

The Efficacy of Peer Support in Community Stroke Rehabilitation

Christopher Vassillious Stamatakis

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Supervised by:

Professor Reg Morris

Dr Julie Wilcox

Dr Samantha Fisher



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Doctor of Clinical Psychology (DClinPsy) at Cardiff University and the
South Wales Doctoral Programme in Clinical Psychology

DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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ABSTRACT

Aims: Peer support has been incorporated into clinical and national stroke guidelines as an important component of community rehabilitation, yet there is a paucity of research in this area. This study aimed to evaluate the efficacy of a community-based stroke peer support intervention for survivors and carers. **Design:** Stroke survivors and carers ($n=47$) were randomly assigned to either a five-week peer support group intervention or a waiting-list comparison condition. Mixed multivariate (MANCOVA) and univariate (ANCOVA / ANOVA) analyses were used to compare mean scores over time on a range of self-report measures. Additionally, mediation analysis was used to explore the processes underlying peer support. **Method:** All participants completed measures of psychological distress (GHQ-30), perceived social support (Multidimensional Scale of Perceived Social Support), quality of life (EQ-5D-3L) and activities of daily living (Barthel Index). Intervention group participants completed a group process questionnaire (TFI-19). Assessments were completed at baseline, post-intervention (five-weeks) and at follow-up (four-weeks). Due to significant differences between the two groups on the Barthel Index at baseline, these scores were added as a covariate in the MANCOVA and follow-up ANCOVAs used in analysis with the outcome variables (i.e. GHQ-30 and EQ-5D-3L). **Results:** Participants in the peer support intervention group reported decreased psychological distress and increased perceived social support and quality of life over time. These changes were significantly greater when compared to the control group, over the same time period. Perceived social support was found to mediate the relationship between group condition and psychological distress. **Conclusions:** Peer support can facilitate improvements in psychosocial wellbeing for stroke survivors and carers. Social support was found to be an important mechanism underlying peer support. Theoretical and clinical implications of peer support in stroke are discussed and recommendations for future research are outlined.

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CHAPTER ONE

INTRODUCTION

1.1 THESIS FOCUS

Strokes are a leading cause of severe adult disability (Go *et al.*, 2014; National Audit Office [NAO], 2005) and have marked cost implications for health services (Naylor *et al.*, 2012; Stroke Association [SA], 2013). Stroke survivors may experience a wide range of psychological difficulties, such as depression (Hackett *et al.*, 2005), anxiety (Campbell Burton *et al.*, 2013) and fatigue (Duncan *et al.*, 2012). Carers of stroke survivors have also reported reduced psychological wellbeing (Ilse *et al.*, 2008) and life-adjustment difficulties (Greenwood *et al.*, 2009). The provision of routine psychological services in stroke care is recommended within national guidelines and frameworks (Department of Health [DoH], 2007; Intercollegiate Stroke Working Party [ICSWP], 2012; National Institute for Health and Clinical Excellence [NICE], 2008). Despite this, there remains an outstanding need to increase and improve psychological services within stroke rehabilitation (NAO, 2010; SA, 2013).

Furthermore, community care (and particularly the availability of psychological resources) within stroke services has been consistently reported to be of a lower standard than hospital-based treatment (Care Quality Commission [CQC], 2011). In Wales, stroke services are also rated as poorer compared to other developed nations (Welsh Government [WG, 2012a]). Improving community-based treatments and access to psychological interventions within stroke services is therefore of paramount importance (NICE, 2010). Limited amounts of research, however, have evaluated the efficacy of community-based psychological interventions (e.g. group therapy) within stroke recovery.

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Utilising peer support as an intervention can facilitate improvements to wellbeing in both physical (Dale *et al.*, 2012b; Hancock, 2009; Parry & Watt-Watson, 2010) and mental health (Resnick & Rosenheck, 2008) services. Peer support refers to a person who has experiential knowledge derived from experience rather than formal training (Heisler, 2007). Both clinical guidelines (ICSWP, 2012) and national strategies (DoH, 2007) advocate the use of peer support within stroke services, although there is only limited evidence for its effectiveness within the empirical literature (e.g. Morris & Morris, 2012).

Peer support is proposed to provide emotional, informational and affirmational support to improve psychological, social and physical wellbeing (Dennis, 2003). A number of benefits have been reported within studies that have utilised peer support in chronic illnesses, including increased empowerment (Ketokivi, 2009), acceptance of conditions and decreased loneliness (Kyngas *et al.*, 2001). Consistent with these findings, peer support can lead to improvements in mental health by promoting hope, belief in recovery, increased self-esteem and social inclusion (Repper and Carter, 2011).

The primary aim of this thesis, therefore, was to evaluate the efficacy of a community-based stroke peer support programme, given the limited evidence available. Quantitative evaluation of the intervention was completed using standardised questionnaires to measure emotional wellbeing. This study also explored the processes that underpin peer support. Peer support, if found to be effective, could be incorporated as an important component of stroke rehabilitation. This could have positive implications for the provision of clinical and psychological services to stroke survivors and their carers after discharge from hospital. This research could have broad theoretical implications regarding the relationship between social support and psychological wellbeing after stroke.

1.2 KEY TERMINOLOGY DEFINITIONS

1.2.1 Stroke

A stroke occurs when there is damage to the brain following oxygen starvation, which may be caused by either a blockage (ischaemic stroke) or a rupture of a blood vessel (haemorrhagic stroke [ICSWP, 2012]). The majority of strokes are ischaemic (85%) and 15% are haemorrhagic (SA, 2015). Strokes occur more commonly in men, but severity may be greater in women (Appelros *et al.*, 2009). Although often considered as a disease of old age, a substantial number of younger people also suffer from the chronic illness, with approximately 25-30% of strokes occurring in those under 65-years of age (NAO, 2005; Teasell *et al.*, 2000).

Strokes are a leading cause of death for both men and women in England and Wales (Office for National Statistics [ONS], 2014). It is also a leading cause of severe adult disability, with stroke survivors often being markedly dependent on their families and services (NAO, 2005; NICE, 2008; SA, 2015). The brain damage caused by a stroke can result in multiple impairments with speech, cognition and movement (ICSWP, 2012), as well as marked emotional and behavioural changes (see Kneebone & Lincoln, 2012).

1.2.2 Peer Support

Peer support refers to a person or group of people who have experiential knowledge of a specific behaviour or stressor that is similar to a target population (Heisler, 2007). It involves the offering of support to others in similar conditions or who have had like-experiences (MIND, 2013). The knowledge acquired in such contexts is derived from experience rather than formal training (Morris & Morris, 2012). Underlying peer support is the premise that individuals in such situations can better relate to and offer more authentic empathy and validation (Mead & MacNeil, 2006). Peer support is included in the national (England) strategy (DoH, 2007) and national clinical guideline (ICSWP, 2012) for supporting individuals and carers after a stroke. Peer support is also recommended for supporting people to manage their mental health in the community (DoH, 2011). The importance of regular access to peer support for carers has also been formally recognised in Wales (WG, 2013).

1.3 THESIS RELEVANCE

1.3.1 Stroke

Stroke is a major health problem. In the UK, there are approximately 1.1 million stroke survivors living with the effects of the chronic illness (British Heart Foundation, 2012). Annually in Wales, it is estimated that 6000 people suffer their first stroke (WG, 2012a). Strokes are a leading cause of death for both men and women in England and Wales (ONS, 2014). Mortality rates in women are 18.6% and 11.3% in men, although these figures reflect a recent improvement in survival (Lee *et al.*, 2011). Combined with an ageing population, the number of people living with the effects of strokes is expected to increase substantially (Truelsen *et al.*, 2006; WG, 2012a).

The consequences of having a stroke are significant, as it is a leading cause of severe adult disability (Adamson *et al.*, 2004; Go *et al.* 2014). As well as being associated with physical health complications, such as comorbid heart disease (Roth, 1993) and overall inactivity (for a review see Smith *et al.*, 2012a), changes to cognitive functioning and emotional wellbeing are commonly reported in stroke survivors and carers (Kneebone & Lincoln, 2012; NICE, 2008).

1.3.2 Stroke Carers

Considering the potential impact of stroke, it is unsurprising that carers can also be markedly affected. Greater than half of the approximate 1.1 million stroke survivors in England and Wales are reliant on a carer for everyday support (NAO, 2005), with the majority being spouses (Anderson *et al.*, 1995). Caring for stroke survivors can result in negative experiences (Ilse *et al.*, 2008) and carers may have many unmet needs (Hafsteinsdottir *et al.*, 2011). Conversely, there has also been emerging evidence that carers of stroke survivors may experience post-traumatic growth (positive psychological changes following a traumatic event [Calhoun & Tedeschi, 1999]) following a stroke (Hallam & Morris, 2014; Gangstad *et al.*, 2009). Due to the range of severe disabilities that a stroke can cause, however, the needs of stroke carers are considered within national strategies (e.g. DoH, 2007) and professional guidelines (e.g. The British Psychological Society [BPS], 2010).

1.3.3 Emotional Wellbeing after Stroke

1.3.3.1 Depression and Anxiety

A wide-range of psychological problems can develop post-stroke, including emotional, behavioural and cognitive changes (see Kneebone & Lincoln, 2012). Depression and anxiety are amongst the most common difficulties reported (NAO, 2010). Depression occurs in 33% of stroke survivors at any one time (Hackett *et al.*, 2005) and is associated with poorer functional outcome (Pohjasvaara *et al.*, 2001) and mortality (Sederer *et al.*, 2006). Depression is not an acute experience, as 30% of stroke survivors are affected up to five-years (Ayerbe *et al.*, 2011) and 10-years (Ayerbe *et al.*, 2013) later. Carers of stroke survivors also report increased levels of depression (Han & Haley, 1999).

Anxiety is another commonly reported problem amongst stroke survivors and carers. In the first published systematic review of anxiety prevalence after stroke, diagnosed disorders occurred in approximately 20-25% of stroke survivors (Campbell Burton *et al.*, 2013). Carers of stroke survivors may also experience high levels of burden, anxiety and loneliness (Greenwood *et al.*, 2009; Murray *et al.*, 2003). In a national survey of carers of stroke survivors, 48% reported high stress levels after three-years, and this increased to greater than 69% after seven-years (SA, 2013).

1.3.3.2 Other Psychological Difficulties

Further psychological difficulties have also been reported, including apathy (Angelelli *et al.*, 2004), posttraumatic stress disorder (Edmondson *et al.*, 2013), emotionalism (increased emotional behaviour following minimal stimuli [Hackett *et al.*, 2010]), anger (Santos *et al.*, 2006), sexual dysfunction (Thompson & Ryan, 2009), fatigue (Duncan *et al.*, 2012) and relationship problems (Murray *et al.*, 2003; SA, 2013). Given the consequences a stroke can have on emotional wellbeing, it is unsurprising that it has a marked impact on the usage of clinical health services (Naylor *et al.*, 2012).

National health strategies (DoH, 2007; WG, 2012a) and clinical guidelines (National Clinical Guideline Centre [NCGC], 2013; NICE, 2008) have therefore focused on approaches to meet the range of physical and mental health needs associated with having a stroke.

1.3.4 National Stroke Strategies

1.3.4.1 Cost Implications of Stroke

The cost of stroke care to the UK is estimated at over £3 billion per year, which rises to approximately £8 billion if informal care costs and those to the wider economy are included (NAO, 2010). In Wales, hospital services for circulatory disease (including stroke) accounted for 8.7% of all NHS Wales expenditure, which amounted to £464.4 million in 2011 – the second highest area of cost (WG, 2012a). Emotional difficulties can exacerbate problems associated with long-term health conditions, including poorer recovery after stroke (West *et al.*, 2010). This has economic implications, as the costs of patients with comorbid depression are typically 45% higher than for those without (Naylor *et al.*, 2012). Reducing the cost burden of stroke is therefore vitally important.

Incorporating clinical psychology services within rehabilitation teams has the potential to reduce the financial implications of stroke. An investment of just under £69,000 can deliver a benefit of over £108,000 to the NHS and social care in approximately two-years (Gillham *et al.*, 2012). National strategies have therefore been developed to improve the clinical care provided by stroke services, whilst also attempting to decrease the financial burden of the chronic illness on health settings.

1.3.4.2 National Stroke Strategies in England and Wales

In Wales, through the Government of Wales Act 2006, there is devolved power within health. Wales' national stroke strategy was developed to improve clinical services, which are rated as poorer compared to those in other developed countries (WG, 2012a). One component for raising the standards of stroke rehabilitation services in Wales is the focus on health and social care needs after stroke (WG, 2012a) and also the inclusion of routinely provided robust psychological support (BPS, 2012). Across England, Northern Ireland and Wales, however, the current level of access to psychology services within stroke units is reported to be less than 50% (Royal College of Physicians, 2012). In England, the national strategy for stroke identified a framework of quality markers for raising the standard of stroke care (DoH, 2007). Whilst improvements in hospital care have been reported, these have not been matched after discharge to the community (NAO, 2010).

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One of the recommendations for improving outpatient services across England and Wales is for stroke survivors and carers to have greater access to a range of community-based rehabilitation resources (DoH, 2007; WG, 2012a). Psychology services have been identified as having an important role within such community rehabilitation (BPS, 2012; CQC, 2011; SA, 2013). This role is further underlined within an NHS Improvement report (Gillham & Clark, 2011), which stated that psychological care is as essential as physical rehabilitation in the culture of stroke services.

1.3.4.3 Improving Community Stroke Rehabilitation Services

Considering the wide range of emotional difficulties reported by survivors and carers following stroke, the role of psychological services is especially pertinent after discharge from hospital. Specialist stroke rehabilitation services can help to decrease mortality, reduce hospital stay / admissions and improve service-user satisfaction and activities of daily living (Langhorne *et al.*, 2005). As previously stated, however, community stroke rehabilitation services have been identified as requiring substantial improvement (CQC, 2011; DoH, 2007; WG, 2012a).

Psychological services can help to facilitate improvements to community stroke services as part of a wider multi-disciplinary team (ICSWP, 2012). Psychological intervention for post-stroke care has been incorporated into national guidelines and frameworks (DoH, 2007; Gillham & Clark, 2011; NICE, 2008). There is, however, an outstanding need to increase and improve psychological resources across these services (NAO, 2010). The availability of psychological treatments within stroke rehabilitation is consistently reported to be poorer than hospital-based intervention (CQC, 2011). Improving access to psychological interventions within stroke services is therefore of paramount importance (NICE, 2010).

1.3.5 Psychological Support after Stroke

1.3.5.1 Psychological Services within Stroke Care

Psychological support has been identified as a key component of rehabilitation in both hospital and community stroke care (ICSWP, 2012; NAO, 2010; NICE, 2013). As well as reducing the cost burden of stroke, the provision of psychological support has the potential to increase patient quality of life five-fold (Gillham *et al.*, 2012). Whilst

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there has been an increased recognition regarding the important role psychology services can have within stroke care, there is an outstanding need to improve its availability. In England, less than 40% of areas provided *good access* to psychological services (CQC, 2011). Furthermore, despite the high prevalence of emotional distress in stroke survivors and carers, psychological support has been rated as the least satisfactory service in long-term care, with only 24% of respondents rating it as *good* or *very good* (NAO, 2010). Consistent with these reports, a large-scale survey of long-term stroke survivors with emotional difficulties reported that the majority were dissatisfied with the provision of psychological services and did not believe that they received adequate help to support their wellbeing (McKevitt *et al.*, 2011b).

With regards to the local service context in Wales, there has been slower progress with improving the standards of stroke community care and the provision of therapeutic interventions, compared with other countries within the UK (National Assembly for Wales [NAW], 2010). The scarcity of such sources of support for survivors and carers led to recommendations for improvements to be made to community and longer-term rehabilitation services, which included increasing the resources within multi-disciplinary teams “as a matter of urgency” (NAW, 2010, p. 53).

A more recent report, written by clinical psychologists working within stroke services, outlined the limited psychological resources available in Wales (Applied Psychologists in Health National Specialist Advisory Group [APHNSAG], 2014). A psychological pathway of care with trained practitioners is reported to be unavailable for the vast majority of the community stroke populations in Wales (APHNSAG, 2014), despite recommendations in national guidelines (ICSWP, 2012). No health board in Wales was identified as having the recommended staffing levels of psychologists working in stroke services, which has had a detrimental impact on the availability of community rehabilitation resources for survivors and carers (APHNSAG, 2014; BPS, 2012).

In the local stroke service that this study took place in (with a health board population of 475, 324 [APHNSAG, 2014]), two psychologists offer outpatient appointments

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fortnightly, which has capacity for seeing approximately eight service-users in total at clinic. There is no other community-based support facilitated by clinicians trained in psychology, available from the local service for stroke survivors and carers. Given the numbers affected by stroke identified previously, this would indicate that locally there are low levels of access to trained psychological support post-stroke. This is consistent with UK-wide reports and surveys (e.g. CQC, 2011; McKeivitt *et al.*, 2011b; NAO, 2010). Further community-based support is available locally through the voluntary sector, such as the Stroke Association Wales (SAW) and access to this service is viewed as a valuable resource by service-users in Wales (SAW, 2014). This support does not, however, specifically focus on the psychological wellbeing of survivors and carers (programmes offered include exercise schemes, signposting and quizzes [SAW, 2014]) and nor does it incorporate intervention from those trained in psychology.

Within the local service, there are no available data (following requests to both the local stroke service and voluntary sector) regarding the satisfaction levels of stroke survivors and carers towards access to community-based psychological support. Given the limited community services described above, the national reports identified previously and the range of difficulties common after stroke, however, it is likely that satisfaction is low, although future surveys would help to clarify this issue. Methods to improve the overall availability and quality of psychological care within local and national stroke services are therefore needed.

1.3.5.2 Psychological Therapy Post-Stroke

As well as the need to improve access to psychological services within stroke, there remains a lack of clarity regarding effective interventions. Psychological adjustment after stroke can be challenging, especially considering the profound role-changes for the patient and family (Broomfield *et al.*, 2014). There is limited evidence for the use of medication for mood difficulties after stroke, emphasising the importance of psychological interventions. In their Cochrane review, Hackett *et al.* (2008) reported that medication had no clear effect on depression in stroke patients and there were also high rates of adverse side-effects. Consistent with this, a systematic review conducted by Campbell Burton *et al.* (2011) reported that there was limited evidence for the use of pharmaceutical drugs for anxiety after stroke.

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With regards to psychological therapies post-stroke, there is a dearth of published research. In the studies that are available, there are methodological limitations to consider, such as poor designs (Kneebone & Lincoln, 2012). Although research for the efficacy of psychotherapy in stroke is in its infancy, there is emerging evidence for its effectiveness (Mitchell *et al.*, 2009; NICE, 2013). Hackett *et al.* (2008) found a small but significant effect of psychotherapy (using problem solving and motivational interviewing approaches) for improving mood and preventing depression. Given that this Cochrane review included only four psychotherapy trials (plus 10-pharmaceutical studies), wider replication and further evidence is needed.

There is mixed support in the research literature regarding the use of cognitive behavioural therapy (CBT) after stroke, despite its recommendation within national clinical guidelines (NICE, 2009). Small studies have reported both significant (e.g. Lincoln *et al.*, 1997) and non-significant effects for its use in stroke (e.g. Lincoln & Flannaghan, 2003). In their review of the literature, Broomfield and colleagues (2011) recommended that CBT should be augmented to account for the sudden cognitive and physical impairments, and profound loss associated with stroke. Behavioural therapy alone for people with low mood and aphasia following stroke has been reported to be effective (Thomas *et al.*, 2013), whilst stroke patients reported reduced tension following attendance at a relaxation-group (Kneebone *et al.*, 2014). There are also promising findings from a recent study regarding the use of mindfulness-based cognitive therapy for stroke patients (Merriman *et al.*, 2015). Caution, however, should be applied to the generalisation of the findings from these studies due to the small sample sizes. Increasing participant numbers and having randomised control trials (RCTs) that include control groups, would improve the quality of the research available.

Given the range of psychological difficulties reported within stroke, other psychological therapies and models of intervention have also been evaluated within research studies. Forster and colleagues (2012), in their systematic review, reported that providing information improved patient and carer knowledge of stroke and overall satisfaction levels, although this did not significantly reduce psychological distress (e.g. depression). Johansson *et al.* (2012) reported that a mindfulness-based group significantly improved mental fatigue, although participants numbers were

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small ($n=29$) and included both stroke survivors and those who suffered from a traumatic brain injury. Taylor and colleagues (2012) used video-conferencing as a method to facilitate a group intervention that provided information about stroke-related topics, as well as problem solving and goal-setting. Participants reported benefits from sharing experiences and information with others, and also from the peer support the programme offered (Taylor *et al.*, 2012). Caution should be applied in the generalisation of the results from this latter study, however, as the participants were based in rural areas across Canada.

Stroke survivors and carers have reported through national surveys that receiving information can increase their empowerment and wellbeing (SA, 2013). Therapeutic strategies that actively involve patients and carers may also have a greater effect on mood, but providing information alone is not enough to facilitate significant improvements in psychological wellbeing (Forster *et al.*, 2012). Further evaluation of psychosocial models and approaches that significantly improve mood is required.

1.3.5.3 Improving the Evidence for Psychological Therapies Post-Stroke

Within the research literature, there are few RCTs of individual or group psychological interventions after stroke. This is despite the evidence for its effectiveness in non-stroke adult (see NICE, 2009) and older adult (Wilson *et al.*, 2008) populations. There is also a paucity of literature regarding the use of psychological therapies for the wide range of emotional difficulties reported after stroke, such as anxiety, post-traumatic stress, apathy, anger and relationship difficulties. This is consistent with the findings from previous research where stroke survivors and carers have reported that their long-term clinical and social needs are not being met after discharge (McKevitt *et al.*, 2011a; SA, 2013). Developing an evidence-base for psychological therapies is vitally important given that:

- the prevalence of emotional distress after stroke is high (e.g. Hackett *et al.*, 2005);
- those affected by stroke have requested increased access to such interventions (SA, 2013);
- the current ratings of psychological services in the community is poor (CQC, 2011); and

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- national guidelines have stipulated the increased role of psychology across clinical services (Gillham & Clark, 2011).

The role of social support may be important to consider within psychological interventions and health (Cohen *et al.*, 2000). There is emerging evidence that psychosocial interventions and self-management programmes are effective for improving wellbeing in stroke survivors and carers (Cheng *et al.*, 2014; Lennon *et al.*, 2013; Reed *et al.*, 2010). Furthermore, peer support self-management programmes can improve wellbeing for a range of chronic health conditions (Foster *et al.*, 2007). Accordingly, as outlined in Section 1.4 below, peer support could be incorporated to overcome some of the difficulties previously highlighted. Peer support models have developed internationally across both physical (e.g. Chronic Illness Alliance [CIA], 2011) and mental health services (Repper & Carter, 2011). Peer support has also been recommended within stroke national strategy (DoH, 2007) and clinical guidelines (ICSWP, 2012). Using such a model could help to improve community stroke and psychological services (e.g. by increasing both the availability of psychological post-stroke support and service-user involvement). There are also encouraging initial findings from group-based peer support research studies within stroke services (e.g. Morris & Morris, 2012). Completing further research that evaluates the effectiveness of peer support as a psychological intervention within stroke is needed and could help to facilitate improvements in community-based services.

1.3.6 Section Summary

Strokes have a marked impact for the individual, their family, health services and communities. Although mortality in stroke is decreasing, morbidity is increasing. Psychosocial difficulties are commonly reported, which has led to the development of national strategies and clinical guidelines to improve stroke care. Due to the range of emotional problems reported after stroke, these guidelines have formalised the important role of psychological services within stroke rehabilitation. Consistently, however, community stroke rehabilitation services, and particularly the provision of psychological care, are rated as poorer compared to hospital care. There is also sparse empirical research regarding the effectiveness of psychological therapy post-stroke and further evaluation studies are required.

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Peer support is a model that has been reported to be effective for improving wellbeing across physical and mental health services. Peer support is also recommended within national stroke strategy and clinical guidelines, yet (as discussed in the following section) there is limited evidence within the research literature for its effectiveness within this area. Evaluating the efficacy of peer support could therefore have marked implications for clinical services, the provision of psychological intervention and the quality of care provided to stroke survivors and carers.

1.4 PEER SUPPORT

1.4.1 The Development of Peer Support

1.4.1.1 Social Support and Wellbeing

There has been a considerable growth over the past 30-years in the amount of literature that has focused on the importance of social relationships on wellbeing. The quantity and quality of social support can affect both mental and physical health (Cohen *et al.*, 2000; Umberson & Montez, 2010). For example, in a recent meta-analytic review, the influence of social relationships on risk for mortality was reported to be comparable to that of smoking and alcohol consumption (Holt-Lunstad *et al.*, 2010). A consistent theme within the literature is that the presence of social relationships can promote overall health and wellbeing (Cohen, 2004; Matire & Franks, 2014). The positive impact of increasing the quality of social support for people with a chronic illness and their carers is also recognised by the World Health Organisation (1998).

The reported benefits of social support for those with health conditions has led to increased interest into how such networks can be incorporated within clinical services (Heisler, 2007). As represented in Figure 1.1, peer support is a mechanism by which individuals experiencing transitional, chronic and acute stressors (such as those that can follow after physical illness) can access social relationships to facilitate improvements in wellbeing (Dennis, 2003).

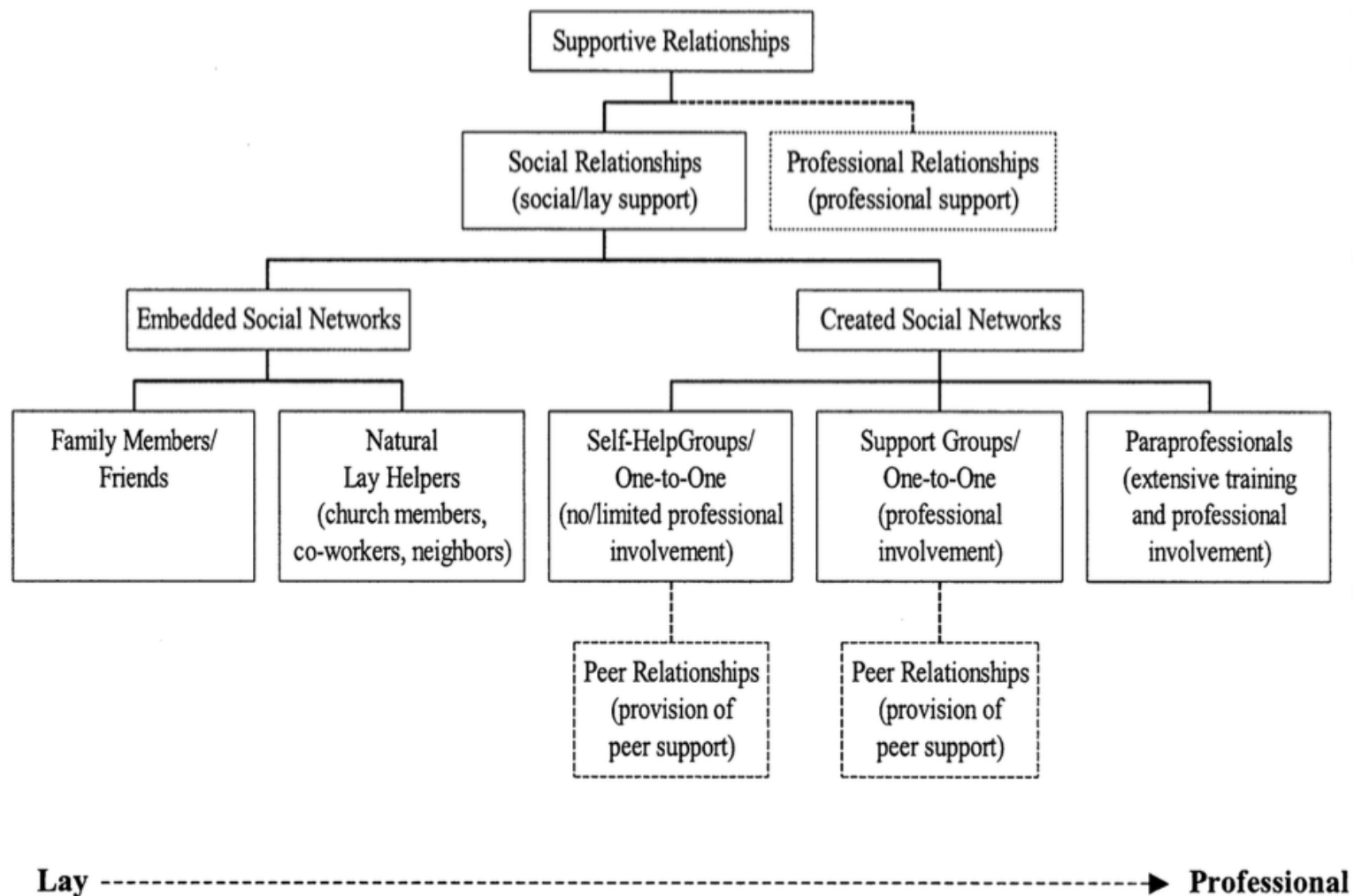


Figure 1.1 Peer support within a social relationship classification (taken from Dennis, 2003).

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1.4.1.2 Characteristics of Peer Support

Within physical illness, peer support can be defined as the provision of support by a created social network or member who possesses experiential knowledge of a specific condition to address a health-related issue (Paul *et al.*, 2007). Peers are often lay individuals selected by clinicians who, after completing training, provide support to others with similar experiences or health conditions (Parry & Watt-Watson, 2010). Peer support models can create non-hierarchical and reciprocal relationships through the sharing of similar life-experiences (Malchodi *et al.*, 2003), which are unlikely to be provided by health professionals (Hoey *et al.*, 2008). Whilst peer support may provide such additional benefits, it is proposed to supplement and not replace the support provided by professional clinical services (Lincoln *et al.*, 2011; Niela-Vilen *et al.*, 2014).

Key components of peer support include the mutual agreement of giving and receiving help, which is based on respect, shared responsibilities and the promotion of hope (Mead & MacNeil, 2006). Three critical attributes of peer support emerge repeatedly within the research literature (see Dennis, 2003):

- *emotional support* – the availability of an individual to discuss personal difficulties to counteract threats of self-esteem to another. This includes expressions of care, attentive listening and reassurance to foster experiences of acceptance and value;
- *informational support* – the sharing of knowledge relevant to a specific problem to an individual seeking methods for overcoming difficulties; and
- *affirmational support* – the communication of information that is relevant to self-evaluation and the appropriateness of emotions, cognitions and behaviours (e.g. enduring frustration and installing hope).

Peer support within a chronic illness setting can be provided using different methods. Arguably the most commonly reported format is through groups co-facilitated by peers and health professionals, but it may also refer to telephone-based support, peer-only led groups, email-based programmes and individual mentoring (see Heisler, 2006). The number of different models of peer support used within studies has potentially had a negative impact on its practical application, as it has been more

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difficult to make standardised comparisons and recommendations due to its lack of homogeneity. In recent systematic reviews, for example, the studies included were criticised for their methodological limitations (e.g. the heterogeneity of samples, designs and outcome measures used) and subsequently there are inconclusive recommendations for its efficacy (Dale *et al.*, 2012b; Lloyd-Evans *et al.*, 2014).

Despite these concerns, the use of peer support has been included in Government strategies (DoH, 2010; 2011), national guidelines for long-term conditions (e.g. stroke [ICSWP, 2012]), clinical guidelines for general services (e.g. adult mental health [NICE, 2011]) and by voluntary-sector organisations (e.g. Mental Health Foundation [MHF], 2012a). It is therefore important to develop studies with more rigorous methodological designs (e.g. using RCTs) to evaluate the efficacy of peer support further.

Much of the peer support research that has been completed has involved the use of group intervention (Hoey *et al.*, 2008), which is recommended as a beneficial forum for supporting others (Niela-Vilen *et al.*, 2014). As chronic illnesses place a substantial burden on health organisations (Messias *et al.*, 2007; SA, 2013), utilising a group-facilitated peer support model may have positive clinical and financial implications (Heisler, 2007; Proudfoot *et al.*, 2012). Establishing the efficacy of peer support as a model is therefore vital as it is potentially a cost-effective intervention, at a time of great pressure across health settings (DoH, 2011; Pistrang *et al.*, 2012; South *et al.*, 2014).

1.4.2 Research Evidence for the Efficacy of Peer Support

Interest regarding peer support has grown markedly within the research literature in the last 15-20 years, across both mental and physical health settings. This has contributed to its inclusion in national strategies and clinical guidelines. Evaluating the efficacy of peer support is therefore critically important.

1.4.2.1 Mental Health

As previously outlined, emotional problems after stroke are common (e.g. Hackett *et al.*, 2005) and there is evidence that peer support can have a beneficial impact within mental health services (MHF, 2012b; Resnick & Rosenheck, 2008). In their literature

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review, Repper and Carter (2011) reported that peer support facilitates recovery as it promotes hope, empowerment, increased self-esteem and social inclusion. Similarly, personal (e.g. self-esteem), practical (including signposting to resources) and social (such as increased inclusion) benefits were also reported following a further review of nine peer support programmes (Faulkner & Kalathil, 2012). These encouraging findings were consistent with those from a recent systematic review, although the authors also concluded that the overall evidence for its effectiveness for people with severe mental health difficulties was more limited (Lloyd-Evans *et al.*, 2014).

There are positive findings within the research literature for the effectiveness of peer support across a range of specific mental health conditions. In individuals diagnosed with schizophrenia, peer support facilitated social reintegration and rehabilitation, as it fostered emotional support, information exchange, companionship and reassurance (Ahmed *et al.*, 2012). Qualitative exploration of the mechanisms underpinning peer support within bipolar disorder indicated that this approach is an important process for developing positive relationships and establishing effective role-models (Proudfoot *et al.*, 2012). Amongst mothers with postnatal depression, peer support was reported to reduce depressive symptoms (Dale *et al.*, 2008) and facilitate recovery processes (Montgomery *et al.*, 2012). Peer support can also help to improve the physical health of people with mental health difficulties (Cook *et al.*, 2009). Evidence from another recent systematic review indicated that peer support may be an effective model for improving the wellbeing of prisoners, particularly for those with mental health needs (South *et al.*, 2014).

Although there are concerns with the methodological designs of studies using peer support (described further in Section 1.4.2.3), there are promising initial findings for its benefits within a mental health context.

1.4.2.2 Physical Health Conditions

Physical health conditions, including stroke, have a marked impact on health services (NAO, 2010). Utilising peer support has been proposed to facilitate improvements across a range of health conditions (CIA, 2011) and can also benefit organisations and systems providing clinical care (MHF, 2012a). For example, peer support programmes facilitated improved rates of smoking cessation amongst disadvantaged

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groups (Ford *et al.*, 2013). Most peer support research has been within chronic health conditions, such as cancer, heart disease and diabetes, and there are only a limited number of studies within stroke care.

In cancer services, peer support has been reported to decrease isolation and improve hope (Pistrang *et al.*, 2012), satisfaction, empowerment (Gottlieb & Wachala, 2007), social support (Ashbury *et al.*, 1998) and mood (Dunn *et al.*, 1999). Peer support is also associated with improved health-related behaviours, such as dietary changes and smoking cessation (Dale *et al.*, 2008). There are concerns regarding the robustness of the research findings in cancer. For example, in their systematic review, Hoey *et al.* (2008) reported that although there was overall high satisfaction levels with peer support programmes, only tentative recommendations could be made due to the methodological limitations consistently observed (e.g. small sample sizes and a paucity of RCTs).

There are also similar initial findings within heart disease. Peer support was reported to increase health-related quality of life (Rees *et al.*, 2004) and following a systematic review of the literature, Parry & Watt-Watson (2010) concluded that peer support improved self-efficacy and wellbeing. Similar methodological problems to those in cancer studies have also been reported, however, including the heterogeneity of interventions and a lack of RCTs (Dale *et al.*, 2008). Further research that overcomes these methodological issues (e.g. using RCTs and validated outcome measures) is required to establish the efficacy of peer support with greater rigor.

In diabetes, Piette *et al.* (2013) reported that patients receiving increased peer support had improved health-related behaviour associated and that this was strongest for those with low levels of social support. Following their systematic review, Dale and colleagues (2012b) reported that peer support showed potential to improve health outcomes for those with diabetes, but also concluded that there is a need to improve the design of studies before robust recommendations can be made.

Peer support has also been reported to be beneficial for individuals other than those directly receiving care. For example, improvements in wellbeing were reported for individuals providing peer support, including increased satisfaction and empowerment

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(Morris & Morris, 2012). Benefits of peer support have been reported at organisational levels too. Chinman *et al.* (2001) reported that there was a 50% reduction in hospital readmission for those accessing peer support compared to traditional outpatient care. Similarly, peer support has been reported to reduce inpatient bed use (Lawn *et al.*, 2008), improve cost-savings (Trachtenberg *et al.*, 2013) and support the heavy workloads of clinical staff (Repper & Carter, 2011). There are encouraging findings, therefore, that peer support may benefit those accessing it, those providing it and the staff working within clinical services.

Despite some promising findings regarding the use of peer support within chronic health rehabilitation, there is a paucity of robust research to allow firm recommendations to be made for its efficacy. There is also a dearth of studies that have included carers, despite the important role they have in the long-term support of those with chronic illnesses (BPS, 2010; DoH, 2007; WG, 2012a). Further rigorously designed studies (e.g. use of RCTs) are required to establish its effectiveness within physical health, given the recommendation of peer support within clinical guidance (DoH, 2007; ICSWP, 2012; NICE, 2011).

1.4.2.3 Limitations of Peer Support

Within the literature, even some of the strongest advocates for the use of peer support recognise the difficulties in its application and evaluation. For example, Dennis (2003) stated that “peer support is a complex phenomenon whose application is vague and highly variable” (p.322). This has implications for conducting research and may reflect the paucity of well-designed studies that incorporate peer support (Dunn *et al.*, 1999). Reviews of the literature have been unable to provide clear recommendations for its efficacy due to the heterogeneity of the samples, designs and measures used (Repper & Carter, 2011).

The concerns noted within the research are in contrast to Government policies, which have included peer support within clinical guidelines (e.g. DoH, 2007). A recent systematic review conducted by Lloyd-Evans *et al.* (2014), reported that the research completed regarding peer support and mental health is of poor quality and has a high risk of bias (Lloyd-Evans *et al.*, 2014). Other concerns noted include the lack of RCTs in the evaluation of the efficacy of peer support and therefore caution should be

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applied with making conclusive recommendations (Hogan *et al.*, 2002). There are also concerns over practical issues, such as the quality of training and amount of supervision received by individuals offering peer support, and how this is reported upon within research studies (Faulkner & Kalathil, 2012).

To summarise, there is evidence in the literature that peer support can be beneficial for those with physical and / or mental health conditions. Limitations with the methodologies of studies, however, have impacted upon the robustness of these findings and the recommendations that can be subsequently made. Despite such concerns, peer support has been recommended nationally within physical and mental health services. There is a need for research to employ sound methodological designs to investigate the efficacy of peer support further. As part of this, it is also important to increase the overall understanding of the psychological processes that facilitate peer support, so that these can be explicitly explored further within the research.

1.4.3 Models of Peer Support

Peer support can provide emotional, informational and affirmational support, which facilitates mutual identification, shared experiences and effective role-modelling (Dennis, 2003). Social support models, principally social comparison theory, stress-buffering, main effects model and helper-therapy principle, have been proposed to underlie peer support and positively affect psychological and physical health outcomes (Cohen *et al.*, 2000; Dennis, 2003; Proudfoot *et al.*, 2012).

1.4.3.1 Social Comparison Theory

According to social comparison theory, individuals make comparisons regarding the opinions and abilities of others to create a sense of normality (Festinger, 1954). As can be seen from Figure 1.2, individuals may compare themselves to others in similar situations and seek further information to benefit their wellbeing (Carmack Taylor *et al.*, 2007). Comparisons of others can be made ‘upwards’ (comparisons with those who are better off), ‘downwards’ (comparing oneself to those who are worse off) or in ‘parallel’ (comparisons against other in the same situation [Bellizzi *et al.*, 2006; Morris & Morris, 2012]). Social comparisons may be particularly relevant to those with chronic health conditions, given the associated uncertainty and anxiety about health and the future (Dibb & Yardley, 2006; Stiegelis *et al.*, 2004).

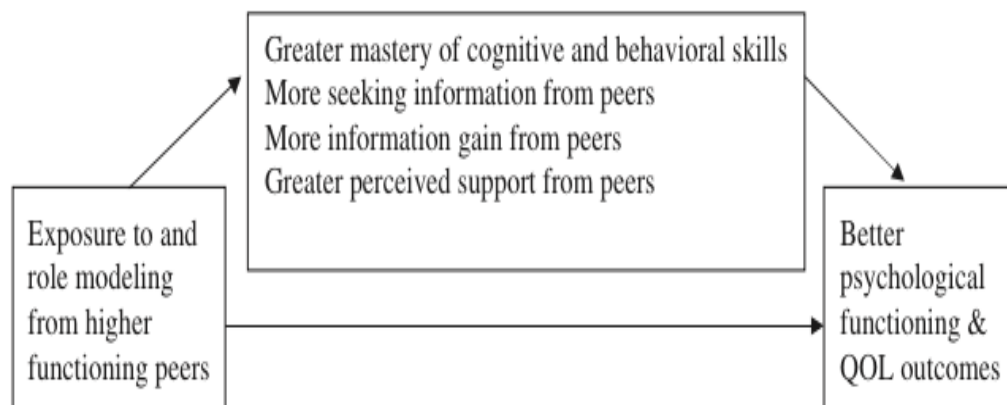


Figure 1.2 The relationship between social comparison processes, peer support and psychological functioning. Adapted from Carmack Taylor *et al.* (2007).

There is evidence within the literature that social comparison processes are important to consider after physical illness, which has implications for the use of peer support. In health conditions, the ability of survivors to manage their experiences arguably depends partly on adaptive coping strategies, which can be developed through observing others who have effectively gone through a similar event (Proudfoot *et al.*, 2012). Stanton and colleagues (1999) reported that both downward (to those who were poorly adjusted) and upward (to well-adjusted targets) comparisons were beneficial to participants coping with cancer. Using social comparisons has also been reported to be beneficial for individuals with mental health difficulties, as it has enhanced self-esteem and protected against stigma (Watson *et al.*, 2007). Making social comparisons may not always be helpful, however, and could be related to whether individuals make better or worse adjustments after chronic illness (Dibb & Yardley, 2006; Morris & Morris, 2012). Little is known regarding what social comparison processes occur in stroke rehabilitation, as there is a paucity of research focusing on it. Further exploration to increase our understanding is required.

1.4.3.2 Stress-Buffering Model

According to the stress-buffering model, social support is beneficial - but only during stressful experiences (Cohen & Wills, 1985). This differs to the social comparison

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theory, which states that people continuously make helpful or unhelpful comparisons with others, regardless of stress. The stress-buffering model also differs as it proposes that perceived or received social support benefits overall wellbeing through the provision of psychological and practical resources needed to cope with stress (Cohen, 2004). The critical factor in this model is the perception that others can provide appropriate aid at times of stress, which may positively change an individual's appraisal of the situation (Cohen & Wills, 1985; Lazarus & Folkman, 1984).

There is evidence within the literature that perceived social support buffers the effect of stress on psychological wellbeing (Cohen *et al.*, 2000; Kawachi & Berkman, 2001). For example, Miller *et al.* (2011) reported that maternal nurturance acts as a buffer against the effects of childhood poverty. Rosengren *et al.* (1993) reported that perceived emotional support buffered the effects of stressful life events on mortality in older adults, but had no benefit for those who experienced few stressful events. Peer support can thus buffer the influence of stress on health by broadening coping resources, highlighting norms and moderating initial appraisals of the stressor (Dennis, 2003). There has been, however, little reported about the role of stress buffering within stroke.

1.4.3.3 Main Effect Model

An alternative to the stress-buffering theory is the main (or direct) effect model, which states that the availability of social resources has a beneficial impact on physical and psychological wellbeing, regardless of stress (Cohen, 2004). As illustrated in Figure 1.3, the main effect model proposes that through access to social relationships (such as peer support), there are a number of pathways that can facilitate improvements to wellbeing. For example, being a member of a social network can lead to individuals receiving support from peers through social influence (e.g. normalisation of experiences, creation of a sense of security) and the provision of specific information (e.g. coping strategies, signposting to local resources [Cohen, 1991]). As part of the pathways included in the model, access to such support and the associated benefits can have a positive impact on psychological (reduced distress), physical (increased activities / exercise) and physiological (suppressed neuroendocrine response) states (Cohen *et al.*, 2000; Uchino, 2006). As a result of these interacting pathways, improvements in overall wellbeing may be reported. The

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potentially positive benefits of belonging to a social network, and the learning from others described in the pathways identified, may be prominent within the mechanisms of peer support (e.g. increased empowerment, promotion of positive mood, decreased isolation). According to the main effect model, therefore, peer support may directly influence wellbeing through the benefits associated with increased access to social relationships, information and social integration (Dennis, 2003).

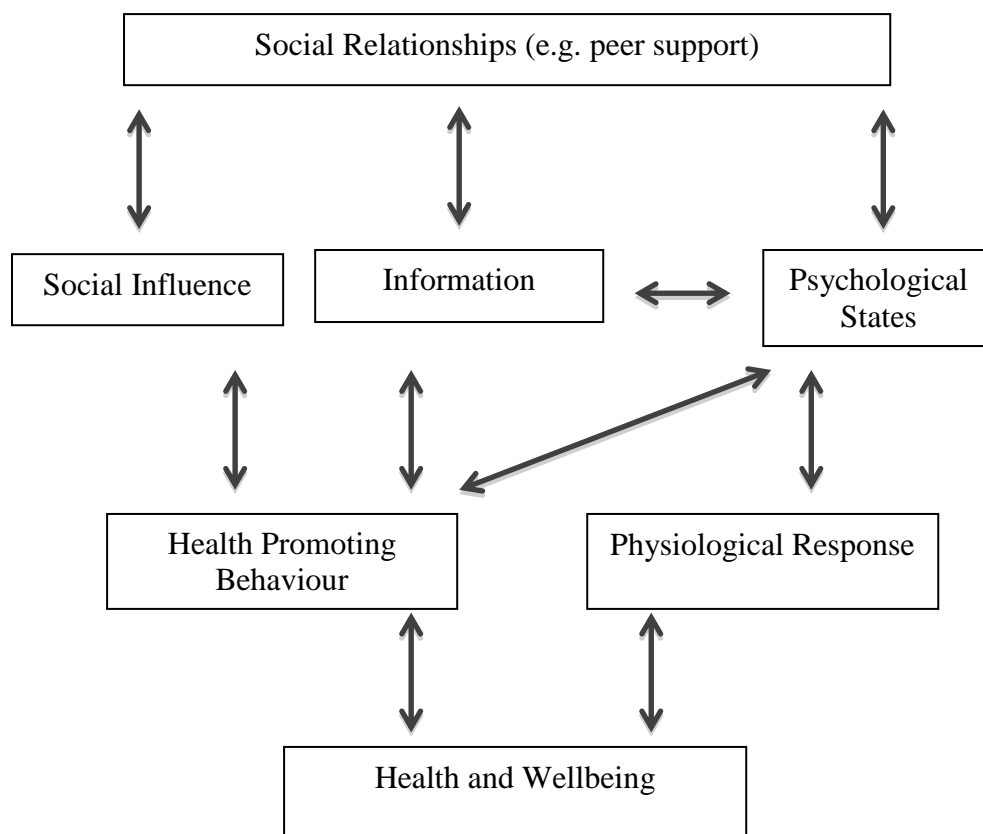


Figure 1.3 Pathways through which social relationships can have direct effects on health and wellbeing (adapted from Cohen *et al.*, 2000).

There is much evidence for the main effect model within the literature (see Lakey & Orehek, 2011). Lakey and Cronin (2008), for example, reported cross-sectional main effects between low perceived support and depression, regardless of the presence of stress. In a large-scale study of depression in bereaved women, there was evidence reported for the main effect model of social support, but none found for buffering effects (Stroebe *et al.*, 2005). Evidence for the main effect model has also been

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reported in studies within physical health settings (Boumans & Landeweerd, 1992; Park, 2007). Other research has found greater evidence for the stress-buffering theory (e.g. Mitchell *et al.*, 2014), whilst support for both of these models simultaneously has also been reported (e.g. Beeble *et al.*, 2009; Rees *et al.*, 2010). Each of these models may therefore contribute to coping depending on the levels of stress, mental health status and availability of social support for each individual (Lakey & Orehek, 2011).

Beneficial effects from social support, as proposed through the main effect model, however, have not always been consistently identified. Mezuk *et al.* (2010), for example, reported only limited evidence for its influence with adult males with cardiovascular disease. Theoretically, there are also possible limitations with the main effect model due to its simplicity (Uchino, 2009). For instance, whilst social support has been identified as a critical attribute of the model, there is little information provided regarding the different effects of specific relationships within these networks (e.g. the different forms of support provided from partners, family, friends and organisations). There has, therefore, been recent interest in distinguishing the models and research regarding social support and health further (Matire & Franks, 2014). For example, differentiating between the measurement of perceived and received support, and also considering the nature of the physical illness (whether it is chronic or acute), may help to develop theory-practice links (Uchino, 2009). Such research may expand upon and clarify the pathways proposed within the main effect model, as this does not explicitly distinguish between perceived and received social support, despite there being more consistent evidence in the literature for the former type (Lueger-Schuster *et al.*, 2015; Nurullah, 2012; Wills & Shinar, 2000). Future research that seeks to expand upon the pathways proposed in the main effect model, such as including measures of perceived social support, may help to inform its utility further. Additionally, as for previous models, little is reported about the main effect model within stroke rehabilitation.

1.4.3.4 Helper-Therapy Principle (Riessman, 1965)

The helper-therapy principle proposes that those who help others gain benefit themselves (Riessman, 1965). For example, helping others can enhance self-worth and competence (Skovholt, 1974). This principle is particularly relevant within peer support as the model is based on the mutual reciprocity and help that members

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provide each other (Dennis, 2003). There is evidence that helping others is associated with improvements in wellbeing (Schwartz *et al.*, 2009) and benefits have also been reported within a mental health and substance misuse context (Magura *et al.*, 2003). There is a paucity of research exploring this within stroke, although in one study completed by Morris and Morris (2012), individuals providing peer support to others reported benefits consistent with this principle. There is a dearth, however, of other research to support or contradict this finding in stroke.

1.4.4 Section Summary

There is considerable evidence for the importance of social support for improving psychological wellbeing. As a component of this, interest into the effectiveness of peer support has developed in the past 15-years. Peer support can provide reciprocal emotional, informational and affirmational support through the sharing of similar life-experiences. There is emerging research reporting the benefits of peer support regarding wellbeing in both physical and mental health conditions. Models such as stress-buffering, main effect and social comparison theory are proposed to underlie the processes involved in peer support. Despite the encouraging findings and its inclusion within national and condition specific clinical guidelines, evidence for its efficacy is compromised by methodological limitations. Further robustly designed studies are required to evaluate its effectiveness, which has potential clinical and financial implications for health services. In the following section a systematic review was carried out to further explore the efficacy of peer support in stroke.

1.5 SYSTEMATIC REVIEW

1.5.1 Systematic Search

1.5.1.1 Search Strategy

A systematic search of the literature was conducted in order to answer the following question: ‘*What is the evidence for the efficacy of peer support in stroke?*’

On March 6th 2015, the following databases were searched (from 1860 to date): Ovid SP (inclusive of Cardiff University Full Text Journals, AMED [Allied and

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Complementary Medicine], Embase, Ovid Medline, PsycINFO and PsycArticles Full Text) and Web of Science.

Following a narrative review of the research literature and discussion with the academic supervisor of the current study, key search terms were identified.

Related to peer support, key search terms used were: peer*, peer support*, peer group*, peer relation*, peer led, befriend*, confidante*, buddy.

Key search terms used that were related to stroke were: stroke, cerebrovascular accident, CVA, cerebral infarct*.

Within each category (i.e. either peer support or stroke) key search terms were combined using Boolean operator 'OR' (e.g. peer* OR peer support* OR peer group* OR peer relation* OR peer led OR befriend* OR confidante* OR buddy) to give total results for each category. The results from each category were then combined using Boolean operator 'AND' – i.e. peer support (terms) AND stroke (terms). These combined terms searched the abstracts and titles of articles in the databases listed above and identified 1661 results. All titles identified during this process were firstly reviewed (see Figure 1.4) to determine if they met the inclusion and exclusion criteria (outlined in Section 1.5.1.2). If there was any difficulty in determining whether the paper fulfilled the specified criteria, the abstract was reviewed. If its relevance remained unclear after this screening, the full article was reviewed.

The strategy used may miss articles where the key search terms were not mentioned in the title or abstract. As such, for the papers that fulfilled the inclusion criteria the reference lists and also the articles that had since cited these were reviewed to search for any further studies. Key authors were also contacted regarding any in-press or other prominent published papers. The authors contacted were: Cindy-Lee Dennis, Michele Heisler, Ian Kneebone, Nadina Lincoln and Melissa Muller.

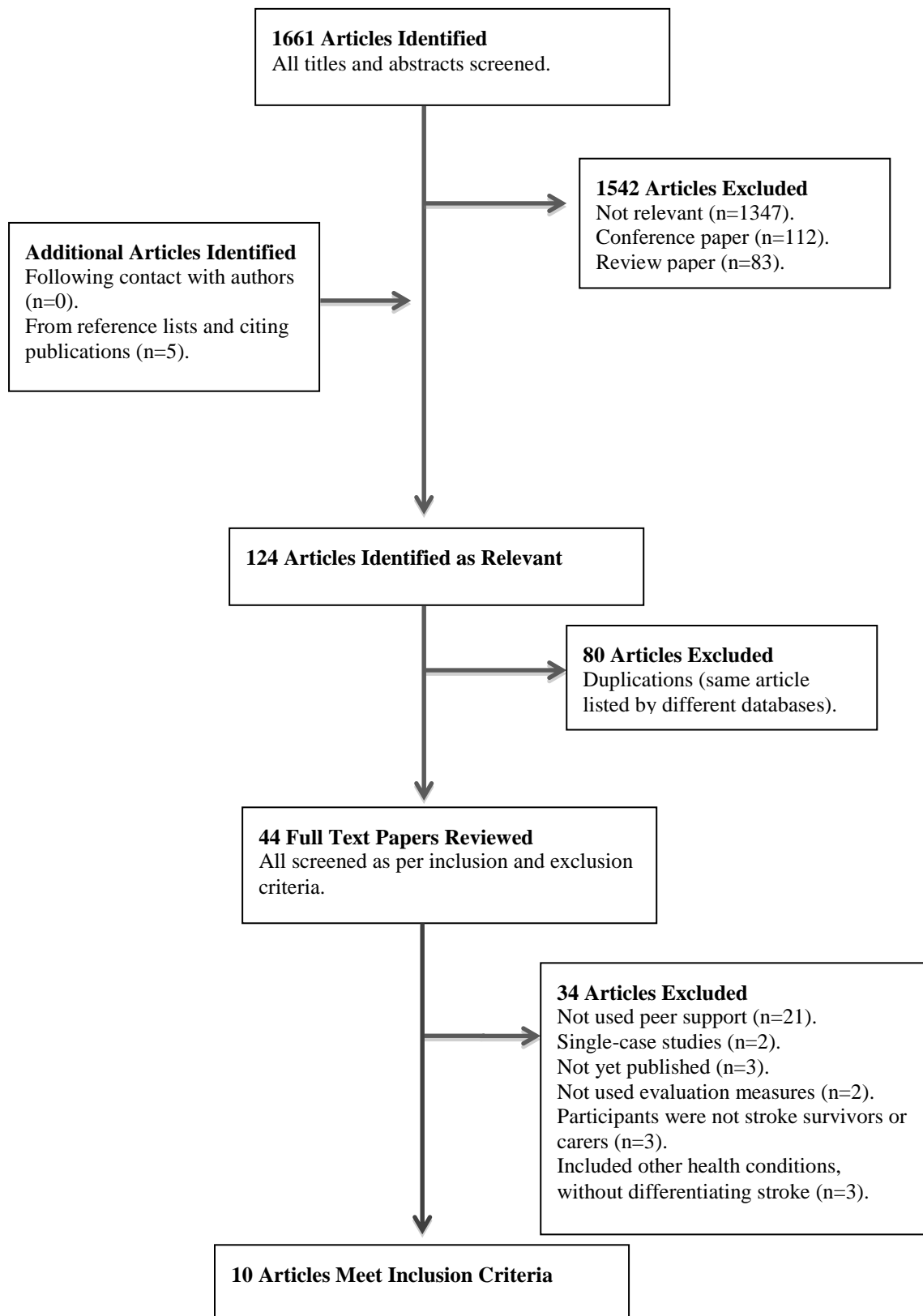


Figure 1.4 Flow chart of the systematic review search process.

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1.5.1.2 Search Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria was applied when reviewing the search results:

Inclusion:

- Peer reviewed papers;
- Empirical studies of primary data;
- Original articles;
- Peer support was an intervention;
- Peer support was evaluated;
- Participants included stroke survivors or stroke carers;
- Papers were available in English;
- Participants were aged over-18 years;
- Studies used either a quantitative or qualitative design.

Exclusion:

- Review papers;
- Dissertations;
- Unpublished research;
- Conference abstracts;
- Single-case studies;
- Studies did not use peer support;
- Not relevant to psychology or behaviour;
- Studies did not evaluate peer support;
- Participants did not include stroke survivors or carers;
- Participants included those with other chronic health conditions, without differentiating from stroke.

1.5.1.3 Review of Papers Identified in Search

After screening of titles and abstracts, 1347 were excluded as they were not relevant (e.g. focused on medical procedures). A further 112 papers were excluded as they were conference proceedings, and 83 were excluded as they were reviews. As such, 119 articles remained. Following direct contact with authors and after reviewing

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reference lists, a further five-studies were identified for screening (n=124). After duplications were removed from this list, the full-text of 44 studies were reviewed.

Upon review of the full-text of these articles, a further 34 were excluded with the most frequent reason being *not used peer support* (n=21). A total, therefore, of 10 articles were included in the systematic review and an overview can be found in Table 1.1. Firstly, six quantitative studies are presented, before four qualitative research studies. A brief narrative summary is also provided to highlight key features, before a quality framework is used to critically appraise the studies.

1.5.2 Overview of Included Studies

Ten articles were included in the systematic review. Six studies used a quantitative-experimental methodology (Aben *et al.*, 2013; 2014; Cadilhac *et al.*, 2011; Kronish *et al.*, 2014; Muller *et al.*, 2014 and Patterson *et al.*, 2010) and four used a qualitative research approach (Kessler *et al.*, 2014; Morris & Morris, 2012; Stewart *et al.*, 1998 and Tregua & Brown, 2013).

Seven of the ten studies reviewed were based within a community setting, with the other three studies recruiting from a hospital-based context (Kessler *et al.*, 2014; Morris & Morris, 2012 and Muller *et al.*, 2014). Participants were recruited through various sources, including community advertisement (Aben *et al.*, 2013; 2014; Cadilhac *et al.*, 2011; Kronish *et al.*, 2014), convenience sampling (Kessler *et al.*, 2014; Patterson *et al.*, 2010; Stewart *et al.*, 1998 and Tregua & Brown, 2013) and inpatient sampling (Morris & Morris, 2012). The specific sampling strategy of Muller *et al.* (2014) was not clearly reported. The sample sizes for the studies using quantitative designs ranged from 13-600, with a mean of 184.17 participants. In the qualitative research studies, the sample sizes ranged from 18-48 with a mean of 28 participants. Three studies were conducted in Australia (Cadilhac *et al.*, 2011; Patterson *et al.*, 2010 and Tregua & Brown, 2013), two were in each of Canada (Kessler *et al.*, 2014 and Stewart *et al.*, 1998), the Netherlands (Aben *et al.*, 2013; 2014) and the USA (Kronish *et al.*, 2014 and Muller *et al.*, 2014) and one occurred in the UK (Morris & Morris, 2012).

Table 1.1 Overview of articles included in the systematic review.

Quantitative-Experimental Design			
Study (Country)		Aben <i>et al.</i> (2013). (Netherlands).	Aben <i>et al.</i> (2014)*. (Netherlands).
n	<i>Total:</i>	153-stroke survivors.	153-stroke survivors.
	<i>Intervention:</i>	77-Memory Self-Efficacy (MSE) group.	77-Memory Self-Efficacy (MSE) group.
	<i>Control:</i>	76-peer support group.	76-peer support group.
Sample Details	<i>Gender</i>	54.9% male.	54.9% male.
	<i>Mean Age (SD)</i>	58 years (9.7).	58 years (9.7).
Method	<i>Recruitment</i>	Participants recruited from two rehabilitation centres, although sampling strategy not fully described.	Participants recruited from two rehabilitation centres, although sampling strategy not fully described.
	<i>Design</i>	RCT, pre-post longitudinal.	RCT, pre-post longitudinal.
	<i>Data Analysis</i>	T-test, linear regression analyses.	T-test, linear regression analyses.
Study Procedure		Nine twice-weekly sessions for both groups. Measures administered at two phases; 3-weeks prior to and 10-days post intervention.	Nine twice-weekly sessions for both groups. Measures administered at 6-month and 12-month follow-up phases.
Peer Support Details		Peer support was the control group. The group was moderated by a psychologist. No active therapeutic interventions were performed.	Peer support was the control group. The group was moderated by a psychologist. No active therapeutic interventions were performed.
Key Outcome Measures		1) Metamemory-In-Adulthood questionnaire (memory). 2) Centre of Epidemiological Studies-Depression Scale. 3) EuroQol EQ5D (health related quality of life).	1) Metamemory-In-Adulthood questionnaire (memory). 2) Centre of Epidemiological Studies-Depression Scale. 3) WhoQol-Bref and EuroQol EQ5D (health related quality of life).
Key Findings		MSE significantly improved after MSE training compared to peer support (p=.019). No other significant results (including depression and quality of life).	MSE significantly improved after attending MSE training, compared to peer support at 6 and 12-month follow-up (p=.010). Quality of life improved significantly after attending MSE training for those aged under-65, compared to peer support (p=.030).
Key Limitations		1) Power not reported. 2) Peer support group details poorly described. 3) Same clinician moderated both groups. 4) Blindness for group allocation unclear. 4) No unsupported condition included. 5) No longer-term follow-up.	1) Peer support group details poorly described. 2) Same clinician moderated both groups. 3) No unsupported condition included.

*Extension of Aben *et al.* (2013) study to include longer period of follow-up.

Table 1.1 Overview of articles included in the systematic review (continued).

Quantitative-Experimental Design			
Study (Country)		Cadilhac <i>et al.</i> (2011). (Australia).	Kronish <i>et al.</i> (2014). (USA).
<i>n</i>	<i>Total:</i>	143-stroke survivors.	600-stroke and TIA survivors.
	<i>Intervention:</i>	48-stroke peer support group. 47-generic chronic health group.	301-peer support group.
	<i>Control:</i>	48-no condition control group.	299-wait-list control group.
Sample Details	<i>Gender</i>	59% female.	59% female.
	<i>Mean Age (SD)</i>	69 (11).	63 (11).
Method	<i>Recruitment</i>	Through public and hospital advertisement after discharge.	Community advertisement and hospital stroke registries.
	<i>Design</i>	Multi-centred RCT.	RCT, pre-post longitudinal.
	<i>Data Analysis</i>	Multivariable analyses, multilevel regression analyses.	Mixed model, t-tests and chi-square analysis.
Study Procedure		Stroke peer support group (8-weekly 2.5 hour sessions); Chronic health programme (6-weekly 2.5 hour sessions); Control group (discharge information pack, signposting to community resources). Data collected at baseline and at 6-months follow-up.	Stroke peer support group (6-weekly 1.5 hour sessions); Wait-list control group (wait 1-year for peer support group, discharge information pack, signposting to community resources). Data collected at baseline and at 6-month follow-up.
Peer Support Details		Groups facilitated by health professional and peer leaders. Peer leaders received training. Sessions focused on problem-solving, behaviour change and community reintegration.	Groups facilitated by two-peers. No peer supporter training information provided. Sessions focused on stroke related modelling, problem solving and self-management.
Key Outcome Measures		1) Recruitment, participation and safety. 2) Health Education Impact Questionnaire 3) Assessment of Quality of Life. 4) Irritability, Depression, Anxiety Scale.	1) Measures related to physical health (e.g. blood pressure and medication adherence). 2) PHQ-8 (depression).
Key Findings		No significant results. Greater treatment completion rates in the stroke peer support group. Improvements over time for each health domain, irrespective of group.	Significant improvements in controlled blood pressure at 6-months ($p=.02$) in peer group. Although non-significant, depression improved at 6-months in peer support group.
Key Limitations		1) Power not adequate. 2) Peers also co-facilitated the generic programme. 3) Stroke group lasted 2-weeks longer. 4) Participant and researcher blindness not clearly reported. 4) Contamination bias as control group accessed support from community resources.	1) Both stroke and TIA survivors included. 2) Generality unclear as sample from poor socio-economic areas in New York. 3) Only depression assessed. 4) Contamination bias as control group was given stroke education materials and had access to community resources.

Table 1.1 Overview of articles included in the systematic review (continued).

Quantitative-Experimental Design			
Study (Country)		Muller <i>et al.</i> (2014). (USA).	Patterson <i>et al.</i> (2010). (Australia).
<i>n</i>	<i>Total:</i>	13-stroke survivors, all aged under 65-years.	43-community based stroke survivors.
	<i>Intervention:</i>	13-stroke peer support group.	22-stroke exercise group.
	<i>Control:</i>	None.	21-peer support group.
Sample Details	<i>Gender</i>	76.9% male.	Exercise group: 59.1% male. Peer group: 57.1% male.
	<i>Mean Age (SD)</i>	45.8 (SD not reported).	Exercise group: 62.5 (7.8). Peer group: 66.5 (11.25).
Method	<i>Recruitment</i>	Sampling strategy not described.	From pre-existing community exercise and peer groups.
	<i>Design</i>	Pre-post longitudinal.	Non-randomised case-comparison study.
	<i>Data Analysis</i>	Wilcoxon ranked sum test.	Mixed-model ANOVA, pre-post longitudinal.
Study Procedure		Nine fortnightly group sessions, lasting 1.5 hours. Needs assessment survey identified key modules (e.g. changes in physical abilities). Data collected at sessions 1 & 9.	Weekly sessions, lasting 1-hour. Data collected at recruitment (participants had attended the group for a minimum of 3-months previously) and 3-months later.
Peer Support Details		Group were professionally facilitated (occupational therapist), with other different allied professionals. A peer (stroke survivor) facilitated one session.	Peer support was the control group. Peers facilitated weekly sessions. Topics included: personal achievements, community-based participation and adjustment after stroke.
Key Outcome Measures		1) Stroke Impact Scale (changes after stroke, including coping, emotional and social factors). 2) Community Integration Questionnaire (participation and activity levels after stroke).	1) Home Functioning Questionnaire (daily task participation). 2) EQ-5D (health-related quality of life).
Key Findings		Significant improvements in activities of daily living ($p=.034$), home integration ($p=.002$) and overall community integration ($p=.028$) only.	Significantly increased daily task participation over a 3-month period ($p=.001$) in both groups. No significant results for health-related quality of life.
Key Limitations		1) Small sample. 2) Sampling strategy not randomised and not fully reported. 3) Researcher bias - participants known prior to study. 4) No control group included. 5) Limited peer involvement in facilitating sessions. 6) Limited mental health assessment. 7) Long-term effects unknown as no follow-up data collected. 8) Less powerful non-parametric test used.	1) Small sample. 2) No randomisation. 3) Measures taken at least 3-months after intervention had started. 4) No longer-term follow-up. 5) Lack of no-intervention control group used. 6) No mood outcome measure.

Table 1.1 Overview of articles included in the systematic review (continued).

Qualitative-Experimental Design			
Study (Country)		Kessler <i>et al.</i> (2014). (Canada).	Morris and Morris (2012). (UK).
<i>n</i>		48-in total: 16-stroke survivors; 8-carers; 7-peer supporters; 7-co-ordinators / professionals.	18-total: 10-group members (7-survivors and 3-carers). 8-peer supporters (5-survivors and 3-carers).
Sample Details	<i>Gender</i>	Stroke survivors: 75% male. Carers: 87.5% female.	61.1% male.
	<i>Mean Age (SD)</i>	Stroke survivors: 64.8 (11.3) No other age details reported.	Not reported.
Method	<i>Recruitment</i>	Retrospective convenience sampling.	Inpatients (plus their carers). Sampling strategy not described.
	<i>Design</i>	Qualitative instrumental case study.	Qualitative instrumental case study.
	<i>Data Analysis</i>	Semi-structured interviews (plus peer supporter diaries) were recorded, transcribed and coded (using qualitative program evaluation recommendations).	Semi-structured interviews and questionnaire analysed using inductive thematic analysis.
Study Procedure		Peer visits pre-discharge and telephone contact at 1, 3, 6, 9 and 12 months post-discharge. Data collected at hospital discharge and at 6-months. Interviews with professionals and peers at single-time point.	Fortnightly group sessions (13 in total), lasting 1.5 hours, with a rolling set of topics decided by group members (e.g. mood, driving).
Peer Support Details		Visits conducted by peers. Organisational support from healthcare professionals. Peers received in-class training and shadowed an experienced peer.	Groups co-facilitated by peers (stroke survivors and carers) and two staff members. Peers completed training prior to group.
Study Evaluation		Interviews to explore processes of peer support programme, including types, benefits and harms of peer support; impact on peers; organisational factors. Analysis of diaries also.	Semi-structured interviews analysed using inductive thematic analysis. Group processes measured by TFI-23 and themes identified for congruence with interviews.
Key Findings		Peers provided emotional and informational support. Not everyone benefitted from the programme. Wide ranging benefits for peers. Professional collaboration valued.	Five superordinate themes: practical issues (communication problems); value of staff; similarity-difference (decreased loneliness); social comparisons; value of peers (e.g. information).
Key Limitations		1) Sampling strategy unclear. 2) Survivors requiring 'long-term' care excluded, but this was poorly defined. 3) Those who agreed to participate may have viewed the programme more favourably. 4) The phase of data collection from professionals and peers not reported. 5) Authors had potential conflict of interest.	1) Small sample and strategy not fully described. 2) Limited information on participant characteristics (e.g. age). 3) Point of data collection not reported. 4) Phases of study reported, but not described. 5) Participants (survivors and carers) separated for part of intervention.

Table 1.1 Overview of articles included in the systematic review (continued).

Qualitative-Experimental Design			
Study (Country)		Stewart <i>et al.</i> (1998). (Canada).	Tregea and Brown (2013). (Australia).
<i>n</i>		20-carers of stroke survivors.	26: 19-stroke survivors (including 2-peer leaders) and 7-family members (including 1-peer leader).
Sample Details	<i>Gender</i>	100% female.	61.5% male.
	<i>Mean Age (SD)</i>	58.8 (10.66).	Stroke survivors: 64.8 (12.9). Family members: 58.3 (9.0).
Method	<i>Recruitment</i>	Convenience sample through several community sources (e.g. professional associations).	Convenience sampling from four community-based peer-led aphasia support groups.
	<i>Design</i>	Qualitative instrumental case study.	Qualitative research approach of focused ethnography.
	<i>Data Analysis</i>	Content analysis of interview transcripts and diaries.	Thematic analysis of focus group and interview transcripts, plus written artefacts.
Study Procedure		Professionals completed initial screening. Participants received twice-weekly home visits over 12-weeks from peers. Interviews of carers conducted at 3-months and 6-months post intervention.	Two peer groups, lasting 2-hours, observed (n=24). Two focus group discussions held (n=10). Semi-structured interviews (n=4). Written documents (e.g. emails between participants) collected.
Peer Support Details		Visits completed by peers only (stroke carers). Peers kept diaries for each visit. Peers attended a one-day training session (e.g. emotional needs).	Group sessions peer-led and met monthly, lasting 2-hours. No information regarding any training peers completed.
Study Evaluation		Content analysis of interviews and diaries / logs from carers, peers and professionals. Study focused specifically on the types of support provided and perceptions of peer support.	Thematic analysis of focus group discussions, semi-structured interviews, observational field notes and written artefacts.
Key Findings		Peers offered emotional, affirmational and informational support. Peer support lessened caregiving demands on carers and improved their confidence and ability to cope.	5 key themes identified: Friendship, Informality, Supportive Environment, Providing Support, and Practical Considerations.
Key Limitations		1) Small sample in rural Canada. 2) Sampling strategy not clearly reported. 3) All were female carers, which may affect result generality. 4) Intervention provided in wide time range (3-18 months). 5) Steps taken to reduce researcher bias when coding data not described (e.g. independency).	1) Small sample. 2) Some participants had received the intervention for 5+ years. 3) Those who attended the focus group only had mild-moderate communication difficulties. 4) Only one stroke survivor and carer interviewed. 5) Limited description of peer support model.

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Of the studies that used a quantitative methodology, three (Cadilhac *et al.*, 2011; Kronish *et al.*, 2014; Muller *et al.*, 2014) used peer support as a stroke self-management intervention group, with survivors only. The other three studies (Aben *et al.*, 2013; 2014 and Patterson *et al.*, 2010) used peer support as a control group to compare with another intervention (memory training programme and exercise-maintenance group respectively), with stroke survivors only. The qualitative studies explored the experiences of stroke survivors, carers and professionals (Kessler *et al.*, 2014), stroke survivors and carers only (Morris & Morris, 2012 and Tregua & Brown, 2013) and carers alone (Stewart *et al.*, 1998), following their participation in a peer support programme.

Different methods of data analysis were used, including mixed t-tests (Aben *et al.*, 2013; 2014; Kronish *et al.*, 2014), ANOVA (Patterson *et al.*, 2010), multi-level regression analyses, (Cadilhac *et al.*, 2011), Wilcoxon ranked sum test (Muller *et al.*, 2014), thematic analysis (Morris & Morris, 2012 and Tregua & Brown, 2013), content analysis (Stewart *et al.*, 1998) and deductive coding (Kessler *et al.*, 2014).

1.5.3 Quality of the Studies

A quality framework was used to guide the critical appraisal of the studies identified in the systematic review. As both quantitative and qualitative methodologies were included, two different quality frameworks developed by Cardiff University's Support Unit for Research Evidence (SURE), were employed to assess the credibility of the studies. The qualitative framework developed by SURE (2013a) was applied to the qualitative studies included in the systematic review. For those that used quantitative methodology, the SURE (2013b) quality framework developed specifically for RCT and other experimental studies was applied. Both of these frameworks were used as they incorporate a number of quality checklists including the former Health Evidence Bulletins Wales checklist, NICE Public Health Methods Manual (NICE, 2012) and previous versions of the Critical Appraisal Skills Programme (CASP, 2010).

As stated above, both quantitative and qualitative research studies were included in the systematic review. Traditionally, systematic reviews have focused on quantitative research and concerns have been noted with processes that include both, such as how to evaluate studies that use different research designs (see Dixon-Woods *et al.*, 2005).

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The inclusion of both can, however, improve the overall systematic review process, as it may identify gaps in the literature and maximise the findings to inform research and practice (Harden, 2010; Mays *et al.*, 2005). Including both types of research designs into systematic reviews can also ensure that the views of service-users are incorporated into the process (Ring *et al.*, 2010). Given the limited studies of peer support in stroke, it was hoped that including both designs would maximise the review and encapsulate a broader amount of available literature to inform the research question and method.

The frameworks identified above (i.e. SURE, 2013a; 2013b) use three categories for rating the quality of studies: *Yes* (i.e. feature is present), *No* (i.e. feature is absent) and *Can't Tell* (i.e. unsure). A numerical scoring system was added to the existing criteria to weight the overall quality of the studies. To enhance reliability, the studies were rated following discussion with the author's academic supervisor (RM) and were categorised as follows:

- Yes = Good (score of 2).
- Can't Tell = Mixed (score of 1).
- No = Poor (score of 0).

Table 1.2 represents the quality framework used to assess the studies in the systematic review that utilised a quantitative methodology (SURE, 2013b). The quality review of studies that employed a qualitative research design is presented in Table 1.3 (SURE, 2013a). A narrative synthesis is subsequently presented.

Table 1.2 Questions to assist with the critical appraisal of quantitative intervention / experimental studies using SURE (2013b).

Scoring Guidance: Main items (criteria numbered and in bold) were rated using: 2= Yes (Good); 1= Can't Tell (Mixed); 0 = No (Poor).						
Sub headings (criteria not in bold) guided the scoring of main items and were rated using: Yes (y), No (n), Not Reported (nr) or Non-applicable (n/a).						
	Aben <i>et al.</i> (2013)	*Aben <i>et al.</i> (2014)	Cadilhac <i>et al.</i> (2011)	Kronish <i>et al.</i> (2014)	Muller <i>et al.</i> (2014)	Patterson <i>et al.</i> (2010)
Quality Framework Criteria						
1. Does the study address a clearly focused question / hypothesis	2	2	2	2	2	2
Population?	y	y	y	y	y	y
Intervention?	y	y	y	y	y	y
Comparator/ Control	y	y	y	y	n	y
Outcomes?	y	y	y	y	y	y
2. Was the population randomised? If YES, were appropriate methods used (e.g. opaque envelopes)?	2	2	2	2	0	0
3. Was allocation to intervention or comparator groups concealed?	1	1	1	2	0	0
Is it possible for those allocating to know which group they are allocating people to?	nr	nr	nr	n	y	y
4. Were participants / investigators blinded to group allocation?	2	2	1	2	0	0
If NO, was assessment of outcomes blinded?	n/a	n/a	y	n/a	n	n
5. Were interventions (and comparisons) well described and appropriate?	1	1	2	1	2	1
Aside of the intervention were groups treated equally?	y	y	y	y	n/a	y
Was exposure to intervention and comparison adequate?	y	y	y	y	n/a	y
Was contamination acceptably low?	n	n	y	n	n/a	n
6. Was ethical approval sought and received?	2	2	2	2	2	2

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7. Was a trial protocol published?	1	1	1	1	0	0
Was a protocol published in a journal or clinical trial registry before participants were recruited?	nr	nr	nr	nr	n/a	n/a
If a protocol is available, are the outcomes reported in the paper listed in the protocol?	nr	nr	nr	nr	n/a	n/a
8. Were the groups similar at the start of the trial?	2	2	1	2	0	2
Are baseline characteristics provided and discussed (e.g. age)?	y	y	y	y	n/a	y
Are any statistically significant differences adjusted for?	y	y	nr	n/a	n/a	y
Are any differences >10%?	y	y	y	n	n/a	y
9. Was the sample size sufficient?	1	2	1	2	0	2
Were there enough participants?	nr	y	nr	y	n	y
Was there a power calculation?	n	y	n	y	n	y
Were there sufficient participants?	nr	y	nr	y	n	y
10. Were participants properly accounted for?	1	1	2	2	1	1
Was follow-up $\geq 80\%$?	y	y	y	y	y	y
Were patients analysed in the groups to which they were randomised?	y	y	y	y	n/a	n/a
Was an Intention to Treat analysis conducted?	nr	nr	y	y	n	n
Was the follow-up period long enough?	n	y	y	y	n	n
11. Data analysis: are you confident with the authors' choice and use of statistical methods?	1	1	2	2	1	1
Were estimates of effect size given?	n	y	y	y	n	y
Were the analytical methods appropriate?	y	y	y	y	y	y
Was the precision of intervention effects (confidence intervals given)?	y	n	y	y	n	n
12. Results: were outcome measures reliable (e.g. objective or subjective)?	2	2	2	1	1	1
Were all outcome measurements complete?	y	y	y	y	y	y
Were all important outcomes assessed?	n	n	n	n	n	n

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Are the authors' conclusions adequately supported by the results?	y	y	y	y	y	y
13. Is any sponsorship / conflict of interest reported?	2	2	2	2	2	2
14. Finally...consider: did the authors identify any limitations?	2	2	2	2	2	2
Are the conclusions the same in the abstract and the full text?	y	y	y	y	y	y
TOTAL QUALITY SCORE (/28)	22/28	23/28	23/28	25/28	13/28	16/28

* Aben *et al.* (2014) was a follow-up study and used the same participants from Aben *et al.* (2013). Only the unique findings for each study were reported.

Table 1.3 Questions to assist with the critical appraisal of qualitative studies using SURE (2013a).

Scoring Guidance: Main items (criteria numbered and in bold) were rated using: 2= Yes (Good); 1= Can't Tell (Mixed); 0 = No (Poor).				
Sub headings (criteria not in bold) guided the scoring of main items and were rated using: Yes (y), No (n), Not Reported (nr) or Non-applicable (n/a).				
	Kessler <i>et al.</i> (2014)	Morris and Morris (2012)	Stewart <i>et al.</i> (1998)	Tregea and Brown (2013)
Quality Framework Criteria				
1. Does the study address a clearly focused question / hypothesis?	2	2	2	2
Setting?	y	y	y	y
Perspective?	y	y	y	y
Intervention or Phenomena?	y	y	y	y
Comparator / Control (if any?)	n	n	n	n
Evaluation / Exploration?	y	y	y	y
2. Is the choice of qualitative method appropriate?	2	2	1	2
Do the authors discuss how they decided which method to use?	y	y	n	y
Is it an exploration of behaviour / reasoning / beliefs?	y	y	y	y
3. Is the sampling strategy clearly described and justified?	1	1	1	1
Is it clear how participants were selected?	y	n	y	y
Do the authors explain why they selected these particular participants?	y	y	y	y
Is detailed information provided about participant characteristics and about those who chose not to participate?	n	n	n	n
4. Is the Method of data collection well described?	2	2	2	2
Was the setting appropriate for data collection?	y	y	y	y
Is it clear what methods were used to collect data? Type of method (e.g. focus groups) and tools (e.g. notes)?	y	y	y	y
Is there sufficient detail of the methods used (e.g. how any topics / questions were generated and whether they were piloted?)	y	y	y	y
Were the methods modified during the study? If YES, is this explained?	n	n	n	n
Is there triangulation of data (i.e. more than one source of data collection)?	y	y	y	y
Do the authors report achieving data saturation?	y	n	n	n

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5. Is the relationship between the researcher(s) and participants explored?	1	1	1	1
Did the researcher report critically examining / reflecting on their role and any relationship with participants particularly in relation to formulating research questions and collecting data?	nr	nr	nr	nr
Were any potential power relationships involved (i.e. relationships that could influence in the way in which participants respond)?	nr	nr	nr	nr
6. Are ethical issues explicitly discussed?	1	1	1	2
Is there sufficient information on how the research was explained to participants?	n	n	n	y
Was ethical approval sought?	y	y	y	y
Are there any potential confidentiality issues in relation to data collection?	n	n	n	n
7. Is the data analysis / interpretation process described and justified?	2	2	2	1
Is it clear how the themes and concepts were identified in the data?	y	y	y	y
Was the analysis performed by more than one researcher?	y	y	y	nr
Are negative / discrepant results taken into account?	y	y	y	y
8. Are the findings credible?	2	2	2	2
Are there sufficient data to support the findings?	y	y	y	y
Are sequences from the original data presented (e.g. quotations) and were these fairly selected?	y	y	y	y
Are the data rich (i.e. are the participants' voices foregrounded)?	y	y	y	y
Are the expectations for the results plausible and coherent?	y	y	y	y
Are the results of the study compared with those from other studies?	y	y	y	y
9. Is any sponsorships / conflict of interest reported?	2	2	2	0
10. Finally...consider: did the authors identify any limitations?	2	2	2	2
Are the conclusions the same in the abstract and the full text?	y	y	Y	y
TOTAL QUALITY SCORE (/20)	17/20	17/20	16/20	15/20

1.5.4 Synthesis of the Studies

This section outlines the main findings and methodological limitations of the studies reviewed, in consideration of the systematic review question – “*what is the evidence for the efficacy of peer support in stroke?*” Firstly, the variable nature of peer support programmes used as interventions within the studies will be considered, as this has implications for the findings and limitations subsequently described.

1.5.4.1 Heterogeneity of Peer Support

During the process of the systematic review, it was apparent that the term ‘peer’ in the context of peer support was used for a variety of descriptions. There were studies that did not meet the inclusion criteria for this review, but which explicitly referred to ‘peer’ as a key-term, although upon full review of the articles this was potentially misleading (e.g. Smith *et al.*, 2012b). Similarly, in the studies that met the inclusion criteria there was wide variability in the components of the peer support programmes provided. Such variance could have a detrimental effect on the quality and efficacy of peer support as an intervention and how it is viewed and reported upon.

Across the studies, there was much heterogeneity in the design of the peer support programmes provided. Eight studies involved group intervention and two, both qualitative research studies, provided individual support through telephone contact (Kessler *et al.*, 2014) and home-visits (Stewart *et al.*, 1998). Three of the six studies that used quantitative methodologies used peer support as a ‘control group’ (Aben *et al.*, 2013; 2014 and Patterson *et al.*, 2010) and its features were poorly reported. Aben *et al.* (2013), for example, described the peer support control group as being moderated by a trained psychologist, but which did not provide any “active therapeutic interventions” (p.111). This statement is potentially invalid and misleading given the therapeutic benefits previously reported upon from peer support in other physical health conditions. Although Patterson *et al.* (2010) provided a general overview of the content and aims of the peer support group evaluated in their study, further details regarding its facilitators, the programmes origins and maintenance were incompletely described.

In the other three quantitative studies (Cadilhac *et al.*, 2011; Kronish *et al.*, 2014 and Muller *et al.*, 2014), peer support was the experimental group and a greater

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description of the properties of the programmes was provided. Both peers and professionals facilitated the peer support groups used in the studies by Cadilhac *et al.* (2011) and Muller *et al.* (2014), although this included only 1 out of 9 sessions in the latter study. In Kronish *et al.* (2014) peers-only led the support group. In these three studies, education, self-management, signposting to community resources and adjustment after stroke were common themes of the peer support programmes.

There was a lack of consistency regarding the length of group intervention provided by the peer support programmes. They included fixed-programmes of six-weekly sessions lasting 1.5 hours (Kronish *et al.*, 2014), eight-weekly sessions lasting 2.5 hours (Cadilhac *et al.*, 2011), nine weekly sessions lasting 1.5 hours (Muller *et al.*, 2014), nine twice-weekly sessions lasting 1-hour (Aben *et al.*, 2013; 2014) and 13-fortnightly sessions lasting 1.5 hours (Morris & Morris, 2012). There were also two rolling programmes (with no specified end date) occurring weekly for one-hour (Patterson *et al.*, 2010) and monthly sessions lasting 2-hours (Tregea & Brown, 2013). Of the individual peer support provided, one study involved peer support via telephone (Kessler *et al.*, 2014), with fixed dates of contact (five scheduled over a 12-month period) and the other study involved twice-weekly home-visits over a 12-week period (Stewart *et al.*, 1998). No two programmes in this systematic review offered the same length, frequency or type of peer support intervention. This variability has implications for the wider generalisation of the findings regarding peer support. Such a lack of standardisation may also have an adverse impact for the inclusion of peer support within clinical guidelines (e.g. NICE).

As well as differences in personnel leading the peer support groups and a lack of programme standardisation, there was also variation in the level of support and training offered to the peers facilitating the groups. Training for the peers leading the peer support programmes has been reported in the literature as a vitally important feature (Faulkner & Kalathil, 2012; Parry & Watt-Watson, 2010), yet six studies failed to report whether any training had been provided (Aben *et al.*, 2013; 2014; Kronish *et al.*, 2014; Muller *et al.*, 2014; Patterson *et al.*, 2010 and Tregea & Brown, 2013). Thus, there were only two studies that evaluated peer support as a group intervention that explicitly stated that they had provided training and support for those facilitating the group (Cadilhac *et al.*, 2011 and Morris & Morris, 2012). Both of the

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studies that used a one-to-one peer support programme reported that they also provided training to peers leading the intervention (Kessler *et al.*, 2014 and Stewart *et al.*, 1998).

When training was provided, the descriptions of its content were variable in detail. Kessler *et al.* (2014) provided the greatest amount of information regarding the training provided, which included multiple hours of in-class education, orientation visits and shadowing of programme co-ordinators. Stewart *et al.* (1998) described that peers leading the programme “conferred periodically” (p.93) with professionals, but also attended structured training (e.g. empathy training) in the initial stages of development. Other studies only vaguely reported the training provided. Cadilhac and colleagues (2011) stated that peers leading the group attended a national stroke training programme, but do not disclose any further information regarding this. Morris and Morris (2012) made brief reference to the provision of training, but did not provide any specific details of what this entailed (e.g. what, when and who was involved).

The studies included in this review indicate that the nature of peer support provided is often variable. The length and frequency of the intervention, the personnel facilitating the support and the training provided to those leading the programmes differs greatly. This amount of heterogeneity should be considered when considering the synthesis of the findings and the limitations of the research, described below.

1.5.4.2 Review of the Study Findings

As previously stated, research regarding the efficacy of peer support in stroke is limited. Four of the ten studies identified in this review were qualitative explorations of the experiences of participants completing a stroke peer support programme. The findings from these studies will be considered first, before synthesis with the results from the quantitative research completed.

Across the four qualitative studies, there were positive findings reported regarding the use of peer support. The studies included experiences described by stroke survivors and carers, but also included accounts from peers and professionals facilitating the programmes too. Morris and Morris (2012) and Tregua and Brown (2013) both

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explored the experiences of stroke survivors and carers who participated in peer support programmes, and peers who led the intervention. The two studies used thematic analysis to introduce common important themes specific to participants attending the group, and for those leading the group. Overlapping similarities included increased social connections (decreased loneliness), receiving emotional (increased confidence and empowerment) and informational support (advice, signposting to community resources) and making social comparisons (hope for the future). Practical issues related to the running of the programme were also identified and included the importance of providing support and training for peers leading the programme. Sampling issues, described later in this section, were apparent for both studies.

Consistent with the above studies, Kessler and colleagues (2014) reported positive findings, whilst also including the experiences of professionals, as well as those of stroke survivors, carers and peer leads. Again, peers were reported to provide both emotional (hope, confidence, validation and encouragement) and informational support (e.g. community services available) to survivors and carers. Across these three studies, the support provided was also identified as different to what professionals could offer, as peers were reported to have been in similar situations and recovered (Kessler *et al.*, 2014). The value of professional support, however, was not diminished and fulfilled a different role (Morris & Morris, 2012).

In the final qualitative study reviewed, only the perspectives of carers were explored (Stewart *et al.*, 1998). Consistent with the findings in the other studies reviewed, family carers of stroke survivors reported that peers who carried out home-visits provided emotional (empathy and increased confidence), affirmational (sharing of experiences and decreased loneliness) and informational (e.g. local resources and advice) support. From these four studies, the type of support provided to stroke survivors and carers through a peer programme was reported to have many similar benefits.

The challenges or negative aspects associated with peer support programmes were not as explicitly explored in these studies as the potential benefits from the intervention. This may explain why so few negative experiences of peer support were reported.

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One theme reported in two of these studies was regarding the (negative) social comparison process others made towards those with more obvious disabilities (Kessler *et al.*, 2014; Morris & Morris, 2012). The qualitative studies overall, however, reported consistent beneficial themes associated with peer support, that was perceived by survivors, carers, peers and professionals. Types of support provided were namely emotional, affirmational and informational.

Quantitative research to substantiate these benefits was recommended by two of the studies identified above (Morris & Morris, 2012; Tregua and Brown, 2013). Overall, and in contrast to the positive outcomes identified by qualitative research studies, there were mixed findings regarding the benefits of peer support in studies that utilised a quantitative experimental approach. Several methodological limitations, however, were also apparent in these studies.

Patterson and colleagues (2010) compared an exercise maintenance group with a similarly designed peer support programme. Over a three-month period, there was a significant increase with daily task participation in both groups ($p=.001$), but not in health-related quality of life. Unfortunately there was no long-term follow-up, a lack of mood-specific assessment measures and also no control group of participants waiting for an intervention. Furthermore participants in both groups had already completed the respective interventions for a minimum of three-months prior to baseline data collection.

There were mixed findings reported in the study by Muller *et al.* (2014). The authors reported that participants who attended a hospital-based peer support programme reported significant improvements in activities of daily living ($p=.034$), home integration ($p=.002$) and overall community integration ($p=.028$). There were, however, no significant changes regarding social integration, recovery and emotions. Although the study had some encouraging findings, caution should be applied to the generalisation of these results as there were several methodological limitations impacting on the quality of this study. This included the small sample size ($n=13$), an unclear sampling strategy (participants were known to the researcher prior to the research study), a lack of long-term follow-up data and an absence of a control group.

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Kronish *et al.* (2014) investigated the effects of attending a six-week peer support group in low socio-economic and primarily Black and Latino communities in the USA. Primary outcomes were related to physical health and there was a significant improvement in controlled blood pressure compared to a waiting-list control group ($p=.02$). Secondary outcomes included assessment of depression using a stroke-validated measure (the PHQ-8), but there were no significant differences reported. No other measure of mood or mental health was completed in this study, possibly as the primary focus was on physical health implications. As such the nature of the peer support programme offered to participants may have focused less on factors specific to mental health.

There were no further significant results reported in the six-studies reviewed. Aben and colleagues found no significant differences in mood, memory or quality of life for participants attending a peer support group (2013), which was consistent at 6 and 12-month follow-up (2014). In these two studies, peer support was the control group, but was poorly described and so the quality of the findings is questionable. Cadilhac *et al.* (2011) completed a phase II RCT, which reported that a stroke peer support programme was safe and feasible. Although improvements in mood were reported six-months post group, the study was not adequately powered to achieve statistically significant changes (Cadilhac *et al.*, 2011). It is hoped that the planned phase III efficacy study will contribute further to the understanding of the effectiveness of peer support as an intervention.

The quantitative studies are therefore equivocal with regard to the efficacy of peer support in stroke. These findings are in contrast to the benefits identified in the qualitative research in this area. There were only two studies that reported statistically significant findings related to behaviour, which included improvements in daily task participation (Patterson *et al.*, 2010 and Muller *et al.*, 2014) and community reintegration (Muller *et al.*, 2014). Kronish *et al.* (2014) reported a significant improvement related to physical health only, but not depression (the only aspect of mental health they measured). No other significant findings were reported after attendance at peer support programmes (Aben *et al.*, 2013; 2014 and Cadilhac *et al.*, 2011). There may, however, be methodological limitations associated with these

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studies that impact upon the quality of the findings reported (and their subsequent implications), which warrants further review.

1.5.4.3 Limitations of the Studies

As previously reported, the heterogeneity of the peer support programmes (e.g. what is provided, training for peers) may have a detrimental impact on its application into clinical settings. Other factors such as the samples included, research designs used and outcome measures utilised, may also need to be considered.

With regards to the samples included, sizes ranged from 13-600, although nine out of ten studies included less than 154-participants. Such small sample sizes have implications on the generalisation of the findings to the larger stroke community.

With regards to the current research, only one of these studies was conducted in the UK (Morris & Morris, 2012). There were individual characteristics of the study samples that may have also impacted upon the quality of the findings. Stewart *et al.* (1998) reported on the experiences of only carers, and this sample did not include any males. The participants in the study by Kronish *et al.* were predominantly Black or Latino (86%). Participants recruited by Kessler *et al.* (2014) and Tregua and Brown (2013) may have been more representative of individuals who viewed peer support more favourably, due to their respective inclusion criteria and sampling strategy.

The features associated with the control groups included in the studies may also have impacted upon the findings reported. There was no treatment-as-usual control groups included in 4 out of 6 quantitative studies. Aben *et al.* (2013; 2014) and Patterson *et al.* (2010) included participants attending a peer support group as the control group, but there was no waiting-list condition also incorporated into the study design. There was no control group at all included in the study completed by Muller *et al.* (2014). In the two experimental studies that included control groups, there may have been contamination bias present as participants were provided with stroke education materials and information about local community resources (Cadilhac *et al.*, 2011; Kronish *et al.*, 2014). The inclusion of a clearer, non-intervention control group may strengthen the findings further.

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Randomisation of participants was not consistently or clearly reported in the studies reviewed and may impact on the validity of the findings. There was no randomisation in the studies by Muller *et al.* (2014) and Patterson *et al.* (2010). In the RCT studies included, the randomisation processes and researcher blinding were not clearly reported upon by Aben *et al.* (2013) or Cadilhac *et al.* (2011). Incorporating RCTs will increase the robustness of the findings further.

The primary aims of the studies and the selection of outcome measures used may also have affected the nature of the findings. Whilst the qualitative studies aimed to explore the experiences (e.g. potential benefits) of those who participated in a peer support programme, the quantitative research had a narrower focus. The primary aims included the impact of a peer support programme on memory (Aben *et al.*, 2013; 2014), its safety and feasibility (Cadilhac *et al.*, 2011), physical health considerations (Kronish *et al.*, 2014) and exercise maintenance (Patterson *et al.*, 2010). Only one quantitative study included in this review had a primary focus on psychosocial adjustment after stroke (Muller *et al.*, 2014). The other five-studies included mood and quality of life as secondary outcomes, but the findings may have been affected as they were not the primary focus of the intervention.

Furthermore, whilst assessment of health related quality of life was commonly included, the measures to evaluate mood and mental health were narrow. With regards to mental health, only a measure of depression was included by Aben *et al.* (2013; 2014) and Kronish *et al.* (2014), despite strokes having a significant impact on a range of emotional considerations (as previously discussed). There were no mood-specific standardised and validated assessments included in the studies by Muller *et al.* (2014) and Patterson *et al.* (2010). Only Cadilhac *et al.* (2011) included a measure of more than one aspect of mental health (the Irritability, Depression and Anxiety scale), but the study was not adequately powered to achieve statistically significant changes in outcomes.

Additionally, peer support is proposed to provide benefits related to social functioning and this was commonly identified as a positive component within the qualitative explorative studies. Surprisingly, none of the quantitative studies measured this aspect of rehabilitation. Overall, the choice of outcome measures in these quantitative studies

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may have made it difficult to capture many of the expected benefits of peer support and militated against positive findings.

With regards to data collection, there were inconsistencies with the amount of follow-up measures collected. In half of the studies, follow-up measurement was included at 6-months (Cadilhac *et al.*, 2011; Kronish *et al.*, 2014) and 12-months post-intervention (Aben *et al.*, 2014). No follow-up data was collected in the other studies (Muller *et al.*, 2014 and Patterson *et al.*, 2010). Including follow-up data will help to increase understanding of the longer-term effects of stroke peer support programmes. The inclusion of measures that encapsulates a range of psychosocial functioning and is completed at various phases, including follow-up, is required in future research.

1.5.4.4 Summary and Implications for Future Research

All of the studies identified above highlight the need for further research within stroke peer support. In the limited research completed, there are mixed findings regarding the efficacy of peer support within a stroke context. Qualitative studies (e.g. Tregua and Brown, 2013) recommended the completion of quantitative evaluation to substantiate the benefits identified from this research approach. The studies that have been completed, however, are affected by methodological limitations, such as small and unrepresentative samples, few RCTs, a lack of control groups to compare the findings, a dearth of follow-up data and narrow outcome measures related to psychosocial functioning.

Upon synthesis of the above studies, a number of recommendations for future research can be made. Due to the quality of the studies included in this systematic review (see Tables 1.2 and 1.3), the findings should be viewed cautiously. None of the studies met the full criteria set in the quality frameworks used to appraise them. The study by Kronish *et al.* (2014) received the highest score out of the six quantitative studies included within the review, due to the inclusion of participant randomisation, measurement of differences at baseline between groups, methods to account for participants and appropriate statistical analysis. The studies by Aben *et al.* (2014) and Cadilhac *et al.* (2011) also scored highly due to their robust research designs (e.g. use of valid outcome measures). Additionally, Cadilhac and colleagues (2011) provided a detailed description of the intervention and comparison groups.

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Given the proposed study's use of a quantitative design, these three studies can therefore be considered the most robust quantitative papers to inform the current research question and method. Limitations apparent in the quantitative studies that reduced their overall quality ratings included, recurring issues with sampling and a lack of clarity with intervention designs. Of the qualitative methods included in the review, the studies by Kessler *et al.* (2014) and Morris and Morris (2012) scored highest within the respective quality framework used and can be considered the most robust of this type of design to inform the current research. This is due to the choices of methodologies and data analyses used, as well as the potential conflicts of interest acknowledged. Commonly in the qualitative research, the sampling strategy, recruitment and influences on participants were poorly reported. The current study and future research should therefore take into account the strengths and limitations identified following use of the quality frameworks to review the existing literature of peer support in stroke.

Due to the limitations with the studies identified in this section, further research regarding the use of stroke peer support as an intervention is required. Group participation can be beneficial for adults with chronic health conditions (NICE, 2009), including stroke (Connect, 2012), and may therefore be an appropriate forum for providing peer support. In comparison to a one-to-one programme, group therapy can facilitate the opportunity for members to meet a greater number of people affected by stroke, allowing potentially more diverse amounts of information regarding the chronic illness to be shared (Rotherham *et al.*, 2015). Further evaluation of a stroke peer support group intervention using a more robust methodological design is therefore warranted.

Additionally, it may also be beneficial for groups consisting of both stroke survivors and carers to be considered in future research. Across the qualitative studies identified in this review, it was consistently reported that carers experienced positive benefits following their attendance at a peer support programme (e.g. Kessler *et al.*, 2014). Surprisingly, the quantitative studies reviewed have only included stroke survivors. There is therefore an absence in the research literature regarding the quantitative evaluation of a stroke peer support group that includes both survivors and carers. There may also be practical benefits of having both stroke survivors and carers

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participate together as, given the physical effects of stroke, transportation has been identified as a barrier to group access (Muller *et al.*, 2014). The majority of carers are spouses (Anderson *et al.*, 1995) and they may be better able to directly or indirectly provide support for survivors to attend community-based intervention programmes. Therefore, evaluating a peer support programme using a quantitative design, which includes both stroke survivors and carers is recommended, as there may be unique and additional benefits to consider (Morris & Morris, 2012).

To summarise, further studies evaluating the efficacy of peer support in promoting positive psychological outcomes after stroke are required to augment existing knowledge. To improve the quality of the findings, future studies should include a quantitative RCT design, use a group peer support programme, include a relevant sample and focus on psychosocial adjustment after stroke for both survivors and carers. A well-chosen control group (waiting-list, treatment as usual) should be included to provide the baseline for the efficacy of the programme. Outcome measures regarding psychosocial wellbeing should also be incorporated.

1.6 STUDY RATIONALE, AIMS AND HYPOTHESES

As discussed in this chapter, strokes are a leading cause of severe adult disability and both survivors and carers may experience a wide range of emotional problems. Decreased rates of stroke mortality and increased morbidity have implications for clinical health services. Psychological services in stroke care has been recognised as having an important role in stroke rehabilitation, yet there is an outstanding need to increase and improve this resource, particularly within community settings.

Peer support has been identified in national guidelines as an important component of psychological rehabilitation after stroke. Its use is widely reported in other physical health conditions, but there is a paucity of studies that have evaluated its efficacy in stroke. As discussed in this chapter, the limited research that has been completed indicates that there is mixed evidence for the benefits of peer support in stroke rehabilitation. Qualitative studies have reported that stroke survivors and carers had positive experiences following their participation in peer support programmes, which

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included the provision of emotional, informational and affirmational support. The few quantitative studies completed, however, provide limited support for these findings. None of these studies have, however, exploited the potential of peer support in groups to include both stroke survivors and carers, and the opportunities for mutual therapeutic benefit this could provide.

Given the limited evidence and methodological limitations reported, the primary aim of this thesis, therefore, was to evaluate the efficacy of a peer support programme within a community stroke service. To date, as far as the author is aware, there has been no quantitative evaluation regarding the psychosocial wellbeing of survivors and carers following their participation in a stroke peer support programme. Accordingly this study aims to evaluate the efficacy of a stroke peer support programme, using a range of standardised psychosocial measures completed by stroke survivors and carers. Given the limited research, this study also aimed to explore the processes (such as social support) that underpin a group peer support programme. The findings could have implications for survivors, carers and community stroke services and for psychological resources within them.

Following the evidence reviewed in this chapter, it is hypothesised that:

1. Participants attending a peer support programme will report significantly reduced psychological distress, as has been reported across other physical health conditions, compared to a waiting list control group.
2. There will be significant improvements in quality of life reported by those attending the peer support group programme, compared to a waiting list control group.
3. There will be significantly improved perceived social support from participants attending the peer support programme, compared to a waiting list control group.
4. There will be significant improvements in activities of daily living following attendance at the peer support group programme, compared to a waiting list control group.
5. The improvements will be mediated by the therapeutic value of the group (i.e. social support will mediate benefits of attending the group regarding psychological distress and quality of life).

CHAPTER TWO

METHODOLOGY

2.1 DESIGN

This study used a quantitative, randomised within and between groups (mixed) design to evaluate a peer facilitated stroke peer support group. The participants were stroke survivors and carers of stroke survivors. The intervention group were compared with a control group who did not receive this therapy. All participants completed psychosocial measures at three time points: before (baseline), post-intervention (five-week period) and at follow-up, one month after the intervention ended.

All participants completed the following measures:

- the General Health Questionnaire-30 ([GHQ-30] Goldberg & Williams, 1988);
- the Barthel Index ([BI] Mahoney & Barthel, 1965);
- the EuroQol-5D ([EQ-5D-3L] Brooks, 1996); and
- the Multidimensional Scale of Perceived Social Support ([MSPSS] Zimet *et al.*, 1988).

Participants allocated to the peer support intervention also completed a measure of group processes, the Therapeutic Factors Inventory-19 ([TFI-19] MacNair-Semands *et al.*, 2010), at the post-intervention and follow-up stages.

Mixed multivariate analysis of covariance (MANCOVA), follow-up analysis of covariance (ANCOVA) and analysis of variance (ANOVA) were used to analyse self-reported changes in psychosocial wellbeing between the different stages of the intervention. Regression-based mediation analysis (Hayes & Preacher, 2014) was

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used to explore the mechanisms by which peer support influenced psychological distress and quality of life.

2.2 PARTICIPANTS

2.2.1 Power Analysis

Sample size was based on assessment of statistical power using G-Power ([Version 3.1.7] Faul *et al.*, 2007), alongside consideration of resource limitations. As discussed in Section 1.5, there is limited data available from previous quantitative research regarding peer support in stroke rehabilitation. Power calculation was therefore based on a medium effect size, as defined by Cohen (1988). Statistical analysis involved MANCOVA and follow-up ANCOVA and ANOVA. For the MANCOVA, based on a medium effect size of $f^2=0.25$, 158 participants were required, using standard parameters of $\alpha = .05$ for .80 power to be detected (Cohen, 1988). To investigate Intervention and Measurement interactions in follow-up ANCOVA and separate ANOVA with three-measurement times for the two-group comparison, a medium effect size $f^2=0.25$ can be detected with 28 participants at 0.80 power and alpha set at 0.05. Due to time constraints, 47-stroke survivors and carers were recruited. A small sample size may result in difficulties with detecting significant differences between groups (Akobeng, 2005). As ANOVA was the primary form of analysis (follow-up ANCOVAs were also completed subsequent to the MANCOVA), however, this sample was well powered to detect a medium effect size using this statistical test.

2.2.2 Inclusion and Exclusion Criteria

Participants were recruited if they met the following inclusion criteria:

- They were a stroke survivor or a carer of a stroke survivor (and the stroke was a minimum of three months previously).
- They were discharged from hospital.
- They were aged 18-years old and above.

The decision to stipulate that a stroke had occurred at least three months previously was based on the expertise of clinicians /supervisors. This would enable the potential

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inclusion of a greater number of community-based participants, whilst allowing for a period of adjustment after discharge from hospital.

As the study was designed to evaluate a method of post-stroke community support for stroke survivors and carers, only participants discharged from hospital were included. The rationale for this approach was due to the high level of unmet psychological need reported by stroke survivors and carers in the community and the paucity of available community services and service models.

Different inclusion criteria were used for participants recruited for the role of peer supporter:

- They were a stroke survivor or carer of a stroke survivor.
- The stroke must have occurred at least 18-months previously.
- Individuals must have felt confident that they could contribute to helping others with stroke.

The decision to specify that the stroke must have occurred for peer supporters at least 18-months previously was based on the premise that post-traumatic growth after stroke may take additional time to develop (Tedeschi and Calhoun, 1996). By setting a minimum time period this would allow participants the opportunity to adjust and develop additional resilience following the stroke and fulfil the role of a peer supporter. Screening of peer supporters took place during preliminary training and further support was provided once the intervention had commenced (see Section 2.3.2.1). Data from peer supporters were collected, but not included in the overall statistical analysis.

All participants were required to be proficient in either English or Welsh. Written information used in the recruitment process (i.e. the leaflet, participant information sheet and consent form) were available for translation into Welsh upon request. The questionnaires had not been validated in Welsh and therefore could not be translated. If required, a translator would have been made available for any Welsh-only speaking participants.

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Participants were excluded if they met the following criteria:

- They were younger than 18-years of age.
- They had any visual, auditory or cognitive difficulties (e.g. communication) to a degree that would impact on their ability to complete the questionnaires (as judged following discussion between individuals, clinicians within the service and the author prior to obtaining consent).
- They could not communicate proficiently in either English or Welsh.

2.3 PROCEDURE

The phases of the study are outlined in Figure 2.1 and a narrative description is also provided below.

2.3.1 Phase 1: Study Approval

Cardiff University agreed to act as Sponsor for the project, as required by the Research Governance Framework for Health and Social Care (see Appendix A). As the study solely recruited participants through the NHS (Cardiff and Vale University Health Board only), ethical approval was obtained from NHS National Research Ethics Service (NRES) research ethics committee (see Appendix B).

As part of the National Institute for Social Care Health Research Permissions Coordinating Unit (NISCHR PCU) review process, host organisation approval was received from the Cardiff and Vale UHB Research and Development Office and the study was classed as pathway-to-portfolio (see Appendix C).

2.3.2 Phase 2: Recruitment

Stroke survivors and carers of stroke survivors who had previously accessed the Stroke Rehabilitation Service in Cardiff and Vale UHB (and whose contact details were therefore listed on the local service's stroke register) were recruited for this study.

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Phase 1:

Study Approval

Cardiff University (Sponsorship); NHS NRES (Ethical Approval); Cardiff and Vale UHB R&D (Ethical Approval).

Phase 2:

Recruitment

Participants
 Leaflets sent by clinicians in local service to potential participants ($n=70$) and follow-up telephone contact also made.

 After giving their verbal consent, potential participants contacted by author (by telephone). Group members ($n=48$) randomly allocated to condition in Phases 3(a) or 3(b).

Peer Supporters
 Telephone contact made by clinicians in local service ($n=8$).

 Training session provided by author and supervisor ($n=6$). Written consent obtained ($n=4$).

Phase 3(a):

Intervention

Peer Support Group I ($n=12$)
 Participants complete questionnaires and provide written consent. Participants attend five group intervention sessions (weekly). Participants ($n=6$ [other 6-drop out]) complete questionnaires at end of group and at one-month follow-up.

Comparison Group I ($n=12$)
 Participants complete questionnaire pack and provide written consent (by telephone and / or post). Participants ($n=10$) complete the questionnaires again after five weeks and a further four weeks later.

 Participants allocated to attend peer support group III.

Phase 3(b):

Intervention / Recruitment

Peer Support Group II ($n=12$)
 Repeated as above, but with new participants ($n=10$) providing data.

Comparison Group II ($n=12$)
 Repeated as above, but with new participants ($n=10$). Participant allocated to attend group III.

Participant Recruitment ($n=10$)
 Repeated as above in Phase 2; allocated to comparison group III or group IV.

Phase 3(c):

Intervention

Peer Support Group III ($n=24$)
 Repeated as above, but with participants allocated from comparison groups I and II ($n=7$).

Comparison Group III ($n=10$)
 Repeated as above, but with participants ($n=4$) recruited solely from Phase 3(b).

Phase 3(d)*

Peer Support Group IV*
 Participants from comparison group III ($n=6$) and newly identified individuals were invited to attend group intervention.

Phase 4:

Debrief

Participant Debrief
 Participant sent debriefing letter.

Figure 2.1 Overview of research procedure. *No data were obtained from this group.

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Two groups of participants were recruited; peer supporters and group members. Both stroke survivors and carers were recruited to become peer supporters and co-facilitate group sessions with clinicians. Concurrently, stroke survivors and carers were also recruited and randomly allocated to either the intervention (peer support group sessions) or comparison group (and later offered the opportunity to complete the intervention).

As reported in Figure 2.1, a further period of recruitment took place during *Phase 3(b)* due to transportation issues affecting participant attendance at *Peer Support Group I*. Stroke survivors and carers recruited in this additional phase were randomly allocated to either *Comparison Group III* or *Peer Support Group IV*. Data were not collected from those allocated to *Peer Support Group IV*.

2.3.2.1 Peer Supporter Recruitment

Stroke survivors and carers of stroke survivors were nominated by clinicians within the service to become peer supporters, based on their previous involvement with the local team. Initially, six stroke survivors and two carers were informed of the proposed study by clinicians in the local service, who contacted them by telephone. Two individuals declined involvement, due to time commitments.

The six remaining individuals (five survivors and one carer) agreed to attend a three-hour training session facilitated by the author and study supervisor, alongside clinicians in the local service (JW and SF). Individuals were informed that there was no obligation associated with attending the training. The training consisted of: information about the proposed group (e.g. practicalities); theoretical knowledge / rationale (about stroke and peer support as a model); and group facilitation skills (e.g. using Socratic questioning). The training involved a combination of teaching, working in pairs, observation and role-play.

Participant information sheets for peer supporters (see Appendix D) were provided to clearly outline the requirements for participating in the proposed study. Following the training session, five individuals gave their written consent to participate in the study as peer supporters, with one person declining (citing personal reasons). The five remaining peer supporters were given the schedule for the forthcoming peer support

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groups and provisionally allocated themselves to co-facilitate on specified dates (depending on their personal circumstances). The peer supporters were informed that they were under no obligation to attend a minimum number of group sessions and could fulfil the role without participating in the study.

By the time of the first intervention group (i.e. *Phase 3[a]* of the study), one-peer supporter withdrew, leaving a pool of four peer supporters in total (one carer and three survivors). At the time of *Phase 3(b)* of the study, one-further stroke survivor volunteered to become a peer supporter and “shadowed” the trained peer supporters in subsequent sessions. By *Phase 4* of the study, a further two-individuals (previous group members) nominated themselves to become peer supporters for any future groups (i.e. after the study had finished). Thus, by the end of the study, the pool of peer supporters had increased to seven.

2.3.2.2 Participant Recruitment

Stroke survivors and carers of stroke survivors ($n=70$) who had previously accessed the stroke rehabilitation service in Cardiff and Vale UHB were informed by the local service of the proposed intervention by leaflet (see Appendix E). Approximately 10-days later, clinicians within the service made telephone contact to any individuals who had not responded to the leaflet. This was to clarify each individual’s level of interest in participating in the study. Any individual who verbally declined to participate was not contacted again, but they were informed that they could contact either the author or clinicians in the service should they change their mind in the future.

Fifty-eight individuals expressed an interest in participating in the study and gave their verbal consent for the author to contact them by telephone. The author provided potential participants with additional information about the study (e.g. the nature of the group, how many weeks it would last). Individuals either gave their verbal consent to participate in the study or declined any further involvement. Individuals were informed that once a pool of participants had been identified (approximately 50-participants to account for attrition rate), they would be randomly allocated to either an intervention group (for five-weeks) or a comparison group (awaiting intervention). All participants were informed that they would be able to attend intervention within

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an approximate 15-week period. Ten individuals declined any further involvement and therefore 48-stroke survivors and carers were randomly allocated to either of the two groups. After randomisation, the author contacted participants by telephone to inform them of their group allocation and proposed start-date. The participants allocated to the comparison condition were automatically invited to attend *Peer Support Group III*.

By *Phase 3(b)* of the study (see Figure 2.1) a further 10-participants were recruited due to transportation issues affecting attendance in *Peer Support Group I*.

Recruitment for newly identified potential participants was repeated as described above. Potential participants ($n=10$) were initially contacted by clinicians in the local service and then by the author, as previously described. Participants were randomly allocated to either *Comparison Group III* (data collected for study) or *Peer Support Group IV* (data not collected for study). An overview of the number of individuals approached who chose not to participate is provided in Appendix F.

2.3.3 Phase 3: Intervention

2.3.3.1 Randomisation

Initially, 48 participants (not including peer supporters) were randomly assigned to one of four groups (either *Peer Support Groups I or II* or *Comparison Groups I or II*). Those allocated to *Comparison Groups I and II* were automatically assigned to *Peer Support Group III*. More than one intervention group was scheduled due to the size constraints of the venue. Carers and survivors were allocated randomly using a quota basis that balanced the number of each across intervention and comparison groups. All survivor-carer dyads were co-randomised (allocated as a joint participant as opposed to singular), to ensure they were allocated to the same group. Not all participants, however, attended with a partner or carer. The only participants who attended “individually” (i.e. without a partner or carer) were stroke survivors.

A series of cards with participant names on were selected at random by the author and supervisor and paired with a condition (e.g. the first name-card chosen went into *Peer Support Group I*; the second into *Comparison Group I*; the third into *Peer Support Group II* and so forth). All carer-survivor dyads were allocated first to ensure equal representation across groups. This process was repeated with stroke survivors until all

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48-names were allocated to a condition. Twelve names in total were allocated to each condition.

Due to arranged transportation issues affecting the number of participants who attended *Peer Support Group I*, a further period of recruitment took place during *Phase 3(b)* to increase the number of participants for the study. Participants were randomly allocated to either *Comparison Group III* or *Peer Support Group IV* using the exact same randomisation process as previous.

2.3.3.2 Stroke Peer Support Intervention Groups

Intervention consisted of five peer support group sessions, occurring on a weekly basis at a day hospital in Cardiff and Vale UHB. The sessions were co-facilitated by a minimum of two peer supporters and lasted between 1.5 and 2 hours. At least one clinician was also present (the author) and acted as a co-facilitator. The study supervisor and clinicians in the local stroke service also attended, but with less frequency.

At the first of the five group sessions, participants identified topics related to post-stroke rehabilitation that they wanted to focus on during the forthcoming sessions. The topics identified were common psychosocial difficulties typically reported within stroke rehabilitation research (e.g. mood, memory, isolation and loss) and also practical considerations (e.g. driving, finances). Topics were often discussed by the participants in more than one session, alongside facilitation from peer supporters and clinicians. A more detailed overview of the group (e.g. its process and co-construction) is provided in Appendix G.

During the first group session, group members were provided with the study questionnaire pack, which included: outcome measures, a participant information sheet and consent form. The group member participation information sheet (see Appendix H) provided an overview of the study, its rationale, requirements, exclusion/inclusion criteria, potential benefits and risks associated with participating. All participants were required to provide their written consent to participate in the study (see Appendices I & J). Individuals were informed that they were able to attend the peer support group even if they chose not to participate in the research study. All

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gave, however, their consent to participate. All participants were required to complete questionnaires (see Appendix K) at three stages: during the first group session, at the end of intervention (after five-weeks) and at one-month follow-up. It took between 20-30 minutes to complete the battery of questionnaires each time.

As previously stated, the size of the venue used to hold the intervention sessions meant that further peer support groups were scheduled. Once *Peer Support Group I* finished, *Peer Support Group II* began the five-week programme. The procedure was repeated identically. The themes identified by the new group members were the same as those identified by the first group. Once the second group completed the five-week intervention, *Peer Support Group III* began. The exact same procedure as described above occurred during this period. *Peer Support Group III* consisted of participants from *Comparison Groups I and II* (see Figure 2.1).

Following this period, participants in *Comparison Group III* were invited to attend the group intervention and formed *Peer Support Group IV*. Data from this group, however, were not included within the research study (as there was no comparison group).

To summarise, there were three separate intervention groups in total, running consecutively, and were completed over a 20-week period.

2.3.3.3 Comparison Groups

Participants randomly allocated to the comparison groups were informed by telephone of their proposed group-intervention start date (i.e. when either *Peer Support Group III or IV* was scheduled to begin). They were provided with participant information sheets and consent forms to return by post. If they consented to participate (confirmed by a follow-up telephone call by the author), they were asked to complete questionnaires over the telephone or by writing within three time-periods, prior to them attending their scheduled intervention group. These three time-periods were consistent with those attending the peer support groups (baseline, five-weeks later and at one-month follow-up). Individuals were informed that they could still join the intervention group without having to participate in the research study.

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Not all of those randomly allocated to either the intervention or comparison conditions proceeded with their participation in the study (e.g. ill health, for personal reasons or they had changed their mind). In total, there was an attrition rate of 18-stroke survivors and carers who did not provide any data for analysis, leaving 47-participants in total (see Appendix F).

2.3.3.4 Peer Supporters

Four peer supporters, who previously attended training as detailed in Section 2.3.2, co-facilitated intervention group sessions. After each individual group session, the author provided supervision and debrief for the peer supporters present. The contact details of the author and supervisor were also provided for peer supporters to use outside of this time if required. Information regarding local support services (e.g. clinicians within the stroke rehabilitation service and Stroke Association Wales) was also provided to support the peer supporters' wellbeing.

By the end of the study, three previous group members volunteered themselves to fulfil the role of peer supporters and shadowed the trained members, as they had not completed the initial training session. No data were collected from individuals who did not attend the training provided for prospective peer supporters.

2.3.4 Phase Four: Participant Debrief

Participants were sent a thank you / debriefing letter (see Appendix L).

2.4 ETHICAL CONSIDERATIONS

2.4.1 Informed Consent

Participants were required to complete and sign a consent form to confirm that they understood the information sheet and that they agreed to take part in the research study. As detailed in the information sheet, all participants were informed of their voluntary participation in the study, that they were free to withdraw at any time, that their data would be anonymised and that any withdrawal from the study would not affect their clinical care.

2.4.2 Data Collection, Confidentiality and Storage

2.4.2.1 Data Collection and Confidentiality

Data collection took place between September 2014 and March 2015. Participants in the peer support group conditions completed the questionnaires either in the group or at home (returned by post or telephone). Participants in the comparison group conditions completed the questionnaires at home (by post or telephone). All participants were given the choice of completing questionnaires in writing or by telephone with the author. Participants were given a unique code to ensure anonymity with their questionnaires, given that these were repeated over three phases. Only the author and supervisor had access to the coding system to identify the participants. Once the participant had completed their involvement in the study, any identifying information was destroyed. For those who completed the questionnaires in writing, participants were asked not to provide their names or any personal identifiable information on their questionnaires. Confidentiality was outlined to participants in the information sheet and debriefing letter.

2.4.2.2 Data Storage

Consent forms and questionnaires were stored separately in a locked cabinet in an office at the South Wales Doctoral Course in Clinical Psychology, Cardiff University, Cardiff. Only the author and supervisor had access to this cabinet.

2.4.3 Participant Wellbeing

Within the information sheet, participants were informed that there was a chance that attending a peer support group and / or completing questionnaires about their experience with stroke may be upsetting. To reduce this risk, the information sheet notified participants that they could stop or withdraw from the study at any time without their rights being affected. Contact details for local services were also provided if participants wanted to seek help for any distress caused.

All participants were provided with the contact details for the author and research supervisor if they became distressed by their participation in the study. Contact details for a clinician independent of the research project were also provided, if participants felt unable to contact the author and / or supervisor.

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For peer supporters, weekly debrief / supervision sessions were held to monitor and support wellbeing.

2.5 MEASURES

Psychometrically validated self-report questionnaires were used to evaluate the effectiveness of a stroke peer support group. A brief demographic survey was also included. A copy of the research questionnaires can be found in Appendix K.

2.5.1 Demographic Survey

Participants were asked to provide demographic information (e.g. age, gender, ethnicity, date of stroke). Headings were identified following consultation with clinicians who have expertise in stroke rehabilitation and also after a literature search.

2.5.2 Mood: General Health Questionnaire ([GHQ-30] Goldberg & Williams, 1988)

The General Health Questionnaire (Goldberg & Williams, 1988) is an internationally used instrument within research studies for assessing the mental health of people living in community settings (Abeyseena *et al.*, 2012; Dale *et al.*, 2012a). Several versions have been developed since the original 60-item version, including the 30-item version used in this study. The shorter version was used in this study as the somatic symptoms found in the 60-item version are removed (to be more suitable for use with those who have experienced a stroke). The GHQ-30 is also reported to have the highest validity of all the GHQ versions (Goldberg & Williams, 1988).

The GHQ-30 includes 30 statements across different dimensions of mental state (e.g. depression and anxiety) and social functioning. Four options are available to responders when answering the questions regarding their health (e.g. not at all, no more than usual, more than usual and much more than usual). The GHQ-30 was scored in the conventional 0-0-1-1 scoring method (Goldberg & Williams, 1988), where a score of 1 is given for any response indicating a deterioration from the usual health state. The total score on the GHQ-30 is the sum of the 30 items (i.e. giving a

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maximum score of 30). Higher scores are indicative of greater distress associated with mental health.

The GHQ-30 has been reported to have good validity (O'Rourke *et al.*, 1998) and reliability coefficients have ranged from .78 to .95 in various studies (see Jackson, 2007). The GHQ-30 has been used in a variety of community settings (Huppert *et al.*, 1989; Mowry & Burvill, 1990) and is a commonly used measure of mental health difficulties after stroke (Bergersen *et al.*, 2013; Brunner *et al.*, 2014). Using the conventional scoring format, a cut-off point of 9 (i.e. $\geq 10 = \text{'Psychiatric Morbidity'}$) has demonstrated high sensitivity (.8) and specificity (.76) within stroke populations for detecting morbidity (O'Rourke *et al.*, 1998).

2.5.3 Activities of Daily Living: Barthel Index (Mahoney & Barthel, 1965)

The Barthel Index ([BI] Mahoney & Barthel, 1965) is a 10-item scale that measures performance across a range of activities of daily living. It includes ratings of how able an individual can (e.g. independently; with some support; dependent on others) complete a given task (e.g. dressing; washing). Scores are recorded using a scale between 0 and 3 to derive a total between 0 and 20 (Collin *et al.*, 1988). As has been reported in previous research (Wade & Collin, 1988), BI scores were classified into five categories: Independent (BI=20); Mild (BI=15-19); Moderate (BI=10-14); Severe (BI=5-9); and Very Severe (BI=0-4). Higher scores indicate greater independence.

The BI is a commonly used measure within stroke rehabilitation research (Kwakkel *et al.*, 2010; Wolfe *et al.*, 1991). Good internal reliability ($\alpha=.83$) and high validity ($\rho=.97$) have been reported for its use in stroke populations (Sadaria *et al.*, 2001). Good discriminative properties have also been reported, with the area under the curve ranging from .785 to .848 (Kwakkel *et al.*, 2011).

2.5.4 Quality of Life: EuroQol 5D ([EQ-5D-3L] Brooks, 1996)

The EQ-5D-3L is a standardised instrument for use as a measure of health outcome. It has five-dimensions included: mobility; self-care; usual activities; pain/discomfort; and anxiety/depression. Each dimension has three levels that are self-rated (1 = no problems, 2 = some problems, 3 = major problems). Total scores, therefore range from 5-15 and higher scores are associated with decreased quality of life.

There is an extensive amount of research to support the validity and reliability of the EQ-5D-3L across many health conditions (Dyer *et al.*, 2010; Pickard *et al.*, 2007). It has been reported that the EQ-5D-3L has reasonable construct, concurrent and convergent validity, as well as good accuracy for predicting outcomes (Hunger *et al.*, 2012; Janssen *et al.*, 2012; Pinto *et al.*, 2011). Use of the EQ-5D-3L is widely reported within the research for chronic health illness (Konerding *et al.*, 2014; Obradovic *et al.*, 2013). It is also routinely used as a general health status questionnaire in stroke services (Brooks, 1996; Golicki *et al.*, 2014; Quinn *et al.*, 2009). Dorman and colleagues (1999) reported good test-retest reliability (unweighted Kappa values were .83) and good validity for measuring physical and social functioning and overall health after stroke.

2.5.5 Social Support: Multidimensional Scale of Perceived Social Support ([MSPSS] Zimet *et al.*, 1988)

The MSPSS (Zimet *et al.*, 1988) is a 12-item scale assessing subjective ratings of perceived social support from three different dimensions (family, friends and significant others). There are seven possible responses to each statement, which are rated on a seven-point Likert-type scale (scored 0-6) giving a maximum total of 72. Higher scores indicate greater perceived social support.

The MSPSS has demonstrated good psychometric properties in previous studies (Ekback *et al.*, 2013; Ramaswamy *et al.*, 2009; Wongpakaran *et al.*, 2011). It has been previously used in stroke research (White *et al.*, 2007; Yu *et al.*, 2013) and is well validated in other chronic health conditions such as cardiovascular disease (Blumenthal *et al.*, 1987) and immune functioning (Copertaro *et al.*, 2014). In a clinical and normal sample of older adults, the MSPSS has been shown to have good test-retest reliability ($r=.73$) and excellent internal consistency (Cronbach's alpha = .87 - .94; [Stanley *et al.*, 1998]).

2.5.6 Group Processes: The Therapeutic Factors Inventory-19 ([TFI-19] MacNair-Semands *et al.*, 2010)

Therapeutic factors are interpersonal processes that operate in group therapy, which can facilitate psychological wellbeing and positive relationships through group

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interactions (Yalom, 1975). The identification of therapeutic factors is an important component of evaluating whether members are benefitting from their participation in a group (Santos *et al.*, 2012). The original Therapeutic Factors Inventory ([TFI] Lese & MacNair-Semands, 2000), containing 99-items, was derived to obtain ratings from group members of the perceived presence or absence of Yalom's (1975) eleven therapeutic factors. Due to the length of this measure, a shortened version, the TFI-19, was developed to assess more global dimensions of the group process with greater efficiency (Joyce *et al.*, 2011).

The TFI-19 is a 19-item self-report measure, designed to assess individual group members' perceptions of the presence of four global therapeutic factors: Instillation of Hope; Secure Emotional Expression; Relational Impact; and Social Learning (Joyce *et al.*, 2011). Each item contributes to one of these four broad factors. An example of a statement on the TFI-19 includes, "*Things seem more hopeful since joining the group*". Items are rated on 7-point Likert-type scale and range from *strongly disagree* to *strongly agree*. Overall scores range from 19-133, with higher scores indicating an increased experience of overall group effectiveness. Data analysis involved comparisons of the total overall score (i.e. the combined value of the four global factors) as reported by MacNair-Semands *et al.* (2010).

The TFI has good test-retest reliability (Cronbach's $\alpha = .90$, [Lese & MacNair-Semands, 2000]). Evidence for construct, concurrent and predictive validity of the TFI-19 have also been reported (Joyce *et al.*, 2011; MacNair-Semands *et al.*, 2010). The TFI-19 has been utilised within research studies to evaluate the effectiveness of group intervention processes (e.g. Johnson & Lambie, 2013; Travaglini *et al.*, 2012). More specific to the design of this study, the shortened version of the TFI has been used previously with stroke survivors and carers (Morris & Morris, 2012), although the questionnaire has not been validated in this population. In this study, only the participants allocated to the peer support intervention completed the TFI-19 (i.e. not those in the comparison group condition).

2.6 STATISTICAL ANALYSIS

2.6.1 Preliminary Data Analysis

Data analysis was completed using SPSS version 20 (IBM Corporation 2011). All continuously distributed data were screened to check for the assumptions of parametric testing. Data were inspected to identify normal distribution, outliers and equality of variance in the sample.

2.6.2 Analysis

Demographic characteristics of the sample were analysed to inform subsequent data analysis (i.e. to identify any potential confounding variables). For categorical data, Pearson's chi-square (e.g. gender) and Mann-Whitney tests (e.g. memory difficulties) were used to determine the significance of associations. The relationships between all continuously distributed demographic data (e.g. age) and the main study variables (e.g. GHQ-30) were analysed using Pearson's correlation coefficients, t-tests, ANOVA, MANCOVA and follow-up ANCOVA. Statistical analysis using these methods explored any significant relationships between the dependent variables, the group variable (e.g. intervention group) and the stage of measurement (i.e. pre-, post-, and follow-up).

Data were also collected from three peer supporters, who co-facilitated the peer support group intervention. As there was no comparison group for this data and due to the small sample, only descriptive data is reported. None of this data was included in the statistical analysis of the sample described above (i.e. $n=47$ and not 50).

2.6.3 Mediation Analysis (Hayes, 2009; Preacher & Hayes, 2004)

Mediation analysis was used to explore the mechanisms of peer support further. According to the simple mediation model (Figure 2.2), independent variable X is proposed to influence dependent variable Y directly, and also indirectly through mediator variable M (Hayes & Preacher, 2014). Therefore, a is the coefficient for predicting M from variable X ; b is the coefficient for predicting Y from M ; and c' is the coefficient predicting Y from X . As stated by the model, c' quantifies the *direct effect* of X , whereas a and b quantifies the *indirect effect* of X on Y through M (Hayes,

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2009). The total effect is represented as c . As such, the *indirect effect* ($a + b$) is the difference between the total (c) and direct effect of X (c').

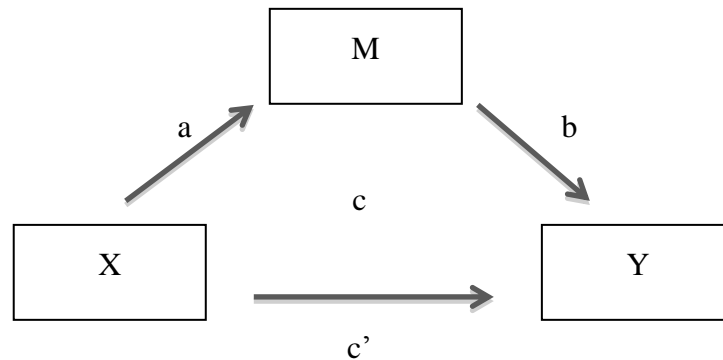


Figure 2.2 Simple mediation model. Adapted from Hayes and Preacher (2014)

With regards to this study, mediation analysis was conducted to explore whether benefits of peer support were mediated by perceived social support. Thus using the simple mediation model (Hayes & Preacher, 2014), this study explored whether peer support (independent variable X) had a *direct effect* on emotional wellbeing and quality of life ([outcome variables] dependent variables Y) and whether these were also mediated (as an *indirect effect*) by perceived social support (variable M).

Preacher and Hayes (2004) proposed the bootstrapping method, a non-parametric test, for mediation analysis. Bootstrapping involves repeatedly randomly sampling observations with replacement to compute the desired statistic. In this study, 2000 bootstrap samples were generated. Data analysis was completed through the PROCESS dialogue box in SPSS. The bootstrapping method provides confidence intervals, and if zero does not fall between the lower and upper bounds of these (at 95%), a significant mediation effect is present (Preacher & Hayes, 2004).

CHAPTER THREE

RESULTS

3.1 PRELIMINARY DATA ANALYSIS

All data were screened to check for errors, missing data and whether values fell within the possible ranges for each variable. All data were inspected visually and analyses were completed to check for the assumptions for parametric testing. The following interval variables (17 in total) were assessed: Age, Time since Stroke (months), Years in Education, BI Total (pre, post and follow-up), MSPSS Total (pre, post and follow-up), EQ-5D-3L Total (pre, post and follow-up), GHQ-30 Total (pre, post and follow-up) and TFI-19 (post and follow-up).

3.1.1 Missing Data and Outlier Check

There were missing data related to demographic information that was not applicable to stroke carers (e.g. date of stroke). One individual did not provide information regarding their living circumstances, but no further missing data were identified. Visual inspection of the data identified one data entry error (related to incorrect value label), which was corrected prior to statistical analysis.

Inspection of the frequency distributions, Q-Q plots and boxplots identified five outliers across all of the variables. This included one outlier on each of the MSPSS *Family* variable (pre and post) and the TFI-19 *Instillation of Hope*, *Relational Impact* and *Total* (all post) variables. Changes to these scores were made (to be one unit above the next highest score in the data set) to reduce the disproportionate impact of the outliers, as described by Field (2009).

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3.1.2 Assumptions for Parametric Tests

The distributions of the variable scores were tested for univariate data normality using the Kolmogorov-Smirnov (K-S) test. The assumption for the normal distribution of data was not met, as the K-S test was significant for 12 of the 17 variables analysed ($p < .05$). If the data are not normally distributed, there is an increased chance of a false positive result (Type I error) if analysed with a test that assumes normality, and in such contexts non-parametric tests are recommended (Field, 2009). There is, however, contradictory research that states that parametric tests are robust when assumptions are violated (see McDonald, 2014). For example, Glass and colleagues (1972) proposed that the false positive rate is not affected by data that are non-normally distributed. Furthermore, when small samples are used, parametric tests may be more robust for use with non-normally distributed data than non-parametric tests (Khan & Rayner, 2003). In consideration of MANOVA, when data are not normally distributed the p statistics maintain the nominal Type I error rate as when data are normally distributed (Finch & French, 2013). In view of the reported robustness regarding the use of parametric tests when data is non-normally distributed, these tests were used for subsequent data analysis. The use of parametric tests for the data of this sample is discussed further in Section 4.4.2.5.

3.2 DESCRIPTIVE DATA

3.2.1 Demographic Characteristics

3.2.1.1 Sample Demographics

Characteristics of the sample are provided in Tables 3.1 and 3.2. The mean (M) age for stroke survivors and carers participating in the study was 65.8 (standard deviation [SD] = 12.8) and ranged between 40-89. Of the 42 stroke survivors, the mean time since stroke was 10.3 months (SD=6.4). In ascending order, 13 survivors (31%) had their stroke between 3-6 months, 19 (45.2%) between 7-12 months, 5 (11.9%) between 13-18 months and 5 (11.9%) above 19 months.

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Table 3.1 Sample age and time since stroke.

		<i>N</i>	Mean	SD	Range (Total)
Age	Total	47	65.8	12.8	40-89 (49)
	Female	21	70.0	14.1	40-89 (49)
	Male	26	62.5	10.9	45-87 (42)
	Stroke Survivors	42	66.0	12.7	42-89 (47)
	Stroke Carers	5	64.6	15.8	40-79 (39)
	Intervention Group	23	63.6	12.9	42-89 (47)
	Comparison Group	24	68.0	12.7	40-88 (48)
Time since Stroke (months)*	Total	42	10.3	6.4	4-27 (23)
	Intervention Group	20	12.9	8.0	4-27 (23)
	Comparison Group	22	7.9	2.9	4-14 (10)

* *N*=42 as not applicable to carers

As reported in Table 3.2, there were a greater number of male participants (55.3%) and the sample largely consisted of stroke survivors (89.4%). Most were white British (89.4%), retired (72.3%) and lived with either a carer or other (74.5%). Most (72%) of the survivors reported having had one stroke previously. Following stroke, 21.3% of participants reported that they *Often* experienced depression and 11.6% also described *Often* having anxiety. Just over a quarter of the sample (25.5%) reported having received treatment for depression or anxiety (e.g. prescribed medication).

The sample in the intervention and comparison groups did not differ significantly with regard to any categorical variables using Pearson's chi-square and Mann-Whitney tests, as listed in Table 3.2 ($p > .05$). The intervention and comparison groups did not differ significantly with regards to 'Age' or 'Years in Education' ($p > .05$). There was a significant difference between the intervention and comparison groups with regards to the mean number of months since stroke. In the intervention group, 'Time since Stroke' was significantly higher compared to the comparison group, $t(23.41) = 2.63$, $p < .05$.

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Table 3.2 Intervention and comparison group demographic characteristics.

Demographic Characteristic	Category	N (47)	%	Intervention [n=23]	Comparison (n=24)	Significance
Mean Age (SD)	N/A	47	100	63.6 (12.9)	68.0 (12.7)	$t(45) = -1.165$, $p = .983$
Mean Time in Months Since Stroke (SD)*	N/A	42	89.4	12.9 (8.0)	7.9 (2.9)	$t(23.41) = 2.632$, $p < .05$
Mean Years in Education (SD)	N/A	47	100	4.8 (1.0)	4.6 (0.9)	$t(45) = 0.741$, $p = .814$
Participant Type	Stroke Survivor	42	89.4	20 (42.6%)	22 (46.8%)	$\chi^2 = 0.274$, $p = .601$
	Carer	5	10.6	3 (6.4%)	2 (4.3%)	
Gender	Female	21	44.7	10 (21.3%)	11 (23.4%)	$\chi^2 = 0.026$, $p = .871$
	Male	26	55.3	13 (27.7%)	13 (27.7%)	
Ethnicity	Asian	1	2.1	1 (2.1%)	0	$\chi^2 = 5.076$, $p = .280$
	Bangladeshi	2	4.3	0	2 (4.3%)	
	Indian	1	2.1	1 (2.1%)	0	
	White British	42	89.4	20 (42.6%)	22 (46.8%)	
	White Irish	1	2.1	1 (2.1%)	0	
Occupation	Employed	8	17.1	4 (8.5%)	4 (8.5%)	$\chi^2 = 2.250$, $p = .325$
	Retired	34	72.3	15 (31.9%)	19 (40.4%)	
	Unemployed	5	10.6	4 (8.5%)	1 (2.1%)	
First Stroke*	Yes	34	72.3	18 (42.9%)	16 (38.1%)	$\chi^2 = 2.027$, $p = .155$
	No	8	17.1	2 (4.8%)	6 (14.3%)	
Living Circumstances^	Alone	12	25.5	6 (13.0%)	6 (13.0%)	$\chi^2 = 5.167$, $p = .160$
	With Partner	28	61.7	12 (28.0%)	16 (37.2%)	
	With Other	6	12.8	5 (11.6%)	1 (2.3%)	
Treatment After Stroke (Mood)	Yes	12	25.5	8 (17.0%)	4 (8.5%)	$\chi^2 = 2.027$, $p = .154$
	No	35	74.5	15 (31.9%)	20 (42.6%)	
Communication Difficulties*	Not at All	15	35.7	6 (14.3%)	9 (21.4%)	$U = 257.500$, $p = .862$
	Mild	25	59.5	13 (31.0%)	12 (28.6%)	
	Severe	2	4.8	1 (2.4%)	1 (2.4%)	
Memory Difficulties*	Not at All	6	14.3	3 (7.1%)	3 (7.1%)	$U = 261.500$, $p = .935$
	Mild	31	73.8	13 (31.0%)	18 (42.9%)	
	Severe	5	11.9	4 (9.5%)	1 (2.4%)	
Relationship Difficulties	Not at All	6	12.8	2 (4.3%)	4 (8.5%)	$U = 215.000$, $p = .107$
	Somewhat	33	70.2	15 (31.9%)	18 (38.3%)	
	Definitely	8	17.0	6 (12.8%)	2 (4.3%)	
Depression	Never	6	12.8	3 (6.4%)	3 (6.4%)	$U = 254.500$, $p = .585$
	Sometimes	31	66.0	14 (29.8%)	17 (36.2%)	
	Often	10	21.3	6 (12.8%)	4 (8.5%)	
Anxiety	Never	9	19.1	5 (11.6%)	4 (8.5%)	$U = 274.000$, $p = .958$
	Sometimes	33	70.2	15 (31.9%)	18 (42.9%)	
	Often	5	10.6	3 (7.1%)	2 (4.3%)	

* Stroke survivors included only (N=42); ^ Data missing from one participant (N=46).

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Of the dependent variables, there was a significant difference between the two groups at the baseline stage on the BI measure only. Participants in the intervention group had higher scores ($M = 16.87$; $SD = 3.17$), reflecting greater independence, compared to the comparison group ($M = 13.92$; $SD = 3.62$); $t(38.16) = -.191$, $p < .05$. Variables that had significant differences between the two groups at baseline were investigated as potential confounding variables in subsequent statistical analysis (see Section 3.2.3). There were no other significant differences between the two groups at baseline. There was a discrepancy in the baseline GHQ-30 scores between the intervention ($M = 13.0$; $SD = 10.1$) and comparison ($M = 8.3$; $SD = 6.4$) groups, although this difference was not significant, $t(45) = 1.892$, $p = .065$.

3.2.1.2 Peer Supporter Demographics

One peer supporter from the initial pool recruited ($n=4$) only co-facilitated two-single intervention sessions (out of 15 in total) and their data were therefore excluded. Demographic data from the three remaining peer supporters were obtained. The mean age was 58.3 years ($SD=3.2$) and ranged from 56-62 years. Two peer supporters were male stroke survivors and their strokes occurred 26 and 27 months previously. The third peer supporter was female and a carer of a stroke survivor. All three described themselves as white-British. Both stroke survivors were registered as volunteers for the local university health board and had retired from work. The carer had volunteered too, but was also employed in an area of work outside of health services.

3.2.2 Descriptive Statistics of Sample

Table 3.3 summarises the means, standard deviations and ranges for the main study variables separately for each group and combined across both. Mean scores on the GHQ-30 reduced in the intervention group from baseline ($M = 13.0$; $SD = 10.1$) to follow-up ($M = 2.6$; $SD = 4.8$), indicating that psychological distress had reduced. Conversely, mean GHQ-30 scores in the comparison group increased (i.e. greater distress) from baseline ($M = 8.3$; $SD = 6.4$) to follow-up ($M = 10.7$; $SD = 5.9$). Higher mean scores were also reported on the MSPSS (indicating increased perceived support) and BI (greater independence) at follow-up for the intervention group ($M = 56.7$, $SD = 14.8$; $M = 17.1$, $SD = 2.9$), compared to the comparison group ($M = 47.0$, $SD = 12.4$; $M = 13.8$, $SD = 3.7$) respectively. The means of both the intervention ($M = 9.0$, $SD = 1.8$) and comparison ($M = 9.9$, $SD = 1.4$) groups on the EQ-5D-3L both

Results

decreased at follow-up, indicating improvements in quality of life. For the intervention group, scores on the TFI-19 increased between post and follow-up stages.

Table 3.3 Descriptive statistics of sample for dependent variables.

Measure	Phase	Intervention Group (n=23)		Comparison Group (n=24)		Combined (n=47)	
		Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
GHQ-30 (Total)	Pre	13.0 (10.1)	0-28	8.3 (6.4)	2-26	10.6 (8.7)	0-28
	Post	5.6 (7.8)	0-26	10.2 (5.8)	1-25	7.9 (7.2)	0-26
	Follow-Up	2.6 (4.8)	0-20	10.7 (5.9)	3-25	6.7 (6.7)	0-25
EQ-5D- 3L (Total)	Pre	9.7 (1.6)	5-12	10.0 (1.4)	7-13	9.8 (1.5)	5-13
	Post	9.0 (1.5)	5-11	9.9 (1.5)	7-13	9.5 (1.5)	5-13
	Follow-Up	9.0 (1.8)	5-12	9.9 (1.4)	7-13	9.5 (1.7)	5-13
MSPSS (Total)	Pre	48.1 (17.4)	8-69	49.0 (11.6)	18-68	48.6 (14.6)	8-69
	Post	52.1 (17.8)	8-72	46.5 (12.8)	19-72	49.2 (15.5)	8-72
	Follow-Up	56.7 (14.8)	20-72	47.0 (12.4)	16-68	51.7 (14.4)	16-72
BI (Total)	Pre	16.9 (2.9)	11-20	13.9 (3.6)	4-20	15.4 (3.6)	4-20
	Post	16.9 (3.2)	11-20	13.9 (3.7)	4-20	15.3 (3.7)	4-20
	Follow-Up	17.1 (2.9)	11-20	13.8 (3.7)	4-19	15.4 (3.7)	4-20
TFI-19 (Total)	Post	91.2 (20.0)	40-117	N/A*	N/A*	N/A*	N/A*
	Follow-Up	99.5 (20.3)	41-121	N/A*	N/A*	N/A*	N/A*

* N/A – not applicable as TFI-19 completed by intervention group only

3.2.3 Confounding Variables

The relationships between ‘Age’, ‘Time since Stroke’, ‘Years in Education’ and the dependent variables (totals at each of the three stages) were explored to identify potential confounding variables. Bivariate correlations were conducted to calculate Pearson’s correlation coefficients and are reported in Table 3.4.

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Table 3.4 Relationships between variables.

	Age	Time since Stroke (n=42)	Years in Education	BI (pre)	BI (post)	BI (FU)	EQ-5D-3L (pre)	EQ-5D-3L (post)	EQ-5D-3L (FU)	GHQ-30 (pre)	GHQ-30 (post)	GHQ-30 (FU)	MSPSS (pre)	MSPSS (post)	MSPSS (FU)
Age	-	-.19	-.28	-.03	-.03	-.04	-.24	-.25	-.17	-.42*	-.28	-.19	.12	.07	.03
Time since Stroke (n=42)		-	.11	-.15	-.18	-.14	.19	.03	.07	.18	-.20	-.19	-.13	-.16	-.09
Years in Education			-	.03	.04	.04	-.13	-.09	-.17	-.02	-.14	-.09	.06	.08	.11
BI (pre)				-	.99*	.97*	-.42*	-.43*	-.44*	-.04	-.20	-.33*	.09	.13	.17
BI (post)					-	.98*	-.39*	-.41*	-.42*	-.06	-.21	-.35*	.09	.12	.16
BI (FU)						-	-.40*	-.42*	-.44	-.04	-.24	-.36*	.07	.11	.17
EQ-5D-3L (pre)							-	.89*	.85*	.49*	.41*	.37*	-.33*	-.30*	-.27
EQ-5D-3L (post)								-	.94*	.39*	.46*	.51*	-.27	-.29*	-.31*
EQ-5D-3L (FU)									-	.28*	.37*	.45*	-.16	-.26	-.29*
GHQ-30 (pre)										-	.48*	.25	-.33*	-.04	.04
GHQ-30 (post)											-	.80*	-.49*	-.36*	-.32*
GHQ-30 (FU)												-	-.27	-.36*	-.46*
MSPSS (pre)													-	.66*	.63*
MSPSS (post)														-	.94*
MSPSS (FU)															-

N=47 unless stated. All values are Pearson's correlation coefficients (*r*). *Denotes significant correlation ($p < .05$).

Results

There was no significant correlation between ‘Years in Education’ and any of the other study variables ($p > .05$). There was a significant negative correlation between ‘Age’ and GHQ-30 at baseline (pre); $r = -.42$, $n = 47$, $p < .01$. As previously reported, there was a significant difference between the two groups regarding ‘Time since Stroke’, but this correlated only with the TFI-19 at follow-up ($r = -.44$, $n = 20$, $p < .05$). Only the intervention group, however, completed this measure and since ‘Time since Stroke’ was not correlated with any of the principal outcome variables, it was not treated as a confounding variable in subsequent analysis. As previously reported, there was a significant difference in the baseline (pre) stage between the two groups on the BI measure. As the BI (pre) significantly correlated with the EQ-5D-3L and GHQ-30, it was added as a covariate in the MANCOVA and follow-up ANCOVAs that were subsequently conducted for these variables. The BI (baseline) did not significantly correlate with the MSPSS and so was not included in the ANOVA conducted for this variable.

3.2.4 Descriptive Statistics of Peer Supporters

The peer supporters mean scores, standard deviations and ranges on the dependent variables are reported in Table 3.5. Peer supporters ($n = 3$) reported decreased psychological distress (as measured by the GHQ-30) between pre and follow-up stages. Improvements in quality of life (EQ-5D-3L) and activities of daily living (BI) were also reported at these same phases. Furthermore, peer supporters reported increased therapeutic benefits associated with the group between the post and follow-up time periods (TFI-19). Conversely, ratings of perceived social support (MSPSS) decreased slightly between the pre and follow-up phases.

Table 3.5 Peer supporter descriptive statistics for dependent variables.

Measure	Phase	Peer Supporters (n=3)	
		Mean (SD)	Range
GHQ-30 (Total)	Pre	4.0 (4.0)	0-8 (8)
	Post	0	0
	Follow-Up	0.7 (1.2)	0-2
EQ-5D-3L (Total)	Pre	10.0 (0)	0
	Post	9.0 (0)	0
	Follow-Up	9.3 (0.6)	9-10 (1)
MSPSS (Total)	Pre	65.0 (6.1)	61-72 (11)
	Post	62.0 (8.7)	56-72 (16)
	Follow-Up	61.0 (11.5)	49-72 (23)
BI (Total)	Pre	13.3 (5.8)	10-20 (10)
	Post	16.0 (4.6)	11-20 (9)
	Follow-Up	17.0 (3.0)	14-20 (6)
TFI-19 (Total)	Post	90.7 (21.0)	69-111 (42)
	Follow-Up	99.3 (21.1)	76-117 (41)

3.3 DATA ANALYSIS

The hypotheses of the thesis were investigated using statistical analysis of mean scores for each of the dependent variables. A mixed (i.e. within and between subjects) multivariate analysis of covariance (MANCOVA) and follow-up analysis of covariance (ANCOVA) were used to compare the mean scores on the two outcome variables (GHQ-30 and EQ-5D-3L) across the three measurement stages. A MANCOVA was conducted to control for the significant differences in BI scores at baseline between the two groups. The key statistic was the Group x Time interaction. Univariate analysis (ANOVA) was used to compare the mean scores on the other dependent variables, the MSPSS and BI, across the three time periods, as these are not outcome measures. A paired samples *t* test was conducted for TFI-19 scores, as only participants in the intervention group completed this variable. Additionally, mediation analysis (as described in Section 2.6.3) was used to explore the processes underlying peer support. The analysis for each hypothesis made in Section 1.6 is reported.

Results

3.3.1 Psychological Distress and Quality of Life

3.3.1.1 GHQ-30 and EQ-5D-3L

Psychological distress was measured using the Total GHQ-30 scores at baseline, post and follow-up stages, whilst the Total EQ-5D-3L scores were used to measure quality of life at these three time periods. A MANCOVA was conducted to compare scores of psychological distress and quality of life within the intervention and comparison groups, whilst controlling for BI (baseline) scores. Homogeneity of variance was analysed using Levene's test for univariate tests and Box's test for covariances, when analysis used ANOVA / ANCOVA and MANCOVA respectively. For this MANCOVA, Box's test was significant ($p < .01$), indicating that there was unequal variance between the two groups. If sample sizes are equal, however, this violation can be disregarded and the use of Hotelling's trace test is recommended, due to its robustness in such a two-group situation (Tabachnick & Fidell, 2006). Using Hotelling's trace test, there was a statistically significant interaction for group and time with psychological distress and quality of life, $T = .90$, $F(4, 41) = 9.27$, $p < .001$. The interaction of Group by Time for each of the variables using ANCOVA / ANOVA is reported in Table 3.6, before each is presented separately.

Table 3.6 Analysing the interactions of Group by Time for variables using ANCOVA/ ANOVA.

Variable	Phase	Intervention Group Mean (SD)	Comparison Group Mean (SD)	Group by Time Interaction Significance
GHQ-30 (ANCOVA)[^]	Pre	13.0 (10.1)	8.3 (6.4)	$F(2,88)= 24.94$, $p < .001^*$
	Post	5.6 (7.8)	10.2 (5.8)	
	Follow-Up	2.6 (4.8)	10.7 (5.9)	
EQ-5D-3L (ANCOVA)[^]	Pre	9.7 (1.6)	10.0 (1.4)	$F(2,88)=6.83$, $p = .003^*$
	Post	9.0 (1.5)	9.9 (1.5)	
	Follow-Up	9.0 (1.8)	9.9 (1.4)	
MSPSS (ANOVA)	Pre	48.1 (17.4)	49.0 (11.6)	$F(1,25,56.11)=6.63$, $p = .008^{**}$
	Post	52.1 (17.8)	46.5 (12.8)	
	Follow-Up	56.7 (14.8)	47.0 (12.4)	
BI (ANOVA)	Pre	16.9 (2.9)	13.9 (3.6)	$F(1,86,83.69)=2.05$, $p > .05^*$
	Post	16.9 (3.2)	13.9 (3.7)	
	Follow-Up	17.1 (2.9)	13.8 (3.7)	

[^] Overall MANCOVA including GHQ-30 and EQ-5D-3L: Hotelling's trace $F(4,41)=9.27$, $p < .001$.

* Using Huynh-Feldt correction. ** Using Greenhouse-Geisser correction.

Results

Follow-up univariate within-subjects tests (ANCOVAs) reported significant interactions with group and time on both the EQ-5D-3L and GHQ-30 variables. Homogeneity of variance was analysed using Levene's test at pre, post and follow-up. Levene's test was significant ($p < .01$) for the GHQ-30 at baseline $F(1,45) = 14.07$, $p = .01$ and thus equal variances was not assumed. The F test is, however, robust against inequality of variances if the sample sizes are equal (Field, 2009). Using Mauchly's test of sphericity, there was a significant difference ($p < .05$) between the variances of differences, and therefore this assumption was violated. The Huynh-Feldt correction was thus used, as sphericity estimates were greater than .75 (Huynh & Feldt, 1976). For the GHQ-30, there was a significant interaction for Group and Time with psychological distress, $F(2, 88) = 24.94$, $p < .001$. Review of the group means indicated that the psychological distress of those in the intervention group significantly changed (reduced), compared to those in the comparison group (Figure 3.1).

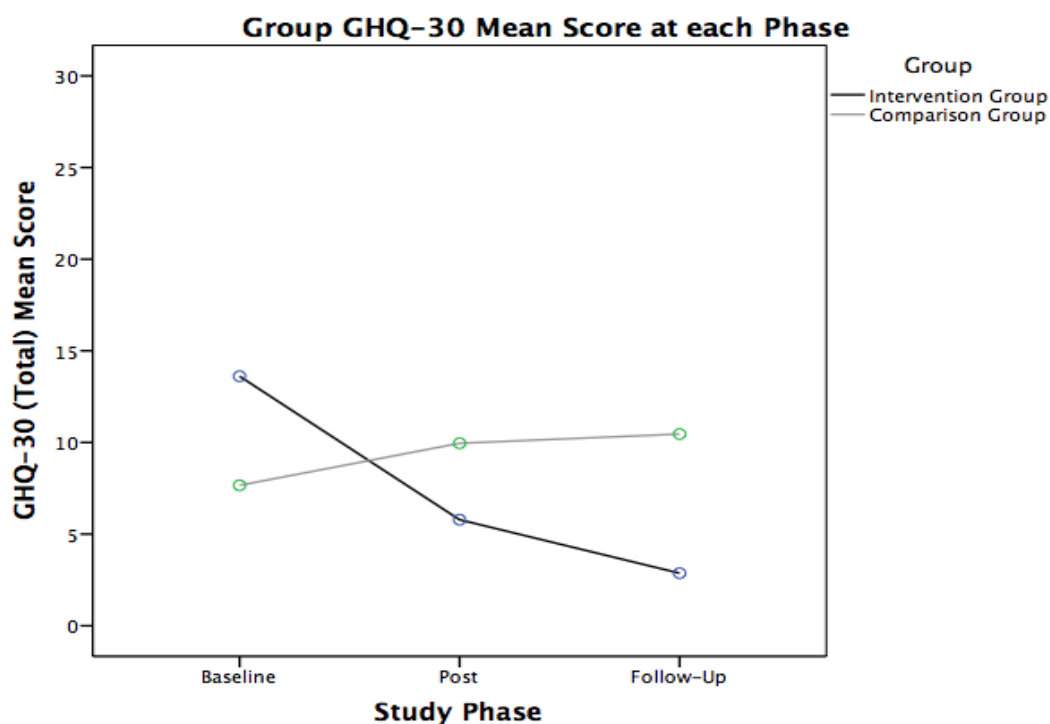


Figure 3.1 Comparison of Group Mean GHQ-30 (Total) Scores over Time.

Results

With regards to the EQ-5D-3L, homogeneity of variance was assumed, as Levene's test was not significant ($p > .05$). Using Mauchly's test of sphericity, there was a significant difference ($p < .05$) between the variances of differences, and therefore this assumption was violated. Accordingly, the Huynh-Feldt correction was used, as sphericity estimates were greater than .75 (Huynh & Feldt, 1976). There was a significant interaction for Group and Time with quality of life, $F(2,88) = 6.83$, $p < .01$. Review of the mean scores indicated that there was a significant change in the quality of life for those in the intervention group (improved), compared to the comparison group (Figure 3.2).

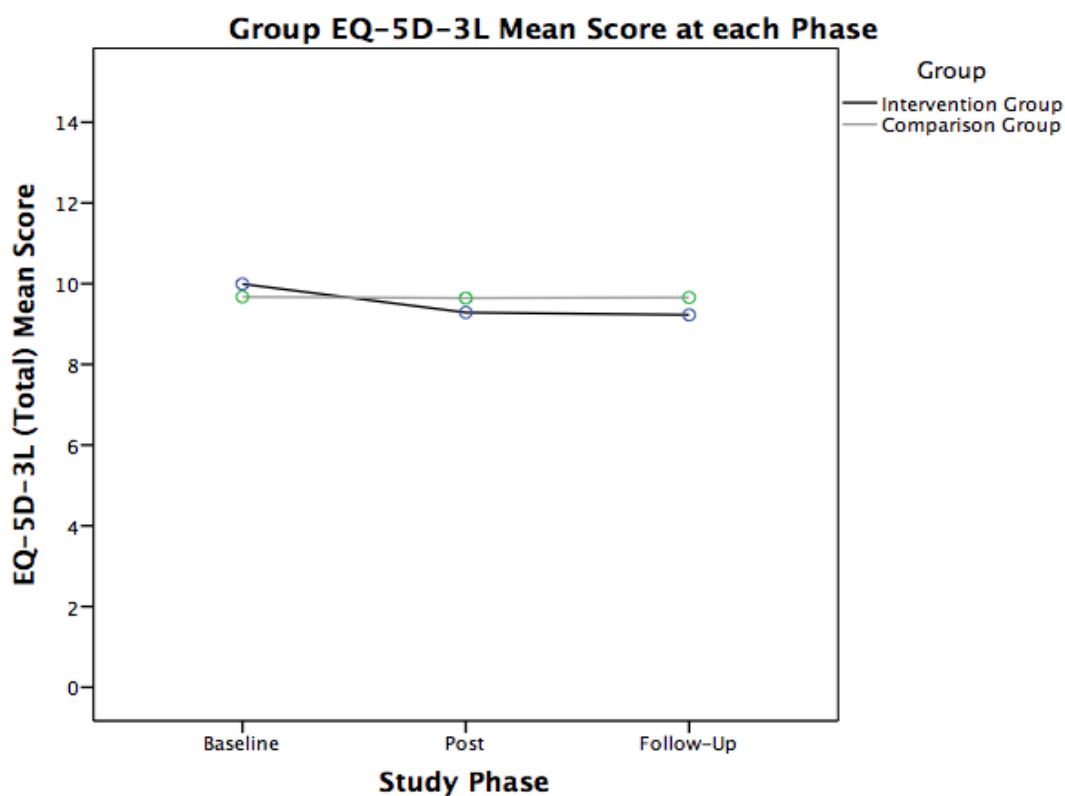


Figure 3.2 Comparison of Group Mean EQ-5D-3L (Total) Scores over Time.

Using Pearson's correlation, there was also a significant positive relationship between the mean change in scores from baseline to follow-up on the GHQ-30 and EQ-5D-3L across participants in both groups, $r = .45$, $n = 47$, $p < .01$.

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A Mann-Whitney test was used to further analyse any changes in score categories (from baseline to follow-up) between groups on the GHQ-30 using cut-off values, as described in Section 2.5.2. Coding of scores was as follows, 1 = Worse (i.e. score moved from 'Healthy' to 'Psychiatric Morbidity', using cut-off score of 9); 2 = Unchanged (score did not change category); 3 = Improved (score moved from 'Psychiatric Morbidity' to 'Healthy'). Changes in scores are illustrated in Figure 3.3. Changes in psychological distress differed significantly based on group, $U = 123.5$, $z = -3.95$, $p < .001$, $r = -.58$. Whilst 32 participants across the two groups remained unchanged, five in the comparison group moved to the 'Worse' ('Psychiatric Morbidity') category (i.e. their GHQ-30 score was above the cut-off of 9 at follow-up), compared to zero in the intervention group. Furthermore, ten participants in the intervention group moved to the Improved ('Healthy') category, compared to none in the comparison group.

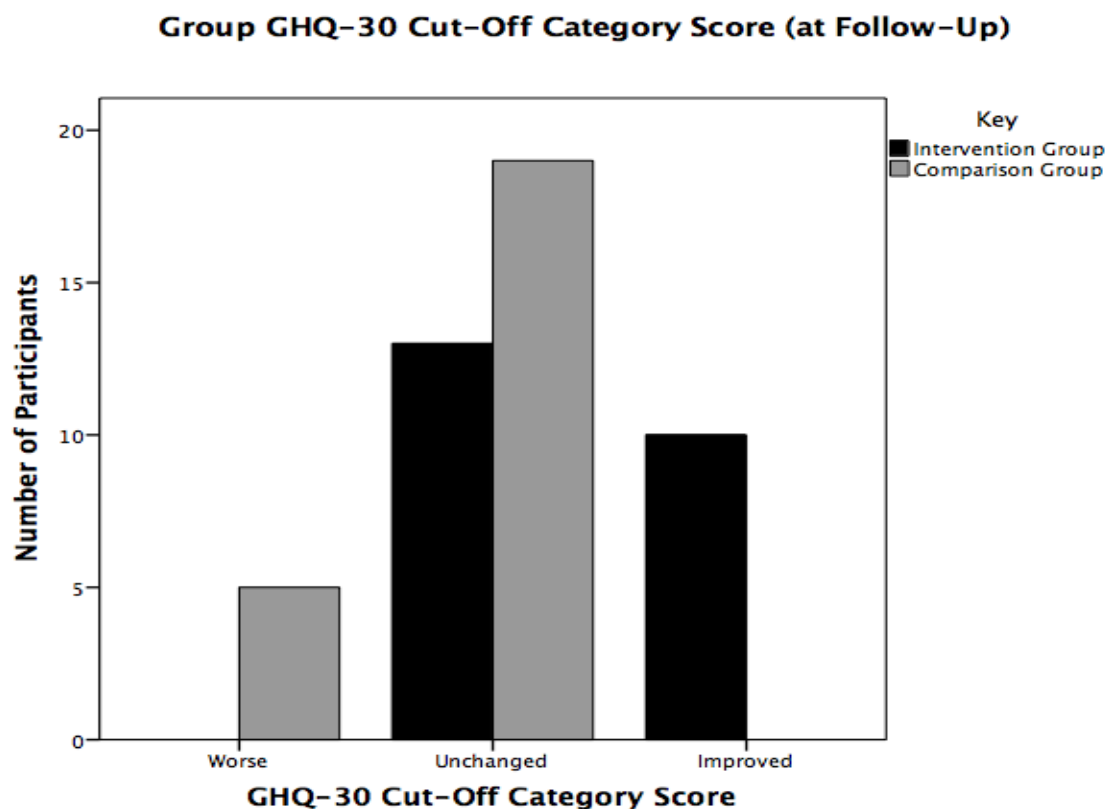


Figure 3.3 GHQ-30 Cut-Off Category Score (change from baseline to follow-up).

Results

3.3.1.2 TFI-19

With regards to the mechanisms and therapeutic benefits associated with attending the intervention group, as measured by the TFI-19, there was a significant difference over time (from post to follow-up), $t(22) = -5.39, p < .01$, as mean scores increased. There were, however, no comparison data for this variable (as the comparison group did not complete a group intervention to be able to complete a group process measurement). Using Pearson's correlation, there was neither a significant relationship between the TFI-19 scores with the GHQ-30 or EQ-5D-3L at follow-up, nor for changes in scores from baseline to follow-up on these measures ($p > .05$).

3.3.2 Perceived Social Support

Perceived social support was measured using the Total MSPSS scores at baseline, post and follow-up stages. A mixed ANOVA was conducted to compare the mean scores of perceived social support within the intervention and comparison groups. Homogeneity of variance was analysed using Levene's test at pre, post and follow-up. As Levene's test was not significant, homogeneity of variance was assumed ($p > .05$). Using Mauchly's test of sphericity, there was a significant difference ($p < .05$) between the variances of differences, and therefore this assumption was violated. Accordingly, the Greenhouse-Geisser correction was used, as sphericity estimates were less than .75 (Field, 2009). Using the Greenhouse-Geisser correction, there was a statistically significant interaction for Group and Time with perceived social support, $F(1.25, 56.11) = 6.63, p < .01$. As can be seen from Figure 3.4, the intervention group's MSPSS (total) mean scores increased from baseline to follow-up, whilst the comparison group's perceived social support decreased from baseline.

Using Pearson's correlation across the whole sample, there were significant negative relationships between the mean change in scores on the MSPSS from baseline to follow-up with the GHQ-30 ($r = -.53, n = 47, p < .01$) and EQ-5D-3L ($r = -.39, n = 47, p < .01$). This indicates that as perceived social support increased, psychological distress reduced and quality of life increased (as reported by lower mean scores on these two variables). There was also a positive correlation between the change in scores on the MSPSS and TFI-19 ($r = .58, n = 23, p < .01$), indicating that as perceived social support increased, so did benefits obtained from group intervention.

Results

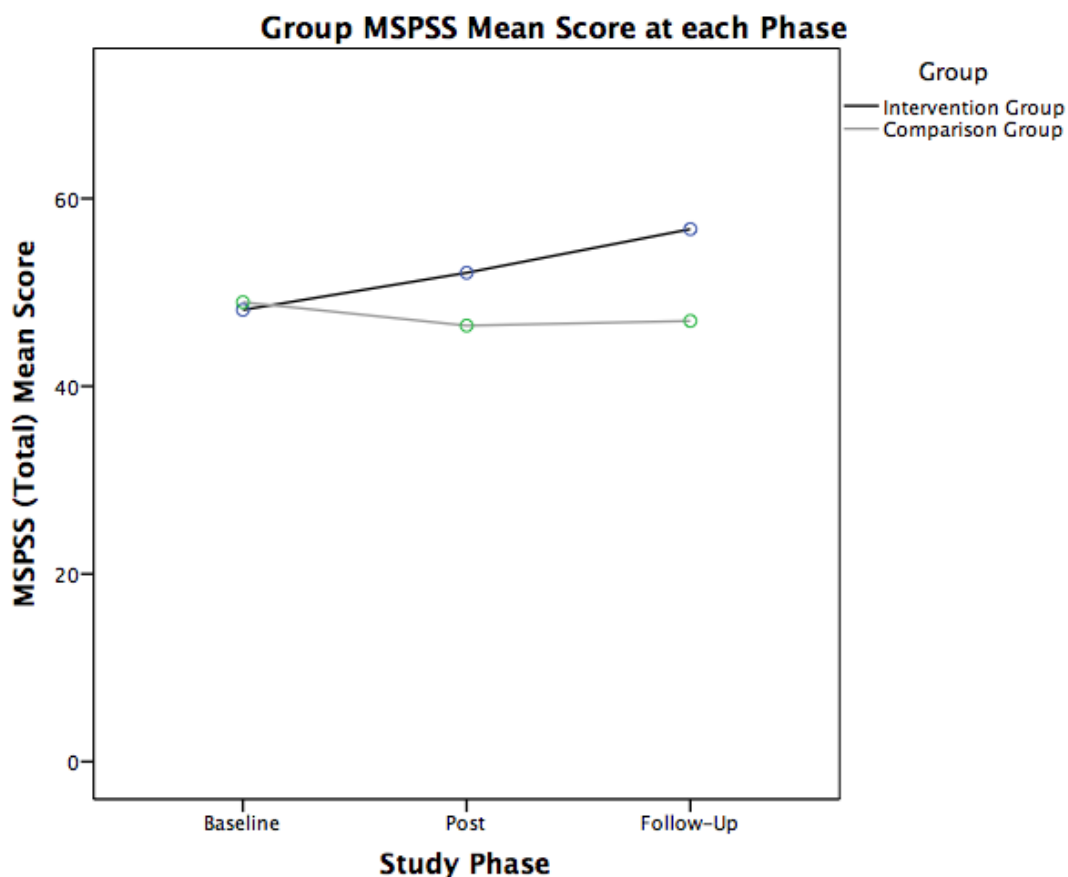


Figure 3.4 Comparison of Group Mean MSPSS (Total) Scores over Time.

3.3.3 Mediation Analysis

Mediation analysis was conducted to further examine the mechanisms underlying group peer support intervention. Mediation analysis was used to explore whether group condition affected psychological distress and quality of life indirectly through perceived social support. Change in scores (from baseline to follow-up) on the MSPSS were therefore explored as potential mediating factors on the relationship between peer support intervention and both psychological distress and quality of life (separately). Mediation analysis was conducted as described in Section 2.6.3. Simple bootstrapping tests (using 2000 bootstrapping samples) were carried out to investigate the significance of perceived social support as a potential mediating variable, whilst controlling for the potential confounding effect of BI Total (at baseline). A significant mediation effect ($p < .05$) is reported if the 95% confidence intervals do not cross zero (Hayes & Preacher, 2014). Data for the mediation analysis are presented in Table 3.7.

Table 3.7 Simple mediation models of the direct and indirect effects of group on psychological distress and quality of life, through perceived social support.

Model	Mediator	Type of Effect (model pathway)	Effect	Confidence Intervals (95%) [^]	
				Lower	Upper
Group Condition (X) and Psychological Distress (Y [GHQ-30 score change from baseline to follow-up])**	Perceived Social Support (M [MSPSS score change from baseline to follow-up])	Total (c)	13.54	8.89*	18.19*
		Direct (c')	10.95	6.08*	15.83*
		Indirect (ab)	2.59	0.39*	6.93*
Group Condition (X) and Quality of Life (Y [EQ-5D-3L score change from baseline to follow-up])**	Perceived Social Support (M [MSPSS score change from baseline to follow-up])	Total (c)	0.75	0.21*	1.30*
		Direct (c')	0.52	-0.07	1.12
		Indirect (ab)	0.22	-0.08	0.89

[^] Using 2000 bootstrap samples for bias corrected confidence intervals. *Significant effect ($p < .05$) reported, as 95% confidence intervals do not cross zero. ** $N=47$.

As can be seen from Table 3.7, perceived social support significantly mediated the relationship between group condition and ratings of psychological distress, as the indirect effect (*ab*) calculated was significant ($p < .05$). The different route effects and significance values are reported in Figure 3.5.

Although there was a significant total effect of group on quality of life, there was not a significant direct effect of group reported. There was also not a significant indirect effect, through perceived social support, found (as reported in Table 3.7).

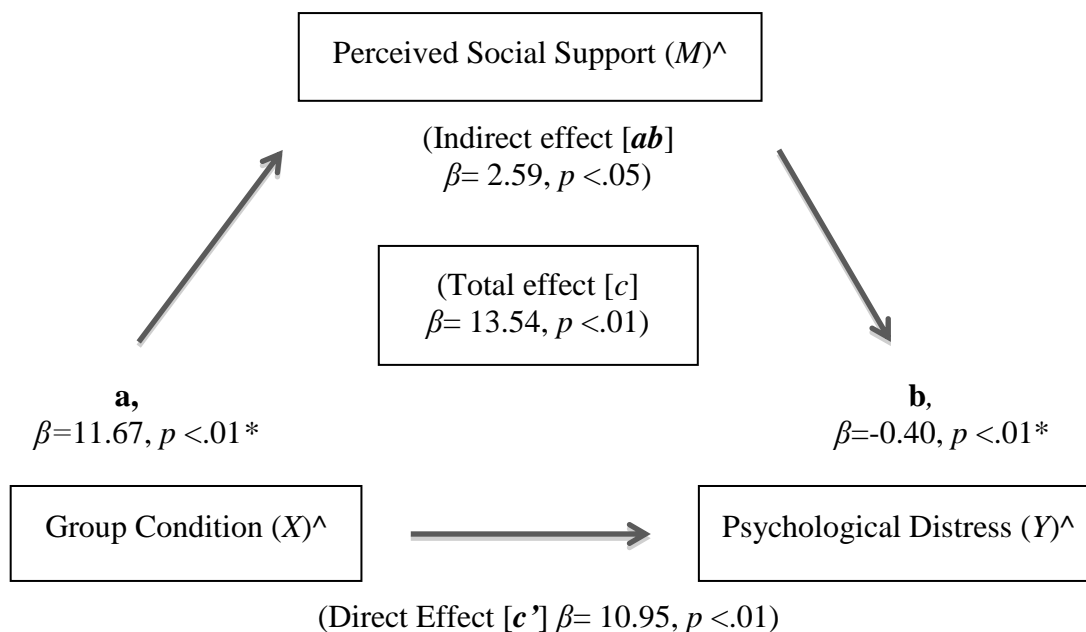


Figure 3.5 Simple mediation model of the indirect effects of group condition on psychological distress, through perceived social support. *The separate a and b route effect values are not available from Hayes' PROCESS. Unstandardised β coefficients for these routes were therefore obtained by regression analysis in SPSS. $^{\wedge}N=47$.

3.3.4 Activities of Daily Living

The BI measured activities of daily living at baseline, post and follow-up stages. As previously reported, there were significant differences ($p < .01$) between the two groups at baseline with regards to the BI (Total) score and this was added as a covariate in subsequent analysis. A mixed ANOVA was completed to compare the mean scores within and across the two groups. Homogeneity of variance was analysed using Levene's test at pre, post and follow-up, and as this was not significant, equality of variance was assumed ($p > .05$). Using Mauchly's test of sphericity, there was a significant difference ($p < .05$) and therefore this assumption was violated. Accordingly, the Huynh-Feldt correction was used, as sphericity estimates were greater than .75 (Huynh & Feldt, 1976). There was no statistically significant group and time interaction on this variable ($p > .05$). There was no overall effect of measurement time across the two groups ($p > .05$), but there was an overall difference between the two groups across all time periods $F(1,45) = 10.14, p < .01$. This is

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commensurate with the difference at baseline reported above. The group mean scores over time on the BI are illustrated in Figure 3.6.

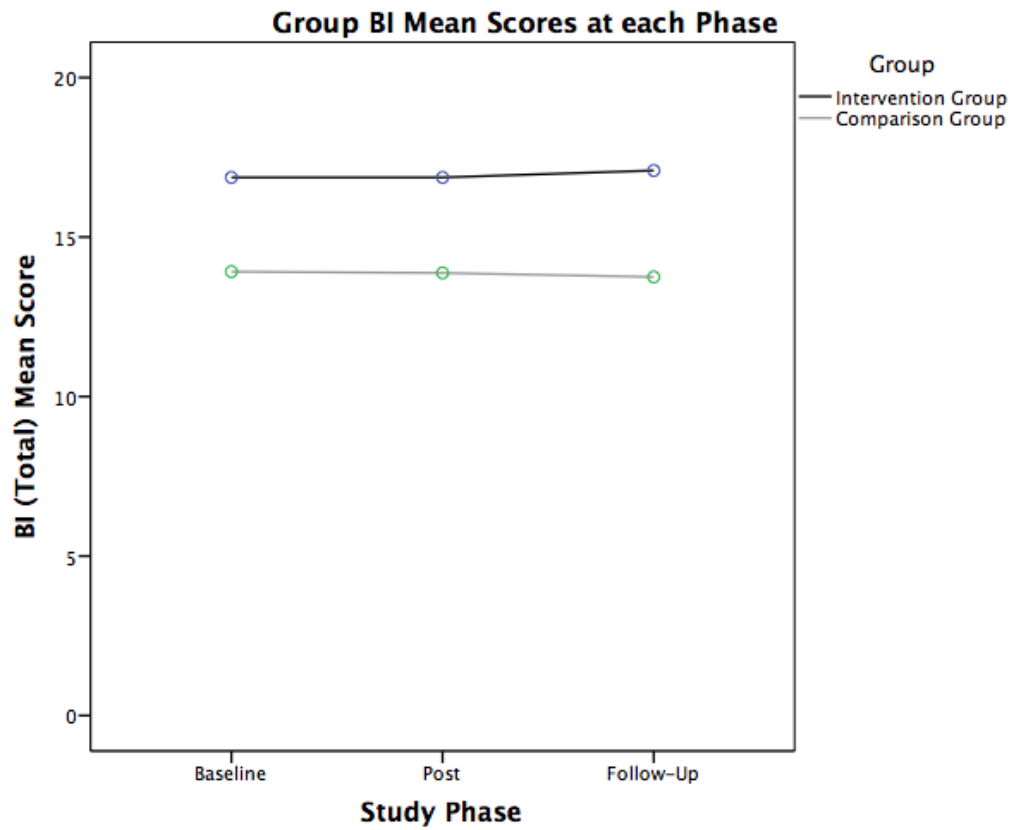


Figure 3.6 Comparison of Group Mean BI (Total) Scores over Time.

CHAPTER FOUR

DISCUSSION

4.1 CHAPTER OVERVIEW

The use of peer support programmes in physical and mental health settings has developed over the last 15-years. Within stroke, peer support has been proposed as an important component of community rehabilitation (e.g. ICSWP, 2012). The primary aim of this study was to evaluate the efficacy of a stroke peer support intervention. As far as the author is aware, this is the first study to have quantitatively evaluated (using a RCT) a stroke peer support programme for stroke survivors and carers. The study focused on evaluating the impact of peer support on psychological and social wellbeing after stroke, as there is a dearth of previous research in this area. The findings of the study support a number of the hypotheses made in Section 1.6, as following participation in a stroke peer support programme, stroke survivors and carers reported decreased psychological distress and increased perceived social support and quality of life over time. Additionally, these changes over time were significantly greater when compared to the changes for those affected by stroke in a waiting-list comparison group over the same period. Furthermore, perceived social support was identified as a mechanism underlying the benefits of peer support and reduced psychological distress. After these findings have been reported, their relation to previous research is considered. The strengths, limitations and implications of the study, and possibilities for future research, are also discussed.

4.2 SUMMARY OF THE MAIN STUDY FINDINGS

4.2.1 Psychological Distress

Hypothesis: Participants attending a peer support programme will report significantly reduced psychological distress, as has been reported across other physical health conditions, compared to a waiting list control group.

Consistent with this hypothesis, participants in the peer support intervention group reported greater changes in psychological distress than those in the comparison group, over time. More specifically, there was a trend towards reduced psychological distress following peer support, whereas this was reported to increase by those who did not receive this intervention, over the same time period. This finding indicates that a stroke peer support group may have a beneficial impact on the mood of those affected by stroke. This is consistent with the positive findings reported in other chronic health conditions that have evaluated peer support programmes (e.g. Parry & Watt-Watson, 2010).

Further to this finding, there was also a significant difference between the two groups when changes in psychological distress using cut-off thresholds for psychiatric morbidity (O'Rourke *et al.*, 1998) were explored. Participants in the peer support group either remained unchanged or improved (i.e. they moved from *Psychiatric Morbidity* to *Healthy*) over time. Contrastingly, participants in the comparison group either remained unchanged (did not move category) or became worse (i.e. moved from *Healthy* to *Psychiatric Morbidity*) over time. This suggests that a peer support programme can reduce the psychological distress of stroke survivors and carers who previously reported difficulties with their mood. If no intervention is provided, however, psychological distress may increase to levels that are suggestive of greater difficulties, for those affected by stroke.

4.2.2 Perceived Social Support

Hypothesis: There will be significantly improved perceived social support from participants attending the peer support programme, compared to a waiting list control group.

Discussion

As hypothesised, stroke survivors and carers who attended the peer support intervention reported greater changes in perceived social support over time, compared to those in the comparison group. This finding suggests that attending a peer support group, with others who have also been affected by stroke, may develop perceived social networks and relationships. The beneficial effect of increased perceived social support on the relationship between peer support and decreased psychological distress was also found. This finding is suggestive of further evidence for the substantial body of research literature regarding the importance of social support on psychological wellbeing (Cohen *et al.*, 2000).

4.2.3 Therapeutic Value of the Peer Support Group

Hypothesis: The improvements (compared to those in the intervention condition) will be mediated by the therapeutic value of the group (i.e. social support will mediate benefits of attending the group regarding psychological distress and quality of life).

Processes underlying peer support were also explored and there is partial support for this hypothesis. The relationship between group condition and psychological distress was mediated by perceived social support. Thus, whilst attending the intervention group had a positive direct effect on psychological wellbeing, there was also an indirect effect through mediation by perceived social support. This suggests that perceived social support is an important mechanism of peer support, as part of the effect of peer support occurs as a result of increasing perceived social support. The mediation effect of perceived social support was not, however, found when considering group condition and quality of life. As there was a significant total effect (but not a significant direct or indirect effect) between peer support and quality of life, this suggests that this relationship may be attributable to factors independent of perceived social support. There is therefore, only partial support for this hypothesis.

Processes associated with attending the group (as measured by the TFI-19) improved four-weeks after the intervention had finished. This indicates that the benefits of attending a peer support group intervention continue beyond its defined period. This finding may suggest that the personal benefits obtained, as indicated by the TFI-19 (e.g. information, hope), and the social relationships formed during the group may have continued (and developed) after the intervention ended. This finding indicates

Discussion

that facilitating peer support through a group forum may have beneficial implications for stroke survivors and carers.

4.2.4 Quality of Life

Hypothesis: There will be significant improvements in quality of life reported by those attending the peer support group programme, compared to a waiting list control group.

As hypothesised, quality of life changed more in the intervention group than the comparison group over time. Stroke survivors and carers reported improvements in quality of life following their attendance at the peer support intervention. For those in the comparison group, quality of life did not change significantly. This finding suggests that peer support positively affects quality of life following stroke. As reported above, there was an overall total effect of group condition on quality of life, but there was no indirect effect from perceived social support. There may, therefore, be other mechanisms not measured in this study affecting this relationship.

4.2.5 Activities of Daily Living

Hypothesis: There will be significant improvements in activities of daily living following attendance at the peer support group programme, compared to a waiting list control group.

Contrary to the hypothesis, there were no significant changes regarding activities of daily living. This indicates that peer support intervention did not influence any greater changes in the daily activities of those affected by stroke, compared to when no intervention was provided. There was, therefore, no support for this hypothesis. This finding may have, however, been affected by the significant differences between the participants in the two groups at the beginning of the study, or due to limitations with the assessment measure used (see Section 4.4.2.4).

4.2.6. Section Summary

The findings support a number of hypotheses made and suggest that peer support may be an effective intervention in stroke community rehabilitation. The quality and

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implications of the study and its findings will now be considered in relation to the wider clinical-research context.

4.3 COMPARISON WITH PREVIOUS RESEARCH IDENTIFIED IN THE SYSTEMATIC REVIEW

The implications of the study are discussed in further detail in Section 4.5. Prior to this, the findings from the present study are compared with the articles identified in the systematic review, as these papers are potentially the most similar to the design and aims of the current research.

As discussed in Section 1.5, few studies have evaluated the use of peer support in stroke and only one of those identified in the systematic review was conducted in the UK (and used a qualitative research methodology [Morris & Morris, 2012]). The findings from previous studies in Australia, North America and Netherlands may not generalise to the UK. This study therefore contributes to the minimal research completed with a sample that is representative of the UK. It also builds on the qualitative study completed by Morris and Morris (2012) by adding a quantitative design and supports the findings that stroke peer support programmes may be effective for survivors and carers within the UK.

Compared with the past qualitative research identified in the review, the current study supported the positive findings regarding the use of peer support in stroke. Recurring themes of decreased loneliness and increased emotional support were previously reported as benefits of peer support (Kessler *et al.*, 2014; Morris & Morris, 2012, Stewart *et al.*, 1998; Tregga & Brown, 2013), which is supported by the findings of the current study. The important role of increased social support in post stroke rehabilitation was commonly identified and was also reported in the current study. Whilst perceived social support increased following participation in a peer support programme, it was also an important mediating effect on reduced psychological distress. Previous qualitative research and the findings from the present study suggest that there is an important relationship between peer support, perceived social support and psychological distress. The current quantitative study, therefore, extends the

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findings identified from past qualitative research regarding the benefits of peer support in stroke.

The findings from the current study are inconsistent, however, with those from the quantitative research identified in the systematic review. For example, Patterson *et al.* (2010) and Muller *et al.* (2014) both reported that activities of daily living significantly increased following peer support, but this was not reported in the current study. This inconsistency may be due to differences in the study designs as there was no control group included in the study by Muller *et al.* (2014), and the primary focus in the study by Patterson and colleagues (2010) was on exercise maintenance. With regards to social support, few of the studies identified included a specific measurement of this variable and so any direct comparison with the findings from the present study are difficult to make. Muller *et al.* (2014) reported that community integration improved after attendance at a peer support group, although only tentative links can be made to the increased perceived social support (and its mediating effect on psychological distress) reported in the current study. Given the limited focus on social support in the previous research, an aim of this study was to explore (and explicitly measure) its relationship with peer support.

In the current study, significant changes in psychological distress were reported after attendance at a peer support intervention. This is in contrast to prior research, as no significant findings were previously reported (Aben *et al.*, 2013; 2014; Kronish *et al.*, 2014). This may reflect that only a measure of depression was included in these studies, whilst the GHQ-30 accounts for other considerations of mental health too (e.g. anxiety). The use of narrow measures in previous research is surprising given the range of psychological changes that can occur after stroke (see Kneebone & Lincoln, 2012). There were further difficulties with comparing the current findings regarding emotional changes as Patterson *et al.* (2010) did not include a mood-specific measure and the study by Cadilhac *et al.* (2011) was not adequately powered. Due to these methodological limitations, it is therefore difficult to compare this finding with the previous quantitative research identified.

With regards to quality of life, it had been previously reported that this did not significantly change following peer support (Aben *et al.*, 2013; 2014; Patterson *et al.*,

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2010). This is contradicted by the findings from the current study, however, as significant changes in quality of life were reported. The contrast in these findings may be attributable to the different designs of peer support intervention implemented in the studies. In the previous research identified above, specific details regarding the peer support intervention were lacking. For example, in the study by Aben *et al.* (2013) a psychologist moderated the peer support group and the nature of this role was unclear, although it was reported that no active therapeutic interventions were performed. Furthermore, in the study by Patterson *et al.* (2010) participants had to have previously attended the peer support intervention for a minimum of 3-months prior to recruitment, so differences may have been more difficult to detect. A further consideration may be related to the inclusion of a non-intervention control group in the present study, whereas peer support was the control group in comparison with another intervention in the prior research (Aben *et al.*, 2013; 2014; Patterson *et al.*, 2010). The significant change in quality of life reported in the current study may be due to this comparison, which was not possible to detect in prior research, as a non-intervention control group was not previously included.

The findings from the current study therefore, partially support the results from the previous research identified in the systematic review. The positive findings from the qualitative research were extended in the current quantitative study (e.g. positive implications regarding emotional and social support). In comparison with the quantitative studies, however, inconsistent findings were reported regarding psychological distress, quality of life and activities of daily living. It was difficult to compare social support, as this had not been explicitly evaluated previously. Methodological differences in the study designs may have contributed to the conflicting findings and it may be beneficial for future research (as discussed in Section 4.6) to explore this further.

4.4 STRENGTHS AND LIMITATIONS OF THE STUDY

4.4.1 Strengths

There may be a number of strengths associated with the current study, which have clinical and research implications.

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4.4.1.1 Study Design

There are several characteristics of the research design that could be considered strengths of the study. Firstly, no previous research has quantitatively evaluated the efficacy of a stroke peer support programme that was attended by both survivors and carers. The positive findings reported from this study have theoretical, clinical and service implications and are reported in Section 4.5. Secondly, the study used an RCT design (with a non-intervention control group). An RCT should be considered as the first choice to determine the efficacy of an intervention, as it reduces selection bias, balances known and unknown prognostic factors, and also allows for results to be included in future meta-analysis (Hutchinson & Styles, 2010). The absence of randomisation in previous studies has led to criticisms of peer support as an intervention and resulted in cautious interpretation of the findings (Collela & King, 2004; Dale *et al.*, 2008; Lloyd-Evans *et al.*, 2014). Increasing the number of RCTs and also the amount of research that includes a clear control group, such as in the current study, may increase the understanding of the effectiveness of peer support further. The present study, due to its design, could also be included in future meta-analysis to contribute to increasing this existing knowledge.

Thirdly, the stroke peer support programme developed within this study was implemented within a community-based clinical service. The need to improve community-based treatments and access to psychological interventions within stroke services has been outlined nationally (CQC, 2011; NICE, 2010). This study may therefore provide support for the inclusion of stroke peer support programmes to contribute to this area of need.

Fourthly, this study focused on explicit measures of psychological constructs (e.g. mood and quality of life) and changes reported over time. Previously, studies of stroke peer support programmes have focused only on single-aspects of mental health (e.g. depression [Aben *et al.*, 2013; Kronish *et al.*, 2014]) or have not included any specific measurement of psychological wellbeing (e.g. Patterson *et al.*, 2010). The GHQ-30 assessment used in this study, however, measures a greater number of mental health considerations, including depression, anxiety and sleep disturbance. Furthermore, this study may be the first to include a measure of (perceived) social support within stroke peer support. Despite its theoretical underpinnings within a peer

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support model (Dennis, 2003), the previous research identified has not explicitly measured social support. Given the wide-ranging emotional changes that can occur after stroke (Broomfield *et al.*, 2014; Kneebone & Lincoln, 2012), the inclusion of holistic measurements of psychological functioning and other psychosocial constructs (e.g. perceived social support) could be viewed as a strength of the study.

4.4.1.2 Inclusion of Stroke Survivors and Carers

This is the first quantitative study to have included both survivors and carers in a stroke peer support programme. Previous quantitative studies regarding peer support in stroke have only included survivors (e.g. Kronish *et al.*, 2014; Muller *et al.*, 2014), despite the benefits for carers being reported within qualitative research (e.g. Stewart *et al.*, 1998). Including carers may introduce different perspectives to facilitate post-stroke rehabilitation (Graven *et al.*, 2013). Additionally, carers of stroke survivors may also experience psychological distress (Carek *et al.*, 2010) and thus could also benefit from the opportunity to meet other carers and survivors within a peer support model. Positive findings regarding peer support after stroke were reported after the inclusion of both carers and survivors in this study. It should be noted, however, that the overall number of carers included in the study was low (five) and therefore caution should be applied with generalising the positive findings associated with their attendance at a peer support group. Possible reasons for the low numbers of carers are discussed in Section 4.4.2.

4.4.1.3 Exploration of the Processes Underlying Peer Support

A further strength of the study is that the processes underlying peer support were explored through mediation analysis. Mediation analysis can further the overall understanding of the mechanisms of an intervention and stimulate the identification of alternative, more efficacious strategies (Gunzler *et al.*, 2013). In this study, perceived social support was identified as a mediating effect on the relationship between peer support and psychological distress. Without the inclusion of mediation analysis the additional benefits (i.e. the indirect effects) of perceived social support may not have been reported. Whilst RCTs are designed to report whether an intervention is effective, they have been criticised for not reporting how an intervention is effective (Hutchinson & Styles, 2010). The use of mediation analysis was an attempt to overcome this limitation in RCT designs. It may be beneficial to further explore the

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important role of perceived social support in future stroke rehabilitation research, which might lead to additional clinical improvements.

4.4.2 Limitations

There may be a number of limitations and weaknesses of the study to consider, which affect the quality of the findings reported.

4.4.2.1 Randomisation

In this study, a RCT design was used to allocate stroke survivors and carers to either the peer support group intervention or a comparison control group. Although RCTs minimise selection bias, and are therefore considered to represent the gold standard in evaluating the effectiveness of healthcare interventions (Odgaard-Jensen *et al.*, 2011), criticisms have been reported with their use. For example, there are ethical concerns associated with delaying the provision of an intervention (for those in the control group) that may be beneficial to wellbeing (Shadish *et al.*, 2008). As this study, however, was the first to quantitatively explore the efficacy of peer support in stroke for survivors and carers, it was unclear whether the intervention would be beneficial. Furthermore, the design of the study enabled stroke survivors and carers initially allocated to the control group to have the opportunity to attend the peer support intervention within an approximate 15-week period. A weakness of the study, however, may concern the randomisation process due to this being completed by the author and supervisor. The study would have benefitted from an independent staff member, who was blinded to the conditions and participants, facilitating the random allocation process to minimise potential research bias.

A further limitation of RCTs is that whilst selection bias is minimised, randomisation bias is created. Randomisation bias occurs as some potential participants may decline to take part due to the nature of the process, and there may be certain shared characteristics of this group that affects the generalisation of the findings (Hutchinson & Styles, 2010). In the initial phase of recruitment for this study, 22 of the 70 (31.43%) stroke survivors and carers approached, declined to participate. It is unclear how many declined on the basis of the randomisation process, but, anecdotally, none explicitly reported their concerns regarding this aspect of the design. This cannot, however, be discounted as a reason for those approached choosing not to participate

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in the study. It was hoped that offering the peer support intervention within an approximate 15-week period regardless of condition would have helped to overcome this difficulty. It may be beneficial for future research to consider appropriate and ethical processes for increasing our understanding of the potential negative effects of randomisation bias. More widely, it would be helpful for future studies to explore the reasons why people decline to participate in research (see Brintall-Karabelas *et al.*, 2011), and whether there are features specific to peer support that may influence such decision-making.

The external validity of RCTs can also be impacted upon by a number of factors, such as the study location and the characteristics of the participants (Rothwell, 2005). In this study, for example, the majority of participants were stroke survivors and described themselves as white-British. There is, however, a higher risk of stroke in other ethnic groups (Heuschmann *et al.*, 2008), which contrasts to the representation of ethnicity across the current study sample. This is despite stroke survivors and carers being approached through the local service stroke register to overcome representation issues. It is possible that the ethnicity details reported may be representative of the local area, or may be an unrepresentative sample of the local stroke register. Alternatively, it may indicate that there are additional factors to consider with supporting ethnic minority groups to access local community health services. This study may, therefore, have benefited from liaison with more diverse local community groups to recruit a greater representation of stroke survivors and carers of different ethnicities (e.g. Somali Integration Society, Cardiff).

4.4.2.2 Generality of the Findings

There are potentially a number of limitations associated with the characteristics of the sample that may affect the generality of the study findings. The limited representation of stroke survivors and carers from different ethnic backgrounds in the sample is reported above (as the majority of participants described themselves as white-British). Caution should therefore be applied with generalising the findings to more diverse ethnic groups. This may be particularly relevant as there is an increased risk of stroke in Black and Asian populations (Go *et al.*, 2014).

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The type of participant (i.e. stroke survivor or carer) may also affect the generalisation of the findings. Participants were predominantly stroke survivors, despite the aim to also include stroke carers. There may have been a number of reasons for this lower than expected number of stroke carers (five). It is possible that the recruitment process may have negatively impacted upon interest from stroke carers. Stroke carers were approached through the stroke survivor, as only their details were available on the clinical database used for recruitment. This may have inadvertently suggested that the proposed study was primarily for the benefit of stroke survivors. Recruitment through general carer-specific organisations may have helped to overcome this (e.g. Carers Trust Wales / Cymru). There was potentially also some hesitancy from carers towards participating in the proposed study as they reported during recruitment that they thought it would be beneficial for the stroke survivors to meet others without them present (to increase their independence). Conversely, stroke survivors who attended the peer support group reported, anecdotally, that as transport was provided this allowed carers to have a period of respite. There may therefore be different factors to consider for stroke carers and survivors that would indicate a need for an element of separate peer support (Morris & Morris, 2012). Finally, the limited number of carers in the study may reflect a general perception that they did not identify any benefits from a proposed peer support programme, although this would contradict prior qualitative research (e.g. Kessler *et al.*, 2014). Given the small number of stroke carers in the sample, a limitation of the study, it is unclear how these results generalise to individuals providing daily support for those affected by stroke.

The age of the participants in the study may also affect the generalisation of the findings. The mean age of the sample was over 65 years of age and most were retired, so caution should be taken when generalising these findings to younger survivors and carers of stroke. This is important to consider as the number of people having strokes between the ages of 20 and 64 increased worldwide by 25% between 1990 and 2010 (Feigin *et al.*, 2014). Although a peer support intervention may benefit younger stroke survivors (as reported by Muller *et al.*, 2014), the needs and focus of the groups may be different to programmes with older stroke survivors and carers (Morris, 2011). The low representation of younger stroke survivors and carers in the study is therefore another potential limitation to consider. As participants in this study were

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predominantly older and retired, further research is recommended to determine the effects of a stroke peer support programme with a younger sample.

4.4.2.3 Control Group

A potential weakness of the study involves the comparison group used and the procedure in which information was collected from those in this condition. The most appropriate form of control group in rehabilitation research is unclear (Schulz *et al.*, 2009), but ethical considerations have been raised given the associated delay or withholding of intervention (Shadish *et al.*, 2008). Previous research has provided minimal support, including access to educational and reading materials, but this can lead to confusion regarding the impact of treatment differences, such as the effect of receiving attention and information from others (Smith *et al.*, 2012b).

In this study, participants in the comparison group were not provided with any educational materials regarding strokes, as these are routinely available at discharge. Participants in this condition were given the option of either completing the assessments over the telephone (with the author) or by post. The rationale for this choice was related to past research, which has reported low return rates when participants were required to respond by post (Simon *et al.*, 2003). Given the relatively small sample of this study, this may have had a detrimental impact upon the validity of the findings reported. All participants in the control condition chose to complete psychological measures at the specified time phases over the telephone with the author, rather than by post. They therefore received brief clinical contact, which may have impacted upon their responses within the measures. Participants in this condition were also aware that they would have the opportunity to attend the intervention within approximately 15-weeks, which may have impacted upon their psychosocial wellbeing. Withholding intervention for a longer period of time may, however, have raised ethical concerns.

Furthermore, as participants in the control condition chose to complete the questionnaires by telephone, this ensured that there was similarity with the delivery method of measures for participants in the intervention group (aside of the baseline assessment phase which were completed during the first group session). Research has indicated that in some contexts service-users in physical health settings may prefer

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telephone contact as a method of communication (Choudhry *et al.*, 2015). Using telephone contact as a delivery method for completing questionnaires across both conditions may therefore have increased consistency within the study design.

A further limitation of this procedure is regarding researcher bias, as the author conducted the contact over the telephone and was not blind to participant condition. Having administrative support from an independent member of the clinical team, who is blinded to participant condition, may have addressed this weakness of the study.

4.4.2.4 Measures

There may be limitations associated with the use of self-report measures in the current study. Generally, the use of self-report measures is impacted upon by communication and cognitive problems that often occur after stroke (Duncan *et al.*, 2002; Long *et al.*, 2008). In this study, participants who required additional help (e.g. with writing) were supported to complete the measures and the majority were also completed over the telephone. As the questionnaires were not completed independently, their responses may have been influenced by social desirability (e.g. those in the intervention group may feel expected to report improvement). A limitation of the study is that only self-report measures were used and inflated perceptions (i.e. individuals may inaccurately perceive their levels / abilities to be higher given the adversity they have faced) after stroke may be common (Resnick *et al.*, 2008). The current study may therefore have been improved if additional methods of data collection were included (e.g. observational ratings). Furthermore the study failed to include a measure developed specifically for carers, such as the Adult Carer Quality of Life Questionnaire (Elwick *et al.*, 2010), which could be included in future research.

There may also have been specific disadvantages associated with the measures chosen. The GHQ-30, for example, has been criticised as it makes reference to changes in mood from a “usual state”, which may reduce the likelihood of detecting chronic disturbance (O’Rourke *et al.*, 1998). Conversely, making a comparison to “usual state” may actually be advantageous as it excludes the persistent effects of stroke (Lincoln *et al.*, 2011). Statements within questionnaires that make a clearer distinction between any changes observed pre and post stroke may improve the clarity of understanding changes in mood since stroke. With regards to activities of daily

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living, the BI has excellent reliability ratings, but its responsiveness (particularly its ability to detect changes amongst the least impaired stroke survivors) is more variable (Salter *et al.*, 2013). Given that the intervention group in this study reported greater scores of independence at baseline, the BI may not have been sensitive enough to detect changes over time with this sample.

In consideration of the MSPSS, the total scores were analysed for changes over time, but the study did not report separate analysis of the three subscales within the measure (i.e. *Family*, *Friends* and *Significant Others*). This may be a limitation of the study as the further exploration and comparison of these items may have revealed additional information about the different forms of social support that are important to acknowledge within peer support. For example, differentiating between the types of social relationships (e.g. whom is providing support and the quality and quantity of it) may be important to consider when measuring social support (Gottlieb & Bergen, 2010). Within a peer support model, relationships with others (such as those with the peers facilitating the intervention, between survivors and carers and / or the friendships outside of the group) may be affected differently and could have a varying impact on emotional wellbeing. Use of the MSPSS subscales to explicitly measure these different types of relationships may increase the understanding of how these were affected by the intervention. Such further exploration of the varying types of social support may help to refine the construct of peer support and should be considered in future research.

There is much debate about which measures should be used in stroke rehabilitation and little specific guidance regarding the selection of appropriate assessments (see Salter *et al.*, 2013). In this study, the measures selected have their limitations, but were chosen in consideration of both practical (e.g. short and easy to administer) and research / clinical factors specific to stroke (see Section 2.5). Further research to determine the most valid and reliable stroke rehabilitation measures, however, would be beneficial for clinicians and researchers.

4.4.2.5 Data Analysis

Limitations regarding the choice of data analysis may have impacted upon the findings from the study. This involves the use of parametric tests with non-normally

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distributed data, significant differences between the groups and variables not being accounted for in the study.

A possible limitation of the study is regarding the use of parametric tests with data that were non-normally distributed. In such contexts the accuracy of the results may be impacted upon (Field, 2009). Data are often, however, non-normally distributed (Bridge & Sawilowsky, 1999) and it has been reported that parametric tests are not affected by a violation of this assumption (Finch & French, 2013; Glass *et al.*, 1972; McDonald, 2014). An advantage of using parametric tests is that they have more statistical power than nonparametric tests and are therefore more likely to detect a significant effect if one truly exists (Howell, 2012). In the current study, therefore, outliers were replaced to reduce their disproportionate impact on the data and given the reported robustness of parametric tests to non-normally distributed data, these were used for data analysis.

Despite randomisation, there were significant differences between the intervention and control groups regarding time since stroke and mean scores on the baseline BI measure (activities of daily living). This indicated that stroke survivors and carers in the peer support group were more independent and had their stroke a greater amount of time ago, compared to those in the control group. Only these two variables were affected and such differences would be expected to occur by chance on a number of occasions. The differences between the group mean scores on the baseline BI variable was accounted for in subsequent analysis with the GHQ and EQ-5D-3L, as it significantly correlated with these variables (i.e. it was added as a covariate in the MANCOVA and follow-up ANCOVAs). Time since stroke was not, however, as it did not significantly correlate with any other variables and would therefore be unlikely to confound group comparisons on outcome measures. Time since stroke may be, however, important to consider as it has been reported to moderate the relationship between posttraumatic growth and psychological distress (Gangstad *et al.*, 2009). This variable could therefore have impacted upon the current study findings.

Statistical controls (i.e. the use of MANCOVA and ANCOVAs) were used to reduce any potential confounding effects in the study, but other unmeasured variables may

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have impacted upon the results. Although living circumstances and prior treatment for mood were accounted for, other group membership details (stroke or non-stroke related) were not asked for. For example, this may include other formal or informal social support groups that participants belonged to, such as those facilitated by third sector organisations (e.g. Stroke Association Wales). This may be important to consider as community support groups can help survivors and carers adjust after stroke (e.g. National Stroke Foundation, 2007). This is consistent with the wealth of literature, including the findings from the present study, which reports the benefits of social support on emotional wellbeing (see Section 1.4.1.1). The participation and membership of stroke survivors and carers in other social groups was not accounted for and could be viewed as a weakness of the study.

4.4.2.6 Peer Supporter Wellbeing

A further potential weakness of the study is that sufficient information regarding the wellbeing of the peer supporters who co-facilitated the stroke peer support programme was not collected. Although peer supporters completed the same measures as the participants, and the findings indicated positive psychosocial outcomes, their data were not included in the overall analysis as it may have skewed the results. Separate analysis was also not possible due to the small pool of peer supporters recruited and also as no relevant control group was included. Benefits to peer supporters have been reported in other conditions (e.g. chronic pain [Arnstein *et al.*, 2002]), but there is a paucity of data within a stroke context. Morris and Morris (2012) reported benefits for peer supporters, including increased empowerment and helpful social comparison processes. Contrastingly, challenges for peer supporters in chronic diseases, including feelings of isolation and helplessness, have also been reported (Embuldeniya *et al.*, 2013). It would, therefore have been advantageous if this study had included sufficient resources to account for the experiences of peer supporters, as there may have been positive and negative factors to consider from their role. Future research in this area could help to develop the overall understanding of peer support further.

4.5 STUDY IMPLICATIONS

4.5.1 Theoretical Implications

The results from the current study have theoretical implications concerning the mechanisms of peer support and also more widely regarding the importance of social support on wellbeing. Additionally, the findings also indicate that it may be important to consider other processes, such as post-traumatic growth, in stroke rehabilitation.

Dennis (2003) proposed that through principles such as mutual reciprocity and shared understanding, peer support can facilitate emotional, informational and affirmational support. The findings from the current study appear to support Dennis (2003), as reduced psychological distress and increased quality of life were reported following peer support. Furthermore, increased levels of perceived social support, after peer intervention, were reported. The benefits of perceived social support were a consistent finding, as it also had an indirect mediational effect on the relationship between peer support and psychological distress. This suggests that perceived social support is an important mechanism of the intervention. This finding is consistent with both the social comparison theory (Festinger, 1954) and the main / direct effect model (Cohen, 2004). Findings from the current study are suggestive that making upwards social comparisons from peers (i.e. seeking information from others who are ‘better’) benefitted the stroke survivors and carers, leading to improvements in their psychosocial wellbeing.

Furthermore, the perceived availability of social resources (as reported from the mediation analysis) was reported to have a positive impact on psychosocial functioning, as consistent with the main effect model (Cohen, 2004). The main effect model proposes that having access to social relationships and networks can have a beneficial impact on psychological wellbeing. The findings from the current study are supportive of this model and they may also contribute to its further development (e.g. the role of perceived social support and influence of peers). The study findings regarding perceived social support and psychological wellbeing, and its relation to the main effect model, are illustrated in Figure 4.1.

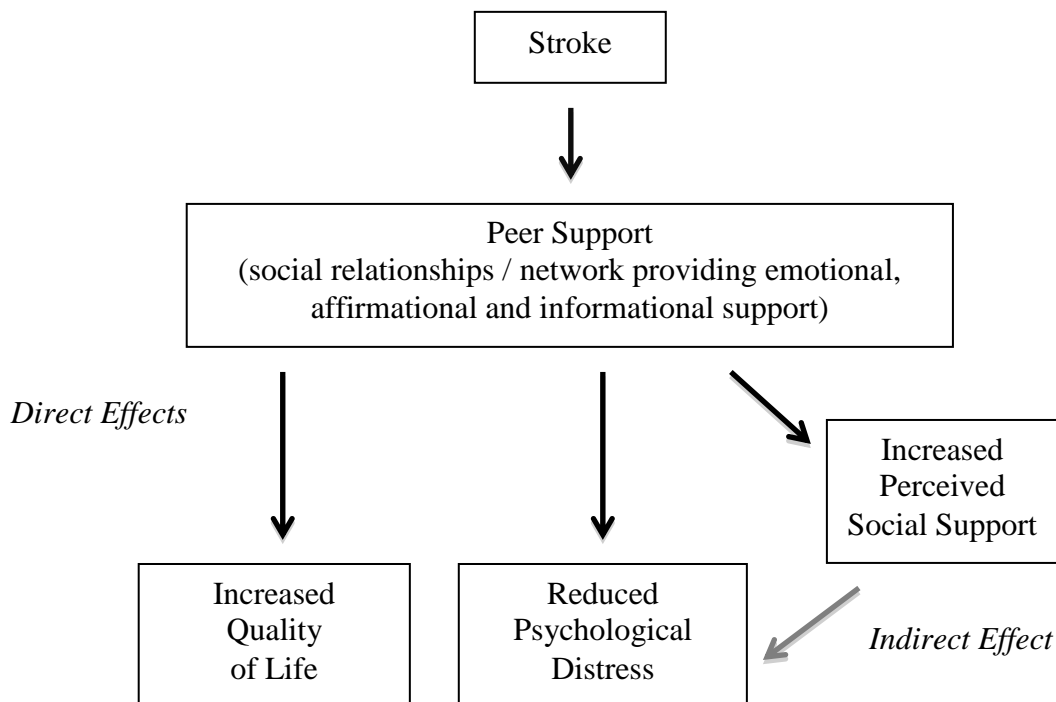


Figure 4.1 Peer support and its relation to the main effect model.

As reported in Figure 4.1, the findings of the study indicate that social support is an important factor when considering the emotional wellbeing of those affected by stroke. Individuals who attended a peer support programme, reported greater changes in reduced distress, improved quality of life and perceived social support, compared to those who did not receive this intervention. Through mediation analysis, perceived social support was also identified as a significant mechanism of the intervention (regarding reduced psychological distress). This finding is consistent with the main effect model, which proposes that being part of a social network (i.e. peer support group) can lead to members giving and receiving support (emotional, informational and affirmational), which can benefit overall psychological wellbeing (reduced distress). The findings from the study indicate that beneficial outcomes may be facilitated directly through peer support as an intervention or indirectly through increased perceived social support. Individuals who did not receive the peer support intervention (i.e. those in the comparison group) did not report such changes with levels of psychological distress.

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The findings from the study may also help to refine the main effect model further. For example, it may be important to distinguish perceived and received social support within theoretical models and research studies (Gottlieb & Bergen, 2010). The current study incorporated a measurement of perceived social support, as this has been reported to have a greater effect on wellbeing within previous research (e.g. Lueger-Schuster *et al.*, 2015). The study findings are supportive of the beneficial impact perceived social support can have on psychological wellbeing, and this could be incorporated into the main effect model (and the pathways proposed) to explain the processes occurring within social relationships with greater clarity. The further exploration of the different types of relationships, such as the perception of available support and the influence of specific figures within the social network (e.g. family, friends and peers) may help to further refine this theoretical model. It could also add to the existing knowledge of peer support as a construct, as it may advocate that the support received from those with experiential knowledge of a stressor is different to that provided from other members of the network (e.g. family and friends). The findings from the current study indicate that including more specific factors into the main effect model, such as the type of social support (i.e. perceived) and whom the support network consists of (e.g. peers, carers), could potentially increase its utility.

The findings from the present study therefore add to the breadth of research regarding the benefits of social support on wellbeing (see Cohen *et al.*, 2000) and indicate that these effects may extend to stroke. Greater social support has been reported to be associated with benefits to physiological functioning (Uchino, 2006), recovery from breast cancer (Peters-Golden, 2002) and post-stroke depression (Tsouna-Hadjis *et al.*, 2000). The detrimental impact of isolation and low social support on psychological distress after stroke has also been reported (Hilari *et al.*, 2010). Furthermore, Huang and colleagues (2010) reported that social support had a mediating role in depression (similar to the findings of the current study) and should be incorporated into community rehabilitation planning by services. The current findings, therefore, add support to the existing literature regarding the theoretical importance of social support and advocate its subsequent inclusion and planning for in community stroke rehabilitation services.

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Combined with previous research, the findings are suggestive that systemic factors may be important to consider post-stroke. Indeed, relationship adjustments and balancing independence and dependence can be challenging for stroke survivors and family members (Jones & Morris, 2012). Interventions that enhance systemic factors relevant to stroke rehabilitation and adjustment could potentially lead to improvements to survivors and carers, whilst also having beneficial implications for services (e.g. reduced clinical contact and improved cost-effectiveness). The consideration of systemic features may be an important role for clinical psychologists, given their core competencies in assessment, formulation, intervention and evaluation (BPS, 2008; The Division of Clinical Psychology [DCP], 2011; The Health and Care Professions Council [HCPC], 2012). The use of a framework that includes the components identified by Wilson and Gracey (2009) may be important to consider in stroke, as this incorporates individual features of the person (such as their values), alongside broader familial social aspects. The findings of this study may therefore have implications for the development of a stroke specific framework model.

Whilst social support is reported to be an important intervention feature, the findings from the study indicate that there may be additional aspects to consider, which is consistent with a recent systematic review by Cheng *et al.* (2014). In the current study, a significant change in quality of life was reported following peer intervention (compared to changes in the control group) but perceived social support did not have a mediating (indirect) effect on this relationship. This indicates that there may be other components involved in this relationship. As other clinical features could also be present, it may therefore be important to include peer support alongside other therapeutic approaches (identified in Section 4.5.2), when considering quality of life after stroke.

A further theoretical consideration that has arisen from this study is regarding PTG. Calhoun and Tedeschi (1999) defined PTG as the positive psychological changes that occur following challenging life circumstances. This may be particularly relevant to stroke, given the range of changes and adjustments made by survivors and carers (Broomfield *et al.*, 2014) and also the positive findings reported in the current study. Within stroke, there is emerging evidence in the literature that PTG is an important

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feature to consider in both survivors (Gangstad *et al.*, 2009) and carers (Haley *et al.*, 2009).

Although PTG was not explicitly measured in the study, the findings indicated that stroke survivors and carers may experience positive psychological changes following the trauma of the chronic illness. This is supportive of the findings from a recent UK study that reported stroke carers ($n=70$) experience PTG (Hallam & Morris, 2014). Tedeschi and Calhoun (2004) proposed that social support is an important factor in promoting PTG, and their model best predicted PTG in the study by Hallam and Morris (2014). As perceived social support was identified in the current study as being an important mechanism underlying peer support, PTG processes may occur within this context also. Furthermore, there may also be PTG associated with the peers providing peer support, given the positive findings reported in previous research (e.g. Kessler *et al.*, 2014) and the indications from the small number in the present study. The impact of peer support on peers leading the intervention, however, has received a limited amount of focus within the research literature. It may therefore be helpful for future studies to consider the relationship between peer interventions, PTG and social support for stroke survivors, carers and peers.

4.5.2 Clinical & Service Implications

The findings from this study suggest that a community-based stroke peer support programme may be an effective intervention for improving the psychosocial wellbeing of survivors and carers. These findings have implications for service-users, clinicians, guidelines and organisations.

Recent clinical guidelines and national reports have focused on the importance of developing the standards of community stroke rehabilitation care in the UK (NAO, 2010; NICE, 2013; WG, 2012a). This has included recommendations for greater collaboration between statutory and third-sector organisations to increase the availability of a range of interventions, such as peer support, for stroke survivors and carers (Broomhead *et al.*, 2011). In conducting this research, it became apparent that in the local service there is a lack of information available regarding the types of psychosocial support stroke survivors and carers want access too. It may be helpful for local services to obtain satisfaction surveys from stroke survivors and carers to

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consider the types of psychological support they would like to have access to post-stroke. This information is currently lacking and its availability could have implications for future research and service development (e.g. the types of psychological support wanted and investigation of its efficacy).

Peer support has been identified as an important component of stroke rehabilitation (DoH, 2007; ICSWP, 2012), yet it may not be widely available (CQC, 2011). In Wales, increasing service-user and carer involvement has been identified as a key feature in national mental health strategy, which could be facilitated by peer support (WG, 2012b). Furthermore, the importance of regular access to peer support for carers has also been formally recognised in Wales (WG, 2013). Whilst peer support has been identified as a valuable component of community rehabilitation in Wales (WG, 2012b), and specifically for stroke in England (DoH, 2007), there is a dearth of literature that has evaluated it as an intervention. Indeed, the present study may be the first to have quantitatively evaluated the efficacy of peer support for stroke survivors and carers. The findings from the current study indicate support for the recognition of peer support in clinical guidelines and national reports. The findings also reiterate the importance for community stroke services to incorporate and develop peer support programmes for stroke survivors and carers to access.

Despite the wide inclusion of peer support in stroke clinical guidelines (ICSWP, 2012) and national strategy (DoH, 2007), there is little specific guidance available to health and social services regarding the required components of such an intervention. This may account for the limited availability of peer support, as reported by the CQC (2011), in areas of the UK. The findings from this study, however, indicate that some specific practical and clinical features may be important to consider. For example, a group-based peer support programme may be effective for facilitating psychosocial improvements post-stroke. Furthermore, the collaboration between peers (including both survivors and carers) and clinicians in leading the programmes may be advantageous. This is consistent with previous research, as stroke survivors and carers have reported that professional involvement was a positive feature of the peer support intervention (Morris & Morris, 2012). Further replication and expansion of the current study will increase the understanding of the findings reported and their implications for clinical services.

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The involvement of professionals within peer support may have implications for clinical psychologists. Facilitating group intervention, providing supervision, delivering training, working with other agencies and taking a lead in service development are all core competencies of the profession (BPS, 2008; DCP, 2010; HCPC, 2012). In view of the current study, these skills may be particularly important for designing, establishing and conducting an effective peer support programme. These competencies are also specific to the role of clinical psychologists within stroke services (ICSWP, 2012).

There are potentially further implications for clinical services to consider regarding the practical arrangements of facilitating a peer support group. For example, stroke peer support programmes have previously consisted of fixed schedules (e.g. Muller *et al.*, 2014) and self-management programmes (e.g. Kronish *et al.*, 2014). Alternatively, as in the present study, peer support may also be facilitated within an open forum with ‘rolling’ topics (e.g. Tregoe & Brown, 2013). There has been no research comparing the effectiveness of such different peer support programmes in stroke. Additionally, peer support programmes across conditions are arguably more commonly facilitated within a group setting (Heisler, 2006), but have also been completed through individual / befriending schemes (Stewart *et al.*, 1998), telephone-contact (Dale *et al.*, 2008) and web-based models (Lorig *et al.*, 2010). The advantages and implications of different designs of peer support programmes are potentially important for clinical services to consider (e.g. resources and responsibilities) and comparisons of these should be incorporated into future research.

Furthermore, whilst including both carers and survivors within a peer support group may have additional benefits (Graven *et al.*, 2013), the difficulty with recruiting carers in the current study may indicate that they have different needs to consider. Morris and Morris (2012) separated carers and survivors for part of the peer intervention sessions, but this resulted in mixed feedback from participants. Future quantitative and qualitative research with a greater number of carers than was included in the present study may be beneficial for understanding this further. A final practical consideration for clinical services to consider is regarding issues with transportation. As reported by Muller and colleagues (2014), there were similar difficulties in the present study with supporting stroke survivors and carers to attend a

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community-based intervention. Many of the participants had stopped driving following their stroke and this had a detrimental impact on their regular attendance. Facilitating peer support remotely (e.g. web-based or telephone) may help to overcome this, but this also raises issues with access to appropriate technology and competencies with its practical application (Lorig *et al.*, 2010). It may be important for services to collaborate closely with other agencies, as recommended in national guidelines (WG, 2012a), to overcome issues with transport (e.g. the use of third sector community support).

Finally, the findings of the study have clinical implications for the provision of psychosocial interventions. Despite a recent increase in the amount of research within stroke, it is unclear which therapeutic interventions are most effective (Broomfield *et al.*, 2014; Lincoln *et al.*, 2011). As previously reported upon, systemic factors and particularly the importance of social support and relationships, may be vital to consider. There has also been emerging interest and developments in the use of other approaches, including: CBT (Broomfield *et al.*, 2011), relaxation (Kneebone *et al.*, 2014), mindfulness (Merriman *et al.*, 2015), motivational interviewing (Watkins *et al.*, 2011) and acceptance and commitment therapy (Graham *et al.*, 2014). Further replication and extension of the studies, however, is required as this research is still in its infancy. The findings from the present study suggest that peer support may also be considered an effective intervention for stroke rehabilitation. Peer support may provide different opportunities for stroke survivors and carers compared to these other approaches (e.g. modelling from others at a different stage of recovery). Due to its focus on mutual reciprocity and shared understanding from peers, alongside guidance and support from clinicians, peer programmes may help to facilitate community reintegration and rehabilitation after stroke. It may, therefore, be helpful to consider peer support as a complimentary intervention to other therapeutic approaches, such as those identified above. Given the core competencies previously described, this has implications for clinical psychologists operating within both a peer support programme and also more widely across stroke and health services.

4.6 FUTURE RESEARCH

Based on the implications of the findings from the current study and the potential limitations identified, a number of recommendations for future research are proposed.

Findings from the current study indicate that peer support may be an effective psychosocial intervention within stroke rehabilitation. Further replication and expansion of the current study is recommended. It may also be helpful to consider using a study design that includes an extended period of follow-up (e.g. 6-12 months) to evaluate any longer-term changes. Given the small sample used in this study, such research could help to explore the processes and efficacy of peer support in stroke further and its long-term effects. Future studies could also consider sequential recruitment of stroke survivors and carers from clinical services to possibly help reduce volunteer and selection bias. Including assessors who are blind to participant allocation and condition may improve the design of future studies in this area.

Perceived social support was identified as an important process within peer support, particularly in consideration of reduced psychological distress. It may be beneficial for future research to measure aspects of social support further (e.g. perceived and received social support, whom is providing the support). This could involve inclusion and analysis of the MSPSS subscales to clarify how members of the support network are affected by the intervention. Such explicit measurement may help to refine the construct of peer support and the utility of social support theories (including the main effect model) further. It is also unclear which variables affected the relationship between peer support and quality of life. Future qualitative research that explores factors relevant to this relationship may be constructive.

It may be helpful to consider collaborating with diverse community groups in recruitment to ensure greater representation of stroke survivors and carers from different ethnic backgrounds. This may be particularly important given the higher risk of stroke in Black and Asian populations. There is a dearth of literature evaluating the efficacy of peer support for stroke survivors and carers combined. Research that includes a greater number of carers can build on the findings from the current study. This will help to increase the understanding of whether carers benefit from peer

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support. The collaboration with carer specific organisations may facilitate this process. It may also be beneficial to include a carer-specific measurement in future studies. Furthermore, future studies could evaluate the robustness of different psychological measures and improve the consistency and confidence of the findings reported across the research. In further consideration of the sample used in the study, there were few younger stroke survivors and carers. Future research therefore could seek to evaluate a peer support programme specific to a younger population, as there may be different considerations to account for (e.g. employment).

It may also be helpful for future research to consider comparing the different formats of peer support (e.g. group and web-based interventions). Increasing the amount of RCTs of peer support programmes would help to compare the different methods of the intervention. This may help to clarify the most effective form of peer support for services to incorporate into their community rehabilitation planning. Furthermore, this study did not sufficiently account for any changes in psychological wellbeing for the peers co-facilitating the programme. Research investigating the range of potential effects on peers leading the peer support intervention in stroke is outstanding.

It may be potentially relevant for future studies to consider the relationship between peer interventions, PTG and social support for stroke survivors, carers and peers, using an explicit measure (e.g. the Post Traumatic Growth Inventory [Tedeschi & Calhoun, 1996]). Such research could have important theoretical (e.g. increased understanding of peer support, PTG and helper-therapy principle) and clinical (e.g. increased prevalence in community rehabilitation services) implications within stroke.

There are a number of developments regarding the use of psychological therapies to support post-stroke rehabilitation. Research that compares the use of peer support with other approaches may have beneficial implications for service-users, clinicians and organisations.

4.7 CONCLUSIONS

Having a stroke can be traumatic for the person affected and their family. It is a leading cause of adult disability and therefore has implications for health organisations too. Improvements to community stroke rehabilitation services are required to increase the quality of care provided. Peer support has been recommended as one form of psychosocial support that can facilitate recovery post-stroke. This study aimed to evaluate the efficacy of a stroke peer support programme, using a quantitative randomised design, given the limited research literature available. The findings from the study suggest that peer support can help to reduce psychological distress and improve the quality of life and amount of perceived social support in stroke survivors and carers. The importance of perceived social support was further emphasised with its mediating effect on the relationship between peer support and psychological distress. The findings indicate support for the recommendations made within stroke clinical guidelines and national reports regarding the inclusion of peer support. This has implications for the provision of effective community rehabilitation services within stroke. There are also implications for clinical psychologists regarding the facilitation, development, supervision and training of others within a peer support programme.

There were a number of limitations with the study identified, including the characteristics of the small sample and the design of the study. Attempts were made to overcome these but they may have impacted on the quality of the findings reported. Further practical aspects associated with conducting a peer support programme were identified and may be important for services to consider. Methods to overcome the limitations reported are recommended. Future research to improve the understanding of peer support within stroke is proposed.

This study aimed to contribute to an area that had received limited focus within the research, but which could have marked implications for stroke survivors, carers, clinicians and services. It is hoped the findings can stimulate further developments to improve the quality of stroke rehabilitation care.

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APPENDICES

Appendix A Cardiff University Letter of Sponsorship

Research, Innovation and Enterprise Services
Director Geraint W Jones
Gwasanaethau Ymchwil, Arloesi a Menter
Cyfarwyddwr Geraint W Jones



Cardiff University
7th Floor
30 - 36 Newport Road
Cardiff CF24 0DE
Wales UK
Tel Ffôn +44(0)29 2087 5834
Fax Ffôn +44(0)29 2087 4189
Prifysgol Caerdydd
Llawr 7
30 - 36 Heol Casnewydd
Caerdydd CF24 0DE
Cymru Y Deyrnas Unedig

15 April 2014

Professor Reg Morris
Clinical Psychology
School of Psychology
Cardiff University
Tower Building,
Floor 11,
70 Park Place,
Cardiff
CF10 3AT

Dear Professor Morris,

Title: The effectiveness of Peer Support within Stroke Services,

I understand that you are acting as Chief Investigator for the above DClInPsy project to be conducted by Chris Stamatakis.

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the Research Governance Framework for Health and Social Care.

Scientific Review

I can also confirm that Scientific Review has been obtained from the DClInPsy supervisory team (Cardiff University).

Insurance

The necessary insurance provisions will be in place prior to the project commencement. Cardiff University is insured with UMAL. Copies of the insurance certificate are attached to this letter.

Approvals

On completion of your IRAS form (for NHS REC and NHS R&D approvals), you will be required to obtain signature from the Sponsor ('Declaration by the Sponsor Representative').

Please then submit the project to the following organisations for approval:

- the appropriate Research Ethics Committee(s);
- National Institute for Social Care Health Research Permissions Coordinating Unit (NISCHR PCU- to arrange host organisation R&D approval).

Once Research, Innovation & Enterprise Services has received evidence of the above approvals, the University is considered to have accepted Sponsorship and your project may commence.

Roles and Responsibilities

As Chief Investigator you have signed a Declaration with the Sponsor to confirm that you will adhere to the standard responsibilities as set out by the Research Governance Framework for Health and Social Care. In accordance with the University's Research Governance Framework, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfill his delegated roles including ensuring adequate supervision, support and training.

Roles and responsibilities are adequately detailed in the research protocol – no contract required.



Registered Charity, 1136855 Eitan Gofrestredig

May I take this opportunity to remind you that, as Chief Investigator, you are required to:

- ensure you are familiar with your responsibilities under the Research Governance Framework for Health and Social Care;
- undertake the study in accordance with Cardiff University's Research Governance Framework and the principles of Good Clinical Practice;
- ensure the Research complies with the Data Protection Act 1998;
- inform Research, Innovation & Enterprise Services of any amendments to the protocol or study design, including changes to start /end dates;
- co-operate with any audit inspection of the project files or any requests from Research, Innovation & Enterprise Services for further information.

You should quote the following unique reference number in any correspondence relating to sponsorship for the above project:

SPON 1310-14

This reference number should be quoted on all documentation associated with this project.

Yours sincerely



Dr K J Pittard Davies
Head of Research Governance and Contracts
Direct line: +44 (0) 29208 79274
Email: resgov@cardiff.ac.uk

Cc Chris Stamatakis

Appendix B NHS NRES Letter of Ethical Approval



Health Research Authority

NRES Committee London - Brent

80 London Road

Skipton House

London

SE1 6LH

Telephone: 020 7972 2554

24 July 2014

Mr Chris V Stamatakis
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
South Wales Clinical Psychology Doctoral Programme
11th Floor, Tower Building, 70 Park Place
Cardiff
CF10 3AT

Dear Mr Stamatakis

Study title:	The Effectiveness of a Peer Support Group within a Community Stroke Service
REC reference:	14/LO/1257
Protocol number:	SPON 1310-14
IRAS project ID:	143240

Thank you for your letter of , responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Julie Kidd, nrescommittee.london-brent@nhs.net .

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Leaflet]	1.0	30 June 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		26 July 2014
IRAS Checklist XML [Checklist_01072014]		01 July 2014
Letter from sponsor [Sponsorship]		15 April 2014
Participant consent form [Peer Supporter]	1.1	24 July 2014
Participant consent form [Peer Member]	1.1	24 July 2014
Participant information sheet (PIS) [Group Member PIS]	1.0	14 June 2014
Participant information sheet (PIS) [Peer Supporter PIS]	1.0	14 June 2014
REC Application Form [REC_Form_01072014]		01 July 2014
Referee's report or other scientific critique report [Scientific Review]		27 February 2014
Research protocol or project proposal [Research Protocol]	1.0	14 June 2014
Response to Request for Further Information		24 July 2014
Summary CV for Chief Investigator (CI) [CV]	1.0	30 June 2014
Summary CV for supervisor (student research) [Supervisor CV]	1.0	30 June 2014
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Study Design]	1.0	14 June 2014
Validated questionnaire [Questionnaires]	1.0	14 June 2014
Validated questionnaire [GHQ-30 Sample]	1.0	30 June 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/1257

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Chair

Email: nrescommittee.london-brent@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mrs Helen Falconer*

Helen Paine, Cardiff and Vale UHB

Appendix C Cardiff and Vale UHB Research and Development Office Letter of
Approval



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3636
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 20743636
Minicom 029 2074 3632

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor C Fegan
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

11 August 2014

Dr Samantha Fisher
Stroke Rehabilitation Service
Llandough Hospital
CF64 2XX

Dear Dr Fisher

Cardiff and Vale UHB Ref and Study Title : 14/MEH/5934 : The Effectiveness Of A Peer Support Group Within A Community Stoke Service

IRAS Project ID: 143240

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the NISCHR Permissions Coordinating Unit. A Governance Review has now been completed on the project.

Documents approved for use in this study are:

Document	Version	Date
NHS R&D Form	3.5	Received 01/07/2014
SSI Form	3.5	Received 01/07/2014
Protocol	1	14/04/2014
Participant Information Sheet: Group Member	1	14/06/2014
Participant Information Sheet: Peer Supporter	1	14/06/2014
Group Leaflet	1	Received 01/07/2014
Illustration of Study Design	1	14/04/2014
Questionnaire	1	14/06/2014
Questionnaire: GHQ-30	1	14/06/2014
Participant Consent Form: Group Member	1.1	24/07/2014
Participant Consent Form: Peer Supporter	1.1	24/07/2014

I am pleased to inform you that the UHB has no objection to your proposal and that this study has been classed as pathway-to-portfolio. You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care.

Please accept this letter as confirmation of permission for the project to begin within this UHB.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if this project has not opened within 12 months of the date of this letter. Failure to do so may invalidate R&D approval.
- Inform NISCHR PCU and the UHB R&D Office if any external or additional funding is awarded for this project in the future
- Submit any substantial amendments relating to the study to NISCHR PCU in order that they can be reviewed and approved prior to implementation
- Ensure NISCHR PCU is notified of the study's closure
- Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
- Provide information on the project to the UHB R&D Office as requested from time to time, to include participant recruitment figures

Yours sincerely,



Professor Christopher Fegan
R&D Director / Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC R&D Lead Mr Alun Morgan
 Chief Investigator, Mr Christopher Stamatakis
 Sponsor: Chris Shaw, RIES, Cardiff University
 Academic Supervisor: Professor Reg Morris, Clinical Psychology
 Doctoral Programme

Appendix D Participant Information Sheet for Peer Supporters

Participant Information Sheet: Peer Supporter

Study Title: A Peer Support Group for Stroke

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. The researcher is available to answer any questions you may have.

What is the Purpose of the Study?

The research will look at the use of a peer support model for improving psychological wellbeing for both survivors of stroke and carers of stroke survivors. Peer supporters are described as people who share similarities with others based on their own personal experiences. Some research has reported that peer support can have a positive effect on the wellbeing of those with chronic illnesses, including stroke.

As such, I am looking to recruit individuals who have previously had a stroke or have cared for someone with a stroke and who feel able to offer support to those who have more recently experienced the chronic illness. The peer supporters and myself will offer 5 group sessions to those who have more recently had a stroke or are caring for someone who has recently had a stroke. The group will meet weekly at Llandough Hospital, Penarth.

Why Have I Been Invited?

You have been invited to participate because you have either experienced a stroke or cared for someone who has had a stroke.

You can participate in this study if:

- You have experienced a stroke.
- You have cared for someone who has had a stroke.
- You are over 18 years of age.
- You are not known to be pregnant.

Do I have to take part?

It is up to you to decide to join the study. The researcher will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part in this research, you will be provided with training regarding how to facilitate group sessions – this will involve 1-2 sessions lasting approximately 2 hours alongside myself and a colleague. The training will also familiarise you with the topics that may be covered in the group sessions, such as mood, memory and relationships, which can all be impacted upon following stroke.

Following this training, you will facilitate group sessions alongside myself for stroke survivors and carers. Five group sessions are planned for.

As part of the research, you will be required to complete several short questionnaires at three stages: the beginning, the end and 1-month post the end of the group sessions. I will be available to go through the questionnaires with you. These questionnaires should take approximately 40 minutes to complete on each occasion. If you agree to participate in this research, you can complete the questionnaires at the venue of the group sessions, by post or over the telephone with me at a convenient time.

If you decide to take part, you will be asked whether you consent to the researcher accessing your medical notes and data. If you provide consent, the researcher will only access your medical notes for information about your stroke.

What will I have to do?

If you decide to take part, you will be asked to attend 1-2 training-sessions prior to the group starting. This will focus on being a “peer supporter”.

Alongside clinicians, you will then be asked to co-facilitate group sessions for those who have recently had a stroke or are caring for someone who has had a stroke. You will be asked to complete questionnaires to evaluate the group.

What are the benefits of this research?

Peer support models have been found to be helpful for chronic health conditions, including stroke. I am hoping that this research can help us to evaluate the use of peer support models in stroke services. This could potentially help to improve the services received by people affected by stroke. Furthermore, in previous research peer supporters also reported their own benefits from participating in such groups (e.g. improved feelings of self-worth).

What are the possible disadvantages and risk of taking part?

If you find completing the questionnaires or co-facilitating the groups raises issues that are distressing, you may find helpful information and insights on the stroke association website (<http://www.stroke.org.uk/>). But if you remain upset or concerned please contact the chief investigator, Chris Stamatakis at 02920 870587 or the project supervisor, Professor Reg Morris at 02920 870582.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You can contact Chris Stamatakis on 02920870582 or at Christopher.Stamatakis@wales.nhs.uk

If you remain unhappy and wish to complain formally you can do this through Cardiff University on 029 2087 9131 or at resgov@cardiff.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the university will have your name and personal details removed so that you cannot be recognised. Your participation in this research will not impact on the care you receive from other health professionals.

What will happen if I don't carry on with the study?

If you withdraw from the study all the identifiable information and data collected from you, to date, will be destroyed and your name removed from all study files.

What will happen to the results of the research study?

It is hoped that the results of the research will be published in a scientific journal. You will be given the opportunity to receive a summary of the findings after the research is complete. You will not be identified in any report/publication related to this research.

Who is organising and funding the research?

Cardiff University is sponsoring this research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South East Wales Research Ethics Committee.

Further information and contact details.

For further information about this study, please contact Chris Stamatakis (Researcher) on 02920870582 or at Christopher.Stamatakis@wales.nhs.uk

Appendix E Leaflet Advertising Peer Support Group

Where will sessions be held?

The group will meet at the **Stroke Rehabilitation Centre, University Hospital Llandough.**

Please contact us if you have any questions?

Contact Details

**Stroke Rehabilitation Centre,
University Hospital Llandough,
Penarth,
Vale of Glamorgan,
CF62 2XX.**

Telephone

Julie Wilcox: 02920 715996
Samantha Fisher: 02920 716827
Chris Stamatakis: 07865079955

Or

E-mail:

julie.wilcox@wales.nhs.uk
samantha.fisher3@wales.nhs.uk

PEER SUPPORT AFTER STROKE



**A support group
for people and their relatives
living with stroke**



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

What is 'Peer Support'?

'Peer support' refers to help provided by people who have experienced stroke (either themselves or as a relative) to those who are adapting to a more recent stroke.

Strokes affect people in many ways and can cause physical, emotional and social challenges to the person and those closest to them.



Peer support after stroke

Peer support aims to help people adjust to life after stroke.

Groups will be run by people with personal experience of stroke together with staff from the stroke unit.

The course will focus on managing difficulties after stroke (e.g. mood, fatigue, memory, losses).

What will happen in the group?

The group will meet every week for 5 weeks. **It is open to anyone who has had a stroke or cared for somebody with a stroke.**

If you attend, you can choose how much you want to say or if you just want to listen to others – that's ok too!

How can I book?

Please contact Julie or Samantha on the details provided above

Appendix F Overview of Number who Chose to and Chose Not to Participate

Overview of Number who Chose to and Chose Not to Participate

Pre-Consent

	Group Member	Peer Supporter
First Recruitment Phase		
Invited to Participate	70	8
Declined Participation	22	2
Completed Training	N/A	6
Provided Consent	48	4
Second Recruitment Phase		
Invited to Participate	10	N/A
Declined Participation	0	N/A
Provided Consent	10	N/A
Overall Total		
Invited	80	8
Declined Participation	22	4
Provided Consent	58	4

Post-Consent

<i>N</i>	Peer Support Group I	Comparison Group I	Peer Support Group II	Comparison Group II	Peer Support Group III	Comparison Group III	Total
Total Allocated	12	12	12	12	20*	10	58
Provided Data	6	10	10	10	7 [†]	4	47[^]
Chose not to participate (without providing any data)	6	2	2	2	13 [†]	6	18

*Participants were automatically allocated from Comparison Groups I and II for this intervention group and four had already dropped out from Comparison Groups I and II prior to this intervention group starting. [†]These participants had already contributed data for Comparison Groups II and III. [^]7-participants provided data for separate comparison and intervention groups.

Appendix G Overview of Group Format and Process

Overview of Group Format and Process

Group Format

Group Structure and Development

Peer supporters (minimum of two) and clinician/s (at least one, including the researcher) facilitated group intervention sessions. Sessions lasted between 1.5-2 hours and were held at a day hospital in the local health board. Peer supporters completed prior training regarding group facilitation skills and information specific to both stroke (e.g. common psychological difficulties post-stroke) and peer support (e.g. benefits identified in research). The researcher and supervisor facilitated the training for the peer supporters.

Peer supporters and clinicians collaboratively discussed methods to support the facilitation of the group prior to it beginning. It was decided that the use of formal techniques (such as PowerPoint) may disrupt the flow of discussion amongst group members and facilitators. Written information would be provided for members, however, through handouts from organisations (e.g. Stroke Association) and a summary of the topics discussed in each group session.

Whilst an aim of the group was to focus on the psychosocial wellbeing of stroke survivors and carers, it was planned that group members would identify topics for discussion during the first session. Peer supporters and clinicians would then encourage further exploration of these areas and offer personal (peer supporter experiences) and professional (clinicians) information specific to these stroke related topics. As consistent with previous studies using peer support, having a 'rolling' agenda of topics, identified by group members, may enable the group to focus on the most prominent psychosocial adjustment difficulties post stroke. As sessions progressed, further topics may be identified following group discussion and added to the 'rolling' agenda. If group members had problems identifying topics, common psychosocial difficulties after stroke, reported in the literature, would be proposed by facilitators and then chosen by survivors and carers.

Adapting Session Content

Any additional needs group members had were initially identified through discussion on the telephone with the researcher, prior to the first session (e.g. wheelchair access, hearing impairments and visual problems). To allow for physical, sensory, communication and cognitive difficulties that group members may have experienced post-stroke, a number of adaptations were made. The physical environment (use of day hospital and therapy room the sessions took place in) was chosen to account for ambulance transport, wheelchair access, disability parking, a quiet therapeutic space and providing a comfortable waiting area. Equipment to compensate for everyday physical / mobility impairments were also shown and discussed during sessions (e.g. using chopping boards for cutting food).

To account for any sensory and memory problems, written information including handouts from organisations and a summary of topics discussed in each session were provided to group members. Facilitators monitored group discussion to ensure that members were not speaking over each other and also summarised and clarified discussion points to ensure those with hearing or cognitive difficulties were provided with clear and concise information. Where possible, demonstrations of technology were included through various modes. For example, the use of mobile phone applications (e.g. relaxation methods and use of alarms) were discussed verbally, shown visually and instructions were also written down. Group members with communication difficulties were provided with support from facilitators to ensure their perspectives were included within group discussion (e.g. additional time to speak, writing information down to be read out on their behalf). Breaks (including refreshments) were held during the sessions in awareness of cognitive difficulties (e.g. attention). Facilitators continuously monitored and ‘checked-in’ with group members during breaks and at the end of sessions, to ensure that their needs were being met and that content was adequately adapted.

Group Process

Facilitator Roles

Initially, clinicians took a more active role with encouraging discussion amongst group members and peer supporters, as they both orientated themselves to the

intervention. As sessions progressed, peer supporters increasingly facilitated group discussion, as they became more confident in their role (clinicians remained present but were less involved than previously). In their roles as group facilitators, peers also offered their own experiences in relation to the topics identified, to stimulate group discussion, learning, curiosity and reflections amongst group members. Clinicians supported this process, by monitoring emotional wellbeing, summarising key points made by group members and encouraging participation in discussions. Facilitator roles were also reflected upon and discussed within supervision (see below).

Group Participation

Group members were encouraged to contribute, interact and share their experiences to topics they had identified (see below). Peers and clinicians supported this process by using facilitation techniques such as open questioning, active listening and promoting non-judgemental exploration of relevant topics. Group members were also informed that they were under no obligation to add anything and could also ‘just’ listen to others. The facilitators monitored levels of emotional distress and negativity during group discussions and were mindful of allowing all group members the opportunity to contribute to the topics explored. This occurred ‘live’ in sessions and also in post-session reflection and supervision (in readiness for the next session). Peers and clinicians encouraged group member participation by contributing personal and professional stroke-related experiences for wider group discussion.

Identification of Topics

Group members were informed that an aim of the group was to focus on psychosocial wellbeing after stroke. In line with this, group members collaboratively and tentatively identified general topics for further exploration over the five-week intervention during the first session. Group members were informed that these topics may change over time and may be reviewed upon in more than one session, but this was dependent upon their preferences (i.e. these items were not to be rigidly followed and could be added or removed). Topics identified by group members were: mood, coping skills (e.g. relaxation), fatigue, sleep, relationships, memory, loss (e.g. identity), daily living skills (e.g. adjustments, learning, driving) and local resources (e.g. Stroke Association Wales).

Discussion and Exploration of Topics

The facilitators supported the discussion of these topics. This included them introducing the areas identified and promoting wider discussion and exploration as a group. Within these discussions, facilitators reported their own personal and professional / academic experiences and knowledge of these areas, difficulties encountered and support / resources that helped to improve these areas of psychosocial wellbeing and functioning. The balance of reporting experiences from both peers and clinicians aimed to stimulate further exploration with the group members. Facilitators were mindful to monitor levels of emotional distress from group members, validate difficulties experienced, promote hope, acknowledge strengths and resilience and identify areas of future clinical and service needs. Facilitators aimed to ensure that all group members wishing to contribute to discussions were provided with the opportunity to give their views and experiences. Through their group management skills (and supervision), the facilitators aimed to create a safe, non-judgemental and supportive environment for group members to discuss and explore the topics identified to increase mutual learning and understanding.

Contact Outside of Group Sessions

Debrief and supervision was provided for peer supporters by clinicians after each session. Group members could also approach peers and / or professionals at the day hospital after the group session had ended, to discuss anything further on an individual basis (e.g. for more information). Contact details for clinicians working in the research team and the local stroke service, as well as local support organisations, were also provided for peers and group members outside of these times.

Appendix H Participant Information Sheet for Group Members

Participant Information Sheet: Group Member

Study Title: A Peer Support Group for Stroke

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. The researcher is available to answer any questions you may have.

What is the Purpose of the Study?

The research will look at the use of a peer support model for improving psychological wellbeing for both survivors of stroke and carers of stroke survivors. Peer supporters are described as people who share similarities with others based on their own personal experiences. Some research has reported that peer support can have a positive effect on the wellbeing of those with chronic illnesses, including stroke.

As such, I am therefore looking to recruit individuals who have recently had a stroke or carers of those who have recently had a stroke to attend this group, run by the peer supporters and myself. This will involve five group sessions and will meet weekly at Llandough Hospital, Penarth.

Why Have I Been Invited?

You have been invited to participate because you have either experienced a stroke or cared for someone who has had a stroke.

You can participate in this study if:

- You have experienced a stroke.
- You have cared for someone who has had a stroke.
- You are over 18 years of age.
- You are not known to be pregnant.

Do I have to take part?

It is up to you to decide to join the study. The researcher will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part in this research, you will be invited to attend 5-weekly group sessions that will cover a range of common difficulties reported post stroke (e.g. mood, memory and relationships).

As part of the research, you will be required to complete several short questionnaires at three stages: the beginning, the end and 1-month post the end of the group sessions. I will be available to go through the questionnaires with you. These questionnaires should take approximately 40 minutes to complete on each occasion. If you agree to participate in this research, you can complete the questionnaires at the venue of the group sessions or over the telephone with me at a convenient time.

If you decide to take part, you will be asked whether you consent to the researcher accessing your medical notes and data. If you provide consent, the researcher will only access your medical notes for information about your stroke.

What will I have to do?

If you decide to partake in this research, you will be invited to attend 5-group sessions for people who have had a stroke or carers of those who have had a stroke. You will be asked to complete questionnaires to evaluate the group.

What are the benefits of this research?

Peer support models have been found to be helpful for chronic health conditions, including stroke. I am hoping that this research can help us to evaluate the use of peer support models in stroke services. This could potentially help to improve the services received by people affected by stroke.

What are the possible disadvantages and risk of taking part?

If you find completing the questionnaires or co-facilitating the groups raises issues that are distressing, you may find helpful information and insights on the stroke association website (<http://www.stroke.org.uk/>). But if you remain upset or concerned please contact the chief investigator, Chris Stamatakis at 02920 870587 or the project supervisor, Professor Reg Morris at 02920 870582.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You can contact Chris Stamatakis on 02920870582 or at Christopher.Stamatakis@wales.nhs.uk
If you remain unhappy and wish to complain formally you can do this through Cardiff University on 029 2087 9131 or at resgov@cardiff.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the university will have your name and personal details removed so that you cannot be recognised.
Your participation in this research will not impact on the care you receive from other health professionals.

What will happen if I don't carry on with the study?

If you withdraw from the study all the identifiable information and data collected from you, to date, will be destroyed and your name removed from all study files.

What will happen to the results of the research study?

It is hoped that the results of the research will be published in a scientific journal. You will be given the opportunity to receive a summary of the findings after the research is complete. You will not be identified in any report/publication related to this research.

Who is organising and funding the research?

Cardiff University is sponsoring this research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South East Wales Research Ethics Committee.

Further information and contact details.

For further information about this study, please contact Chris Stamatakis (Researcher) on 02920870582 or at Christopher.Stamatakis@wales.nhs.uk

Appendix I Participant (Group Member) Consent Form

Consent Sheet: Group Member

Research Title: The Effectiveness of Peer Support in Community Stroke Services

Name of Researcher: Chris Stamatakis

Participant identification number:

1. I confirm that I have read and understand the '*Participant Information Sheet: Group Member*' for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study will be looked at by the researcher, Cardiff University staff and may be looked at by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this evaluation study. This is only applicable for participants who are stroke survivors (thus carers of stroke survivors will not have their medical records looked at). I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

Signature of Participant Date

Name (Please Print).....

Signature of Researcher..... Date.....

Name (Please Print).....

OPTIONAL:

I **would** like a summary of the findings of this study sent to my email **or** postal address below:

(If you **would not** like to receive a summary of the findings, please leave this section blank)

Email address:

Or

Postal Address (including post code)

.....
.....

.....
.....
.....
.....

Appendix J Participant (Peer Supporter) Consent Form

Consent Sheet: Peer Supporter

Research Title: The Effectiveness of Peer Support in Community Stroke Services

Name of Researcher: Chris Stamatakis

Participant identification number:

5. I confirm that I have read and understand the '*Participant Information Sheet: Peer Supporter*' for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
7. I understand that relevant sections of my medical notes and data collected during the study will be looked at by the researcher, Cardiff University staff and may be looked at by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this evaluation study. This is only applicable for participants who are stroke survivors (thus carers of stroke survivors will not have their medical records looked at). I give permission for these individuals to have access to my records.
8. I agree to take part in the above study.

Signature of Participant Date

Name (Please Print).....

Signature of Researcher..... Date.....

Name (Please Print).....

OPTIONAL:

I **would** like a summary of the findings of this study sent to my email **or** postal address below:

(If you **would not** like to receive a summary of the findings, please leave this section blank)

Email address:

Or

Postal Address (including post code)

.....
.....

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.....
.....
.....

Appendix K Questionnaire Pack

Questionnaires

Instructions:

This questionnaire should take no longer than 30-minutes to complete.

Questionnaires will be **anonymous**. Therefore, please do not write your name on the questionnaire.

Please try to answer all the questions even if you are unsure about some of them. However, it is your right to stop completing the questionnaire or leave out certain questions at any time should you wish to.

Part 1: About you...

- 1. Participant Number: _____
- 2. Today's Date: ____/____/____
- 3. Please give your age: ____ years old

4. Please indicate your gender (Please tick the box which applies to you)

Male Female

5. Please indicate your ethnicity (Please tick which ever box/boxes applies to you)

- | | | | |
|---------------------------|--------------------------|--------------------|--------------------------|
| British | <input type="checkbox"/> | Caribbean | <input type="checkbox"/> |
| Irish | <input type="checkbox"/> | African | <input type="checkbox"/> |
| Other White | <input type="checkbox"/> | Any other Black | <input type="checkbox"/> |
| White and Black Caribbean | <input type="checkbox"/> | Chinese | <input type="checkbox"/> |
| White and Black African | <input type="checkbox"/> | Other ethnic group | <input type="checkbox"/> |
| White and Asian | <input type="checkbox"/> | | |
| Any other mixed | <input type="checkbox"/> | | |
| Indian | <input type="checkbox"/> | | |
| Pakistani | <input type="checkbox"/> | | |
| Bangladeshi | <input type="checkbox"/> | | |
| Any other Asian | <input type="checkbox"/> | | |

6. Please indicate your occupation (Please tick the box which applies to you)

Retired Please state your previous job title _____

In employment Please state your current job title _____

Unemployed If relevant, please state previous job title _____

7. When did you have a stroke? _____ (date)

8. Was this the first time you experienced a stroke? (Please tick the box which applies to you)

Yes No

9. What are your current living circumstances?

Live with carer

Live with other (not carer)

Live alone

Since you experienced the stroke...

1. Has your ability to communicate with others been affected? (Please tick the box which applies to you)

Not at all

Mildly

Severe

2. Do you experience memory difficulties? (Please tick the box which applies to you)

Not at all

Mildly

Severely

3. Have your relationships with those living with you, or those closest to you, been affected? (Please tick the box which applies to you)

Not at all

Somewhat

Most definitely

4. Are you currently feeling ... (Please tick the box which applies to you for both feelings categories)

Low in mood or depressed

Never

Sometimes

Often

Anxious or worried

Never

Sometimes

Often

5. In the past two years, have you been treated for depression or anxiety? (Please tick the box which applies to you)

Yes

No

6. Educational experience

Age Left School: _____

Highest qualification:

O-Level / GCSE

A-Level

Diploma or Certificate

Degree

Higher Degree

PART 2: Specific questions about life since the stroke.

i) Barthel ADL Index (Mahoney & Barthel, 1965)

Sometimes having a stroke can impact how we perform everyday activities. The following questions ask about how you have been coping with everyday tasks **over the last two weeks**. Please tick the box (i.e. ✓) with the number that describes how independently you are able to do the following the tasks:

	0	1	2	3
Feeding				
	Unable	Needs Help	Independent	
Bathing/Showering				
	Dependent	Independent		
Grooming				
	Needs help	Independent		
Dressing				
	Dependent	Needs help	Independent	
Bowels				
	Incontinent	Occasional accident	Continent	
Bladder				
	Incontinent	Occasional accident	Continent	
Toilet use				
	Dependent	Needs some help	Independent	
Transfers				
	Unable	Major help	Minor help	Independent
Mobility				
	Immobile	Wheelchair independent	Walks with help	Independent
Stairs				
	Unable	Needs help	Independent	

ii) GHQ-30 ([sample] Goldberg & Williams, 1988)

We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer all the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about your present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

Have you recently:					
1	Been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2	Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3	Been having restless, disturbed nights?	Not at all	No more than usual	Rather more than usual	Much more than usual
4	Been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
5	Been getting out of the house as much as usual?	More so than usual	Same as usual	Less than usual	Much less than usual
6	Been managing as well as most people would in your shoes?	Better than most	About the same	Rather less well	Much less well
7	Felt on the whole you were doing things well?	Better than usual	About the same	Less than usual	Much less well
8	Been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
9	Been able to feel warmth and affection for those near to you?	Better than usual	About same as usual	Less than usual	Much less well
10	Been finding it easy to get on with other people?	Better than usual	About same as usual	Less than usual	Much less well
11	Spent much time chatting with people?	More time than usual	About same as usual	Less than usual	Much less than usual
12	Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
13	Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
14	Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual

15	Felt that you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
16	Been finding life a struggle all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
17	Been able to enjoy your normal day-today activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
18	Been taking things hard?	Not at all	No more than usual	Rather more than usual	Much more than usual
19	Been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
20	Been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
21	Found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
22	Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
23	Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
24	Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
25	Felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
26	Been feeling hopeful about your own future?	More so than usual	About same as usual	Less so than usual	Much less hopeful
27	Been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
28	Been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
29	Felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
30	Found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual

iii) Social support – MSPSS (Zimet *et al.*, 1988)

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

1	2	3	4	5	6	7
Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree

		1	2	3	4	5	6	7
1	There is a special person who is around when I am in need.							
2	There is a special person with whom I can share my joys and sorrows.							
3	My family really tries to help me.							
4	I get the emotional help and support I need from my family.							
5	I have a special person who is a real source of comfort to me.							
6	My friends really try to help me.							
7	I can count on my friends when things go wrong.							
8	I can talk about my problems with my family.							
9	I have friends with whom I can share my joys and sorrows.							
10	There is a special person in my life who cares about my feelings.							
11	My family is willing to help me make decisions.							
12	I can talk about my problems with my friends.							

iv) EQ-5D-3L Health Questionnaire (Brooks 1996)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own
health state
today**

Best
imaginable
health state

100



90

80

70

60

50

40

30

20

10

0

Worst
imaginable
health state

v) The Therapeutic Factors Inventory ([TFI-19] MacNair-Semands *et al.*, 2010)

Please rate the following statements as they apply to your experience in your group by circling the corresponding number, using the following scale:

1= Strongly Disagree to 7= Strongly Agree

- | | | | | | | | | |
|-----|--|---|---|---|---|---|---|---|
| 1. | Because I've got a lot in common with other group members, I'm starting to think that I may have something in common with people outside group too. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | Things seem more hopeful since joining group. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | I feel a sense of belonging in this group. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. | I find myself thinking about my family a surprising amount in group. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. | It's okay for me to be angry in group. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. | In group I've really seen the social impact my family has had on my life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. | My group is kind of like a little piece of the larger world I live in: I see the same patterns, and working them out in group helps me work them out in my outside life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. | Group helps me feel more positive about my future. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. | It touches me that people in group are caring of each other. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. | In group sometimes I learn by watching and later imitating what happens. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. | In group, the members are more alike than different from each other. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. | It's surprising, but despite needing support from my group, I've also learned to be more self-sufficient. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. | This group inspires me about the future. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. | Even though we have differences, our group feels secure to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. | By getting honest feedback from members and facilitators, I've learned a lot about my impact on other people. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16. | This group helps empower me to make a difference in my own life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

17. I get to vent my feelings in group. 1 2 3 4 5 6 7
18. Group has shown me the importance of other people in my life. 1 2 3 4 5 6 7
19. I can “let it all out” in my group. 1 2 3 4 5 6 7

Appendix L Debrief Letter to Participants



Peer Support in Stroke: Debrief Letter

Dear Sir/ Madam

Thank you for participating in this research. The aim of this study was to evaluate the use of peer support for both stroke survivors and carers. We hope that the answers you provided will:

- develop our knowledge of how people are affected after stroke.
- increase our understanding of whether a peer support model can help to improving wellbeing after stroke.
- help us to have a greater understanding of the processes regarding peer support.

Hopefully, this will identify the types of support that are helpful and lead to improvements in community stroke services.

Please be assured that the data you provided will be kept strictly confidential and will be stored anonymously. Your consent form will be kept separately in a locked cabinet at the South Wales Doctoral Course in Clinical Psychology, Cardiff University. You are free to withdraw your information without needing to provide a reason. If you have any concerns about the research, please feel free to contact the researchers (contact details are at the bottom of the letter). If you remain unhappy and wish to complain formally, you can do this by contacting Cardiff University on 02920 879131 or resgov@cardiff.ac.uk.

I will be very happy to send you a summary of the findings from the study.
You may have indicated this on the consent form, but if not please feel free to contact me to request this information.

Thank you again for your participation and please do not hesitate to contact me with any questions.

Yours truly

Chris Stamatakis
christopher.stamatakis@wales.nhs.uk
Trainee Clinical Psychologist

Professor Reg Morris
reg.morris@wales.nhs.uk
Clinical Psychologist &
Programme Director

South Wales Doctoral Programme in Clinical Psychology
School of Psychology
Cardiff University
11th Floor, Tower Building
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582