can inhibit them from satisfactory community integration (Davis, 2005; Joachim & Acorn, 2000; Tam, Chan, Lam, & Lam, 2003). A number of qualitative studies with younger stroke survivors have found that younger stroke survivors perceive their invisible symptoms to be challenging and frustrating (Murray & Harrison, 2004; Röding, Linderström, Malm, & Öhman, 2003; Stone, 2005). The different challenges associated with invisible disabilities, are discussed in more detail below.

The general public often incorrectly believe that you can recognise when a person has had a brain injury, only if they have visible proof of that injury (Linden & Boylan, 2010). Stone (2005) suggests that this common misconception was formed because society has been taught to distinguish disabled individuals from non-disabled individuals on the presence or absence of visual or auditory cues (Stone, 2005). However, this perception is often unwarranted, as research has demonstrated that approximately 40% of individuals with disabilities have no visible sign of disability (Asch, 1984). This common

misconception is a significant contributor to the following problems experienced by individuals with invisible disabilities.

A lack of “proof”. People with invisible disabilities often have difficulty with securing the assistance or accommodation that they need to function successfully. They often have to explain their disability, because they have no visible proof. This not only creates discomfort, but it often results in them being subjected to dis-belief from the wider community (Davis, 2005). Stone (2005) states that this is due to the attitude held by society of "seeing is believing". Not being taken seriously means that they are less likely to receive the support they need (Davis, 2005).

Those whose disabilities are invisible may also have to convince other people that they really are disabled, not seeking some special-unfair-advantage: thus, what they must do is meet a burden of proof. They thus face a double blind: either they forgo assistance or accommodation they need - and thus suffer the consequences of attempting to do things they may not be able to do safely by themselves - or they endure the discomfort of subjecting themselves to strangers' interrogations. (Davis, 2005, p.154)

This creates a dilemma for individuals with invisible disabilities. They run the risk of being judged as incompetent or lazy if they keep quiet. However, if they disclose their disability they may not be believed and therefore run the risk of being judged as an attention or sympathy seeker (Stone, 2005). Either outcome is unpleasant and can generate stress and discomfort for individuals with invisible disabilities (Davis, 2005). Further they may be denied support from disability services (Mukherjee, Reis, & Heller, 2003). This lack of support can also come from within the disabled community, with those with invisible disabilities being sometimes rejected by individuals with visible disabilities.

Stone (2005) investigated experiences of 22 females with invisible disabilities between the ages of 8 and 49 who had suffered a haemorrhagic stroke. The participants expressed frustration at repeatedly needing to give explanations for their invisible disabilities and felt they could not meet the expectations that other people held for them. Others would also judge the stroke survivors to be "lazy, incompetent or something else equally derogatory" (Stone, 2005, p. 295). This led to avoidance of situations where they would encounter difficulties. Even people close to them would often forget or deny their invisible disabilities.

If it had been a LEG or something or if it had to be amputated, then people would say, 'okay, well YES, that person has a disability,' but you know, you look at me, I'm healthy, [They say] 'what's wrong with her?' ... I think, yeah, the hardest part for me of having the aneurism was... dealing with other people. (young stroke survivor cited in Stone, 2005, p.301)

Participants in Murray and Harrison's (2004) study expressed similar difficulties with emotional difficulties following stroke such as emotional lability. "I might grin when I shouldn't ... I can be sarcastic ... I laugh when I shouldn't" (stroke survivor cited in Murray & Harrison, 2004, p.811). They found invisible emotional difficulties harder to deal with than the physical or cognitive difficulties that were more visible to other people.

Look at me I look all right. But you know that up there, (pointing to head) that there is a problem and not enough attention is given to it. Basically, look at me, people wouldn't know that I have had a stroke, but the emotional problems can't be seen. Look at him over there. He would say there is nothing wrong with me because you can't see the problem. Something should definitely be done about the problem that you can't see. You look at me and there is nothing wrong with me. I look normal and OK... (stroke survivor cited in Murray & Harrison, 2004, p.811)

Some participants with little physical disability expressed a preference for a visible disability, as they believed that visible disabilities generated more empathy and understanding from others.

Unrealistic expectations. People often hold unrealistic expectations for individuals with invisible disabilities (Gouvier et al., 1991). Swift and Wilson (2001) investigated lack of knowledge and misconceptions surrounding brain injury using semi-structured interviews with 19 brain-injured individuals. Ten participants whose problems were not visible, felt at a disadvantage when compared to a brain-injured person whose disabilities were visible. Because they looked "normal", family members, friends, work colleagues and members of the general public held unrealistic expectations with regards to recovery, performance and their personality. According to Swift and Wilson (2001) "normal behaviour, in terms of personality and performance, is expected from a normal-looking person, and the cognitive problems mentioned previously are over-looked" (p.156).

Röding et al. (2003) investigated experiences of two women and three men between the ages of 37 and 54 who had suffered a haemorrhagic stroke and had invisible disabilities. They felt that their invisible disabilities were not as legitimate as other visible disabilities, as illustrated by this quote:

I usually say that it might have been easier if my arm was paralysed and hanging or if I had trouble with the speech. Then it would have been easier for my family to understand why mommy cannot unload the dishwasher or why she cannot pack a gym bag. (female cited in Röding et al., 2003, p.871)

Socialisation. Foster, Leathem and Humphries (2016) examined whether visibility of injury influenced peoples' willingness to socialise with adolescents with brain injury. Participants were shown a vignette of an adolescent who had suffered a brain injury and a

picture of an adolescent with or without a head scar and then asked to complete a survey enquiring about their willingness to socialise with the adolescent. The results showed that respondents were more willing to socialise with adolescents who had visible signs of their brain injury (e.g., the head scar) than adolescents who did not. This would suggest that individuals with no visible signs of their disability would experience increased social isolation.

Incorrect attributions. A further challenge for individuals with invisible disabilities is that the general public often make incorrect attributions about the behaviours of people with invisible disabilities (McClure, 2011). An explanation for this is that numerous behaviours that result from a brain injury (e.g., fatigue and irritability) are ambiguous (Snyder, Kleck, Strenta, & Mentzer, 1979; Kleck & Dejong, 1983) and can also be due to other causes (e.g., personality or norms of adolescence, age or gender) (Hastings, Remington, & Hopper, 1995). New Zealand research by McClure and Abbott (2009) found that participants are more likely to attribute behaviours to the persons' personality rather than to brain injury when the undesirable behaviours are ambiguous. Research has demonstrated how the undesirable behaviour of a brain injured male adolescent is attributed primarily to his adolescence when there are no visible signs of his brain injury. Participants attributed the undesirable behaviours to brain injury more when there were visible markers of the brain injury (e.g., a scar) (McClure, Buchanan, McDowall, & Wade, 2008; McClure, Devlin, McDowall, & Wade, 2006; McClure, Patel, & Wade, 2011).

Wainwright, McClure and McDowall (2017) examined the effect that the age of a stroke survivor had on the attributions made by the general public on typical behaviours resulting from stroke (fatigue, depression, irritability and social activity). Participants were presented with a vignette that outlined behavioural changes of a male. There were

three different age descriptions of the male (22, 72, and age unstated). Results showed that when the stroke survivor was aged 22 years, participants attributed the behaviours more to personality than to age or stroke, whereas when the stroke survivor was aged 72 years, participants attributed the behaviours more to age than to personality or stroke. These results show that individuals incorrectly attribute behaviours resulting from stroke to factors other than stroke and that these attributions are affected by the age of the stroke survivor (Wainwright et al., 2017).

McClure (2011) states that these incorrect causal attributions have a number of different negative consequences for people with invisible disabilities. These include an increase in frustration and feeling misunderstood, unrealistic hopes for rehabilitation, inadequate strategies for rehabilitation, and poorer family functioning (Guilmette & Paglia, 2004; McClure et al., 2006; Swift & Wilson, 2001). People who make these misattributions fail to allow for the brain injury as a reason for the person's undesirable behaviour (McClure, 2011). These attributions also lead to accusations of malingering, where people assume that a person with a brain injury is making false or exaggerated complaints in order to receive attention or special privileges (Chamberlain, 2006). These outcomes hinder persons with brain injury in establishing social relationships and reintegration into society.

In summary, younger stroke survivors are often left with disabilities; these can be visible or invisible. The difficulties experienced as a consequence of these is a recurrent theme in previous literature all showing that the experience of both visible and invisible disability creates a number of problems for younger stroke survivors.

Post Stroke Rehabilitation for Younger Stroke Survivors

As noted above, younger stroke survivors encounter many problems post stroke, the consequences of which should be taken into consideration when developing

rehabilitation strategies aimed at maximising community reintegration and post stroke wellbeing. However, despite the range of problems experienced, rehabilitation often exclusively focuses on the physical aspects of recovery (Bendz, 2003; Medin, Barajas, & Ekberg, 2006; Röding et al., 2003), and there is a reported lack of support post discharge for younger stroke survivors (Sadler, Daniel, Wolfe, & McKeivitt, 2014).

Studies have also found that young stroke survivors perceive assessments, interventions and rehabilitation programmes developed for older stroke survivors to be inadequate in dealing with the problems they experience (Morris, 2011). Young stroke survivors in the Röding et al. (2003) study experienced frustration as a consequence of the lack of age-adapted rehabilitation, and one person in Stone's (2014) study felt that she did not belong to a support group created for stroke survivors of all ages.

... I mean, I did join this stroke club in [a nearby town], a couple of years ago.

Um, I used to go there and ... at the end of it, I thought, I do not belong here, they're all old people that have had it happen to them. And I do not belong here, and why am I coming here? (cited in Stone, 2015, p.6)

Morris (2011) reviewed the current literature on the psychological consequences of stroke in patients under 65, more specifically their experiences of post stroke services. The following unmet practical needs included: Caring for young children, relationships with spouse, sexuality, invisible cognitive disabilities, fatigue that affects engagement in age appropriate activities, loss of employment, reduced intellectual fulfilment, and financial problems. Medin et al. (2006) reported that younger stroke survivors perceive a lack of support in returning to work post stroke. Furthermore, Morris (2011) suggested that there are currently no interventions that aim to target these unmet needs.

Singhal et al. (2013) suggested that there is a call for research that investigates factors that can reduce the burden of stroke on young people. However, to date there are

no randomized controlled studies addressing the effect of interventions aimed at reducing distress in younger stroke patients, a fact that has been recognized and acknowledged in previous research (Kneebone & Dunmore, 2000; Morris, 2011). The Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) stated that it is important to prioritise research on New Zealand stroke rehabilitation and community support services for stroke survivors under the age of 65.

In conclusion, stroke is becoming increasingly more common in individuals under the age of 65. As this occurs in a period of life where these individuals have active careers and are responsible for young families there are a number of salient problems that can arise. These can include employment loss, relationship strain, social isolation and financial issues. As a result of this it can be concluded that this is a population who would benefit from specific therapy, aimed at targeting specific problems and salient needs following stroke, to decrease post stroke distress.

CHAPTER 4: POST STROKE DEPRESSION AND ANXIETY

Post Stroke Depression

Post stroke depression (PSD) is the most common emotional disturbance following stroke (Carod-Artal, 2010) and has been defined as "depression occurring in the context of a clinically apparent stroke, as opposed to silent vascular disease" (Carod-Artal, 2010, p.570). It is emphasized that depression is sequential to the event of a stroke (Whyte, Mulsant, Vanderbilt, Dodge, & Ganguli, 2004).

Hackett, Yapa, Parag and Anderson (2005) conducted a systematic review of observational studies on the frequency of PSD and estimated that 33% of stroke survivors present with depressive symptoms at any time during follow up. More recent research has produced similar findings in that approximately 30% of stroke survivors develop PSD (Schöttke & Giabbiconi, 2015). Furthermore, stroke survivors are approximately six times more likely to develop depression compared to age matched controls (non-stroke patients) even two or more years following the stroke event (Whyte et al., 2004) with peak in prevalence three to six months post stroke (Whyte & Mulsant, 2002). Depression is also significantly more likely to develop following stroke than other illnesses resulting in similar disabilities (Burvill et al., 1995).

Ayerbe, Ayis, Crichton, Wolfe and Rudd (2013) analysed data from stroke survivors registered in the South London Stroke Register between 1995 and 2009 who had had their first ever stroke. Participant numbers at each time point ranged from 1101 (at 3 month follow up) to 16 (at 15 year follow up). Using the Hospital Anxiety and Depression Scale (HADS), the longitudinal research found that at 3 months post stroke 33% of the stroke survivors experienced depression and the prevalence of depression ranged from 29% to 39% across the 15 years.

Similar prevalence rates of depression have been found within New Zealand with 29.6% of 418 stroke survivors who completed the General Health Questionnaire – 28 (GHQ-28) five years following their stroke reporting symptoms of depression (Feigin et al. 2010).

PSD in younger stroke survivors. Prevalence rates of depression in younger stroke survivors are similar. In a retrospective study of 272 young adults (15-45 years) who had suffered their first ever ischemic stroke between 1974 and 2001, Varona et al. (2004) found that 22% met a diagnosis for depression and required psychiatric help. Similarly, Srivastava, Taly, Gupta and Murali (2010) found that just over a third of the 51 younger (<60 years) participants met the criteria for depression as did half of Teasell et al. (2000) under 50 year old (n=55) participants. While this percentage may seem high, these were not formal diagnoses of depression, but generated from staff reports on the participants' charts. Had the stroke survivors been assessed formally this percentage may have been lower.

Consequences of PSD. Many epidemiological studies have shown that PSD is associated with poor functional and cognitive outcomes as well as increased disability in stroke survivors (Berg, Palomaki, Lehtihalmes, Lonnqvist, & Kaste, 2003; Pohjasvaara, Vataja, Leppavuori, Kaste, & Erkinjuntti, 2001). PSD affects quality of life (Gaynes, Burn, Tweed, & Erickson, 2002) and the rehabilitation process is negatively impacted (Herrmann, Black, Lawrence, Szekely, & Szalai, 1998; Paolucci et al., 2001), as depressed mood and anhedonia can prevent survivors of stroke from participating entirely in rehabilitation activities. PSD also increases healthcare usage by stroke survivors (Carod-Artal, Egido, Gonzalez, & Varela de Seijas, 2000; Carod-Artal, Trizotto, Coral, & Moreira, 2009).

Risk factors of PSD. The general consensus across research is that early recognition and active management of PSD is important in the treatment and prevention of PSD in stroke patients (Turner-Stokes & Hassen, 2002). However, mixed opinions and incomplete knowledge of the risk factors associated with, and the causes of PSD are constraining current treatments (Thomas & Lincoln, 2006).

Biological mechanisms have been proposed as explanations; however, the neuropsychiatric foundations of PSD have not been conclusively clarified in the existing literature. Previous research has suggested that ischemic damage to neural circuits that control mood regulation, specifically frontal sub-cortical circuits, leads to a depletion of biogenic amines, which results in depressogenic symptoms (Capaldi & Wynn, 2009). Robinson, Kubos, Starr, Rao and Price (1984) proposed that left hemisphere damage, particularly left anterior lesions were associated with PSD. However, other studies do not support this finding (e.g., Berg et al., 2003) and MacHale, O'Rourke, Wardlaw and Dennis (1998) reported that PSD is associated with lesions to the right hemisphere.

A meta-analysis by Carson et al. (2000) found no definitive evidence for a relationship between location of lesion and PSD. Vataja et al. (2014) revisited the relationship on the grounds of the methodological limitations of the previous research, including small and unrepresentative patient populations. The authors also stated that previous studies based their data on computer tomography technology, which is less sensitive than magnetic resonance imaging (MRI). Accordingly, Vataja et al. (2014) used MRI to examine seventy stroke survivors with one brain infarct, three months post stroke. The results showed that infarcts located on the frontal-subcortical circuits (i.e., the caudate and pallidum, particularly on the left side) predisposed the stroke survivors to PSD.

Level of impairment has also been suggested as a risk factor for PSD. Hackett and Anderson (2005) carried out a systematic review on studies prior to 2004 that investigated risk factors for PSD. The results from a total of 17,934 stroke survivors showed that stroke severity, physical disability and cognitive impairment were consistently related to depression in the stroke participants. Similarly, in New Zealand research, Barker-Collo (2007) found that increased scores on the Beck Depression Inventory were related to reduced physical and cognitive functioning.

Using a prospective, longitudinal epidemiological methodology to determine risk factors for PSD at three months post stroke, De Ryck et al. (2013) assessed 135 participants for functional and cognitive deficits, stroke characteristics, stroke severity and PSD. The results demonstrated that 28.1% of the participants were diagnosed with depression. The results were similar to those found in the studies by Hackett and Anderson (2005) and Barker-Collo (2007) in that the depressed stroke survivors had significantly more physical and cognitive impairment than the non-depressed stroke survivors. There was also a higher prevalence of speech and language dysfunction and apraxia seen in participants with PSD (De Ryck et al., 2013).

It must be noted that it is difficult to make causal inferences with respect to lesion location and cognitive impairment as risk factors for PSD. For example, while cognitive deficits such as impaired verbal memory are associated with left hemisphere lesions, it could be said that the depression is a result of the cognitive difficulties that arise when there is an infarct in this area, rather than the PSD arising primarily due to an infarct in the left hemisphere (Barker-Collo, 2007).

Demographic characteristics have also been studied. In earlier research there have been mixed findings regarding an association between age and PSD. Chemerinski, Robinson and Kosier (2001) found no correlation between age and PSD whereas,

Frühwald, Löffler, Eher, Saletu and Baumhackl (2001) reported that as age increases so does the risk of developing PSD. On the other hand, Barker-Collo (2007) found that younger individuals have a heightened risk of developing PSD as did Visser et al. (2015) who also found that women had higher scores of PSD than men. It is possible that outcomes of these studies are mixed due to methodological limitations such as limited sample sizes. Alajbegovic et al. (2014) examined risk factors for depression using a larger sample size of 210 stroke survivors and found that younger stroke survivors (<60) were more likely to have depression than older stroke survivors.

Researchers have also proposed psychosocial causes of PSD (Gainotti, Azzoni & Marra, 1999). For example, it has been suggested that the risk of depression increases in individuals who are unable to evaluate their situation and come up with solutions to their problems (Whyte, Mulsant, Rovner, & Reynolds, 2006). Consequently, Hegel, Barrett and Oxman (2000) proposed that prophylactic problem solving therapy may reduce the risk of depression. Another theory is that PSD develops due to the linkage between having an external locus of control and feelings of hopelessness (Morrison, Johnston, & Walter, 2000). However, empirical evidence is lacking to support these proposals, and further studies of psychosocial factors are needed.

White, Attia, Strum, Carter and Magin (2014) looked at predictors of depression and anxiety in community dwelling stroke survivors, specifically the relationship between scores on the Hospital Anxiety and Depression Scale (HADS) and a number of different variables including level of disability, quality of life, social support and community participation. Depression at baseline was positively associated with low social support and low community participation. Further, low community participation and higher disability were associated with the onset of depression (if not depressed at baseline).

Visser et al. (2015) also found that stroke survivors that lived alone had higher scores on the CES-D than those who lived with a partner.

Post Stroke Anxiety

Anxiety is the second most prevalent psychological disorder post stroke and although not studied as extensively as PSD, research has shown that between 20% and 32% of stroke patients suffer from symptoms of anxiety (Ästrom, 1996; Broomfield, Quinn, Abdul-Rahim, Walters, & Evans, 2014; Burvill et al., 1995; Campbell Burton et al., 2013; Castillo, Starkstein, Fedoroff, Price, & Robinson, 1993; House, Dennis, Moridge, Warlow, Hawton, & Jones, 1991; Mellon et al., 2016). Leppävuori, Pohjasvaara, Vataja, Kaste and Erkinjuntti (2003) found that 57 (20.6%) of 277 patients aged between 55-85 presented with generalized anxiety symptoms (PSA), compared to 1181 (29%) of Broomfield et al.'s (2014), 4,079 stroke survivors who had Hospital Anxiety and Depression scale (HADS) anxiety scores indicative of probable or possible anxiety, and 21.1% had scores indicative of moderate to severe anxiety 3 months post stroke in a New Zealand study (Barker-Collo, 2007).

Studies have also found that PSA does not appear to diminish over time. Ästrom (1996) conducted a longitudinal study where participants who initially showed symptoms of generalized anxiety disorder (GAD) were re-tested three years later. The results showed that 75% of those participants continued to experience symptoms of GAD. Morrison, Pollard, Johnston and MacWalter (2005) found similar results after assessing stroke survivors on six occasions following their stroke: on hospital admission, 10-20 days after admission, 1 and six 6 months following discharge, and 1 and 3 years post stroke, with levels of anxiety remaining stable across all time points. In a meta-analysis of studies published before 2011, Campbell Burton et al. (2013) found that 20% of stroke

survivors experienced PSA after one month following their stroke which rose to 24% six months or more post stroke.

However, more recent research has found that anxiety scores as measured on the HADS decrease over time throughout a 12 month period. White et al. (2014) explored patterns of post stroke depression and anxiety over a 12 month period ($n = 134$). Data was collected at baseline, 3, 6, 9 and 12 months post stroke using the HADS. Although the percentage of participants meeting thresholds for depression remained relatively consistent (22%, 29%, 22%, 28%, 20%), the percentage of participants who met thresholds for anxiety significantly decreased at each respective time-point (47%, 34%, 29%, 25%, 14%). The authors attempted to investigate factors predicting resolution of anxiety post stroke including perceived social support, lifestyle activities and physical disability. However, these variables were not associated with reductions in anxiety scores over time. The cut off scores used in this study could provide an explanation for the reported improvement in anxiety caseness.

In a recent study conducted to validate the HADS-anxiety scale in stroke patients, it was found that a score of 4 or 5 was the ideal cut off when screening for anxiety (Sagen et al., 2009). The authors used 8 as a cut off score for anxiety; therefore, it is possible that the prevalence of significant anxiety symptoms reported by White et al. (2014) has been underestimated. There was also no information documented with regards to medication use or community support provided, these are factors that could impact on anxiety scores in participants. The differences in results from the study by White et al. (2014) could also be due to a difference in time points where anxiety was measured.

Previous studies have found that anxiety has persisted up to 3 years post stroke (Ästrom, 1996; MacWalter, 2005). Should the time points have been extended in the study by White et al. (2014), levels of anxiety may have been similar to previous research

at 3 years post stroke. Future research is needed to explore the difference in results between the study by White et al. (2014) and previous studies. One variable that could be taken into consideration is perceived provision of information following stroke. As the study by White et al (2014) is more recent, it could be that stroke survivors are now provided with more information following stroke, which may have an effect on the experience of anxiety post stroke. Again, more research is needed to explore this and other potential variables.

PSA in younger stroke survivors. Broomfield, Scoular, Welsh, Walters and Evans (2013) conducted an observational study, which investigated the relationship between the age of the stroke survivor and PSA in 3,831 community living stroke survivors. The study used the HADS-A and found that 31.5% of all participants scored above 8 on the HADS-A. It was also found that 35.5% of stroke survivors aged under 50 years scored above 11 on the HADS-A, compared to 7.2% of stroke survivors who were over 80 year olds. This study demonstrates that younger age is a risk factor for PSA.

Consequences of PSA. Daily functioning, quality of life, interpersonal relationships, and functional outcomes are adversely affected by anxiety in stroke patients (Ästrom, 1996; Carod-Artal & Egidio, 2009; Ferro, Caeiro, & Santos, 2009; West, Hill, Hewison, Knapp, & House, 2010). PSA has also been associated with increased dependency in Activities of Daily Living (ADL) (Castillo et al., 1993), deteriorating disability over time (Ästrom, 1996), severity of PSD (Pohjasvaara et al., 2001), mortality (Burvill et al., 1995) and a reduction in social networks (Pohjasvaara et al., 2001).

Risk factors of PSA. As with PSD there is mixed research on the risk factors associated with PSA. Risk factors for PSA are also understudied compared with PSD, and there are a limited number of studies that investigate possible risk factors. Ästrom (1996) found that right hemisphere lesions are significantly correlated with PSA and that co-

morbid PSD and PSA correlate with left hemisphere lesions. Castillo et al. (1993) found that anxiety was more prevalent in stroke survivors who had posterior right hemisphere lesions. The study also found that worry without the presence of an anxiety disorder was linked to anterior lesions. However, Barker-Collo (2007) found that left hemisphere lesions were associated with anxiety. Therefore, the relationship between location of lesion and PSA has not been conclusively determined. It is suggested that future research uses MRI with a large number of participants to more thoroughly examine the relationship between lesion location and PSA.

Castillo et al. (1993) found that there is no significant correlation between cognitive functioning, physical functioning, or social functioning, with White et al. (2014) actually reporting a negative correlation, i.e., that anxiety was associated with having less disability at any time over the 12 month study period. However, White et al. (2014) excluded participants with severe aphasia and cognitive difficulties thus perhaps masking the true representation of the association between disability and PSA. This is supported by Barker-Collo's (2007) finding that cognitive impairment was significantly associated with PSA.

Demographic variables have also been studied as risk factors for PSA. Barker-Collo (2007) found no significant relationship between gender and age and PSA (although this study had a limited sample size of 73 individuals). The larger study (4,079 stroke survivors) by Broomfield et al. (2014) mentioned previously, found when examining data on the HADS that female sex and younger age were independent predictors of PSA. In the study by Morrison et al. (2005) being female was also significantly associated with higher anxiety.

Post-Traumatic Stress Disorder

Stroke is an unexpected life threatening event often occurring with no warning that can result in immediate disability. It is not surprising then that 25% of the 40 participants who had either suffered a stroke or a transient ischemic attack in Favrole et al's. (2013) study, went on to develop symptoms of post-traumatic stress disorder (PTSD), with 10% of participants meeting a DSM-IV formal diagnosis of PTSD. In addition to the direct trauma of a stroke, post stroke patients may also fear the occurrence of another stroke (Ästrom, 1996). Lawrence (2010) synthesised a number of qualitative studies regarding experiences of younger stroke patients who were anxious to know what caused their stroke so that they could take precautions to prevent another stroke.

In conclusion, PSD and PSA are commonly experienced by stroke survivors and have many negative consequences, including a negative impact on the rehabilitation process and an increase in mortality. Previous research has suggested a number of risk factors for these common outcomes post stroke including stroke localisation, age and social support. However, research is still inconclusive with regards to these risk factors and further research is needed so that medical professionals can more effectively identify individuals who are at risk of PSD and PSA. Individuals who present with these risk factors can then be monitored vigilantly, in order to prevent the onset of these disorders.

Psychosocial variables are currently understudied as risk factors for PSD and PSA, however it is suggested that factors such as social isolation, a lack of community support, and ineffective problem solving may result in emotional distress post stroke. Research investigating the different problems that stroke survivors experience and their effect on post stroke wellbeing is needed.

The following chapter will discuss the non-pharmacological interventions that have been investigated to reduce or prevent PSD and PSA.

CHAPTER 5: PSYCHOLOGICAL INTERVENTIONS FOR POST STROKE

DEPRESSION AND ANXIETY

A number of studies have investigated stroke survivors' perceptions of post stroke health service provision. Within these studies stroke survivors report that rehabilitation focuses predominantly on physical improvements and lacks psychological and social support (Bendz, 2003; McKevitt, Redfern, Mold, & Wolfe, 2004; Murray, Ashworth, Forster, & Young, 2003; Peoples, Satink, & Steultjens, 2011). In a study by Mellon et al. (2016), 63.5% of participants ($N = 256$) reported that they did not receive adequate psychological support post stroke. When treatment is focused on psychological issues, the majority of treatments for depression and anxiety in stroke have focused on the use of antidepressants (Campbell Burton et al., 2011; Mast & Vedrody; 2006 Paolucci, 2008; Whyte et al., 2006). Although previous research has found antidepressants to be effective in treating and preventing PSD (Mast & Vedrody, 2006; Paranthaman & Baldwin, 2006) and PSA (Campbell Burton et al., 2011), intolerance to antidepressants, failure to respond, potential side effects, and reduced treatment adherence (Paul, Dewey, Sturm, Macdonell & Thrift, 2006) suggests the need for research into the efficacy of non-pharmacological interventions (Kneebone & Dunmore, 2000).

Despite this, research into non-pharmacological treatments for PSD and PSA is limited (Graham et al., 2015; Kneebone & Dunmore, 2000). A small number of studies have evaluated the efficacy of non-pharmacological interventions to treat or prevent PSD but even fewer studies looking at non-pharmacological interventions for PSA (Campbell Burton et al., 2011). Psychological treatments that have been trialled with stroke survivors include Cognitive Behavioural Therapy, Behavioural Therapy, Problem Solving Therapy, Acceptance and Commitment Therapy and Motivational Interviewing. The

studies incorporating these different treatments and their effects on PSD and PSA will be outlined in Table 4 and discussed within this chapter.

Table 4

Summaries of studies that evaluate the efficacy of psychological interventions for the treatment of PSD and PSA

Author, Year (reference)	Age Mean; SD	PSD/ PSA	Design	N	Experimental Intervention/s	Control	Results
Lincoln, Flannaghan, Sutcliffe and Rother (1997)	67.1, 13.8	PSD	AB single case experimental studies	19	Cognitive Behavioural Therapy	No control	5 participants significantly improved between baseline and treatment, 14 participants no significant difference and 1 deteriorated.
Rasquin, Van De Sande, Praamstra and Van Heugten (2009)	46.2, 5.5	PSD	AB single case quasi experimental studies	5	Cognitive Behavioural Therapy	No control	60% significant improvement in mood at 1 and 3-month follow-up sessions.
Lincoln and Flannaghan (2003)	67.1, 12.7	PSD	Randomised controlled trial	123	Cognitive Behavioural Therapy	Attention placebo/ Standard care	No significant differences found between the treatment group and the control groups.
Thomas, Walker, Macniven, Haworth and Lincoln (2013)	67.0, 13.5	PSD	Randomised controlled trial	105	Behavioural therapy	Usual care group	Significantly greater improvements for the treatment group than the control group. Results remained significant for up to 6 months post intervention.
Kneebone and Jeffreis (2013)	62 & 80 yrs.	PSA	AB single Case designs	2	Cognitive behavioural therapy	No control	Both clients improved from levels of concern to sub-clinical levels on measures of anxiety.
Robinson et al. (2008)	67.3, 11.2	PSD	Randomised controlled trial	176	Escitalopram or Problem Solving	Placebo pills	Placebo group 4.5 times more likely to develop depression than escitalopram group (22.4% vs. 8.5%), and 2.2 times more than PST group (11.9% vs. 8.5%).

Mikami et al. (2014)	68.3, 10.4	PSA	Randomised controlled trial	149	Therapy (PST) Escitalopram or 12 sessions of PST	Placebo pills	Placebo group 4.95 times more likely to develop GAD over 12 months than escitalopram group, 4.00 times more likely than PST group.
Mitchell et al. (2009)	57, no SD	PSD	Randomised controlled trial	101	Behavioural intervention with PST + antidepressants	Usual care and antidepressant medication	Immediately post-treatment and at twelve months, depression scores in the intervention group were significantly lower compared to controls.
Hadidi, Jappe, Cullen and Savik (2014)	“older adults”	PSD	Randomised controlled trial	10	PST - 12 weeks	Attention control group 12 – weekly education sessions	Bilateral amygdala activity decreased in the attention control group but increased in the PST intervention group. Increase in amygdala activity was correlated with a reduction in depression scores.
Hadidi, Lindquist, Buckwalter and Savik (2015)	73, no SD	PSD	Randomised controlled trial	22	PST - 10 weeks	Care as usual control group	Treatment group subsyndromal depression (cut off score of 5 on CES-D) reduced from 91% (M=8.7) at baseline to 30% (M=3.1) at follow-up. Deemed “clinically” significant, compared to control group, 73% (M=7.8) to 60% (M=7.8). PST “extremely helpful” or “helpful” for 83% and 81% “confident” or “very confident” in using PST to resolve issues
Alexopoulos et al. (2012)	70.9, 8.5	PSD	Randomised controlled trial	24	Ecosystem focused therapy (PST + family work)	Education on stroke and depression	60% of EFT group achieved remission of depression; 20%, no change, 20% remitted. versus 20% remission in control group.

Graham et al. (2015)	Male in 40's	PSD PSA	AB Single Case Design	1	Acceptance & Commitment Therapy	No control	Anxiety decreased from "extremely severe" to "mild", depression from "moderate" to "mild", stress from "extremely severe" to "moderate".
Watkins et al. (2007)	70, no SD	PSD	Randomised controlled trial	411	Motivational Interviewing	Usual care control group	Significantly more of intervention group (49.0%) had normal mood at follow up, than control group (39.1%).
Watkins et al. (2011)	70, no SD	PSD	Randomised controlled trial	411	Motivational Interviewing	Usual care control group	Significantly more of intervention group (48%) had normal mood (GHQ-28 score of <5 than control group (37.7%) at 12 month follow up.

In summary, the results of CBT for PSD are inconclusive and there is very limited research examining its efficacy for PSA. A single case study has been presented for the efficacy of ACT for reducing PSA (Graham et al., 2015), however there is no further research examining the efficacy of ACT for PSA and nothing for PSD. Behavioural therapy and motivational interviewing have been found to be effective for reducing PSD in older stroke survivors (Thomas, et al., 2013; Watkins et al., 2007; Watkins et al., 2011), however there are limited studies investigating these therapies and no studies investigating their effects on PSA. Problem Solving Therapy, the therapy of choice for the current study has been investigated for its efficacy in reducing both PSD and PSA. Previous research has shown promising results for this therapy with older stroke survivors (Alexopoulos et al., 2012; Hadidi et al., 2014; Hadidi et al., 2015; Mikami et al., 2014; Mitchell et al., 2009; Robinson et al., 2008), and further justification for selecting this therapy for the current study will be discussed in the following chapter.

Psychological Intervention Studies with Younger Stroke Survivors

Singhal et al., (2013) suggested that there is a call for research that investigates factors that can reduce the burden of stroke on young people. As mentioned in chapter 3, the problems that younger stroke survivors encounter stretch far beyond physical difficulties, yet research has demonstrated that rehabilitation often exclusively focuses on the physical aspects of recovery (Bendz, 2003; Röding et al., 2003). To date there are no studies addressing the effect of interventions aimed at reducing PSD in younger stroke patients, a fact that has been recognized and acknowledged in previous research (Kneebone & Dunmore, 2000; Morris, 2011). Furthermore, treatments for anxiety post stroke in all age groups have received much less attention (Campbell Burton et al., 2011). The Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) stated that it is important to prioritise research on New Zealand stroke rehabilitation and community support services for stroke survivors under the age of 65.

In conclusion, research examining the benefits of psychological treatments for depression and anxiety post stroke is limited. The existing research has evaluated the efficacy of different therapies including CBT, ACT, PST, and motivational interviewing. The literature that exists suggests that therapies such as problem solving therapy and motivational interviewing may be beneficial for stroke survivors. As highlighted in chapter 3, previous studies have not included research with younger stroke survivors, and this is a population who experience a range of different problems that may benefit from psychotherapy. Further research conducting randomised controlled trials, with larger sample sizes, are needed to evaluate the efficacy of psychotherapy for reducing PSD and PSA in younger stroke survivors.

CHAPTER 6: PROBLEM SOLVING THERAPY

This chapter will discuss the theory of problem solving therapy and the rationale for its use with younger stroke survivors.

Problem Solving Theory of Distress

Coping refers to “the person’s cognitive and behavioural efforts to manage (reduce, minimise, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person’s resources” (Folkman, Lazarus, Gruen, & DeLongis, 1986, p. 572). Coping styles can be distinguished in a number of different ways, such as avoidant, passive and active (Wolters, Stapert, Brands, & Van Heugten, 2010). These coping styles can also be defined as problem focused or emotion focused. If an individual adopts a problem focused coping style they actively try to address and confront the problem. The individual will attempt to gain skills to solve the problem or try to change the difficult situation. Whereas, an individual who adopts an emotion focused coping style, will follow a more passive approach and will try to regulate their emotional reaction to the problem, rather than actively change the stressful situation (Folkman et al., 1986). The individual may try and suppress their emotions or may use distractions to take their mind off their problems (Cook & Heppner, 1997).

Wolters et al. (2010) examined coping styles in traumatic brain injured patients. The study found that higher HRQoL is associated with a more active problem focused coping style rather than a passive emotion focused coping style. Unfortunately, this study also found that active problem focused coping decreases overtime, whilst passive emotion focused coping increases. This suggests that if active problem focused coping can be increased long term following traumatic brain injury then HRQoL could be increased. Furthermore, Herrmann et al. (2000) found that stroke patients use a less active problem

oriented coping style than other brain damaged patients (patients with malignant brain tumours and patients with traumatic brain injuries). Moreover, Darlington et al. (2007) aimed to examine the relationship between coping strategies and quality of life in stroke survivors. The authors interviewed 88 stroke survivors just before discharge, at 2 months, at 5 months, and at 9-12 months after discharge. The research found that quality of life is mainly determined by general functioning in the first 5 months after discharge. However, as time since stroke progressed, coping strategies became a more powerful determinant of quality of life, whereas the importance of general functioning decreased. It can be inferred from this that improved coping strategies could be advantageous for long term quality of life of stroke survivors.

Further, research has shown that stroke survivors who demonstrate active coping, and coping strategies where they accept changes have been linked with increased quality of life. Elmståhl, Sommer and Hagberg (1996) interviewed 66 stroke survivors on how they handled difficult events to determine their coping strategy style and found that stroke survivors who demonstrated active coping strategies improved more on an index of activities of daily life at both 1 year and 3 year follow up, than participants who demonstrated non-active coping strategies. Smout et al. (2001) assessed coping strategies in eight younger stroke survivors between the ages of 20 and 55. Coping strategies were assessed using semi structured interviews and were defined as either assimilative or accommodative. Assimilation was defined as a coping strategy that involves trying to change one's situation, when it may in fact not be able to be altered. An individual who uses this strategy tries to reduce the gap between their actual situation and their desired situation. Accommodation was defined as a coping strategy that allows the individual to see the problem in another light. An individual who uses this coping strategy accepts the fact that their original goals can no longer be met. This makes the situation seem less

negative and more tolerable. Assimilation is thought of as the predominant coping strategy immediately after an aversive event, whereas the level of accommodation rises progressively over time. The results showed that the stroke survivors who used more accommodative coping strategies had a higher quality of life than the individuals who used assimilative coping strategies.

Research has shown that it is possible to influence coping styles. Backhaus, Ibarra, Klyce, Trexler and Malec (2010) aimed to determine whether coping strategy training could improve psychological functioning and self-efficacy in 20 brain injury survivors, using a randomized controlled pilot study design. The intervention group received 12 sessions of treatment and the control group were put on a wait list to receive treatment at a later date. The results showed that the coping strategy therapy had a positive influence on the participants as they showed significantly improved perceived self efficacy when compared with the control group, both at post treatment and follow up. Further, the control group demonstrated increased emotional distress as measured by the brief Symptom Inventory – 18 (BSI-18) when assessed at the 3 month follow up. In comparison, the therapy group remained stable over time. This suggests that training in coping strategies can increase psychological wellbeing in brain injured individuals.

Coping and problem solving are two different concepts. Where coping focuses on the ability to manage stressful situations and the emotions that arise from such situations (Folkman et al., 1986), problem solving refers to the practice of generating solutions to specific problems (Nezu, Nezu, & D’Zurilla, 2012). Although problem solving is considered as a strategy for coping, not all coping strategies involve problem solving.

There are two main problem solving dimensions. These include: (1) problem orientation and (2) problem solving styles (Nezu et al., 2012). Problem orientation defines the way that an individual reacts to problems that they encounter in their day-to-day lives.

This includes a focus on the individuals' cognitive and affective reactions that they experience when they are dealing with and solving these problems. Problem orientation can be either positive or negative. An individual with a positive problem solving orientation views problems with optimism and believes that they can solve them. That individual will see opportunities for self-development when a problem arises and will not view problems as threats. On the contrary, an individual with a negative problem solving style will be afraid of problems and perceive them as a threat. When presented with problems, an individual with a negative problem orientation will make negative self-evaluations and will lack confidence in their problem solving skills and abilities (Nezu et al., 2012).

Problem solving styles describe individual's behavioural and cognitive reactions when presented with problems (Nezu et al., 2012). These can either be functional or dysfunctional. Functional problem solving styles are defined as rational problem solving. Dysfunctional problem solving styles are split into two categories: (1) impulsive/careless problem solving style and (2) avoidant problem solving style. The rational style involves systematic and deliberate planning. Individuals who exhibit this style will collect pertinent facts and information, recognise the obstacles, determine a realistic goal, and come up with a number of alternative solutions. They will then weigh up the pros and cons of the alternative solutions and generate an effective plan. On the other hand, individuals who demonstrate an impulsive/carelessness style will actively try to solve the problem, however unfortunately will do it in a way that is rushed and incomplete. There generally isn't any consideration of the consequences of their ideas. Finally, the avoidance style involves a significant amount of procrastination. Individuals who utilise this style tend to be passive and often deny the existence of problems and will rely on others to solve them (Nezu et al., 2012).

PST works from the premise that people experience long lasting emotional distress (depression, anxiety and anger) as a result of the overpowering effects of stress, and the inability to reduce stress in their day to day lives. A major life event, such as a stroke can cause immense immediate stress for the individual and result in a collection of new and different daily problems e.g., unemployment (Singhal et al., 2013), which can cause financial strain (Daniel et al., 2009).

The “stress generation” theory explains that stress causes distress, which can result in more stressful problems for the individual (Nezu et al., 2012). For example, a stroke can result in symptoms that make it difficult for the stroke survivor to socialise which can be distressful in itself but may also generate problems in relationships (creating more stress). Relationship strain can lead to divorce and distressful feelings of isolation and loneliness, which may eventually lead to depression, thus, demonstrating the downward spiral of the experience of stress and distress. This suggests that it would be worthwhile intervening to prevent the downward spiral of stress generation which PST purports to do (Nezu et al., 2012). The figure below illustrates the effects that effective and ineffective problem solving can have on mental health.

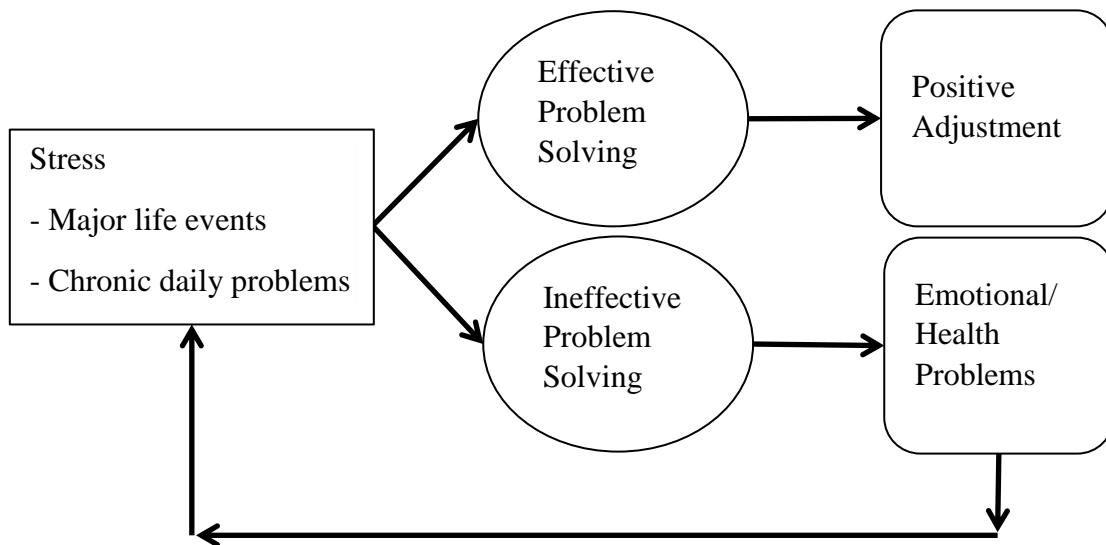


Figure 1. Problem-solving model of stress (Nezu et al., 2012).

Figure 1 demonstrates how stress, as a result of both major life events and continuous daily problems, can eventually result in either positive adjustment, or emotional problems such as anxiety, depression and anger. According to the figure, in order to reach positive adjustment, one needs to employ effective problem solving, such as a rationale problem solving style. Whereas, ineffective problem solving, such as an impulsive/careless style or an avoidant style can lead to emotional or health problems.

A recent study provides evidence for the problem solving model of distress. Visser et al. (2015) investigated the relationship between high and low depression scores, and different coping strategies and problem-solving skills used by 166 stroke patients. They also looked at the effect that these variables have on HRQoL independent of depression. Consistent with previous studies, the results showed that 39.2% of the participants had high depression scores on the CES-D following their stroke. Those with high depression scores on the CES-D used more emotion-oriented coping, negative problem orientation and avoidance style and used less positive problem orientation. The

study also found that positive problem orientation was an independent contributor of HRQoL. This suggests that stroke patients may benefit from training in positive problem orientation skills in order to decrease symptoms of depression and anxiety and increase HRQoL.

In conclusion, problem solving has the potential to be an effective coping strategy when dealing with stress. However, the problem orientation needs to be positive and the problem solving style needs to be functional, as negative and dysfunctional problem solving skills can result in emotional problems such as depression and anxiety. This has been demonstrated in previous research with stroke survivors. Therapy which aims to increase effective problem solving skills should be a focus of rehabilitation for stroke survivors.

The therapy. As PST operates from the theory that the client's symptoms stem from their everyday problems, the therapy offers the client training in adaptive problem solving attitudes and skills. It is assumed that if the client acquires more effective problem solving strategies, then the patient's symptoms should improve. Thus, preventing psychopathology and increasing positive well-being in clients so that they can deal more effectively with stressful problems in their day to day lives (Bell & D'Zurilla, 2009; Mynors-Wallis, 2005; Nezu et al., 2012).

During PST, the therapist teaches the patient how to use a step-by step process to solve life problems (Bell & D'Zurilla, 2009; Mynors-Wallis, 2005; Nezu et al., 2012) as shown in Table 5.

Table 5

The seven steps of problem solving therapy

The seven stages of problem-solving treatment (Mynors-Wallis, 2005)

1. Explanation of the treatment and its rationale.
2. Identification, definition, and breaking down of the problem.
3. Establishing achievable goals.
4. Generating solutions.
5. Evaluating and choosing the solution.
6. Implementing the chosen solution.
7. Evaluating the outcome after the solution has been implemented.

PST encompasses both a behavioural and a cognitive component. For the behavioural component, clients are required to carry out a number of specific tasks designed to solve particular problems they are facing. The cognitive component involves discussions around the fact that problems need not be seen as overwhelming and/or impossible but seen instead as solvable challenges. A set of practical steps is demonstrated that will lead to an effective resolution (Nezu et al., 2012). PST follows a clear structure to work through the stages outlined in Table 5 and can be administered in four to six sessions (Mynors-Wallis, 2005). Therapy begins with an explanation of the link between the distress that the client is experiencing and the practical difficulties that they are currently facing. To establish this link, clients are encouraged to identify their psychological symptoms, such as low mood, loss of appetite, irritability or worry. They are then asked to create a list of problems they are currently experiencing. The link is then made between the experience of these problems and their symptoms. The practical details of the therapy should then be explained to the client, for example how many sessions, how long each session will last, and homework tasks assigned.

During stage two the participant is asked to choose a problem to work on from the list they generated during stage one. The client is encouraged to choose a problem that is feasible for problem solving, and more complex problems are often held over until subsequent sessions, once the client has had a chance to learn the problem solving technique (Nezu et al., 2012). Once the problem is chosen, the client is encouraged to define the problem. This involves the identification of the following four aspects (Mynors-Wallis, 2005)

1. What is the problem?
2. When does the problem occur?
3. Where does the problem occur?
4. Who is involved in the problem?

During stage three the client and therapist work collaboratively to establish what the goal is that the client wants to achieve. This involves an explanation of SMART goals. They should be Specific, Measurable, Achievable, Relevant, and Timed (Bell & D’Zurilla, 2009; Mynors-Wallis, 2005; Nezu et al., 2012).

The next stage involves the generation of solutions. Clients are encouraged to brainstorm as many possible solutions to the problem that they can think of. Creativity is encouraged, and no solution is disregarded. In stage five clients are required to evaluate the pros and cons of each solution and choose the solution they think will be best for solving their problem (Bell & D’Zurilla, 2009; Mynors-Wallis, 2005; Nezu et al., 2012).

In stage six the client is required to generate a clear action plan for the preferred solution. The aim is to make the plan as clear as possible; therefore, it should include specific dates, times and resources needed. Participants are then encouraged to go away and implement the plan. The final stage of PST occurs in the next session and involves an

evaluation of the outcome after the solution has been implemented (Bell & D’Zurilla, 2009; Mynors-Wallis, 2005; Nezu et al., 2012).

Rationale for Using Problem Solving Therapy

As stroke survivors have reported that rehabilitation focuses predominantly on physical improvements and lacks psychological and social support (Bendz, 2003; McKeivitt et al., 2004; Murray et al., 2003; Peoples et al., 2011), it is important to provide this neglected psychological support and evaluate its efficacy. Therefore, there is a need for future research to investigate a variety of different non-pharmacological interventions (CBT, PST, and ACT) for PSD, PSA and HRQoL across all ages of stroke patients. More specifically, there is a need for research into the effects of non-pharmacological interventions for younger stroke patients (18-65) as this is an area that has been neglected in previous research.

This section will discuss the rationale behind why PST was chosen as the therapy that will be used with younger stroke survivors in the current study. PST recognises the fact that stressful daily problems arise from having a chronic disease, which in turn increases the risk of psychological stress and emotional problems such as symptoms of depression and anxiety (Nezu et al., 2012). Previous literature has documented the numerous problems and needs that arise post stroke for younger stroke patients (for example; Clarke, 2009; Lawrence, 2010; Martinsen et al., 2012; Morris, 2011; Stone, 2014).

In addition to this, Herrmann et al. (2000) unfortunately found that stroke patients use a less active problem oriented coping style than other brain damaged patients (patients with malignant brain tumours and patients with traumatic brain injuries). This is an important piece of research as effective coping strategies are salient in helping stroke survivors in their post stroke journey (McKeivitt et al., 2004). Further, more recent research has demonstrated that stroke patients with higher depression scores demonstrate

a more negative problem orientation and show a more avoidant problem solving style (Visser et al., 2015). The authors suggested that stroke survivors would benefit from training in positive problem solving and that future research should investigate the effects of therapy aimed at improving problem solving skills in stroke survivors (Visser et al., 2015). A recent study by Visser et al. (2016) endeavoured to do so and found significant differences after 8 sessions of PST on improvements in task-oriented coping between a PST group and a treatment as usual control group. This suggests that PST helps to develop stroke survivors' ability to take direct action when solving problems in order to reduce the amount of stress that the problem causes. Improvements in health related quality of life were also found suggesting that positive problem solving facilitates wellbeing.

Additionally, the New Zealand Stroke foundation's 2010 clinical guidelines for stroke recommend that stroke survivors be provided with training in active problem solving and goal setting (Stroke foundation of New Zealand and New Zealand Guidelines Group, 2010). However, in previous research, stroke survivors have identified problems with the way in which goals are set during rehabilitation in collaboration with health care professionals (Murray et al., 2003). This suggests a lack of goal setting during post stroke care. New Zealand research by Ahuja et al. (2013) used semi-structured interviews to gather qualitative data for 11 stroke survivors aged between 49 and 72, regarding their post stroke perceptions and experiences. The study investigated problems experienced as well as coping strategies used post stroke. Goal setting was reported amongst the participants as a crucial factor in making progress post stroke. This is similar to research by Jones, Mandy and Partridge (2008) who found stroke survivors benefit from having control over their goals in relation to their physical recovery. Therefore, if health care

professionals can encourage and work with stroke survivors to set goals, then this may enhance their rehabilitation process.

Consequently, the problem solving therapy method seems applicable to stroke patients, as goal setting is central in this therapy and PST can be implemented to teach stroke patients positive problem solving skills, which in turn may increase their HRQoL as well as decrease PSD and PSA (Nezu et al., 2012).

Although a review by Ellis, Mant, Langhorne, Dennis and Winner (2010) found that stroke liaison workers had no significant impact on the mental health of stroke survivors when compared to usual care, this should not suggest that problem solving would not be of benefit to stroke survivors. It is acknowledged that an aspect of the stroke liaison worker's role is to help solve problems experienced by stroke survivors, however problem solving is different in the fact that it is a more targeted intervention which aims to decrease and prevent psychopathology and increase positive well-being by enhancing coping strategies in clients so that they can deal more effectively with stressful problems on their own in their day to day lives.

Theoretical Underpinnings. CBT conceptualizes distress as a maladaptive symptom, which requires treatment. Thus, therapy aims to improve the client's ability to control distress (Beck, 2011). This may be problematic for therapy with stroke patients as distress has been found to be a common consequence of stroke (Burvill et al., 1995), and given the number of functional consequences of stroke (Clarke, 2009; Lawrence, 2010; Morris, 2011), it would appear that distress is an expected, normal and rationale reaction following stroke. Through the process of conceptualizing distress as maladaptive, CBT may be unknowingly undermining the understandable distress experienced by stroke survivors (Gregg, Callaghan, Hayes, & Glen-Lawson, 2007).

A further key component of traditional CBT is cognitive restructuring, which teaches clients to monitor and challenge the thoughts, assumptions, and beliefs that may bring about their distress (Beck, 2011). Consequently, in order to reduce psychopathology, the CBT therapist helps clients to challenge maladaptive beliefs and develop more adaptive beliefs, which in turn should reduce distress. However, in chronic illnesses perceptions or beliefs around their illness may be objectively correct and therefore there is little room for the therapy to make changes to the client's cognitions (Graham, Rose, Hankins, Chalder, & Weinman, 2013; Harrison et al., 2014). Cognitive restructuring may also be unsuitable for stroke survivors due to common symptoms of stroke. Kangas and McDonald (2011) commented that individuals with cognitive impairment might find this explicit metacognitive strategy difficult. Therefore, instead of focusing on cognitive restructuring perhaps the main focus of therapy with stroke patients should be around helping them to cope more effectively with their day to day problems.

Different psychotherapies are based on different theoretical frameworks. CBT is based on the notion that cognitions play a pivotal role in the etiology and maintenance of depression. Whereas PST states that depression can be a result of the interaction of stressful events and/or problems and various problem solving deficits. It could be said that distress control and cognitive restructuring unique to CBT afford few benefits for stroke patients. Although both CBT and PST have been successful in treating depression in other populations, perhaps it is the theoretical underpinnings of PST that is more suited to stroke patients as PST does not focus on identifying, challenging and altering irrational beliefs to reduce psychopathology; instead the focus is more practical as PST aims to help participants cope more efficiently with stressful problems in their day to day lives. Not only does PST avoid the risk of undermining the distress experienced by stroke patients, but this process may be more applicable to stroke patients given the number of day to day

problems that they have to deal with post stroke (Clarke, 2009; Lawrence, 2010; Morris, 2011).

Acceptance and Commitment Therapy views distress as a normal part of life. Instead of attempting to alter individuals distressing cognitions, ACT teaches clients to still experience their distress, whilst carrying out valued behaviours (Hayes, Strosahl, & Wilson, 2012). Therefore, like PST, ACT does not undermine the distress that stroke survivors are likely to experience. However, PST was chosen over ACT due to the previous research stating that young stroke survivors experience a number of unmet needs and problems following stroke. PST is seen as a more practical approach that can be used to help participants to resolve these issues which in turn may positively affect their mental wellbeing.

Further, given the scope of this research and the methodology of this study, PST has its advantages over other therapies, as it is a form of therapy that can be administered in a group format. This is advantageous for a number of reasons. Namely, because stroke survivors have reported a lack of social support post stroke (Bendz, 2003; McKeivitt et al., 2004; Murray et al., 2003; Peoples et al., 2011). Running the therapy in a group setting allows for an increase in social support and the gathering together of likeminded people who have had similar experiences. This is therapeutic in itself. Group therapy also allows for a larger number of participants, which can be used to form a control trial to better evaluate the efficacy of an intervention with younger stroke patients.

In summary, PST was chosen as the therapy of choice for the current study due to a number of reasons. Firstly, PST does not run the risk of undermining any distress that stroke survivors experience as a natural reaction to stroke, as the main focus is training clients in adaptive problem solving attitudes and skills, rather than altering dysfunctional cognitions. Furthermore, it does not utilise metacognitive strategies that individuals with

cognitive impairment post stroke may struggle with. Its salient components of goal setting and problem solving have been suggested as crucial in the post stroke journey to recovery. Finally, it appears to be the most applicable therapy to the documented problems and unmet needs experienced by younger stroke survivors.

CHAPTER 7: THE CURRENT STUDY

Given the difficulties expressed by younger stroke survivors, and the limited research surrounding interventions for this population, further research is needed to identify effective interventions for this population. The current study is comprised of two parts. Part 1 aimed to investigate what problems are experienced by younger (18-65) stroke survivors in New Zealand. Part 2 aimed to investigate the efficacy of a post stroke psychotherapeutic intervention with younger (18-65) stroke patients.

Part 1 involved an online survey conducted with younger stroke survivors around New Zealand. The Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) stated that it is important to prioritise research on New Zealand stroke rehabilitation and community support services for stroke survivors under the age of 65. They suggest that in order to ensure a personalised and heightened level of care, which enhances post-stroke rehabilitation, health professionals need to have in-depth knowledge of the problems stroke survivor's experience. In order to understand individualised post-stroke experiences, information was gathered from stroke survivors. The results from the survey were used to inform part 2 of the current study.

Previous research has identified a number of unmet needs and problems expressed by younger stroke survivors. There is an identified need for therapy to help younger stroke survivors identify their problems, and then develop coping strategies to alleviate any consequential psychological distress. PST aims to identify problems that are important to the participant and then develop strategies to deal with these problems. The primary aim of study 2 was to investigate whether PST is an effective group intervention for decreasing depression and anxiety and increasing quality of life and problem solving skills in younger stroke survivors (18-65) who had experienced their stroke between 6 months to 3 years previously. By then it was expected that they would be living back in

the community but would be experiencing problems in their day to day lives. It is also important to study longer term outcomes as they are affected by different factors (e.g., return to employment, finances) than short term outcomes (e.g., inpatient care).

Research Questions

The following section of this chapter includes a description of the research questions that were investigated by part 1 and 2 of the current study.

Part one. The research questions for part 1 were addressed by an online survey which was developed specifically for the study. The survey was based on a combination of previous qualitative and quantitative research regarding the different problems that younger stroke survivors experienced internationally. Table 6 outlines each of the problems investigated, and the research studies that these questions were based on. The researcher endeavoured to generate a more in-depth understanding of each problem experienced, therefore after each question, participants were provided with an opportunity to describe examples of each problem in an open-ended format. Additionally, at the end of the survey, participants were able to describe any other problems that they were experiencing, that had not been investigated within the survey. See Appendix B for the survey.

Table 6*Problems investigated and supporting research studies*

Problem Investigated	Background research
Family life disruption	Daniel et al., 2009; Martinsen et al., 2012; Teasell et al., 2000
Marital breakup	Teasell et al., 2000
Family conflict	Teasell et al., 2000
Intimacy problems	Daniel et al., 2009; Morris, 2011
Employment loss or disruption	Glozier et al., 2008; Morris, 2011; Teasell et al., 2000
Social isolation	Murray & Harrison, 2004; Stone, 2014
Altered finances	Daniel et al., 2009; Kersten et al., 2002
Disruption of leisure activities	Daniel et al., 2009
Limited access to community support services	Low et al., 2003
Lack of information post stroke	Low et al., 2003
Education and study	Van de Port et al., 2007
Self-esteem	Keppel & Crowe, 2000; Morris, 2011; Murray & Harrison, 2004
Invisible disabilities	Lawrence, 2010; Murray & Harrison, 2004; Röding et al., 2003; Stone, 2005
Intellectual fulfilment	Kersten et al., 2002; Low et al., 2003
Transportation difficulties	Ing et al., 2014
Forming new relationships	Murray & Harrison, 2004

As these research questions are based on previous research it was hypothesised that the participants in this study would identify each of the problems outlined in Table 6 as at least “somewhat of a problem” when asked to indicate on a 4-point scale (1 = not a problem at all, 2 = somewhat of a problem, 3 = a significant problem, and 4 = a major problem all of the time) how much of a problem each item is.

Part two. The research questions for study 2 were assessed using a between-subject and within-subject, repeated measures design. The between-subject research questions were as follows: (1) Will depression and anxiety scores reduce significantly more in the PST group than in the wait-list control group between baseline and time 2? (2) Will quality of life and problem solving skills improve significantly more in the PST group than in the wait-list control group between baseline and time 2?

The within-subject research questions were as follows: (1) What is the efficacy of PST for reducing symptoms of depression and anxiety? (2) What is the efficacy of PST for increasing quality of life and problem solving skills? (3) Will young stroke survivors rate PST as being helpful and enjoyable? (4) What aspects of PST did young stroke survivors find the most helpful and least helpful? (5) Will young stroke survivors use this method of problem solving with future problems that they encounter?

It was hypothesised that:

1. There would be no difference between the waitlist control group and the treatment group scores at baseline.
2. The wait-list control group would improve slightly on the outcome measures, between baseline and time 2, i.e. scores on the Centre for Epidemiologic Depression Scale (CES-D) and the Hospital Anxiety and Depression Scale – Anxiety sub-scale (HADS – A) would decrease. This is based on previous research indicating that anxiety and depression symptomatology in individuals improves over a waiting period (Arrindell, 2001; Hesser, Weise, Rief, & Anderson, 2011; Posternak & Miller, 2001; Young, 2006).
3. Problem solving group scores on the CES-D and the HADS-A would decrease significantly more than the control group between baseline and time 2 (between-subject design).
4. Problem solving group scores on the Social Problem–Solving Inventory-Revised: Short Form (SPSI-R:SF) and the Stroke Specific Quality of Life Scale (SS-QOL) would increase significantly more than the control group between baseline and time 2 (between-subject design).

5. The problem therapy group will show a significant improvement on all outcome measures (CES-D, HADS-A, SPSI-R:SF, SS-QOL) between baseline and time2/time3 (within-subject design).

CHAPTER 8: STUDY 1 METHOD

This chapter provides a detailed account of the methodology used to conduct study 1 (survey) and to address the research questions outlined in chapter 7. As chapter 10 includes the manuscript for this study and therefore briefly outlines its methodology, the current chapter will only include methodological discussions and justifications that are in excess of the requirements of the manuscript in order to avoid any repetition of content. Specifically, it includes study design, sample size, participants, measures, procedure, statistical analyses, and ethical considerations.

Study Design

The current study involved the distribution of an online survey and employed a qualitative and quantitative cross-sectional design to investigate the problems experienced by younger stroke survivors in New Zealand.

The primary purpose of the survey was to obtain an overview of the different problems experienced by younger stroke survivors in New Zealand. A research methodology was required that would give the younger stroke survivors an opportunity to describe and discuss their experiences. Literature states that surveys are an effective tool for this purpose (Sapsford, 2007). Furthermore, surveys afford the respondent with an opportunity to provide anonymous, personal, self-reported information (Rea & Parker, 2005).

A survey was chosen for the current study due to a number of advantages: (a) they are less time intensive for participants than a focus group or an interview (Watkins, Meiers, & Visser, 2012), (b) surveys are inexpensive and time-efficient to create which reduces time, human and financial resources (Kumar, 2010), (c) an online survey has no geographical boundaries, which allows for a nationwide survey, resulting in a potentially large sample size and more generalizable results, (d) the researcher exercises minimal

control over the respondents, as a consequence, there are few ethical concerns regarding researcher influence (Mitchell & Jolley, 2012), and (e) anonymity is ensured with surveys, which may encourage participants to disclose more accurate personal information (Kumar, 2010). See Appendix B for a copy of the survey.

Sample Size

It was estimated that a minimum of 50 participants would need to be recruited. This number is based on research by Kersten et al. (2002) who suggest that this number would be large enough to allow the results to be generalized to a wider stroke population.

Participants

Demographic statistics regarding gender, age, ethnicity and time since stroke are included in manuscript 1 (chapter 10). Participants' years of education were 12+ years (64%) and less than 12 years (36%). More than half of the participants who answered the employment question (n = 82) were not working (62%) and of the 82 participants who answered, "what is your relationship status?" 42% were married, 17% were single, 16% were divorced or permanently separated, and 18% in a relationship but not married. Of the 81 respondents who answered, "where are you currently residing", 59% owned their own home, 33% lived in rental accommodation and 7% in their parents' home. No one was residing in a rehabilitation centre at the time of survey.

Measures

Survey questions focussed on difficulties with and disruptions to: family life, marital relationships, intimacy; forming new relationships, employment, return to or beginning study, finances, leisure activities, loss of home, social isolation, access to community support, intellectual fulfilment, lack of information, transport, invisible disabilities and self esteem.

The online survey software Qualtrics was used to administer the survey and collect the data. A link was created that took participants straight to the survey, and this

link was included in advertisements regarding the study. As Qualtrics is an online programme, respondents needed to use computers with internet access to complete the survey. Once completed, Qualtrics automatically generated and stored the data on the secured website, www.qualtrics.com. Once data collection was completed and the online survey was closed, all data was transferred to the researcher's computer and stored in password-protected files.

Procedure

The advertisement for this survey included a brief statement about the study as well as the link that took participants straight to the online survey. Participants who clicked the link were taken straight to the information sheet that provided additional information about the study and emphasised anonymity and privacy. Participants were informed that they could contact the researcher with any questions (contact details for researcher and supervisors were provided), were under no obligation to consent to the research, and had the right to withdraw from the study at any time.

Participants were then directed to the demographic section and were asked to indicate whether they were between the ages of 18 and 65 and whether they had suffered a stroke. If the participants replied "no" to either of these questions they were re-directed to a page that thanked them for their time and interest and informed them that they were unable to complete the survey. Those who answered "yes" were able to proceed with the survey with the understanding that participation implied consent.

At the end of the survey participants were thanked for their participation and were given the opportunity to state whether they wanted to be contacted with a summary of the results of the study. If they answered "yes" to this question the participants were asked to provide their email addresses which were stored in a pass-word protected file on the researcher's computer. Once the obtained data had been analysed by the researcher, a summary of the findings were emailed to these participants.

Prize draw. At the end of the survey participants were asked whether they wanted to go into the draw to win a \$100 grocery voucher. To go into the draw, participants were required to provide their email addresses. Using a random numbers table (Rand Corporation, 1995) the winner was randomly selected from the total pool of participants who agreed to be in the prize draw. In order to ensure anonymity, only the researcher viewed the email addresses of the respondents. Once the winner had been drawn, the identifying information was deleted.

Ethical Considerations

A significant ethical concern for study 1 was the psychological vulnerability of participants due to the nature of the questions. In order to help manage this concern, participants were forewarned that the questions may cause them some emotional distress. As stated above, they were also informed that they were under no obligation to complete the survey and could withdraw at any time. At the end of the survey, contact details for psychological support organizations were provided for any participants who experienced emotional distress and wanted to talk to someone about it. The organisations mentioned at the end of the study included: Samaritans, The Depression Helpline, Healthline, Lifeline, and Youthline. They were also given the www.hdc.org.nz website and told that it provided a list of mental health services in their area.

All research data was kept anonymous in a password protected file and will be held for a period of 10 years. Subsequent to this term, all data will be destroyed.

Risk of emotional harm to the principal investigator was managed through supervision.

Statistical Analyses

Mixed Methods design. The survey included both open and closed questions. Data collected was both quantitative and qualitative in nature. The mixed method design was chosen as it allows for the collection of more enriching information from which to

generate conclusions concerning the current study (Mertens, 2010). There was no dominant paradigm used in the current study, and a similar process as described by Johnson, Onwuegbuzie and Turner (2007) was followed in that both the qualitative and quantitative data was collected concurrently throughout the duration of the research. This is opposed to a sequential process; where one type of data follows on from another type (i.e. qualitative data is collected as a result of already collected quantitative data) (Johnson et al., 2007).

The mixed method was also used for the purpose of expansion, triangulation, and complementarity of data (Johnson & Onwuegbuzie, 2004), where expansion refers to the increase in the range and breadth of research through the use of differing methods of inquiry. Triangulation enables verification and convergence of findings from multiple methods and designs. Finally, complementarity refers to the results from one method, elaborating, enhancing, illustrating and clarifying the results from another method (Johnson & Onwuegbuzie, 2004). Details of the analyses are provided below.

Quantitative data management and analysis. The quantitative data from the closed questions were analysed using the Statistical Package for the Social Sciences (SPSS; version 23.0 for Windows, IBM Corp., Armonk, NY). Descriptive statistics were used to analyse each of the dependent variables. These included frequency and percentage response distributions, measures on central tendency (mean) and dispersion measures (standard deviation). The dependent variables included participants' ratings of the extent of which they experienced each of the 16 problems listed in Table 6.

Qualitative data management and analysis. Content analysis was selected as the method of qualitative analysis for the current study as many of the responses to the open questions were brief and therefore unsuitable for thematic analysis (Braun & Clark, 2006). Themes within the data were identified and labelled using codes, their frequencies

were then calculated and reported (Elo & Kyngäs, 2008; Krippendorff, 2012, Smith, 2000). Krippendorff (2012) states that qualitative data can be effectively converted into quantitative data through the use of different methods including: the identification of themes within the data, frequency counts, and the validation of these themes by numerous individuals (inter-rater reliability). According to Meehan, Vermeer, & Windsor (2000) individual's perceptions of a phenomenon can be efficiently examined through the use of content analysis. It has also been noted that content analysis is appropriate for psychological inquiries (Krippendorff, 2012; Wilkinson, 2000).

Process. The analysis was primarily inductive, as categories were created based on content and themes embedded within the data (Elo & Kyngäs, 2008). However, because the principal investigator had prior knowledge of the different problems that younger stroke survivors experienced due to the review of previous research (e.g., Daniel et al., 2009; Stone, 2014), the analysis also included a deductive element (Elo & Kyngäs, 2008). Nevertheless, the principal investigator attempted to ensure that the identified codes reflected the respondents' reports, rather than the results from previous studies.

As suggested by Elo and Kyngäs, (2008), the principal investigator began by reading all of the excerpts repeatedly to get a deep understanding of what had been reported. Codes were then assigned to all of the different themes that emerged from these excerpts. Meehan et al. (2000) suggests that codes should be assigned to significant themes; however, initially codes were assigned to all themes that were deemed to be unique. After the initial analysis 320 codes were identified. The codes were then re-assessed and merged according to common themes (for example, the codes "cognitive symptoms", "physical symptoms", "fatigue", "communication difficulties" and "hypersensitivity to noise" were merged into "post stroke symptoms"), resulting in 170

codes across the 17 different open-ended questions (16 problems plus the final “other problems” option). Therefore, on average there are approximately 10 codes per question.

Each participant’s response was coded as a single unit; however, as some participants provided responses that related to multiple codes, all applicable codes were assigned to each response (Krippendorff, 2012). As a consequence, the frequencies and percentages reported in the manuscript refer to the total number of responses within each code, rather than the total number of respondents to each survey question. The in-text tables within the results section of the manuscript (see chapter 10) only include the most commonly occurring codes, as according to content analysis, the most commonly occurring responses are the most relevant (Wilkinson, 2000).

Inter-coder reliability. In order to increase the objectivity of the current study, and to improve the consistency and strength of interpretation, inter-code reliability was determined. Inter-coder reliability is the degree of agreement between multiple coders on how to code or categorise components of the data (Howitt, 2013). For the current study, this process involved a random selection of 20% of the responses from the survey. Mouter and Vonk Noordegraaf (2012) suggest that randomly selecting a sample of the body of content is common practice and sufficient for the calculation of inter-coder reliability. In addition, the authors state that using all of the content is often impracticable and gives no additional value (Mouter & Vonk Noordegraaf, 2012). The 20% selection was given to an additional coder who was a doctorate-level researcher and was familiar with the technique used for inter-coder reliability. The additional coder was also provided with a list of codes for each question as well as the code description and examples. Riffe, Lacy and Fico (2005) state that the researcher should provide additional coders with a list of instructions and rules that defined and operationalised the codes, therefore this was also given to the additional coder.

The calculation of Cohen's kappa was used to determine the observed level of agreement between the two coders. Percentage agreement is another statistical calculation that is often used to determine the level of agreement between multiple coders; however, this was not used, as it does not consider any agreement that may have occurred due to chance (Hallgren, 2012). The determined kappa indicated "substantial" agreement, $\kappa = 0.79$ (Landis & Koch, 1977).

Subsequent to an investigation of contrasting codes, it was decided that the majority of differences between coders were due to oversights of more suitable codes or incorrect utilizations of a rule. As a consequence, the two coders met to discuss these findings and further discussion revealed that perceptions of code applications were mostly agreed upon, with the exception being the code "post stroke identity". It was decided that the coders both had different perceptions of what post stroke identity actually was, therefore the codes remained dissimilar. Following this consultation, Cohen's kappa was recalculated and found to indicate "almost perfect" agreement ($\kappa = 0.99$).

CHAPTER 9: STUDY 2 METHOD

This chapter provides a detailed account of the methodology used to conduct study 2 and to address the research questions outlined in chapter 7. Specifically, it includes study design, sample size, recruitment, participants, measures, procedure, ethical considerations, and statistical analyses. As with chapter 8, only information that is surplus to the methodology outlined in the publication (chapter 11) is included to avoid any repetition of content.

Study Design

The current study involved the evaluation of the efficacy of PST for younger stroke survivors and employs both a within-subject and between-subject condition.

For the between-subject analysis a wait-list control group was included to account for spontaneous remission and the natural passing of time (Posternak & Miller, 2001). A wait-list control group was selected as the comparison group over a social control group due to the ethical implications of withholding a possibly beneficial treatment from the younger stroke survivors (Baucom, Hahlweg & Kuschel, 2003).

Approximately six weeks of involvement in the study was required from baseline to the post treatment assessment. This did not include the 3 month follow up. Participants were assessed in the week of the commencement of the PST sessions and then again in the same week following the final therapy session. Participants on the waitlist were assessed approximately five weeks before beginning therapy, then again in the week before starting therapy.

Group therapy as opposed to individual therapy was chosen for a number of reasons: (a) group therapy has the potential to alleviate social isolation (Earley, 2013), this is beneficial as research has shown that younger stroke survivors experience social isolation (Murray & Harrison, 2004; Stone, 2014), (b) group participants have the opportunity to learn off each other through observation (Earley, 2013), (c) hope can be

gained by participants from hearing the successes of other group members (Earley, 2013), (d) group members can experience an increase in self-esteem through hearing that other group members experience similar difficulties, and they are not the only ones (Earley, 2013), (e) group members can also feel empowered by providing help to the other group members (Earley, 2013), (f) social skills can also be taught and practiced in group settings, group members may become better at relating to others, and practicing tolerance, appreciation and empathy (Early, 2013). In addition, group therapy also has applied advantages over individual therapy for healthcare workers, as it is more cost and time effective (Tucker & Oei, 2007).

Recruitment

Originally the inclusion criteria only allowed for participants between the ages of 18 and 65, however the principal investigator was contacted directly by five participants who wanted to be involved in the study so the inclusion criteria was altered to stroke survivors who were between the ages of 18 and 65 at time of stroke. Participants were included if they had experienced symptoms of depression or anxiety or if they felt that their quality of life had been affected as a result of their stroke. Participants were excluded from this study if they had severe aphasia or were unable to attend group therapy sessions.

Recruitment occurred in two stages. Initially recruitment began in Wellington where members from the neurology team at Wellington hospital were asked to make recommendations for participants who met the inclusion criteria. Possible participants were contacted and given information about this study via health professionals from the neurology team. Possible participants were sent out an information pack about the research project, as well as the contact details of the researcher. A copy of the information sheet can be found in Appendix C. In order to honour privacy and give participants time to decide on their own, an 0800 number was set up for possible participants to phone with

queries and to register interest in participation. A freepost envelope and email information were included in the pack for clients to respond. The researcher made no direct contact with any participant unless it was requested to do so by the participant themselves. If they decided to participate they were required to complete a consent form and post it back using the freepost envelope. A copy of the consent form can be found in Appendix D.

A total of 88 information packs were posted out by the Wellington hospital and eight consent forms were returned (9.1% response rate). Of these, 2 out of the 8 participants were unable to start therapy until later in the year, therefore it was decided that an initial group of six would take part in the initial assessment session. The principal investigator contacted the participants to discuss timings for the initial assessment session and the six therapy sessions.

In the current study, the initial assessment session lasted for approximately one hour. During which, the principal investigator was given the opportunity to meet one on one with potential participants and answer any further questions that they may have had. Confidentiality was explained, and potential participants were informed again that they had the right to decline participation or withdraw from the study at any time. Demographic information and baseline data were collected during the initial assessment session. As the assessment sessions were in the week of the first therapy session, participants had already been informed prior to the initial assessment session when they would be beginning therapy.

Of the six potential participants who attended their initial assessment sessions, one did not meet criteria for the study, as the participant scored 0 on the measures for anxiety and depression. The participant also reported that they were doing well and did not experience any significant problems; however, they were still keen to take part in the study. During supervisory consultation, a number of points were considered before

deciding on the potential participant's participation in the therapy sessions: (a) the effect on other group members, should the participant discuss not having any problems, (b) the time and resources spent by the participant to partake in therapy, should they not actually benefit from the sessions, (c) the effect on the data where there could potentially be no room for change between baseline, post treatment and follow up, and (d) the effect on the participant should they be told that they were unable to participate. Following supervision, it was decided that the principal investigator would contact the potential participant and give them the opportunity to decide whether or not they wanted to participate. The aims of the therapy sessions were discussed, in that the goal is to reduce levels of depression and anxiety, to increase quality of life, and to teach coping strategies to resolve any potential problems. However, the participant was told that they were still welcome to participate should they want to. The potential participant decided to withdraw from the study. Therefore, five participants began therapy that week.

Phase two of recruitment began as a result of the online survey (study 1). The researcher had been contacted by various younger stroke survivors around New Zealand expressing their interest and gratitude for research into the area of younger stroke survivors. The researcher discussed the intervention study with these younger stroke survivors. One of whom, was residing in Tauranga, and was also a member of a Facebook group for younger stroke survivors in the Tauranga area. He/she also met once a month with a group of younger stroke survivors in the Tauranga area and mentioned that the group members may want to participate. It was then decided that recruitment would be extended to Tauranga and the same recruitment procedure that was carried out in Wellington, was followed.

Health professionals from Tauranga hospital posted out 116 information packs. An additional six information packs were given out to the younger stroke group who met

once a month in Tauranga. Of which, 18 consent forms were initially returned. It was decided that these 18 potential participants could form the wait list control group. It must be noted that due to the locations of the stroke survivors (Tauranga and Wellington), random selection was not used to assign participants to the two different groups (wait-list and control group). The principal investigator contacted the 18 potential participants and arranged initial assessment sessions in Tauranga. Of the 18 participants, one decided to withdraw after a discussion of the aims of PST, as they reported that they were doing well and had replied to the information pack as they wanted to help other younger stroke survivors. The potential participant did not complete the baseline measures. An additional participant scored well below the cut off scores for anxiety and depression similar to the scores of the Wellington participant who decided not to participate. The researcher considered the supervisor consultation previously mentioned and had the same discussion with this participant, stating the aims of PST and gave the younger stroke survivor the opportunity to decide whether they wanted to participate. He stated that he would still really like to participate and was therefore included in the study. This resulted in a wait-list control group of 17 participants who were told that they were on the wait-list and would be contacted in the near future about beginning therapy. Any change in outcome measure during the wait-list period was measured and is reported in the results section.

Of the 17 wait-list group participants, one participant's baseline measures were deemed to be invalid as the participant did not complete the measure on his own, and the scores on these measures were vastly different to the scores at the other three time points. Therefore, their measures were not used in the wait-list analysis.

Subsequent to the initial assessment sessions with the wait-list group in Tauranga, an additional three participants posted their consent forms back and were added to the treatment group, to begin therapy with the participants in the waitlist group. The addition

of the three returned consent forms provided a total of 21 returned consent forms (17.21% response rate). Of the 20 participants who had agreed to partake in therapy, 1 withdrew before therapy began. Therefore 19 were split into three groups based on the time slots and days that suited those best for therapy. For convenience to the participants, there was no random assignment to groups. The limitations of this are discussed in chapter 12.

The principal investigator was also contacted by three younger stroke survivors in Christchurch, however after consultation with her supervisors regarding budget and time restraints, it was decided that the study would not extend to the South Island.

Since the beginning of the first Wellington group, two more consent forms were returned from the information packs sent out through the hospital, thus increasing the response rate from Wellington to 11.36%. This resulted in an additional four potential participants, including the two who were unable to start therapy until later in the year. Following this, second rounds of initial assessment sessions were carried out in Wellington with the four participants. All of which began therapy together.

In total, 210 information packs were sent to potential participants in Wellington and Tauranga, from this 31 were returned (14.76% response rate). Further, 28 younger stroke survivors across five groups (2 in Wellington and 3 in Tauranga) took part in the therapy sessions. These 28 formed the treatment group for the within-subject design. The data from the 16 participants on the wait-list control group were compared with 13 who completed treatment and were not put on a wait-list group were used for the between-subjects design.

Measures

A description of the measures is provided in manuscript 2 (chapter 11). These same measures were used with both treatment and wait-list control groups, to evaluate improvements in depression, anxiety, quality of life and problem solving skills pre and

post treatment. Chapter seven specifies the study hypotheses made for each outcome measure at the different assessment points.

Depression. The *Center for Epidemiologic Depression Scale (CES-D)* (Radloff, 1977) was chosen to measure severity levels of depression as it only takes 10 minutes to complete and has been validated in stroke populations. Hadidi, Lindquist, Treat-Jacobson, and Savik (2011) stated that the CES-D is a valid tool for differentiating between symptoms of depression and symptoms resulting from stroke.

Anxiety. The *Hospital Anxiety and Depression Scale – Anxiety sub-scale (HADS – A)* (Zigmond & Snaith, 1983) was chosen as it is one of very few anxiety scales that have been validated in a stroke population (Lincoln, Kneebone, Macniven, & Morris, 2012; Sagen et al., 2009) and only takes two to five minutes to complete.

Problem Solving. The *Social Problem–Solving Inventory-Revised: Short Form (SPSI-R:SF)* (D’Zurilla, Nezu, & Maydeu-Olivares, 2002) was used to measure participants’ social problem solving ability.

Quality of life. The *Stroke Specific Quality of Life Scale (SS-QOL)* is a patient-centered outcome measure intended to assess health related quality of life (HRQOL) specific to individuals with stroke (Williams, Weinberger, Harris, Clark, & Biller, 1999).

Feedback Forms.

The principal investigator created the feedback forms and a description of these is provided in the publication (chapter 11). Open-ended questions were also included in both the individual session and overall feedback forms for the following reasons. Firstly, to determine what was helpful and unhelpful about each session and the overall therapy. Secondly, to generate any comments or suggestions that participants had about the sessions and PST as a whole. Finally, to seek suggestions to make the therapy more suited to younger stroke survivors. An honours student who helped with the facilitation of the

PST groups used the answers to the open-ended questions for her research project; therefore, this analysis is not included within the current thesis.

Procedure

Assessment procedure. On receipt of the signed consent forms, participants were rung, and an initial assessment session was scheduled with each individual participant. Each initial assessment was approximately one hour long and was run by the principal investigator. The Wellington assessment sessions were carried out in the Massey University psychology clinic and the Tauranga assessment sessions were carried out in the participants' homes. Demographic information and baseline measures were taken on the CED-S, HADS-A, SPSI-R:SF, and the SS-QOL.

To assess the wait-list control group in Tauranga at time 2 (before they started therapy), the same four measures were posted to the participants in the week before the initial therapy session started. The wait-list participants were asked to complete the same four measures and bring them along to the first session to give to the principal investigator who then sealed them in an envelope.

At the final session of the six week programme, all participants were asked to complete the assessment measures (four questionnaires) and place them in a sealed envelope. At 3 month follow up, all participants were mailed out the same assessment measures, along with a freepost envelope and were asked to post the measures back.

Cultural heritage and identity were considered throughout the duration of the assessment sessions with all participants (Whakawhiti, 1991). More specifically the following principles were considered that are intrinsic to Māori culture.

Whakawhanaungatanga (the process of establishing relationships) (Bishop, 1999) was prioritized (Whakawhiti, 1997). Time was spent at the beginning of each session building rapport and listening to the participants post stroke and life story (Whakawhiti, 1997).

The principal investigator also introduced herself and her research journey. The principal

investigator wanted to ensure that all participants felt comfortable before asking them to reveal personal information. The dimension of whanaungatanga (the participants' relationship to their family) was also acknowledged (Durie & Hermansson, 1990), and participants were encouraged to bring whanau along to the initial assessment session. Finally, Ngā manu kōrero (the domain of time) was also considered (Durie, 2007). Although assessment sessions were originally scheduled for approximately one hour, the principal investigator left plenty of time between each appointment session so that the participant was able to tell his/her story and did not feel rushed or unheard.

Participants were given the choice of either a \$20 supermarket or \$20 petrol voucher as a koha to thank them for their time at the first testing session. On receipt of the completed questionnaires at 3 month follow up participants were sent their choice of a second \$20 voucher.

Facilitators. The principal investigator was the primary facilitator for all five of the treatment groups. A co-facilitator (i.e., honours or doctoral students) was present during all sessions. The Principal investigator sought supervision with her supervisors throughout the 4 months that the therapy sessions were run.

Intervention procedure. Similar to the assessment sessions, cultural heritage and identity were also considered throughout the duration of treatment sessions (Whakawhiti, 1997). This was done in a number of ways. Firstly, whakawhanaungatanga (the process of establishing relationships) (Bishop, 1999) was prioritized in the beginning of the sessions. Participants were all given the opportunity to introduce themselves to the group and tell their stories (Whakawhiti, 1997). Food and hot drinks were also brought to each session as a koha for participants (Durie, 2007). Participants also had the opportunity to bring a whanau member with them to the sessions.

The therapy of choice was problem solving therapy, and the facilitator and participant manuals are included in Appendix E and F, and outline how the sessions were run. However, it is important to note that the facilitator manual was simply a rough guideline of the content that was covered. Flexibility was ensured, and the principal investigator strived to make the group members feel as comfortable and engaged as possible. Rapport was not compromised for the sake of structure.

The facilitator and co-facilitator arrived half an hour early, before each session, in order to set up the room. The groups were run around a table where all participants were seated, facing each other. A whiteboard was also used throughout the sessions. Food and drinks were provided at each therapy session.

At the end of the sessions the facilitator stepped out of the room so that the co-facilitator could distribute the feedback forms to each group member. These feedback forms were distributed after every session and participants were asked to place them in a sealed envelope. The principal investigator informed the participants that she would not see the feedback forms until well after therapy has finished and encouraged the participants to be as honest as possible. The session feedback form is included in Appendix G and the overall feedback form is included in Appendix H.

Materials. Participants in the PST group were provided with a clear file containing a participant manual. A number of problem solving work sheets were also distributed throughout the sessions and could be added to their clear file. Participants were encouraged to bring their folders to each session. Please see Appendix F for the manual.

Statistical Analyses

All data was analysed using SPSS version 23 for windows (SPSS; version 23.0 for Windows, IBM Corp., Armonk, NY).

Data exploration was completed to check for normal distribution, homogeneity of variance, and outliers (Field, 2013).

A mixed analysis of variance (ANOVA) was used to determine any differences in improvements between groups on the CES-D, HADS-A, SPSI-R:SF and the SS-QOL from baseline to time 2. Models were created for all outcome variables with outcome interval, group condition, and the interaction between these variables as predictors. The primary analysis of interest with a mixed design ANOVA is the interaction between group and outcome interval on the four outcomes measures. With an interaction, the wait list control group and the treatment group would change differently between the two outcome intervals (Baseline and time 2) (Tabachnick & Fidell, 2001). In addition, the main effect of outcome interval and the main effect of group were investigated for each outcome measure, in order to determine the effects of the independent variable on the dependent variable at baseline and time 2 (Tabachnick & Fidell, 2001).

A repeated measures ANOVA was used to determine whether there were any significant changes on the CES-D, HADS-A, SPSI-R:SF and the SS-QOL, from baseline to post treatment to follow up, for the treatment group.

Results from data analysis were reported in nine parts: (1) Depression: CES-D; (2) Anxiety: (HADS-A); (3) Problem solving total: (SPSI-Total); (4) Positive problem solving (SPSI-PPO); (5) Negative problem solving: (SPSI-NPO); (6) Rationale problem solving: (SPSI-RPS); (7) Impulsive/Careless problem solving (SPSI-ICS); (8) Avoidant problem solving (SPSI-AS); and (9) Stroke specific quality of life SS-QOL. Note that problem solving has been broken down to each of the six subscales that represent different aspects of problem solving as outlined in D’Zurilla et al. (2002). This allows for the exploration of the effect of problem solving therapy on each of the different aspects of problem solving.

Responses on the session rating forms were analysed using descriptive statistics. This was done to determine participants' ratings of helpfulness, enjoyment and future use of PST. These included frequency and percentage response distributions, measures on central tendency, and dispersion measures.

Ethics

Although it was expected that ethical concerns would not outweigh the potential benefits for the stroke population, a number of ethical considerations were made and will be mentioned below.

Participants had their stroke within 6 months to 2 years of the proposed study and were experiencing symptoms of depression and anxiety. Although many stroke survivors may recover to the point where their cognitive deficiencies are not severe enough to interfere with the decision-making process, some stroke survivors will have damage to the areas of the brain that involve judgement and reasoning. Therefore, these stroke survivors may not be able to make a truly informed decision regarding participation in the proposed study. Only participants who were able to consent to participation in the current study were chosen. Decisions regarding this were made in collaboration with health professionals from the neurology department at Wellington and Tauranga hospital. It was decided that the following three conditions were to be upheld: participant capacity (the ability of the participant to understand the nature of the research, as well as its risks and benefits, in order to make an informed decision), voluntariness (freedom from undue coercion, be it deliberate or unintended) and disclosure (the provision of all information needed for the potential participant to assist them in the decision-making process). Commencement of treatment did not go ahead until the researcher had received a signed consent form. All participants were given the right to terminate the procedure at any time during the study.

Privacy of possible participants was upheld as possible participants were

contacted and given information about this study via health professionals from Wellington hospital. They were sent out an information pack about the research project, as well as the contact details of the researcher. In order to honour privacy and give participants time to decide on their own an 0800 number was set up for possible participants to phone with queries and to register interest in participation. A freepost envelope and email information were included in the pack for clients to respond. The researcher made no direct contact with any participant unless requested to do so by the participant themselves. If they decide to participate they were required to complete a consent form. The researcher did not make direct contact with any participant unless requested to do so by the participant themselves.

It was anticipated that minor psychological discomfort may result from the group nature of the intervention; for example, some participants may have felt uncomfortable when discussing the different problems, they experience. However, participants were informed that they could withdraw from the study at any point if they wished to or if they experienced distress. In addition, participants were reminded that there was no obligation to reveal information that may make them feel uncomfortable.

Demographic, psychometric, and testing data will only be made available to the scientific community upon request and all research data will be kept anonymous. All data will be kept in secure storage facility for a period of 10 years. Subsequent to this term, all data will be destroyed.

Risk of emotional harm to the principal investigator was managed through supervision.

**CHAPTER 10: A CROSS-SECTIONAL SURVEY OF THE EXPERIENCES OF
YOUNGER STROKE SURVIVORS IN NEW ZEALAND: A MIXED METHODS
STUDY**

This paper is currently under review with The New Zealand Medical Journal and the formatting is in the required style for submission. It must be noted that information within this article will be a repetition of what has already been mentioned in the previous chapters, as well as in the final discussion chapter. The content of this manuscript has been condensed to what is deemed appropriate for publication by The New Zealand Medical Journal.

A cross-sectional survey of the experiences of younger stroke survivors in New Zealand: A mixed methods study

Original Article

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Abstract

Aim: Most research about post-stroke difficulties is focused on those who experience stroke over 65 years. Internationally, research in the area of younger stroke survivors is increasing, however, there still remains limited research in New Zealand investigating this. Given the specific cultural context of New Zealand, it is important to investigate whether the problems experienced by this demographic are unique and how they impact the post stroke journey.

Method: A mixed methodology design incorporating both quantitative and qualitative data was followed. A 31 item self-made online survey was used to collect data regarding problems experienced by younger stroke survivors who were recruited through the New Zealand Stroke Foundation. Participants were also provided with open-ended questions so that they could elaborate on the problems they experienced.

Results: Although 13 of the 16 problems that were enquired about were stated as being at least somewhat of a problem, problems associated with invisible disabilities was rated as a significant problem. Responses to the open ended questions provided a deeper understanding of how these problems are experienced, and the variability across all stroke survivors, demonstrating that the post-stroke journey is unique to each individual.

Conclusions: Post-stroke services should endeavour to acknowledge and address these different difficulties, in order to enhance the rehabilitation process and quality of life of the younger stroke survivors.

Keywords: Stroke, younger people, qualitative, quantitative, problems, experiences, invisible disabilities

Introduction

Stroke is the third leading cause of death and disability in New Zealand,^{1,2} with a prevalence estimated to be around 60 000.^{2,3} Approximately 6000 New Zealanders suffer from a stroke every year,⁴ and due to a combination of improvements in medical care, a deeper understanding of stroke pathology, and an aging population, an increasing number are living in the community.

Approximately one third of stroke survivors will be left with some permanent disability.⁵ These deficits can be life changing, and have significant effects on physical, social, psychological, and financial functioning.⁶⁻⁸ Post-stroke depression (PSD) is the most common emotional disturbance,⁹ with approximately 33% of stroke survivors presenting with depressive symptoms at any time during follow up.¹⁰ Post-stroke anxiety occurs in approximately 20 – 29% of stroke survivors.^{11,12}

Although stroke can occur at any age, the majority of people understand stroke to be a disease of old age,¹³ yet approximately 25% of individuals with first ever stroke in New Zealand are under 65 years old.⁴ While there are similarities, research has shown that young and older stroke survivors report different practical and psychological problems and experiences following stroke due to being at different stages of the life course.^{14,15} Young stroke survivors are often at the stage where they are starting to form families or are already responsible for young children and have active careers,^{14,16} and may find themselves on a completely different path from their anticipated life trajectory. Reported consequences following stroke among this population include family life disruption,^{17,18} marital breakup,¹⁸ family conflict,¹⁸ altered sex life,^{14,17} social isolation,^{19,20} employment loss or disruption,^{14,18,21} altered finances,^{17,22} disruption in leisure activities,¹⁷ lack of ability to begin or re-engage with education,²³ and transport difficulties.²⁴

Despite the unique difficulties that younger stroke survivors experience, rehabilitation offered for younger stroke survivors is generally the same as older stroke survivors. Studies have found that young stroke survivors perceive assessments, interventions and rehabilitation programmes developed for older stroke survivors to be inadequate in dealing with the problems they experience,²⁵ with unmet needs for financial assistance, non-care activities, intellectual fulfilment and help in returning to work.²⁶ From this, it appears that post-stroke rehabilitation may focus on a one size fits all model

where in reality, something that works for older aged adults does not seem to be appropriate for younger stroke survivors.^{14,20}

Further, post stroke rehabilitation often exclusively focuses on physical aspects of recovery, and there is limited therapy offered for psychological difficulties, which are common post stroke.²⁷ Younger stroke survivors would benefit from age appropriate psychological support that can be tailored to their specific needs and problems experienced, with the aim of reducing their psychological distress. At the very least this would alleviate the frustration experienced by younger stroke survivors as a result of the lack of age adapted and appropriate rehabilitation services.²⁵

In addition to being young, and the increased challenges that seem to occur for younger aged stroke survivors, cultural diversities within the stroke populations may also affect the post stroke journey. Examples of cultural diversities within New Zealand may include specific national identities as outlined in a survey conducted by Colmar Brunton for the NZ Herald.²⁸ The survey found that 69% of the 1009 New Zealanders considered themselves to be easy going and laidback. This could lead to an under-reporting of problems experienced by younger stroke survivors in New Zealand, which could differ from international research.

Varying experiences of healthcare services internationally may also affect problems reported by younger stroke survivors. In a survey investigating the health care experiences in New Zealand, Australia, United States, Canada and the United Kingdom it was found that New Zealanders reported some of the uppermost levels of dissatisfaction with the healthcare system overall.²⁹ This included concerns regarding wait times for hospital care and the lack of public funding for health care.²⁹ Both of which may affect problems experienced post stroke, particularly in the area of access to community support services.

Research investigating the experiences of stroke survivors of any age in New Zealand is limited. Similar to the findings from international research, Ahuja et al.³⁰ reported common problems in the areas of loss of employment, relationship impairment, financial burden, decreased function and family burden using semi-structured interviews with 11 stroke survivors aged between 49 and 72. This study also found that stroke survivors coped with the problems resulting from stroke through family support, goal setting, and learning and accepting one's limitations.

Similarly, Dyall et al.¹ investigating the experiences of eight Māori stroke survivors, through semi-structured kanohi kit e kanohi (face to face) interviews reported problems including loss of income, change in family structure, loss of self-esteem, social isolation and withdrawal, loss of mana (prestige), and feeling whakama (embarrassed) as the head is tapu (sacred). Participants believed that their behaviour post-stroke was similar to mental illness and reported a lack of communication between health care professionals and themselves, and a lack of information and support post-stroke.

The findings from these New Zealand studies are limited because participant numbers were small, participants were over 49 years and recruitment was limited to Auckland, Canterbury, and Otago regions. Further, the frequency and severity of the problems experienced was not reported and they did not include a mixed methodology.

The Stroke Foundation of New Zealand and New Zealand Guidelines Group stated that it is important to prioritise research on New Zealand stroke rehabilitation and community support services for stroke survivors under the age of 65.³¹ They suggest that in order to ensure a personalised and heightened level of care, which enhances post-stroke rehabilitation, health professionals need to have in-depth knowledge of the problems stroke survivors' experience. The best way to understand individualised post-stroke experiences is to gather information from the stroke survivors themselves. Additionally, the Stroke Foundation of New Zealand and New Zealand Guidelines Group recommend that stroke survivors should be provided with training in active problem solving and goal setting.

For all of these reasons, it is important to conduct research into the area of younger stroke survivors, within the New Zealand context, to get a better idea of what difficulties they experience. Should problems that are specific to the New Zealand culture emerge, then post stroke rehabilitation services in New Zealand can use these findings to enhance the wellbeing of their clients.

The current study aimed to use a mixed methodology design to investigate the experiences of younger stroke survivors in New Zealand (18 to 65 years) using a nationwide online survey based on a combination of previous qualitative and quantitative research regarding the different problems that younger stroke survivors experienced internationally. Using a mixed methodology design in this way would allow for the collection of more enriching information from which to draw conclusions.³²

Method

The survey was advertised through the Stroke Foundation of New Zealand, via their online channels (e.g., Facebook and emailing list of members). Inclusion criteria were that participants must have had a stroke between the age of 18 and 65. Ethical approval was gained from the Health and Disability Ethics Committee (15/CEN/124).

The online survey was developed specifically for the study by a research team who had considerable experience working with stroke survivors and other individuals who had experienced a brain injury. The specifications of the Fleck Reading Index were followed to ensure that the readability level would be appropriate for the younger stroke survivors.³³ Items within the survey were based on a combination of previous qualitative and quantitative research regarding the problems that younger stroke survivors experienced internationally including research on family life disruption,^{17,18,34} marital breakup and family conflict,¹⁸ an altered sex life,^{14,17} employment loss or disruption,^{14,18,35} social isolation,^{19,20} altered finances,^{17,22} disruption of leisure activities,¹⁷ community support services,²⁶ provision of information post-stroke,²⁶ education and study,²³ self-esteem,^{14,19,36} invisible disabilities,^{15,19,25,37} intellectual fulfilment,^{22,26} transportation difficulties,²⁴ and difficulties forming new relationships.¹⁹ Problems with invisible difficulties was defined as “consequences of stroke that cannot be seen by an observer. Fatigue and memory difficulties are examples of invisible disabilities”.

The survey included 14 demographic items and 16 post-stroke items that they were rated on a 4-point scale (1 = not a problem at all, 2 = somewhat of a problem, 3 = a significant problem, and 4 = a major problem all of the time). Participants could list any other problems that were not included in the survey and were given the opportunity to provide qualitative examples of problems.

Responses to the survey were analysed using descriptive statistics and content analysis as many of the responses to the open questions were brief and unsuitable for thematic analysis.³⁸ Themes within the data were identified and labelled using codes, their frequencies then calculated and reported.³⁹⁻⁴¹ This was completed for each of the 17 open ended questions included in the survey; therefore codes were repeated across different survey items (e.g., “stroke symptoms” was a code used in multiple questions). The calculation of Cohen’s kappa was used to determine the observed level of agreement

between the two coders (inter-coder reliability) and was found to indicate “almost perfect” agreement ($\kappa = 0.99$).

Results

A response rate for this study could not be calculated as the survey was advertised online through social media channels of the stroke foundation, as well as word of mouth of the younger stroke survivors. One hundred and twelve questionnaires were submitted online with various degrees of completeness, i.e., 77 (68.75%) of respondents completed at least 60% of the survey. The majority of responders were female (65%) with 29 (33%) under the age of 44 years, 29 (33%) between the ages of 45 to 54, and 29 (33%) between 55 and 65. Most respondents (75%), were New Zealand European, 10% were Māori, 2% Asian, 1% Pacific Islander and 12% selected “other” as their ethnic group. These figures are slightly different to what might have been expected from Feigin et al’s.⁴² figures for younger stroke survivors in New Zealand, i.e., the average age of onset for Māori is 61 years, 64 for Pacific Islanders, and 75 for European New Zealanders. For the majority of respondents, it had been less than 5 years since their stroke (72.29%).

A series of one-way ANOVAs were conducted to determine whether there were any differences in the problems reported depending on the demographic status of participants. As shown in Table 7, a significant difference was found between the age groups (18-24, 25-34, 35-44, 45-54, and 55-65 years) for participants’ mean rating of how much they experienced marital problems. A post hoc Tukey test showed that the 25-34 year old age group ($M = 1.30$, $SD = .675$) differed significantly from the 45-54 ($M = 2.18$, $SD = .945$) year old age group. The other age groups (18-24, 35-44, and 55-65 years) were not significantly different from one another. No other significant differences were found for the relationship between demographic factors (gender, time since stroke, ethnicity and education) and problems reported.

Table 7

Results from the one-way ANOVAs conducted to calculate demographic differences in problems experienced

Problem experienced	Age group	Gender	Time since stroke	Ethnicity	Education
Invisible disabilities	$F(4,69) = .228$, $P = .922$	$F(1,71) = .097$, $P = .756$	$F(9,63) = .755$, $P = .658$	$F(4,68) = 1.938$, $P = .114$	$F(1,70) = .001$, $P = .973$
Employment loss/ disruption	$F(4,72) = 1.684$, $P = .163$	$F(1,74) = 2.143$, $P = .147$	$F(9,66) = 1.102$, $P = .374$	$F(4,71) = .30$, $P = .714$	$F(1,73) = .101$, $P = .752$
Difficulty with self esteem	$F(4,69) = .572$, $P = .684$	$F(1,71) = 2.974$, $P = .089$	$F(9,63) = 1.005$, $P = .445$	$F(4,68) = .896$, $P = .471$	$F(1,70) = .322$, $P = .573$
Difficulty with finances	$F(4,69) = 1.691$, $P = .162$	$F(1,71) = .761$, $P = .386$	$F(9,63) = 1.222$, $P = .298$	$F(4,68) = .250$, $P = .909$	$F(1,70) = .056$, $P = .813$
Reduction in leisure activities	$F(4,72) = 1.028$, $P = .399$	$F(1,74) = 1.161$, $P = .285$	$F(9,66) = .480$, $P = .883$	$F(4,71) = .836$, $P = .507$	$F(1,73) = .259$, $P = .612$
Family life disruption	$F(4,75) = 2.278$, $P = .069$	$F(1,77) = 2.255$, $P = .137$	$F(9,69) = 1.610$, $P = .130$	$F(4,74) = .473$, $P = .755$	$F(1,76) = .077$, $P = .782$
Lack of information post-stroke	$F(4,67) = 1.687$, $P = .163$	$F(1,69) = .033$, $P = .855$	$F(9,61) = 1.090$, $P = .383$	$F(4,66) = .616$, $P = .653$	$F(1,68) = .368$, $P = .546$
Limited access to community support services	$F(4,67) = 1.302$, $P = .278$	$F(1,69) = .089$, $P = .766$	$F(9,61) = .784$, $P = .632$	$F(4,66) = .735$, $P = .571$	$F(1,68) = 3.137$, $P = .081$
Difficulty returning to or beginning study	$F(4,70) = 1.594$, $P = .186$	$F(1,72) = .014$, $P = .905$	$F(9,64) = 1.431$, $P = .194$	$F(4,69) = .968$, $P = .431$	$F(1,71) = .011$, $P = .918$
Social isolation	$F(4,73) = 1.341$, $P = .263$	$F(1,75) = .003$, $P = .960$	$F(9,67) = .852$, $P = .571$	$F(4,72) = 1.417$, $P = .237$	$F(1,74) = .778$, $P = .381$
Problems with transport	$F(4,69) = .894$, $P = .473$	$F(1,71) = .270$, $P = .605$	$F(9,63) = .796$, $P = .621$	$F(4,68) = 1.172$, $P = .331$	$F(1,70) = .463$, $P = .499$
Reduced intellectual fulfilment	$F(4,68) = .588$, $P = .672$	$F(1,70) = 2.106$, $P = .151$	$F(9,62) = 1.748$, $P = .097$	$F(4,67) = 1.243$, $P = .301$	$F(1,69) = 1.101$, $P = .298$
Difficulty forming new relationships	$F(4,71) = 2.476$, $P = .052$	$F(1,74) = .009$, $P = .924$	$F(9,66) = .711$, $P = .698$	$F(4,71) = .365$, $P = .833$	$F(1,73) = .296$, $P = .588$
Intimacy problems	$F(4,74) = .977$, $P = .425$	$F(1,74) = 1.004$, $P = .320$	$F(9,68) = .349$, $P = .955$	$F(4,73) = .518$, $P = .723$	$F(1,75) = .086$, $P = .770$
Marital problems	$F(4,73) = 2.635$, $P = .041$	$F(1,75) = .353$, $P = .554$	$F(9,67) = .727$, $P = .682$	$F(4,72) = .623$, $P = .648$	$F(1,74) = 1.028$, $P = .314$
Loss of home	$F(4,69) = 1.005$, $P = .411$	$F(1,71) = .515$, $P = .476$	$F(9,63) = 1.080$, $P = .390$	$F(4,68) = 1.077$, $P = .375$	$F(1,70) = .586$, $P = .446$

The average ratings of problems (1= not a problem – 4= constant major problem) experienced by respondents are shown in Table 8. Problems with invisible disabilities was the highest rated problem with an average rating of 3.09 (SD = 0.83). Marital (M = 1.78, SD = 0.91), intimacy (M = 1.82, SD = 0.87), and loss of home (M = 1.54, SD = 0.88) were not experienced as problems (rated less than 2).

Table 8

Total number of participants, percentage who rated the problem as experienced, percentage who rated the problem as severe, moderate or mild and average ratings of problems experienced post-stroke

Post-stroke problems	N	% Exp.	Rating			Mean	SD
			Sev	Mod	Mild		
Problems with invisible disabilities	74	96	35	43	18	3.09	0.83
Employment loss or employment disruption	77	91	31	38	22	2.91	0.95
Difficulty with self esteem	74	88	23	30	35	2.64	0.97
Difficulty with finances	74	84	23	23	38	2.53	1.02
Reduction in leisure activities	77	88	13	39	36	2.53	0.87
Family life disruption	80	90	11	35	43	2.49	0.83
Lack of information post-stroke	72	71	19	26	26	2.38	1.09
Limited access to community support services	72	71	13	36	22	2.32	1.03
Difficulty returning to or beginning study	75	65	20	24	21	2.29	1.15
Social isolation	78	74	10	28	36	2.23	0.95
Problems with transport	74	58	16	28	14	2.19	1.15
Reduced intellectual fulfilment	73	77	8	25	44	2.18	0.89
Difficulty forming new relationships	77	67	8	21	38	2.03	0.93
Intimacy problems	79	56	4	19	33	1.82	0.87
Marital problems	78	50	4	21	26	1.78	0.91
Loss of home	74	23	2	3	18	1.54	0.88

Note. Rating scale: 1 = not a problem at all; 2 = somewhat of a problem; 3 = a significant problem; and 4 = a major problem all of the time

Figure 2 shows the percentage of respondents who experienced the problem. Any respondent who selected either “somewhat of a problem”, “a significant problem” or “a major problem all of the time” was included in the figure as “having experienced the problem”.

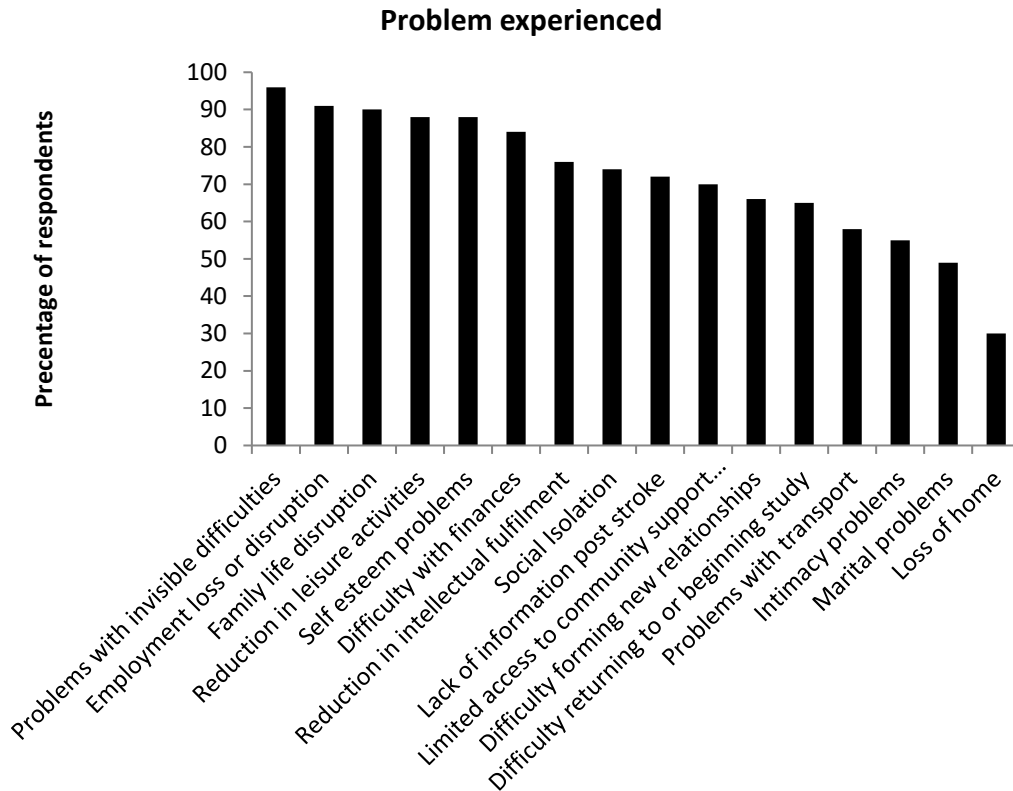


Figure 2. Percentage of respondents who experienced the problem.

Table 9 shows the coding schemes (including descriptions and examples), and the frequencies and percentages of response categories for participants’ most reported examples of problems. As some participants provided responses that fitted into multiple categories the frequencies and percentages refer to the total number of responses within each category, rather than the total number of respondents to each survey question. Further, the tables include only the main categories resulting from each question (i.e., only those categories that obtained percentages equal to or greater than 10), as according to content analysis, the most commonly occurring responses are the most relevant.⁴³

Table 9

Coding scheme and frequency of the most common response categories for participants' reported examples of problems

Code	Description	Example	Freq	%
Invisible Disabilities (N=41)				
Fatigue	Fatigue was mentioned as an invisible disability that caused problems	“Fatigue is a major one. When I get tired my body won't work properly, including my speech”	30	34.4
Cognitive symptoms	Cognitive difficulties, including memory, concentration, planning, reasoning, language, and organisation	“Memory difficulties effect me on a daily basis”	20	23.0
Lack of understanding	A lack of understanding from others about the invisible symptoms of stroke and how they affect the stroke survivor.	“I LOOK normal. People thus expect "normal". They DO NOT LISTEN when I say that I can only do 1 thing at a time, or that I NEED (not just want) something. Even my children say that I am "just making excuses"”	15	17.2
Other codes			22	25.3
Total			87	100
Employment loss or disruption (N=47)				
Hour reduction	Loss of job or reduction of hours. Or their partner gave up work to care for them	“I was working 3 part – time jobs, often 10 – 12 hr days. Now I get an invalids benefit”	22	34.4
Stroke symptoms	Post-stroke symptoms such as cognitive, communication and physical difficulties	“Due to lack of short term memory, etc... I am unable to be employed”	11	17.2
Financial strain	Reduced or no employment has resulted in financial strain on the stroke survivors and their families	“lack of Money is the biggest issue. Having to live on a benefit. It limits me having money for my 10 year old daughter who shpuld be taken to mcdonalds, swimming pools) movies etc etc. Have to limit my food and since my stroke was related to diabetes this is a major worry. No money to go to doctor, get medicines. Lack of money to pay bills which creates strrss. Have to sit ar home cause no money to take girlfriend out or to go out with mates “	10	15.6
Fatigue	The stroke survivors mentioned fatigue when providing examples of employment loss or disruption	“Finding suitable work that’s works around fatigue issues was very hard”	7	10.9
Other codes			14	21.9
Total			64	100
Self-esteem problems (N=33)				

Loss of confidence	The stroke survivors mentioned a loss of confidence, self-worth or self esteem	"I found loss of confidence very debilitating"	10	26.3
Embarrassing	The stroke survivor discussed embarrassment or feeling foolish, due to symptoms of stroke such as falling, physical attributes or the fact that they had had a stroke at a young age	"I also felt ashamed getting a stroke at my age when I had been looking after my body well ie. I was the right weight and fit. I used to feel 'invincible' but not now and this does make you feel quite vulneable"	7	18.4
Post-stroke identity	Not being the person they were before the stroke or wanting to be the person they were before the stroke, or not being able to do tasks that they could do before the stroke	"All i can remember is longing to be the person that i was prior to the stroke. When you are dealing with all these symptoms of fatigue and memory difficulties you feel like a totally different person"	5	13.1
Emotional distress	Experiences of emotional distress such as anxiety, low mood or low motivation	"Frustration with lack of progress and anxiety, the future and so on" "certainly have down times"	5	13.1
Other codes			11	28.9
Total			38	100
Difficulty with finances (N=39)				
Wage reduction	Wages cut due to loss of job, or potential earning reduced as a result of stroke at a young age	"I was earning \$75,000 a year pre Stroke to \$15,000 post Stroke"	14	41.2
Financial support	Minimal financial support available following stroke	"Supported living benefit minimal when have a family to support and lose it quickly with part time work"	6	17.6
Reliance	Having to rely on someone else for finances	"effects my wife's work as well due to being on supported living benefit. She tries to work but needs to have care for me and work enough to support my family"	5	14.7
Increased costs	Costs were increased in areas such as transport and rehabilitation	"An impact financially is the increased cost of doctors visits and medication"	4	11.8
Other codes			5	14.7
Total			34	100
Reduction in leisure activities (N=42)				
Stroke symptoms	Post-stroke symptoms including cognitive, communication and physical difficulties, fatigue and sensitivity to noise	"Plus the lack of strength of my arm and leg limits me from doing a lot as well"	33	42.3
Physical activity	Physical activities such as running, biking and sports were reduced	"I can't walk, swim or cook bake or anything I used to do very disabled"	11	14.1
Reduction in ability	No longer able to do what they did before the stroke or found activities much harder	"I go to line-dancing for exercise (just manageable. I used to dance at a higher level/stye, but can no longer do that) for exercise"	8	10.3
Other codes			26	33.3

Total			78	100%
Family life disruption (N=41)				
Reliance	Reliance on family members to take care of them, help them, or do tasks for them	“My wife needed to give up work to rehabilitate and care for me”	9	15
Financial Strain	Reduction in/or loss of employment as well as financial struggles within the family and the consequences of this	“our family was torn apart as we could no longer afford to live where we were living prior to my stroke”	8	13.3
Stroke symptoms	Symptoms of stroke disrupted family life including cognitive, communication, physical difficulties and fatigue	“as well as having aphasia and communication a big problem”	7	11.7
Family separation	Family members were separated post-stroke	“I was away from my daughter for months on end and it took most of the remaining year to regain that trust and bond with her”	7	11.7
Post-stroke identity	The stroke survivors were not the same person or were unable to do tasks the same as before. Affecting themselves, family members, employers and people in their social group	“my employer was disappointed that, the old tradesman he employed did not have the same skill level as prestroke”	6	10
Family understanding	Family members had trouble understanding what was going on for them, and because they looked normal they were expected to be ok	“As my stroke does not have any residual outside signs, my family does not understand that I have limitations”	6	10
Other codes			17	28.3
Total			60	100
Lack of information post-stroke (N=37)				
Post-stroke information	Not a lot of information available post-stroke regarding the rehabilitation process and what life will be like	“There is more information about preventing stroke, than surviving stroke and those that have survived are living lives that are frustrated, angry and no one seems to care.”	17	32.7
Inappropriate information	The stroke survivor talked about receiving information immediately after their stroke however due to the circumstances (e.g. being in the acute phase) they weren't sure of the usefulness of the information. Very little information given upon discharge from hospital and this is when the stroke survivor would have appreciated it	“A very significant problem immediately upon discharge from Hospital when I felt extremely vulnerable and most needed support. I think it's appalling that not everybody who has undergone the stroke experience and is left with disability is equally well-informed about potential help”	9	17.3
Sought own support	The stroke survivors or their family members sought their own support, which was not provided for them by post-stroke services	“Only because my wife has compensated by research has this been minimised”	6	11.5

Other codes			20	38.5
Total			52	100%
Limited access to community support services (N=33)				
Lack of help	There was a lack of help or support post-stroke	“Had hardly any help or assistance from any where. Got taxi funding to get to and from work but nothing else”	21	47.7
Other codes			23	52.3
Total			44	100
Difficulty returning to or beginning study (N=33)				
Stroke symptoms	Symptoms of stroke such as cognitive, communication and physical difficulties and fatigue made it difficult to study return to study	“I cannot cocenttrate,my vision is usually blurry and I am tired”	20	74.1
Lack of confidence	A lack of confidence in their abilities	“I’m not confident enough to start anything right now”	3	11.1
Other codes			4	14.8
Total			27	100
Social isolation (N=38)				
Social structure	The stroke survivors social structure (family and friends) had changed in some way	“You really get to see who your true friends really are. Those are the ones who stand by you and are still here today”	15	26.3
Post-stroke symptoms	Post-stroke symptoms such as cognitive difficulties, communication difficulties, fatigue and physical symptoms	“I often feel so tired and prefer to spend time on my own, sleeping rather than socializing”	13	22.8
Confidence	The stroke survivors mentioned confidence when providing examples of problems with social isolation	“Confidence”	6	10.5
Other codes			23	40.4
Total			57	100
Problems with Transport (N=40)				
Inability to drive	The stroke survivors mentioned being unable to drive	“I cannot drive, and have just recently started using the bus service - which I hate as I miss driving”	19	47.5
Reliance	Having to rely on someone else for transport	“Being dependent on others is hard. I have been fiercely independent my whole life and asking for help was never something that came easy for me. Even now, I find it very very difficult. I accept help when it is offered but not always”	10	25
Financial difficulty	Extra costs associated with an inability to drive	“had a self elected assessment which cost \$409.00 and I would never do it again...”	8	20

Other codes			3	7.5
Total			40	100
Reduction in intellectual fulfilment (N=28)				
Stroke symptoms	Post-stroke symptoms such as cognitive symptoms, fatigue and communication difficulties make it difficult to gain intellectual fulfilment	“couldn't concentrate on complex problems for too long which made me frustrated and angry that I couldn't do the things I used to. Also I can now really only deal with one complex problem at a time”	16	53.3
Post-stroke ability	Could not do tasks post-stroke the same as before their stroke	“I get e bit frustrated at not being able to do things I used to do”	5	16.7
Confidence	A lack of confidence was mentioned for problems with intellectual fulfilment	“Again loss of confidence”	3	10.0
Emotional distress	Emotional distress in situations involving intellectual fulfilment	“Still have difficulty dealin with stressful situations and if I'm given tight timeframes I am inclined to secretly panic a little”	3	10.0
Other codes			3	10.0
Total			30	100
Forming new relationships (N=34)				
Stroke symptoms	Symptoms of stroke such as cognitive and communication difficulties and fatigue can make it difficult to form new relationships	“My aphasia makes it really hard to meet new people”	11	25.6
Anxious in social interactions	Anxious in public or when making social contact	“I am conscious that people see a physical disability & a lot think you have mental problems also”	7	16.3
Confidence	The stroke survivors mentioned a lack of confidence	“I feel like my confidence has taken a hit”	5	11.6
Other codes			20	46.5
Total			43	100
Intimacy problems (N=24)				
Reduction in sex or desire	Reduced libido and interest in sex. Reduced performance such as keeping an erection, as well an as actual reduction in sex.	“Don't experience any intimate feelings”	10	37.0
Stroke symptoms	Post-stroke symptoms such as fatigue, cognitive difficulties, physical symptoms and fatigue affected interactions with others	“fear of seizure trigger and mobility challenge”	9	33.3
Other codes			8	29.6
Total			27	100
Marital Problems (N=32)				
Negative effect	The quality of personal relationships had been affected by stroke or the relationship has ended	“separated from partner after my stroke”	5	12.5

Gratitude for Partner	Gratitude for their partner	“I was lucky enough to have a partner that stuck around during to hardest and darkest moments of my stroke and recovery, as now we are stronger than ever”	4	10
Family understanding	It was difficult to get their partner to understand what was going on for them	“At times I hated her, as she pushed me hard to get better – I felt she did not understand”	4	10
Impact on livelihood	Stroke had an impact on their livelihoods such as driving and finances	“There is little financial and emotional support for us both” “and financial stress also played a factor in this”	4	10
Stroke symptoms	Marriage was effected by post-stroke symptoms such as cognitive and communication difficulties and fatigue	“I worried about how my stroke would affect her and because of my aphasia we could not talk about it”	4	10
Other codes			19	47.5
Total			40	100
Loss of Home (N=25)				
Relocate	The stroke survivor had to change their living circumstances	“We had to give up our home as we could no longer afford it after my stroke and moved in with my partners family”	10	71.43
Financial difficulties	The stroke survivor mentioned how financial difficulties impacted home ownership	“My parents have built a flat for me because I can't afford anything”	4	28.57
Total examples			14	100%
Other Problems (N=58)				
Stroke symptoms	Symptoms of stroke including cognitive, language and physical difficulties as well as fatigue	“seizures brought a whole new level of fear”	42	34.1
Emotional distress	Emotional distress or lack of coping skills	“...so i've experienced i feel every downside possible. depression, fatigue, discrimination, low self esteem, suicidal thoughts, attempts”	16	13.0
Post-stroke needs	Post-stroke needs were not met such as accessibility for disability, support groups, funding, transport, and information	“Once you are discharged from hospital you just become another statistic. There is n follow up and it is always so hard to speak to anyone other than a nurse in the stroke ward. Your GP even has difficulry talking to anyone with authority”	14	11.4
Other codes			51	41.5
Total			123	100

Discussion

The purpose of this study was to develop a deeper understanding of the problems experienced by younger stroke survivors in New Zealand using a mixed methodology study. Of the 16 problems investigated (see Table 8), 13 were reported as at least somewhat of a problem. Overall the findings of this study are predominantly supportive of international research.

The similarities to international research include younger stroke survivors experience of family life disruption,^{17,18,34} employment loss or disruption,^{14,18,35} social isolation,^{19,20} altered finances,^{17,22} disruption of leisure activities,¹⁷ a lack of community support services,²⁶ provision of information post-stroke,²⁶ difficulty re-engaging with education and study,²³ low self-esteem,^{14,19,36} invisible disabilities,^{15,19,25,37} intellectual fulfilment,^{22,26} transport difficulties,²⁴ and difficulty forming new relationships.¹⁹

While previous research has also reported that younger stroke survivors experience marital breakup¹⁸ and an altered sex life,^{14,17} the average ratings of intimacy and marital problems for the younger stroke survivors in the current study indicated that these were less of a problem. However, this finding must be interpreted with caution, perhaps the survey lacked a clear definition of intimacy or participants may have been reluctant to disclose information regarding their altered sex life in an impersonal online survey.

The findings also support the limited research from within New Zealand, in that stroke survivors experience a loss of employment, relationship impairment, financial burden, decreased function and family burden.³⁰ It also supports findings from research carried out by Dyllal et al.¹ who found reported problems included a loss of income, a change in family structure, loss of self-esteem, social isolation, limited information, a lack of communication between health care professionals and themselves, and a lack of information and support post-stroke.

Unique to this study, was the use of the mixed methodology to investigate the problems experienced by younger stroke survivors. This not only allowed for an understanding of how much of a problem each item was but provided respondents with the opportunity to offer further detail of the problems they experience. There were many different examples provided for each investigated problem, and frequencies of reported codes were not particularly high (predominantly less than 50% of the total responses per

question) highlighting that the post-stroke journey is unique to the individual and rehabilitation services should be tailored accordingly.

This study is also unique as it analysed the impact of additional demographic factors (age by group, gender, time since stroke, ethnicity and education) within the younger stroke survivor age group. With the exception of the influence of age on the extent to which marital problems are experienced, there were no other significant differences found. The fact that the participants in the 45-54 year old age bracket experienced more difficulties with marital problems than the 25-34 year old age bracket could be explained by the theory that problems may change according to the couple's developmental stage⁴⁴. For example, couples who are newly married may experience different problems than couples who have been married for an extended period of time⁴⁴. In particular married couples who are in the "middle years" stage experience problems in their marriage as a result of parental tasks including the challenges that come with taking care of adolescents⁴⁴. This is consistent with previous research that found that younger stroke survivors find it difficult to respond to the needs of their children following stroke^{34,45}, which according to the marriage developmental stage theory⁴⁴ would impact the problems experienced as a couple.

Stroke is a devastating life event that occurs unexpectedly in the life journey. From the qualitative responses, it appeared that how that journey plays out was dependent on the person's pre stroke identity or ability (i.e., what was important to them, what they enjoyed doing, where they worked, who they were), as this was referenced in responses to numerous questions. The implication of this is that health care professionals need to take the time to get to know each individual stroke survivor (including their pre and post-stroke self) in order to enhance their rehabilitation process and quality of life.

"Stroke symptoms" (physical or cognitive difficulties) was often the most frequently reported code within the examples given, accounting for more than 20% of the total number of responses within each category. This was true for examples with forming new relationships, returning to or beginning study, a reduction in leisure activities, reduction in intellectual fulfilment, problems with intimacy, problems with social isolation and as an example of other problems. The clinical implication for this is that support is needed, to assist stroke survivors on strategies to compensate for these symptoms in different post-stroke activities such as returning to employment, study and leisure activities.

An open-ended question at the conclusion of the survey asked whether the younger stroke survivors experienced any other problems not specifically inquired about in the survey. Again, physical or cognitive difficulties or fatigue symptoms were frequently mentioned thus increasing the emphasis on these areas. Emotional distress was the only other example of other problems that had a response frequency of over 10% and was not enquired about within the survey. This supports previous research which states that emotional distress is common post-stroke,⁹⁻¹² and highlights the fact that emotional distress has a significant impact on the rehabilitation process, so it should be addressed alongside other post-stroke symptoms.

“Problems with invisible disabilities” was both the highest rated problem and the only problem that was stated as a significant problem. This supports previous qualitative research, which has found that younger stroke survivors perceive their invisible symptoms to be challenging, and frustrating.^{15,19,25} This finding also contributes to the scientific literature, as there has been no quantitative research investigating the extent of which younger stroke survivors have difficulty with invisible disabilities. The quantitative element allows for an investigation into how much younger stroke survivors experience this as a problem as they are given an opportunity to rate this. Qualitative research regarding invisible disabilities only outlines this as a problem; it does not indicate how problematic the younger stroke survivors find these.

The responses to the open ended questions also provide a deeper understanding of what aspects of invisible disabilities cause the most problems for younger stroke survivors. Fatigue was the most mentioned invisible symptom; therefore, it appears to be the most challenging aspect. This supports previous research, which has found that between 35% and 95% of stroke survivors experience fatigue following stroke.⁴⁶ The finding that stroke survivors perceive a lack of understanding from others about the symptoms of their stroke also supports previous research.^{15,19,25} The mixed methodology allowed for a deeper exploration into younger stroke survivors experiences of invisible disabilities.

A strength of the current study was that participants were able to take part regardless of their level of impairment. Also, to account for cognitive difficulties and or fatigue, participants were able to complete small parts of the survey and return when they were feeling more able to carry on. Although interpretation of the qualitative data was

more difficult due to mistakes made as a result of aphasia or cognitive impairment, the inclusion of participants with these symptoms allowed for the data to be more generalizable to the stroke population.

Although this study was not restricted to certain cultures, the cultural diversity of the respondents was limited, with the predominant ethnicity of participants being New Zealand European. As there were few Māori participants and the risk of stroke is higher for Māori than New Zealand Europeans, and the average age of onset is lower for Māori, the current results may not generalise.

Perhaps the online survey was not appropriate for Māori stroke survivors. Qualitative research investigating the experiences of 16 Māori participants who had undergone a neuropsychological assessment found that the participants perceived the process as Euro-Western culture dominated and experienced cultural invisibility.⁴⁷ This meant that there was often no consideration of the participant's cultural identity, background or tikanga Māori such as the value of whakawhanaungatanga (building relationships).⁴⁷ This may have been something inherent in the current survey that prevented the participation of Māori. Although this survey was conducted online, there were certainly opportunities to increase visibility of the Māori culture, for example using Te Reo Māori throughout the survey, or including space for Māori participants to mention their iwi and to write about their whakapapa. The researcher could have also disclosed more information about herself, thus assisting the whakawhanaungatanga process.

Previous qualitative research in New Zealand (n = 8), by Dyllal et al.¹ has found that Māori stroke survivors experience a loss of mana (prestige) and that they feel whakama (embarrassed) as the head is tapu (sacred), and they believed that their behaviour post-stroke was similar to mental illness. Thus, indicating that the experience of stroke is also unique within different cultures and highlights the need for rehabilitation services in New Zealand to be more specific in relation to Māori stroke survivors and to value and uphold Māori tikanga. It is important to gather more information about the experiences of younger Māori stroke survivors in New Zealand so that rehabilitation can be tailored to their particular values and needs. Perhaps future research could investigate young Māori stroke survivors' experiences in order to develop a deeper understanding of their post-stroke journey.

This study may also be limited as participation was voluntary, resulting in a self-selected sample.⁴⁸ The respondents may have experienced problems post-stroke and therefore may have been more likely to endorse and report these problems. Stroke survivors who have not experienced problems may have chosen not to participate, thus resulting in self-selection bias, and a less representative sample of the younger stroke survivor population.⁴⁸

Implications for Clinical Practice

As problems with invisible disabilities was rated as the highest experienced problem and the respondents reported a lack of understanding from others regarding this, it could be suggested that younger stroke survivors and their support persons, family and friends would benefit from education regarding the impact of invisible disabilities post stroke. Previous research has outlined a number of difficulties that arise as a consequence of invisible disabilities. One of which is a difficulty with a lack of proof, individuals with invisible disabilities often have difficulty securing the assistance or accommodation that they need to function successfully.⁴⁹ They often have to explain their disability, because they have no visible proof.¹⁵ This not only creates discomfort for the disabled person, but it often results in them being subjected to dis-belief from the wider community.⁴⁹ Due to this lack of proof, the stroke survivors family and friends also often doubt that the stroke survivors are left with any disability and therefore hold unrealistic expectations of their capability levels.^{15, 25} These consequences can have a negative impact on the stroke survivors psychosocial functioning and can inhibit them from satisfactory community integration,^{15, 25, 49} therefore they should be discussed with the stroke survivor and their families and strategies to prevent or cope with these difficulties should be offered by rehabilitation services. The general population may also benefit from education about common invisible symptoms post stroke so that peoples' reactions to these do not impair stroke survivors' reintegration back into society.

A lack of information was a problem experienced by a large number of the younger stroke survivors in this sample. When asked to provide examples of this lack of information, many of the participants referred to the limited information given after the acute phase regarding the rehabilitation process and what life would be like post-stroke. This supports the research by Dyall et al.¹ whose participants mentioned that there was a lack of information and support post-stroke.

Participants were often presented with a lot of information in the acute phase, when in hospital and unable to understand or remember what was being said to them. The implication for this is that perhaps it is better to provide the information when the stroke survivors leave hospital and are attempting to rehabilitate back into the community (3 – 6 months post-stroke). Future research could evaluate a process by which the younger stroke survivor is given the majority of information regarding post-stroke rehabilitation once they are discharged from hospital or an inpatient unit. Alternatively, a group could be set up for people who are in this stage post stroke, who meet and are given information about the post-stroke rehabilitation process.

Pamphlets given out in the acute phase post-stroke were also mentioned as being inappropriate by the current sample for reasons such as an inability to read. Future studies could design a resource that is more user-friendly and less language dense, which includes sources of information, that are more easily digestible for someone who has recently suffered a stroke, and whose cognitive processing skills may be limited. This could include pictures, diagrams, video clips, or games.

Conclusion

Younger stroke survivors in New Zealand experience a range of different problems including employment loss or disruption, problems with invisible disabilities and family life disruption. However, as stroke is commonly seen as an older aged disease, younger stroke survivors' problems are often overlooked. Post-stroke services should endeavour to acknowledge and address these different difficulties, as well as get to know the individual stroke survivors so that they feel heard and supported and believe that their problems have been validated. Problem solving for these different difficulties should also be integrated into post-stroke services, to enhance the rehabilitation process and quality of life of the younger stroke survivors.

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**CHAPTER 11: THE EFFICACY OF PROBLEM SOLVING THERAPY TO
REDUCE POST STROKE EMOTIONAL DISTRESS IN YOUNGER (18-65)
STROKE SURVIVORS**

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The efficacy of problem solving therapy to reduce post stroke emotional distress in younger (18-65) stroke survivors

Problem solving therapy with younger stroke survivors

Original Article

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Abstract

Purpose: To investigate the efficacy of problem solving therapy for reducing the emotional distress experienced by younger stroke survivors.

Method: A non-randomised waitlist controlled design was used to compare outcome measures for the treatment group and a waitlist control group at baseline and post-waitlist/post-therapy. After the waitlist group received problem solving therapy an analysis was completed on the pooled outcome measures at baseline, post-treatment and 3-month follow-up.

Results: Changes on outcome measures between baseline and post-treatment ($n=13$) were not significantly different between the two groups, treatment ($n=13$) and the waitlist control group ($n=16$) (between-subject design). The pooled data ($n=28$) indicated that receiving problem solving therapy significantly reduced participants' levels of depression and anxiety and increased quality of life levels from baseline to follow up (within-subject design), however, methodological limitations, such as the lack of a control group reduce the validity of this finding.

Conclusions: The between-subject results suggest that there was no significant difference between those that received problem solving therapy and a waitlist control group between baseline and post-waitlist/post-therapy. The within-subject design suggests that problem solving therapy may be beneficial for younger stroke survivors when they are given some time to learn and implement the skills into their day to day life. However, additional research with a control group is required to investigate this further. This study provides limited evidence for the provision of support groups for younger stroke survivors post stroke, however, it remains unclear about what type of support this should be.

Keywords: Stroke, younger people, depression, anxiety, problem solving, therapy, perceived support

Introduction

In 2010, the worldwide prevalence of stroke was 33 million, with 16.9 million people experiencing their first stroke [1]. Stroke is the second leading global cause of death and accounts for 11.3% of total deaths worldwide [1]. Due to a combination of improvements in medical care, a deeper understanding of stroke pathology, and an aging population, an increasing number are living in the community.

Approximately one third of stroke survivors will be left with some permanent disability [2], which can be life changing. There are significant effects on physical, social, psychological, and financial functioning [3, 4, 5]. Post-stroke depression is the most common emotional disturbance [6], with approximately 33% of stroke survivors presenting with depressive symptoms at any time during follow up [7], and approximately 20 – 29% experiencing post-stroke anxiety [8, 9].

Although stroke can occur at any age, the majority of people understand stroke to be a disease of old age [10], with approximately 25% of individuals with first ever stroke under 65 years old [11, 12]. While there are similarities, research has shown that young and older stroke survivors report different practical and psychological problems and experiences following stroke due to being at different stages of the life course [13, 14].

Young stroke survivors are often at the stage where they are starting to form families or are already responsible for young children and have active careers [13, 15] and may find themselves on a completely different path from their anticipated life trajectory. Reported consequences following stroke among this population include family life disruption [16, 17], including difficulty caring for younger children [13], marital breakup [17], family conflict [17], altered sex life [13, 16], social isolation [18, 19], employment loss or disruption [13, 17, 20], altered finances [12, 16], disruption in leisure

activities [16], education [21], intellectual fulfilment [22], transport difficulties [23], and invisible cognitive disabilities and fatigue that affects engagement in age appropriate activities.

Despite the broad range of problems experienced by younger stroke survivors, rehabilitation often focuses exclusively on the physical aspects of recovery [24, 25]. Further, rehabilitation offered for younger stroke survivors is generally the same as older stroke survivors and studies have found that young stroke survivors perceive assessments, interventions and rehabilitation programmes developed for older stroke survivors to be inadequate in dealing with the problems they experience [25].

Singhal et al. [20] highlight the need for research that investigates factors that can reduce the burden of stroke on young people. However, to date, there are no randomized controlled studies addressing the effect of interventions aimed at reducing distress in younger stroke patients, a fact that has been recognized and acknowledged in previous research [13, 26]. The Stroke Foundation of New Zealand and New Zealand Guidelines Group [27] stated that it is important to prioritise research on New Zealand stroke rehabilitation and community support services for stroke survivors under the age of 65.

Further, when treatment has focused on psychological issues in older stroke survivors, the majority of treatments for depression and anxiety in stroke have focused on the use of antidepressants [28, 29, 30, 31]. Although previous research has found antidepressants to be effective in treating and preventing post-stroke depression [29, 32] and post-stroke anxiety [28], intolerance to antidepressants, failure to respond, potential side effects, and reduced treatment adherence [33] suggests the need for research into the efficacy of non-pharmacological interventions [26].

The importance of improving problem solving skills following brain injury has been highlighted in previous research from neuropsychological rehabilitation studies [34,

35, 36, 37, 38]. Problem solving therapy is designed to teach individuals to problem solve more effectively so they can cope better with problems that arise in their day to day lives [39]. This has produced promising results for alleviating emotional distress in older stroke survivors. For example, Robinson et al. [40] found that a placebo group was 4.5 times more likely to develop depression than participants who received escitalopram, and 2.2 times more likely to develop depression than participants who took part in problem solving therapy. Likewise in examining generalized anxiety disorder, Mikami et al. [41] reported that a placebo group was 4.95 times more likely to develop generalized anxiety disorder than the escitalopram group and 4.00 times more likely than the problem solving therapy group.

In further work, Hadidi et al. [42] randomly assigned 22 stroke survivors (55 - 89 years) to a problem solving therapy group or a control group (care as usual), and found that subsyndromal depression at baseline reduced from 91% (treatment group) and 73% (control group) to 30% and 60% respectively ten weeks later, based on a cut-off score of 5 on the Centre for Epidemiological Studies Depression Scale (CES-D). Although the differences between groups did not reach statistical significance, the drop from a mean CES-D score of 8.7 to 3.1 in the treatment group was deemed to be clinically significant compared to no change in the scores on the CES-D control group (baseline = 7.8 vs. end of treatment = 7.8). Participants were also asked to rate the helpfulness of the problem solving therapy, 83% found problem solving therapy to be “helpful” or “extremely helpful” and 81% reported that they felt “confident” or “very confident” in using problem solving therapy to resolve issues.

Using functional magnetic resonance imaging (fMRI) Hadidi et al. [43] reported increased bilateral amygdala activity in the problem solving therapy intervention group but decreased in the control group (who received weekly stroke education sessions). The

increase in activity was correlated with a reduction in depression scores, which was postulated to be due to the rejuvenation of emotional reactivity systems (located in the amygdala) that had previously been blunted.

In summary, younger stroke survivors experience unique problems following stroke that cause significant distress. Problem solving therapy has been found to be effective in treating post stroke emotional distress in older stroke survivors but has not been specifically tried with stroke survivors under the age of 55.

The aim of the current study was to determine whether problem solving therapy is effective for reducing post stroke emotional distress in younger stroke survivors (aged 18-65 at time of stroke). A waitlist control was used to control for spontaneous remission and the natural passing of time [44]. It was hypothesised that problem solving therapy would be associated with greater improvements in symptoms of depression and anxiety, effective problem solving skills and quality of life, than in a waitlist control condition. It is also hypothesised that the within-subject design would show significant improvements in outcome measures for participants from baseline to follow-up.

Method

Ethics. Ethical approval was gained from the Health and Disability Ethics Committee (15/CEN/124). The study was also registered with the Australian New Zealand Clinical Trials Registry (ANZCTR), registration number: 12615000840583.

Design. A non-randomised waitlist controlled design was used as shown in Figure 3. In the between subject condition, Time 1 (pre-waitlist/pre-treatment condition) was compared to Time 2 (post-waitlist/ post-treatment).

The two groups were then collapsed into a single treatment group in a within-subject condition comparing Time 1 (post-waitlist/pre-treatment), Time 2 (post-treatment) and Time 3 (3-month follow-up).

Participants. Participants were younger stroke survivors who had experienced a stroke between the ages of 18 and 65 years, within six months to three years of the current study. This did not have to be participants' first stroke, they did not have to have received a formal diagnosis of depression and or anxiety and functional impairment was not formally documented. Simply, participants were experiencing symptoms of depression or anxiety or felt that their quality of life had been affected as a result of their stroke. Participants were excluded if they were could not engage in group therapy.

Sample size and Power. To provide a power of 80% at a two-sided 5% level of significance, the study required 14 participants in each group (waitlist control group and treatment group). This is based on research by Hadidi et al. [42] who conducted a pilot study examining the feasibility of problem solving therapy for stroke survivors. The study reported a Cohen's d value of 0.8 when they compared differences between groups in depressive symptoms.

Recruitment Procedure. As outlined in Figure 3, recruitment in Wellington and Tauranga involved eligible participants who were selected from a search of hospital

records of stroke survivors admitted within the previous six months to three years. No consideration was given to participants' level of physical, cognitive or psychological functioning, as it was intended that this would be assessed during the initial interview. Potential participants were then posted information packs and direct contact was made only when consent forms were returned. Additional participants ($n=2$) were members of a younger stroke survivor Facebook group in Tauranga who had taken part in a previous online survey study.

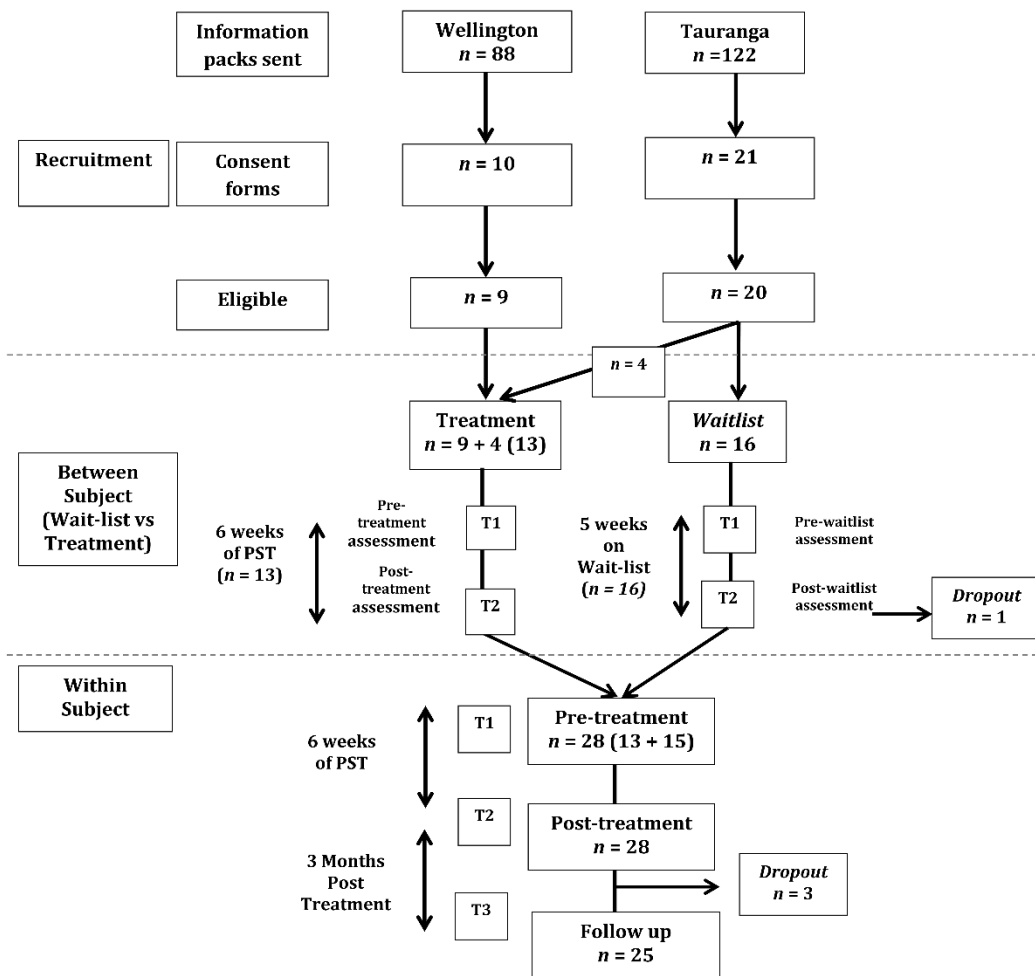


Figure 3. Participant recruitment and allocation to groups for within and between subjects.

Note. T1-T3 represent the points at which the waitlist and treatment group members were assessed. The assessment measures used at each time point were the Center for Epidemiologic Studies Depression Scale (CES-D), the Hospital Anxiety and Depression Scale – Anxiety sub-scale (HADS – A), the Stroke Specific Quality of Life Scale (SS-QOL), the Social Problem-Solving Inventory-Revised: Short Form (SPSI-R:S).

Measures

Depression. The Center for Epidemiologic Studies Depression Scale (CES-D) is a 20 item self-report questionnaire used to determine the severity and frequency of depressive symptoms during the past week [45]. Shinar et al. [46] validated the instrument with a sample of stroke survivors and reported high inter-rater reliability ($r =$

.76, $p < .001$), sensitivity (73%) and specificity (100%). The CES-D has been suggested to be a valid tool for differentiating between symptoms of depression and symptoms resulting from stroke [47].

Anxiety. *The Hospital Anxiety and Depression Scale – Anxiety sub-scale (HADS – A)* is a self-report questionnaire that consists of two subscales made up of seven items that measure depression and anxiety [48]. Internal reliabilities on the HADS-A and the HADS-depression subscale have ranged from acceptable to excellent, for both community adults and chronically ill individuals worldwide. Cronbach's α has been found to range between .68 and .93 for the HADS-A and between .67 and .90 for the HADS-D [49]. The HADS has also shown adequate concurrent validity when compared with other measures of anxiety and depression (e.g., Beck Depression Inventory and Spielberger's State-Trait Anxiety Inventory). Correlations ranged from .49 to .83 [49].

Quality of life. The Stroke Specific Quality of Life Scale (SS-QOL) consists of 49 items and covers 12 domains: energy, family, roles, language, mobility, personality, self-care, social roles, thinking, upper extremity function, vision, and work/productivity [50]. Internal reliability of the domains was found to be high with Cronbach's α scores equal to or greater than .73 [50] and test-retest reliability, internal consistency, construct, and convergent validity adequate to excellent in participants with stroke [51, 52].

Problem Solving. The Social Problem-Solving Inventory-Revised: Short Form (SPSI-R:S) [53] is a 25 item questionnaire, which measures five domains of social problem solving: positive problem orientation, negative problem orientation, rational problem solving, impulsivity/carelessness style, and avoidance style. Elevated domain scores indicate a greater use of that problem solving skill. Test re-test reliability on the SPSI-R:S has been found to be adequate ($r = .79$) as well as internal consistency (Cronbach's $\alpha = .85$), with strong structural and convergent validity [53]. The

psychometric properties of the SPSI-R:S have been examined using 219 university students [54] with reliability and convergent and divergent validity of the scale reported as adequate to excellent.

Feedback Forms. Two types of feedback forms (individual session forms and overall session forms after session six) including open and closed questions, assessed the efficacy of problem solving therapy. An independent researcher gathered the feedback forms to increase anonymity and therefore reduce the likelihood of grateful testimonials.

The individual session feedback forms created for the study asked participants to indicate how much they agreed with the statements “*I ENJOYED this problem solving therapy session*” and “*This Problem solving therapy session was HELPFUL*”. Answers ranged from 0 = strongly disagree to 4 = strongly agree. Open-ended questions were used to determine in what way sessions were helpful, what was found to be unhelpful and to generate any comments or suggestions that the participants had about the sessions.

The overall feedback form asked participants to identify which step of problem solving therapy they found most and least helpful and to indicate how much they agreed with the statement “*I will use Problem solving therapy in the future to resolve issues*”. Answers ranged from 0 = strongly disagree to 4 = strongly agree.

Procedure

Demographic information and baseline data were collected by the principal investigator during the initial assessment session.

Six group sessions of problem solving therapy were run with five groups of 4-8 participants, the first two sessions running 90 minutes and the last four approximately 60 minutes. Assessment points for the between subjects and the within-subject design are outlined in Figure 3.

The therapy structure followed that outlined by Mynors-Wallis [39], but was adapted to fit within a group setting. As it was anticipated that group discussions would increase the time taken to learn each step, the first six steps (problem solving therapy explanation and rationale, problem definition, goal setting, solution generation, solution selection, and action plan implementation) were spread over the first two sessions (similar to Hadidi et al's. [42] study of stroke survivor participants). Evaluation (step 7) occurred at the beginning of the third session.

Results

Baseline characteristics of participants are shown in Table 10. At the time of the study participants were aged between 22 and 67 years, with the majority between the ages of 55-65 (48.3%), 27.6% between 45 and 54, and 6.8% under the age of 44. The average age at time of stroke was 54.86 years (SD = 9.38).

Most lived in their own home (72.4%), some in a rented home (24.1%) and 3.4% in their parents' home. Almost half as many participants were employed after the stroke (44.8%), compared to before (86.2%). The majority were not seeing a psychologist (n = 27) and one participant was currently taking antidepressants. According to the participants' self-reports, 65.5% had earlier experienced aphasia and 51.7% physical difficulties as a result of the stroke. Of the 65.5% who stated they had experienced aphasia, only 2 participants indicated that this would interfere with their participation in therapy; therefore, they were accompanied by a support person who compensated for any major difficulties. It must be noted that no formal testing was completed to ascertain participants' level of functional impairment.

Table 10*Baseline Characteristics*

Variables	Total <i>n</i> = 29	Waitlist Control (<i>n</i> = 16)	Treatment (<i>n</i> =13)
Age Mean (SD)	56.34 (9.57)	55.50 (11.56)	57.38 (6.69)
<u>Time since stroke <i>n</i> (%)</u>			
6-12 Months	6 (20.7)	4 (25.0)	2 (15.4)
1-2 Years	16 (55.2)	8 (50.0)	8 (61.5)
2-3 Years	7 (24.1)	4 (25.0)	3 (23.1)
<u>Gender <i>n</i> (%)</u>			
Male	17 (58.6)	11 (68.8)	6 (46.2)
Female	12 (41.4)	5 (31.3)	7 (53.8)
<u>Education <i>n</i> (%)</u>			
12 + yrs	9 (31)	0	9 (69.2)
≤ 12 yrs	20 (69)	16 (100)	4 (30.8)
<u>Marital status <i>n</i> (%)</u>			
Married/Defacto	20 (69.0)	11 (68.8)	9 (69.2)
Widowed	2 (6.9)	0	2 (15.4)
Divorced/separated	2 (6.9)	0	2 (15.4)
Single	4 (13.8)	4 (25.0)	0
Other	1 (3.4)	1 (6.3)	0
<u>Ethnicity <i>n</i> (%)</u>			
NZ European	21 (72.4)	11 (68.6)	10 (76.9)
Māori	5 (17.2)	5 (31.3)	0 (00.0)
Pacific Island	2 (6.9)	0	2 (15.4)
Asian	1 (3.4)	0	1 (7.7)
<u>Instruments</u>			
	Mean (SD)	Mean (SD)	Mean (SD)
CES-D	16.79 (9.88)	16.81 (6.79)	16.77 (13.05)
HADS-A	6.59 (4.31)	6.56 (2.99)	6.62 (5.67)
SS-QOL	177.41 (43.38)	173.25 (45.38)	182.54 (42.03)
SPSI-R:S	99.76 (19.49)	95.94 (18.71)	104.46 (20.13)

Data exploration. Data exploration indicated that all data were normally distributed except for the HADS-A (waitlist group) and the SPSI-R:SF (treatment group). Homogeneity of variance tests indicated that there was a significant difference between groups for the HADS-A. No outliers were identified.

Table 11

Means and Standard Deviations for control and treatment group across baseline and time 2

Measure	Control Group Baseline Pre-waitlist	Control Group Time 2 Post-waitlist	Treatment Group Baseline	Treatment Group Time 2
CES-D	16.81 ± 6.79 (n = 16)	14.75 ± 9.08 (n = 16)	16.77 ± 13.05 (n = 13)	15.46 ± 14.56 (n = 13)
HADS-A	6.56 ± 2.99 (n = 16)	6.13 ± 3.72 (n = 16)	6.62 ± 5.67 (n = 13)	6.69 ± 5.45 (n = 13)
SS-QOL	173.25 ± 45.38 (n = 16)	179.75 ± 45.65 (n = 16)	182.54 ± 42.03 (n = 13)	195.62 ± 33.27 (n = 13)
SPSI- Total	95.94 ± 18.71 (n = 16)	98.13 ± 16.52 (n = 15)	104.46 ± 20.13 (n = 13)	99.08 ± 20.69 (n = 12)
SPSI-PPO	102.13 ± 23.34 (n = 16)	97.40 ± 17.66 (n = 15)	109.77 ± 19.53 (n = 13)	98.00 ± 22.94 (n = 12)
SPSI-NPO	105.75 ± 18.93 (n = 16)	100.80 ± 18.76 (n = 15)	100.92 ± 23.47 (n = 13)	97.00 ± 19.89 (n = 12)
SPSI-RPS	103.19 ± 20.99 (n = 16)	96.53 ± 17.72 (n = 15)	104.54 ± 16.29 (n = 13)	98.25 ± 21.81 (n = 12)
SPSI-ICS	112.75 ± 23.34 (n = 16)	102.00 ± 18.00 (n = 15)	99.85 ± 22.38 (n = 13)	100.00 ± 15.92 (n = 12)
SPSI-AS	104.81 ± 22.16 (n = 16)	101.47 ± 15.83 (n = 15)	100.08 ± 18.34 (n = 13)	103.83 ± 17.64 (n = 12)

Note: The possible range on outcome measures are as follows; CES-D 0-60; HADS-A 0-21; SS-QOL 49-245; SPSI-Total 29-140; SPSI-PPO 47-135; SPSI-NPO 74-146; SPSI-RPS 56-137; SPSI-ICS 73-162; SPSI-AS 76-157.

Treatment group versus waitlist control group. Table 11 includes the means and standard deviations on all outcome measures for both groups at baseline and at time 2. A mixed design ANOVA was used to examine the interaction between group and outcome interval on the four outcomes measures. As shown on Table 12 there were no significant interactions i.e., the groups changed similarly between pre-waitlist/pre-

treatment (baseline) and post-waitlist/post-treatment (time 2) on the CES-D, HADS-A, SPSI-R:SF (including subscales) and the SS-QOL.

In addition, the main effect of outcome interval and the main effect of group were investigated for each outcome measure, in order to determine the effects of the independent variable on the dependent variable at baseline and time 2. Table 12 also demonstrates that there were no main effects within the current study.

Table 12*Results from the Mixed Design ANOVA*

Measure	Interactions (Outcome Interval x Group)	Main effect of Outcome Interval	Main effect of group
CES-D	$F(1,27) = .064,$ $P=.802, \eta p2 = .002$	$F(1,27) = 1.273,$ $P=.269, \eta p2 = .045$	$F(1,27) = .008,$ $P=.931, \eta p2 = .000$
HADS-A	$F(1,27) = .157,$ $P=.695, \eta p2 = .006$	$F(1,27) = .077,$ $P=.783, \eta p2 = .003$	$F(1,27) = .040,$ $P=.842, \eta p2 = .001$
SS-QOL	$F(1,27) = .264,$ $P=.612, \eta p2 = .010$	$F(1,27) = 2.34,$ $P=.138, \eta p2 = .080$	$F(1,27) = .759,$ $P=.391, \eta p2 = .027$
SPSI-Total	$F(1,25) = 2.760,$ $P=.109, \eta p2 = .099$	$F(1,25) = 1.632,$ $P=.213, \eta p2 = .061$	$F(1,25) = .710,$ $P=.408, \eta p2 = .028$
SPSI-PPO	$F(1,25) = .329,$ $P=.571, \eta p2 = .013$	$F(1,25) = 2.755,$ $P=.109, \eta p2 = .099$	$F(1,25) = .257,$ $P=.617, \eta p2 = .010$
SPSI-NPO	$F(1,25) = .194,$ $P=.663, \eta p2 = .008$	$F(1,25) = 1.290,$ $P=.267, \eta p2 = .049$	$F(1,25) = .478,$ $P=.496, \eta p2 = .019$
SPSI-RPS	$F(1,25) = .032,$ $P=.859, \eta p2 = .001$	$F(1,25) = 2.379,$ $P=.136, \eta p2 = .087$	$F(1,25) = .177,$ $P=.678, \eta p2 = .007$
SPSI-ICS	$F(1,25) = 3.702,$ $P=.066, \eta p2 = .129$	$F(1,25) = .450,$ $P=.508, \eta p2 = .018$	$F(1,25) = 2.087,$ $P=.161, \eta p2 = .077$
SPSI-AS	$F(1,25) = 1.584,$ $P=.220, \eta p2 = .060$	$F(1,25) = 1.235,$ $P=.277, \eta p2 = .047$	$F(1,25) = .080,$ $P=.779, \eta p2 = .003$

Note: $\eta p2$ = partial eta squared.

The results suggest that problem solving therapy had very little effect on depression and anxiety symptoms between baseline and time 2, with only a slight reduction after therapy on the CES-D and no reduction on the HADS-A. The control group reduced more than the treatment group on these measures. The increase on the SS-QOL for the treatment group was greater than the control group, however, this was not significant. Problem solving therapy did not improve participants' total problem solving,

positive problem orientation, rational problem solving, impulsive/careless problem solving, or avoidant problem solving between baseline and time 2, however it did improve participants' negative problem orientation. Being on the waitlist control improved participants' total problem solving, negative problem orientation, impulsive/careless problem solving and avoidant problem solving, however it did not improve their positive problem orientation and rational problem solving.

Pre-Post-Follow-up changes in the combined problem solving therapy

sample. The waitlist control group and treatment group were then combined, and a one-way repeated measures ANOVA used to examine whether there were any significant changes on each outcome measure, from baseline to post-treatment to follow-up. Note that the baseline data for the waitlist control group came from their post waitlist outcome measures.

Table 13 includes the means and standard deviations on all outcome measures for the combined problem solving therapy group across the three time points.

Table 13

Means and Standard Deviations for combined problem solving therapy treatment group across baseline to follow-up for the treatment group

Measure	Treatment Group Baseline	Treatment Group Time 2	Treatment Group Follow-up
CES-D	15.93 ± 10.97 (n = 28)	15.00 ± 11.92 (n = 28)	13.00 ± 10.14 (n = 25)
HADS-A	6.39 ± 4.69 (n = 28)	6.00 ± 4.64 (n = 28)	4.32 ± 4.12 (n = 25)
SS-QOL	184.29 ± 40.25 (n = 28)	196.61 ± 32.30 (n = 28)	197.75 ± 39.84 (n = 24)
SPSI-Total	101.41 ± 18.48 (n = 27)	99.63 ± 17.90 (n = 27)	100.84 ± 18.04 (n = 25)
SPSI-PPO	103.48 ± 19.54 (n = 27)	102.67 ± 20.45 (n = 27)	98.00 ± 16.25 (n = 25)
SPSI-NPO	99.52 ± 19.79 (n = 27)	98.93 ± 15.71 (n = 27)	95.72 ± 18.63 (n = 25)
SPSI-RPS	100.00 ± 17.52 (n = 27)	100.93 ± 20.40 (n = 27)	96.64 ± 19.18 (n = 25)
SPSI-ICS	100.85 ± 20.15 (n = 27)	102.56 ± 17.05 (n = 27)	97.80 ± 18.15 (n = 25)
SPSI-AS	100.89 ± 17.05 (n = 27)	103.07 ± 17.10 (n = 27)	99.44 ± 14.31 (n = 25)

Note: The possible range on outcome measures are as follows: CES-D 0-60; HADS-A 0-21; SS-QOL 49-245; SPSI-Total 29-140; SPSI-PPO 47-135; SPSI-NPO 74-146; SPSI-RPS 56-137; SPSI-ICS 73-162; SPSI-AS 76-157.

Depression. A one-way repeated measures ANOVA indicated a significant time effect between baseline and time 3, Wilks' Lambda = .666, $F(2,23) = 5.757$, $p < .01$, $\eta^2 = .334$. The 95% confidence interval for the effect of time on depression levels is between 1.62 and 6.62 percent. Follow up comparisons of each pairwise difference indicated that the reduction in depression scores was significant between baseline and time 3. There was no significant difference between baseline and time 2, and time 2 and time 3.

Anxiety. A one-way repeated measures ANOVA indicated a significant time effect between baseline and follow up, Wilks' Lambda = .706, $F(2,23) = 4.780$, $p < .05$, $\eta p^2 = .294$. The 95% confidence interval for the effect of time on anxiety levels is between .68 and 3.63 percent. Follow up comparisons of each pairwise difference indicated that the reduction in anxiety scores was significant between baseline and time 3, but not between baseline and time 2, or time 2 and time 3.

Quality of life. A significant increase from baseline to time 3 was found, Wilks' Lambda = .702, $F(2,22) = 4.677$, $p < .05$, $\eta p^2 = .298$. The 95% confidence interval for the effect of time on quality of life levels is between 5.35 and 27.32 percent. Follow up comparisons of each pairwise difference indicated that the increase in quality of life scores was significant between baseline and time 3, but not between baseline and time 2, (although this was almost significant), or time 2 and time 3.

Problem Solving. There was no significant change indicated between baseline and time 3 on overall problem solving, (Wilks' Lambda = .961, $F(2,22) = .445$, $p = .646$, $\eta p^2 = .039$), positive problem orientation, (Wilks' Lambda = .985, $F(2,22) = .167$, $p = .847$, $\eta p^2 = .015$), negative problem orientation, (Wilks' Lambda = .922, $F(2,22) = .929$, $p = .410$, $\eta p^2 = .078$), rationale problem solving style, (Wilks' Lambda = .954, $F(2,22) = .527$, $p = .598$, $\eta p^2 = .046$), impulsive/carelessness problem solving style, (Wilks' Lambda = .953, $F(2,22) = .541$, $p = .590$, $\eta p^2 = .047$), avoidant problem solving style, (Wilks' Lambda = .917, $F(2,22) = 1.001$, $p = .384$, $\eta p^2 = .083$).

Feedback Forms

Individual session feedback forms. As shown on Table 14, the average rating of overall enjoyableness across all 6 sessions ($M = 3.41$ $SD = .655$) was slightly higher than the average rating of helpfulness ($M = 3.32$, $SD = .710$).

Table 14

Mean and Standard Deviation of participants' ratings of helpfulness and enjoyableness of each therapy session

Session	Helpful	Enjoyable
Session 1 (n=27)	3.26 ± .712	3.26 ± .656
Session 2 (n=26)	3.31 ± .679	3.38± .571
Session 3 (n=20)	3.40 ± .503	3.55 ± .510
Session 4 (n=20)	3.25 ± .910	3.40 ± .940
Session 5 (n=23)	3.26 ± .915	3.39 ± 722
Session 6 (n=25)	3.44 ± .507	3.52 ± .510

Note. The possible ratings are as follows: 0 = strongly disagree, 1 = disagree, 2 = neither agree nor disagree, 3 = agree, and 4 = strongly agree

Overall feedback forms. Participants were also asked to rate which of the seven problem solving steps was most helpful and how likely they were to use the problem-solving steps in the future, as shown in Table 15. Just over half of the participants (52%) stated that they strongly agreed with the statement “I will use Problem solving therapy in the future to resolve issues”, 44% stated that they agreed with the statement and 4% stated that they neither agreed nor disagreed with the statement.

Table 15

Frequency and percentage response distributions of each Problem Solving Therapy step as rated as most and least helpful

Problem solving step	Most Helpful	Least Helpful
Explanation and rationale	2 (8.3%)	6 (26.1%)
Problem definition	4 (16.7%)	2 (8.7%)
Establishing goals	4 (16.7%)	0 (0%)
Generating Solutions	6 (25.0%)	0 (0%)
Evaluating and choosing solutions	2 (8.3%)	1 (4.3%)
Implementing the solution	0 (0%)	2 (8.7%)
Evaluation	3 (12.5%)	5 (21.7%)
All steps were helpful	3 (12.5%)	NA
None were unhelpful	NA	7 (30.4%)

Discussion

Between-subject discussion. Statistical analysis of the between-subject results demonstrated that there was no significant difference in improvements on outcome measures from baseline to time 2 between the waitlist control and treatment group. Contrary to the hypotheses then, these results suggest that there were no apparent benefits of receiving problem solving therapy when evaluated against a waitlist control group.

One possible explanation for this involves the theory of perceived support, which describes an individual's confidence in the fact that adequate support will be available when needed [55], thus making unsolved problems appear less threatening [56]. Research has demonstrated that perceived social support is a strong protective factor for depression and anxiety [57]. As this is a population who report a lack of support post stroke [13, 18,

19, 24, 25], it is possible that the anticipation that support would be available in due course helped to alleviate distress for the waitlist participants.

This supports the problem solving theory of distress [58], which states that when problems become overwhelming, and ineffective problem solving is employed, emotional distress will result. However, if problems can be made to seem less overwhelming due to effective problem solving, then a positive adjustment will occur. It could be suggested that even just agreeing to partake in this study acts as a step towards effective problem solving for the waitlist control group and as a consequence, their distress decreased. Other factors should also be considered for the improvements seen in the waitlist, including the passage of time and spontaneous recovery.

It must be noted that the between-subject result did not include a follow-up measurement as the two groups were combined for the within-subject analysis. Should this study have kept the two groups separate and included a follow-up measurement; the results may have demonstrated a significant difference between the groups. It may have taken a while for the treatment group to learn and apply the skills to their day to day lives, and therefore the resulting positive effects may have taken some additional time to emerge [59].

Within-subject discussion. Within-subject hypotheses regarding the significant decreases in depression and anxiety and the significant increase in quality of life of the treatment group were confirmed. This is consistent with previous research, which found that problem solving therapy is an effective intervention for stroke survivors [40, 41, 42, 43, 59]. Unique to this study was the investigation of the efficacy of psychotherapy with younger stroke survivors, which has not been studied in previous research. The aim of the study was to tailor the group therapy sessions to the younger

stroke survivors needs by focusing on the problems they reported. Furthermore, treatments for anxiety post stroke in all age groups have received much less attention [60], therefore the current study contributes to the limited literature regarding treatments for this.

The significant improvements in depression, anxiety, and quality of life emerged at the three month follow up assessment for each of these three outcomes. It has been suggested that learning based interventions may take some time to impact psychosocial variables, thus resulting in improvements months after treatment has finished [59]. Problem solving therapy is a learning based intervention that aims to teach participants a more effective way to problem solve. In addition to the time taken to learn these skills, problems in participants' lives may take a while to resolve. Once problems are solved, this can lead to experiences of self-mastery and self-control which can result in positive feelings and alleviation of distress [61]. This is something that may have happened between post-treatment and follow up once the participants had additional time to continue working through their problems.

There was no improvement in problem-solving skills following problem solving therapy, an intervention designed to target these skills. This is congruent with a recent study by Visser et al. [59] whose participants experienced no improvement in problem-solving skills following problem solving therapy. The author suggests that perhaps the intervention improves problem solving therapy in a broader sense with regards to coping and not just a specific skill set for problem solving. Unfortunately, coping was not measured within the current study and is a limitation of this research. The average scores on the SPSI-R:SF and its subscales all fell within the normative group average for both groups, across each of the different time points. The fact that the group members'

problem solving scores were already in the normal range, to begin with, may be an explanation for the lack of significant improvement in problem solving skills.

Limitations. Due to the participant localities, participants were not randomly assigned to the waitlist or the control group, therefore this study cannot be classed as a randomised controlled trial, which is known as the gold standard for intervention trials [62]. This is a limitation as for when participants are not randomly allocated to groups there is the potential for selection bias. Further, as any unidentified confounding participant and/or environment characteristics were not evenly distributed across the two groups, it would have been difficult to ascertain whether any improvements were due purely to the therapeutic intervention of interest.

For the between-subject analysis, a waitlist control group was selected as the comparison group due to the ethical implications of withholding a possibly beneficial treatment from the younger stroke survivors [63]. Although the waitlist control group reduces threats to internal validity by controlling for history, maturation and spontaneous remission of participants as time passes, other potential confounding variables such as therapist attention, social support or placebo effects were not controlled [44]. The use of an attention-placebo condition, a social control group or another type of psychotherapy (e.g., Cognitive Behavioural Therapy or Acceptance Commitment Therapy) could help control for these extraneous explanations.

The within-subject analyses include a number of methodological limitations. The lack of a true control group means that it is impossible to determine whether the improvements of participants was due to the treatment itself rather than other extraneous factors, such as a result of spontaneous functional recovery or the moderating impact of other environmental and emotional changes. The passing of time must also be considered

as an explanation for improvements between baseline and follow up for the within-subject analysis. Confounding variables mentioned in the previous paragraph, such as history and maturation were not controlled for, and therefore may have resulted in participant improvements.

The baseline analysis demonstrated that there were no significant differences between groups with the four outcome measures or the majority of the group demographics. However, significant differences between groups were found for ethnicity and education. This could have been problematic as previous research has demonstrated that higher education levels are related to greater improvements in therapy [64] and that ethnicity can affect treatment outcomes with ethnic minorities generally experiencing fewer improvements than non-minorities [65].

Although younger stroke survivors were defined as individuals between the ages of 18 and 65 for the current study, it must be noted that there may be a vast difference in the needs of age ranges within this. For example, the needs of an 18-year-old, a 45-year-old and 65-year-old may differ greatly. Further research should be conducted which breaks down the current studies' age range even further to determine specific needs of these age groups. It can then be investigated which treatment approaches work best for the respective age groups.

An additional limitation of this study is the criteria used for inclusion of participants. It is recognised that in the introduction it is stated that PST needs to be tested in younger stroke survivors under the age of 55. This was the original aim of this study, however, after initial consultation with the local hospital, and the anecdotal information that approximately 15% of stroke survivors are under the age of 55, it was decided that the inclusion criteria would be expanded to age 65. Due to further recruitment difficulties

as a result of limited numbers of stroke survivors under the age of 65 in Tauranga and Wellington, the criterion was made to be even broader. For example, participants were included in the study if they experienced symptoms of depression or anxiety and did not have to meet the full diagnostic criteria for these disorders. This highlights the challenge of conducting research with younger stroke survivors. Additionally, functional impairment and number of strokes were not objectively measured, documented or included in statistical analyses. A broad inclusion criterion in research does not provide evidence for the effectiveness of treatment in specific subgroups.

The decision to include participants was often based on participants' subjective reports rather than objective evidence of distress. Therefore, the participants' baseline scores on the HADS-A and the SPSI-R:SF should also be considered. The mean score on HADS-A for both groups was lower than the cut-off score used to indicate mild anxiety (8-10) [39] and the SPSI-R:S total scores, as well as each of its 5 subscales, all fell within the normal ranges for problem solving (86-114) [44]. Therefore, the participants would not meet a diagnosis of anxiety and their problem solving would be deemed to be sufficient. Perhaps there was not much opportunity for problem solving therapy to influence these measures. Although the CES-D was the primary measure for the current study, and the inclusion criteria were for participants who had symptoms of depression and anxiety, not a full diagnosis, future studies should include participants who meet the criteria for the disorders that they are trying to measure in order to get a true sense of the efficacy of problem solving therapy.

There were two participants who were recruited via Facebook. These two participants joined the waitlist group as they resided in Tauranga, therefore participants recruited via social media were not equally distributed between the two groups. Recruitment via Facebook is potentially problematic as it introduces additional selection

biases into the study. Following this recruitment procedure may have meant that the current study was over-represented by those individuals who spend a large amount of time involved in social media communities. The use of Facebook when recruiting for studies of this nature also limits the studies accessibility to those who have access to and can use a computer and the Internet.

When examining the within-subject results it is difficult to disentangle what was actually helpful to the younger stroke survivors. There are a number of factors that may have been helpful. Simply having the presence of a therapist may have reduced the participants' symptoms of depression and anxiety and increased quality of life [66]. In addition, the social support provided by the group environment may have resulted in beneficial effects as research has found that younger stroke survivors experience social isolation post stroke due to physical and cognitive symptoms [18], feelings of being misunderstood [19] and difficulty forming relationships [18]. Research has demonstrated that social isolation often contributes to the development and maintenance of depression in stroke survivors [67]. The group environment within the current study may have promoted social interaction, reciprocal support, and shared validation. Further, the opportunity to discuss similar difficulties may have helped the group members to realise that their experiences are shared and their concerns are more universal than originally thought [68]. These are all potentially positive experiences, which in themselves may contribute to the lessening of distress for the younger stroke survivors. Research has shown that younger stroke survivors often report and are frustrated by a lack of age adapted and appropriate support [13, 24, 25]. Therefore, the provision of support aimed at targeting problems experienced by younger stroke survivors may have contributed to a reduction in feelings of distress. Other placebo effects are also not controlled for such as

positive expectations and the desire to please therapists [69]. Future studies should incorporate comparison groups that control for these previously mentioned factors.

The current study is also limited as the principal investigator was both the therapist and data collector in the current study which may have resulted in expectation bias in participant responses [70]. This also affects the acceptability of feedback form data as a result of a social desirability bias. Since participants would have anticipated that the therapist would eventually be viewing this data, they may have answered questions in a more favourable light so as not to offend.

Implications for clinical practice. The between-subject results suggest the problem solving therapy is not an effective intervention for younger stroke survivors and therefore should not be incorporated into rehabilitation services. The within-subject results tentatively suggest that problem solving therapy may be beneficial for younger stroke survivors, however, there are multiple confounding variables in this phase of the study and further research needs to be completed before changes are made to post stroke rehabilitation.

Conclusion. The between-subject design demonstrated that problem solving therapy is no more effective for reducing depression and anxiety and increasing quality of life and problem solving post stroke than a waitlist control group from baseline (pre-waitlist/ pre-treatment) to time 2 (post-waitlist/ post-treatment), the within-subject design results may indicate that problem solving therapy is an effective, helpful and enjoyable group therapy for younger stroke survivors, however, methodological limitations reduce the validity of this finding.

The perceived support discussion would suggest that having support groups set up and offered to younger stroke survivors once they leave hospital may act as a protective

factor against the development of emotional distress. Younger stroke survivors would, therefore, feel less isolated in their post stroke journey and would know that there were resources available to help. This would at the very least help to alleviate the frustration experienced by younger stroke survivors as a result of the lack of age adapted and appropriate rehabilitation services. Future randomised controlled trials are needed to specifically determine what type of support should be prioritised.

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CHAPTER 12: DISCUSSION

The current chapter will focus on the main findings that arose in Studies 1 and 2 and is divided into six sections: (a) summary of the main findings, (b) researcher observations, (c) contributions to existing literature, (d) implications for health professionals, (e) limitations of the current study, (f) recommendations for future research, (g) benefits to my development as a researcher, and (h) conclusions.

Summary of Main Findings

The aims of this research were to gain insight into younger stroke survivors experiences post stroke and to run and evaluate therapy sessions designed to help younger stroke survivors with their post stroke distress. The study utilised a mixed methods design, in order to explore alternative perspectives and gather contextually rich information, which allowed for a deeper understanding of the research focus.

Study 1. Participants were asked to consider sixteen post stroke difficulties, which were drawn from current literature. The results demonstrated that the majority of the investigated problems were experienced as at least “a significant problem”, with the exception of intimacy problems, marital problems, and loss of home. Qualitative analysis suggested considerable diversity within each ‘problem area’ as there were many different examples provided for each investigated problem, and frequencies of reported codes were not particularly high (predominantly less than 50% of the total responses per question). This highlights that the post-stroke journey is unique to the individual and rehabilitation services should be tailored accordingly.

Study 2. Study 2 involved the evaluation of the efficacy of PST to reduce PSD and PSA and increase QOL and problem solving skills in younger stroke survivors. The within-subjects analysis indicated that there was a significant reduction in depression and

anxiety symptoms and a significant increase in quality of life between baseline and follow up. High levels of treatment satisfaction were reported indicating that the therapy sessions were beneficial to the younger stroke survivors. However, between-subject analysis indicated that there were no apparent benefits of receiving PST when evaluated against a waitlist control group as both groups improved.

Major Themes Arising from both Studies

The previous section (plus chapters 10 and 11) summarised the findings from study 1 and 2 separately, however as there are aspects of each study that are similar, the following section will summarise findings that relate to both studies.

Lack of support. A lack of support post stroke is something that was identified by participants in both Study 1 and Study 2. This is congruent with previous research outlining the frustration that younger stroke survivors report due to a lack of age appropriate support (Bendz, 2003; Morris, 2011; Röding et al., 2003), and specifically a lack of support post discharge (Sadler et al., 2014). Although there was no statistical support for the provision of PST, study 2 therapy group discussions suggested that age appropriate support for young stroke survivors is a significant deficit. Participants reported that they were either left to their own devices on discharge or were told to join support services that had been set up for older stroke survivors. These groups did not address the specific problems that they had and activities (e.g., bingo) were not appropriate for their demographic. In addition, the younger stroke survivors would discuss how friends and family did not understand what they were going through, which resulted in experiences of social isolation.

Although statistical significance was not established, depression symptoms did reduce among both treatment participants *and* waitlist participants, perhaps indicating that even the prospect of receiving support had the ability to reduce distress among the young

stroke survivors in study 2. This result provides evidence for the theory of “perceived support”, which describes an individual’s confidence that adequate support will be available when needed (Cheng, 1997), and it has been found to be a strong protective factor for depression and anxiety (Roohafza, 2014).

Provision of information. Similar to the findings of a lack of support, the results from the online survey suggest that the younger stroke survivors found a lack of information post stroke to be a problem. When asked to provide examples of this lack of information, many of the participants referred to the limited information given after the acute phase regarding the rehabilitation process and what life would be like post-stroke. This supports the research by Dyall et al. (2008) whose participants mentioned that there was a lack of information and support post-stroke. Recent guidelines for adult stroke recovery suggest that efforts should be made to continue rehabilitating stroke survivors once they have left hospital (Winstein et al., 2016).

Emotional distress was also a problem reported by the survey respondents. A systematic review by de Man-van Ginkel, Gooskens, Schuurmans, Lindeman and Hafsteinsdottir (2010) found that severity levels of depression are reduced by the provision of information. This relates to study 2, as PST is an intervention that can provide information on dealing with problems that arise post stroke (Mynors-Wallis, 2005). Based on the feedback forms, the six weeks of PST was found to be helpful by participants with 96% indicating that they would use the problem solving steps in the future. Generating solutions was the problem solving step rated as the most helpful by of the participants, followed by problem definition, and establishing goals. These three steps are all aspects of information processing and have the potential to relieve distress based on the findings by de Man-van Ginkel et al. (2010). Recommendations for future research

regarding the provision of information for younger stroke survivors are outlined later on in the current chapter.

Invisible disabilities. Problems with invisible disabilities was the highest rated problem on the online survey. Qualitative analysis revealed a lack of understanding from family and friends regarding these invisible symptoms was a problem, which was reinforced during PST sessions with participants finding it difficult to explain the effects of their stroke, as friends and family thought they looked ok and therefore they should be ok. Group members also explained how service providers often did not understand the effects of the stroke and it was difficult to secure the support that they needed. This is in line with previous research, which demonstrates the difficulties that younger stroke survivors experience as a result of their invisible disabilities (Murray & Harrison, 2004; Röding et al., 2003; Stone, 2005).

Fatigue was the most frequently reported example of an invisible disability with 34.4% of survey responses mentioning it. This was reflected in the problems reported by participants during the initial session of PST, and is congruent with previous research, which has found that between 35% and 95% of stroke survivors experience fatigue following stroke (Duncan, Wu, & Mead, 2012).

Emotional distress. Difficulty with emotions was something that was also common to the findings in both studies. In study 1, when respondents were given the opportunity to describe any other problems they had experienced post stroke, emotional distress was a frequently provided answer. Emotional distress was also frequently mentioned when participants were asked to give examples of problems with “forming new relationships”, “reductions in intellectual fulfilment”, and “self-esteem problems”.

Some form of emotional distress (e.g., irritability, lack of motivation, frustration), or the inability to control emotions was included in 4 out of the 5 group problem lists with “difficulty in controlling my emotions” chosen as a problem to work on throughout therapy (group problem lists are provided in Appendix I). This supports previous research which states that emotional distress is common post-stroke (Barker-Collo, 2007; Broomfield et al., 2014; Carod-Artal, 2010; Hackett et al., 2005), and highlights the fact that emotional distress has a significant impact on the rehabilitation process, so it should be addressed alongside other post-stroke symptoms.

Lack of confidence. A lack of confidence was something that was described in 12 out of the 16 open ended questions in the survey. This was also something that was mentioned by numerous younger stroke survivors during initial assessment sessions and throughout the six therapy sessions. It was apparent that the younger stroke survivors may have had difficulty solving their problems because they did not have the confidence in their ability to work through these on their own. Verbal feedback at the end of the sessions supported this, in that a number of the stroke survivors reported feeling more confident and in an increase in self-esteem subsequent to the therapy sessions.

An explanation of this could be provided by the mechanisms behind PST. During PST clients gain an understanding of their current symptoms and everyday problems. In addition, structure is given to their problem solving, which enhances the individual’s ability to resolve their day-to-day problems more effectively. This structure teaches the stroke survivors to define their problem, set realistic goals and endeavour to achieve them. A sense of self-mastery and the resulting positive feelings are created when problems are partially or completely resolved (Mynors-Wallis, Gath, Day, & Baker, 2000), and thus resulting in an increase in confidence.

The significant reduction in symptoms of depression and anxiety and improvement in quality of life at three month follow up observed in study 2 may also reflect this increase in confidence. Research has stated that learning based interventions may take some time to impact psychosocial variables, thus resulting in improvements months after treatment has finished (Visser et al., 2016). PST is a learning based intervention that aims to teach participants a more effective way to problem solve (Mynors-Wallis et al., 2000). As the group members began to learn the steps and apply these to resolve their problems, they may have become more confident. This therefore may have led to the reduction in distress, which became apparent in the outcome measures at 3 month follow-up. Future research could explore the concept of confidence and the effect that PST has on this.

Identity. Stroke is a devastating life event that occurs unexpectedly in the life journey. From the qualitative responses in study 1, it appeared that the post-stroke journey was dependent on the person's pre stroke identity or ability (i.e., what was important to them, what they enjoyed doing, where they worked, who they were), as this was referenced in responses to numerous questions.

In support of this, the younger stroke survivors expressed their frustration that they were often expected to join rehabilitation services whose activities were not appropriate for their age group. This may suggest that they would prefer rehabilitation services that were more congruent with what was meaningful and enjoyable to them. The implication of the findings from study 1, and group member reports in study 2 is that health care professionals need to take the time to get to know each individual stroke survivor (including their pre and post-stroke self) in order to enhance their rehabilitation process and quality of life. Further, rehabilitation support groups should be tailored to different age groups of stroke survivors.

Researcher Observations

In addition to the quantitative and qualitative results provided from the studies there are some researcher observations, which may contribute to a more in depth understanding of the results and may be helpful when working with younger stroke survivors in the future.

Problems addressed. The researcher observed that PST can be used to address a variety of different problems including practical, emotional, cognitive, social and even physical difficulties. These include health issues such as smoking, diet changes, making time for self/self care, increasing pleasurable activities, telling people about their stroke/getting them to understand, angry outbursts, emotion regulation, dealing with hypersensitivity (e.g., ear plugs, ear muffs, IPod), sleep difficulties, confidence, change in role in the family (wanting to feel needed), increasing motivation, working on communication, working on licences, government changes, funding problems, worries about having another stroke, relationship difficulties, getting back into exercise, getting back to work, and getting rid of a walking stick and walking straight. For example, one of our group members walked into the 5th session without his walking aid. He had labelled his walking aid as one of his problems he had wanted to work through, and his goal had been to “try and get rid of it”. Through his use of the problem solving steps he succeeded. Other participants wanted to work on ways to control their emotional outbursts, whilst others wanted to find opportunities for cognitive development. These observations regarding the adaptability and flexibility PST provide additional support for its suitability for this population. Appendix I includes a list of all of the original group problem lists that were created at the beginning of therapy (note that participants also had their own individual problem list).

Problem Solving Steps. It appeared to the researcher that the seven problem solving steps could be condensed into four or five, as participants often appeared eager to work quickly through certain steps and spend more time working on others. Generating solutions was the step that the group members seemed to want to spend the most time on while evaluation was favoured less, and although time was allocated for this step at each session, discussions were shorter with group members keen to move on to the next problem. Verbal feedback was also given regarding step one (explanation and rationale). Participants questioned the helpfulness of the theory behind PST and almost appeared frustrated by it. They did not seem to appreciate some of the language used such as problem solving orientation and style. If the researcher was to run the groups again, less time would be spent on step one of PST (see the facilitator manual in Appendix E).

All three of these observations were supported by study 2 findings in which participants rated 'generating solutions' as the most helpful step and 'explanation and rationale' as the least helpful. Based on these observations and the results from feedback forms, it could be suggested that younger stroke survivors may benefit from a four step programme including establishing goals, generating solution, evaluating and choosing solutions and implementing the solution.

Social support. The appreciation of the social support provided by the group situation was also apparent. In line with previous research, the younger stroke survivors talked a lot about losing touch with friends due to a number of reasons such as being too tired to spend time with them, or as a result of their lack of understanding. Being in a group of individuals who understood what each other were going through appeared to be extremely beneficial. Verbal feedback was given throughout the sessions regarding how helpful each group member found it to hear about other stroke survivors' struggles and successes. This is in support of research by Morris and Morris (2012), which investigates

the experiences of participants who took part in hospital based peer support groups post stroke. Using an inductive thematic analysis following semi-structured interviews, the research found that the value of peers was a salient theme throughout the qualitative data. The participants spoke of the benefits of developing connections, the provision of information and advice, the gain in confidence from other peers, and an increase in awareness of the difficulties post stroke.

Group introductions at the beginning of each group allowed for the facilitation of shared stories and the building of rapport between group members. This is something that should be prioritised if future groups were to be set up for younger stroke survivors. The researcher also observed many of the group members arranging to continue seeing each other after the PST sessions finished.

Assessment measures. It may have been beneficial to incorporate other outcome measures into the assessment points of study 2, as it appeared that the PST influenced other aspects that may be beneficial to the younger stroke survivors. As mentioned earlier, confidence and self-esteem seemed to improve following the PST sessions and could have been measured using The Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965). Another interesting measure to incorporate may be one that investigates coping in its broader sense, (such as the Coping Inventory for Stressful Situations; Endler & Parker, 1990) and not just the skills involved with problem solving.

In addition, many participants expressed frustration and difficulty in completing the SPSI-R:SF, finding it hard to read and the questions confusing, in turn possibly impacting the validity of their responses. Some refused to complete the measure for a second or third time.

Willingness to participate. The majority of participants expressed appreciation for research into this area and were keen to help in any way they could. For example, a younger stroke survivor who had completed the online survey for study one personally contacted the researcher and offered her assistance for the research, and other stroke survivors around New Zealand including Christchurch, Hamilton and Auckland, offered their gratitude and assistance. This could potentially have affected the results due to response bias (van de Mortel, 2008) i.e., the desire for change may have resulted in the participants reporting more beneficial outcomes than what actually occurred.

The stroke survivors' willingness to participate and help in this area also meant that participants volunteered regardless of their current level of distress. Some participants scored well below the cut off scores for risk of depression and mild anxiety, yet still wanted to participate even when they were reminded of the aims of PST (to reduce PSD and PSA and to increase quality of life and problem solving). As some participants were not experiencing great amounts of distress before therapy began, as evidenced on their psychometric scores, there was little space for improvement, thus affecting the overall change scores for the treatment group. Future studies should endeavour to only include participants who meet the criteria for depression and anxiety.

Contributions to Existing Literature

Although the contribution of study 2 to existing literature is modest, the combination of the results of studies 1 and 2 are valuable. There is limited research in New Zealand investigating the area of stroke in younger survivors and study one contributes specific research surrounding the problems that this population faces. In addition, providing opportunity for further detail of the problems, gave deeper understanding of their post stroke journey. Such understanding can assist health professionals to tailor rehabilitation strategies for this group.

Study two is the first study to investigate the effects of non-pharmacological therapies aimed at reducing post stroke distress in younger stroke survivors in New Zealand and adds to the limited international research investigating stroke survivors younger than 55. Further, previous research has predominantly focused on PSD, therefore, the inclusion of an outcome measure that investigates anxiety, quality of life and problem solving is also an aspect of this research that contributes to the existing literature.

Implications for Health Professionals

Given that younger stroke survivors report a lack of information about what the post stroke journey will be like, as well as frustration due to others lack of understanding about their invisible symptoms, provision of education sessions post stroke would be useful. These could incorporate the stroke survivor and their families/support persons and friends and be run after the acute phase, when stroke survivors are reintegrating back into the community. Information could be provided regarding what common symptoms are (both visible and invisible), how they may manifest, and beneficial ways for the stroke survivors and their family members to respond to these difficulties. In support of this suggestion, research by Foster et al., (2016) demonstrated that individuals were more likely to socialise with brain injury survivors when they had knowledge on how to interact with brain injured individuals. This may make social interactions easier for the survivor and reduce social isolation. Education (e.g., media campaigns) could also be provided for the general public on how to interact with individuals who have suffered a stroke with the aim of reducing the social isolation experienced by younger stroke survivors.

Such information sessions could also include speakers who are stroke survivors, and who have been through the post stroke journey as the group members from the

current study seemed to benefit from hearing each others' success stories as well as difficulties. The speakers could talk about what they had experienced, what had been helpful and unhelpful, and what resources are accessible in the community. Many of the current studies group members expressed an interest in volunteering their time to other stroke survivors so that they could alleviate some of the struggling prevalent in the post stroke journey.

Results from both studies suggest that younger stroke survivors would benefit from support post stroke that focuses specifically on the younger stroke survivor population. This would at the very least help to alleviate the frustration experienced by younger stroke survivors as a result of the lack of age adapted and appropriate rehabilitation services. Having support groups set up and offered to younger stroke survivors once they leave hospital may act as a protective factor against the development of emotional distress.

Limitations of the Current Study

Self-selection bias. Participation in study 1 was voluntary, which resulted in a self-selected sample (Bethlehem, 2010). The respondents may have experienced problems post-stroke and therefore may have been more likely to endorse and report these problems. Stroke survivors who have not experienced problems may have chosen not to participate, thus resulting in self-selection bias, and a less representative sample of the younger stroke survivor population (Bethlehem, 2010).

Delayed reports. As the survey was asking participants to report on problems they have experienced post stroke, and for more than half of the respondents that had been over two years ago, lapses in their memory may have impacted the accuracy of their reports. Memory difficulties is also a well-documented consequence of stroke (Knapp,

2010; Uchino et al., 2011). The reliability of memory and memories being susceptible to forgetting, illusions and distortions is a well-known phenomenon (Greenhoot, 2012).

However, the concern regarding delayed recall is reduced if the event is extraordinary, rather than ordinary (Norris & Kaniasty, 1992). Research suggests that an increase in salience of the event relates to an increase in the reliability of the delayed reports (Funch & Marshall, 1984), and that people often remember events that cause significant changes in their lives, even though they may forget minor events (Raphael, Cloitre, & Dohrenwend, 1991). Within the current study, a stroke is considered to be a major life event that has the potential to impact the participants' lives greatly.

Accordingly, the reliability of their reports is likely stronger.

Temporal Stability. As we did not include a temporal stability assessment for the questionnaire in study 1, we cannot rule out possible extraneous variables such as the participants' mood on that day, their physical health, and motivational factors (Field, 2013).

Sample size. Study 2 involved a small sample, which reduced the power of statistical testing and therefore, limits the validity of the conclusions of the study (Faber & Fonseca, 2014). Accordingly, it is difficult to determine whether PST had no effect on the treatment group when compared to the wait-list group, or whether there was insufficient power to identify a significant effect (Oakes & Feldman, 2001). In addition, it is unlikely that a small sample size represents the variability of the greater population from which it is selected from, especially considering the heterogeneity across presentations of stroke survivors. As a result, type II errors are common in small sample sizes, where the research fails to capture the effects that actually occur in the population (Oakes & Feldman, 2001).

As participation was voluntary, certain types of stroke survivors may have chosen to participate in the current study. For example, they may have been more motivated than other stroke survivors. This therefore lessens the generalizability of the results.

Randomisation. As, participants were not randomly assigned to the groups due to their localities, this study cannot be classed as a RCT and the inferences that can be made about the results are limited. The baseline analysis demonstrated that there were no significant differences between groups on the four outcome measures. It was also found that the majority of the group demographics were not significantly different, with the exception of ethnicity and education level. This could have been potentially problematic as previous research has demonstrated that higher education levels are related to greater improvements in therapy (Hawley, Leibert, & Lane, 2014) and that ethnicity can affect treatment outcomes with ethnic minorities generally experiencing less improvements than non-minorities (Huey & Polo, 2008). Future studies should incorporate larger sample sizes in which younger stroke survivors are randomised to treatment and control groups.

Inclusion criteria. Due to recruitment difficulties, it was decided that participants would be included in this study if they had symptoms of depression or anxiety and not an actual diagnosis. While this allowed for the inclusion of more participants; it may have also reduced the effect size that PST had on the outcome variables (depression, anxiety, quality of life, problem solving skills). For example, the mean score on the HADS-A for both the treatment and control groups was lower than the cut-off score used to indicate mild anxiety (8-10) (Zigmond & Snaith, 1983) and the SPSI total scores as well as each of its five subscales all fell within the normal ranges for problem solving (86-114) (D’Zurilla et al., 2002). Perhaps there was not much opportunity for PST to influence these measures and therefore resulting in a type II error. Future studies should include

participants who meet the criteria for the disorders that they are trying to measure in order to get a true sense of the efficacy of PST.

Group combination. Participant recruitment difficulties also resulted in the decision to combine the wait-list and the treatment group to form the within-subject design. This resulted in a number of problems. Firstly, the wait-list group did not include a follow up assessment point; therefore, this could not be included in the between-subjects analysis. The within subjects analysis revealed that the improvements in outcome measures emerged at follow up, rather than between baseline and time 2 (post-treatment).

An explanation for this result is that learning based interventions may take some time to impact psychosocial variables, thus resulting in improvements months after treatment has finished (Visser et al., 2016). PST is a learning based intervention that aims to teach participants a more effective way to problem solve. In addition to the time taken to learn these skills, problems in participants' lives may take a while to resolve. Once problems are solved, this can lead to experiences of self-mastery and self-control, which can result in positive feelings and alleviation of distress (Mynors-Wallis et al., 2000). This is something that may have happened between post treatment and follow-up once the participants had additional time to continue working through their problems. Should a follow-up measure have been included in the between-subjects design, a significant interaction effect may have emerged between the PST group and the wait-list group in improvements on the outcome measures from baseline to follow up, thus supporting the efficacy of PST.

It also appears that the effect of being on the waitlist may have influenced the within-subject depression results when the two groups (waitlist and treatment) were combined. An additional analysis was conducted to check for any differences in reductions throughout treatment between the participants who were originally on the

wait-list and the participants who were not. This analysis revealed that the reduction in the depression scores of the treatment groups (participants who were not originally on the wait-list) from pre-treatment to post-treatment to follow-up was greater than the participants who were originally on the waitlist (although this difference was not significant).

From this it could be inferred that the wait-list group may have experienced a decrease in depression scores as a result of simply being on a wait-list and therefore there was not as much room to improve throughout treatment due to a ceiling effect. As a consequence, this may have affected the results of the combined treatment group and created a smaller treatment effect than if the groups hadn't been combined.

Another suggestion is that the perceived support experienced by the wait-list was enough to reduce distress levels and that PST had little additional effect. If this is the case, it is difficult to tease out whether PST resulted in the improvements in the 15 who were not on the wait-list originally or whether these were due to just simply knowing that the support was available. It could be said that perceived support is powerful enough to improve younger stroke survivors' wellbeing regardless of the treatment of choice. Future research should endeavour to keep the two groups separate for analysis. They should also include a social support group or another form of treatment such as CBT or ACT to rule out confounding variables such as perceived support and to determine whether the therapeutic elements of PST are more beneficial to younger stroke survivors than other forms of support or treatment.

Confounding variables. It is also difficult to disentangle what was helpful to the younger stroke survivors in study 2. When examining the with-in subject results, it appears that there are a number of factors that may have been helpful to this population.

Simply having the presence of a therapist may have reduced the participants' symptoms of depression and anxiety and increased quality of life (Elkin, 1999).

In addition, the social support provided by the group environment may have resulted in beneficial effects as research has found that younger stroke survivors experience social isolation post stroke. This is due to a number of reasons, including their physical and cognitive symptoms (Murray & Harrison, 2004), feelings of being misunderstood (Stone, 2014), and difficulty forming relationships (Murray & Harrison, 2004). Research has demonstrated that social isolation often contributes to the development and maintenance of depression in stroke survivors (Hackett & Anderson, 2005). The group environment within the current study may have promoted social interaction, reciprocal support, and shared validation. Further, the opportunity to discuss similar difficulties may have helped the group members to realise that their experiences are shared, and their concerns are more universal than originally thought (Lewinsohn & Clarke, 1999). These are all potentially positive experience which in themselves may contribute to the lessening of distress for the younger stroke survivors.

Research has shown that younger stroke survivors often report and are frustrated by a lack of age adapted and appropriate support (Bendz, 2003; Morris, 2011; Röding et al., 2003). Therefore, the provision of support aimed at targeting problems experienced by younger stroke survivors may have contributed to a reduction in feelings of distress. As mentioned previously, future studies should incorporate comparison groups that control for these factors.

Expanding from this, if PST was beneficial to the group members, it is difficult to determine what aspects of PST resulted in the improvements in the within-subject design. According to the feedback forms “generating solutions”, “problem definition” and “establishing goals” were reported to be the most helpful steps. However, the therapy can

be fragmented even further. For example, “generating solutions” was rated as the most helpful step, however, many different solutions were generated that could have been potentially beneficial to the group members. One way to unravel what aspects of PST were helpful (if it was PST that resulted in the improvements for participants) is to conduct a qualitative study and have younger stroke survivors complete the sessions of PST. Then conduct interviews with each participant where the researcher can enquire about what was the most helpful to each therapy participant.

Individual vs. Group therapy. Group therapy was chosen for a number of reasons such as the social isolation that younger stroke survivors experience post stroke (Murray & Harrison, 2004; Stone, 2014), and the promotion of reciprocal support and shared validations that group environments offer (Lewinsohn & Clarke, 1999). Although these are conceivably advantageous to the participants, the possible disadvantages must be considered as well.

In a group environment, individuals are not afforded the benefit of being the focus of attention. There may have been participants who were more comfortable sharing their problems within a group environment; therefore, more attention may have been given to those people, while for others would have been more open in individual therapy (Norcross & Goldfield, 2005). Similarly, the level of rapport between the therapist and each individual participant is not as strong in group therapy.

Session number and structure. In previous research, PST has been completed over a varying number of sessions e.g., Hadidi et al. (2014) used 10 sessions, and Robinson et al. (2008) used six sessions initially in the first 10 weeks, however included an additional six reinforcement sessions at 4, 5, 6, 8, 10 and 12 months. In the current study six sessions were completed as recommended in the manual by Mynors-Wallis (2005). It was also thought that six sessions would be a good number to increase time and

cost effectiveness. If the current study found that six sessions of PST were beneficial to the stroke survivors then this could be used to support the implementation of the therapy structure into post-stroke rehabilitation services. A more recent study by Visser et al. (2016) found significant differences after eight sessions on improvements in health related quality of life and task-oriented coping between a PST group and a treatment as usual control group. However, there was no significant difference on improvements in depression. It appears then that it is still unclear as to the number of sessions that would be the most beneficial in terms of symptom improvement as well as cost and time effectiveness. Future research could compare groups with varying session numbers to determine what number is the most effective for stroke survivors.

The initial six problem solving steps that are usually taught within the first session of PST as outlined by Mynors-Wallis (2005) were spread over the first two sessions. This was done as it was anticipated that group discussions and the sharing of problems would result in additional time needed to learn these steps. The sessions ran to time in each of the five groups with this layout. Should the six steps plus introductions and house-keeping rules been executed in session one, the group sessions would have needed to last up to three hours. This may not have been suitable for the participants, as fatigue is known to be a common problem that occurs in up to 72% of stroke survivors (Colle, Bonan, Leman, Bradai, & Yelnik, 2006). The study by Hadidi et al. (2014) also split the teaching of the PST steps over two sessions with their older stroke survivor participants. The subsequent sessions were spent going through additional problems. The study found that PST was advantageous; however, no justification was given for this methodological adaptation.

Although splitting the teaching of the seven problem solving steps across two sessions rather than one may have been beneficial to allow for group discussions, it also

may have been a limitation to the current study not only because there was one less session that the participants could focus on practicing these steps but because the participants didn't seem to like the discussions surrounding the theory of PST. It is difficult to weigh up whether it was more beneficial to ensure that the participants received an in-depth understanding of the problem solving process, or to give them an additional session to work through their problems. Future studies could compare outcomes of the different structures in which the problem solving steps have been taught.

Cultural limitations. Although neither study 1 or 2 were restricted to certain cultures, the cultural diversity of the respondents was limited, with the predominant ethnicity of participants in both studies being New Zealand European. The onset of stroke in New Zealand varies depending on ethnicity and gender. For Māori, the average age of onset is 61 years, for Pacific people it is 64 years and for European New Zealanders it is over 75 years (Feigin et al., 2006). This would suggest that there are more younger stroke survivors in New Zealand who are of Māori and Pacific Island descent and that future research should take steps to ensure adequate representation of these groups.

In addition, previous qualitative research in New Zealand (n = 8), by Dyall et al. (2008) has outlined some outcomes post stroke that are specific to the Māori culture. The study found that Māori stroke survivors experience a loss of mana (prestige) and that they feel whakama (embarrassed) as the head is tapu (sacred), and they believed that their behaviour post-stroke was similar to mental illness. Thus, indicating that the experience of stroke is also unique within different cultures. It is important to gather more information about the experiences of younger Māori stroke survivors in New Zealand in order to develop a deeper understanding of their post-stroke journey. Future research could also endeavour to tailor post stroke rehabilitation services so that they uphold

Māori tikanga, in order to increase Māori participation in post-stroke health care services, this may result in an increase in positive outcomes for Māori stroke survivors.

Recommendations for Future Research

In light of the findings, researcher observations and limitations of the current study, a number of recommendations can be made for future research in this area.

A number of participants reported that they were either not given enough information or they were overloaded with too much information that they could not process immediately after their stroke. Therefore, an additional online survey could investigate what resources would be helpful immediately post stroke for younger stroke survivors and what would have enhanced their inpatient stay experience.

It would also be beneficial to determine what is already being done and what would have been helpful after the inpatient phase when participants are reintegrating back into the community such as the provision of emotional support, family conferences, stress reduction techniques (e.g., mindfulness), or information regarding available services (i.e., physio therapy, speech language therapy, occupational therapy, return to work, financial assistance, or dieticians).

The justification for this further research arises from information from study 1 as well as anecdotal evidence from the young stroke survivors in study 2, who discussed the fact that there is no offer of assistance when they leave the hospital. A number of the survivors discussed the fact that they had reached the stage that they are at, because they had been proactive with their rehabilitation and had actively searched for help.

Focus groups could also be run with younger stroke survivors aimed at creating a resource (e.g., website, pamphlet, phone application, information evening, video) that can be used by younger stroke survivors post stroke. This resource should consider post stroke cognitive difficulties and fatigue. From this a prototype of a resource could be

created. This would then be taken back to the focus group and the focus group would be surveyed and interviewed about their ideas on the resource.

As stroke can occur at any age, research should also be conducted with stroke survivors under the age of 18. Throughout the duration of the study, the researcher came into contact with individuals who were under the age of 18. This was mainly through advertising on Facebook and comments from stroke survivors under the age of 18. These include (1) “Would be great to have something for stroke survivors younger than 18yrs! And it would be so helpful to parents/caregivers/ (and the general population). Would be so helpful to have a piece of NZ research to refer to” and (2) “I wish that there was research like this for people under the age of 18”.

The online survey used in study 1 could also be used for stroke survivors under the age of 18, however questions could be adapted to suit their demographic. Interviews could also be carried out with this population and qualitative analysis could be conducted in order to get a deeper understanding of what these younger stroke survivors.

There is an online website (<http://www.youngstrokethrivers.org.nz/>), which has been set up to support stroke survivors up until the age of 18. This researcher has been in contact with the founder of this website and she is supportive of the investigation of experiences of stroke survivors under the age of 18.

It could be valuable to survey or interview health professionals about their awareness and knowledge of the post-stroke treatment pathway for younger stroke survivors. The researcher is aware that the reports from the younger stroke survivors are subjective, and it is important to determine what the perception of health professionals are regarding the post stroke process. This would allow for a balanced view of the available resources. The fact should be considered that there actually are resources available and

perhaps there is a disparity between communicating what is available, rather than an actual lack of support and resources.

It is also important to carry out research in the area of stroke in Māori and Pacific Islanders in order to get a deeper understanding of their post stroke experiences. Although there are options of surveys or interviews in research, it is suggested that interviews be conducted, especially with Māori stroke survivors as the process of whakawhanaungatanga is valued in their culture and it is important to uphold Māori tikanga throughout research practices (Bishop, 1999; Whakawhiti, 1997). Extensive cultural consultation and supervision should also be sought before research is conducted in this area. Research investigating the benefits of therapies for younger stroke survivors could also incorporate Kaupapa Māori principles similar to the research by Bennett (2009) and Bennett, Flett and Babbage (2014).

As discussed earlier, future research needs to be carried out that employs a more rigorous scientific method. Participants should be randomised to groups and a control group should be used that has the ability to rule out potential confounding variables such as social support and therapist effect. Future studies should also endeavour to incorporate larger sample sizes.

Benefits to my Development as a Researcher

The current study has helped me to develop as a researcher in a number of ways. Firstly, I have learnt how to navigate difficult conversations with potential participants who want to participate, but do not meet the eligibility criteria. This was done alongside consultation with my supervisors and the process we followed is outlined in chapter 9.

Secondly, as a researcher and a trainee clinical psychologist I came across some internal conflicts during the process of this study. The main conflict was between attempting to be a good researcher and balancing this with the values that come with being a clinical psychology trainee (e.g., responsibility to society). There are two

examples of this. The first was the fact that the initial research proposal for the current study involved a randomised controlled trial. The RCT included a social control group who would receive no form of therapy. As the research progressed and it became clearer that younger stroke survivors were frustrated by the lack of help that they receive, I decided that all stroke survivors within the study would receive some form of treatment. Benefiting the stroke survivors, however, lessening the inferences that could be made from the findings, due to the number of confounding variables and the lack of randomisation to groups.

The second example was the choice to be more flexible on the inclusion criteria with regards to the age of the participants. Initially the study was to include participants who were between the ages of 18 and 65, however a number of phone calls were received from individuals who were 66 or 67 and were noticeably distressed by the lack of help that they were receiving. With the resources to potentially alleviate some of this distress, I did not feel comfortable turning these stroke survivors away. From this it was decided that the inclusion criteria would be adjusted to between the ages of 18 and 65 at time of stroke, thus increasing the average age of the studies participants. However, this was problematic as the research was supposed to be investigating younger stroke survivors. In hindsight, perhaps I could have included these participants in therapy sessions, however conduct a second analysis excluding these individuals' data.

Thirdly, I have learnt from a number of practical mistakes. The major one was not adding space for participants to include their contact details on the returned consent forms. Thus, potential participants could not be contacted directly! This meant going back to the neurologist at Wellington hospital, for the contact details of those who had returned their consent forms. This felt unprofessional and messy. This was rectified in the consent forms posted out in Tauranga.

Finally, I have learnt how to balance grateful testimonies and risk with regards to the feedback forms. The researcher wanted the participants to be honest as possible whilst filling out the feedback forms so that a true evaluation of PST could occur. Therefore, the researcher wanted to inform the participants that she would not see the feedback forms until well after the PST sessions were finished. It was decided that the co-facilitator would organise the distribution of the feedback forms and would place them in a sealed envelope once complete. The researcher stepped out of the room whilst this transpired. This gave the participants the opportunity to write what they wanted on the forms, however increased the level of risk to the participants, as if something was written on the feedback forms that indicated that the participants were at risk of harm, then the feedback forms would potentially not be read for up to a month later. To balance this, it was decided that the researcher's primary supervisor would monitor the feedback forms for any risk issues. Because of this the participants were asked to write their names on the forms. This appeared to be an acceptable compromise between complete anonymity and reduction of risk to participants.

Conclusions

Research into the area of stroke in younger people is limited, particularly within New Zealand. The current study had two aims. The first of which was to develop a deeper understanding of the problems that younger stroke survivors experience, employing both a quantitative and qualitative analysis. The second aim was to evaluate the efficacy of PST with younger stroke survivors, using both a within-subject and between-subject design.

Study 1 provides information regarding the range of different difficulties that younger stroke survivors experience and how these impact their lives. Although there are universal difficulties experienced by the stroke survivors in New Zealand, the qualitative

analysis suggests that the post stroke journey is unique to each individual, and therefore rehabilitation strategies should be tailored accordingly.

Unfortunately, study 2 did not provide a significant amount of evidence for the efficacy of PST with younger stroke survivors when compared to a wait-list control group. However, it did suggest that the provision of some form of support would be beneficial to this population. Limitations of the study, including a small sample size, the combination of the two groups and the lack of a follow-up result for a control only group, make it difficult to draw definite conclusions. Therefore, future studies should endeavour to delve deeper into this area utilising a number of the recommendations made within this discussion section. Namely, increasing the sample sizes, including a social support control group or another type of therapy, and keeping the groups separate until follow-up measures have been taken.

Despite the lack of evidence for PST, the results from both study 1 and 2 can be used by health care professionals during the post stroke rehabilitation including the provision of education sessions to the stroke survivor and their family and setting up support groups for younger stroke survivors around New Zealand. Additional recommendations for future research in this area were also made and should they be implemented, they may have the potential to enhance the area of post stroke rehabilitation for younger stroke survivors in New Zealand.

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APPENDICES

APPENDIX A: RESEARCH CASE STUDY

The Assessment and Treatment of a 15-year-old male with Post Traumatic Stress Disorder: How my doctoral research contributed to my work with this young person

Charlotte P. R. Chalmers

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Clinical Psychology Intern at Kapiti Youth Support

This case study represents the work of Charlotte Chalmers during her internship in 2017. Clinical Supervision was received during the assessment and therapy for the individual described within the case study. All names and identifiable information within the case study have been changed to protect the anonymity of the client.

Abstract

The current case study outlines the benefits that my doctoral research has had on my work as a clinical psychology intern. In order to demonstrate this, I have discussed a client from Kapiti Youth Support, whose assessment and treatment plan has benefited from different learnings that surfaced throughout my research with younger stroke survivors. This case study will begin with a summary of my research, followed by a description of my client and will end with how my research has contributed to my development as a practitioner using the client to highlight these learnings.

Keywords: Problem solving, cognitive difficulties, Post-Traumatic Stress Disorder

Summary of My Research

Stroke affects approximately 6000 New Zealanders every year (Tobias, Cheung, Carter, Anderson, & Feigin, 2007). Approximately 25% of individuals with first ever stroke in New Zealand are under 65 years old (Tobias et al., 2007). Stroke survivors commonly experience post stroke depression, anxiety, and low quality of life, which impacts negatively on the rehabilitation process (Barker-Collo, 2007; Broomfield, Quinn, Abdul-Rahim, Walters, & Evans, 2014; Carod-Artal, 2010; Hackett, Yapa, Parag, & Anderson, 2005). Research has also shown that stroke survivors who have higher depression scores demonstrate more ineffective problem solving skills than stroke survivors with lower depression scores (Visser et al., 2015). There is limited research into the efficacy of non-pharmacological treatments for the experience of emotional distress following stroke (Kneebone & Dunmore, 2000; Morris, 2011). Research that is available provides promising results for the efficacy of problem solving therapy (PST) for treating post stroke depression in older stroke survivors (Alexopoulos et al., 2012; Hadidi, Jappe, Cullen, & Savik, 2014; Hadidi, Lindquist, Buckwalter, & Savik, 2015; Mitchell et al., 2009; Robinson et al., 2008), however, there is no research on this or any form of psychotherapy with younger stroke survivors (18-65 years) (Kneebone & Dunmore, 2000; Morris, 2011).

My research had two aims. The first was to collect information on problems experienced by younger (18-65) stroke survivors in New Zealand via a short online survey. Quantitative data was analysed using descriptive statistics and demonstrated that younger stroke survivors in New Zealand experience a number of different problems, with the most significant being difficulty with invisible disabilities. The qualitative analysis suggested that the variability in how these problems affect the younger stroke

survivors is large, and this should be taken into account by health professionals working with the younger survivors on their post stroke journey.

Using information gathered from the survey the second aim was to evaluate the efficacy of PST for reducing symptoms of depression and anxiety, and increasing effective problem solving skills and quality of life in younger stroke survivors (aged 18-65). This was done by using a group intervention format with six sessions over six weeks. Thirteen participants were recruited for the problem solving therapy group, and this was compared with a wait-list control group ($n = 16$) (between-subject analysis). These two groups were then combined to conduct the within-subject analysis. A total of 28 participants completed therapy. For the between-subject analysis, measures at baseline (pre-waitlist/pre-baseline) were compared with post-waitlist/post-treatment measures. This demonstrated that PST was no more effective than being on a wait-list control group. Measures were taken at baseline, at the final therapy session and at three-month follow up for the within-subject analysis. This analysis demonstrated significant improvements on depression, anxiety, and quality of life measures between baseline and follow up after six weeks of PST. Participants also rated the sessions and overall PST as helpful and enjoyable when asked to complete feedback forms.

The main recommendations from this research are that it would be beneficial for the provision of education sessions post stroke that incorporates the stroke survivor and their families/support persons. It is suggested that these be run after the acute phase when stroke survivors are reintegrating back into the community. Information could be provided regarding what common symptoms are (both visible and invisible), how they may manifest, and beneficial ways for the stroke survivors and their family members to respond to these difficulties. It is also recommended that these sessions include speakers who are stroke survivors, and who have been through the post stroke journey. The

speakers could talk about what they had experienced, what had been helpful and unhelpful to them, and what resources are accessible in the community. Finally, it is recommended that some form of support group be set up for younger stroke survivors in order to reduce the isolation that younger stroke survivors experience, however, it remains unclear what type of support this should be and future studies should be conducted to further explore this area.

Case Study

Referral

Matt Hosie was internally referred to the Mental Health Team at Kapiti Youth Support in February 2017 by Kim Ryan (Kapiti Youth Support General Practitioner). Matt and his mother had attended an appointment with Kim to discuss Matt's difficulties in returning to school. The referral requested psychological intervention to treat the symptoms of anxiety that Matt was experiencing.

Client presentation

Matt Hosie, a 15-year-old Caucasian male of English descent attended the initial session on time and was accompanied by his father (Tom Hosie). Matt was well groomed and appropriately dressed in casual clothing. The appointment was during school hours; however, Matt was not dressed in school uniform as he was not currently attending school. Matt's clothing was noticeably baggy and he appeared to be very thin. Matt was wearing a cast on his left arm as a result of a road bike accident. He appeared confident and at ease during the assessment as evidenced by a relaxed posture in his arm chair, a calm facial expression, good eye contact, spontaneous speech and an absence of any fidgeting or excessive movement. There was also no evidence of slowed speech or movement. Matt's mood was both observed as and described as happy. His affect was

appropriate to the content of the conversation, with good range. Matt was polite, personable and engaged well. He appeared motivated for therapy. His judgement appeared intact, and he showed good insight into the causes and consequences of his anxiety (i.e. he knows that being around people he does not trust causes him to be fearful, irritable, and snappy). Matt's speech was of normal rate, rhythm, tone, and volume. There was no evidence of thought disorder. There were no abnormalities noticed in perception or cognition. Some risk issues were identified regarding risk to Matt, as the perpetrators of his physical assault continued to live in the community and Matt was worried that they may harm him.

Genogram

Matt currently lives at home with his Dad (Tom, 53 yrs.), his Mum (Shirley, 38 yrs.), his younger sister (Charlotte, 7), his older brother (Luke, 18) and Luke's girlfriend (Lisa, 16). Matt stated that "he likes it at home" and that they "hardly argue". Matt also has a half brother and sister, a niece and a soon to be born nephew. Matt has two aunts on his paternal side and his grandfather and grandmother are together. Matt's maternal grandparents are no longer together but both live in the Kapiti area. Matt also mentioned close family friends, Helen and Daryl who are "like grandparents" to him. They live locally and appear to be good support for the Hosie family.

Client's perspective of presenting issue

Matt discussed his experience of a physical assault in December 2016 (during the school holidays), where he and his friend were at the public library. Matt reported that his friend went outside whilst Matt was in the toilet and was "attacked" by two other students. When Matt came out of the toilet, his friend was unconscious on the ground. The perpetrator then asked Matt to fight him but Matt reported that he refused to.

Allegedly the perpetrator hit Matt anyway and then started kicking him while he was on the ground. Eventually, the perpetrators left and the police were called.

Since then, Matt reported that he “keeps thinking about the event”, and that he will experience “times when he thinks the event is happening again as he can picture “exactly what happened”. He becomes “irritable and annoyed” when this happens. He now avoids (or becomes extremely anxious) in public places that remind him of the assault. This includes the mall, the library, bus stops, train stations, and local parks. He will avoid leaving the house on his own and no longer walks his dog, which he used to do daily. Matt also reported that he becomes anxious if groups of people start walking towards him. At these times he becomes sweaty, finds it difficult to breathe, and his heart will begin to race when he is in these environments and that he “just wants to get out of the situation”. Matt reported that prior to the assault; he would spend a lot of time in these areas hanging out with his friends. When asked why he had stopped going to these areas he stated that they “remind him of the assault” and is also worried that the perpetrators may be around. He does not trust strangers or anyone who could be connected to the perpetrators or their gang and will only talk to people he trusts about the event and feels “uncomfortable” when talking about what happened. He mentioned that he has also stopped seeing his friends as much as he used to and is slowly losing friends since the assault.

Matt reported that his mood has been “up and down” and that memories of the event lower his mood. He stated that he is a 9-10 (0 = extremely low, 10 = extremely high) normally, and thoughts of the event lower his mood to an 8. Matt has no thoughts of suicide or self-harm. He stated that if his mood drops to an 8 he will go to the boxing gym, will work out, will listen to music, or will go to the movies.

Tom (Dad) reported that Matt tosses and turns most nights (6 out of 7 nights a week) and that he will get up and out of bed at night. It takes him 30 minutes to fall asleep at 10:30 pm, and he is usually awake for about an hour when he wakes up during the night. He stated that when this happens he replays the event “over and over” in his head and he is “unable to stop this”. Despite this, Matt denied any experiences of fatigue or low energy.

Matt explained that he is underweight and that he has lost weight as he has no appetite. He is currently taking supplements to increase his weight that were prescribed by Kim Ryan (Kapiti Youth Support GP). Matt denies any self-esteem or body image issues or fear of gaining weight. He reported that he is not restricting his food intake purposively and is not vomiting after meals. He denied any other inappropriate compensatory behaviour.

Matt reported that his concentration is “no good”; however, he stated that his motivation is “good” and he appears goal orientated. Matt mentioned that he wants to go into the army and that he needs NCEA level 1 to do this. There was no evidence of thoughts of worthlessness.

Matt is currently not attending Sea View college and the thought of going back there increases his anxiety levels to a 10/10 (0 = low, 10 = high), as some of the students there remind him of the assault. The perpetrators of the assault also attend Sea View College and he is fearful of being assaulted again, therefore this fear and avoidance is serving to protect him from further assault.

Matt identified his goals for therapy as (1) “to be able to go out of home by myself”, (2) “to get back to school”, and (3) “to hang out with friends more”

Matt also identified a number of other “problems” in his life that he did not know how to resolve and reported that these were becoming “overwhelming”. These included quitting smoking, finding a part time job, and making new friends.

Parents’ perspective

Both Tom and Shirley expressed concern regarding “how anxious Matt has been since the assault last year”. Shirley reported that Matt used to be “very socially active” and would go out and hang out with his friends most days during the week (5 out of 7). She stated that he used to be “comfortable” going to places on his own, however, he no longer leaves the house without them and even if they accompany him he is “always on edge” and is constantly looking around him. She explained that he will now leave the house to socialise less than once a week and will only go if they drive him to the social activity and pick him up again. Shirley reported that she has been escorting Matt “everywhere”, this includes doctors' appointments, meetings at school, and to the gym for boxing. Shirley stated that she is "very protective of Matt" and "does not want him to get himself in a situation where he will get hurt".

She stated that it was hard for Matt to talk about the assault originally (March-May 2016) and would become "frustrated and angry" with them, should they ask him about it. He will now talk to them about it if they ask, however, he does not offer much information and appears "cautious" when talking about it. Shirley also stated that Matt is “very quick to anger” with his family members and often ends up “snapping at them”, which is a “big change” from his behaviour prior to the assault.

Both Tom and Shirley reported that they worry about the perpetrators still being in the community as well as at Matt’s school. Shirley does not want Matt to go back to school yet due to the “considerable anxiety” that he experiences there and the “danger of

being around the bullies”. Her goals for Matt are “to get an education but in a happy way”. Tom reported that he would like Matt to go back to school as he supports Matt’s goal to get into the army and thinks that school will help with this. Tom stated that he wants to “protect Matt” as he too was bullied at school and understands what the “fear of bullies” is like. Tom stated that he is encouraging Matt to continue with his boxing lessons so that he can learn ways to “defend himself” should he be attacked again.

Matt’s mother reported that she is “not happy” for Matt to go on medication, due to “dependence issues” and “side effects”, although Matt stated that he did not mind taking them.

What has been tried?

Matt has been seeing Mike Tungatt (counsellor at Kapiti Youth Support), which Matt and Shirley report has been “helpful”, however they stated that Matt needs “a little bit extra” so he can learn some strategies to deal with his anxiety.

Matt reported that he is currently seeing Lorenzo (regional health school tutor) a few times a week for an hour and that Lorenzo is encouraging Matt to go back to school. Both Matt and Shirley reported that they are not happy about this and think that “Lorenzo is asking Matt to go back to school too soon”.

Client’s Mental Health History

Both Matt and his mother reported that Matt does not have a history of mental health difficulties and that his current behaviour is “a complete change” since the assault last year. She described Matt as a “confident, social and easy going young man, who looks after his siblings and gets on well with all family members”.

Family Mental Health History

Tom reported that there is no history of mental illness on Matt's paternal side. Shirley stated that she "was anxious" however she was never formally diagnosed with a mental illness and never sought help for this. She stated that she is no longer "anxious". Shirley reported that her aunty has mental health issues which she was put on medication for originally, however, these left her in a "vegetative state" so she came off these. Shirley reported that her Aunty was eventually admitted to a psychiatric hospital; however, she was unsure of the formal diagnosis.

Medical History

Matt, Shirley and Tom report that Matt has no history of medical issues and state that he is currently in "good health".

Matt is currently seeing Dr. Kim Ryan (General Practitioner) for his difficulty maintaining weight. His BMI as of the 1st of February 2017 was a 16.9 indicating that he is *underweight*. Dr. Ryan has ruled out any medical explanations for this weight loss and recognises that it is a symptom of the anxiety he is currently experiencing. Matt is currently taking Ensure powder daily which is a supplement that assists with weight gain.

Developmental History

Shirley reported that Matt was born 10 days late. The birth was described as "normal". Shirley described hers and Matt's father's well-being and general health during her pregnancy as "normal" and that the process was "cruisey". No difficulties were reported regarding Matt as a baby and Shirley reported no significant events during his childhood. His motor, language and social development were described as "normal" up until preschool began. Matt reported that his childhood was "happy" and good", and could not recall any significant negative events during his childhood.

Shirley mentioned that when Matt began school at 4.5 years the staff at school raised concerns with regards to his learning and felt that he was behind in reading, spelling, and writing. Shirley reported that Matt was assessed at age 8 and was diagnosed with Dyspraxia.

Shirley described Matt as "very active" at preschool and that his concentration was never the best. She stated that he was always able to make friends in primary school; however, he had difficulty keeping them. She stated that "he made the wrong choices with friends" and that he would "get into trouble with them".

Education and occupational history

Matt reported that he attended preschool and primary school in London (where he was born) which were described as "ok", and Matt described that he has always "struggled" at school. He moved to New Zealand at aged 8 and transferred to Sunshine primary in Hamilton. Matt and his parents report that the transition went well and Matt had no difficulties beginning school in New Zealand. Matt then began Waterfall intermediate in Johnsonville after the family moved from Hamilton when Matt was aged 10. This was also described as "successful" and any difficulties transitioning were denied. Matt's family then moved to Kapiti when Matt was 12 and he began Sea View College. Matt reported that he is "not bothered" by the number of changes in schools and that Sea View College was going really well until the assault and that he has not attended school since the beginning of the year. Matt is currently engaged with Health school and spends half a day a week with the Health school tutor completing school work.

Matt reported that he would like to find part time employment and asked for help regarding this. Matt also stated that he would like to join the army and recognises that he needs NCEA level 1 to do this.

Substance Use History

Matt and his Dad report that Matt has one drink on a Friday or Saturday with his parents and that he does not go to parties. Matt reported that drugs are a no go in his family and that he has not and will not try them.

Matt reported that he smokes 5-6 cigarettes a day because it "calms him down"; however, he wants to stop as he is aware that it is "bad for his health".

History of leisure and pastimes

Matt attends boxing training 2-3 times per week. He also reported a passion for cooking, however, does not pursue this due to a "fear of being bullied further". He reported that he used to spend time biking and hanging out with his friends, although this reduced as a result of his anxiety. He also mentioned that he has stopped walking his dog as a result of anxiety and that he won't go out without his Mum or Dad being there.

Forensic and Legal History

Matt has not had any forensic or legal issues.

Cultural and Spiritual History

Sonya reported that their family is Christian, however, the "Christian faith is not a huge part of their family" and they do not attend church regularly.

Matt describes that he was born in the UK and that this is "important to him". He mentioned that he has spent almost half his life in New Zealand and that he "loves" it here. Matt and his father reported that they "really enjoy" the sporting culture of New Zealand and "love watching the rugby together". Matt does not report any need for the sessions to be adapted to his spiritual or cultural identification.

Psychometrics

Given Matt's symptoms of Post-Traumatic Stress disorder the PTSD Checklist – Civilian Version (PCL-C) (Weathers, Litz, Huska, & Keane, 1994) was administered. The PCL-C is a 17-item self-report measure that assesses PTSD symptoms in civilian populations. Its items parallel the diagnostic criteria B, C, and D for a DSM-IV diagnosis of PTSD (Weathers et al., 1994). Respondents are asked to rate items on a 5-point scale (1 = not at all, 5 = extremely) indicating the extent of which they have experienced symptoms of PTSD within the previous 30 days. A PCL-C score of 44 or higher indicates possible PTSD (Blanchard, Jones-Alexander, Buckley, & Forneris, 1996; Terhakopian, Sinaii, Engel, Schnurr, & Hoge, 2008). The PCL-C has been found to be a valid and reliable screening measure for PTSD (Blanchard et al., 1996; Ruggiero, Del Ben, Scotti, & Rabalais, 2003). Matt scored a 46 on the PCL-C, which meets the cut-off for possible PTSD.

Given that Matt reported a number of problems in his life that he finds "overwhelming" the Social Problem–Solving Inventory-Revised: Short Form (SPSI-R: SF) (D'Zurilla, Nezu, & Maydeu-Olivares, 2002) was administered to determine his problem solving abilities. The SPSI-R: SF is a 25 item questionnaire, which measures five domains of social problem solving: positive problem orientation, negative problem orientation, rational problem solving, impulsivity/carelessness style, and avoidance style. Individuals are required to rate each item on a 5-point Likert Scale. Scores on each of the five domains can be calculated individually by summing the score of the items within the specific domain. A total score can also be calculated by adding the items on the positive domains (positive problem orientation, rational problem solving) and the reverse of the scores of the items in the negative domains (negative problem orientation, impulsivity/carelessness style, avoidance style). Elevated domain scores indicate a greater

use of that problem solving skill. Higher total scores on the SPSI-R: SF indicates thoughts, emotions, and behaviours that are characteristic of better social problem-solving abilities. The SPSI-R: SF has strong psychometric properties and has been found to be a reliable and valid measure of problem solving abilities (D'Zurilla, Nezu, & Maydeu-Olivares, 2002; Hawkins, Sofronoff, & Sheffield, 2009).

Matt's total social problem solving standard score was 70 which is below the normative group average. For positive problem orientation his standard score was 100 and for rational problem solving it was 92, these both fall within the normative group average. His negative problem orientation and avoidant style both fell within the above normative group average at 129 and 122 respectively. Finally, his impulsivity/carelessness style standard score was a 145 which indicated that he is extremely above the normative group average.

These overall scores indicate that Matt has a defective or dysfunctional approach to problem solving and that he is more likely to view problems as a threat to wellbeing. These scores suggest that he will doubt his ability to solve problems, and will become frustrated and upset when confronted with problems in his day to day life. When presented with problems, Matt may either procrastinate and avoid them, or try and impulsively solve problems without thinking through effective strategies. Therefore, training in effective problem solving would be beneficial for Matt

Goals for therapy

1. "To get out of home on my own"
2. "To get back to school"
3. "To hang out with my mates again"

Case Formulation

Matt is a 15-year-old male, presenting with Post Traumatic Stress Disorder following the experience of a traumatic event where he was physically assaulted. Matt has experienced a 3-month history of recurrent, involuntary and intrusive, memories of the assault which he finds distressing, as well as psychological distress and physiological reactions (heart pounds, begins sweating) when exposed to reminders of the event. Matt avoids external reminders of the assault and does not feel comfortable talking about it. Matt is also quick to anger, has difficulty sleeping, struggles with concentration, has experienced a reduction in pleasurable activities and is isolating himself from his friends.

Matt may have been genetically predisposed to developing PTSD as there appears to be a family history of mental illness, as evidenced by his great Aunty who was prescribed medication for a psychological condition and admitted to an in-patient unit, and his Mothers experience of anxiety (although she did not have this formally diagnosed). Matt's Dyspraxia may also be a predisposing factor for his anxiety as research states that individuals with dyspraxia are at a higher risk of developing anxiety than typically developing individuals (Missiuna et al., 2014).

Exposure to his mother's seemingly anxious nature and perhaps a possible threat and danger oriented cognitive style may also be a predisposing factor. It is possible that Matt may have learnt and adopted a similar cognitive style where he believes all situations involve some level of fear or danger, thus creating core beliefs such as "the world is dangerous" and "I can't trust others", which would predispose him to distress and anxiety in multiple situations. Although Matt's parents are supportive, their protective nature may have predisposed Matt to his current anxiety as he may have missed opportunities to learn how to accurately detect threats in new situations as well as to learn that he can cope with difficult situations.

The precipitating factor appears to be the physical assault Matt experienced in December last year. This could have reinforced possible core beliefs of “I can’t trust others” and “the world is dangerous”. The fact that the perpetrators are in the community and at school may also be perpetuating his distress and Matt’s fear of them may be somewhat rational as they could potentially harm him again.

Matt’s avoidance of situations that remind him of the traumatic event (e.g. school, the mall, the library, streets the community) is a perpetuating factor as this reduces opportunities for him to habituate to the perceived threat in these situations or to realise that he is actually safer in these situations than he predicts. This avoidance also reduces his social contact which may also be a perpetuating factor for his irritability and lack of interest in activities he used to enjoy as he does not have the opportunity to reap the positive benefits (e.g. increase in mood and self-efficacy) that social activities provide.

The dyspraxia may also be perpetuating Matt’s anxiety as a common symptom is an inability to plan and organise thoughts (Colley, 2006). This may be making it difficult for Matt to process and rationalise the event as well as the level of threat prevalent in other situations.

Matt also appears to use his parent’s as a safety behaviour as he will not go anywhere without one of them accompanying him, thus again reducing his opportunity to habituate to the anxiety that these situations elicit. Tom (Dad) and Shirley’s (Mum) parenting style may also be a perpetuating factor as their overprotection may serve to accommodate or enhance the avoidant strategies that Matt appears to be using. Also, a lack of knowledge about anxiety and what maintains it (e.g. avoiding feared stimuli) by Matt and his family may be an additional maintaining factor.

Matt has many protective factors including his motivation for therapy and his recognition that he needs to learn some extra strategies to help him recover. Matt is polite and has an easy-going nature which allowed for establishment of rapport and a strong therapeutic relationship. Matt is also goal orientated and wants to get into the army. He has done his research and acknowledges what is involved in this process and is therefore motivated to complete NCEA level 1 and 2. Matt's good physical health and engagement in physical activities such as boxing are strengths. Although Matt's parents are somewhat over-protective, their lack of conflict, supportive nature and commitment to helping Matt are protective factors.

Diagnostic Considerations

Matt meets the DSM-5 criteria for Post Traumatic Stress Disorder.

Benefits of my doctoral research to my clinical practice

My doctoral research has enriched my clinical psychology training in a number of ways. I have divided these into four sub headings. The first is experience working with symptoms of brain trauma/cognitive decline and other difficulties that accompany these, the second is the learning of problem solving therapy itself, the third is general learnings and the final is the enhancement of my group facilitation skills. The following section will discuss how my research has helped me to develop as a clinical practitioner and will be related to my work with Matt.

Clients with brain trauma and/or cognitive decline

Through my work with the younger stroke survivors, I gained experience working with individuals with physical and/or cognitive symptoms following stroke. This knowledge can be used to incorporate into my future work with clients who have experienced brain trauma and/or cognitive decline. I have learnt how to adapt my

treatment plan to compensate for any cognitive difficulties that my clients may present with. This includes a careful consideration of what therapeutic techniques would be appropriate and effective for my client's cognitive capacities.

For the younger stroke survivors, the therapy of choice was problem solving therapy. I chose this as it is a practical therapy which focuses on behavioural tasks to make adaptations in the stroke survivors' day to day lives (Mynors-Wallis, 2005; Nezu, Nezu, & D'Zurilla, 2012). Alongside this, individuals who partake in problem solving therapy learn strategies to cope more effectively with problems they encounter (Mynors-Wallis, 2005; Nezu et al., 2012). I chose more practical/behavioural approaches over the traditional CBT approaches such as cognitive restructuring, which teaches clients to monitor and challenge the thoughts, assumptions, and beliefs that may bring about their distress (Beck, 2011). I felt that extensive cognitive restructuring may have been unsuitable for stroke survivors due to common symptoms of stroke such as difficulties with communication, memory, processing speed and attention. Further, Kangas and McDonald (2011) commented that individuals with cognitive impairment might find this explicit metacognitive strategy difficult.

As Matt presented with Dyspraxia, he experienced a difficulty with articulation and understanding of language, as well as a difficulty planning and organising his thoughts, therefore the treatment plan was adjusted to accommodate this. As with the younger stroke survivors, Matt's treatment plan followed a more practical and behavioural approach rather than focusing on cognitive processes such as cognitive restructuring. This included exposure work to address his symptoms of PTSD as well as problem solving for other difficulties that had become overwhelming for Matt.

I have learnt how to adapt my communication style accordingly so it suits the individual's cognitive level. For example, the importance of short succinct sentences with

pauses in between to compensate for any delay in information processing. My work with the younger stroke survivors has also reiterated the importance of not using psychological jargon such as “problem orientation”, (terminology that is intrinsic to PST), as the participants provided negative feedback on this. These are skills that I was able to implement with Matt to compensate for his difficulty understanding language. Throughout our sessions together I made sure that my language was appropriate for his level of competency, and I continuously checked in with him to make sure he was following the therapeutic content.

In order to compensate for memory difficulties with the younger stroke survivors, I included visual aids (e.g., a manual with diagrams and numerous handouts) to help with memory consolidation. This is something that was included in my work with Matt, as he often struggled to remember what had been discussed in the previous session. At the end of each session with Matt (and the younger stroke survivors), I always made sure that enough time remained so that we could summarise what we had covered together, in the hope that repetition of the information would assist Matt to remember the content. We also went through the manual and handouts together as an additional form of content repetition.

I have also learnt to consider practical implications to compensate for any physical disabilities that my clients may have. For example, the use of materials for people who cannot use their dominant hand, which is a common symptom of stroke. Although unfortunately, I did not have the research budget to provide digital equipment for my group participants, they were encouraged to bring along any materials that would assist them in recording information from the sessions (e.g., a laptop or voice recorder). Visual difficulties are something that I will always consider as a result of my research process, and I will adapt materials accordingly. Vision is often affected post stroke and

my research study used four different psychometrics (including the SPSI-R:SF which is printed in very small blue writing). While fatigue and frustration were considered at the outset during test selection, vision was not. Many of the participants provided feedback regarding the difficulty they had reading the survey which may have impacted the validity of their answers. The layout of the therapy room for individuals who use walking aids or are in wheel chairs is also something that I have learnt to adapt accordingly.

Working with the younger stroke survivor population also reminded me to remain humble in my interactions. For example, in the first session of each group, we did a round of introductions. I introduced myself and informed the group members of the clinical psychology programme that I am enrolled in. One of the young stroke survivors began her introduction stating that she “would never beat that”. This reminded me that therapist self-disclosure has the ability to affect the client as well as the therapeutic alliance and this should always be taken into consideration so what is said is appropriate. In future introductions with similar populations, I will be more likely to introduce myself using more neutral comments. This is something that I incorporated into my initial session with Matt (and with other clients). I now follow the structure of my pepeha when I introduce myself; this incorporates where I grew up and my family structure rather than a focus on academic achievements.

Working with a stroke population also enhanced my understanding of the importance of support persons. The current study had a number of participants who required a support person and appeared grateful that they could bring them along to the group. The support persons were also able to provide good insight into the stroke survivor’s situations which may have been therapeutically beneficial. Matt’s parents joined Matt in the initial assessment sessions and were able to describe Matt’s change in behaviour from before the assault to what he is now presenting with. This was helpful for

my formulation which in turn informed Matt's treatment plan. In the beginning, Matt's parents were also able to alleviate some of his anxiety in getting to therapy, as due to his symptoms of PTSD, Matt did not feel comfortable going anywhere on his own. Although as mentioned earlier, this was somewhat of a safety behaviour for Matt so this was addressed throughout therapy.

Alongside this, I also learnt how to balance information gathering from two sources in assessment sessions (i.e. caregiver and stroke survivor). Having a caregiver in the room proved to be beneficial to a point, however, I had to learn how to gently guide the conversation back to the stroke survivor and encourage them to speak for themselves wherever possible. As although it was helpful to hear the caregivers' perspectives of their partners/family members/ clients difficulties, it is often the stroke survivor who can best explain what was going on for them and they, therefore, needed space to do this. The stroke survivors also needed to feel validated and heard, thus increasing the importance of time taken to hear their story. I also needed to learn how to manage caregiver's anxiety and concern with regards to the younger survivors' wellbeing so that it did not take precedence over the stroke survivors' difficulties. This is knowledge that I was able to implement in the initial assessment sessions with Matt, as his mother would often either answer my questions immediately or interrupt Matt and speak over him. To balance this, I would direct my eye contact at Matt or use his name when I wanted an answer from him. I also had to gently explain that although I appreciated her input, it was important for me to hear Matt's perspective.

I also had to learn to work with caregivers whose behaviours may have actually been perpetuating the younger stroke survivor's difficulties, such as preventing them from leaving the house or carrying out tasks independently for fear that they may suffer another brain injury. Learning how to approach this respectfully and validating the

caregivers' concerns whilst using psychoeducation to gently explain that their behaviours may in fact not be helping was a valued skill that can be used with caregivers in my internship work. With Matt's parents, I used psychoeducation to explain the importance of exposure work before setting him homework tasks to complete. This allowed Matt to learn how to expose himself to anxiety evoking situations without the use of safety behaviours (having Mum and Dad accompany him).

Problem Solving as a therapeutic technique

Receiving training in and learning the steps of problem solving therapy for the benefit of my research has been very helpful and this has been something that I have been able to use in my therapy sessions with my clients.

As with any other therapy, it is important to understand the theory behind the techniques used. The process of learning PST increased my understanding that client's symptoms may stem from an inability to cope effectively with their day to day problems. Therefore, PST offers clients training in adaptive problem solving attitudes and skills. It is assumed that if the client acquires more effective problem solving strategies, then the patient's symptoms should improve. Thus, preventing psychopathology and increasing positive well-being in clients so that they can deal more effectively with stressful problems in their day to day lives (Mynors-Wallis, 2005; Nezu et al., 2012). This is a model that I was able to describe to my stroke survivors as well as clients such as Matt that I have used the problem solving techniques with.

I also learnt the seven steps of problem solving therapy which therapists use to teach a step-by-step process to solve life problems (Mynors-Wallis, 2005; Nezu et al., 2012). Table 16 outlines the seven steps of problem solving therapy.

Table 16

The seven stages of problem-solving treatment (Mynors-Wallis, 2005)

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1. Explanation of the treatment and its rationale.
 2. Identification, definition, and breaking down of the problem.
 3. Establishing achievable goals.
 4. Generating solutions.
 5. Evaluating and choosing the solution.
 6. Implementing the chosen solution.
 7. Evaluating the outcome after the solution has been implemented.
-

Therapy begins with an explanation of the link between the distress that the client is experiencing and the practical difficulties that they are currently facing. To establish this link, clients are encouraged to identify their psychological symptoms, such as low mood, loss of appetite, irritability or worry. They are then asked to create a list of problems they are currently experiencing. The link is then made between the experience of these problems and their symptoms.

During stage two the participant is asked to choose a problem to work on from the list they generated during stage one and define it. This involves the identification of the following four aspects (Mynors-Wallis, 2005)

1. What is the problem?
2. When does the problem occur?
3. Where does the problem occur?
4. Who is involved in the problem?

During stage three the client and therapist work collaboratively to establish what the goal is that the client wants to achieve. This involves an explanation of S.M.A.R.T

goals. They should be Specific, Measurable, Achievable, Relevant, and Timed (Mynors-Wallis, 2005; Nezu et al., 2012).

The next stage involves the generation of solutions. Clients are encouraged to brainstorm as many possible solutions to the problem that they can think of. Creativity is encouraged and no solution is disregarded. In stage five clients are required to evaluate the pros and cons of each solution, and choose the solution they think will be best for solving their problem (Mynors-Wallis, 2005; Nezu et al., 2012).

In stage six the client is required to generate a clear action plan for the preferred solution. The aim is to make the plan as clear as possible; therefore, it should include specific dates, times and resources needed. Participants are then encouraged to go away and implement said plan. The final stage of PST occurs in the next session and involves an evaluation of the outcome after the solution has been implemented (Mynors-Wallis, 2005; Nezu et al., 2012).

As mentioned previously Matt presented with difficulties in problem solving, therefore, the seven steps to problem solving therapy were incorporated into Matt's treatment plan. One session was spent teaching Matt the steps and the problem solving structure was used throughout the course of therapy when Matt discussed problems that he was unable to solve. As therapy progressed Matt became more effective in solving his own problems and was able to work through the seven steps on his own.

General learnings

I also had practice in varying my therapeutic style to the needs of each individual client. Some of the stroke survivors appeared to appreciate a more empathetic style, whilst others preferred an interaction style with less effect. Being able to read each client, determine their needs and adapt accordingly are skills that will be helpful as I progress

with my clinical training. Matt seemed to prefer a less empathetic style that was more direct and incorporated challenges; therefore, this was the style I followed with him.

Maintaining a therapeutic alliance and professionalism in the face of anger at government agencies was also a challenge that I encountered and grew from. Many of the stroke survivors expressed their opinions regarding the health care they had received and often looked to the group facilitators for agreement. I had to maintain a level of professionalism (i.e., not speaking badly about these professional agencies) whilst validating the distress that the group members were experiencing. This is something that arose with Matt's case. Both Matt and his parents were angry at the school for the way they were handling the assault, as Matt was put into the same class at the beginning of the year as the perpetrators. This was something that was often expressed in session; therefore, I had to validate these concerns without saying anything that would compromise my professionalism.

As clinical psychology trainees, the ability to listen to feedback and apart accordingly is an effective skill. I was able to practice asking for feedback and being appreciative of constructive criticism so I could adapt the sessions accordingly. Ways that I adapted the therapy was through my communication style (e.g., slowing my speech down) and my use of language (e.g., not using the psychological jargon inherent to PST). This provision of feedback also improved my self-reflection skills which are valuable for an effective and safe practice. The feedback also allowed for a more collaborative style of therapy which is an important aspect of the therapeutic process as it provides the client with more autonomy and agency which can boost confidence and morale. Feedback is something that I elicited from Matt at the end of each session in case our sessions needed to be adapted. In order to generate feedback, I would verbally ask Matt at the end of each session how he found the work and asked if he required any changes. I also used the

Outcome Rating Scales (ORS; Miller, Duncan, Brown, Sparks & Claud, 2003) and Session Rating Scales (SRS; Duncan, Miller, Sparks, Claud, Reynolds, Brown & Johnson, 2003) at the end of every session.

Finally, the current study has increased my understanding and execution of the scientist practitioner model. Namely, the practice of collecting data regarding the client's progress and analysing said data in order to evaluate the effectiveness of the intervention and then adapt accordingly. In order to assess Matt's progress, the psychometric originally used to assess his PTSD symptoms (PCL-C) was used multiple times throughout our sessions. Increasing my knowledge regarding the scientist practitioner model also affords me with a more solid understanding of the literature that will inform my practice.

Group facilitation

The PST sessions resulted in an improvement of my group facilitation skills in that I improved my personal skills of creativity and flexibility in order to facilitate discussions that were not only beneficial to the group but keep them interested and involved. Further, I worked on refinement of my clinical skills such as minimal encouragements and active listening to encourage communication within the group so that the facilitator and I were not doing all of the talking.

Being able to consider, listen to and validate each client's stories and opinions can prove difficult when group members are from different backgrounds and there are varying strong opinions within a group, particularly with regards to culture, gender, spirituality, and politics. It is important that group facilitators monitor the level of emotional intensity so that it does not escalate and prevent progress within a session. I was able to practice ensuring that each group member felt validated whilst gently manipulating the conversation back to a more non-judgemental, neutral ground to avoid or lessen any conflict.

I was able to practice my organisation skills as a result of having to balance participants' availability, for example, some participants worked or had children, and therefore, they could only attend sessions after hours or in their lunch breaks. This involved a considerable amount of organisation and flexibility. Dealing with lateness or missed sessions was also something that I learnt to adapt to. This involved spending some extra time with the late participants during or after the session, or contacting participants between sessions. Having the co-facilitator at every session made this process a lot easier.

At Kapiti Youth Support I have had the opportunity to complete group work as I have lead sessions with our LGBTIA¹ group. I will also have more opportunity to implement my group facilitation skills in the second half of the year as I will be facilitating a group run for youth with challenging behaviours.

Conclusion

My doctoral research involved the implication and evaluation of Problem Solving Therapy with younger stroke survivors who were suffering from symptoms of anxiety and depression. This process has been a valuable experience for a number of reasons and this document refers to how my research has contributed to my advancement as a clinical psychology intern using the case of Matt to highlight some of these learnings. Namely, it increased my competency in working with individuals who have suffered a brain injury or experience cognitive deficits, it resulted in training in problem solving therapy and it provided experience with group therapy. I look forward to the advancement of my clinical training even further and the opportunity to implement these skills.

¹ LGBTIA refers to Lesbian, Gay, Bisexual, Transgender, Intersex and Asexual

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APPENDIX B: ONLINE SURVEY FOR STUDY 1

Information Page



The experiences of younger stroke survivors post stroke Information Sheet

Who is doing this research?

My name is Charlotte Wainwright, and I am a student at Massey University. I am currently conducting this research project as partial requirement of completing a Doctoral degree in Clinical Psychology. The primary supervisor for this project is Professor Janet Leatham.

What is this research about?

This project is based on survey data and aims to investigate common problems experienced by younger stroke survivors post stroke in New Zealand. The findings of the current study can be used to inform healthcare professionals of specific problems that younger stroke survivors experience post stroke, so that these can be focused on during the rehabilitation process. The findings may also benefit future research with the aim of reducing psychological distress post stroke. You are invited to complete this survey, which will take approximately 5 to 10 minutes of your time.

Who can participate?

If you are between the ages of 18 and 65 and have suffered a stroke, you are invited to participate in the current study.

Your rights as a participant

Your participation in this study is entirely voluntary. You are free to decline to participate. If you do agree to participate in this study, you may withdraw at any time without being penalized for doing so. Completion and submission of the questionnaire implies consent. You are free to omit answers to any particular questions if you wish.

Data collected during this investigation will be securely stored at Massey University. Participation in this investigation is anonymous and the data will be viewed only by the researcher, the primary supervisor, and the computer programmer/analyst of the School of Psychology of Massey University. All data will be stored for ten years, after which it will be destroyed.

You have the choice to enter into a draw to win a \$100 supermarket voucher on completion of this survey. Information for this will be provided at the end of the survey.

What happens after the study?

You can choose to be sent an information sheet with the results of the study. These results will

be summarized and will be in the form of grouped test results. No individual results will be identifiable.

How do I begin?

Completion and submission of the following questionnaire implies your consent to participating in the research

Please click on the >> **Next** button below if you would like to continue and participate in this research.

Contact information

Thank you very much for your time and help in making this study possible. Please contact me or if you have any questions or complaints about this study:

Researcher

Charlotte Wainwright, Doctoral Student School of Psychology
Massey University Wellington
Telephone: +64 4 801-5799 extension 63783 Email: [REDACTED]

Supervisors

Professor Janet Leathem School of Psychology Massey University Wellington
New Zealand
Telephone: +64 4 801-5799 extension 63610 Email: J.M.Leathem@massey.ac.nz

Doctor Simon Bennett School of Psychology Massey University Wellington
New Zealand
Telephone: +64 4 801-5799 extension 63609 Email: S.T.Bennett@massey.ac.nz

Massey University School of Psychology – Te Kura Hinengaro Tangata
Wellington, New Zealand
T +64 4 801-5799 ext 63210 : W psychology.massey.ac.nz

*This project has received ethical approval from the Health and Disability Ethics Committee,
Application Number: 15/CEN/124*

*If you have any concerns about the conduct of this research that you wish to raise with
someone other than the researcher(s), please contact
Health and Disability Ethics Committee: Ph 0800 4 ETHICS; Email: hdec@moh.govt.nz.*

What is the highest qualification you have achieved?

5th form/ Year 11	Polytechnic Qualification
6th form/ Year 12	Undergraduate University Degree
7th form/ Year 13	Postgraduate University Degree

Time since stroke?

< 1 month	1 – 3 months
3 – 6 months	6 – 12 months
12 – 24 months	1 – 2 Years
2 – 3 Years	3 – 5 Years
5 – 10 years	> 10 years

Where are you currently residing?

Rented home	Own home
Parent's home	Rehabilitation centre

Are you currently in paid employment?

Yes	No
-----	----

If yes, were you in the same job prior to your stroke?

Yes	No
-----	----

If not, were you in paid employment prior to your stroke?

Yes	No
-----	----

Are you currently studying?

Yes	No
-----	----

Were you studying prior to your stroke?

Yes	No
-----	----

Experiences post stroke

Instructions

Thank you for participating in this study. This survey contains a series of questions regarding your experiences post stroke and has evolved from previous research outlining commonly experienced problems post stroke.

The findings of the current study may be used by health care professionals during the rehabilitation process post stroke, and also for future research aimed at reducing psychological distress post stroke. We appreciate your input.

The questionnaire requires roughly 5 to 10 minutes of your time.

Your responses are anonymous and data will be held in a secure file.

Please complete all the sections below if possible. You have the right to decline to answer any particular question.

NOTE: *The following questions may cause you some distress. Should this happen, please remember that you are free to cease participation in this survey at any time. Contact details will be provided at the end of this survey if you would like to talk to someone about any distress experienced.*

Many thanks for your assistance with this survey.

The following statements are examples of common problems experienced by stroke survivors. Please indicate the extent to which the following problems apply to you. You also have the option to expand on your answer and provide an example of when this has been a problem to you.

Since your stroke, how much of a problem is family life disruption?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*)...

Since your stroke, how much of a problem are marital problems?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem are intimacy problems?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is a difficulty forming new relationships?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is employment loss or employment disruption?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is a difficulty returning to, or beginning study?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is a difficulty with finances?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is a reduction in leisure activities?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem is loss of home?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem is social isolation?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem is limited access to community support services?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem is reduced intellectual fulfilment?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem is a lack of information post stroke?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example *(optional)* ...

Since your stroke, how much of a problem are problems with transport?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem are problems with invisible disabilities?

Invisible disabilities are consequences of stroke that cannot be seen by an observer. Fatigue and memory difficulties are examples of invisible disabilities.

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Since your stroke, how much of a problem is difficulty with self esteem?

Not at all a problem	Somewhat of a problem
A significant problem	A major problem all of the time

For example (*optional*) ...

Please list any other problems that you may be currently experiencing or have experienced since your stroke

Help	Help in times of distress
------	---------------------------

If you experienced any distress during the duration of this survey and would like to talk to someone about this, the following contacts are free phone services (available 24 hours a day) which provide confidential support to anyone who is experiencing emotional distress.

Samaritans	0800 726-666
The Depression Helpline	0800 111 757
Healthline	0800 611 116
Lifeline	0800 543 354
Youthline	0800 376 633

If you would like to talk to someone face to face, the www.hdc.org.nz website provides a list of mental health services in your area

APPENDIX C: INFORMATION SHEET FOR STUDY 2



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Participant Information Sheet

Study Title: The efficacy of Problem Solving Therapy for Younger Stroke Survivors

Locality: Psychology Clinic at Massey University of Wellington

Address: 24 King Street, Mount Cook (near the Basin Reserve)

Lead researcher: Charlotte Wainwright

Contact phone number: 0800 367 007

Ethics Committee reference number: 15/CEN/124

You are invited to take part in a research study to examine the efficacy of problem solving therapy for younger stroke patients.

My name is Charlotte Wainwright, and I am a Doctoral Student in Clinical Psychology at Massey University. As part of a research project, I am seeking volunteers to take part in a six week Problem Solving Therapy Course. I am recruiting stroke survivors between the ages of 18 to 65, as at present there is very little research aimed at the benefits of psychotherapy for this age group. I am conducting my research under the supervision of Professor Janet Leathem and Doctor Simon Bennett.

This study will involve up to 56 individuals ages 18 to 65, who have suffered a stroke. Ten groups of six to eight people will be formed. Whether or not you take part is your choice - participation is entirely voluntary. If you do not wish to take part you do not need to give a reason, and it won't affect your future health care in any way. If you do want to take part, but change your mind later, you can pull out of the study at any time. You may wish to talk to a friend, family or whānau member, or a healthcare provider before you make a decision. Feel free to do this. Please note that there are no costs involved in taking part in the study.

If you have any questions regarding the study please contact me on the above 0800 number. If you agree to take part in this study, please sign the Consent Form on the last page of this document and return the document using the provided free post envelope. You will then be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 7 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the purpose of the study?

The aim of this study is to evaluate the efficacy of problem solving therapy with younger stroke patients for symptoms of depression and anxiety, low quality of life, and problem solving abilities. Research has shown that younger stroke patients express a number of unmet needs and problems following stroke. The research regarding the use of problem solving therapy, to work through these issues is very promising. It is hoped that the current study will contribute to a clearer understanding of the benefits of problem solving therapy with younger stroke patients.

What will my participation in the study involve?

Participation in this study will involve six sessions for six weeks. For the problem solving therapy group, the first two sessions will be 90 minutes, the remaining four will be 45 minutes. The whole study will consist of seven visits: a one on one interview (approximately one hour) and six group sessions. The total involvement time for this study will be approximately 8 hours. There may be some simple homework activities for you to complete during the week to put into practise the skills that you learned during the sessions.

The initial one on one interview will involve four short questionnaires (approximately ten minutes per questionnaire). These will measure your anxiety and depression symptoms; your quality of life; and your problem solving abilities. After the final session, you will be asked to fill out the same four questionnaires. These same four questionnaires will be sent to you to fill out three months after the final therapy session. Please note that you do not have to answer all the questions and you may stop the interview at any time. All participants will be offered a summary of the findings at the conclusion of the study.

Who can participate?

If you are/have:

- Had your stroke between the ages of 18 and 65 and
- Willing and able to take part in six therapy sessions and
- Not suffering from severe aphasia

What is Problem Solving Therapy?

Problem solving therapy (PST) is a brief psychological intervention, which is usually carried out over a series of four to eight sessions. PST can be run individually or within a group format. Throughout the sessions the therapist and the attendees work collaboratively to identify certain problems that are occurring in the attendee's lives. The focus is then placed on one or more of these identified problems in order to develop a structured plan to solve the problems. Throughout these therapy sessions there is also a focus on improving the attendees' general approach to problem solving, so that they can deal more effectively with problems in the future.

Problem Solving Therapy involves a number of different steps

- Explanation of the treatment and it's rationale
- Identification and definition
- Establishing SMART goals

- Generating solutions
- Evaluating and choosing the solution
- Implementing the solution
- Evaluation

What are the possible benefits and risks of this study?

Stroke survivors often experience a number of problems, that if unresolved can lead to frustration and stress. These problems can vary from basic day to day tasks such as dressing and grooming, to more complex issues such as unemployment and relationship difficulties. Research has shown PST helps individuals to cope more effectively with both minor and major stressors in order to reduce the impact of problems in day to day life. PST can be used to work with problems arising from Stroke by breaking down the complex problems into more simple problems that can be easier to manage.

It is therefore anticipated that participants will benefit from taking part in the study by attaining the skills to cope with salient problems and learning how to manage them more effectively. Participants are also expected to notice improvements in psychological wellbeing such as a relief of symptoms of depression and anxiety and an enhancement of quality of life.

The potential risks of participating in this study are minimal. You may experience some discomfort with regards to discussing your problems within a group format. However, we will have a behavioural contract within our groups, which will ensure confidentiality, and you do not have to say anything that makes you feel uncomfortable.

This study has been approved by the Health and Disability Ethics Committee and has been funded by the Massey University Postgraduate Research Fund.

Who pays for this study?

You will not be expected to pay any money to participate in this study. As thanks for participating in this study and to offset the cost of transport, you will receive your choice of either a \$20 petrol voucher or a \$20 supermarket voucher for the initial assessment session, and another voucher once you have returned the questionnaires sent out three months after the final therapy session. Should you have difficulty getting to therapy sessions, the researcher will organise transport to get you to the venue.

What if something goes wrong?

If you were injured in this study, which is unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What are my rights?

Your participation in this study is entirely voluntary. You are free to decline to participate. If you do agree to participate in this study, you may withdraw at any time without being penalized for doing so. You have the right to access information collected about you as part of the study. Please contact the lead researcher directly if you would like to do so.

You will be informed of any new information that becomes available during the study during the assessment sessions or via a phone call.

Will my information remain confidential?

The interview and questionnaires are anonymous, and files will be coded with anonymous identification numbers to prevent identification of individuals. Only the researcher and supervisors directly involved in the study can access any written material. All material will be kept in a secure location and destroyed after 10 years. No material that could personally identify you will be used in any reports on this study. Please note that while confidentiality will be encouraged in groups, it cannot be guaranteed due to the nature of group work. The information collected will be used for the research project and may be submitted for publication in an academic journal; only collective data from the entire sample will be described. Further, should your discussions reveal any concern about your mental health, than this information may be shared with a mental health professional. This will be discussed with you first.

What happens after the study?

You can choose to be sent an information sheet with the results of the study. These results will be summarized and will be in the form of grouped test results. No individual results will be identifiable.

Thank you very much for your time and help in making this study possibly. Please contact me if you have any questions or complaints about this study:

Charlotte Wainwright, Doctoral Student
Telephone: 0800 367 007
Email: [REDACTED]

Professor Janet Leathem
Telephone: 04 8015799 extension 63610
Email: J.M.Leathem@massey.ac.nz

Doctor Simon Bennett
Telephone: 04 8015799 extension 63609
Email: S.T.Bennett@massey.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Maori health support please contact:

Name: Te Roopu Pookai Taaniwhaniwha
Address: 213/215 Bedford St
Cannons Creek
Porirua
Phone: 04 237 9608

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

APPENDIX D: CONSENT FORM FOR STUDY 2



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Consent Form

The efficacy of Problem Solving Therapy for younger stroke survivors

I have read and I understand the participant information sheet.

I have had the opportunity to discuss this study with the researcher, and I am satisfied with the information I have been given. I have a copy of this consent form and information sheet.

I have also had the chance to seek support from whānau, family members, friends, legal aids, and/or health care professionals to help me make my decision regarding participation in this study.

I have had sufficient time to decide whether or not to take part in this study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from this study at any time, and this will in no way affect my continuing health care.

I consent to the research staff collecting and processing my information, including information about my health.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

Yes

No

I understand that the study will include a total of 7 visits, and will take approximately 8 hours to complete over a period of approximately 2 months.

I understand that my participation in this study is confidential and that only the researcher and her supervisor will see any data collected from me over the course of this study.

I wish to receive a copy of the results

I understand that I can contact the researcher or supervisors if I have any questions about this study:

Charlotte Wainwright, Doctoral Student

Telephone: 0800 367 007

Email: [REDACTED]

Professor Janet Leathem

Telephone: 04 8015799 extension 63610

Email: J.M.Leathem@massey.ac.nz

Doctor Simon Bennett

Telephone: 04 8015799 extension 63609

Email: S.T.Bennett@massey.ac.nz

I _____ hereby consent to take part in this study.

Signature:

Date:

Study explained by:

Signature:

Please write your contact details below, so that the researcher can contact you on receipt of the consent form.

Phone Number:	
Email Address:	
Postal Address:	

This project has received ethical approval from the Health and Disability Ethics Committee, Application Number: 15/CEN/124

If you agree to take part in this study, please sign this Consent Form and return the document using the provided free post envelope.

Problem Solving Therapy for Younger Stroke Survivors

**Group sessions to help younger stroke survivors cope
more effectively with problems that arise in their day to
day life**

Guidelines for programme facilitators

Sessions adapted from Mynors-Wallis (2005) and Nezu, Nezu and D’Zurilla (2013)

****Note: This manual is simply a rough guideline of the content that will be covered. Flexibility will be ensured. The therapist will ensure that the group members feel as comfortable and engaged as possible. Rapport will not be compromised for the sake of structure.***

Session one

Session 1 – Introduction to problem solving therapy and problem list

Materials: Participant manual, the “what is effective problem solving” handout, the “SSTA model” handout, the effective vs. ineffective problem solving hand-out, the problem indicator handout, the problem list handout

Welcome to the Problem Solving Therapy group programme. This is a six week programme that will help you learn how to solve problems in your lives more effectively. The first two sessions will be 90 minutes long. The last four will be just 45 minutes.

Introductions of facilitators and participants

Before we begin we have a few housekeeping aspects to cover, but before that introductions – if you could just say your name, when you had your stroke and a bit about yourself so that we can all get to know each other a little better.

**Activity: Go around the room and everyone introduce self to the group.*

So ... housekeeping ...

1. Confidentiality
2. Group rules and behavioural contract
3. Collaboration
4. Commitment
5. Homework
6. Feedback forms

Confidentiality

Everything you say here today will remain confidential; however, there are a few exceptions to this. Firstly, as a clinical psychology student, one requirement is that I have frequent discussions with my supervisor, and we may have a talk about our sessions. The second is that if there is any risk of harm to you or others I may need to contact the appropriate authorities. I will try to talk to you about this first, however sometimes this isn't always possible.

Group rules and behavioural contract

This is a collaborative process; we will work together as a group to learn the seven steps of problem solving therapy. A lot of the tasks we can't do for you. The best way for you to learn is to attempt all of the tasks. We will be here to demonstrate for you, guide you and answer any questions you may have. But we need to work together for you to get the best out of these sessions.

Just some final housekeeping things...

Commitment

As I said when we spoke by phone and our meetings, it is important that you attend all six sessions. This will ensure that you'll make the most out of problem solving therapy and to learn the steps effectively. And, as a courtesy if something *does* come up would you please let me know.

Homework

Every week there will be some "homework". Yes – I know....

People understandably have very mixed reactions to the idea of homework. So, if you are now thinking "oh no" please do not be discouraged.

Homework is just another word for independent practice. It is a chance to try out what you have learned, knowing you also have the support and help of Tamrya and me if you get stuck.

We will talk about homework at the beginning and end of most sessions. Do not worry if you get stuck as we will address successes and difficulties in the following session. Just give the homework tasks your best shot and think of them as the best avenue to enhance your newly learned skills.

Feedback forms

At the end of each session, it would be wonderful if you could fill out the feedback form which the co-facilitator will hand out, and place them in an envelope so I do not see them until after we finish our therapy together. This is so we can determine what is helpful and unhelpful to you, so that other young stroke survivors can benefit from future therapy in problem solving. If you could please write your names on the form, that would be great. This is because my supervisor will be monitoring these for any issues of risk, or any changes we need to make during the therapy sessions. As I mentioned before I will definitely not see these until after our sessions are over, so please be as honest as possible.

So that's the housekeeping!

Now on to the therapy. The 6 sessions will cover the Seven Steps of Problem Solving Therapy.

You've probably not heard of it, but if you go to page four of your manual you'll see that PST follows seven steps.....

These include explanation and rationale, problem definition, establishing goals, generating solutions, evaluating and choosing the solution, implementing the solution, and evaluation. This first session will focus completely on the first step of PST, the explanation of and rationale behind problem solving therapy, as well as some tips to maximise your problem solving skill learning. We'll be covering just what the therapy is about and why it has proven useful in the past and why it's likely to be helpful for you.

A note on problem solving

Unfortunately, not every problem can be fixed. Sometimes, the best option for working through a problem is to accept that the problem exists. An example of this may be a loss of a loved one. No matter how hard you try and problem solve, unfortunately it won't bring that person back.

The good news is that you can use the steps that you will learn during these six sessions to alter your reactions and attitudes to problems that may arise. Secondary problems that arise from these uncontrollable events can also be worked on using problem solving therapy. For example, an individual may experience social isolation after the death of their husband. This is a problem that can be worked through.

Problem solving therapy concentrates on the here and now rather than on mistakes of the past. Therefore, we will focus on improving the future rather than regretting the past.

Problem-solving may not solve all your difficulties, but it can help you to start dealing with your problems. As your symptoms improve you will feel more in control of your problems and your life.

Problem Orientation

Firstly, we will have a chat about problem orientation and style as it is important to understand what effective and ineffective problem solving actually are, before we teach the steps towards effective problem solving. This may also help you to see what your approach to problem solving is now, and to determine whether you need to make any changes.

The first hand-out we will be using is titled "What is Effective Problem Solving" and this contains some information about problem orientation and style.

**Hand-out: Give out "What is effective problem solving hand-out"*

Problem orientation is the way that someone reacts to problems that they encounter in their day to day lives. This includes a focus on the way that the person thinks and feels about a problem. Problem orientation can be either positive or negative. Your hand-out provides examples of common attitudes that align with positive and negative problem orientations.

**Activity: Facilitator to discuss problem orientation with group and give examples*

Problem Solving Style

Problem solving styles describe peoples' behavioural reactions when presented with problems. You will see in your hand-out that these can be effective or ineffective. Effective problem solving follows a planful problem solving style, whereas ineffective problem solving follows an impulsive-careless style or an avoidant style.

**Activity: Facilitator to discuss problem solving style with group and give examples.*

Have a think about what type of problem solver you are. Here's an example...

A person may receive a bill in the mail that is far more than he can afford. An individual with a positive problem orientation will view this problem as a solvable challenge and will be realistically optimistic that they can solve it. A person with a negative problem orientation will become overwhelmed by the bill and will become emotionally distressed. An impulsive problem solver may immediately pay the bill using their credit card but incur large interest fees from the bank. An avoidant problem solver may hide the bill in the back of their draws, and may deny that they even received it. On the other hand, a planful problem solver may do their research about different options to pay the bill. They may ring up the company who supplied the bill and talk to them about payment plans with low interest. Or they may talk to their family or friends about a loan, or schedule an extra few shifts at work so they can pay off the bill.

An extra tip on how to become an effective problem solver

An important part of effective problem solving is learning how to stop, take a breath and think when you encounter a problem.

We call this the SSTA model

**Hand-out: Give out SSTA method hand-out*

S = STOP

S = Slow Down

T = think

A = Act

So, we do this for the following reasons...

- You want to STOP the tendency to think negatively about the problem.
- Watch for negative self talk such as “I can’t do this”, “Bad things always happen to me”, “this is too hard”, “this is all my fault”.
- You want to STOP the tendency to avoid or run away from the problem.
- You want to stop the tendency to make impulsive decisions to try and solve the problem.
- You want to stop the tendency to choose what seems the easiest or fastest solution without thinking it through.
- Use more positive self statements when a problem occurs such as
 - I can solve this problem
 - If I try, I can do it
 - There will be an end to this difficulty
 - I can cope with this

You can then take the time to think more planfully about what to do about the problem, with a less negative emotional response.

You can then proceed with the problem solving steps which you will be taught in the next few sessions

Explanation and Rationale

**Hand-out: Give out effective vs. ineffective problem solving hand-out*

Now we will move on to explanation and rationale of Problem Solving Therapy. You will see on the third hand-out that we give you that there is a diagram. This diagram demonstrates how stress, as a result of both major life events and continuous daily problems, can eventually result in either positive adjustment, or emotional problems which can affect wellbeing. According to the figure, in order to reach positive adjustment, one needs to employ effective problem solving, such as a planful problem solving style. Whereas, ineffective problem solving, such as an impulsive style or an avoidant style can lead to emotional distress.

Unresolved problems in our lives can cause us to feel down or blue. They can make us feel like our life is getting out of control and overwhelming us. Problem-solving treatment is a systematic method for learning to clarify our problems and find solutions for them. As we start to make progress on solving our problems, we start to feel more in control of our lives, and with this increased feeling of control we start to feel an improvement in our mood. Improvement follows action, so we will put a lot of emphasis on having definite tasks for you to work on, at home, between visits.

Recognition of psychological symptoms

As mentioned earlier, unresolved problems in our lives can result in a number of negative symptoms. In order to understand that symptoms are caused by problems that we are experiencing in our lives we need to recognise what these symptoms are. These can be negative feelings, physical symptoms, negative thoughts, or negative behaviours and we will call these problem indicators. In your manual, you will see an example of some problem indicators. I will give you all a hand out now for you to write down your own problem indicators. We can then share them as a group if you feel comfortable with that. If not, I will give some common problem indicators.

**Hand-out: Give out problem indicator hand out*

**Activity: Participants to fill out problem indicator hand-out. Group to share their ideas if they feel comfortable doing so. Facilitator to draw problem indicator diagram on board.*

Recognition of problems

Next let's look at the problems that you are experiencing in your day to day lives. Remember to focus on the present, and to choose problems that are actually solvable. If you have a particularly complex problem, try to break this down into a number of smaller problems. Don't go into too much detail about the problems, we will move on to this in later steps. For now, just write down a broad overview of the problems you are experiencing.

**Hand-out: Give out problem list hand out*

**Activity: Give the group time to write down their own problems*

If participants are having trouble mentioning problems, facilitator can ask about the following different areas...

- Relationship with partner/spouse
- Relationships with children, parents, siblings, and other family members
- Relationship with friends
- Work
- Money
- Housing
- Health
- Legal Issues
- Alcohol and Drugs
- Leisure activities

Practical details of treatment

We are now approaching the end of our first group session together. I would like to briefly mention the practical details of the next five sessions. Session two will be approximately 90 minutes long and we will go through the remaining six steps of problem solving therapy. This session will also be collaborative with the whole group and we will use one problem to work on. The final four will be 45 minutes long and the work will be more independent. You will work through your own problems on your own problem list. We will be here to offer help and guidance. It is important that you are able to commit to the remaining five therapy sessions so that you can get the most out of it.

Homework

Your homework is very light this week. I would like you to read over the hand-outs we have given you this week and make sure you have an understanding of problem orientation, the therapy explanation and the therapy rationale. If you have any questions, note them down and we will address these at the beginning of the next session.

Feedback Form

Facilitator to step out of the room. Co-facilitator to hand out therapy session rating forms. Ask participants to place these in an envelope. Seal the envelope. Label the envelope session one.

Session two

Session 2 – Steps 2 through 6

Materials: *the “getting the facts!” handout, the SMART goals hand-out, the “generating alternative solutions” hand-out, the “potential solutions” hand-out, the my action plan hand-out, the homework hand-out*

Homework review

Does anyone have any questions about your homework review and what we covered last week?

Choosing a problem

Next we will choose a problem from our group list that we produced last week. We will use this problem to learn the next six steps of problem solving therapy. The problem needs to be not only significant and important but it also needs to be a feasible problem to learn these skills. We want the problem to be clear, specific and objective. It is a good idea to choose a simpler problem first so that you all can get a chance to learn these skills. It's not absolutely crucial which problem we choose for this first session. It's better

to choose a problem that you feel we can make some progress with rather than choosing one that is going to overwhelm us. More complex problems can be worked on in following sessions. The problem that we choose we will create in to a clear and specific problem statement.

Defining the chosen problem

The next step is to define the problem. This involves a number of questions beginning with who, what, where, when, why and how? We will now give you hand-out six which is titled "Getting the facts". You can write the problem on the top of the sheet. We will work through this together with the problem we have chosen on the board. Please note down your answers on this hand-out.

**Hand-out: Give out "Getting the facts" hand-out*

**Activity: Work through the definition together on the board. Participants to record the different aspects on their hand-out.*

Facilitator to record what is on the board

Establishing achievable goals for problem resolution

We now want to choose one or more achievable goals. The goals need to be realistic and attainable and we need to know what in particular we would like to see changed about our problem. This is something that we would like you as a group to come up with. As in future sessions when you are working on your own problems, we will encourage you to come up with your very own goal.

We also encourage you to make these goals SMART goals. If you look at your training manual you will see that SMART stands for...

Specific – A clear definition of what the goal is

Measurable – It can be clearly determined whether or not the goal has been achieved

Achievable – The goal needs to be able to be achieved

Relevant – The goal is linked to the problem

Timed – There is a timescale by which the goal will be achieved

We will write down the goal on the next hand-out

**Activity: Group to come up with a goal. Facilitators to write out ideas on the board*

**Hand-out: Give out S.M.A.R.T goals hand-out*

**Activity: Participants to write their goal on the hand-out*

Facilitator to write out S.M.A.R.T goal that the group has chosen

Can give example from Mynors and Wallis (2005) manual

Generating Solutions

Our next step is to generate solutions. As a group, we will come up with a range of potential solutions for our goal that we have set. Creativity is encouraged, no idea is discouraged. Go nuts. We want to enforce that the first idea that comes to mind is not always the best idea and we want as many possible solutions that we can think of.

Keep in mind the following ideas

- Quantity Leads to quality
- Defer judgement
- Think of a variety of ideas
- Creativity is encouraged

**Hand-out: Give out “generating alternative solutions” hand-out*

Share your ideas with the group and we will have a chance to write them down on this hand-out after we have come up with many different creative solutions

**Activity: Group to share ideas of possible solutions. Facilitator to write these down on the board. Group to write solutions down on their hand-out.*

If the group is struggling with creative ideas, facilitators to add in ridiculous ideas.

**Activity: Can use the “what can this be used for technique?” Pull out cell phone, ask about the different uses... participants will probably just say you can text with it, you can call with it... facilitator to add in... you can throw it, you can use it as a paperweight, you can use it as a mirror, you can use it to pat your dog, and so on until the group understands that they are to be as creative as possible.*

Facilitator to write here the possible solutions

Evaluating and choosing the solution

Next, we want to evaluate these solutions and choose one or more to implement. We will weigh up the advantages and disadvantages of each solution. We will again do this on the board and then you will have the opportunity to write them down on hand-out nine.

Think about will this solution...

1. Make a significant impact on the problem?
2. Have advantages or disadvantages in relation to your time, effort, money, or emotional distress?
3. Have positive or negative effects on your friends and family?
4. In all likelihood be carried out in a satisfactory fashion?

**Hand-out: Facilitator to give out potential solutions hand-out*

**Activity: Write the pros and cons of each solution down on the board*

Facilitator to write out what is on the board

Once we have chosen a solution write it down and on the “my action plan” hand-out.

**Hand-out: Give out “my action plan” hand-out*

**Activity: Participants to write down the chosen solution*

Facilitator to write down the chosen solution

Implementing the preferred solution

Now you have chosen the solution we need to firm up the solution into a clear plan of action. This plan needs to be detailed. Therefore, we want to include detailed actions and specific dates, times and resources needed. Let’s do this on the board, and then you can write the action plan down on your handout. Remember the explanation of SMART goals? You can use this acronym here also.

Remember to think about

- What is needed to be done or obtained?
- Where is it to be done?
- Whom does it involve?
- How will it be done?
- When will it be done?
- What resources do you need to complete the plan?

**Activity: Write out the action plan on the board. Participants to record this down on their hand-out.*

I think that the implementation plan that we have here is a really good one. I think you have all done very well in being clear about what you want to do and how to go about doing it. The really important step now is for you to make sure that you do this over the next week. We will be meeting for only 45 minutes over the next four weeks. What you actually do between these sessions is going to be as important, if not more important, than what we talk about in the sessions. It’s you making a difference to your life in the real world that is going to make you feel better, rather than what we talk about here in our sessions.

Homework

So, you have guessed what the homework is. Yes, it is to go away and implement your action plan. Keep a record of steps you achieve, the successes you have and the difficulties you encounter on your homework hand-out. Before we finish the session today, do you have any worries, concerns, or questions about what you need to do before next time?

**Hand-out: Give out homework hand-out.*

Session three

Session 3 – Review and practice session 1

Materials: *The problem solving worksheet, the homework hand-out*

Evaluation

The final stage of problem solving therapy will now be completed. This is where we evaluate how you went with your action plan, yes, your homework.

**Activity: Facilitator to discuss successes and difficulties with the group.*

If problems arise examine the following...

Should the goal be defined more clearly?

Are the goals realistic?

Have new obstacles arisen?

Are the implementation steps difficult to achieve? If so, why?

Is the participant committed to working on the problem?

Problem two

Now we will go over the steps to problem solving therapy. Can anyone list them for me?

**Activity: Facilitator to help with group discussion about the seven steps. Facilitator to write the steps out on the board.*

Great, now choose a problem from your own list that you want to work on. The following hand-out contains the steps that you need to work through. Please go ahead and fill these out. We will wander around the room and help each of you with your sheets. Ask questions at any time.

**Hand-out: Give out problem-solving worksheet*

**Activity: Participants to fill out hand-out. Facilitators to assist when needed.*

Homework

Your homework is to go away and implement your new SMART action plan, or carry on with your plan from last session if you encountered difficulties and were unable to obtain your goal. Fill out your homework hand-out so that we can evaluate the performance next session. Please also read the hand-out titled “planful problem solving” to make sure you are familiar with the steps of problem solving therapy.

**Hand-out: Give out homework hand-out*

**Hand-out: Give out “planful problem solving” hand-out*

Session four and five

Session 4 & 5 – Review and practice session 2 & 3

Follow the same protocol as session three

Materials: *The problem solving worksheet, the homework hand-out*

Session six

Session 6 – Review and final session

Materials: *The problem solving worksheet, the homework hand-out*

Evaluation

Let’s evaluate how you went with your action plan from last week.

**Activity: Facilitator to discuss successes and difficulties with the group.*

If problems arise examine the following...

Should the goal be defined more clearly?

Are the goals realistic?

Have new obstacles arisen?

Are the implementation steps difficult to achieve? If so, why?

Is the participant committed to working on the problem?

Problem five

Now we will go over the steps to problem solving therapy. Can anyone list them for me?

**Activity: Facilitator to help with group discussion about the seven steps. Facilitator to write the steps out on the board.*

Great, now choose a problem from your own list that you want to work on. The following hand-out contains the steps that you need to work through. Please go ahead and fill these out. We will wander around the room and help each of you with your sheets. Ask questions at any time.

**Hand-out: Give out problem-solving worksheet*

**Activity: Participants to fill out hand-out. Facilitators to assist when needed.*

Wrap up

Facilitator to go over the seven steps and key points taught throughout the therapy sessions.

Remember to use these seven steps when you come across future problems.

Your training manual is yours and you should feel free to refer to it at any time.

Are there any final questions?

Homework

Continue practicing planful problem solving

Review hand-outs and training manual

**Hand-out: Give out homework hand-out*

Assessment session two

Participants to fill out questionnaires and surveys and place them in sealed envelopes.
Co-facilitator to supervise.

Brief Structure of the Problem Solving Therapy Sessions

The Problem Solving Therapy will involve six sessions in total. The first two sessions will be run for 90 minutes. The final four sessions will run for 45 minutes. Ideally, there will be 6-8 participants in each group.

There are seven steps to problem solving therapy, these include....

1. Explanation and rationale
2. Problem definition
3. Establishing goals
4. Generating solutions
5. Evaluating and choosing the solution
6. Implementing the solution
7. Evaluation

Session 1 will cover step 1 of the problem solving therapy process. This will include an explanation of problem solving therapy and its rationale and psycho-education about problem indicators. Participants will also be asked to generate a list of problems that they are currently experiencing in their day to day lives.

In Session 2 participants will be taught the next five steps of problem solving therapy. During each subsequent session participants will work on step seven (evaluation) and solving different problems from their problem list using steps 2 through 7. At the beginning of each session (3-6) participants will evaluate their action plan (step 7).

Session handouts are attached at the end of this protocol. The content of sessions and details are as follows:

Session 1 – Introduction to Problem Solving Therapy

Welcome introductions and housekeeping

Seven Steps

Problem solving orientation

Problem solving style

Explanation and rationale

Problem indicators

Problem list

Practical details

Session 2 – Steps 2 through 6

Selecting and Defining

S.M.A.R.T Goals

Generating Solutions

Evaluating and selecting solutions

SMART Action Plan

Session 3 – Review and Practice Session one

Review of progress

Planful problem solving practice

Session 4 – Review and Practice Session two

Review of progress

Planful problem solving practice

Session 5 – Review and Practice Session three

Review of progress

Planful problem solving practice

Session 6 – Review and final session

Review of progress

Planful problem solving practice

Wrap up

Overview of Problem Solving Therapy Sessions

Session 1: Introduction to Problem Solving Therapy (90 minutes)	Session 2: Steps 2 through 6 (90 minutes)	Session 3: Review and practice session one (45 minutes)	Session 4: Review and practice session two (45 minutes)	Session 5: Review and practice session three (45 minutes)	Session 6: Review and final session (45 minutes)
Welcome and Introductions (25 min)	Last session and homework (5 min)	Review of progress (20 min)	Review of progress (20 min)	Review of progress (20 min)	Review of progress (20 min)
Seven Steps (5 min)	Selecting and Defining (15 min)	Planful Problem Solving Practice (20 min)	Planful Problem Solving Practice (20 min)	Planful Problem Solving Practice (20 min)	Planful Problem Solving Practice (10 min)
Problem Solving Orientation and Style (10 min)	S.M.A.R.T Goals (10 min)	Homework explanation (5 min)	Homework explanation (5 min)	Homework explanation (5 min)	Wrap up (10 min)
5 min break	5 min break				Homework explanation (5 min)
Explanation and rationale (15 min)	Generating Solutions (15 min)				
Problem Indicators (15 min)	Evaluating and Selecting Solutions (15 min)				
Problem List (10 min)	Create SMART Action Plan (20 min)				
Homework explanation (5 min)	Homework explanation (5 min)				

Problem Solving Therapy for Younger Stroke Survivors

Group sessions to help younger stroke survivors cope more effectively with problems that arise in their day to day life

Name:

Training Manual

Sessions adapted from Mynors-Wallis (2005) and Nezu, Nezu and D’Zurilla (2013)

Introduction

Welcome to our group!

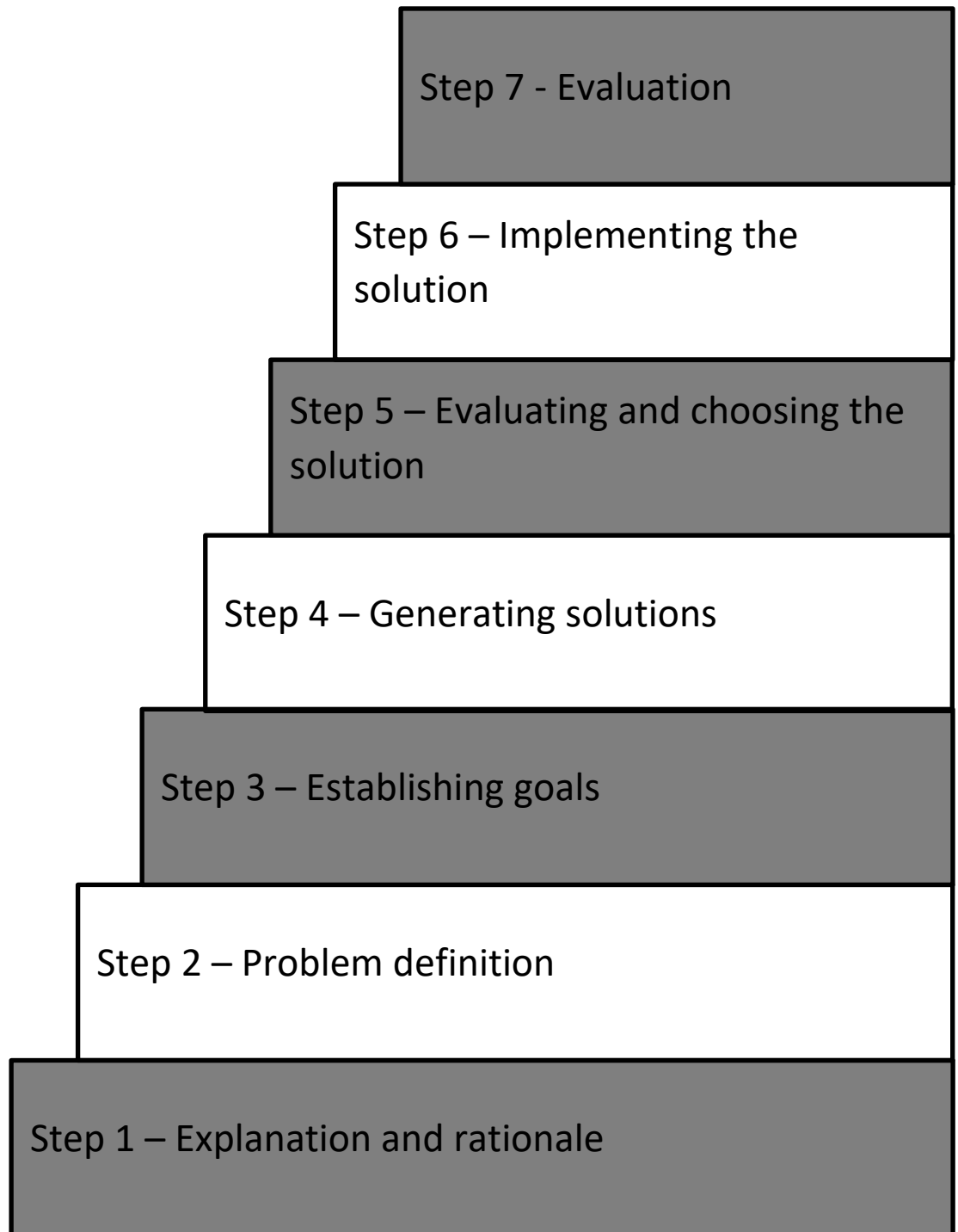
Problem solving therapy or PST is a brief, focused type of psychological therapy that has been created to help people learn to solve problems in their lives more effectively.

Over the course of the therapy sessions, you can expect to learn more about your approach to solving problems. You can also expect to learn how to identify the problems you have in your life, and to learn skills and strategies to help you solve them effectively. You will practice these skills and strategies on your own real life problems.

This is your training manual, and it is yours to keep and refer to as often as you like. The manual contains information about problem solving and will follow through a set of steps to effective problem solving. Work sheets will also be distributed to assist you to practice these steps. Please keep these in your folder once you receive them.

Feel free to ask questions at any time!

The Seven Steps of Problem Solving Therapy



A Note on Problem Solving

Unfortunately, not every problem can be fixed. Sometimes, the best option for working through a problem is to accept that the problem exists. An example of this may be a loss of a loved one. No matter how hard you try and problem solve, unfortunately it won't bring that person back.

The good news is that you can use the steps that you will learn during these six sessions to alter your reactions and attitudes to problems that may arise. Secondary problems that arise from these uncontrollable events can also be worked on using problem solving therapy. For example, an individual may experience social isolation after the death of their husband. This is a problem that can be worked through.

Problem Solving Therapy focuses on the present, rather than trying to fix circumstances from the past. Therefore, throughout our six sessions we will focus on improving the future, rather than regretting the past.

Problem-solving may not solve all your difficulties, but it can help you to start dealing with your problems. As your symptoms improve you will feel more in control of your problems and your life.

In order to effectively learn the seven steps to problem solving therapy it is a good idea to choose a simpler, feasible problem to solve. More complex problems are generally held over until later sessions. This will be explained in more detail later on in our sessions.

Problem Orientation

Problem orientation is the way that someone reacts to problems that they encounter in their day to day lives. This includes a focus on the way that the person thinks and feels about a problem. Problem orientation can be either positive or negative. Your hand-out provides examples of common attitudes that align with positive and negative problem orientations.

Problem Solving Style

Problem solving styles describe people's behavioural reactions when presented with problems. You will see in your hand-out that these can be effective or ineffective. Effective problem solving follows a planful problem solving style, whereas ineffective problem solving follows an impulsive-careless style or an avoidant style. Refer to your hand-outs for more information about problem solving style.

An example

A person may receive a bill in the mail that is far more than he can afford. An individual with a positive problem orientation will view this problem as a solvable challenge and will be realistically optimistic that they can solve it. A person with a negative problem orientation will become overwhelmed by the bill and will become emotionally distressed. An impulsive problem solver may immediately pay the bill using their credit card but incurs large interest fees from the bank. An avoidant problem solver may hide the bill in the back of their draws, and may deny that they even received it. On the other hand a planful problem solver may do their research about different options to pay the bill. They may ring up the company who supplied the bill and talk to them about payment plans with low interest. Or they may talk to their family or friends about a loan, or schedule an extra few shifts at work so they can pay off the bill. Thus, providing a number of alternatives to solve the problem.

S.S.T.A Model

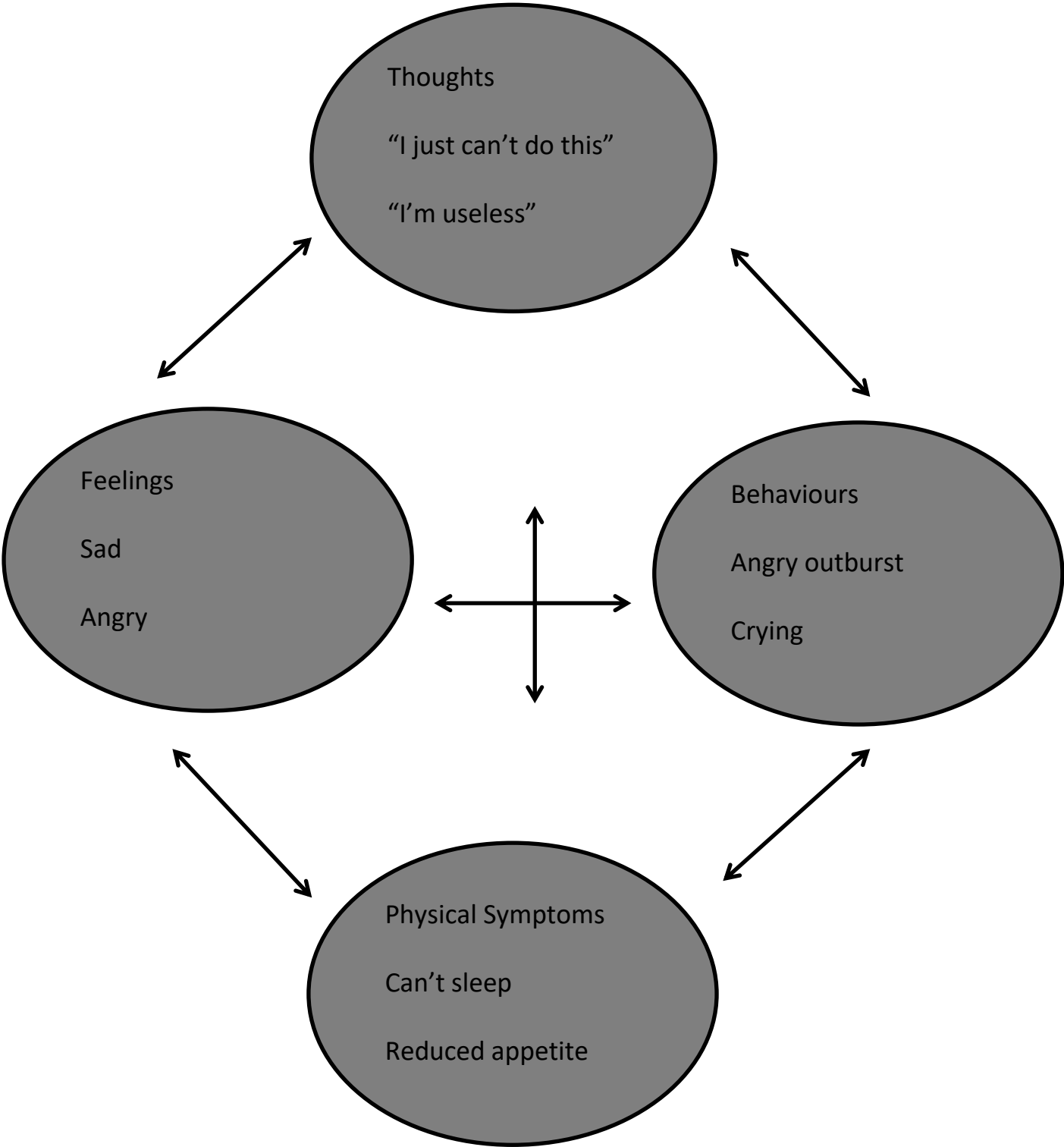
S = STOP

S = Slow Down

T = Think

A = Act

Problem Indicators



Explanation and rationale

- Daily problems can either result in positive adjustment or emotional distress.
- Symptoms result when you are unable to resolve your symptoms effectively.
- If you can learn how to solve your problems more effectively, then your symptoms should resolve.

REMEMBER...

- Problem-solving treatment will be four six treatment sessions over six weeks.
- You will take an active part in the treatment process.

Homework

Please read over the previous pages and your hand-outs for homework this week. If you have any questions note them down here and we will address these at the beginning of the next session.

Defining the chosen problem

- Who?
- What?
- Where?
- When?
- Why?
- How?

S.M.A.R.T goals

Specific – A clear definition of what the goal is

Measurable – It can be clearly determined whether or not the goal has been achieved

Achievable – The goal needs to be able to be achieved

Relevant – The goal is linked to the problem

Timed – There is a timescale by which the goal will be achieved

REMEMBER...

- The group has agreed on a goal that they want to accomplish.
- The chosen goal is your own goal, not the facilitators.
- The chosen goal is a S.M.A.R.T goal.
- The goal is appropriately challenging.

Generating solutions

- Quantity Leads to Quality
- Defer judgement
- Think of a variety of ideas
- Creativity is encouraged

REMEMBER...

- Need to consider lots of solutions.
- It is not only obvious solutions that might be of merit.
- You are the expert of your problem and you are more likely to generate successful solutions to your problem than we (the facilitators) would.

Evaluating and choosing the solution

Think about will this solution...

- Make a significant impact on the problem
- Have advantages or disadvantages in relation to your time, effort, money, or emotional distress
- have positive or negative effects on your friends and family
- In all likelihood be carried out in a satisfactory fashion

REMEMBER...

- Each potential solution has pros and cons
- Choose the solution that will best achieve the goal
- Evaluate potential solutions properly
- One or more solutions have to be chosen

Action plan

- What is needed to be done or obtained?
- Where is it to be done?
- Whom does it involve?
- How will it be done?
- When will it be done?
- What resources do you need to complete the plan?

REMEMBER...

- Clear plan of action which implements the solutions chosen for the goals set.

Home Work

Go away and implement your action plan. Keep a record of steps you achieve, the successes you have and the difficulties you encounter

Task	Completed yes/no	Date and time completed

Successes

Difficulties

Evaluation

If you encountered difficulties with your action plan have a think about the following questions ...

- Should the goal be defined more clearly?
- Are the goals realistic?
- Have new obstacles arisen?
- Are the implementation steps difficult to achieve? If so, why?
- Are you committed to working on the problem?

Now you have learnt the seven steps to problem solving therapy. The final sessions will involve practicing your newly learnt skills. Remember practice makes perfect.

Good Luck!

APPENDIX G: INDIVIDUAL SESSION FEEDBACK FORM

Name: _____

Age: _____

The following are general questions about **this session of Problem Solving Therapy**. Please indicate the extent to which you agree or disagree with each statement.

1. I ENJOYED this problem solving therapy session

0	1	2	3	4
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree

2. This Problem Solving Therapy Session was HELPFUL

0	1	2	3	4
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree

4. In what way was this session helpful?

5. What did you not find helpful about this session?

6. Please write any other comments or suggestions you have about this session?

APPENDIX H: OVERALL FEEDBACK FORM

Name: _____

Age: _____

The following are general questions about **all six** of the **Problem Solving Therapy Sessions**.

**1. Which step of problem solving therapy did you find the most helpful?
(Tick one)**

1. Explanation and rationale
2. Problem definition
3. Establishing goals
4. Generating Solutions
5. Evaluating and choosing the solution
6. Implementing the solution
7. Evaluation

2. Which step of problem solving therapy did you find the least helpful? (Tick one)

1. Explanation and rationale
2. Problem definition
3. Establishing goals
4. Generating Solutions
5. Evaluating and choosing the solution
6. Implementing the solution
7. Evaluation

Please indicate the extent to which you agree or disagree with the following statement

3. I will use Problem Solving Therapy in the future to resolve issues

0	1	2	3	4
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree

10. Please write any other comments or suggestions you have about Problem Solving Therapy as a whole.

11. Do you have any suggestions to make this therapy more suited to younger stroke survivors?

APPENDIX I: ORIGINAL PROBLEM LIST CREATED BY EACH GROUP

Table 17

Original problem list created by each group

Group 1	Group 2	Group 3	Group 4	Group 5
Relationship difficulties	Lack of motivation	Angry outbursts	Loss of function	Difficulty controlling emotions
Reduction in leisure activities	Difficulty staying on task	Fear of another stroke	Reduction in leisure activities	Uncertainty about future
Continuing rehabilitation without resources	Difficulty communicating	Lack of self-esteem	Decreased time with family and friends	Reduction in pleasurable activities
Financial issues	Sleep difficulty	Perceived as a worse employee	Social isolation	Does the government care about me?
Future employment	Lack of understanding	Feeling guilt	Lack of control over emotions	Lack of finances
Self-confidence	Anxious thoughts	Employment issues	Given up career/job	Lack of knowledge about younger stroke survivors
Dietician	Employment	Irritability	Financial stress	Lack of psycho-education
Lack of information	Tenancy	Frustration	Relationship issues	Difficulty with sleep
Lack of support	Rehabilitation programme	Being in limbo	Can't tie shoes	No Job
Responsibility for help	Lack of information and understanding at work	Sore muscles	Can't do up buttons	Feelings of uselessness/worthlessness
Family members health	Confidence	Taking lots of medication	Dependency on others	Lack of independence
Cultural issues	Short term memory	Poor sleep	Sleep issues	
Sleep	Problems with boss	Lack of motivation		
	Presenting to colleagues	Pleasurable activity loss		
	Lack of pleasurable activities	Driving		
		Confidence		
		Moving house		
		Loosing licences		
		Frustration with speech		
		Loss of co-ordination		
		Having to rest frequently		

APPENDIX J: STATEMENT OF CONTRIBUTION TO DOCTORAL THESIS CONTAINING PUBLICATIONS

DRC 16



MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION TO DOCTORAL THESIS CONTAINING PUBLICATIONS

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Charlotte Chalmers

Name/Title of Principal Supervisor: Janet Leatham

Name of Published Research Output and full reference:

The efficacy of problem solving therapy to reduce post stroke emotional distress in younger (18-65) stroke survivors

Chalmers, C., Leatham, J., Bennett, S., McNaughton, H., & Mahawish, K. (2017). The efficacy of problem solving therapy to reduce post stroke emotional distress in younger (18–65) stroke survivors. *Disability and rehabilitation*, 1-10. doi:10.1080/09638288.2017.1408707

In which Chapter is the Published Work: Chapter 11

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or

- Describe the contribution that the candidate has made to the Published Work:

The candidate was the primary researcher for this publication and the publication outlines part two of the research aims for this doctoral thesis. Therefore, along with the support of her supervisors, the candidate generated the research hypotheses, collected and analysed the data and completed the write up.

Charlotte
Chalmers

Digitally signed by Charlotte
Chalmers
Date: 2018.01.30 10:58:12 +13'00'

Candidate's Signature

30/01/2018

Date

Janet Leatham

Digitally signed by Janet Leatham
Date: 2018.01.30 11:11:00 +13'00'

Principal Supervisor's signature

30.1.18

Date