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MAJOR RESEARCH PROJECT

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EXPLORING HOW NARRATIVE THERAPY MAY FACILITATE PSYCHOSOCIAL ADJUSTMENT
FOLLOWING STROKE

Section A: Psychological adjustment post-stroke: A literature review

Word count: 5489 (plus 358 additional words).

Section B: An investigation of how narrative group therapy may facilitate psychosocial
adjustment following stroke

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SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

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Summary of the MRP portfolio

Section A is a review of the literature on psychological adjustment following stroke.

Empirical research is critically reviewed with reference to two research questions: (1)

What do we understand about adjustment following survival of stroke? (2) What

psychosocial interventions have been used to support adjustment post-stroke and

what are the outcomes? Theoretical models for adjustment to stroke are drawn upon

to illuminate the findings. Gaps within the literature are discussed and future

directions for research are suggested.

Section B describes a study using mixed methods to explore how narrative group

therapy may facilitate adjustment following stroke. Ten participants attended six

weekly sessions of narrative group therapy. Results of outcome measures and

inductive thematic analysis are presented and discussed with reference to existing

literature. Clinical and research implications are considered.

Section C is a critical appraisal of the qualitative study, including critical reflections on

the research process relating to the following topic areas; research skills learned and

further areas for development, what would be done differently if the project were to

be repeated, consequences of the research in terms of clinical practice, and future

research projects.

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SECTION A: LITERATURE REVIEW

Psychological adjustment post-stroke: A literature review

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Abstract

A stroke is an abrupt and sudden event that can have catastrophic consequences across physical, emotional, cognitive and social domains. Rehabilitation is typically focused on mobility and restoration of physical function, even though 'unseen' emotional difficulties can impair a person's recovery and rehabilitation. One third of stroke survivors struggle with depression and anxiety following stroke (Hackett, Anderson, House, & Xia, 2008; Whyte, Mulsant, Vanderbilt, Dodge & Ganguli, 2004), whilst others are able to successfully navigate the consequential losses, changes and uncertainty. How this process of adjustment and adaptation occurs is not well understood. A better understanding of the challenges post-stroke and coping strategies employed is arguably critical to the development of interventions to support adjustment and enable engagement in rehabilitation.

This review evaluates the literature on adjustment following stroke. Empirical research is reviewed and critiqued in terms of methodology, findings, and limitations, with reference to two research questions: (1) What do we understand about adjustment following stroke? (2) What psychosocial interventions have been used to support adjustment post-stroke and what are the outcomes? Theoretical models for adjustment to stroke are drawn upon to illuminate the findings. Gaps within the literature are highlighted, including the lack of interventions for individuals with communication deficits, and interventions that facilitate the negotiation of new post-stroke identities with long-held beliefs and experienced changes. Future directions for research are suggested.

Introduction

Stroke and the consequences of surviving

A stroke is an interruption to the blood supply to the brain, which stops the supply of oxygen and nutrients, resulting in damage to brain tissue. This usually occurs because of a blockage by a blood clot or because a blood vessel bursts (World Health Organisation, 2012). A stroke is an abrupt event and can have catastrophic consequences. Every year approximately 111,000 people in England have a stroke, approximately 10,000 below retirement age (British Heart Foundation, 2009). Stroke is the third largest cause of death in England, and is the single largest cause of adult disability (National Audit Office, 2005).

As medical interventions have advanced, decreased mortality means more people are surviving strokes and living with the consequences. The most commonly documented effects are physical, including paralysis and weakness, spasticity, difficulties with mobility and fatigue. Survivors also report sensory impairments, such as visual field loss, eye movement problems and visual processing deficits. One third will have some sort of communication deficit, and it is estimated that nearly all survivors will have some form of cognitive impairment (Stroke Association, 2012).

Rehabilitation is typically focused on mobility and restoration of physical function, in order to increase independence and promote discharge from hospital. However, in addition to observable physical effects, there can be unseen, emotional difficulties which can impair a person's recovery and rehabilitation. Poor rehabilitation following stroke leads to increased length of hospital admission (Schubert, Burns, Paras & Sioson, 1992), can impede recovery over the longer-term and has a detrimental effect on quality of life. Furthermore, emotional difficulties following

stroke, especially depressive symptoms, have been linked to higher mortality rates (Ellis, Zhao, & Egede, 2010; House, Knapp, Bamford, & Vail, 2001).

Access to psychological support is recommended in the national stroke strategy (DOH, 2007), the national clinical guideline for stroke (Royal College of Physicians, 2008) and the national standards for psychological support after stroke (NHS Improvement, 2011), yet these standards cannot recommend specific evidence-based interventions for mood disturbance, as the research to date is inconclusive (Hackett, Anderson, House, & Xia, 2008).

Rationale for the review

One third of stroke survivors struggle with depression and anxiety following stroke (Hackett et al., 2008; Whyte, Mulsant, Vanderbilt, Dodge & Ganguli, 2004); whilst others are able to successfully navigate the consequential losses, changes and uncertainty. Adjustment, as defined for the purposes of this review, is “the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by the changed circumstances in their lives” (Brennan, 2001, pg. 2). However, how this process of adjustment and adaptation occurs is not well understood. A better understanding of the challenges post-stroke and coping strategies employed is arguably critical to the development of interventions to support adjustment, in order to enable people to fully engage in rehabilitation and lead fuller lives (Ch’ng, French & Mclean, 2008).

Review

Systematic searches were completed using a range of databases (see Appendix A for methodology). Sixteen papers were identified and categorised according to two research questions: (1) What do we understand about adjustment following stroke? (2) What psychosocial interventions have been used to support adjustment post-stroke and what are the outcomes?

What do we understand about adjustment following stroke?

Six studies were identified that used qualitative methods to explore recovery following stroke (see Appendix B for methodological details). Five of the studies used interviews (Burton, 2000; Carlsson, Moller & Blomstrand, 2009; Dowswell et al., 2000; Jones, Mandy & Partridge, 2008; Murray & Harrison, 2004), and one held a series of focus groups (Ch'ng et al., 2008). Participants ranged from six weeks to 12 years post-stroke across the studies, with some studies investigating recovery specifically at one (Burton, 2000; Carlsson et al., 2009; Dowswell et al., 2000) or two years (Murray & Harrison, 2004). Other studies purposely sampled participants at different periods post-stroke (Ch'ng et al., 2008; Jones et al., 2008). Stroke severity ranged from mild to severe, or was not specified.

All of the studies described the impact of stroke on individuals' lives. The author of the current review synthesised the findings from the six studies into three major themes: physical impact, emotional impact and social impact.

Physical impact. Participants across studies struggled with adjustment to the physical consequences of stroke (Burton, 2000; Jones et al., 2008; Murray & Harrison, 2004). The management of physical symptoms, uncertainty about prognosis, preoccupation with communication difficulties and loss of personal care skills were

described as key challenges experienced in the early stages of recovery (Burton, 2000; Ch'ng et al., 2008; Jones et al., 2008). Difficulties managing plateau periods in physical recovery became relevant as recovery progressed (Burton, 2000) and all participants in Carlsson et al.'s (2009) study expressed strong preoccupation with the risk of suffering a second stroke and how they might cope.

Experiences of healthcare affected coping. 'Good' experiences of professionals and rehabilitation boosted beliefs about being able to cope (Carlsson et al., 2009; Jones et al., 2008), yet the period following discharge was described as the most challenging by all participants in Ch'ng et al.'s (2008) study, and many in Burton's (2000) study. Participants reported feelings of abandonment and concerns of being sent home although not 'back to normal', affected perceptions of being able to cope (Carlsson et al., 2009; Ch'ng et al., 2008; Jones et al., 2008). The time post-discharge was identified as when awareness of the impact of physical disabilities was most heightened (Burton, 2000; Ch'ng et al., 2008; Jones et al., 2008), but for others, discharge from hospital was viewed as a marker of ongoing recovery (Jones et al., 2008).

Emotional impact. Participants across studies talked of mixed emotions in relation to recovery, and there was a non-linear presentation of emotions over time (Burton, 2000). Many participants were grateful for having survived, and acknowledged that others were worse off, but the stroke had resulted in many changes and losses (Burton, 2000; Carlsson et al., 2009). For some, the co-occurrence of both positive and negative emotions was a challenge, as was the confusion this caused in other people (Carlsson et al., 2009).

Participants described difficulties expressing emotions or making inappropriate emotional responses (Murray & Harrison, 2004), and expressed concerns about

emotional stability (Carlsson et al., 2009). They described behaviours such as inappropriate crying as “disturbing” and “socially unacceptable” (Murray & Harrison, 2004, p.814), which undermined participation in social activities. These emotional difficulties were identified by Murray and Harrison (2004) as “a key aspect of their experienced disability” (p. 811), which was further compounded by invisibility to other people (Carlsson et al., 2009). The unseen emotional difficulties and lack of understanding from others resulted in participants expressing a preference for a physical ‘visible’ disability, due to a belief that others would show more empathy and understanding (Murray & Harrison, 2004).

None of the participants in the interview studies talked about receiving or being offered professional help for emotional issues. There was a sense of acceptance that effects on mood were another consequence post-stroke. The participants in Ch’ng et al.’s (2008) focus groups identified that “there was insufficient attention paid to their emotional needs during the process of recovery” (p. 1142), and described difficulties accessing psychological support (Ch’ng et al., 2008).

The theme of loss was evident in all studies, and went beyond cognitive and physical losses and the loss of activities and social networks. Loss of control was reflected in increased dependency on others (Burton, 2000; Jones et al., 2008). The loss of physical and mental capabilities led people to describe a “profound loss of self or part of self” (Murray & Harrison, 2004, p.810). Participants across studies also identified their post-stroke selves as ‘new’, which implied that their old self had been lost, for example, experiencing a “strangeness and unfamiliarity” with their current self (Murray & Harrison, 2004, p. 811). The new selves were also compared to the old selves, as a measure of recovery progress (Burton, 2000; Dowswell et al., 2000), and there was often dissatisfaction at the gap between the representation and current

reality, particularly with regard to disability. The process of adjustment appeared to involve a negotiation of new identities, encompassing the new self and experienced changes (Murray & Harrison, 2004).

Across the studies, the different authors identified that acceptance and adjustment appeared dependent on the perceptions of the individual. Dowswell et al. (2000) acknowledged that some people found it difficult to adjust because they did not see themselves as ill, but were unable to do things they used to. For others, their self-image did not include the possibility of illness or disability. Judgements about illness and the kinds of people who get ill, make adjustment very difficult and can lead to denial of difficulties (Dowswell et al., 2000). Hope was identified by Burton (2000) as a feature of emotional recovery, with early physical recovery enforcing the possibility of full recovery in time (Jones et al., 2008).

Social impact.

Social support. Social support was mentioned first in each focus group, when asked about what had been helpful to recovery (Ch'ng et al., 2008). The support of family and friends was identified as valuable and the unique contribution of stroke support groups was recognised. Participants talked about being understood by others, having their experiences normalised, and gaining practical tips for dealing with disability (Carlsson et al., 2009; Ch'ng et al., 2008).

Social isolation. Physical disability was indicated as a factor in isolation, as difficulties with access and transport made participants reliant on others to visit (Dowswell et al., 2000). Physical markers of disability were also identified as barriers to interaction, with concerns that wheelchairs and walking aids drew attention to disability or the misinterpretation of mobility or communication difficulties inhibiting interaction (Murray & Harrison, 2004). Participants described being uncomfortable

with their current disabled state, feeling ashamed or not wanting to burden friends or relatives. Furthermore, friendships deteriorated as previously shared interests and activities were no longer compatible with the new self (Murray & Harrison, 2004).

Impact on relationships. There was a clear deterioration in relationships for the majority of participants across the studies, affecting those already established and the opportunities to create new ones. Family relationships often bore the brunt of frustration and anger at the deterioration of friendships (Burton, 2000; Murray & Harrison, 2004). Participants discussed concerns about forming and maintaining romantic and sexual relationships, due to observable disability. Low opinions of own sexual desirability, perceptions of unattractiveness and body issues were shared. For other participants, the consequences of stroke had resulted in marital breakdown (Ch'ng et al., 2008; Murray & Harrison, 2004).

Role changes. Changes in role were identified by participants across studies. Acceptance of change in roles was deemed necessary for adjustment (Dowswell et al., 2000; Murray & Harrison, 2004), but role re-appraisal did not necessarily reflect acceptance (Burton, 2000). In the early stages of recovery, participants talked of a feeling of "rolelessness" (Dowswell et al., 2000, p.513) or frustration and helplessness at the inability to assume previous roles (Ch'ng et al., 2008; Dowswell et al., 2000). There were reversals in gender roles, with both sexes expressing concern at not being able to look after their partner as they had previously. The swap from caregiver to care receiver was identified as a challenging transition for many participants (Dowswell et al., 2000; Murray & Harrison, 2004).

Summary and critique

The findings from the qualitative studies demonstrate that adjustment post-stroke requires adaptation in physical, emotional and social aspects of life. The experiences described reveal that adjustment is not a linear and continued process, nor is it purely about adjustment to impairments or disability. The process of adjustment also includes dealing with the uncertainty of living with a new 'self', within a changed social context and the adaptation of long-held knowledge and perceptions.

In consideration of Yardley's (2000) criteria for good quality research (Appendix C), the articles promote the understanding of the impact of stroke, and identified practical outcomes, such as the provision of information, support during discharge, and the importance of responding to individual needs.

Of the six studies reviewed, two did not specify the qualitative analysis method employed, although they described the process of grounded theory (Ch'ng et al., 2008; Dowswell et al., 2000), and demonstrated transparency and rigour, hence inclusion in the review. Jones et al. (2008) provided a detailed list of the measures undertaken to ensure integrity of analysis, and all used verbatim quotes to support findings. The use of email correspondence to interview participants (Murray & Harrison, 2004), reflected a sensitivity to context for some stroke survivors, and promoted inclusion.

What psychosocial interventions have been used to support adjustment post-stroke and what are the outcomes?

Individual Interventions. Seven individual intervention studies were identified, designed to support adjustment or alleviate emotional difficulties following stroke (see Appendix D for methodological details).

Motivational Interviewing (MI) as an early stage intervention has been demonstrated to support adjustment to stroke (Watkins et al., 2007, 2011). Following four weekly MI sessions at four weeks post-stroke, there was a significant benefit of MI on mood and MI was shown to be protective against developing depression at three month follow-up. The benefit of MI on mood continued at 12 months, although there was no longer a protective benefit against depression, but there was a protective effect of MI against death, with statistically higher mortality in the control group over the course of the first year post-stroke (Watkins et al., 2011). MI was not found to impact on measures of functional ability.

MI was considered to improve recovery by aiding the recognition of necessary psychological and practical adjustments following stroke, building confidence in ability to adapt and identifying realistic goals. The benefit of these skills was thought to increase engagement in rehabilitation and therefore improve recovery (Watkins et al., 2007, 2011). The finding that four sessions of MI was effective for mood in the early stage of recovery, advocates short term psychological support, or for healthcare professionals to be trained to use MI techniques in their usual interactions with patients, potentially supporting adjustment longer-term.

A four week Rational Emotive Behaviour Therapy (REBT; Chang, Zhang, Xia & Chen, 2011) intervention also demonstrated efficacy for symptoms of anger, depression and functional ability, compared to care as usual control. The intervention consisted of a knowledge component including education on health and lifestyle factors, and stroke recovery and a behavioural training component, which included belief changes, forgiveness training and anger management.

Both intervention and control groups showed improvements on measures of depression and functional ability, but the changes were significantly greater in the

intervention group, based on analysis of change scores. It is not possible to disentangle which aspects of the intervention were most effective, as the educational and behavioural components were presented together. Moreover, the behavioural training component also appeared to use cognitive strategies as part of belief change and forgiveness training.

Early intervention Ecosystem focused therapy (EFT) for post-stroke depression has been demonstrated to be more effective in demonstrating a decline in depressive symptoms, and reducing reports of disability, over a 12 week intervention, than an educational control (Alexopoulos et al., 2012).

The EFT intervention focused on an action-oriented 'new' perspective on recovery, problem-solving skills, and 'reengineering' family involvement.

Alexopoulos et al. (2012) suggest that the benefits of EFT include increased behavioural activation and self-efficacy, but this is not discussed in reference to the outcome measures used in the study. There is no evaluation of which aspects of EFT were most effective.

There is inconclusive evidence to support Cognitive Behavioural Therapy interventions for depression post-stroke. Lincoln, Flannaghan, Sutcliffe & Rother (1997) conducted a CBT intervention with 19 depressed participants, using a single-case experimental design. Individual formulation led to the development of treatment programmes administered over ten sessions. Treatment included behavioural aspects of activity scheduling, behavioural tests, graded task assignments, and encouragement to practice tasks difficult due to stroke, and cognitive techniques of addressing negative thoughts, employing distraction techniques before moving on to identify, challenge and test unhelpful cognitions.

Lincoln et al. (1997) reported a tendency for improvement in mood over the time of the intervention, although as there was no control group, the effects cannot be entirely attributed to the intervention. When the depression scores from the baseline phase were compared to those during the treatment phase, there was individual variation between cases, and some people benefitted from the CBT intervention. At three months, the patients as a group showed an improvement in depression scores from baseline, but no significant difference on measures of functional ability.

The limitations of the single case experimental design were addressed by Lincoln and colleagues in a larger randomised control trial, with 123 participants (Lincoln & Flannaghan, 2003). However, there were no significant differences between no-treatment control, attentional placebo or CBT intervention groups on measures of mood and functional ability at one, three and six months. There were improvements in depression scores over time, but these improvements were independent of the intervention. A similar pattern of results may have been evident in the pilot study (Lincoln et al., 1997), as there was an improvement in scores, but without a control group the improvements cannot be attributed to the intervention.

The authors suggest reasons why the intervention was not effective. The average number of sessions offered was 9.85 sessions, whereas a review of seven studies using CBT with older adults reported an average of 16.5 sessions (Koder, Brodaty & Anstey, 1996). Furthermore, they also suggest that the small sample size could have resulted in insufficient power. There are no details provided about the training for the professionals delivering the intervention. Furthermore, the studies by Lincoln and colleagues (1997, 2003) do not use stroke specific measures and it may be that the chosen measure was insensitive to other aspects of adjustment or coping facilitated by the CBT intervention.

Jones, Mandy and Partridge (2009) conducted a workbook intervention based on principles of chronic disease self-management (CDSM; Holman & Lorig, 2004; Lorig & Holman, 2003). Ten participants were supported to use and complete a workbook at home. The workbook contained four main sections: vignettes describing different problems; stories describing solutions to common post-stroke problems; examples of strategies used; and a diary section for participants to record the setting and evaluation of small weekly targets.

Using a single subject design, the workbook intervention was found to statistically change scores of stroke self-efficacy and locus of control but not generalised self-efficacy, functional activity, or mood. However, nine of ten participants had lowered scores on mood measure, but this was not statistically reliable.

Group Interventions. Three studies identified in the literature search evaluated group interventions.

A seven week CDSM programme (Kendall et al., 2007) run in small groups, covered health and well-being, emphasis of group interaction and support, solution-focused behaviours, and active management of chronic conditions. However, the CDSM programme did not have an effect on self-efficacy or quality of life at three, six, nine, and 12 months follow-up, when compared to controls. There was an indication that the CDSM intervention may have temporarily prevented a decline in some aspects of well-being, but any improvements in the intervention group in the early follow-up analysis were matched by the control group by 12 months. There is no evaluation of the group setting or of the experience of teaching the sessions, which may have provided valuable information into how a self-management programme is best implemented. Group dissemination appeared to be a way of including as many people

as possible, without considering how group dynamics may be of influence. The observed effect of the intervention in preventing a decline in the short term could be useful in rehabilitation settings and could potentially promote adjustment over the difficult transition of discharge from hospital.

Time-limited writing groups were set up by Hartke, King and Denby (2007) to produce an essay for publication about stroke recovery. Six groups of three to six participants were conducted over 4-7 weeks, and co-facilitated by a psychologist and a stroke survivor.

Themes from the essays clustered into personal growth and changes in self-concept, and coping with recovery. These themes were reached by consensus amongst the authors, although no specific qualitative methodology is identified. Themes were potentially defined by asking participants to write about an aspect of their recovery that might be useful for others to read. Participants wrote about 'reinventing themselves', through 'learning from mistakes' and 'accepting responsibility'. Hartke et al. (2007) report that changes post-stroke were "most often [...] viewed positively by participants" (p.30) and that the struggle to recover provided a new sense of self acceptance. With regard to coping with recovery, the content of the essays communicated the journey of a long and uncertain rehabilitation. Difficulties such as loss, uncertainty and isolation were identified, as well as the need for staying hopeful, reaching out to others and taking control of life. An analysis of the group evaluation questionnaire revealed that participants most commented on liking the "bonding, sharing and interaction fostered by the group" (Hartke et al., 2007, p. 31).

Scales of depression, perceptions of disability and psychological well-being administered pre- and post-participation in the group, unsurprisingly did not measure significant change. Specifically, themes from the essays suggested participants were

possibly well-adjusted and able to seek support, evidenced by joining a writing group to publish an essay. The authors acknowledge the self-selected sample, but maybe do not fully appreciate the difference in their sample to other studies, being several years post-stroke, well educated and inclined to write about their experiences.

The participants in Hartke et al.'s (2007) writing groups were several years post-stroke, and the qualitative review suggested that the transition of discharge was particularly challenging for survivors of stroke. Vohora and Ogi (2008) developed and conducted an inpatient group intervention for the mid to early stages of recovery. Group sessions used a 'pan-theoretical approach' and comprised elements of CBT, psychodynamic, systemic and solution-focused therapy. One group met five times over two and a half weeks for one hour. The sessions were facilitated by a clinical psychologist.

The group content used the metaphor of recovery from stroke as a journey, and aimed to normalise the reactions and emotions experienced by stroke survivors, support the 'rebirth of identity', give space to regain control and experience exercising choice, share experiences through discussion and raise awareness of the effects of mood on rehabilitation engagement.

The six participants, who were identified as having difficulties with adjustment, were asked to anonymously complete feedback forms at the end of each group. No standardised outcome measures were administered. Discussion and sharing were identified as the most helpful aspects of the group, including discussing problems and generating solutions, and finding comfort in others expressing similar concerns. The ward staff felt that the group addressed common issues and concerns, and was seen as a much needed intervention. The potential benefit for interventions in a rehabilitation setting before discharge is demonstrated and could be protective against the

difficulties in adjustment longer-term, yet the participants were not followed-up after discharge to confirm this.

Summary and critique

The review of the effectiveness of interventions for supporting adjustment to stroke reveals the variety of models that can inform interventions. Each intervention demonstrated support for efficacy on an aspect of adjustment, but as the qualitative review revealed, adjustment is a complex construct, and different interventions may be needed to address different aspects.

The interventions demonstrated effectiveness with regard to mood (Alexopoulos et al., 2012; Chang et al., 2011; Watkins et al., 2007, 2011), perceptions of disability (Alexopoulos et al., 2012; Hartke et al., 2007) and self-efficacy (Jones et al., 2009), although some interventions did not demonstrate a benefit on the primary outcome (Kendall et al., 2007). The interventions targeted some of the aspects of adjustment revealed in the qualitative review. MI proposed to address issues of control, provide information and acknowledge uncertainties (Watkins et al., (2007, 2011). CBT intended to address problems with mood by challenging perceptions and assumptions, as well as the behavioural aspects of CBT, REBT and EFT to promote engagement with activity (Alexopoulos et al., 2012; Chang et al., 2011; Lincoln et al., 1997; Lincoln & Flannaghan, 2003). EFT considered a wider perspective of the individual's 'ecosystem' and social context and CDSM intended to increase self-efficacy and feelings of control (Jones et al., 2009). The group interventions provided social support, identified as lacking or difficult to access, as well as opportunities to be understood by others who had a shared experience (Hartke et al., 2007; Vohora & Ogi, 2008). One aspect of adjustment pertinent in the qualitative studies, which was not

addressed directly by the interventions reviewed, was the experience of a new 'self' and the incorporation of the experienced changes into a new identity.

The review raises questions about the timing of interventions and the potential selection bias within the sample. The participants were self-selecting and potentially identified themselves as in need of therapy. There may be other individuals who declined participation, as they perceived emotional difficulties to be an inevitable consequence of stroke (Lincoln et al., 1997). There was a vast range of time since stroke represented across the intervention studies, from 28 days to 12 years. This makes comparisons between interventions difficult and further research is required to ascertain when intervention may be the most effective, although the review suggests early intervention may be of most benefit (Alexopoulos et al., 2012; Watkins et al., 2007, 2011). The review also highlights that improvements were observed in the control groups of three of the studies (Chang et al., 2011; Kendall et al., 2007; Lincoln & Flannaghan, 2002). This demonstrates the need for adequate control conditions in order to interpret findings, raises questions about the trajectory of adjustment and highlights the need for follow-up.

There were common limitations across studies. All individual intervention studies excluded survivors with communication deficits, which is understandable for talking therapies, but those with aphasia and more severe strokes need to be considered, as they may have greater difficulties with adjustment (Bronken, Kirkevold, Martinsen, & Kvigne, 2012). The Hartke et al. (2007) writing group did include participants with communication deficits, with adaptations made to make participation possible. Behavioural interventions may also be adaptive to stroke survivors with communication difficulties, but were not explored in the reviewed studies.

The Cochrane review of interventions for post-stroke depression suggests a manualised framework, with training and supervision (Hackett et al., 2008), but the studies varied in training providers of the interventions, and also in reports of the training. There were also discrepancies in the quality control of adherence to the model reported. There were variations in the outcome measures used, which makes direct comparison of interventions unreliable. In addition, some of the studies did not use stroke-specific measures, and so effects of interventions on adjustment may have been missed.

Theoretical Context for understanding adjustment post-stroke

Coping theory. The transactional stress and coping theory (Lazarus & Folkman, 1984) proposes that coping is the process of managing a series of transactions between the individual and their environment. Psychological distress occurs when internal or external demands are evaluated by the individual as beyond their resources, particularly if the demands are perceived as a threat of harm or loss, and beyond the individual's control. The multifaceted consequences described in the literature, for example social isolation, change of role and depression will arguably impact on an individual's perception about being able to cope. The evaluation or appraisal of these factors determines psychological adaptation and leads to the selection of coping strategies. Thus, intervention can play a role in promoting recovery by facilitating perceived coping and adjustment. The findings suggest that early MI intervention to help recognise the necessary adaptations following stroke can build confidence in ability to adapt (Watkins et al., 2007, 2011).

Although not a stage-model, coping, as presented by Lazarus and Folkman (1984), could be understood as representing a discrete response to a specific threat.

The literature reviewed above suggests the need for an approach that reflects the process of adaptation over time. Adjustment to stroke does not indicate a series of changes that one needs to cope with, but a process of learning, development and accommodation of change (Brennan, 2001).

Social-Cognitive Theories. Whereas coping theory models how individuals respond to a traumatic life event, social-cognitive theories look at wider personal and social changes required in the context of the traumatic event. In addition to coping with the event, the individual also draws conclusions or makes assumptions from the trauma, some of which can be the source of further psychological distress. However, more recent research suggests that some of the conclusions drawn from traumatic events can act as a “catalyst for positive psychological and interpersonal change” (Grubaugh & Resick, 2007, p. 146), with growth beyond premorbid levels. This reaction was reflected in the essays in Hartke et al.’s (2007) study, and is known as posttraumatic growth (Tedeschi & Calhoun, 2004).

Schemas are modified with every new experience: whether appraised as positive or negative, the information is either ‘assimilated’ into existing assumptions or ‘accommodated’ by modifying the existing assumptions to incorporate new information (Piaget, 1952). Illness is seen as a threat, and adjustment to illness is seen as a resolution between the threat and existing assumptions (Cohen & Lazarus, 1979). Intervention could aid the integration between the pre-stroke assumptions and post-stroke reality (Burton, 2000; Dowswell et al., 2000).

Social–Cognitive Transition (SCT) model of adjustment. The SCT model (Brennan, 2001) synthesises complementary aspects of coping theory and social-cognitive theory, with an additional consideration of social context on experience. Behavioural coping strategies are recognised as facilitating the rebuilding of core

assumptions, and individuals develop an internal representation of the world through their social and cultural contexts and life experiences. This enables the making of predictions based on assumptions, which are either confirmed or disconfirmed by subsequent experience. Whilst assumptions tend to be strengthened by confirmation, disconfirmation of an assumption due to experience can lead to a period of disorientation, whilst the assumption is accommodated.

This model can support an understanding for both positive and negative ‘adjustments’ as part of a process of adjustment to illness, and the cyclical nature of the recovery process. Initially designed to account for adjustment to cancer, Brennan’s (2001) SCT model has been recently modified to relate specifically to adjustment following stroke (Taylor, Todman & Broomfield, 2011).

The Social-Cognitive Transition Model for Stroke (SCoTS). SCoTS (Taylor et al., 2011) is very similar to the SCT model but has variations that relate specifically to adjustment post-stroke. Disparity between pre- and post-stroke levels of disability, cognitive deficits, and intra- and inter-personal responses, are understood to interact with the wider social environment, and influence coping strategies and potential adjustment (Taylor et al., 2011).

SCoTS suggests a dynamic process of adaptation and adjustment which can lead to a variety of outcomes for survivors of stroke. These issues are observable in the qualitative findings with individual perceptions of ability or disability impacting on adjustment (Burton, 2000; Dowswell et al., 2000), dissatisfaction at the gap between the representation of self and the current reality and the setting of goals within the context of pre-stroke lives (Burton, 2000).

Social constructionist model of identity. Identity, within the social constructionist epistemology, is not seen as an “objective truth” which is fixed and

predetermined, but is a dynamic process which is constructed and reconstructed throughout life (Vignoles, 2011). The concept of identity is considered to be constructed through the language used in interactions with others, during which individuals define and redefine themselves, through shared meaning and understanding (Jenkins, 1996). The resulting construction of identity also occurs within the wider social, cultural, political, economic and historical contexts, that surround the individual (Grimm, 2003; Vignoles, 2011). Our understanding of ourselves and of the world is shaped by the meanings we attribute to our experiences, and those meanings will be influenced by our interactions and by these boarder discourses (White & Epston, 1990).

The social cognitive model would align with this understanding of identity, constructed through the interplay of cognitive, emotional and social aspects, with the concept of the self realigned and modified on the basis of experiences. The wider context, or discourse, would be understood within the social-cognitive model to make certain aspects of identity more salient to the individual, and therefore influence the meaning that is ascribed through interactions (Oyserman & James, 2011). Stroke is determined by biological phenomena, but the meaning of the stroke for an individual will be personally, socially and culturally determined, impacting on the construction of post-stroke identity. For example, the social discourses could possibly include the lowering of the social worth of older people or those with disability within a capitalist society (Hareven, 1995), leading to the loss of roles, and an experienced of loss of worth. If the stroke survivor had a belief such as “without my work, I am useless”, the influence of this wider social discourse would be more salient and would shape the content of post-stroke identity.

Future directions

Further research into adjustment following stroke is required to better understand which interventions are most effective and when. The qualitative review has demonstrated the complex nature of adjustment, and the SCoTS model describes the cyclical process of adapting to new challenges. Interventions need to be developed to complement both.

A range of models has been applied to emotional difficulties post-stroke, and there is need for replication of models in order to build an evidence-base for the efficacy of interventions. More research is needed, and future studies should consider the selection of outcome measures, to enable meaningful cross-study comparisons. Mixed methodologies may provide insight into which elements of an intervention are of most value.

A recurring theme from the qualitative findings discussed above, was loss and specifically a “profound loss of self” (Murray & Harrison, 2004, p.180) due to physical, emotional and social change. The process of adjustment appeared to involve a negotiation of new identities encompassing the new self and the experienced changes. Whilst the interventions reviewed appeared to target some of the aspects of adjustment revealed in the qualitative review, the experience of a new self and the development of a new identity was not targeted. Narrative therapy could be an intervention that would allow the integration of pre-stroke beliefs and post-stroke reality, and consider the impact of the wider social context of stroke, illness and disability on the construction of post-stroke identity. The findings from the Hartke et al. (2007) study and the SCT and SCoTS models suggest that growth can occur following the trauma of stroke, and an intervention to support the reconstruction of a

preferred identity, or develop an alternative narrative could be of benefit to stroke survivors.

Potential areas for future research which could develop our understanding in this area include:

- The efficacy of behavioural and psychosocial interventions for survivors with communication deficits, considering these individuals are often excluded from intervention studies and may be at higher risk of adjustment difficulties.
- Prospective studies of the trajectory of adjustment following stroke to inform the most effective time for intervention.
- Interventions for incorporating the new 'self' post-stroke as a coherent identity, possibly using mindfulness, acceptance and commitment therapy or narrative therapy techniques.

References

- Alexopoulos, G. S., Wilkins, V. M., Marino, P., Kanellopoulos, D., Reding, M., Sirey, J. A., Raue, P. J., Ghosh, S., O'Dell, M. W. & Kiessess, D. N. (2012). Ecosystem focused therapy in poststroke depression: a preliminary study. *International Journal of Geriatric Psychiatry*, 27, 1053–1060.
- Brennan, J. (2001). Adjustment to cancer – Coping or personal transition? *Psycho-oncology*, 10, 1–18.
- British Heart Foundation (2009). Stroke Statistics. Retrieved from <http://www.bhf.org.uk/idoc.ashx?docid=d2bf06aa-004f-44b1-bafb-412f99f4b695&version=-1> on 12/12/12.
- Bronken, B. A., Kirkevold, M., Martinsen, R., & Kvigne, K. (2012). The aphasic storyteller: Co-constructing stories to promote psychosocial well-being after stroke. *Qualitative Health Research*, 22(10), 1303–1316.
- Burton, C. R. (2000). Living with stroke: A phenomenological study. *Journal of Advanced Nursing*, 32(2), 301-309.
- Carlsson, G.E., Moller, A., & Blomstrand, C. (2009) Managing an everyday life of uncertainty – A qualitative study of coping in persons with mild stroke. *Disability and Rehabilitation*, 31(10), 773–782
- Ch'ng, A. M., French, D., & Mclean, N. (2008). Coping with the challenges of recovery from stroke: Long term perspectives of stroke support group members. *Journal of Health Psychology*, 13, 1136-1146.
- Chang, K., Zhang, H., Xia, M. A. & Chen, C. (2011). Testing the effectiveness of knowledge and behaviour therapy in patients of hemiplegic stroke. *Topics in Stroke Rehabilitation*, 18(5), 525-535.

- Cohen, F. & Lazarus, R.S. (1979). Coping with stress of illness. In G.C. Stone, F. Cohen, & N.E. Adler (Eds.), *Health Psychology*. Jossey Bass: San Francisco.
- Department of Health (2007). The National Stroke Strategy. London
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing*, 9, 507–515.
- Ellis, C., Zhao, Y. & Egede, L. E. (2010). Depression and increased risk of death in adults with stroke. *Journal of Psychosomatic Research*, 68(6), 545-551.
- Grimm, R. (2003). Narrative Therapy with Older Adults. In J.L. Ronch & J.A. Goldfield's (Eds.), *Mental Wellness in Aging: Strength-Based Approaches* (pp. 237 - 271). Baltimore, MA: Health Professions Press.
- Grubaugh, A.L. & Resick, P.A. (2007). Posttraumatic growth in treatment seeking female assault victims. *Psychiatry Quarterly*, 78, 145-155.
- Hackett, M. L., Anderson, C. S., House, A., & Xia, J. (2008). Interventions for treating depression after stroke. *Cochrane Database Systematic Review*, 2, 1–89.
- Hareven, T.K. (1995). Changing images of aging and social construction of the life course. In M. Featherson & A. Wernick (Eds.), *Images of aging: Cultural representations of later life* (pp. 119-134). New York: Routledge.
- Hartke, R. J., King, R. B., & Denby, F. (2007). The use of writing groups to facilitate adaption after stroke. *Topics in Stroke Rehabilitation*, 14(1), 26-37.
- Holman, H. & Lorig, K. (2004). Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports*, 119, 239–43.

House, A., Knapp, P., Bamford, J., & Vail, A. (2001). Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at 1 month. *Stroke*, 32, 696–701.

Intercollegiate Stroke Working Party. (2008). *National Clinical Guideline for Stroke*, 3rd edition. London: Royal College of Physicians.

Jenkins, R. (1996). *Social Identity*. London: Routledge.

Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation*, 30(7), 507 – 516

Jones, F., Mandy, A., & Partridge, C. (2009). Changing self-efficacy in individuals following a first time stroke: Preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522–533

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., Jill Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science & Medicine*, 64, 735–746.

Koder, D. A., Brodaty, H., & Anstey, K. J. (1996). Cognitive therapy for depression in the elderly. *International Journal of Geriatric Psychiatry*, 11, 97–107.

Lazarus, R. S., & Folkman, S. (1984). *Psychological Stress and the Coping Process*. New York, NY: Springer.

Lincoln, N. B., & Flannaghan, T. (2003). Cognitive behavioural psychotherapy for depression following stroke: A randomised control trial. *Stroke*, 34, 111-115.

Lincoln, N. B., Flannaghan, T., Sutcliffe, L., & Rother, L. (2007). Evaluation of cognitive behavioural treatment for depression after stroke: A pilot study. *Clinical Rehabilitation*, 11, 114–122.

- Lorig, K. & Holman, H. (2003). Self-management education: History, definition, outcomes and mechanisms. *Annals of Behavioural Medicine*, 26, 1–7.
- Murray, C.D. & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretive phenomenological analysis. *Disability and Rehabilitation*, 26(13), 808-816
- National Audit Office (2005). Reducing Brain Damage: Faster access to better stroke care. London
- NHS Improvement (2011). National standards for psychological support after stroke. London.
- Oyserman, D. & James, L. (2011). Possible identities. In S.J. Schwartz, K. Luyckx, & V.L. Vignoles' (Eds.), *Handbook of Identity Theory and Research* (pp. 117-149). New York: Springer.
- Piaget, J. (1952). *The origins of intelligence in children*. New York: International Universities Press, Inc.
- Royal College of Physicians (2008). National clinical guideline for stroke. London.
- Schubert, D.S., Burns, R., Paras, W. & Sioson, E. (1992). Increase of medical hospital length of stay by depression in stroke and amputation patients: A pilot study. *Psychotherapy and Psychosomatics*, 57, 61-66.
- Stroke Association (2012). Retrieved from <http://www.stroke.org.uk> on 09/12/12.
- Taylor, G. H., Todman, J., & Broomfield, N. M. (2011). Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological Rehabilitation* 21(6), 808-824.
- Tedeschi, R.G., & Calhoun, L.G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, 15(1), 1-18.

- Vignoles, V.L. (2011). Identity motives. In S.J. Schwartz, K. Luyckx, & V.L. Vignoles' (Eds.), *Handbook of Identity Theory and Research* (pp. 403-433). New York: Springer.
- Vohora, R. & Ogi, L (2008). Addressing the emotional needs of stroke survivors. *Nursing Times*, 104(42), 32-36.
- Watkins, L. C., Auton, F. M., Deans, F. C., Dickinson, A. H., Jack, A. I. C., Lightbody, E. C., Sutton, J. C., van den Broek, D. M., & Leathley, J. M. (2007). Motivational Interviewing early after acute stroke: A randomized controlled trial. *Stroke*, 38, 1004-1009.
- Watkins, L. C., Wathan, V.J., Leathley, J.M., Auton, F.M., Deans, F.C., Dickinson, A.H., Jack, A.I.C., Sutton, J.C., Van de Broek, D.M., & Lightbody, E.C. (2011). The 12 month effects of early Motivational Interviewing after acute stroke: A randomized controlled trial. *Stroke*, 42, 1956-1961.
- White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. New York: Norton.
- Whyte, E.M., Mulsant, B.H., Vanderbilt, J., Dodge, H.H., & Ganguli, M. (2004). Depression after stroke: A prospective epidemiological study. *Journal of the American Geriatrics Society*, 52(5), 774-778.
- World Health Organisation (2012). Retrieved from http://www.who.int/topics/cerebrovascular_accident/en/ on 09/12/12
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

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SECTION B: EMPIRICAL PAPER

An investigation of how narrative group therapy may facilitate psychosocial
adjustment following stroke

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SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Purpose: The purpose of the study was to evaluate whether narrative group therapy could facilitate psychosocial adjustment in survivors of stroke, and to explore the impact of stroke on survivors' lives through their shared narratives.

Methods: Ten participants took part in a six-week narrative group therapy intervention for stroke survivors. Quality of life, use of coping strategies and illness representations were measured pre- and post-intervention, and thematic analysis was conducted on the content of the intervention sessions.

Results: There was no statistically significant change on the outcome measures post-intervention. However the inductive thematic analysis resulted in the identification of four master themes: Using the group, negative talk, positive talk and relationships. These themes, respectively, revealed that the social aspects of the group allowed comparing experiences and exchanging information; participants were able to discuss the perceived negative aspects of surviving a stroke; with support, participants could identify the adaptations and achievements made since the stroke; and how the stroke impacted on relationships between the survivor and the systems around them.

Conclusion: The findings indicate that narrative therapy requires further evaluation in terms of facilitation of adjustment. However, the thematic analysis supports the utility of group discussions and the provision of information to stroke survivors and their carers, thus indicating potential development of psychoeducation group programmes, provisionally as part of a stepped care model.

Introduction

A stroke is an abrupt and sudden event that can have catastrophic consequences across physical, emotional, cognitive and social domains. Rehabilitation is typically focused on mobility and restoration of physical function, and the emotional experience can become overshadowed (Mukherjee, Levin, & Heller, 2006). One third of stroke survivors struggle with depression and anxiety following stroke (Hackett, Anderson, House, & Xia, 2008; Whyte, Mulsant, Vanderbilt, Dodge & Ganguli, 2004), and depressive symptoms have been linked to higher mortality rates (Ellis, Zhao, & Egede, 2010; House, Knapp, Bamford, & Vail, 2001; Watkins et al., 2011), and poor rehabilitation outcomes (Ramasubbu, Robinson, Flint, Kosier, & Price, 1998). These difficulties have been recognised in the National Stroke Strategy (DOH, 2007) and the National standards for psychological support after stroke (NHS Improvement, 2011), which recommend access to psychological support throughout the patient journey.

Adjustment to stroke. The process of coming to terms with the changes post-stroke often occurs within a context of uncertainty with regards to disease course, treatment and rehabilitation potential (Lyon, 2002). The definition of adjustment for the purposes of this article is “...the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by the changed circumstances in their lives” (Brennan, 2001, pg. 2).

Research has shown that degree of psychosocial adjustment to stroke is not explained by levels of physical impairment (Sinyor et al., 1986), and is more likely to be influenced by the person’s perception of their post-stroke situation (Lyon, 2002).

Individual illness representations may explain the variations in distress (Twiddy, House, & Jones, 2012), which may be compounded by perceptions of the wider social

network. Glass, Matchar, Belyea, and Feussner (1993) demonstrated that individuals with milder strokes may be more at risk of social isolation and poor adjustment, due to family and friends underestimating their need for support.

Positive adjustment to the consequences of stroke may also depend on the effective use of coping strategies (Lyon, 2002). However, stroke patients have been found to use fewer active problem-solving coping strategies than patients with different brain injuries, such as Parkinson's disease or brain tumours (Herrmann et al., 2000). Strategies such as avoidance could lead to a lower level of participation in rehabilitation (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Sinyor et al., 1986) and withdrawal from social interaction (Andersen, Vestergaard, Ingemann-Nielsen, & Lauritzen, 1995; Feibel & Springer, 1982; Wade, Legh-Smith, & Hewer, 1987). Furthermore, beliefs about perceived adequacy, the ability to change the situation (Vitaliano, De Wolfe, Maiaro, Russo, & Katon, 1990) and locus of control can reduce participation in rehabilitation, thus impeding recovery in the long-term and affecting quality of life.

Empirical research of adjustment in stroke. Research evaluating post-stroke adjustment comprises a small number of predominantly qualitative studies. Key themes emerging from the findings include adjustment to the physical, emotional and social consequences of stroke. Difficulties included management of physical symptoms, uncertainty about prognosis, preoccupation with communication difficulties and loss of personal care skills (Burton, 2000; Ch'ng, French, & Mclean, 2008; Jones, Mandy, & Partridge, 2008; Murray & Harrison, 2004).

Acceptance and adjustment appear dependent on the perceptions and assumptions of the individual (Burton, 2000; Carlsson, Moller, & Blomstrand, 2009; Ch'ng et al., 2008; Dowswell et al., 2000; Jones et al., 2008; Murray & Harrison, 2004),

rather than linked to severity of stroke or level of disability. A sense of loss was predominant (Burton, 2000; Carlsson et al., 2009; Ch'ng et al., 2008; Dowswell et al., 2000; Jones et al., 2008; Murray & Harrison, 2004), most notably a “profound loss of self or part of self” (Murray & Harrison, 2004, p. 810) experienced from the loss of physical and mental capabilities. Post-stroke identity was seen as new and unfamiliar, and was compared to the self pre-stroke as a measure of recovery (Burton, 2000; Dowswell et al., 2000), often with dissatisfaction at the gap between the representation and current reality. The process of adjustment appeared to involve a negotiation of new identities encompassing the new self and experienced changes (Murray & Harrison, 2004).

Social support, social isolation, the impact of stroke on relationships and role changes were also identified as key themes in recovery from stroke (Carlsson et al., 2009; Ch'ng et al., 2008; Dowswell et al., 2000; Murray & Harrison, 2004).

The experiences described in these studies suggest that post-stroke adjustment is not a regular and continued process, but one of set backs and disruption. The findings also indicate that process of adjustment is not purely about adjustment to impairments or disability, but also includes managing the uncertainty of living with a new ‘self’, within a changed social context and the adaptation of long-held knowledge and perceptions.

Psychosocial interventions for adjustment in stroke. Research investigating the effectiveness of psychosocial interventions post-stroke is comprised of individual and group interventions, based on a range of psychological models.

Short-term, early intervention motivational interviewing (Watkins et al., 2007, 2011) and Rational Emotive Behaviour Therapy (REBT; Chang, Zhang, Xia & Chen, 2011) have been demonstrated to be effective for reducing depressive symptoms post-

stroke, compared to controls. Ecosystem Focused Therapy (EFT; Alexopoulos et al., 2012) has also been reported to support a decline in depressive symptoms, over a 12 week intervention, as well as reducing perceptions of disability, in comparison to an educational control group. Ratings of stroke related self-efficacy and feelings about locus of control have been enhanced using a workbook intervention based on principles of the chronic disease self-management programme (CDSM; Holman & Lorig, 2004; Lorig & Holman, 2003). The evidence for Cognitive Behavioural Therapy (CBT) interventions is inconclusive (Lincoln, Flannaghan, Sutcliffe & Rother, 1997; Lincoln & Flannaghan, 2003). All individual interventions demonstrated support for effectiveness on an aspect of adjustment, such as mood and perceptions of disability, but as the qualitative studies revealed, adjustment is a complex construct.

Group interventions have been demonstrated to provide the social support that the qualitative studies identified as lacking or difficult to access, as well as providing opportunities to be understood by others with a shared experience (Hartke et al., 2007; Vohora & Ogi, 2008). One aspect of adjustment pertinent in the qualitative studies, which was not addressed directly by the interventions reviewed, was the experience of a new 'self' and the incorporation of the experienced changes into a new identity.

Theoretical mechanisms of adjustment following stroke

The Social-Cognitive Transition Model for Stroke (SCoTS; Taylor, Todman & Broomfield., 2011) is based on Brennan's (2001) Social-Cognitive Transition (SCT) model of adjustment which was developed for understanding adjustment to cancer. SCT integrates complementary aspects of coping theory and social-cognitive theory, with additional consideration of the influence of social context. Behavioural coping

strategies facilitate the rebuilding of core assumptions, and the importance of these assumptions in our ability to adapt is highlighted in the context of social interaction. SCT proposes that individuals develop an internal representation of the world through social and cultural contexts and life experiences. Predictions are developed based on assumptions, which are either confirmed or disconfirmed by subsequent experience. Whilst assumptions tend to be strengthened by confirmation, disconfirmation can lead to disorientation whilst the assumption is accommodated. This theory supports an understanding of both positive and negative adjustment to stroke, and the dynamic nature of the recovery process, potentially leading to a variety of outcomes.

The adjustment of core assumptions involves “huge amounts of cognitive processing and emotional distress” (Brennan, 2001, p.9), and for stroke survivors, this occurs in addition to a brain injury. The extant research demonstrates that this can cause feelings of confusion, loss, sadness and anger (Dowswell et al., 2000), as individuals struggle to modify their assumptive worlds (Taylor et al., 2011). SCoTS identifies further constraints specific to stroke, including disparity between pre- and post-stroke levels of disability, cognitive deficits, and intra- and inter-personal responses, which interact with the wider social environment, and influence coping strategies and potential adjustment (Taylor et al., 2011).

Narrative therapy and how it may facilitate adjustment. SCoTS suggests four areas for psychological intervention: Life trajectory; attachment relationships; self-beliefs; and stroke-specific beliefs (Brennan, 2001; Taylor et al., 2011). These areas are discussed within a CBT framework (Taylor et al., 2011), although the central tenets of narrative therapy could also provide a framework to facilitate adjustment by exploring these areas.

Narrative therapy (White & Epston, 1990) views problems not as intrinsic to the individual or their relationships, but recognises the multiple ways an experience can be interpreted (Carr, 1998). The process of “storying” experiences allows new identities to be formed and developed (Carr, 1998; White & Epston, 1990). Gaps and omissions in an individual’s narrative can be explored creating an opportunity to develop alternative stories and “re-author” the narrative to affirm an identity preferred by the individual (White, 2007; White and Epston, 1990). The process of talking about alternative stories allows revision of negative assumptions and can provide a platform for seeking solutions (Hill, 2011).

Thus, the use of narratives provides an opportunity to make sense of the disruption that occurs following the onset of illness (Murray, 2000), and especially in stroke, where the disruption is sudden and unexpected. The sudden loss of abilities and roles that are intrinsic to a person’s sense of self is a common experience often leading to a loss of identity (Mukherjee et al., 2006), as the aforementioned research suggests. There is also evidence from a small number of studies that one-to-one support to frame life stories and illness narratives is beneficial post-stroke (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Ellis-Hill, Payne & Ward, 2000, 2008; Faircloth, Rittman, Boylstein, Young, & Puymbroeck, 2004). Qualitative analysis revealed a lack of cohesion between the physical self and identity (Ellis-Hill, Payne & Ward, 2000), threats to identity through the loss of activities (Bronken et al., 2012) and the need to develop a new sense of self to incorporate a new identity (Ellis-Hill, Payne & Ward, 2008), echoing the findings from the qualitative research discussed above.

Group Narrative Therapy. As the construction of problem-saturated identities occurs within the wider social context (Grimm, 2003), it would make sense that alternative stories are tested within a social environment. Narrative therapy and group

work appear to be well suited (Hill, 2011), as the group provides a framework for sharing problems, exploring alternatives and developing new meanings, whilst serving as a witness to change (Dean, 1998; Laube, 1998). Group members validate and normalise experiences and encourage the development of alternative narratives (White & Epston, 1990), which concurrently builds the sense of expertise amongst group members (Dean, 1998). Additionally, for stroke survivors, a group experience could challenge the expectations of wider society, and the meaning of recovery.

These factors have been supported by studies using narrative group therapy for substance misuse (Hill, 2011), psychosis (Vasallo, 1998) and with older adults (Gardner & Poole, 2009; Poole, Gardner, Flower & Cooper, 2009). Qualitative findings demonstrate that the use of the group as a team to reflect was one of the most useful aspects of the therapy (Poole et al., 2009), as well as the use of externalisation as an accessible way to draw out shared experiences (Gardner & Poole, 2009; Hill, 2011).

The present study

The National Stroke Strategy (DOH, 2007) and the National standards for psychological support after stroke (NHS Improvement, 2011) have highlighted the importance of psychological rehabilitation for survivors of stroke. The impact of poor emotional adjustment results in poor cognitive, functional, and morbidity outcomes, as well as financial implications for healthcare services. A review of the current evidence base identified issues of identity and 'self' as key themes, suggesting the need for a more comprehensive understanding of how psychosocial interventions can promote adjustment following stroke. Given the process of adjustment appeared to involve a negotiation of new identities, narrative therapy may provide a framework to explore the representations of 'self', illness and disability associated with stroke in order to

promote psychosocial adjustment. Therefore, in the absence of empirical evidence, this study aimed to evaluate the utility of a narrative group therapy intervention for stroke using a mixed method design. The study aimed to add to extant research by exploring the overarching question:

- What can the narratives of the post-stroke survivors in the sample tell us about the subjective impact of stroke on their lives?

And to consider more specifically:

- Are the concepts of self and identity observable within the group discussions?
- Are alternative narratives identifiable within the group discussions?
- Will there be any changes on the quality of life, coping strategies and illness perception outcome measures post-intervention?

Method

Participants

Participants were recruited from two stroke rehabilitation wards and a community stroke team, within the same National Health Service (NHS) Trust. Participants were eligible to take part if they were over 18 years, had a clinical diagnosis of stroke, had been discharged from acute care, and were capable of providing informed consent. Communication or cognitive impairments that might impede their participation in the group, were assessed by referring clinicians.

Ten participants agreed to participate in the study. The participants ranged in age from 45 to 77 years (mean age 66), eight of the ten participants were men and time since stroke varied from three months to almost three years (mean = 21.4 months). The

sample was 100% white British. Types of stroke included two transient ischemic attacks (TIA), two left hemisphere strokes, and six right hemisphere strokes, two were unknown. Five of the participants had retired prior to the stroke, four were currently unable to return to work, and one participant was working part-time from home. All but one of the participants were married and lived at home with their spouse.

Ethical considerations

Ethical approval was obtained from an NHS local Research Ethics Committee and the relevant Research and Development department (Appendix E). Ethical approval was obtained for a substantial amendment to remove the control group from the design, due to difficulties with recruitment (Appendix E). The British Psychological Society Code of Ethics and Conduct (BPS, 2009) was adhered to throughout the study and written, informed consent was provided by all participants.

Design

The study was initially designed as a pilot randomised control trial with an intervention group and a delayed-intervention (control) group with pre, post and follow-up qualitative measures. The power calculation was based upon medium to large effect sizes reported in the literature for the measures used in the study with a similar population. Using a more conservative medium effect size, with an alpha error probability of 0.05 and a power of 0.8, the total sample size calculated by GPower was 10, for 2 groups and 3 measurements. The researcher aimed to recruit 10 participants to the intervention group and 10 participants to the control group.

Due to difficulties with recruitment, the study was reduced to one intervention group with pre- and post-intervention measures, and the addition of qualitative analysis

of the content of the group sessions and a post-intervention focus group. The qualitative analysis aimed to provide information on how the impact of stroke would be 'storied' within a group context, as well as identify any aspects of the intervention deemed most significant for the participants, and to explore the mechanisms of any change demonstrated on the quantitative measures.

Intervention. The intervention was a six-week narrative therapy group facilitated by a qualified clinical psychologist with systemic therapy experience. The syllabus for the intervention (Appendix F) was adapted by the researcher from a group intervention for MS (van den Heuvel, n.d.), based on a workbook for MS using narrative therapy techniques (Johnson, 2009). The syllabus was further adapted using recommendations from the narrative therapy literature. The core tenets of objectifying and personifying the problem, externalisation, mapping the influence of the problem, mapping the influence of the person, tracing the history of the problem, identifying unique outcomes, widening the audience, witnessing change and celebrating achievements (Carr, 1998) were included in the syllabus and accompanying workbook (Appendix G). The syllabus was checked by the group facilitator for adherence to the principles of narrative therapy.

Outcome Measures.

The Stroke Specific Quality of Life Scale (SS-QOL; Williams, Weinberger, Harris, Clark & Biller, 1999). The SS-QOL (Appendix H) was designed to measure health related quality of life following stroke. It consists of 49 items divided into 12 domains including: Family roles, language, mobility, mood, personality, social roles, and thinking. Williams et al. (1999) report high internal reliability (≥ 0.73) for each domain and satisfactory

construct validity, except for the language and thinking domains (see Williams et al., 1999 for further discussion), and conclude the measure to be moderately responsive to change.

The Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988). The WCQ (Appendix I) assessed coping styles in response to a specific stressful situation. The WCQ consists of 66 items, measured on a four-point likert scale (not used, used somewhat, used quite a bit, used a great deal), that form eight sub-scales of coping style. Example coping styles include confrontive coping, distancing, avoidance and planful problem-solving. The WCQ is the most widely used measure of styles of coping, and reports satisfactory internal reliability (.61-.79) and construct validity (Folkman & Lazarus, 1988).

The Brief Illness Perception Questionnaire (B-IPQ; Broadbent, Petrie, Main & Weinman, 2006). Illness perceptions were measured using a modified version of the B-IPQ (Appendix J). The B-IPQ assesses cognitive and emotional representations of illness using eight single-item dimensions on a 10-point likert scale. Dimensions include consequences, personal control, treatment control, identity, concern, and emotional response. Satisfactory reliability and validity have been established across the dimensions (see Broadbent et al., 2006 for more detail).

Procedure

Potential participants were identified by nursing staff on two stroke rehabilitation wards and in a community stroke team, and provided with a participant information sheet (Appendix K). The contact details of interested individuals were then given to the researcher, with permission, and an initial meeting was arranged over the telephone. In addition to participants recruited via the stroke services, further participants were recruited via word of mouth through a stroke support group.

Initial meetings took place in participant's homes one week before the intervention and involved answering questions about the study, providing details about the group, obtaining written consent to participate (Appendix L), and completion of the pre-intervention measures. Some participants preferred assistance to answer the questions on the self-report measures. GPs were informed of participation in the study.

A clinical psychologist delivered the six 2-hour weekly intervention sessions. Sessions were audio-recorded for qualitative analysis and as a check for adherence to the intervention syllabus.

The focus group was conducted after the final intervention session by the researcher, with the facilitator present, and participants completed the post-intervention measures.

Data analysis

Quantitative Analysis. Descriptive statistics were used to describe the demographic characteristics of the sample. Shapiro-Wilk tests confirmed that several of the matched-pairs of questionnaire data were not normally distributed. Therefore, a conservative decision was made to use a series of Wilcoxon Matched-Pairs tests to compare the differences between the pre- and post-intervention scores. Effect sizes were also reported in order to provide a measure of difference, in addition to the p-value, that would not be confounded by the small sample size. The effect sizes were calculated using matched pairs rank biserial correlation coefficients, a method prescribed by King, Rosopa and Minium (2011), as an appropriate measure of effect size for the Wilcoxon Matched-Pairs test.

Qualitative Analysis. The content of the intervention sessions were analysed using inductive thematic analysis (Braun & Clarke, 2006). Firstly the sessions were

transcribed by the researcher, facilitating familiarity with the data, and data from each session were then read carefully to identify meaningful units. Units were then grouped with similar units and given provisional definitions. In some cases, the same unit was ascribed more than one definition. The data groups were then combined into overarching themes, and the data set was re-read to ensure all meaningful units had been coded and incorporated into the themes. These themes were checked in supervision, and with participants at the post-intervention focus group, and deemed an accurate representation of their experiences. The organisation of the data within the themes was then finalised by the generation of a thematic map (Braun & Clarke, 2006; Appendix M), which helped to produce the master themes and subthemes presented in Table 2.

Quality Assurance. Yardley's (2000) guidelines for conducting qualitative research were applied throughout the study. When developing initial themes, the text was coded and re-read to ensure patterns across the data set were encapsulated in the analysis (Braun & Clarke, 2006; Appendix N for excerpts of transcripts). This ensured the data could be traced from initial coding, to initial generation of themes, to the analysed set of master and sub-themes presented, thus promoting transparency (Yardley, 2000). As well as checking the themes with the group facilitator, independent peer supervision provided an audit of one transcript, checking codes and emergent themes. Verbatim extracts from the transcripts were used in the results to promote transparency and coherence and increase the credibility of the findings (Yardley, 2000). Respondent validation was conducted by sharing the initial themes with participants during the focus group.

Results

Group attendance

All ten participants started and finished the group, with five participants attending all six sessions. One participant missed half a session, three missed one session, and one participant was absent for two and a half sessions.

Treatment fidelity

The session recordings were assessed by the researcher in relation to the protocol. Key tenets of narrative therapy, including the use of externalising language, tracing the history of the problem, constructing alternative stories through identifying unique outcomes, and witnessing change were evident within the outsider witness model that the group intervention provided.

Quantitative results

Table 1 lists the median scores, ranges and effect sizes for the pre- and post-intervention time-points for the sub-domain scores of SS-QOL, WCQ and B-IPQ. There was one significant difference for the Personality subscale of the SS-QOL ($z = -2.37$, $p = 0.018$, $r_c = .62$), although this was no longer statistically significant following Bonferroni correction for multiple comparisons. A trend and associated large effect size was indicated for the Positive Reappraisal subscale of the WCQ ($z = -1.84$, $p = 0.066$, $r_c = .68$). None of the other outcome measures indicated statistically significant differences between pre- and post-intervention administration.

Table 1: Median scores, ranges and effect sizes of SS-QOL, WCQ and B-IPQ subscales at pre- and post-intervention.

	Median pre- intervention score (range)	Median post- intervention score (range)	Effect size
<i>SS-QOL</i> ¹			
Energy	6 (9)	6 (11)	$r_c = .20$
Family	5 (10)	7 (8)	$r_c = .33$
Language	13 (20)	15 (19)	$r_c = -.11$
Mobility	21 (18)	21 (18)	$r_c = .17$
Mood	17 (15)	19 (13)	$r_c = .24$
Personality	3 (7)	11 (12)	$r_c = .62$
Self care	15 (20)	23 (17)	$r_c = .53$
Social roles	11 (15)	11 (15)	$r_c = .06$
Thinking	7 (9)	6 (10)	$r_c = .11$
Upper extremity function	15 (16)	21 (20)	$r_c = .31$
Vision	15 (11)	14 (11)	$r_c = .06$
Work/productivity	7 (7)	6 (9)	$r_c = .13$
Total score	132 (111)	144 (110)	$r_c = .66$
<i>WCQ</i> ²			
Confrontive coping	7.90 (12.64)	8.11 (14.33)	$r_c = .15$
Distancing	17.65 (16.92)	13.91 (14.77)	$r_c = -.42$
Self-controlling	17.34 (10.35)	13.40 (15.86)	$r_c = .33$
Seeking social support	15.18 (24.41)	15.01 (14.71)	$r_c = .15$
Accepting responsibility	13.03 (16.42)	9.77 (16.62)	$r_c = -.64$

Escape-avoidance	14.89 (17.82)	12.99 (17.21)	$r_c = -.64$
Planful problem solving	8.87 (16.03)	13.13 (14.83)	$r_c = .46$
Positive reappraisal	9.51 (12.61)	13.40 (15.69)	$r_c = .68$
<i>B-IPQ</i> ³			
Consequences	8 (6)	8 (6)	$r_c = .06$
Timeline	7 (8)	6.5 (7)	$r_c = .15$
Personal control	5 (4)	5 (7)	$r_c = .11$
Treatment control	8 (7)	9 (8)	$r_c = .20$
Identity	9 (7)	7 (7)	$r_c = -.06$
Concern	10 (7)	8.5 (8)	$r_c = .06$
Coherence	7 (10)	7 (6)	$r_c = .28$
Emotional representation	8 (8)	8 (8)	$r_c = -.06$
Perception of threat	52 (37)	46 (23)	$r_c = -.55$

¹ Higher scores indicate better functioning

² Higher scores indicate greater use of strategy

³ Lower scores indicate reduced strength of illness perception

* $p < .05$

Thematic Analysis

The thematic analysis of the intervention sessions resulted in four master themes and 14 subthemes, outlined in Table 2, which will be explained with illustrative quotations (see Appendix O for audit trail of analysis).

Table 2: Master themes and sub-themes derived from the thematic analysis

Master Themes	Sub-themes
Using the group	<ul style="list-style-type: none"> • Expectations for the group • Comparisons • Information
Negative Talk	<ul style="list-style-type: none"> • Difficult thoughts and emotions • Unmet Expectations • Loss • Restrictions
Positive Talk	<ul style="list-style-type: none"> • Achievement • Adaptation • Good Experiences
Relationships	<ul style="list-style-type: none"> • Relationship to stroke • Relationship with other group members • Relationship with family and changes in roles • Relationships with wider systems

Using the group. This master theme, comprising three subthemes, encapsulates how group members used the social element of the group to make the experience useful for them.

Expectations for the group. Group members did not describe specific expectations for the group, yet there was a sense that participants were *“hoping something good would come out of it”* (P1, G4)¹, as well as being *“...an afternoon out”* (P5, G1) and an opportunity for *“meeting other people”* (P2, G1). In addition to the social aspect of the group, there was concern about having to overcome impairments in order to engage fully with the group, or a sense of needing to perform: *“My god, it’s like being back at school”* (P2, G1).

Comparisons. Many participants used the group as an opportunity to make comparisons between their own experiences and those of other group members. They recognised similarities and differences amongst their experiences, often feeling better about their own situation as a result:

P2: *“I do feel lucky”*

P6: *“But it is easy to feel lucky when he sees me, and he sees [P4]² trying to walk”*

P2: *“Yeah”*

P6: *“You want to come along on a Monday afternoon and see people in a wheelchair. They can’t walk. It makes you appreciate what you have got.”*
(G3).

Stroke was also compared to other chronic health conditions, either from personal experience or from observations of others. Stroke was experienced as something that cannot be fixed like a heart attack: *“But with Stroke, you can’t fix the plumbing can they?”* (P4, G2), and as an additional stress: *“I’ve had cancer, I really don’t need stroke”* (P10, G6).

¹ Participant number, group session number

² Material removed for confidentiality or clarity

Information. The group was used by almost all participants to seek, share and gain information, as well as a platform to complain about the *“lack of good information”* (P5, G2) available to stroke survivors. In addition, their lack of knowledge about their own health condition was evident:

P4: *“I think we all don’t want a reoccurrence of what we’ve got”*

P2: *“Yes, I’d agree with that”*

P1: *“Absolutely”*

F³: *“So do you do stuff to avoid it then?”*

P4: *“I don’t know what to do for it”*

F: *“Why do you think that is?”*

P4: *“Well, cos a stroke is not like a cold, it just gives you a whack and that’s it”*

P3: *“So many factors, isn’t there, into stroke”* (G4).

Negative talk. This master theme, comprising four subthemes, captures the perceived difficulties and challenges associated with living with the consequences of stroke

Difficult thoughts and emotions. Many participants named *“aggression”* (P4, G2), *“aggravation”* (P5, G2) and *“frustration”* (P5, G1) in regard to managing life post-stroke, and the changes in their personal circumstances. There were discussions about death, with death suggested as an escape from current circumstances or as protective for their families, as some felt their families would have been better off if they had died: *“If I’d have died, my wife could go on with her life”* (P6, G2). The uncertainty the stroke evoked was also a salient topic, with uncertainty about prognosis: *“In my case, the biggest thing is not knowing”* (P2, G1); and uncertainty about the future: *“You*

³ F indicates group facilitator

can't make forward plans, or travel or anything like that [...] just little things in your life, that you want to look forward to" (P1, G2).

Unmet expectations. The participants talked about wanting *"to get back to normal"* (P6, G3), and placing expectations on themselves to recover: *"It's just that progress is slow."* (P4, G1). There was a sense that their bodies had let them down, and the expected outcome of living a healthy life had changed: *"It's very strange, I was very fit and suddenly, I had cancer and I was having a stroke"* (P10, G4).

The group members discussed experiences of the NHS and many felt that the follow-on care post-discharge was lacking in comparison with the acute care in hospital. There also appeared to be a sense that healthcare professionals used impersonal rehabilitation targets and there was a lack of trust that they would receive the support required:

P3: *"Well, that's the point you see. They only give you, I mean, everybody here will tell you. You get 6 weeks and that's it, finished."*

F: *"Then what happens? What happens after that?"*

P3: *"You're just left"*

P5: *"Left in the cold, kicked out"*

P6: *"Dumped on the pile"* (G2).

The sense of being let down and abandoned extended to unmet expectations of support and fairness from wider services and society:

"I'm 57 now, and I started work when I was 14 and half, and I've never claimed for anything in my life. And you get told no, you can't have anything. You're not entitled to anything" (P2, G2).

Loss. Participants described a multitude of losses, including loss of independence and increased dependence upon their wives or daughters. Many had

experienced the loss of friendships and a sense of rejection since their stroke: *“That’s the thing, you find out who your friends are”* (P2, G2).

There was discussion about the loss of future hopes and plans, including those for retirement, and a loss of spontaneity due to the effort and planning involved in what used to be simple activities, such as walking up steps:

“I sat down in plenty of time and I planned it. I planned what I was going to do. For weeks I sat down and looked at them, and I walked up one day, and I was worried I would fall backwards and hurt myself, but I walked up and down and practiced a couple of times without falling over, and I thought I’d done well, but I’m tired!” (P6, G3).

For the two younger members of the group, there was also a feeling of loss of identity through losing their job: *“Going from working 60, 70, 80 hours a week to not doing nothing at all”* (P2, G1).

Restrictions. The majority of the group talked about difficulty adjusting to the practical limitations now placed upon them. These ranged from *“...the simple things like eating, and you can’t use a knife and fork, cos you can’t use something in both hands”* (P4, G1), to more complex skills, such as driving. For those who drove before the stroke, the restriction on driving represented a loss of independence that was shared amongst members of the group:

P2: *“That’s why I stopped driving, why I’ve been told to stop driving”*

P10: *“That is really hard”*

P2: *“Tell me, how do we all think the same about that sometimes, I don’t know, I get very frustrated about it all”*

P6: *“About driving?”*

P5: *“We all do, I think”*

P4: *"Yes, I do"* (G4).

The origin of the restrictions experienced by participants differed. Some restrictions were due to impairments following the stroke, such as communication or mobility difficulties, some were enforced by rules placed upon individuals by healthcare professionals: *"They tell me I can't drink, can't smoke, can't take sugar, well, I can't do bloody nothing really"* (P2, G1). Some restrictions were financial, and some were self-imposed due to fear or uncertainty: *"It's the case with me, basically, if its cold, I don't go out"* (P2, G1).

Positive talk. This master theme, comprising three subthemes, captures the positive experiences, changes and achievements since the stroke. The content of this theme was observable in the later group sessions, and heavily supported by the facilitator, as some participants had difficulty considering alternative stories to their dominant problem-saturated narrative.

Achievement. Many participants had to relearn physical skills, such as *"Learning to walk without a stick"* (P5, G3) and *"Losing my left hand [and] learning how to write again"* (P4, G3), and many were focused on regaining practical skills, such as driving and restarting hobbies.

There were some opportunities for new achievements post-stroke, such as having the time to read or taking on new challenges:

"Yes, I'm the media volunteer, that's why, for the Stroke Association. I volunteered because I want to say things about, and have an opinion, so I actually put myself forward for that role" (P3, G3).

There was a sense of satisfaction with achieving goals and a positive relational aspect of sharing achievements and progress in rehabilitation with family members.

Adaptation. Participants' discussions suggested that both physical and mental adaptations were necessary following a stroke. Almost all participants talked about finding new ways to do things, such as taking more time to complete tasks, or adapting objects around the home for a new purpose: *"I usually use my stick all the time, but I've managed to use the trolley as my stick."* (P4, G3).

Part of adaptation was *"acceptance"* (P1, G2) and the *"the realisation that there are certain things that you can't do"* (P1, G2), but there was also a sense of determination. Determination was a commonly used word throughout the groups, and was described by many participants as if a channel for frustration.

Good experiences. Many participants shared good experiences of NHS care, most notably the initial emergency services and the services received whilst in hospital:

P5: *"To be fair, I found the service I got to be really good"*

P1: *"So did I"* (G3).

Relationships. This master theme, comprising four subthemes, encapsulates the relationships between the individual group members and the systems around them.

Relationship to stroke. The externalisation exercise revealed that for some members of the group, the stroke had resulted in something that was once whole, being broken into pieces: *"If you are working in pottery, you'd just have broken bits on the floor where you've thrown it at the wall in frustration"* (P4, G1). This image represents the loss, aggression and permanent damage associated with stroke. For others, the stroke was a constraining presence, like a cloak or being in prison. These images suggest that a sense of self has been lost, either due to being shattered or

broken, or due to being somehow unobtainable. For some participants, the broken pieces could be put back together like a jigsaw, but for others, the stroke was an unjustified life sentence.

Furthermore, participants discussed the word 'stroke' and the mismatch with the experience. 'Stroke' was deemed too nice a word and "*brain attack*" (P3, G2) was suggested as an alternative:

P1: "*No, your brain hasn't been stroked nicely, it's been...*"

P3: "*Exactly, it's been attacked, yeah*" (G2).

In addition the term "*mini stroke*" (P7, G1), in relation to a TIA was deemed unable to encapsulate the devastating consequences for one couple in the group.

Relationship with other group members. Developing relationships between the group members allowed them to support each other. Humour was used to normalise difficult shared experiences and to encourage each other: "*Yeah, we learn to laugh at each other, don't we [...] Not that we are laughing at each other, just expressing support, I suppose*" (P3, G4).

One of the two female participants provided an alternative voice to the dominant male experience within the group, and often put forward a suggestion of the how a female partner might feel:

P2: "*And on the other hand, if it had done the job properly, she'd have enough money to live on*"

P1: "*But I guess she would prefer to have you around, than not around at all*" (G2).

Relationship with family and changes in roles. Spousal relationships were most talked about and there was an appreciation of the support received by the men in the group from their wives. In almost all cases, the wives had taken on the role of carer,

and there had been many practical changes within the household. There was a reversal in the male and female roles that the participants described before their stroke, with the wives sometimes becoming the breadwinners, and performing tasks that the men in the group used to do, such as DIY, driving or dealing with finances. At the same time however, there were also aspects of the spousal relationship that remained stable, with wives running the home and caring for their husbands:

P4: *"My wife often says what do you want for supper and I haven't got a clue"*

F: *"Have you ever had a clue?"*

P4: *"No, not really!"*

P2: *"You came in from work and it was on the table"*

P4: *"That's right yeah"* (G4).

In addition to role changes, there were also changes in intimacy between partners. Many of the men expressed a reduced sexual relationship with their wife's, which was deemed to be a negative consequence of the stroke, but in time, this had come to be replaced by emotional intimacy:

"I feel closer to my wife than I probably ever did. We were more sexually active beforehand, yet I feel more closer to her now, cos you just learn to be different." (P3, G2).

The closeness participants developed with their wives was extended to the wider family. Participants began to thicken alternative stories and acknowledged that they now had more time to spend with children and other relatives, than they did before the stroke. There was parental concern at the impact of the stroke on their children: *"...my youngest daughter's not quite so well [...] she's worrying about me. She's got all that pressure"* (P2, G2), as well as frustration at the reversal of the parent-child relationship in older participants:

P1: *"I'm old enough to be old, and know what its like to be old, at 73, your children suddenly start treating you as"*

P5: *"Like a child"*

P1: *"Yeah, they do things for you, which you would normally do for them..."*
(G2).

There was also recognition of generational patterns between fathers and sons. Participants recognised themselves in their fathers, and worried about their sons: *"I feel myself that he's looking at me and saying if I'm not careful I'm going to end up the same way as dad."* (P2, G3)

Relationships with wider systems. Participants discussed mixed relationships with healthcare professionals. Some found support through their GPs, whilst others felt *"You are fighting the system, all the way through"* (P2, G2). There was evidence of a passive reliance on medicine to 'cure' or 'fix': *"But they still can't get my balance back, which is frustrating"* (P2, G2).

Participants also discussed their relationships within wider society, and what society expects of a man, and of someone who is disabled. There was a sense of hiding weakness or vulnerability: *"You need to harden up, don't you, after the stroke"* (P3, G2); as expressions of emotion questioned masculinity:

P2: *"It's the old things isn't it, if you don't laugh you cry"*

F: *"It's alright to cry though"*

P2: *"No, it ain't"* (G4).

There was concern from some members about feeling *"a bit of a fraud"* (F, G4) due to not looking disabled, and apprehension about misunderstandings from others about why they were unable to do things they used to do, such as return to work:

“What I’ve had is, one or two acquaintances have said, I’ve known someone who’s had a stroke and they’re back at work now” (P2, G2).

Evaluation of intervention: Focus group

The questions in the focus group (Appendix P) revealed that participants, in general, enjoyed the group experience. The social aspects, of *“talking”* (P5) and *“discussion”* (P6) and sharing experiences was highlighted as the most useful part, as well as the opportunity to spend time with people in a similar situation, and feel accepted. There were uncertainties about what would be expected of the participants and thus, they did not know what to expect: *“We didn’t really know what the group was going to bring”* (P4). There was consensus that the participants would recommend a similar group to other stroke survivors, but for some, it was *“difficult to pinpoint”* (P5) any noticeable changes as a result of attending. One participant reflected that attending the group had allowed him to weigh up the relative strengths and weaknesses of himself and of the stroke, *“so now the stroke is part of my life, not ruling my life”* (P3).

Discussion

Quantitative findings

The study aimed to add to extant literature by addressing whether the group narrative therapy intervention could facilitate psychosocial adjustment following stroke, by exploring the impact of stroke on participants’ lives. The outcome measures were used to explore whether any changes in quality of life, use of adaptive coping strategies and illness representations observable using the outcome measures. Health-related quality of life was measured using the SS-QOL, as it had been used in previous

stroke intervention studies (Chang et al., 2011; Kendall et al., 2007). Of the 12 domains, only scores on the personality subscale improved pre-and post-intervention, although this effect did not withstand Bonferroni correction. It is possible that the failure to find any statistically significant changes may have been due to reduced power due to the small sample size, as the effect size was large ($r = .524$), although type I error due to multiple comparisons cannot be excluded. The personality domain of the SS-QOL contained three statements: “I was irritable”, “I was impatient with others”, and “my personality has changed”. These statements refer to emotional states that may be more noticeable through interaction with others, and change on this sub-scale may reflect the influence of the discussion-based group intervention.

Of the eight domains of the WCQ, there was a trend and associated medium effect size for positive reappraisal, suggesting that the experience of the intervention may have encouraged the use of more active coping strategies. This may have been promoted within the group by the comparing of experiences and strategies and in the swapping of information. None of the other domains on the WCQ or the BIPQ indicated any significant change, although there were medium effect sizes for some comparisons. Again, this may have been due to the sample size. As a result of recruitment difficulties, the design of the study was scaled down and the control group was removed. The results of this exploratory study however, do not require a control group for interpretation, but future studies would benefit from the use of a delayed-treatment control, to substantiate any findings and to increase power.

Thematic Analysis

Inductive thematic analysis and feedback from the focus group suggest that despite the lack of statistical changes on the outcome measures, participants enjoyed

attending the group and found it useful. The social component of the group provided the opportunity to practice talking and being amongst people in a similar situation. The statements from the focus group also reflect the 'using the group' theme, where the group was used as a way to compare experiences and exchange information. This reflects previous findings that the benefits of groups included being understood by others, having experiences normalised and gaining practical tips for dealing with disability (Carlsson et al., 2009; Ch'ng et al., 2008). Exchanging stories can affirm personal experiences (Bronken et al., 2012), and in other studies, support from groups has been found to help stroke survivors develop alternatives to unhelpful coping strategies (Evans & Northwood, 1983).

The analysis sought to explore what the narratives of post-stroke survivors tell us about the impact of stroke on their lives, and for the participants in the study, the impact was predominantly problematic. There was a focus on the physical loss of function and consequential loss of skills, which led to restrictions on activity and independence. Discussions around the subject of loss, were similar to those described in other qualitative studies (Burton, 2000; Carlsson et al., 2009; Ch'ng et al., 2008; Dowswell et al., 2000; Jones et al., 2008; Murray & Harrison, 2004). Loss of independence and reliance on others was a prominent topic, and related to how the participants' post-stroke selves did not meet their pre-stroke expectations of themselves. The loss of identity through the loss of employment encapsulated the loss of role, social contacts and possibly brought up feelings of uncertain contribution and worth. Furthermore, the inability to drive was a further loss that appeared representative of independence (Ch'ng et al., 2008).

The group provided an opportunity for 'negative talk', which may not always be possible outside of the groups. Discussions about how dying would have allowed loved

ones to move on with their lives, was often one that was too difficult to bring up at home. The validation of unmet expectations of the self, of participants' bodies, of recovery, of the healthcare and benefits systems, and the sharing of difficult feelings may have been a new experience for some of the male participants in the group. This was done cautiously however, and there were discussions about being "manly". Many of the feelings discussed were irritation, aggravation and frustration, rather than acknowledging any sadness.

Amongst the 'negative talk', unique outcomes and exceptions were also evident: achievements and the adaptations made since the stroke created 'positive talk' within the group. It was difficult for the facilitator to draw out these exceptions, and discussion often returned to problem-saturated narratives. Part of the process of adjustment is the acknowledgement of loss and the development of new goals for the post-stroke self. For some participants, such an acknowledgement would have meant letting go of the goal of returning to normal. The focus on pre-stroke functioning appeared to either motivate participants to achieve targets and work hard at rehabilitation, or it kept them stuck, as their assumptions about ability were disconfirmed by the current reality (Taylor et al., 2011).

In relation to the wider literature, and the identification of identity and self as an important part of the process of adjustment, the results demonstrate an observable discussion of self and identity and a development of alternative narratives, for some participants. There were mixed opinions as to whether participants felt they had benefitted psychologically from attending the group. Changes were "hard to pinpoint" for some, although one participant shared his experience of now experiencing himself as separate from his stroke. Participant 3 explicitly described a change in his relationship with the stroke, and how he could observe the strengths and weaknesses

of the stroke as separate to his own. For other participants, the development of alternate narratives may still have been in progress at the final session, with Participant 2 complaining about the restrictions on his life at the beginning of group 1, and talking about feeling “*lucky*” as the group sessions progressed.

The sense of self, observed within the group discussions, appeared to be relational and redefined in response to interaction with others. Multiple discourses, including the opinions of other group members, individual’s spousal relationships, relationships to the stroke, and consideration of what wider society might think, all influenced the construction of the post-stroke identity. This description is underpinned by the constructs of narrative therapy, and the idea that our identities are constructed by our interactions, within multiple contexts. For many of the group members, the overwhelming context for their identity was the fact they were suffering with the physical consequences of surviving stroke.

The results tentatively support the use of narrative-based discussions as a framework for facilitating adjustment, as proposed by the SCoTS model (Taylor et al., 2011). Life trajectory, attachment relationships, self-beliefs and stroke-specific beliefs were suggested by Taylor et al. (2011) as areas for intervention, and each were addressed through the discussions within the group. Furthermore, the findings of the current study also advocate the effectiveness of a group intervention for supporting these discussions and allowing for the reconstruction of alternative narratives.

Limitations of the study

The limitations of the current study include the small sample size. The use of a delayed-treatment control group would have provided additional power, and therefore the findings can only tentatively support development of a larger-scale

study. Without recruitment restrictions, the demographics of the group could have been better considered. There was a 4:1 male to female ratio in the group, and although many stroke studies have more male participants, in consideration of facilitating group processes, a more balanced representation would have been preferable.

Of ten participants, six voices dominated. Two of the participants did not contribute to group discussions, and this may have impacted on group dynamics. One participant's communication impairment made participation difficult, although this was not the case for the other participant. Had the intervention been longer, the facilitator may have had more time to draw out the quiet voices within the group. Additionally, with more sessions there may have been opportunities to further develop the alternative narratives.

Research implications

The study contributes a new therapeutic approach for stroke that requires further evaluation. Future studies examining the utility of narrative therapy interventions in stroke could consider the use of different outcome measures, such as goal attainment scaling, as the measures used in the current study may have been insensitive to the process of change. The timing of the intervention could also be manipulated to investigate the most appropriate timing of interventions to facilitate the process of adjustment. Furthermore, the development of alternative narratives could be examined further using individual interviews with participants, pre- and post-group intervention.

Clinical implications

The findings suggest several implications for clinical practice. The process of seeking of information about stroke and the services available, which was evident in the group discussions, suggests that accessible information should be provided post-stroke about the physical, emotional and cognitive consequences of stroke.

Furthermore, the lack of understanding about stroke and secondary stroke prevention, which was also observed within the group, should be addressed with survivors and carers as part of clinical working, as recurrent strokes have been linked to post-stroke depression (Dafer, Rao, Shareef, & Sharma, 2008).

The findings demonstrate meeting as a group and discussing experiences was valued by participants, particularly sharing information and learning more about stroke. It could be hypothesised that the provision of a discussion group which incorporates psychoeducation, within a stepped care model, could promote adjustment.

Conclusions

The findings indicate that narrative group therapy for facilitating adjustment requires further evaluation. However, the findings also suggest that the opportunity for group discussion may in itself be beneficial. The study highlights the clinical implications of information provision for survivors and carers, and for support following discharge from post-acute care.

References

- Alexopoulos, G. S., Wilkins, V. M., Marino, P., Kanellopoulos, D., Reding, M., Sirey, J. A., Raue, P. J., Ghosh, S., O'Dell, M. W. & Kiess, D. N. (2012). Ecosystem focused therapy in poststroke depression: A preliminary study. *International Journal of Geriatric Psychiatry*, 27, 1053–1060.
- Andersen, G., Vestergaard, K., Ingemann-Nielsen, M., & Lauritzen, L. (1995) Risk factors for poststroke depression. *Acta Psychiatrica Scandinavica*, 92, 193–198.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brennan, J. (2001). Adjustment to cancer – Coping or personal transition? *Psycho-oncology*, 10, 1–18.
- British Psychological Society (2009). *Code of Ethics and Conduct*. Leicester: British Psychological Society.
- Broadbent, E., Petrie, K.J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60, 631-637.
- Bronken, B.A., Kirkevold, M., Martinsen, R., & Kvigne, K. (2012). The aphasic storyteller: Co-constructing stories to promote psychosocial well-being after stroke. *Qualitative Health Research*, 22(10), 1303–1316.
- Burton, C. R. (2000). Living with stroke: A phenomenological study. *Journal of Advanced Nursing*, 32(2), 301-309.
- Carlsson, G.E., Moller, A., & Blomstrand, C. (2009) Managing an everyday life of uncertainty – A qualitative study of coping in persons with mild stroke. *Disability and Rehabilitation*, 31(10), 773–782

- Carr, A. (1998). Michael White's Narrative Therapy. *Contemporary Family Therapy*, 20(4), 485-503.
- Carr, A. (1998). Michael White's Narrative Therapy. *Contemporary Family Therapy*, 20(4), 485-503.
- Ch'ng, A. M., French, D., & Mclean, N. (2008). Coping with the challenges of recovery from stroke: Long term perspectives of stroke support group members *Journal of Health Psychology*, 13, 1136-1146.
- Chang, K., Zhang, H., Xia, M. A. & Chen, C. (2011). Testing the effectiveness of knowledge and behaviour therapy in patients of hemiplegic stroke. *Topics in Stroke Rehabilitation*, 18(5), 525-535.
- Dafer, R. M., Rao, M., Shareef, A., & Sharma, A. (2008). Poststroke depression. *Topics in Stroke Rehabilitation*, 15(1), 13-21.
- Dean, R. G. (1998). A narrative approach to groups. *Clinical Social Work Journal*, 26(1), 23-37.
- Department of Health (2007). The National Stroke Strategy. London
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing*, 9, 507-515.
- Ellis, C., Zhao, Y. & Egede, L. E. (2010). Depression and increased risk of death in adults with stroke. *Journal of Psychosomatic Research*, 68(6), 545-551.
- Ellis-Hill, C, Payne, S., & Ward, C. (2000). Self-body split: Issues of identity in physical recovery following a stroke *Disability and Rehabilitation*, 22(16), 725-733.

Ellis-Hill, C, Payne, S., & Ward, C. (2008). Using stroke to explore the life thread model:

An alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation*, 30(2), 150-159.

Evans, R.L. & Northwood, L.K. (1983). Social support needs in adjustment to stroke.

Archives of Physical Medical Rehabilitation, 64(2), 61-64.

Faircloth, C. A., Rittman, M., Boylstein, C., Young, M. E., & Van Puymbroeck, M. (2004).

Energizing the ordinary: Biographical work and the future in stroke recovery narratives. *Journal of Aging Studies*, 18(4), 399-413.

Feibel, J.H. & Springer, C.J. (1982). Depression and failure to resume social activities

after stroke. *Archives of Physical Medical Rehabilitation*, 63(6), 276–277.

Field, A. (2005). *Discovering Statistics Using SPSS (2nd ed.)*. London: Sage.

Folkman, S., & Lazarus, R. S. (1988). *Manual for the Ways of Coping Questionnaire*. Palo

Alto, CA: Consulting Psychological.

Gardner, P. & Poole, J. (2009). One story at a time : Narrative therapy, older adults, and

addictions. *Journal of Applied Gerontology*, 28(5), 600-620.

Glass, T. A., Matchar, D. B., Belyea, M. & Feussner, J. R. (1993). Impact of social support

on outcome in first stroke. *Stroke*, 24, 64-70.

Grimm, R. (2003). Narrative therapy with older adults. In J.L. Ronch & J.A. Goldfield's

(Eds.), *Mental Wellness in Aging: Strength-Based Approaches* (pp. 237 - 271).

Baltimore, MA: Health Professions Press.

Hackett, M. L., Anderson, C. S., House, A., & Xia, J. (2008). Interventions for treating

depression after stroke. *Cochrane Database Systematic Review*, 2, 1–89.

Hartke, R. J., King, R. B., & Denby, F. (2007). The use of writing groups to facilitate

adaption after stroke. *Topics in Stroke Rehabilitation*, 14(1), 26-37.

- Herrmann, M., Curio, N., Petz, T., Synowitz, H., Wagner, S., Bartels, C., Wallesch, C. W. (2000). Coping with illness after brain diseases: A comparison between patients with malignant brain tumors, stroke, Parkinson's disease and traumatic brain injury. *Disability and Rehabilitation*, 22, 539–546.
- Hill, N.L. (2011). Externalising conversations: Single session narrative groups interventions in a partial hospital setting. *Clinical Social Work Journal*, 39(3) 279–287.
- Holman, H. & Lorig, K. (2004). Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports*, 119, 239–43.
- House, A., Knapp, P., Bamford, J., & Vail, A. (2001). Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at 1 month. *Stroke*, 32, 696–701.
- Johnson, J. (2009). *Shrinking the monster: A multiple sclerosis workbook*. Multiple Sclerosis Society. Retrieved from: <http://www.mssociety.org.uk/ms-resources/shrinking-monster> on 2/5/2009.
- Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability and Rehabilitation*, 30(7), 507–516
- Jones, F., Mandy, A., & Partridge, C. (2009). Changing self-efficacy in individuals following a first time stroke: Preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522–533
- Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science & Medicine*, 64, 735–746.

- King, B.M., Rosopa, P.J. & Minium, E.W. (2011). *Statistical Reasoning in the Behavioural Sciences*. New Jersey: John Wiley & Sons, Inc.
- King, R. B., Shade-Zeldow, Y., Carlson, C.E. Feldman, J. L. & Philip, M. (2002). Adaptation to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation*, 9(1), 46–66.
- Laube, J.J. (1998). Therapist role in narrative group psychotherapy. *Group*, 22(4), 227–243.
- Lincoln, N. B., & Flannaghan, T. (2003). Cognitive behavioural psychotherapy for depression following stroke: A randomized controlled trial. *Stroke*, 34, 111–115.
- Lincoln, N.B., Flannaghan, T., Sutcliffe, L., & Rother, L. (2007). Evaluation of cognitive behavioural treatment for depression after stroke: A pilot study. *Clinical Rehabilitation*, 11, 114–122.
- Lorig, K. & Holman, H. (2003) Self-management education: history, definition, outcomes and mechanisms. *Annals of Behavioural Medicine*, 26, 1–7.
- Lyon, B.L. (2002). Psychological stress and coping: Framework for poststroke psychological care. *Topics in Stroke Rehabilitation*, 9(1), 1–15.
- Mukherjee, D., Levin, R.L. & Heller, W. (2006). The cognitive, emotional, and social sequelae of stroke: Psychological and ethical concerns in post-stroke adaptation. *Topics in Stroke Rehabilitation*, 13(4), 26–35.
- Murray, C.D. & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretive phenomenological analysis. *Disability and Rehabilitation*, 26(13), 808–816
- Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, 5(3), 337–347.

NHS Improvement (2011) National standards for psychological support after stroke.

London

Poole, J., Gardner, P., Flower, M. C., Cooper, C. (2009). Narrative therapy, older adults, and group work?: Practice, research, and recommendations. *Social Work with Groups*, 32, 288 – 302.

Ramasubbu, R., Robinson, R. G., Flint, A. J., Kosier, T., & Price, T. R. (1998). Functional impairment associated with acute poststroke depression: The stroke data bank study. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 10(1), 26 – 33.

Sinyor, D., Amato, P., Kaloupek, D. G., Becker, R., Goldenberg, M., & Coopersmith, H. (1986). Post-stroke depression: Relationships to functional impairment, coping strategies, and rehabilitation outcome. *Stroke*, 17, 1102-1107.

Taylor, G. H., Todman, J., & Broomfield, N. M. (2011). Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological Rehabilitation* 21(6), 808-824.

Twiddy, M., House, A., & Jones, F. (2012). The association between discrepancy in illness representations on distress in stroke patients and carers. *Journal of Psychosomatic Research*, 72, 220-225.

Vassalo, T. (1998). Narrative group therapy with the seriously mentally ill: A case study. *Australian and New Zealand Journal of Family Therapy*, 19, 15-20.

Vitaliano, P.P., De Wolfe, D.J., Maiaro, R.D., Russo, J., & Katon, W. (1990). Appraised changeability of a stressor as a modifier of the relationship between coping and depression: A test of the hypothesis of fit. *Journal of Personality and Social Psychology*, 59, 582–592.

Vohora, R. & Ogi, L (2008). Addressing the emotional needs of stroke survivors. *Nursing Times*, 104(42), 32-36.

Wade, D.T., Legh-Smith, J., & Hower, R.A. (1987). Depressed mood after stroke: A community study of its frequency. *British Journal of Psychiatry*, 151, 200–205.

Watkins, L. C., Auton, F. M., Deans, F. C., Dickinson, A. H., Jack, A. I. C., Lightbody, E. C., Sutton, J. C., van den Broek, D. M., & Leathley, J. M. (2007). Motivational Interviewing early after acute stroke: A randomized controlled trial. *Stroke*, 38, 1004-1009.

Watkins, L. C., Wathan, V.J., Leathley, J.M., Auton, F.M., Deans, F.C., Dickinson, A.H., Jack, A.I.C., Sutton, J.C., Van de Broek, D.M., & Lightbody, E.C. (2011). The 12 month effects of early Motivational Interviewing after acute stroke: A randomized controlled trial. *Stroke*, 42, 1956-1961.

White, M. (2007). *Maps of Narrative Practice*. New York: W.W. Norton

White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. New York: Norton.

Whyte, E.M., Mulsant, B.H., Vanderbilt, J., Dodge, H.H., & Ganguli, M. (2004). Depression after stroke: A prospective epidemiological study. *Journal of the American Geriatrics Society*, 52(5), 774-778.

Williams, L.S., Weinberger, M., Harris, L.E., Clark, D.O., & Biller, J (1999). Development of a stroke-specific quality of life scale. *Stroke*, 30(7), 1362-9.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

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SECTION C: CRITICAL APPRAISAL

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This section provides reflections and critical discussions about the process of carrying out this project. The appraisal is structured around the following four questions:

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

The experience of conducting this study has broadened my knowledge of research methodologies and analysis techniques. My previous research in cognitive neuropsychology used quantitative methods and I have valued the opportunity to learn about, experience and employ qualitative methods. This has led to an understanding that qualitative methods are not only complementary to quantitative methods but that they could be a valuable prerequisite for the design of interventions. Furthermore, I feel that as well as expanding my knowledge of psychological research methodologies, the process of listening to, transcribing and analysing the experiences of survivors of stroke, has expanded my knowledge and understanding of the consequences of stroke and the impact on people's lives.

I have previously worked in a research department as a lone researcher with sole responsibility for recruitment, data collection, and analysis. This project has required me to learn to work with teams, and to consider how research is viewed within clinical teams, by staff members who already feel they are working to full capacity. I have had to build relationships with staff, as a researcher and as a trainee clinical psychologist, neither of which were familiar to staff, and to build trust and to present my project, and myself, as trustworthy and worth investing time in. In addition, I have had to relinquish full control over aspects of the project and rely on

others for help with recruitment and data collection, something I have struggled with at times during the process of trying to complete this study.

I have also developed an understanding of the need to be flexible and build in contingencies when aspects of the project did not go to plan. It was important to be able to adapt the study, without losing sight of the original research questions, or compromising the quality of the research conducted.

Conducting this study has involved the negotiation of the NHS ethics process, which I did find difficult. This was a new experience for me, and at times I was daunted by the complexity and a fear of being inaccurate or unintentionally misleading. However, I appreciated the requirement to really think through the details of the project and understand the need for rigour. I now feel much better equipped for proposing new NHS applications in my continuing research career.

Upon reflection, I believe that some of the greatest learning has been in my own personal development. I found the process of conducting this research difficult, as I was still writing up my PhD when I started the course, and felt overwhelmed by the prospect of starting another research project. I believe that I was ambitious with what I expected myself to be able to achieve, and with hindsight can see that a four group RCT may not have been a realistic proposal. I was naive to the other competing demands of the training course, and had underestimated the impact of personal circumstances on my ability to complete the project. When I had to make the decision to defer submission of the MRP, I felt as though I had failed. This assumption has since been challenged by the reactions of my peers, and the fact that I was offered a job, over other qualified candidates. I have learned the importance of looking after myself and ensuring that I am fit to practice; as well as to reflect upon my decisions and to consider not needing to be so ambitious in the future.

2. If you were able to do this project again, what would you do differently and why?

In terms of the design of the study, there are several aspects I would consider doing differently. I would have interviewed each participant about their experience of stroke before and after the narrative group therapy intervention. I think the epistemology of the intervention may have been better suited to an alternative method to explore any change in narrative, rather than the use of quantitative measures. Furthermore, the post-intervention interviews could have served as an opportunity to ask each participant for their feedback about the group experience. The use of the focus group in the current study continued many of the processes evident in the group sessions, with many voices silent, and potentially many opinions about the intervention lost. A one-to-one interview may have elicited a discussion about experienced individual changes, which were not evident in the group sessions.

In terms of the intervention, I would make sure all eight sessions were conducted to allow the facilitator more opportunities to engage the less vocal participants, and to allow more time to explore the alternative stories and unique outcomes. I would encourage the facilitator to have made more use of the workbook within the sessions and to have used the completion of the questions in the workbook to facilitate and support discussion within the group. This may also have been a consequence of the limited time available and the workbook was used within the current study as a homework tool. If I were to conduct the study again, I would also interview the facilitator about her experience of running the groups and how she felt the design of the intervention met with the needs of the clinical group. The information from the interview may have provided further data about the feasibility of this intervention and how the protocol could be changed if the study were to be replicated.

There were difficulties with recruitment for the current study, and with hindsight I should have explored the opportunities for recruitment more fully at the beginning of the MRP process. If I had the opportunity to run the study again, I would consider the impact of an absence of a psychology service in the area I was recruiting from. When I was setting up the project, I naively thought that a lack of access to psychology may make people more likely to participate and teams more likely to suggest potential participants. On reflection, I think the lack of access to psychology made it difficult for staff teams to fully understand how psychology can be beneficial for stroke and the lack of established referral pathways to psychology made recruitment extremely difficult. Had participants been referred through an existing psychology service, they may have been more prepared for what therapy might entail and more open to the experience.

Furthermore, the method of recruitment was set up to ensure only willing participants were approached by the researcher, but this method did not provide data on the number of potential participants who were approached and declined. The data concerning the number of individuals who did not want to take part could provide insight into what factors prevent uptake of a therapy group amongst survivors of stroke, and be useful in the design of future interventions.

3. As a consequence of doing this study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?

My approach to clinical work has been influenced enormously by the experience of conducting this research. I have been working in a stroke neuropsychology service since January 2013, and have been aware of trying to implement the information I have gained into my clinical practice. I am very aware of

the need to provide information to survivors of stroke and to their families, and to take the time to explain what stroke is and the consequences it might have. Prior to conducting this research, I would have thought this type of information would have been provided by medical staff, and indeed it may be, but I now acknowledge the importance of making this information available to people and how it may be necessary to repeat it at different stages of the recovery process.

Additionally, I have found the post-acute ward on which I work to focus on deficit and loss, but the findings from this research have encouraged me to challenge this and to seek out strengths, sources of support and ways of adapting. Using the experiences described by the participants in the group sessions, and in our individual meetings, I now feel more comfortable and experienced in discussing what the future may hold for survivors who may only be six to eight weeks post-stroke.

A further consequence of conducting this research has been to really acknowledge the role of the carer in post-stroke recovery. The majority of participants in the group were male, all were married, and there were discussions about role changes and dependency. For many of the participants, their carer was in control of what they ate, where they went and what they did, so information about secondary stroke prevention and the consequences of stroke are important; As well as considering of the effects of the stroke on the carer, and how they can best be supported.

In my job, we are currently rolling out an education and discussion group across the inpatient wards in the trust. As a consequence of my experience gained through this research, I have been asked to take a lead on the development of the (previously piloted) groups, and have added a concurrent set of groups for family members to attend. Furthermore, conducting this study has reinforced the importance of research

within clinical practice for the advancement and evaluation of care, and in addition to the value of evidence-based practice, supporting the role for practice-based evidence.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

This research project has generated further questions, and supports the use of group interventions to help the process of adjustment following stroke. One avenue for exploration could be the timing of the intervention, and whether earlier intervention can help to promote adjustment or whether individuals need to experience the challenges of life post-stroke in order to motivate the adaptation required. Intervention at an earlier stage of recovery may help individuals to manage the difficult transition of discharge from hospital to the community and the feelings of abandonment that can be experienced. The use of a mixed methods approach would provide the opportunity for a rich understanding of the processes involved, but further consideration should be given to the choice of outcome measures, and stroke-specific measures chosen.

An alternative proposal could also be to consider the needs of younger survivors of stroke. As stroke is such a heterogeneous condition, I wonder whether future group interventions could be designed to reduce some of the differences between group members, and whether that would facilitate discussions relevant to enabling adjustment and adaptation. A group for younger survivors of stroke could provide the space to consider the specific difficulties faced, such as loss of income or difficulties with childcare.

In addition, I feel it would be valuable to explore the experience of stroke as a couple and how it impacts on intimate relationships. There was discussion in the

current intervention about a loss of sexual intimacy but how some participants had developed a closer relationship with their partner. The dominant voice in the current study was of the male partner who had experienced the stroke, yet I wonder how their female partners experienced the change in relationship or how couples manage when it is the woman who has had the stroke. These aspects also link into identity and body image, which were not explicitly discussed by the participants in the current study. These issues may be a factor for survivors which requires further investigation, and again, may feel more relevant to younger survivors, especially those not already in relationships.

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SECTION D: APPENDICES OF SUPPORTING MATERIAL

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
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JUNE 2013

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Appendix A: Literature search methodology for Section A

The following electronic databases were searched from the earliest year of publication up to the end of December 2012: PsychInfo, Medline, Cochrane Database of Systematic Reviews and Web of Knowledge. Google Scholar was also searched.

The search terms STROKE and PSYCHO* were combined with ADJUST*, COPING, ADAPT* and INTERVENTION or THERAPY. The search strategy included both the mapping and exploding of terms.

Manual searches of reference lists of identified articles were performed in order to identify any literature not included in the database search. In addition, the researcher arranged to receive regular notification of newly published articles relevant to search terms, in order to remain up-to-date with the literature.

Articles were included if they investigated an aspect of psychological or social impact of stroke, including individual and group interventions and were written in English.

Additional publications, including empirical papers, review papers, book chapters and policy documents were used to gather background information and information relating to theoretical frameworks. This material is referenced where relevant.

Appendix B: Tabular presentation of qualitative studies reviewed in Section A

Study	Country	Sample characteristics	Study aim	Methodology	Analysis	Themes
Burton (2000)	UK	<p>N=6</p> <p>Mean age =67.3 (range = 52-81)</p> <p>M:F = 2:4</p> <p>Time since stroke = not reported, although 1st interview conducted in hospital</p> <p>Ethnicity = not reported</p>	To identify the lived experience of recovery from stroke from the patient's perspective	Semi-structured interviews	<p>Grounded Theory – Participants followed for 1 year from first interview</p>	<p>Issues in physical recovery</p> <ul style="list-style-type: none"> - Initial personal experiences of stroke - Early recovery - Slowing down - New challenges <p>Issues in emotional recovery</p> <ul style="list-style-type: none"> - Uncertainty - Hope - Loss of control - Anger/frustration <p>Issues in social recovery</p> <ul style="list-style-type: none"> - Changing roles - Isolation
Carlsson, Moller & Blomstrand (2009)	Sweden	<p>N=18</p> <p>Mean age = 52 (range = 30-69)</p> <p>M:F = 11:7</p> <p>Time since stroke = 1 year</p>	To investigate how people with mild stroke coped with their new life situation during the first year post-stroke	Semi-structured interviews	Grounded theory	<p>Individual concerns of coping</p> <ul style="list-style-type: none"> - Health promotion - Self-reliance - Values & goals - Personality traits - View of life and future - Emotions <p>Relational concerns of coping</p> <ul style="list-style-type: none"> - Family relations

Appendix B: Tabular presentation of qualitative studies reviewed in Section A

		Ethnicity = not reported				<ul style="list-style-type: none"> - Patient-professional relations - Work relations <p>Environmental conditions</p> <ul style="list-style-type: none"> - Complexity - Intensity - Disturbing factors
Ch'ng, French & McLean (2008)	Australia	<p>N=26</p> <p>Mean age = 60.9 (range = 22-79)</p> <p>M:F = 12:14</p> <p>Time since stroke = 6 months – 12 years</p> <p>Ethnicity = not reported</p>	To understand the challenges and coping behaviours that promote adjustment in order to inform development of psychological support interventions	Focus groups	Not specified but reference Strauss & Corbin (1990) in description of analysis, and a model synthesising core themes is presented	<p>Challenges faced over time</p> <ul style="list-style-type: none"> - Early challenges - Rehabilitation challenges - Later challenges <p>What helped participants cope?</p> <ul style="list-style-type: none"> - Social support - Active strategies <p>Perceptions of psychological support needs</p>
Dowswell et al. (2000)	UK	<p>N=30 stroke patients, 15 caregivers</p> <p>Mean age = not reported</p>	Part of a larger RCT to examine effects of home visits by specialist nurses. Qualitative study aimed to identify what was important to	Semi-structured interviews conducted separately with stroke survivors and	Not specified but reference Strauss & Corbin (1990) in	<p>The overall impact of stroke</p> <p>Social activities, psychological and physical well-being</p> <p>Final evaluation of progress: Adjustment and the end of</p>

Appendix B: Tabular presentation of qualitative studies reviewed in Section A

		<p>M:F = not reported</p> <p>Time since stroke = 13-16 months</p> <p>Ethnicity = not reported</p>	<p>patients and caregivers in the recovery process and how patients and caregivers measured progress in the year following stroke</p>	caregivers	description of analysis	recovery?
Jones, Mandy & Partridge (2008)	UK	<p>N=10</p> <p>Mean age = 61.8 (range = 29-75)</p> <p>M:F = 6:4</p> <p>Time since stroke = 6 weeks -13 months</p> <p>Ethnicity = 80% White British, 10% White European, 10% Black Caribbean</p>	<p>To learn about the individual beliefs and personal strategies used to support recovery following stroke</p>	Semi-structured interviews	IPA	<p>Internal processes</p> <ul style="list-style-type: none"> - Personal strength and control over recovery - Generalised optimism and hope - Perceived dependence following stroke <p>External influences</p> <ul style="list-style-type: none"> - Markers of independence - Therapeutic interactions
Murray & Harrison (2004)	UK	<p>N=10</p> <p>Mean age = 48.8 (range = 38-81)</p>	<p>To investigate the meaning and experience of being a stroke survivor</p>	Semi-structured interviews, either face-to-	IPA	<p>Distrupted embodiment and loss of self</p> <p>Invisibility of emotional</p>

Appendix B: Tabular presentation of qualitative studies reviewed in Section A

		M:F = 4:6 Time since stroke = 4-18 years Ethnicity = not reported		face or via email		difficulties Gender, romance and sexuality Social interaction
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Appendix C: Characteristics of good qualitative research (Yardley, 2000)

Reproduced from Yardley (2000)

Essential qualities are in bold, with examples of the form each could take shown below.

Sensitivity to context

Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.

Commitment and rigour

In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.

Transparency and coherence

Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.

Impact and importance

Theoretical (enriching and understanding); socio-cultural; practical (for community, policy makers, health workers).

Appendix D: Tabular presentation of intervention studies reviewed in Section A

Study (date) Country	Sample characteristics	Study design	Control	Measures used	Main findings
Watkins et al. (2007) UK	n=411 Mean age = 70 (range = 61-78) M:F = 6:4 Time since stroke = 2-4 weeks	A randomised control trial design Motivational interviewing (MI) intervention (n=204) Four weekly one-to-one sessions Delivered by nurses and non-clinical psychologists 4 day training Follow-up 3 months post-stroke	Care as usual (n=207)	General Health Questionnaire (Goldberg & Hiller, 1979) Yale screening tool (Mahoney et al., 1994) Stroke Expectations Questionnaire (Watkins, Leathley & Davies, 1998) Barthel ADL Index (Wade & Collin, 1988)	Effect of MI on mood (p=0.03) at 3 months MI was shown to be protective against developing depression at follow-up (p=0.03). There was no effect of MI on functional ability or SEQ outcome data
Watkins et al. (2011). UK	Same as Watkins et al. (2007)	Same as Watkins et al. (2007), with addition of 12 month follow-up	Same as Watkins et al. (2007)	Same as Watkins et al. (2007)	Benefit of MI on mood seen at three months continued at 12 months (p=0.02) No protective benefit against depression observed at 12 months.

Appendix D: Tabular presentation of intervention studies reviewed in Section A

					<p>There was no effect of MI on functional ability or SEQ outcome data</p> <p>A protective effect of MI against death ($p=0.03$), with statistically higher mortality in the control group at 12 months</p>
<p>Chang, Zhang, Xia and Chen (2011).</p> <p>China</p>	<p>n=66</p> <p>Mean age = 58.6 (range =34-84)</p> <p>M=45, F=21</p> <p>Time since stroke = 28-264 days</p>	<p>Rational Emotive Behaviour Therapy (REBT).</p> <p>4 weekly 1-2 hour sessions, one-to-one</p> <p>Interventions delivered by a psychology graduate student</p> <p>No information about training provided</p>	Care as usual control	<p>Chinese version of the State-Trait Anger Expression Inventory (STAXI; Spielberger, 1988)</p> <p>Hamilton Anxiety Scale (HAS; Hamilton, 1959)</p> <p>Hamilton Depression Rating Scale (HAM-D; Hamilton, 1960)</p> <p>Chinese version of the Stroke Specific Quality of Life Scale (SS-QOL; Wang, Ma, Li & Wang, 2003)</p> <p>Chinese version of the Barthel Index.</p>	<p>At baseline, female participants reported more symptoms of anxiety and depression ($p<0.001$), lower QOL ($p<0.05$) and lower ADL ability ($p<0.01$) than male participants.</p> <p>Intervention group improvement on measures of anger ($p<0.001$), depression ($p<0.001$), quality of life ($p<0.001$) and ADLs ($p<0.001$)</p> <p>The care as usual control group also showed significant improvements in depression ($p<0.001$), anxiety ($p<0.05$),</p>

Appendix D: Tabular presentation of intervention studies reviewed in Section A

					and ADLs, ($p<0.001$) but the improvements in depression and ADLs were significantly less than seen in the intervention group, based on further analysis of change scores.
Alexopoulos et al. (2012). USA	n=24 Mean age = 70.9 M=13, F=11 Time since stroke = not reported, but participants recruited from rehabilitation hospital, with first intervention session one or two days prior to discharge.	Matched, pre- & post-intervention design Ecosystem Focused Therapy intervention (n=12) for depressed stroke survivors 12 weekly sessions, for 45 minutes Training in EFT consisted of reading and discussing the manual with the research team	Education for stroke and depression control (n=12)	Hamilton Depression Rating Scale (HAM-D; Hamilton, 1960) World Health Organisation Disability Assessment Schedule II (WHODAS-II; Epping-Jordan & Ustan, 2000)	EFT decreased depressive symptoms over the course of the intervention compared to control ($p=0.054$) EFT improved disability symptoms over the course of the intervention compared to control ($p=0.015$)
Lincoln, Flannaghan, Sutcliffe & Rother (1997).	n=19 Mean age=67.1 (range = 31-89)	AB single-case experimental design CBT intervention for	None	Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961)	Five cases = significant improvement ($p\leq 0.05$) One case = significant

Appendix D: Tabular presentation of intervention studies reviewed in Section A

UK	<p>M:F = 8:11</p> <p>Mean time since stroke = 43 weeks (range = 8-109 weeks)</p>	<p>stroke survivors diagnosed with depression</p> <p>Up to 10 one-to-one sessions (mean = 8.4)</p> <p>Delivered by CPN or assistant psychologist with experience in CBT</p> <p>No specific training for stroke intervention specified</p>		<p>Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)</p> <p>Barthel ADL Index (Wade & Collin, 1988)</p> <p>Extended Activities of Daily Living scale (EADL; Nouri & Lincoln, 1987)</p> <p>Wakefield Depression Inventory (WDI; Snaith, Ahmed, Mehta & Hamilton, 1971).</p>	<p>deterioration (p=0.02)</p> <p>14 cases = no significant difference</p> <p>Decrease in depression as measured by BDI for group as a whole (p=0.02), trend for WDI (p=0.06). No effect on HADS (p=0.27)</p> <p>No change in functional abilities</p>
<p>Lincoln & Flannaghan (2003).</p> <p>UK</p>	<p>n=123</p> <p>Mean age=66.1</p> <p>M=63, F=60</p> <p>Time since stroke = 1, 3 & 6 months</p>	<p>A randomised control trial design</p> <p>CBT intervention (n=39) for stroke survivors diagnosed with depression</p> <p>Up to 10 one-to-one sessions (mean = 9.85)</p> <p>Follow-up at 3 & 6</p>	<p>Standard care (n=41)</p> <p>Attentional placebo (n=43)</p>	<p>Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961)</p> <p>Wakefield Depression Inventory (WDI; Snaith, Ahmed, Mehta & Hamilton, 1971).</p> <p>London Handicap Scale (Harwood, Rogers, Dickenson & Ebrahim, 1994)</p>	<p>There were no statistically significant differences between groups at baseline, 3 months or 6 months on any outcome measures (p≥0.20)</p>

Appendix D: Tabular presentation of intervention studies reviewed in Section A

		months		Extended Activities of Daily Living scale (EADL; Nouri & Lincoln, 1987)	
Jones, Mandy and Partridge (2009). UK	n=10 Mean age = 61.5 (range =46-75) M:F = 7:3 Mean time since stroke = 24.2 weeks (range = 12-72 weeks)	Multiple participant single subject design Individual workbook intervention, based on chronic disease self-management programme Outcome measures administered at 14 time-points, with intervention introduced at randomly assigned time-point 5-11 weeks into study	None	General Self-Efficacy Scale (Schwartz & Jerusalem, 1995), Recovery Locus of Control Scale (RLOC; Partridge & Johnston, 1989) Stroke Self-Efficacy Questionnaire (SSEQ; Jones, Reid & Partridge, 2008). Rivermead Morbidity Index (Collen, Wade, Robb & Bradshaw, 1991) Rivermead Activities of Daily Living scale (Whiting & Lincoln, 1980). Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	SSEQ and RLOC scores improved post-intervention (p<0.05) No effect of intervention on generalised self-efficacy, functional ability or mood, although nine participants had lowered HADS scores, but was not significant (p-value not reported)

Appendix D: Tabular presentation of intervention studies reviewed in Section A

Kendal et al. (2007). Australia	n=100 Mean age = 65.96 (range = 25-82) M=67, F=33 Time since stroke = within first few months of discharge	Longitudinal randomised control trial CDSM group intervention to promote progressive psychological recovery 7 weekly, 2 hour sessions 8 groups conducted within 18 months Follow-up at 3, 6, 9, & 12 months by telephone	Care as usual control	Self-Efficacy Scale (Lorig et al., 1996) Stroke Specific Quality of Life Scale (SSQOL, Williams et al., 2001).	No effect of CDSM programme on self-efficacy, as intervention group demonstrated higher levels of self-efficacy than controls before intervention. There was an effect of time on individual scales of SSQOL, indicating the intervention may have temporarily prevented a decline in some aspects of well-being, but any improvements identified in the intervention group in the early follow-up analysis were matched by those in the control group by the 12 month follow-up.
Hartke, King & Denby (2007). USA	n=26 Mean age = 56.22 (range =33-75) M=54% Time since	Semi-structured writing group intervention Six groups conducted over 4-7 weeks. 1.5 hours long. 3-6 participants per group Facilitated by a	None	Centre for Epidemiological Studies –Depression Scale (Radloff, 1977) Personal Opinion Questionnaire (Bolton & Brookings, 1998) Scales of Psychological Well-	26 essays produced. Two themes from essays: personal growth and changes in self-concept due to stroke; and coping with recovery. No effect of intervention on outcome measures. There was a trend towards an

Appendix D: Tabular presentation of intervention studies reviewed in Section A

	stroke = 8.37 years (range = 1.39-18.86 years)	psychologist and a stroke survivor		Being – Short Form; (Ryff, 1989)	increase in the positive scale of identity as a person with a disability subscale (p=0.09)
Vohora & Ogi (2008). UK	n=6 Mean age = 83 (range = 71-90) M:F = 2:4 Time since stroke = not reported, but inpatient intervention	Pilot study of rehabilitation ward group intervention using a pan-theoretical approach Five sessions, facilitated by clinical psychologist and assistant psychologist No discussion of training, but manual was used for delivery of intervention	None	No standardised measures used, but anonymous feedback was collected after each group session	Only two participants attended all five sessions 70% participants found discussion/sharing experiences helpful 61% participants reported discussion/sharing experiences as the most helpful aspect of the group. 31% participants felt meeting others on the ward was the most helpful outcome

Appendix E: Research Ethics Committee and Research and Development department approval documents

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Appendix F: Narrative group therapy intervention protocol

Narrative therapy groups brief protocol (version 3, January 2013)

The job of the therapist within the NT framework is to help people identify what they want from their own lives and to help them to reconnect with their own strengths and own knowledge (McLean & White, 1996)

Within each of the sessions, time will be made available for people to share their thoughts and experiences of the process and how they feel it relates to them, as well as general reflections about expectations for the group.

Session 1

General introductions – establishing ground rules, discussing expectations, hopes and fears for the group, introduce narrative therapy

- Establishing rules → consider the rules as a group, and what is most important to the members of the group. Discuss confidentiality, how each member's contributions will be valued, suggest that members may respond to each others comments, but that they are under no pressure to do so.
- Discuss expectations → what do people want from the group? What do they expect will happen? How will they know if they have got what they wanted?
- Introduction to NT → Problems can create and develop their own identities, and then have an influence over the individual, the couple, the family and wider. One thing we can do to help is to externalise the problem, so that the degree of influence it has over the person can be compared to the degree of influence the person has over the problem. If we create a character that personifies the problem, we can separate ourselves from the problem and see the problem as something we can take action against, rather than seeing the problem as located in ourselves.
- Lots of things can keep us stuck with our problem, these might be beliefs and ideas from our external social environment or beliefs and ideas about our own motivations or ability to change.

Objectifying and personifying stroke – use the handbook to personify their stroke character, discuss how life stories influenced by stroke, evaluate effects of stroke on life (pages 1-6)

- Q → What restrictions did the stroke place on your life?

Appendix F: Narrative group therapy intervention protocol

Externalising – invite participants to name their ‘stroke problem’, and write down or draw what stroke is like to them, if willing, ask participants to share their representations to draw out common themes and develop group narrative

- Q → How did the stroke affect your life? What parts of your life did the stroke affect? Work? Family? Hobbies? Relationships? Sex?

Session 2

Link to previous session – group exercise to use graphical representations of stroke to explore the effects of stroke on the lives of the group members, by drawing a spider web around the ‘stroke’ with connecting links to the effects.

Tracing the history and deconstructing – enquiry into the problem’s history and the history of the person’s relationship to the problem, taking into account people’s wider contexts and cultures that assist in sustaining it with the aim to deconstruct these. Work as a large group and in pairs, and use the handbook to plot the relationship with stroke over time.

- Promote the conversation about the relationship between the person and the problem, rather than the identity of a ‘problem-person’. Move away from problem-saturated identities

Session 3

Identifying unique outcomes - therapeutic conversations will be guided towards exploring times when the problem had less, little or no influence over the person. Group members to fill out positive and negative timelines in handbook (p.7-8) and share safe examples with the group. The aim is to contribute to a ‘richer’ description of a person’s life, their values, commitments, beliefs, and strengths etc, and to assist people in reconnecting with these.

- Ask ‘relative influence’ questions to promote the realisation that beliefs and ideas are challengeable and find the unique outcome. Once the unique outcome is noticed, participants will begin to notice that they have already challenged the belief already, maybe in a small way, and this is the beginning of the development of a re-authored account of the person’s relationship with the problem
- Consider the power of the beliefs and the things the beliefs have stopped the participants from doing
- Consider the successes, memories and accomplishments each person has made since their stroke (p.9-10)

Appendix F: Narrative group therapy intervention protocol

- **Q → What were the first signs that you challenged the stroke? What impact did this challenge have on you? What impact did it have on others around you?**
- **Q → How did you prepare for this challenge? What helped you to become ready? What actions by you made a difference? Is there anything in your past that supported you to make this challenge? Which person in your past would be least likely to be surprised by this development?**

Session 4

Link to previous sessions – attempt to identify common themes or problems that emerged from the spider web in session 2

Externalise and personify stroke – use techniques and exercises used in previous sessions to provide a framework for individual stories from group members to be heard, use the group to identify changes in stories since session 2, discuss the similarities and differences in these changes. Revisit handbook pages 7-10.

- **Help to develop the re-authored accounts by linking the unique outcomes which highlight strength, individual agency and awareness of the wider social pressures**
- **Q → How would you measure the influence you have had over your stroke? How did you measure the influence the stroke had over you? What helped tip the balance in your favour?**

Session 5

Widen the audience – build on the previous session that focused on unique outcomes by using a reflective team exercise to thicken alternative stories and develop the emerging 'group narrative'. Discuss wider cultural beliefs that assist in the maintenance of the problem and continue to build on multiple perspectives of the problem. Consider how the group can help to prevent the problem making a comeback and what life might be like without the problem.

- **Q → What did you discover about yourself? What did others notice about you? Who were the important people who did not notice the challenges you have made? What would you have liked them to have noticed?**
- **Consider a team of witnesses or supporters who could see the participant as more than their stroke – past and present**

Appendix F: Narrative group therapy intervention protocol

- **Role of facilitator and group members to validate the new accounts and pull out the alternative stories from what the group members are sharing**
- **In pairs → one participant can share a story of how they have challenged the effects of their stroke, and then the other partner can consider the following questions → What expressions caught your imagination or struck a chord with you? Was there a specific word that struck you in particular? Was there a particular image the story evoked? What did the words tell you about the other person's values, beliefs and hopes? What is it about your experience that accounts for why these words struck you? What do you think you might have learned from this conversation?**
- **For homework – ask members of the group to write letters, in which they make their commitments to their alternative stories about themselves known.**

Session 6

Witnessing change

- **In pairs → Group members will be invited to share their letters, and then their partner will feedback their achievements to the wider group**
- **As a large group, identify the similarities between people's letters and the shared narrative of the group. Ask the questions → What expressions caught your imagination or struck a chord with you? Was there a specific word that struck you in particular? Was there a particular image evoked for you? What did the words tell you about the group's values, beliefs and hopes? What is it about your experience that accounts for why these words struck you? What do you think you might have learned from this conversation?**
- **Use handbook pages 11-13 to reflect on how far the group has come.**
- **Use the last part of the group to celebrate member's achievements and document commitments based on alternative stories.**
- **Focus group and completion of measures**

Narrative Therapy Workbook



What is your stroke character like?

Is it a like a person?

An angry man?

A spoilt child?

An irritating
neighbour?

A dreadful
mother-in-law?

Is it like an animal?

A sneaky snake?

A heavy elephant?

A black dog?

A spiteful cat?

Or maybe it is just an
indescribable blob!

What does your stroke character look like?



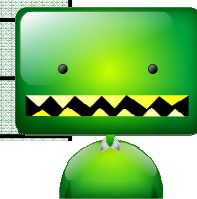
My stroke character can be described as...

My stroke character's name is



How does your stroke character affect you?

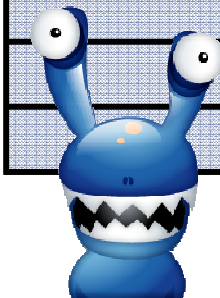
What does it do?



What are its tricks, methods or rules?



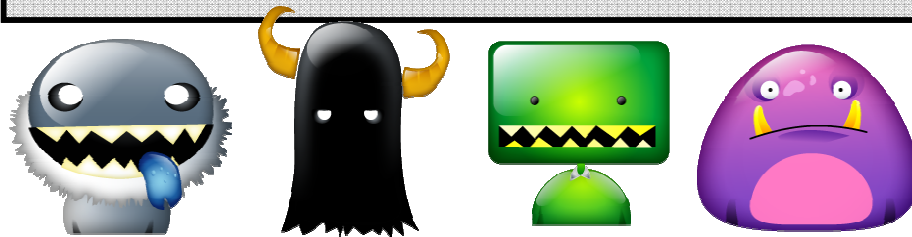
What does it make you think?



What does it make you feel?



How has it affected your
hopes for the future?



How is your character likely
to behave in this group?

In the last year

Positive
events
timeline

A vertical timeline for recording positive events. It consists of a central vertical line with eight horizontal tick marks extending to the right, and seven horizontal lines extending to the left, providing a space for writing.

In the last year

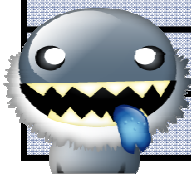
Negative
events
timeline

A vertical timeline for recording negative events. It consists of a central vertical line with eight horizontal tick marks extending to the right. The first tick mark has a short horizontal line extending to the left, serving as a starting point for writing.

How come my stroke character
could not spoil the positive
events identified?



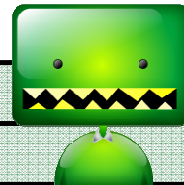
What does this say about my
values, desires and preferences
and my ability to follow these?



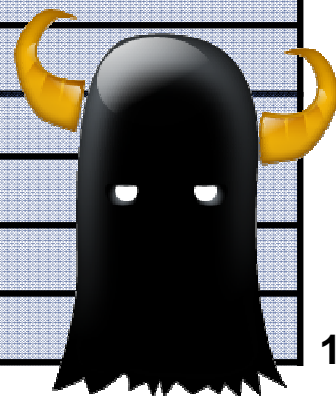
Who would be least surprised
by you saying this?



What does this mean
for the future?



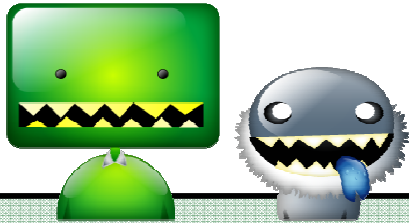
How can the group use its closeness to keep the identified problem from making a comeback, to prevent it from being so strong and powerful?

A black, ghost-like figure with yellow horns and white eyes, positioned in the bottom right corner of the page.

If all the troubling characters
we have named were to go to
another room and we were left
here without them, **what
would it be like here...**

[illegible]

... and what would it be like over there?

[illegible]

Any other thoughts...?

[illegible]

Appendix H: Stroke Specific Quality of Life Scale (SS-QOL)

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Appendix I: Ways of Coping Questionnaire (WCQ)

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Appendix J: Brief Illness Perception Questionnaire (B-IPQ)

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**Narrative therapy groups for survivors of stroke
Participant Information sheet (Version 4, October 2012)**

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to understand why the research is being done and what taking part will involve. Please take time to read the following information carefully and discuss it with others if you wish. *Please ask the investigator any questions you may have about the study.* Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are investigating how people who have suffered a stroke view their condition and any problems they may have with adjusting to the change in their lives. This is an important area for investigation because how people feel they are coping and their adjustment following a stroke can affect rehabilitation and the speed of recovery.

Who is arranging the research study?

The research is being carried out by Amy Mulroue, as part of her Clinical Psychology Training, and Dr. Janet Rich, Clinical Psychologist. The study is being carried out in collaboration with Professor Paul Camic at Canterbury Christ Church University and is funded by Canterbury Christ Church University.

Who has reviewed the study?

The study has been reviewed by the City Road and Hampstead Review Ethics Committee.

Appendix K: Participant Information Sheet

What does taking part involve?

Taking part in the study will involve participating in 8 weekly narrative therapy group sessions. Narrative therapy is a therapeutic technique that sees problems as separate from people and uses conversations to help people discover their unrecognised skills and strengths. Narrative therapy focuses on ways of coping and feelings of control and these techniques have been demonstrated to be effective in helping adjustment to chronic health conditions and disability.

The groups in this study will be made up of 10-12 people. The group meetings will last for two hours and will be recorded on a digital voice recorder, with the recordings stored on an encrypted device, until they are destroyed at the end of the study. Taking part in the sessions will involve contributing to the group discussion, working in pairs and writing in a workbook, which will be yours to keep at the end of the study.

In order to evaluate the effectiveness of the narrative therapy groups, you will be asked to complete three questionnaires on three separate occasions – before the group starts, once the group has finished, and two months after the last meeting. The questionnaires ask about how you are feeling since your stroke and how you feel about the effects of your stroke. The questionnaires will be coded so that you cannot be recognised from them.

Are there any risks involved in taking part?

There are no obvious risks involved in this study. However, at times people may feel uncomfortable talking about their stroke and how they have changed. We hope that attending the group will be supportive and we will be sensitive to the information that is shared. If you do become upset, then the group

Appendix K: Participant Information Sheet

facilitator will be available for you to talk to, if you wish, or we can provide information about further support. All information will be treated in confidence.

It is important to remember that the experience of stroke is very individual. Different people encounter different degrees of disability, difficulties and distress, and everybody is on their own personal journey of recovery. Some effects of stroke are clearly visible, but other difficulties can be 'unseen'. Participation in the narrative therapy groups will involve sharing experiences with other people who have also had a stroke, and whom might be at a different stage in their recovery.

Are there any benefits to taking part?

You will have the opportunity to engage in a supportive group and you may find the content of the group and the workbook helpful.

Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. You will also be given a copy of your signed consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If your ability to provide informed consent changes during the study, we would like to use the information you have provided, but we would not ask you to participate further. If you do not wish to take part, the standard of your medical care will not be affected.

Appendix K: Participant Information Sheet

Will my travel expenses be paid for me?

We are unable to pay travel expenses, but we can provide NHS transport to attend the groups. The initial meeting with the researcher can take place at a location convenient to you.

Will anyone else be told about my participation in the study?

We would like to inform your GP of your participation, with your consent.

Confidentiality

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you will be anonymous so that you cannot be recognised from it.

What will happen to the results of the research study?

Participants in the study will not be identifiable from the results. The results will be written up and submitted to an academic journal for possible publication. The study will also be written up and submitted to Canterbury Christ Church University as part of a submission for a Clinical Psychology Doctoral degree. If you wish, we can send you a short report about the findings of the study.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study the normal National Health Service complaints mechanisms are available to you and are not compromised in any way because you have taken part in a research study.

Appendix K: Participant Information Sheet

If you have any complaints or concerns please contact the project co-coordinator: Dr Janet Rich, 01323 648 275

Otherwise you can use the normal university complaints procedure and contact the following person: Professor Paul Camic, Department of Applied Psychology, Canterbury Christ Church University, Salomons Campus at Tunbridge Wells, Broomhill Road, Southborough, Tunbridge Wells, Kent, TN3 0TG

Who do I contact for further information?

For further information about the study, please contact Amy Mulroue, Department of Applied Psychology, Canterbury Christ Church University, Salomons Campus at Tunbridge Wells, Broomhill Road, Southborough, Tunbridge Wells, Kent, TN3 0TG.

Telephone: 07989 67 66 97 Email: am466@canterbury.ac.uk

Appendix L: Participant consent form

CONSENT FORM (Version 4, October 2012)

Title of Project: Narrative therapy groups for the survivors of stroke.

Name of Researchers: Amy Mulroue and Dr. Janet Rich

Please initial box

1. I confirm that I have read and understand the Participant Information Sheet (version 4 October 2012) 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 may be looked at by individuals from Canterbury Christ Church University, or from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

4. I agree to my GP being informed of my participation in the study

☐

5. I agree to take part in the above study, and for the group sessions to be recorded.

☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Name of Researcher

Date

Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix M: Table documenting theme development process

Master Theme	Sub theme	Initial code relating to sub-theme
Positive Talk	Achievement	Regaining practical skills
		Relearning physical skills
		Finding new opportunities
		Satisfaction with achievements
		Sharing achievements with others
	Adaptation	Finding a new way to do things
		Finding a new way to think about things
	Good Experiences	Good experiences of NHS care
Using the group	Comparisons	Comparisons between stroke and other health conditions
		Comparing own experiences to others' experiences
		Recognising differences
		Recognising similarities
	Information	Seeking Information
		Sharing Information
		Availability of information
		Gaining Information
	Expectations for the group	Hoping to gain something
		Difficulties of being in a group
Negative Talk	Difficult thoughts and emotions	Thoughts about death
		Emotional reactions to the consequences of stroke
	Unmet Expectations	Medical professionals & NHS
		Recovery
		Own body
		Support from society
	Loss	Loss of independence
		Loss of future plans
		Loss of friendships
		Loss of spontaneity
		Loss of identity through loss of job
	Restrictions	Limitations in practical skills
		Impairments
		Restricted options
		New rules to follow
Relationships	Relationship to stroke	A previous whole, now in pieces
		A constraining presence
		Mismatch between language and experience
	Relationship with other group members	Use of humour to normalise experiences
		Encourage each other
		Provide an alternative voice
	Relationship with family and changes in roles	Appreciation of role of partner
		Sex/intimacy with partner
		Closeness in relationships
		Accept Support
		Stable factors in relationship

Appendix M: Table documenting theme development process

		Male-female/ Adult-child/ Parent-child/ Wife-carer
	Relationships with wider systems	Difficult relationships, unsupportive experiences with medical professionals
		Supportive relationships with medical professionals
		Expectations of masculinity
		Expectations of disability
		Expectations of help

Appendix N: Excerpts of transcripts from group sessions with initial coding

This has been removed from the electronic copy.

Appendix O: Audit trail of master themes, sub-themes and sample quotes

Master Theme	Sub theme	Initial code relating to sub-theme	Example quotes	Source
Positive Talk	Achievement	Regaining practical skills	"... driving"	Group 3, P3
			"And when you did [drive]?" / "I just felt normal, I was just so determined"	Group 4, F & P1
			"Making a cheese sauce [...] from scratch"	Group 3, P2
			"Playing table tennis again"	Group 3, P5
			"Going back to work"	Group 3, P3
		Relearning physical skills	"Losing my left hand, learning how to write again"	Group 3, P4
			"Learning to walk without a stick"	Group 3, P5
			"You were about to say, you'd been learning to..." / "Dress myself"	Group 4, F & P7
			"...I had to learn everything again"	Group 4, P6
			"How many of you have had to relearn to walk?" / "All of us, I think" / "Most of us, I would have thought"	Group 4, F, P5, P3
			"It's about targets, the things I want to do. I want to walk, I want to [inaudible], I couldn't do that then, I want to talk again, which I couldn't do before, it's like starting again. It's the targets, I want to do and I push myself til I do it"	Group 3, P6

Appendix O: Audit trail of master themes, sub-themes and sample quotes

		Finding new opportunities	"We do far more sitting around"/ "Do you? Is that a good thing?"/ "No bad"/"What does that give you the luxury of, when you have to sit around though?"/ "Only reading, that's all"/ "Only reading"/ "Which I didn't do a lot before, so I guess is an improvement. I read more."	Group 3, P4 & F
			"But you've all, before the stroke would you have had the time or the inclination"/ "What, to do something like this? No!"/ "I wouldn't have bothered"/ "I wouldn't have time"/ "But that's a huge thing that you've done"/ "We're here to help. Here to help other people and ourselves"	Group 4, F, P2, P3,
			"My wife and I only got two days a month together, basically,"/ "Before?"/ "Yeah, because of my work and her work. Now, of course we've got more time"	Group 3, P2 & F
			"Yes, I'm the media volunteer, that's why, for the SA. I volunteered because I want to say things about, and have an opinion, so I actually put myself forward for that role"	Group 3, P3
			"You use time more effectively now"	Group 3, P3
			"And I do cooking and things, normally I would just cut out the recipe and keep it in a drawer and now I cook it, and so I concentrate on the things that I can do."	Group 6, P1
		Satisfaction with achievements	"You've got to set yourself something to do, and make sure you do it, and if do it, feel good."	Group 4, P6
			"I have money now and time and I make art stuff, I can do it, I couldn't, I had to work, course. That's one thing, two, I can't do anything. I can't speak, I can't read, I can't anything, but happily art I am able to do that. That's what I'm saying, my life has very lucky because art, I can still doing that."	Group 4, P10

Appendix O: Audit trail of master themes, sub-themes and sample quotes

			"I thought I was enjoying life. I probably enjoy it now more"/ "We've got a new life"/ "Exactly. But I've had to make a new life"/ "Make a new life, yeah"	Group 3, P3 & P6
		Sharing achievements with others	"They don't comment. I managed to get up two steps, I managed to get up them, and I felt wonderful, I thought, but my wife just walked up"/ "That's an achievement of yours isn't it?"/ "Yes, to me, but to other people, it don't mean a thing"	Group 3, P6 & F
			"Oh, yes, they are very encouraging. I say I've done this or I can't do that and they say , its only three months so it will come"	Group 4, P1
			"Who in your life, alive or dead, would be least likely to be surprised about what you've been able to achieve?"/ "My wife"/ "And mine, and my children too, and my doctor believe it or not. She said you'll get through, because you are so determined"/ "I think my children."	Group 3, F, P3, P5, P4
	Adaptation	Finding a new way to do things	"You've got to learn how to do things. You have to take control. I've got to find ways of doing things, the same things, but instead of talking me 5 minutes, it takes me 5 weeks"	Group 3, P6
			"But you find other ways of doing it"	Group 2, P6
			"I use the same set of skills, but I've got to find a different way round. Same problem, but I've got a different way of curing the problem"	Group 3, P6
			"...but when you walk around with this great big heavy, heavy, heavy cloak, stroke, how does that make you change how you interact with your wider environment?"/ "I just do the same things"/ "You do the same things, Do you do the	Group 2, F & P6

Appendix O: Audit trail of master themes, sub-themes and sample quotes

			same things?"/ "No, I think I do, but I tend to take longer"/ "Do you feel self conscious in your social environment, because you take longer"/ "I just do what I know I can do"	
			"Yes, and I forget, I can't do the things I used to do. Instead of using one hand, You've got to use two hands"	Group 1, P2
			"Cos you know what you used to be able to do, rather than get frustrated, I just channel my energies into finding another way to do it"	Group 1, P3
			"My wife does all the cooking, and at the end of the meal, she'd say I wish someone else would do this and that, and so I brought a trolley, so now I can clear everything, plates and put them in the dishwasher. [...] She does appreciate it, yes. I must say when I'm walking, I usually use my stick all the time, but I've managed to use the trolley as my stick. As long as the trolley doesn't run away, that's all that matters!"	Group 3, P4
			"One thing I want to try is, I used to enjoy gardening very much, and even weeding and that sort of thing, [...] The fact is, that there is a border there and I often say to my wife, corr there's a load of weeds in there, they want to come out, but I know that she has enough to do without getting down and doing those. I can't get on my hands and knees, so what I've thought to myself is, I've got a long handled little fork, I can loosen those up and I've bought a grabber. I thought well, I can pick it up with those, I haven't tried it yet, but I'll try."	Group 3, P4
			"I can't do it now, but I can later. Because I set myself the target and I can manage to do it now. Not as good. No where near as good. But I can do it [...] in a different way"	Group 4, P6
			"Yes, If I've got water and I tip back, that's when I choke. If I	Group 4,

Appendix O: Audit trail of master themes, sub-themes and sample quotes

			sit forward and drink I'm alright"	P4
			"The seat over the bath"/ "Yeah, I don't want one of those"	Group 1, P3 & P2
			"I used to do everything when they went out [...] I wasn't allowed in the garden, so I used to wait til they went out and go out in the garden and do things and then tell them when they got back!"	Group 1, P6
			"Think about everything, think about the things you can't do, you've got time to work them out"	Group 2, P6
		Finding a new way to think about things	"Acceptance [...] It's the realisation that there are certain things that you can't do"	Group 2, P1
			"In time you make new friends, and you lose old ones and make new ones"	Group 2, P6
			"Yes, I am much calmer now"	Group 3, P1
			"Perhaps I'm lucky cos perhaps I've got stronger; my personality has got stronger because of the stroke."	Group 1, P3
			"Yeah, I think my stroke made me more, sort of, determination, and it just brought out another quality that I probably had inside me already, without being too big headed, ummm, and made it stronger."	Group 1, P3
			"Yes, My stroke is on my right and I'm left handed, so that was lucky."	Group 1, P1
			"Strength of recovery, I think. Perseverance to get out the other end"	Group 4, P5
			"But it's all these small things that give us hope and give us encouragement to carry on. The worst thing is trying to do	Group 2, P5

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			something and not improving”	
			“And also with me, is a determination to get well again. But that’s because mine was slight and the possibility of recovery is good.”	Group 1, P1
			“So despite it all, you’re determined to do...?”/ “Well, to get back where I was before the stroke, that’s the objective. But unless you’ve got determination, I don’t think you’re gunna to succeed”	Group 3, F & P5
			“But I’m not pushing too hard, I’m just letting it take its time.”	Group 1, P1
			“Do you want to get back to where you were?”/“But you could get somewhere better”	Group 1, P6 & P2
			“...I’m going to leave you to have a think how your priorities have changed”/ “They have to. You have no choice. You’re forced to relax your standards for your own achievements and for your expectations.”/ “Is that a bad thing? Is that a good thing?”/ “Its curiously releasing”	Group 4, F & P1
		Good experiences of NHS care	“I really do defend the NHS”	Group 3, P1
			“I would have been dead. The ambulance response is good I find.”	Group 3, P4
			“See I collapsed early in the morning, in the bathroom, and my daughter is a medic, so my wife rang her up and she said dad’s had a stroke. Call 999, and within minutes the ambulance was there. [...] And then when I got here, they put me straight through a scan, and they knew exactly where it was, and so I’ve got no complaints”	Group 3, P5

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			"To be fair, I found the service I got to be really good"/ "So did I"	Group 3, P5 & P1
Using the group	Comparisons	Comparisons between stroke and other health conditions	"With the heart attack, you know, they checked it out, they said I could recover with stents, I have three stents, and then your back to A1"/ "But this is not the same is it?"/ "No, that's what I mean, they finish with you"/ "They fixed your plumbing, didn't they?"/ "But with Stoke, you can't fix the plumbing can they?"	Group 2, P4 & F
			"The difference, I've found, is that one of my very good friends have got cancer, [...] but the thing is, he had a Macmillan nurse that sorted out all the papers for him. People who have a stroke do not have any of that support"	Group 2, P2
			"Stroke is harder than cancer" The stroke is more, more, than cancer, actually."/ "For you the stroke is..."/ "I've had cancer, I really don't need stroke"	Group 6, P10
		Comparing own experiences to others' experiences	"So, has everybody been in hospital?"	Group 1, P2
			"Everybody dialled 999 and..."	Group 1, P2
			"Can I ask what sort of pills everybody is on?"	Group 1, P2
			"I saw you holding your hand, is your hand always cold?"/ "Cold, yes"/ "Mine is too"	Group 1, P1, P10
			"I'm so bloody lucky"	Group 4, P2
			"I do feel lucky"/ "But it is easy to feel lucky when he sees me, and he sees [...] trying to walk"/ "Yeah"/ "You want to	Group 3, P2, P6

Appendix O: Audit trail of master themes, sub-themes and sample quotes

			come along on a Monday afternoon and see people in a wheelchair. They can't walk. It makes you appreciate what you have got."	
			"You assess yourself against others"	Group 3, P5
			"I can't shower on my own"/ "I can shower, but I can't bath... I can't get in, can't get out"/ "Oh I can't"/ "You got that seat thing?"/ "Pardon?"/ "That seat thing"/ "The seat over the bath"/ "Yeah, I don't want one of those"	Group 1, P4, P2, P5, P3
			"But I can walk"/"Well, that's something"/"I can talk"/"Good"/"Well, that's not too bad then is it?"/"No, no, I'm not really complaining"	Group 1, P2, P4, P5, P7
			"And when did your mind get back into gear? [...] Cos mine, for two months I've sat at my desk and just nothing happened"	Group 3, P1
			"Is your concentration gone?"	Group 1, P1
			"Are you one of these people who like their own company?"/ "Me, no, well, not really. But I don't mind, I don't have a problem with it"/ "I hate being on my own. I don't like my own company at all"	Group 4, P2 & P5
			"For me, I see people in a wheelchair on a Monday, and I think I'm better off than him, cos I can walk round alright"	Group 6, P6
		Recognising differences	"No, I'm living alone"/"Oh right"/"It must be terrible then"/"Do you have a pet?"/"No"/"Nothing?"/"But I have daughters, and they are supportive"	Group 1, P1, P5, P2, F
			"Its affected us all in different ways and different severity."	Group 4,

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			You have trouble reading but you can write, you can talk. I can't talk properly, but I can read. I can read and I can learn how to talk, I go to classes and I come here, even here and talk"	P6
			"But I'm probably one of the youngest here and..."	Group 1, P2
			"Some people are more able than others to get this information"	Group 1, P5
			"And also with me, is a determination to get well again. But that's because mine was slight and the possibility of recovery is good."	Group 1, P1
		Recognising similarities	"Cos like you said the other day, you are learning about stroke through everybody else as well"	Group 3, P2
			"I think you'll find we're all the same"	Group 1, P5
			"What about socialising?" / "It is very hard work. Do you find the same?" / "Yes, I don't bother really"	Group 2, F, P1, P6
	Information	Seeking Information	"...Why should someone need to do a risk assessment on me for a job that I've done for 13 years?" / "Well, they have to do a risk assessment anyway" / "Why?" / "Cos that's part of the law. Don't matter if it's for you or anybody else [...] that's not an individual thing" / "So that's nothing to worry about?" / "No, it's nothing to do with you individually" / "Oh right. Oh that's new laws that I didn't even know about. I should go and have a look on the internet"	Group 3, P2 & P3
			"Exactly. I think knowledge has been my greatest healer for my stroke. [...] Well, the more knowledge I sort of gained being part of the groups and reading stuff about stroke, the	Group 3, P3

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			more I understand about it, the more I can come to terms with my own stroke. And now I don't see it as a disability to me, it may look like a disability but I've just learned that now, like everyone else has here, to do something differently. You still do the same things, you just do everything differently."	
			"My wife finds for me what she can, and what I can do and what I cant do. I'll try anything once. Why am I here? Why am I here? Cos I think it might help, either me or somebody else."	Group 2, P6
			"Your partner or wife, or whoever, carer, you know, they have enough to do without trying to find out where you can get help and support."	Group 1, P5
			"We've all got individual needs, and we need the information to get out of the system, as much as we can"	Group 6, P6
		Sharing Information	"Perhaps it was what I'm put on this planet for, perhaps I was here to do this group, you know. I don't want to upset anyone, but I don't believe in religion, or anything, but perhaps fate has put this in my way to do this for everyone else. I've put my experiences down in a book, cos I've written a book, myself, which will be going online soon, so anyone can read it, which is only 84 pages, but it explains my life and my stroke, in experiences with my family, and my friends, so, they've all written piece about my stroke. [...] So others can understand, a way of sharing the stroke with everybody"	Group 1, P3
		Availability of information	"What do they think you should be doing anyway? What ever the rule books say, is what they say, and the rule books aren't there for the stroke survivors. Everything is different, cos we're all different"	Group 1, P3

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			"Its information, its information all the time"/ "Lack of"/ "Lack of, yes"/ "If the information was there, you wouldn't have to fight to get it."	Group 2, P2 & P6
			"Lack of good information"	Group 2, P5
			"I think we all don't want a reoccurrence of what we've got"/ "Yes, I'd agree with that"/ "Absolutely"/ "So do you do stuff to avoid it then?"/ "I don't know what to do for it"/ "Why do you think that is?"/ "Well, cos a stroke is not like a cold, it just gives you a whack and that's it"/ "So many factors, isn't there, into stroke"	Group 4, P4, P2, P1, P3
			"Your partner or wife, or whoever, carer, you know, they have enough to do without trying to find out where you can get help and support."	Group 1, P5
			"I think a handbook should be given to every stroke patient"	Group 1, P5
			"I think I said it before, there should be a little booklet that tells you what you need to do, and if somebody's had a stroke, they or their partners, or whoever, should be given the booklet so you know where to go and what to do."	Group 3, P5
			"Does anybody have anything they think needs to be aired, or thought about?" / "The availability of information towards individuals?"	Group 1, F & P6
			"I haven't had a stroke"/"OK! What did you have?"/"A bleed"	Group 1, P6 & F
		Gaining Information	"Your realisation, that every job has to go through a health and safety risk assessment, may be an achievement for today. Maybe you can tick that box."/ "I was just thinking	Group 3, F & P2

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			about phoning and speaking to some of the lads there and sorting out a risk assessment, you know"	
			"Cos like you said the other day, you are learning about stroke through everybody else as well"	Group 3, P2
			"So it shows you that when you've had a stroke, people should start talking to you, to encourage the neurons to grow, but you don't get any conversation at all"/ "That's fascinating. So this has allowed you to do that?"/ "This does, yeah, but this should be part of your first treatment really"	Group 4, P5 & F
			"That's where these groups come in handy, cos we can express what we want, and perhaps understand what we want better, so when we go out of the group, we can try and put it forward in your own lives"	Group 6, P3
	Expectations for the group	Hoping to gain something	"...but you all volunteered to come into the group, didn't you?"/ "Only to help"/ "Yes, I'm trying to connect it with the caring"/ "And to help myself."/ "Oh yeah, absolutely"/ "Hoping something good would come out of it"/ "Self-preservation"/ "But you've given something, haven't you?"/ "Yes"	Group 4, F, P5, P1, P4
			"I had no idea what to do and I, and what I'm trying to do, if you like. I was thinking about it, well, what's going to achieve, their going to achieve"	Group 4, P10
			"For me, it makes me think more deeply of me, inside me. You know, what's going on, and we talk about this. It doesn't just finish when we shut the door, it goes round a little bit"	Group 4, P3
			"I'm finding these group discussions very"/ "Therapeutic"/ "Yes, very therapeutic, and because you bounce off one another"/ "And tiring!"/ "They are tiring, do you not get	Group 3, P4, P5, P3, P2

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			tired?"/ "I think any mental working makes you tired"/ "You are mentally thinking about what your going to say before you've said it, in case you upset somebody else"	
			"But none of us would be here if we weren't determined, because we're here because we think we are going to get something out of this class"	Group 3, P1
			"Meeting other people"	Group 1, P2
			"Its an afternoon out"	Group 1, P5
		Difficulties of being in a group	"Talking about that, speaking in this sort of situation, everybody can speak, but I really have a problem, I can't speak and it's very very difficult. This particular situation I think it's stressful. Actually I've found before, stressed a great deal of this situation."	Group 4, P10
			"My god, it's like being back at school"	Group 1, P2
			"Its like the 11+"	Group 1, P5
Negative Talk	Difficult thoughts and emotions	Thoughts about death	"And on the other hand, if it had done the job properly, she'd have enough money to live on [...] No, the money, the insurance companies would have paid out, and that would have been all over"	Group 2, P2
			"...Something has been inflicted upon you, and if this thing had done a good enough job, then you wouldn't have to suffer the way you are suffering now?"/ "No, and nor would my family"	Group 2, F & P2

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			"If I'd have died, my wife could go on with her life"	Group 2, P6
			"They should have let me die"	Group 2, P6
			"They should have done a good job. [...] They should have finished me off. I would have been a lot happier than I am now, I can tell you that"	Group 2, P2
			"Depression, that is"/ "That is depression"/ "Well, no its not, its reality"/ "No, it's not everyone's reality"/ "No, it's my reality."	Group 2, P5, P6, P2, P1
			"First they said you've got to stop smoking, and I said alright, and then they said you've got to stop drinking, and I said alright, but then they said you've got to stop taking sugar, which I have, but what the hell's left? I can't drive."/ "You might as well die"	Group 1, P2 & P6
		Emotional reactions to the consequences of stroke	"Aggression is one of the worst things"	Group 1, P4
			"Yep, aggression"	Group 2, P4
			"We've all got good wives or partners, and they are very good,"/ "But we treat them badly, we speak to them badly occasionally"/ "I was going to say, sometimes, silly little things cause a niggle, and you get aggressive, and"/ "No, you don't mean to do that, but it is something you"/ "Yeah"/ "It's usually verbally, though"/ "Things you say. You don't realise what you've said, or that you shouldn't have said it"	Group 1, P4, P2, P5

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			"Aggravation, I 'spose"	Group 2, P5
			"Its frustrating"	Group 1, P6
			"That's what's frustrating"	Group 1, P6
			"I'm not angry, I'm indignant"	Group 2, P1
			"I find the frustration is cos I'm quite an independent guy, having to rely on other people all the time, which annoys me."	Group 1, P5
			"I'd agree with what X said, you know, the things I used to do, I just sit there now and watch others do it."/ "That's difficult though, isn't it?"/ "Yes, it is when you see them doing it not the way you'd do it. That's when it gets irritating"	Group 3, P5 & F
			"So basically our roles have been reversed, and I get frustrated, I hate it."	Group 3, P2
			"But they still cant get my balance back, which is frustrating"	Group 2, P2
	Unmet Expectations	Medical professionals & NHS	"The neurologist said to me, if you don't improve in two years, you wont improve [...] It just didn't give me much hope"	Group 2, P4
			"You may have had an expectation that society, NHS, was like a safety net, that would be able to catch you if something went wrong, and fix you. Then you are thrown into a system, and its very confusing, regardless if you've got any problems with understanding or damage in the brain that makes it	Group 2, F

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			more difficult for you to process anything. But you are thrown into a brand new system and you are having to negotiate your way, with your significant other, you are having to go into a system that doesn't look or communicate the way you thought it did."	
			"What follows after the stroke. I think they've got the first part right. They come and get you and sort you out, but then its after you've had the stroke"	Group 3, P2
			"Yeah, the only thing I would say, is what I said earlier on, is that the follow up is appalling"	Group 3, P5
			"Well, that's the point you see. They only give you, I mean, everybody here will tell you. You get 6 weeks and that's it, finished."/ "Then what happens? What happens after that?"/ "You're just left"/ "Left in the cold, kicked out"/ "Dumped on the pile"	Group 2, P3, F, P5, P6
			"Well, I'd say, sort of like, the NHS, the establishment. You have to be pig headed about being seen, cos today's target, in 6 weeks it will be this, and in 6 months it will be this, and you have to fight that all the way through"	Group 3, P3
			"You do have to accept it. But it does get very frustrating when they can't actually tell you [...] what the problem is"/ "I don't think they know to be honest"	Group 1, P2 & P5
			"So you were talking about your finding that it runs out very quickly, the support runs out very quickly"/ "Yes, the time span is too short"/ "So its limited"/ "Limited, yeah"	Group 2, F, P5, P6
			"Cos they don't know what's wrong with me. They said I've had a stroke, but I ain't got any better..."	Group 1, P2
			"The way I look at it, everybody knows that the NHS wants	Group 3,

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			more money and by lack of care at the beginning, in the long run it costs them more money"	P5
			"As we know, doctors don't know that much about stroke, do they? They know less than we do!"	Group 6, P3
		Recovery	"We want to get back to normal"	Group 3, P6
			"It's just that progress is slow."	Group 1, P4
		Own body	"Its very strange, I was very fit and suddenly, I had cancer and I was having a stroke"	Group 4, P10
			"Its that instant, you was alright, then in an instant, you half yourself"	Group 2, P6
			"Everything is all steady at one stage, and then all of a sudden, at the click of your fingers, your life is totally changed, upside down, inside out."	Group 1, P3
		Support from society	"I'm 57 now, and I started work when I was 14 and half, and I've never claimed for anything in my life. And you get old no, you can't have anything. You're not entitled to anything"	Group 2, P2
			"That's right. What I've had is, one or two acquaintances have said, I've known someone whose had a stroke and they're back at work now"	Group 2, P2
	Loss	Loss of independence	"I don't know your situation, but when I walk around the street, I can fall and hit my head all the time, just all that time, I mustn't, I must think about it at each moment. That sort of situation, walking around in London, would be great, but it is impossible for that reason"	Group 2, P10
			"You lose your independence, that's the problem"	Group 1,

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				P5
			"Yes, your independence is gone"	Group 1, P5
			"You lose your own freedom"	Group 1, P3
			"I don't go on my own [...] I get someone to take me"	Group 2, P6
			"Your life is controlled"/ "You've lost your independence, I think"/ "You're controlled by"/ "Loss of control, ain't it"	Group 2, P2, P5, P3
			"I find the frustration is cos I'm quite an independent guy, having to rely on other people all the time, which annoys me."	Group 1, P5
			"I can't go where I want to go, do what I want to do"	Group 1, P6
			"You haven't a choice"/ "You know, I don't like people helping me, I get annoyed, cos I think I should be able to do it on my own"/ "Don't get a choice, otherwise you'd do it"	Group 4, P1, P2, P6
			"Nah, I can't do anything. I am learning slightly to compensate, but I get driven everywhere and I have to ask if I want to go somewhere in particular."	Group 1, P6
			"I have to ask people to do everything"	Group 1, P6
			"I'm reasonably active, but the thought of going to London on my own, for example, which is something I'm used to doing, is an enormous, I couldn't face it, I know. I'd need my daughter, or someone with me"	Group 2, P1
		Loss of future	"2008 I retired, 2009 I had a heart attack, 2010 I had the	Group 2,

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		plans	stroke”	P4
			“A lot of us had only just retired and then we had our stroke. I’d only been retired three weeks and bingo”	Group 2, P5
			“I retired in the August, and then had this, and that was it.”	Group 2, P6
			“Yeah yeah, I retired and I wanted to play a lot of golf, and that was the end of that. Retired in January, had this is February, and that was the end of it. I can’t even grip a golf club now, with my hand. So that’s my main objective, to get back on the golf course.”	Group 1, P5
			“There is also the loss of hope. You can’t make forward plans, or travel or anything like that [...] just little things in your life, that you want to look forward to, that you plan and want to do”	Group 2, P1
		Loss of friendships	“I’ve got no friends. The people I thought were my friends have disappeared. I make new friends”	Group 3, P6
			“That’s the thing, you find out who your friends are”	Group 2, P2
		Loss of spontaneity	“Thinking is difficult”/ “Thinking ahead, isn’t it”/ “Thinking that you’ve got a problem and you cant think about it how you would normally think about it”	Group 2, P5 & P3
			“In my head, I can tell them the right thing, but I can’t let them see me. In my head I can talk, but it comes out of here, and they cant understand what I say, it don’t matter [tearful]”	Group 2, P6
			“I sat down in plenty of time and I planned it. I planned what I was going to do. For weeks I sat down and looked at them,	Group 3, P6

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			and I walked up one day, and I was worried I would fall backwards and hurt myself, but I walked up and down and practiced a couple of times without falling over, and I thought I'd done well, but I'm tired!"	
			"No... Today I planned that I was coming out, but if I haven't got anything on I just stay indoors."	Group 1, P2
		Loss of identity through loss of job	"Going from working 60, 70, 80 hours a week to not doing nothing at all"	Group 1, P2
			"In case my employers, I go back to last week and paranoia, and I was paranoid that they wanted to get rid of me, cos it was just like, the money dried up, they weren't paying me, the SSP dried up, it was like well. It felt like they didn't want to have me, so I had to sort of have to prove that I was worth employing and we could make a position available"	Group 3, P3
			"Basically I was running the place, when my big boss was away. But 6 months ago I resigned, you know, I had 6 months on SSP, and basically, I resigned before I was pushed, cos I thought it would be better if I resigned"	Group 3, P2
			"...Why should someone need to do a risk assessment on me for a job that I've done for 13 years?" / "Well, they have to do a risk assessment anyway" / "Why?" / "Cos that's part of the law. Don't matter if its for you or anybody else [...] that's not an individual thing" / "So that's nothing to worry about?" / "No, its nothing to do with you individually" / "Oh right. Oh that's new laws that I didn't even know about. I should go and have a look on the internet"	Group 3, P2 & P3
	Restrictions	Limitations in	"I don't know your situation, but when I walk around the	Group 2,

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		practical skills	street, I can fall and hit my head all the time, just all that time, I mustn't, I must think about it at each moment. That sort of situation, walking around in London, would be great, but it is impossible for that reason"	P10
			"That's why I stopped driving, why I've been told to stop driving"/ "That is really hard"/ "Tell me, how do we all think the same about that sometimes, I don't know, I get very frustrated about it all"/ "About driving?"/ "Well all do, I think"/ "Yes, I do"	Group 4, P2, P10, P6, P5, P4
			"When it comes to work, you know, my old job, well, I resigned, I resigned, cos basically I can't drive now either"	Group 1, P2
			"I used to be a driver. I drove everywhere, every week."/ "So did I"/ "Now, I can't"	Group 1, P6 & P1
			"Yes, it is the simple things like eating, and you can't use a knife and fork, cos you can't use something in both hands."	Group 1, P4
			"My wife cuts up my food and I eat it with a fork"	Group 1, P4
			"Its all the things that you can't do, that you used to do"	Group 1, P6
			"I'm reasonably active, but the thought of going to London on my own, for example, which is something I'm used to doing, is an enormous, I couldn't face it, I know. I'd need my daughter, or someone with me"	Group 2, P1
			"With me, with my balance, I used to be able to carry, 4 cups of tea, 5 cups of tea into the lounge at one go, but for god's sake I can't carry 2 now"	Group 1, P2
			"I'd agree with what X said, you know, the things I used to do,	Group 3,

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			I just sit there now and watch others do it.”/ “That’s difficult though, isn’t it?”/ “Yes, it is when you see them doing it not the way you’d do it. That’s when it gets irritating”	P5 & F
			“I can do it, but they wont let me get up a ladder to do it”	Group 1, P5
			“I can change a bulb, I can do the wiring, I know what to do, but I just can’t get up there,”	Group 1, P6
		Impairments	“Well you don’t know do ya? You talk and talk normally in your head, but what comes out is rubble. People try to understand what I say, and you think your saying the right words, but you’re not saying the right words.”	Group 1, P6
			“Yes. There are things I can’t do now, I can’t read, I can’t speak, I can’t talk, or write as well, I can’t do my gym. I like this, and this and this, but I can’t do it.”	Group 2, P10
			“What goes on in here is different from what comes out your mouth. So have to think about what to say, you have to plan it, and then make them understand. Whereas people now, can give the answer straight away, but we’ve got to plan ours”	Group 4, P10
			“In my head, I can tell them the right thing, but I can’t let them see me. In my head I can talk, but it comes out of here, and they cant understand what I say, it don’t matter [tearful]”	Group 2, P6
			“So you have to think about different ways of doing things, but you have to think twice as hard to get from A to B or to do...”/“I don’t go from A to B”/ “What do you do?”/ “I get taken”	Group 2, F & P6
		Restricted	“You can’t make forward plans. Well, I’d love to go on	Group 2,

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		options	holiday, abroad, where the sun shines on your back [...] Do you pay £100 to buy a passport and then not be able to get travel insurance, think about it. If I went abroad and there was a problem again, how much would it cost? I would not get cover."	P2
			"I think it is more boring"/ "You think it is more boring?"/ "That's depression"/ "My life's just boring"	Group 2, P2, F, P6
		New rules to follow	"They tell me I can't drink, can't smoke, can't take sugar, well, I can't do bloody nothing really"	Group 1, P2
			"Yeah. I was told I had to stop smoking, so I stopped smoking. I had to stop smoking, we didn't have any money to buy them."	Group 4, P2
			"First they said you've got to stop smoking, and I said alright, and then they said you've got to stop drinking, and I said alright, but then they said you've got to stop taking sugar, which I have, but what the hell's left? I can't drive,"	Group 1, P2
			"It's the case with me, basically, if its cold, I don't go out, I don't go out. I live in the middle of [the] high street, and if it's cold I won't do out."	Group 1, P2
Relationships	Relationship to stroke - externalisation	A previous whole, now in pieces	"Yeah. It's the jigsaw pieces in a smile, because its like, when you, I class my stroke as a jigsaw piece that's fallen on the floor but made of infinity pieces, yeah, so the only picture you've got to put it back together is the past, present and the future, but you haven't got a picture of any of it, what you've got left to try and put the pieces back together is"/ "Are some of those pieces lost?"/ "Well, not necessarily lost, just scattered, if you image, just infinity amount of pieces, and to try and pick one piece up at a time and put it back together,	Group 1, P3 & F

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			and the smiling bit is when you get a piece and you put it together. Internally you think, I've done something, I got another piece of my life back, and eventually you put another piece of the jigsaw in there, and you get another piece of your life back."	
			"If you are working in pottery, you'd just have broken bits on the floor where you've thrown it at the wall in frustration"	Group 1, P4
		A constraining presence	"I've heard this said before, a stroke is worn like a cloak, and you can't shake it off."	Group 1, F
			"Me, with a question mark over my head, in a prison"	Group 6, P6
		Mismatch between language and experience	"Why is it called a stroke? Does anyone know? I've not thought about it. It is quite a nice word, stroke"/ "That's the problem with the word. Its too nice"/ "It is"/ "Brain damage, brain attack, its more hard hitting. It doesn't hit hard enough"/ "No, your brain hasn't been stroked nicely, its been"/ "Exactly, its been attacked, yeah"/ "Very true"/ "The word is too nice. It's the wrong word"	Group 2, P1, P3, P5
			"My wife had a mini stroke, and ever since then she's gone down and down and down"	Group 1, P7
		Change in relationship	"It has made me think about the stroke differently. So I can now distinguish between me and the stroke,"	Group 6, P3
	Relationship with other group members	Use of humour to normalise experiences	"It's the old things isn't it, if you don't laugh you cry"/[...]/ "Well, with stroke you do both anyway"/ "Simultaneously!"	Group 4, P2, P3, F
			"Yeah, we learn to laugh at each other, don't we [...] Not that we are laughing at each other, just expressing support, I	Group 4, P3

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			suppose”	
			“We take the micky, but we’re the same. I take the micky out of X and he takes the micky out of me, and X and we are all together”	Group 4, P6
		Encourage each other	“Your talking’s got better since you’ve been here”	Group 4, P1
		Provide an alternative voice	“She doesn’t feel that way, I’m sure”	Group 2, P1
			“And on the other hand, if it had done the job properly, she’d have enough money to live on”/ “But I guess she would prefer to have you around, than not around at all”	Group 2, P2 & P1
	Relationship with family and changes in roles	Appreciation of role of partner	“We’ve all got good wives or partners, and they are very good,”/“But we treat them badly, we speak to them badly occasionally”	Group 1, P4 & P2
			“Are you on your own, or are you married?” / “Oh, no, I’m married, thank god! Well, I am at the moment”	Group 1, P5 & P2
			“No, I’m living alone”/“Oh right”/“It must be terrible then”/“Do you have a pet?”/“No”/“Nothing?”/“But I have daughters, and they are supportive”	Group 1, P1, P5, P2, F
			“My wife does everything and I’d like to help her, but I can’t even carry a cup of tea. I’ve got to try and clear a place and everything, but I’m relying on this trolley to hold me up, without it I’d fall down on the floor”	Group 2, P4
			“Yes, yeah, that’s it. My wife now has to work, well, she’s always worked, but she’s now having to work even harder, cos we ain’t getting a great deal of money coming in”	Group 2, P2

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		Sex/intimacy with partner	"Intimacy between partners has changed, yes?" / "Oh yes" / "Yes" / "It has died" / "Died!"	Group 2, F, P4, P2, P6
			"I feel closer to my wife than I probably ever did. We were more sexually active beforehand, yet I feel more closer to her now, cos you just learn to be different. Mentally we get on now. [...] Yeah, cos we both sort of think the same things, want the same goals, so..."	Group 2, P3
			"The emphasis is on the other side [...] The emphasis has moved from the sexual side to the" / "To more bonding and so on" / "Yeah"	Group 2, P5 & P3
			"On the other hand, I feel much closer to my children. I feel closer to them and I feel closer to my wife, but in a different way. Its not all sex and that, when you go to bed, it's not sex and all that, its different things. You cuddle up together and that, used to with sex it is bang bang, but its not the same"	Group 4, P6
		Closeness in relationships	"As far as relationships with the family, we are probably closer now, cos there is more time in the day."	Group 2, P2
			"How has your relationship changed with your family?" / "Closer" / "Closer?" / "Yeah, closer, I've got a lot closer" / "Yeah, me too"	Group 2, F, P6, P3, P10
			"I feel closer to my wife and the family. Cos they do a lot for me, they come and see me more"	Group 3, P6
			"On the other hand, I feel much closer to my children. I feel colder to them and I feel closer to my wife, but in a different way..."	Group 4, P6
			"Yeah, I think we've got a different perspective on life, and you've both got the same perceptive, luckily we have, and	Group 2, P3

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			some people might not have that strength between them, and that's going to divide and put a wedge between the two."	
			"I hear from them now more on the phone"	Group 5, P7
		Accept Support	"You cant make money, it takes a supportive family"	Group 2, P6
			"Oh, yes, they are very encouraging. I say I've done this or I can't do that and they say , its only three months so it will come"	Group 4, P1
			"Impossible, if I didn't have people. It really helped a lot. They, my wife, do everything. It is absolutely impossible on my own."	Group 4, P10
		Stable factors in relationship	"I'm relying on my wife, she does it. I don't do it. I eat what's put in front of me"	Group 4, P5
			"My wife often says what do you want for supper and I haven't got a clue"/ "Have you ever had a clue?"/ "No, not really!"/ "You came into work and it was on the table"/ "That's right yeah"	Group 4, P4, F, P2
			"Do you think you look after yourselves a bit better now?"/ "No, I don't think so"/ "No, not really"/ "Really?"/ "I think we're looked after, aren't we?"	Group 4, F, P5, P2
			"...but you've managed to get all the way over to Italy"/ "Very, my people, my friends and my wife helped"	Group 4, F & P10
		Role: Male-female	"Yeah, my wife, she carried and put up the TV, and went an insured the car and serviced the car, doing things like painting, and hanging pictures, but all the things that men do,	Group 3, P6

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			they have to do it. So she has to find a way to do it"	
			"Yeah, it all comes back to the idea of family roles. I know what I'm supposed to do, but I can't do anything. My wife does both roles now"	Group 2, P6
			"Where you were the breadwinner and all of a sudden that changes. Yeah, I really find it difficult."	Group 4, P2
			"Yes, yeah, that's it. My wife now has to work, well, she's always worked, but she's now having to work even harder, cos we ain't getting a great deal of money coming in"	Group 2, P2
			"my wife goes out to work at half past six in the morning, and some days I get up when she goes out... I get up and I go downstairs and I sit and have coffee, and I sit and have coffee til about 10 o'clock, and then my day is mapped out. I have my breakfast, I do whatever I have to do, I make the bed and I do the dusting and I won't do the hovering cos it hurts my head, and then she'll come home and I sit down in the afternoon, and four o'clock, five o'clock I might go down and have another cup of coffee, and then I sort out dinner. So basically our roles have been reversed, and I get frustrated, I hate it."	Group 3, P2
		Role: Adult-child	"Hahaha and when you don't get your own way, you become a spoilt child"	Group 2, P2
			"...when I've been caught eating something I shouldn't have eaten and those sorts of things"	Group 2, P2
			"But you really become a small child. You have to relearn everything"	Group 2, P1
			"That's their protective instincts"	Group 1, P5

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			"They think you might harm yourself"	Group 1, P6
		Role: Parent-child	"Well, doing a job, I can't think what to say [...] to my son who is doing it all"	Group 2, P6
			"I feel myself that he's looking at me and saying if I'm not careful I'm going to end up the same way as dad. Because, OK, I've had a stroke, but my father was diabetic and basically, the diabetes killed him, and it's not much further on from where I am. And he's thinking the same, like I said I've given up drink and given up smoking, and as soon as I'd gave up smoking, he stopped smoking. I don't know, I think that boys joke about it cos they've got thoughts of themselves, don't you think?"	Group 3, P2
			"The one thing my illness has done is make my youngest daughter not quite so well [...] Yeah, not well, she's worrying about me. She's got all that pressure"	Group 2, P2
			"My kids sort of grew up over night"	Group 2, P3
			"It's a bit like growing old suddenly [...] I'm old enough to be old, and know what its like to be old, at 73, your children suddenly start treating you as"/ "Like a child"/ "Yeah, they do things for you, which you would normally do for them, and its exacerbating to have a stroke. And everyone's perception of you is the same"	Group 2, P1
			"I was getting money out of the cash machine, and my daughter said 'get out of the way, I'll do it for you'. I am perfectly capable of getting money from the cash machine"	Group 5, P1
		Role: Wife-carer	"We all need a wife to take care of our tablets"	Group 1,

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				P1
			"I've got a wife, she takes care of all that"	Group 1, P6
			"I was going to say, with my wife, she is a wonderful carer, you know, I can't fault her, but she is no longer a wife, if you know what I mean"	Group 2, P4
	Relationship with wider systems	Medical: Difficult relationships, unsupportive experiences	"I think the medics have got it all wrong, in that they don't give enough or the physios don't like types of physios, you know the, what-do-ya call em? The mental, the ones that deal with mental, what's her name? [...] The reason I brought that up was, I mean, if, you know we all get a certain amount of paralysis of one type or another, be it speech or limbs or whatever. The sooner they can get working on them, and get them working again, the more easier it is for the mental side of it preparing, that's what I've found"	Group 2, P5
			"You are fighting the system, all the way through"	Group 2, P2
			"So, you're kind of smashing those barriers are you?" / "Yeah, but you have you do it yourself" / "You have to do it yourself. You don't get no help" / "You have to knock down your own doors, and make a stance"	Group 3, F, P3, P2
			"But they still can't get my balance back, which is frustrating"	Group 2, P2
			"You do have to accept it. But it does get very frustrating when they can't actually tell you... what the problem is"	Group 1, P2
		Medical: Supportive relationships	"I'll show you how good she is, my hand was like that, I couldn't undo it at all, and she came and within half an hour, she got my fingers open"	Group 2, P5

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			"The doctor said to me, you'll be ok, cos you're determined, to get back"	Group 1, P5
			"I seen the doctor more in the last 18 months than I have in the last 35 years"	Group 4, P2
	Wider society	Society: Expectations of masculinity	"It's the old things isn't it, if you don't laugh you cry"/"Its alright to cry though"/ "No, it ain't"	Group 4, P2 & F
			"You should be able to go out and earn money and keep everybody happy"	Group 2, P2
			"research suggests that men are very bad at going to their GPs about health problems, they'll leave it and leave it [...]" / "Its not manly"	Group 2, F & P3
			"You need to harden up, don't you, after the stroke"	Group 2, P3
			"I've never actually been in hospital, I go as an outpatient. The day it happened, [...] I couldn't lift my arms above my head. I was driving to work with a fag hanging out of my mouth, thinking I probably shouldn't be doing this, I couldn't remember how I got to work, and I couldn't remember how I got home."	Group 1, P2
		Society: Expectations of disability	"I'm wondering if you feel a bit of a fraud, cos it doesn't look like it. Do you see what I mean?" / "Yeah, I probably am" / "You look alright"	Group 2, F, P2, P6
			"Will anybody take any notice?"	Group 1, P5
			"That's right. What I've had is, one or two acquaintances have said, I've known someone whose had a stroke and	Group 2, P2

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			they're back at work now"	
		Society: Expectations of help	"Well, to be honest, I'm sorry, I had someone come to see me, and when she filled in the forms cos basically my writing is absolutely crap, she never got me anything, and when I phoned up to ask what do I do now, I've got no money, she said your claims failed, we cant do anything."	Group 2, P2

Appendix P: Excerpts of responses to the focus group questions

All Responses have been removed from the electronic copy.

How have you found the overall experience of being in the group?

Did the group meet your expectations?

What would you consider the most important aspect that you will take away from this experience?

What was most useful or helpful?

What felt unhelpful?

Would you say your relationship with your stroke has changed? Do you think about your stroke and the impact on your life differently?

Has anyone close to you noticed any changes in you?

Would you recommend a group like this to a friend/family member who had had a stroke?

If we were running a group like this again, what could we change?

Appendix Q: End of study report for Research Ethics Committee and Research and Development department

End of study report

Full title of study: A pilot investigation into the effects of narrative therapy groups to facilitate psychosocial adjustment in survivors of stroke (REC reference: 11/LO/1882)

Background

The National Stroke Strategy (DOH, 2007) and the National standards for psychological support after stroke (NHS Improvement, 2011) have highlighted the importance of psychological rehabilitation for survivors of stroke. The impact of poor emotional adjustment to stroke results in poor cognitive, functional, and morbidity outcomes, as well as financial implications for healthcare services. A review of the current evidence base identified that the process of adjustment appeared to involve a negotiation of new identities encompassing the new self and experienced changes (Murray & Harrison, 2004). Narrative therapy was proposed as a framework to explore the representations of 'self', illness and disability associated with stroke in order to promote positive psychosocial adjustment. Therefore, in the absence of empirical evidence, this study aimed to evaluate the utility of a narrative group therapy intervention for survivors of stroke using a mixed method design.

Method

Ten participants took part in a six-week narrative group therapy intervention for stroke survivors. Quality of life, use of coping strategies and illness representations were measured pre- and post-intervention, and inductive thematic analysis was conducted on the content of the intervention sessions.

Findings

There were no statistically significant changes on measures of quality of life, use of coping strategies and illness representations post-intervention. However the inductive thematic analysis resulted in the identification of four master themes: 'using the group', 'negative talk', 'positive talk' and 'relationships'. The analysis revealed that the social aspects of the group intervention allowed participants to compare experiences of stroke and recovery, often feeling better about their own situation as a result and to seek, share and gain information and strategies for coping. The group provided an opportunity to discuss the perceived negative aspects of surviving a stroke, and talk through difficult emotions and thoughts associated with loss. With the support of the group facilitator, participants were also able to identify the adaptations and achievements they had made since the stroke and tentatively begin to reclaim

Appendix Q: End of study report for Research Ethics Committee and Research and Development department

their identity as someone separate from the stroke. The participants also shared how they had become closer to their families since the stroke and the impact of stroke on wider relationships was explored.

Implications

The findings suggest several implications for clinical practice. Firstly, the process of seeking of information about stroke and available services suggests that accessible information should be provided to the survivors of stroke about the physical, emotional and cognitive consequences of stroke.

Furthermore, the lack of understanding about stroke and secondary stroke prevention should also be addressed, as recurrent strokes have been linked to the development of post-stroke depression (Dafer, Rao, Shareef, & Sharma, 2008). This information needs to be made available to partners and carers, as the findings show that much of the responsibility for diet and exercise activity falls to the carer.

The findings indicate that narrative therapy requires further evaluation in terms of facilitation of adjustment. It was however evident that the opportunity to meet as a group and discuss experiences was valued by the participants. One aspect that participants found helpful was the sharing of information and the opportunity to learn more about stroke. It could be hypothesised that the provision of a discussion group which incorporates psychoeducation, could promote adjustment.

Feedback to participants

Participants were sent a 'Thank you' letter for taking part in the study and a brief summary of the research findings.

Publication and dissemination of findings

The findings of this study will be disseminated to the research site and will be submitted to Disability and Rehabilitation for publication.

References

Dafer, R.M., Rao, M., Shareef, A., & Sharma, A. (2008). Poststroke depression. *Topics in Stroke Rehabilitation, 15*(1), 13-21.

Department of Health (2007). The National Stroke Strategy. London

NHS Improvement (2011) National standards for psychological support after stroke. London.

Disability and Rehabilitation Instructions for Authors

Disability and Rehabilitation is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

Disability and Rehabilitation is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Submissions and Peer-Review

All submissions should be made online at ***Disability and Rehabilitation***'s ScholarOne Manuscripts site: <http://mc.manuscriptcentral.com/dandr>.

Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is „Anonymous“ or „Not Anonymous“ during manuscript submission, and should pay particular attention to the below:

Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main Document” and will be sent to the referees. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

All submissions should include a separate title page that contains contact information for the author(s). This should be uploaded as a “Title Page” and will not be sent to referees.

If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor's decision is made, irrespective of whether the authors names(s) were included as part of the original submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they are reminded not to include identifying information in the “Authors” Response” section during the upload of their revised paper. Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using „Track Changes“ (for minor revisions). Please contact the Editor if you require more information. Systematic Reviews should be submitted as a „Review“ and Narrative Reviews should be submitted as „Perspectives in Rehabilitation“. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.

Education and Training

This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovative approaches to this process and provide multi-disciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings. Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing. Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given.

Photographs of patients should be avoided, but if essential, patients' consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients' eyes.

Appendix R: Publication guidelines of journal chosen for publication

Word Limit

There is no stated word limit to papers submitted to *Disability and Rehabilitation*. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

Disability and Rehabilitation considers all manuscripts at the Editor's discretion; the Editor's decision is final. Please see below for information on the Journal's Appeal Procedure.

Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to ***Disability and Rehabilitation***, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which ***Disability and Rehabilitation*** incurs, and their papers will not be published. Copyright will be transferred to ***Disability and Rehabilitation*** and Informa UK Ltd., if the paper is accepted.

IMPLICATIONS FOR REHABILITATION

A feature of the Journal is a boxed insert on „Implications for Rehabilitation“. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. **All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature.** This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission. Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation

- Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
- CBR needs to be „owned“ by those involved and subject to re-interpretation to be effective in other cultures.

Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. These should be submitted as „Image“ files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Appendix R: Publication guidelines of journal chosen for publication

Structure of Paper

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files). An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as "title page" on ScholarOne Manuscripts. This will not get sent to referees.

Abstracts

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text. *Purpose* State the main aims and objectives of the paper. *Method* Describe the design, and methodological procedures adopted. *Results* Present the main results. *Conclusions* State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation. The abstract should not exceed 200 words.

Nomenclature and Units

All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Copyright Permission

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor. This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

Code of Experimental Ethics and Practice

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written $10.0 \text{ SD } 2.65$. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0. Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig). The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript: *Insert table 2 about here*. Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Appendix R: Publication guidelines of journal chosen for publication

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading "Declaration of interest". If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest*. When submitting a paper via ScholarOne Manuscripts, the "Declaration of interest" field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission. Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

Click here to view our full Declaration of Interest Policy.

Mathematics

Click for more information on the presentation of mathematical text.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus. Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fethers LJ. Complete wetting from polymer mixtures. *Science* 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. *The pharmacological basis of therapeutics*. 8th ed. New York: Pergamon; 1990. p 1334-60.

Appendix R: Publication guidelines of journal chosen for publication

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. *Brain Injury* 23(11):853-865. <http://www.informaworld.com/10.1080/02699050903283221>. Accessed 2009 Oct 06

Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: <http://bmj.bmjournals.com>

Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: <http://www.cdcnpin.org/>

APPEAL PROCEDURE

Disability and Rehabilitation and Disability and Rehabilitation: Assistive Technology

The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected. The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal

I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer

II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.

III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal

If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of *Disability and Rehabilitation*, the Editor of *Disability and Rehabilitation: Assistive Technology* will be contacted, and if an appeal is not upheld by the Editor of *Disability and Rehabilitation: Assistive Technology*, the Editor of *Disability and Rehabilitation* will be consulted.

II. The Editor will either confirm the decision or recommend that a further review be obtained.

III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, *Disability and Rehabilitation*

Marcia Scherer, Editor, *Disability and Rehabilitation: Assistive Technology*