Personal experiences and processes in an Acceptance and Commitment Therapy group for stroke survivors: An Interpretative Phenomenological Analysis

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# **Table of Contents**

# **Contents**

Acknowledgement	ii
Abstract	vii
Chapter one: Introduction	1
1.1 Overview of the Chapter	1
1.2 Impact of Stroke	1
1.2.1 Psychological Impact Following Stroke	2
1.2.1.1 Depression and Anxiety	2
1.2.1.2 Psychological Difficulties	3
1.3 How Stroke Patients Can Be Supported	4
1.3.1 Pharmacological Treatment	4
1.3.2 Psychological Interventions Following Stroke	5
1.3.3 Psychological Intervention for Post-brain-injury Psychological Distress	6
1.4 Group Factors and Process	13
1.4.1 Applicability of Group Intervention for ABI/TBI Populations	16
1.4.2 Group Interventions for Stroke Survivors	21
1.5 ACT and Stroke Population	26
1.5.1 ACT Model	26
1.5.2 Applicability to Stroke	27
1.5.3 An ACT Group Intervention for Stroke Survivors	29
1.6 Relevance to Counselling Psychology	31
1.7 Conclusions and Situating the Present Study	33
1.8 Research Questions	35
Chapter two: Methodology	36
2.1 Overview	36
2.2 Rationale for qualitative approach	36
2.3 Rationale for interpretative phenomenological analysis	38
2.4 Interpretative phenomenological analysis	41
2.5 Epistemological dilemmas	43
2.6. The research process	45
2.6.1 Sampling	46

2.6.1.1 Inclusion/exclusion criteria	47
2.6.1.2 Participants' details	48
2.6.2 Recruitment procedure	49
2.6.2.1 Recruitment challenges	50
2.6.3 Data collection	51
2.6.3.1 Interview procedure	51
2.6.3.2 Interview follow-up	52
2.6.3.3 Reflecting on interview questions and interviews	52
2.6.4 Materials used	54
2.6.5 Ethical considerations	55
2.7 Analytical procedure	56
2.7.1 Validity criteria	58
2.7.2 Reflexivity	60
2.7.2.1 Researcher's background and interest in the topic investigated	62
2.7.2.2 Personal reflexivity	63
2.7.2.3 Reflections on the process of analysis	64
Chapter three: Analysis of data	67
3.1 Overview	67
3.2 Master Theme 1: "It Is Just So Difficult	69
3.2.1 Overview	69
3.2.2 Sub-theme 1: "What's the Group Going to Be Like?" – Initial Apprehensions	69
3.2.3 Sub-theme 2: Handle with Care – Group Relationships	73
3.2.3 Sub-theme 3: "It Was A Short One"	76
3.3 Master Theme 2: Means to a Connection	79
3.3.1 Overview	79
3.3.2 Sub-theme 1: United by Stroke	79
3.3.3 Sub-theme 2: "As If There Is A Connection"	82
3.3.4 Sub-theme 3: Accepted Here Vs Judged Out There	86
3.4. Master Theme 3: Restoring Confidence and Hope	90
3.4.1 Overview	90
3.4.2 Sub-theme 1: "It Could Be Worse"	90
3.4.3 Sub-theme 2: "You Are Not Alone"	93
3.4.4 Sub-theme 3 : "Believe In Yourself" – Learning From Others	97
3.5 Theme 4: "Things Won't Be the Same" – Moving Towards Acceptance	100
3.5.1 Overview	100
3.5.2 Sub-theme 1: "Need to Know How"	101

	3.5.3 Sub-theme 2: "There Is A Life After Stroke" – Increased Acceptance of Responsibility	103
	3.5.4 Sub-theme 3: "This Is Me Now" – Emergence of Compassionate Self	105
	3.5.5 Sub-theme 4: "I Can't Get Used to" – Ongoing Challenges	108
	Chapter four: Discussion	113
	4.1 Introduction to the Discussion	113
4	4.2 Overview of the Findings	113
	4.3 Discussion of the Main Research Findings	114
	4.4 Implication for Clinical Practice and Counselling Psychology	128
	4.4.1 Implication for an ACT Group	128
4	4.4.2 Factors Affecting Groups	130
4	4.4.3 Time factor	132
4	4.5 Critical Overview of the Study	134
4	4.5.1 Strengths	134
4	4.5.2 Limitations	134
4	4.6 Conclusions and Recommendation for Future Research	135
4	4.7 Post-viva Reflexivity	139
4	4.7.1 Ethical Considerations	139
4	4.7.2 Analysis	140
4	4.7.3 Literature Review	141
Re	ferences	143
1	Appendices	167
1	Appendix A – UEL Ethics Approval	167
1	Appendix B – NHS Ethics Approval	168
1	Appendix C – Information about the research	171
1	Appendix D - Consent to participate	176
1	Appendix E - A letter to a GP	178
1	Appendix F – Research passport	179
1	Appendix G – An examples of interview questions	180
1	Appendix H - Poster	182
1	Appendix I – The participants debrief and list of support services	184
1	Appendix J- An example of an initial coding of the data	185
1	Appendix L- Major Themes table with corresponding emergent themes plus sample extracts from the data: - Participant 2- Mary	s of 193
1	Appendix M – An example of dairy entry	196
1	Appendix N- An example of a brief consultation/training for other professionals.	198

# List of tables:

Table 1: Participants' Demographic Information	49
Table 2: Master themes and Subthemes	67

# Abstract

Rationale: The literature review examined the importance of group-based interventions as a vehicle for the process of change in acquired and traumatic brain injury populations. However, the existing literature lacks consistency and is limited in stroke populations with only one quantitative ACT group-based study evaluating effectiveness for post-stroke difficulties, with no qualitative research in this area. Research question: This thesis aims to address the existing gap by exploring stroke survivors' experiences of interacting with each other in the ACT-based group. The current study aims to gain insight into individual perceptions on whether or not stroke survivors find it beneficial to be in the presence of other stroke survivors and how group processes and the ACT tools may support or hinder their recovery. Aims: This study aims to add to the scarce research dedicated to the stroke population, and to inform the clinical practice of Counselling Psychologists and other professionals when working with stroke populations. Method: Data gathered from eight semi-structured interviews was analysed using Interpretative Phenomenological Analysis (IPA). Findings: The collected data generated four master themes: "It is just so difficult"; Means to a connection; Restoring confidence and hope; and "Things won't be the same": moving towards acceptance. The master themes aim to encapsulate the participants' views on what they found meaningful or challenging about being in the ACT group setting with other stroke survivors. The findings indicate the role of the group process to be of great value in measuring recovery progress and restoring self-esteem and self-agency. Furthermore, participants experienced apprehension at the start, throughout, and at the end of the group but this also formed part of the process of acceptance. The benefits of ACT tools in adjusting were reflected on, alongside the challenges in comprehending them. The findings of the current study are discussed in the context of group theory and research,

and a suggestion for clinical practice is outlined, such as a need for homogeneous group structure, inclusion of significant others or time factors. The relevance to Counselling Psychology is outlined, followed by the strengths and limitations of the current study, and recommendations for further research.

Key words: Stroke, Qualitative research, Group therapy.

# **Chapter one: Introduction**

#### 1.1 Overview of the Chapter

The literature review provides insight into existing research and an overview of the literature that was used as a basis to form the rationale for this study. It begins with a description of the impact of stroke on quality of life, and of mental health issues resulting from that illness. This is followed by a brief description of available treatment for stroke population including pharmacological, CBT and third-wave therapies supported by existing outcome and qualitative research. A specific focus on group process and theory is described and referenced for the applicability for stroke survivors. Further literature focussing on the evaluation of group intervention for traumatic brain injury (TBI) and acquired brain injury (ABI) clients in stroke-related studies is highlighted. A brief synopsis of the ACT model and its applicability in stroke population is outlined and an evaluation of outcome study of ACT group intervention for stroke is presented. The last section concludes with the rationale for this study and highlights the relevance to Counselling Psychology (CP).

# **1.2 Impact of Stroke**

Stroke is defined by the World Health Organization (WHO) as "a clinical syndrome consisting of rapidly developing clinical signs of focal (or global in case of coma) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin" (NICE, 2009, p. 2). To simplify, stroke takes place when blood supply to the brain is halted causing significant damage to the brain cells with the possibility of causing death if not treated medically (Stroke Association, 2016).

Stroke is a serious and debilitating illness with significant implications for one's day-today life. Stroke might have a devastating impact on one's physical functioning. Depending on the obstruction in the brain, stroke might cause paralysis, memory problems and speech/language difficulties. Often, stroke can cause vision impairment and chronic pain or fatigue. Stroke-related disability can improve with time but frequently becomes a permanent effect, causing life-long physical limitations and challenges (Stroke Association, 2013). As the result, stroke survivors express concerns about social acceptance and personal identity (Barker, Reid, & Cott, 2004). Historically, stroke was only associated with older adults; however, recent research on stroke suggests that a number of young people, including children, are also at risk (Stroke Association, 2013). The World Health Organization has predicted that stroke will be one of the most commonly occurring health problems in the world by 2020, with 150,000 people already affected in the United Kingdom every year (WHO, 2011), and the social care cost and economic implication estimated to reach £8.9 billion a year in the UK (Saka, McGuire & Wolfe, 2009).

# 1.2.1 Psychological Impact Following Stroke

#### **1.2.1.1 Depression and anxiety**

The psychological distress caused by stroke has been well documented, and suggests that the prevalence of depression after stroke varies from 25% to 79%, and can still be experienced five years after the event (Hackett et al., 2005; Hackett, Köhler, O'Brien & Mead, 2014; Matsuzaki et al., 2015). The existing literature indicated depression to be one of the most pervasive psychological conditions experienced after stroke and one that often is negatively correlated with adherence to treatment (Gurr & Muelenz, 2011). Some studies also suggested depressive symptoms may be associated with increased

mortality (Williams, Ghose, & Swindle, 2004) and reduced quality of life (Matsuzaki et al., 2015).

A recent systematic review shows that over 24% of stroke patients suffer from anxiety in the first few years, often relating to fear of having another stroke (Lincoln, Sutcliffe, & Unsworth, 2000). It has been suggested that the anxiety may be experienced not only immediately after a stroke but it may actually increase as the person's post-stroke difficulties reach the chronic stage (Burton et al., 2011). Similarly to depressive symptoms, anxiety may be a source of further physical and psychological difficulties that negatively impact on one's wellbeing and quality of life after stroke (Tang, Lau, Mok, Ungvari, & Wong, 2013). However, despite the significance of the emotional impact of stroke on one's quality of life, the initial interventions still often prioritise physical recovery, treating psychological needs as secondary (Pearce et al., 2015).

## 1.2.1.2 Psychological difficulties

Psychological problems following stroke are not limited to depression or anxiety. The existing research points to additional emotional reactions that stroke survivors may battle as a result of their brain injury. Often, the irreversible physical changes caused by stroke produce disability-related loss in the context of identity (self) expressed in loss of independence, loss of employment or change to their role in social domains (Couchman, McMahon, Kelly, & Ponsford, 2014). The change in identity is often expressed in longing for losses endured, and contributes to isolation and impacts on the quality of relationships with themselves and others (Salick & Auerbach, 2006; Seeto, Scruby & Greenhill, 2017) when the dynamic of the relationship changes to care-receiver and care-giver (Couchman et al., 2014).

Many stroke survivors report struggling to regulate their emotions, which can be caused by damage to the brain structure (Philippi, Mehta, Grabowski, Adolphs, & Rudrauf, 2009). Hence, post-stroke changes are also reported in relation to behavioural difficulties, such as verbal and physical aggression and feelings of frustration and anger (Baguley, Cooper, & Felmingham, 2006). Further research also shows levels of selfesteem and confidence decreasing in this population along with their sense of agency and an active coping style is often replaced by a withdrawn approach to life (Visser, Heijenbrok-Kal, Spijker, Ribbers, & Busschbach, 2013). Hence, Darlington and colleagues (2007) indicate that coping strategies are crucial in determining and rebuilding post-stroke quality of life.

Some studies also explored social issues related to post-stroke changes, such as higher levels of dependence on others, avoidance of pre-stroke activities or delays in defining new life directions, which all seem to be associated with elevated stress levels (Taylor, Poland, Harrison, & Stephenson, 2011). Furthermore, heightened or uncontrollable emotional reactions have been identified as factors that hinder adjustment to such a transformation, which is often reported as the most difficult process in the course of recovery (Hackett, Köhler, O'Brien, & Mead, 2014).

With the promising number of people surviving stroke today (NICE, 2013), those who survive are likely to face psychosocial challenges. Hence, there is an ongoing and increasing need to provide not only physical but also psychological interventions aiming to support this population of patients in the process of adaptation and life reclamation.

# **1.3 How Stroke Patients Can Be Supported**

# **1.3.1 Pharmacological Treatment**

According to NICE guidelines (2013) pharmacological treatment is available to patients whose mood and anxiety level are assessed to require it, and appropriate medication may be prescribed, such SSRIs, SNRIs or tricyclic medication (Hackett, Anderson, House, & Xia, 2008).

However, adverse effects of antidepressants were noted in the literature, indicating conflicting evidence. For example, Narushima and Robinson (2002) reviewed available treatments for depression and anxiety in the post-stroke population, including pharmacological reviews. Their study indicates some medication such as Nortriptyline can be efficacious in treating depression after stroke, but simultaneously increases the risk of elevated depressive symptoms six months after ceasing medication. In addition, Juang and colleagues (2015) indicate that the use of antidepressants such as SSRIs may increase the risk of stroke reoccurrence, which may impact on how stroke survivors decide to approach mood management.

Furthermore, Hackett et al. (2008), in a systematic review of fourteen trials involving 1,515 participants, nine medications (fluoxetine, sertraline, trazodone, piracetam, maprotiline, mianserin, nortriptyline, indeloxazine, and methylphenidate) and psychological interventions (problem-solving and motivational interviewing) shows inadequate evidence supporting the use of antidepressants. On another hand, the study highlights the positive effect of psychological strategies. In conclusion, pharmacological interventions might be somewhat beneficial to the stroke population but must be used with caution and there is a need for further research into alternative psychological support.

#### **1.3.2 Psychological Interventions Following Stroke**

The updated NICE guidelines on interventions for stroke survivors (2016) clearly stress the need for psychological input in the process of recovery from stroke. Furthermore, the guidelines imply that a multidisciplinary team approach with psychological support should be offered to all recovering stroke patients. Despite the recommendation, there are no specific suggestions as to what type of therapeutic approach may be most beneficial, although IAPT is recommended, suggesting a CBT-based approach may be frequently used as suggested by Stalder-Lüthy et al. (2013). Additionally, proposed guidelines imply that evidence-based interventions must be implemented, yet psychological interventions are more often based on general population research and less on stroke survivors specifically (Intercollegiate Stroke Working Party, 2016). Despite growing interest in stroke interventions in recent years, this area still lacks research and clinical guidance seems to be in its infancy (Kootker et al., 2014) with Lincoln et al. (2013) suggesting a lack of suitable psychological interventions available to the community.

Thus, it is not surprising that some studies reviewing stroke patients' experience of provided care indicate un-met needs. For example, one study by Low and colleagues (2003) pointed to unsatisfactory levels of rehabilitation therapies stressing lack of post-acute stage therapeutic input. Lack of satisfaction was also voiced by the National Audit Office (2010) that reviewed stroke services, where over half of patients and carers rated psychological care as "poor" or "very poor".

It appears then, that there is demand for psychological support and a growing role for psychologists in providing suitable interventions for this population in addition to an ongoing need for stroke-focused research.

**1.3.3 Psychological Intervention for Post-brain-injury Psychological** Distress In this section a brief summary of the literature of the main therapeutic interventions is presented. Most of the studies refer to either ABI or TBI rather than stroke specifically.

It seems that most of the interventions explored in existing research aim to test efficacy and effectiveness of particular models, and focus on the reduction of symptoms. These were mainly captured in quantitative studies. Perhaps, as NHS delivery is based on diagnostic criteria such as DSM-V or the ICD-10, the research has placed emphasis on deficits and searched for answers that can reduce post-stroke psychological distress that often manifests in depression or anxiety symptoms (Majumdar & Morris, 2018).

According to the systemic review by Stalder-Lüthy and colleagues (2013) where thirteen studies were reviewed, between CBT, counselling, and mindfulness, the CBT model was used most frequently to reduce depressive symptoms in ABI populations. Despite differences in the format of delivery of the intervention (e.g. group, individual, telephone) and length (5–10 sessions), there was medium effectiveness (0.68) relating to treatment of post-brain-injury depression. However, Kneebone's (2013, 2015) case studies suggest for CBT to be more beneficial to this group of clients, it must be tailored to cognitive impairments by implementing external aids such as symbols or pictures and focusing on remaining abilities rather than regaining lost ones.

Furthermore, through the support of RCTs studies and other outcome research, there has been growing support for the efficacy of CBT interventions for this population. The findings suggest that the CBT model has been beneficial in reducing symptoms of low mood and restoring self-esteem in clients experiencing aphasia (Thomas et al., 2012) by implementing a behavioural activation strategy. Similarly, in other CBT studies focusing on illness-related trauma, participants report reduced PTSD symptoms as a result of CBT strategies (Bryant, Moulds, Guthrie, & Nixon, 2003). The beneficial aspects of CBT with ABI/TBI survivors were also extended to anger management studies indicating improved coping mechanisms, and the efficacy of CBT was indicated in moving away from emotional coping responses towards problem-focused coping, which is associated with better adjustment (Bradbury et al., 2008). The systematic review indicated that the advantages of CBT also come from its structured format, which may be helpful for patients with cognitive deficits, and some studies implied that the flexibility of CBT in adjusting to memory impairments by repeating the material in sessions is beneficial. Also, through CBT techniques, patients report increased sense of control, which seems to be essential for recovery in this population (Stadler-Luthy et al., 2013). However, despite promising reports, the outcomes of studies point to flaws and issues that CBT seems to encounter. In the above studies, the reduced symptoms of depression or anxiety were not sustained after a long period of time (Thomas et al., 2012) with (at times) the stress levels remaining unchanged throughout (Bryant et al., 2003; Anson & Ponsford, 2006). Bryant's study (2003) also reported inconclusive results in supporting the ABI population in community integration and social interactions. Furthermore, the experience of loss often reported after brain injury is associated with grief (Rochette, Tribble, Desrosiers, Braco, & Bourget, 2006); however, none of the outcome studies clearly addressed this emotional issue (Stadler-Luthy et al., 2013).

Some other criticism refers to CBT assumptions that aim to reduce problematic symptoms, and most of the above studies investigated the efficacy of this model in equipping brain injury survivors in controlling and managing thoughts and feelings and setting practical goals in order to avoid emotional distress (Williams, Vaughan, Huws, & Hastings, 2014). However, the results of the study showed that this strategy might not be effective enough. On one hand, perceiving problems as needing to be eliminated indicates that the psychological distress is located within an individual which may result

in self-blame and feeling that emotional struggles are 'not normal' (Couchman et al., 2014). This in turn might cause additional distress and facilitates the process of avoiding these problems. Thus, attempts to control unwanted experiences can be ineffective and even counterproductive (Forman, Herbert, Moitra, Yeomans, & Geller, 2007).

Furthermore, for stroke survivors with impaired executive function, perhaps CBT tools such as Cognitive Restructuring (CR) that aim to challenge negative thoughts and seek alternatives at the same time might be deemed too cognitively demanding and abstract (Kangas & McDonald, 2011; Blanchet, Paradis-Giroux, Pépin & McKerral, 2009). Stroke clients can also face difficulties setting goals within the CBT framework. Loss of identity and constant comparisons with the pre-stroke self may cause frustration and confusion in one's reality (Dowswell et al., 2000; Ellis-Hill, Payne, & Ward, 2000; Pound, Gompertz, & Ebrahim, 1999). Thus, each time a stroke survivor faces a task that they used to be able to complete or one that is cognitively demanding, it may increase their level of psychological distress as a consequence (Kangas et al., 2011).

This also raises a question about what factors and processes might have been missed in above approach or research. It is possible that using quantitative measures in isolation did not allow the exploration of the maintaining factors of depression or stress. This point can be highlighted by Townend et al.'s (2010) mixed-methods study of the acceptance of disability. A quantitative analysis on depression reported that over 30% of patients were diagnosed with depression a month after a stroke, and this persisted at nine months (Townend, Tinson, Kwan, & Sharpe, 2010). However, it is the qualitative data that illuminated the link between acceptance of disability and low mood. Patients often reported feeling 'useless' and were not accepting of their health-related changes (Townend et al., 2010). It seems, then, that there was a deeper meaning behind the depressive mood linked to acceptance in itself, which came to the fore through explorative questioning of individual participants. Thus, it can be suggested that without a more exploratory approach, it is difficult to gain insight into the factors maintaining depression after stroke. This exploratory approach also facilitated new insight into individual stroke survivors' experiences, namely highlighting how shame, low selfesteem or loss underlie depressive and anxiety symptoms (Seeto, et al., 2017).

Furthermore, it appears that CBT research has focused on deficit/loss after brain injury. Yet there is growing field of literature that emphases psychological growth as a vehicle for recovery (Linley & Joseph, 2004). That concept seems to focus more on rebuilding resilience, inner strength, when individuals can reflect on their life in a new context (Grace, Kinsella, Muldoon, & Fortune, 2015). Psychological growth after traumatic events such as stroke postulates that an individual can move beyond the baseline and become open to new possibilities and positive changes despite their difficulties (Grace et al., 2015).

Hence, other ways of supporting stroke survivors in their predicaments have been provided by a recent review of the suitability of third-wave therapies for psychological wellbeing following stroke by Smith (2017). The third-wave therapies such as Mindfulness, Compassion-Focused Therapy (CFT) and Acceptance and Commitment Therapy (ACT), despite their nuances and own focus, share a key concept acknowledging the importance of present-moment awareness, without a need to judge or challenge one's struggles, but with a view to accepting them (Smith, 2017).

In this review, the researcher critically evaluated brain injury inclusive of stroke-related mixed-methods studies and concluded that third-wave therapies demonstrated utility in improving stroke patients' psychological wellbeing by promoting acceptance of stressful life events and learning to live alongside it (Harris, 2009). Although the author

questioned the quality of measures used in the chosen studies, the qualitative data has indicated third-wave therapies to be a significant source of support to live more meaningful lives, move towards adjusting to post-stroke changes, manage overwhelming feelings through grounding techniques and remaining focused on what is possible now rather than comparing to past abilities (Merriman, Walker-Bircham, Easton, & Maddicks, 2015).

The other aspects of this critical overview focused on concepts such as compassion. In qualitative interviews, Ashworth et al. (2015) explored participants' experiences of compassion-focused interventions in group and individual settings. He noted that participants reported being more kind to themselves and self-criticism or blame decreased as a result of the interventions. On the other hand, Shields and Onsworth (2013), based on their single case study using integrated CBT/CFT interventions, note that the participants were wary of self-compassion and caring for themselves as they associated it with being selfish. Hence, the above findings further highlight the dichotomy in individual experiences and the subsequent challenges in applying a psychological framework to the stroke population.

Further factors like psychological flexibility, although explicitly measured in only one of the included studies (Graham, Gillanders, Stuart, & Gouick, 2015), indicated a positive correlation with social interaction (Smith, 2017). Moreover, other qualitative studies of individuals recovering from stroke indicated that quality of life is often determined by levels of social engagement and is important in the process of recovery (Haslam et al., 2008). However, Graham et al.'s (2015) study used global measures rather than measures enabling the monitoring of individual progress tailored to participants' specific challenges. That might mean that the choices on the questionnaires

may not have been meaningful for the individuals and in effect may have not reflected their progress in different areas, thereby limiting the applicability of the findings.

Other mindfulness-based studies commented further on changes in quality of life (Marino et al., 2015; Moustgaard et al., 2007) resulting from this intervention. The researchers reported that the overall scores on quality of life increased from 60–80 on a 100-point scale in one study, and in 10 of out 13 subscales in another. However, those scores were not equally distributed, and with small sample sizes (N=1, N=23) and varied measures the results are unclear (Smith, 2017). Nevertheless, improving quality of life has been reported as an important aspect of post-stroke recovery, as it impacts on one's ability to carry on living in a meaningful way (Mierlo et al., 2013). Since factors such as adaptation, sense of control and self-worth have been associated with reported health-related quality of life, they should be considered as important factors in the psychological interventions delivered for people with stroke.

In this review, Smith (2017) also indicated group process to be important. For example, Ashworth et al.'s (2015) qualitative data revealed participants found security in the group, enabling them to draw strength from each other, while affiliative group relationships facilitated change in developing a compassionate approach to oneself. The group also enabled people to share common difficulties that normalise the experiences of loss (Merriman et al., 2015) and attending the programme gave participants a sense of routine and purpose (Moustgaard et al., 2007). However, Smith (2017) notes that only three studies out of five comment on group processes and the quality of the reports are low; for instance, no clear analytical method was specified or the number of people expressing their view was not documented.

In summary, it is difficult to point to a specific choice of intervention that offers universal solutions to complex brain injury-related difficulties (Sorensen, 1997). The above studies point to the non-linear recovery process and a complexity of subjective experiences that cannot be measured by quantitative studies. A review by Redfern et al. (2006) including 67 studies evaluating psychological interventions for this population concludes that high quality evaluations of complex interventions are largely missing; hence it is problematic to draw confident conclusions about the benefits they can offer.

On the other hand, there are some commonalities in the above empirical research; that is, they target specific impairments (e.g. coping skills, social integration) which did not seem to fully respond to the myriad of post-stroke changes. Thus, to better address the complex cognitive and psychosocial needs following stroke, such as social isolation, or adjustment, the group-based interventions were found to enhance the rehabilitation process through the operation of non-specific therapeutic factors that serve as mediators for change across multiple experienced difficulties (Patterson et al., 2016). Still, the review of existing literature on group-based interventions following TBI indicates a lack of research exploring effectiveness of the group as medium *per se*, which is also in line with Smith's (2017) review, where little attention was paid to the group process in the discussed stroke studies.

## **1.4 Group Factors and Process**

Recognition of the personal context in which learning and applying coping skills takes place is reported as an important aspect in enhancing goal attainment (Ownsworth, Fleming, Shum, Kuipers, & Strong, 2008). The setting or environment in which psychological support takes place may influence participants' experience of the treatment and facilitate or hinder the beneficial outcome.

Still, comparison of individual and group psychological interventions in the general population have been explored for many years. More recently, the accumulation of

studies shows no significant difference between those two forms of psychotherapy delivery (Baines, Joseph, & Jindal, 2004). Both individual and group therapies have been highly recommended as treatments for psychological problems within mental health settings (Wesson, 2013). However, group therapy has been advocated as a unique vehicle triggering therapeutic change, and it plays an important part of current National Institute for Health and Care Excellence (NICE) guidelines when supporting service users in their health-related predicaments (NICE, 2009). In addition, due to the increasing number of stroke survivors (Stroke Association, 2013), the need to deliver psychological support in group formats might be an appealing way to meet current NHS financial demands (Majumdar et al., 2018).

There are numerous concepts influencing psychotherapy groups that may enhance the significance of the group process in recovery for stroke patients. As Prochaska and DiClemente (1982) suggest, the process of change is independent of psychotherapy approaches, which points to the group factors/process as being beneficial in its own right in the journey of reclaiming life after stroke.

One of the theories applied in the group context is social comparison theory (Festinger, 1950), which suggests an individual can benefit from the process of multiple comparisons with others, enabling them to evaluate their situation in a new light. However, comparing oneself with others may have a negative effect as well. As stroke clients frequently report loss of confidence (Seeto et al., 2017), this process of comparison may hinder their recovery by negatively interpreting their circumstances and capacity to change. This highlights that group processes are complicated and perhaps intangible.

The other theoretical stance refers to social identity (Tajfel & Turner, 1979), which implies that the individual partly establishes their sense of self through belonging to the group. Further literature also suggests that collective identity achieved in the group increases positive evaluation of the therapy and it is correlated with self-esteem (Aviram & Rosenfeld, 2002). Moreover, being a member of the group might positively influence one's wellbeing and facilitate the process of adjusting to life difficulties (Haslam et al., 2008). In stroke literature, positive social interaction is reported to be correlated with better wellbeing, positive growth and reduction of feelings of alienation (Clarke, 2003).

Conversely, the relationships in group settings can be challenging as it is understood according to different aspects, such as member–member, group–member, and member–leader (Kivlighan, 2011). The participants must learn to interact on these different levels, which can be demanding in comparison to individual treatments. Also, there is the risk of tensions occurring within the group, which may interfere with cohesion and impact the outcomes for individuals (Whitaker, 2003).

Additionally, group literature frequently refers to group factors/processes such as cohesiveness, vicarious learning, altruism or universality that are recognised as contributing to the therapeutic change (Schmalisch, Bratiotis, & Muroff, 2010; Yalom, 1995). Cohesiveness is often referred to as a bond between group members or an emotional connection (Corey & Corey, 1992). For the stroke population, due to reported feelings of loss of identity, creating a bond and belonging to the group might encourage establishing a sense of self again (Seeto et al., 2017). However, the process of creating attachment in the group seems to be complex and the definition of cohesion is still not agreed upon in the current literature (Kivlighan, 2011).

The process of building universality indicates shared experience and commonality of that experience between members, which often normalises their struggles and brings emotional relief. This process particularly seems to be empowering in reducing feelings of shame or blame and is reported in studies with clients with OCD who received CBT group therapy (Spragg & Cahill, 2015). As feelings of shame or blame are also reported by stroke survivors due to changes in their physical and emotional status, the above group process could be beneficial in addressing those difficulties as well. However, the recent literature seems to pose a dilemma, whether common experience might result from a homogenous group population, e.g. depression clients only, or if the same quality of universality and its impact on the experience of the group can be achieved in heterogeneous groups, e.g. those with multiple long-term health conditions (Biggerstaff & Thompson, 2008).

Another factor that may contribute to positive change is learning. The role of vicarious learning is strongly emphasized in Bandura's theory of social learning (1977), which implies that the learning happens through observing others. In the group setting, learning is also facilitated by positive feedback that often encourages self-efficacy and confidence (Legg, Stott, Ellis, & Sellars, 2007). One of the predicaments reported in post-stroke life is loss of self-esteem and belief in one's own capacity, hence learning in the group setting might increase confidence levels for this population.

In conclusion, offering a group intervention to stroke survivors might enable them to address some of the difficulties they face on a daily basis with support from and with others 'in the same boat'.

# 1.4.1 Applicability of Group Intervention for ABI/TBI Populations

As mentioned previously, a large number of studies have been dedicated to ABI or TBI survivors, with few studies dedicated to the stroke population in isolation. Hence, this section evaluates available studies of brain-injury research and explores existing knowledge of the suitability of group-based interventions.

Ownsworth et al. (2000) conducted a RCT study, in which individual, group and combined-format therapy were compared in their efficacy in facilitating goal attainment and improving psychosocial functioning following ABI. The individual's goals were based on occupational activities that were meaningful to participants. The results of the study suggest that individual therapy enabled participants to achieve their goals better; however, it was the group-based intervention that enabled them to build confidence in their behavioural competency, leading to improved psychological wellbeing and sustaining the outcome after 6 months compared to individual interventions. Both individual and group therapies seemed to have different goals, suggesting the results cannot be directly compared.

Additionally, it is also likely that in the group context the further input from peers and in-group interactions could have enhanced mutual learning and broadened strategies beyond personal ones, although that was not considered by the authors. It is notable that Visser's (2013) RCT study, which described changes in the group as a "placebo effect", also omitted the potential impact of group processes. The group effects might be more complex and its nuances harder to capture by quantitative measures, which make them under-reported in this type of research.

However, the increase of hopefulness in addition to confidence in group contexts is also reported in Vickery et al.'s (2006) study that explored effectiveness of psychotherapy interventions focusing on challenging negative views of self and moving towards other meaningful aspects of identity. The result of the study indicated a beneficial impact of group therapy on views of self, concluded from significant differences reported by participants.

Conversely, there are no further measures or qualitative reports expanding on *how* the change occurred and if the reported shift further contributed to any functional changes

or their quality of life. Additionally, without clear descriptions of utilised framework and control groups it is hard to conclude if the reported changes were due to specific treatment models or other factors, e.g. group process that may enhance a sense of confidence (Yalom & Leszcz, 2005). Therefore, the mechanisms supporting the above psychological gains remain uncertain.

Furthermore, the concept of self is also at the core of other studies by Aboulafia-Brakha and colleagues (2013) and Ownsworth and colleagues (2008). Researchers conducted quantitative studies evaluating the feasibility of CBT group programmes for ABI and TBI population in the context of self-awareness and emotional regulation (anger). The therapeutic framework focused on increasing emotional self-awareness, emotional regulatory skills such as relaxation, CR and prevention strategies. The conducted analysis enabled researchers to extrapolate the applicability of this model to increasing self-awareness and managing anger in this population based on medium difference in scores at pre- and post-treatment.

However, those results need to be interpreted tentatively due to small sample sizes. The researcher also commented on the size of the group as a relevant factor in the group experience (Aboulafia-Brakha, Greber Buschbeck, Rochat, & Annoni, 2013). Small groups in this study (N=2–4) may have brought additional challenges, as some of the participants withdrew due to feeling incompatible with other group members, reducing the group at some points to one person, which may have changed the experience of intervention for the remaining attendee. According to the literature, the group size should give ample chance for interactions and contribute to sense of identity (Corey et al., 1992) but also instil hope and motivation to change through the presence of others and the observation of therapy working (Spragg et al., 2015). Thus, small groups might have contributed negatively to the above report. Conversely, the presence of the same

clinician throughout the research design may have influenced answers on the selfreported measures to more favourable ones. Thus, the measured change in the above study might be affected by numerous factors.

This issue of measuring change seems to be also present in Ownsworth et al.'s (2008) research that evaluated CBT-based intervention on shifts in self-awareness leading to change in psychosocial functioning. Analysis of the changes in participants was captured by a newly introduced self-awareness scale: the Self-regulation Skills Interview (SrSI) (Ownsworth, McFarland, & Yound, in press). The group results have indicated that self-awareness has not improved during the study.

The findings, however, can be explained by the newness of the scale which might not have been sensitive to multiple factors relating to changes in self-awareness. As a common assumption in quantitative design is that change is linear and gradual, the predicators of change tend to be measured once or twice, providing only snapshots of the change processes without further insight as to change (Hayes, Laurenceau, Feldman, Strass, & Cardaciotto, 2007). This is perhaps why there was a discrepancy between relatives reporting fewer emotional problems in participants' behaviour as a result of the group, but this not being replicated by participants themselves. This type of design does not provide further information as to why and how the group processes affect the change and could be better explored through qualitative interviews.

This point can be strengthened by qualitative reports of participants who engaged in an 8-week CBT videoconference group intervention who did not report any changes in emotional regulation as hypothesised by the researcher (Tsausides, D'Antonio, Verbanova & Spielman, 2014). Interestingly, in the post-group debrief interviews attendees indicated that they were missing face-to-face interactions with others as that would enhance connection to other members. They also expressed a need to be able to

talk with others prior to the start of the session. Social interaction is closely linked with developing a group relationship that is a vehicle for change (Kivlighan, 2011). Therefore, perhaps one explanation of the results was a lack of certain group factors that might have influenced the outcome. It seems that the group processes and the framework in which the group is delivered cannot be treated as separate entities and consideration of all possible dynamics contributing to and hindering outcomes for the stroke population may need to be regarded.

Another qualitative study by Couchman et al. (2013) explored experiences of ABI attendees and family members in multifamily group therapy based on solutions-focused and problem-solving therapy principles. Similarly to Vickery et al. (2006), the facilitators aimed to encourage broadening the definition of "deficient" self toward other values in life such as hobbies. The outcome of this thematic analysis largely concentrated on group processes such as social comparison that enabled individuals to normalise their experience and alleviate their sense of loneliness. The comparison with others supported them also to judge their own progress in the recovery. The feeling of being understood fostered connections and a sense of belonging. Participants also reported group interaction was a foundation for achieving integrity as an individual, within family and social settings (Couchman et al., 2013).

Being part of the group enabled participants to give advice to others, which meant shifting from the 'patient' identity to a helper. The group literature stresses the important role of mutual support for each other and refers to it as "altruism" (Spragg et al., 2015). The opportunity to help others leads to emotional relief (Morris & Morris, 2012), feeling useful (Barton, 2002), and enhances revision of the negative view of self (Vickery et al., 2006). As result of this shift, participants reflected on behavioural changes such as self-care or engaging in day-to-day tasks.

Unlike previously mentioned studies, participants stressed the usefulness of learning from others whose experiences mirrored their own. That aspect in particular highlights the importance of homogeneity in group settings, where attendees through shared experience rebuild their sense of self and deepen their understanding of stroke (Pearce et al., 2015). The limitation of the study was the lack of triangulation to enable the researcher to receive participants' feedback about the findings. Still, it illustrates the unique experiences of the group members, pointing to dynamic group process that drove change and also furthered the argument for the value of qualitative methodology as an adjunct to quantitative design.

# 1.4.2 Group Interventions for Stroke Survivors

As mentioned in Smith's (2017) study the existing research on stroke only has been growing in recent years, and it is still limited when comes to group interventions delivered for this population. This section will give an overview of existing literature dedicated to stroke survivors only, as identified by this researcher.

The current studies continue to show both group process and therapeutic models to be intertwined in the aim of supporting stroke survivors, but also indicates the role of group factors as independent facilitators of change. For example, based on assumptions that telling a story would enhance reflection and adjustment of traumatic life events, Kirkevold et al. (2014) presented primary data evaluating the feasibility of the narrative therapy group for stroke patients. Their mixed-method design aimed to explore the applicability of both individual and group formats. The overall outcome of the data indicated satisfaction in both individual and group settings, indicating equal effectiveness of both model and group processes. However, participants in the group therapy highlighted the value of sharing their experience and how mutual learning increased their feeling of being supported and hopeful about the future. The process of

self-disclosure is frequently reported in group literature as an important factor in expressing emotions, revaluating them in context of a larger group and a contributing factor into building cohesiveness of the group (Corey et al, 1992).

The primary importance of self-disclosure was acknowledged in the report evaluating narrative therapy for stroke survivors (Chow, 2015). The researcher suggested that the topics discussed and talking about their predicaments increased their sense of clarity and acceptance (Kirkevold et al., 2014) but also allowed participants to externalise their problems. Consequently, that act invites participants to separate their identity from stroke, whereby they change how they connect with their illness (Chow, 2015).

On one hand, an important aspect of both studies is the development of the new narrative that facilitates change in their relationship to their illness. The meaning that an individual attributes to the illness may influence their psychological distress and impact on recovery (Krenz, Godel, Stagno, Stiefel, & Ludwig, 2014). The language used to label the illness (e.g. 'intruder') reflects the construction of a narrative tying together the illness and the self, and one which may disempower the individual (Shahar & Lerman, 2013). Thus, ability to change this view of the illness might stimulate positive upheaval in that relationship. For example, a study on cancer indicated that transforming the disease from "challenge" to "value" contributed to a lower level of depression and anxiety (Degner, Hack, O'Neil & Kristjanson, 2003). A similar outcome was reported by Mathias et al. (2014) where ACT intervention through use of metaphors supported participants in developing a new relationship with chronic pain and increased confidence.

On the other hand, researchers reported collaborative group working was a vehicle in the process of improving participants' emotional adaptation, outlining further the importance of the group relationship. Peer support may improve psychological adaptation and improve recovery in health condition (Morris & Morris, 2012) through discovering other perspectives and being encouraged by other members (Beesley et al., 2011; Yalom, 2005).

However, both studies have some limitations: for example, Chow's study is a description of the model only and the finding has not been scientifically explored. Kierkevold's (2012) study has a small sample size, specifically in a group intervention. The unknown number of sessions in both studies also makes it harder to draw conclusions regarding clinical applicability. Additionally, lack of a control group decreases access to possible meaningful information e.g. as the study was designed for patients who suffered stroke within 8 weeks, thus measures of quality of life or psychological distress may vary at that stage compared to later stages of living with stroke. Also, significant differences in participants' age might have contributed to the overall experience of the group as the researchers reported younger attendees focused more on work-related issues in comparison to older adults. Saying that, a number of studies (Johansson, Bjuhr, & Ronnback, 2012; Visser et al., 2013) suggested efficacy of group-based interventions for stroke patients to be independent of age and stage of post-stroke living – which in itself suggests that further research is needed.

Two other pilot studies (Barton, 2002; Merriman, Birchman, Easton, & Maddicks, 2015) pointed to the significance of another group factor: universality as an important process in adjusting to stroke. Barton et al.'s (2002) research on the group intervention was based on models of bereavement and loss (this was previously omitted in CBT studies), whereas Merriman et al. (2015) tested the effectiveness of mindfulness in group sessions. The participants in both studies regarded a common experience as a bridge to explore ways of coping with distressing emotions, allowing participants to process them further. The significance of this experience has been identified by Yalom

(2005) as a notion that enables one to disavow feelings of isolation or oddness and is a source of relief. This concept was also reported in cancer studies, where shared difficulties facilitate mutual understanding and normalise experiences (Sekse et al., 2013). Recognition of similarities also stimulates validation for the "invisible" pain (Mathias et al., 2014) or helps to reduce shame in individuals experiencing OCD (Spragg et al., 2014).

Overall, support for both mechanisms (the model and the group processes) is visible in the literature, however, how stroke patients make use of them is harder to discern from some quantitative studies. Some of the above mixed-method literature (e.g. Kirkevold et al., 2014; Merriman et al., 2015) due to qualitative analysis allow further insight into dynamic processes of change and benefits of interventions for stroke survivors, often driven by group factors. Thus, discussion of available qualitative research exploring lived experiences of group intervention in stroke population is outlined below.

#### Qualitative studies

Research studies in stroke populations that place focus on the experience of participants is limited. It is therefore prudent to encompass research from their perspective. The following three qualitative studies (thematic analysis and two grounded-theory studies) explore stroke patients' experiences in a peer support group (Morris & Morris, 2012), art therapy (Beelsey et al., 2011) and volunteer stroke services (Legg & Scott, 2007). The main aim of the studies seem to be increasing social interaction through building confidence, and improving social skills in hope of improving quality of life. Previous research shows that 50% of stroke survivors struggle with staying connected to friends, community and social life and this impacts on their wellbeing (Salter, Hellings, Foley & Teasell, 2008). Ironically Lynch et al. (2008) demonstrate the importance of social support and relationships in the process of recovery.

Across all three studies, participants echoed the previously mentioned enjoyment of being part of the group and perceived their groups as warm and supportive environments (Legg et al., 2007). Social comparison, learning from each other and peer feedback were found to be crucial to restoring confidence (Morris et al., 2012). Additionally, shared themes also included the need for interaction with others who went through the same experience, as that provided a safe setting for participants, where their 'handicaps' were easily understood (Beesley et al., 2011). Those findings indicate further the significance that stroke survivors ascribe to being a member of a community who mirror the same experience.

Interestingly, this significance of group underlying dynamics is stressed in two of the presented studies (Morris et al., 2012; Legg et al., 2007). That is, both interventions were not driven by any therapeutic framework and relied solely on processes occurring between members. Still, the participants reported personal growth similar to feedback in other studies based on mindfulness groups (e.g. Meriman et al., 2015), CFT (e.g. Ashworth et al., 2014) or CBT (e.g. Ownsworth et al., 2008). This suggests that despite the body of literature promoting efficacy of particular interventions for brain-injured individuals (e.g. Bradbury et al., 2008; Kanags et al., 2011), the above findings provide further support that stroke survivors may experience improvement in their emotional and behavioural functioning resulting from group processes (Ownsworth et al., 2008).

In all three studies the exclusion criteria referred to stroke patients with severe communication difficulties, cognitive impairments and significant depression. This seems to be a common issue in the existing literature, with a few in-between studies that include e.g. aphasia patients. Omission of individuals with severe common post-stroke challenges limits study to a specific group within the stroke population. Although qualitative studies do not aim for generalisation, transferability is an important aspect of this design (Willig, 2008).

# **1.5 ACT and Stroke Population**

#### 1.5.1 ACT Model

As mentioned earlier, Acceptance and Commitment Therapy, so-called "third-wave" therapy, has been attracting more interest in the recent decade. A brief description of the model is now outlined.

Acceptance and Commitment Therapy (ACT) has grown over recent years in the treatment of the general public, and health psychology. The ACT model is driven from Relational Frame Theory, which focuses on how context influences one's thoughts and behaviours (Hayes et al., 2004). The main difference of ACT, in comparison to other behavioural or cognitive approaches, lies in its aims. ACT focuses on changing one's relationship with individual internal experiences such as thoughts and feelings, instead of challenging the content of the experience. The goal is then to increase one's psychological flexibility by welcoming and being conscious of experience, approaching it in a non-judgemental way and still being able to engage in actions or behaviours that are directed by the unique values (Hayes et al., 2004). Thus, the main idea is to help individuals to accept what cannot be changed and live a meaningful life. In addition, ACT is a trans-diagnostic approach that moves away from diagnostic-specific treatment models. That is, instead of focusing on a single set of difficulties, ACT can target generic psychological skills (Clarke, Kingston, James, Bolderstone, & Remington, 2014).

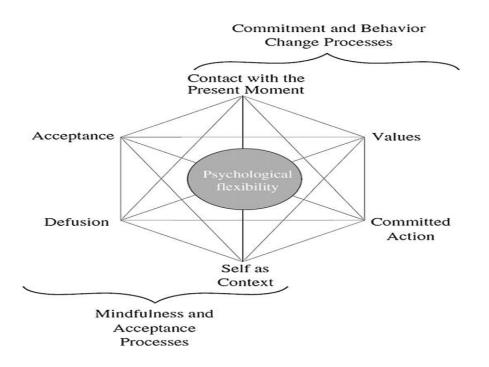


Figure 1. A model of psychological processes of ACT (Hayes et al., 2004).

There are six core processes in ACT that influence psychological flexibility: contact with the present moment, which refers to the here and now and allows a person to engage fully with what one does; acceptance, the process of being open to the experience without the need to fight it or avoid it; cognitive diffusion, referring to creating a distance from distressing thoughts – looking at them rather than from them; self as context, which gives the ability to observe oneself and be able to notice different roles that remain the same despite changes; values, which guide our behaviour and are motivations for further action; committed action, which is value-guided and goal-driven behaviour (Hayes et al., 2006).

### **1.5.2 Applicability to Stroke**

Existing literature exploring experiences of stroke indicates the complex needs that this population faces; therefore a trans-diagnostic approach such as ACT could be advantageous in addressing multiple stroke-related predicaments by changing their

relationships to psychological and contextual events, where post-stroke distress is conceptualised as a human experience and part of life (Hayes et al., 2006).

ACT, due to its counter-intuitive method of accepting, as opposed to challenging, the difficult experience, has a focus towards achieving a valued and fulfilling life (Clarke et al., 2014). This stance can be beneficial for stroke survivors who experience loss of direction in their life and wish to rearrange their lives despite unwanted changes (Rochette et al., 2006).

The loss of self and identity is frequently reported in stroke (Seeto et al., 2017). However ACT, through utilisation of mindfulness and cognitive defusion tools aims to decrease negative self-evaluation and redefine the concept of self by encouraging more flexible viewpoints through creating an awareness of the self, and by encouraging individuals to reconnect with personal values (Hayes, 2004).

The sudden occurrence of stroke is often experienced as a shattering and unexpected event, leaving individuals little time to prepare and deal with the complexity of poststroke life (Rochette et al., 2006). Often, adjustment is placed on a continuum of the past and present self, and the researchers propose that there is no fully successful way of adjusting to stroke due to the constant conflict between the present and past life. Doolittle (1991) and Seeto et al. (2017) posit that recovery from stroke requires identification of what matters and what is meaningful to individuals. Thus, the notion of acceptance within the ACT model may facilitate the process of adaption and coming to terms with their changed circumstances by rediscovering subjective life values (Hayes, 2004). Moreover, the literature indicates a correlation between increased acceptance of poor health and positive view of the self (Williams, Vaughan, Huws, & Hastings, 2014). Furthermore, this mode does not require cognitive capacity (which might be affected due to stroke), that has been shown to be challenging in CBT models of treatment (Kangas et al., 2011). Learning the techniques is assisted by role-plays, metaphors or mindfulness techniques. These strategies do not seem to require high executive functioning, reasoning or evaluation skills. Thus, it seems be user-friendly without need for stroke survivors to understand the underlying process of the model, as was pointed out in two recent reviews (Kangas et al., 2011; Soo, Tate, & Lane-Brown, 2011).

Additionally, ACT literature, albeit limited, it also reported as beneficial when delivered in group formats e.g. in fibromyalgia (Wicksell et al., 2013), psychosis (Bacon, Farhall, & Fossey, 2013), pain (Mathias et al., 2015), social phobia (Ossman, Wilson, Storaasli, & McNeill, 2006), treatment resistance (Clarke et al., 2014) or diabetes (Hadlandsmith, White, Nesin, & Greco, 2013). However, up to now, ACT-related research is also sparse when it comes to group therapy for brain injury and stroke specifically. Hence, it is yet little known how this model may facilitate or hinder progress in stroke populations. The researcher was able to locate only one quantitative ACT group study dedicated to stroke patients. An evaluation of this study is outlined in the following section.

# **1.5.3 An ACT Group Intervention for Stroke Survivors**

Although the literature review by Soo et al. (2007) and Kangas et al. (2011) posits ACT as being a suitable therapeutic model in addressing complex brain injury-related needs, the researcher located only one study (Majumdar & Morris, 2018) focusing on the effectiveness of ACT group-based interventions for stroke populations. 53 participants took part in the study and were randomly allocated to two groups: ACT (N=26) and the control group (TAU) (N=27). The group lasted 4 weeks with 2-hour didactic group sessions per week. The study included adult stroke patients, who were not diagnosed with aphasia or severe cognitive impairments. Participants with previous other TBI or

ABI were excluded, focusing the outcome of the study on stroke survivors. The measures (PHQ-9, GAD-7, HR-QOL, hope scale, mental wellbeing) were collected by researchers pre- and post-group sessions at 2-month follow-ups. Their carers were invited to the course for support. The researchers indicated that their presence was not inhibiting the sessions as the programme was not interactive but only didactic using PowerPoint presentations (Majumdar et al., 2018). The size of the group varied from 6–22 with 50% being carers.

The result reported by the researchers indicated significant change (54% of participants) in depression compared to TAU which was maintained at the follow-up measures. This result was replicated in measures of increasing hopefulness, but no changes were found in anxiety, mental wellbeing and quality of life. A number of possible factors might have contributed to the reported results. One is the didactic form of sessions. The above qualitative studies frequently reported social interaction (Tsaousides et al., 2014) and specifically sharing and talking about the experience as the most beneficial aspect of the group experience (Couchman, 2013; Kirkevold et al., 2012). Hence, being in a setting that inhibited that interaction perhaps also removed an important mechanism that facilitates emotional processing and increases the chance of positive change. Participants in Aboulafia-Brakha et al.'s (2013) study indeed suggested a need for more emotionally oriented discussions.

Learning from each other in addition to a facilitator's input (e.g. Legg et al., 2007) was also discussed as a profound aspect of group life. Since that might not be possible in a didactic setting, participants might have had less opportunity to revise and enrich their coping skills amongst each other. Above all, the length of the group perhaps did not allow attendees to process and reflect on the learnt strategies. Furthermore, assuming participants might have struggled with concentration due to stroke-related changes and mental fatigue (Matsuzaki et al., 2015), there was the possibility they would have found it challenging to absorb or comprehend all the information delivered in a lecturing style. Consequently, that would affect the efficacy of the presented tools. Also, the small sample size and lack of comparison with other treatments indicates that the additional factor might have caused the positive changes on the depression and hopefulness scales.

The researchers suggested hopefulness was acquired in the study through skills such as directing values and committing action towards a more meaningful life (Majumdar et al., 2018). However, if this was the case one would expect the quality of life score to mirror those changes, as according to the definition of QOL, individual perceptions on their position is grounded in the context of their values (WHO, 2011). The other explanation proposed by the researchers is that better measures would have captured the change more effectively. However, the authors did not consider more holistic, bottom-up explanations that would involve seeking participants' voices and perspectives on the changes emerging from their group. As the previously discussed literature suggested, qualitative inquiry into lived experiences can provide further insight and knowledge into how stroke survivors make sense of and utilise the ACT group factors in the process of change.

# **1.6 Relevance to Counselling Psychology**

The evaluated literature indicates a limited number of studies dedicated to ACT psychological intervention in stroke population. However, due to a growing number of people who have experienced a stroke in the UK, there is a need to expand on existing knowledge and strategies to promote the process of change. Although there is broad research on clients' experiences of therapy in general populations, there are limited numbers of studies focusing on stroke survivors. Furthermore, current stroke-related

research shows that multiple processes and changes after stroke seem to require more holistic and integrative therapeutic understanding of clients' experiences in therapy. The broadening understanding of human experience is at the core of CP practice, hence aligning the current study with CP principles (Douglas et al., 2016; Karademas, 2009).

The synthesis of literature on group treatment for those suffering stroke implies the process of recovery after stroke could be facilitated further by group processes, where sense of belonging, universality or social interaction were shown to be important vehicles for change (Patterson, Fleming, & Doig, 2017). As counselling psychologists engage not only in individual but also in group interventions, the outcome of the current study allows further insight into clients' perspectives on experiences of being with others in ACT group interventions, therefore providing clinicians with supplementary information which could be considered in their practice.

The theoretical and methodological underpinning of the current study is in line with IPA, in which the process of analysis explores the subjective lived experiences of stroke patients (Smith et al., 2012). The subjective and reflexive aspects of IPA correspond with CP assumptions that stress the importance of understanding the individual meanings that clients attach to their experiences (Douglas et al., 2016; Borcki & Wearden, 2006). That cannot be achieved through pre- and post-testing hypotheses proposed by quantitative inquiry, but through allowing patients to tell their story in their own words (Smith, Flowers, & Larkin, 2012). This is in line with the current study, which aims to develop further idiosyncratic understanding of the phenomena, and aims to contribute to stroke-related clinical practice.

As there is no study exploring stroke survivors' experiences of being with others in an ACT group, the current study could be informative to therapists who choose to draw upon this model. Moreover, the ACT and CP ethos stresses the importance of

developing clients' strengths and acknowledging the influence of wider context on emotional distress (Hayes, 2006; Douglas et al., 2016). The trans-diagnostic nature of ACT is not concerned with diagnosis and symptom reduction but focuses more on the universal process that underline these (outlined in Section 1.5). This is in line with CP's view that questions the benefit of diagnostic criteria and instead celebrates individual experiences. Lastly, the core concept of acceptance and living a more fulfilling life encompassed in an ACT model has been long emphasised by humanistic and existential approaches, in which CP practice is grounded.

## **1.7 Conclusions and Situating the Present Study**

The review found the majority of existing literature is still dedicated to general acquired or traumatic brain injury with scarce available data dedicated to stroke survivors only. Considering the variety of psychological difficulties (mood disorder, psychosocial difficulties, anger, loss in numerous life dimensions) experienced by this population, there is ongoing need to explore psychological support to improve their quality of life and the current study aims to add to the gap in the literature.

Exploration of the outcomes of brain injury and stroke has been largely enhanced by quantitative studies (Levack, Kayes, & Fadyl, 2010). Although they do provide valuable knowledge, the existing research looks largely to reduce symptoms of depression and anxiety or to find evidence-based support for a psychological framework that is effective in targeting specific post-stroke difficulties or function, such as anger or coping skills. Those studies implement top-down approaches where participants' perspectives are absent. Hence, this study will address this issue by implementing qualitative methodology to gain insight into lived experiences of stroke survivors.

The mixed-method studies and the majority of qualitative studies did often focus on gathering participants' feedback, with the feedback regarding the specific intervention rather than their experience of participation in the group *per se*, so the current study will aim to enquire into the group as a medium for stroke populations. Since the literature review also highlighted a complementary relationship between modality and group factors with no clear aspects contributing to the effectiveness of the group, this researcher will remain curious and open-minded as to how stroke patients experience ACT-based group therapy.

The qualitative literature adds additional volume by describing the complexity and nuance of human experience (Smith et al., 2012). It gives the researcher an opportunity to access the personal views of participants on their journey and enables her to elucidate further phenomena of the process of change, recovery and improving quality of life following stroke (Couchman et al., 2014). However, some of qualitative studies illustrate significant flaws in methodology, such as the limitations of the proposed theory in the grounded theory study by Beesley et al. (2011), or the absence of specific analysis methodology (Barton, 2002; Merriman et al., 2015). Thus, the current study would aim to address these issues by aligning to the validity criteria proposed by Yardley (2008).

Furthermore, the literature review suggests that the third-wave therapy's transdiagnostic nature allows one to address multiple psychological struggles and processes. ACT intervention was shown to be applicable to stroke-related predicaments by changing their relationship to experiences rather than challenging it (Kangas et al., 2011). Due to the lack of qualitative enquiry into factors stimulating psychological growth in ACT programmes for stroke populations, the process of research could offer greater insights into the feasibility and necessary combinations of the group factors that facilitate or hinder positive change supported by the ACT model. Given the current lack of consistent evidence for treatment of psychological difficulties after stroke, with group process being shown to be a profound factor in achieving change (Ownsworth et al., 2008) it seems to be paramount to explore how this population can benefit from sharing experiences in group settings. Furthermore, the unclear findings from quantitative studies on ACT group programmes for stroke survivors sets a rationale for applying qualitative design by shifting emphasis to service users' perspectives rather than specific interventions.

## **1.8 Research Questions**

The above justifies the inquiry into subjective experiences of group dynamics and processes amongst stroke survivors who attended ACT group interventions. The aim of the study is then to explore how being in the group might hinder or benefit stroke populations, and how stroke clients perceive psychological change as a result of attending the group.

# **Chapter two: Methodology**

#### 2.1 Overview

In this chapter I discuss the rationale for my chosen methodology and employing the IPA method in order to answer my research question. Further, the process of recruiting the participants and designing the research question is outlined. The following sections also include consideration of the ethical procedures I followed.

In the present section, I have used the first person writing style where relevant with the aim of highlighting my own role as a co-constructor of the analysis together with the interviewees. According to the literature, using the first person is in keeping with the epistemological paradigm of the IPA and part of active reflexivity process (Webb, 1992).

# 2.2 Rationale for qualitative approach

How we seek out new knowledge governs the preferred process that aims to answer the research question. As Smith suggests, research should be designed to explore "humanly significant problems with method chosen" (Smith, 2001, p. 443). As this study's objective is to explore individual experiences and meaning attached to participation in group therapy, I have employed a qualitative method that is consistent with the aim of this research.

The qualitative approach is concerned with the investigation of experiences within the specific context, and it aims to understand various perspectives on studied phenomena that participants may hold (Hodges, Hernandez, Pinto & Uzzell, 2007). Therefore, it allows new knowledge to arise that conveys individual meanings that participants have attached to their lived experience (Willig, 2008). Furthermore, the qualitative approach

recognises that an experience is not an objective entity and, therefore, in contrast to the quantitative method, it does not/cannot explain data through numerical values, and does not engage in statistical analysis (Goodyear, Claiborn, Lichtenberg, & Wampold, 2005; Smith, Flowers, & Larkin, 2012). Instead, qualitative approaches offer a variety of methods that enable the understanding of data by looking at a unique experience through a magnifying glass of detailed analysis. Hence, this approach offers a complementary form of investigation and can offer a novel insight into knowledge, including that which is related to health problems (Yardley, 2000).

By focusing on depth rather than breadth of the phenomena, qualitative research cannot be extrapolated to the greater population as results of the quantitative method can, but this framework enables greater understanding of the essential nature and quality of the experience, driven from contextual reports and interviews with participants (Morrow, 2005), which is of interest to this study. However, the fact that generalisation is not feasible is often seen as a significant flaw of this approach, as, according to critics of qualitative studies, the study loses its scientific power (Pringle, Drummond, McLafferty & Hendry, 2011). Still, although that generalisation might not be explicitly applicable to a qualitative study, as Reid, Flowers and Larkin (2005) suggest, the similarities across analysis can have wider implications and can still contribute greatly to further developing existing theories. Moreover, Cadwell (2008) argued that "theoretical dialogue" in qualitative studies refers to wider literature, therefore making a contribution to theory. By this, the gained insight into individual experience can mean insight into the wider population. This is why Smith et al. (2012) encourage qualitative researchers to think of the results in terms of "theoretical transferability rather than empirical generalisability".

Following a stroke, most people experience physical difficulties linked with the psychological challenge of adjustment and acceptance and significant loss of self (Kleiber, Reel, & Hutchinson, 2008). This suggests that the journey towards reconciliation and reclaiming life after a stroke is not only physical, but also depends highly on the opportunity to restore one's identity, which is a complex phenomenon (Salter, Hellings, Foley, & Teasell, 2008). For that reason, I employed the qualitative method and intended to approach the current study in a more holistic way through the biopsychosocial model that is in line with Counselling Psychology.

## 2.3 Rationale for interpretative phenomenological analysis

As mentioned previously, there are a number of qualitative methods available to the researcher and, depending on the enquiry and aim, different frameworks should be used. I initially considered Grounded Theory method, which aims to produce new theories grounded in "observation of the reality" (Hayes, 2000, p. 184). This approach would still have allowed for being context-specific and for the data to be driven by the real world. However, this method utilises a deductive and hypothesis-driven approach, and the primary concern was to develop explanatory theory (Shinebourne, 2011). Nevertheless, the intention of this study was to explore individual experience and indepth understanding of being in group therapy, rather than proposing a new theoretical explanation of this phenomenon. Thus, on that basis, this method was discarded as inappropriate for the current study.

The second method considered was discursive analysis, which enables the study of how people use their language to construct realities (Smith, 2004). Although experience is mediated by language, and discourse is treated as a tool to communicate that experience, my focus was on personal accounts, not on language itself, so this made discursive analysis an unsuitable method for this research. The above methods were found to contradict the goals of the current study, in which the main focus was on significant experience and sense-making of stroke patients who attend ACT group therapy.

Based on the above, I utilised Interpretative Phenomenological Analysis (IPA) (Smith et al., 2012). This approach is concerned with individuals' perception of their embodied experience, and also embraces phenomenological and interpretative traditions. Contrary to discourse analysis, this methodology enabled me to take an insider point of view; that is, it allowed me to get close to participants' experiences and engage with their meaning-making processes by using a double hermeneutic (a process of interpretation) (Biggerstaff et al., 2008; Smith, 2004). Taking into account that the aim here was to explore that experience on the deeper level, rather than verbal communication, this proved to be the ideal method of analysis for this project.

Furthermore, IPA is inductive in its nature, and allows spontaneous data to emerge during the analysis, which facilitates an exploration of personal accounts (Smith et al., 2012). Therefore, in contrast to Grounded Theory, IPA brings to the fore participants' perceptions through capturing the relationship between themes that arise during analysis (Smith et al., 2012). Due to the above, I considered IPA to be more attuned with this research's exploratory and experiential interest.

In addition, IPA recognises that the process of analysis or interpretation and meaningfinding is a shared experience between participants and the researcher. That is, although the IPA focuses on capturing the subjective experience of the participants, the researcher interacts closely with the data during the analysis, and the interpretation of the data is viewed through both lenses – participant and researcher (Smith et al., 2012). Reflecting on and acknowledging this is extremely important in this methodology (Wertz, 2005) and it made it possible to be transparent about my clinical experience in the area of research and personal beliefs towards health-related issues, and how those could influence the process of analysis. This factor was an additional reason for choosing IPA as a method for the current study.

The qualitative studies previously discussed in Chapter One suggested that it is an ideographic narrative about experience that brings about meaningful knowledge and enriches our practice (e.g. Townend, Tinson, Kwan, & Sharpe, 2010). Hence, following the phenomenology and appreciation for human beings' individuality that IPA celebrates, this method of enquiry was suitable for the current study. In addition, the quantitative method is theory-driven and seeks to understand laws and causes, but this assumes that all human reactions are determined by these laws (e.g. physical symptomology of stroke) (Howitt, 2010). This approach defines the human in a mechanical way, which is in line with naïve realist paradigms. In contrast, as a critical realist (explained further in Section 2.5), I learnt to appreciate the influential role of the environment, and acknowledge that human behaviour is not rule-governed. Thus, in order to explore subjective experiences, IPA is influenced by Heidegger's notion of "person in context" (Smith et al., 2012), offering a focus on semantic rather than lawful study, which makes this method align with the research question.

In addition, I think that IPA is congruent with the ethos of Counselling Psychology, which also assumes the individual experience to be fundamental, and that the primary concern is to uncover and enhance understanding of the uniqueness of the individual (Eatough & Smith, 2007).

IPA interpretative traditions are also visible in the work of counselling psychologists in that the interpretative approach, building trust and good working relationships are relevant to examining context-specific features of experiences and it also has a direct link to clinical practice (Smith et al., 2012). Since interpretations are commonly used by

counselling psychologists in their clinical work, the IPA process of interpretation makes it once again consistent with often-used clinical skills.

Overall, the qualitative method and IPA specifically, is well situated within Counselling Psychology traditions, and can offer a view of "what resides beneath" human experience (Haverkamp, Morrow & Ponterotto, 2005, p. 123). This made this method relevant to my study and congruent with the clinical ethos of counselling psychologists.

## 2.4 Interpretative phenomenological analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative research method that explores how people make sense of their lived experiences. According to IPA philosophy, individuals tend to reflect on major changes in their lives and the IPA researcher aims to participate in the process of making sense of these reflections (Smith et al., 2012). Thus, IPA is concerned with individuals' subjective accounts rather than the formulation of objective statements. Meaning and understanding of participants' idiographic experience is not fully possible, hence IPA relies on the researcher's own preconceptions, knowledge and views to make sense of those experiences through the process of interpretation (hermeneutics) (Brocki & Wearden, 2006).

IPA draws on phenomenological enquiry that is concerned with an individual's experience and existence, narratives and their understanding of the world around them. It suggests that the meaning of experiences lies in perception, and time and context must be taken into account when interpreting this meaning (Landridge, 2007). Phenomenological paradigm is drawn from Husserl's philosophy, which focused on experiences within the consciousness of the person and encouraged researchers "to go back to things themselves" away from our pre-existing categorisation system (Smith et al., 2012). That is, the essence of phenomena can be understood if the researcher

engages in "phenomenological attitude", by bracketing previous knowledge (epoche) in order to concentrate on a phenomenon. Still, bracketing does not mean previous experiences are absent or removed entirely; it means they are minimised to enhance new ways of thinking about the phenomena at hand (Smith et al., 2012).

Although phenomenology was instigated by Husserl, IPA draws on Heidegger's existential philosophical understanding of human experience (1962), which perceives a person as a part of the wider world, embodied in social, cultural, and historical milieu ("the person in context") and introduced the concept of inter-subjectivity (relatedness to the world) (Shinebourne, 2011).

Heidegger also questioned the possibility of gaining knowledge without interpretating one's experience. Hence, within IPA, the researcher aims to produce analytic perceptions grounded within participants' sense-making, although understood and analysed by the researcher (Biggerstaff & Thompson, 2008). This theory of interpretation (hermeneutics) instils the importance of an inquisitive although empathic position to interpretations, whereby the researcher attempts to make sense of the participants' sense-making (double hermeneutics).

The other key characteristic feature of IPA is idiography. This stance asserts the significance of the uniqueness, individuality and focus on the particular rather than the nomothetic method (i.e. IPA does not aim to produce general laws of human behaviour) (Smith et al., 2012). The commitment to the particular is manifested in both the depth of analysis, and how particular phenomena have been experienced (understood) from the perspective of the particular person in the specific context (Biggerstaff & Thompson, 2008).

In summary, IPA adopts a philosophical position whereby, through interpretative methodology, it allows access to idiographic experience of one's world. In order to attempt to encapsulate and explore participants' perceptions of their experiences in a collaborative act of search for meaning, IPA emphasises the need for researcher self-reflection, which requires one to explicitly identify and put to the side one's pre-conceptions and knowledge relevant to the phenomena at hand (Smith et al., 2012). It is paramount to highlight that acknowledging of prior knowledge does not guarantee the researcher a fully objective stance to the data (Larking et al., 2006).

# 2.5 Epistemological dilemmas

Through the course, I have learnt that my clinical work and research approach are interlinked and bound by a set of assumptions and beliefs that I have developed. The assumptions are related to how I rely on theoretical guidance, and how I learn about clients' issues. The literature often highlights the importance of placing oneself as a psychologist within philosophical paradigms in order to guide the research process (Harper, 2011). Philosophical traditions refer to the nature of knowledge (epistemology), and to understanding what reality is (ontology). There is also the role of researcher and participant (rhetoric), and scientific rigour (methodology) (Hayes & Wood, 2011). It seems that different authors approach the explanation of the paradigms differently based on various dimensions. For example, Ponterotto (2005) adopted Guba and Lincoln's 1994 framework and looked at paradigms through ontological, epistemological, and methodological lenses. He proposed four categories: positivism, post-positivism, constructivism-interpretivism, and critical-ideological.

However, I found myself leaning towards Willig's 2012 way of mapping epistemological assumptions. The key here seems to be the extent to which collected

material is perceived to reflect reality (realism-relativism), which is more in line with my understanding of epistemology. My early professional clinical experience was aligned more with realism ethos that asserts there is one version of reality and that truth is fixed. The knowledge produced under this assumption is meant to be objective, and therefore does not leave room for subjective accounts, which is the core interest of my research (Harper, 2011). My further clinical experience in health-related difficulties and my work with a group of psychologists allowed me to expand my view and I rejected my previous philosophy by engaging in a more open understanding of human experience, leading me to adopt a critical realist position.

Critical realism still acknowledges the existence of truth, but this truth is directly created by individuals and it consists of meanings (Hayes, 2000). According to Heidegger (1962), as a critical realist we cannot ignore that, as individuals, we live within a set of social, cultural, and language structures that make us part of "out-there" reality. This approach represents less radical versions of positivism and enables us to acknowledge the existence of context-specific reality, but also allows us to recognise the fact that individuals construct the meaning of their world by accessing their perceptions and thoughts (Ayers, 2010).

I have noticed that going through the process of recovering from a stroke can depend on social factors or previous experiences that are not always obvious to the individual. Thus, it is important to acknowledge that one's experience could be often influenced by other factors that cannot be easily accessible but could be explored through a process of interpretation (Willig, 2012). This is in line with Bhasker (1975), who suggests reality to consist of three domains: the empirical (observable), the actual (relational) and the real (hidden process), where the mechanism, events and experiences residing from the above domains cannot be thought about separately. Furthermore, critical realism asserts

that experience cannot be just understood through language (Larkin et al., 2006) and therefore within this epistemology the emphasis is on the importance of collaborative relationships between researcher and participants in a journey of searching for meaning (Smith et al., 2012).

As a critical realist, in order to try to capture an individual's understanding of the world, I must look at it through their lenses but remain also aware of my own ideas. That would be made possible by engaging in phenomenological frameworks of enquiry. Landridge (2007) advocates phenomenological methods as suitable for the study of lived experience, as it focuses on subjective experience and rejects subject–object dualism that imposes an explanation beforehand. In contrast, the phenomenological approach to human experience allows for many different meanings to arise during analysis, leading to the birth of alternative knowledge about the world (Smith et al., 2012). This is in line with the current research, which is concerned with participants' individual stories and exploring their unique perceptions and the similarities and differences in their experiences of being in a group with other stroke patients.

## 2.6. The research process

The research was carried out as part of the requirements for obtaining a doctorate qualification in Counselling Psychology at the University of East London (UEL). The initial stage involved obtaining ethical approval from both UEL (Appendix A) and the NHS ethics committee (Appendix B). As a result of the NHS ethics committee meeting, amendments were made to the following: on the information sheet for participants, permission for carers to attend the interview was added (Appendix C); the consent form was expanded by adding information about audio recording of the meeting (Appendix D); and a letter to a GP confirming participation in the study was designed and added to

the relevant documents (Appendix E). The last stage focused on obtaining a research passport from the NHS site facilitating the current study, allowing the researcher to commence data collection (Appendix F).

#### 2.6.1 Sampling

The choice of participants is crucial in an IPA study, and must be in line with qualitative paradigm, where the focus is on idiographic experiences (Smith et al., 2012). The main concern for IPA is an appreciation of the uniqueness of each participant. For this reason, a large sample size is thought to be unsuitable for this method, as there is a risk of losing the qualitative values of depth and breadth. A small sample enables detailed and thorough analysis case by case, which is already time-consuming. As Smith et al. (2012) suggested, there is no rule regarding the perfect sample size in IPA (usually one to eight), and this often depends on the aim of the study, the richness of the data, and if the researcher wants to compare and contrast single cases. There is also a pragmatic restriction that the researcher must take into account. Following the literature suggestions and university requirements, I interviewed eight individuals that attended the ACT group.

Typically, IPA study aims for a homogeneous sample. That is, the focus is on recruiting participants from a specific context with a particular experience, for whom the research question will be meaningful and personal (Shinebourne, 2011). This is paramount to obtaining insight into a particular experience. I consider the sample to be chosen purposely and in line with the research question for the following reason. In the case of the current study, the definition of homogeneity encompassed the following: the experience of stroke and attending the ACT group intervention designed for stroke population; the participants who attended the groups suffered stroke at different times,

but over a year prior to the group, as set by the group criteria, which adds to the reasonable homogeneity of the sample.

According to Smith et al. (2012) homogeneity will depend on a study's aim and at times the potential population could vary (e.g participants could have attended an ACT group where the facilitation style diverged). Having this in mind, only participants who attended the group facilitated by the same clinicians in the same service were invited to take part in the interviews. In addition, both groups from which participants were recruited were based on the same group format and content. This aspect of homogeneity potentially enabled participants' accounts to be fairly context-specific.

As discussed previously, IPA analysis looks at cultural, social, and economic influences on participants' experiences (Willig, 2012). The current study was conducted on an NHS site characterised by minor ethnic groups; therefore, there was a greater likelihood that the participants would have different cultural backgrounds. Although cultural or economic homogeneity could not be met, this particular facet actually added to the richness of the data. In addition, the chosen participants represented current diverse communities in most areas of London and the rest of the UK, making the sample acutely more transferable and relevant to groups of multicultural clients.

Although all the participants were adults (meeting some criteria for homogeneity of the sample), the age-specific selection was not considered a crucial selection factor. This is in line with the research question, which does not aim to explore phenomena related to a specific age bracket.

# 2.6.1.1 Inclusion/exclusion criteria

To ensure a fairly homogenous sample, participants had to meet specific criteria that were in line with NHS site recruitment criteria for ACT groups. The inclusion criteria included participants with symptoms of mild to moderate depression or anxiety, which is primarily related to their stroke, but not to their other life experiences. Participants were able to communicate in English. No other psychological intervention was offered during the group participation stage. The sample included both sexes of participants and was adults only (18+). In line with the aim of the study, all participants attended an ACT group facilitated within the same service. The exclusion criteria would refer to participants experiencing severe mental health problems, or those who were actively suicidal or self-harming. This was to prevent inducing possible further distress during the interview process. Also, due to the nature of the study, individuals with a severe cognitive impairment or communication difficulty were not invited to take part in the study. As IPA rely on language as a tool to communicate and reflect on the experience, this study, similarly to others discussed in Chapter One, excluded participants whose severe cognitive impairments or post-stroke speech problems would prevent them from sharing their accounts in the detail that is required in IPA. As mentioned before, this exclusion criteria was also in line with exclusion for the group itself, which consequently impacted on inclusion/exclusion criteria for this study, which prevented to address the above mentioned issue in the literature.

# 2.6.1.2 Participants' details

The participants were recruited from an East London NHS site, from two groups: one ending in June 2016, and other ending in August 2016. A total of eight participants were invited to take part in the interviews. The sample consisted of three females and five males, ranging in age from 29 to 70. All participants suffered stroke, resulting in being referred to the group. Two participants came from the Asian community, with two participants being white British, three identified themselves as black British, and one as South American. None of the recruited participants were in employment. Most of the

participants were married or in a long-term relationship, with two describing themselves as single. Pseudonyms were given in order to protect the identity of the participants (see Table 1).

Participants	Age	Gender	Ethnicity	Marital status	Employment
1. John	29	Male	Black British	In a relationship	Unemployed
2. Mary	70	Female	Black British	Single	Unemployed
3. Steven	69	Male	White British	Married	Unemployed
4. Kevin	61	Male	White British	Single	Unemployed
5. Patrick	52	Male	S. American	Married	Unemployed
6. Kate	36	Female	Asian	In a relationship	Unemployed
7. Mark	65	Male	Asian	Married	Unemployed
8. Laura	44	Female	Black British	Married	Unemployed

Table 1. Participants' demographic information

## 2.6.2 Recruitment procedure

Recruitment took place through the London NHS Trust and after obtaining relevant ethics approvals from UEL and the NHS. I cooperated with the facilitator of the group to provide an information leaflet about the nature of the research for potential participants during the assessment session and I also attended the last group session to provide further information about the study. In agreement with the NHS ethics committee and my supervisor, it was decided I would not contact potential participants directly, in order to follow the principle of autonomy (Beauchamp & Childress, 2001). Once contacted by the participants (directly or through the facilitator of the group), I conducted a brief screening process over the phone that included assessment of the current risk level and checked the inclusion and exclusion criteria. At this stage, confidentiality was verbally explained to participants in order to provide them with reassurance, and to enable trust to develop from an early stage. After verbal agreement to participation, a convenient day and time was arranged. All interviews were conducted in the local NHS building.

## 2.6.2.1 Recruitment challenges

The process of recruitment brought about certain obstacles that I had to overcome in order to be able to obtain a suitable number of participants. One of the main issues I faced was difficulty in agreeing to a time and day convenient for the participants. Stroke is a serious and debilitating illness with significant implications for one's day-to-day life and has a devastating impact on one's physical functioning (e.g. mobility, speech problems, memory difficulties) (Stroke Association, 2013). As a result, individuals often prioritise their physical health medical appointments. It was difficult for them to find the time and physical strength to attend a meeting that was not necessarily explicitly linked with their recovery. For that reason, often our meetings had to be postponed. That had significant impact on the time dedicated to the recruitment process. One of the participants, due to her deteriorating depression and struggle to cope, postponed the interview for almost two months.

On another occasion, a participant made a conscious effort to attend the interview after a few previous cancellations, but unfortunately, the reception staff did not inform me about his arrival. Understandably, the participant felt disrespected and angry towards me. As result, I had to discuss that issue with the administration manager in order to put in place a strategy that would prevent further misunderstanding. Most importantly, the relationship with the participant suffered a great deal, and I spent some time regaining his motivation and trust in participation. Fortunately, the participant agreed to meet me again and took part in the interview.

#### 2.6.3 Data collection

#### 2.6.3.1 Interview procedure

In accordance with the IPA method, data was collected by scheduling face-to-face, semi-structured interviews. This method is recommended as the most suitable with which to explore subjective and descriptive understandings of experiences (Willig, 2008). The interview questions were developed based on other qualitative studies exploring experiences of psychological intervention (e.g. Mathias, Parry-Jones, & Huws, 2014), but were tailored to this study's aims (Appendix G). The interviews were guided by the participants' answers, and open-ended questions were used to facilitate richer data and a better understanding of the participants' experiences. Following the guidelines set by Smith and Osborn (2003), I designed interview questions with the aim of putting emphasis on the lived experience. They were framed broadly and openly, and I intended to find out how participants perceived being with others in the group intervention. The questions focused around general experience in the group, the turning points, and different time moments in the group, instead of purely exploring the content of the sessions. Additionally, the negative and positive experiences of others in the group were evoked. The interview questions served as a guide, and the process itself was participant-led (Biggerstaff et al., 2008).

Before commencing the interview, participants once again were briefed about the interview process, had confidentiality explained to them, and were asked to sign a consent form. On one occasion, a carer signed the form.

All interviews were recorded and transcribed verbatim. The lengths of the interviews varied, with an average of 58.43 minutes. I took into account some of the cognitive and communication problems caused by stroke, thus allowing more time for some of the interviewees. Following the interview, the participants were given the opportunity to provide feedback or reflect on the interview. Also, a debrief process took place after the interview to ensure participants' emotional safety. The telephone numbers of supportive agencies were provided (Appendix I).

In order to facilitate reflexivity and to avoid potential biases, after each interview I commented on the interview experience, content, and initial reactions I encountered (see Section 2.6.3.3).

#### 2.6.3.2 Interview follow-up

Upon request, I provided two interviewees with the copy of the transcript. That offered the opportunity to review the accuracy of the transcript and add additional comments. The exercise provided a measure of validity for the current study (Yardley, 2008). Both participants confirmed the transcript reflected our conversation, and they both felt they had nothing to add at this point.

#### 2.6.3.3 Reflecting on interview questions and interviews

The initial development of the interview questions was based on a previous study that used IPA to explore experiences of ACT groups for clients who suffered from chronic pain (Mathias et al., 2014). However, as a new IPA researcher, I was unsure about the structure of the questions, and the explorative function that they should provide. In order to review the questions and gain further insight, I discussed the interview guide with my supervisor. As a result, I added an initial question that aimed to establish a good rapport with the interviewee (Smith et al., 2012). The opening question was neutral in nature and invited participants to provide general information about themselves. I believe this enhanced a sense of comfort and trust between us.

In addition, I conducted a role play of the research interview with one of my cohort colleagues before the first interview, whose feedback indicated certain flaws and repetitions in the interview schedule. Based on that exercise, I removed and rephrased some of the questions to more open-ended ones. I also added the question "What advice would you give to others who will attend the group?" as that seemed to trigger further reflective narrative from the participants.

Before the initial interview, I found myself to be extremely anxious and unsure about the process. I was concerned that my therapeutic skills would override my interviewing abilities, which then, in turn, might affect the quality or the depth of the data generated. In order to manage the initial self-doubt, I followed my supervisor's advice by reviewing the interview schedule, but also used it in a flexible manner (Smith et al., 2012). At the same time, I was aware of occasionally moving away from the topic and schedule, which at times caused a dilemma between losing new data that might be explored, and following participants too far from the aim of the investigation (Brocki & Wearden, 2006).

Looking back at two initial interviews, I realised that my anxiety was an obstacle at times, and affected my ability to explore certain narratives so that I rambled on occasion. That might have prevented participants from reflecting on their experience. I learnt then to slow down the process of the interviews. I incorporated more of my listening skills and used prompts only when participants needed assistance in reflecting on the experience. Becoming more of an active listener and following participants' concerns enabled me to facilitate further exploration of the phenomena and keep the interviewee in the role of experiential expert (Willig, 2008).

I noticed that in later interviews my confidence had grown and I was able to enjoy the conversation we had much more. Through this, the rhythm of the dialogue seemed to flow better, and although it was difficult at times to draw the participant into the interview process, the dynamic was consistent and provided interesting insights into the data (Smith et al., 2012).

I also found difficulty in applying bracketing throughout the interview process. Although IPA researchers are advised to approach interviews with an open mind and allow the process to be participant-led, unfortunately, striking the balance between remaining curious about new data and simultaneously staying within the limits of the research question proved to be challenging at times. I felt worried if the participant diverged from the research question and I had to redirect the conversation towards the aim of the study. This meant that I sometimes felt I was leading the interviewees.

#### 2.6.4 Materials used

The research utilised the following materials:

- 1. Digital voice recorder
- 2. Mobile phone
- 3. Poster providing information about study and contact details (Appendix H)
- 4. Information sheet for participant
- 5. Consent form
- 6. Letter to GP

## 2.6.5 Ethical considerations

As mentioned previously, prior to data collection ethical approval was obtained from relevant professional bodies that enabled access to the NHS site and recruitment process. A number of issues were also considered when conducting this study. An information leaflet was given at the time of assessment to allow participants to make an informed and autonomous decision about their involvement; they were asked to contact the researcher by phone or email if they wished to proceed. Completed consent forms were obtained from those who were involved. Confidentiality was explained at the beginning of the interview, and their voluntary participation highlighted.

I was aware that the interview process might evoke difficult emotions and cause distress to participants. Thus, participants' wellbeing was paramount throughout the process, and they were reminded that they could withdraw from the study at any point. In addition, participants were given time during and after the interview to reflect, and were provided with the details of supportive agencies, in line with BPS ethical research principles (British Psychological Society, 2014).

I was aware of possible mobility difficulties and physical disabilities and thus, where necessary, participants were encouraged to attend the meeting with their carers or relatives. Additionally, I ensured that the chosen interview location had a lift available; alternatively, a ground-floor room was used.

My mental wellbeing was also considered by engaging in regular supervision and peer support groups. No immediate risk was identified throughout the process.

The data was anonymised and stored in line with the Data Protection Act (1998). That is, personal details were coded in the data set. The electronic data was then stored on a password-protected computer. In addition, the examiner and the supervisor also had access to the obtained data. The raw material was kept in a locked drawer at my residence during the data collection period, and will be destroyed after five years. Participants were made aware that the collected data can be published in the future, but that their personal details will be protected.

#### 2.7 Analytical procedure

Smith et al. (2012) outlined guidance and steps that I used to analyse existing data. Each transcript was analysed individually to prevent previous analysis affecting the process (Yardley, 2000). The initial step focused on reading the data, which aimed to increase my familiarity with the story and immerse myself in the text (Callary, Rathwell, & Young, 2015). This process was enhanced by listening to and reading the interviews simultaneously. This activity enabled me to pay closer attention to the tone of the voice and the rhythm of the dialogue. This initial stage also focused on noticing anything that was significant, such as rising emotions within the interview. I then noted the comments and used these later to inform analysis (Appendix J). The next step required me to approach data in a more explorative way, in line by line analysis. That is, I engaged in analysis of data through three different processes: descriptive comments, linguistic comments, and conceptual comments (Pietkiewicz & Smith, 2014) (Appendix K). I also made a conscious effort to explore the text phrases, and the whole transcript. Questions such as "what does this word/sentence mean to the participant?" were kept in mind throughout that stage. This process allowed increased insight into the data, and enhanced understanding of the lived experience, and is in line with the hermeneutic cycle (Wertz, 2005).

The above process enabled emergent themes to evolve for each individual transcript. The themes were to capture the complexity of the phenomena and represent both the synergistic process (participants' statements) and my interpretation (Smith et al., 2012). Once the themes in individual transcripts were identified and organised chronologically, I looked for any connection and overlap across the themes within that transcript. That was achieved by mapping those connections. To do this, I copied the emergent themes onto separate pieces of paper and used a large space (on the floor) to group them together. Following Smith et al.'s (2012) suggestions, I used various methods to study these: abstraction, by identifying commonalities across emergent themes, e.g. the impact of social comparison; subsumption, which enabled emergent themes to become major themes by bringing a number of related themes together, e.g. the original theme of anxiety was collapsed into a broader theme and named "What's the group going to be like? – initial apprehensions"; polarization, to enhance the clustering by noticing differences between emergent themes, e.g. participants reported post-group positive changes but also commented on the ongoing challenges. This process allowed me to organise the emergent themes into major themes for each individual interview before moving on to the next participant's account (Appendix L).

The next stage involved repeating all the above for each individual transcript, and recurrent themes across transcripts were identified. As a result, the table of master themes and corresponding sub-themes (Table 2, Chapter Three) was composed, with examples of supporting verbatim extracts from the data that also provided a measure for validity (Smith et al., 2012).

During the process of analysis, my intention was to remain as faithful as possible to participants' accounts and minimise influencing the data by engaging in reflexive practice (i.e. discussion in supervision, with peers or in personal therapy). To enhance the process I used a reflexivity diary to try to bracket off the influential subjective presumptions, such as pre-existing knowledge about the topic (Yardley, 2000), as

outlined in Section 2.7.2.1 below. Furthermore, by approaching each transcript in isolation, I aimed to bracket off learning/ideas from the previous cases when working on another.

#### 2.7.1 Validity criteria

IPA as a qualitative study has attracted a lot of criticism about its validity and quality as a scientific way of exploring research phenomena (Chamberlain, 2011; Smith et al., 2012). As a result, numerous authors took on a challenge to set a criterion to establish a framework against which the validity and quality can be checked (Smith et al., 2012). However, Smith and colleagues warned that a rigid framework might oversimplify the subtle principles of qualitative research. Furthermore, they indicated guidelines proposed by Yardley (2000, 2008), that suggested that a pluralistic approach seemed to better suit the IPA methodology.

One of the principles proposed by Yardley (2008) is "sensitivity to context", which can be demonstrated by the researcher's awareness of relevant literature and theories, and being sensitive to the socio-cultural milieu of the study (Smith et al., 2012). By engaging in the process of literature review, followed by establishing relevant research questions and applying methodology that would be sensitive to an ideographic experience of an ACT group from the perspective of stroke clients, I hope the current study meets the above criteria. According to Smith et al. (2012), sensitivity to context can also be illustrated in the process of collecting data, where the researcher ought to display specific skills, such as empathy and dedication to the interview, with the aim of putting the participants at ease and being aware of the power dynamic in the interview. I displayed sensitivity to the context by clarifying my position as an independent researcher at the beginning of each interview, and was sensitive to participants' distress and hesitations throughout. That seemed to facilitate good working relationships and enabled participants to share their reflections about the group. The latter principles overlap with a second characteristic of commitment and rigour, proposed by Yardley (2008). This can be illustrated by the level of attention paid in the collection data phase (as above) and the assurance of depth of analysis. Following the idiographic principle of IPA, I immersed myself in the individual data first, dedicating myself to analysing a single account before moving on to the next transcript. This, I believe, also shows my commitment to the process. According to Yardley (2008), rigour can be demonstrated in the quality of the sample or the interview. Smith et al. (2012) indicated that the homogeneous sample is fundamental and needs to be chosen carefully, which is described in the methodology chapter of the current study. In addition, in the interview process the researcher should aim to strike a balance between closeness and separateness, which can be challenging for a novice researcher like myself (Smith et al., 2012). In order to apply this principle, I rehearsed the interview schedule with a cohort colleague, which enabled me to revise some of the questions. Furthermore, the interview guide included open-ended and probing questions to encourage deeper exploration of the data.

Further, part of the rigour refers to the complexity of the data analysis; in the case of IPA that is double hermeneutic. The analysis of the data needs to move beyond description to a systemic interpretation of meaning-making (Smith et al., 2012). I hope this is sufficiently demonstrated in Chapter Three.

Transparency and coherence was also advocated in Yardley's guidelines. The author suggests that, for example, the clearly described steps of the research process enable the reader to judge reliability and validity, as evidenced in the methodology chapter. Coherence reflects how well the actual research complies with the theoretical underpinnings of IPA. As a researcher, I think I have stayed loyal to the ethos proposed by IPA by implanting phenomenological and hermeneutic principles throughout the research; for example, in my commitment to the ideographic approach, reflexivity, and managing bias through diary-keeping. The final criteria set for the validity of qualitative research refer to importance and impact (Yardley, 2008). The author indicates that the true reflection of validity lies in the applicability and usefulness of the study carried out. I hope that the presented outcomes have been meaningful, and have outlined the practical and clinical applications for practitioners who work with stroke patients.

#### 2.7.2 Reflexivity

Reflexivity can be understood as a process of 'an explicit evaluation of the self' (Shaw, 2010, p.234) through which the researcher considers their influences on the study. According to Willig (2008), the researcher can impact the data during the analysis process on two levels: as an individual and as a theorist; hence, qualitative research including IPA explicitly acknowledges the active role of the researcher in the process of interpretation and analysis. This approach (reflexivity) encourages the researcher to develop an awareness of the impact their background and assumptions might have on the research process. Thus, the researcher's preconceptions need to be made clear in order to maintain awareness of theories that potentially might dictate ways in which data is approached, and also to inform the reader of our "audit trail" (Rolfe, 2006, p. 309). Within IPA, reflexivity is a crucial process that the researcher engages in throughout the whole study. As it is impossible to know in advance what subjective assumptions will play an influential role, the researcher must be aware of it and use selfreflection as a way of managing it all the time (Shinebourne, 2011). This activity not only prevents the researcher from fully controlling the analysis, but enables the researcher to be more open and receptive of participants' subjective interpretations of

their lives and can be perceived as key skills for using the IPA method (Rodham, Fox & Doran, 2015).

Ahern (1999) refers to "reflexive bracketing", which enables the researcher to bring to the fore potential biases without needing to remove them from the study. The process of bracketing requires the researcher to put aside personal assumptions and beliefs about data in order to enter into a participant's narrative. Saying that, hermeneutic phenomenological theorists such as Le Vasseur (2003) argue that the bracketing is not reliable and suggest that the researcher's position cannot be fully excluded. Furthermore, according to Giorgi (2009), IPA does not clarify a procedure for implementing bracketing, which leaves that process open to the researcher's subjective understanding.

It seems that researchers' approaches to reflexivity will vary, but may depend on their epistemological position. The critical realist position emphasises personal reflexivity, which attempts to clarify the researcher's role and acknowledges their active role in that process (Clarke & Brown, 2003).

Therefore, it is important to highlight that, throughout the interviews and further processes, I was mindful of my existing knowledge informed by relevant clinical practice and literature. I tried to be aware of my own agenda during the interviews, and the necessity of supporting participants to describe their own experience without interfering. In attempting to maintain this awareness I employed a number of strategies, such as remaining reflective throughout by keeping diaries (Appendix M) and discussing in supervision any issues that had arisen with the processes (Giles, 2002).

# 2.7.2.1 Researcher's background and interest in the topic investigated

As a researcher engaging with IPA methodology, I thought it was important to share my professional and personal interest in that study. The topic of the research was influenced by my clinical experience while working and then becoming a trainee in a psychological department offering treatment to people affected by long-term health conditions. During that time, I was often involved in facilitating group treatments along with individual support to people who experienced strokes. As a clinician working within the NHS system, I learnt that the measures used to review outcomes of the groups were not sensitive to ideographic experiences of attendees, and did not capture the real changes and impact on their lives; hence, the attendees and psychologists involved did not have the opportunity to report important and personal shifts that took place during the group interventions, which I found frustrating and unfair. I discussed my emotional reaction in supervision, and in conjunction with course learning this enabled me to integrate my personal frustration with a professional objective. I came to realise, interestingly, that my upbringing in Poland under the political regime there and the restrictions of communism followed by militarism seemed to trigger the ongoing and everlasting need for freedom to voice my opinions and therefore (at times) act as a mouthpiece for others. It seems that part of myself fuelled my further interest in pursuing this study in order to create opportunities for individuals to share their stories. By engaging in further reading around group psychology, and specifically focusing on researching ACT group interventions for stroke patients, I was unable to come across any qualitative studies specifically exploring this model of treatment in group formats that were designed for post-stroke difficulties. This prompted me further to explore this avenue in the hope of contributing to the literature on group experiences in the context of health.

Additionally, the clinical work also equipped me with further knowledge about stroke and experience of stroke. Initially, I was often surprised by own preconceptions about illness; for example, the correlation between age and the recovery process in strokerelated cases. This enhanced my epistemological position as a critical realist and influenced my appreciation of how differently people talk about their health experiences, and how that may diverge from the views of health professionals, who cannot always see their real pain (Biggerstaff et al., 2008). With this in mind, I carried a lot of empathy for these participants and approached them with an open mind.

I also reflected on the fact that I was recruiting and interviewing participants where I held an existing role. That is, I was still part of the team that facilitated the group and was an employee of the same trust. My dual role as clinician and researcher needed to be explored in the context of enabling criticism of the group by the participants without them feeling constrained by my involvement with the team. In an attempt to ensure an equal power dynamic and emotionally detach myself from the team member role, I was determined to clarify I was an independent researcher right from the beginning.

Overall, my involvement in facilitation of the groups and other clinical knowledge could have influenced the process of interviewing, choice of words, questions and interpretations of data.

# 2.7.2.2 Personal reflexivity

Through my experience of working with health-related issues, I became very aware of how loss of health might impact on ones' life. Changes in family dynamics, social roles or lifestyles were commonly reported by clients. Gradually, this awareness impacted on my always strong drive for independence and induced a fear of suffering long-term health problems that could lead me to need to rely on others. The possibility of loss of autonomy and my identity as an individual overlapped with the actual experience of the participants, and facilitated developing greater empathy but also admiration for those who face health-related predicaments every day. Nevertheless, the feeling of anxiety related to change was paramount for me and for that reason, I had to remain conscious of my own feelings and fears in order to prevent the data being perceived through my own lens. An example of how that potentially influenced the data analysis is given in the section below.

The often-described health-related changes were not the only aspect I could relate to. The suddenness and unexpectedness of stroke happening without any warning and as a shock, mirrored my personal experience in the unforeseen loss of my father in very difficult circumstances. Consequently, that experience has shaken my belief in the security of the world I live in and has introduced a new fear, altering my hopeful and trusting approach to life. My optimistic nature has been replaced by the voice of suspicion and a tendency to expect the worse. However, throughout the study process I aimed to remain reflexively aware of all of the above.

# 2.7.2.3 Reflections on the process of analysis

The process of analysis, in my view, is best described as a rollercoaster ride. I found myself being really excited about the initial stages of analysis, and was looking forward to discovering emerging themes. According to Smith et al. (2012), one can approach data analysis from different angles; that is by treating each interview as a separate one, or by building up meaning based on the first interview. In my view, the former is more in line with the idiographic experience, and I hoped it would enable me to better understand the participants. Hence, I tried to approach each personal account by searching for meaning in participants' narratives. This method enabled me to notice specific factors/themes for each participant that stood out for me. For example, Laura

(participant 8) was focused mainly on learning as a way of gaining skills to prevent a further stroke, and this was a paramount goal for her in the group. The analysis of Mary's account had the most significant impact on me. Her sorrow and sadness, experienced as a result of a change in family dynamics, and the role she played prior to experiencing a stroke, resonated with my own health-related fears (mentioned in the above section), triggering a highly emotional reaction. Mary became emotional herself during the interview when speaking of losing control and being treated as a "little girl". I realised I had begun to feel very protective towards her, which was possibly triggered by my early experiences of being controlled, with no power to choose (described above), and despite my efforts not to influence the data, her experiences inspired me to label one of the resulting themes "Accepted here vs. Judged out there".

Throughout the analysis, I also faced feelings of being unable to progress and I found it difficult at times to move beyond descriptive analysis. I found this particular stage frustrating, and this possibly added to my difficulty in seeing underlying meaning hidden in the data. Through personal therapy, I was able to reflect on my sense of "stuckness", and with further reflection was able to see more clearly how I was mirroring Mary's feelings of frustration relating to becoming dependent and physically, cognitively, and emotionally restricted. Her narrative describing the process of returning to her room after the group ended gave me the impression of being "locked in", and unconsciously I was absorbing her experience. This awareness enabled me to separate my feelings from hers, and it allowed me to re-engage with the analysis.

Furthermore, most participants were foreign-born, and the clarity of their spoken English varied. On some occasions I struggled to fully understand what was said in the interviews, resulting in some of the data not being explored and being missed from the verbatim transcripts. This, in turn, may have impacted on the process of analysis and hindered my arrival at a deeper meaning that would reflect participants' experiences. Nevertheless, as I am not a native English speaker either, I empathised with the participants over how speaking a non-mother-tongue language can be challenging. It is difficult to express thoughts and feelings in the same way that a native speaker would do. With that consideration in mind, I made an extra effort to engage in all narratives, even if they were lacking linguistic cohesiveness, and used them consciously to represent the themes. In addition, I felt privileged to interview a diverse group of participants as they represented current communities in the UK and are a true exemplification of clients we, as counselling psychologists, set out to support and help.

### **Chapter three: Analysis of data**

### 3.1 Overview

This chapter aims to offer insight into how the participants, within group context, make sense of their experiences of being with other stroke patients while attending an ACT programme. Four master themes and their component sub-themes (Table 2) will be presented, with each theme evidenced by verbatim extracts from participants to ensure a close focus on the meaning of the participants' subjective experience.

Master Themes	Subtheme/	Frequency
	"What's the Group Going to Be Like?"– Initial Apprehensions	6
	"I wasn't sure what to expect, what the set-up's going to be like"	
	Handle With Care – Group Relationships	5
"It Is Just So Difficult"	"The first sessions it was little bit complex, you have to wait, you have to give [it] time because, you know, some people interrupt all the time"	
	"It Was A Short One"	5
	"It's good for me, I liked that session but it was a shame I wish it was for a long time (I;um) it was a short one"	
	United by Stroke	4
	"Not that you go there just to meet people but you meet people who've had the same sort of thing"	
	"As If There Is A Connection"	5
Means to a Connection	"The one who couldn't speak very much, he had to rely on his carer or his wife to explain which isn't quite the same as somebody saying it themselves"	

	Accepted Here vs Judged Out There	
	"And sometimes the usual response [from friends] I've got is 'No, it'll go away, it's in your head,' but I didn't get that response from them [in the group] you know I think I got a lot of kindness in return"	5
Restoring Confidence and Hope	It Could Be Worse	8
	"They've overcome the issue so it's kind of a relief then I would say just seeing them gave me more courage"	
	"You Are Not Alone"	6
	"You can see there's other people in the same situation to yourself which you [do] not realise when you're inside your house"	
	"Believe in Yourself" – Learning From Others	6
	<i>"If I see someone I am saying you go there and share it with people and you learn a lot"</i>	
"Things Won't Be the Same" – Moving Towards Acceptance	Need to Know How "If I go to bed I turn turn turn turn turn but yeah that doesn't help so I learn from them that OK you just stay still and you sleep eventually, sleep I tried which actually worked"	7
	"There Is A Life After Stroke" – Increased Acceptance of Responsibility	8
	"Like I said, I feel better, like I learnt I have to find my own door to cope"	
	"This Is Me Now" – Emergence of Compassionate Self	5
	"Yeah, the group helped with managing, there are things that yeah, you have lost, but if you can manage the ones left"	
	"I Can't Get Used to" – Ongoing Challenges	6
	<i>"It seems very difficult to make any changes, I think"</i>	
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 Table 2: Master Themes and Sub-themes

### 3.2 Master Theme 1: "It Is Just So Difficult"

### 3.2.1 Overview

This master theme encapsulates how participants experienced various hesitations about being in the group. The first sub-theme, "'What's the group going to be like?' – Initial Apprehensions", captures participants' initial suppositions about the group and feeling scared of being judged or exposed. To follow, the second sub-theme, "Handle With Care – Group Relationships", illustrates how some of the participants struggled to sustain a connection with others in the group that contributed to a split in a group bond. The final sub-theme, "It Was A Short One", demonstrates difficulties in coping with the termination of the programme, giving rise to a range of emotions such as disappointment and anger.

# 3.2.2 Sub-theme 1: "What's the Group Going to Be Like?"– Initial Apprehensions

Six participants highlighted their early assumptions of group experiences, such as being unsure how to interact with others in the group, feeling apprehensive about personal disclosure or fearful of gaining more information about stroke itself. Subsequently, this prevented them from being more actively engaged in the initial stage of their group experience.

For example, Kate, for whom stroke triggered low moods and caused withdrawal from her family and social life, described her feeling of confusion over how to behave in the group, which fuelled her initial hesitation about attending therapy.

Erm, well... at first obviously it was a bit scary... I was a bit apprehensive you know... you don't want to, you know, just sit there... I didn't want to sit there complaining, and making things up so a bit... I was a bit apprehensive about going initially... (Transcript 6, p.1, 19–21)

Kate reflects on feeling "apprehensive" initially in the group due to her assumptions of how she should behave whilst being there. That is, it seems she doesn't feel she can "just sit there" – so she senses she needs to engage in doing something more. She then wants to share but that might have been seen as "complaining" about her life, and she does not think that would be helpful either. That in turn implies she is facing conflict as to what to do: stay quiet or complain. That perhaps means she is trying to figure out her position and identity in the group and does not want to be perceived as a complainer, which perhaps recalls experiences of being judged by others outside the group (she mentioned this in the interview). Consequently, this dilemma leads her to feel really apprehensive about continuing to attend, as she reiterates herself: "I was a bit apprehensive about going initially" but also implies that this feeling has changed later. Therefore both fear and confusion may have prevented her from engaging at the initial sessions, and this is also confirmed later in the interview as she says "so I think the first couple of sessions I was quiet... I think I was just sussing the group out" (Transcript 6, p.1, 25–26). That may also imply she is trying to work out how to fit in. Interestingly, Kate repeatedly uses the qualifier "*a bit*" throughout her narrative, which may be an attempt to minimise her feelings, and she also tries to normalise feelings of it being "scary" when she uses "it was" and "obviously" to express personal views in more general terms.

Similarly, Patrick, who struggled with stroke-related loss of physical abilities and being the breadwinner, also reflects on an initial apprehension with the group experience which perhaps was fuelled by an underlying feeling of shame associated with the way he identifies himself following stroke.

### (... you mentioned that initially for you it was embarrassing)

Ah yeah, because you, you know, you have to explain yourself and they are like just the way you are, you walk in there, people you never seen in your life, you have to talk about what's happened to you, you mention it. It's a little bit embarrassing at the beginning, because you don't know nobody, but eventually when people started talking, you know, everything comes more easier day by day, moment by moment you can see there is, you know, happens takes place as well in a different way, and you find there are ways that make you understand, but at the beginning it was very hard... (Transcript 4, p. 1, 24–29)

Patrick's feeling at the beginning of the group seems to be connected to his expectations of what ought to be happening in a group setting, such as "*explain yourself*" or "*have to* talk about it..." The following statement, "it's a little bit embarrassing", may express his feeling of fear of being exposed or misunderstood. Patrick's choice of the words "mention it" also highlights his early hesitation in sharing with others, which could potentially be due to his experience of premature relationships within the group captured in "you don't know nobody". This point is emphasised within the narrative on two further occasions as he refers to other members as "strangers" and "people you never seen in your life", alluding to an initial distance between him and other members despite recognition of mutual experience ("they are just like the way you are"). Nevertheless, Patrick refers to a significant change in his emotional experience during the group, indicating reduced tension when "everything become easier and easier". His description of the shift that takes place in both his perception and the meaning of the group for him is powerfully captured in the phrases "day by day, moment by moment", which accentuate gradual change but also "when people start talking" being a reference point of when the change began. Patrick ends by describing again the initial experience as "very hard" which suggests a reconnection with his initial experience in the group

and further highlights the contrast between how challenging it was for him at first,

compared to later sessions.

On the other hand, Laura, whose goal for the group was to find out more about stroke, paradoxically linked her initial feeling of fear to an expectation of learning more about it.

It was a bit, umm, a bit scary at first...

### (What do you mean, scary?)

[I] mean scary because you gonna learn about something that affected your life... only just really for a few months you didn't know how you were gonna react to learn about this illness, it was scary and frightening at first but it was... it was fine in the end.

(Transcript 8, p. 2, 57–61)

Laura described the challenges of being in the group at the beginning as "scary". She indicates she relates this to the notion that new information about her stroke/physical health could leave her feeling more destabilised and uncertain, as shown by her repeated choice of the words "frightening" and "scary" and the brittle tone of her voice when she says: "you gonna learn about something that affected your life". She further associates a sense of uncertainty and assumption at that time with her inability to cope with new stroke-related information: "you didn't know how you were going to react". Like many of the others, she also generalises that feeling by the use of "you" in her narrative. Additionally, Laura's description of stroke as "this illness" implies that she might have perceived stroke as a separate part of her life. Hence, her statement "only just really for a few months" gives the impression she is worried that there might not be sufficient time to receive support. However, in the same way as Patrick, Laura's concerns diminished with time spent in the group, which points to a shift in the initial worries and these feelings being temporary.

### 3.2.3 Sub-theme 2: Handle with Care - Group Relationships

Five participants described difficulties in the group related to the division amongst group members, exposing how delicate a group bond may be. A number of factors such as participants' previous experiences outwith the group and unequal opportunities to share contributed to a feeling of unfairness resulting in 'I and them' or 'them and us' disunity amongst attendees. Subsequently, it was indicated that a lack of receptiveness from others could cause attendees to disengage.

For instance, Mark, who had been looking forward to and initiated referral to the group, describes his disappointing personal experience of feeling excluded from the group:

... I got involved in the group, you know, and carry on, right... but somebody thinks they didn't get their chances oh (sigh) that was such an excluding feeling, you know, you know sort of feeling I was looking forward, you know, that friendly feeling... it was going through the window, you know, what's happening and I'm thinking is there something wrong with me, usually I'm the one, they pick on me [laughs]...

(Transcript 7, p. 2, 62–68)

Mark's words "I got involved" and "carry on" demonstrate his willingness and persistence in staying active in the group. However, this process was interrupted as he described being complained about by "somebody" and further highlighted this by his short pause during our conversation that may represent that interruption. Furthermore, using "oh" may signify Mark felt disappointed by the situation and indicates a moment within which his experience of the group changed. He contrasted ("but") his initial expectation of a "friendly feeling" with the "excluding feeling" he encountered, which possibly placed him as an "outsider". This may suggest a divide amongst group members where it develops into 'I and them'. It seems his emotion at that point was hard to explain ("that was such..."). As result of the incident, his initial hope for close relationships was diminished ("it was going through the window"). Mark seems to try

to reflect further on that event but his words "*what's happening*" allude to his continued lack of understanding of the reason for the fractured bond.

According to Mark, there is a sense of being bullied/singled out in the group as he says "*I'm the one they pick on*", and the division is further captured in the words "*I*" and "*them*". It seems as if he describes old patterns being replicated as he suggests this "*usually*" being his experience. His laughter at the end of the narrative may demonstrate his difficulty with the repeated experience of being, in his view, "*picked on*" and wanting to use humour as a way of disavowing difficult emotions.

Further group splits are suggested by Mary's narrative. Her stroke impacted significantly on her mobility, contributing greatly to feeling socially isolated. Mary frequently reported enjoying the social aspects of the group. However, in her narrative, Mary seems to reflect on a 'them and us' division.

### (Were there any not-so-good moments in the group, something you dislike or you are not happy about?)

There are one or two, when they start talking they never finished they never give anybody time to talk.

### (OK, and what did you think about when they started talking?)

They keep on talking about the same thing all the time that's why, they did not give never any people a chance to talk ...

(Transcript 2, p. 3, 120–126)

Mary identified a number of people that were interfering with the flow of the group. Her repeated use of "*never*" or "*keep on talking*" including double negatives, seems to emphasise her unhappiness with the persistent interruptions within her group experience. She expresses her dissatisfaction as she describes how they "*never give anybody time to talk*". By her use of "*anybody*" it seems she thinks of it as a general issue. She continues to highlight her frustration because of the lack of valuable contributions these individuals make as they reiterate "*the same thing all the time*".

Subsequently, there is a sense of unfairness and anger captured in the agitated tone of Mary's voice, as she felt there was a lack of opportunity for her to share her own experience. The explicit use words such as *"them, they"* vs *"any people"* suggest further the separation from the rest of the attendees. This seems to allow a rupture in the group relationship to occur, revealing the need for equal sharing within the group, otherwise the group relationship may be affected.

In contrast to Mark and Mary, Patrick seems to express some balance in his narrative by pointing to both positive and negative sides of being with others in the group.

There is a positive side; there is a negative side. The positive side I have told you; the negative side is that there are some people, you know, talking too much all the time... want attention on themselves, thinking they are the most suffer it... yeah. There is some people that suffer more because a stroke hits you in many different ways, in a different part of your body [speaks with conviction], but some people have more movements than another, so we understand that this guy suffers more... yeah... but this kind of thing... you have to go in there with a very open mind, otherwise you take one, two sessions you walk away...

(Transcript 4, p. 3, 102–108)

Within the narrative, Patrick referred to "the positive side" that is discussed in the following themes but he also connects his negative experience with attention being taken away from him by "some people" speaking a lot, indicating a struggle to make his voice heard in the group. Similarly to Mary, he initially refers to others' persistent behaviour of "talking" as being disproportionate ("too much all the time") and unfair due to the restricted opportunity to speak. Firstly, the use of "they, and thinking they" expressed in an ironic tone of voice alludes to Patrick's emotional distance from others and disagreement with the idea of others suffering more post-stroke difficulties and therefore permitting "them" more "attention" in the group. Furthermore, Patrick's use of "we" and "that guy" in his narrative further suggests a level of splitting in the group unity, but also by the use of "we" he seems to assert the opinion of the larger group.

However, Patrick tries to reflect, empathise and understand their behaviour through his own sympathetic approach by speaking with conviction about the different physical limitations caused by stroke (*"stroke hits you in many different ways"*). Furthermore, in order to stay connected to the group and for their relationship to flourish, Patrick instructs others to approach the group experience with a *"very open mind"*, stressing the importance of receptiveness for others and advocating for acceptance of diverse strokerelated problems (*"some people have more movements than another"*). The adverb *"otherwise"* suggests that without these qualities, the group alliance can become very fragile and susceptible to a rupture, in which case attendees would *"walk away"*.

### 3.2.3 Sub-theme 3: "It Was A Short One"

The other difficulties expressed by participants related to the group ending and this was captured in the narrative of five participants. Ending the programme was described as an emotionally difficult encounter, leaving some participants feeling as if the termination of the group was mismatched with their hopes for longer support. Ending the group triggered feelings of disappointment and sadness as participants expressed their need for the group to "go on" (Transcript 8, p. 6, 230). Some participants acknowledged the ending of their group journey but continued their emotional development through maintaining relationships with other attendees.

Throughout the interview, Mary expressed enjoying time spent in the group and often highlighted the length of group time as insufficient.

(So when the sessions ended how did you feel?)
I went back to watching my own telly in my room.
(And how did you feel when the sessions ended?)

*Oh* [inaudible] I was annoyed I never forget... I thought it was going on for six months. It was short. (Transcript 2, p. 10, 443–448).

In response to my questions relating to ending the session, Mary describes her behaviour rather than addressing the feeling that she was experiencing. The act of returning to her room possibly suggests returning to her previous routine. Simultaneously, there seems to be a sense of loneliness captured in Mary's words as she describes "my own telly" and "my room" which has connotations of isolation and sets an atmosphere of sadness also expressed in her voice. Subsequently, Mary expresses feeling "annoyed" and says "I never forget", which suggests how powerful the emotions were as she uses the present tense, implying a difficulty in dealing with the ending of the group. It may be that Mary needed more time as she had hoped the group would go on for "six months". Therefore, the group duration does not seem to match her expectations, leaving her feeling that "it was short".

Similarly, Laura also highlights her need for extended time in the group.

... it was the talking therapy group... who referred me to the stroke group cos the talking therapy thought it would be good to be in a group session, so I could learn, I could be with people who suffered the same problem that I did and then when that group was finished I just felt I just wanted to go on but it wasn't like that, it was just for a period of time...

(Transcript 8, p. 6, 226–231)

It seems Laura had hoped to receive continued support by belonging to a group of people with similar conditions and understanding, where she could "*learn*" from others who also suffered stroke. However, "when the group was finished", Laura reports feeling not ready to walk away and wanting more of the experience, as she says, "*I just wanted to go on*". It seems Laura's expectations/needs and perhaps false hope were contrasted ("but") with the reality "it wasn't like that, it was just for a period of time".

Laura does not explain what difference it would have made to have more time in the

group, but does indicate her lack of contentment with the existing group length.

Kate approached the ending differently. For her, termination is a continuous experience as she has prolonged the group relationships outwith the sessions.

Erm yeah it was quite [pause] I found it emotional, which again I'm not usually one for being emotional, and I think I have become emotional, erm, expressing myself a bit more, and the group it was, erm, yeah I keep in touch with one or two people.

### (Oh, OK.)

Just to see how we're getting on, and doing, and see if at some point in the future we can build up to maybe meeting up...

(Transcript 6, p. 4, 151–156)

The initial pause in Kate's narrative points to a moment of reflection on the ending of the group. It sounds as if the termination had a significant emotional impact on her which was captured in "I found it emotional". The change of language from present and present perfect progressive tense indicates that Kate battles between her pre-group "usually" non-emotional self and new post-group "I have become emotional" self, which she may have come to recognise with the help of the group. However, selfexpression seems to be a new skill learnt by Kate, and it appears she still withholds from self-disclosure by quantifying her level of disclosure to "a bit more". Therefore, it could be said that "keeping in touch" with some of the group members actually reflects her willingness to continue her journey of personal development and connection with others. Consequently, the process of ending could be then extended and processed gradually. Her use of "build up to maybe meeting up" suggests her uncertainty about the strength of the relationship with others needed in order to meet them in person. As Kate may see the relationship with "one or two people" as premature, she requires more of a tentative approach by saying "how we're getting on" to ascertain whether there is an option to meet in the future.

### **3.3 Master Theme 2: Means to a Connection**

### 3.3.1 Overview

This master theme captures how participants experienced the process of developing group relationships and what factors contributed to their emerging sense of togetherness. Some participants described feeling closer to one another through identifying stroke-related difficulties that were captured in the first sub-theme "United by Stroke". Ground rules and time spent in the group were crucial ingredients in establishing a collaborative meaningful alliance amongst group members which contributed to a sense of group unity. Importantly, building trust to enable one to be vulnerable in the group was cautiously developed and is spoken about in sub-theme two "As If There Is A Connection". The final sub-theme "Accepted Here Vs Judged Out There" illustrates how their sense of belonging to the group was tightened through validation and a non-judgemental group environment, which was in contrast to their relationships outside the group.

### 3.3.2 Sub-theme 1: United by Stroke

This sub-theme describes different aspects of developing togetherness in the group through the process of "*opening up*" and was expressed by four participants. For some attendees, the sense of togetherness was facilitated by sharing stroke-related pain and vulnerabilities. Identifying some similarities in their predicaments normalised their experience and enhanced positive experiences of the group. Even right from the beginning of the programme, some participants felt privileged to learn more about stroke from others, which in turn seemed to contribute greatly to members bonding. For example, Kate seems to associate developing bonds in the group with the process of sharing their predicaments.

*Erm... I think we connected a little bit more when we all opened up.* 

#### (Mmm mmm)

So when we talked about our experiences, our difficulties, I came to the realisation, I guess, that we're not the only one going through this, that it was for me...

(Transcript 6, p. 6, 229–232)

Kate highlights the process of "connecting" right at the beginning of her narrative by indicating the group's closeness occurred when open communication took place. Her continuous use of the word "we" alludes to going through that process together and contrasts the reflections made by Patrick and Mary regarding "them and us" group divisions. However, for Kate, the sense of unity may not be fully developed at this stage, as she says they "connected a little bit more". This on one hand may suggest progress in developing the group's relationship, but at the same time this process is not complete. However, this experience appears to be furthered when Kate highlights the moment of having shared experiences that enabled her to reflect and increase her own understanding and "realisation" of the group's experiences and their shared pain. It is apparent there was shift in closeness by group members as Kate's use of languages moves from using "I", which describes a sense of isolation within this journey, to a unifying "we're not the only one" which signifies a shared experience and connection. That may also imply that previously she thought she was the only one and that this recognition was meaningful for her is evidenced in "that it was for me".

Mary describes her experience of initial sharing that facilitated a sense of cohesion in similar terms.

The first session everybody have to introduce yourself, and say the name and which kind of stroke you've got, it was good, it was helpful for a lot of people... it made for a happy group it was good... you learned from other people the kind of stroke they've got different from that they told you in the hospital... you feel like you are not alone you know just like you know...

(Transcript 2, p. 1, 25–33)

Mary refers to the initial format of mutual group sharing ("everybody"), which involved introduction and some primary self-disclosure. Through saying "the name" with what "kind of stroke" they had, participants highlighted their individuality at first. This form of communication seems to have a beneficial impact on Mary's experience of the group and her approval is repeatedly captured in her words "it was good". This initial disclosure to others in the group was a positive experience not just for Mary but also other attendees, as she suggests "it was helpful for a lot of people". Sharing information about different kinds of stroke was significant for Mary and created a sense of belonging and emotional satisfaction ("it made for a happy group"). Mary then elaborates on the reason why she thinks sharing their individual and unique experiences had such a binding and helpful effect. According to Mary, learning more about different types of stroke increases her knowledge, builds her own awareness of others' predicaments which may have been similar to hers. Consequently, that recognition seems to have decreased her own feeling of loneliness as she highlights "you are not alone".

Similarly, Steven, whose stroke left him wheelchair-bound and who reported feeling depressed after his stroke, was able to experience a sense of connection in the group, however, by identifying similarities while listening to what was shared.

## (Were there other parts of the group that were helpful for you?)

[Silence 10 secs]

Hearing a little bit about what people were saying about what they were able to do and so on.

[Silence 5 secs]

### (Mmm and how that was good, why do you think that was good in the group?)

[Silence 5 secs]

Just know that some people some were similar problems or experiences...

(Transcript 3, p. 4, 176–182)

Steven hearing about others sharing their experiences was highly important; it seemed he paid particular attention to their abilities and "what they were able to do". It seems Steven would rather listen to what is being said ("hearing... about"). Additionally, Steven seems to be selective of how much he internalises, saying "hearing a little bit". In the interview, Steven's mood was very low, and that made me wonder how that impacted on his interaction and reflection about the group. The pauses and being selective in his answers might be reflective of how he felt in the group, too. It is perhaps due to his mood that it took him longer than others to participate, resulting in becoming more of a listener. Still, Steven seemed to be able to identify with others' struggles and experiences that were "similar" to his, although not all ("some"). This could suggest that having shared experiences might allow connections with others in the group and normalise his difficulties, in contrast to the initial separation when he spoke of other attendees as "they" and "people".

### 3.3.3 Sub-theme 2: "As If There Is A Connection"

This sub-theme captures the experiences of six participants and illustrates group connections as an ongoing and a cautiously approached process. Discussing confidentiality was paramount to assist in growing trust "*a bit more*" (Transcript 6, p. 7, 308) in the group resulting in deepening disclosure. The time factor was also crucial in

order to enable collaborative and friendship-like bonds to emerge, which was only possible after a significant number of sessions. The connection to the group was also experienced as familiarity with a group environment rather than with members of the group, indicating further that the full bond was not yet formed. However, having a close link with the group and feeling comfortable enabled participants to experience less anxiety.

One of the aspects enabling attendees to build close and meaningful relationships in the group was reflected on by Kate. In her narrative, she pointed to confidentiality as a means of developing trust.

You know, but once I got over that [initial anxiety] and we talked about confidentiality in the group, and erm after I got over that it was fine. I think it was just that initial... sort of learning to trust each other.

### (OK, OK, so what do you think how the trust develop in the group...)

I think everyone must have felt for me. I felt comfortable and I felt like I'm not going to be judged, so I was able to trust a bit more and open up a bit more... and I guess the way people responded to that was positive... and I guess then that made me trust a bit more.

(Transcript 6, p. 7, 299–308)

Kate suggests that anxiety at the beginning of the group stopped her from expressing herself. Perhaps she felt fearful of becoming exposed and vulnerable in front of others as she could not trust them. She points to "confidentiality" as a turning point for her initial lack of trust ("after I got over that I was fine"). It seems that setting the ground rules addressed her concerns and provided reassurance and safe boundaries. Also, the use of her phrase "we talked" describes a mutual discussion about confidentiality which suggests an agreement of the group rules, which possibly comforted her further in the group as it required everyone to comply. Kate connects the above discussion with the process enabling the group "to trust each other" but also indicating further the feeling

of trust needing to be reciprocated by all members of the group. It could be said that *"learning"* to trust is a process that is not easily achieved, as when she tentatively suggests *"I think"* that the group members felt empathy. Additionally, further emergence of trust was possible only when Kate believed that *"everyone"* in the group felt for her. The process of sharing and developing trust seems to depend on feeling *"comfortable"*, not *"judged"* and the *"positive"* feedback received in the group. Nevertheless, trust is a process that might not yet be fully attained, as she repeatedly restricts it by saying *"a bit more"*. Although her narrative seems to highlight a group connection, she still sets a conscious and careful tone, indicating that the relationship and trust is still in development.

Similarly, Steven also indicates a not fully developed bond where his experience of relating is in the context of familiarity to a place rather than the people themselves:

*I did feel anxious about it and that improved a bit but, er, later in the sessions...* 

### (What do you think helped you to be a little bit more relaxed later in the group?)

*I* suppose there was an element of being in a familiar place.

(Transcript 3, p. 3, 97, 126–128)

Steven's account indicates a shift in his feeling of anxiety when he initially came to the group. However, the change he refers to seems to be small, which is captured in his words "a bit". He contrasts his early anxiety with "later in the session", indicating improvement being possible with time. In response to my prompting question, by saying "I suppose", Steven sounds unsure what exactly made the shift possible; however, he indicates a sense of familiarity as a contributing factor to his reduced feelings of anxiety. Interestingly, his comment ("an element of being in a familiar place") may have indicated a decrease in his uncertainty about the place itself and brought him some sense of stability. Steven mentions being shy in the interview;

perhaps this is why for him it was more challenging to develop a deep bond with other members.

Unlike others, Patrick spoke of more developed group connections that he compared to a friendship.

I think so after six, seven sessions, in the beginning you are coming... just listen you very scared to actually participate in what they say, what happens, but eventually after five, six, seven sessions you come like a friend, you come like you see them more time, they share with you more things, you share with them it's seven, eight, nine times, you come in very easy, you coming to understand the situation you know, you go home, you think about it, you come back again, you sitting there, you tell about your difficult... moments you have in your life...

(Transcript 4, p. 2, 87–92)

Throughout his reflections, Patrick stresses time as being a fundamental factor in developing a connection within the group ("after six, seven session; after five, six, seven sessions; you see them more time"). He compares his own feeling of anxiety and fearfulness in participating at the "beginning" of the group to later highlighting the time needed to change the quality of their relationship. Firstly, Patrick seems to be more detached and withheld as evidenced in how he would "just listen" to others due to "feeling scared" of what is being said and fearful of contributing, indicating minimal bond to the group. "But" with time passing, there is significant change in the nature of their interaction as they become more "like a friend". The word "friend" gives a sense of closeness that Patrick experiences later in the group, although he uses "you" and "they" throughout his narrative, alluding to tentative connections. It seems that meeting other stroke survivors time after time and participating in collaborative sharing ("they share...; you share...") fosters closeness between them. In his narrative, Patrick moves away from the scary feelings and speaks of his own increasing participation by disclosing "more things". This may indicate the development of trust and a sense of his

anxiety decreasing as he feels comfortable to "come in very easy". Additionally, as time passes the relationship becomes more solid and he seems to engage in reflective cycles, whereby he "thinks about" what is being said outside the group and shares more when "you come back" again. Patrick speaks of disclosing "difficult... moments" which alludes to sharing his own intimate experiences, further symbolising the development of trust in the group.

### 3.3.4 Sub-theme 3: Accepted Here Vs Judged Out There

This sub-theme encapsulates participants' thoughts about their relationships within the group in comparison to their external friendships. Participants indicated feeling blamed by friends and family for self-inducing stroke due to their previous lifestyle. The perceived identity of being *"stupid"* (Transcript 2, p. 2, 76) outside the group was challenged by feeling equal and having some self-worth within the group setting. Furthermore, the group members had fundamental qualities such as non-judgemental attitudes, mutual understanding, providing validation and believing in group members. These qualities were highly important and were found to enhance group relationships.

A passage from Patrick's interview illustrates the contrasting experiences of being blamed for self-inducing stroke by friends, which is counterbalanced by non-judgmental group attitudes that enhanced his sense of belonging.

Ah people think like... you work more, you know, you were looking to get, to get stressed, you are supposed to enjoy yourself more, to swim, to do more each of things like that, you talk like it harder to be able to talk to people, because they think you bring things on yourself, some said 'I told you, you were very stressed, you're rushed from job to job', you were trying to find comfort in your own friends, so in this group the advantage is like this, that I've seen with time... you see that everybody have the same situation like myself, nobody judge nobody you know...

(Transcript 4, p. 1, 39-44)

Patrick seems to generalise his experience of being blamed by everyone outside the group when referring to what "people think". He suggests that others implied he was responsible for his stroke as he says "you were looking to get stressed". His words "you are supposed to enjoy more, swim more ... " may allude to pressure to have a balanced lifestyle, and indicate that he could have avoided his stroke. He frequently repeats "more" to exaggerate societal expectations to do beyond what's "normal". The sense of being blamed for having a stroke is then once again highlighted in his narrative "they think you bring things on yourself" and "I've told you, you were very stressed". Patrick hints that his difficulty in being "able to talk to people" is due to his perception of others blaming him and lack of emotional support. Subsequently, the past progressive tense ("you were trying") suggests Patrick's numerous previous attempts to seek "comfort" in his friends but the sadness in his voice and immediate redirection to the benefits of the group alludes to failure in achieving it. In contrast, he is able to notice the "advantage" of being with others in the group. The word "advantage" suggests the positive and beneficial aspects of group relationships compared to external relationships. Through his observation of the group over a number of sessions ("I've seen with time"), he alludes to a sense of sameness ("like myself") with others. He highlights mutual empathy and compassion as he repeats that "nobody" judges and finds a sense of acceptance as "everybody" in the stroke group is like him.

Furthermore, Kate in particular stresses the sense of being believed as a distinctive factor in the group that seems to contribute to her positive connection with its members.

I think I mentioned before that some people have said 'are you sure it's not in your head' and... I think there's an acceptance isn't there in that group, definitely of, of ourselves... and of each other's experiences. We weren't questioning each other's experiences, and accepting of what the person was saying. I know I didn't have to feel like I have to defend myself or justify or convince people actually... yeah... (Transcript 6, p. 6, 237–243)

Kate brings up previously mentioned statements from her friends, in which the truth of her illness is questioned and alluding to feeling disbelieved ("are you sure it's not in your head?"). Kate moves on to reflect on her contrasting experience of the group approach. Her narrative suggests a sense of being believed and their experiences being unquestioned by group members, noted tentatively in "I think there is an acceptance". Although she initially seems to question the acceptance ("isn't there"), she then contrasts it with "definitely" to suggest a reciprocal approval of post-stroke identity and their new lives; Kate uses plurals such as ("ourselves and... each other's experiences") through which she highlights their mutual experiences. She emphasises the validation in not having to explain herself and being doubted ("accepting of what the person was saying"). This experience once again seems to be extended to other attendees when she says "we" and "the person" to represent anyone in the group and their mutual acceptance of each other. In contrast, the words "defend myself" and "justify" implies she no longer feels under attack, as her new post-stroke identity is not being questioned in the group. Thus, it seems the group setting provides her with a compassionate environment, where she does not need to prove anything. "I didn't have to ... justify or convince people" and she can just be herself. At the end of this excerpt, Kate implies confirmation "yeah" of experiencing an unconditional welcome from the group, where she could be herself without the need to fight against others' judgements.

Additionally, Mary contrasted feeling devalued out with the group with feeling respected in the group, facilitating the sense of meaningful alliance.

Sometimes you tell them [friends, family] they think you are stupid because you've got your stick, so when you are among people, see them in the group you feel happy, you feel OK.

(Mmm, so you think some people think you are stupid because of your stick?)

*Oh yes, cos sometimes when you are talking they don't listen, they just ignore you.* 

(Mmm and did you feel like that in the group that some people...?)

No, no, not in the group.

#### (So what was it like in the group?)

It was OK, so even though you are all the same, you, everybody listening to everyone...

(Transcript 2, p. 2, 76–83)

Mary describes a sense of not being taken seriously when she speaks with family and friends. She suggests they think she's "*stupid*" just because she is disabled. It seems the "*stick*" symbolises illness and disability but gives a negative connotation of someone/her being imperfect or "broken", therefore not needing to be taken seriously. It can be said there is a sense of disconnection from her family/friends as she generalises "*them*" and "*they think*". Mary's quiet tone of voice while she says "*ignore*" also indicates a sense of feeling invisible and devalued. In contrast, in her group experience, Mary reports more positive feelings such as "*happy*" and "*OK*" which seem to be subsequent to recognition of being "*the same*", which appears to normalise her disability. By her repeated "*no*", she further contrasts the group relationship with her external experience. Most importantly, Mary depicts equality within the group as she describes the experience of "*everyone listening to everybody*" and therefore feeling part of the group, respected and valued.

The above themes (one and two) seem to highlight the change in interaction amongst participants; while initially there were difficulties in forming the group, and beginning to speak up, these difficulties were perhaps more anticipatory, and over time, strong agreement has emerged about the value of a different and non-judgemental space. Despite some early confusion about similarity and difference, it seems that after a while, there is a sense of everyone growing collective understanding of each other and cohesion beginning to grow as they find themselves dealing with the aftermath of stroke together.

### 3.4. Master Theme 3: Restoring Confidence and Hope

#### 3.4.1 Overview

This master theme explores participants' reassessments of their perception of their circumstances, where they felt more confident and more hopeful. Participants report increasing their self-esteem through various aspects. They were able to reflect on their physical abilities and restore a sense of control through the process of comparison with other attendees, as illustrated in sub-theme one "It Could Be Worse. Sub-theme two, "You Are Not Alone", describes a growth in confidence as a result of challenging social isolation and the realisation that they are not alone in their post-stroke predicaments. Lastly, sub-theme three, "Believe In Yourself – Learning From Others", emphasises further how the process of learning from other members or the facilitators contributes to increased self-esteem. The new knowledge is then used to manage numerous emotional and physical stroke-related difficulties.

### 3.4.2 Sub-theme 1: "It Could Be Worse"

All eight participants commented on and indicated re-evaluating their circumstances through the process of social comparison. By seeing others in a worse situation, participants were able to positively reflect on their physical abilities, and also restore control and increase confidence in their own recovery process. Comparing themselves to others in a less fortunate position gave participants a sense of gratitude and allowed them to start to reclaim choice over their lives. Seeing group members in a better situation increased a sense of hope, motivation and acceptance of stroke-related predicaments. The new insight resulting from comparison with others indicates a more positive outlook for the future by opening opportunities for a more hopeful life after stroke.

For instance, Laura speaks about meeting others in the group who are in a less fortunate position. This seems to have enabled her to reflect on her own circumstances, and increased her sense of confidence to engage in treatment such as physiotherapy.

I'll be moaning about, erm, say oh I'm struggling to get up and down my stairs, but then there's people, one lady that was in a wheelchair, she can't move any at all, so you then realise that you're not the worst.

### (And how did it affect you then knowing that you're not the worst?)

It helped, because it helped to motivate you to do more in terms of for instance in your physical wellbeing that you try to do... with when the physiotherapists give you exercises, and you do it when they are there, and the following day then after that you leave it till the next week, but then things like that motivate you to wanting to do... exercise more even when the physiotherapist is not around.

### (And how important is for you to keep, to stay motivated?)

It's very important, because it does help if your self-esteem is low, it brings you back to where I was a year ago...

(Transcript 8, p. 8, 321–331)

Laura's use of temporal references in the first sentence alludes to her usual way of responding to post-stroke difficulties, describing the limitations in physical movements. However, meeting other stroke survivors who "*can't move any at all*" may have been an epiphany as subsequently Laura was able to reflect and revise perception of her personal situation, which broadened her view on her own disability. The use of word "*moans*" might be one indication of her reflection, in that her previously perceived battle with stroke ("*struggles*") actually might now feel less overwhelming. It may be said that Laura realises that her physical limitations are not so confining (as the wheelchair is) and she still has a choice in what she can do compared to others in the

group. The impact of that comparison is also stressed in the repeated use of "helped", the past tense suggests a more finalised process and how crucial that realisation was for her, as she was stuck in her "moaning" but woke up to a new perspective. The new motivation seems to be one of the beneficial aspects of that experience (comparison) and she uses it to restore her physical wellbeing by engaging in necessary treatment trajectory e.g. physiotherapy. Laura shows an increased willingness to recover ("wanting to do... exercise more") and is changing her behaviour by engaging in exercises that may prevent her from getting worse. As a result of the psychological change, crucially for Laura, her "self-esteem" seems to increase.

In Kevin's narrative, in which he showed that loss of independence was the most challenging aspect after stroke, he begins to rebuild his self-efficacy through recognising he still has choice in his life.

Erm, it could have been worse, I mean I could have... lost the feeling for a long time, I mean, one bloke in the stroke club had his stroke about four years ago, and he's only just got his voice speech, so I'm lucky in that respect, I can speak if I had problems, I can still talk to a few people if I want to...

(Transcript 5, p. 6, 245–247)

Kevin opens his narrative with an immediate realisation "*it could be worse*". He has reached new conclusions about his circumstances, through comparing with other people whose recoveries were significantly longer than his, and realising that his situation could have been much more challenging. At that point he seems to grow in appreciation for his life as he stresses "*I'm lucky*" and attributes his luck to reduced severity of the impact of stroke. Although he seems to feel grateful, that insight seems to be somewhat restricted (*"in that respect"*) to his ability to speak and feel only, suggesting that he may still think differently about other areas of his post-stroke life. It is possible that his need to communicate is paramount and meaningful for Kevin, as he draws attention to this ability within the narrative. It can be said, Kevin's confidence in his own capacity ("*I can*" or "*if I want to*) to articulate his problems may mean he can receive help or find solutions when needed ("*I can speak if I had problems*") and also sustain his connection to people ("*I can still talk to a few people*").

Contrastingly, Kate reflects on her increased motivation resulting from comparing herself to others who had already moved on with their problems, which gave her hope for the future.

I think... other people were ahead that they'd come to terms with what had happened, whereas I was still struggling... so just seeing how they accepted their condition, and were working with it rather than against it, I think that helped, it motivated me.

(Transcript 6, p. 10, 428–430)

Kate reflects on her comparison with others who progressed in their recovery and "were ahead" of her, implying visible distance between her emotional struggles and others already progressing with the post-stroke life. Also, by using the words "they" and "I", she highlights further the gap between them in psychological progression. Through acceptance of their stroke, there seems to be an emotional growth that hasn't been reached by Kate at this time as she is "still struggling". It seems Kate sees herself as "still" trapped and battling against the stroke as she recognises she is not quite there yet. However, by observing others ("just seeing") being successful in the process of accepting the changes and managing stroke in their lives ("working with it rather than against it") "helped" her to revise her position. Therefore, there is a sense of hope that it may get better, and the empowerment captured at the end of her reflection "that helped, it motivated me", suggests a more positive outlook on her journey with stroke.

### 3.4.3 Sub-theme 2: "You Are Not Alone"

This sub-theme emerged from the accounts of six participants and describes the process of increasing confidence and hope through challenging feelings of isolation. Being amongst others has a significant impact on their pre-group feeling of loneliness, as the group environment brings reassurance that there are "*always*" (Transcript 2, p. 8, 356) people in the same boat. Furthermore, knowing there are others whose experiences mirror their own, validates and normalises their own emotional difficulties. Subsequently, participants felt a sense of relief as they were able to tackle their self-doubt. Having shared experiences in the group and knowing that stroke can happen to anyone helped to develop self-agency and the motivation to "go on" (Transcript 4, p. 11, 451).

Mary describes feeling reassured that her "*suffering*" was not solitary, and realising that she would be less likely in future to "*feel alone*" with her predicaments.

For me it was important meeting people, talking about things. Before, you think you are alone, but you know that you are not alone. There are always people who are suffering the same like you.

### (Mmm mmm and how that helps you...?)

Is telling me you are not alone... when they all talk to you, you feel better...

(Transcript 2, p. 8, 355–360)

Mary's individual ("for me") experience of "meeting people" was significant and "important" for her. The group seems to create a space to share "things", which may not be specific to just stroke but may include general issues. Initially, although Mary refers to her experience of feeling lonely "before" the group, she uses the present tense ("you are alone"), suggesting an ongoing battle with that feeling. However, she has diverted her narrative towards her new understanding of her loneliness after meeting others by saying "you are not alone". Having used the present tense here as well may imply this knowledge is as current as feeling lonely but it may need more

reinforcement, which she seems to reflect on next. That is, she proposes a revised belief that "there are always people who are suffering the same", indicating that belonging to the group and recognising that others share the same experiences might reduce the feeling of loneliness in the struggle. That conclusion seems to be a powerful one, as her identification with others and repeated "not alone" throughout her narrative bring her emotional relief whereby she "feels better".

Similarly, Kate echoed these feelings of alienation with her predicaments but the group experiences also provided further reassurance for the legitimacy of her emotional experience.

It was definitely good meeting people, cos I know I'm not the only one who feels like this, and I know that it's OK, because if you think you are the only one that feels like this then you think I shouldn't feel like this, but in the group when other people are feeling the same as you, I think it's OK then, isn't? ... Cos then I'm not the only one, I'm not making it up, cos these people experience it too...

(Transcript 6, p. 11, 462–466)

Kate speaks of meeting other stroke survivors in a definite manner, indicating her lack of doubt as to the beneficial aspects of that experience. She further elucidates she was feeling alone with her emotional reactions until she met others. Her equivocacy ("*I shouldn't*") in regards to her feelings seems to be challenged by others in similar predicaments within the group, which reassure her "*that it's OK*". Kate indicates that her lack of awareness of the existence of others living with same difficulties led her to discount her emotions, as if they were unacceptable to her and others ("*I shouldn't feel like this*"). Thus, learning there are others feeling like her seems to initiate a resolution to a conflict between experiencing her feelings and normalising them. As she begins to permit herself to feel emotions due to being validated, there is still, however, a trace of doubt whether it is acceptable or not ("*isn't it?*"). Repeating three times "*I'm not the* 

*only one*" points to the special importance she ascribes to being in the company of others with the same experiences, which enables her to affirm her feelings as legitimate through the experience of others (*"not making it up, cos these people experience it too"*). In particular, the words *"these people"* seem to stress the importance of their stroke-related identity, which enables her to begin to rebuild confidence in herself and her own emotional responses. Still, her tentative narrative expressed in the present progressive tense suggests that this process might not be finalised yet.

Additionally, Patrick reflects on the shared group experience as motivation for taking charge of his life, resulting in increased determination and independence.

Like I said, the group helped a lot, because there is different kinds of people in there in the same situation you are, so the group helped you to understand more quickly, to getting real more quickly, to speed your process to live the way you live right now... you know, you stop thinking the past, start living the present, you see what you can do for yourself, the group brings you to reality check...

#### (OK, what do you mean?)

Like you have to change cos there is no other way... so you have to go on...

(Transcript 4, p. 10, 443–454)

Due to the presence of "different kinds of people" who are facing the same situation, Patrick felt the group "helped a lot". It is possible to say that the former statement and use of generic "you" means his experience of stroke might have been normalised as he realises stroke can affect not just people like him. It seems Patrick felt stuck as he was unable to "stop thinking [about] the past"; however, the group experience enables Patrick to move forward much quicker ("quickly, more quickly, speed"). There is a strong sense of impatience as he engages in rumination and feels the need to progress forward. After being supported by the group, Patrick experiences a "reality check" and "getting real" alludes to the process of exploring alternatives in the group and instilling the hope of moving forward (*"so you have to go on"*). This realisation may allow him to increase his confidence through becoming curious about *"what you can do for yourself"* and thus to start living in the present.

### 3.4.4 Sub-theme 3 : "Believe In Yourself" - Learning From Others

This sub-theme encapsulated six participants' experiences of *"restoring confidence"* (Transcript 7, p. 8, 359) through the process of learning from others. Some participants noticed a shift in their self-esteem when they recognised similarities between their ideas and those of others in the group. Gaining further understanding about stroke-related symptoms also provides necessary insight into their illness and therefore functions as a prevention plan for future episodes. Additionally, learning from facilitators empowers participants and increases a sense of control over emotional and physical pain.

For instance, Mark reflects on the process of being reassured about his own way of thinking but also learning from others that contributes to restoring his self-esteem.

... when sometimes they asked me the first session I telling, you know that 15 different category of that question, 15 of which I didn't expect them to say, my idea is not like that, and if I did and then that give [pause] give me a bit of confidence as well...

### (Oh, OK.)

Yeah confidence, confidence, restoring the confidence there...

(Transcript 7, p. 8, 354–359)

Mark describes his experience of participating in the "first session", indicating on occasions being "asked" to take an active part in the group. It seems he shares his "idea" with others, but also listens to others expressing their own thoughts. It sounds as if he was taken by the variety of answers others were disclosing when he says repeatedly "15 different categories". Mark "did not expect" to be exposed to the

amount of information that was shared, suggesting further learning from the group. Subsequently, he contrasts his "*idea*" with others indicating the differences and alluding to broadening his awareness as a result, as captured in "*my idea is not like that*". Additionally, Mark concludes that when he "*did*" have the same opinion as others his "*confidence*" increased and he felt reassured. Initially, he recognises his self-esteem has changed "*a bit*", but as he continues to repeat "*confidence*" three times, he seems to feel more reassured about the positive impact the whole experience had on bringing his confidence back.

Additionally, Laura indicates that the importance of learning from others about strokerelated symptoms has augmented her confidence and given her clarity on how to approach stroke in the future.

### I've learnt from others as well.

#### (Mmm and how the learning kind of help you...)

It helped, because as I keep saying there's like symptoms you know the symptoms... If you know the symptoms it's a help. I've learned from that so you know, what to do... go and check over and not just go home like I did before.

(Transcript 8, p. 5, 186–195)

Laura indicated learning from other attendees in addition to their learning "as well" being a substantial factor in her group experience. It may be said she notices an increase in her awareness as she twice highlights feeling "helped". It seems Laura develops new insight into her ability to recognise stroke-related physical "symptoms". The significance of new insight into stroke is accentuated not only in her repetition of the word "symptoms" but within the phrase "as I keep saying there's like symptoms". In the interview Laura repeatedly spoke about fear of another stroke and how she and professionals failed to recognise and act on TIA signs, thus it may be said that her need to be able to recognise the early signs of stroke seems crucial in feeling more confident

and prepared for potential future events where she knows "what to do" and perhaps implies her sense of better control. Additionally, the words "go and check over" may serve as part of her new prevention plan in the face of the recent stroke-related experience where due to her own lack of knowledge she was unable to recognise the medical emergency.

Contrastingly, John speaks of learning from the facilitators through which he feels empowered and more in control of his pain.

Yeah because the way you know, when they explained lots of things to us... yeah about our emotions, about everything, yeah, and the way in which things happen like now that if we feel pain we know that OK, yeah, it's going to affect and determine our emotions, so the way we will able to like control it, you know, like not take the pain to hide that all this has started that this pain has been there for so long, but that's just a phase that's going to go away... then it's kind of like they make you have like more belief in yourself...

(Transcript 1, p. 3, 110–122)

John alludes to learning from the facilitators of the group ("they explained... to us"), which broadens his horizons, he feels he is learning a "lot of things". He extends learning beyond personal experience when he generalises it to others in the group ("us", "we"), indicating the possibilities for shared learning in the group. It seems the facilitators were able to help John to reflect more on the process, as this experience expands his awareness of both his emotional and physical pain. It seems John used to avoid his emotions prior to the group as shown in the word "hide", but his current understanding of pain has changed ("like now"). Through this new insight, he is able to manage his pain and have a sense of "control". The modal verbs "will be able" demonstrates his ability and confidence to manage it "now" in an effective way. His new coping skills seem to be fused with the process of tolerating his pain without the need to disavow and conceal his emotions ("not take the pain to hide") but also further

his awareness that the pain will "determine our emotions". John seems to confront the reality of his predicament when acknowledging the long existence of his physical pain, but shows his current mental ability to work through the emotional and physical effect of the pain ("that's going to go away"). For this reason, John once again highlights his sense of self-efficacy ("belief in yourself") and feeling of being in charge of his wellbeing.

### 3.5 Theme 4: "Things Won't Be the Same" – Moving Towards Acceptance

### 3.5.1 Overview

This master theme consists of four sub-themes and illustrates an ACT principle related to change through the process of acceptance. This master theme captures the positive changes reported by the participants but also highlights the continuing hardships of moving on and adjusting. The initial sub-theme "Need to Know How" demonstrates how some participants accept they have new needs and how integrating therapeutic strategies enable them to meet those needs. Sub-theme two, "There Is A Life After Stroke' – Increased Acceptance of Responsibility", demonstrates how participants were able to adjust and accept their illness, starting to move on with their lives by becoming more active in the process of recovery. Participants also spoke about changes in their identity that are positive but also drawn from "lack of choice" and this is discussed in sub-theme three, "This Is Me Now' – Emergence of Compassionate Self". Accepting themselves and the reality after stroke is very challenging and requires a lot of dedication, practice and compromise. This is not easily achieved and is as a continuous battle for many participants, which is explored in the final sub-theme: "I Can't Get Used to' – Ongoing Challenges".

### 3.5.2 Sub-theme 1: "Need to Know How"

Seven participants express benefitting from the group. They indicate that they are more able to accept the psychological needs within the context of their stroke together and consequently feel able to apply relevant taught ACT skills to realise such needs and move towards recovery.

For instance, Kate describes the beneficial aspects of the relaxation method introduced in the group.

I didn't realise how long it had been since I'd relaxed or felt... yeah relaxed, yeah, I actually miss not being anxious, I never used to worry or stress about anything and then this came along and then it just made me really anxious and a worrier and you know just consumed by this pain and... the relaxation just takes me, gives me a break from it all...

(Transcript 9, p. 14, 366–369)

Kate refers to a stroke as a point of time ("then this came along") since which her psychological state of mind has changed and she has become "a worrier". It seems anxiety and inability to relax might have been a constant experience as she notices the difference in her state of mind when she says "I didn't realise how long it had been since I'd relaxed or felt... yeah relaxed, yeah". Kate furthers that realisation when she talks about being "consumed" by pain, suggesting her life was taken over by poststroke problems. Her longing to feel relaxed and contrasting her current emotional state with the pre-stroke anxiety and pain-free life perhaps led to her to accepting relaxation as a necessary coping strategy in order to restore temporarily ("a break") a calm state of mind.

In contrast, Laura seems to recognise and accept her need for positive thinking in order to feel more equipped and prepared to manage her condition. Yes, it helped me to think positive, you think more positive, you don't have too many negative thoughts, you think more positive now, oh yeah I've got a stroke and this is what I need to do...

(Transcript 8, p. 11, 474–475)

Laura's extract shows how the group "helped" her to accept her psychological needs of thinking in a more helpful manner within the context of her stroke, which is evidenced in the repeated word "positive". She seems to be drawn towards the cognitive strategy discussed in the group that enables her to experience fewer "negative thoughts" and more hopeful thoughts in the present moment when she says "think more positive now". Subsequently, the acceptance of her needs and recognition of this helpful tool seem to enable her to accept her condition as she says "oh yeah, I've got a stroke". Consequently, the change in her way of thinking about stroke might equip her to manage her post-stroke life ("this is what I need to do").

On the other hand, Kevin's narrative provides an insight into his reflection on behavioural strategy, enabling him to address his need to stay independent.

Oh I want to spread my wings, not spread my wings but go out and (name) said you've got to take it in smaller steps, like see the doctor speak to DVLA erm think about who you're going to see down there, when you gonna see them, things that you need to plan ahead of

(Transcript 5, p. 10, 406–408)

Kevin's tone suggests a great desire for liberation as he expresses his need to "spread my wings" and be free, which seems in line with the values that he expressed in the interview such as wanting to be independent. However, his statement and the defeated tone of "not spread my wings but..." suggests a conflict he experiences between accepting his limitations since the stroke and the impact this has in allowing him to be able to "spread his wings". Nonetheless, the group and ACT concepts have allowed him to accept the limitations to his liberation and come to feel that he can still "go out" and live a valued life. However, that may be achieved through adjusting his behaviour

by taking "*smaller steps*" and therefore perhaps taking things more gently. Reflecting on what he needs enables him to identify how/who can help to resolve his problems. Kevin then stresses planning "*ahead*", which seems to reinforce his acceptance of what needs to happen to remain independent.

### 3.5.3 Sub-theme 2: "There Is A Life After Stroke" – Increased Acceptance of Responsibility

This sub-theme was captured in the narratives of all the participants and illustrates the process of acceptance in post-stroke life through highlighting emotional and behavioural responsibility in order to reclaim their lives. Some of the participants reflected on trying to integrate stroke into their lives as a result of resolving an internal conflict between constantly fighting against reality and passively accepting stroke. Accepting their own physical limitations and opening up to the idea of asking for help in order to have their needs met were some of the changes noted by the participants. Furthermore, to continue significant relationships, everyone found they must take responsibility in making small amendments.

Laura, like many of the others, questions "*why I had to have a stroke*" (Transcript 8, p. 1, 19) which speaks of her feeling of unfairness and could be understood as her not being in charge of her own life. She, along with other participants, refers to the sense of taking back control after a seemingly uncontrolled event.

You have to take responsibility of things, there's so much you can do...

(Transcript 8, p. 16, 669)

In this short extract, Laura seems to capture and reflect on her need to be proactive in order to change her life. The *"responsibility"* heightens her sense of ownership of her

own destiny and speaks of self-determination. It may be said that Laura's words "*so much*" accentuate the lack of restrictions and endless opportunities for choice in how she can go about it. In other words, her narrative suggests Laura is not a victim of her predicament; she is not helpless but an active agent of her own life.

Additionally, Kevin's narrative demonstrates how his increased openness and adjustment to his value of not wanting *"to rely on anyone"* (Transcript 5, p. 6, 248) enables him to continue to take personal responsibility for his life.

Now I've got to do the cleaning, but if I feel I need help I can go to one of them and say can you help me with this, I can't lift the mattress up...

(Transcript 5, p. 10, 421-422)

In Kevin's narrative he acknowledges the tasks he aims to complete as he articulates what he's "got to do". That is followed by his recognition that he will "need help" at times and requires support with carrying out some of the jobs. It seems Kevin still shows a conscious choice either to seek help or not ("if I feel I need help"), which may make the behaviour of asking for help more tolerable and in line with his values of being independent. He is aware where he can seek help, and the word "can" suggests personal agency, giving him the option of taking responsibility for himself in his decision making while recognising his limitations ("I can't").

Unlike the others, Kate expresses a sense of shared responsibility in her adjustment to life after stroke, as a way to maintain her friendships.

So... like try and see my friends, I might not be able to do everything I could before erm but you know, even if it's meeting for a coffee or... we just have to change what we do together rather than not seeing them at all...

(Transcript 6, p. 13, 545–547)

In this abstract, Kate expresses that she wants to interact with her friends and makes an effort to do so. She sounds unsure of how she would do this considering her restrictions ("*I might not be able to do everything*"), and compares herself with her pre-stroke self ("*I could before*"). However, it seems Kate emphasises that "*even if*" the option now is to meet for a coffee only that would still enable her to maintain a social life. Kate suggests "*we just have to change*" which can imply it does not require as much effort to ensure the adjustment is possible for both but she also indicates that despite restrictions, she can still actively participate, "*just*" not in the same way she used to. Thus, Kate seems to display more flexible thinking about the situation by indicating possible compromises that would enable her to continue to maintain relationships. Additionally, by her use of "*we*" and "*together*", she suggests mutual work on the process of adjusting, which contrasts with her earlier narrative that expressed solitary responsibility ("*I might not be able to do everything*"). This may suggest that Kate's understanding of adjustment also extends to her friends taking an active part in it. Achieving mutual compromise is preferable to "*not seeing them at all*".

## 3.5.4 Sub-theme 3: "This Is Me Now" – Emergence of Compassionate Self

All eight participants reported changes in self-identity. Some participants presented the new self in a positive light, whereby they moved away from self-critical thinking towards a more compassionate self which enhanced their appreciation for their remaining skills and abilities. Additionally, some of the participants recognise they have a choice between battling with stroke and passively accepting it within their identity, regardless of how unwelcome stroke remains, however, that decision seems to bring a sense of emotional comfort.

Kate reflects on a turning point in the group session where she becomes resigned to the stroke and tries to accept it as a part of her new identity.

But... I think there was a session, I don't know, I am just tired of fighting, and I'm going to like not like what's happened, but accept that this is me now...

(Transcript 6, p. 3, 129–130)

Kate's narrative points to a significant session in the group programme, when she realises something is changing. It seems it may be difficult for her to acknowledge the new insight or to figure out what caused that change, as she says "*I don't know*". It appears the interview brought her back to that particular point in time as she admits to feeling exhausted by "*fighting*" in the present tense. From her narrative, there seems to be a conflict whereby she is experiencing an emotional struggle as she is "*tired*" of the battle with her disability. Nonetheless, the group seems to enable her to develop a compassionate approach to herself, whereby she seems to recognise her choice of either carrying on fighting or accepting it despite not liking it. Subsequently, she made the decision to incorporate stroke in her identity ("*this is me now*") regardless of the unwanted changes.

Similarly, Patrick referred to the process of merging stroke within his life which has been problematic for him. He tried to adjust and accept post-stroke difficulties and give up the battle of "now and before".

... yeah you coming like to eight, nine, ten sessions for me, I said I am coming to understand more about how to live with these things together with me now, that thing is not going to go away, it's going to be with me forever the more years, I try live with them or reject them or ask why so try to cope to learn to live with them, how I achieve with them this way not the way it was before. I just think it's more easier now...

(Transcript 4, p. 3, 93–97)

Patrick's narrative indicates how a significant number of sessions were needed for him to begin to learn and "understand" how to "live" with his condition. He articulates in his narrative why he was attending the group, and that his expectations were to learn to "live with these things". The description of stroke in a plural form, "things" and "them", indicates stroke may cause Patrick multiple difficulties and he seems to experience a psychological dilemma when he struggles to accept stroke in his life ("that thing"). Simultaneously, the words "together" or "with me" implies he cannot ignore it, either. Furthermore, it seems he realises stroke is a permanent experience as he says "it's going to be with me forever". Patrick seems to reflect on his need to assimilate stroke into his life and accept the post-stroke changes in saying "with me now". Based on his own understanding of integrating stroke into his life, Patrick reflects on his coping strategies: he could either "try" to combine it with his life, fight against it or challenge it. However, it seems his choice now is to try to "learn to live with them" and accept it into his life. By making this choice, Patrick mentions a sense of achievement as he compares "the way it was before", inclining him towards further acceptance of stroke but as a lifelong unwanted guest. It seems this decision might have been a positive change as he feels it is "easier now" which may suggest him managing better with his disability as he has stopped fighting it.

John on the other hand spoke about accepting his new self in a more positive light, by reflecting on the transition from his negative self towards developing a more compassionate self.

Just that little we can do means a lot. Instead of us condemning ourselves that we used to do a lot, but just that little we should appreciate ourselves for it...

(Transcript 1, p. 9, 359–360)

John starts his journey with what sounds like a new way of thinking about his disability. He seems to accentuate the significance of the *"little"* ability he has, suggesting how meaningful what he can do is. He seems to place attributing self-critical and belittling attitudes towards his post-stroke self in the past by saying *"condemning ourselves"*. It sounds as if his lack of appreciation for himself after stroke was persistent and that was his dominant behaviour for a long time as he *"used to do a lot"*. However, his new recognition and insight enables him to be grateful for what he can do and achieve despite limitations in his physical abilities, as he stresses twice (*"that little"*). Consequently, the disapproving self is then transitioned into a compassionate and self-soothing self, from where he is able to *"appreciate"* himself now. He also uses *"we"* throughout his narrative to suggest collective group conclusions and perhaps he alludes to everyone needing to be more compassionate towards themselves after suffering stroke.

### 3.5.5 Sub-theme 4: "I Can't Get Used to" - Ongoing Challenges

This sub-theme echoes the experiences of six participants reflecting on their persisting struggles. It was found that adjusting one's life post-stroke is a long process and requires one to integrate and accept ongoing hardships. The participants described their difficulty in maintaining a new way of thinking. Some of the participants continue to struggle to move on from the old self, resulting in feeling sad and they perceive the recovery process as *"hard work"* (Transcript 6, p. 5, 188). Also, losing employment as a result of stroke and becoming part of the *"benefit system"* (Transcript 8, p. 6, 256) meant ceding control and becoming reliant on others, which proved very challenging.

John reflects on the process of developing cognitive strategies, highlighting the hardship of integrating a new way of thinking:

It takes a lot before the mind can process it OK, you need to start working this way, because what the mind has known for a very long time is this particular way, so it's like you are re-training yourself, training the mind...

(Transcript 1, p. 8, 345–350)

John suggests "a lot" of effort is required to retrain the mind to think in a certain way but he also hints at some resistance to new ways of thinking. His words "you need to start" give a sense of pressure, urgency and his lack of progress. This difficulty in amending his thinking style is possibly caused by the rigid and rooted habitual thinking that he has been applying in his life for a "very long time". There is a sense of this task being very hard and challenging. For John, being able to think differently requires relearning and reprogramming himself, but also, his repetition of "the mind" is a reminder that stroke is brain damage, and that the challenges of retraining the mind in this context are massive. Using the present progressive tense indicates that for John adopting a new way of thinking is still an unfinished process or perhaps is not fully possible to integrate.

Kate on the other hand echoes most participants' persistent conflict between their old and new selves.

... I think I think cos it [recovery] is hard work, and I do get a bit down with it. I just want to get up and wear my footwear that I used to wear, go for a run like I used to be able to do...

(Transcript 6, p. 5, 187–189)

Kate seems to *"think"* about her recovery journey in the context of actual physical tasks, which indicates that a lot of commitment and diligence is involved in the process.

As a result of the hardship, Kate "get[s] a bit down", although it seems she minimises the impact it has on her wellbeing ("a bit"), which may be her way of coping with the challenge that recovery sets. Kate seems to be longing for the easiness of her past life, where she could "just" be as she wishes. She reflects on her old life, which possibly makes her new circumstances harder to adapt to and move on. There is a strong sense of loss of who she used to be and what she was "able to do", such as exercising, which perhaps also helped to manage her wellbeing in the past. However, it is more challenging now, due to her physical restrictions, resulting in difficulty to obtain relief from the "hard work".

Laura reflects on her internal struggle to resign herself to the *"benefit system"* and battles to accept it as part of her identity.

I'm not a person you know, I been working with my company since 2005, I'm not used to this benefits system, so when something doesn't go the way you think it should go, it really gets me panic and anxious but I now learn that's the system so I'm... in a different system that I'm not used to, I'm used to my wages being in my account, I'm not used to like if you didn't do this one they gonna stop your benefit and it really agitate me to think of that, they can stop this I know if I go to work I get my pay so... you just have to learn that these are the things and let go until I'm well enough to be back at work you just have to be part of the system, which I can't get used to cos the system is not me... it was I've never ever entered into a job centre before and I really find it difficult to go to those places, not that I can't fill a form but if you not tick a box or if you not do this... they can it just get me agitated and frustrated. I just want to go back to work but at the same time work is saying you have to be well enough to come back

(Transcript 8, p. 6, 255–265)

Laura opens her narrative with "I'm not a person" perhaps suggesting she's been stripped of her identity and implying a great sense of loss. She has been used to earning her own money for a long time. Thus, for Laura "the benefit system" seems to exemplify that she is no longer self-reliant and she depends on someone else now. Perhaps the novelty of the situation makes her feel out of control and when "things doesn't go the way you think" it heightens her feeling of "panic" and anxiety. Although Laura has learnt how to manage the system, she continues to perceive it as an alien idea that she is "not used to". She is used to knowing when she is going to get her wages, which suggests some independence and certainty. However, now the stroke has caused her to need to rely on an "other" system that controls her, which she cannot avoid, but gets "really agitated". When she went "to work" she ruled her life and knew when she would get the pay in her account. Laura is aware she can resolve her conflict. That is, she is hoping that when she is "well enough" she can take control and return to work. Till then, she continues to suggest that she has to learn to deal with these things and "let go". However, it seems Laura is reluctant to adjust as even now she is denying her identity as part of the "system", which is to say someone who is on benefits and this is represented by her saying "is not me". She continues to reject this by stating that she "has never entered a job centre" and finds it challenging to be there. Perhaps "to go to those places" is "difficult" as it requires Laura to accept her reliance on others and her disability. Laura explains she is perfectly capable of completing the "forms", but making trivial mistakes can have massive consequences, which makes her "frustrated".

It appears Laura feels overwhelmed with these feelings and circumstances, thus she longs to be herself again (*"I just want to go back to work"*). However, she recognises that she has to be *"well enough"* to do so, but she doesn't know if that is possible. This uncertainty perhaps leaves her feeling even more trapped in the current situation.

## **Chapter four: Discussion**

### 4.1 Introduction to the Discussion

This chapter will present the main findings from analysis of the data, which will be further discussed in the context of the research question and in relation to existing theories and literature, highlighting similarities and differences. The application to clinical practice and Counselling Psychology is then outlined. The limitations and strengths of the study are examined, making suggestions for future research followed by the post-viva reflection section.

### **4.2 Overview of the Findings**

Analysis of the data produced four master themes that reflected accounts of sharing experiences of being amongst stroke patients in an ACT group. The first master theme, "This is just so difficult", described various hesitations that participants encountered throughout the programme. This common experience at the beginning of the group reflected participants' feelings of being "scared" due to expectations they held about what might happen in the group i.e. fear of being judged or exposed. Participants expressed also feeling apprehensive about relationships with other attendees, highlighting the delicacy of the group dynamic. The duration of the session seemed also to cause dissatisfaction with the programme, with participants pointing to insufficient time as a factor in leading them to feel distressed.

The second master theme, "Means to a connection", encapsulated how participants experienced the process of relating to others in the group. One of the greatest contributing factors to a sense of unity was self-disclosure. Through the process of sharing participants felt reassured, developed trust one for another, and increased their sense of belonging to the group. However, group cohesiveness did not easily emerge and participants pointed to numerous factors that seemed to be required to increase their trust in the group, such as establishing ground rules. One of the methods contributing to tightening this bond amongst attendees was in fostering a non-judgmental approach and giving each other positive feedback, which was frequently compared to the lack of validation and support in the out-group interactions.

The following theme, "Restoring confidence and hope", explored the process of promoting self-esteem, mutual encouragement, and empowerment amongst participants. Group processes such as social comparison, learning from each other, and universality seemed to enable participants to reappraise their situation, whereby they felt motivated to engage in their recovery. Subsequently, some participants also reported increased acceptance of their post-stroke difficulties as a result of being with others in the group.

As well as the experience of being with other stroke survivors, participants reflected on therapeutic learning and further changes in the group, explored in master theme four, "Things Won't Be the Same: moving toward acceptance". Participants seemed to accept their new needs and identified ways of managing those needs through therapeutic strategies such as relaxation, thoughts balancing and adjusting their behaviour. They also reported changes in processing and accepting a level of responsibility for their recovery and became more compassionate toward themselves. However, their learning in the group also encompassed their recognition of continuing struggles which reflected the complexity of their ongoing journeys towards re-establishing their post-stroke lives.

### 4.3 Discussion of the Main Research Findings

# "How do stroke survivors experience being with other stroke survivors in group intervention?"

Throughout the group, participants reflected on group processes which influenced their experience of being with others in the programme. Specifically, two initial master

themes captured their narratives regarding the experience of being with each other in the group, which will be discussed in the following section.

The first master theme, "It's just so difficult", reflects participants' fears of engaging with the group. Their initial anxieties were driven by uncertainty as to what to expect from the group, but also not knowing how to interact with others. The process of selfdisclosure became problematic at this stage as participants did not want to be perceived as complainers and their feeling of embarrassment was fostered by their unfamiliarity with the other group members. The initial apprehensions and confusion are not unique to this population and it is a common phenomenon experienced in the group setting (Corey & Corey, 1992) and TBI group studies (Theodore, D'Antonio, Varbanova & Spielman, 2014). Yalom and Leszcz (2005) also described first meetings as a search for viable roles, carefully finding out if one will be respected or rejected. However, the stroke survivors often experienced isolation resulting from having to cope on their own and feeling shame at the loss of their capacities (Adamsen, 2002; Ashworth, Clarke, Jones, Jennings & Longworth, 2014), as well as feeling a need to match the public perception of 'normal' by which they would avoid stigma (Pearce et al., 2015). That might explain the dilemma posed by participants in this study (quiet versus engaged), suggesting that communicating personal difficulties and exposing vulnerabilities are even more challenging for this population, but it has not been highlighted in previous stroke-related studies.

Additionally, anxiety in the initial stage can be provoked by other factors such as learning more about stroke in the group, as expressed by participants in this study. Although learning from others is a well-known factor contributing to positive outcomes and satisfaction in group settings (e.g. Adamsen, 2002; Spragg & Cahill, 2014; Corey et al., 1992), the information-gathering about stroke in this study was linked with profound fear at the beginning of the programme and this is a unique finding. Crowe et al. (2016)

identified fear of further stroke as one of the themes in his qualitative study, where participants associated stroke with death, resulting in rising awareness of mortality in its aftermath. Hence, feeling afraid in the face of new information may explain the current attendees' initial hesitation in participating. This further indicates how experience of stroke is traumatising and may increase resistance to the therapy.

The difficulties in the group were also concerned with maintaining the group relationship. Participants' stories indicated the fragility of group unity, expressed in temporary episodes of disharmony amongst the group members. Some of the reasons for distancing amongst attendees were associated with lack of equal access to sharing experiences in the group or feeling "excluded" from the group. A sense of togetherness and respect have been shown to be paramount for group members and it is often compared to the therapeutic relationship (Hogg & Tindale, 2003; Yalom et al., 2005). This suggests that for stroke survivors in the current study, members having the same status throughout the group was paramount to maintaining a sense of belonging.

On the other hand, conflicts are unavoidable in social interactions, and therefore it is not surprising that some of the participants reflected on it in their narratives. Tensions in the group could be fostered by pre-group experiences, then enacted in the group (Aviram & Rosenfeld, 2002). Schmalish and colleagues (2010) indicated that past experiences such as feeling unheard, rejected (as reported in the current study and the stroke literature), or other interpersonal problems may be reciprocated in the group, leading to hurt feelings resulting in a negative impact on the quality of the relationship. Interestingly, some participants recognised the need for mutual empathy and receptiveness to individual differences as a necessary ingredient for group bonds to grow. This is in line with studies with ABI population groups (Couchman, McMahon, Kelly & Ponsford, 2014; Pearce et al., 2015) that reported collective understanding and empathy as influential on cohesion in the group and facilitating learning and sharing.

The final negative experience of the group related to the length of the programme. Participants indicated a wish for extended numbers of sessions. Attendees expressed feeling disappointed and even angry as a result of termination of the groups. These experiences are in line with other group literature that highlights frequent difficulty in ending the group (e.g. Yalom et al., 2005), it was also expressed by participants attending other ACT groups (e.g. Fogelkvist, Parling, Kiellin & Gustafsson, 2016; Ossman, Wilson, Storaasli & McNaill, 2006) and stroke population (Beesley, White, Alston, Sweetapple & Pollack, 2011). The latter suggested participants' need for more time in the group to make changes and improve coping skills; plus, extending the number of sessions has been recommended by Aboulafia-Brakha, et al. (2013) in CBT study for TBI population. However, unlike findings from previous research, in the current study, some of attendees associated the ending of the sessions with a threat of returning to loneliness, resulting in an emotional reaction at the end of the group. Stroke seems to be a catalyst for a sense of isolation, hence stroke survivors often perceive discharge from services not as a sign of progress but as discontinuing of help (Crowe et al., 2015). On the other hand, some participants put off the termination by planning further gatherings with group members after the programme ended. This can be understood as a form of safety behaviour that enables participants to manage termination-related anxiety (Corey et al., 1992) or pursuit of ongoing emotional development as reported by participants in this study.

The master theme two, "Means to a connection", embraced the notion of developing member-to-member bonds, resulting in cohesion. One of the underlying processes that enabled the closeness to emerge was by sharing and listening to discussion in the group. Some participants in the current study suggested that the initial communication triggered a sense of unity, which has not been mentioned in previous stroke group studies. It seems that the informative content of self-disclosure may play a significant role in the emergence of closeness. According to Cooper et al. (2013), even early communication, as long as it is accepted by others in the group, can be perceived as meaningful and provoke participation and further solidarity. Additionally, other research has indicated that stroke survivors often report a lack of relevant information about their illness and express a need for further guidance (Pearce et al., 2015). Furthermore, lack of familiarity with brain injury is also linked with withdrawal from various social domains (Couchman et al., 2014). Therefore, the finding in the current study further amplifies that sharing experiences of stroke is an important factor in group intervention and one that increases awareness about illness, a recognition of shared experience that helps to normalise post-stroke struggles and foster group bonds. These findings are also in line with studies of cancer patients, where participants through sharing relevant information found common ground that promoted bonding (Sekse et al., 2013).

Additionally, participants in the current study emphasised the connection to the group members as being an ongoing process that required time and needed to be facilitated by group rules. That is, most of the participants approached group relationships with caution and took time to overcome initial doubts. For some of the attendees, discussing confidentiality was necessary to begin to develop trust, and they engaged only when unconditional regard was displayed by everyone in the group. Norms and agreements about confidentiality may affect the development of cohesion. The group 'contract' sets the foundation for safety in the group and enhances the emergence of trust (Schmalish et al., 2010). However, the need to be accepted by *all* group members in the current study might point to increased sensitivity of negative judgements outside the group in this population, which impact on their self-esteem and leave them more cautious of social interactions (Couchman et al., 2014). Hence, as mentioned previously, previous negative experiences prior to the programme may have been replayed in the group;

therefore participants in the current study required more time and more reassurance to develop closeness than has been indicated in previous stroke-group research.

The connection to the group was also expressed in terms of connection to the group environment. Although most of the literature refers to cohesion as a member–member relationship, according Yalom's description of cohesiveness (1995), it can be also expressed through a sense of comfort and familiarity in the group as reflected in the current study. In line with the literature, a feeling of unity can still be experienced by all participants, but the intensity and format can differ and depend on interpersonal factors (Corey et al., 1992). For example, as opposed to the above, some participants spoke of closeness in the context of friendship, indicating very close bonds. The current study, in conjunction with previous qualitative research on group experience that referred to cohesion as a sense of community (Sekse et al., 2013), mutual support (Legg, Stott, Sellars & Ellis, 2007), or being part of the same experience (Mathias, Parry-Jones & Huws, 2014), suggests a multidimensional meaning that participants ascribe to their relationships and highlights the importance of subjectivity despite collective identity in the group settings.

Another factor enhancing the bond amongst participants was the process of comparing their experiences within the group to the outgroup interactions. In the current study, participants spoke of the great pain of being dismissed, disbelieved, and pushed to the side by family and friends. Thus, finding validation and acceptance in the group was a crucial experience that enabled them to connect further, strengthen their bonds and trust other attendees sharing similar difficulties. These findings echoed other stroke-related quantitative and qualitative studies (i.e. Legg et al., 2007) which also emphasised how a lack of understanding of one's experience contributes to mental health problems, resulting in social disconnect (Salter, Hellings, Foley & Teasell, 2008). For example, Mathias et al. (2015), in their pain ACT group study, reported participants' pain

symptoms were frequently dismissed by family and friends. In the current study, participants expressed how misjudgements or being blamed stopped them from sharing with others, increasing their emotional and physical isolation. This is in line with stroke literature indicating the undermining impact of negative judgements from others on an individual's view of themselves (Horne, Lincoln, Preston & Logan, 2014). Thus, comparing relationships with others in their everyday lives with supportive group members seemed to increase a sense of collective identity, and therefore challenged their feelings of isolation and validated their emotions. This echoes previous findings. According to both Yalom (1995) and the ACT principles (Hayes & Strohals, 2004), the "consensual validation", or warmth and compassion, are important aspects in increasing confidence and self-efficacy, which, in turn, is a crucial element of the process of recovery (Pearce et al., 2015).

Overall, different factors and processes were reflected on by participants in this study, indicating numerous challenges in the group. Experiences outside the group seemed to influence their willingness to share and build closeness with others. The group bond seemed to depend on agreeing the group rules and allowing a long time to build trust and feel accepted by each other.

Furthermore, although the informative content of the mutual disclosures normalised their difficulties and fostered their sense of togetherness, participants also felt fearful of learning new information about stroke, which is a novel finding in stroke group studies. The commonly expressed need for longer support programmes was enhanced by their reported fear of becoming lonely again. However, group therapy can have a positive impact on wellbeing and influence the process of adjustment (Haslam et al., 2008), which is further outlined in the following section.

"How do stroke survivors experience change when with others in an ACT group intervention?"

Participants in the current study reflected on changes in their levels of confidence, elevated hope and motivation that was facilitated by being in the group. Post-strokerelated psychological stress is often associated with reduced confidence resulting from loss of abilities, social roles and disability; therefore tackling this is an important part of the recovery process (Horne et al., 2014). All eight participants reported having revised their views of their circumstances through the process of social comparison. Seeing others in worse situations seemed to trigger reflection and emotional growth; their daily "struggles" became "moans" and they often felt relieved and "lucky". Similar reports were found in Beesley et al. (2011), where stroke survivors felt more appreciation for their progress and gained new perspectives on life. These elevated confidence levels impacted on their willingness to engage actively in the process of rehabilitation, as shown in this study. The literature emphasised confidence and self-efficacy as important factors in self-management after chronic illness and decreasing the burden of illness (Pearce et al., 2015). The existing literature, however, is divided about whether downward comparison is helpful or not as indicated in Morris and Morris's 2012 study in stroke population. However, the current study suggests that downward comparison is beneficial and appears to serve a role of interpersonal feedback, which, facilitated by learning to put themselves in others' shoes, enabled some of them to regain a sense of agency and measure their progress. The self-management studies frequently stress the impact of group interaction on self-efficacy as an instigator of mental strength and on developing adaptive coping strategies that could improve quality of life outside the group (Adamsen, 2002; Perace et al, 2015; Grace, Kinsella, Muldoon & Fortune, 2015). The notion of universality was mentioned earlier as a factor contributing to cohesion. However, confidence and self-belief was also increased through recognition of common ground and shared experiences amongst participants. This process validated the experience of stroke itself, which can feel so isolating to many stroke patients

(Matsuzaki et al., 2015) and is often expressed in participants' narratives: "I'm not the only one". Meeting other stroke survivors appears to have a profound impact on resolving internal emotional conflicts, enabling some participants to recognise their feelings as acceptable but also bringing the reassurance of reducing the feeling of being alone with their predicaments. This is in line with group literature, where according to Yalom (1995), the shift from suffering in isolation triggers relief, and it is one of the steps that group members take towards therapeutic change. Other studies, such as Adamsen's (2002), also indicate the common experience as a vehicle that alleviates social isolation and restores a sense of normality. Canicci (2013) suggests that awareness of others facing similar difficulties can increase an individual's willingness to make space for unpleasant internal sensations and thus fostering acceptance, which alludes to the mutual function of both group process and ACT principles in the current findings, which has not been always suggested in previous research (e.g. Majimdar & Morris, 2018; Onsworth et al., 2000; Visser, Heijenbrok-Kal, Spijker, Ribbers & Busschbach, 2013).

Furthermore, the current studies revealed that this affinity was related to the importance of first-hand experience, in line with other reports where the group members felt better understood by other members and received more meaningful support amongst participants as opposed to family and friends (Couchman et al., 2013; Newton, Larkin, Melhuish & Wykes, 2007; Mathias et al., 2014). Thus, one can conclude that the process of increasing self-belief in groups of stroke survivors depends partly on homogeneity among participants, as it is the common ground that enables them to revise a previously experienced sense of inadequacy. However, the findings from the current study are in conflict with Brassington and colleagues' 2016 study suggesting that transdiagnostic applicability of the ACT model allows using this framework in a range rather than in a disorder-specific group setting. The result from their quantitative study indicated transdiagnostic groups to be effective in supporting people living with longterm health conditions; however, they were harder to maintain.

In current study, mutual group support also accelerated the "reality check" that appears to serve as a mediator of hope and improved confidence in the process of "moving on", which was not mentioned in the previous stroke group studies. This is in line with Pearce and colleagues' (2015) suggestion that improving self-management and recovery can be enhanced through coming to consensus about realistic individual targets.

Finally, "restoring confidence" is facilitated by the process of learning from others. Participants commented on the value of sharing their knowledge and comparing it with others' perspectives. Expanding awareness of stroke-specific symptoms is particularly important in developing prevention plans in case of future medical emergency. On the other hand, learning from facilitators appears to help to better manage some strokerelated symptoms such as pain, as indicated by some of the participants. The learning from others was expressed again as a collective process experienced by the group and created an increased sense of control over the emotional and physical manifestations of stroke. Previous studies have often focused on testing the efficacy of particular psychological interventions and attributed changes in e.g. depression or anxiety to specific factors such as cognitive diffusion (Mathias et al., 2015), problem-solving (Visser et al., 2013), or social skills training (Onsworth et al., 2000). However, the current study and other stroke literature also credits this mutual aid process with a source of valuable help for others (Legg et al., 2007; Morris et al., 2012). This is manifested by members engaging in giving advice, sharing experiences and tools in relation to problems (Schmalish et al., 2010). The collective support and learning in the group often benefit members in that they experience positive emotions such as confidence, as in the current report. Increased hope was also reported by Majumdar and Morris's 2018 study on ACT groups for stroke survivors. However, the result was not

sustained after 2 months. The interviews in the current study were conducted between 2–6 months after the end of the group and it appears participants reflected on their changing levels of hope within that time, suggesting the ACT group intervention can bring longer benefits to stroke survivors. The difference in the structure of the groups (interactive vs didactic) and the length of the programme (8 vs 4 sessions) might contribute to the difference in these reports. Participants in the current study clearly indicated that active participation was fundamental for their experience and therapeutic change, emphasising the need for even longer group sessions. Emotional disclosure and sharing in the group setting is believed to be very important for individuals and it is associated with greater therapeutic outcomes (Rennung & Gortiz, 2015).

Further changes were discussed in the final theme: "Things Won't Be the Same: Moving towards acceptance". Some participants through identifying their needs were able to find therapeutic tools, allowing them to better manage their predicaments. Mindfulness is one of the main concepts of the ACT model and aims to offer an alternative way of relating to personal experiences (Bedard et al., 2003) that enables one to accept one's current struggles and create a space for thoughts and feelings (Merriman, Walker-Bircham, Easton & Maddicks, 2015). In this study, some participants reflected on the usefulness of mindfulness but described it as relaxation. Kate in particular stressed how relaxation enabled her to "get a break", indicating that she preferred distraction or experiential avoidance to openness to difficult experiences and the non-judgemental approach to self and context that is expected by ACT. Similarly, cognitive diffusion aims to reduce focus on the content of one's thoughts and enables one to perceive them just as the thought (Hayes, 2004). Still, in this study, participants referred to reduction of negative thoughts, which is more in line with CBT cognitive restructuring technique, albeit it was linked to increased acceptance of stroke. The use of mindfulness and diffusion in this manner has been found also in other studies that explore individual experiences of ACT groups (Bacon, Farhall & Fossey, 2014; Bloy, 2013). One possible explanation is that the therapist failed to introduce the above concepts (although it is unlikely as the therapist had relevant experience) or had insufficient time to practise them in sessions. Alternatively, construing mindfulness as relaxation may be the easiest way to understand the complex construction of the concept. Having said that, through different methods (e.g. breathing exercises), mindfulness improves emotional wellbeing and decreases stress (Smith, 2017), hence it might have been experienced as reduction in anxiety. This, however, goes against ACT principles that aim to accept rather than reduce the distressing symptoms (Hayes, 2004). Additionally, as some of the participants had used the CBT method prior to the ACT group, perhaps they were more familiar with CBT concepts. Introducing cognitive diffusion might then have been contradictory and confusing as it requires individuals to tolerate distressing thoughts rather than act on them (Kangas & McDonald, 2011).

In the current study, some participants also reflected on behavioural techniques such as chunking and pacing through which they were able to resolve conflict between their own values (being independent) and the limitations imposed upon them by stroke. By considering behavioural adjustments they were able to improve their quality of life and re-engage in their preferred activities. According to ACT principles, psychological flexibility enables participants to pursue meaningful life despite their limitations and serves as a mediator in their continued journey to recovery (Majumdar et al., 2018).

The changes in acceptance and adjustment were also expressed in the context of responsibility and control over their lives. The reference to responsibility was expressed by participants becoming active agents and increasing awareness of the extent of their own capability to act upon life challenges. The group intervention appears also to help participants to restore their sense of choice as to how they want to conduct their lives despite their limitations. For example, Kevin emphasised it in his narrative by pointing

out that he only asks for help when he feels help is needed now. Therefore, the data indicates that the ACT intervention might have stimulated change in participants' relationships with stroke, whereby they acknowledge the restrictions but are able to live with them collaboratively. This finding is also in line with Majumdar et al. (2018) where the outcomes were reporting acceptance of what cannot be changed and focusing on achievable and meaningful goals. Still, the reported changes in the current study could be triggered by or in conjunction with group processes that increased participants' confidence and self-agency. Jones's 2010 study with stroke survivors indicated an association between self-efficacy and taking an active part in self-management, and group work was reported to be a vehicle for the shift from victim to agent for chronic illness sufferers (Adamsen, 2002).

However, unlike other studies, in the current research the sense of responsibility in making amendments was also extended to significant others. Participants indicated that maintaining meaningful relationships was a motivator for behavioural change but it had to be reciprocated by significant others. That change in perception perhaps might be driven by the need to manage isolation; alternatively it indicates a shift from self-blame and emotional withdrawal towards openness and a mutual process of adjustment, which in ACT terms might be understood as the change from experiential avoidance towards therapeutic exposure and becoming engaged (Ossmann et al., 2006; Bacon et al., 2013). The notion of moving away from critical, inadequate self was reflected further by participants in this study. After suffering stroke, attendees often referred to themselves as skill-less, with no valuable roles to play in their lives. Dilemmas as such as this are broadly noted in stroke-related literature (Kangas et al., 2011; Soo, Tate & Lane-Brown, 2011) and indicate rejection for the post-stroke self and lack of compassion (Crowe et al., 2015). However, after attending the group sessions, participants began to rethink their ideas of themselves and presented themselves in a kinder manner. The change in

compassion seemed to arise from the resolution of their internal dilemmas of fighting against disabilities by trying to live with them, underlined by realisation that stroke is "forever". Consequently, this gave them a sense of choice whereby they were trying more willingly and compassionately to accept and live with the challenges. For example, John indicated that previously his damning self-perception prevented him from appreciating his remaining abilities, no matter how small they might be. According to the literature, compassion activates our affiliative/soothing system, which aids in balancing our emotional regulatory systems, particularly in response to threat, such as illness. A growing body of research indicates that compassion is crucial for mental wellbeing in ABI survivors (Ashworth et al., 2014) and self-compassion has been found to be fundamental in accepting the changes caused by stroke (Crowe et al., 2015; Smith, 2017), however, it was not previously indicated in identified stroke-group studies. It is also facilitated by a common sense of humanity and connectedness (Smith, 2017), which might explain why it was experienced in a group setting such as this one.

Still, the process of developing acceptance in the current study is expressed as a struggle where attendees did not simply integrate stroke into their lives or identity but decided to live alongside their health predicaments, indicating that acceptance is a necessity. This phenomenon is congruent with other study, where severely disabled stroke survivors felt that they had no choice but to use a wheelchair (Barker, Reid & Cott, 2004) but saw this as unwanted dependency. That might be further explained by the results of Merriman et al.'s 2015 study, in which participants were also resistant to acceptance as they found this concept contradictory to the frequently promoted rehabilitation services message of striving to improve and not accepting their current situation.

The difficulty in acceptance and adjustment were also reflected in commenting on ongoing challenges. Those included difficulties in recovery, getting used to new behaviours, relearning cognitive strategies or rejecting their sudden dependence on the benefit system. The previous stroke research focuses mainly on positive changes from groups, yet the findings from this study seemed to complement previous findings by acknowledging their ongoing struggles. A possible explanation of these results may lie in the time needed to achieve cognitive changes. Long-held values, beliefs and traumadriven changes require not only a longer period of time to adjust but ongoing positive feedback from others (Wong, Ip & Lee, 2016). Additionally, previously mentioned difficulties in acceptance might be reflected in their continuing struggles between reconciling their desire to remove the health problems as fast as possible and considering them as long-term processes (Hertenstain et al., 2012). This is perhaps why stroke participants in Majumdar et al.'s 2018 ACT group study did not report any changes to quality of life and their anxiety remained unchanged. Being mindful of barriers to fully adjusting can be frustrating and impact on one's motivation (Pearce et al., 2015), resulting in fear, which was also reported as one of the obstacles to reengaging in an activity of their choice (Horne et al., 2014). Still, ACT, in its principles, encourages the recognition of how painful and threatening change can be, without the need to fight against it (Hayes, 2004). This possibility is reflected in participants' new awareness of remaining challenges alongside their re-appraised perspectives.

## 4.4 Implication for Clinical Practice and Counselling Psychology 4.4.1 Implication for an ACT Group

The literature review indicates that group work as a therapeutic intervention in its own right, along with ACT theoretical background, is suitable for addressing multiple difficulties including health-related problems such as diabetes (Gregg et al., 2007), chronic pain (Mathias et al., 2012), epilepsy (Lundgren, Dahl, Melin & Kies, 2006), or cancer (Rost, Wilson, Buchanan, Hildebrandt & Mutch, 2012). The conclusion from the current study and other qualitative stroke-related investigations (e.g. Legg et al.,

2007) suggests that the condition-specific tailored group seemed to play an important part in the experience of commonality, resulting in normalising the otherwise isolating experience of stroke, and restoring confidence in oneself. Being with others who face the same tensions, as participant Laura shared, enables one to 'go in depth' and provides group members with useful information. As suggested in the current findings, it is in comparing oneself to others with the same problem that enables participants to measure their progress.

Perceived uniqueness in the context of illness causes one to increase social isolation in everyday life, and decreases the opportunity for one's experience to be validated and accepted by others (Yalom, 1995). This, in turn, can have an integral consequence on one's mental health and impact on one's quality of life. Hence, with respect to the results reported by Brassington (2016) on heterogonous ACT group design, whose study was based on responses to questionnaires, where subjective experiences and depth of underlying factors could not be explored; the report from the current study would still suggest the applicability of homogenous groups in clinical practice to be of great benefit to the members. This suggestion is also in line with Counselling Psychology principles that advocate for creating a therapeutic space, where clients' ways of coping or not coping, losses and undesirable changes can be shared in the environment without fear of judgement (Douglas, Woolfe, Strawbridge, Kasket & Galbraith, 2016).

Furthermore, the findings from the current study also indicate discrepancies in comprehending ACT-specific tools such as cognitive diffusion or mindfulness concepts. This suggests that stroke survivors did not understand the philosophy very well, and therefore may not be getting the full benefit of the ACT. Therefore, clinicians utilising the ACT model, not only counselling psychologists but also clinical psychologists working with this population, might need to be aware of the reported challenges.

Subsequently, tailoring clinical practice might involve careful explanation and checking understanding of the concepts more frequently with this group of clients.

A further recommendation is based on enabling change in how patients think about themselves. In the current study, participants reported a decrease in self-criticism, and self-compassion was, therefore, found to increase. In accordance with other studies, self-compassion is associated with acceptance of stroke and improves coping with the aftermath (Crowe et al., 2015), therefore it might need to be considered as a significant tool in an ACT intervention when developing a new relationship with the post-stroke self.

The condemning and self-critical views reported by participants in this study and previous literature (Ashworth et al., 2014) affects self-esteem and mood, resulting in poorer engagement with the rehabilitation process (Pearce et al., 2014). Thus, providing relevant consultation or training to other medical professionals, such as nursing teams and health assistants or physiotherapists, could provide them with relevant skills to recognise these difficulties and implement this knowledge in supporting this population. A sample consultation session is presented in Appendix N. In recent years, counselling psychologists have embraced more consultative responsibilities in their remit (Murphy, Osborne & Smith, 2013) that have now become part of their curriculum. Consultation is often used to facilitate or enrich the work of other professionals. For example, a number of studies have suggested that providing psychological consultations to front-line healthcare workers can improve the quality of the care they provide to patients (Farrand & Woodford, 2015).

### 4.4.2 Factors Affecting Groups

One of the findings suggests that stroke survivors in the group setting found it difficult to open up, and attendees in the current study required reassurance from *all* participants in order to develop trust and courage to participate. Initial anxiety about learning more about stroke limitations was also voiced and complemented existing group literature. Hence, clinicians working with this population in group and individual settings might be more conscious of these factors. Perhaps focusing on building a good working relationship in individual therapy or focusing on fostering the group bond needs to be considered as the primary therapeutic goal when working with stroke clients. Developing a safe environment would thus provide a basis for addressing stroke-related anxieties. Forming a working relationship in the therapeutic setting is embedded in the work and philosophy of Counselling Psychology, where clinicians engage with all aspects of clients' presentation (Douglas et al., 2016). Therefore, recognising clients' needs to optimise this relationship in order to encourage participation and facilitate change lies comfortably within Counselling Psychologists' skills.

A sense of loneliness outside the group in contrast with the group bond reported in the current study facilitates a sense of belonging, but also seems to increase apprehension about ending the group for fear of becoming lonely again.

Hence, the question remains as to how the process of developing a sense of belonging to support the course of recovery can be transferable beyond the scope of the group. How can the newly gained confidence, and potential for further adjustment, be integrated in everyday life once the group ends? As social isolation and social support plays such a significant role in rehabilitation and restoring quality of life, it would be advisable for the group intervention to be inclusive of the above dilemmas to build resilience. For example, preparing participants for transition could be considered an integral part of the group intervention by expanding the group space to discuss anxiety related to discharge; allowing implementation of problem-solving strategies whilst in the group; expanding the group session by including carers/significant others; and holding client-reflective sessions, allowing the issues to be explicitly voiced. Multi-family therapy for the ABI population suggests greater appreciation and awareness in both carers and individuals with ABI has led to rebuilding close relationships (Couchamn et al., 2014).

The large body of research on peer support groups in cancer and HIV (Adamsen, 2002) and stroke self-management groups (Morris et al., 2012; Pearce et al., 2015) indicates that peer support groups are as meaningful and empowering as more formal therapeutic settings. Therefore, research would suggest encouraging departing attendees to set up their own support groups, which would serve as provision for a support network and enable them to take charge of their process of recovery.

Counselling Psychology in its core emphasises building individuals' strength and promotes empowerment, but also takes into account the influence of contextual factors such as family, friends and social support (Karademas, 2009). Thus, a holistic approach within Counselling Psychology could consider supporting stroke survivors in a recovery process that involves one's development of independence but also includes intervention focusing on social inclusion. The loss of integration between an individual and their environment can be addressed not only in an group setting, but can be transferable to individual therapy where the process of discharge and rebuilding connections with others needs to be addressed.

### 4.4.3 Time factor

Notions of time appear to be important for participants in this study. Right from the beginning attendees indicated a need for significant time to build bonds or to develop trust in the group, most likely due to shame and loss in confidence after stroke. They often referred to a moment in the group in reference to a point in time when they felt able to establish their identity in the group and start enjoying the group benefits. Moreover, when participants expressed a desire for longer therapy, this could result from complex needs, underlying anxieties and lack of trust, all enacted in the group.

Hence, it plausible to suggest that participants' dissatisfaction with the length of the group was related to insufficient time for them to process the change and build more confidence in functioning autonomously. Furthermore, previous research into group interventions varied in length and did not provide consistent results in the outcomes; for example, Maumdruj and Morris's 2018 study tested the efficacy of 4-week groups, showing medium results on depression and none for anxiety or quality of life; Merriman et al.'s short interventions (2015) indicated a need for change in pace of intervention in stroke population; whereas Couchaman et al. (2014) reported on a 12-week programme which indicated significant changes for both carers and ABI population but some of the attendees still requested that the group be even longer.

The current economic atmosphere in the NHS makes it challenging to provide ongoing support, whereby the restrictions put upon counselling psychologists may provoke ethical dilemmas when clients' diverse needs are compromised due to limitations in the system. However, in order to maintain the commitment to a client-centred ethos of Counselling Psychology (Douglas et al., 2016), instead of focusing on modality, the emphasis should be more on exploring group processes such as sharing experiences or discussing solutions to common issues as they seem to foster change in the most challenging areas expressed by stroke survivors in this study. For example, the process of sharing experience in the current study normalised symptoms, increased confidence and led to a restored sense of choice. Hence, it is perhaps counselling psychologists' skills in navigating change through the group process that might enable us to align our limited resources with clients' complex needs. Additionally, as discussed in Chapter One, the changes to NICE guidelines addressing stroke populations' specific needs could be considered in order to improve quality of care in response to stroke survivors' dissatisfaction with available support services (Low et al., 2003).

### 4.5 Critical Overview of the Study

### 4.5.1 Strengths

This study had several strengths and limitations. Its strengths included the use of qualitative analysis which allowed for in-depth exploration and insight into participants' experiences of an ACT group for stroke population. It was a primary study that explored stroke participants' experiences of being with other stroke survivors in the ACT programme. Another strength lay in the timing of the interviews after attending the group. Although some of the participants attended the interview shortly after completing the group, the majority completed the therapy approximately 6 months prior to interview. The collected data was rich and provided an opportunity to see the degree to which participants maintained the gains they made during the group therapy, as opposed to other studies that lacked support for changes in the follow-up measures (e.g. Majumdar et al., 2018).

### 4.5.2 Limitations

One of the principles of IPA is the ability to "bracket off" the researcher's own knowledge and experiences in order to increase idiographic understanding of phenomena (Smith et al., 2012). Although I reflected on my relevant experience and made it explicit, it was challenging at times to remain neutral during analysis or during the interviews. Thus, it is possible that some of the interview questions were influenced by my own expectations, such as looking out for group factors, and I may have led participants during the interview. I have tried to minimise influencing the interview by playing them back and reflecting on the process. It is also possible that the analysis itself might have been "polluted" by assumptions gained through the experience of delivering group interventions. Saying that, the IPA literature acknowledges the process of co-constructing meaning, and highlights the importance of awareness of researcher's bias as a way of minimising our personal and professional impact on the data. Still, it is likely that other researchers without similar experiences might have elicited different themes and focused on different aspects of the data.

In an effort to promote my neutrality as a researcher, with a view to encouraging participants' openness and honesty in their feedback, I highlighted my independent stance prior to the meetings. However, as the interviews took place on NHS premises and I was still part of the same service, I believe this setting and actions might have silenced some of the experiences and prevented participants from fully trusting me; therefore, they possibly produced favourable and less critical accounts. In order to facilitate a good honest alliance and increase the trust, it would be preferable to carry out the interviews in a more neutral setting, and with a researcher who is not connected to the NHS service delivering the intervention (Cooper, 2008).

IPA researchers use language as a tool to access an individual's world and reality, and it is a vehicle by which participants make sense of their experiences (Willig, 2008). Four of eight participants were foreign-born, which sometimes impacted on my understanding of their message, and I was unable to comprehend all the words. Although I made every effort to capture the essence of the details and the overall accounts, it is possible that my understanding was skewed and may not have always reflected their full meaning and experience. When this happened, I would ask participants additional questions to facilitate exploring the same narrative from a different angle, by which clarity and understanding of context would be increased.

### 4.6 Conclusions and Recommendation for Future Research

Department of Health and NICE guidelines advocate service user perspectives and experiences as a valid and essential part of the evaluation of services, including mental health services (NICE, 2013); thus, implementing a therapeutic framework driven only by quantitative data would not address the above requirement. Hence, qualitative paradigms are needed to gain insight into a client's psyche and lived experience in order to tailor existing therapeutic models to service users' needs. It is within the remit and principle of counselling psychology to celebrate individuality in working with a client, thus understanding gained from interviews such as this study could broaden understanding of problems presenting in either an individual or group setting.

The main aim of the research question was to explore the experiences of stroke patients interacting with others in an ACT group. A further focus was to explore stroke participants' experience of change and their understanding of that. Analysis of the data enabled insight into the personal views of service users concerning the group dynamic, and enabled further insight about the importance of group process per se that contributed to positive changes in the journey to rehabilitation. Sharing in the group and having first-hand experiences indicated a need for group homogeneity to be considered in group structure and to be applied in clinical practice. However, further quantitative research could expand on the possible factors that contribute to homogeneity, such as age or gender. This approach would enable clients to gain relevant learning from and connections with other members who shared similar problems. Unlike other studies (e.g. Morris et al., 2015), participants benefited from both upward and downward comparison, showing that this process is not linear. Thus, it would be interesting to explore this aspect further in order to gain more understanding of what might contribute to such differences by conducting further qualitative research in stroke population and exploring their experience of social comparison. The results of such study would perhaps indicate benefits of social comparison as yet another therapeutic tool useful for this population. Group cohesion in the current study was based on the process of building trust and was described by some of the participants in terms of friendships.

This reveals how a group relationship can be multi-layered, and its meaning depend on individual experiences encountered in the group, often also compared with day-to-day context.

Difficulty in adjusting to dissolving the group is commonly experienced and also discussed by Yalom (1995). Nevertheless, more attention is perhaps needed in a clinical setting to address that fear in group situations, specifically in a health-related context, by attending to the termination-related anxiety and exploring possible avenues to manage it. Social isolation, and being misunderstood and judged, was expressed in this study and also captured in stroke-related literature (Matsuzaki et al., 2015). Recognising that the right social support network is one of the main keys to a successful outcome in the process of recovery suggests that clinical interventions should be tailored to this particular need.

Gaining acceptance and adjusting to life difficulties is one of the main aims of ACT and a major process in living with chronic illness (Barker et al., 2015; Livenh & Antonak, 2005). Participants in this study expressed significant intra- and interpersonal changes, such as acceptance of post-stroke self or re-engagement in social activities gained through the group process but also through some of the ACT tools. They also indicated changes in self-efficacycy, recognised as an important factor in recovery. A specific technique such as relaxation and cognitive diffusion was commonly pointed to as a beneficial strategy implemented in the group. Albeit helpful in managing anxiety and distressing thoughts, the understanding of these concepts was not in line with ACT proponents. Thus, future research could explore the experience of being taught such tools with a view to clarifying the reported discrepancies by utilising the qualitative, questioning experience of an ACT model for the needs of this population. Although participants made the choice to assimilate stroke with their lives, the concept of acceptance was described as a personal struggle and presented as a battlefield and reflected in continuing difficulties. According to the literature, experiences of acceptance can vary from 'grateful acceptance', 'internal acceptance' or 'acceptance as necessity' (Barker et al., 2015). The ACT understanding of acceptance promotes psychological flexibility and willingness to experience internal struggles (Hayes, 2004). It seems that due to the varied comprehension of that concept and the experience of it voiced in the current study, there is a need to explore individual experiences of acceptance in stroke population. Findings from such a study would strengthen clinical practice not just in mental health settings but in physical rehabilitation services. Furthermore, a mixed-method design would enable the provision of a more comprehensive answer to the mechanism of change by looking at the process and possible correlation of ACT tools and outcomes simultaneously in stroke.

Although the current study did not aim to explore the efficacy of the ACT-based group interventions, unlike the results from Majumdar and Morris's quantitative study (2018), the current findings indicated changes were sustained for longer than two months. Due to discrepancies in the reported findings, further mixed-method research might provide further insight into beneficial aspects of the group intervention based on ACT principles. If so, such results would strengthen the applicability of both group factors *per se* and the ACT model as suitable for stroke population.

Despite NHS economic restrictions, as a counselling psychologist part of our repertoire is to keep drawing a map that service users can rely on in their individual journeys towards improving the quality of their lives. Thus, taking into consideration suggestions derived from this study, one would hope to not only further understanding of the group process as a significant mechanism fostering the change in stroke population, but to tighten the identified gap in the literature on an ACT group designed for stroke survivors, and to provide insight into concepts like acceptance and time as important factors in supporting stroke survivors in the journey to recovery.

## 4.7 Post-viva Reflexivity

In line with a request made by the examiners, the following section encompasses reflections on some of the changes made to this research project. Due to the large number of amendments made to the thesis, a brief explanation of the ethics, analysis and literature review is presented below.

## **4.7.1 Ethical Considerations**

One of the research principles outlined by BPS refers to respect for autonomy (BPS, 2014). As a psychologist, it is essential to respect the right to choose to participate in research activities. That is, psychologists must accept that individuals may freely choose to withdraw from research and request that their data be destroyed at any time. I kept this responsibility in mind as a trainee counselling psychologist when approaching participants, explaining and conducting interviews with those who agreed to take part in this study. Still, at the same time, the code of Human Research Ethics allows time limits on data withdrawal: "Where there are necessary time limits on data withdrawal, for example up to a point at which data are aggregated, these limits should always be made clear to participants" (BPS, 2014 p.9).

After discussion in the exam, I revisited the BPS website to ensure my action as a researcher was in line with the BPS and counselling psychologist ethos, as it has been paramount to me to convey my respect for individuals during the research process. As indicated above, I had made explicit their right to withdraw but simultaneously it seems that I restricted that right by indicating I could still use their data despite their withdrawal without further clarification being made in the existing ethics document. Further learning from the examination process and rereading the BPS research code of

conduct highlighted for me the need to be very transparent about the data-gathering and the importance of clarification of the limits on data withdrawal (if such limit is applicable and grounded in rationale for the study). Despite my professional and personal preference to comply with any request for withdrawal, my plans for the gathered data sounded ambiguous in the written terms and conditions. Furthermore, the current version might have indicated an unequal power dynamic, with participants' autonomy and rights being reduced, which contradicted my aim as a researcher. This process brought further to the fore the value of the scientist/practitioner advocated by Counselling Psychology and the need for professional integrity in every detail of our work. It is important to highlight that adherence to concepts defining the highest standards of work of the counselling psychologist, either in clinical work or in the research field has had always been of great value to me as a professional and I do not take the above learning lightly.

## 4.7.2 Analysis

The process of analysis is the core of IPA study and requires analytical and reflective skills (Smith et al., 2012). I found the methodology challenging, though the fact that it has often been reported as perplexing for novice IPA researchers brought a bit of relief when I had to revisit it. Looking back on the initial and revised drafts of the analysis section enabled me to appreciate the work needed and connect to the data when I reengaged. Initially, I was not sure how to immerse myself in the data and balance out my interpretation of the data with participants' experiences. With the help of further supervision, I gained more insight into linguistic analysis entwined with context that enabled me to tease out nuances or similarities in participants' experiences. Being aware of the examiners' critique, the biggest change following my rereading of the 'bible' of the IPA (Smith et al., 2012) was that I attempted to analyse the data without

reference to the literature. I believe being over-focused on past studies in the first instance was a reflection of my insecurity in the IPA analytical process and I used literature largely to back up my findings. Although I'm aware of option to include references from literature in my analysis, I decided to redirect my attention to participants' narratives only on the second attempt. In hindsight, I think that process enabled me to understand the participants better as I was not being influenced by theory and was not trying to retrofit their experience into existing literature. As result, the meaning of some of the themes has changed, which has been reflected in retitling some of them and reorganising some of the data.

Through that process I learnt to further appreciate the concept of "bracketing off"; I actually felt liberated when I decided to commit to literature-free analysis. Saying that, it was still a challenging exercise that required a lot of time, effort and managing my own anxieties relating to delivering an appropriate analytical standard stood in the way of fully enjoying the journey. That might be a reflection of the parallel process with anxiety experienced by participants in the group, where they struggled to meet their prestroke standards and needed to accept the changes.

### 4.7.3 Literature Review

Revisiting the literature review was an interesting journey. Initially, the scope of the literature review reflected the initial research question that focused more on aspects of ACT interventions and discussed research related to the efficacy and suitability of that modality for stroke survivors. However, as the outcome of the analysis resulting from some of the interview questions pointed more toward group process as the main experience, therefore, the project became less integrated. Due to my decision to maintain the same data, the body of the literature had to reflect and give a rationale for the concepts discussed in analysis. I had known that method as a way of answering

questions, but the starting point was to do some groundwork through relevant studies in order to understand the question. However, the knowledge gained through the process of reviewing literature may affect our preconceptions on the topic (Zenobia, Fung & Chien, 2013). This is, I think, what went wrong initially. My interest in the topic was governed by wanting the individual voice of the group members to be heard and reflected in the actual group experience; however, as a result of my experience of the clinical practices, the focus on ACT *per se* became my blind spot during the literature review. Subsequently, I took a different direction based on my interest in the literature review that caused discrepancies between what was emerging from the data and the initial research question. Based on this reflection, I embarked on a new literature search focusing on findings from the data. I was aware that literature on group processes is broad; therefore, I have applied search criteria that was relevant to the topic, such as health-related interventions, narrowing to brain injury and stroke.

Rewriting the literature review was also driven by examiners' comments indicating lack of my voice in that process. My learning through supervisions and feedback pointed to subjectivity again. Although a literature review is more of an objective report of existing studies and theories, it is still the researcher's reading of the data that is presented and their evaluation of what new work is needed and why. With that in mind, my aim was to introduce readers to relevant literature that would lead them to understand *my* curiosity in the area and justify my research proposal. As a result, the current literature focuses more on the importance of the group process as a mechanism for change in the context of stroke-debilitating difficulties with ACT principles being more secondary in clients' experience.

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# **Appendices**

## **Appendix A – UEL Ethics Approval**



31st August 2016

#### Dear Maya,

Project Title:	How do stroke patients experience being in an act group: An interpretative phenomenological analysis
Researcher(s):	Maya Starling
Principal Investigator:	Maya Starling

I am writing to confirm that the application for the aforementioned NHS research study reference **16/WA/0135** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is 31<sup>st</sup> August 2020. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing <u>researchethics@uel.ac.uk</u>.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

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

Yours sincerely,

Catherine Fieulleteau Research Integrity and Ethics Manager For and on behalf of Dr Lisa Mooney University Research Ethics Committee (UREC) Research Ethics Email: <u>researchethics@uel.ac.uk</u>

## Appendix B – NHS Ethics Approval



Gwasanaeth Moeseg Ymchwil Research Ethics Service



WALES REC 7 PO Box 108 Building 1 St David's Park Jobswell Road Carmarthen SA31 3WY

Tel: 01267 225045 Email: <u>sue.byng@wales.nhs.uk</u>

Mrs Maya Starling University of East London Water Lane E15 4LZ

6 May 2016

Dear Mrs Starling

Study title:

REC reference: IRAS project ID: HOW DO STROKE PATIENTS EXPERIENCE BEING IN AN ACT GROUP: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS. 16/WA/0135 202980

Thank you for your emails of 5 and 6 May 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Ms Sue Byng, sue.byng@wales.nhs.uk.

#### Confirmation of ethical opinion

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

#### Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for NHS permission for research is available in the Integrated Research Application System, <u>www.hra.nhs.uk</u> or at <u>http://www.rdforum.nhs.uk</u>.

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

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

Sponsors are not required to notify the Committee of management permissions from host organisations

#### Registration of Clinical Trials

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

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

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

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

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

Ethical review of research sites

NHS sites

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

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants	2	03 May 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		25 August 2016
GP letter	1	06 May 2016
Interview schedules or topic guides for participants	1	07 March 2016
IRAS Checklist XML [Checklist_30032016]		30 March 2016
Letters of invitation to participant	1	05 March 2016
Research presentations marking sheet		18 November 2015
Research proposal feedback form		11 November 2015
Response to validation query		07 April 2016
Participant consent form	3	03 May 2016
Participant information sheet (PIS)	3	03 May 2016
REC Application Form [REC_Form_30032016]		30 March 2016
Research protocol or project proposal	1	05 March 2016
Response to Request for Further Information [Email 1]		05 May 2016
Response to Request for Further Information [Email 2]		06 May 2016
Summary CV for Chief Investigator (CI) Mrs Maya Starling		05 March 2016
Summary CV for supervisor (student research) Dr Melanie Spragg		07 March 2016

#### Statement of compliance

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

#### After ethical review

#### Reporting requirements

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

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

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

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <a href="http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/">http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/</a>

#### **HRA** Training

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

#### 16/WA/0135 Please quote this number on all correspondence

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

Yours sincerely

Suckyg

#### pp. Dr Gareth Davies Chair

Email:sue.byng@wales.nhs.uk

Enclosures:	"After ethical review – guidance for researchers"	
Copy to:	Prof Neville Punchard Ms Stephanie Butler, NOCLOR	

**Appendix C – Information about the research** 





# School of Psychology Research UNIVERSITY OF EAST LONDON

School of Psychology Stratford Campus Water Lane London E15 4LZ

The Principal Investigator(s)

Maya Starling Email:u0315277@uel.ac.uk

**Study title:** How do stroke patients experience being in an ACT group intervention?

# Information about the research study

**Dear Participant** 

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in research study. The study is being conducted as a part of my Doctorate in Counseling Psychology degree at the University of East London.

# **Project explanation**

Stroke can bring about a lot of changes in people's personal life with adjustment being one of the most common challenges. Different psychological treatment has been offered in the past to help to accept those changes. One of the recent treatments is Acceptance and Commitment Therapy (ACT). The main aim of my research is about exploring individual experience of being in an ACT group. Therefore, taking part in the research would mean to talk about how you found participating in the group and talk about in more detail what was your experience of being in stroke focused treatment. I would hope that sharing your personal view on above experience would help to facilitate future psychological support for stroke patients in NHS.

# What would taking part involve?

As a part of this process, you will be asked to take a part in one to one an interview that will last from a 1 to 1 and half hours. Your carer or relative may attend the interview with you if you wish or need support on the day of the interview.The interview will be audio-recorded.

# What are the possible benefits of taking part?

Participating in the study would allow you to provide detailed feedback and account of your experience in the confidential environment. It also gives an opportunity to participate in making changes in the treatment and would allow improving future psychological services for stroke patients.

# What are the possible disadvantages and risks of taking part?

Although some people find talking about their issues easily, this process may also evoke difficult emotions. I will ensure that your comfort will be respected at all times and you will have the right to stop or withdrawn from the interview at any time without any consequences.

The researcher *is not* part of Psychology team who facilitate the ACT group, thus I hope you will feel comfortable to talk about your personal experience.

# **Further supporting information:**

# Location of the interview

The interview will take place in Vicarage Lane Health Centre, Stratford. The interview room is pre-booked and provide comfortable, safe and private environment. The time of the interview will be agreed in advance at your convenience.

# **Confidentiality of the Data**

All information shared during the interview is treated as confidential. Your personal details will be available to researcher only. The recorded interview will be transcribed and anonymised. Although quotations will be anonymised it may **be** possible to identify you by what you have said.

Once the research is complete all audio recordings, transcripts will be securely kept for up to 5 years in which further analysis can take place. Your contact details will be kept separately from other details, so you can not be identified. After period of 5 years all collected data will be destroyed.

# Disclaimer

You are not obliged to take part in this study and should not feel forced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. Should you withdraw, your anonymised data will be used in the write up study and analysis.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

# If you have any concerns

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr. Melanie Spragg (<u>m.spragg@uel.ac.uk</u>) or Dr Jane Lawrence (j.lawrence@uel.ac.uk), School of Psychology, University of East London, Water Lane, London E15 4LZ.

# Or

Chair of the School of Psychology Research Ethics Subcommittee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you

Yours sincerely,

Maya Starling

Version 3

Signature: M Starling

Date: 03/05/16

# Study reply slip

Please contact me about this project

Name:

Telephone number:

Email address:

## **Appendix D - Consent to participate**





Participant Identification Number for this study:

#### Consent to participate in a research study

# Title: "HOW STROKE PATIENTS EXPERIENCE BEING IN AN ACT GROUP INTERVENTION: AN INTERPRETATIVE PHENOMOLOGICAL ANALYSIS (IPA)"

Name of researcher: Maya Starling

Please initial box

1.I confirm that I have read the information sheet dated...... (version.......) 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 involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data.

3. I was informed about and give permission to audio record of my interview. It has been explained to me

what will happen once the research study has been completed.

4. I understand and give permission to use direct quotation from my interview in the final report.

5. 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.
I also understand that should I withdraw, the researcher can use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

6. I understand and give permission for my GP to be informed of my participation in the above

study

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

I wish to receive feedback in person about the outcome of the study	Yes/No
Participant's Name (BLOCK CAPITALS)	
Participant's Signature	
Witness/carer signing on behalf of the participant	
Researcher's Name (BLOCK CAPITALS)	
Researcher's Signature	
Data	
Date:	

Version 3 Signature: M Starling Date: 03/05/16





Date

Dear (Doctor Name )

RE: HOW DO STROKE PATIENTS EXPERIENCE BEING IN AN ACT GROUP: AN INTERPRETATIVE PHENOMENOLIGCAL ANALYSIS.

Patient:(Name)

My name is Maya Starling, and I am a trainee counselling psychologist at the University of East London conducting a research study at East London NHS trust.

I am writing to inform you that your patient has agreed to participate in the above research. The study aims to explore individual experience of being in the group treatment for stroke patients.

I have enclosed a copy of the Patient Information Sheet for your reference, however if you have any queries or require further information please contact on <u>u0315277@uel.ac.uk</u>.

Regards

Maya Starling

Version 1

06/05/16

## Appendix F – Research passport



1st Floor, Bloomsbury Building St Pancras Hospital 4 St Pancras Way NW1 0PE

Tel: 020 3317 3045 Fax: 020 7685 5830/5788 www.noclor.nhs.uk

May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- Patient contact: only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- Informed consent: original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- Data protection: measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- Health & safety: all local health & safety regulations where the research is being conducted must be adhered to.
- Serious Adverse events: adverse events or suspected misconduct should be reported to the R&D office and the Research Ethics Committee.
- Project update: you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- Publications: it is essential that you inform the R&D office about any publications which result from your research.
- Ethics: R&D approval is based on the conditions set out in the favourable opinion letter from the Research Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Research Ethics Committee and R&D Office as soon as possible.
- Monthly / Annually Progress report: you are required to provide us and the Research Ethics Committee with a progress report and end of project report as part of the research governance guidance.
- Recruitment data: if your study is a portfolio study, you are required to upload the recruitment data on a monthly basis in the website: <u>http://www.crn.nihr.ac.uk/can-help/funders-academics/nihrcrn-portfolio/recruitment-data/</u>
- Amendments: if your study requires an amendment, you will need to contact the Research Ethics Committee. Once they have responded, and confirmed what kind of amendment it will be defined as, please contact the R&D office and we will arrange R&D approval for the amendment. If your study is Portfolio Adopted, amendments must be submitted for R&D review via the NIHR CRN (CSP), please refer to the Amendments Guidance for Researchers: <u>http://www.crn.nihr.ac.uk/can-help/fundersacademics/gaining-nhs-permissions/amendments/</u>
- Audits: each year, noclor select 10% of the studies from each service we have approved to be audited. You will be contacted by the R&D office if your study is selected for audit. A member of the governance team will request you complete an audit monitoring form before arranging a meeting to discuss your study.

NCLET018T - 4.0.0 - 29.07.15 - Research Site NHS Permission Letter, IRAS R&D Reference: 202980

Page 2 of 2

# Appendix G – An examples of interview questions

## **Examples of interview questions:**

Starting off with brief introduction of myself, plus what explain what will happen in the interview. To highlight 1'm the independent researcher.

- 1. Opening question- can you tell me about yourself
  - How did you come to the group?
- 2. Can you tell me what was like to be in the group ?
  - What was like for you when you attended the first session?
  - What about middle part (what have you noticed ?)
  - What was like for you on the last session?
  - Was the session that stood up for you ? (what was different or the same about it?)
  - What did being in the group mean to you?
  - What were the best or worst moments?

3. What was like for you to meet others in the group?

- What did you like or dislike about meeting others
- What was the experience of meeting others
- What did it mean to meet others?
- 4. Have you noticed any changes since attending the programme?
  - What possibly facilitate the change /or what prevented the change to take place?
  - What does it mean to be able to make these changes
  - How they are helpful or unhelpful
- 5. How did you view yourself before and after the stroke ?
  - roles in life (work, family)
  - identity
  - abilities (including physical)
- 6. How this view has changed since being in the group?
  - Could you give an example of the change you noticed
  - How important the change it is for you and the future life/family
- 7. How the changes took place?
  - Were the significant turning points/moments in the group,
  - When they happened?
  - What/ who prompted the changes
- 8. What was useful in being in the group, and what wasn't?
  - Can you tell me more about what was useful and how was useful

- Was the parts that were more useful than others
- What worked for them,
- How significant it was to participate in the group?
- 9. What did you take away from the experience?
  - Specific strategies, are they different in any way now from when they started?
- 10. What advice would you give to others who will attend the group?
- 11. Is there anything from the interview they would like to explain more, reflect on?
- 12. Is there anything I did not ask about, that you would like to add now?
- 13. Why did you decide to participate in the interview?
  - What did you hope to gain?

If you would like to add anything comet you are welcome to contact me and meet me with me again Debrief participant, check how they feel after interview, any questions they might have right after interview **Version 1, date:07.03.16** 

M Starling

Appendix H - Poster





Have you attended Acceptance and Commitment therapy group after experiencing stroke??



# And would you like to talk about your experience in a confidential research interview?

My name is **Maya Starling**, and I am a trainee counselling psychologist at the University of East London conducting a research study which explores the experience of being in the group treatment and how having such experiences might impact on how you make sense of stroke and your experience of participating in the group.

I am seeking to interview adults who have had suffered stroke and attended most of the above support group recently. The interview may last between one and two hours and will be arranged to take place on a day convenient for you.

If you would like further information, you can e-mail me on u0315277@uel.ac.uk or leave a message for me on

Thank you for your interest

Version 2, date: 03/05/16 M Starling

## Appendix I – The participants debrief and list of support services

#### Debrief

Ask how they felt after interview, any questions they might have right after interview. Inform participants they can contact either researcher or director of studies if any concerns and enquire were to be raised at any stage of the research process.

Remind about participating in validation of the data analysis and asked how contact can be made.

Provide relevant support service contact details in case of the distress.

#### Support services details:

Samaritans 116 123

(24 hour crisis line for people contemplating harming themselves)

Saneline 0300 304 7000 6pm - 11pm every day

(Practical information, crisis care and emotional support)

NHS and other services

If you need, please contact your GP on the usual number during surgery hours.

Outside of surgery hours you can call NHS Direct 111,

Assessment and Brief Treatment Team (ABT Team)

If you are in crisis during office hours, you can refer yourself to the ABT Team:

East Ham Memorial Building

1st/2nd Floors, Shrewsbury Road East Ham

London E7 8QR

Tel: 020 3288 5100

Fax: 020 3288 5101

(Covers the Borough of Newham)

## Appendix J- An example of an initial coding of the data

Participant 8, Laura Duration: 1h 12m 19s

I - yes it's running so yeah so thank you for agreeing to have a chat with me and I wonder if you just want to start from telling me a bit about yourself

P-umm I - whatever comes to mind

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P – well I'm a support worker ... last year about on my way to work I felt ill so... I went to A&E and a Ø had a stroke... transferred to Royal London where I learn I had a TIA 3 months earlier, all of this was new to me so ... I didn't understand, so during my therapy gave a letter but I was still a bit curious why I had to have a stroke. I understand that it's because of the it could have been different things so... the occupation therapist and the physiotherapist and all the health persons who came to visit me... I'm still learning but I'm still a bit more curious about this group, about the stroke about life  $\sqrt{N_{\mu}}$ after stroke I was interested ENATE I-mmm

P – so I attended and it was still under the same umbrella the neuro team and these other erm

- people that were helping me as well as my GP to get back my life together
- I ok so how did you get referred to to the stroke group ,do you remember?

P-the stroke group yes, because I was seen by ... because the stroke group is under the umbrella of the neuro office where I attended in (area) and I did met a lady who was from the Stroke Association, so eventually I was referred erm to this group because I keep saying why did I have to, didn't understand why I had to have a stroke, so this group helped because it tells us about stroke the prevention, so this is how it started. I was referred to it cos I was under the same umbrella that the... team

- I-mmm
- P make up of

I – mmm they kind of look after you

P-veah

I - so what was your experience of being in the group... that group ?

P – my experience in the group was good because I learnt about umm why I...not really why I had the stroke I learned ... about the prevention and the cause and life after the stroke and it did help because I didn't know a lot about like about blood clot and things like that you see, these things on the adverts but you don't really think in your mind cos you don't expect it to happen to you and the signs, I didn't know the signs, I just felt ill I was vomiting I think or ... you think it's just one of those 1.0 days when you eat something bad and overnight and you just having the flu... but little did I know until I attended this group, as well I learnt more about the signs and since if this happened again, if I had a TIA then.. stroke, TIA in June and stroke in November, if I was aware of it more maybe I would\_ 600000 have gotten treatment quicker, so attending the group like has helped because I've learnt more I - mmm and do you remember when you went to the first session do you remember, how it was like for you to be with others and kind of going to the first session ? P - the first session it was a bit... strange cos I would have figured it would have been these people of the second

who had had stroke but they had pretty different symptoms different ... things but everyone in the room had suffered stroke at some time so eventually ... it got easier , like it was the people that had chouge suffered the same illness that you have, it might be different outcome and different times, intende symptoms but you... still it's got to do with the stroke and life after stroke and people who suffered a stroke, so it was helpful similar thou

I - how was helpful to learn this

1

be text it's helpful (stressed helpful) because if I was to leave this room now and have those signs that had a year ago at least I know... what I need to do because I felt ill from the Wednesday but I didn't go for medical treatment until the Friday because I didn't know the signs 47 48 I - mmmP - but not only with the group, doctors, all ... the health bodies you've learned that these signs are what you should look for but with the group weekly basis you go more in depth (stressed depth) because a doctor might say oh this is this for 20 minutes, 15 minutes but with a group an hour or 2 51 hours you go more in depth, you can have more questions that the GPs wouldn't b I – (inaudible) P – yeah but you have to be fair cos there's other people that is waiting so the group did help 53 I - so just coming back to the initial session how did you feel when you were going there the initial kind., of feeling 56 P – it was a bit umm a bit scary at first 57 58 I – what do you mean scary? P – I mean scary because you gonna learn about something that affected your life... only just really for a few months you didn't know how you were gonna react to learn about this illness, it was scary Quil and frightening at first but it was... it was fine in the end 1003 Jumi-I – mmm P - it was fine in the end I – and how was it to meet others at that initial session how did it feel to be with others at the first 64 session? from somebody else so... you learn more and you anxious to hear what is happening because I would when the have thought ow I was the only one not ideally because I would any other than the source I would append the source I would be a source I wo have thought ow I was the only one, not ideally because I was on a stroke ward so you know it's not myself only but to actually be face to face with somebody and you can actually ...ask questions cos 69 you are in a room with that person in the hospital you could go to the other persons bed but it wouldn't be nice cos at that time that person might be in a really suffering and in pain so you don't want to go to the bed and say oh oh I'm so ... what happened to you people don't want to speak 72 73 about it that is at the moment I – mmm 74 P - but this is after they might want to speak , might not want to speak at the group 75 I - yeah but to have the what was like to have this opportunity to speak with others about stroke P - yeah yeah you got opportunity to speak to others and to find out how it affected them (stressed them) so it was good 78 I - so how was good for you 79 P - it was good because you learn about other people's symptoms as I said before and because 80 everyone's symptoms different, so you learnt I – yeah 82 P - you be thinking oh I was just vomiting but somebody else would say it wasn't vomiting, it was SUN 83 diarrhoea cos you might be thinking oh facial drop or ... just complain about other things so you learn 84 more from other people as well about other symptoms, so it was just worth it, it was good if you 85 going just thinking about your symptoms you wanna learn about symptoms that happened to you 86 but there's other symptoms out there that... affect stroke 87 88 I - mmm

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P –and people like that know because I was Doctors were shocked that I was vomiting for more than  $hum\ell$ half an hour but no one realised the bus driver, because I didn't have facial drop so they maybe just thought oh maybe she's pregnant or she didn't have breakfast but ... even with my staggering MANG walking people didn't realise these things so ... it was good to learn (stressed learn) I - mmmP - even when the doctors saw and no one else, I don't think so but they realised that what they can 94 NO see because me myself I didn't know that facial drop was like like clumsy like if you had this paper and it fell you be thinking something was wrong, but for someone just to be vomiting and still 97 looking the same you wouldn't know ...what is what 98 I - mmm yeah 99 P-I didn't get any medical attention when I was in the public because I don't think they knew what 100 was happening 101 I - yeah ok so with with session kind of you know further session how did it feel to be with others in 102 the group 103 P - it felt ok because I wanted to be in the group, I wanted to learn more you know, what affected mentioned 104 me and what prevention I can 105 I – mmm mmm 106  $P \rightarrow to$  prevent it if it does happen then learn more other things as you go along so... it was helpful 11001 I - mmm have you have noticed errm like I said in terms of your experience of seeing other people 107 108 who had stroke erm how did it feel to you personally to be in that group? 109 P - umm just a bit anxious at first, at first I was anxious cos you just wanna know what has happened 110 to the other person 111 I – mmm P-you could learn from there so 112 I – mmm 113 P - it was like anxiety and it was depressing learning about other people ())14 compa. I - you said it was depressing to learn about people what... 115 116 P - it was because I find that if I'm sitting here just telling you all my sad stories its depressing but at 117 the same time you're learning 118 I - mmmP - so it was depressing and learning and interesting cos it was a mixture of everything really 119 120 (stressed really) I - ok can you give me an example like in terms of you know learning, what did you learn from 121 P - when they say like the importance of your medication 122 123 I-mmhmm P - and the importance of ... looking things they would say like the positive and negative cos most of 124 the time we think of... because we didn't get this appointment is all so negative but you have to ⊀ 🕖 125 think about the positive things as well and they tell you things like that and try not to worry because  $\mathbb{N}$ 126 maybe you could book it for the following day but you you just want it for today or maybe you could wold 0127 ring back later in the day, so they teach you all in the group that tells you that not teach you tells you want that there is want complete that the source of the source 128 that there is ways sometimes you may be thinking oh I didn't get this appointment with my GP but 129 then you now knowing that you could maybe get it at the hospital or there's other services that is 130 131 available so you learn .. you learn cos I was thinking ...oh I have to have my appointment at my GP and then you learn, that I didn't know that I should have called 999 not that, I don't know this but I 132 quience was thinking I was thinking oh its just vomiting why should I call 999 but then I learned that if I had 133 NE AR AND 3

#### [Type text]

2	[Type text]
milone .	
2 0 134	called 999 and told them what my medication I'm taking prior, then maybe we would have known
10/ 135	that something was happening and so I could have gotten the medical attention
1. 101196	I – mmm P – so going to the group you know these things don't hesitate calling 999 cos if it's just vomiting
00191 137	
138	why would you ring emergency service for that. I'll wait til I'm well enough in the morning, so if had
139	rang them and say they would have asked me if I was on any medication and I would have said yes
140	I'm on this one and then they could have picked up that something was happening and the signs and $arphi$
W 141	the symptoms then I'll get medical attention quicker then maybe I wouldn't be so ill by the Friday
60 <sup>1</sup> 142	so you learn these things from the group
,143	I-mmm
144 Nº 144	P-don't hesitate to ring confidance, adding cm
Q 145	I – and how do you think it's important to learn these things
146	P – it's important for for your wellbeing and everyday life you learn more not only because of the
100/0147	strokes but in general you learn (pause) you learn more every day every day is a learning process and
148	you're not too sick and you're not too old so it's just a learning process and it differences
149	experiences of everyone so at the group you learn I mean these things I would have known but at
1Ch, 1120	the same time you wouldn't think it's important when you go to the group and you learn the
W19 1510	importance about especially your illness it is likely that it can happen again so these are the
152	factors you have to look for these are the things that is important to prevent it so it's not happen so
CO 253	its good the group was good
154	I - was there any other strategies that you that you remember that was discussed?
155	P – we talked about both like the negatives and the positives if you're on the bus and things like that
20 156	they've used a lot of things they do things like the circles the life circles
157	I-ok Oricent
2020158	P – so there was a lot of things that they done positive and negative and if you think you're in a
(e. 159	negative what you need to do to go to the positive so and there is healthy eating cos I didn't take
160	certain things serious. I knew that salt would be for instance if you've got blood pressure, salt is you
• <sup>161</sup>	don't need so much salt but I didn't know that and at the same time eating too many fruits can
162	mean too many fruits too many sugarcos you are thinking that fruit is so healthy but you have to -10/00
0163	eat it in not too much,moderate
164	I – mmm
NO 0/165	P – and I was thinking well I wanna get better, so eat less salt but have more fruit but that can affect
166 167	your cholesterol, so there's things that I've learned I've walked away and I've learned
60	I - mmm
( <sup>0</sup> 168	P – not that I'm not having fruit but these were things that were discussed in the group and it's all about umm because I was placed on cholesterol tablets and I'm not about that problem but the
169 170	about umm because I was placed on cholesterol tablets and I'm not about that problem but the doctor was saying because you're in the middle like borderline we don't want you to have that
170	problem
172	I – to be at risk
172	Develope the second of putting these tablets in place so I didn't know these things but it's
ACHININ	good, now I'm taking cholesterol tablets, I don't want to go back to the Doctor and they then say 'oh now your over, so I've learnt something there a lot that I've learnt that the group has taught myself but I don't know about others
175	now your over so I've learnt something there a lot that I've learnt that the group has taught myself
1.101	how your over, so i ve learnt something there a lot that i ve learnt that the group has taught mysel
176	I – mmm mmm but was there anything that you learned from other people that were in the group
¢/11	- minin minin but was there anything that you learned notificate people that were in the group
У	
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#### [Type text]

a

ing 1	P - erm there was so many things but like for instance people wouldn't take their medication and
178	
179	people would just, there was one bit in the medication people would take their medication or miss
180	this one and say take the other one it doesn't work like that and like people who like different
8 181	symptoms like I said earlier their symptoms is different from you so you learn that
182	I-mmhmm Of Link
	P – one fella he was just going to work and he felt dizzy and he was driving so you wouldn't know
e +184	P – one fella he was just going to work and he felt dizzy and he was driving so you wouldn't know dizziness is because of strokes but because it's shutting your brain down, it's getting dizzy those
ep. 185	experiences I've learnt from others as well
186	P- I've learnt from others as well
3 187	I – mmm and how the learning kind of help you or didn't help you from others the stories that you
188	P- I've learnt from others as well I - mmm and how the learning kind of help you or didn't help you from others the stories that you heard P - it helped because as I keep saying there's like symptoms, you know the symptoms I - ok P - if you know the symptoms it helps. I've learned from that so you know what to do if you are getting these blurry visions not that you must have a stroke just stroke, that your likelihood because
5 189	P – it helped because as I keep saying there's like symptoms, you know the symptoms
190	I-ok Sypulphorming
191	P - if you know the symptoms it helps. I've learned from that so you know what to do if you are
192	getting these blurry visions not that you must have a stroke just stroke, that your likelihood because
193	you've got TIA because I've suffered it. I've had 2 a day I know that let me not mess around, I know
194	that somebody said they had blurred vision at the session. I didn't have it but let me take this in
195	consideration go and get check over and not just go home like I did before, though I didn't have that
196	problem so you learn from other peoples experiences like that for example
197	I-mmm
5 198	P – because he was driving and he just felt dizzy so and he would have felt like he was just having a
199	bad day like I was having vomiting, so you learn from other peoples symptoms from the group in
Se200	that way
201	I – yeah ok and do you remember if there was any session that stood up for you, that was different
202	or special
202	P – well the session that stood out for me was interesting cos like erm my sleeping habit, cos my
203	sleeping habit was really bad and I didn't realise that erm since the stroke it can affect your sleeping
204	pattern, so that group was good for me because I have a problem with my sleeping
205	- mmm
Con 2	P – really, massive my sleeping was really different and I couldn't understand why the problem was
207	like what we spoke about. I remember on that day when they speak about that topic I was
208	interested more than ever (stressed more than ever) cos my sleeping pattern was not like normal
209	
210	so I remember that was really interesting for me cos
- ART A	I – mmm ok it was interesting because you had problems with sleep before
\$ 212	P – yeah sleeping but eventually it took a while even up til now. I still have problem but I learn cos I
Q_213	was always so tired even when I went to my appointment and I was always saying to my GP why but $\sqrt{e^{N2}}$
00 214	then you learn that some of the medications that you take, it makes you feel so tired and I didn't
215 .	know cos I didn't have much sleep, I was always anxious andagitated but then you learn because
216	you're not sleeping, all these symptoms is gonna come about and then at the same time you up to
217	you having to get your life with what has happening and you start to get ever so anxious. Things
218	were changing, so it's bound to affect your life when you're not sleeping but there was these things
219	about my medication that I just wanted to say, well I have to stop taking these tablets, there no good to but of
220	and then not only the medication, I wasn't helping myself and then when it got to a stage I wasn't 🥂 Mieu
221	seeing my own I was seen by the talking therapy at Catherine Road
222	l – mmm

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# Appendix K– An example of exploratory comments

Original data	Exploratory comments ( Linguistic, descriptive, conceptual)	Emerging themes
Original data P – erm well at first obviously it was a bit scary I was a bit apprehensive you knowyou don't want to you know just sit there I didn't want to sit there complaining and making things up so a bit I was a bit apprehensive about going erm initially but again like I said what options did I have ? I'm limited in my options really so erm I went to try it and yeah it wasn't as bad as I thought it would be actually erm people were really nice, the people leading the course were really nice I – mmm P – erm so I think the first couple of sessions I was quiet (stressed quiet) I think I was just sussing the group out thinking ok what's this about erm but then yeah afterwards I think as the course as the group progressed I started to feel more relaxed and by the end of it I was fine	Erm – hesitation, thinking about response Initially she felt anxious, scared, unsure, something unpleasant can happen, did not want to use time to complain, was unsure about attending, but felt it was the only option; initial hesitation related to attending the group due to anxiety, uncertainty, possibly feeling pressure as she perceived that as the last/only way of help? She had no options, she tried, the experience was not what she anticipated initially, people being nice both to the participants and facilitators; feeling it is the last option, pressure on herself to attend and try to use the group to her advantage, entering group feeling somehow hopeless, uncertain, doubtful, but had different experience to her initial assumptions, fears? Initial sessions she was withdrawn; she was more of an observer at first, initial stage of the group socially challenging; quiet – not participating, observing Sussing the group out – figuring out the dynamic, her place in the group?	Initial feelings of apprehension about the group Apprehension Group - last hope; Pressure to use the group efficiently; Entering group with uncertainty; Overall experience differed Sussing the group out Trying to
	She was trying to understand the group purpose; being suspicious With time she was more confident, less anxious and was fine; process of adapting to the group, from being suspicious towards more relaxed and being comfortable	understand/being suspicious Process of adapting to the group
<ul> <li>I – mmm and do you remember how it was in the first session when you arrived there do you remember what you were feeling or thinking of ?</li> <li>P – yeah quite anxious because I'm actually quite a shy person if I don't know somebody erm yeah I am</li> </ul>	Yeah – at that instance possibly clear recognition of emotions? Feeling anxious as she was shy in unfamiliar setting and with new people, anxious, socially challenging due to dear of judgement? Uncertain about the group, expectations from others, what was	Initial anxiety; Socially challenging Uncertainty about

shy erm I wasn't sure what to expect what the set ups going to be like, you know is it one of those are they sitting round in a circle saying my name is such and such and you know erm this is my problem that kind of stuff I don't know I associate that with alcohol anonymous (laugh) I – mmm P – but it was quite a nice welcoming	involved in being in the group treatment, association with AA treatment; initial fear re expectation of her in the group, her participation, exposure and feeling embarrassed, vulnerable in front of others Alcoholics Anonymous – existing image of group treatment in society?? (influence of social norms/reality) It was nice, welcoming; it was respectful, approving instead of exposing	group Fear of being exposed Initial vulnerability Social norms imposed on expectations Approving vs exposing
I – ok what was nice how they were nice what did you		
notice	She felt warmth from the facilitators, understanding; understanding	
P – I think just you know I felt a lot of warmth from	<ul> <li>being accepted for who she was, not being judged</li> </ul>	Being understood
the the facilitators and they were quite welcoming	Positive feelings in the group	Positive feelings
and errr I think understanding they seemed to	Err- thinking about, taking to time to reflect	
understand I think yeah	I've noticed she has been taking time to think about answers and	
I – can you tell me more about they understanding	as if she was reflecting while she was doing, her answers felt really	
P – yeah it was just I think because I'm quite young	genuine and honest	Age- social norms
and I think people sometimes don't understand	Being young and people don't understand her feelings; being young	Being misunderstood
my you know, what I'm feeling or what I'm	in the group, being young and having stroke outside the group – her	
experiencing erm you know and erm and I think I was	vs. outside reality; being misunderstood by others, but in the group	
in an environment where I could be me rather than	she did not have to worry about that, being herself, others don't	Group- self and safe;
you know I think sometimes people think I'm making	trust her experience, disregard for her experience, I could be me –	Others disregard for
it up	being herself without being judged	her experience
I – mm what do you mean?	Age – social expectations, norms – young person is not unwell	Her vs others
P – making up my health condition or that I'm in pain		
you know a couple of friends have said to me are you	Her experience not being real to others; I'm not real, who am I now?	
sure it's not in your head erm obviously that's quite	Reactions from friends towards her health conditions and pain	Outgroup vs group

upsetting (stressed upsetting) you feel like you have to justify yourself I mean how can you explain the condition and try and convince people that you do have it I – mmm P – but in that group I wasn't I wasn't treated like I was being judged	suggesting her experiences not be real, causing her sadness; others' perception on her health problems being dismissed, lack of support causing influence on her mood, not being believed Comparing group vs. others? Need to explain herself, convince others that her pain is real, feeling helpless, alone, isolated, but in the group was different, being accepted; being herself in the group, being allowed to be herself in the group	Being disbelieved Being ignored Outside world - being alone Pressure to explain herself vs being herself in the group
I – mmm	In group – she was not under attack, being accepted as she was with	Group - not under
P – or that I had to defend myself or you know try and	her physical manifestations and feeling unhappy	attack
convince people that yes it's I am in pain and you	Being unhappy – lack of acknowledgement from others, lack of	
know I'm not happy yeah	support	Outside - being alone
I – and what did it mean to you to not to be judged	Yeah – realisation reflection	
P – well it helped me relax a bitfelt less anxious but	Non-judgemental attitude helped to relax in the group; it enabled	Being accepted in the
it meant that I could just share how I'm feeling I	her to share her feelings, being open, not having anxiety what	group
could be open and honest I thinkand not worry	others think of her or if her experience is real or not; group provides	Being able to share
about you know what they are going to think of me are they going to think I'm making it up or lying	unconditional acceptance, welcome anyone independent of their imperfections, troubles, freedom, I'm not a liar!	Being honest and open
I – mmm		Being believed vs
P – yeah		disbelieved
I – was that a good thing that you could speak openly	Yeah – confirmation of the above	
about your experience	Initially being open was challenging, it was new – it took courage to	Initial sharing -
P – erm yeah at first it was a bit uncomfortable	speak openly and be transparent with others, being exposed and	uncomfortable
because it was something different (different)	not be criticised	Speaking openly was a
	Different – unusual for her	new experience

Appendix L- Major Themes table with corresponding emergent themes plus samples of extracts from the data: - Participant 2-Mary

Major themes	Emergent themes
Pre-stroke self "before stroke, who were you? P – very active I – very active P_very very active I-can you tell me more about ? P – well I do everything by myself" L159-164/p4	- an independent self - active self
All is lost "…you can't go anywhere the children and grandchildren can't come to you they feel that you are dead []" L68-69/p2	-"that thing stroke" -"you are dead"-loss of self -loss of independence - loss of employment - physical pain - "I'm frustrated" -"it isn't my choice"
<b>Current identity</b> "everything changed I'm not Mary I know before I don't feel like me I'm not the way I was before you could sort the washing and do everything for you" L181-182/p5	-"I don't feel like me" -" the way people react to you" -being sick –persistent identity - others are like me- social identity in context of illness -"as if you are a little girl"
Pre- group expectations "since I had that thing I'm still (inaudible) surviving bit by bit I came here to chat to see what they can do so" L7-8/p8	-looking for hope -sameness -"to help herself and find others who wants the same thing"
<b>Initial stage of the group</b> "you learned from other people the kind of stroke they've got different from that they told you in the hospital" L29- 31/p1	-learning from others -"you are not alone"
Ongoing sessions experiences "we have to feel a little bit comfortable []it felt comfortable I – what was comfortable about being in the group P – well when you go everybody knows	<ul> <li>-being able to be honest</li> <li>-focused on healthy part of self</li> <li>-feeling comfortable</li> <li>-free to talk</li> <li>-connection and unity in the group</li> <li>- confidentiality</li> <li>-change of scenery</li> </ul>

you you go there you go every week you	
spend three hours and you remember	
everything nothing really goes out they	
are free to talk [], telling you what to	
bring and what not to bring that affect	
me" L43-438/p9	
Ending-"I wish it was for long	-"back to the room"
time"	-"I was annoyed"
	- "it was too short"
" $P - it$ 's good for me I like that session	
but it was a shame I wish it was for a	
long time (I;mm) it was short one" L97-	
<i>98/p3</i>	
Comparing to others in the	-comparing to others in the group
group-'You are not worse off'	-"I'm not that bad"
group- rou are not worse on	- we are suffering the same: from
"· · · · · · · · · · · · · · · · · · ·	being worse to be the same
"cos it means you are not alone they	-
are so friendly but some are better than	
others , some colleagues were worse than me	
I - ok so seeing other people that that	
might be worse than you what do you	
think of it ? P – when we are suffering we are	
suffering the same	
I - yeah	
P - so you are not worse worse worse	
off" L221-224/p5-6	
Socialising in the group	-social interaction during break
Socialising in the group	-"you are having tea outside with
	others"
"in the attenness they are used	-being normal: you don't feel you are
<i>"in the afternoon they gave uswe had the best tea and some biscuits Yyeah,</i>	sick
that's good always the best I don't	-"you sickness goes a bit quicker"
drink tea in the house but when I go	-"I feel good in myself"
there I always drank tea" L101-	-making new friends
105/p3	-change if atmosphere instead of
100/p0	"sticking in my room"
Hijacking the group	-some people took over the session
injucting the group	- fear of losing the positive feeling
"there are one or two where there at not	about the group
" there are one or two when they start	
talking they never finished they never	
give anybody time to talk" L122-123/p3	you want to try it straight away
Encouragement in the group	-you want to try it straight away -giving and receiving advice
	-free will – individual motivation
"() I say oh those people they talk	
	-encouragement inrougn
about it maybe she will give you her advice and you will take it and you will	-encouragement through communication

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give it to her you also take it I – mmm so how did you feel when you could talk to this lady about P – I feel good when you go home you want try it straight away" L367-371/p9 Group as a benchmark	-"They feel you are dead" -"I'm talking silly"
"sometimes you tell them they think you are stupid because you've got your stick so when you are among people see them in the group you feel happy you feel okay" L76-77/p2	-"as if you are a little girl": feeling powerless -them vs us -it hurts -feeling happy in the group -"we are equally important" -being looked after and being happy -Having value -being visible again -in the group you are normal -everybody listening to everyone
<b>Connect with old part of self</b> " there is not another group like that I guess in September I would like to take a trip with my grandchildren but my son is you know I ring him four times so I can see them more I don't want to be disturb for them after that you know I would like to join in" L395-397/p9	-motivation to do things in life -hope for the future -things are better now -being active again
Specific strategies "mmm and talking to her about the sleep what how did it help? P – because you know you are not the only one who is not sleeping I – yeah, ok ok P – then they would tell so many things and then you know you sleep a little bit and if I put the telly on I fall asleep then I say oh put it off that was what helped absolutely, that was helpful" L241- 245/p6	<ul> <li>-try to mix with people</li> <li>- you are not alone</li> <li>-I'm eating differently</li> <li>-"if you follow the step, you are the driver"- bus driver metaphor</li> <li>- "if something is bothering you, you just have to() brush it away": cognitive strategies</li> </ul>
What future holds (ongoing challenges)	-limitations in adjustment -back to reality- hesitation to reclaim her life -ongoing need for acceptance and
"but you can't go everywhere where they are pushing you around all the time" L352/p8	validation?

## Appendix M – An example of dairy entry

#### November 30<sup>th</sup> 2016

Re-reading John's interview. I've noticed he spoke about religious aspects that I did not explore. It is a real shame I did not follow it up, as it evident his religious beliefs were (possibly) intertwined with the group experiences as he brought it up. I wonder how he felt after that exchange. He may have seen me as not being interested in his religious beliefs as he has never mentioned them again. As a result John may have just complied with the interview and became a nice interviewee, but he stopped trusting me as I was unable to really hear his story? Clearly, my focus was on my agenda of exploring the obvious. Also, I'm not particularly religious myself, hence I may have inadvertently downplayed that aspect of the interview with John. <u>This is a reminder to for me to stay</u> open-minded!

## January 2<sup>nd</sup> 2017

I have been analysing Mark's transcript. I have read it before and I remember struggling to connect to his story. I began to wonder what stood in my way to empathise with this particular participant. I have looked at my initial reflections again after the interview, and I found a note saying 'critical of facilitator'. I started to question: how I see this participant, or from what role/position I approached his story. I possibly felt 'attacked' when he spoke about the clinician and that drew me to feel defensive about the work I was doing (being a group facilitator). This is a good time to stop, as it seems I hold the same stance now (being defensive against his criticism toward my colleagues). It seems it is my work experience and the usual role I play in that scenario (facilitating the group) that has been blinding me and preventing to engage in his narrative. It is not about my view on the group dynamic; it is about his experience, his right to express his disappointment. As a researcher I need to stay in the role of the researcher and remain compassionate! I can see I was at risk of deviating from his anger and frustration as I felt uncomfortable. By writing this diary entry I can now reengage with his narrative and try to see his point of view, be curious again about what it was like for him to feel excluded, bullied and unsupported by the facilitator. I can now see how his experiences (maybe add 'of attending the group') can add richness to the analysis.

# Appendix N- An example of a brief consultation/training for other professionals.

**Task**: Skills training/Consultation for nurses/care assistants and rehabilitation teams delivered in the form of the workshop.

**Aim:** Training to be based in the community/hospitals and rehabilitation centres. The main approach would be based on the psychoeducation based on the finding from this study.

- 1. The rationale behind this workshop would be to support and provide additional skills to the district nurses, health care assistants and physiotherapists who work directly with stroke survivors. The rationale behind this workshop is to provide support and additional skills to district nurses, healthcare assistants and physiotherapists who work directly with stroke survivors
- 2. To enhance their skills in managing stroke related emotional difficulties such as self-criticism and acceptance.
- 3. To promote and highlight the importance of psychological wellbeing whilst experiencing physical health problems.
- 4. To think more broadly and holistically about service users within medical teams who only apply biological models of care.
- 5. To improving communication between different medical professionals and psychologists and encourage multidisciplinary approach towards caring for service users.

## Factors to consider:

- 1. The workshop to be will be an interactive group. Participants will be encouraged to take part in different tasks related to the topics discussed.
- 2. One of the main aims of the consultation is to overcome differences in professional values in order to facilitate change (Sangganjanavanich and Lenz, 2012). Due to existing tensions between medically trained staff and their unwillingness to adopt a psychological approach towards an individual (Wade and Halligan, 2004) workshops must be sensitive and acknowledge this issue in order to encourage the individual to adopt different ways of thinking about the problem, to facilitate learning and develop good working alliances (Hylander, 2012).
- 3. The amount of time professionals can dedicate to the workshops will dictate the length of the consultation and covered material.

## The topics of the consultation may include:

1. Introduction and discussing the aims of the consultation in collaboration with participants

- 2. Exploring information about the nature of their work and issues experience in the context of supporting stroke survivors and their skills in managing those.
- 3. The need to discuss ending (exploring individual's views/apprehensions and worries related to ending care)
- 4. Inclusion of significant others in the rehabilitation and medical treatment, encouraging individual and shared responsibility in achieving treatment goals, including enhancing empowerment, develop confidence in self-management and asking for help when needed.
- 5. If interventions are delivered in group format, encourage social comparison as a process likely to facilitate positive change in viewing self as a tool to measure the individuals progress ( it might also benefit physiotherapy groups).
- 6. Notions of acceptance- psychoeducation indicating possible difficulties in accepting post stroke changes perceived as 'no choice' and conflicting messages that individuals may be presented with by various services that could contribute further to the acceptance dilemmas
- 7. Awareness of self-critical self and encouraging compassionate view of self (e.g supporting clients to notice their inner strength and self-worth as a stroke survivor)
- 8. Awareness of reassurance and time needed to develop good working relationships in stroke population as a base for progress and change (e.g exploring ways about how professionals can develop positive alliances)
- 9. Collecting feedback regarding consultations and introduced concepts

## An example of practical exercises:

- 1. Open- ended questions that enables explore exploration of mental health issues
- 2. Rebuilding self-esteem and addressing experiential avoidance: revisiting personal values and reconnecting with inner strengths (Hayes, 2006).
- 3. Mindfulness exercises: compassionate imagery exercise, breathing exercises, safe place exercise.
- 4. Definition of compassion describing suffering as a part of human experience rather than individual and shameful (Ashcroft, et al., 2014) and how compassion can be used to address difficulties.
- 5. 'Tricky brain' (Gilbert, 2009) furthered by neuro-circuitry caused by stroke resulting in emotional difficulties.

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