Exploring and Using Storytelling for People with Stroke: Implications for Occupational Therapy Practice and Research

by

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A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF PHILOSOPHY

School of Sport, Exercise and Rehabilitation Sciences
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June 2023

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Abstract

Stroke is the largest cause of severe adult disabilities in the United Kingdom (UK). Psychosocial well-being is often threatened after stroke and survivors may experience a wider range of psychosocial difficulties such as depression, anxiety, general psychological distress and social isolation. Effective psychosocial rehabilitation is associated with decreased depression and anxiety, improved quality of life and community participation following stroke. A novel intervention that has attracted attention is storytelling, a relatively new behavioural intervention that can help stroke patients meet their psychological needs. Reviews of storytelling interventions in chronic illness groups have revealed consistent evidence demonstrating a variety of benefits, including lower levels of depression, increased socialisation and higher levels of perceived quality of life. However, the usefulness of storytelling as a therapeutic intervention in stroke has received less attention, even though it can be an approachable and cost-effective intervention to promote psychosocial well-being following stroke. Moreover, it can be utilised as an educational tool to improve psychological and communication skills of healthcare professionals (HCPs) who work with stroke patients. Previous research has shown that student HCPs lacked confidence in their core communication skills and that there is scant evidence of psychological and communication skills training in UK institutions for trainee HCPs. Receiving health care from professionals who have received psychological training has been proved to improve patients' well-being.

This thesis presents four studies to establish the usefulness of storytelling as a therapeutic intervention to promote psychosocial well-being in stroke survivors and as an educational tool to enhance the psychological and communication skills of HCP students who work with stroke patients . Study 1 was an integrated review aimed to establish existing evidence of the effects

of storytelling and ‘peer sharing interventions’ on coping with the psychosocial difficulties following stroke and to explore the mechanisms underlying specific outcomes. The review found that storytelling interventions can alleviate loneliness, promote hope and positivity, and facilitate coping through information sharing. The key mechanisms influencing these results seem to be social comparisons and social control. Study 2 was a qualitative study aimed to examine illness narrative master plots as expressed by people who had had a stroke. The results provided a novel perspective on illness narrative by identifying a new master plot expressed by people with stroke, entitled ‘overcoming the monster’. The plot relates to stroke as the different experiences related to, and following the onset of stroke can represent a monster which needs to be overcome. Examples of a ‘monster’ for people following a stroke include interpersonal challenges, mental health challenges, isolation and changes to their social identities. Study 3 aimed to explore the responses of physiotherapy students to three versions of this master plot. It found that ‘overcoming the monster’ elicited more empathic responses from students than has been identified in other master plots. Study 4 aimed to test the impact and understand the experience of physiotherapy students who participated in a novel placement that integrated the model of emotions, adaptation and hope tool and a narrative-based approach with simulated training (role play) and in-person training with stroke survivors. The results were improved communication skills, increased self-efficacy, reduced stigma and enhanced empathy among physiotherapy students .Overall, narrative-based/storytelling interventions appeared to be potentially useful therapeutically in promoting the psychosocial well-being of stroke survivors, as well as a valuable educational tool for improving the psychological and communication skills of HCP students.

Acknowledgements

Praise be to Allah for his support, blessing, assistance and guidance in undertaking and completing this PhD thesis. The research reported here would not have been feasible without the participation, support and encouragement of many people.

I would like to express my sincere gratitude to Dr Andrew Soundy, my first supervisor, for giving me the opportunity to pursue a long-held dream of exploring this area of research and earning a doctorate. You have been a significant source of motivation throughout my doctoral studies and I am not sure what I would have done if it had not been for your ongoing support. I would like you to know how much I appreciate it. I am also grateful to my second supervisor, Dr Sheeba Rosewilliam, for providing invaluable support throughout my PhD journey.

I would also like to thank the stroke survivors and the BSC year 1, BSc year 3 and MSc pre-registered physiotherapy students who participated in the studies reported in this thesis. The research would not have been possible without their participation. Special thanks go to Princess Nourah Bint Abdulrahman University in Saudi Arabia for sponsoring my PhD studies.

To my parents, children and siblings: Thank you for your patience, encouragement and support. Finally, important and special thanks go to my sister and best friend, Prof. Reem Al-Wafi. I cannot adequately express my gratitude for your advice, guidance, support, kindness and thoughtfulness. I am looking forward to all the time we will have together in the future.

List of Papers and Conference Abstracts

The following articles, which are directly linked to the thesis, were either published during the candidate's PhD programme at the School of Sport Exercise and Rehabilitation Sciences or were being reviewed at the time the thesis was submitted. Therefore, parts of this thesis contain verbatim text from published work. Parts of the thesis produced from published material will resemble this work in terms of organisation and content, with minor alterations as needed to establish the overall thesis argument. At the beginning of each relevant chapter, a summary of each article and its use in this thesis is presented.

Published articles

Alawafi, R., Rosewilliam, S., & Soundy, A. (2021). An integrative review considering the impact of storytelling and sharing interventions in stroke. *Behavioral Sciences, 11*(6), 88. (Appendix 1)

Alawafi, R., Rosewilliam, S., & Soundy, A. (2022). A qualitative study of illness narratives: 'overcoming the monster' master plot for patients with stroke. *International Journal of Therapy and Rehabilitation, 29*(9), 1-13. (Appendix 2)

Alawafi, R., Rosewilliam, S., & Soundy, A. (2023). Overcoming the monster! Perceptions of physiotherapy students regarding the use of stroke master plots for building therapeutic relationships; a vignette study. *BMC Medical Education*,23 (311) ,1- 9.(Appendix 3)

Conference presentation

Alawafi, R., & Soundy,A. The value and benefits of novel placement training for physiotherapy students to support people with stroke: A multi-methods pilot study. Presentation, CSP Annual Conference, Birmingham. November 2023.

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ABBREVIATIONS

ADL	Activity of daily living
BADL	Basic activity of daily living
CIQ	Community Integration Questionnaire
CVA	Cerebrovascular accident
DALY	Disability-adjusted life year
FAI	Frenchay Activities Index
GSE	General Self-Efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare professional
HRQOL	Health-related quality of life
IADL	Instrumental activity of daily living
ICH	Intracerebral haemorrhage
IRI	Interpersonal Reactivity Index
MEAH	Model of emotions, adaptation and hope
NHS	National Health Service
NICE	National Institute of Health Care and Excellence
OMS-HC-15	15-item Open Minds Scale for healthcare providers
OT	Occupational therapist
PT	Physiotherapist
QOL	Quality of life
RCT	Randomised controlled trial
SIS	Stroke Impact Scale
TIA	Transient ischemic attack
UK	United Kingdom
WHO	World Health Organisation

CHAPTER 1

STROKE

1.1 Overview of the disease

1.1.1 Definition of stroke

The terms ‘stroke’ and ‘cerebrovascular accident’ (CVA) are used interchangeably to denote one of the most common types of cerebrovascular disease, affecting the vessels that supply blood to the brain (Snyder, Nussbaum, & Robins, 2006). It was traditionally referred to as apoplexy, a Greek term meaning ‘to strike down’ (Pound, Bury, & Ebrahim, 1997; World Health Organisation [WHO], 2022). The term used in this thesis will be stroke.

Stroke is a potentially fatal medical condition, occurring when blood supply to part of the brain is cut off, causing deprivation of oxygen and nutrition which damages or kills brain cells (British Heart Foundation, 2021; National Health Service [NHS], 2022; Portegies, Koudstaal, & Ikram, 2016). The current World Health Organisation (WHO) definition of stroke (proposed in 1970 and still widely in use) is “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than of vascular origin” (WHO, 1970, cited in Aho et al., 1980). However, in the 40 years since it was introduced, this definition, which relies heavily on clinical symptoms, is considered to be outdated by improved imaging capabilities (Adams Jr et al., 2007; Sacco et al., 2013). According to a revised definition for the twenty-first century, stroke is “a central nervous system infarction (tissue death) including brain, spinal cord, or retinal cell death attributable to deficiency of oxygen, and supported by neuropathological, neuroimaging, and/or clinical evidence of permanent injury” (Sacco et al., 2013, p. 2064).

1.1.2 Anatomy and pathology

Although it is beyond the scope of this thesis to provide comprehensive and detailed information about the anatomy and pathophysiology of stroke, understanding the clinical consequences of stroke requires healthcare professionals (HCPs) to be familiar with the anatomy of the brain (Auriel, 2009). According to a study of the global burden of diseases, injuries and risk factors, stroke is still the second leading cause of death worldwide and a major contributor to adult disabilities (Roth et al., 2020). This puts stroke at the top of the public health agenda in the twenty-first century, and it is an essential field for public health research (Donkor, 2018). Therefore, researchers, scientists and clinicians are under significant pressure to understand the pathogenic mechanisms underlying stroke in order to deliver effective preventative approaches and successful therapeutic interventions (Manzoor, Albaradie, & Alhussainawi, 2014).

1.1.3 Brain anatomy and function

The brain is divided into three parts: the cerebrum, cerebellum and brainstem (Figure 1.1). The cerebrum is the largest part of the brain and is divided into right and left cerebral hemispheres, each having its primary connection to the opposite side of the body (Figure 1.2). Each hemisphere has four lobes: frontal, parietal, temporal and occipital (Fitzgerald, 2012; Moore, Agur, & Dalley, 2015; Snell, 2010). Figures 1.3 and 1.4 respectively show the brain lobes and their functions. The cerebellum is situated inferior to the cerebrum and is responsible for controlling muscle movement, as well as maintaining body posture and balance (Moore et al., 2015; Snell, 2010). The brainstem serves as a transmission centre between the cerebrum and cerebellum, and controls several automatic functions such as breathing, heart rate and body

temperature (Basinger & Hogg, 2019). Figure 1.5 depicts the areas of the brain where stroke impairments can occur and the impact and loss of function that can result.

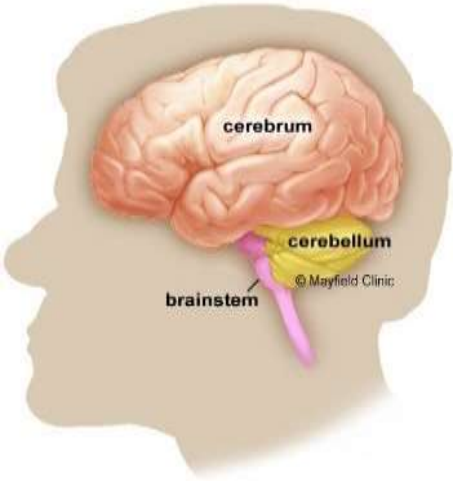


Figure 1.1. Main parts of the brain (Mayfield Clinic, 2018)

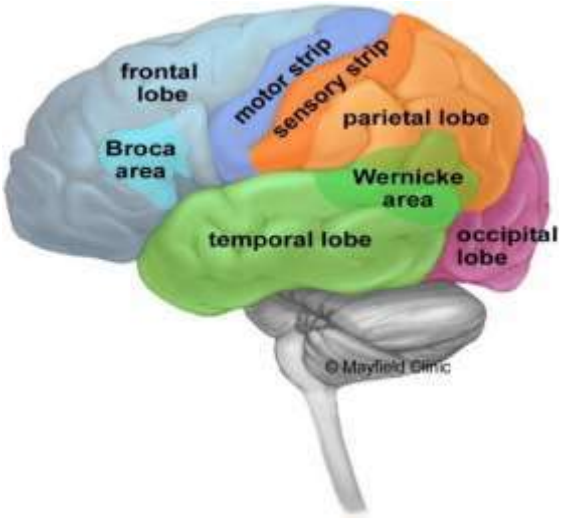


Figure 1.3: The brain lobes (Mayfield Clinic, 2018)

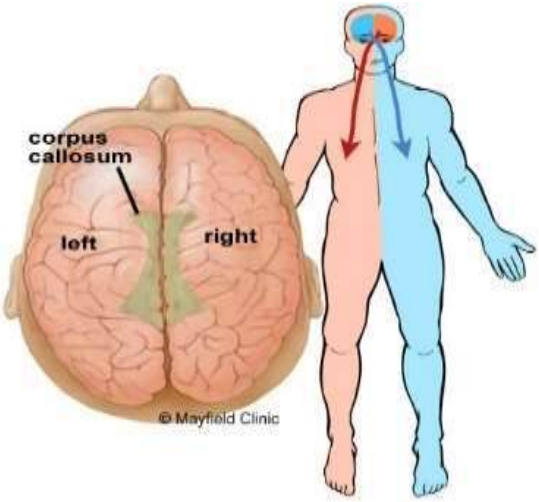


Figure 1.2. The cerebrum consists of two hemispheres, left and right (Mayfield Clinic, 2018)

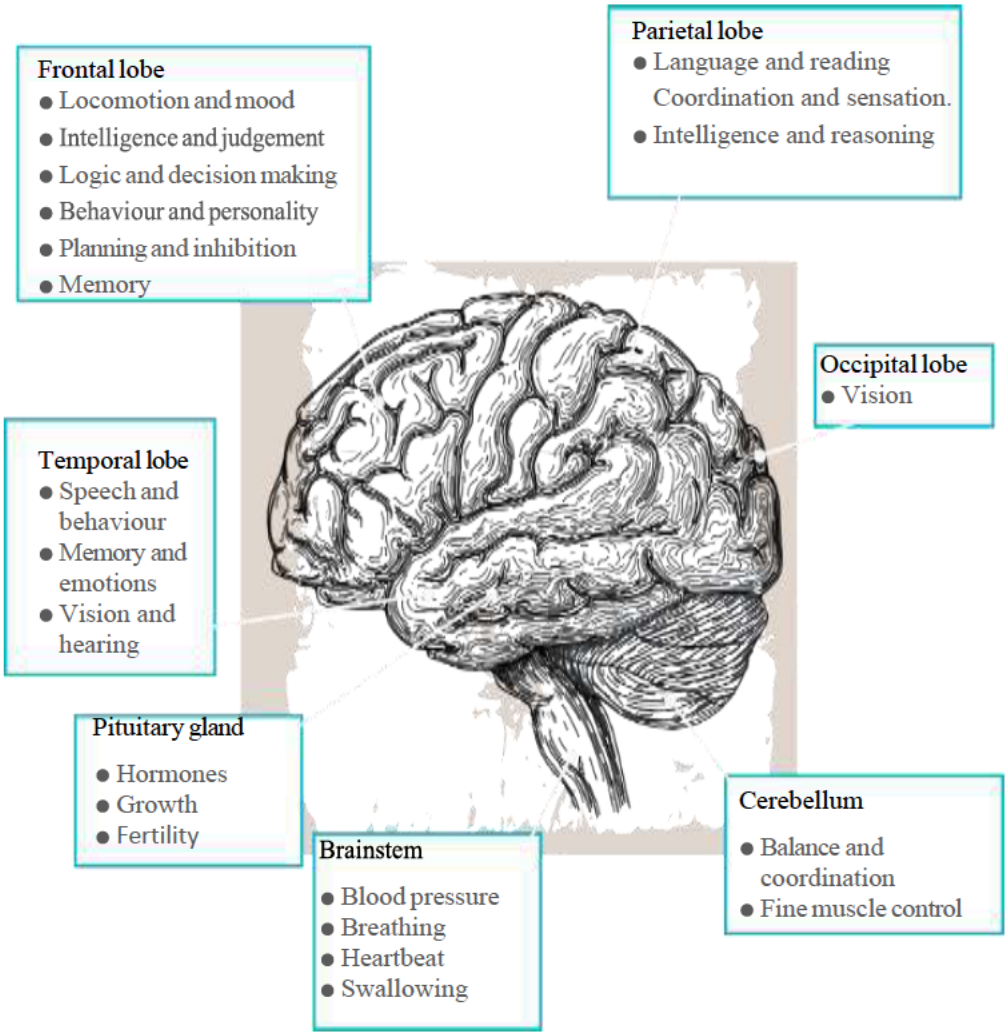


Figure 1.4: The brain lobes and their functions (Puthenpurakal & Crussell, 2017)

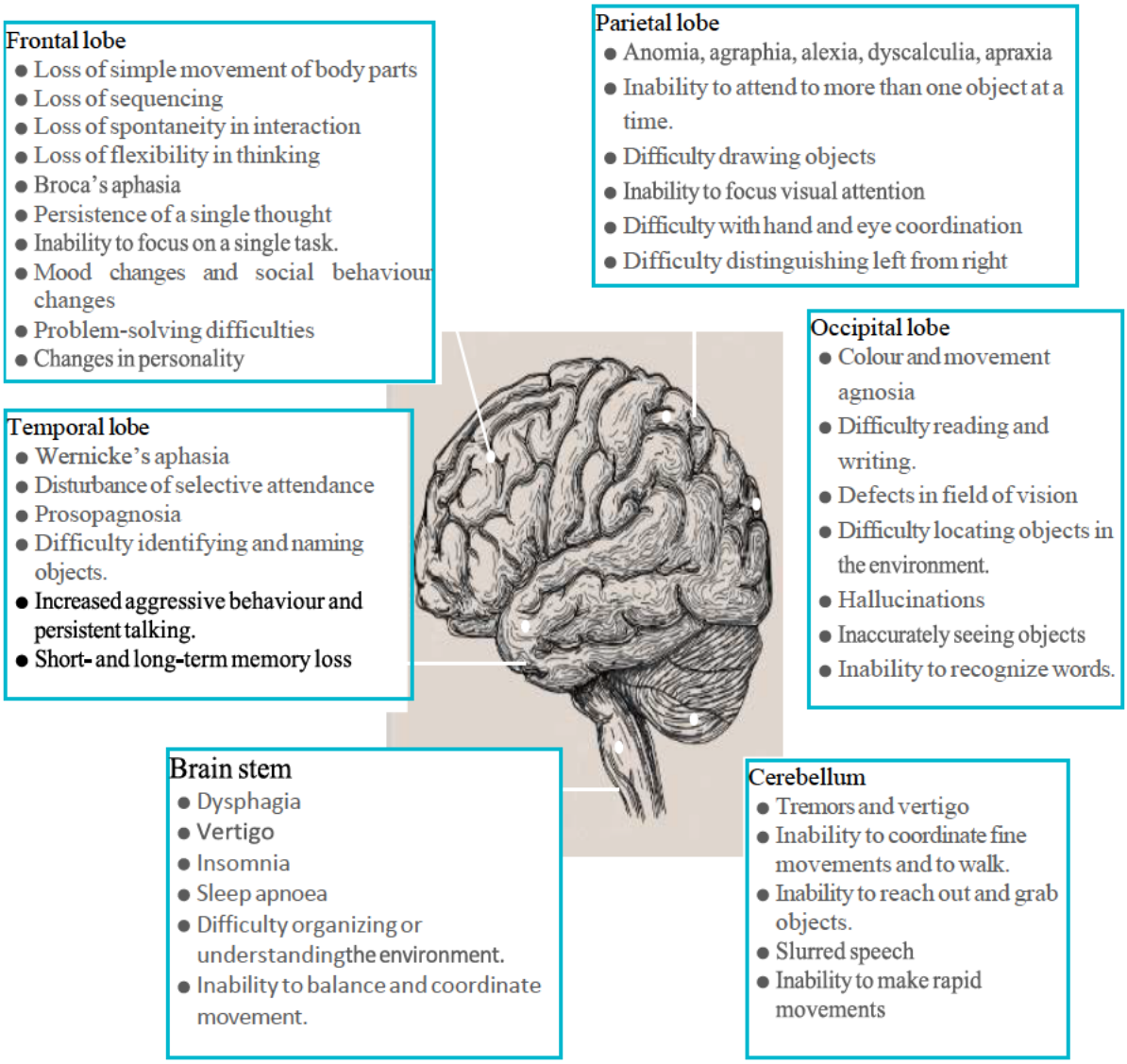


Figure 1.5: Potential stroke impairments based on brain regions (Puthenpurakal & Crussell, 2017)

1.1.4 Pathology of stroke

There are two main pathological mechanisms that underpin the brain damage in stroke, termed ischemic and haemorrhagic disturbance of cerebral blood circulation (Truelsen, Begg, & Mathers, 2006). These are illustrated in Figure 1.6.

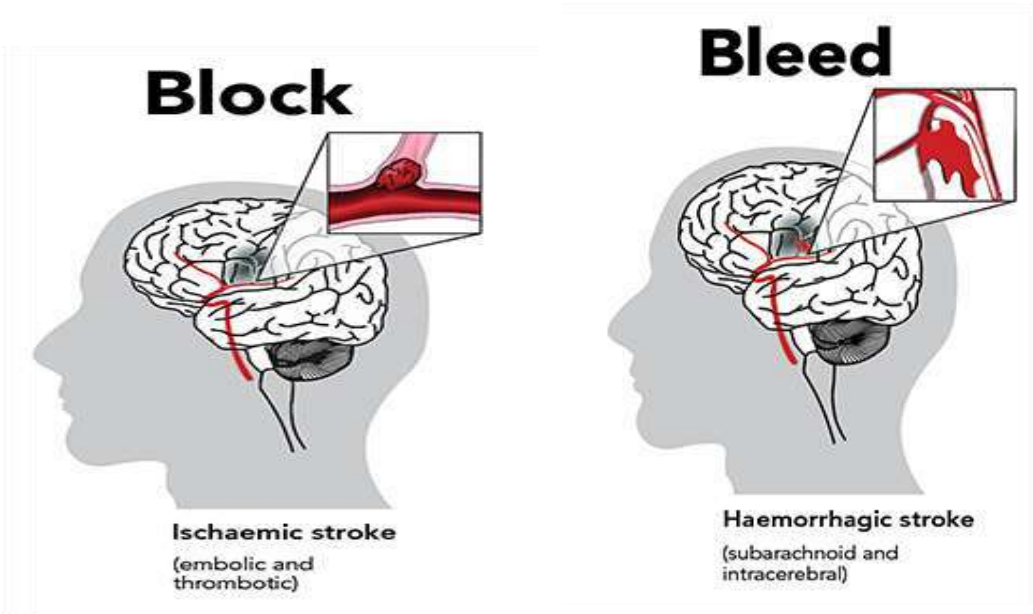


Figure 1.6: The two main causes of stroke (Stroke Foundation, 2022)

Ischemic stroke occurs when a blood vessel supplying the brain is blocked. Up to 87% of all stroke incidents are ischemic (American Stroke Association, 2022). The major cause of ischemic stroke is fatty deposits lining the blood vessel walls, known as atherosclerosis, which can cause the arteries to become narrowed (Stroke Association, 2022a). Ischemic strokes are classified into two types: cerebral thrombosis and cerebral embolism.

Cerebral thrombosis is caused by a blood clot (thrombus) that develops inside a blood vessel (American Stroke Association, 2022). A thrombus can occur in either large or small arteries in the brain. One which occurs in large arteries will stop blood flow to larger areas of the brain. These types of stroke commonly lead to the greatest level of disability (LeWine, 2022).

Cerebral embolism is caused by a blood clot that develops somewhere in the circulatory system, typically the heart or the major arteries of the upper chest and neck. A portion of the clot dislodges and travels into the brain via the arteries until it reaches arteries that are too small for it to pass through. Atrial fibrillation, an irregular heartbeat, is a major contributor to embolism (American Stroke Association, 2022).

A transient ischemic attack (TIA), also known as a mini stroke, is caused by temporary blockage of blood supply to the brain. The effects last only a few minutes to a few hours and are fully resolved within 24 hours, causing no permeant damage. Nevertheless, a TIA can be a serious warning of a future full stroke incident (American Stroke Association, 2022; Truelsen et al., 2006).

Haemorrhagic stroke is relatively uncommon, accounting for around 13 percent of stroke incidents (American Stroke Association, 2022). However, haemorrhagic strokes are considered more serious than ischemic ones and are associated with a greater risk of death within the first three months and beyond (Bhalla, Wang, Rudd, & Wolfe, 2013). Haemorrhagic strokes occur when a weak vessel bursts, allowing blood to leak into the surrounding brain. The blood builds up and compresses the tissue around the brain, which can damage the brain cells (American Stroke Association, 2022). Haemorrhagic strokes are classified by their location in the brain as either intracerebral or subarachnoid.

Intracerebral haemorrhage, the most common type of haemorrhagic stroke, happens when an artery within the brain breaks and blood enters the brain tissues. The usual cause is high blood

pressure (Stroke Association, 2022a; Stroke Foundation, 2022). Subarachnoid haemorrhage occurs when a bleed leaks into the protective layer of fluid that covers the brain, known as the subarachnoid space (Stroke Association, 2022a; Stroke Foundation, 2022). Its main cause is the rupturing of an aneurysm, which is a ballooned-out blood vessel. Aneurysm walls are fragile and can rupture, allowing bleeding into the subarachnoid space (Stroke Foundation, 2022). Figure 1.7 provides a visual illustration of the different locations of intracerebral and subarachnoid haemorrhages.

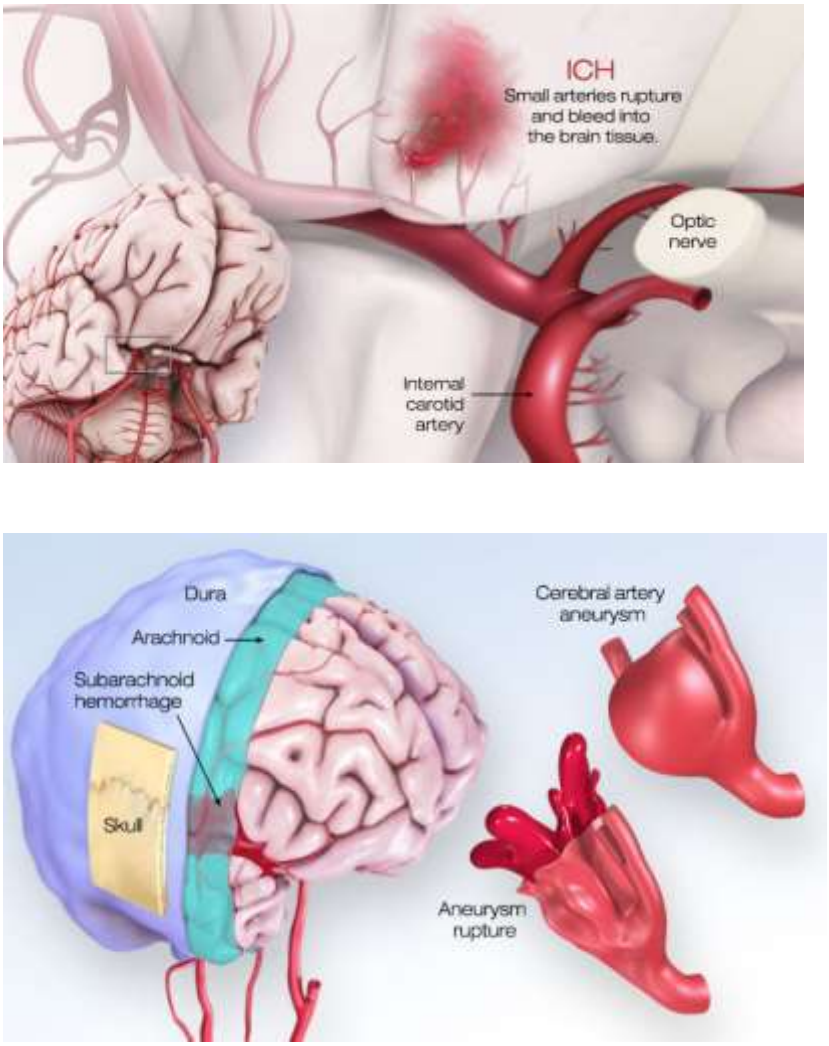


Figure 1.7: Intracerebral (ICH) and subarachnoid haemorrhage (American Heart Association, 2022)

1.1.5 Stroke risk factors

According to Mir and Albaradie (2014), a risk factor for stroke is defined as a feature of an individual that can increase the risk of developing stroke. Risk factors can be broadly classified as modifiable and unmodifiable. Modifiable risk factors are those which can be managed and changed, such as poor diet, smoking, consuming alcohol, being inactive and obesity. On the other hand, factors which cannot be treated or modified include advanced age, family history of cerebrovascular disease, gender and certain ethnic characteristics such as being black (O'Donnell et al., 2016). Table 1.1 provides an outline of the main modifiable and non-modifiable risk factors associated with ischemic and haemorrhagic stroke. Table 1.2 shows the risk associated with each factor.

Table 1.1: Main modifiable and non-modifiable risk factors for stroke (Boehme, Esenwa, & Elkind, 2017; O'Donnell et al., 2016)

Modifiable risk factors	Non-modifiable risk factors
High blood pressure	Age
High cholesterol level	Ethnicity/Race
Smoking	Gender
Waist-to-hip ratio	
Alcohol intake	
Lifestyle inactivity	
Carotid or other artery disease	
Unhealthy diet	
Diabetes mellitus	
Psychological distress	
Depression	
Genetics	

Table 1.2: Risk level of modifiable factors (Modified from O'Donnell et al., 2016)

Modifiable or treatable risk factors	Level of increased risk	Type of stroke
High blood pressure	51.8% (blood pressure >160/90 mmHg)	Intracerebral haemorrhagic
High cholesterol level	24.9%	Ischemic
Smoking	18.9%	Intracerebral haemorrhagic
Diabetes type 2	5%	Ischemic
Alcohol consumption	3.8%	Intracerebral haemorrhagic
Lifestyle: inactivity	28.5.%	Ischemic
Psychological stress	4.6%	Ischemic
Depression	5.2%	Ischemic
Unhealthy diet	18.8%	Intracerebral haemorrhagic
Waist-to-hip ratio	26.5%	Ischemic
Carotid or other artery disease	6.7%	Ischemic

1.1.6 Stroke statistics worldwide

Globally, stroke has risen to epidemic levels and now affects more than 110 million people worldwide. One in four adults aged over 25 years will experience a stroke over the course of their lifetime and 12.2 million people will experience their first stroke this year (World Stroke Organisation, 2022a). According to the most current Global Burden of Disease report (Roth et al., 2020), stroke remains the second leading cause of mortality and the third leading cause of death and disability combined, as expressed by disability-adjusted life-years lost (DALYs). A DALY is a year lost due to illness, disability or early mortality (World Stroke Organisation, 2022b). The global burden of stroke, as measured by the number of stroke incidents, deaths and stroke-related disabilities, rose significantly between 1990 and 2010: stroke-related deaths were up by 43.0%, the incidence of stroke rose by 70.0%, stroke prevalence increased by 102.0% and stroke-related DALYs rose by 143.0%. The worldwide cost of stroke is estimated to be more than US$ 721 billion (World Stroke Association, 2022b). Figure 1.8 shows the top ten global causes of death in 2000 and 2019 according to the WHO (2020).

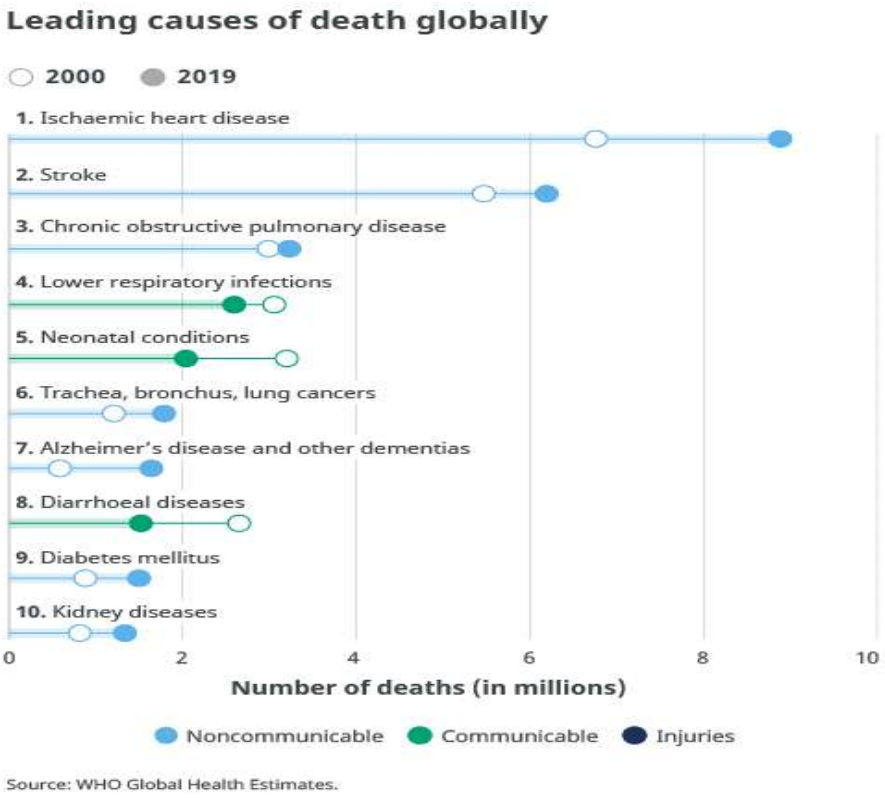


Figure 1.8: Top ten global causes of death, 2000 and 2019 (WHO, 2020)

1.1.7 Stroke in the UK

According to the most recent statistics, a stroke occurs every five minutes in the UK, totalling 100,000 stroke incidents each year (Stroke Association, 2022c). The Stroke Association's latest State of the Nation report discloses that stroke is considered the fourth leading cause of mortality in England and Wales and the third leading reason of mortality in Scotland and Northern Ireland. Approximately 38,000 people died from stroke in the UK in 2016 (Stroke Association, 2018a). It is estimated that one death in 14 is caused by stroke, comprising 6% of all deaths in men and 7% in women. Table 1.3 shows the number of people who died of stroke in England, Scotland and Northern Ireland in 2016. Wafa, Wolfe, Bhalla and Wang (2020) conducted a population-based analysis of data from south London patients diagnosed with

ischemic stroke between 2000 and 2015. After adjusting for population changes, they found that deaths from stroke decreased by 24% over the 15-year period (Figure 1.9).

Table 1.3: Mortality in the UK, 2016 (Stroke Association, 2018a)

Country	Male	Female	Total
England and Wales	13,877	18,750	32,627
Scotland	1,712	2,430	4,142
Northern Ireland	434	568	1002
Total	**16,023**	**21,748**	**37,771**

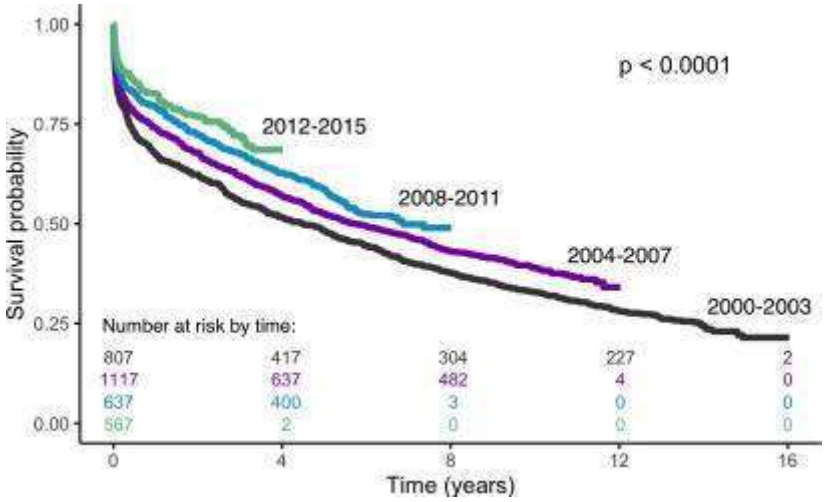


Figure 1.9: UK survival rates after ischemic stroke, 2000-2015 (Wafa et al., 2020)

Understanding the scope and variety of effects for a condition as prevalent as stroke can be extremely helpful in determining how to allocate limited resources (Stroke Association, 2018b). The Stroke Association (2018b) estimates that the number of first stroke incidents in UK adults aged 45 years will rise by 59% from 2015 to 2035 and that the number of people aged 45 and over who are living with long-term consequences of stroke will increase by 123% during the same period, as Figures 1.10 and 1.11 show.

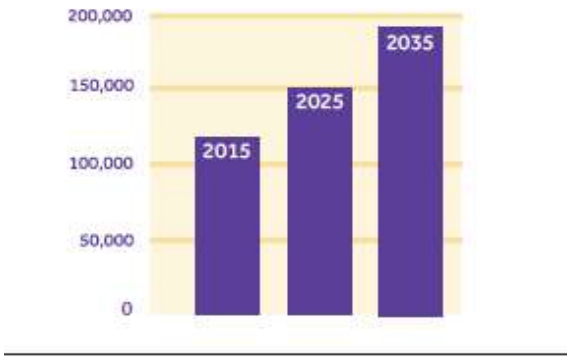


Figure 1.10: Incidence of stroke by number of people in the UK, 2015 to 2035 (Stroke Association, 2018b)

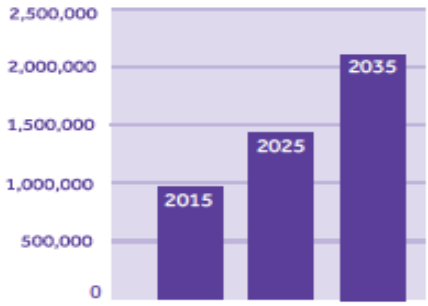


Figure 1.11: Prevalence of stroke in the UK by number of people, 2015 to 2035 (Stroke Association, 2018b)

Reducing the mortality rate of stroke in the UK and thus improving the survival rate will increase the number of people living with long-term consequences of stroke, leaving 1.3 million stroke survivors living in the UK (Stroke Association, 2022c). This has likely been influenced by improvements in technology and in social and healthcare systems, in particular successful preventative approaches and post-stroke care services. Stroke is influenced by age and there has been a massive demographic change in the UK population as life expectancy has increased; in other words, people are living longer than before (King et al., 2020). There are currently more than 11 million over-65s in the UK and within a decade this number is expected to grow to 13 million, i.e. about 22% of the total population (Centre for Aging Better, 2022). Many stroke survivors have to cope with long-term physical, psychological, social and functional residuals (Skoglund, Westerlind, Persson, & Sunnerhagen, 2019). Figure 1.12 shows the percentage of the 2016 population of each of the four nations of the UK comprising stroke survivors.

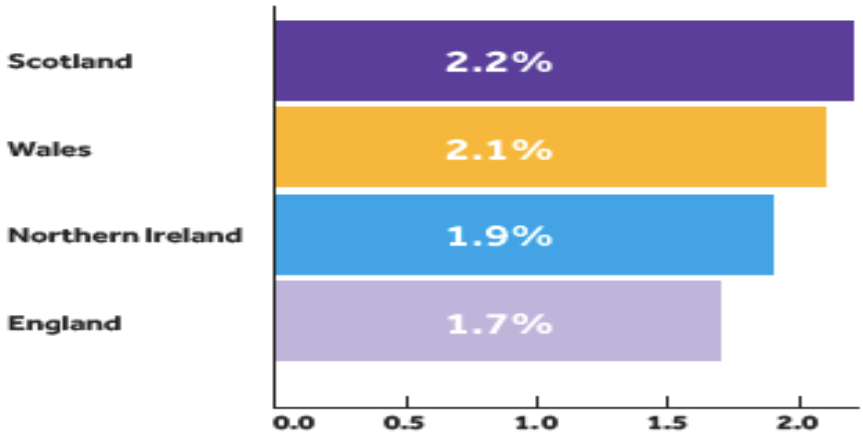


Figure 1.12: Percentage of stroke survivors in UK population, 2016 (Stroke Association, 2018a)

1.1.8 Socio-economic impacts of stroke

Stroke can place heavy demands on both people and economy (Di Carlo, 2009). In economic terms, the cost of stroke treatment in the UK is anticipated to increase rapidly over the next 20 years (King et al., 2020). The economic consequences of stroke in the UK extend beyond stroke survivors and their families to sectors of society including the NHS, social care services, reducing employment and productivity more generally (Stroke Association, 2018b). The total annual cost of stroke in the UK in people aged 45 and older will increase from £26 billion in 2015 to £43 billion in 2025 and £75 billion in 2035, representing a 194% rise in 20 years (Stroke Association, 2018b). Figures 1.13 and 1.14 show respectively the total cost of all new stroke cases in the UK by sector and the total cost of people living with the consequences of stroke by sector in 2015. In the UK, the burden of stroke patients is reflected in the significant expenditure on delivering healthcare services to them (Xu et al., 2018). Preventing, treating and managing the consequences of stroke all put a significant economic burden not only on the NHS but on the whole community (Patel et al., 2020). One the other hand, the cost of social care services rises from only 11% in the first year post stroke to 22% (around £4.6 billion) for long-term care (Patel et al., 2020).

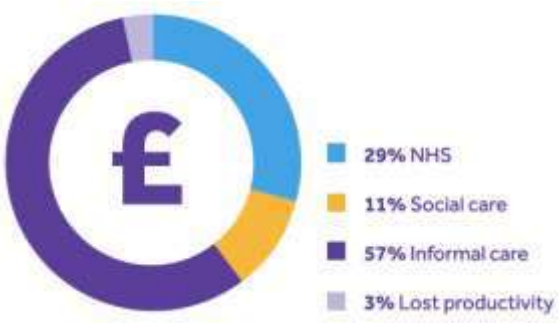


Figure 1.13: Total UK cost of incidence of stroke by sector, 2015 (Stroke Association, 2018b)

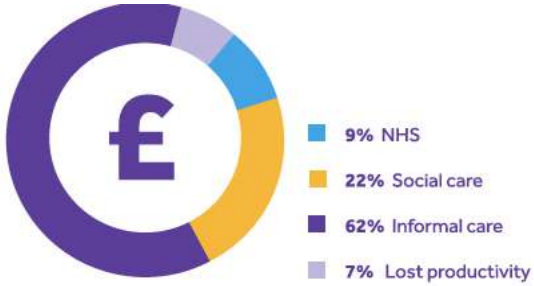


Figure 1.14: Total UK cost of prevalence of stroke by sector, 2015 (Stroke Association, 2018b)

1.1.9 Impact of stroke on individuals

Having discussed the social and economic consequences of stroke, this section turns to the impact on individuals, beginning with symptoms and impairments. The FAST stroke campaign (Public Health England, 2018b) sought to make the public aware of the urgent need to call the emergency services if they noticed any of the signs and symptoms of stroke, the early ones being weakness of the arm, changes to the face and slurred speech (NHS, 2019). It is essential to respond quickly to these early signs and treat them, to limit the risk of developing another stroke (NHS, 2019). Stroke is a heterogonous illness whose resultant impairments are primarily determined by the location (Figure 1.7) and severity of the injury in the brain (American Stroke Association, 2022; National Institute of Neurological Disorders and Stroke, 2022). Nevertheless, there are common impairments (Figure 1.15) such as weakness or complete paralysis of one side of the body, visual and speech difficulties and reduced cognitive ability (NHS, 2019; Stroke Association, 2022a).

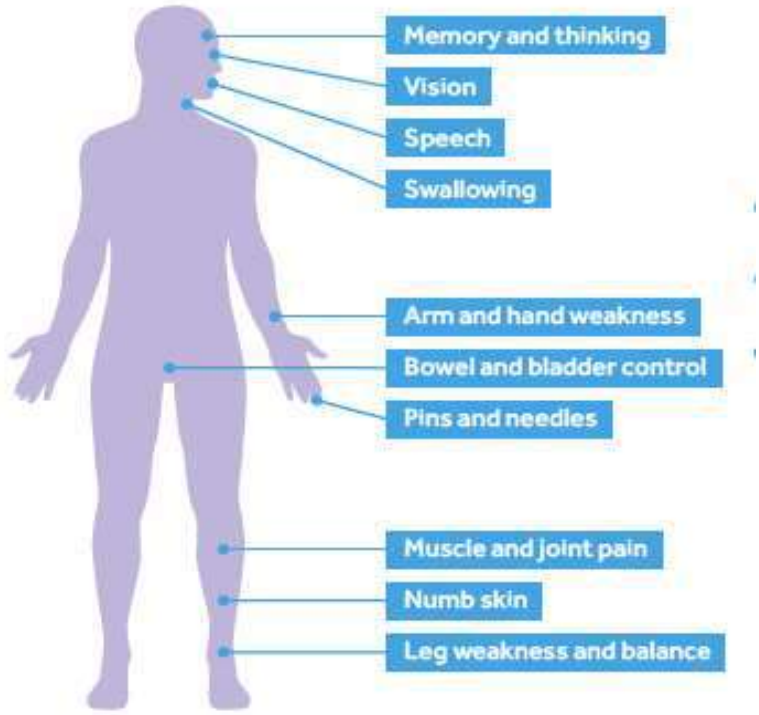


Figure 1.15: Common impairments caused by stroke (Stroke Association, 2018a)

While stroke is a sudden event, it has significant long-term consequences for patients, families and communities (Fryer, Luker, McDonnell, & Hillier, 2016). Stroke can lead to a broader range of disabilities than many other conditions (Brain Research UK, 2022; Stroke Association, 2016). Adamson, Beswick and Ebrahim (2004) aimed to determine whether stroke was the most common cause of disability in the UK by performing a secondary analysis of data from a survey of disability conducted in 1996 by the Office of National Statistics. They found that stroke was linked to more individual domains of disability than any other health disorder including heart, respiratory, musculoskeletal and digestive conditions. These individual domains were mobility, gross motor skills (reaching and stretching), fine motor skills, communication, bladder and bowel control, hearing and vision. The burden of stroke on the

individual arises from impairments and disabilities related to the condition and a combination of an increasingly ageing population and reduced mortality rates (Stroke Association, 2018b). Improving the stroke survival rate means that those who survive face greater long-term physical, cognitive, functional, psychological and social consequences (Opara & Jaracz, 2010). In 2018, the UK Stroke Association (2019) conducted a survey of 11,000 stroke survivors and their caregivers (the largest ever such survey) to learn more about the lived experience of survivors and how their strokes had impacted them. More than two thirds (69%) reported that stroke had affected their independence and 42% described this effect as moderate to severe. The most common types of disabilities consequential to stroke are physical, particularly mobility difficulties and limitations in carrying out physical activities such as walking, gripping and holding objects, all of which can have a major impact on personal independence (Ellis-Hill et al., 2009). On the other hand, there are hidden post-stroke effects that are not obvious to other people (Carlsson, Möller, & Blomstrand, 2004). Nine out of ten stroke victims said they had at least one cognitive problem, such as memory or concentration problems. Additionally, 44% reported anxiety and depression symptoms, 42% reported mood swings, 16% had considered suicide and 74% reported a lack of confidence (Stroke Association, 2019).

The biopsychosocial model of health can provide a comprehensive understanding of the impact of many factors of an illness , ranging from biological (e.g. structures and functions) to psychological (e.g. depression and anxiety) and social (e.g. social interaction and community activities) ,and how their interaction might impact a person's health (physical and emotional) (Kontou et al., 2022). The biological factors are frequently associated with the relationship between illness and physical health (El-shamaa, El-Banouby, & Mustafa, 2011). For example, a stroke can cause weakness on one side of the body .The social factors are interpersonal

relations such as relationships with others and participation in community (El-shamaa, El-Banouby, & Mustafa, 2011).Stroke impairments can effect on a person's ability to participate in community activities and sustain healthy social relationships. Psychological factors linked to mental and emotional well-being that are also associated with behaviour (El-shamaa, El-Banouby, & Mustafa, 2011).Sudden lifestyle changes result in mental health problems such as depression and anxiety. Professionals must understand how biopsychosocial variables interact in order to better understand the disease's and utilise it as foundation for planning the intervention (Wijma, van Wilgen, Meeus, & Nijs, 2016).

1.1.10 Impact of stroke on psychosocial well-being

Stroke can significantly threaten the psychosocial well-being of stroke survivors and their partners of care (Bakas et al., 2014; Cheng, Chair, & Chau, 2014). Psychosocial well-being includes several dimensions which can be affected after a stroke: 1) basic mood of happiness and absence of sadness; 2) engaging in meaningful activities; 3) having good social relationships; 4) feeling mutual love; 5) self-concept, including belief in one's own abilities, self-acceptance and usefulness (Kirkevold et al., 2018). Studies have reported significant and far-reaching impacts of stroke on psychological well-being (Barker-Collo, 2007; Burton et al., 2013; Hackett, Yapa, Parag, & Anderson, 2005; Peter Knapp, Young, House, & Forster, 2000; Kouwenhoven, Kirkevold, Engedal, & Kim, 2011). Psychological problems post stroke can undermine the benefits of rehabilitation services and increase mortality rates (Ferro, Caeiro, & Santos, 2009; Hackett, Anderson, House, & Halteh, 2008a; Hackett, Anderson, House, & Xia, 2008b); they may also have a substantial negative impact on longer-term functioning and quality of life (QOL) (Ferro et al., 2009; Teoh, Sims, & Milgrom, 2009). Stroke can affect

identity and cause feelings of worthlessness, and survivors' refusal to accept their disability is strongly linked to their experience of depressive symptoms (Townend, Tinson, Kwan, & Sharpe, 2010).

Depression and anxiety are the most common psychosocial difficulties reported after stroke (Wan-Fei et al., 2017). Almost one third of stroke survivors experience depression at some point and up to five years post stroke incident (Hackett & Pickles, 2014). In addition, a seven-year follow-up study found that 19% of stroke survivors experienced depression (Dam, 2001). A more current study observed a 55% prevalence rate of depressive symptoms over a 15-year period (Ayerbe, Ayis, Crichton, Wolfe, & Rudd, 2013). Some researchers have suggested that depression post stroke is a direct consequence of infarcted lesions damaging the nervous circuits that control mood. According to others, depression might develop as a result of extreme sensibility and the inability to deal with the severe losses brought on by a stroke (Kouwenhoven et al., 2011). Post-stroke depression is associated with poor rehabilitation outcomes and higher mortality rates, and is considered a significant predictor of QOL (Paolucci, 2008). Moreover, anxiety is reported to be prevalent after stroke, as 20-25% of stroke survivors reported experiencing anxiety (Burton et al., 2013; Tang, Lau, Mok, Ungvari, & Wong, 2013). Anxiety prevalence increased to 44% among stroke survivors with aphasia (Morris, Eccles, Ryan, & Kneebone, 2017).

Psychological distress, dependence in performing daily activities and changes to social relationships and interactions can all affect stroke survivors' quality of life negatively (Kim, Kim, & Kim, 2014). QOL is a multifaceted concept comprising three broad domains: physical, mental and social. Clinicians and scholars in the discipline of medicine frequently refer to health-related quality of life (HRQOL), which concentrates on the effect of a disease on people's self-perceptions of their health and well-being or their sense of satisfaction with life

(Jaracz & Kozubski, 2003). HRQOL is lower in post-stroke patients than in the general population and lower than in the same people before the stroke incident (Yeoh et al., 2019). In a large, prospective, population-based, multi-ethnic study of 207 first-time ischemic stroke patients, the HRQOL score at six months after stroke was 27% lower than the pre-stroke score and the HRQOL decreased yearly for five years after the stroke (Dhamoon et al., 2010). Moreover, stroke can have a significant impact on people lives, leading to reduced HRQOL even among stroke survivors who do not experience residual disabilities (Lai, Studenski, Duncan, & Perera, 2002). Carlsson et al. (2004) explored the experiences of fifteen people who had experienced a mild stroke with few or no symptoms. A year after their stroke, participants reported impacts on many dimensions of their everyday lives. A more recent study (Dhamoon et al., 2010) found that the HRQOL score was still 12% lower at six months, even among stroke patients who had become functionally independent.

Many stroke survivors live with long-term difficulties in coping with the challenges of everyday life (Aström, Asplund, & Aström, 1992; Hackett, Duncan, Anderson, Broad, & Bonita, 2000; Lo, Chau, & Chang, 2021). Their ability to carry out activities of daily living (ADLs) and re-engage in their communities, where they perceive their self-identity and satisfaction to derive from, has been found to be negatively impacted by the experience of stroke-related impairments and disabilities (Clarke & Black, 2005; Cott, 2004; Lord, McPherson, McNaughton, Rochester, & Weatherall, 2008; McKenna, Chen, & Barrett, 2017; Secrest & Thomas, 1999). ADLs are defined as the everyday activities that an individual performs to maintain health and well-being (Legg, Lewis, Schofield-Robinson, Drummond, & Langhorne, 2017). They range from basic activities of daily living (BADLs) such as hygiene and grooming, eating and dressing, to the more complex instrumental activities of daily living

(IADLs), which are related to independent living in the community (Legg et al., 2017; Mlinac & Feng, 2016).

Many factors affect stroke survivors' ability to carry out ADLs (McKenna et al., 2017). Mercier, Audet, Hébert, Rochette and Dubois (2001) conducted a study of a hundred stroke survivors aged 55 to 79 years, to assess the relative impacts of cognitive, perceptual and motor impairments on their independent ability to perform ADLs. The results show that all such impairments can create disabilities significantly associated with a reduced ability to perform ADLs independently. Of these, motor impairment is considered to have the most significant impact and to be the strongest predictor of post-stroke performance of ADLs. More recent studies also show that cognitive problems, depression and fatigue can all have negative impacts on performing ADLs (Blomgren et al., 2019; Schöttke, Gerke, Düsing, & Möllmann, 2020).

Among 50 million stroke survivors worldwide, it is estimated that 25% to 74% require some or complete assistance with ADLs (Miller et al., 2010). Stroke survivors may need assistance from family members in performing personal hygiene tasks, potentially disrupting their family relationships and impairing their self-dignity and self-esteem (Legg et al., 2017). A comprehensive review and synthesis of qualitative data regarding the psychological journey after stroke found that difficulties in carrying out daily activities and the need for assistance tended to disrupt relationships and roles (Lincoln, Kneebone, Macniven, & Morris, 2011), while dependence on others in carrying out self-care activities it often associated with various cognitive, social and emotional problems (de Weerd, Rutgers, Groenier, & van der Meer, 2011).

The main domain for measuring post-stroke HRQOL is autonomy in performing ADLs (Won, 2008). Previous research has found that stroke survivors who needed help from others because

they are unable to carry out BADLs independently may experience low HRQOL, undergo institutionalisation and suffer an increased fatality rate (Von Bonsdorff, Rantanen, Laukkanen, Suutama, & Heikkinen, 2006). Mackenzie and Chang (2002) report that HRQOL as measured by the 36-item Short Form Survey was associated with disability in performing BADLs according to the Functional Independence Measure and the modified Rankin Scale, which are tools that measure dependency in performing BADLs among stroke patients (Broderick, Adeoye, & Elm, 2017). Another study observed that stroke survivors at three months after stroke had lower HRQOL than members of the general population of the same age and sex (Gunaydin, Karatepe, Kaya, & Ulutas, 2011). The results of this study, conducted among elderly Turkish stroke survivors, show that physical functioning status was the main factor affecting HRQOL. More recently, Kim et al. (2014) administered a questionnaire to 68 stroke survivors and were able to identify a significant relationship between independence in performing ADLs and quality of life. In particular, mobility was one of the ADLs having the most significant impact on HRQOL.

It is crucial for stroke survivors to be able to perform not only the basic activities of daily living, but also more complex behaviours that would allow them to continue living independently at home and engaging in community life (Blomgren et al., 2019; Carod-Artal, González-Gutiérrez, Herrero, Horan, & Seijas, 2002). McEwen, Mayo and Wood-Dauphinee (2000) conducted a performance-based assessment aimed at inferring quality of life post stroke. They observed that higher IADL scores were associated with more positive post-stroke psychological well-being. Degree of independence in performing IADLs is correlated with high quality of life, as it lowers the risk of depression and anxiety and improves health outcomes (Liao & Chang, 2020; Storeng, Sund, & Krokstad, 2018).

IADLs are related to more complicated daily activities such as household tasks, employment (both paid and unpaid), leisure and social activities, managing finance and medication. Studies with long-term follow-up suggest that stroke can negatively affect the performance of IADLs years after the event (Singam, Ytterberg, Tham, & von Koch, 2015; Walsh, Galvin, Loughnane, Macey, & Horgan, 2015; Wolfe et al., 2011). Stroke-related cognitive impairments and disabilities are frequently the main factors limiting independence in performing IADLs, whereas physical disabilities, often caused by motor impairments, are more likely to disrupt the ability to perform BADLs (Mlinac & Feng, 2016). The performance of IADLs demands higher cognitive skills than that of BADLs (Babulal, Huskey, Roe, Goette, & Connor, 2015; Blomgren et al., 2019; Stolwyk, Mihaljcic, Wong, Chapman, & Rogers, 2021; Sveen, Thommessen, Bautz-Holter, Wyller, & Laake, 2004). Moreover, research has revealed a significant relationship between IADL performance and depression post stroke (Lai, Duncan, Keighley, & Johnson, 2002). Forty percent of survivors are functionally dependent in performing IADLs three year after stroke (Sennfält, Norrving, Petersson, & Ullberg, 2019). When Van der Zee, Visser-Meily, Lindeman, Jaap Kappelle, and Post (2013) measured the participation level of 111 stroke survivors, they found that almost half had experienced restricted participation in domestic tasks, outdoor activities and physical exercise at one year post stroke and that a third of participants reported dissatisfaction regarding their level of participation. Moreover, in the UK, approximately one in four strokes occurs in people of working age and around half of these survivors are able to work after stroke (Daniel, Wolfe, Busch, & McKevitt, 2009; Stroke Association, 2022d). Employment and return to previous roles are crucial to quality of life and stroke survivors who do not return to work may be at higher risk of depression (Hackett, Glozier, Jan, & Lindley, 2012).

Stroke survivors can experience a decline in their social participation due to lack of opportunities to socialise through employment and social activities; therefore, social isolation is common after stroke (Peter Knapp et al., 2000; Kouwenhoven et al., 2011; Salter, Foley, & Teasell, 2010). Social participation is a complex concept and multiple elements can contribute to this restriction in social activities (Kim et al., 2014). Factors that have been identified as predictors of restriction in social participation include increased age at the onset of stroke, severe stroke-related disabilities, dependency on ADLs, psychological distress, depression, experiencing another stroke and decreased cognitive and communication abilities (Desrosiers et al., 2006; Gall, Dewey, Sturm, Macdonell, & Thrift, 2009; Patel, Coshall, Rudd, & Wolfe, 2002; Singam et al., 2015). A comprehensive qualitative meta-synthesis conducted to understand the experience of stroke survivors identified restriction in social activities as a common theme (Salter, Hellings, Foley, & Teasell, 2008). An inception cohort study using the Frenchay Activities Index (FAI) to measure the level of social activities in Dutch stroke survivors at one year post stroke (Schepers, Visser-Meily, Ketelaar, & Lindeman, 2005) found that that the FAI score in the cohort was lower than in the general population as reported in the earlier literature (Hachisuka et al., 1999; Turnbull et al., 2000; Schuling et al., 1993, cited in Schepers et al., 2005). In a later long-term prospective cohort study, Jansen, Schepers and Visser-Meily (2012) observed a deterioration in the level of social activities at three years post stroke. Low levels of social participation have been associated with low self-perceived physical health (Cornwell & Waite, 2009), lower life satisfaction (Activities, Soroker, Ring, Avni, & Katz, 2007), a high risk of depression (Santini et al., 2016), psychological distress (Feng & Astell-Burt, 2016) and adverse events following a stroke (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005). Social participation and social support are central to well-being, are important in determining self-related quality of life after stroke and can protect survivors

against post-stroke depression (Nichols-Larsen, Clark, Zeringue, Greenspan, & Blanton, 2005).

1.2 Context: UK policy and clinical guidelines

1.2.1 Psychological and emotional support

The policy and clinical guidelines operative in the UK are supportive of providing emotional and psychological support to stroke survivors and their carers. In England, the National Service Framework for Older People (Department of Health, 2001) recognises that stroke has a substantial effect on survivors' lives and that stroke survivors should have easy access to support. The National Stroke Strategy standards (Department of Health, 2007) require the provision of emotional support throughout the stroke pathway, including by the voluntary sector. The Cardiovascular Disease Outcomes Strategy (Department of Health, 2013) requires commissioners and providers to focus on emotional and psychological support for stroke survivors and their carers. In Scotland, the Better Heart Disease and Stroke Care Action Plan acknowledges the emotional consequences of stroke and advocates for accessible access to emotional support in both hospital and community settings (Scottish Government, 2009). In Northern Ireland, Transforming Your Care (Northern Ireland Government, 2011) makes recommendations to improve the psychological health and well-being of stroke patients. Finally, in Wales, the 2017–2020 Stroke Delivery Plan (Welsh Government, 2012) calls on local health services to offer emotional support.

Regarding the clinical guidelines in England, the fifth edition of the National Clinical Guidelines for Stroke (Rudd, Bowen, Young, & James, 2017) recommended that stroke services provide emotional support to all survivors across acute and community settings, regardless of whether they present mental or cognitive problems. The importance of emotional

support post stroke is also highlighted by the UK National Institute of Health and Care Excellence (NICE, 2013). Nevertheless, to date access to psychological services within stroke units in the UK is very limited, at around only 5% (Gittins et al., 2020). This may be because the availability of psychological services for stroke patients varies across the UK and depends mainly on where they live (Boakye et al., 2019). Moreover, HCPs may not have enough time or be sufficiently trained to handle psychological issues brought up by their patients (Lincoln et al., 2011). The cost of health care for patients with long-term health conditions and psychological problems was found to be typically 45% higher than for patients without such problems (Naylor et al., 2012). This can have economic consequences for healthcare services; minimising the cost burden is therefore a significant priority.

1.2.2 Social support

Stroke survivors and their caregivers should be considered for approaches to facilitate social support. Health and well-being studies have defined social support as the accessibility or delivery of a relationship, information or support that enables an individual to effectively manage daily life in the presence or absence of a health crisis (Beckley, 2006). The elements of social support include emotional components (e.g. listening, caring, acceptance), practical help, providing information, companionship (e.g. sense of belonging and socialisation) and validation (Shumaker & Brownell, 1984; Wills & Shinar, 2000). There is evidence that social support is important for physical and functional status (Glass, Matchar, Belyea, & Feussner, 1993; Hershkovitz, Beloosesky, Brill, & Gottlieb, 2004; Tsouna-Hadjis et al., 2000; Villain, Sibon, Renou, Poli, & Swendsen, 2017), for psychological recovery after stroke (Hilari et al., 2010; Knapp & Hewison, 1998; Volz, Möbus, Letsch, & Werheid, 2016) and for community participation (Erler, Sullivan, McKinnon, & Inzana, 2019). In England, social support is

included in the recommendations of the National Strategy for Stroke (Department of Health, 2007) and in clinical guidelines for assisting stroke survivors and their careers in the community following stroke (NICE, 2013).

1.2.3 Long-term management

The WHO defines a condition as chronic or long-term if it persists for several years and requires ongoing management (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). Given the potential long-term physical, emotional, psychological and social consequences of stroke described above, stroke is considered a chronic condition that requires continuing long-term management (O'Neill, Horgan, Hickey, & McGee, 2008). In the UK, providing health and social services to people with chronic conditions entails significant cost to the NHS, as these account for 50% of all general practitioner appointments and 75% of admissions to both health and social care services (Department of Health, 2013). The importance of supporting stroke survivors in managing the long-term consequences of stroke is acknowledged by a number of policies (Department of Health, 2007; NICE, 2013) and guidelines (Rudd, Bowen, Young, & James, 2017).

1.3 Promoting psychosocial well-being after stroke

Providing psychosocial support and intervention is an important element for rehabilitation and reintegration into the community after stroke and is linked with experiencing positive health outcomes and quality of life (Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). It can play an essential role in how stroke survivors deal with having a chronic illness and can also impact on their self-efficacy, self-esteem and motivation (Cudney et al., 2005). Consequently, rehabilitation programmes that focus on patients' psychosocial well-being are required (Hackett et al., 2005).

Psychosocial interventions are defined as including both psychological and social elements (Thompson & Ski, 2013). The former target a person's behaviour through processes such as motivational interviews and counselling, and are evaluated by psychologically orientated sub-scales and questions (Gerrig, Zimbardo, Campbell, Cumming, & Wilkes, 2015). Social elements refer to individuals' interactions with their social environment using measures that include social sub-scales or questions, such as the QOL scale (Northcott & Hilari, 2018). Several studies have examined interventions aimed at enhancing the psychosocial well-being of stroke patients and at preventing anxiety and depression (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Kirkevold, Martinsen, Bronken, & Kvigne, 2014; Lawrence, Booth, Mercer, & Crawford, 2013; Lennon, McKenna, & Jones, 2013; Watkins et al., 2011). Research has shown that providing informational support (De Man-van Ginkel et al., 2010; Forster et al., 2012), counselling (Salter et al., 2010), emotional support (Northcott & Hilari, 2018), practical support (Kautz, 2007), motivational interviewing (Watkins et al., 2011) and liaison with stroke services may all promote psychosocial well-being after stroke. However, the only intervention having a significant effect was motivational interviewing (Cheng et al., 2015). A randomised controlled trial of this intervention showed a statistically positive effect compared with routine post-stroke care and concluded that motivational interventions might improve stroke patients' mood at three and twelve months follow-up (Watkins et al., 2011). In contrast to physical and functional needs, psychological needs increase with time, which reflects the necessity of providing adequate long-term services (Taylor et al., 2014). Moreover, it has been suggested that post-stroke adaptation is a lengthy, non-linear process that involves both improvements and failures, and that personal traits as well as pragmatic and psychological coping mechanisms may be important (Kirkevold, 2002; Sarre et al., 2014).

Another common approach to psychosocial intervention after stroke is self-management, which is the key response of healthcare systems worldwide to the difficulties of long-term conditions (WHO, 2002). In the UK, self-management is encouraged during stroke rehabilitation and is now part of the stroke care pathway (Fryer et al., 2016). Self-management has been defined as a process in which patients with chronic conditions such as stroke are supported to participate actively in their recovery (Frantz, Schopp, & Rhoda, 2021). This definition has been encouraged by the WHO (2021). It has alternatively been described as an approach in which HCPs teach patients how to make decisions, solve problems or set goals in order to manage the physical and psychosocial effects of their conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Taylor et al., 2014). Many self-management approaches are supported by evidence, particularly in the areas of behaviour modification, self-efficacy and goal setting (de Silva, 2011; Warner, Packer, Villeneuve, Audulv, & Versnel, 2015). Moreover, as determined by a Cochrane review published in 2016, self-management interventions within a self-efficacy conceptual framework are the most beneficial in improving patients' psychological state and QOL after a stroke (Fryer et al., 2016), as there is a direct link between self-efficacy and activity engagement, emotions and quality of life following stroke (Gustavsson, Bergström, Denison, & von Koch, 2013).

Self-management approaches promote person-centred care by providing patients with skills and knowledge in order to manage and improve their condition based on their needs, values and beliefs (Fu et al., 2020). This is evidenced by research demonstrating that recovery following a stroke can be improved when the patient, his or her family or care network collaborate with medical professionals and are supported to identify their own objectives and tasks to assist recovery (Fu et al., 2020). Considering this, there is still a pressing need to develop and enhance psychosocial interventions in stroke rehabilitation (Bragstad et al., 2020)

1.4 Storytelling-based interventions in a healthcare context

Storytelling is an emerging and encouraging low-cost, low-risk psychosocial intervention that could be useful for patients with chronic illnesses (Evans, Crogan, & Bendel, 2008). It is defined as "the effort to communicate events using words (prose or poetry), images, and sounds often including improvisation or embellishment", because stories are "reflective, creative and value laden, usually revealing something important about the human condition" (Haigh & Hardy, 2011, pp. 408-411). Telling stories is a natural and universal communication tool (Randall, 2014). It is an important aspect of life, since it is often used to describe who we are as individuals, who we want to be and what beliefs we possess (Schoenau & Jackson, 2016). Storytelling allows individuals to articulate their own reality, emotions and future hopes (Gucciardi, Jean-Pierre, Karam, & Sidani, 2016; Randall, 2014). Telling their own stories gives people control over how they want to be represented, promotes self-reflection, and constructs and maintains self-identity (Abma, 2003; Frank, 2000; Martinsen, 2006; Polkinghorne, 1988).

Studies have suggested that sharing one's story after a traumatic life event is a basic need that can improve health and facilitate positive psychological or emotional adaption and response to illness (Evans, Crogan, & Bendel, 2008; Frank, 2010, 2013; Soundy, 2018). Telling a story entails the teller reliving events, which involves discussing emotions (Larkey & Hecht, 2010). Storytelling allows for the transformation of psychological and emotional discomfort into a language that allows people to 'forget' or step beyond their stressful experiences (Evans et al., 2008; France, Hunt, Dow, & Wyke, 2013; Soundy, Smith, Cressy, & Webb, 2010). The significance of patients' stories has been acknowledged in their ability to enhance clinical practice and communication (Cole-Kelly, 1992; Trisha Greenhalgh & Hurwitz, 1998; Platt et al., 2001). In a healthcare context, storytelling and narrative-based approaches have been

utilised in a variety of forms and for a variety of reasons, with people suffering from a variety of illnesses (Byrne & Soundy, 2020; Gucciardi et al., 2021). Storytelling may serve, for instance, as an educational tool for patients with chronic conditions (Cangelosi & Sorrell, 2008), as a way of instilling hope in children diagnosed with cancer (Hedtke, 2014), as a strategy to minimise social isolation among patients with breast cancer (Høybye, Johansen, & Tjørnhøj-Thomsen, 2005) and as medium for people with cancer to express their emotions (Fioretti et al., 2016). Moreover, patients' stories have been utilised to explore experiences of illness, to assist HCPs in understanding their patients and to establish relationships with their families (Clarke, Hanson, & Ross, 2003).

Storytelling is a novel approach that help patients with chronic conditions to better understand their own illness and learn how to manage it (Greenhalgh et al., 2011; Houston et al., 2011). The implementation of storytelling in managing chronic conditions is based on the notion that everyone has their distinctive experiences related to living with and managing their illness (Gucciardi, Jean-Pierre, Karam, & Sidani, 2016; Mitton, Adair, McKenzie, Patten, & Perry, 2007). Listening to the stories of others facilitates self-refection, reveals that others may be going through similar experiences and offers an insight into what might be possible after the illness (Greenhalgh, Collard, & Begum, 2005). Thus, sharing stories enables patients to learn new practical coping skills and strategies and to integrate them into their own lives (Cangelosi & Sorrell, 2008; Greenhalgh et al., 2011; Greenhalgh et al., 2005). Narratives are used as motivators, persuaders or role models for other patients to respond to their actions and can also help to overcome resistance and speed up the processing of information (Kreuter et al., 2007; Slater & Rouner, 2002). Sharing stories within a group format not only facilitates organisational learning, where open discussion helps group members learn and understand various topics related to disease management in all its practical complexities (Gucciardi et al.,

2016), but also creates a sense of trust and belonging among peers, providing opportunities to develop valuable relationships and support networks, thus mitigating the social isolation and stigma that many stroke survivors experience (Gucciardi et al., 2016; Gucciardi et al., 2021). Despite the promising findings, evidence for the effectiveness and value of storytelling in stroke is still limited and further research is required (Ch'Ng, French, & Mclean, 2008; Faircloth, Boylstein, Rittman, & Gubrium, 2005; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004).

1.5 Storytelling interventions in healthcare training

Healthcare professionals, including physiotherapists (PTs) and occupational therapists (OTs), recognise the significance of psychosocial approaches as a component of patient care that can help them manage a wide range of clinical presentations (Soundy et al., 2021). HCPs are aware that acquiring psychological and communication skills can enhance patient outcomes in adherence, confidence and other psychosocial areas (Soundy et al., 2021). Being treated by HCPs with psychological training has clearly shown health advantages for patients (Coronado, Patel, McKernan, Wegener, & Archer, 2019). For HCPs, including PTs and OTs, working in the NHS as part of the Health Care Professions Council in the UK, the application of psychological skills and techniques is a specified need (Alexanders & Douglas, 2016). Key components of communication are empathy (Baddeley & Bithell, 1989) and listening (Alexanders & Douglas, 2016; Verbeek, Sengers, Riemens, & Haafkens, 2004). However, data from a prior review showed that HCP students felt underequipped in their fundamental communication skills (Hill, Davidson, & Theodoros, 2010). This could be due to a lack of emphasis on incorporating psychological and communication skills training into HCP courses at undergraduate level (Heaney, Green, Rostron, & Walker, 2012). There is still no established

approach to teaching psychological skills on undergraduate HCP courses in UK universities (Alexanders & Douglas, 2016; Heaney et al., 2012; Zangoni & Thomson, 2017). Psychological skills training in such courses across the UK lacks standardisation in both content and nature (Alexanders & Douglas, 2016; Ballengee, Covington, & George, 2020), creating the potential for challenges including lack of knowledge in recognising the skills that fall under their scope of practice, lack of confidence in utilising these skills and limited transferability to clinical practice, because practical training is limited, occurs in unrealistic contexts or is conducted with healthy peers (Driver, Lovell, & Oprescu, 2021; Higgins & Gray, 2020).

An increased emphasis on relationship-based interventions in care settings (Trevithick, 2011) reflects the importance of creative and novel techniques of connecting with patients. According to research, more theory-based training is needed when teaching HCP students psychological communication skills (Jevon & Johnston, 2003). Narrative-based interventions have been shown to cause positive change for patients and promote the best practice for HCPs (Charon, 2009; Haigh & Hardy, 2011; P. Hardy, 2007). It has been demonstrated that storytelling-based educational interventions improve students' narrative competency and HCP-patient communication (C. Hardy, 2017). Storytelling HCPs who are narratively competent are more likely to identify and interpret patients' difficulties and assist them through their disease journey, which can enhance outcomes (Chen, Huang, & Yeh, 2017; Soundy, Smith, Cressy, & Webb, 2010). Listening to personal stories can increase emotional understanding and empathy, which can aid in the development of rapport and trust between HCPs and patients (Drumm, 2013; Killick & Boffey, 2012). This could be particularly important, as there is evidence that HCPs can lose their empathy during training (Soundy et al., 2010). According to research, storytelling is widely employed in the building of relationships and improves client-centred practice (Killick & Boffey, 2012; Soundy et al., 2010). Moreover, storytelling has been utilised

to teach HCPs ethical values and behaviours (Hensel & Rasco, 1992; Nicholas & Gillett, 1997). Transferring skills and information from an educational context to practice may not be a direct process. Utilising storytelling interventions may be a useful method to ascertain what types of illness narratives could influence HCP students' learning and as a result, impact their clinical practice. While there has been little research into the impact of illness narratives on student learning and clinical practice, the use of storytelling as a standardised educational tool to impart skills and knowledge and a therapeutic intervention to improve the psychosocial well-being of stroke survivors presents a significant opportunity.

1.6 Thesis aim, objectives and organisation

The overarching aim of this thesis is to explore storytelling as a therapeutic intervention in stroke and as an educational tool to improve the psychological and communication skills of student HCPs who work with stroke patients. This will be achieved by pursuing the following objectives through the body of research studies presented in subsequent chapters.

Objective 1 is to explore and establish the existing evidence of the psychosocial outcomes and mechanisms of storytelling and sharing interventions for stroke survivors. This will be achieved by conducting integrated reviews. This knowledge will guide the identification and establishment of such interventions and their benefits in stroke (chapter two).

Objective 2 is to examine illness narrative 'master plots' (common and recognisable story plots related to the experience of illness) as revealed by stroke survivors. Until now, research has focused on defining predetermined illness narrative master plots: the 'restitution', 'chaos' and 'quest' narratives. These narrative master plans, however, represent severe psychological reactions to the illness; alternative narrative plots must be recognised in order to best support stroke survivors and to examine their possible implications. This will be achieved by

conducting a qualitative study using semi-structured interviews to examine the illness narratives that demonstrate the master plots of ‘overcoming the monster’ and ‘assist’. ‘Overcoming the monster’ is the name of one stroke patient’s master plot that has not been thoroughly researched (chapter three).

Three different and unique examples of the master plot of ‘overcoming the monster’ will obtained from Objective 2, summarised into a vignette in order to explore how student HCPs respond to them via a questionnaire. The respondents will include first year and final-year undergraduate (BSc) pre-registration physiotherapy students, as well as pre-registration master’s (MSc-preg) students to compare first-year students lacking clinical experience with those in their third year who have completed the number of clinical hours required for a physiotherapy therapy degree. Students’ responses to such a plot are crucial for improving therapeutic interactions (chapter four).

Objective 3 is to test the impact and understand the experiences of physiotherapy students who will take part in a novel storytelling-based placement intervention involving training and simulated practice in curriculum design and clinical practice. This will be achieved by conducting an explanatory mixed-methods pilot study (chapter five).

Figure 1.16 illustrates the structure and content of the thesis.

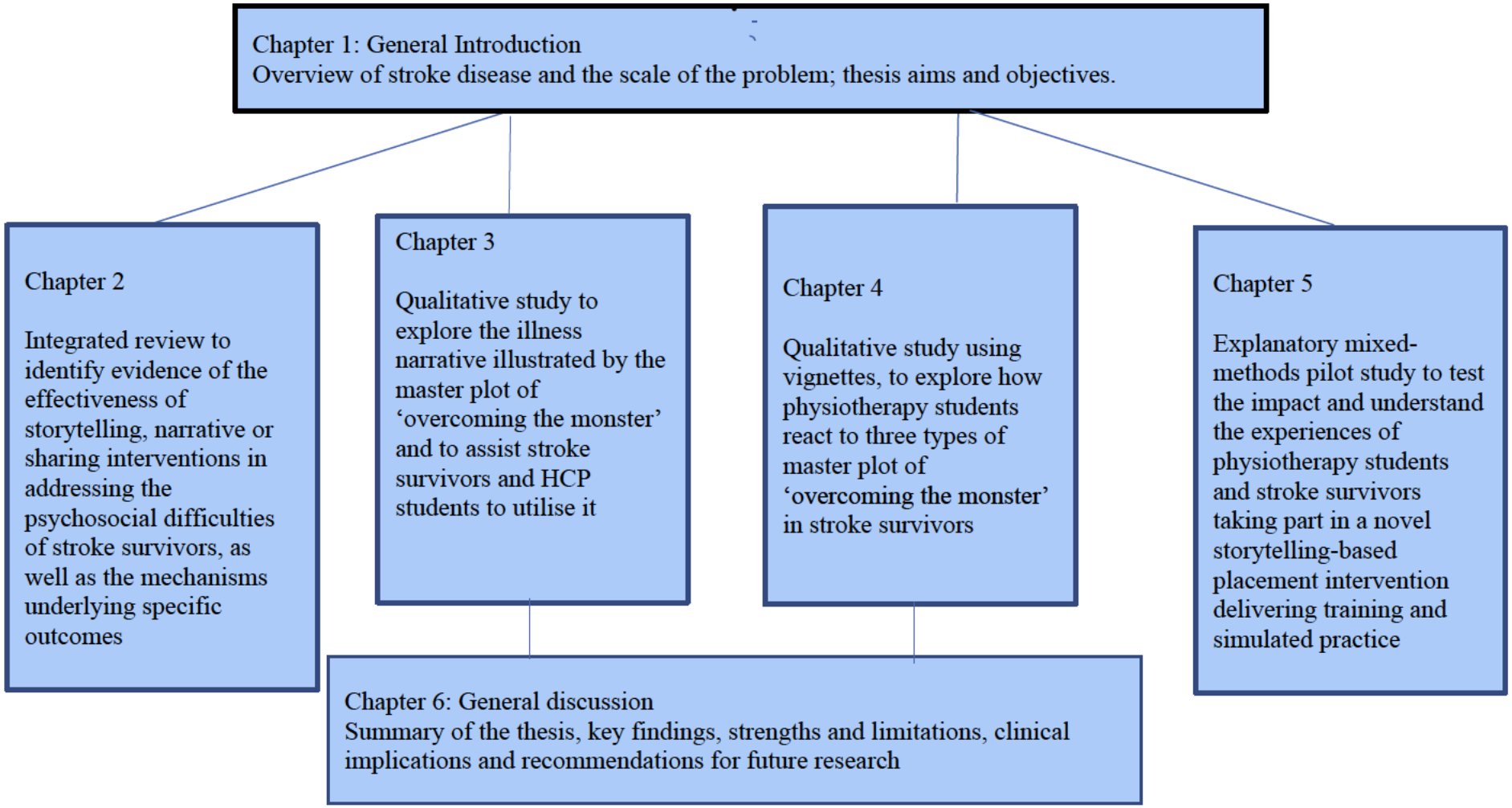


Figure 1.16: Outline of the thesis, with chapter objectives

CHAPTER 2

AN INTEGRATED REVIEW CONSIDERING THE IMPACT OF STORYTELLING AND SHARING INTERVENTIONS IN STROKE

This chapter has been published previously within the manuscript by Alawafi, Rosewilliam, & Soundy (2021). The chapter has been written for the purpose of the current thesis but the results given are the same.

Publication

Alawafi, R., Rosewilliam, S., & Soundy, A. (2021). An integrative review considering the impact of storytelling and sharing interventions in stroke. *Behavioral Sciences, 11*(6), 88 (Appendix 1).

2.1 Abstract

Background: Review-based research is required to determine the psychosocial outcomes and mechanisms of storytelling and sharing interventions for stroke survivors. The benefit and establishment of such interventions will be guided by this knowledge.

Methods: The integrative review was undertaken in three steps: (a) a systematic search strategy was conducted to target articles published between 2009 and January 2020 that looked at storytelling and sharing interventions for stroke survivors; (b) a critical appraisal of the studies' quality was conducted; and (c) synthesis was completed in three stages: data reduction, data display and conclusion.

Results: Fourteen studies totalling 745 participants were found to satisfy the eligibility requirements. Five themes emerged reflecting the outcome and mechanisms that were found to be linked to with a stroke intervention. These themes were: introducing the concept of hope and learning to be positive, the enhanced ability to cope, the impact of loneliness and social interaction, impact on emotions, depression and related emotions such as fear

Conclusions: Storytelling interventions seem to affect loneliness, provide hope and positivity and facilitate coping through sharing of information. Social comparisons and social control appear to be the primary mechanisms affecting these results.

2.2 Introduction

As discussed in Chapter One, a stroke has a significant impact on negative mood states, social identity and relationships. Psychosocial interventions that offer social support in the form of motivation, information and emotion are clearly needed (Kirkevold, Bronken, Martinsen, & Kvigne, 2012). Effective psychosocial rehabilitation is associated with improved health outcomes and community participation for stroke survivors (Newell, Lyons, Martin-Misener, & Shearer, 2009). Psychosocial interventions have also been associated with improved quality of life and prevention of anxiety and depression following stroke (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Kirkevold, Martinsen, Bronken, & Kvigne, 2014; Lawrence, Booth, Mercer, & Crawford, 2013; Lennon, McKenna, & Jones, 2013; Watkins et al., 2011). Various psychosocial interventions are available for people with stroke. One that has received recent attention is storytelling, a relatively new behavioural intervention that can meet the psychosocial needs of stroke survivors. Storytelling is defined as an exchange of information with a peer, which frequently involves personal stories (Haigh & Hardy, 2011). Among the positive effects that have been linked to the storytelling and peer-sharing processes in people with stroke and brain injury are (1) to be able to recognise personal experience that others hear openly, (2) to be able to express feelings via stories and (3) to be able to gain knowledge and reflect on one's own personal story (D'Cruz, Douglas, & Serry, 2019; Kitzmüller et al., 2019). Storytelling is a fundamental aspect of life, a way in which we naturally express who we are and the values we uphold. It is among the most natural ways to give meaning to one's illness-related experiences (Schoenau & Jackson, 2016). Historically, storytelling has served a variety of functions, such as helping others recognise dangers, providing information, entertaining and preserving cultural heritage (Lugmayr et al., 2017). Reviews of storytelling interventions in chronic illness groups have revealed consistent evidence of a variety of benefits, including the

capacity to develop a collective group voice and acquire knowledge, and the potential to improve the group's mental well-being, lower levels of depression, enhance socialisation and raise levels of perceived quality of life (Byrne & Soundy, 2020; Gucciardi et al., 2021). To the best of the author's knowledge, no integrative study has been undertaken to examine the benefits and effects of storytelling and sharing for people with stroke. The main goal of this integrated review is to identify evidence of the effectiveness of storytelling, narrative and sharing interventions in addressing post-stroke psychosocial challenges and to record the results. A further aim is to explore the experiences of stroke survivors and other stakeholders such as caregivers, family and HCPs or other staff who participate in storytelling and sharing interventions, in order to identify the mechanisms underlying specific outcomes.

2.3 Methods

The general framework proposed by Whittemore and Knafl (2005) was used to conduct and report the integrated review in three main stages: 1) eligibility criteria and literature search process, 2) data evaluation and 3) data synthesis. The 21-item ENTREQ (enhancing transparency in reporting the synthesis of qualitative research) checklist was used to support the presentation of the review (Tong, Flemming, McInnes, Oliver, & Craig, 2012). Appendix 4 shows the completed checklist. he PRISMA flow diagram, which is the preferred method of reporting items of systematic and meta-analysis, was used to demonstrate the process of literature search and study selection (Moher, Liberati, Tetzlaff, Altman, & Group*, 2009). The review took the subtle-realist paradigmatic stance, which acknowledges the unique nature of experiences while attempting to identify common realities to which individuals can relate. The primary focus of this review is common features among the included studies.

2.3.1 Protocol and registration

A protocol was registered with PROSPERO with the following ID: CRD42020160984.

2.3.2 Eligibility criteria

To establish study eligibility, the PICOS (Participants, Intervention, Comparison, Outcomes, Study design) standardised framework was utilised.

Participants were eligible if they had been clinically diagnosed with stroke, according to the standard WHO definition of a "clinical condition characterised by suddenly and rapid developing signs of focal or global interruption of cerebral functions that should last more than twenty-four hours or could lead to death, with no evident cause other than vascular origins" (WHO, 1988, cited in Truelsen, Begg, & Mathers, 2006, p. 1). Participants with any of the three major types of stroke (ischemic stroke, intracerebral haemorrhage or subarachnoid haemorrhage) were eligible. Participants with a TIA, which lasts less than 24 hours and frequently has no lasting effects, were excluded (Johnston, 2002). No time limit was established for the period following a stroke due to the paucity of supporting data regarding the utilisation of storytelling. Any gender or ethnicity group was eligible for inclusion, but participants had to be at least eighteen years old. The views of various cohorts of the relevant intervention, such as HCPs, caregivers and family members, were allowed to be included.

Intervention: The primary intervention being evaluated had to use narrative-based or storytelling techniques that included the following: sharing stories or peer sharing or interaction discussions taking place in a group that included sharing experiences, challenges or stories related to illness, as well as sharing details about stroke diagnosis and living with it. The key element of the intervention under evaluation was interaction between at least two stroke survivors to identify the psychosocial content of the experiences or narratives. Different

delivery methods, such as digital (online) or in-person, were allowable. The delivery format, such as one-on-one activities, group projects or delivery over the phone or the internet, was not specified. The study's aim had to be to evaluate and record the effectiveness and benefits of these interventions in supporting stroke survivors to manage psychosocial and emotional difficulties post stroke. Studies that explored the personal experience of stroke survivors taking part in interventions where sharing or discussion took place were also accepted. Interventions led by peers, by HCPs or by a combination of different leaders were included. Studies that examined only educational-based interventions were excluded, or studies that did not use a specific. For example, narrative analysis and examining the stroke experience were not included

Comparison: Studies that used either active or inactive control groups were eligible to be included in this review, as well as studies without any control groups.

Outcomes: Studies using any kind of data collection techniques were allowed, but they had to document the impact or perceived benefit and experience of participating in interventions in helping stroke survivors, caregivers or families deal with psychosocial or emotional difficulties following the stroke. The primary outcomes of qualitative studies were perceived values, experiences or phenomena in relation to taking part in the intervention under evaluation, while those of the quantitative studies were measures that detected the effect of the intervention of interest on psychosocial and emotional well-being.

Study design: Any type of study design was eligible to be included in this review. Studies using mixed, quantitative and qualitative methodologies were all included. Qualitative studies included, but were not limited to, observational cohort, phenomenology and narrative studies. Quantitative studies included, but were not limited to, randomised controlled trials (RCTs),

cluster RCTs, pilot RCTs, quasi-experimental studies and pre/post-test studies. The research team did not impose any limitations on study language and all studies were Google translated before being included. Review studies and conference abstracts were not included.

2.3.3 Literature search

To improve the rigour of this review and reduce inaccurate and biased searching (Whittemore & Knafl, 2005), a thorough and systematic electronic literature search was carried out in accordance with established guidelines (McGowan et al., 2016). The search strategy consisted of the following four main stages (Schoenau & Jackson, 2016).

First stage: A preliminary and general search was conducted across Web of Science to explore the key words of the title and abstract as well as the index terms used to report the articles.

Second stage: The main researcher carried out a second search utilising defined keywords along with the subject heading/MeSH throughout the following subject-specific electronic databases: the Cochrane Stroke Group's specialised register of trials, MEDLINE, CINAHL, AMED, EMBASE, ZETOC, the ProQuest Nursing and Allied Health Database, PsycINFO and SCOPUS from the inception of the database until 16 January 2020.

Third stage: A supplementary search was carried out by searching Google Scholar and Science Direct. The first twenty pages of the results were scanned for relevant studies.

Fourth stage: Finally, an effort was made to widen the search to identify additional potentially eligible studies by screening the reference lists of retrieved studies or reviews.

A variety of key words were used: Stroke* OR Cerebrovascular Disease* OR CVA AND Storytelling OR Storytelling intervention OR Story* OR Narrative OR Narration OR Narrative Intervention OR Narrative Interview OR Illness-narrative OR Story-Sharing OR Group-

experience OR Group circle OR Talking circle OR Peer group OR Peer support OR peer OR Group education OR Expression OR Emotions OR Self-management OR Self-care OR Health education OR Patient-self management.

2.3.4 Study selection

During the first stage of the selection process, the main researcher identified papers that potentially met the inclusion criteria by scanning the titles and abstracts of all the citations, removing duplicate studies and excluding all studies that were not eligible. After identifying and selecting all potential papers, the main researcher obtained the full text for more detailed information to identify those that fulfilled the inclusion criteria. Members of the research team (AS and SR) were asked to resolve any disagreements about inclusion.

2.3.5 Data extraction

For each individual study included, the main researcher utilised a predetermined data extraction form to gather the following demographic and design-related data: (1) demographic variables (participants' age, gender, stroke type and location, time since stroke, co-morbidity/severity of stroke, employment status after stroke, marital status, living conditions and geographical location and (2) information on study design (methodology, aim, eligibility criteria, data collection methods and analysis). Key intervention details were extracted using the TIDieR checklist (Hoffmann et al., 2014) (Appendix 5).

2.3.6 Data evaluation

All articles were evaluated for quality by the main researcher (RA). The 13-item COREQ framework, adapted from the 32-item COREQ (Tong et al., 2012) was used to evaluate the quality of each qualitative study (Appendix 6). This assessment revealed reporting limitations

(Carroll & Booth, 2015). The certainty assessment was based on each study's score. One study was evaluated in this manner yet was included because of the insight provided in the results section. This was utilised as a quick and easy way to include or exclude studies. The internal validity of each quantitative and mixed-method study was assessed using the Cochrane risk of bias tool (Higgins & Green, 2008) (Appendix 7). The results were checked by the research team and any disagreements were resolved.

2.3.7 Certainty assessment

The main researcher and two other members of the team (AS and SR) performed the certainty assessment. Classes of evidence were connected to evidence strength and quality scores for the quantitative research (Burns, Rohrich, & Chung, 2011), while for qualitative research the CERQual assessment tool was applied to evaluate quality scores and evidence confidence (Lewin et al., 2018). These evaluations were mapped onto the themes of the results to give a sense of the degree of confidence in the results.

2.3.8 Data synthesis

The data analysis was founded on the core principles of integrative analysis, which require data to be ordered, coded, categorised and summarised. Data reduction, data display and conclusion drawing, the three major stages outlined by Whittemore and Knafl (2005), were adhered to.

Data reduction necessitates categorisation of the data into types of evidence. For the present review, this was accomplished by taking a qualitative-led approach (Soundy & Reid, 2019), whereby the researcher immersed herself in the data, tabulated the results (Popay et al., 2006) and open coded them. The results were then mind-mapped (Arai et al., 2007), which involved juxtaposing them (Noblit & Hare, 1989) and establishing how the studies were linked to each other.

Data display and comparison involved gathering data from various sources, displaying them in terms of variables and subgroups, then looking for any patterns, relationships or themes. This was accomplished by creating a thematic map based on a mind map and adding study results to it in an effort to saturate each theme (Saunders et al., 2018). The researcher maintained a subtle realist focus on the primary themes, meaning that any subtheme or code required at least two studies supporting it to be accepted at this stage. This accomplished the data reduction needed for this process as specified by Whittemore and Knafl (2005). At this point, quantitative findings were presented in matrices based on the qualitative thematic map developed. This identified whether and how quantitative data might be integrated into the qualitative thematic analysis.

The final stage of the integrated synthesis meant drawing conclusions, verifying theme, and presenting them, which determined the specifics of the data display. A qualitative-led synthesis was conducted (Soundy & Reid, 2019) by first presenting qualitative data and then integrating quantitative findings to support an established theme or subtheme. Reduction was completed by focusing on the psychosocial outcomes and mechanisms that were associated with health (Thoits, 2011). Detailed descriptions of the data synthesis process are given in Appendices 8 to 12.

2.4 Results

2.4.1 Search output and studies included

The initial literature search identified 756 potentially relevant studies, reduced to 190 by removing duplicated studies. The main researcher screened these based on titles and abstracts, eliminating 172 studies which did not meet the inclusion and exclusion criteria. The remaining 18 studies were identified as worthy of further examination and full texts were retrieved and

analysed for eligibility. Of the 18 studies retrieved, four were excluded because they did not meet one or more of the pre-identified inclusion and exclusion criteria. The remaining fourteen studies were included in the integrated synthesis. These comprised six qualitative studies (Christensen, Golden, & Gesell, 2019; Clark, Bennett, Ward, & Jones, 2018; Hancock, 2009; Kessler, Egan, & Kubina, 2014; Kirkevold, Martinsen, Bronken, & Kvigne, 2014; Morris & Morris, 2012), two RCTs (Appalasamy, Quek, et al., 2020; Chow, 2018) and six mixed-method studies (Appalasamy, Joseph, et al., 2020; Corsten, Konradi, Schimpf, Hardering, & Keilmann, 2014; Corsten, Schimpf, Konradi, Keilmann, & Hardering, 2015; Gurr, 2009; Masterson Algar et al., 2020; Muller, Toth-Cohen, & Mulcahey, 2014). Figure 2.1 provides a full breakdown of the process of searching and selecting studies.

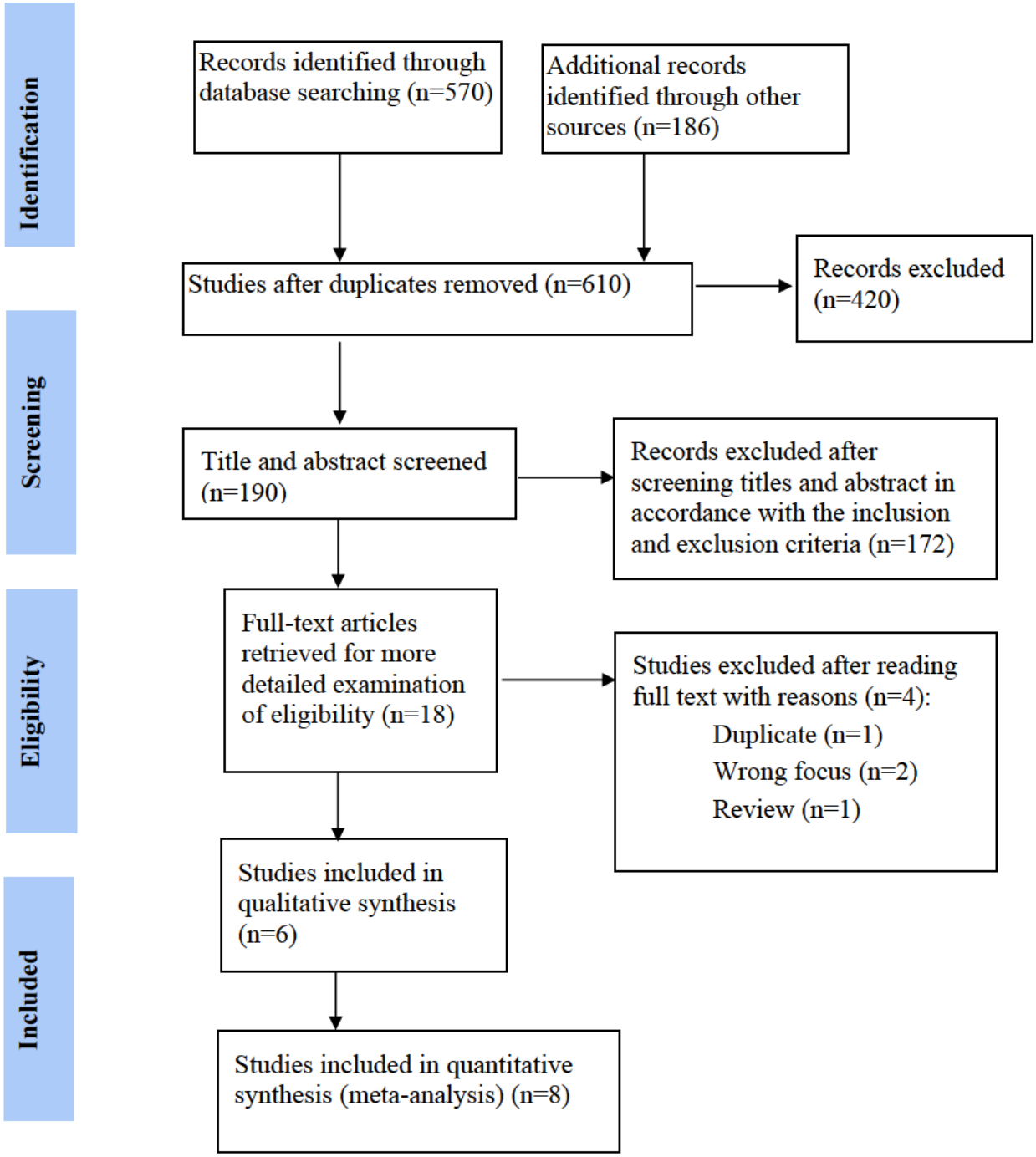


Figure 2.1: Amended PRISMA flowchart of refinement and identifying articles (Moher et al., 2009).

Table 2.1: Demographic and participant characteristics per study: Stroke survivors

Study (Participants)	Male [M], Female [F]; n (%) Total	M	F	Age in years; range (mean)	Living conditions	Marital status	Employment status after stroke	Time since stroke	Type/location of stroke; n (%)	Severity of stroke
Gurr (2009) (Stroke survivors)	80	41	39	Not reported	Not reported	Not reported	Not reported	Acute rehabilitation phase	Not reported	Not reported
Hancock (2009) (Stroke survivors)	9			40-75 (65)	Not reported	Not reported	Full time work (n=1) unemployed (n=8)	Range: < 1 year – > 9 years post stroke	Not reported	Issues with balance & mobility, physical disabilities (usually paralysis of one side of the body), communication & swallowing, memory & mood
Morris & Morris, 2012	7	5	2	44-95	Not reported	Not reported	Not reported	Range 3-10 months	Right sided 5 Left sided 2	4 had mild and 1 severe dysphasia 5 had mobility problems (2 used wheelchairs and 3 walking aids) 4 had cognitive difficulties (memory)
Kessler et al., 2014 (Stroke survivors)	16	12 (75)	4 (25)	(64.8)	4 lived alone; 10 with spouse; 2 with other family members	Not reported	Not reported	Acute phase	Clot 14 (87.5) Bleed 2 (12.5) Left 3 (18.8) Right 13 (81.3)	Barthel Index score 78.8 (SD 21.7) = moderate dependency

Study (Participants)	Male [M], Female [F]; n (%)			Age in years; range (mean)	Living conditions	Marital status	Employment status after stroke	Time since stroke	Type/location of stroke; n (%)	Severity of stroke
	Total	M	F							
Kirkevold et al. (2014)	25	17	8	33-89	22 lived alone, 3 discharged to care home after stroke, 1 returned home after intervention	Not reported	Not reported	Approx. 4-8 weeks to 6 months	Not reported	Physical disabilities varied from mild to severe. A majority had moderate effects. Many experienced fatigue, vision or hearing impairments, memory and concentration problems. Participants with communication problems suffered from moderate to severe aphasia.
Muller et al. (2014)	13	10	3	24-60	Not reported	6 single, 5 married, 1 had partner, 1 divorced	All worked before stroke, 1 retired before stroke; 4 volunteered after stroke	Range: < 1 year – 8 years (n=5) > 1 (n=4) 1-2 (n=3) 3-5 (n=1) 6- 8	Not reported	Not reported
Corsten et al. (2014)	17	9	8	(63.59)	Not reported	Not identified	Not identified	Mean: 40.82 months	All except 2 participants had aphasia as result of left CVA	All participants had chronic aphasia, but type varied. Severity ranged from mild to moderate.

Study (Participants)	Male [M], Female [F]; n (%) Total	M	F	Age in years; range (mean)	Living conditions	Marital status	Employment status after stroke	Time since stroke	Type/location of stroke; n (%)	Severity of stroke
Corsten et al.(2015) (Post-stroke aphasia patients)	27	15	12	(60.85)	Not reported	Not reported	Not reported	Mean: 60.82 months	All except 3 participants had aphasia as result of left CVA	Severity of aphasia ranged from mild to moderate 8 Broca's, 5 anomia, 3 Wernicke's, 2 global, 9 others Depression not assessed as it was an exclusion criterion
Clark et al. (2018)	14	6	8	47-78 (58)	Alone (n=6), with spouse (n=6), with spouse and daughters (n=2)	Not reported	Unemployed (n=4), Employed (n=3), Retired (n=3), Volunteer (n=2)	Range: 4 - 174 months	Not reported	Permanent impairments (mood problems, motor dysfunctions and weakness, poor balance, fatigue and aphasia; 1 had mild expressive aphasia)
Chow (2018) Intervention group [IG] vs control group [CG]	192	IG (61.5) CG (62.5)	IG (38.5) CG (37.5)	IG (72.49) CG (72.84)	Alone: IG 14%, CG 11% With others: IG 81%, CG 85%	Married: IG 67%, CG 73% Significant others: IG 29%, CG 23%	Not reported	1-2 years	Ischemic stroke: IG 83.72%; CG 81.82%	Initial MMSE mean scores: IG 26.11; CG 26.24 Only 8% of participants in both groups had some extent of speech problems
Christensen et al. (2019) (Stroke survivors & partners of care)	32	9 (28)	23 (72)	Average 67	Not reported	78% married, 13% divorced, 6% widowed, 3% single	72% retired, 25% employed, 3% disabled	In the community	Not reported	Not reported

Study (Participants)	Male [M], Female [F]; n (%)			Age in years; range (mean)	Living conditions	Marital status	Employment status after stroke	Time since stroke	Type/location of stroke; n (%)	Severity of stroke
	Total	M	F							
Masterson-Algar et al. (2020)	5	2	3	38-60	2 with spouse who was key source of support; 2 alone; 1 with teenage children & limited family support	Not reported	All unemployed	< 6 months	Right parietal infarction (n=1) Lacunar infarction (n=1) Left frontal infarct (n=1)	Not reported
Appalasamy, Joseph et al. (2020)	54	> 50% males in both groups		CG (56); IG (53)	Not identified	Not identified	> 50% of participants unemployed. Approx. 50% exposed to stroke education	Not identified	> 80% ischemic	Most participants had many stroke risk factors such as hypertension.
Appalasamy, Quek, et al. (2020)	216	Almost 20% more men than women in both groups		Ranged from 20 and 90 years old	Not identified	Not identified	More than 60% of participants unemployed	Not identified	More than 90% ischemic	Hypertension; 60% had diabetes; several had many stroke risk factors; > 80% were prescribed al least 3 types of stroke preventative medications

2.4.2 Study demographics and characteristics

2.4.2.1 Participants

Demographic data and characteristics of participants for each study are listed in Table 2.1. The studies included 745 participants (675 stroke survivors). The smallest, by Masterson-Algar et al. (2020), used a sample of five, while the largest (Appalasamy, Quek, et al., 2020) had a sample of 216. Subjects ranged in age from 20 to 95 years. A majority of the studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Kessler et al., 2014; Kirkevold et al., 2014; Muller et al., 2014) recruited more males than females. In three of these (Appalasamy, Joseph, et al., 2020; Chow, 2018; Muller et al., 2014) males significantly outnumbered females. The time intervals since the stroke started ranged from two weeks (the acute stroke phase) to 174 months. Those who took part in the studies with the largest populations (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018; Kessler et al., 2014; Masterson-Algar et al., 2020) experienced ischemic stroke. The nature of the stroke was not known in the five other studies (Christensen et al., 2019; Clark et al., 2018; Gurr, 2009; Hancock, 2009; Kirkevold et al., 2014; 2012; Muller et al., 2014). Stroke survivors with one or more of mobility issues, motor impairments, balance issues, cognitive problems, fatigue, communication and swallowing difficulties, and mood disorders were included in seven studies (Chow, 2018; Clark et al., 2018; Corsten et al., 2014; Corsten et al., 2015; Hancock, 2009; Kirkevold et al., 2014). Stroke survivors who were moderately dependent in doing basic daily tasks were included by Kessler et al. (2014). Participants in the studies by Appalasamy, Joseph et al. (2020) and Appalasamy, Quek et al. (2020) had a variety of stroke risk factors, the majority of which were primary hypertension and diabetes. The remaining studies (Christensen et al., 2019; Gurr,

2009; Masterson-Algar et al., 2020; Muller et al., 2014) lacked data on the characteristics or state of health of their participants.

In half of the studies, subjects lived in their homes, and the majority shared housing with a spouse or other family members (Chow, 2018; Clark et al., 2018; Kessler et al., 2014; Kirkevold et al., 2014; Masterson-Algar et al., 2020), while the remaining studies did not provide information regarding participants' living situation (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Christensen et al., 2019; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Hancock, 2009; Morris & Morris, 2012; Muller et al., 2014). Of the 675 participants, 164 were married, 51 had significant others, seven were single, five divorced and one widowed, while the marital status of the remaining 447 participants was unknown. Participants' employment status was unknown in six studies (Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Kessler et al., 2014; Kirkevold et al., 2014), while the majority of subjects in the others studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Christensen et al., 2019; Clark et al., 2018; Hancock, 2009; Masterson-Algar et al., 2020; Muller et al., 2014) were unemployed.

2.4.2.2 Interventions

The TIDieR checklist (Hoffmann et al., 2014) was used to report details of the elements of each intervention (Appendix 4). Different types of intervention were indicated. The primary intervention being evaluated was narrative-based in seven studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Kirkevold et al., 2014). Five studies took a peer support approach in a one-to-one (Kessler et al., 2014; Masterson-Algar et al., 2020) or group format (Christensen et al., 2019;

Hancock, 2009; Morris & Morris, 2012) and in the two remaining studies (Clark et al., 2018; Muller et al., 2014), peer support was delivered in self-managed intervention groups.

The interventions were hospital-based in five studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Gurr, 2009; Morris & Morris, 2012; Muller et al., 2014); in three (Corsten et al., 2014; Kessler et al., 2014; Kirkevold et al., 2014) they were carried out in both hospital and community settings; in one (Clark et al., 2018) the location was not reported; and the remaining five interventions were community-based (Chow, 2018; Christensen et al., 2019; Corsten et al., 2015; Hancock, 2009; Masterson-Algar et al., 2020). Two interventions were led by peers (Kessler et al., 2014; Masterson-Algar et al., 2020) and five by professionals (Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Kirkevold et al., 2014). These professional leaders were respectively a narrative therapist (Chow, 2018), speech therapists and educational professionals (Corsten et al., 2014; Corsten et al., 2015), speech therapists, an occupational therapist and a physiotherapist (Gurr, 2009) and trained health professional staff and a speech therapist (Kirkevold et al., 2014). Two other interventions were video presentations (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020) and the remainder were a mix of peer and professionally led (Christensen et al., 2019; Muller et al., 2014) or were led by a mix of peers, partners of care or family members and HCPs, namely a nurse specialising in patient education, social workers and speech therapists (Hancock, 2009; Morris & Morris, 2012). Clark et al. (2018) did not report who led the intervention in their study. Intervention sessions lasted from five minutes to two hours and were repeated weekly or monthly for a period of two weeks to 12 years.

2.4.2.3 Timing, frequency, number and duration

Studies varied in the timing of delivering the intervention during the stroke survivor's pathway. Only three of the fourteen studies (Clark et al., 2018; Kessler et al., 2014; Kirkevold et al., 2014) discussed the timing of the intervention and they differed as to the appropriate time to offer it during the recovery journey. Two studies found that delivering this type of intervention immediately after the incident stroke was considered too early (Clark et al., 2018; Kessler et al., 2014). A potential danger of providing peer support visits for newly diagnosed stroke patients during acute hospitalisation was identified by a partner of care who explained that the patient would not be medically stable and not ready for this type of visit (Kessler et al., 2014). However, none of the stroke patients identified any concern regarding the timing of peer visits and all participants considered the emotional support provided by peers to be beneficial and to aid psychological adaptation at a time when they felt overwhelmed by the unknown (Kessler et al., 2014). In the study by Clark et al. (2018), some stroke survivors found that enrolling in a self-management group as soon as one month after the occurrence of stroke, for example, might be too early. Newly diagnosed stroke patients might be feeling overwhelmed and unable to process the information that would be given: "*For the first month or so, I don't think I would have taken it in"* (Jess) (Clark et al., 2018). In contrast, five of the 14 participants in the Clark et al. (2018) study preferred to be offered the intervention immediately after their stroke ("the sooner the better"), as they felt emotionally down and "traumatised" by the stroke and needed somebody to talk to in order to understand their situation.

Six participants in the study by Clark et al. (2018) suggested that the appropriate time to access the self-management group would be after discharge, during the transition from a supportive hospital environment to being alone in the community, particularly after the rehabilitation services ceased and when support was lacking. Clark et al. (2018) suggest that offering this

type of intervention during this period is essential for improving stroke survivors' self-efficacy. Their finding is consistent with the result reported by Kirkevold et al. (2014) that some stroke survivors considered the timing of the dialogue-based psychosocial group, during approximately the first six months post stroke, to be acceptable. Offering the intervention at the end of the recovery journey, such as 40 months post stroke, might on the other hand be too late, as some stroke survivors would already have learned self-management strategies from other stroke groups, developed social networks and relationships with other stroke survivors and formed support networks earlier in their personal stroke journeys (Clark et al., 2018). However, other long-term stroke survivors reported that they would still like to access the group later in their stroke journey (Clark et al., 2018).

2.4.2.4 Frequency, number of sessions and duration of the intervention

Four of the fourteen studies provided information on the frequency and duration of the intervention and the number of sessions (Appalasamy, Joseph, et al., 2020; Kessler et al., 2014; Kirkevold et al., 2014; Masterson-Algar et al., 2020). Frequent encounters were considered to be appropriate (Kessler et al., 2014; Kirkevold et al., 2014). Peer supporters participating in the study by Kessler et al. (2014) frequently reported concerns regarding their ability to recall the required routines and procedures of the intervention, because they were scheduled to provide the intervention only once a month. As to the stroke patients, some recommended that the intervention should be scheduled weekly, especially at the beginning (Kirkevold et al., 2014). In regard to the video presentation, the ability to view the video frequently was considered appropriate (Appalasamy, Joseph, et al., 2020).

Only one study (Kirkevold et al., 2014) reported findings on the duration of the intervention and number of sessions; participants' opinions varied, but none considered that they had too

many encounters. Some stroke survivors felt that the scheduling of eight sessions over six months was reasonable, whereas others, particularly those with communication difficulties, who received only the individualised dialogue with healthcare professionals, felt that eight sessions were not enough and that the intervention ended rather too soon, suggesting that it ought to last at least a year (Kirkevold et al., 2014). Stroke survivors with communication difficulties required more time to complete the sessions; therefore, the intervention was extended to around ten to twelve months, whereas those without communication difficulties, who received the two initial individualised dialogues with HCPs followed by six group dialogue sessions, completed the intervention as planned within six months (Kirkevold et al., 2014). One hour was assigned for the one-on-one sessions and two hours for the group sessions. However, while most individual sessions, particularly for those without language difficulties, were managed to finish within an hour, the duration of individual sessions varied among those with language difficulties, particularly soon after the stroke, as they quickly became exhausted in their efforts to express themselves. As a result, each session had to be modified individually and took 1.5 hours on average (Kirkevold et al., 2014). Masterson-Algar et al. (2020) did not specifically evaluate the number of sessions in their study, which comprised individualised coaching with peers; however, peer supporters and stroke patients alike highlighted the value of having a set number of sessions, because this made it easier to plan and define the intervention process and then adhere to it, moving neither too quickly nor too slowly.

2.4.2.5 Mechanism of intervention

Delivery of each intervention could be tailored to many factors and might impact on its effectiveness. Four possibilities were identified: 1) tailored to the format of the intervention (one-to-one versus group-based format, 2) tailored to individuals' poststroke disabilities and challenges, 3) tailored to a specific age group and 4) tailored to personality or specific

characteristics (Appalasamy, Joseph, et al., 2020; Clark et al., 2018; Corsten et al., 2015; Kessler et al., 2014; Kirkevold et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012).

2.4.2.6 Tailored to the format of the intervention

Only two studies (Kessler et al., 2014; Masterson-Algar et al., 2020) offered the intervention in a one-to-one format; participants' opinions were generally positive regarding the format of these interventions.

Kessler et al. (2014) found that newly diagnosed stroke patients and health professionals expressed concern about the number of peer supporters present on a single hospital visit. Individualised interactions with one peer supporter were preferred and providing a visit by two peer supporters was appropriate, while more than two peers might be daunting to new stroke patients. Although Masterson-Algar et al. (2020) did not specifically assess the format of the intervention, both stroke survivors and peer supporters reported experiencing positive personal outcomes after participating in one-on-one peer-led coaching sessions, and no concerns were raised about this element of the intervention. In the study by Corsten et al. (2015), one-on-one biographical narrative interventions were viewed favourably because they allowed for private conversations without fear, the patients having built a rapport of trust with the professionals, given adequate time to construct a story and the professionals' tolerance for communication difficulties.

In contrast, nine of the 14 stroke participants in the Clark et al. (2018) study valued the potential benefits of both emotional and practical assistance provided by peers within the group settings, particularly the potential value of collective problem solving. One participant stated explicitly that she personally preferred a group setting because she felt the individualised format would

limit her exposure to the viewpoints of only one individual, while a group of peers would provide a broader and more diverse outlook and multiple ideas for dealing with challenging circumstances (Clark et al., 2018). The benefits of group settings were also noted by Corsten et al. (2015), who included the opportunity to interact with like-minded people and to share similar experiences in a relaxed environment.

Stroke survivors who received the group dialogue format and the individualised dialogue with an HCP were mostly satisfied with the format they participated in (Kirkevold et al., 2014). The group format gave participants a forum for sharing experiences and ideas, yet it was more challenging to meet individual needs compared to the one-to-one format; consequently, some participants felt that the group format was somewhat restricting, because the intervention focused more on issues and topics that were shared by all the participants rather than on their unique concerns and the knowledge they needed regarding their specific conditions (Kirkevold et al., 2014). Participants in the study by Corsten et al. (2015) found the timing of group meetings unfavourable and reported a preference for individual flexibility. Only one study (Morris & Morris, 2012) evaluated group size and it reported conflicting results regarding the ideal size: when groups had more than five or six people, some participants felt uncomfortable sharing, while some care partners recommended that smaller groups might encourage more people to participate.

2.4.2.7 Tailored to individuals' poststroke disabilities and challenges

Stroke can cause a wide range of disabilities and symptoms and there was significant variation within groups as to the long-term needs of stroke survivors, revealing a need for sessions to be tailored to these factors (Clark et al., 2018; Kirkevold et al., 2014; Morris & Morris, 2012). Eight of the 14 participants in the study by Clark et al. (2018) emphasised the need for each

group to be tailored to its members' individual symptoms, as these would be managed differently by each stroke survivor and a one-size-fits-all approach would not be suitable. One participant elaborated by stating that tailoring the intervention to individual needs would make it more relevant to their personal circumstances; she suggested that the content of the sessions should be tailored to different levels of cognition (Clark et al., 2018). In line with this finding, differences in the type of stroke among group members reduced the relevance of the intervention, as one participant who had suffered a haemorrhagic stroke reported that he had many unanswered questions and felt that the intervention had not addressed them. Communication problems such as deafness and aphasia that were present in a peer group hindered "harmonious interaction", which was significant for participants (Morris & Morris, 2012).

Similarity with other stroke survivors could strongly affect the group process and was identified by participants as a vital determinant of effective peer interaction (Morris & Morris, 2012). Members with the most noteworthy similarities were seen to be the best sources of support (Morris & Morris, 2012). Differences in disabilities or circumstances and comparison with other stroke survivors had both negative and positive outcomes and could affect mental well-being and the ability to relate to others and to cope (Clark et al., 2018; Corsten et al., 2015; Kessler et al., 2014; Morris & Morris, 2012). HCPs participating in the study by Kessler et al. (2014) identified a potential danger when patients newly diagnosed with mild stroke encountered peer supporters with more noticeable physical disabilities. The organisation team also received feedback calls from new stroke survivors reporting that they did not appreciate visits by peer supporters who had significant and noticeable physical dysfunctions, such as one who was unable to walk and used a wheelchair. Participants found this to be distressing and discouraging (Kessler et al., 2014). Conversely, one peer supporter felt that since he did not

present with an obvious disability, he might lack “credibility” among newly diagnosed stroke patients (Kessler et al., 2014). One partner of care in the study by Morris and Morris (2012) felt that comparison with other stroke survivors who were in more challenging circumstances was not effective and that “it lowers your spirits a little bit”. However, some stroke survivors considered that seeing other survivors in a more difficult condition gave them the feeling that they were not very sick themselves and that there were others in a worse condition than them (Corsten et al., 2015; Morris & Morris, 2012).

2.4.2.8 Tailored to a specific age group

Three studies (Clark et al., 2018; Kirkevold et al., 2014; Morris & Morris, 2012) found that it was important to tailor the group sessions by age, because (1) age changes the difficulties and needs that an individual with stroke might experience and affects “group relatability” (Clark et al., 2018) and because (2) too wide an age range limits the relevance of the information provided (Kirkevold et al., 2014; Morris & Morris, 2012) and (3) weakens the connections among group members (Morris & Morris, 2012).

2.4.2.9 Tailored to personality or specific characteristics

Two studies (Clark et al., 2018; Morris & Morris, 2012) identified the need to tailor the intervention to personalities as opposed to poststroke disabilities and age, because participants’ personalities could affect group dynamics and processes. One participant in the study by Clark et al. (2018) suggested that if an individual was shy, it would be more helpful to take a one-to-one approach rather than a group-based one.

2.4.2.10 The involvement of staff and other contributors

Five studies (Clark et al., 2018; Corsten et al., 2015; Kessler et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012) found that opinions were varied as to the involvement of staff members in the intervention of interest as facilitators or leaders.

The presence of staff members and their contributions to the interventions were considered important (Kessler et al., 2014; Morris & Morris, 2012). Both stroke patients and their partners of care appreciated staff involvement in the group sessions, helping them in "getting the facts from the meetings"; giving their professional viewpoints and hearing carers' concerns could also help staff to understand the challenges that partners of care and families faced. Similarly, the collaboration and commitment of the HCPs despite their heavy caseloads, as well the ongoing support they provided to the programme team, were identified as contributing significantly to the programme's success (Kessler et al., 2014).

The views of participants varied regarding who they would prefer to lead or facilitate the interventions (Clark et al., 2018; Corsten et al., 2015; Masterson-Algar et al., 2020). Some participants in the Clark et al. (2018) study stated that they would prefer the groups to be facilitated by healthcare professionals who had varied expertise and professional backgrounds, such as physiotherapists, nurses and counsellors, whereas many others were less keen on this idea, questioning the usefulness of HCPs' knowledge ("What do they know?"). They felt that it would be more valuable to participants if the group were facilitated by an individual who had had a stroke, as they would be experienced and familiar with the condition, making it easier for them to relate on a personal level: "They have been me" (Clark et al., 2018). The common desirable characteristics of peer facilitators identified by all participants in the study by Kessler

et al. (2014) were that they should be good listeners, friendly, confident, knowledgeable about stroke resources and programmes, and respectful of others.

On the other hand, some participants in the Clark et al. (2018) study recommended that a mixture of professionals and peers would provide varied opinions. HCPs would assist in the organising of the intervention, with one participant noting that organisational skills and ability to remember could be affected by a stroke, while a stroke survivor as facilitator would have been in a similar situation and could bring a realistic perspective on what occurred (Clark et al., 2018).

2.4.2.11 The involvement of partners of care, family or friends

Three studies (Clark et al., 2018; Kirkevold et al., 2014; Morris & Morris, 2012) also identified the need to involve partners of care, families or friends in the intervention and the value of doing so. Participants in two of these (Clark et al., 2018; Morris & Morris, 2012) acknowledged the importance of including those caring for stroke survivors, who could offer advice to patients and help them to understand what was "going on", thus providing the right support and encouragement for patients to better self-manage their conditions, while several participants in the study by Kirkevold et al. (2014) felt the need to address the informational and support needs of their families by explicitly including them in the intervention.

2.4.2.12 Nature of the intervention

The structure, content and atmosphere of the intervention or sessions could impact on participants and the process of the intervention (Clark et al., 2018; Corsten et al., 2015; Kirkevold et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012).

Two studies (Masterson-Algar et al., 2020; Morris & Morris, 2012) identified the importance of starting the intervention with a briefing or introduction. Peer supporters participating in the

study by Morris and Morris (2012) felt that stroke patients and their partners of care could have been better prepared by providing a briefing about the purpose of the group, while one peer supporter in the Masterson-Algar et al. (2020) study suggested that in order to reduce anxiety about meeting a strange person in a strange place, it would have been preferable if a third party had introduced the new stroke patients to their peers in the first interaction.

In the study by Morris and Morris (2012), peer supporters expressed varied opinions on the structure and content of the group sessions. One felt that rather than allowing participants to talk about random topics, it would have been beneficial to impose a more structured content, with discussion of different and specific topics at each session, whereas another peer stated that one of the most positive aspects of the sessions was having the opportunity to speak about personal concerns. In the study by Corsten et al. (2015) the topics discussed in the biographic narrative intervention were considered beneficial, although looking back on the past led to conflicting views, with some but not all participants being happy to recall pleasant moments they had almost neglected, such as a good professional life. Most participants in the Kirkevold et al. (2014) study considered that addressing specific topics related to stroke patients' challenges, problems, needs and experiences was relevant to their recovery and adaptation, while many found it important to address survivors' psychosocial needs after stroke, which were not explicitly raised by rehabilitation HCPs during the sessions. In relation to video narrative intervention, Appalasamy, Joseph et al. (2020) noted the need to keep the message brief, truthful and understandable. Creating an environment in which participants would feel comfortable in being open and sharing personal information with strangers was identified as important, because it might help them to feel that they fitted in and could relate to others in the group (Clark et al., 2018).

2.4.2.13 Training, information and materials provided to peer supporters

Three studies discussed the importance of providing training and information for peer supporters (Kessler et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012). Appropriate training gave peer supporters the opportunity to develop their communication skills and increased their confidence in their ability to fulfil their roles as peers (Kessler et al., 2014; Morris & Morris, 2012). In addition, the provision of training would ensure that all peer supporters were aware of the routines and procedures required by the programme (Kessler et al., 2014). However, one peer supporter felt that the training session given would have been more beneficial if peer supporters had had the opportunity to submit their concerns first to the staff, in order to identify the best way to assist them (Morris & Morris, 2012). The training also consisted of providing information, materials and handbooks (Kessler et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012). Participants' opinions varied regarding the informational support provided to peer supporters during the training sessions (Masterson-Algar et al., 2020; Morris & Morris, 2012). One carer/peer supporter in the study by Morris and Morris (2012) reported finding that some of the training materials were overwhelming for peer supporters and suggested more practical sessions and less theory. By contrast, a peer supporter in the study by Masterson-Algar et al. (2020) found it confidence-building to know that the booklet provided during the training session was a source of information that peers could refer to later.

2.4.2.14 Practical considerations (location and transportation)

Transportation issues and the location of the intervention could either hinder or facilitate participation in the intervention for both stroke survivors and peer supporters (Clark et al., 2018; Kessler et al., 2014; Masterson-Algar et al., 2020). Kessler et al. (2014) found that peer

supporters who needed to use the local modified transportation services felt frustrated at being unable to avoid occasionally arriving late at the venue and missing parts of some sessions. Similarly, stroke survivors participating in the Clark et al. (2018) study saw the need to use public transport as a significant barrier to attendance, since motor impairments caused by stroke could make this difficult; they therefore emphasised the importance of convenient transport arrangements. On the other hand, covering parking costs and providing transportation were significant facilitators of participation in the intervention for peer supporters and stroke patients respectively (Clark et al., 2018; Kessler et al., 2014). The location of the intervention should be easily accessible to participants to facilitate attendance (Clark et al., 2018; Masterson-Algar et al., 2020). Participants in the study by Clark et al. (2018) considered it important to deliver the intervention somewhere local, as travelling long distances after stroke could be "too tiring". Indeed, one stroke survivor could not participate in the intervention due to the "large geographical distance" involved (Masterson-Algar et al., 2020).

2.4.3 Critical appraisal of research

The principal researcher independently and critically assessed the listed studies' quality. No study was eliminated for lack of quality. Data appraisal per research type is fully considered and broken down in the appendices; see Appendix 5 for a qualitative assessment and Appendix 6 for a quantitative and mixed-methods assessment.

2.4.3.1 Qualitative study appraisal

The six qualitative studies were critically assessed using the 13-item version of the COREQ framework adapted by Soundy et al. (2016) from the 32-item COREQ framework (Tong, Sainsbury, & Craig, 2007), in order to identify fatally flawed studies (Dixon-Woods, Fitzpatrick, & Roberts, 2001), defined as those scoring less than 3/13 on the COREQ and considered to present methodological problems or reporting-related problems so significant as to cause the reader to question the findings. The critical appraisal identified only one fatally flawed study (Hancock, 2009), which scored 2/13 on the COREQ. A second blind examination by AS revealed the following strengths: 1) the interview script was well-developed and based on stroke research, literature and peer support; 2) the sample was purposive and included maximum variation; 3) the response rate was 100%; 4) a pilot interview was conducted; 5) the study was linked with policy research; 6) it was a multi-centre study; 7) it included many verbatim quotes and 8) the data provided interesting points, relatable to other studies and their findings. Accordingly, the two researchers (RA and AS) decided to include the study in the integrated review. While none of the remaining studies was considered fatally flawed, some weaknesses in reporting were identified, the most prevalent being: 1) There was a lack of reflexivity, making it challenging to determine how the researchers' personal traits and their interactions with participants might have affected the process and credibility of the findings

(Christensen et al., 2019; Hancock, 2009; Kessler et al., 2014; Morris & Morris, 2012); and 2) no attention was given to sample size (Christensen et al., 2019; Kirkevold et al., 2014; Morris & Morris, 2012; Hancock, 2009). These results were utilised to support the methodological flaws in CERQual (Lewin et al., 2018). A summary assessment of the qualitative studies is presented in Table 2.2.

2.4.3.2 Quantitative study appraisal and risk of bias

Quantitative studies (n=3) and mixed methodological studies (n=5) were both assessed using the Cochrane risk of bias tool (Higgins & Green, 2008). There were found to be the following high risk of bias criteria: 1) lack of protocol (n=6), 2) lack randomisation processes (n=5), 3) lack allocation concealment (n=6). Five domains were identified as having a high risk of bias in four of the eight criteria (Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Muller et al., 2014). Table 2.3 lists and describes the components of risk of bias assessment.

2.4.3.3 Classes of evidence

In accordance with the definition of classes of evidence by Burns et al. (2011), three studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018) were assessed as at moderate low risk, rated II, one (Masterson-Algar et al., 2020) at moderate high risk, rated III, and four (Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Muller et al., 2014) at high risk of bias, rated IV.

Table 2.2: Summary assessment of qualitative studies

	Fatally flawed (Dixon-Woods & Fitzpatrick, 2001)	**13-item version of COREQ (Soundy et al., 2016): One point for each criterion met**			
Author (year)	Inclusion score ≥ 3	Domain 1 (5 items): Research team and reflexivity	Domain 2 (5 items): study design	Domain 3 (3 items): analysis and findings	Total
Hancock (2009)	Included	1/5	1/5	0/3	2/13
Morris & Morris (2012)	Included	0/5	2/5	3/3	5/13
Kessler et al. (2014)	Included	2/5	5/5	3/3	10/13
Kirkevold et al. (2014)	Included	5/5	3/5	3/3	11/13
Clark et al. (2018)	Included	4/5	4/5	3/3	11/13
Christensen et al. (2019)	Included	2/5	2/5	1/3	5/3

Table 2.3: Summary assessment of overall bias risk of quantitative studies (Higgins & Green, 2008)

Trial* and type	Components of risk of bias/key risk criteria						Summary within trial	Classes of evidence (Burns et al., 2012)
	1	2	3	4	5	6		
Gurr (2009) **Mixed methods, including qualitative themes**	H	H	H	H	L	H	H=5 L=1 U=0	Level of evidence: IV Risk of bias: High Design: Case series
Muller et al. (2014) **Pre and post study, no control group**	H	H	H	H	L	H	L=1 H=5 U=0	Level of evidence: IV Risk of bias: High Design: Case series
Corsten et al. (2014) **Mixed methods**	H	H	H	H	L	H	H=5 L=1 U=0	Level of evidence: IV Risk of bias: High Design: Case series
Corsten et al. (2015) **Mixed methods**	H	H	H	H	L	H	H=5 L=1 U=0	Level of evidence: IV Risk of bias: High Design: Case series
Chow (2018) **RCT**	L	H	L	H	L	H	H=3 L=3 U=0	Level of evidence: II Risk of bias: Moderately low Design: Moderate quality RCT
Masterson-Algar et al. (2020) **Mixed methods**	H	H	H	L	L	L	H=3 L=3 U=O	Level of evidence: III Risk of bias: Moderately high Design: Moderate cohort study
Appalasamy, Joseph et al. (2020) **Mixed methods**	L	L	H	L	L	L	H=1 L5	Level of evidence: II Risk of bias: Moderately low Design: Moderate quality RCT
Appalasamy, Quek, et al. (2020) **Single blind RCT**	L	L	U	L	L	L	L=5 U=1	Level of Evidence: II Risk of bias: Moderately low Design: Moderate quality RCT

Trial* denoted by first author. Risk of bias criteria: 1) Selection bias=random sequence generation; 2) selection bias=allocation concealment; 3) Detection/performance bias=blinding of personnel, assessors and participants; 4) Attrition bias=incomplete outcome data; 5) Reporting bias=short-term selective outcome reporting; 6) Other bias=potential threats to validity, e.g. consideration of protocol.
Level of risk of bias: H=high risk; U=unclear risk ; L=low risk.

2.4.4 Synthesis of research

This subsection presents five themes that offer a narrative synthesis of the evidence, taking into account the reported outcomes, the summary of evidence and any potential or probable psychosocial mechanism that may contribute to the outcomes. Table 2.4 provides a summary of the evidence.

Table 2.4: Summary of evidence

Theme	Level of evidence: Burns et al. (2011) for quantitative evidence and CERQual (Lewin et al., 2018) for confidence in evidence	Summary of evidence	Suggested mechanisms
Introducing the concept of hope & learning to be positive	1 level II study 5 qualitative studies with high CERQual scores	There is a high likelihood that the intervention can introduce hope.	Social comparison Social control
Enhanced ability to cope	3 Level IV studies 1 qualitative study with low CERQual score	It is probable that the intervention can improve the person's coping ability	Feeling understood and heard by others Social comparison Social control Self-efficacy
The impact of loneliness and social interaction	1 Level IV studies 8 qualitative studies with high CERQual score	It is possible that relationship building and peer support can have an impact on loneliness and isolation.	Feeling understood and heard by others Validated sense of suffering Social comparison Social control
Impact on emotions: Depression and related emotions	1 level II study 2 Level IV studies 2 qualitative studies with low CERQual scores	The intervention's effect on emotional states cannot yet be determined. Well powered studies are required to determine whether the confusion, anger, sadness and tiredness findings—which were shown to be statistically insignificant but very large effect size—can be replicated.	Feeling understood and heard by others Validated sense of suffering
Impact on emotions: Fear	2 Level IV studies 1 qualitative study with low CERQual score	The intervention probably had no effect on fear.	Feeling understood and heard by others
Enhanced awareness of stroke	1 level II study 1 Level IV study with low CERQual score	The intervention probably improved knowledge about stroke.	Social comparison Social control

Theme 1: Introducing the concept of hope and learning to be positive regarding the future

Reported outcomes: The intervention, in both individual and group forms, seemed to aid in the initiation of the concept of hope following a stroke diagnosis and in assisting stroke survivors to feel optimistic about the future (Appalasamy, Joseph, et al., 2020; Christensen et al., 2019; Hancock, 2009; Kessler et al., 2014; Morris & Morris, 2012). In the Morris and Morris (2012) study, five stroke survivors and their partners of care (n=5/10) and six peer supports (n=6/8) agreed with the statement "*Things seem more hopeful since joining the group*" and all participants with the exception of one peer supporter (n=17/18) agreed that *"the group helps me feel more positive about my future"*. Chow (2018) quantified this, stating that participants in the narrative therapy group showed a significant enhancement in the Herth Hope Index score compared to the control group who received a psychoeducational intervention, an effect that persisted four months after the intervention ($p \leq 0.05$). Peers were a source of inspiration for the future (Kessler et al., 2014; Kirkevold et al., 2014; Morris & Morris, 2012). All participants apart from one stroke survivor and one partner of care (n=16/18) agreed that *"the group inspires me about the future"* (Morris & Morris, 2012).

Proposed mechanisms: Hope and a sense of optimism appeared to have increased within interventions primarily through social comparison. Three specific aspects of the interventions contributed to this: 1) Communicating with someone who had experienced a comparable circumstance and taking the effort to listen and exchange stories were found to validate the experience of suffering (Kessler et al., 2014). Hearing other survivors' recovery stories led to the belief that "*there is life after a stroke"* and recovery is achievable, which was previously uncertain (Hancock, 2009). 2) Participants found the opportunity to share their own stories to be especially beneficial (Gurr, 2009). A sense of hope was generated by being with other stroke survivors who were going through a similar experience and seeing how they improved. The

group setting provided a forum for people to share how they effectively handled challenging circumstances following their stroke, assisting others in learning how to handle their own situations (Hancock, 2009; Kirkevold et al., 2014; Morris & Morris, 2012). 3) The capacity to apply the shared experiences to managing one's own life was mentioned by the participants (Morris & Morris, 2012).

Theme 2: The enhanced ability to cope

Reported outcomes: According to Muller et al. (2014), the majority of participants (n=10/13) agreed or strongly agreed that *"I learned new ways of coping with issues related to stroke"* and more than half (n=8/13) claimed that they employed the techniques they had learnt outside the group. In the study by Kirkevold et al. (2014), participants indicated that both the individual and group-based dialogue interventions helped their attempts to cope and that this support was crucial, especially in the first six months. The dialogue intervention assisted participants in discussing the difficulties they faced in daily life, identified their coping mechanisms and helped them as they experimented with various techniques and looked into unexpected circumstances (Kirkevold et al., 2014; Morris & Morris, 2012). The new and different challenges after stroke that survivors had to learn to cope with ranged from carrying out daily activities to dealing with different social situations and understanding their own emotions (Kirkevold et al., 2014; Morris & Morris, 2012). According to Appalasamy, Joseph et al. (2020), the intervention encouraged taking a proactive approach and taking action in the direction of stroke prevention. Humour and maintaining a positive attitude in the groups were frequently mentioned as crucial elements of successful recovery (Hancock, 2009). Muller et al. (2014) monitored participation in the exercises and activities that were presented in the group modules with a post-participation survey. They noted that more than 50% of participants (n=8/13) started engaging in various daily and leisure activities outside the group setting. Other

assessments of the intervention, however, revealed that only the home integration of the Community Integration Questionnaire (CIQ) and the handicap domain of the Stroke Impact Scale (SIS) approached statistical significance (p = 0.002 and p = 0.034 respectively). Both domains concentrated on carrying out essential everyday activities inside the home, but the self-perceived recovery domain of the SIS and the CIQ's social and productive integration domains failed to reach significance. Substantial difference in quality-of-life reporting was found by Corsten et al. (2014) for (a) benefits to physical (p = 0.037) and psychosocial (p = 0.00001) complaints and (b) reduced perceived physical (p = 0.009) and psychosocial (p = 0.001) burden.

Proposed mechanisms: Making the effort to listen and exchange stories with peers who had had a good experience with recovery helped survivors to recognise how others had coped and to recognise what was possible through rehabilitation in a positive manner, which promoted motivation in the direction of recovery and facilitated psychological adaptation (Kessler et al., 2014). It provided an environment where members could collectively educate each other by providing advice and ideas on coping and managing (Morris & Morris, 2012). Acquiring stroke-related knowledge not only educated participants and assisted them in understanding their diagnosis, but also provided them with "concert skills" that they then applied outside the group context (Christensen et al., 2019; Hancock, 2009). Sources of self-efficacy may have had a role in this. Appalasamy, Quek et al. (2020) found a significant (F = 12.41, p <0.001) improvement in self efficacy compared to a control group. Alternatively, humour may help participants to see stroke differently when it has previously been perceived as a burden.

Theme 3: Impact on loneliness and social interaction

Reported outcomes: Participating in interventions of interest appeared to enhance social well-being. The interventions alleviated the feelings of isolation and loneliness (Clark et al., 2018; Masterson-Algar et al., 2020; Morris & Morris, 2012). Taking the time to share, listen and connect to people who had gone through similar situations helped to lessen feelings of loneliness (Christensen et al., 2019; Clark et al., 2018; Kirkevold et al., 2014; Morris & Morris, 2012). In Hancock's (2009) study, all nine participants mentioned the importance of being among other stroke survivors, while at least 50% of study participants valued the hospital visits or phone calls they had from their fellow stroke survivors. Participants generally felt isolated and reported that the interventions provided them with something to occupy their time following a stroke (Kirkevold et al., 2014; Masterson-Algar et al., 2020).

Many participants made new friends as a result of their participation in groups (Christensen et al., 2019; Hancock, 2009; Morris & Morris, 2012). Making new friends with similar interests and with whom members might relate was made possible by the group (Morris & Morris, 2012). One participant in the study of Hancock (2009) stated that she had developed friendships with other stroke survivors in the group because of their willingness to listen to and communicate with her, as opposed to other individuals who might have said, "*I can't be bothered*." Muller et al. (2014) quantified this, reporting that the majority of participants (n=10/13) agreed or strongly agreed with the statement "*I have made new friends".* Although participants in the study by Masterson-Algar et al. (2020) did not report this experience, a peer supporter identified a potential danger for participants of becoming attached to peers whom they had met on a personal level and suddenly could no longer meet when the intervention ended. Muller et al. (2014) quantified this and observed that more 50% of participants (n=8/13) cited socialisation as the most significant benefit of joining the group. Almost half of

participants (n=6/13) stated that they had spoken to other participants outside the group setting via a variety of channels, such as phone calls (n=6/13), in person (n=8/13), text messaging (n=2/13), Facebook (n=2/13) and email (n=5/13). However, statistical analysis of the intervention revealed that the CIQ social integration domain did not achieve significance *(p* = 0.148).

Participating in the groups gave participants a sense of belonging to a community of identity and togetherness (Christensen et al., 2019; Gurr, 2009; Morris & Morris, 2012). Group sessions created a sense of identity and togetherness through connecting them with other stroke survivors. Fifteen of the 18 participants in the Morris & Morris (2012) study agreed with the statement *"I feel a sense of belonging to the group"*. Group inclusion improved the feeling of community, even for passive members who only listened and chose to not participate in the group or had limited communication skills (Gurr, 2009).

Proposed mechanisms: One participant in the study by Kirkevold et al. (2014) described participating in this type of intervention as inspirational and essential when facing something as serious as a stroke. Peers were also seen as a source of inspiration to seek a peer role in the future, which facilitated social identity development (Kessler et al., 2014). Most facilitators, including HCPs and family members (n=6/7), said that hearing the personal stories of the group members improved facilitators' ability to understand participants "*as people"* (Gurr, 2009). Sharing experiences within the group allowed participants to empathise with each other and created a sense of trust and understanding among them (Christensen et al., 2019). Groups served participants as long-term social networks and sources of support, continuing to validate their suffering even when they were not in a group setting (Christensen et al., 2019). There was probably a correlation between meeting new peers and experiencing less distress associated with being alone. Additionally, the groups offered members a platform to review and edit their

own narratives. The distinctive group setting gave people the chance to present their own stories, reflect on them and hear those of others who had experienced similar things. This gave them the opportunity to revise their own stories.

Theme 4: Impact on emotions

Reported outcome (Depression and related emotions): Chow (2018) observed an increase in the scores of participants on the Chinese Geriatric Depression Scale (estimated effect size 0.05); however, this was insignificant in the narrative therapy group at one month (T1) post intervention when compared to the baseline (T0) score. Depression scores fell significantly compared to T1 at two months (T2; estimated effect size 2.24) and at four months post intervention (T3; estimated effect size 2.04). Following participation in the intervention group, Gurr (2009) found an insignificant decline in mean depression scores on the Hospital Anxiety and Depression Scale (HADS): mean pre-group score was approximately 8.5; mean post-group score just above 7.5. Corsten et al. (2014; 2015) found in both studies a positive and significant effect of feeling less tired after the group (p = 0.06; p = 0.00001). The effect size was quite significant (d = 1.02) in one case (Corsten et al., 2014) and small (d = 0.30) in the other (Corsten et al., 2015). Despite additional insignificant findings by Corsten et al. (2014), moderate to very large effect sizes were found for the following moods: confused (d = 1.26), sad (d = 0.89), angry (d = 1.07) and tense (d = 0.68).

According to qualitative data, interacting with other stroke survivors, sharing experiences and having one's own experiences validated played a part in lessening the depression commonly experienced by stroke survivors (Christensen et al., 2019; Hancock, 2009). Furthermore, two individuals cited keeping busy by participating in the monthly scheduled peer support groups

and observing other stroke survivors with impairments who nevertheless had good attitudes as elements that helped them overcome their depression after stroke (Hancock, 2009).

Proposed mechanisms: It is likely that being heard and allowed opportunities to express oneself improves mood-related outcomes as a direct effect of the session (Corsten et al., 2014; Corsten et al., 2015). This may enable or improve the ability of an individual to reflect on their personal story and experience.

Reported outcome (Fear): Participating in the intervention appeared to be helpful in terms of lessening fear after a stroke and instilling a sense of confidence (Hancock, 2009; Kessler et al., 2014). Fear was commonly stressed as a significant challenge in accepting the diagnosis of stroke (Hancock, 2009). One participant reported that the peer support group had helped her to understand the condition and thus to overcome her fear after suffering a stroke (Hancock, 2009). However, it should be noted that while Corsten et al. (2014) and Corsten et al. (2015) observed positive improvement, this was insignificant (p = 0.30 and 0.50 respectively). Corsten et al. (2014) reported a moderate effect size (d = 0.56), but Corsten et al. (2015) reported no effect size (d = 0.06). According to Appalasamy, Joseph et al. (2020), the narrative intervention assisted participants in overcoming their fears and the difficulties brought on by their stroke.

Proposed mechanisms: Prior to attending, Clark et al. (2018) examined how stroke survivors perceived the possible difficulties of a self-management group. The group members thought that some people would find it difficult and "*distressing to hear*" some portions of the sessions, such as revisiting painful memories and discussing stroke experiences. The organisers of the programme studied by Kessler et al. (2014) were aware of the potential for the intervention to put emotional strain on the peer supporters, since they believed that it would entail revisiting the pain associated with prior stroke experiences, which might heighten fear, concern or

anxiety. However, no participating peer supporters actually reported experiencing any of these feelings (Kessler et al., 2014). According to Appalasamy, Joseph et al. (2020), the intervention likely reduced feelings of fear by boosting confidence.

Theme 5: Enhanced awareness and knowledge of stroke

Reported outcome: One of the reasons for stroke survivors to attend the groups was to gain and receive knowledge (Christensen et al., 2019; Hancock, 2009). All participants in the Hancock (2009) study (n=9) indicated that HCPs had not adequately addressed their questions and several reported feeling that during hospitalisation, they had not sufficiently understood their condition and how to manage recovery, but that their understanding improved when they met their peers. Furthermore, gaining knowledge related to stroke and recovery was one of the motives for participants to continue to attend the groups and was linked to recovery from stroke (Christensen et al., 2019). Appalasamy, Quek et al. (2020) identified a significant increase in stroke knowledge ($F=11.54$, $p<0.001$). The interventions provided stroke survivors and their caregivers with helpful information on stroke prevention, rehabilitation and how to locate and use community-based stroke support resources (Christensen et al., 2019; Kessler et al., 2014; Morris & Morris, 2012). Peer-provided information about managing a stroke in the community was deemed more useful than advice given in hospital by medical professionals (Hancock, 2009; Kessler et al., 2014). One individual felt that the information offered by a peer with "*substantial experience subsequent to their stroke"* was really helpful (Morris & Morris, 2012). Fellow stroke survivors offered experiential knowledge and information gained from real-life personal experiences, which aided in the creation of relatedness (Kessler et al., 2014; Morris & Morris, 2012). One of the advantages of the groups was listening to the experiences of others, which one participant described as an "*enriching experience*" (Kirkevold et al., 2014). The group environment provided a platform to meet with stroke survivors at different stages of

recovery, which enabled members to access varied knowledge related to recovery (Christensen et al., 2019). Muller et al. (2014) quantified this by stating that a majority of participants (n=10/13) agreed or strongly agreed that since joining a peer support group, they knew *"more about community and stroke resources"* and that the peer support group increased their understanding of their condition, recovery after stroke and opportunities like volunteer work and adapted leisure activities. Participants in the Christensen et al. (2019) study reported that finding information about stroke and post-stroke recovery was challenging and that their caregivers significantly appreciated the chance to gain knowledge from other stroke survivors and specialists.

Proposed mechanisms: Possible mechanisms underlying this theme include social comparison, listening to others' stories and more direct advice given utilising social control (Appalasamy, Joseph, et al., 2020).

2.5 Discussion

The results of the current review have shown that narrative or peer sharing interventions can have a positive effect on key psychosocial outcomes, and that this is frequently a result of social comparison and social control. The findings reported in this integrated review were based on a limited number of studies with small sample sizes and the findings might have been overestimated due to publication bias .The present recommendations centre on the studies with the highest strength of evidence, which revealed that the intervention can generally introduce a feeling of positivity and hope, lessen loneliness and facilitate coping through information sharing. The decrease in loneliness is confirmed by past research (Byrne & Soundy, 2020). Additionally, previous reviews have found that storytelling interventions can support coping, improve knowledge (Gucciardi et al., 2021) and provide individuals with the opportunity to

articulate and comprehend their real-life emotions and experiences in relation to their condition (Gucciardi et al., 2021; Soundy & Reid, 2019). Furthermore, it has been noted that storytelling reduces psychological distress and enables discussion of worries and fears (Soundy & Reid, 2019).

Previous reviews of evidence on chronic illnesses have identified and validated the social and internal mechanisms indicated in the present study. For example, self-reflection has been highlighted as a key process and mechanism via which the positive effect of a storytelling intervention can be established, as it enables individuals to develop and redevelop the plots of their own stories (Byrne & Soundy, 2020; Gucciardi et al., 2021; Soundy & Reid, 2019). Social comparisons may also alter how someone views their own circumstances and reduce their sense of isolation (Byrne & Soundy, 2020). The ability to relate to others may allow a therapeutic environment created by increased trust (Byrne & Soundy, 2020; Soundy & Reid, 2019), where people feel as though their experiences are validated (Soundy & Reid, 2019).

Given that the individualised and group formats produced various experiences, it was helpful to assess the interventions in each of these settings. The individualised format could be customised to meet each person's needs and address any challenges they might face in their recovery from a stroke; however, it might not be cost effective. On the other hand, the group format could be inexpensive and there are benefits for both parties when participants share their experiences of disease and health. This could result in the acquisition and evaluation of new knowledge, resources connected to strokes, and useful coping methods (Cangelosi & Sorrell, 2008). According to the US Department of Health and Human Services (2010), participating in groups could be useful for patients with chronic diseases such as stroke; therefore, groups may be more suitable than the individualised format for offering a storytelling intervention. The current review indicates that smaller groups may be more effective in

enhancing the value of sharing and being heard. It is necessary to gain a better knowledge of the effect of social comparison and how it may affect results. For example, downward comparison (comparing oneself with those considered to be in a worse situation) may have a positive effect on a persons' assessment of their own well-being (Harrison, Ryan, Gardiner, & Jones, 2017; Sadler, Sarre, Tinker, Bhalla, & McKevitt, 2017). Conversely, upward social comparison (with those considered to be in a better situation when facing similar challenges) has been linked with lower life satisfaction as compared to downward comparisons (Frieswijk, Buunk, Steverink, & Slaets, 2004). According to Harrison et al. (2017), individuals who make downward social comparisons may be less likely to seek assistance for their personal needs. More research is needed to determine whether upward social comparisons are beneficial and to identify how to incorporate and maximise the advantages of downward social comparisons. There is also a need to examine whether, how and under what circumstances social control is applied to peers. Future studies are needed to determine whether stroke survivors and their caregivers or families should participate in storytelling groups. The advantages of including caregivers or families in group sessions, such as enhancing the exchange of information and assistance, were similarly noted in the three qualitative studies reviewed (Clark et al., 2018; Kirkevold et al., 2014; Morris & Morris, 2012). This is confirmed by Hartford, Lear and Nimmon (2019), who found such assistance crucial. Stroke can have a devastating impact not only on survivors but also on their families (Haley, Roth, Hovater, & Clay, 2015) and it would be beneficial to explicitly include them.

The present review failed to demonstrate objective positive effects of the narrative intervention on mood. It may be that the interventions were too short to cause positive changes in mood, or that administering verbally the outcome measures of mood status may have affected their validity, as they were originally designed to be self-administered (Chow, 2018; Corsten et al.,

2014; Corsten et al., 2015; Gurr, 2009). Future research should consider the effect of such interventions on mood, because changes in mood have been found to coincide with various chronic diseases (Soundy & Reid, 2019). Other significant factors that should be taken into account are how early the diagnosis was made and how pronounced the symptoms were, because these may be crucial in determining if and how mood changes take place (Soundy et al., 2019).

2.6 Limitations of the Studies

The studies reviewed here were subject to potential limitations regarding the heterogeneity of the interventions, the participants, study design and assessment instruments.

2.6.1 Heterogeneity of the interventions

First, implementation of the interventions in clinical practice may have had adverse effects, due to the heterogeneity of the interventions in terms of type, design and personnel. Across the studies reviewed, there was wide variety in the types of intervention used. The data in Appendix 4 shows that only seven (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Gurr, 2009; Kirkevold et al., 2014) consisted exclusively of storytelling or narrative-based interventions and that five of those were carried out exclusively, led or facilitated by professionals (Chow, 2018; Corsten et al., 2014; Corsten et al., 2015; Kirkevold et al., 2014). Four studies (Hancock, 2009; Kessler et al., 2014; Masterson-Algar et al., 2020; Morris & Morris, 2012) used peer support interventions with a significant component of peer sharing and interactions, while the main themes of the peer support interventions in the other studies were educational, self-management and group discussions. Although the inclusion criteria admitted studies where at least 50% of the intervention under evaluation consisted of storytelling/narrative-based approaches or peer

sharing or group discussion, such variance in the type of intervention is a major weakness of this review and may have determined the impact on quality and effectiveness of storytelling or narrative-based therapeutic interventions and how they are considered and reported. Similarly, there was significant heterogeneity in the design of the interventions: seven were group interventions and two (Kessler et al., 2014; Masterson-Algar et al., 2020) provided individual-based interventions carried out exclusively by peers. Individual and group sessions were combined in three of the studies (Corsten et al., 2014; Corsten et al., 2015; Kirkevold et al., 2014) and two studies used video-based interventions (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020).

In several studies, the features of the interventions were poorly reported in regard to content (Chow, 2018; Christensen et al., 2019; Hancock, 2009) and developmental rationales (Chow, 2018; Christensen et al., 2019; Hancock, 2009; Kessler et al., 2014; Morris & Morris, 2012). In one study (Clark et al., 2018) the key intervention details were not reported, whereas the rest of the studies provided a more detailed description of the interventions' properties and seven of them (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Corsten et al., 2014; Corsten et al., 2015; Kirkevold et al., 2012; Masterson-Algar et al., 2020; Muller et al., 2014) described the development of interventions based on sound theoretical frameworks that guided their aims, structure and process. Basing a storytelling or narrative intervention on a conceptual or theoretical framework assists in explaining its main components and the mechanisms underlying outcomes or change; moreover, it widens the applicability of the intervention and adds significant value to the conclusions (Reeves, Albert, Kuper, & Hodges, 2008). Nevertheless, the present review found that there were multiple theoretical or conceptual frameworks underpinning the seven exclusively narrative-based interventions; these included socio-cultural and social-construction-oriented theories (Corsten et al., 2014; Corsten et al.,

2015), the theory of sense of coherence and narrative therapy (Kirkevold et al., 2014), social learning theory (Appalasamy, Joseph, et al., 2020) and other philosophies such as guided self-determination (Kirkevold et al., 2014). There is an emerging, as yet limited, literature on narrative theories and frameworks, including the storytelling approach to enhancing health and modifying behaviour (Hinyard & Kreuter, 2007; Larkey & Hecht, 2010). These theoretical and conceptual frameworks offer guidelines for the further development and implementation of storytelling-based interventions (Gucciardi, Jean-Pierre, Karam, & Sidani, 2016).

There was a lack of consistency in the length of the group interventions offered, which included a fixed intervention of seventeen weekly sessions lasting 1-1.5 hours for two or three weeks (Gurr, 2009), 13 fortnightly sessions lasting 1.5 hours (Morris & Morris, 2012), six group sessions every two weeks for around two months and monthly sessions for another two months, lasting two hours (Kirkevold et al., 2014), nine twice-monthly sessions lasting 1.5 hours over 18 weeks (Muller et al., 2014) and weekly sessions lasting two hours over eight sequential weeks (Chow, 2018). In addition, there was a rolling intervention, with no particular end date, comprising monthly sessions whose number and duration were not reported (Hancock, 2009) and another comprising sessions of 1-2 hours held once per month or every two months (Christensen et al., 2019). The two individual-based interventions provided a fixed date of contact. One involved peer sharing and interactions through telephone calls which were scheduled five times over a year (Kessler et al., 2014) and the other comprised six face-to-face interaction sessions lasting an hour (Masterson-Algar et al., 2020). Determining the length and frequency of the interventions was challenging, as there was no agreement across studies. Earlier research on the effectiveness of psychosocial interventions has varied widely on this issue (Burton & Gibbon, 2005; Watkins et al., 2007). No two interventions in this integrated review were alike in the type, setting, length and frequency of the interventions. This

heterogeneity has significant implications for the generalisability of the results regarding storytelling/narrative-based interventions. The lack of standardisation of the interventions may be seen to affect consideration of such interventions within clinical practice and guidelines. Further research is required to address this issue.

There was also a difference among studies in regard to the optimum time that this type of intervention should be offered after stroke. Two studies (Clark et al., 2018; Kessler et al., 2014) suggested that participants were not ready to receive the intervention immediately after stroke, which aligns with previous research into similar interventions (Satink, Cup, de Swart, & Nijhuis-van der Sanden, 2015). In contrast, participants in the studies by Clark et al. (2018) and Kirkevold et al. (2014) considered the period after discharge and transition to home as the appropriate time to offer the intervention. It remains unclear whether there is a universally appropriate time to offer this type of intervention during the stroke survivor's recovery journey; it may well vary from person to person.

As well as a lack of standardisation of interventions, there was also variation in personnel leading the interventions and in the training and support they received. A significant component to consider when implement a storytelling or narrative-based intervention is the person who will lead or facilitate the intervention and their roles and responsibilities (Gucciardi et al., 2016). In the majority of the reviewed studies, the facilitators were healthcare professionals with varied expertise and backgrounds; opinions regarding their involvement also varied across studies. The HCPs were able to give their professional views and assist in organising. However, available resources might often not permit the enlistment of professionals as leaders or facilitators (Gucciardi et al., 2016). In other research into chronic conditions such as cancer, peer-led groups have been documented as significantly outnumbering professional-led groups (72% and 28% respectively) (Stevinson, Lydon, & Amir, 2010), which is consistent with other

studies which have found a significant preference for peer leaders with the same conditions over HCPs (Fu et al., 2003; Jaglal et al., 2013; Lorig et al., 1999). This may be due to two advantages of peer-led interventions. Firstly, they minimise the burden on healthcare resources, as peer-led interventions can provide significant long-term access to support and social participation opportunities for patients and their families (Tregea & Brown, 2013). Secondly, there may be a reciprocal gain, whereby individuals both give and receive support beyond the advantages of either alone (Pound, 2011; Pound, Duchan, Penman, Hewitt, & Parr, 2007). Moreover, peer-led interventions may help a move from the traditional context of staff-patient interaction, which could be empowering to patients, as they consider themselves knowledgeable via their lived experiences of the condition (Gucciardi et al., 2016). This review has found peer-led interventions to be effective in helping stroke survivors to cope with the devastating impact of stroke (Kessler et al., 2014; Morris & Morris, 2012). However, a disadvantage is that peers may need training to develop the skills required to facilitate storytelling or narrative interventions, as outlined by Greenhalgh et al. (2011).

2.6.2 Participants

The demographic data in Table 2.1 shows that participants ranged in age from 20 to 95 years, making the findings generalisable to wider age groups. There were more male participants than females, which is closely representative of the global stroke population, as stroke is more common among men worldwide (Appelros, Stegmayr, & Terént, 2009). Sample size ranged from 10 to 216, with 11 of the 14 studies having fewer than 100 participants. These small samples may be seen to restrict the generalisability of the results to a wider stroke population. There was also a significant diversity in terms of time since stroke onset, from two weeks to 174 months, with different needs and stages of recovery, all of which may impact on the

evaluation of the interventions. Long-term stroke survivors, for instance, might have recovered completely and faced fewer difficulties than patients who had just been diagnosed. Time since stroke is a variable that should be explored in future research.

2.6.3 Study design and assessment instruments

Only two of the studies reviewed were randomised control trials with researcher blinding. Randomisation of participants and the inclusion of a control group might have strengthened the validity of the results and including more RCTs might have increased the strength of this review. Future well-designed studies are required. The limitations of the qualitative research were evident in the study design, absence of reflexivity, data analysis and reporting of results. The results may thus not be generalisable, but they may nonetheless be transferable to various stroke settings.

The primary aims of the studies and their use of assessment tools could also have influenced the results reported. Although the qualitative studies aimed to explore the experiences of participants in the interventions of interest (e.g. their potential benefits), different outcome measures were used in the quantitative and mixed-methodology studies, which could be criticised as yielding inadequate data to be able to pool studies based on particular assessment instruments and interventions. Most studies did not take into account participants' physiological factors, which are crucial because they could affect how people perceive an intervention. For example, higher blood pressure has been linked to increased cognitive loss (Forte & Casagrande, 2020). With respect to data collection, only four studies (Appalasamy, Joseph, et al., 2020; Appalasamy, Quek, et al., 2020; Chow, 2018; Corsten et al., 2014; Corsten et al., 2015) provided follow-up data. Incorporating such data would assist in gaining an understanding of the longer-term effects of narrative interventions.

2.7 Implications

Storytelling and peer sharing interventions seem to be effective in boosting positive feelings and providing hope in a manner that empowers stroke survivors. They should be regarded as potentially valuable approaches to promoting positive psychosocial adaption. Consideration should be given to peer sharing and storytelling in various contexts, such as one-on-one interactions, group settings and online platforms; for example, stroke stories can be found on the UK Stroke Association website (https://www.stroke.org.uk/stroke-stories, accessed 12 May 2021). It is important to make attendance an individual option and to take the preferences of participants into account when determining if, when and how storytelling is offered. Professionals and researchers should be aware of situations in which the group environment may be less beneficial, such as when a social comparison might be viewed as out of reach and difficult to accomplish. Future research is required to determine the benefits and usefulness of attending group interventions with family members or caregivers. Further study should explore how hope and emotions may be measured in order to detect changes caused by storytelling. Finally, more well powered and well designed trials are required.

2.8 Conclusions

The findings of the present review seem encouraging and indicate that peer-group interventions may result in positive psychosocial effects for stroke survivors. It is essential to realise that peers play a vital role in knowledge sharing and the potential alleviation of loneliness; therefore, within the limitations set out above, they should be recognised as a valuable part of stroke rehabilitation, although additional research is needed to validate the effectiveness and therapeutic benefits of peer-led storytelling interventions in enhancing stroke survivors' psychosocial well-being.

CHAPTER 3

A QUALITATIVE STUDY OF ILLNESS NARRATIVES ILLUSTRATING THE MASTER PLOT OF 'OVERCOMING THE MONSTER' AND ASSISTING STROKE SURVIVORS AND HEALTHCARE PROFESSIONALS TO UTILISE IT

This chapter reports in full the contents of a published manuscript (Alawafi, Rosewilliam, & Soundy, 2022). It includes verbatim text from the published manuscript and changes made for the purpose of this thesis.

Publication

Alawafi, R., Rosewilliam, S., & Soundy, A. (2022). A qualitative study of illness narratives: 'Overcoming the monster' master plot for patients with stroke. *International Journal of Therapy and Rehabilitation, 29*(9), 1-13. (Appendix 2)

3.1 Abstract

Background/aims: There is a need for research to examine illness narrative 'master plots' (common and recognisable story plots related to the experience of illness) as they are revealed by people with stroke. Up to this point, the literature has concentrated on identifying pre-established illness narrative master plots: the restitution, chaos and quest narratives. However, these narrative master plots reflect severe psychological responses to the illness; other narrative plots must be recognised in order to most effectively support stroke patients. Further research is needed to determine the existence of any additional master plots and to examine their possible implications. The aim of this chapter is to report a qualitative study using semi-structured interviews to examine illness narratives that illustrate the master plot of overcoming the monster and help stroke survivors to utilise it.

Methods: A narrative methodology was used within the context of a social constructivist worldview. A purposive sample of people who had been diagnosed with stroke was selected. A single semi-structured online interview was carried out and a categorical-form narrative analysis was performed in five steps.

Results: Eight participants in total were interviewed. Six responses were identified after analysis as illustrative of experiences associated with a master plot entitled 'overcoming the monster'. The 'monster' was portrayed in a variety of ways, including: a mental health issue or an expression of internal feelings; a feeling of social isolation; a threat to the person's independence; and a poor interaction or experiences with health care. Participants identified specific strategies for overcoming the monster. These included adopting a new perspective on life, setting and achieving major and minor goals, persistence and determination in face of difficulties, providing support to others via activities and seeking support.

Conclusion: Healthcare professionals should recognise the significance of this narrativisation of stroke, since research has demonstrated that HCPs can stereotype encounters based on plots and try to fix them. These findings highlight the need to understand each individual's experience rather than reacting quickly to a narrative type that appears to fit. Ways of understanding the master plot of overcoming the monster differ and may require time to be observed.

3.2 Introduction

Healthcare professionals and patients narrate the impacts of a stroke in different ways. Stereotypically, HCPs focus on identifying physiological and neurological symptoms, whereas patients interpret the experience in relation to their own biographical history to find meaning (Boylstein, Rittman, & Hinojosa, 2007). Current best practice guidelines (Mountain et al., 2020) emphasise the importance of considering many areas; in order to obtain optimal practice and cover all recommendations, HCPs including occupational therapists and physiotherapists may overlook the value of the individual story. Individuals' personal accounts of their illnesses should be valued by HCPs because this fosters social awareness, reduces the stigma associated with the illness being treated and impacts on medical research and regulations (Boylstein et al., 2007). This awareness would probably address some psychosocial needs of patients and caregivers (Mountain et al., 2020). Stroke survivors who tell stories have the opportunity to build meaning and (re)establish a sense of social identity (France, Hunt, Dow, & Wyke, 2013). Listening to patients' accounts of illness improves HCPs' knowledge of their psychosocial well-being and this information can be used to guide interventions that promote mental well-being following stroke (Pluta, Ulatowska, Gawron, Sobanska, & Lojek, 2015; Soundy, 2018).

Personal accounts of illness are stories told by patients about their experiences that help them make sense of it (Soundy & Reid, 2019). Illness narratives are typically distinguished by master plots, representing broad storylines that are easily recognised and commonly expressed by those suffering from chronic illness (Frank, 1995; Soundy et al., 2013). These master plots demonstrate the impact of illness on a person, focusing on key psychological factors such as psychological adaptation, emotions and hope (Soundy, 2018). Exploring illness narrative master plots could help researchers and HCPs including occupational therapists to detect an

individual's underlying psychological and emotional reactions to disease (Soundy, 2018). However, a master plot should not be interpreted as a complete representation of a patient's experience. A patient may express multiple master plots at once, and any particular master plot may alter over time (Soundy et al., 2013).

The work of Frank (1995) reveals the most frequently cited illness master plots to be the restitution, quest and chaos narratives. In the restitution narrative, patients seek to be restored to their prior level of health and identity, whereas in a quest narrative, they try to accept and adjust to their illness. The use of the chaos narrative, by contrast, indicates that the patient does not accept the illness (Egbert, Pluta, Powęska, & Łojek, 2021; France et al., 2013). However, Frank (1995) argues that these initial master plots need further consideration. Soundy et al. (2013) identify thirteen master plots related to chronic and neurological illnesses including stroke. A description of each of these narratives is provided in Table 3.1. Limited research has explored the illness narrative master plots expressed by stroke survivors. So far, the research into stroke has centred on identifying pre-established illness narratives (France et al., 2013). Other master plots from history and culture are frequently portrayed in movies (Booker, 2004). 'Overcoming the monster' is one such master plot that may be particularly prevalent in stroke patients. According to Booker (2004), it can be identified when a person's life is endangered by an all-powerful monster which the hero must fight and defeat. Historically, the monster has been portrayed as a creature (e.g. a giant) which has control over the hero. The main part of the narrative is that the monster or evil is defeated and its power is taken away. To the best of the researcher's knowledge, the experiences of stroke patients have not yet been examined against illness narrative master plots.

Table 3.1: Common illness narrative master plots in chronic and neurological illness (Soundy et al., 2013**)**

Restitution narrative	The restitution narrative is told by an individual with the goal of being returned to their former health and identity. Praying to feel well could be an example of this (Hawkins, 1990). It is encouraged by the anticipation that others want to hear restitution stories (Frank, 1995).
Heroic narrative	Heroic or epic narratives are related to the preservation or defence of established social ideals (Kelly & Dickinson, 1997). Chanfrault-Duchet (1991) claims that these narratives are highly valued in the community. Robinson (1990) identifies two types of heroic narrative: An implicitly heroic narrative is perceived by others as an exceptional way to handle and reflect on diseases, although the teller may not see it in that light, whereas an explicitly heroic narrative is one in which the individual represents a struggle or battle against their disease. This may be more in line with Kelly's (1994) example of a courageous and heroic reaction to disease.
Detective narrative	The detective story centres around a search for answers to the mystery of the illness. Robinson (1990) defines it as the need to respond to two fundamental questions: Why me? What can be done about it? According to Robinson (1990), this narrative may evolve into a "detached documentary" that tracks the individual's progress and changes, or it may become more of an adventure narrative.
Comic narrative	A comedy narrative gives the individual a new perspective on their disease. Kelly (1994) describes a patient who was confused and amused by what she had experienced and in particular, by the way the doctors had handled the situation.
Ironic or satirical narrative	An ironic or satirical narrative gives the patient the opportunity to highlight different possible outcomes. Kelly (1994) discusses a patient who needed an operation to preserve her life but which resulted in deformity.
Disembodied or detached narrative	The disembodied or detached narrative records life experiences through the eyes of a third party, using emotionally flat interactions. Such narratives may be devoid of any effort to assess the meaning of the patient's illness. As a result, this narrative may either consciously or unconsciously develop into a heroic or tragic one (Robinson, 1990). According to Kelly (1994), a patient identifies experiences as if they were not hers, perceiving her body to be something apart from herself.
Romantic narrative	The romantic narrative is all about the struggle for meaning in one's life. It describes a patient's participation in a competition (Kelly & Dickinson, 1997). According to Chanfrault-Duchet, the story is "Romanesque", defined as a "quest for authentic values in a degraded world" (1991, p. 80). Kelly (1994) demonstrates the romantic narrative by a story of a patient who said she was going to get well because of the prayers of her church and others.
Quest narrative	Patient acceptance and use of illness is implied in the quest narrative. In this way, it looks forward to what lies ahead (Frank, 1995). This can be compared to the "regeneration paradigm of illness" (Hawkins, 1990), according to which a patient's former self may die and be replaced by a new one during illness.

Supernatural narrative	In the supernatural narrative, God is identified as an ally (supporter) who offers salvation (rescue) to those who are ill. The path to death becomes a path to life, while losses become gains (Robinson, 1990).
Didactic narrative	In the didactic narrative, a patient describes the lessons he or she has learned from being ill.
Tragedy narrative	In the tragic story, there is an unavoidable or overwhelming consequence (Bury, 2001; Kelly, 1994; Robinson, 1990).
Sad narrative	The sad narrative conveys a sense of loss and helplessness as a result of a disease that is beyond the narrator's control. There is a distinct separation between the narrator and what they hoped for, yet this is not as extreme as a tragedy narrative (Robinson, 1990).
Chaos narrative	The chaos narrative includes a statement of loss; it leaves no room for distancing oneself from the experience of illness and the future is bleak and uncertain. Patients who adopt the chaos narrative have no reflective understanding of what has occurred (Frank, 1995).

For those who have survived a stroke, the monster might be expressed in various unique ways, including direct symptoms of the stroke or experiences related to having a stroke such as depression, which often occurs after a stroke (Wood, Connelly, & Maly, 2010), feelings of isolation (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015; Salter, Hellings, Foley, & Teasell, 2008) or alterations to the person's social identity (Hinckley, 2006). These symptoms and experiences reflect and are correlated with the factors that undermine hope (Soundy, Stubbs, Freeman, Coffee, & Roskell, 2014) and trigger psychological distress (Laporte & Aita, 2021). This is significant because each master plot expresses hope in a unique way (Soundy et al., 2013). Therefore, it is likely that altering, eliminating or challenging a person's illness master plot will probably have an impact on that person's psychological well-being (Soundy et al., 2014). It is important for HCPs to understand how to handle master plots in encounters. For instance, metaphors used in illness narratives convey a viewpoint or trait associated with the experience of having a stroke (Boylstein et al., 2007). The most prevalent metaphors used to describe stroke experiences include 'journey' and 'battle', which imply social disempowerment (Ferguson et al., 2010). Indeed, the idea that recovery is a battle and that the patient is a fighter is prevalent in the stroke literature (Boylstein et al., 2007). Therefore, it is crucial for patient empowerment to be able to work effectively with patient narratives (Luker et al., 2015). Considering this, more research is required to determine whether and why overcoming the monster is significant for stroke survivors. Moreover, research should examine what individuals use in their stories to represent the monster and should seek to discover how they overcome it, in order to gain greater support for the elements of dealing with the monster. There is also a need for research into the factors that might influence the process; for example, the ability to re-evaluate one's circumstances, make personal decisions and accept what has occurred, as well as the ability to utilise support resources and learn from other people

(Woodman, Riazi, Pereira, & Jones, 2014). Building a better understanding of individual stories will be a critical first step in this research. This may be best accomplished by qualitative research with a small group of people who can reflect on their own journeys and experience in greater depth. The aims of the present study were to identify illness narratives illustrating the master plot of overcoming the monster and to explain the significance of such plots to stroke survivors and healthcare professionals.

3.3 Methods

3.3.1 Design

For this study, a narrative methodology was supposed, to be embedded in a social constructivist view of world, with a relativist ontology and subjectivist epistemology (Labonte & Robertson, 1996). This approach assumes that every person's experiences of reality is equally legitimate and that knowledge is perceived as being created through encounters before being established on a psychological level. The methods adopted by the current study are reported using a standardised framework (O'Brien, Harris, Beckman, Reed, & Cook, 2014).

3.3.2 Settings

All interviews were conducted online via Skype from the home of one of the study team members at a specific point in time. This method was selected to enable the research team to collect data while protecting both the interviewer and participants form infection during the COVID-19 outbreak and to adhere to the national restrictions. The family members could be present, but their perspectives were not sort. Prior to the interviews, the interviewer obtained demographic data on gender, age, type of stroke and time since stroke onset.

3.3.3 Ethical approval

The study was conducted in accordance with the applicable Code of Practice for Research (University of Birmingham, 2021), alongside other revenant guidelines such as the Mental Capacity Act (UK Government, 2005) and the Data Protection Act (UK Government, 2018). All data were anonymous and kept in a locked office in a secure place at the University of Birmingham. These data will be kept for 10 years. Approval was granted by the Ethics Committee of the University of Birmingham (Reference: 17-0149).

3.3.4 Participants

Participants were purposively recruited via a well-known website (not reported to protect participants' identity) and a local community stroke group in Birmingham, allowing research projects to be advertised across these two settings. People who were interested emailed the researchers and were sent an information sheet and consent form, which they were asked to return to the research team (Appendix 13). The information sheet provided a full explanation of the study's aims and what might be involved. During the consent process, individuals were given the time to discuss the study with others if they wished. At this point, participants emailed the researchers to set up an interview. The chosen sample size was based on its ability to disclose rich key elements of a single master plot as expressed via the individuals' experiences. Data gathering was ended once it was decided that there was enough rich data to understand how examples of various master plots were expressed. After five interviews, the research team reviewed the transcripts and decided that two more interviews were required to guarantee that an adequate variety of examples were given. Participants were required to meet the following inclusion criteria: (a) they had to be at least two years post-stroke in order to reflect on their stroke pathway journeys ; (b) any type of stroke was acceptable; (c) they were adults aged over

18, (d) they had no cognitive or speech difficulties that would prevent them from adequately understanding and answering questions or communicating via Skype or Zoom; (e) they could give informed consent. Anyone needing translation services was excluded from participating.

3.3.5 Semi-structured interview guide

To explore narrative master plots, a single semi-structured interview schedule was created and pilot tested. A member of the research team undertook a pilot 'think aloud' interview via Zoom with an individual who had a stroke before the main interviews were conducted. Following the pilot interview, no changes were made to the guide (Appendix 14). The interview schedule, comprising four major sections and twenty-nine questions, is reproduced in Appendix 15. The average duration of an interview was 60 minutes. Zoom was used to audio-record the interviews. A transcript was produced automatically, then the lead and supervising researchers independently verified the accuracy of the scripts.

3.3.6 Analysis

The aim of the present study is not to make statistical generalisations; rather, it seeks to influence readers and encourage them to consider how the present findings can relate to other people's experiences (Smith, 2018). Because of this, the researchers did not attempt to establish data saturation of the information or consistency between the generated codes; instead, they provided detailed examples of the master plot using a particular analytical procedure. Each single interview transcript was viewed as a story or narrative. After the interview and data collection processes were completed, participants were chosen to be included in the analysis if their illness narratives reflected aspects of the 'overcoming the monster' master plot. A categorical-form type of narrative analysis (Earthy & Cronin, 2008) was carried out in five stages (Figure 3.1).

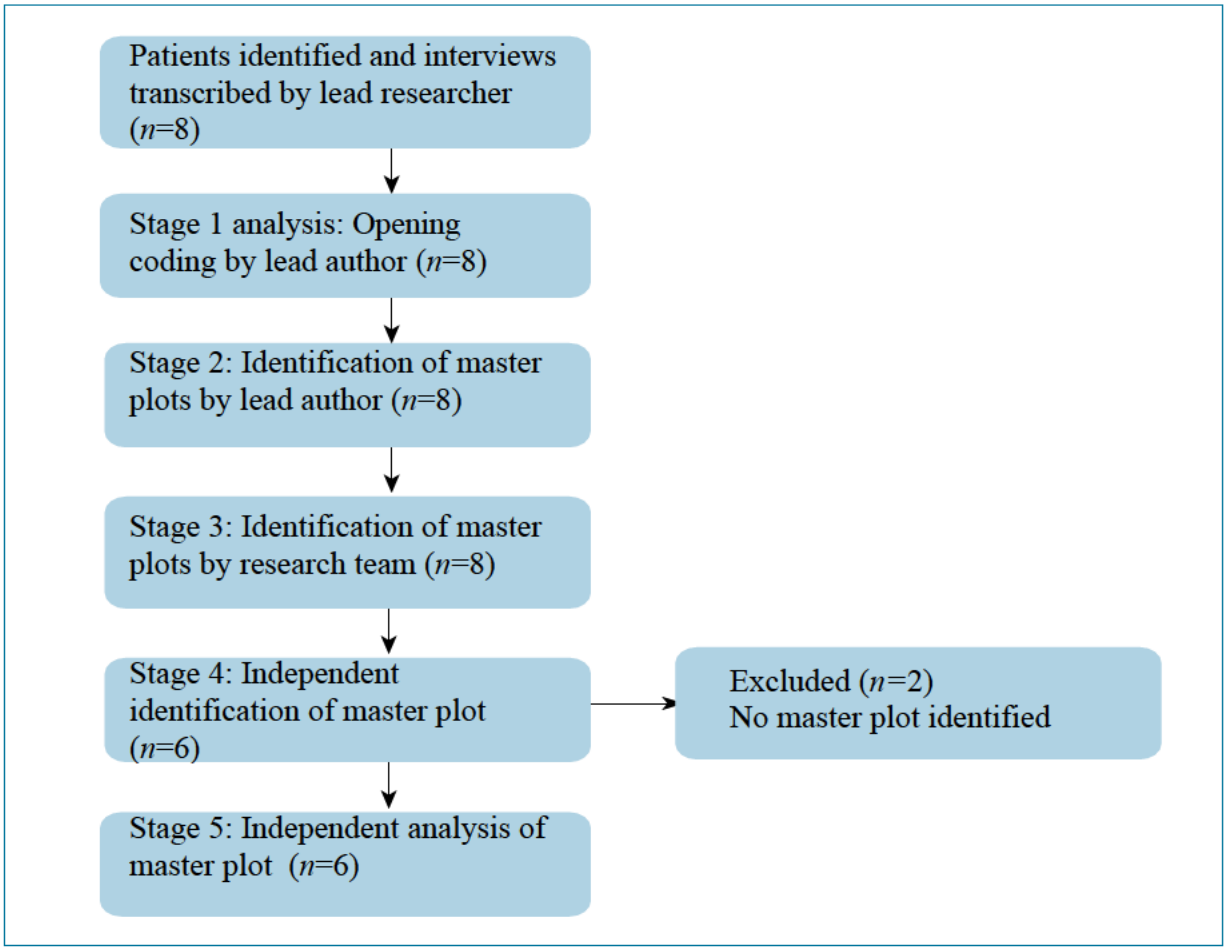


Figure 3.1: Flowchart of the selection method

Stage 1 involved open coding (Popay et al., 2006; Pope, Mays, & Popay, 2007; Soundy & Reid, 2019), in which the main researcher immersed herself in each transcript to detect codes and make comments on pertinent excerpts of each transcript in regard to which master plots they could be associated with and why.

Stage 2: The main researcher made a compelling case to the main supervisor regarding the identification of each master plot.

Stage 3: The research team assessed transcripts for the most common plot types against those that had already been established (Booker, 2004; Soundy et al., 2013).

Stage 4: Independent evaluation was obtained to verify how each participant's conceptualisation of overcoming the monster was expressed. According to the research team, the majority of the participant interviews clearly revealed this master plot (n=6/8, 75%).

Stage 5: The plot was examined to provide more detail and to help understanding. The expression of the master plot was decided upon at this stage and for each participant, the master plot was summarised.

3.3.7 Trustworthiness of the narrative data

In accordance with Andrews (2021), the following steps were taken to guarantee quality: the data identifying examples of monsters were compared to known and verified findings of other research to ensure the truthfulness and trustworthiness of the data (Luker et al., 2015; Soundy et al., 2014). The section on researcher characteristics and reflexivity in the Standards for Reporting Qualitative Research (SRQR) (O'Brien, Harris, Beckman, Reed, & Cook, 2014) means acknowledging that the personal interest of the research team members (A.S& R.A) in the master plot may distort the analysis's conclusions and constrain the study's scope. The primary data collector for this study was an occupational therapist (R.A.) and identified the types of monsters that stroke survivors expressed in order to make this information more accessible and to better understand how HCPs contributed to the development of the master plot. The small sample size and the focus on a single master plot may have restricted attention to the untold narrative, understanding of temporal fluidity and the multifaceted features of the individuals' narratives.

3.4 Results

3.4.1 Demographics

Eight interviews were conducted in total and the narratives of six participants (two men and four women with a mean age of 59±14 years) were retained for analysis. Table 3.2 provides a breakdown of participants' demographic data.

Table 3.2: Breakdown of participants' demographics

Participant ID	Ethnicity and sex	Age	Time with stroke	Type of stroke
1	White British male	62 years	15 years	Ischemic
2	Asian British female	40 years	13 years	Multifocal
3	White British male	64 years	12 years	Ischemic
5	Asian British female	63 years	8 years	Ischemic
6	White British female	80 years	16 years	Ischemic
7	White British female	46 years	4 years	Ischemic

3.4.2 Findings relating to the 'overcoming the monster' master plot

Several important results emerged linking participants' stories to the master plot. Appendix 16 reproduces participants' narratives connected to the master plot and Table 3.3 itemizes the elements of the 'overcoming the monster' narrative.

Table 3.3: Elements of the 'overcoming the monster' narrative

ID	What was the monster?	What needed to be overcome?	How was it overcome?	Consequences	Critical moments
1	1. The condition posed a threat to his mental health, capacity to work and sense of self. 2. The problems faced and negative features of the hospital experiences	1. The physical state, the inability to move. 2. Psychological state of disbelief in what was possible. 3. Lack motivation and trying to overcome the feeling of being beaten by the experience of illness while recognising that it was possible that his situation could be improved.	1. Setting goals and actions that must be accomplished, ranging from simple and basic goals like going to the lavatory independently, and progress to more complex ones like influencing research or giving a conference presentation. 2. Gaining the benefits of familial support. 3. Fighting for his independence and reclaiming territory that once represented him.	1. Attaining personal goals. 2. Making a difference and being able to help other people.	1. Identification of the necessity for hope in some form, and that there is a risk of false despair, as much as false hope. He accomplished this by focusing on improvement rather than recovery. 2. Identification of what was wrong with his interaction with HCPs and the need to alter it. A mission was initiated. 3. Having family members who encouraged and supported him at a time of feeling 'fragile'.
2	1. The mental health experiences that resulted from her internal perception of her situation. 2. Challenges and struggles she faced in attempting to alter her situation and access support.	1. The sense of isolation and abandonment. 2. Being able to provide for her children without relying on others.	1. The need to 'fight' with social services to receive support for her children. 2. Consultation was sought 3. She recognised the need to help herself 4. Volunteering.	Being able to support people who have suffered a stroke and are going through similar struggles.	1. The feeling of being abandoned in hospital. 2. The need to get support for children.

3	1. The physical impacts of the stroke and how they affected his ability to leave hospital and his life after discharge 2. His physical status, being unable to move 3. The uncertainty of HCPs about the value of the activities chosen.	1. Acquiring the range of motion necessary to be discharged 2. The fear that he would not be able to return to normal (pre-stroke) in 3-6 months, as he had initially anticipated following his stroke. 3. Being able to continue working. 4. Achieving mobility and movement against the odds.	1. Improving mobility. 2. Identifying who he desired to be and who he did not desire to be 3. The quality of being determined or 'bloody-minded'. 4. Undertaking non-prescribed activities persistently to gain benefit.	1. By volunteering, he was able to utilise his disabilities to support others.	1. That returning to normal pre-stroke life was not going to happen. 2. Realising the possibility of change in mobility.
5	1. Coming to terms with what was happening in the hospital and the necessity to be independent. 2. Isolation and inability to relate to people in comparable situations.	1. Sense of isolation and the inability to exchange experiences with people within the hospital. 2. The psychological problems as a consequence of this.	1. Identification of goals or what she wanted to accomplish in her life following stroke. 2. Achievements were identified and related to what she wanted to accomplish post stroke. 3. Determination to 'prove everyone wrong'.	1. Identifying the need to 'give something back'. 2. Becoming a stroke specialist counsellor and volunteer at a hospital. 3. Using her own experience to share with and support other stroke survivors in moving on and understanding that a 'new' life is possible. 4. Identifying to other stroke survivors that they did not have to seek restoration or accept that 'life was over'. 5. Having the ability to identify, listen, and understand other stroke survivors in order to support them	1. Coming to terms with what had happened on her own and the need to move on with her life quickly after discharge from hospital. 2. Starting her journey or mission of helping others. 3. HCPs failed to do what she felt was necessary.

6	1. Experiencing a threat to her independence and way of life. 2. Independence was critical, not having a caregiver or being reliant on others.	1. Feeling of loneliness, lack of social interaction and inability to relate to others. 2. Recognising the negative effects of isolation and the need for rehabilitation. 3. Realising that uncertainty may be embraced if seen as an adventure	1. By 'fighting all the time' and accepting and benefiting from all treatment that was offered to her. 2.By utilising experiences (had the benefits of falling over 4 years before stroke) to create change	Embracing change and understanding that it is unpredictable, yet willing to embrace it as an 'adventure'	1. Being unable to communicate or interact with others, losing independence and being reliant on others in the hospital. 2. Having experienced the advantages of identifying and seeing the potential for adventure.
7	1. Experiences of mental health problems including depression. 2. Experiencing disheartenment and lack of motivation.	1. The need to be motivated in order progress and engage in rehabilitation. 2. There was a real desire to carry on and change: *"I want to carry on."*	1. The support and motivation she received from her daughter. 2. Motivated to not let her daughter down.	1. Identifying a way out of a situation where her mental health problems did not affect her and where her symptoms were different	1. Having mental health problems and feeling unmotivated. 2. Her daughter's involvement in the process of change.

3.4.3 Identification of the monster and what needed to be overcome

The monster indicated in some of the participants' stories might be mental health issues, experiencing a sense of defeat or crushing, or having a different sense of self.

For participant P1, this took the form of overcoming a sense of feeling crushed by the stroke experience while progressively realising that it could be overcame.

> *My friends and family could see a horrific deterioration in my psychological state, especially when I tried to go back to work. And they were afraid to talk to me about it because they knew how fragile I was. My wife was amazing in that there were times when I was crying my eyes out, saying I just couldn't do it. I couldn't go back to work. And she knew that if I didn't do it, that would be the end.*

Some participants came to the realisation that their return to 'normal' might take longer than they anticipated. Others stated that one issue needing to be resolved was a lack of motivation. Another monster that needed to be defeated was a sense of loneliness. This was triggered by experiencing a sense of isolation or being unable to connect with others who were going through similar experiences:

> *What really sticks out in my mind about that period is the healthcare team not realising … there's a person inside the body, and the communication to get to know me … never occurred. That was the negative side.* (P6)

The monster was also seen as a threat to independence, such as feeling that daily life was threatened and having to be open to any potential change:

> *I quickly realised that a lot of them [other stroke survivors] wanted everything doing for them and I wasn't going to be like that.* (P3)

The healthcare experience was regarded as a monster that needed to be defeated. However, it was also recognised to be a monster that did not need to exist.

> *I had my own room in the hospital, which was very nice. But I didn't meet any other people. Although it was a stroke ward, I didn't meet any others. It would have been nice for staff to talk to me about my experience, or to put me in contact with someone else in a similar situation in hospital, but that didn't happen.* (P5)

The monster might also be the poor quality of care that patients received, diminishing their sense of dignity. P2 described the following as the challenges encountered when seeking and not obtaining help and care from services:

> *I was the only young person, a 27-year-old mum, a pregnant woman who had had a stroke. I didn't know of anybody else [in the same situation]. I was told to speak to Help the Aged. I didn't really want to go to a day centre where I could sit with other people who have had a stroke. I wanted to be an active mother and [have] an active involvement in my baby's life. There was talk about help that I would get… But when I was discharged, there was none and we had to fight to get help… The adult services were saying no because I had a baby and the children's services were saying, "Well, it's you that had the stroke, so you need the help".*

3.4.4 How the monster was overcome

Two main strategies that participants used to overcome the monster involved the characteristics of the individual and the various strategies for creating change and progress.

Several participants concentrated on their own distinguishing characteristics as a component of how they would defeat the monster, such as being "bloody-minded", determined to prove everyone wrong or motivated not to let others down.

> *The key thing is that there is life after stroke because a lot of people think their lives are at an end. It's just a matter of finding what you enjoy doing. What do you want to do? What can you do at this stage? You've got to keep that hope alive.* (P6)

> *I read about a man who was … some kind of trainer in the SAS, talking about the types of people that they liked. And one of the things he had said was [that] determination to do, to achieve, was not enough. It was persistence [that was needed]. I have discovered that with persistence … if I don't do my exercises regularly, I go backwards. So that has really helped me, [knowing] that I have to be always persistent… I remember my children, when they were trying to walk, they just persisted and persisted. And they didn't mind falling over, because … we say: "Oh, well done".* (P7)

Among the strategies for creating change and progress, people were able to enhance their progress by embracing a distinct internal viewpoint. For example, P5 indicated a determination to move on immediately and start a new life after discharge:

> *I was in [hospital name], which has a specialised regional rehab unit, which keeps you occupied all day. When I got home, I had to start thinking what it was I wanted to do.*

For P1, it was crucial to start with simple, small goals that were less difficult to accomplish, then to eventually progress to larger, more imposing ones:

> *They [the goals] started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal… The next one I had was to shower independently and I learnt how to do that… Then I had to get my confidence back to go and start that process again, to go and wash independently, which finally the OTs allowed me to do. Then the next one was to stand up and give my son a hug on his 16th birthday.*

3.4.5 Consequences

Stroke survivors identified the two key consequences of defeating the monster as setting goals and accomplishments and having an influence on others.

Some participants made it very apparent that it was important to set goals and then adjust them when progress was made:

> *I've achieved every goal that I've set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I gave up on that particular one... My goals change, and as you start to appreciate how you've improved or you can improve, you then can change your goals … I think improvement is infinite, and that's what we should be doing in terms of giving people hope.* (P1)

> *I wanted to move house. I wanted to continue with things I was already doing. And I suppose getting back to ordinary life.* (P5)

One of the most commonly quoted positive effects of defeating the monster was being able to impact others and achieving the motivation to support individuals who had gone through similar experiences. P5 had volunteered at a hospital and had become a counsellor in order accomplish this, but at the time of the study, she was more interested in research:

> *I did get involved with [a major UK stroke charity] and, as I say, counselling. But I've stopped the counselling now. I've pulled away from the [stroke charity], because I want to move on with my life. I don't want to be kept being pulled back, if you like. So doing research … still keeps me involved, but in a good way.*

3.4.6 Critical moments within the plot

Two defining points in each person's path were frequently mentioned: the moment when they realised that there was not enough help or that the help provided had negative effects, and the moment when they realised that change was needed.

Several participants referred to inadequate help by recounting poor encounters and a lack of assistance from hospitals and HCPs:

> *She'd [participant's wife] get my right hand, like a train, the wheels going round. And we'd do this. And that got my arm moving. And the one physio[therapist], because I had a home care team come in, used to ask me what I was doing. [The physiotherapist said] it was a pointless movement. But it got my arm going.* (P3)

> *I still think that we have to acknowledge that healthcare professionals must give hope. I don't accept [that they] may be giving false hope, and I answer that [with] no one talks about false despair. And I think false despair is the evil twin of false hope. By not giving hope, people [are falling] into this vortex of false despair, which is far more destructive.* (P1)

> *I used to do some art therapy in a hospital with an art therapist. And it was all voluntary. We'd go onto a stroke ward and we'd do a bit of art. And I would be there to talk stroke recovery and the art therapist would be there to just provide the art and stuff. And so many people said how they valued that, just because it's something different. And that it was nice to talk to somebody who had had a stroke and managed to get home and live with the effects of stroke. But unfortunately, the hospital didn't want us to go any more*. (P5)

When participants reflected on the impact of the stroke and the changes it had caused, there were several pivotal moments involving the realisation that change was needed:

> *I'm still coming to terms with it …. But I don't mind that… it's kind of an adventure to me. Well … 4 years before my stroke I fell over ... and I lost my sight totally in one eye… And from that time on, it gave me the advantage of looking at life as learning new things … I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating, actually.* (P6)

> *I did join the [name of group]... I think hearing other people's stories was quite helpful…I decided I needed to look forward and be motivated by what I heard from others*. (P5)

3.5 Discussion

This is the first study to consider the master plot of 'overcoming the monster' for people with stroke. The monster was portrayed in various ways. This included mental health problems and experiencing the consequences of poor care such as diminishing one's sense of independence and sense of self. Participants also recognised a timeframe when overcoming the monster was impossible; this might be viewed as a period when survival took priority. At such times, the words of HCPs are crucial in influencing the well-being of stroke patients. To overcome the monster, individuals needed to be able to see what changes were necessary and to identify a reason to fight for that change, such as their relationship with a loved one.

HCPs should be aware of their 'medical voice' (using common medicalised terminology or phrases in reaction to hearing a patient's experiences), which could develop as a result of training, and how it affects the way they respond to individual narrative master plots (Soundy, Smith, Cressy, & Webb, 2010). HCPs must also be mindful of the diverse, sometimes contradictory stories that patients may concurrently present and should be equipped to respond accordingly (Egbert et al., 2021). Responding assertively to a master plan that may be viewed as unrealistic, such as restitution, may result in the creation of a monster from the patient's view of point. HCPs might be able to identify what the monster is for each patient. This might be accomplished by investigating metaphors that could bring to light a patient's unique narrative and motivate the patient (Ferguson et al., 2010). HCPs should also understand that the specific narrative of overcoming the monster may be more approachable if it comes from a peer (Salter et al., 2008) and should recognise that stories told by stroke survivors form a valuable resource that HCPs can use. The manifestation of monsters in specific and different forms has been linked to previously recognised elements that undermine a patient's hope

(Soundy et al., 2014) and reflect a wide range of psychological distress characteristics (Laporte & Aita, 2021). This is crucial because many patients in clinical settings present with distress. Lennon et al. (2020), for example, found that over 80% of physiotherapists encountered psychological distress on a weekly basis. HCPs need to be aware of the factors that give patients hope (Soundy et al., 2014), since they are closely related to how each participant overcomes his or her specific monster. This could be improved by straightforward therapeutic approaches intended to help those who are experiencing psychological distress. For example, the model of emotions, adaption and hope serves as the foundation for a quick interaction based on five straightforward questions (Soundy et al., 2016). Taking a storytelling approach to interactions with stroke patients may be helpful, because storytelling interventions in stroke are linked to favourable psychological outcomes, such as the enhancement of coping skills and support and the strengthening of optimism and hope (Alawafi et al., 2021). It is critical to realise that the development of a master plot can take years and that patients and HCPs may have to wait until additional narratives are presented. Patients' initial plots, expressed in e.g. the restitution or chaos master plots, must be handled cautiously to avoid the creation of a monster. Instead of emphasising the plot's flaws, it may be more valuable to understand how people might be encouraged by learning techniques to increase adherence (Oyake, Suzuki, Otaka, & Tanaka, 2020). Motivation was built in the current study through positive and rewarding experiences, as well as recognising the significance of minor improvements. This conclusion is supported by previous research that reported a strong association of family support with improved motivation and self-efficacy (Ninuk, Delila Rini, & Erna, 2020). It may be crucial to create environments that foster autonomy in people who lack motivation (Souesme & Ferrand, 2019). Encouraging and promoting independence is essential in these situations; allied health workers must concentrate on positive changes, no matter how modest, in order to boost the patient's

self-efficacy and increase their ability to defeat the monster. This may be seen as a reflection of how significant it is to pay close attention to the way the story is told (Tropea, 2012).

3.6 Clinical implications

Overcoming the monster may be characterized as a non-static master plot which develops over time and which may not be visible immediately following the incident of stroke. There is the potential for HCPs to identify more typical plots and attempt to address them, unaware of what the monster might be or that their communication might have created it. Attempting to comprehend patients' metaphors may offer a simple way to start the process of detecting such a monster. This might include patients' portrayal of their recovery as a fight or battle, of themselves as persistent or as having the personality of a fighter, or other metaphors centred on the concept of a journey. It could also be achieved through the use of a therapeutic tool (Soundy et al., 2022). For instance, the current investigation has identified poor communication with HCPs as one type of monster. To avoid this and enhance their interactions with patients, clinicians critically require training in appreciating the psychology of master plots and this should be the subject of further study. HCPs can utilise this information to empower patients to overcome their monsters. Furthermore, HCPs need to recognise that the rehabilitation process could be benefited by fostering access to peer stories through alternative mechanisms (e.g. face to face or digitally, such as via online support groups or videos) which may explain how their own monster was defeated. Indeed, patients may benefit from encountering other viewpoints and personal journeys of all kinds.

3.7 Limitations

The value of this study may be constrained by its concentration on a single master plot that has already been established. The prevalence of this specific master plot cannot be determined. Due to the worldview adopted by the present research and the study's goals, no independent blind coding process was used in the analysis and no measures of agreement among researchers were produced.

The study had a modest number of participants, all of whom were willing to share their stories and to participate in the semi-structured interviews. Therefore, it is crucial to highlight the possible existence of other as yet unidentified metaphors that could be associated with this master plot. It might be interesting to conduct future studies of illness narratives illustrating the master plot of overcoming the monster within a large and diverse sample, which could contribute to our understanding of such plots. There was limited consideration of the potential influence of key demographic variables such as educational level on the master plots identified. According to Hinckley (2006), patient personality, cultural influences and psychological adaptation are all known to affect how people tell their stories after having a stroke. Future research is required to consider this. Finally, the outcomes of this research might differ according to the severity of the deficiencies experienced (e.g. language, perception or memory) or the side of the brain affected (Egbert et al., 2021) and this too should be addressed by future researchers.

3.8 Conclusions

The present study offers a novel perspective on the master plots within the illness narratives expressed by people with stroke. This could have implications for the HCPs, who might be provided insight into the master the plot of "overcoming the monster." It might also be useful

for allied health providers to obtain insight into the variables affecting this specific plot. This study supports previous research on the importance of non-directive ways to listen to stories. More research is required to examine the reactions of HCPs to this narrative master plot.

CHAPTER 4

OVERCOMING THE MONSTER! PERCEPTIONS OF PHYSIOTHERAPY STUDENTS REGARDING THE USE OF STROKE MASTER PLOTS FOR BUILDING THERAPEUTIC RELATIONSHIPS: A VIGNETTE STUDY

This chapter reports in full the contents of a published manuscript. It includes verbatim text from the published manuscript and changes made for the purpose of this thesis.

Publication

Alawafi, R., Rosewilliam, S., & Soundy, A. (2023). Overcoming the monster! Perceptions of physiotherapy students regarding the use of stroke master plots for building therapeutic relationships; a vignette study. *BMC Medical Education*,23 (311) ,1- 9.(Appendix 3)

4.1 Abstract

Background: There is a need for research that examines how student healthcare professionals (HCPs) respond to various illness narratives. Narrative master plots identify common types of illness narratives expressed by individuals with a stroke. 'Overcoming the monster' is the name of one stroke patient's narrative master plot that has not been thoroughly researched. Research is required to understand the responses of student HCPs to this specific master plot.

Objectives: To explore how physiotherapy students react to three versions of the 'overcoming the monster' master plot in stroke survivors.

Methods: A qualitative narrative vignette study was conducted at a UK university in the West Midlands which granted the researchers access to physiotherapy students on a pre-registration courses. The purposive sample consisted of physiotherapy students who volunteered to fill out a single vignette questionnaire at a specific time. The vignettes provided three different and unique examples of the master plot of overcoming the monster as expressed by individuals who had had a stroke. Students responded to each by answering particular questions that elicited demographic information and questions that elicited reactions to the various examples of the master plot. The results were analysed using categorical content analysis.

Results: Thirty-two first-year (BSc) students, thirty-nine first-year (pre-registration) MSc students and nineteen third-year (BSc) students took part. None of those in either first-year cohort had engaged in any clinical placement hours, whereas all participating third-year students had completed the necessary number of hours of clinical placement for the physiotherapy programme. Students frequently showed empathy towards the master plot. They often appreciated the version of the narrative that showed how challenges following a stroke might be perceived as an adventure. All groups acknowledged the value of family support and

were motivated by the version of the story in which a family member was viewed as a source of motivation and encouragement. The version of the story which highlighted the flaws of the current healthcare system was more often identified by final year BSc students and MSc students. However, first-year students, particularly BSc students, claimed that the vignette had a stronger emotional impact on them.

Conclusion: The master plot of overcoming the monster elicited empathetic reactions from students than has been identified in other master plots. This is significant because it emphasises the importance of students recognising patients' stories and the difficulties or 'monsters' experienced by stroke survivors. Training HCPs on the value of listening, understanding and reflecting on the various master plots they may encounter in practice will enhance therapeutic partnerships.

4.2 Introduction

Stroke can cause complex and long-term disability, which is the most significant effect and means that patients require constant care and support (Bowen, James, & Young, 2016; Edmans, 2010). Student HCPs are expected to provide patient-centred care (Bowen et al., 2016). The therapeutic relationship between patients and HCPs is central to this approach (Pierce et al., 2007), having an impact on patient engagement and satisfaction with their treatment, as well as improving stroke rehabilitation outcomes (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010; Kayes, Mudge, Bright, & McPherson, 2015). The foundation of a successful therapeutic relationship is communication and if this is ineffective, patients' psychosocial well-being may be negatively impacted (Alawafi et al., 2022). The effectiveness of communication between HCPs and patients is subject to particular risks. For example, it may be impaired by the strain that high caseloads have on HCPs (Pierce et al., 2007) or by inherent prejudices against patients (FitzGerald & Hurst, 2017). Special attention must be paid to the training of student HCPs so that they have the skills needed to establish better therapeutic relationships with their stroke patients (Kayes & McPherson, 2012; Kayes, McPherson, & Kersten, 2015).

One possible strategy for developing therapeutic relationships between stroke patients and HCPs is the sharing of illness narratives (Kirkevold et al., 2014). According to research among HCPs and stroke survivors, there are a variety of benefits to sharing stories, including patient empowerment, increased involvement and shared decision making (Wohlin Wottrich, Stenström, Engardt, Tham, & Von Koch, 2004). The chronic illness trajectory model (Corbin, 1998) recommends that patients with long-term conditions such as stroke should tell stories about their illness. After a stroke, having the chance to deliver a narrative tends to help patients to make sense of their experiences and grow emotionally and socially. Storytelling

interventions can help stroke survivors' psychological health and emotions (Alawafi, Rosewilliam, & Soundy, 2021). Therefore, it is essential for HCPs to become familiar with such benefits in order to support the storytelling process (Alawafi et al., 2021).

Illness narrative master plots offer a means to comprehend illness experiences and are represented through overarching plots that are frequently presented in connection with a specific and distinct illness experience (Soundy et al., 2013). Thirteen distinct master plots (Chapter 3, Table 3.1) have been identified by studying the narratives of patients with various neurological diseases (Soundy et al., 2013). Examples are the detached master plot, which indicates that the narrator perceives the incidents related to the illness in a detached and unemotional manner, the comic master plot, in which disease is viewed differently, and the detective master plot, which depicts a quest for answers after illness. Recent studies have expanded knowledge in this domain to include other master plots, an important one being that of overcoming the illness incarnated as a monster. Booker (2004) identifies this as a version of a major narrative plot found in literature. This master plot is particularly relevant to stroke, as the various experiences associated with the onset of stroke and its aftermath can resemble a monster that must be defeated. Examples of this monster identified by individuals after stroke include mental health problems, interpersonal difficulties, a sense of isolation and changes to their social identity (Alawafi et al., 2022).HCPs who work with stroke patients need to be aware of the importance of this master plot and recognise how illness narratives can be empowered and disempowered by interaction (Luker et al., 2015).

There is limited research into how HCPs perceive and respond to illness narrative master plots, as well as into the effects of their response on the care delivered to patients (Soundy et al., 2010). Further research is required to determine whether ongoing clinical experience affects how students view and respond to illness narratives. One way to investigate how HCPs view

and respond to illness narratives is to use a vignette, which is an illustration of a particular moment in a story using the voices and viewpoints of multiple characters (Grbich, 2013). Vignette-based studies on HCPs (physiotherapy students) have shown that empathy can be diminished via training and that clinically trained students can respond to various master plots by concentrating on what is wrong with them and attempting to fix them (Soundy et al., 2010). Overcoming the monster differs from previously identified master plots in that it does not test the student's understanding of what is feasible in rehabilitation, but rather displays what is feasible and has been accomplished. More research is needed to determine how HCPs might work more efficiently with various narrative master plots (Alawafi et al., 2021, 2022) and using different stories that show how people change post stroke. Considering these research lacunas, the aim of the current study was to obtain an understanding of how physiotherapy students view and respond to three vignettes representing the master plot of overcoming the monster from the narratives of stroke survivors.

4.3 Method

4.3.1 Design

A narrative vignette study (Soundy et al., 2010) was undertaken. This entailed presenting three illness narratives of people who had had a stroke. These were common real-life accounts covering the time around discharge leading up to their post-rehabilitation journey. The stories outlined the main problems faced by the patients and contained three variations on the master plot of overcoming the monster, where each stroke survivor presented a different monster.

4.3.2 Setting

The study was conducted in the School of Sport, Exercise and Rehabilitation Sciences at the University of Birmingham during the academic year 2021/2022. The vignette was distributed to student physiotherapists in written form during a lecture or through email for completion of an online form.

4.3.3 Sampling and sample size

The purposive sample consisted of two cohorts of first year and final year undergraduate (BSc) physiotherapy students, as well as one cohort of pre-registration graduate (MSc-preg) physiotherapy students. Students in the first year of the BSc and MSc cohorts had never learned about illness narratives, whereas third-year BSc students were more familiar with the notion of narratives and with listening to and comprehending stories. Sample size was based on the principle of information power (Malterud, Siersma, & Guassora, 2016), which states that researchers should take into account the study's aim, the sample they employed, the type of analysis they used, any existing theories and the data quality. An earlier study (Soundy et al., 2010) involved 122 BSc students in total (77 first year and 45 third year) and concentrated on three distinct narrative master plots utilising remarkably comparable questions for analysis. It was determined that a similar number would be adequate for the present study, given the increased emphasis on one narrative master plot. As the aims, questions and analysis methods of the present study were comparable with those of the earlier one, we concluded that employing the same approach of asking three cohorts of students for their responses would yield a sufficient number of responses to compare the three groups.

4.3.4 Procedure

A member of the research team (AS) contacted physiotherapy students on one occasion by sending a generic email to the addresses associated with each year group. The study was also presented at the beginning of a designated module in which all students were present. At the time, students were not being taught by AS, although he would have been known to students in all cohorts. Those who responded by email were sent information on the study that had been ethically approved (Appendix 17). If they consented, they had to click a link to access the vignette or attend a lecture to receive it (Appendix 18). If the vignette was distributed in hard form, it was distributed by a different module leader on one identified occasion to any students who agreed to complete it. The researchers were not present to see who completed or did not complete the vignette, but they did collect completed sheets following the lecture. The vignette was followed by a survey (Appendix 19).

4.3.5 Vignettes

RA and AS developed the qualitative vignettes in three steps process based on work prior to this vignette study. Step one involved the researchers reviewing the verbatim interviews of six stroke survivors who were identified as reflecting the master plot of overcoming the monster, acquired during the study of Alawafi, Rosewilliam, and Soundy (2022). Step two required the researchers to choose vignettes that demonstrated clear examples of the master plot. AS created a set of four selection criteria, whereby a vignette might be chosen if (a) the verbatim quotes from the interview scripts could clearly demonstrate what the monster was and how it was defeated, (b) a brief paragraph could be simply constructed to express the master plot verbatim, (c) the ‘monsters’ or the stroke-related experiences were deemed common for patients with stroke, or the elements of the master plot were deemed remarkable, significant, or unusual and

(c) the chosen master plots were easily distinct from others chosen. At step three, AS generated the versions and sent them to RA for evaluation, comments and agreement. The three selected vignettes were given the titles of Story A, B and C, but they portrayed three different versions of the illness narrative master plot of overcoming the monster.

4.3.6 Assessment

Students were asked to answer seven questions related to each story (Appendix 19). The questionnaire contained items intended to elicit demographic information from students, as well as their perceptions of the vignette. The vignette questionnaire was created using previous research (Soundy et al., 2010), because the earlier questionnaire elicited vital data on participants' views and responses to narratives, thus constituting a tool to compare current physiotherapy students' responses with those gathered in the earlier research.

4.3.7 Analysis

Descriptive statistics were conducted for Question 2 (Q2), including the number of times (n) and percentage (%) that each word was used relative to the number of responses obtained. Responses to open survey questions were subjected to categorical-content narrative analysis (Lieblich, Tuval-Mashiach, & Zilber, 1998), which involved the researcher breaking down these responses into self-contained areas of content. It is usual during content analysis to quantify the existence and meaning of specific terms or themes (Soundy et al., 2010). The analysis was performed by the lead researcher (RA), while AS acted as a critical observer/ friend by reflecting on and challenging interpretations as they emerged in relation to the data (Melia, 2000; Norris, 1997).

4.3.8 Ethics

Ethical approval was obtained from the University of Birmingham under the reference ERN_17-0149C. The study was carried out in line with the University Code of Practice for Research (2021). All applicable standard operating procedures established by the University of Birmingham's School of Sport, Exercise and Rehabilitation Sciences were also followed. The study conformed to the Data Protection Act (2018). All digital data folders were protected securely by password and all printed documents were stored in a secure location. These data will be kept for 10 years to enable enough time for evaluation, reappraisal or additional research, as well as to address any questions or issues regarding the study's data, methodology or results.

4.4 Results

4.4.1 Demographics of respondents

A total of 90 students (39 MSc year 1, 32 BSc year 1 and 19 BSc year 3) participated in the study. These comprised 25 males (28%) with an average age of 25.0 years and 65 females (72%) with an average age of 20.1 years. Seventy-five of the students (83%) had never been assigned a neurological placement and sixty of them, including all of the first-year BSc students, had no placement experience. Table 4.1 offers a more detailed breakdown of respondents' demographics.

Table 4.1: Respondents' demographics (N=90)

	Frequency	Percent
Gender		
Male	25	27.8
Female	65	72.2
Age (years)		
17	2	2.2
18	15	16.7
19	11	12.2
20	14	15.6
21	7	7.8
22	7	7.8
23	11	12.2
24	6	6.7
25	6	6.7
26	3	3.3
28	1	1.1
29	1	1.1
30	2	2.2
31	2	2.2
34	1	1.1
No response	1	1.1
Year of study		
First	71	78.9
Third	19	21.1
Course		
MSc (1st year)	39	43.3
BSc (1st year)	32	35.6
BSc (3rd year)	19	21.1
Neuro placement		
No	75	83.3
Yes	15	16.7
Number of placements		
Not answered	1	1.1
0	60	66.7
1	4	4.4
2	6	6.7
3	12	13.3
3 days on neuro ward	1	1.1
4	4	4.4
6	1	1.1
Fully employed on neuro ward	1	1.1

4.4.2 Descriptive statistical summaries and narrative responses

This section reports descriptive statistical summaries and narrative responses by first and final year BSc students and first-year MSc pre-registration students related to stories A, B and C. Responses to individual questions are summarised in Table 4.2. More details of responses to each question are given in appendix from 20 to 26.

Table 4.2: Descriptive summary of students' responses to individual questions

Story	Cohort	Year	Most attractive story n (%)	Most unusual story n (%)	Story the student would want to hear n (%)	Story the student would want to tell n (%)	Most common story n (%)	Three most common words (frequency; % of total number of students)		
A	BSc	1	6 (19%)	1 (3%)	14 (45%)	10 (32%)	20 (64%)	Motivational (19; 59%)	Family (9; 29%)	Love (6; 19%)
	MSc	1	11 (28%)	2 (5%)	18 (46%)	14 (39%)	14 (36%)	Motivational (22; 56%)	Family (13; 33%)	Sad (6; 15.4%)
	BSc	3	1 (5%)	0	7 (36%)	8 (42%)	8 (42%)	Motivational (19; 59%)	Family (9; 29%)	Love (6; 19%)
B	BSc	1	14 (45%)	17 (55%)	1 (3%)	4 (13)	6 (19%)	Sad (9;19%)	Despair (6; 19%)	Neglected (6; 19%)
	MSc	1	17 (44%)	13 (33%)	2 (5%)	5 (14%)	16 (41%)	Neglected (9; 23%)	Sad (8; 20%)	Mental health (7; 18%)
	BSc	3	12 (63%)	5 (26%)	0	3 (16%)	4 (21%)	Despair (6; 31%)	Negative [hospital experience] (4; 21%)	Frustration (3; 15%)
C	BSc	1	11 (35%)	12 (39%)	15 (48%)	14 (45%)	3 (10%)	Persistent (15; 42%)	Motivational (6; 19%)	Inspiring (6; 19%)
	MSc	1	10 (25%)	22 (56%)	12 (30%)	12 (33%)	4 (10%)	Persistent (14; 36%)	Motivational (9; 23%)	Positive (11; 28%)
	BSc	3	6 (31%)	13 (68%)	12 (63%)	5 (26%)	2 (11%)	Persistent (8; 42%)	Inspiring (6; 31%)	Positive (6; 31%)

4.4.2.1 Immediate reaction to each story

Story A: The monster is identified through the challenges created by the stroke and references to mental health difficulties. It is overcome through motivation, emotional support and the patient's relationship with her daughter.

Most MSc students as well as BSc years 1 and 3 students were touched and uplifted by the story and the daughter's support for her mother. This was identified more by first-year BSc students (14/32, 44%) and slightly less by first-year MSc students (12/39, 31%) and final year BSc students (6/19, 31.6%). For example, one student described the story as "*heart-warming, loving and touching*" (BSc female year 1, P62). Year one students in both BSc (11/32, 34%) and MSc cohorts (7/39, 17.9%) felt more sad than final year BSc students (2/19, 11%). However, final year BSc students reported feeling empathy for the individual (4/19, 21%) which was slightly similar to the year 1 MSc students (6/39, 15.4%) and slightly more than the BSc year 1 students (4/32, 12.5%).

Most students in all cohorts (BSc year 3: 16/19, 84%; BSc year 1: 22/32, 69%; MSc year 1: 29/39, 74%) recognised the importance of family support and identified it as an importance factor in promoting an individual's emotional and physical well-being. Respondents considered family members as sources of external motivation that the patient needed to recover and move on with her life while coping with stroke and the impact of experiencing two strokes. This section was identified by two-thirds of 3rd year BSc students (12/19, 63%), but only approximately a third of the other cohorts (MSc: 12/39, 31%; BSc 1: 10/32, 31%). One student demonstrated this by writing:

> *It highlights to me the importance of family support during a difficult time. I think that is the most important thing to the person who is telling the story and they make it clear that they needed that support to keep going.* (Female BSc year 3, P73)

Clearly more final year BSc students (7/19, 37%) than respondents in the first-year cohorts (MSc: 4/39, 10%; BSc: 2/32, 6%) were able to identify how common it was for stroke patients to lose motivation due to the length of rehabilitation and the frustrating nature of the process.

> *I think it's a common theme that some patients, particularly the elderly, struggle with motivation and it is often ignored as most people assume every patient is determined to get better.* (Female BSc year 3, P75)

> *I feel like the emotions the patient was feeling at the start of the story are quite common post strokes for patients as it is very easy for people to lose motivation after they are discharged from hospital.* (Female BSc year 3, P81)

Furthermore, more final year BSc students (12/19, 63%) than first year students in both cohorts (MSc: 9/39, 23%; BSc: 4/32, 13%) identified significant healthcare challenges after stroke. For example, a first year MSc student wrote:

> *The stroke was not fully treated and/or she did not have the correct or personal recovery programme specifically for her case. The daughter family was the main rehab for her recovery not the [NHS] untailored recovery programme.* (Female MSc, P20)

Some third-year students (3/19; 15.78%) stressed the importance of providing support to family members of a stroke survivor, due to the significant role the daughter played in her mother's recovery. Finally, the importance of the local support system, such as from friends, was also identified, mostly by MSc students (6/39,15.38%). This may be because the story focused on family, but friends' support cannot be ignored. More details of responses to story A are given in appendix. 20.

Story B: The second story identified difficulties in the hospital experience as the monster, which was overcome by being able to recognise the difficulties and seeking to alleviate them.

Most final year BSc students (14/19, 73.7%) identified the shortcomings of the hospital environment. Less numbers of year 1 students highlighted this although numbers were still considerable (MSc 24/39, 62%; BSc 14/32, 44%). The shortcomings identified by students

including the healthcare professional's misdiagnosis, inadequate care, patient neglect, a lack of communication between the patient and a lack of patient-centered care.The impact on patients' mental health of the ward environment was also criticised by some students, with broadly similar numbers across cohorts (BSc year 3: 6/19, 32.2%; BSc year 1: 7/32, 21.9%; MSc year 1: 10/39, 25.6%). A good example of this is one female 3rd year student's opinion that the story "*highlights flaws in healthcare systems and shows how it affects patients and negatively impacts their recovery. Shows how patient-centred care is sometimes not achieved and the needs and wishes of patients aren't always taken into account"* (P72). Students frequently used terms to describe this story that expressed their shock, annoyance and frustration at learning about the person who reported it. This was more common among year 1 BSc students (11/32, 34.4%) than BSc year 3 students (5/19, 26.3%) or year 1 MSc students (7/39, 18%). It is interesting to note that some third-year BSc students (4/19, 21.10%) found this story realistic and were able to acknowledge the unfortunate nature of the mistake, but they understood it in the context of broader problems facing the NHS, such as staffing shortages and patient overloading, illustrated by this response: *"The patient shed light on the unfortunate but realistic experiences that happen to stroke patients where their stroke might have been missed in the early stages"* (Male BSc year 3, P80). Students reported feeling empathy for the individual and this was more evident in both BSc cohorts (year 1: 11/32, 34.4%; year 3: 10/19, 52.63%) than in the MSc cohort (7/39, 17.9%). Details of responses to story B are given in appendix 20

Story C: The monster was identified as a loss of control following the stroke and the identification of negative or challenging experiences, e.g. the patient's inability to speak or

express himself. A central way the monster was overcome was to view negative experiences as an adventure, showing that life and new experiences can become an adventure.

High numbers of students in all cohorts (year 1 BSc: 18/32, 56%; year 1 MSc: 16/38, 42%, n=1 missing data; year 3 BSc: 14/19, 74%) deemed this stroke survivor to have an amazingly rare positive attitude and mindset after what they considered a life-changing experience. This was associated with a large number of students who considered the story motivating and inspiring to read (BSc year 3: 7/19, 37%; BSc year 1: 7/32, 22%; MSc year 1: 4/38, 11%). It is interesting that number of final year BSc students classified this story as surprising because it was unexpected and reflected a distinct philosophy (8/19, 42.1%), whereas only one member of a year 1 cohort described it as surprising. At least half or more of all students consistently identified the characteristics of the protagonist of this story. They emphasised the capacity for an individual to find strength, determination and motivation intrinsically, empowering him to persist with the rehabilitation programme in order to progress in his recovery journey. This was demonstrated by comparable response rates among groups (BSc year 3: 12/19, 63%; MSc year 1: 19/38, 50%; BSc year 1, 15/32, 47%). These responses exemplify this assessment:

> *He is very self-motivated with the understanding that he won't recover straight away (or 100%).* (Female MSc, P10)

> *[He] has had the experience of a previous traumatic injury so he knows how to cope with major changes in life and is self-aware and has developed his own understanding of the importance of persistence.* (Female BSc year 3, P87)

> *Inspired by the positive outlook of the patient* (Female BSc year 1, P66)

> *His story is an encouraging one as seen by how his condition improved and progressed as he persisted in doing exercise*. (Female BSc year 1, P45)

Appendix 20 provide further details of responses to story C.

4.4.2.2 Relative appeal of the stories

While story B drew the most attention overall from the students, it appears to have been most appealing to third year BSc students (12/19, 63.15%), followed by the first-year BSc cohort (14/31, 45%, n=1 missing) and MSc students (17/39, 44%). What attracted the most attention to story B was the shocking aspect of the horrific experience described by the individual within hospital environment and how destructive this could had been to his physical and mental health. Story C attracted the second greatest attention, from around a third of students (BSc year 1: 11/31, 35%, n=1 missing; BSc year 3: 6/19, 32%; MSc: 10/39, 25%). The main reason for students being attracted to story C was that they were drawn to the patient's attitude and perspective on his illness and life. Despite all of the challenges he experienced as a result of a life-altering disease, he was driven and persisted in his recovery from stroke after only one conversation with a trainer. He also did not let his diagnosis define him, degrade him or take over his life; instead, he used his experience of sickness to craft a new path and direction for himself through self-reflection. Finally, story A was more attractive to first-year students (MSc 28%, BSc 19%) than to the final-year students, only one of whom (5%) found it most attractive. Appendix 22 lists overall values and compares values among participant groups. The main factors drawing attention to story A were family-related: how a person's journey to recovery might depend greatly on external sources of inspiration and support including family members (in this case, a daughter) and how the mother found herself wanting to change and improve herself because of her love for her daughter. According to one participant, this story clearly demonstrates that HCPs cannot support patients emotionally; rather, they need support from their loved ones:

> *This reminds me, doctors, physiotherapist CANNOT do much to heal patients psychologically, but instead they need support from their family*. (Female BSc year 1, P68)

4.4.2.3 Perceived commonness of the stories

When participants were asked which of the stories they would expect to be most common, a majority selected story A. This choice was most often among first-year BSc students (20/31, 65%, n=1 missing) than the other cohorts (third-year BSc: 8/19, 42%; MSc: 14/39; 36%). Most of the students who chose story A believed that it would be common because family members are usually the people who provide emotional support to their sick relatives and patients commonly seek motivation and support from loved ones. Family was considered the driving force behind their ability to overcome obstacles and make progress in their rehabilitation.

> *Common - many people empowered by family - family members (offspring) often support patient's needs*. (Female BSc year 1, P55)

The second rationale for selecting story A as the most common was that the case appears to be clinically somewhat generic: since stroke recovery is a lengthy and complex process with complications along the way, it is normal for stroke survivors to be depressed and have difficulty coming to terms with their loss of independence and abilities.

> *I think story A is probably the most common. Stroke has a very difficult, long recovery. After incident patients' lives dramatically change and it's difficult for them to think positively, especially when progress is so minimal and slow.* (Female BSc year 3, P89)

MSc students were most likely to choose story B as the most common (16/39, 41.02%), in contrast with only around 20% with the around 20% (BSc year 1 6/31, 19%. BSc year 3 4/19, 21%) of students.Many respondents who picked story B explained that they did so because it reflected the current shortcomings in the NHS, which they ascribed to a number of factors, including excessive strain on resources, HCPs' ability to apply screening protocols and procedures, the negative culture in wards and the potentially detrimental biased attitudes of HCPs. For example, one students stated:

> *Story B - I think there are a lot of people / patients that are seriously suffering in hospitals and finding it challenging to try and recover. The will to survive might be gone as well. That's why it is essential to have a supportive environment to reignite their will to live.* (Male MSc, P24)

The second most common explanation given by respondents for choosing story B was that unpleasant stories about stroke are often heard because having a stroke is a painful experience.

Only around 10% of all students identified story C as the most common (MSc year 1 4/39, 10%; BSc year 1 3/31, 10%; BSc year 3 2/19, 11%).The most usual explanation was that the teller describes various common and long-term physical, cognitive and communication problems that many stroke patients experience, such as inability to carry out basic activities of daily living and reduced memory and concentration. For instance, one student wrote:

> *Story C – because of how the individual describes not knowing what was happening in the first month. I think this experience is common, unless you were [an HCP] /was close with a stroke survivor, you wouldn't know what a stroke experience is like & a lot of the time your memory & concertation is reduced & fatigue is enhanced after stroke so it might be harder to learn and understand the effects of a stroke after you've had it.* (Female BSc year 3, P87)

A second reason for choosing story C as common was the psychological aspect of progressively coming to terms with what had happened, requiring a changed outlook and adjustments to one's viewpoint and mindset after a life-altering catastrophe. According to one respondent, it was common because once patients are educated about their situation, they are often better able to come to terms with what has happened and become determined to progress:

> *Story C- when people realise that they have been given the tools but it is them that need to be motivated & do the work. There is a change in their outlook & how they carry themselves*. (Female MSc, P34)

Appendix 23 gives overall values for the most common stories and compares values between student groups

4.4.2.4 The most unusual story

When invited to identify the most unusual story, the majority of students across cohorts named story C. This was most true of final-year students (n=13, 68%), followed by the MSc (n=22, 56%) and first-year BSc cohorts (12/31, 39%, n=1 missing). Story C was perceived to be unusual due to the positive and hopeful approach to life of the teller, as well as their view of life and the recovery process as an exciting and adventurous experience. The individual in story C shows extraordinary positivity in the face of adversity, which was believed to be extremely rare and difficult to attain following multiple life-changing incidents.

> *C - as it is very rare to find someone that has such a positive outlook on life after experiencing stroke.* (Female MSc, P10)

> *The 3rd story (C), as I feel that this was a very unique approach to coming to terms with their injury and not many patients would have the confidence to want to experience new things.* (Female BSc year 3, P86)

Story C was also identified as unusual due to the teller's traits and personality. She was seen as self-motivated to improve without support from others such as family, persistent, determined and mentally strong, with self-awareness that was believed to be rare, particularly after several life-altering events including stroke:

> *C - I believe that finding people who are motivated to better themselves after a traumatic event is a rare case. It can be overwhelming therefore the most unusual.* (Male MSc, P21)

Story B was identified as most unusual by the second largest number of respondents. It was adjudged most unusual by first-year BSc students (17/31, 55%, n=1 missing), followed by MSc (13/39, 33%) and BSc year 3 students (5/19, 26%). Story B was considered unusual because it does not reflect the standard treatment and care given to stroke patients in hospital. It was perceived to be unusual to misdiagnose classic symptoms of stroke:

> *B, because I think that it's rare that it takes 3 days to diagnose someone with stroke. This is a problem that needs addressing.* (Female BSc year 1, P42)

In terms of the nature of experiences and different circumstances that the individual faced with the healthcare system during the period of diagnosis and recovery, story B was characterised as "different", "quite [a] severe case", "quite deep", "very negative" and "more unique". It was also considered unusual in reflecting the negative side of someone's recovery journey and in shedding light on the negative side of working in a hospital, as people often mention only the positive aspects of their experience:

> *B - They mentioned a lot about the unpleasant side or things he faced when he had the stroke/injury (people usually focus more on the recovering part).* (Female BSc year 1, P60)

Only three MSc students identified story B as unusual, because of the teller's personality and characteristics; he was described as "knowledgeable" on his illness and as having a strong will to overcome various physical and mental difficulties, thus changing a negative experience into a positive one. For instance, one student stated:

> *B - The patients seemed knowledgeable on the condition, whereas I think most people are unaware and leave everything in their doctors' hands.* (Male MSc, P3)

Only three students, all from year 1 cohorts, considered story A unusual. Appendix 24 lists overall values and compares values between student groups.

4.4.2.5 Preferred story to hear

When participants were asked which story they would prefer to hear from a close family member or friend if they had a stroke, Story C was the most frequently chosen by BSc year 3 students (12/19, 63%), compared with almost half of first-year BSc students (15/31, 48%, n=1 missing) and a little less than a third of the MSc cohort (12/39, 31%). A similar percentage of first-year BSc students (14/31, 45%) and of MSc students (18/39, 46%) chose story A, which was preferred by a smaller percentage of BSc year 3 students (7/19, 37%). Story B was the least often chosen, by only three first-year students (2 MSc, 1 BSc). Appendix 25 lists overall values for preferred stories to hear and compares values between student groups

As to reasons for these choices, story C was preferred because of its very positive and optimistic undertone. It is a story of hope and motivation, demonstrating that life does not end after a stroke and that there is still joy to be found. Illustrations of this can be seen in students' responses. For instance, one explained that "*it is a story of hope and is encouraging that things will end up good"* (Female MSc, P14). Another stated:

> *I would choose C. It is empowering to me…. and I believe if one of my close friends/relatives got ischemic stroke, they would not want to listen to depressing stories or common stories. Instead, they need encouragement and the power to move on, the other two stories would be helpful as well but from the perspective of someone who has just got a stroke, story C should be the best.* (Female BSc year 1, P55)

Students admired specific traits such as persistence and a determination to achieve that were illustrated by this story. Some expressed the view that such motivation would comfort them with the belief that the stroke patient would be determined to improve and persevere with their rehabilitation programme in order to reach the highest potential quality of life. Thus, a female year 3 student wrote: *"Story C – This individual sounds the most independently resilient (intrinsic motivation)"* (P87).

Story A was preferred because of the positive and inspiring tone throughout. Students most often valued that this story for showing that the teller was not alone and would receive emotional support and care from others. This support helped students to believe that a better recovery and more positive outlook was possible, as this response illustrates:

> *Story A. This is because I would want a friend or relative to have someone there caring for them and loving them. I would want love to be the motivation to carry them through the tough times as love is unconditional.* (Female BSc Year 1, P58)

4.4.2.6 Preferred story to tell

As to which of the stories respondents would prefer to tell if they were in similar circumstances, the results indicate a similar level of preference for stories A and C. Final-year BSc students (8/19, 42%) and MSc students (14/36, 39%, n=3 missing) chose story A ahead of the other two, while BSc year 1 students chose it less frequently (10/31, 32%, n= 1 missing), more often reporting a preference for story C (14/31, 45.2%). Other cohorts had slightly lower numbers (MSc: 12/36, 33%; BSc year 3: 5/19, 26%). A smaller proportion selected story B (MSc: 5/36, 14%; BSc year 1: 4/31, 13%; BSc year 3: 3/19, 16%). Appendix 26 compares overall values on these responses and compares values between student groups.

Many students stated that they would tell story A because they believed it would be the most relatable to them, due to the relationships they had with their families, perceiving themselves as family oriented and more likely to rely on their families for support and motivation throughout their recovery journey. This reflects an understanding of the importance of interpersonal relationships as sources of support and motivation during rehabilitation. Two female students gave these explanations:

> *I think I would tell the first story (A) because I feel like it would be the one I would relate to the most, as it is the most common of what may happen to myself, and I would definitely need my family to support me throughout my recovery.* (BSc year 3, P86)

> *Story A: ……motivation can come from external sources, showing that by accepting support, you can overcome certain obstacles.* (MSc, P13)

Others stated that they would prefer to tell story A because it seemed the most realistic, reflecting both the highs and lows of the recovery journey. Story A was also considered to help the patient to be positive, pragmatic and having a purpose or meaning to continue recovering.

> *I would choose story A, as I like to be realistic.* (Male MSc year 1, P2)

> *Story A - I would feel down for a while as I would have lost some control over basic bodily functions, but after a while I would be able to find a reason to continue fighting.* (Female BSc year 1, P61)

Story C was identified as preferable because it shows the ability to evolve and cope with a life-altering illness in a positive and unique way by perceiving life as an adventure. This story was also considered one that could motivate and empower others:

I'd take time to process the huge change that happened, but I'd learn to accept and find positivity in my new way of life. (Female BSc year 1, p41)

I'd like to think I would be like the third who took life as it came and wanted to make the most of their situation trying to improve. I like the way they saw life as an adventure even if it was different now to how it used to be. (Female BSc year 1, P43)

Story B was the most frequently chosen by students across cohorts because they believed that it motivated individuals to be independent, persistent, and self-driven in order to achieve all of their goals, as these responses indicate:

> *I would like to tell story B because this individual seems to have been extremely motivated by his stroke and they have achieved every goals set for them, which really inspires me and I hope by telling this story other people can be inspired too*. (Female BSc year 1, P57)

> *Encourages people to do their own research and be persistent when asking doctors questions*. (Male MSc, P3)

4.5 Discussion

To the best of the author's knowledge, this is the first study to consider the reactions of HCPs (physiotherapy) to versions of the master plot of overcoming the monster. Students frequently expressed empathy for this master plot. Students frequently valued the version of the story that demonstrated how challenges following a stroke could be viewed as a "adventure. Students also valued and were inspired by the story version in which a family member was viewed as a source of motivation and encouragement. The final year BSc and MSc students were more likely to relate to the story variant that focused on the flaws of the health care system. However, first-year students, particularly BSc students, reported that the vignette had a greater emotional impact on them.

Story A was identified as the most common. Interestingly, year 1 students appeared to be more emotionally affected by this story; in particular, BSc students expressed more feelings of sadness. One the other hand, final-year BSc student felt more empathy towards the individual in this story and recognised how common it is for stroke patients to lose motivation as a result of the length of rehabilitation and the frustrating nature of the process, which was less evident in first-year cohorts. This finding contradicts previous research (Soundy et al., 2010), which found that physiotherapy students can lose their empathic response to stories after clinical training. There is a need for HCPs and student HCPs to recognise that a stroke patient may tell various potentially conflicting stories (Egbert et al., 2021) and that the opportunity to listen to the difficulties expressed by patients is crucial in order to sympathise with them.

Participants in the current research frequently wanted to hear story A. The results demonstrate how student HCPs can understand the value of family support and the significance of the

motivational influence that families may have during the stroke recovery process. As a result of ongoing initiatives in the UK (Rudd, Bowen, Young, & James, 2017) to reduce the length of institutionalisation, the healthcare system is becoming more reliant on informal caregivers, usually spouses, partners or family members (Aziz, Pindus, Mullis, Walter, & Mant, 2016). Numerous studies have shown the importance of positive family support for stroke patients' physical and mental health (Elloker & Rhoda, 2018; Galvin, Cusack, O'Grady, Murphy, & Stokes, 2011; Osawa & Maeshima, 2010; Salter, Foley, & Teasell, 2010). However, this finding may mean that student HCPs perceive professional emotional support as less important. Family members frequently lack the knowledge and training necessary to give stroke survivors the proper level of physical and emotional care (Creasy, Lutz, Young, & Stacciarini, 2015). The National Institute for Health and Clinical Excellence (NICE, 2013) and the Intercollegiate Stroke Working Party National Clinical Guidelines (Rudd et al., 2017) recommend that HCPs should carry out routine evaluation and treatment of mood following stroke. However, follow-up support can be inconsistent and medically oriented, failing to sufficiently address patients' complex and specific needs. Following discharge, many patients depend on the support of family and friends, and on self-management techniques (Turner et al., 2019). HCPs may have knowledge of the impact of stroke on mental well-being (Terrill, Schwartz, & Belagaje, 2018) and be motivated to provide emotional support and care to their stroke clients; however, Simpson, Ramirez, Branstetter, Reed and Lines (2018) identified challenges including lack of time, physical recovery expectations and inadequate educational preparation. To resolve the conflict between clinical practice realities and adherence to professional values and clinical guidelines for best practice, educational training or a programme of simple and cost-effective emotional support approaches such as narrative-based intervention might be useful.

Story B was found to be attractive to a large number of participating students, but they often did not identify it as one that they would want to tell if they were in a similar situation. All groups identified the shortcomings of this story associated with the hospital and some participants across the groups expressed feelings of shock, frustration and annoyance. However, MSc and third-year BSc students appeared to be aware of the difficulties currently facing the NHS, including a shortage of staff across all HCP categories, heavy workloads, insufficient resources, and inadequate training, all of which tend to hamper the establishment of a therapeutic relationship and the capacity to offer high-quality patient care (Bailey, 2021). This indicates that clinical experience and age may have a role in healthcare experience expectancies, as previous research has suggested (Hahtela et al., 2015). For instance, younger recently graduated nurses assessed their workplace more positively than did older registered nurses.

As with story A, participants consistently showed empathy for story B. The references to a family member in Story A and to unpleasant experiences with the hospital setting in Story B appeared to be factors with which physiotherapy students might empathise. The capacity to relate the stories to their personal experience, whether in terms of their own family or professional life, as well as considering the healthcare setting, seem to be essential components in creating empathy, as shown by previous research (Rieffestahl, Risør, Mogensen, Reventlow, & Morcke, 2021). Empathy is one of the key psychosocial skills that can enhance patients' psychosocial outcomes such as compliance and confidence (Driver, Lovell, & Oprescu, 2019). It is critical to understand which master plots elicit empathy and which do not. For example, physiotherapy students have previously linked a decrease in empathy to the chaotic narrative (Soundy et al., 2010). This is significant because this story is connected with the severity of

cognitive impairment or the desire of patients to openly discuss their personal experiences after a stroke (Egbert, Pluta, Powęska, & Łojek, 2021).

Story C was most frequently described as unusual by final-year BSc students. What they considered unusual about this story might be a coping mechanism which if corrected without careful consideration might affect patients' hopes, motivation and mental well-being (Soundy et al., 2010). Nevertheless, a moderate number of students among all cohorts were attracted to story C. There was an overwhelming recognition of the positive attitude and qualities expressed within it that were motivating and inspiring. Students across all cohorts valued such characteristics, including internal strength, determination and motivation. Student HCPs have been shown to respond positively to stories that are inspiring and convey a positive recovery message (Yamashita & Nakajima, 2022). Considering this, the capacity to relate to a master plot is probably affected by components in the story that demonstrate how difficulties are overcome, as opposed to master plots that do not demonstrate this. The plot shows the character in a positive light while simultaneously revealing their prior hardships. The master plot does not or would not threaten rehabilitation goals during a student-patient interaction. Nonetheless, stories which are lodged in the present, such as the chaos master plot, or which look to the future, such as restitution and quest stories, may be interpreted as having an effect on rehabilitation goals and the relationship between students and clinicians (Soundy et al., 2010). In addition, it is critical to understand that students' responses may potentially result from inherent bias (FitzGerald & Hurst, 2017). For example, vignettes identifying a patient's educational level, culture or race might elicit a variety of reactions from students (Coons, Watson, Yantzi, Lightfoot, & Larocque, 2017). One function of narrative training should be to reduce judgment of the difficulties patients confront while strengthening comprehension of those difficulties and the variety of stories that might be conveyed (Soundy et al., 2022).

Students can listen more and improve patient care by understanding that patients are more than just their illness (Liao & Wang, 2020; Milota, van Thiel, & van Delden, 2019).

4.6 Implications

Participating students appeared to be empathic in their understanding of the difficulties experienced by stroke patients, represented as the monster in these vignettes. Giving time during interactions to accomplish this will aid in the development of therapeutic relationships. Student HCPs need to establish environments in which stories can be shared and patients' personal challenges can be understood. Patients' presentation of some master plots may elicit a response from student HCPs indicating their perception of a need to fix the story (using positive interventions). However, student HCPs should keep in mind that sharing the story is therapeutic in itself, that it creates trust and that an individual's story will probably evolve as time passes and further opportunities arise to share their story and listen to others.

There may be significant value in ensuring that HCPs' education includes placements with the objective of listening to and understanding people experiencing stroke and other chronic illnesses. Patients may require time and space, as well as direct questions during encounters, to recognise a monster and the realisation that the capacity to overcome it may evolve with time. During clinical placements, student HCPs could benefit from the opportunity to reflect on their responses to various master plots. Finally, training curricula need to emphasise how students' responses may be influenced by implicit bias and by bias towards specific master plots.

4.7 Limitations

The people presenting narratives in this research were chosen from a group of individuals who had more time to recover and faced fewer challenges in telling their story than many other stroke survivors. The current work has not taken account, for example, of the impacts of aphasia and incapacity to narrate caused by a stroke.

More research is needed to determine how common the master plot of overcoming the monster is. The current work was centred on this one plot and it is unclear how other master plots might evolve or interact with it.

Participants' reactions to each narrative seemed to differ according to clinical experience and possibly age. More research is required to gain a better understanding of the effects of both of these factors.

The numbers in each group of participants were unequal and different methodologies were employed to complete the survey. This may have restricted the ability to fully understand the responses given by the final-year students.

The content analysis concentrated on the most prevalent student expressions, a procedure which may have narrowed the scope of the present findings.

The applicability of this work to other student HCPs has not been established.

4.8 Conclusions

Students consistently expressed empathy towards this master plot. This is fundamental, because it highlights how important it is for student HCPs to fully understand their patients' stories and the challenges or monsters that they may have faced. It might be useful for student HCPs to determine what each patient's particular monster may be, which means taking the

time needed to understand the patient and their story. It seems that it is especially important to motivate students to listen to patients and understand their difficulties, to detect problems in the story that may not currently correspond with the goals of stroke rehabilitation.

CHAPTER 5

THE VALUE AND BENEFITS OF NOVEL PLACEMENT TRAINING FOR PHYSIOTHERAPY STUDENTS TO SUPPORT PEOPLE WITH STROKE: A MULTI-METHOD PILOT STUDY

5.1 Abstract

Objectives: To test the impact and understand the experiences of physiotherapy students who participated in a novel placement that combined training, simulated practise, and practical practice with stroke survivors in the community.

Methods: A two-phase multi-method pilot study was designed. Phase 1 was a pre-experimental study and phase 2 a qualitative study using conventional content analysis. Both phases were based on a novel placement and intervention. A purposive sample of physiotherapy students and stroke survivors was conducted. Primary outcome measures were the Froehlich Communication Survey (phase 1) and a self-reported questionnaire (phase 2). Phase 1 quantitative data were analysed using descriptive statistics and confidence intervals. Phase 2 qualitative data were subjected to content analysis.

Results: Seven physiotherapy students (three first-year BSc, four second-year BSc) and twelve stroke survivors participated in the study. Encouraging positive changes among students were identified by the primary outcome measure (the Froehlich scale) and three secondary outcome measures, namely the General Self-Efficacy scale, the Open Minds scale for healthcare providers and the Perspective Taking sub-scale of the Interpersonal Reactivity Index. All participants considered taking part in the intervention to be a positive experience. Other important benefits are identified.

Conclusion: The novel placement delivered an improvement in communication skills, an increase in self-efficacy, a reduction in stigma and an improvement in perspective taking. The development of future curricula and clinical practice may benefit greatly from novel placements intervention that fosters therapeutic communication skills.

Practical implications: The use of novel placement interventions that utilise training and simulated practice in curriculum design and clinical practice may be crucial for fostering the therapeutic communication skills of student HCPs.

5.2 Introduction

Psychological and communication skills constitute a crucial component of patient care that can improve patients' compliance and confidence, and help HCPs to handle a wider range of clinical presentations (Driver, Lovell, & Oprescu, 2019). Receiving care from physiotherapists who have undergone psychological training has been shown to improve patients' well-being (Coronado et al., 2019). The UK Health Care Professions Council lists the use of psychological techniques and skills as a requirement for physiotherapists employed by the NHS (Alexanders & Douglas, 2016). However, past research has found that student HCPs lacked confidence in their fundamental communication skills, including empathy and listening (Hill et al., 2010) and that during training, physiotherapy students could lose their empathy towards particular interactions (Soundy et al., 2010). The presence of empathy in interactions is impacted by a substantial lack of understanding of active listening skills among both qualified and student physiotherapists (Wloszczak-Szubzda & Jarosz, 2013). Research has revealed little evidence of psychological and communication skills training for student HCPs in UK universities (Alexanders, Anderson, & Henderson, 2015; Heaney et al., 2012). Consequently, physiotherapy students encounter a number of issues, such as difficulty in recognising the skills that fall under their area of practice, fear of using those skills in clinical settings, lack of experience and training that offers restricted transferability to clinical settings because it happens in unreal environments or with peers without disabilities (Higgins & Gray, 2020).

Psychological skill training is needed (Soundy et al., 2021).Short courses are particularly valuable (Soundy et al., 2022) .One course is based on the model of emotions, adaptation and hope (MEAH) (Soundy, Roskell, Elder, Collett, & Dawes, 2016) that can be taught in a short space of time (less than one hour). The MEAH was created as a result of twelve theory-

generating reviews (Soundy, Liles, Stubbs, & Roskell, 2014). The reviews focus on the expression of illness from individuals with a variety neurological chronic illness. This includes Parkinson's disease, multiple sclerosis, stroke, and spinal cord injury, as well as palliative diseases , such as cancer and motor neuron disease, served as the basis for this work (Hole, Stubbs, Roskell, & Soundy, 2014; Reid & Soundy, 2019; Soundy & Condon, 2015; Soundy et al., 2016; Soundy et al., 2013; Soundy, Stubbs, & Roskell, 2014).The reviews provided models and processes consistently linked to the expression of hope and to cognitive processes pertaining to psychological adaptation. The MEAH was the last model to be created with the purpose of reconceptualising how individuals convey psychological adaptation and hope (Soundy, Roskell, Elder, Collett, & Dawes, 2016).Another distinctive quality of the MEAH is its ability to map the psychology of common illness plots (Soundy, 2018). Because of this characteristic, it is ideally suited to support the application of narrative-based interventions.

Soundy et al. (2016) established the foundation for using the MEAH as a reliable screening tool. Later, Soundy, Hemmings, and Gardiner (2021) used the MEAH as a screening tool and the basis of a therapeutic interaction during the COVID-19 outbreak. According to their study, the screening tool could be utilised to help facilitate a quick therapeutic interaction. Following this, Soundy et al. (2021) then designed a training courses to enable physiotherapy students to screen and assist patients with chronic neurological conditions, based on the MEAH. A recent pilot study has shown that it can serve both as a therapeutic tool which can be completed within ten minutes to support people with stroke and as a screening tool used on its own to determine psychological adaptation (Soundy et al., 2022).

The techniques that have been developed for MEAH training differ from the usual interactions that physiotherapy students would have. They shift the focus away from trying to fix or guide patients and towards listening and exploring their problems as the patients themselves perceive them (Soundy et al., 2016). Using the MEAH had no adverse effects on people but benefited their mental health (Soundy, Hemmings, and Gardiner, 2021). The MEAH has also been linked with improved capacity to handle challenging conversations and tended to motivate HCP students to use this technique (Soundy et al., 2021).

The most recent study by Soundy et al. (2022) has showed the value of using simulation with actors before students apply the tool in interactions with people with chronic diseases. As result of these pilot studies, secure educational experiences and interactions for patients and students can be developed. Students must have the opportunity to practise their communication skills and gain real experience with service users as part of learning how to communicate with them (Forbes, Mandrusiak, Russell, & Smith, 2017; Soundy et al., 2021). In response to this need, the present study sought to create a two-week novel placement by combining elements of Dr Soundy's earlier work (Soundy et al., 2021) with a clinical placement at a stroke community centre. To the best of the authors knowledge this is the first study to apply the MEAH training within a community group setting.

5.3 Aim

The aim was to understand the impact on students of their experience of a novel placement that combined training, simulated practise, and in-person practise with stroke survivors using the MEAH and narrative intervention. This was addressed via six objectives.

5.4 Objectives

1. To identify changes in communication across two time points (pre- and post-intervention);

2. To identify changes in secondary outcome measures such as stigma, attitudes and empathy.

3. To understand how students experience the training and simulation activities and their interactions with the community stroke survivors .

4. To understand stroke survivors' experiences as participants in the placement.

5. To use the results to make placement recommendations for student HCPs;

6. To utilise the results to explore any benefits for students and patients;

5.5 Methods

5.5.1 Design

A two-phase multi-method pilot study was undertaken. Phase 1 was a pre-experimental study, following the CONSORT recommendation and flow diagram (Lancaster & Thabane, 2019). Phase 2 was a qualitative study using conventional content analysis, reported according to the standards for reporting qualitative studies (O'Cathain et al., 2015). The intervention elements are reported in accordance with the TIDieR guidelines (Hoffmann et al., 2014).

5.5.2 Eligibility

Year 1 and year 2 pre-registration physiotherapy students at the University of Birmingham were eligible to participate in this study. If a student was enrolled in another research project based on communication or psychology, they were excluded. No restriction was placed on the number of clinical placements that had been attended.

5.5.3 Setting

The novel placement was conducted in person at the University of Birmingham School of Sport, Exercise and Rehabilitation at (days 1 and 3) and students were invited to a stroke club in Birmingham (days 2 and 4) to interact with stroke survivors. The stroke club meeting was held each week at the same time for a two-hour period. The group coordination chose this as the best approach and preference.

5.5.4 Sampling and sample size

A purposive sample was taken from a list of pre-registration physiotherapy students at the University of Birmingham, where approval to provide training had previously been given. A student mailing list was used, as it had been used to recruit students in past studies (Alawafi, Rosewilliam, & Soundy, 2022a) and offered the potential to provide access to a sizable pool. An example of an email sent to students is shown in Appendix 27. Students who emailed the research team stating their willingness to participate in the two-week placement were sent an information sheet and requested to provide consent (Appendix 28). They were also asked to complete a brief demographic sheet and pre-assessment form (Appendix 29). Following the placement, students were asked to complete a brief qualitative process evaluation questionnaire (Appendix 30). The group leader of the stroke club advertised for stroke survivors willing to participate as part of the intervention . People who were interested emailed the research team. The researchers then sent each volunteer an information sheet via email and asked them to provide consent (Appendix 31). Following the placement, participants were asked by physiotherapy students to complete a brief demographic survey and answer five feedback questions (*Appendix* 32).

A sample size of 10 to 30 participants was established as appropriate for the primary outcome measure (Isaac & Michael, 1995). Calculation of sample size for the qualitative part of the study was based on the principle of information power for qualitative interviews (Malterud, Siersma, & Guassora, 2016), which states that sample size is determined by the study's specific aim, its use of pre-existing theory and its approach to analysis. The main aim of the analysis was to identify common experiences among physiotherapy students. Previous research identified a sample size of 20 as appropriate to identify common issues (Soundy & Condon, 2015). The exact sample size was determined by data saturation (Saunders et al., 2018).

5.5.5 Intervention

This section is reported according to TIDeR checklist (Hoffmann et al., 2014).

Name :The novel placement training for physiotherapy students to support stroke survivors ,UK

Why: This intervention was developed to enhance the therapeutic communication between physiotherapy students and people with stroke based on previous research by Dr. Soundy (Soundy et al., 2021).The intervention included training and simulated practice by means of the MEAH and narrative intervention. However, the key element of the intervention was the opportunity to apply the MEAH tool with stroke survivors.

What :A two-week period was scheduled to provide the following contents. Week 1: (a) learning the MEAH screening tool for therapeutic conversation. On day 1, a lecturer was delivered by one of the research team members provided background information and examples of using the MEAH as a therapeutic tool in clinical practice, followed by simulation activities, during which students used the tool with an actor who followed a script for a stroke survivor based on previous successful research (Soundy et al., 2022). This training interaction,

which prepared students for potentially challenging conversations, was followed by a group debrief. On day 2, there was an introduction and welcome meetings for stroke survivors who were members of the stroke club. Physiotherapy students attended the morning meeting .The club had authorised students to attend two consecutive meetings. Student HCPs used the MEAH to facilitate conservations with individuals who had a stroke and gathered very brief feedback from them. At the conclusion of these sessions, patients and staff participated in a group debrief .Week 2: (b) small peer-led group session to consider stories of overcoming difficulties and management. On day 3, students met with a member of the research team and were giving training on the notion of storytelling and the benefits of peer-led interventions ,then on day 4, they met once more with members of the stroke club. Each stroke survivor (if willing) shared with the group a key story about how they had overcome a significant challenge. They were also encouraged to share their stories of how they had modified their behaviour to cope better with their stroke. Finally, the students gathered quick feedback from the stroke survivors before attending a group debrief. All of the training material offered was part of the University of Birmingham curriculum.

Who provided : A member of the research team (A.S.) delivered the two lectures . A paid actor provided stimulation practise. The stroke club's group leader promoted for intervention among stroke survivors and scheduled the two sessions. Stroke survivors led a small storytelling group session.

How : The delivery of the two-week placement was conducted face to face and arranged in groups

*Where:*The intervention took place in two locations (West Midlands, Birmingham), one of which was a classroom at the University of Birmingham School of Sport, Exercise, and

Rehabilitation (days 1 and 3), and the other was a local community stroke club w (days 2 and 4) .

When and how much: The dates were set over a two-week period in June 2022. The start date for novel placement: Monday, 20 June 2022. The first day of training lasted four and a half hours and began with a 50-minute lecture followed by simulation activities and group debriefing .The third day of training consisted of a 50-minute lecture on storytelling-based interventions .The training on days 2 and 4 lasted two hours and included a welcoming meeting, practical sessions in which students used the MESH tool with stroke survivors, a small storytelling group, and group debriefing.

*Tailoring :*During all training days, students and stroke survivors could ask questions.

Modifications: No modification was made.

Intervention Assessments: Physiotherapy students were asked to fill out a pre-assessment form (Appendix 29). Following their placement, students were asked to submit a post--assessment form (Appendix 29) as well as a brief qualitative process evaluation form (Appendix 30). Following the intervention, stroke survivors were asked to answer five feedback questions (Appendix 32).

5.5.6 Demographic information

Students were asked to provide demographic information on their age, gender, year of study, total number of placements and whether they had any past teaching or experience related to psychological adaptation, hope, emotions or illness narratives

5.5.7 Outcome measures

Students completed outcome measures (Appendix 29) at the baseline and post intervention. Reminder emails were sent to any student who had not returned the form. After their placements, students were also asked to complete a qualitative process evaluation survey comprising open-ended questions (Appendix 30).

The four outcome measures used have been demonstrated to be sensitive to the training topics. The primary outcome measure was the Froehlich Communication Survey (Froehlich, Pardue, & Dunbar, 2016), which assesses 25 items related to agreement with statements about communication on a scale from 1 (much improvement needed) to 10 (no improvement needed). Thus, the possible total score ranges from 25 to 250, with higher scores indicating better communication.

Three secondary outcome measures were employed. The General Self-Efficacy Scale (GSE) (Schwarzer & Jerusalem, 1995) consists of ten items, each assessed on a Likert-type scale of four responses from not true at all (1) to exactly true (4). Total scores thus range from 10 to 40, with higher scores indicating higher levels of self-efficacy.

The Interpersonal Reactivity Index (IRI) comprises 28 items to measure empathy on a 5-point Likert-type scale (De Corte et al., 2007). After reading a statement, participants rate how accurately it captures their feelings. Ratings range from ‘describes me very well’ (4) to ‘does not describe me well’ (0). There are four subscales, measuring two cognitive and two affective

aspects of empathy. The cognitive aspects are fantasy items, which assess readers' capacity to picture the thoughts and actions of fictional characters, and perspective-taking, which considers the capacity to adopt the psychological perspective of others. The two affective aspects are empathetic concern, which is the capacity to recognise the feelings of illness of others who are suffering, and personal distress, which is a self-centred emotion resulting from stressful and difficult interpersonal circumstances. This last is the only sub-scale where a lower score indicates improvement.

The 15-item Open Minds Scale for healthcare providers (OMS-HC-15) (Kassam, Papish, Modgill, & Patten, 2012; Modgill, Patten, Knaak, Kassam, & Szeto, 2014) uses a five-point Likert-type scale, with reverse coding for five items, to measure stigmatisation in a range from 15 to 75. Higher scores indicate attitudes and behaviour that are more stigmatising.

After the placement, a qualitative process evaluation (Creswell & Creswell, 2017) using open-ended questions was completed (Appendix 30).

Participating stroke survivors were also required to complete a short demographic survey and answer five questions about their experience after the placement (Appendix 32).However, they were not study participants and the target of the intervention was educational outcome for students.

5.5.8 Analysis

Descriptive analysis was conducted. Confidence intervals were calculated to consider change across the two time points, i.e. between pre- and post intervention. The qualitative data were subjected to conventional content analysis (Hsieh & Shannon, 2005; Mayring, 2021).

5.5.9 Ethics

Ethical approval was obtained from the University of Birmingham Ethics Committee under reference ERN_22-0410.

5.6 Results

Eight physiotherapy students (four male, four female) participated in the intervention. All eight replied to two emails over the course of two weeks. Everyone who was recruited took part in the intervention, but one participant was excluded from the analysis due as they did not submit their post-assessment result. Figure 5.1 illustrates this process. Three first-year and four second-year students on the BSc physiotherapy programme participated. Their average age was 19.5±7.1 years. Seven of them completed the qualitative process evaluation survey following the intervention (Appendix 30). Students undertook interactions with 12 stroke survivors (8 male, 4 female) participated in the interventions. Their average age was 65.6±6.7 years and the time since their stroke ranged from two to fifty years. Tables 5.1 and 5.2 summarise participants' demographics. . Most interactions between students and stroke survivors were 1:1 (with the same stroke survivor); but, because there were more stroke survivors than students, some students saw two different stroke survivors.

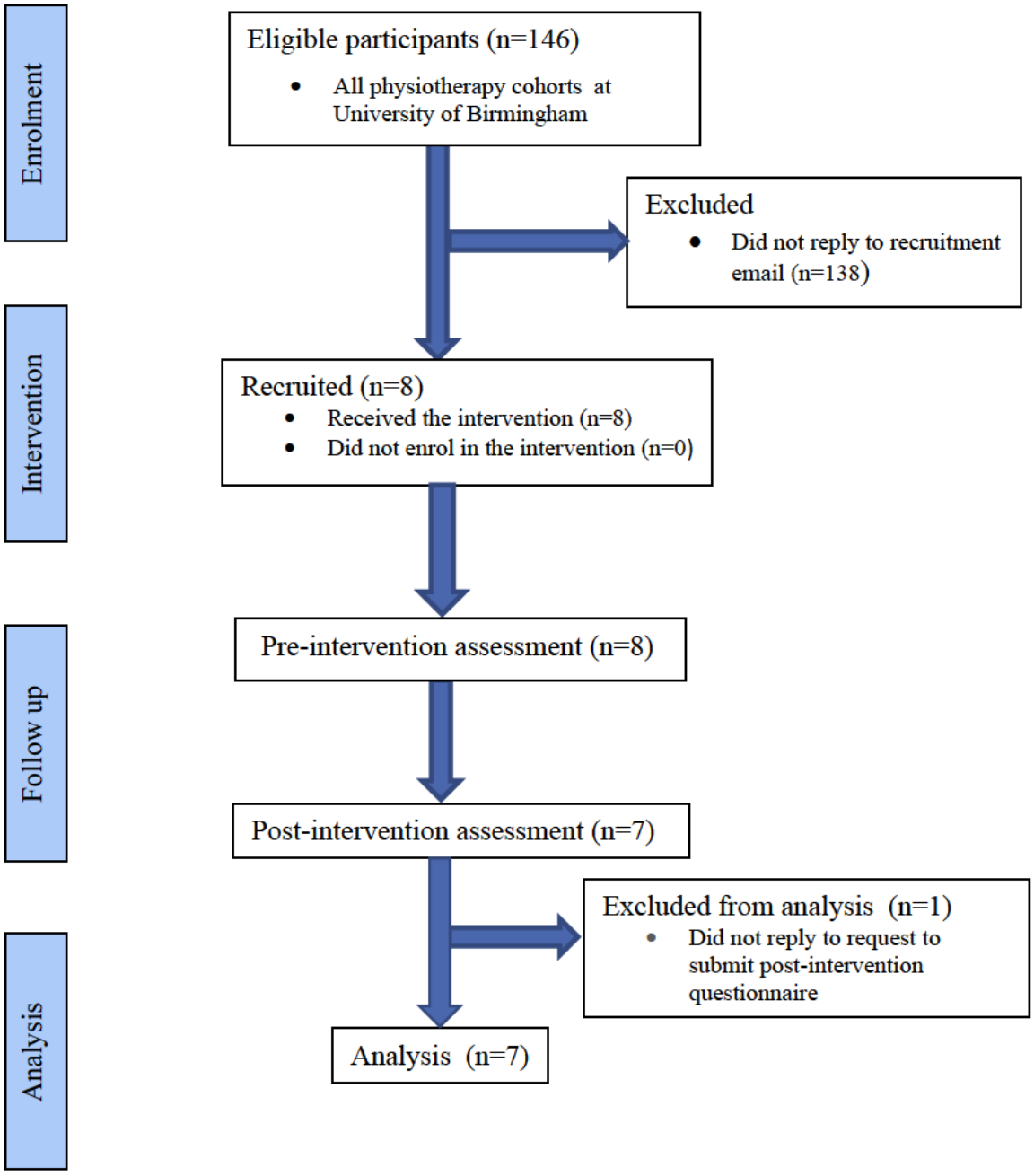


Figure 5.1: CONSORT 2010 flow diagram.

Table 5.1: Physiotherapy students' demographic information

ID	**Age (years)**	**Gender**	**Year** of study	**Number of placements since** starting **the course**	**Have had teaching or experience related to psychological adaptation, hope, emotions, or illness stories (narratives)**
P1	19	Male	First	1	No
P2	20	Female	Second	3	No
P3	20	Male	Second	3	No
P4	19	Male	First	1	No
P5	19	Female	First	1	Yes
P6	21	Female	Second	4	Yes
P7	19	Male	Second	2	No

Table 5.2: Stroke survivors' demographic information

ID	*Intervention*	*Age (years)*	*Gender*	*Type of stroke*	*Time since stroke*
S1	MEAH Week 1	60	Male	Not sure	2 years 6 months
S2		74	Male	Not sure	10-12 months
S3		80	Female	Mini stroke	50 years
S4		83	Male	Not sure	20 years
S5		51	Female	Right MCA	9 years 3 months
S6		54	Male	Left side unknown	3 years
S7	Narrative Week 2	65	Male	N/A	10 years
S8		54	Male	Severe (LT) unsure	3 years
S9		68	Female	Ischemic stroke	2 years
S10		55	Female	Stroke left	11 years
S11		61	Male	Stroke with aphasia	2.5 years
S12		83	Male	Not known	7 years

5.6.1 Primary outcome measure

The following significant changes that did not cross zero were identified by confidence interval estimates for the change from baseline. The Froehlich scale identified positive changes in communication (mean change 19.1±17.7). The 95% confidence interval of the change did not cross zero [2.8 ,35.5]. Table 5.3 provides details.

5.6.2 Secondary outcome measures

The only sub-scale of the IRI scale to demonstrate a 95% confidence interval of the change not to cross zero was the perspective-taking subscale. Other scales that identified positive changes included a negative change in stigma attitudes from the OMS-HC-15, 95% CI [-2.4, -0.1] and the GSE, which identified increased self-efficacy [0.2 ,4.1]. Table 5.3 gives details.

Table 5.3: Mean & standard deviation of scores and 95% CI change across time

	IRI: Fantasy Scale	IRI: Perspective taking scale	IRI: Empathetic concern	IRI: Personal distress scale	Froehlich	OMSHC	GSE
Baseline	14.6	18.7	17.6	10.9	167.9	34.9	28.9
SD	5.2	4.6	5.1	4.7	25.7	6.5	3.9
Post	17.4	20.1	17.6	10.9	187.0	33.6	31.0
SD	1.40	3.8	4.3	4.3	23.5	7.5	3.9
Mean change	2.9	1.4	-0.7	0.9	19.1	-1.3	2.1
SD	5.6	1.1	3.3	2.3	17.7	1.3	2.1
Mean change (95% CI)	-2.3, 8.0	0.4,2.4	-3.7,2.3	-1.3,3.0	2.8, 35.5	-2.4, -0.1	0.2, 4.1

5.6.3 Qualitative findings

5.6.3.1 Feedback from students on the intervention (MEAH tool and narrative approach)

Most students (5/7, 71.4%) regarded the intervention as a valuable opportunity to put theory into practice because it included training sessions and an opportunity to apply the MEAH tool and narrative approach to stroke survivors in the community. Participant P7 stated:

> *It is a good experience to put theory into practice as we first have training on the MEAH tool and narratives, then we use the tool to speak to the people with stroke. (Male, second year, P7)*

Some students (2/7, 28.6%) viewed the intervention as a learning opportunity that put a greater emphasis on the psychosocial component of providing healthcare services, as P1 explained:

> *It was quite a broadening experience, focusing more on the mental health side of the patients rather than just focusing on how to [deliver] treatment, when in reality if you focus on [mental health], it helps in treating the patient.* (Male, first year, P1)

Several students (5/7, 71.4%) identified the most significant aspect of the intervention as the opportunity to speak and listen to stroke survivors' stories, as P4 noted:

> *The thing that stood out is probably when the stroke patients told me that they were grateful when someone like us listens to their story. They explained that there are not a lot of opportunities for them to share their story and not a lot of people are willing to spend time listening to them.* (Male, first year, P4)

For some participants (3/7, 42.9%), another important aspect of the intervention was the training session (simulated practice play), because it provided a better understanding of how stroke survivors might respond differently to the stroke event and how to manage different clinical presentations.

> *There was a training session before going out and chatting with stroke patients. The training session was very informative and gave a lot of useful tips when dealing with patients of different backgrounds. [The simulations included] depressed patients, anxious patients, high-energy patients etc.* (Male, second year, P3)

Some students (2/7, 28.6%) valued meeting with stroke survivors who had a very positive outlook on life. A strong majority of participants (6/7, 85.7%) perceived the intervention as a valuable placement and practice. It could demonstrate a genuine concern for stroke patients, as it gave them a chance to voice their feelings and concerns, thus helping to establish a personal connection between patients and professionals. As a result, almost all students (6/7, 85%) identified that the placement improved their understanding of how a therapeutic relationship can be improved. This was regarded as something that could create led better treatment

compliance and increase sense of empathy towards patients, exemplified by these two comments:

> *This approach can show the heart of caring for the stroke patient…. This approach builds trust between the patient and the physiotherapist when the physiotherapist shows care toward the patient's story. By doing so the treatment outcomes can improve, as the patients are more willing to share their needs with the physiotherapist.* (Male, first year, P4)

> *The importance of staying true to yourself in healthcare and remaining compassionate. It is hard to find one's professional identity as a student, and this intervention is a good reminder to preserve natural empathy that experience [in clinical practice] may reduce. (Female, second year, P6)*

Additionally, most students (5/7, 71.42%) perceived it to allow physiotherapists to conduct a subjective assessment in more holistic way, as it focuses on the psychosocial effects of stroke, which are an overlooked aspect of healthcare delivery; participating students felt that in clinical practice the focus of the interaction can be on functional ability. P6 was one who reflected on the importance of more holistic care:

> *On placement I have observed many colleagues, especially those with years of experience, disregarding the psychosocial needs of patients and not engaging with them. I can understand the temptation to distance oneself in these work structures due to the workload and pressure, but it is crucial to understand this does not help the patients long-term. We need to opt toward a fuller methodology of care, encompassing rigorous and holistic values*. (Female, second year, P6)

Several students (4/7, 57.4%) highlighted the importance of understanding of each patient's viewpoint on their illness, as this would assist in identifying their goals and give information as to what motivated them toward those goals. For example:

> *It gives a basic understanding for HCPs of the patient's perspectives and ultimately creates a plan for the patient and to set realistic goals.* (Male, second year, P3)

Most students (6/7, 85.7%) considered the MEAH tool to provide some structure and guidance on obtaining specific information related to the screening tool, while also giving patients a platform to share their stories. P4 (male, first year) felt that it allowed "*the stroke patient to*

share their story according to their will in a clear structure", while P2 (female, second year) opined that *"with the MEAH tool, the questions are direct and specific, which is useful, when appropriately integrated, to guide the conversation"*. A third participant agreed:

> *The MEAH tool…is easy to read and keeps everything simple. Guided questions are very open-ended so even if people share a lot of things and non-stop, them will seldom go off-track and I don't need to interrupt them.* (Male, second year, P7)

Some students (3/7, 42.9%) believed that the brief MEAH tool would improve communication skills and the ability to reflect on communication. P3 (male, second year) concluded that his active listening had *"improved … through using the tool and practicing when having a conversation with stroke patients"*.

Most participants (5/7, 71.42%) agreed that the intervention should in future be used more widely by physiotherapists to support people with neurological conditions such as stroke. Two participating students cited feedback from people with stroke in support of this suggestion:

> *Feedback received from stroke patients was that they are willing to support these types of interventions in the future. They enjoyed talking and sharing their stories and thought it would be beneficial to other stroke patients.* (Male, second year, P3)

> *Feedback from the service users was positive about the intervention. And, in my opinion, sometimes people just need someone to talk to, but they did not have the chance to share their feelings as most of the service users were open to share their stories and experiences.* (Female, second year, P2)

Three participants (3/7, 42.9%) discussed when could be the appropriate time to deliver the MEAH tool and their conclusions were mixed, as these two contributions illustrate:

> *To people who I met in the community stroke group, I think the length of time and level of content is appropriate because they could usually verbally communicate or they have their adaptive communication method (i.e., I saw a patient who used pre-typed words in his tablet to communicate), which makes communication easier. However, to people who just had an acute stroke or other acute neurological conditions, they might not be able to verbally communicate. They might be confused, or they may be in a huge mental distress, and it takes a long time for them to go through all questions. Besides, acute stroke patients get fatigued very quickly, so it might not be possible to go through all the content before patients get fatigued.* (Male, second year, P7)

> *I think the screening tool would be ideal for hospital as patients would likely be in a more acute stage of their condition, meaning the possible difficulties they're facing may be more present, making the conversations perhaps more emotionally difficult, but with perhaps greater reward. (Female, first year, P5)*

Two students (2/7, 28.6%) identified the potential for the MEAH tool to elicit interactions that were too prescriptive and 'clinical'. This was most likely to happen if participants felt it necessary to ask every question on the guide, rather than focusing on the answers given by stroke survivors. P4 (male, first year) warned that "*if physiotherapists are not being trained using this approach, there will be a feeling of interviewing the stroke patients."*

Most students (5/7, 71.42%) considered that the intervention process was clear, the instructions were direct, the content was appropriate and the intervention was easy to understand and apply. The same number (5/7, 71.42%) felt that the duration of the intervention was adequate. However, others thought the time could have been extended (2/7, 28.6%) and that there should have been more visits to practise the intervention with stroke survivors (2/7, 28.6%). For instance, P3 (male, second year) noted that there were *"only two sessions for participants to speak with stroke patients, and each session lasted approximately 30 minutes, which I thought was not enough"*, while another student stated: *"I think it can be a little long, as the gentleman I was speaking to expressed so"* (Female, second year, P6).

5.6.3.2 Stroke survivors' feedback on the MEAH intervention

All participating stroke survivors found the experience positive. Being able to share and talk with the students was the aspect that they most often reported positively. This approach was identified as being able to help in three ways: (a) it kept their minds active and learning (S3; S4: 2/6, 33.3%); (b) it was easy to understand (S5: 1/6, 16.7%); (c) the benefit was being able to help prepare students to interact more with the patients (S3; S6: 2/6, 33.3%). The following examples illustrate this:

I am learning and so are the students. (Female, S3)

Helps keep his mind active. (Male, S4)

Positive approach and easy to understand. (Female, S5)

It is good to prepare students to engage more with patients and to be friendly. (Male, S6)

None of the stroke survivors made any negative comments about students using the MEAH and all reported that they would be happy to support more students in this way. For example, a female stroke survivor stated, *"I am happy to help with their learning*" (S3). A male stroke survivor agreed: *"Yes, I think improving communication helps patient engage with treatment"* (S6). However, one male patient with memory difficulties (S2) found that there were *"too many questions"* to remember.

All individuals identified the MEAH as an approach that would be beneficial for people who had more recently had a stroke, as the following examples show:

Yes. Talking and talking is better. Having conversations is happy. (Male, S1)

Yes. Everyone needs a chance to be spoken to. Someone with stroke has the mind working but the body isn't. They need time or some motivation. (Female, S3)

Yes, a chance to share and speak up. (Female, S5)

However, two stroke survivors (33.33%) expressed the view that the approach had to focus mainly on listening. For instance, a male participant (S6) stated: *"Yes, but I think just listening to them is important".*

5.6.3.3 Stroke survivors' feedback on their participation in the narrative intervention

The experience of participating in the storytelling intervention was reportedly positive for all participating stroke survivors. Two of them (33%) said that they preferred sharing experiences with students to interacting with doctors:

Good, better than doctors in and out. (Male, S8)

Good, better than doctors. (Male, S11)

The aspects of the intervention identified as positive were feeling happy to share, listening to patients, educating others and sharing information:

Positive, felt happy to share story. (Male, S7)

Listening to patients is important. (Male, S8)

Educating people. (Female, S9)

I am grateful that the information I gave could be helpful for the students' training. Did not ask anything too personal or offensive. (Male, S12)

When survivors were asked about the negative aspects of the intervention, two people (S7; S12) commented on the length and content of the questions, while another (S11) thought the clubhouse was not the best place to share stories and that a quieter environment would be much preferable.

Questions are not clear enough and too long. (Male, S7)

You could have asked 'Are you angry about the stroke?' (Male, S12)

The clubhouse is not the best environment. Would be able to share more if it is in a quiet place. (Male, S11)

All participants except S8 said that they would be happy to help students apply the intervention in the future, as these examples illustrate:

Yes, need more students like helping people learn. (Female, S9)

Yes, it is also good for me to talk to other people. (Male, S7)

Yes. Could train my talking. (Male, S12)

There were mixed feelings about whether this approach would be beneficial for people who had recently had a stroke. Two survivors (S9; S11) responded affirmatively, stating that the intervention would be beneficial for newly diagnosed patients in helping to improve self-management and give people a chance to express their feelings and opinions.

> *Yes, because they allow space to provide your opinion and identify how you feel.* (Female, S9)

> *Yes, every start is difficult. Doctors seldom make you aware and it is frustrating. My experience is: let them know the healthcare system is like that and the importance of self-management.* (Male, S11)

On the other hand, two individuals (S8; S12) answered that they were unsure whether or not others would benefit from the intervention because each person is unique.

> *Yes, but hard to say, as everyone is different.* (Male, S8)

> *Don't know, not one person is the same so I can't tell you if others would be benefit by that*. (Male, S12)

Finally, only one participant (S7) expressed the opinion that this intervention would not be helpful to people who had recently had a stroke.

5.7 Discussion

This is the first study, to the best of the researcher's knowledge, to use the MEAH tool to train physiotherapy students to deliver a brief therapeutic intervention to people with stroke. Both students and stroke survivors considered their participation in the intervention to have been a positive experience. Following the intervention, potentially valuable changes were identified in the primary outcome measure (the Froehlich scale) and all three secondary outcome measures: the GSE, the OMS-HC-15 and the perspective-taking subscale of the IRI. These findings are consistent with those of previous research that identified the MEAH as a valuable

approach to training physiotherapy students in order to improve their psychological and communication skills (Soundy et al., 2021; Soundy et al., 2022).

The main value of the intervention was associated with chances to practise a psychological skill, first in a simulation environment and then with people who had had a stroke. The value of practising these skills should not be understated, a conclusion which aligns with previous research (Holopainen et al., 2020; Pritchard, Blackstock, Nestel, & Keating, 2016; Soundy et al., 2022). It is essential that training providers build in time to practise psychological skills in simulated environments and within clinical groups. It may be that this can be improved by adopting different teaching methods such as active participation (Ballengee et al., 2020; Mata et al., 2021).

One of the significant findings emerging from the current study was improved communication skills. Psychological support as a core principle has been lacking in the education of physiotherapists and other healthcare professionals, according to researchers such as Baddeley and Bithell (1989) and some institutions (Australian Physiotherapy Association, 2016; Health and Care Professions Council, 2013). The current study provides one example of how to fill the gaps in communication skills and knowledge that previous studies have identified (Connaughton & Gibson, 2016; Wloszczak-Szubzda & Jarosz, 2013).

All stroke survivors participating in the current study provided positive feedback regarding the application of the MEAH as a screening tool and the most frequently reported positive factor was being able to share and interact with the students. Many stroke survivors agreed that the MEAH approach would be helpful for those who had had strokes more recently. The intervention provided a valuable chance to put theory into practice because it consisted of practice sessions and a chance to use the MEAH tool on stroke survivors in the community.

5.7.1 Value of the narrative-based intervention

Most students reported that using the storytelling intervention helped them build effective therapeutic relationships with the service users. A person's psychosocial well-being may be negatively impacted by their interactions with HCPs in a significant way (Llewellyn, McGurk, & Weinman, 2005). Sharing and utilising illness narratives could be one method for developing therapeutic relationships between patients and HCPs (Soundy & Reid, 2019). The value of hearing a stroke survivor's story has been demonstrated by prior research and it is important to give each person in a conversation enough time to explore their own story, so that what is important to them can be stated directly rather than assumed or implied (Reid & Soundy, 2019). Further research is required to establish the effects of narrative intervention on the behaviours, beliefs and attitudes of both practising and student HCPs.

All participating stroke survivors found the storytelling intervention to be a positive experience and all except one indicated that they would be happy to assist students in using the approach in the future, a finding in alignment with past research (Alawafi et al., 2021). Storytelling is a novel behavioural intervention that can help stroke patients with their psychosocial needs (Alawafi et al., 2021). Several positive effects of storytelling have been identified in people with stroke and brain injury (D'Cruz, Douglas, & Serry, 2019; Kitzmüller et al., 2019), namely identifying personal experiences that others freely hear, releasing emotions via stories, and learning and reflecting on one's own story (Alawafi et al., 2021). Storytelling, a fundamental aspect of life, is a way we naturally express our individuality and the values we uphold. It is among the most natural ways to give meaning to the experiences of illness (Schoenau & Jackson, 2016). However, there were differing opinions on whether this approach would help those who had recently suffered a stroke, which was in line with the most recent review of the subject and could be the topic of future research (Alawafi et al., 2021).

5.8 Limitations

The current study is recognised to be subject to several limitations. First, the quantitative results are limited by the small sample size and the use of exploratory pre- and post-test methods to test change. Therefore, the effectiveness of the intervention cannot be determined; however, the results are in line with the effectiveness found in earlier studies. Future studies are required, using larger samples and more rigorous methodologies.

A second limitation is that a member of the research team conducted the intervention, which may have affected participating students' reactions. Additionally, all participating students were in the first or second year of a physiotherapy BSc. The failure to recruit any postgraduate or third-year students meant that comparisons could not be made between students with and without clinical experience. Further research is needed to determine whether this omission was crucial.

The generalisability of the findings may also be influenced to some extent by the varied ability of the students to adhere to the questions and to apply the interaction according to the MEAH tool. For instance, roughly a quarter of students did not adhere to the MEAH screening tool but remained fixated on the primary challenge, frequently returning to a general subjective evaluation. Most of the students in the current study thought that the content of the MEAH was appropriate and that in future physiotherapists should apply it more frequently to assist people with neurological conditions such as stroke. This constitutes an interesting contrast with a finding of earlier research (Soundy et al., 2022).

5.9 Practical implications

A brief training exercise that utilised the MEAH tool and a combination of simulated practice and in-person practice with service users was demonstrated to improve communication skills and self-efficacy and to reduce stigma.

The MEAH can give physiotherapists and students a simple structure and guidance for conducting subjective assessments in a client-centred, holistic manner. To increase confidence and competency, practical advice and more training (such as role-playing) on how to use the tool might be necessary prior to its use with service users.

The present study suggests that narrative-based interventions (storytelling by patients) can be useful in enhancing the therapeutic relationship between patients and students and in providing insight into patients' present situation, perceptions, psycho-emotional coping mechanisms and hope. This is a cost-effective approach to improving therapeutic relationships whose value and benefits make it suitable for future incorporation into the curriculum of student HCPs.

5.10 Conclusions

Training including the MEAH tool and a narrative-based approach, combined with simulated and in-person practice with service users, all appeared to improve students' communication skills and enhance therapeutic relationships. Future curriculum development for allied health professions, as well as placement and clinical practice, should take such training into account.

CHAPTER 6

GENERAL DISCUSSION

6.2 Storytelling as a therapeutic intervention in stroke

The integrated review reported in chapter two and the multi-methods study in chapter five were conducted to explore the potential therapeutic application of storytelling/narrative-based interventions to support stroke survivors. The integrated review found that storytelling and peer sharing can have positive effects on key psychosocial outcomes, frequently as a result of social comparison and social control. The current recommendations are based on studies with the strongest evidence, which demonstrated that such interventions can generally provide a sense of positivity and hope, reduce loneliness and promote coping through information exchange (Alawafi et al., 2021). The findings reported in chapter five also reveal a positive influence on the psychosocial well-being of stroke survivors who participated in the storytelling intervention. The positive outcomes for participants included: being happy to share, feeling that they were being listened to, being able to educate others and sharing information. The findings of the studies reported in chapter two and chapter five indicate that narrative-based interventions may be valuable in promoting positive psychosocial outcomes after stroke. This is consistent with positive results documented in studies of narrative-based interventions for other chronic health conditions (Byrne & Soundy, 2020; Gucciardi et al., 2021). These findings illustrate the psychosocial factors consistently as mechanisms including social comparison, social support, self-reflection as well as an impact on social identity, which benefits knowledge and motivation of individuals. This is also supported by mechanistic work by Thoits (2011) which considers the impact of social control.

6.3 Storytelling as an educational tool to improve communication skills in student HCPs

Three empirical studies were conducted to investigate the potential application of storytelling/ narrative-based interventions as an educational tool to improve the communication skills of student HCPs. The study presented in chapter three identified the novel master plot of overcoming the monster as expressed by people with stroke (Alawafi et al., 2022). Given that the metaphors of battle and journey are two of those most used to characterise stroke experiences (Ferguson et al., 2010), this master plot may be considered particularly relevant in stroke survivors. Indeed, the notion that recovery is a battle and that the patient is a fighter is common in the stroke literature (Boylstein et al., 2007), but the master plot of overcoming the monster differs from this and may need more time to be observed. Therefore, it was considered important for both practising and student HCPs to be aware of such a plot. Hence, the knowledge obtained in the chapter three study was used to gain insight into how student HCPs viewed and responded to three variations of the master plot of overcoming the monster. This master plot was found to elicit more empathic reactions from students than other master plots (Soundy et al., 2010). This is particularly significant because it emphasises the need for students to understand stroke survivors' experiences as well as the difficulties or monsters that they may encounter. It was concluded that student HCPs should be trained in the importance of listening to and understanding the varied stroke experiences encountered in practice in order to enhance communication skills and develop good therapeutic relationships. The study reported in chapter five demonstrated that training including the MEAH tool and the narrative-based approach, combined with simulated and in-person practice with stroke survivors, improved students' communication skills, self-efficacy and empathy while reducing stigma. Student HCPs can use the MEAH as a simple tool to enhance therapeutic interactions with

stroke survivors. These results echo those of prior research that found the MEAH to be a useful way to train physiotherapy students, strengthening their psychological and communication skills (Soundy et al., 2021; Soundy et al., 2022). The key benefit of the intervention was the opportunity to practise the MEAH tool, first in a simulated (role play) setting, then with stroke survivors. The conclusion that it is vital to practise psychological and communication skills is in line with earlier research (Holopainen et al., 2020; Pritchard et al., 2016; Soundy et al., 2022). Similarly, the finding reported in chapter five, that interventions based on patients' narratives might be a valuable way to enhance therapeutic relationships between stroke survivors and students, as well as providing an opportunity to gain insight into each patient's current situation, perceptions, psycho-emotional coping mechanisms and hope, is consistent with the findings reported in chapter two (Alawafi et al., 2021).

6.4 Quality of evidence

The quality of the evidence presented in this thesis has been evaluated to ensure the formulation of meaningful conclusions. All of the studies reported in chapters two (Alawafi et al., 2021), three (Alawafi et al., 2022), four (Alawafi et al., 2023) and Five were conducted in accordance with a specific type of quality framework, concerned not only with ethics but also with enhancing the quality, completeness and transparency of reporting the most notable elements of research (Simera et al., 2010).

In chapter two, the general framework proposed by Whittemore and Knafl (2005) was utilised to conduct and report the integrated review in three main stages: 1) eligibility criteria and literature search, 2) data evaluation and 3) data synthesis. The 21-item ENTREQ transparency checklist was also used to support the presentation of the review (Tong, Flemming, McInnes, Oliver, & Craig, 2012). Appendix 3 shows the completed checklist.

Moreover, the integrated review was registered on PROSPERO and used the PRISMA flow diagram, which is the preferred method of reporting items of systematic reviews, to represent the processes of literature search and study selection (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009). The PICOS framework was employed to determine the eligibility criteria and structure the integrated review questions. To enhance the rigour of the review and minimise inaccurate and biased searching (Whittemore & Knafl, 2005), a comprehensive and systematic electronic literature search using several databases was conducted in line with established guidelines (McGowan et al., 2016). To resolve any disagreements about inclusion, a member of the research team (AS and SR) was identified. A predetermined data extraction form was used to gather the key demographic and design-related data. The key intervention details were extracted using the TIDieR checklist (Hoffmann et al., 2014). See Appendix 4.

The 13-item COREQ framework, adapted from the 32-item consolidated criteria for reporting qualitative research (Tong et al., 2012) was used to evaluate the quality of each qualitative study (Appendix 5). The internal validity of each quantitative and mixed-method study was evaluated using the Cochrane risk of bias tool (Higgins & Green, 2008) (Appendix 6). The findings were submitted to the research team for review and any disagreements were resolved. Furthermore, the certainty assessment was carried out by the principal researcher and two members of the research team (AS and SR). For the quantitative research, evidence classes were linked to evidence strength and quality scores (Burns, Rohrich, & Chung, 2011), while the CERQual evaluation tool was used to assess the quality scores and evidence confidence of the qualitative research (Lewin et al., 2018). These assessments were mapped onto the themes of the findings to provide a sense of confidence in the findings.

As regards the evidence quality of the integrated review, there were only two randomised control trials and six mixed-method studies. In accordance with the definition of classes of

evidence by Burns et al. (2011), three studies were assessed as moderate low risk, rated II, one as moderate high risk, rated III, and four as at high risk of bias, rated IV. In all work reported in this thesis, every attempt has been made to limit bias and provide data transparently.

Among the qualitative studies included in the review, the critical appraisal identified only one fatally flawed study (Hancock, 2009), which scored 2/13 on the COREQ framework (Tong et al., 2012). However, a second blind examination (by AS) revealed the following strengths: 1) the interview script was well-constructed and informed by stroke research, literature and peer support; 2) the sample was purposeful, with maximal variation; 3) the response rate was 100%; 4) a pilot interview was conducted; 5) the study was related to policy research; 6) it was a multi-centre study; 7) it encompassed many verbatim quotes; and 8) analysis of the data offered fascinating findings that were relevant to other investigations and their findings. Therefore, the two researchers (RA and AS) decided to include the study in the integrated review. None of the remaining studies was considered fatally flawed.

The studies reported in chapters three and four were performed in accordance with the Standards for Reporting Qualitative Research checklist, which aims to enhance the transparency of all areas of qualitative research by establishing explicit reporting guidelines (O'Brien, Harris, Beckman, Reed, & Cook, 2014). In chapter five, the phase 1 pre-experimental study was reported according to the CONSORT recommendations and flow diagram (Lancaster & Thabane, 2019), while the phase 2 qualitative study was reported according to the guidance for reporting qualitative research proposed by O'Cathain et al. (2015). Finally, the intervention elements were reported in accordance with the TIDieR intervention guidelines (Hoffmann et al., 2014).

6.5 Overall strengths, limitations and implications for practice and research

Based on the findings of chapter two and chapter five, this thesis has established the usefulness of storytelling and peer sharing as an approachable therapeutic intervention to enhance the psychosocial well-being of stroke survivors, such as by increasing positivity, strengthening hope and improving coping. Furthermore, it has provided valuable data on the mechanisms behind positive outcomes (social comparisons and social control), as well as the logistical components of the interventions and their impact on outcomes (Alawafi et al., 2021). However, these present findings may have been underestimated because they are based on an integrated review of a limited number of studies with small sample size (Alawafi et al., 2021) and a multi-method pilot study, also with a small sample (chapter five). Therefore, the effectiveness of the intervention needs further investigation, and more well powered, well designed studies with large samples are required. Further research also is needed to gain a better understanding of the impact of social comparison and how it may impact on the outcomes. For instance, more research is needed to establish if upward social comparisons are helpful, as well as how to integrate and maximise the advantages of downward social comparisons. Additional studies to determine whether, how and under what conditions social control is applied to peers would also be advised.

This thesis has failed to demonstrate any objective positive effect of the storytelling approach on mood. Future research should explore how hope and mood may be measured in order to detect changes caused by storytelling. It may also be beneficial to consider utilising a study design that includes a prolonged period of follow-up (e.g. 6-12 months) to detect changes in mood and to evaluate other longer-term effects. The significance of how early the diagnosis

was made or how severe the symptoms were must be also considered, because these factors may be critical in deciding whether and how change occurs.

Comparing the various storytelling formats, such as one-on-one interactions, group settings and online platforms, may be useful for future research. In order to compare the various intervention strategies, more RCTs of storytelling interventions are needed. This would potentially make it easier to determine the best type of storytelling intervention to include in any community rehabilitation strategy. Further research is needed to establish the value and benefit of attending group sessions with family members or carers.

The master plot of overcoming the monster was examined in chapter three, which reported the first study to examine the significance of this master plot for stroke survivors. This has implications for healthcare professionals because it is a significant master plot they need to be aware of. However, this study is limited by its focus on a single master plot that had already been identified and it is unclear how other master plots may evolve or interact with it. Moreover, the study had a modest number of participants; therefore, the prevalence of this specific master plot is undetermined and further work is required to determine how commonly this plot appears in stroke narratives. Furthermore, the study enrolled participants who were willing to participate in the semi-structured interviews. Therefore, it is important to emphasise that there may be other metaphors related to this master plot that have yet to be discovered. Further research into illness narratives that illustrate the master plot of overcoming the monster in a large and diverse sample would make an interesting contribution to our knowledge of such plots. Little consideration was given to the interaction or influence of major demographic variables such as educational level on the master plots identified. According to Hinckley (2006), patients' personality, cultural factors, and psychological adaptation are known to have an impact on how people convey their stories following strokes. Additional research should

take this into account. Importantly, the detailed implementation of this study may depend on how severe the impairments are (for example, affecting language, perception, or memory) or which side of the brain is afflicted (Egbert et al., 2021). Further studies must take these issues into account.

The study reported in chapter four was the first to examine the reaction of student HCPs to a variation of the master plot of overcoming the monster (Alawafi et al.,2023). Among the master plots that appeared to be available to HCPs and student HCPs were those of quest, restitution and chaos, which exhibited a severe reaction to disease (Frank, 1995). This research provided insight into different illness narratives in stroke, as well as different psycho-emotional adaptation and hope responses to the illness. In addition, this study draws some significant comparisons with past research on students' responses to story types (Soundy et al., 2010). The master plot of overcoming the monster elicited a more sympathetic response from students than other master plots (Soundy et al., 2010). This is significant because it highlights the importance of students understanding the patients' experiences, as well as the difficulties or monsters encountered. In clinical settings, creating an environment in which stories can be shared and patients' personal challenges can be understood, as well as allowing time during interactions to accomplish this, will promote the establishment of therapeutic relationships.

Nevertheless, there are number of limitations associated with this study. Individuals telling their stories were selected from a group of people who had had more time to recover and who encountered less difficulties in telling their stories than would be the case with many stroke survivors. Furthermore, the effects of aphasia and the inability to narrate caused by a stroke were not considered. More diverse stroke populations should be included in future studies.

Responses to each narrative appeared to differ based on clinical experience and possibly age. Further research is needed to gain a better understanding of these two factors. The numbers in each group were not comparable and different methodologies were used to complete the survey. This may have limited the ability to completely comprehend the responses of the final-year cohort. Therefore, the applicability of this work to other student HCPs has not been established and further research should address these limitations. Moreover, the content analysis focused on the most common student expressions. This method may have restricted the scope of the findings and further analysis is required to determine how reactions are considered.

The study presented in chapter five evaluated a novel placement that utilised the MEAH tool and took a narrative-based approach. Following the intervention, positive changes were identified in the primary and secondary outcome measures. The key benefit of the intervention was the opportunity to practise communication skills, first in a simulated (role play) setting, then with stroke survivors. It is critical that training providers include time for students to practise communication skills in simulated settings and clinical groups to increase confidence and competency.

The MEAH tool gave physiotherapy students a simple structure and guidance to deliver a brief therapeutic interaction to people with stroke. Most student participants in the study considered the content of the MEAH appropriate and concluded that physiotherapists should use it more regularly in future to support people with neurological diseases including stroke. This is an interesting contrast to previous findings (Soundy et al., 2022).

Moreover, the study indicates that considering interventions involving storytelling by patients can be a valuable strategy for strengthening therapeutic relationships between patients and

students, as well as enhancing understanding of patients' current situation, perceptions, psycho-emotional coping mechanisms and hope. A major benefit of such interventions to improve communication skills and therapeutic relationships is that they can be integrated into the educational programmes of future student HCPs. However, further research is needed to determine the impact of narrative intervention on healthcare providers' and students' behaviours, beliefs and attitudes.

Three significant limitations of the chapter five study should be considered. First, the quantitative results are weakened by the small sample size and the exploratory pre- and post-test approach to testing change. As a result, the effectiveness of the intervention cannot be established; however, the results are consistent with the efficacy found in previous studies (Soundy et al., 2022). Future research must employ larger samples and more rigorous methodology such as RCTs. Secondly, participants were mainly first- and second-year BSc physiotherapy students and there were no postgraduates or third-year students among them, which may restrict the validity of comparisons between students with and without clinical training experience. Further research is required to establish whether this omission was crucial. Finally, the generalisability of the results may be influenced slightly by the students' capacity to adhere to the questions or implement the interaction according to the MEAH tool.

6.6 Conclusion

The main outcome of this thesis has been to explore the application of narrative/storytelling-based interventions as educational tool to improve students' communications skills and their therapeutic relationships with patients. It is hoped that this work will inform future HCP curricula and clinical practice. The integrated review has established the effectiveness of such therapies in stroke patients, which could be the focus of future research. However, future

research is required to confirm the effectiveness and therapeutic value of peer-led storytelling interventions in promoting the psychosocial well-being of stroke survivors. Finally , this thesis has offered a novel perspective on illness narratives as well as an understanding of how students responded to and viewed the new master plot.

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APPENDICES

Appendix 1 - Alawafi et al. (2021)

Appendix 2 - Alawafi et al. (2022)

Appendix 3 - Alawafi et al.(2023)

Appendix 4 - Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement for *chapter two*

Appendix 5 – The demographic and design-related information on included studies

rm for chapter two

Appendix 6 - The Completed 13- item modified COREQ framework (Soundy et al .,(2016) adapted from the 32-item COREQ framework (Tong et al., 2007) for *chapter two*

Appendix 7 - Assessment of the overall risk of bias for quantitative studies (Higgins & Green, 2008) for *chapter two*

Appendix 8 - Synthesis stage 1 presenting examples of the qualitative tubulation for *chapter two*

Appendix 9 - Synthesis stage 2 an example of the descriptive analysis undertaken for ch*apter two*

Appendix 10 - Synthesis stage 3 mid mapping for c*hapter two*

Appendix 11 - Synthesis stage 4 the thematic development for *chapter two*

Appendix 12 - The second stage of the thematic development for *chapter two*

Appendix 13 - Information sheet and Consent form for *chapter three*

Appendix 14 - Pilot interview for *chapter three*

Appendix 15 - The interview schedule for *chapter three*

Appendix 16 - Individual identification of master plots by participant for *chapter three*

Appendix 17 - Information sheet for *chapter four*

Appendix 18 - The Narrative Vignette for *chapter four*

Appendix 19 - The survey for *chapter four*

Appendix 20-Immediate reactions to each story *chapter four*

Appendix 21-Words describing each story (A,B and C) *chapter four*

Appendix 22-Relative appeal of the stories *chapter four*

Appendix 23-Percived commonness of the stories *chapter four*

Appendix 24-The most unusual story *chapter four*

Appendix 25-Preffered story to hear *chapter four*

Appendix 26-Preffered story to tell *chapter four*

Appendix 27 - Initial Email Advertising training for students *chapter five*

Appendix 28 - Information sheet and Consent form for students *chapter five*

Appendix 29 - Questionnaire pack given across email to student physiotherapists for *chapter five*

Appendix 30 - qualitative process evaluation questioner for *chapter five*

Appendix 31 - Information sheet for people with stroke and sonsent form for *chapter five*

Appendix 32 - Short feedback questions given across to people with a Stroke for *chapter five*

Appendix 1-Alawafi et al. (2021)

behavioral sciences

MDPI

Review

An Integrative Review Considering the Impact of Storytelling and Sharing Interventions in Stroke

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Abstract: Background: Review-based research is needed which can establish the psychosocial outcomes and mechanisms of "storytelling and sharing" interventions for people with stroke. This information will act to inform the value and development of such interventions. Methods: An integrative review was conducted in three stages: (a) a systematic search strategy was undertaken to focus on articles between 2009 until January 2020 to locate articles the considered storytelling and sharing interventions for people diagnosed with stroke; (b) critical appraisal was undertaken to assess study quality; and (c) synthesis within three stages including data reduction, data display and conclusion. Results: Fourteen articles (including 727 participants) were identified that met the eligibility criteria. Five themes were identified that represented the outcome and mechanisms that appeared to be associated with a stroke intervention. These included introducing the concept of hope and learning to be positive, the enhanced ability to cope, the impact of loneliness and social interaction, impact on emotions, depression and related emotions such as fear. Conclusions: Storytelling interventions appear to impact loneliness, introduce positivity and hope and enable coping through knowledge exchange. The main mechanisms which appeared to influence these outcomes were social comparisons and social control.

Keywords: stroke; storytelling; narrative; peer support; group dynamic; group process; group sharing; psychosocial well-being; emotion; integrative review

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Citation: Alawafi, R.; Rosewilliam, S.; Soundy, A. An Integrative Review Considering the Impact of Storytelling and Sharing Interventions in Stroke. *Behav. Sci.* **2021**, *11*, 88. https://doi.org/10.3390/bs11060088

Academic Editor: Joseph Ciorciari

Received: 27 April 2021
Accepted: 11 June 2021
Published: 16 June 2021

Publisher's Note: MDPI stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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1. Introduction

The experience of a stroke has a profound effect on negative mood states, social identity and relationships [1]. For instance, within the first two years following a stroke, around a third of people with stroke report depression and around one fifth report anxiety [2]. There is a clear need for psychosocial interventions which provide emotional, informational and motivational social support [1]. Good psychosocial rehabilitation is associated with better health outcomes and community reintegration for people with stroke [3]. Storytelling is a recent behavioural-based intervention that can address the psychosocial needs of people with stroke. The process of storytelling and peer sharing (a term used to represent sharing of information with a peer which often involves personal stories; where stories is the most common 'vehicle' used to share experiences) can have a multitude of beneficial effects identified across people with stroke and brain injury [4,5]: (1) being able to identify personal experience that others hear freely; (2) being able to release emotions through stories; and (3) being able to learn and reflect on your own story. As an essential part of life, storytelling is a natural way of expressing who we are and what values we hold. It is one of the most natural ways of giving meaning to the experiences of illness [6]. Traditionally, storytelling has been undertaken for multiple purposes including helping others understand dangers, transferring knowledge, entertaining and maintaining cultural heritage [7].

Literature reviews that consider storytelling interventions across chronic illness groups have found consistent evidence which illustrates a number of benefits including; an ability to create a collective group voice and learning, ability to mobilise the group's mental well-being, reduced levels of depression, increased socialisation, and increased levels of perceived quality of life [8–10]. To the best of the authors' knowledge, no integrative review has been conducted to consider the value and impact of 'storytelling and sharing' on individuals with stroke. The principle aim of this integrated review is to identify evidence of the impact of storytelling/narrative or sharing interventions on managing the psychosocial challenges after stroke and to document the outcomes. In addition, it aims to explore the experiences of stroke survivors and other stakeholders (carers, family, health care professionals or other staff) participating in "storytelling and sharing" in order to identify the mechanisms underpinning specific outcomes.

2. Materials and Methods

An integrative review framework [11] was selected. Three stages were performed: (1) eligibility criteria and literature search process; (2) data evaluation; and (3) data synthesis. The presentation of the review was supported by the ENTREQ [12] (see Supplementary Materials Table S1). A PRISMA flow diagram was used to document the output of search results [13]. A subtle-realist paradigmatic position was adopted. This recognises the individual nature of experiences while seeking to identify "common realities" that individuals can relate to. The common features across the included studies are the main focus of this review.

2.1. Protocol and Registration

A protocol was registered with PROSPERO with the following ID: CRD42020160984.

2.2. Eligibility Criteria

The PICOS (participants, intervention, comparison, outcomes and study design) standardised framework was used to determine eligibility for inclusion in the review.

2.2.1. Participants

Studies were eligible if they had used people with a clinical diagnosis of stroke. The standard WHO definition of stroke was adopted: a "*clinical condition characterised by sudden and rapidly developing signs of focal or global interruption of cerebral functions that should last more than twenty-four hours or could lead to death, with no evident cause other than vascular origins*" [14]. Participants who had been diagnosed with any of the three main subtypes of stroke, namely ischemic stroke, intracerebral haemorrhage and subarachnoid haemorrhage, were included. No limit was identified for the time post stroke, because of the lack of evidence around using storytelling and because past reviews [8–10] have identified consistent results which are likely common across participants. Participants who had been diagnosed with transient ischemic stroke (TIA) were excluded, as TIA lasts less than 24 h and often does not lead to any long-term impairment [15]. Participants must have been aged eighteen or older and from any gender or ethnic group. The opinions of multiple cohorts of the intervention of interest, for example healthcare professionals, carers and family members, were included. Where varied population groups were included, separate analyses of findings for participants with stroke were needed.

2.2.2. Intervention

The core intervention under assessment had to contain storytelling or narrative-based approaches that involved the following: sharing stories or peer sharing or interactive discussions occurring in a group that involved exchanging illness-related stories or experiences or challenges or sharing information related to diagnosis of and living with stroke. The main component of the intervention of interest was contact between at least two stroke survivors in order to capture the psychosocial content of the experiences/narratives. Dif-

ferent formats of intervention were accepted for instance including; Poetry, body mapping, visual arts, and theatre. Different forms of delivery were acceptable including digital (online based) or in person. No specification was made as to the delivery format, e.g., one-to-one activities, group-based work or telephone/internet delivery. The aim of the study had to involve examining and documenting the impact or value of these interventions in assisting stroke survivors to cope with psychosocial and emotional challenges after stroke. Articles that examined the individual experiences of stroke patients participating in interventions where sharing or discussion occurred were also included. Interventions led by peers, by healthcare professionals and by any combination of varied stakeholders were accepted. Articles that explored only education-based interventions or articles that did not employ a particular intervention, for instance narrative analysis, or explore the experience of stroke were excluded.

2.2.3. Comparison

Any active control or inactive control groups were accepted, while studies that did not use any control groups were also included in this review.

2.2.4. Outcomes

Studies using any type of data collection method were included; however, it had to record the effect or perceived value and experience of engaging in the intervention in assisting stroke survivors or carers or families to cope with psychosocial or emotional challenges post stroke. The primary outcomes of qualitative studies were perceived benefits or experiences or phenomena in relation to participating in the intervention of interest. The primary outcomes of the quantitative studies were measures that captured the impact of the intervention on psychosocial and emotional well-being.

2.2.5. Study Design

Any study design was acceptable. Both qualitative, quantitative and mixed method studies were included. Qualitative studies included, but were not limited to, observational cohort, phenomenology and narrative studies. Quantitative studies included but were not limited to randomised controlled trials (RCTs), cluster RCTs, pilot RCTs, quasi-experimental and pre/post-test studies. No restriction was made on study language, studies were translated using Google translate and assessed for clarity by the research team before inclusion. Theses, conference abstracts and review studies were excluded.

2.3. Literature Search

A comprehensive and precise electronic literature search was conducted in line with standardised guidelines in order to increase the rigour of this review and minimise incomplete and biased searching [11,16].

The primary researcher and corresponding author conducted electronic searches using a combination of the identified keywords and subject heading/MeSH across the following subject-specific electronic databases: the Cochrane stroke group's specialised register of trials, MEDLINE, CINAHL, AMED, EMBASE, ZETOC, the ProQuest Nursing and Allied Health Database, PsycINFO and SCOPUS from inception of database until 16 January 2020.

A variety of key words were used: Stroke* OR Cerebrovascular Disease* OR CVA AND Storytelling OR Storytelling intervention OR Story* OR Narrative OR Narration OR Narrative Intervention OR Narrative Interview OR Illness -narrative OR Story-Sharing OR Group-experience OR Group circle OR Talking circle OR Peer group OR Peer support OR peer OR Group education OR Expression OR Emotions OR Self-management OR Self-care OR Health education OR Patient-self management.

The primary researcher then conducted supplementary searches. This included; (a) the first 20 pages of Google Scholar and Science Direct. Additionally, (b) the reference lists of retrieved studies or reviews.

2.4. Study Selection

In the initial stage of the selection process, the primary researcher and corresponding author scanned the titles and abstracts of all of the citations for eligibility, removed duplicate studies and identified studies that potentially met the eligibility criteria. Once all potential papers had been identified and selected, the researcher retrieved and read the full text to determine which of them truly met the inclusion criteria. A third author (SR) was identified to resolve any disagreements for inclusion.

2.5. Data Extraction

The primary researcher used a predefined data extraction form for each individual study included in order to extract essential study-design related data and demographic information as follows: (1) participants' demographical variables (age, gender, stroke type and location, time since stroke, co-morbidity/severity of stroke, marital status, living conditions and geographical location), and (2) design related information (methodology aim, eligibility criteria, data collection methods and analysis).

2.6. Data Evaluation

The primary author undertook a quality assessment of all articles. This included using a qualitative assessment tool and quantitative assessment tool. The quality of each qualitative study was critically assessed using the 13-item COREQ framework [17], adapted from the 32-item consolidated criteria for reporting qualitative research (COREQ) [18]. This assessment demonstrated the limitations in reporting [19]. The scoring of the studies was used for the certainty assessment. One study was examined in this way yet still included because of the insight given in the results section. This was used as a simple way to include or exclude articles [19]. The Cochrane risk of bias tool was applied to assess the internal validity of each quantitative and mixed-method study [20]. The results were presented to the corresponding author to check. Disagreement were resolved by the third author.

2.7. Certainty Assessment

Both the primary and corresponding author undertook the certainty assessment. The strength of evidence and quality scores for the quantitative research was linked to classes of evidence [21]. The confidence of evidence and quality scores for the qualitative research was assessed using the CerQual assessment tool [22]. These assessments were mapped on the results themes to provide an indication of confidence in findings. See Supplementary Materials for details.

2.8. Data Synthesis

Data analysis was guided by the general principles of integrative analysis, which require that data are ordered, coded, categorised and summarised. The overarching stages specified by Whittemore and Knafl [11], namely data reduction, data display and conclusion drawing, were followed. (a) The data reduction stage requires a classification of data into types. This was achieved by using a qualitative-led open coding approach [23], which involved immersion in data, and tabulation of results [24]. Next, mind-mapping [25] of the results was undertaken; this involved juxtaposing the results [26] and determining how studies were related to one another. (b) Data display and comparison involved taking data from individual sources and displaying them in terms of variables and subgroups, then considering the existence of patterns, relationships or themes. In order to achieve this, a thematic map based on the mind map was produced and results of studies were added to it in an attempt to saturate each theme [27]. At least two studies were needed to support any subtheme or code in order for them to be included at this stage. This achieved data reduction, as required by Whittemore and Knafl [11] during this process. (c) The final stage, of conclusion drawing, verification and presentation of the integrated synthesis, determined the details of data display. This was achieved by integrating findings together into a qualitative synthesis of findings. Reduction and focus were given towards psychosocial

outcomes and mechanisms that were linked to health [28]. Table S5 and onwards in the Supplementary Materials provides full descriptions of data synthesis process.

3. Results

3.1. Search Output and Studies Included

The initial literature search of electronic databases resulted in 756 potentially relevant studies. Following screening 190 were selected to consider. Fourteen studies were included in the integrated synthesis. This included six qualitative studies [29–34], two RCTs [35,36] and six mixed-method studies [37–42]. Figure 1 gives a full breakdown of the process of searching and identifying studies.

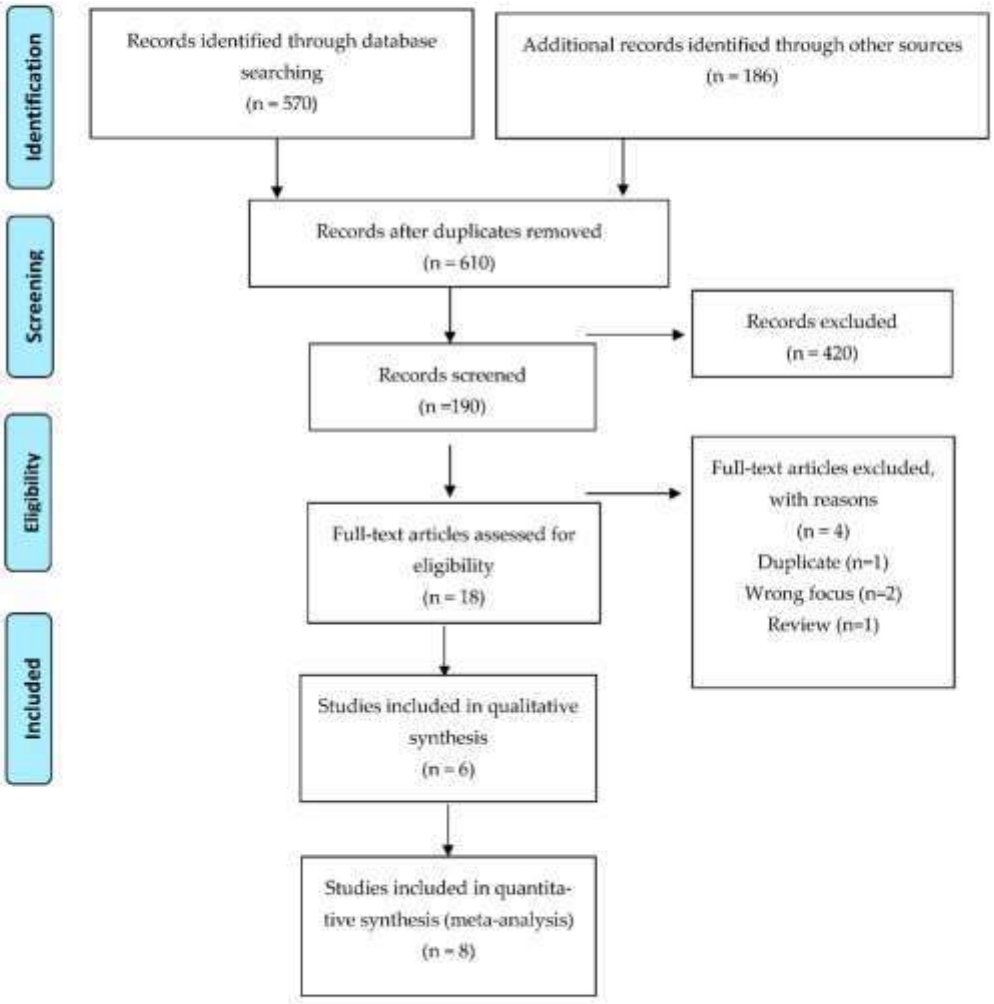


Figure 1. PRISMA 2009 Flow Diagram.

3.2. Study Demographics and Characteristics

Participants

Demographic information and participants' characteristics per study are presented in Table S2. A total of 727 participants (657 stroke survivors) participated in the studies. The smallest study had a sample size of nine [31] and the largest had 216 [36]. Subjects ranged in age from 20 to 95 years. More than half of the studies recruited both males and females [32–37,39]. Three of these [33,35,39] had significantly more males than females.

Time since stroke onset ranged from two weeks post stroke to 174 months post stroke. Participants in the studies with the largest populations [32,35,36,38,40] had ischemic stroke. The type of stroke in the remaining studies [29–31,33,34,37,39] was unknown.

Seven studies included stroke survivors who suffered from one or more of the following impairments: mobility problems, motor impairments, balance problems, cognitive problems, fatigue, communication and swallowing difficulties and mood disorders [29,31,33–35,41,42]. Kessler et al. [32] included stroke survivors who had moderate dependence when performing basic activities of daily living. Appalasamy et al. [36,40] included participants with several stroke risk factors and most had primary hypertension. The remaining studies did not provide information regarding their participants' health or characteristics [30,37–39].

Half of the studies used subjects who lived in their own homes and the majority lived with a spouse or other family members [29,32,33,35,38], while the remaining studies did not disclose details of participants' living environment [30,31,34,35,37,39–42]. Among the 727 participants, 164 were married, 51 had significant others, seven were single, five divorced and one widowed, while the marital status of the other 499 was not disclosed. The details of the intervention (including duration, frequency, format of session) are included in the Supplementary Materials (see Table S10).

3.3. Critical Appraisal of Research

The main researcher independently critically assessed the quality of the included studies. No study was excluded due to quality. The Supplementary Materials gives full consideration and a breakdown of data assessment by study type; see Table S3 for qualitative appraisal and Table S4 for quantitative appraisal.

3.3.1. Qualitative Study Appraisal

The lowest scoring study was Hancock [31] that scored 2/13. This study was examined for fatal flaws but specific strengths were identified including; (a) well developed interview schedule and piloting (b) critical insight in findings, verbatim quotes, and (c) findings which were consistent with other studies. Overall weaknesses in reviewed qualitative studies included: (1) lack of reflexivity, making it difficult to assess how the researchers' personal characteristics and their relationships with participants might have impacted the process and credibility of the results [30–32,34] and (2) no consideration of sample size [30,31,33,34]. These findings were used to inform the methodological limitations identified in CerQual [22].

3.3.2. Quantitative Study Appraisal and Risk of Bias

The Cochrane risk of bias tool was used to assess quantitative (n = 3) and mixed methodology studies (n = 5) [20]. The following high risks of bias were identified: (1) no protocol (n = 6), (2) no randomisation procedures (n = 5), (3) no allocation concealment (n = 6). Four of the eight studies had five domains identified as at high risk of bias [37,39,41,42]. Assessment of the components of risk of bias are outlined and described in Table S4.

3.3.3. Classes of Evidence for Quantitative Research

In accordance with the definition of classes of evidence [21], three studies [35,36,40] were assessed as moderate at low risk, rated II, one [38] as at moderate high risk, rated III, and four [37,39,41,42] were evaluated as at high risk of bias, rated IV.

3.4. Synthesis of Research

This subsection reports five themes which provide a narrative synthesis of evidence with considerations given to reported outcomes, summary of evidence and possible or likely psychosocial mechanisms that could explain outcomes. A summary of evidence is given in Table 1.

Table 1. Summary of evidence.

Theme	Level of Evidence [21] for Quantitative Evidence and CerQual Confidence [22] of Evidence	Summary of Evidence	Suggested Mechanisms
Introducing the concept of hope and learning to be positive	1 level II study 5 qualitative studies with high CerQual confidence of evidence	It is very likely that the intervention can introduce hope	Social comparison Social control
The enhanced ability to cope	3 Level IV studies 1 qualitative study with low CerQual confidence of evidence	It is likely the intervention can enhance the individual ability to cope	Feeling understood and heard by others Social comparison Social control Self-efficacy
The impact of loneliness and social interaction	1 Level IV studies 8 qualitative studies with high CerQual confidence in evidence	It is likely that peer support and the development of friendship can impact isolation and loneliness	Feeling understood and heard by others Validated sense of suffering Social comparison Social control
Impact on emotions; depression and related emotions	1 level II study 2 Level IV studies 2 qualitative studies with low CerQual confidence of evidence	It is not yet possible to determine the impact of the intervention on mood states. Well powered studies are needed to consider if the statistically insignificant but very large effect sizes identified on negative mood states (confusion, anger, sadness and tiredness) can be repeated.	Feeling understood and heard by others Validated sense of suffering
Impact on emotions; fear	2 Level IV studies 1 qualitative study with low CerQual confidence of evidence	It is unlikely that the intervention impacted fear	Feeling understood and heard by others
Enhanced awareness of stroke	1 level II study 1 Level IV studies with low CerQual confidence of evidence	It is likely that the intervention enhanced understanding of stroke	Social comparison Social control

3.4.1. Theme 1: Introducing the Concept of Hope and Learning to Be Positive Regarding the Future after Stroke

Reported Outcomes

The intervention, in both individualised and group formats, appeared to help in introducing the notion of hope after the diagnosis with stroke and helped stroke survivors to be positive regarding the future [30–32,34,40]. In the study by Morris & Morris [34], five stroke survivors and their partners of care (n = 5/10) and six peer supports (n = 6/8) agreed with the statement *"Things seem more hopeful since joining the group"* and all participants apart from one peer supporter (n = 17/18) agreed that *"the group helps me feel more positive about my future"*. This was quantified by Chow [35], who reported that stroke survivors in the narrative therapy group demonstrated a significant improvement in the Herth Hope Index score over the control group who received psychoeducational support and the improvement continued four months after the intervention ($p \leq 0.05$). All participants apart from one stroke survivor and one partner of care (n = 16/18) agreed that *"the group inspires me about the future"* [34].

Mechanism Suggested by Evidence

Social comparison appeared to be the primary mechanism through which hope and a perception of positivity increased within interventions. This was achieved in 3 ways; (1) Speaking with an individual who had gone through a similar situation and taking time to listen and share stories was identified as validating the feeling of suffering [32]. Listening to the recovery stories of other survivors could led to the realisation that *"there is life after a stroke"* and that recovery is possible, which was unknown before [31]. (2) The ability to share their own story was particularly valuable to participants [37]. Being in a group with other stroke survivors who were in a similar situation and observing how they improved created a sense of hope. The group context created a space for individuals to share how they successfully managed difficult situations after their stroke, which helped others to learn how to manage their own situations [31,33,34]. (3) Participants identified the ability to transfer the experiences shared into management of their own lives [34].

3.4.2. Theme 2: The Enhanced Ability to Cope

Reported Outcomes

Muller et al. [39] reported that the majority of participants (n = 10/13) agreed or strongly agreed with the statement *"I learned new ways of coping with issues related to stroke"*, while more than half (n = 8/13) stated that they used the strategies they had learned outside the group context. Participants in the study by Kirkevold et al. [33] reported that both the individual and group-based dialogue interventions supported their efforts to cope and that this help was important, particularly in the first six months. The dialogue helped participants to describe the challenges such as daily activities and emotional and social situations with which they had to cope, highlighted their coping options and supported them as they tried different strategies and as they examined unanticipated situations [33,34]. Appalasamy et al. [40] identified that narratives promoted a proactive stance and action towards the preventative treatment about stroke. Using humour and being positive in the groups were also commonly identified as a significant component of successful recovery [31].

In a post-participation survey, Muller et al. [39] tracked engagement in activities and exercises that were introduced in the group modules. They found that more than half of participants (n = 8/13) began to participate in different leisure and daily activities beyond the group setting. However, other evaluations of the intervention showed that only the handicap domain of Stroke Impact Scale (SIS) and the home integration domain of the CIQ reached significance: $p = 0.034$ and $p = 0.002$ respectively. Both domains focused on performing basic activities of daily living within the home environment, whereas the SIS self-perceived recovery domain and the social and productivity integration domains of the CIQ did not reach significance. Corsten et al. [41] identified a significant difference in quality of life reporting (a) benefits to physical ($p = 0.037$) and psychosocial ($p = 0.00001$) complaints and (b) reduced perceived physical ($p = 0.009$) and psychosocial ($p = 0.001$) burden.

Proposed Mechanism

Taking time to listen and share stories with peers who had positive experiences of recovery helped survivors to understand how others had managed and to identify what was possible through rehabilitation in a positive way, which strengthened motivation towards recovery and aided psychological adaptation [32]. Gaining stroke-related knowledge not only enabled participants to be informed and helped them to understand their diagnosis, but also equipped them with "concrete skills" that they then transferred outside the group context [30,31]. Sources of self-efficacy may be important to this. One study [36] identified a significant ($F = 12.41$, $p < 0.001$) increase in self efficacy when compared to a control group. Alternatively, humour may allow participants to view stroke in a different way when the experience has been experienced as a burden.

3.4.3. Theme 3: Impact on Loneliness and Social Interaction

Reported Outcomes

Engaging in the interventions of interest seemed to aid social well-being. The interventions counteracted a perceived sense of isolation and loneliness [29–34,38]. Having time to share, listen and relate to others who had been through similar experiences decreased the feeling of loneliness [29,30,33,34]. In the study by Hancock [31], nearly all nine participants stressed the significance of being with other stroke survivors. Additionally, at least half of participants appreciated the hospital visits or phone calls they received from peers [31]. Participants felt alone and the interventions were something to occupy their time after the incidence of stroke [33,38].

In the process of participating in groups, individuals gained new friendships [30,31,34]. The group provided an opportunity to make new friends in common, to whom participants could relate [34]. One participant reported that other stroke survivors in the group had become friends because they took the time to talk and listen to her, in contrast to other people who might say *"I can't be bothered"* [31]. One study quantified this by noting that a majority of participants (n = 10/13) agreed or strongly agreed that *"I have made new friends"* [39]. Although, participants in the Masterson-Algar et al. [38] identified a danger of friendships that were built up and then suddenly lost post-intervention. This was quantified by Muller et al. [39], who found that more than half of participants (n = 8/13) reported socialisation as the most important part of attending the group. Nearly half of the participants (n = 6/13) reported having communicated with other participants beyond the group setting by various means including text messages (n = 2/13), Facebook (n = 2/13), email (n = 5/13), telephone (n = 6/13) and actual or planned personal meetings (n = 8/13). However, statistical evaluation of the intervention showed that the social integration domain of the Community Integration Questionnaire (CIQ) did not reach significance ($p = 0.148$).

Mechanisms Behind Evidence

Exchanging experiences with other stroke survivors who had gone through similar situations was identified by one participant as inspirational and essential, in particular when facing something as serious as the incidence of stroke [33]. Peers were also seen as a source of inspiration to seek a peer role in the future, which facilitated social identity development [32]. A majority of facilitators (n = 6/7; including health care professionals and family) reported that sharing stories with the group helped them to understand participants *"as people"* [37]. Groups became long-term social networks and support resources for participants and continued validating the sense of suffering outside the group context [30]. Getting to know new peers was likely associated with less distress of being alone. The groups also provided an opportunity to revisit and revise their own story. The unique group environment allowed individuals to present their own story, reflect on it and listen to stories from similar others which provides an opportunity to modify their story.

3.4.4. Theme 4: Impact on Emotions

Reported Outcome Depression and Related Emotions

Chow [35] measured depression, and found baseline to one month was insignificant increase in depression (estimated effect size 0.05). However, a significant reduction at 2 months (estimated effect size 2.24) and four months (estimated effect size 2.04). Gurr [37], identified an insignificant decrease in the mean depression score on the Hospital Anxiety and Depression Scale (HADS) after participating in the intervention group (mean pre-group score approximately 8.5; mean post-group score just above 7.5). Corsten et al. [41,42] across both studies identified a positive and significant change for feeling less tired following the group ($p = 0.06$; $p = 0.00001$), this equated to a very large effect size ($d = 1.02$) [41] and small effect size ($d = 0.30$) [42]. Despite further insignificant results from Corsten et al. [41], moderate to very large effect sizes were noted across the following moods; confused ($d = 1.26$), sad ($d = 0.89$), angry ($d = 1.07$), and tense ($d = 0.68$).

Qualitative data identified that sharing experiences with other stroke survivors and validating one's own personal experiences played a role in reducing the depression commonly experienced by participants [30,31]. Moreover, two participants identified being occupied by attending the monthly scheduled peer groups and meeting stroke survivors who had disabilities, yet displayed positive attitudes, as factors which helped them in overcoming their depression after stroke [31].

Mechanism

It is possible that feeling listened to and being able to share likely enhances mood related outcomes as a direct result of the session [41,42]. This may allow or enhance the individual's ability to reflect on their own story and experience.

Reported Outcome: Fear

Engaging in the intervention seemed to be beneficial in reducing fear after the stroke and instilling a feeling of reassurance [31,32]. It should be noted however that positive changes were noted by Corsten et al. [41,42] but they were not significant ($p = 0.30$; $p = 0.50$, respectively). Corsten et al. [41] identified a moderate effect size ($d = 0.56$), but Corsten et al. [42] identified no effect size ($d = 0.06$). Appalasamy et al. [40] reported that the narrative intervention helped reduce fear and enable participants to overcome the challenges created by stroke.

Mechanism

Clark et al. [29] explored stroke survivors' perceptions of the potential challenges of a self-management group prior to attendance. Participants felt that certain aspects of the groups, such as sharing experiences of stroke and recalling distressing memories, might be difficult and "distressing to hear" for some individuals. The potential emotional impact of the intervention on the peer supporters was identified by programme organisers, who thought that it might mean reliving the distress related to earlier experiences of stroke, thus increasing fear, worry or anxiety [32]. Appalasamy et al. [40] suggested that confidence was raised through the intervention which likely countered the experience of fear.

3.4.5. Theme 5: Enhanced Awareness of Stroke and Knowledge

Reported Outcome

Seeking and receiving knowledge was one reason that stroke survivors gave for attending the groups [30,31]. Appalasamy et al. [36] found significantly increased knowledge of stroke ($F = 11.54$, $p < 0.001$). Stroke survivors and their partners of care received valuable informational support from the interventions, about stroke prevention and recovery, finding and accessing stroke support services in the community [30–32,34]. This type of information, related to living with stroke in the community and provided by peers, was considered more helpful than that offered by HCPs during hospitalisation [31,32]. One participant considered the information provided by a stroke survivor who had "*substantial experience subsequent to their stroke*" as particularly valuable [34]. Peers provided experiential knowledge and information derived from real lived experience, which facilitated relatedness [32,34]. One study [39] quantified this by reporting that a majority of participants ($n = 10/13$) agreed or strongly agreed with the statement "*I know more about community and stroke resources*" after attending the peer support group, and that the same number agreed or strongly agreed that the group widened their knowledge of condition, post-stroke recovery and opportunities such as voluntary jobs and modified leisure activities. Participants in the Christensen et al. [30] study asserted that information related to stroke and recovery from stroke was difficult to find and that they and their carers significantly valued the opportunity to learn from both peers and experts.

Mechanism

Social comparison and listening to stories as well as more direct advice using social control may well have existed within this theme and acted as a mechanism [40].

4. Discussion

The current review has demonstrated that narrative or peer sharing intervention can positively impact important psychosocial outcomes and this is most often due to social comparison and social control. This integrated review was based on a limited number of studies with small sample sizes, which might lead to an underestimation of the findings reported. The current recommendations focus on the findings with the highest strength of evidence which suggested that the intervention most often can; introduce a sense of positivity and hope for individuals, reduce loneliness, and enable coping through knowledge exchange. The reduction in loneliness is supported by past evidence [8]. In addition, past reviews have identified that storytelling interventions can enable coping and enhance knowledge [10] and provide an opportunity to express and understand true experiences and feelings related to the illness [10,23]. Additionally, storytelling has been reported to reduce psychological distress and allowed fears and worries to be discussed [23].

Social and internal mechanisms identified within the current review have also been identified and supported by past review evidence in chronic illnesses. For instance, self-reflection has been identified as a key process and mechanism through which positive impacts of storytelling can be found, as it allows participants to create and re-create plots of their own story [8,10,23]. Further to this, social comparisons can help change the perception of their own situation and make the individual feel less isolated [8]. It may be that relatedness with others enables a therapeutic environment generated by enhanced trust [8,23], where participants feel that their experiences are legitimized [23].

It was useful to evaluate the interventions in both one-to-one and group formats, as the two formats created different experiences. The one-to-one format could be tailored to the individual needs and difficulties occurring in the post-stroke trajectory; however, it would be less likely to be cost-effective. The group format could be less expensive and there are mutual advantages when members exchange their stories related to illness and health, potentially leading to the learning and examination of new information, stroke-related resources, practical coping skills and strategies [43]. The National Institute for Health and Clinical Excellence [44] identifies group participation as potentially beneficial for people with chronic conditions including stroke. Therefore, it might be an appropriate format for providing a storytelling intervention, in comparison with the one-to-one format. Within the current review it is possible that smaller group sizes may be more optimal to promote the benefits of sharing and feeling heard. Greater understanding of the impact of social comparison is needed and how it may influence outcomes. For instance, downward comparison (comparing oneself to those perceived as being worse off) can have a positive impact on the individual appraisal of their own well-being [45,46], whereas upward social comparison (comparing oneself to those perceived as better off who face a similar problem) has been associated with less life satisfaction when compared with downward comparisons [47]. Research [46] has also highlighted that people making downward social comparisons can be less likely to seek support for their own needs. Further research is required to evaluate if upward social comparisons are useful and how to introduce and optimize the benefits from downward social comparisons. Further research also needs to be able to consider if, how and when social control is used for peers.

Future research is required to consider if a storytelling group should include both stroke survivors and their carers or families. The three qualitative studies exploring this aspect of interventions [29,33,34] consistently identified the benefits of involving carers or families in the group sessions such as informational exchange and support. This is supported by past research [48], which identified such support as essential. Further research is required to consider the impact of the intervention on mood states, as changes have been identified across other chronic illnesses [23]. Additionally, consideration is

needed around the impact of how close the diagnosis was or how severe the symptoms were as these aspects may be important in identifying if and how changes occur [49].

4.1. Limitations of the Studies

The heterogeneity of the interventions regarding type, design and personnel may have had an adverse effect on their implementation in clinical practice. There was a large range of time since stroke for participants across studies and further research must consider time since stroke as an aspect to explore further. Methodological limitations identified as having contributed to a decrease in overall quality included lack of randomization and blinding of personal assessors. Only two studies were a randomized control trial and further well-designed studies are needed. Studies did not consider the impact of physiological parameters of participants which are important as they may impact on the experience of the intervention, for instance higher blood pressure has been associated with greater cognitive decline [50]. It was difficult to consider the exact instances of social control as against social comparison from the literature. Limitations apparent in the qualitative studies were related to study design, lack of reflexivity, data analysis and the reporting of findings. The findings may be transferable to other stroke settings, whilst not being generalizable.

4.2. Implications

Storytelling and peer sharing appear to be an useful intervention to enhance positive emotions and offer hope in a way that empowers people with stroke. It should be considered as an accessible method to encourage positive psychosocial adaptation. Peer sharing and storytelling should be considered in different formats including one-to-one, group settings and e-formats; for instance, the UK The Stroke Association's website provides stroke stories (stroke association https://www.stroke.org.uk/stroke-stories, accessed on 12 May 2021). It is important that the participant preference be accounted for by giving the individual choice about attendance and also identify if, when and how storytelling is used. Clinicians and researchers need to be mindful of instances when the group setting could be less useful (i.e., when a social comparison could be considered out of reach and impossible to achieve). Further research needs to consider the value and use of sharing the group with their family members or carers. Finally, future research should consider how hope and emotions can be captured to identify change created by storytelling and further well-powered and well-designed trials are needed.

5. Conclusions

To conclude, the current evidence appears to be positive and identify positive psychosocial outcomes gained from peer group interventions. It is important to recognize that peers provide an essential role for knowledge exchange and an ability to reduce loneliness and should be (within the limits of the implications section) considered as part of rehabilitation following a stroke. Future research is required to confirm the effectiveness and therapeutic value of peer-led storytelling interventions in promoting the psychosocial well-being of stroke survivors.

Supplementary Materials: The following are available online at https://www.mdpi.com/article/10.3390/bs11060088/s1, Table S1: Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement. Table S2: Demographic and design-related information on included studies. Table S3: The Completed modified COREQ critical appraisal assessment. Table S4: Summary assessment of overall risk of bias. Table S5: The opening coding processes. Figure S1: The mind mapping display. Tables S6–S10: Data display and comparison.

Author Contributions: Conceptualization, R.A. and A.S.; methodology, R.A. and A.S.; validation, R.A., A.S. and S.R.; formal analysis, R.A. and A.S.; investigation, R.A.; resources, R.A. Saudi Government studentship support; data curation, R.A.; writing—original draft preparation, R.A., A.S. and S.R.; writing—review and editing, A.S. and S.R.; supervision, A.S. and S.R.; All authors have read and agreed to the published version of the manuscript.

Funding: This research received support in the form of a PhD studentship from the Saudi Government.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: Data available in the Supplementary Materials.

Acknowledgments: The Government of Saudi Arabia for financially supporting the PhD. Princess Nourah Bint Abdulrahman University for supporting the PhD studies.

Conflicts of Interest: The authors declare no conflict of interest.

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Appendix 2 -Alawafi et al. (2022)

IJTR

RESEARCH

A qualitative study of illness narratives: 'overcoming the monster' master plot for patients with stroke

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Abstract

Background/Aims Research that considers illness narrative 'master plots' (common and recognisable story plots related to the experience of illness), as expressed by individuals who have had a stroke, is needed Thus far, the literature has focused on identifying pre-established illness narrative master plots: the restitution, the chaos and the quest narrative. However, these narrative plots represent extreme psychological responses to the experience of illness; other narratives need to be understood in order to most effectively support individuals with stroke. Further research must identify if other master plots exist, and consider the implication of such plots.

Methods A narrative methodology was undertaken, contextualised within a social constructivist worldview. A purposive sample of individuals with stroke undertook a single online semi-structured interview. A categorical-form narrative analysis was undertaken in five stages.

Results A total of eight individuals were interviewed. Following analysis, six individuals were identified as illustrating experiences related to a master plot termed 'overcoming the monster'. The 'monster' was represented in several ways, which included: a mental health problem or an expression relating to internal feelings; a sense of being isolated from others; a threat to the individual's independence; and a negative interaction or experience related to health care. Individuals identified clear strategies for 'overcoming the monster'. These included: adopting a different way of viewing life; identifying and attaining both big and small goals; persistence and determination in the face of adversity; and giving support to others through activities and receiving support.

Conclusions Allied health professionals need to understand the importance of this narrativisation of stroke because research has shown that allied health professionals can stereotype interactions by plots and seek to correct them. Implications of these findings ilustate the importance of understanding the individuals experience, not immediately reacting to a narrative type that may seem to fit, understanding the plot of overcoming the monster varies and may need time to be observed.

Key words: Experiences; Narrative; Perceptions; Qualitative; Stroke

Submitted: 29 July 2021; accepted following double-blind peer review: 15 June 2022

Introduction

Allied health professionals and patients narrate the effects of a stroke differently. Most typically, allied health professionals professionals focus on the identification of physiological and neurological effects, while patients create meaning by interpreting the event in the context of their own biographical history (Boylstein et al, 2007). Allied health professionals need to appreciate patients' personal accounts of illnesses, as this helps to establish social awareness, reduce stigma towards the condition being treated and influence research and healthcare policies (Boylstein et al, 2007). This understanding would also likely address some of the psychosocial needs identified by patients and caregivers (Mountain et al, 2020). Telling stories provides patients with stroke (hereafter called stroke survivors) an opportunity to create meaning and re-establish a sense of social identity (France et al, 2013). Listening to narratives enhances the allied health professionals' understanding of a patient's psychosocial wellbeing (Pluta et al, 2015).

Illness narratives are often identifiable by a 'master plot', which represent general storylines that are easily recognisable and frequently expressed by individuals with a

How to cite this article: Alawafi R, Rosewilliam S, Soundy A. A qualitative study of illness narratives: 'overcoming the monster' master plot for patients with stroke. Int J Ther Rehabil. 2022. https://doi.org/1012968/ijtr.2021.0131

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chronic illness (Frank, 1995; Soundy et al, 2013). Master plots should not be considered a complete reflection of a patient's experience. A patient may express different master plots at the same time, and a master plot may change over time (Soundy et al, 2013). The three most cited illness narrative master plots include the quest master plot (this plot identifies the full benefits of what has happened), the chaos master plot (this plot narrates the hopelessness of what has happened, underlined by loss from the past) and the restitution master plot (this plot focuses on an expectation of a complete recovery in the future) (Frank, 1995; France et al, 2013; Egbert et al, 2021). However, other master plots have been expressed by stroke survivors. For instance, Soundy et al (2013) has identified 13 master plots. Further to this, other master plots are found in history and culture, and are often portrayed in film (Booker, 2004).

One master plot frequently expressed by stroke survivors is termed 'overcoming the monster'. Booker (2007) states that this master plot can be summarised as the conceptualisation of a patient's life being threatened by an all-powerful monster. Once identified, the hero must fight and defeat the monster. In this story archetype, the monster is typically represented by a creature (eg, a giant). The creature holds power over the hero, but the most significant part of this narrative is that the monster or evil force is killed or overthrown and its power defeated.

For stroke survivors, the monster is often identified as symptoms of the stroke or the experiences associated with having a stroke. This could include depression, which has a high prevalence following a stroke (Wood et al, 2010); experiences of isolation (Luker et al, 2015; Salter et al, 2008); or changes to the individual's social identity (Hinckley, 2006). These symptoms and experiences represent and align with the factors that remove hope (Soundy et al, 2014) and cause psychological distress (Laporte and Aita, 2021). This is important, because hope is uniquely expressed in each master plot (Soundy et al, 2013). Therefore, challenging, preventing or changing an individual's illness master plot will likely influence their psychological wellbeing (Soundy et al, 2014).

Allied health professionals need to be aware of how to manage master plots within interactions. For instance, metaphors found within the narrative illustrate a perspective or characteristic that accompanies the experience of having a stroke (Boylstein et al, 2007). The most common terms associated with the experience of stroke include 'journey' and 'battle', which suggest social disempowerment (Ferguson et al, 2010). Conversely, the conception of recovery being a 'war' and the patient as a 'fighter' are ever-present in stroke (Boylstein et al, 2007). Therefore, being able to work effectively with patient narratives is important for patient empowerment (Luker et al, 2015).

Given this, further research is needed that identifies if and why 'overcoming the monster' is an important narrative for stroke survivors. Gaining an insight into individual narratives is best achieved initially through a qualitative study that can capture rich detail and experiences. The aim of this study was to identify stories that illustrated the master plot of overcoming the monster and help stroke survivors and allied health professionals to understand the value of the stories.

Materials and methods

Design

A narrative methodology was adopted, situated within a social constructivist view of the world, with a relativist ontology and a subjectivist epistemology (Labonte and Robertson, 1996). This means that each persons experience of relaity is equally valid, and knowledge is considered as being constructed through interactions and then formed on a psychological level. A standardised framework was used to report methods (O'Brien et al, 2014).

Setting

Interviews were conducted from the supervising researcher's home and delivered through Skype at a single time point. This method was chosen to protect individuals from infection during the COVID-19 pandemic and to adhere to local restrictions. Before the interviews, demographic information was gathered, including data on sex, age, type of stroke and time since onset of stroke.

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Ethical approval

Ethical approval was obtained from the ethics committee of the University of Birmingham (reference: 17-0149). Individuals were required to provide written informed consent before the interviews began.

Participants

Participants were purposively sampled from a well-known website (not identified, to shield participants' identities) that allows advertisement of research projects and advertised at a local community stroke group. Interested individuals emailed the authors to arrange an interview, following consent procedures. The sample size was chosen for its capacity to reveal rich aspects of a singular master plot as expressed through the experiences of individuals. The sample size was stopped when it was determined that enough rich data was available to understand how different examples of the masterplot are expressed. Following five interviews, authors considered examples and established that two further interviews were needed to ensure a breadth of examples were provided.

Participants were included if they were 18 years of age and over and had experienced a stroke at least 2 years previously. Any type of stroke was included if individuals were able to comprehend and answer questions and communicate through Skype or Zoom. Participants were excluded if a translator was required.

Semi-structured interview guide

A single semi-structured interview guide was developed and pilot-tested. No changes to the guide were made following the pilot interview. The interview schedule contained four major sections and 29 questions, and can be requested from the authors. The average interview time was 60 minutes. The interviews were audio-recorded via Zoom. A transcript was automatically generated, and scripts were independently checked for accuracy by the lead and supervising authors.

Data analysis

The aim of this research is not to claim statistical generalisability, but, rather, to impact the reader and consider how the current findings may apply to the experiences of others (Smith, 2018). Therefore, the authors did not seek to establish data saturation of the content or establish agreement between codes generated; however, the researchers detailed examples of the narrative master plot through a specific analytical process.

Following the interviews and data collection, individuals' testimonies were selected for analysis if their story featured elements of the 'overcoming the monster' narrative master plot. A categorical-form type of narrative analysis (Earthly and Cronin, 2008) was conducted. Five stages of analysis were performed (Figure 1).

Stage 1 included open coding, during which the lead author immersed herself in the text. They identified codes and comments on relevant excerpts of each interview in relation to which master plots they could be identified with and why.

Stage 2 required the lead author to present a defendable case to the supervising author for each master plot identified.

During stage 3, both authors examined the scripts for the most prevalent plot type against those previously identified (Booker, 2007; Soundy et al, 2013).

During stage 4, independent assessment was sought, to evidence the expression of the conceptualisation of 'overcoming the monster' for each participant. Authors agreed that this master plot was clearly identifiable in the majority of the participant interviews (n=6/8, 75%).

Stage 5 involved an examination of that plot, to further detail and understand it. During this stage, the expression of the master plot was agreed upon and a summary of the master plot for each participant was provided

- What was the monster?
- What needed to be overcome?
- How was it overcome?
- What were the consequences?
- What were the critical moments?

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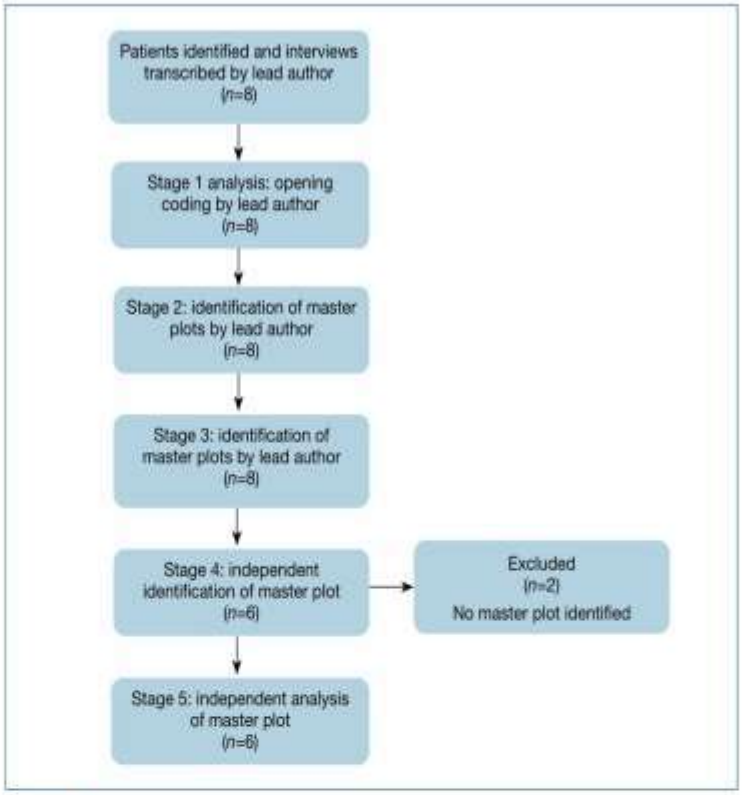


Figure 1. Flow chart of the selection method.

Trustworthiness in the narrative

To ensure quality, Andrews' framework (2021) was used and adhered to in the following ways. Truthfulness and trustworthiness of the data identifying examples of monsters was compared against known and established experiences from other research (Soundy et al, 2014; Luker et al, 2015). Critical reflexivity involves the acknowledgement that the personal interest of the supervising author in narrative master plots may have influenced decisions around analysis and limited the focus of the study.

The accessibility of this article was enhanced by identifying the types of monsters expressed by stroke survivors. This, in turn, provided a greater understanding of the role allied health professionals play in co-constructing the master plot. The attention to the untold narrative, the awareness of temporal fluidity and the multilayered nature of the participants' stories may be limited by the small sample size and the focus on the specific master plot of 'overcoming the monster'.

Results

Demographics

Six participant stories (two men and four women, with an average age of 59 ± 14 years) were selected from a total of eight interviews. Table 1 provides participants' demographic data.

Findings relating to the 'overcoming the monster' master plot

Several key findings were identified across participant stories that connected their narratives to the master plot (Appendix 1).

Identification of the monster and what needed to be overcome

The 'monster' cited within some of the participants' narratives could be identified as mental health problems, feeling defeated or crushed, or the experience of a different sense of self.

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Table 1. A breakdown of participant demographics

Participant ID	Ethnicity and sex	Age	Time with stroke	Type of stroke
1	White British male	62 years	15 years	Ischemic
2	Asian British female	40 years	13 years	Multifocal
3	White British male	64 years	12 years	Ischemic
5	Asian British female	63 years	8 years	Ischemic
6	White British female	80 years	16 years	Ischemic
7	White British female	46 years	4 years	Ischemic

For P1, this was manifested as overcoming a sense of feeling crushed by the experience of stroke, but gradually identifying that it was possible to overcome:

> 'My friends and family could see a horrific deterioration in my psychological state, especially when I tried to go back to work. And they were afraid to talk to me about it because they knew how fragile I was. My wife was amazing in that there were times when I was crying my eyes out, saying I just couldn't do it. I couldn't go back to work. And she knew that if I didn't do it, that would be the end.'

Some participants realised that they would not be back to 'normal' as soon as they thought. Others identified a lack of motivation as an aspect of what needed to be overcome. A sense of isolation was another monster to be defeated. This was triggered by not being able to identify with others in a similar situation, or feeling and experiencing isolation from others:

> 'What really sticks out in my mind about that period is the healthcare team not realising … there's a person inside the body, and the communication to get to know me … never occurred. That was the negative side.' (P6)

The monster was also conceived of as an undermining of independence such as experiencing a threat to daily living and needing to be open to any change that occurs.

> 'I quickly realised that a lot of them [other stroke survivors] wanted everything doing for them and I wasn't going to be like that.' (P3)

Problems with the healthcare experience was identified as a monster that needed to be overcome. However, it was also acknowledged to be a monster that did not have to exist:

> 'I had my own room in the hospital, which was very nice. But I didn't meet any other people. Although it was a stroke ward, I didn't meet any others. It would have been nice for staff to talk to me about my experience, or to put me in contact with someone else in a similar situation in hospital, but that didn't happen.' (P5)

The monster could be the negative experience of care received, which, in turn, had a negative impact on dignity. P2 expressed this as the difficulties faced when seeking and not receiving support and care from services:

> 'I was the only young person, 27-year-old mum, a pregnant woman who had had a stroke. I didn't know of anybody else [in the same situation]. I was told to speak to Help the Aged. I didn't really want to go to a day centre where I could sit with other people who have had a stroke. I wanted to be an active mother and [have] an active involvement in my baby's life. There was talk about help that I would get… But when I was discharged, there was none and we had to fight to get help… The adult services were saying no because I had a baby and the children's services were saying, "well, it's you that had the stroke, so you need the help".'

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How the monster was overcome

Two principal ways in which the monster was overcome included the characteristics of the person and the different ways of instigating change and improvements.

The characteristics of the person

Several participants focused on their own personal characteristics that comprised one aspect of the ways in which they would overcome the monster, including being 'bloody-minded', determined to prove everyone wrong or motivated not to let someone else down:

> 'The key thing is that there is life after stroke because a lot of people think their lives are at an end. It's just a matter of finding what you enjoy doing. What do you want to do? What can you do at this stage? You've got to keep that hope alive.' (P6)

> 'I read about a man who was … some kind of trainer in the SAS, talking about the types of people that they liked. And one of the things he had said was [that] determination to do, to achieve, was not enough. It was persistence [that was needed]. I have discovered that with persistence … if I don't do my exercises regularly, I go backwards. So that has really helped me, [knowing] that I have to be always persistent… I remember my children, when they were trying to walk, they just persisted and persisted. And they didn't mind falling over, because … we say [to them]: "Oh, well done".' (P7)

The different ways of instigating change and improvements

Individuals were able to make further improvements by adopting a different internal worldview. For instance, P5 expressed a determination to 'move on' quickly after discharge and begin a new life.

> 'I was in [hospital name], which has a specialised regional rehab unit, which keeps you occupied all day. When I got home, I had to start thinking what was it I wanted to do.'

For P1, it was important to begin with initial, smaller goals, which were a struggle to achieve, but would ultimately lead to bigger and more impressive goals:

> 'They (the goals) started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal… The next one I had was to shower independently and I learnt how to do that… Then I had to get my confidence back to go and start that process again, to go and wash independently, which finally the OTs allowed me to do. Then the next one was to stand up and give my son a hug on his 16th birthday.'

Consequences

Two main consequences were referred to as a result of overcoming the monster: goals and achievements, and having an impact on others.

Goals and achievements

Identifying goals that were to be achieved, and changing these goals as improvements were made, was clearly expressed by some participants:

> 'I've achieved every goal that I've set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I gave up on that particular one... My goals change, and as you start to appreciate how you've improved or you can improve, you then can change your goals … I think improvement is infinite, and that's what we should be doing in terms of giving people hope.' (P1)

> 'I wanted to move house, I wanted to continue with things I was already doing. And I suppose getting back to ordinary life.' (P5)

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Having an impact on others

One of most consistently identified benefits of overcoming the monster was the ability to influence others and fulfilling the desire to help those with similar experiences. For instance, P5 had undertaken volunteering at a hospital, becoming a counsellor to achieve this, but now was more involved with research:

> 'I did get involved with a [major UK stroke charity] and, as I say, counselling. But I've stopped the counselling now. I've pulled away from the [major UK stroke charity], because I want to move on with my life. I don't want to be kept being pulled back, if you like. So doing research … still keeps me involved, but in a good way.'

Critical moments within the plot

As part of individuals' journeys, two pivotal occurrences were often expressed: the moments when they recognised limited or negative support, and where change was identified.

Recognising limited or negative support

Several participants identified negative interactions and lack of support from allied health professionals and the hospitals:

> 'She'd [participant's wife] get my right hand, like a train, the wheels going round. And we'd do this. And that got my arm moving. And the one physio[therapist], because I had a home care team come in, used to ask me what I was doing. [The physiotherapist said] it was a pointless movement. But it got my arm going.' (P3)

> 'I still think that we have to acknowledge that healthcare professionals must give hope. I don't accept [that they] may be giving false hope, and I answer that [with] no one talks about false despair. And I think false despair is the evil twin of false hope. By not giving hope, people [are falling] into this vortex of false despair, which is far more destructive.' (P1)

> 'I used to do some art therapy in a hospital with an art therapist. And it was all voluntary. We'd go onto a stroke ward and we'd do a bit of art. And I would be there to talk stroke recovery and the art therapist would be there to just provide the art and stuff. And so many people said how they valued that, just because it's something different. And that it was nice to talk to somebody who had had a stroke and managed to get home and live with the effects of stroke. But unfortunately, the hospital didn't want us to go anymore.' (P5)

Identifying change

Several critical moments existed when participants considered the effects that the stroke had had on their lives and the changes that had brought about:

> 'I'm still coming to terms with it …. But I don't mind that… it's kind of an adventure to me. Well … 4 years before my stroke I fell over ... and I lost my sight totally in [my] eye… And from that time on, it gave me the advantage of looking at life as learning new things … I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating, actually.' (P6)

> 'I did join the [name of group]... I think hearing other people's stories was quite helpful…I decided I needed to look forward and be motivated by what I heard from others.' (P5)

Discussion

To the best of the authors' knowledge, this is the first study to consider the importance of the master plot of 'overcoming the monster' for people with stroke. The monster was

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represented in different ways. This included poor experiences of health care, including the undermining of participants' sense of self and independence. Participants also identified periods when the act of overcoming the monster was not possible, during which survival became the priority. At such a time, allied health professionals' voices are critical in influencing the wellbeing of the individual. Overcoming the monster required the ability to see that change was needed and identify a reason to fight for that change.

Allied health professionals professionals must be mindful of the 'medical voice'(using common medicalised terms or phrases in response to hearing the experiences of the patient) that can result from healthcare training, which influences how they respond to patients' narrative master plots (Soundy et al, 2010). Allied health professionals must also acknowledge and be prepared for the different and sometimes conflicting stories that may be simultaneously narrated by patients (Egbert et al, 2021). Responding in an authoritative way to a master plot that could possibly be perceived as unrealistic, such as the restitution master plot, may create a 'monster' from the patient's perspective. Allied health professionals must focus on understanding what the 'monster' may be for each patient. This could be achieved by exploring metaphors that could reveal a patient's particular narrative and empower the individual (Ferguson et al, 2010). Allied health professionals may also need to recognise that particular stories of overcoming the monster could be more accessible from peers (Salter et al, 2008) and understanding that stories from stroke survivors are a very important resource that can be accessed.

The expression of certain different types of monsters was associated with previously identified factors that undermine a patient's hope (Soundy et al, 2014) and represent broad attributes of psychological distress (Laporte and Aita, 2021). This is important, as an extremely high volume of patients present with distress in clinical practice. For instance, it has been reported that psychological distress is encountered on a weekly basis by approximately 80% of physiotherapists (Lennon et al, 2020). Allied health professionals need to understand the factors that encourage hope for patients (Soundy et al, 2014), as these are closely linked to how participants overcame their particular monster. This could be enhanced by simple therapeutic tools designed to support people in psychological distress. For instance, the model of emotions, adaptation and hope provides a basis for a short interaction based on five simple questions (Soundy et al, 2016). Further to this, adopting a storytelling approach to interactions with stroke survivors may also be beneficial, as storytelling interventions in stroke are associated with positive psychosocial outcomes, such as the improved ability to cope and increased hope and support (Alawafi et al, 2021).

Understanding that the creation of a master plot can take years is important; allied health professionals and patients may need to wait for other narratives to be expressed. Initial plots identified by patients, such as the restitution master plot or the chaos master plot, require careful support to ensure that a monster is not created. Rather than focusing on what is wrong with the plot, there may be more value to understanding how individuals may be motivated through an awareness of the strategies to enhance adherence (Oyake et al, 2020). Within the present study, motivation was gained from positive and successful experiences and understanding the importance of small improvements. This finding is supported by the significant association between family support with motivation and self-efficacy (Kurniawati et al, 2020). For individuals lacking motivation, it may be important to develop environments that are supportive of autonomy (Souesme and Ferrand, 2019). Supporting and enabling independence is critical in these instances; allied health professionals should focus on positive improvements, however small, as this could lead to gains in self-efficacy and improve the patient's capacity to overcome the monster.

Clinical implications

The narrative of 'overcoming the monster' may evolve over time and may not initially be seen straight after stroke. It is possible for allied health professionals to recognise more commonly encountered plots and seek to correct them, but allied health professionals must understand what the 'monster' is for the patient and that a poor interaction could create a monster. Allied health professionals need to consider the value of providing patients with access to other people's stories via a variety of mediums (eg in-person or online support groups, videos). Particular narratives could be considered for their specific illustrations of

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different monsters and how these were overcome, as it may benefit the patient to encounter a variety of perspectives and personal journeys. Additionally, allied health professionals may benefit from listening to patients' stories. This could be undertaken through use of a therapeutic tool (Soundy et al, 2021), or be as simple as exploring patient metaphors.

Limitations

This research may be limited by its focus on one previously identified master plot. How prevalent this particular master plot is cannot be established. Because of the world view assumed within the research and the aims of the study, a process of analysis using independent blind coding was not undertaken, and no measures of agreement between authors were established. The applicability of this work may vary, depending on the extent of deficits experienced (eg in language, perception or memory) or the side of the brain affected by stroke (Egbert et al, 2021). These results do not outline other demographical details, such as levels of education, and it is acknowledged that stroke narratives vary as a result of patient personality, cultural factors and psychological adaptation (Hinckley, 2006), which the present study was not able to take into account.

Conclusions

'Overcoming the monster' represents an important master plot that allied health professionals must understand. Allied health professionalsmay further benefit from gaining an awareness of the factors that influence this particular monster plot. This article supports past evidence on the importance of listening to patients' stories in a non-directive way. Further research is needed that considers allied health professionals' responses to this narrative master plot.

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Acknowledgements

The authors would like to thank the participants who volunteered their time to contribute to this work.

Conflicts of interest

The authors declare that they have no conflicts of interests.

Key points

- 'Overcoming the monster' appears to be an important master plot. The monster could represent a range of experiences of stroke, including feelings of isolation, mental health issues or a threat to independence.
- Being able to share this master plot appeared to be important to patients. Poor interaction and support from healthcare professionals could create a 'monster' for patients.
- Healthcare professionals need to understand that this narrative may be overlooked or even denied during an interaction.
- Patients should be given the opportunity to express their master plots, even if the healthcare professional believes that these are unrealistic or do not fit with the aims of therapy.
- Healthcare professionals need to be aware of strategies that enhance communication, including being attentive to descriptions of events, such as metaphors; being able to use non-judgemental and non-directive communication skills to enhance understanding of the patient's experiences and distress; and understanding motivational strategies that will encourage patients.

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Funding
The first author has received PhD funding from the Saudi Arabian Government.

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Appendix 1. The breakdown of components in the overcoming the monster narrative

Participant	What was the monster?	What needed to be overcome?	How was it overcome?	Consequences	Critical moments
1	1. The threat of the illness on his mental health, ability to work and sense of self 2. The problems encountered and negative experiences aspects in hospital	1. Mobility 2. Participant's psychological state; not believing what was possible 3. Low motivation and overcoming the feeling crushed by the experience, but identifying that it was possible to improve your situation	1. Identifying goals and actions that are to be achieved from initial, smaller goals, ranging from going to the lavatory alone to influencing research and presenting at conferences 2. Having and benefitting from family support 3. Fighting for independence and back taking ground	1. Achieve personal goals 2. Influence change and help others	1. Identifying that hope is needed in some form, and that there is a danger of false despair, as much as false hope. He did this by focusing on improvement, rather than recovery 2. Identification of the need to change what was wrong with the healthcare interactions he experienced. A mission was begun 3. Having family that support and encouragement at a time of feeling fragile
2	1. The internal view of her situation and the mental health experiences that resulted 2. The difficulty and challenges faced when trying to change her situation and obtain support	1. Isolation and the feeling of being abandoned 2. Being able to support her children independently	1. Needing to 'fight' with social services to get support for her children 2. Seeking counselling 3. Identifying a need to help herself 4. Volunteering	1. Being able to help others with a stroke who faced similar difficulties	1. Feeling abandoned in hospital 2. Getting support for children
3	1. The physical effects of the stroke impacting on the ability to leave hospital and on living post-discharge 2. The inability to move 3. The doubt of healthcare professionals about the benefit of activities selected	1. Achieving the range of motion in order to be discharged 2. The fear of not achieving normality in 3-6 months as he had originally believed would be the case post-stroke 3. Continuing to work 4. Attaining mobility and movement against the odds	1. Increasing mobility 2. Identifying who he did and did not want to be 3. Identificaiton of being determined or 'bloody-minded' 4. Undertaking activities that were not prescribed persistently in order to obtain benefit	1. Using his disability to help others by volunteering	1. Identifying that 'going back to normal' was not attainable 2. Realisation that that mobility could change

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Appendix 1. The breakdown of components in the overcoming the monster narrative (continued)					
Participant	**What was the monster?**	**What needed to be overcome?**	**How was it overcome?**	**Consequences**	**Critical moments**
5	1. The need to independently come to terms with what was happening in hospital 2. Being alone and not being able to identify with others in a similar situation	1. The inability to share experience with others within hospital and the feeling of isolation 2. The psychological difficulties as a result of this	1. Identification of what she wanted to achieve 2. Identification of achievements made that linked to what she wanted to achieve 3. Determination to 'prove everyone wrong'	1. Wanting to 'give something back' 2. Becoming a counsellor and volunteer at a hospital 3. Seeking to use her own experience to share with and help others move on and see that a 'new' life is possible. Helping them to realise that they did not have to seek to be restored or conceive of their life as 'being over' 4. Being able to identify, listen and understand others in order to help them	1. Independently coming to terms with what has happened and the need to move on soon after discharge 2. Beginning a journey of helping others 3. That healthcare professionals were not able to do what she perceived as required
6	1. Experiencing a threat to independent living 2. Not having a carer or being dependent on others	1. The isolation and inability to relate or talk to others 2. Identifying the need for rehabilitation and negative outcomes of isolation 3. Understanding that uncertainty can be embraced when seen as an adventure	1. By fighting and benefiting from treatment 2. By using experiences to create change	1. Openness to change and a willingness to embrace uncertainty as an adventure	1. The inability to speak with others or form community; being dependent on others in hospital 2. Past experience of the benefit of finding and seeing the adventure that could be experienced
7	1. Mental health challenges, including depression 2. Lack of motivation and being disheartened	1. Motivation to engage in rehabilitation 2. Motivation to want to change	1. Receiving encouragement from her daughter 2. Motivation to not disappoint her daughter	1. Finding a way to a place in which mental health problems did not impact her and where symptoms were different	1. Experiencing mental health difficulties and a lack of motivation 2. Engagement with her daughter to create change

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Appendix 3 – Alawafi et al.(2023)

Alawafi et al. BMC Medical Education (2023) 23:311
https://doi.org/10.1186/s12909-023-04301-5

BMC Medical Education

RESEARCH Open Access

Overcoming the monster! Perceptions of physiotherapy students regarding the use of stroke master plots for building therapeutic relationships; a vignette study

Rana Alawafi[1,2], Sheeba Rosewilliam[3] and Andrew Soundy[1*]

Abstract

Background Narrative master plots identify illness stories which are recognisable within clinical settings. Responses to different master plots by physiotherapy students can lack empathy and need to be understood further. One narrative master plot for people with stroke that has not been well studied is called 'overcoming the monster'. Research is needed to understand physiotherapy students' reactions to this master plot.

Objective To examine the responses of physiotherapy students to three variations of the master plot called 'overcoming the monster' generated from patients who have had a stroke.

Methods A qualitative narrative vignette study was undertaken. A university in the West Midlands (England) was used to access physiotherapy students on the pre-registration programs. A purposive sample of students volunteered to complete a single vignette questionnaire at one time point. The vignette provided three unique examples of the master plot overcoming the monster as told by people with stroke. Students responded to each by asking specific questions that captured demographic information and questions that captured reactions to the different versions of the master plot. Categorical-content narrative analysis was undertaken.

Results Thirty-two first year (BSc) students, thirty-nine first year (pre-registration) MSc students and nineteen third year (BSc) students participated in this study. Neither first year groups had undertaken any clinical placement hours. All third-year students had finished the required clinical placement hours for the physiotherapy course. Students consistently demonstrated empathy towards this master plot. Students often valued the variant of the story which illustrated how difficulties following stroke could be experienced as an 'adventure'. Students also valued and were motivated by the story variant that considered a family member as a source of motivation and encouragement. The story variant which focused on the shortcomings of the health care system was more often related to by the final year BSc students and MSc students. However, first year students, particularly BSc students, reported being more emotionally affected by the vignette.

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Conclusion All variants of the master plot overcoming the monster appeared to generate empathetic responses. This is important because it highlights the value of students' understanding the patients' story and challenges or 'monsters' faced. Therapeutic relationships will benefit from training physiotherapy students on the importance of listening and exploring challenges people with stroke face.

Keywords Stroke, Neurology, Physiotherapy students, Illness narratives, Master plot

Background

According to the Stroke Association [1] a stroke is defined as an event which affects the blood supply to the brain, which kills brain cells and affects how the body works. Stroke is the world's second leading cause of mortality and the leading single cause of disability [2]. Stroke is a devastating condition with complex long-term physical, cognitive, psychological, and functional disabilities that demand care and support [3]. Student health care professionals are required to deliver a patient-centered approach to care [4]. Fundamental to this approach is the therapeutic relationship between patients and (student) health care professionals [5]. Therapeutic relationships can positively influence patient outcomes during stroke rehabilitation, as well as satisfaction of services received [6, 7]. Communication is central to establishing an optimal therapeutic relationship. Poor communication can have a negative impact on patients' psychosocial well-being [8]. There are specific risks to the quality of communication between patients and healthcare professionals such as stress from heavy caseloads [5] or inherent biases toward the patients [9]. There is a need to pay attention to the teaching skills provided to student healthcare professionals that help develop better communications skills and hence improved therapeutic relationships for people with stroke [10, 11].

Sharing illness narratives is one approach that can build therapeutic relationships between patients with stroke and (student) healthcare professionals [12]. Research [13] with physiotherapists and people who have suffered a stroke identified several benefits of sharing stories, this includes patient empowerment and greater involvement and shared decision making. The opportunity to share a personal narrative following stroke aids the ability to make meaning from the experiences and recover emotionally and socially [14]. Hence, storytelling interventions can aid the psychological health and emotions of patients who have had a stroke [15]. Healthcare students like physiotherapists need to be aware of these benefits.

Illness narrative master plots are recognisable stories of illness identifiable by the overarching plot often told in relationship to a particular and unique experience of illness. Research [16] has identified 13 master plots told by people with neurological illnesses. For instance, these include plots like the detached master plot which views events of the illness in a detached way with little emotion, the comic master plot which views the experiences of illness differently, or the detective master plot which illustrates a search for answers following illness. Recently, research has extended this understanding to more master plots. One significant master plot is called 'overcoming the monster'. This narrative master plot was defined by Booker [17] as a major plot existing in literature. The plot relates to stroke as the different experiences related to, and following the onset of stroke can represent a monster which needs to be overcome. Examples of a 'monster' for people following a stroke include interpersonal challenges, mental health challenges, isolation and changes to their social identities [8]. Physiotherapy students need to be aware of the importance of this master plot and understand how stories can be empowered or disempowered through interactions [18].

There is a paucity of research considering physiotherapy students' reactions to different illness narrative master plots or the impact of this reaction on stroke care provision [19]. One way to understand physiotherapy students' reaction to stories is to use a vignette. A vignette is a demonstrative account of specific points in a story, based on the voices and perspectives of various participants [20]. Vignette based research on physiotherapy students has highlighted that empathy can be lost through training and that students in later years with clinical experience can focus their responses on what is wrong with the plot [19]. Overcoming the master plot is different from past master plots because it does not challenge the student's understanding of what may be possible in rehabilitation rather it reveals what is possible and has been achieved. Research is needed that identifies how student healthcare professionals can work more effectively with different narrative master plots [8, 15] and using different stories that show how people change post stroke [21].

Given the above, the aim of this study was to gain an insight into how physiotherapy students perceive and react to three vignettes that represent the master plot called overcoming the monster from people following a stroke.

Method

Design

A narrative vignette [19] was used. In this case, it included providing three narrative master plots identified as overcoming the monster each with a different

'monster' identified from individuals who had suffered a stroke.

Setting

A university in the west midlands was selected for the research during the academic year of 2021/2022. The vignette was given to student physiotherapists in written formats during a lecture or via an email for an online form to be completed.

Sampling and sample size

A purposive sample was taken from two cohorts of undergraduate pre-registration physiotherapy students first year (BSc) and final year (BSc) students and one cohort of pre-registration master (MSc) physiotherapy students. First year BSc and MSc students had never been taught about illness narratives. Third-year students, on the other hand, were familiar with concept of narratives and listening and understanding stories.

We considered sample size based on the concept of information power [22]. The principles of information power are that authors should consider the aim of the study, the sample used, the type of analysis, identification of any established theory and quality of the data. A previous study [19] used 122 (77 BSc Year 1 and 45 BSc year 3) students in total and focused on three different narrative master plots using very similar questions for analysis. Given the greater focus on one narrative master plot it was identified that a similar number would be appropriate. Given the past study had similar aims, questions asked and analysis strategy we believed using the same strategy of requesting response from three cohorts of students would provide a useful number of responses to contrast between the three groups.

Procedure

Physiotherapy students were contacted on a single occasion by A.S via a generic email to each year group email address. The study was also presented at the start of a nominated module where all students were present. Physiotherapy students were not being taught by A.S at that time point of the study. Although students of all cohorts would know him. If students responded by email, the follow-up email provided the ethically approved information about the study and identified that if the student was happy to undertake the study. Students were required to click on a link for the vignette. Alternatively, students could have received it as a hard copy in a lecture. If students received a hard copy of the vignette it was given out by a separate module leader on one identified occasion to any students who wanted to complete it. The researchers were not in attendance to see who did or did not complete the vignette but collected the completed sheets from the session's lecturer after the lecture was over. The vignette was accompanied by a survey using a questionnaire.

The qualitative vignette itself was created by R.A and A.S. The development of the vignette questionnaire was based on past research [19]. The reason for this was because the previous questionnaire study provided useful information about students' perceptions and reactions to a narrative. Moreover, this also provided a way to compare responses of physiotherapy students to past responses.

Outcome measure

Demographic data was identified within the vignette questionnaire. The questions were designed to elicit students' reactions and perception about the vignette. The vignettes were created within a three-step process based on work conducted prior to this vignette study. Step 1 included authors reviewing the verbatim interviews of 6 people with stroke, that were identified as representing the master plot overcoming the monster (the interview manuscripts were taken from research by Alwafi et al. [8]). Step 2 required authors to select vignettes that represented clear examples of the master plot. A.S developed the selection criteria for the vignettes identifying that the vignette could be selected if (a) verbatim statements from the participants interview script could clearly illustrate what the monster was and how it was overcome, (b) that the verbatim expression of the master plot could be easily arranged in a short paragraph, (c) the 'monsters' or experiences were considered by all authors as common for people with stroke. Alternatively, aspects of the master plot that were identified as striking, important or unusual. Finally, (d) each master plot selected had to be clearly distinguishable from the others chosen. Step 3. Once AS developed these plots based on the above criteria they were sent to other researchers for evaluation of clarity, and agreement. The three selected vignettes were labelled 'Stories A, B, and C' (Appendix A) but they represented the illness narratives that demonstrate 3 variations of the master plot overcoming the monster. The students were then requested to complete seven questions about each story (see Appendix B).

Analysis

Descriptive statistical analysis were undertaken for Question 2 (Q2) including the number of times (n)each word was used and the percentage (%) of words occurrence in relation to the number of replies received. The open responses of the survey were analysed using a categorical-content narrative analysis [23]. This requires the researcher to breakdown open responses to self-contained areas of content. During content analysis it is normal to quantify the presence and meaning of certain words or themes e.g., [19]. The main researcher carried

out the analysis (R.A). Author (AS) served as a 'critical observer/ friend ' [24, 25], reflecting on and challenging explanations as they arose in respect to the data.

Results

Demographics of the respondents

A total of 90 students (39 MSc year 1; 32 BSc year 1; and 19 BSc final year 3 students) agreed to take part in this study. There were (25/90; 28%) male students with an average age of 25.0 years and (65/90, 72%) female students with a mean age of 20.1 years. Seventy-five (75/90, 83%) had not been on a neurological placement. Sixty students including all from BSc year 1 identified as having no placement experience. Table 1 provides a further break down of the group demographics.

Table 1 Demographics of the Respondents

Total 90	Frequency	percentage
Gender		
Male	25	27.8
Female	65	72.2
Respondent's Age		
17	2	2.2
18	15	67.4
19	11	12.4
20	14	15.7
21	7	7.9
22	7	7.9
23	11	12.4
24	6	6.7
25	6	6.7
26	3	3.4
28	1	1.1
29	1	1.1
30	2	2.2
31	2	2.2
34	1	1.1
No response	1	1.1
Year of Study		
First year	71	78.9
Third year	19	21.1
Course		
MSc pre-registration (year 1)	39	43.3
BSc (year 1)	32	35.6
BSc (year 3)	19	21.1
Neuro Placement		
No	75	83.3
Yes	15	16.7
Number of placements		
Not Answered	1	1.1
No placement experiences	60	67.4

Responses to each variation of the stories

A descriptive summary of student responses is given below and a summary of these responses is given within Table 2.

The findings from narrative content analysis of the various stories along with the descriptive statistics are presented below.

Summary of Story A the monster is identified through the challenges created by the Stroke and references mental health difficulties. The monster is overcome through motivation, emotional support and relationship with her daughter.

Story A appeared more attractive to the first-year students (MSc 28%, BSc 19%) compared to the final year BSc students where only one student (5%) identified this story as most attractive. The majority of students identified story A as the most common story of all three. Year 1 BSc students identified this as most often (20/31, 65%) with smaller amounts identified by other groups (year 3 BSc 8/19, 42%; year 1 MSc 14/39;36%). A similar number of first year BSc (14/31, 45%) and first year MSc students (18/39,46%) selected story A as the story they would prefer to hear. The BSc year 3 students selected it slightly less (7/19, 37%). Story A was most often selected as a preferred story to tell themselves if in a similar situation by final year BSc students (8/19, 42%) and MSc year 1 students (14/36, 39%). BSc year 1 students selected it less often (10/31, 32%). Many students would tell story A because they feel it would be the one that they would relate to the most. Only 3 students thought Story A was unusual. All three students were from the year 1 cohorts.

Most MSc students and BSc year 1 and 3 students felt uplifted and touched by the story and by the way the daughter supported her mother. This reaction was identified by around a half of year 1 BSc student (BSc 14/32; 50%) and slightly less prevalent for year 1 MSc students (12/39;31%) and in final year 3 BSc students (6/19;42%). For instance, one student stated, "*Story A. It is heartwarming, loving and touching*" (BSc Female Year 1 Student, P62). A majority of students across all student groups (BSc Year 3, 16/19; 84%; BSc Year 1, 22/32;69%; MSc Year 1, 29/39;74%) identified the importance and value of family members supporting the mental and physical well-being of the individual. Students often identified that the family member was a needed source of motivation to recovery and manage the impact of suffering two stroke. This was recognized by around two thirds of third year BSc (12/19,63%) but only in around a third of the other groups (MSc 12/39,31%; 1st year BSc 10/32,31%).

More year 1 students in both the BSc (11/32, 34%) and MSc (7/39, 17.9%) cohorts felt sad compared to the final year 3 students (2/19, 11%). However, the year 3 students

Table 2 A descriptive summary of student responses to individual questions

Story	Cohort	Year	Most attractive story (n & %)	Most unusual story (n & %)	Story the student would want to hear (n & %)	Story the student would want to tell (n & %)	Most common story (n&%)	Three most common words (frequency, % against number of students)		
A	BSc	1	6 (19%)	1 (3%)	14 (45%)	10 (32%)	20 (64%)	Motivational (19; 59%)	Family (9;29%)	Love (6; 19%)
	MSc	1	11 (28%)	2 (5%)	18 (46%)	14 (39%)	14 (36%)	Motivational (22; 56%)	Family (13;33%)	Sad (6;15.4%)
	BSc	3	1 (5%)	0	7 (36%)	8 (42%)	8 (42%)	Motivational (19; 59%)	Family (9;29%)	Love (6;19%)
B	BSc	1	14 (45%)	17 (55%)	1 (3%)	4 (13%)	6 (19%)	Sad (9;19%)	Despair (6;19%)	Neglected (6;19%)
	MSc	1	17 (44%)	13 (33%)	2 (5%)	5 (14%)	16 (41%)	Neglected (9; 23%)	Sad (8;20%)	mental health (7;18%)
	BSc	3	12 (63%)	5 (26%)	0	3 (16%)	4 (21%)	Despair (6;31%)	Negative [hospital experience] (4;21%)	Frustration (3;15%)
C	BSc	1	11 (35%)	12 (39%)	15 (48%)	14 (45%)	3 (10%)	Persistent (15;42%)	Motivational (6;19%)	Inspiring (6;19%)
	MSc	1	10 (25%)	22 (56%)	12 (30%)	12 (33%)	4 (10%)	Persistent (14: 36%)	Motivational (9;23%)	Positive (11;28%)
	BSc	3	6 (31%)	13 (68%)	12 (63%)	5 (26%)	2 (11%)	Persistent (8;42%)	Inspiring (6;31%)	Positive (6;31%)

Note: please note some % were affected by a missing number from the year 1 cohort: The most attractive, unusual want to hear and common columns had other answers and won't add up to 100

identified as feeling empathy towards the individual (4/19, 21%) which was slightly similar to the year 1 MSc (6/39,15.4%,) and slightly more than the BSc year 1 students (4/32, 12.5%).

More final year BSc students (7/19, 37%) were able to identify how common it was for patients who had a stroke to lose motivation due to the length of recovery and frustrating nature of the process. This was less evident in the first-year groups (MSc 4/39,10%; BSc 2/32, 6%). Further to this, year BSc 3 students highlighted the considerable healthcare challenges following stroke (12/19, 63%) which was higher than the year one students (MSc 9/39, 23%; BSc 4/32, 13%). For instance, a final year student stated: "*The stroke was not fully treated and or she did not have the correct or personal recovery programme specifically for her case. The daughter family was the main rehab for her recovery not the untailored recovery [NHS] programme*"(MSc-preg Female Year 1, P20).

Summary of Story B *The story identifies difficulties within the hospital experience as the monster; being able to recognize the difficulties and seeking to improve them was the way the monster was overcome.*

Story B was the story that was identified as most attractive across all students. The third-year BSc students appear to be the most drawn to this story (12/19, 63%), followed by the two first year cohorts BSc (14/31, 45%) and MSc students (17/39, 44%). A large number of MSc students selected story B as the most common story (16/39,41%), with the around 20% (BSc year 1 6/31, 19%; BSc year 3 4/19, 21%) of students identifying it as most common. Many students highlighted faults with the NHS that contributed to this being a common story. This included overwhelming stress on the NHS, the healthcare professional's ability to implement screening protocols/procedures and negative culture in the wards. For instance, one student stated: "*Story B- I think there are a lot of people /patients that are seriously suffering in hospitals and finding it challenging to try and recover. The will to survive might be gone as well. That's why it is essential to have a supportive environment to reignite their will to live*" (MSc male year 1 student, P24).

Students also recognised that it was common to hear unpleasant stories because stroke was regarded as a difficult experience to live through. A relatively low number of students selected Story B as the preferred story to tell (MSc year 1 5/36, 14%; BSc year 1 4/31, 13%; BSc year 3, 3/19, 16%). Story B was most often selected by students across the cohorts because it considered motivated people to be independent, persistent and self-driven to accomplish all their goals. One student stated: "*I would like to tell story B because this individual seems to have been extremely motivated by his stroke and they have achieved every goal set for them, which really inspires me and I hope by telling this story other people can be inspired too*" (BSc female year 1 student, P57). Another student stated: "*[story B] encourages people to do their own research and be persistent when asking doctors questions*" (MSc male year 1 student, P3).

This story considered was most unusual for the BSc first year students (17/31, 55%), followed by the MSc students (13/39, 33%) then the BSc year 3 students (5/19, 26%). The majority of year 3 BSc students highlighted the shortcomings of the hospital environment (14/19, 74%). Less numbers of year 1 students highlighted this although numbers were still considerable (MSc 24/39, 62%; BSc 14/32, 44%). The shortcomings identified by students including the healthcare professional's misdiagnosis, inadequate care, patient neglect, a lack of communication between the patient and a lack of patient-centered care. The students were also critical of the ward environment on the mental health of the individuals; similar numbers highlighted this across programs (BSc year 3 6/19, 32%; BSc year 1 7/32 22%; MSc year 1 10/39 26%). One student illustrated this; "*[the story] highlights flaws in healthcare systems and shows how it affects patients and negatively impacts their recovery. Shows how patient centered care is sometimes not achieved and the needs and wishes of patients aren't always taken into account*" (BSc female year 3 student, P72).

Students consistently identified this story with words that demonstrated their shock, annoyance and frustration at seeing the narrative reported by the individual. This was most prevalent for the year 1 BSc students (11/32, 34%) and less prevalent for the BSc year 3 students (5/19, 26.3%) and the year 1 MSc students (7/39, 19%). Interestingly, some third-year BSc students (4/19, 21%) identified the story as realistic and were able to identify the mistakes as unfortunate but understood it from the perspective of broader challenges with the NHS and problems faced like short staffing and patient overload. One student stated; "*The patient shed light to the unfortunate but realistic experiences that happens to stroke patients where their stroke might have been missed in the early stages*" (BSc male year 3 student, P80). Students identified that they felt empathy towards the individuals this was most often in BSc cohorts (year 1 11/32, 34%; year 3 10/19, 53%) and less often in the MSc cohort (7/39, 19%).

Summary of Story C. *The monster was identified as a loss of control following the stroke and the identification of negative or challenging experiences e.g., the inability to speak or express herself. A central way the monster was overcome was to view negative experiences as an adventure. Life and new experiences become an adventure.*

Students were equally attracted to story C (BSc year 1 11/31, 35%; BSc year 3 6/19, 32%; MSc year 1 10/32, 25%). Around 10% of all students identified story C as the most common (MSc year 1 4/39, 10%; BSc year 1 3/31, 10%; BSc year 3 2/19, 11%). Those that identified the story as common did so by referencing the common physical and cognitive problems that many stroke patients experience such as losing ability to perform basic activities, speech, reduced memory and concentration. Story C was also identified as common due to the ability of people to adjust to one's viewpoint and mindset after a stroke. The BSc year 3 students most often selected story C as their preferred story (12/19, 63%). This was similar to the year 1 BSc students who most often selected it (15/31, 48%). Slightly less students from the MSc cohort identified C as the preferred story (12/39, 31%). Students valued particular characteristics demonstrated in this story including persistence and determination to succeed. Also, students said that motivation would reassure respondents that their loved ones would be determined to progress and persist with their rehabilitation programme in order to achieve the best quality of life possible. BSc year 1 students stated that they would tell Story C if they were in a similar situation (14/31, 45.2%). This was slightly less from other cohorts (MSc year 1 12/36, 33%; BSc year 3 5/19, 26%). The value of the story for these students was the perceived ability to demonstrate the capacity to evolve and cope with a life-changing disease in a positive and novel way by viewing life as an adventure. For instance, one student stated: "*... because it is a story of hope and is encouraging that things will end up good*" (MSc-preg Female Year 1 Student, P14). Despite it being preferred, the majority of students across cohorts identified Story C as the most unusual for two cohorts (BSc year 3 13/19, 68%; MSc year 1 22/39, 56%), and perceived as unusual by less BSc year 1 students (12/31, 39%). Story C was assumed to be unusual due to the individual's positive and hopeful outlook on life and seeing how life and recovery journey was an excitement and adventure.

High numbers of all year groups (year 1 BSc 18/32, 56%; year 1 MSc 16/38, 42%, n=1 missing data; year 3 BSc 14/19, 74%) perceived that the story illustrated an amazingly rare positive attitude and mindset following the stroke. Several students found the story motivating and inspiring to read (BSc year 3 7/19, 37%; BSc year 1 7/32, 22%; MSc year 1 4/38, 11%). Interestingly this was identified as a surprising story for a number of final year students as it was unexpected and represented a unique ideology (8/19, 42%) whereas only one student in the year 1 cohorts identified it as surprising. At least half or more of all students identified the characteristics of the individual of this story most often. They highlighted the ability of someone to find strength, determination, and motivation intrinsically, enabling her to persevere with the rehabilitation program to move forwards in her recovery journey from stroke. This was illustrated by similar response levels across groups (BSc year 3, 12/19, 63%; MSc year 1 19/38, 50%; BSc Year 1 15/32, 47%).

Discussion

To the best of the authors knowledge this is the first study to consider how physiotherapy students respond to the master plot 'overcoming the monster.' Physiotherapy students consistently wanted to hear story A it and could identify with it and with the importance of family. Final year students identified empathy with story A, whilst more first year students identified feeling sad because of this story. A large proportion of students were attracted to story B, but often did not want to tell it. A moderate proportion of students across cohorts were attracted to story C and valued the characteristics of the person who told them. However, many final year students were surprised that it would be told.

Physiotherapy students recognized the challenges and poor experience of inpatient care identified in Story B. Third year and pre-reg MSc students appeared to be aware of the challenges facing the National Health Service (NHS) that included lack of staffing across all health care professionals, an excessive workload, an inadequate level of resources, and training, all of which have an impact on building a therapeutic relationship and the ability to provide high-quality patient care [26]. This may suggest clinical exposure and age may influence the expectations of healthcare experience, something that has been identified in past research [27]. For example, younger newly qualified nurses evaluated their work environment more positively, whereas senior registered nurses evaluated their workplace more negatively [27].

There were several important comparisons that this study has with past research on students' responses to narrative types. In the current study, physiotherapy students did not question whether the patient accepted what had happened or if the story was realistic. This is in contrast to past research. For instance, in another vignette study by Soundy [19] physiotherapy students viewed a 'quest master plot' and questioned if acceptance had occurred and considered a 'restitution master plot' and questioned if it was actually realistic. Further students who heard the 'chaos narrative' identified the individual as depressed. It is important to understand that, in the current study, students did not use such 'labels' which can infer a judgement to the nature of the master plot or the person telling it. Rather, physiotherapy students appeared empathetic to the plot.

Health care professionals can influence which narrative types exist within an inpatient or outpatient environment [28]. Interactions with patients should provide opportunity to consider peoples' stories and health care professionals should be aware of their own preference for particular master plots. This awareness could help isolate any bias towards particular narratives when listening to a patients' narrative [19, 21]. It is also important for students and health care professionals to understand how a patient defines the plot may be different from how they define it. For instance, an individual in the study by France et al. [21] regarded himself as 'cured' despite an ongoing disability. The current findings support the importance of sharing stories rather than seeking to correct stories [15].

Empathy was consistently expressed towards story A and story B. Reference in story A to a family member and reference to poor experiences with the hospital environment in Story B appeared to be aspects which physiotherapy students could empathise with. This is supported by past research [29]. Empathy is one of the core psychosocial skills that can improve patients' psychosocial outcomes, including adherence and patient confidence [30]. It is important to understand what master plots generate empathy and what do not. For instance, a reduction in empathy has been previously associated with the chaos narrative by physiotherapy students [19]. This is important since this story is associated with the severity of cognitive impairment or the want of patients to overtly consider their own experiences following a stroke [31]. However, stories that are inspiring and reveal a positive recovery message are met with a positive response by health care students [32]. Overcoming the monster master plot looks at the past to identify how someone overcame a difficulty. The plot reveals the persons character in a positive light and also reveals their past struggles. The master plot does not challenge rehabilitation goals that had been set, during a student-patient interaction. Contrastingly, stories like the chaos master plot are 'lodged' in the present, or stories like the restitution and quest look to the future and could be perceived as impacting rehabilitation goals and the student-clinician interaction [19]. Further it is important to recognise that students' reactions can also be from inherent biases [9]. For instance, vignettes with a patient educational level, culture and ethnicity can generate different responses from students [33]. Hence training using narratives should encourage less judgement of challenges faced by patients and more understanding of how challenges are presented and the range of stories that can be told [34]. Being able to understand that the patients are more than their disease can help students listen more and positively impact patient care [35, 36].

Implications

Physiotherapy students appeared to be empathic to understanding the 'monster' or challenges faced by patients who have had a stroke. Giving time within interactions to do this will help build therapeutic relationships. Physiotherapy students need to create environments where stories can be told, and the personal challenges of patients understood. Physiotherapy students could benefit from time to self-reflect on their

responses to different narrative master plots during clinical placements.

There may be master plots told by patients that evoke a response from the student physiotherapists where the student perceives a need to correct the story (using positive interventions). However, student physiotherapists should consider that the telling of the story is therapeutic, it builds trust and the individual's story will likely evolve with time and opportunities to share and listen to other stories. Training programmes need to include training which highlights how implicit bias and bias towards particular master plots may influence the students' reaction.

Clinical placement education that offers opportunities to listen and understand experiences of stroke would be of great value to student physiotherapists. Patients may need time and space as well as direct questions within interactions to identify a monster and the understanding that the ability to overcome the monster may evolve over time.

Limitations

Individuals presenting this narrative were identified from a group who had a long time to recover and less challenges to narrate their story. How common 'overcoming the monster master plot' is needs further consideration. The current manuscript is focused on one plot and how other master plots evolve or how they interact with this master plot is not established. Responses to each narrative appeared to vary with clinical experience and potentially age. Further research is needed to develop understanding of both these factors. Numbers across groups were not equal and different methods were used for completing the survey. This may limit a fuller understanding of the responses by the final year students. The content analysis focused on the most common expressions by student. This process may have limited the focus of the current results. The generalisability of this work to other healthcare students has not been established due to the specific population of students included. Finally, the effects of aphasia and inability to narrate due to a stroke is not considered within the current manuscript.

Conclusion

Students responded to the master plot of overcoming the monster with more empathy compared to other narrative master plots. This is significant because it emphasizes how crucial it is for students to understand the patients' stories and difficulties or 'monsters' encountered. It is important that physiotherapy students take time to identify what the 'monster' may be for a patient, and this requires time for getting to know a patient and their story. It appears more important to encourage students to listen and understand challenges, to identify the problems in the story that may not fit currently with the goals of stroke rehabilitation.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12909-023-04301-5.

Supplementary Material 1

Acknowledgements

The Government of Saudi Arabia for financially supporting the PhD. Princess Nourah Bint Abdulrahman University for supporting the PhD studies.

Author contributions

R.A. and A.S.; methodology, R.A. and A.S.; validation, R.A., A.S. and S.R.; formal analysis, R.A. and A.S.; investigation, R.A.; resources, R.A. Saudi Government studentship support; data curation, R.A.; writing—original draft preparation, R.A., A.S. and S.R; writing—review and editing, A.S. and S.R.; supervision, A.S. and S.R.; All authors have read and agreed to the published version of the manuscript.

Funding

The primary author was supported by The Government of Saudi Arabia for her PhD costs.

Data availability

Data is available in the supplementary file.

Declarations

Nothing to declare.

Competing interests

The authors declare that they have no competing interests.

Ethics approval

Ethical approval was obtained from the University in the West Midlands Reference number: ERN_17-0149 C. The review was undertaken by The Science, Technology, Engineering and Mathematics Ethical Review Committee. Research was undertaken in accordance with the Declaration of Helsinki and in accordance with the University guidelines and regulations for research. The research protocol was approved by the University ethics committee. Informed consent was obtained from all participants.

Consent for publication

Not applicable.

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Received: 14 November 2022 / Accepted: 26 April 2023
Published online: 05 May 2023

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Appendix 4-Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement for

No	Item	Guide and description	Page number
1	Aim	State the research question the synthesis addresses.	1-2
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	4-5
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	3-4
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	2-3
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	3-4
6	Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	3-4
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	3-4
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	In ementary file Table S2

No	Item	Guide and description	Page number
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	5
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	6
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope*[25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	6
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	6
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Page 6 & ementary files S3 and S4
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	4 and 5
15	Software	State the computer software used, if any.	n/a
16	Number of reviewers	Identify who was involved in coding and analysis.	. RA and A.S ,

No	Item	Guide and description	Page number
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	ementary file S5
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	S7
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Inductive process
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.	S8 and S9
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	Page 6-10

Appendix 5 - The demographic and design-related information on included studies

Study	Methodology, aim & Eligibility	Participants, Sampling and Setting	Key intervention details in line with TIDieR checklist(Hoffmann et al., 2014)	Data collection methods, aim and focus and analysis
Gurr (2009)	Design: Mixed methodology, including depression outcome measures and qualitative themes Aim: To explain the application and assessment of psychosocial group sessions for stroke patients in acute stage of rehabilitation Eligibility : Stroke patients admitted to stroke rehabilitation unit with minimum length of stay 2	Sample size: 80 stroke survivors (41 males and 39 females) Age: Not reported Living condition: Not reported Material Status: Not reported	The intervention: "Share your story group" (personal narrative group), no control group Developmental rationale: Developed and assessed by working party of 2 speech/ language therapists and 2 trainee clinical psychologists aiming to: (1) Create a space where thoughts and feelings related to impact of their stroke and rehabilitation progress could be shared. (2) Create a safe environment for common emotional support. (3) Improve social interaction and peer support (4) Enhance rehabilitation opportunities	Data collection :Objective and subjective tests Hospital Anxiety and Depression Scale (Zigmond and Snaith,1983) used to evaluate participants' emotional status before and after the intervention. A Likert rating scale used after the intervention to elicit feedback from participants regarding the usefulness of the programme for their recovery. Participants' contributions were recorded verbatim throughout the group sessions Data analysis:

	weeks, medically stable, could give consent, physically able to sit in a chair or wheelchair, could communicate with or without the assistance of communication aids and cognitively able to sustain concentration throughout the sessions. Country :UK	Time since stroke: Acute phase of rehabilitation Type/location of stroke : Not reported co-morbidity/severity of stroke, : Not reported Recruitment: sampling strategies not identified Setting: Stroke rehabilitation unit Country :UK	Content: Two sessions: First session: Introduction and ground rules. Participants invited to share their experiences of diagnosis with stroke. Second session: Looking at stroke survivors' emotions, thoughts about rehabilitation process and hopes for future. Topics: Week 1 - "Tell us about your stroke" Week 2 - "How is your rehabilitation going?" and "How do you see the future?" Setting: Stroke Rehabilitation unit (acute phase) Provider: Professional-led groups,	Paired sample T-test Recordings transcribed, then gathered into themes according to topic and meaning

			run by 2 facilitators and a rota of group leaders: 2 speech and language therapists, 1 occupational therapist (OT), 1 physiotherapist (PT) and 1 trainee clinical therapist. OT & PT trained by trainee clinical psychologist. Length: Total 17 group sessions, each with 3-6 participants, lasting 1-1.5 hours per week for 2-3 weeks Cost to participants: Not identified Tailoring: Not identified Modification: Not identified	

			Fidelity assessed: Not identified	
Hancock (2009)	Design: qualitative study Aim: to examine the experiences of stroke survivors of participating in stroke peer support groups Eligibility: all stroke survivors participating in Stroke Recovery/March of Dimes Canada peer support groups	Sample size: 9 stroke survivors Age in years [Range or Mean]: 40-75 Mean=65 Living conditions: Not reported Marital status: Not reported Time since stroke: Range < 1-year post stroke- > 9 years	The intervention: Stroke Recovery Canada (local peer support group) Developmental rationale: Initiated in response to the need to fill a gap in stroke services and research in Canada, as few supports had been offered to stroke survivors and their families to help them through recovery. Based on non-medical model, linking stroke survivors with others, aimed at enhancing recovery and developing support network for survivors.	Data collection: Semi-structured interviews, lasted an hour Aim: Interviews explored the experiences of stroke survivors participating in peer support groups for the following purposes: 1) to recognise the experiences of stroke survivors and emphasise the role of peer support in their lives after stroke, 2) to increase awareness of peer support groups and their benefits, 3) to provide opportunities for stories to be shared with other stroke survivors and public, 4) to widen stroke research beyond the realm of medical model, 5) to enable professionals to gain an insight into experiences of stroke survivors participating in peer support groups in order to inform further initiatives

		Type/location of stroke: Not reported co-morbidity/severity of stroke, Balance and mobility problems, physical disabilities (usually paralysis of one side of the body), communication and swallowing issues, memory, and mood problems Recruitment: sample was recruited from seven local peer support groups; strategy not identified Country :Canada	Content: 1) educational topics by speakers, 2) time allocated for group discussion, 3) sharing and 4) recreational activities 2 groups were developed specially for younger stroke survivors Setting: Community Provider: 6 out of 7 groups led by stroke survivor, care provider (spouse or family member) or a combination of both. Last group coordinated by staff social worker. Length: Most groups held monthly, but some more frequently for specific	Data analysis: Not reported

			programmes, e.g. weekly exercise class. Cost to participants: Not identified Tailoring: Not identified Modification: Not identified Fidelity assessed: Not identified	
Morris & Morris (2012)	Design: Qualitative instrumental case study Aim: to explore the experiences of stroke patients, partners of care and volunteer peer	Participants: Total 18, comprising 10 group members (7 stroke survivors(5males& 2 females) & 3 partners of care) and 8 peer supporters (5 former stroke survivors & 3 partners of care)	The intervention: Hospital-based peer support groups	Data collection: Semi-structured interviews Questionnaire

	supporters of participating in peer support groups during hospital rehabilitation Eligibility criteria All stroke patients hospitalised in the stroke rehabilitation unit and their partners of care. Patients who were bedridden, had severe language or cognitive disabilities or refused to participate were excluded. Participants, including peer supporters, had to participate in at least two sessions to be included in the study.	Age in years [Range or Mean]: Range 44-95 Living conditions: Not reported Marital status: Not reported Time since stroke: Range 3-10 months Type/location of stroke: Right sided stroke (n=5) Left sided stroke (n=2) co-morbidity/severity of stroke,	Developmental rationale: Based on earlier work on the therapeutic value of peer support groups Content: A rolling set of topics agreed by group members (stroke survivors plus their carers) at each session, e.g. moods, recovery. These were discussed in all groups and small groups (divided into stroke survivors and partners of care groups) Setting: stroke rehabilitation unit Provider: co-facilitated peers (former stroke survivors and partners of care) and 2 staff members. Training sessions completed by peer supporters prior to the group	Seven opened-ended questions and 21 Likert-type items drawn from standardised Therapeutic Factors Inventory (TFI) (Lese & MacNair-Semands, 2000) were administered as semi-structured interviews with stroke survivors and their partner of care and as postal questionnaire for peer supporters Aim of the data collection: Interviews to increase knowledge of peer support groups by exploring the experiences of stroke patients, carers and peer supporters. The TFI questions were used to gain information related to the group-therapeutic process and examine their links with aspect of participants' experiences that showed in the qualitative analysis of the interviews. Data analysis: Semi-structured interviews were recorded and transcribed verbatim. Interviews and

		4 had mild and 1 severe dysphasia 5 had mobility problems (2 used wheelchairs and 3 walking aids) 4 had cognitive difficulties (memory) Recruitment: Sample strategy not identified Setting: Inpatient (stroke rehab unit) Country :UK	Length: total of 13 group sessions twice a week, lasting 1.5 hours Cost to participants: Not identified Tailoring: speech and language therapists were available when patients required their assistance Modification: Not identified Fidelity assessed: Not identified	questionnaire responses were subjected to inductive thematic analysis.
Kessler et al. (2014)		Sample size:	The intervention: Individual peer support programme	Data collection:

	Design Qualitative instrumental case study Aim To evaluate an individual peer support programme with multiple groups of participants Eligibility criteria Admitted to acute care setting after first stroke, showed desire to participate in the peer support programme and had adequate cognitive and communication skills to engage in the interviews (with or without communication aids).	Total 38: 16 stroke survivors(75% males), 8 partners of care, 7 peer supporters, 3 program coordinators and 4 HCPs/ Age in years [Range or Mean]: Mean 64.8 (11.3) Living conditions: 4 lived alone, 10 lived with spouse & 2 with other family members Marital status: Not reported Time since stroke: Acute phase Type/location of stroke	Developmental rationale: To give newly diagnosed stroke patients the opportunity to meet stroke survivors who had positive experiences of community reintegration. Content: Peer hospital visit to newly diagnosed stroke survivors and their partners of care if they were present prior to discharge to introduce hope, followed by post-discharge telephone calls to either stroke survivors or their carers, to provide ongoing support and information on living with stroke and community resources Setting: Acute inpatient unit - community	Open-ended semi-structured interview and peer support diaries Interviews with stroke survivors and their partners conducted soon after discharge and at 6 months Interviews with other participants conducted at one point in time throughout the study. The aim of the data collection:: Interviews to examine the individual peer support programme covered: 1) Type of support, 2) benefits and harms of peer programme for stroke survivors and their partners of care, 4) effect on peer supporters and 5) organisation-related factors. Data analysis:

		Recruitment: Type: clot 14 (87.5%) bleed 2 (12.5%) Location: left 3 (18.8%) right 13 (81.3%) co-morbidity/severity of stroke, : Barthel Index score Stroke survivors (SD), range 78.8 (21.7) = moderate dependency Setting Acute inpatient unit	Provider: Peer-led Visits conducted by peers. HCPs provided organizational support. Peers completed in-class group training and shadowed an experienced peer Length: Total of 17 acute hospital visits and 28 follow-up telephone calls 1 visit per week, lasting 10 minutes Telephone calls at 1, 3, 6, 9 and 12 months after discharge, lasting 5-60 minutes Cost to participants:	Interviews and peer supporters' diaries were recorded, transcribed, and coded following MacPherson and McKie (2010) on the use of qualitative data in programme evaluation

		Country: Canada Recruitment Retrospective convenience sampling	No cost identified to participants, but pay was offered to organization staff and HCPs to provide support during the intervention Tailoring: The 2 peer supporters who carried out the hospital visits were matched to complement each other in terms of strength and severity of disability. Modification: Initially, post-discharge follow-up calls were made by paid HCPs; however, due to financial constraints, peer supporters made calls to recent stroke survivors whom they visited Fidelity assessed: Not identified	

Kirkevold et al. (2014)	**Design** Qualitative feasibility study Aim To evaluate the intervention focusing on stroke survivors' experiences. Multiple case study approach, studying each participant in detail Eligibility Adults aged 18 and older, had a stroke in the past 8 weeks, medically stable, had adequate cognitive ability to participate and could benefit from the intervention (decided by the physicians and stroke	Sample size: 25 stroke survivors (17 males & 8 females) Age in years [Range or Mean]: Range 33-89 Living conditions: 22 lived at home alone, 3 discharged to care home after stroke, one returned home at end of intervention Marital status: Not reported	The intervention : Dialogue-based psychosocial nursing intervention Developmental rationale: Initiated in response to the need to develop an effective programme to address the psychosocial difficulties after stroke, as earlier research on similar interventions showed modest effect Overall aim was to promote psychosocial well-being and adjustment of community stroke survivors Based on previous work (systematic reviews of psychosocial interventions, qualitative research and theories addressing psychosocial well-	Data collection: Demographic data collected prior to the intervention Health professionals' log notes and participant's work sheets collected during the intervention. Individual in-depth qualitative interviews (open-ended question with more particular topical questions) held two weeks after the intervention. Interviews with patients having communication difficulties were video recorded Aim of the data collection: Log notes and work sheets to describe the process of the intervention. Log notes focused on experiences of content, structure and process of each session.

	team), wished to participate in the intervention, spoke Norwegian. Aphasic patients were included after their language ability was evaluated by a speech therapist. Patients with dementia or severely ill (decided by physicians and stroke team) were excluded.	Time since stroke: Approx.4-8 weeks post stroke to 6 months Type/location of stroke: Not reported co-morbidity/severity of stroke, Physical disabilities varied from mild to severe. A majority had moderate effects. Many experienced fatigue, vision or hearing impairments, memory and concertation problems. Participants with	being and coping: Theory of sense of coherence (Antonovsky, 1987), narrative theory (McAdams, 2009; Polkinghorne, 1988) and other philosophies, e.g. guided self-determination (Zoffmann, 2004) Content: Delivered in 2 formats: individual dialogue with trained HCP (nurse) and group intervention with peers and group facilitators. The individual intervention aimed to build therapeutic relationship with each participant, understand each personal situation and identify any issues before they started the group. Each session guided by a topical outline covering substantial issues shown in stroke research as	Work sheets provided information on participants' thoughts, feelings, needs, worries, values, goals and experiences in preparation and throughout the sessions. Interviews to explore stroke survivors 'experiences of participating in the intervention Data analysis: Interviews were transcribed verbatim. Interviews, log notes and work sheet notes were analysed using qualitative content analysis (Graneheim & Lundman, 2004).

		communication problems suffered from moderate to severe aphasia Recruitment: Purposeful sampling Setting Hospitals and care homes in three regions of Norway: two large cities and a rural area Country: Norway	particularly relevant to post-stroke trajectories, e.g. relationships, everyday concerns. However, sessions were more open & unstructured, to allow participants to express any concerns. Worksheet consisted of prompts relevant to topic of each session, e.g. key words, unfinished sentences Setting: Individual intervention Pre-discharge: hospital/ rehabilitation unit Post-discharge: home or care home	

			Group intervention: Community Provider: Professional led. Length: Total 8 sessions over 6 months 2 initial individual dialogues lasting an hour, followed by 6 group dialogues of 2 hours. Two initial meetings held before and immediately after discharge, then every 2 weeks for 2 months and every 4 weeks for the last 2 months Cost to participants: Not identified	

			Tailoring: Assigned to either group or individual intervention based on geographical location of participants and presence of communication difficulties. Participants with aphasia offered only individual intervention. Trained staff with good knowledge of assisting those with communication difficulties facilitated sessions for participants with aphasia Planned topics were changed if a participant desired to discuss a topic that differed from that assigned for a specific session. Modification:	

			The intervention delivered to aphasic patients had to be prolonged, as topics planned for each session could not be covered. Fidelity assessed: Facilitators completed 16 hours of training prior to the intervention and were supervised throughout the intervention in individual and group supervision meetings. Trained facilitators who delivered intervention to aphasic participants were under supervision throughout the intervention by speech therapists	

Muller et al.(2014)	Design Pre-post longitudinal study in three stages: programme development, implementation and evaluation. Aim To explain development, results and assessment of the YESS group for younger stroke survivors Eligibility Stroke patients 18-65 years old, cognitively intact and able to sustain attention during a 60-90-minute session, able to physically attend the sessions and to communicate verbally or with a communication aid.	Sample size: 13 stroke survivors all under the age of 65 years old, ranged from 24-60 10 males and 3 females Living conditions: Not reported Marital status: 6 single, 5 married, 1 had partner, 1 divorced Employment All worked before stroke, one retired before stroke and 4 volunteering after stroke Time since stroke: Range: < 1 year - 8 years	The intervention: Young empowerment stroke support (YESS) programme, no control group Developmental rationale: Aim: to offer support and education to stroke survivors aged 65 and under. Three theoretical perspectives guided establishment and implementation of the YESS programme: 1-Group dynamic theory (Yalom & Leszcz, 2005) provided the overall format, using the "therapeutic mechanism of change" within the group context. 2-Social learning theory (Cole & Tufano, 2008) guided the application of the intervention, using the value of peer	Data collection: Objective test Survey The aim of the data collection: 1) Stroke impact scale (SIS) (Duncan et al., 2001) to detect changes after stroke. including emotional, social factors and coping 2) Community integration questionnaire (CIQ) (Dijkers, 2000) to detect level of participation and activity after stroke within home environment and community. Participants completed both outcomes prior to the first the group and again at 9th session (end of the intervention)

	Participants who required physical assistance were allowed to participate only if family members were present.	(n=5) > 1 (n=4) 1-2 (n=3) 3-5 (n=1) 6- 8 Type/location of stroke: Not reported co-morbidity/severity of stroke, Not reported Recruitment Sample strategy not identified	interaction, active participation and cognitive behavioural methods within groups. 3- Model of human occupation (Kielhofner,2008) was used to actively experiment, model and repeat new behaviours within groups. This approach, with in-group feedback, is effective in promoting new performance and roles. Content: Needs assessment survey of younger stroke survivors determined the key group models, e.g. change in mood, decrease in socialization Setting: Rehabilitation-based hospital programme (outpatient)	3) Member satisfaction survey to evaluate the outcomes of the intervention and to elicit more specific information on how group process and modules meet the intervention's objectives that SIS and CIQ did not detect. Administered at the end of intervention Data analysis : Wilcoxon ranked sum test.

		Country: U.S.A	Provider: Professionally led by occupational therapist and other HCPs. Only one session facilitated by peer (stroke survivor) Length: 13 peer support groups Nine twice-monthly, 90-minute sessions over 18 weeks Cost to participants: Participants had to arrange their own transport. Participants who needed physical assistance could attend only if a family member was present.	

			Tailoring: The duration of each session was chosen to lessen potential cognitive and physical limitations Modification: Not identified Fidelity assessed: Not identified	
Corsten et al. (2014)	**Design**: case series (pre and post test design, with follow up evaluation at three months with no intervention) Research type:	Sample size: 17 participants with chronic post stroke aphasia (9 males and 8 females) Age in years [Range or Mean]: Mean: 63.59 years	**The intervention:** adopted biographic-narrative intervention for stroke survivors with post chronic aphasia Developmental rationale:	Data collection: Quantitative measures (self-administered) were completed during the week before the intervention (baseline), the week post intervention and at 3 months follow up . The assessment of self-reported states of mood using VAMS were administered at the end of first interviews and the last interviews and at the end of first and last group session

	Expletory **Aim**: To develop and assess of an "interdisciplinary multi-model of biographic - narrative approach to enhance QoL in people with post stroke aphasia Eligibility : A phasic stroke patient with no sever disorder in speech perception and depression symptoms according to The Aachen Aphasia Test (Huber et al., 1983) and the Geriatric Depression Scale(Sheik and Yesavage, 1986).	Living conditions: Not reported **Marital status**: Not reported. co-morbidity/severity of stroke, All participants had chronic aphasia, but varied type. Severity of aphasia ranged from mild to moderate. Time since stroke:	The biographic-narrative intervention based on the following theories (1) Socio-cultural theories (Bauer et al., 2008; MacAdams, 2008). (2) Social -construction -oriented theories (3) Based on the idea that stroke can impact on the Quality of Life (QoL) as it alters sense of self and ability to return to previous activities, routine and roles which all contributed to an individual's identity. Re-constructing sense of identity and re-created sense of meaningfulness in life are essential to QoL (Clarke and Black, 2005) (4) Narrative therapy utilizes stories as a methods of re-constructing sense of self and facilitate coping process. (5) The aim of the intervention: to enhance QoL, reinforce identity-re-negation, social participation and sense of self-competence Setting:	1) 1Health Related Quality of Life (HRQL) measured by pictorial version of Aachen life Quality Inventory(ALQI) (Engell et al., 2003) 2) Cognitively based long-term Life satisfaction measured by with Satisfaction with Life Scale (SWLS) (Diener et al. 1985). Short term affective sta 3) tes of mood measured by the German version of Visual Analog Mood Scale (VAMS) (Stern,1997) Qualitative data: 10-15 minutes semi-structures interviews was carried out with topic guide aimed at focusing on personal growth and change in identity .The interview was conducted at

		Average :40.82 months post stroke Type/location of stroke: Apart from 2 participants, all had aphasia as result of left C.V.A **Recruitment**: consecutive sampling **Setting**: ambulant rehabilitation unit and aphasia support groups Country: Germany	At ambulant rehabilitation units and at the Catholic University of Applied Sciences in Mainz Content: Total: 12; 5 faces to face interviews and 7 group sessions over 10 weeks. The first three face to face interviews were designed as a narrative interview (unstructured in-depth interview) aimed at attaining identity re-negation. The first part of the interview aimed at providing opportunity to tell personal stories without interruption. The second part of the interview included question related to any issues were raised during the initial narration	baseline to discover participants' expectation while at post intervention and at 3 months follow up, the interviews aimed at detecting if life perception and sense of self-esteem had changed after participation in in the intervention. Data analysis : For all quantitative measured, Wilcoxon signed ranked test was and paired *t*-tests were used The qualitative data video or tape recorded, transcribed. Orthographically, coded and identified themes . The analyzed based on ground theory (Bryant & Charmaz,2007) Software (QDA-Software MAXQDA 110 was utilized to manage the data

			The last 2 interviews were in the format of semi-structured interviews aimed at exploring issues and to prepare for group sessions in particular with people with sever aphasia. The group sessions were designed to promote learning from peers and enhancing social interaction .The groups' theme presented were related to health or leisure activities .For each group subject, managing the past, present, and future was the focus. The length: Total 12 (5 face to face interviews and 7 group sessions (each group included 5-7 participants), lasted	

			maximum of 90 minutes over 10 weeks. One interview was carried out weekly over the first three weeks. The group sessions started at the second week and for three weeks, one session was conducted weekly .During week 4, only one group session conducted. There was beak (no intervention) at week 5 and 8. At week 6 there were one interview and one group sessions. The following week (week 7) there was only one group session. During week 9, there were 1 group sessions and one interview and the last week (week 10), there was only one group session. The face to face interviews were begun first to provide opportunity to tell life story. There were breaks at week 5 and 8 to enable participants to integrated narrative experiences into their daily life perspective. Interviews 4 and 5 were aimed at preparing members for group sessions	

			Provider: Professional led by 2 facilitators speech therapist and pedagogue. Both had experiences in dealing with language disorders as well as knowledge of biographic approach. The facilitators who ran the group session introduced the group themes and promoted group discussion.	

			Modification: the intervention utilized biography work that especially modified for people with aphasia Tailoring Intervention (narrations) was supported by multi-model ; strategies such as pictures writing, pictograms in case of sever aphasia one to one support help from speech therapist was provided to participants with severe case of speech production Cost to participants: Not identified	

			Fidelity assessed: Not identified	
Corsten et al.(2015)	**Design:** Mixed methods design with pre and post-test and a follow up evaluation 3 months following intervention **Research type**: Expletory study **Aim**: To provide a quantitative and qualitative evaluation of the change in QoL in-stroke survivors with post	Sample size: 27 post stroke aphasia patients 15 males and 12 females Age in years [Range or Mean]: Mean, 60.85 years co-morbidity/severity of stroke,	**The intervention**: structured (adopted) biographic-narrative intervention for stroke survivors with post chronic aphasia Developmental rationale: The biographic-narrative intervention based on the following theories (6) Socio-cultural theories (Bauer et al., 2008; MacAdams, 2008). (7) Social -construction -oriented theories	Data collection: Quantitative measures (self -assessment), participants were promoted by the researcher by reading out each question and written down answered Assessments were completed before week 1(baseline), the week post intervention and at 3 months follow up . The assessment of self-reported states of mood using VAMS were administered at the end of first interview and the last interviews and at the end of first and last group session.

	stroke chronic aphasia after participating in an adopted interdisciplinary biographic-narrative intervention Eligibility : Stroke survivors with no sever speech disorder and depression symptoms according to The Aachen Aphasia Test (Huber et al., 1983) and the Geriatric Depression Scale Short Form (Sheik and Yessvage, 1986).	Severity of aphasia ranged from mild to moderate 8 Broca's, 5 Anomia, 3 Wernicke's, 2 global and 9 others Depression were not assed as it was an exclusion criterion Type/location of stroke: All participants expect from 3 had aphasia as result of left cerebrovascular accident Time since stroke: Mean: 60.82 months Living conditions:	(8) Based on the idea that stroke can impact on the Quality of Life (QoL) as it alters sense of self and ability to return to previous activities, routine and roles which all contributed to an individual's identity. Re-constructing sense of identity and re-created sense of meaningfulness in life are essential to QoL (Clarke and Black, 2005) (9) Narrative therapy utilizes stories as a methods of re-constructing sense of self- identity ,making sense of the illness experience ,re-constructing sense of purpose and meaningfulness in life and identify own strengths and available resources which could assist people in managing personal and environmental difficulties (Brody, 1994) . Content:	1) Health Related Quality of Life (HRQL) measured by pictorial version of Aachen life Quality Inventory (ALQI) (Engell et al., 2003) 2) Short term affective states of mood measured by the German version of Visual Analog Mood Scale (VAMS) (Stern,1997) 3) Cognitively based long-term Life satisfaction measured by with Satisfaction with Life Scale (SWLS) (Diener et al. 1985). Aim of the data Quantitative measures: To discover change in QoL over the time Qualitative data : Semi-structured interviews carried out at the week post intervention, lasted 10-15 minutes sung a topic guide

		Not reported **Marital status**: Not reported **Setting:** ambulant rehabilitation unit and aphasia support groups **Recruitment:** consecutive sampling	5 faces to face in-depth interviews and 7 group sessions (each group included 5-7 participants). To provide an opportunity to tell own stories, the face to face interview was initiated first and the group sessions started in the second week, both were carried out weekly with one week break at week 5 and 8 in order to provide participants time to incorporate narrative experiences into their everyday life perception. One interviews and 2 groups sessions conducted following each break. The first three face to face interviews were designed as a narrative interview (un-structured in-depth interview) aimed at attaining identity re-negation. The participants were given opportunities to tell their life stories without interruption.	Aim of the data collection: Semi-structured interviews aimed at exploring the mechanism of the intervention that underpin identify development and its effect on QoL. The main questions focused on the participant's experiences of participating in the intervention and their emotions after the intervention. Additionally, there were questions related to change in identify and the affect on everyday life Data analysis: For quantitative data Wilcoxon ranked sum test paired *t*-tests were used Qualitative data

		Country: Germany	The last 2 interviews were in the format of semi-structured interviews aimed at exploring issues. The group sessions were designed to promote learning from peers. enhancing social interaction and support identify construction . The groups' theme presented were related to health or leisure activities to facilitates self-reflection on identity, exploring one's self and any strategies that could help in managing the new or changed situation. For each group subject managing the past, present, and future was the main focus. At the beginning of each group session, each member contributed to the topic The length:	The interviews were taped, video recorded, transcribed orthographically according to the principles of Du Bois (1991) and coded. The qualitative analysis was guided by interpretative principle from ground theory (Corbin and Strauss ,2008). 2 researchers analyzed the qualitative data .

			One session per weeks Five face to face interviews and 7 group session over 10 weeks, lasted 90 minutes Provider: Professional led by speech therapist and a education professional with expertise in biographic approach. The facilitators who ran the group session introduced the group themes and promoted group discussion S**etting**: at university Cost to participants:	

			Not identified Modification: the intervention utilized biography work that especially modified for people with aphasia. The size of the group had to be modified due to 2 members missed the first session and 3 missed the last session Tailoring: The face-to-face interviews was carried out by one of the facilitators, whereas the group sessions were conducted by both. However, in case of sever aphasia, the interviews were carried out by the speech and language therapists. Additionally, during both format of the intervention,	

			assisting with communication skills was provided as needs Augmentative communication and one to one support help form speech therapist were provided to participants with severe case of speech production were provided with Fidelity assessed: Not identified	
Clark et al. (2018)	Design: Qualitative Aim: To gain insight into stroke survivors' thoughts on group self-management	Sample size 14 stroke survivors (6 males and 8 females) Age in years [Range or Mean]:	The intervention: Specific group self-management programme for stroke survivors prior to attendance	Data collection: Semi-structured interviews Aim of the data collection: 1) To explore survivors' experiences of self-management during their individual stroke

	intervention and how it could be delivered Eligibility Stroke survivors with one or more strokes, able to be interviewed verbally (patients with communication difficulties were included if they understood a two-step command and were able to express thoughts) and receiving care in a UK stroke care pathway	Mean 58, range: 47-78 Living condition: Alone (n=6), with spouse (n=6), with spouse and daughters (n=2) Marital status : Not identified Employment: Unemployed (n=4), Employed (n=3), Retired (n=3) Volunteer (n=2)	Developmental rationale: Based on previous work on the importance of addressing long-term unmet needs of stroke survivors by providing opportunity to access SMPs, in particular group-based. A feature of group delivery is to offer a place where similar experiences can be shared, reciprocal gain, reinforcement of self-management skills and many other values. Content: No details provided The length: Not identified The provider: Not identified	journey in order to determine when/where to offer the group in the recovery journey/stroke path 2) To explore values, ideas and difficulties of the groups in order to gain insight into possible benefit and challenges Data analysis : In line with qualitative research guidelines (Braun, 2013), data collection and analysis were conducted simultaneously. Data management used NVivo 10 (SPSS Inc, Chicago, IL)

		Type/location of stroke: Not reported Time since stroke: Range: 4 - 174 months post stroke co-morbidity/severity of stroke, Permanent impairments (mood problems, motor dysfunctions and weakness, poor balance, fatigue and aphasia; 1 had mild expressive aphasia	The setting: Not identified Modification : Not identified Tailoring: Not identified Fidelity assessed: Not identified	

		Recruitment Consecutive sampling from the Sobell Stroke Database at Queen Square obell stroke database at Queen Square Setting National Hospital for Neurology and Neurosurgery, Queen Square, London Country: UK		
Chow (2018)	Design Double blind RCT Aim To evaluate the effectiveness of group narrative therapy among Chinese stroke survivors and compare them with	Sample size :192 stroke survivors Males : Intervention group 61.46% Control group 62.50% Age in years	The intervention: Narrative therapy (NT) group intervention, with control group Development rational Based on earlier work on the effectiveness of NT in improving well-being in different populations.	Data collection: Objective measures Seven outcome measures taken at baseline, 1, 2- and 4-months post intervention: 1) 10-item self-esteem scale (Rosenberg, 1965)

	treatment as usual (psycho-educational approach) Eligibility Adults aged 60 years and older, diagnosed with stroke over the past 1-2 years, had completed hospital or rehabilitation-based programme, mobile with or without mobility aids, not experiencing current psychological distress, mental health or psychotic problems, intact hearing, able to carry out minimal daily activities, scoring 18 or more on Cantonese Chinese Mini-Mental State Examination, intellectually intact, not diagnosed with personality disorder, no history of suicide or violent behaviour and agreed to meet the expectations of the group	[Range or Mean] Means: Intervention group 72.49, control group 72.84 Living conditions Alone: intervention group 14%, control 11% With others: intervention group 81%, control 85% Marital status: Married: intervention group 67%, control 73% Significant others:	The theoretical basis was social constructionism and narrative therapy Content: Narrative therapy within group. It included therapeutic conservation between therapist and participants by asking therapeutic questions, participants shared stories Setting: Community Provider: Facilitated by narrative therapist	2) Pearlin Mastery Scale to measure to what extent participants felt their life outcomes to be under their control (Pearlin & Schooler, 1978). 3) Herth Hope Index to measure survivors' hopefulness, overall acceptance of stroke as a chronic illness and post-stroke life (Herth, 1992). 5) Chinse Geriatric Depression Scale Short Form to measure depression (Lee et al., 1993). 6) Life Satisfaction Scale-Chinese to measure satisfaction with various needs of older stroke survivors (e.g. relationships, health) (Lou et al., 2008). 7) Stroke knowledge; eight self-reported items to assess survivors' subjective understanding of their conditions (e.g. symptoms, rehabilitation) (Chow, 2008)

		intervention group 29%, control 23% Time since stroke: 1-2 years post stroke Type/location of stroke: Ischemic stroke intervention group (83.72%) Control group (81.82%) co-morbidity/severity of stroke,	Length: Intervention group 2 hours per week of NT group sessions for 8 sequential weeks Control group Treatment as usual: psycho-educational sessions on same schedule. Cost to participants: Not identified Tailoring: Not identified Modification: Not identified Fidelity assessed:	Data analysis: SPSS 23 Windows

		Initial MMSE mean scores: intervention group 26.11; control group 26.24 Only 8% of participants in both groups had some extent of speech problems Recruitment Cluster, selected randomly from stroke registries of five regionals clusters of the Hong Kong Hospital Authority Country: China (Hong Kong)	Trained staff who delivered the control intervention group were supervised by HCP to ensure fidelity. Fidelity of intervention group was not discussed.	
Christensen et al.		Sample size :32 in total: stroke survivors and their	The intervention:	Data collection :

(2019)	Design: Qualitative study Eligibility criteria Stroke survivors and partner of care who attended peer support groups	partners of care (9 males and 23 females) Age in years [Range or Mean] Average 67 years Living conditions Not reported Marital status: 78% married, 13% divorced, 6% widowed, 3% single Employment::72% retired, 25% employed, 3% disabled Time since stroke: In the community	Stroke peer support group Development rational: Stroke survivors and their partners of care received and provided social, emotional, affirmational and information support through peer support groups. The sharing of experiences enhanced understanding of others Content: The sessions consisted of presentations of educational topics with time allocated for discussion. Setting: Community	Focus group sessions using a semi-structured discussion guide and open-ended questions, lasting 30-60 minutes Sessions held over two months (from October to December 2016) at the same time and locations as the scheduled groups. The aim of the data collection : Focus groups using open-ended questions to allow participants to engage in discussions in order to explore the psychological, informational and social benefits of participating in stroke peer support groups to stroke survivors and their partner of care Data analysis :

		Type/location of stroke: Not reported co-morbidity/severity of stroke, Not reported Recruitment: Sample strategy not identified Setting Four rural North Carolina stroke support groups Country : U.S.A	Provider: One group facilitated by a formal stroke survivor, one by a nurse who was also the main carer of a stroke survivor and the remaining groups by nurses who had experience of patient education. Length: 4 sessions of 1- 2 hours once a month or every 2 months, for 6 to 12 years. A majority had not attended since the programme began. Cost to participants: No cost to participants identified	Focus group were audio recorded, transcribed verbatim and analysed using an inductive coding approach and thematic content analysis (Hsieh & Shannon, 2005).

			Tailoring: Not identified Modification: Not identified Fidelity assessed: Not identified	
Masterson-Algar et al. (2020)	Design Mixed methodology on co-design principles (Batalden et al., 2016; Clarke et al., 2017). Aim To construct and evaluate a novel peer-led coaching intervention to improve meaningful leisure and social participation following stroke.	Sample size : Phase 1: 79 stroke survivors, Phase 2: 18 stroke survivors and 10 family members, Phase 3: 5 stroke survivors (2 males and 3 females)and 5 peer supporters(Age in years [Range or Mean]	The intervention: Peer-led coaching intervention (individual-based), with no control intervention Development rational: Initiated in response to the need for a peer-led intervention to improve meaningful social and leisure participation, as	Data collection: 1) Quantitative measures 2) Interviews The aim of the data collection :

	Eligibility criteria All stroke patients who had been hospitalised with stroke within the previous 6 months and had been discharged home. Patients discharged to care homes were excluded.	Range : 38-60 Living conditions 2 with spouse who was key source of support; 2 alone 1 with teenage children & limited support from family Marital status: Not reported Employment : All were unemployed Time since stroke:	professional-led intervention had little effect. Based on peer coaching model, utilising "transformational leadership and performance profiling", based on personal construct theory (Kelly, 1955) The peer coaching model is based on: 1) exchange between peers and stroke survivors could offer motivation for participation; 2) peers offer "experiential knowledge"; 3) sharing stories allows peers to relate to stroke survivors, make connections and offer empathy. Content:	Quantitative measures to evaluate function (Barthel Index), mood (General Health Questionnaire v12), and participating in leisure (Individualised leisure profile), social activities (Stroke impact scale) at 6 months post stroke. Interviews with stroke survivors and family members on their experiences related to leisure and social participation at 6 months post stroke. Interviews with stroke survivors and peer supporters to evaluate the intervention from their perspectives Data analysis:

		Within 6 months post stroke Type/location of stroke: Right parietal infraction (n=1) Lacunar infraction (n=1) Left frontal infarct (n=1) co-morbidity/severity of stroke, Not reported Recruitment Sample strategy not identified Setting	Face-to-face sessions with a trained peer to identify and attain social and leisure-related goals. "Peer handbooks" were provided to support training and the conduct of the intervention. "Stroke survivors' handbook" gave information related to the intervention, outline of its goals and content of each coaching session. Setting: Community: public places, e.g. coffee shop, library Provider:	Numerical data analysed on SPSS v22. Interviews digitally recorded and transcribed, following constructivist grounded theory (Charmaz, 2002)

		Stroke survivors and family members were recruited from stroke registry of three sites. Peer supporters were recruited from local stroke groups and local newspapers Country: UK	Peer-led by former stroke survivors who completed training workshops (4 days in 3-hour class sessions, over 2 weeks. Length: Maximum of 6 one-hour sessions Cost to participants: Not identified Tailoring: Peers were matched with stroke survivors based on post-stroke impairment and geographical location. Setting of the coaching sessions determined by participant's preference	

			Modification: Not identified Fidelity assessed Peers were in regular contact with the researcher during the intervention for ongoing support.	
Appalasamy, Joseph, et al. (2020)	**Design**: mixed methods research A parallel group randomized controlled trail (RCT), with control group (who received standard care (patient education, counselling with neurologist, outpatient appointment, self-	**Sample size**: 54 stroke patients (more than 50% males than females in both groups) Age in years: Mean :56 years for control group and 53 for the intervention group Employment status:	**The intervention**: face to face video narrative presentation + hospital standard care Development rational: The video narrative intervention based on the social learning theory, health belief model construct and the motivational promotes to encourage stroke	Data collection: Baselines sociodemographic data, medical information collected at baseline (T0) quantitative measures were collected at baseline(T0) and after the study at 3 months post randomization period (T1) Main outcome measures are the following (1) Assessing self-perceived in understanding and taking medication by MUSE at baseline (T0) and for 3 months post randomization (T1) to

	monitoring check, information on stroke prevention and medication) Single blind randomised controlled trail The intervention group received (standard care + video narrative intervention . Semi-structured interview Aim: To assess the feasibility and acceptability of study process . Additionally, to gain preliminary results of	more than 50% of the participants were unemployment Living conditions: Not identified Marital status: Not identified Time since stroke: Not identified Type/location of stroke: Majority of the participants (>80%) had ischemic stroke morbidity/severity of stroke,	survivors to develop self-efficacy skills Content: A real model stories in video (a story of a neurologist and a stroke survivors) in order to show real emotions, while focusing on the importance to adhere to stroke preventative medication Stories were culturally appropriate Subtitles and short quotes were integrated to enhance attentiveness and comprehension of the purpose of the videos	detect change through the intervention and comparing the results with the control group (2) To evaluate participant's knowledge of stroke and associated treatment measured by the Stroke Knowledge Test (SKT) (3) To assess patient's perception of their illness and belief towards their medications measured by Brief Illness Perception Questionnaire (BIPQ) and Brief about Medicine Questionnaire (BMQ). (4) To assessed perceived psychical and mental health by Short Form (36) Health Survey The feasibility of the study processed was evaluated by determining the recruitment, retention, and completion rate of the study was assessed at baseline (T0) In addition, participant's feedback on the burden of the trial process and outcomes measures **Qualitative data:** semi-structured with consent participants from the intervention group (phone interview, lasted 10 minutes)after completion of the trail (2 weeks post

	the effect of video narrative on medication understanding and use self- efficacy(MUSE) and blood pressure control Eligibility: All adults aged 18 and over , diagnosed with their first stroke within 6 months of the recruitment phase, attended the Neurology Outpatient Department of Hospital in Kuala Lumpur(HKL), were taking stroke risk preventative medications prescribed by (HKL) and could give consent and comprehended the English and Malay language Post stroke survivors with depression symptoms and cognitive impairments were excluded	Most of the participants had many stroke risks factors such as hypertension. 50% had diabetes, almost 90% were prescribed al least 3 types of stroke preventative medications Recruitment: selected randomly from outpatient neurology clinic at HKL **Country:** Malaysia	Provider: A researcher met each participant individually for conducting assessment or video viewing **Setting:** at a neurology outpatient clinic Length: The intervention period over 3 months Cost to participants: The one of the most common causes of dropout from study was fear of increasing stress The outcome measure (questionnaire) administered were time-consuming and exhaustive	(T1) to obtain participants' feedback and opinions regarding the acceptability of the intervention Data analysis: Quantitative Data IBM SPSS Qualitative Data 8 Phone Interviews 12 Written feedbacks The interviews were recorded and transcribed verbatim and coded The interviews transcript and written feedback of participants were analyzed using thematic analysis

			Tailoring: Not identified Modification: Culturally appropriate messages Provided in both English and Malay langue to mee the need of participants Questionaries were translated form English to Malay languages. pilot trail was connected with 5 participants and experts before the actual trial to ensure content validity. Fidelity assessed: Validation of the intervention procedures and the content of the video narrative intervention had been assessed in previous study (Appalasamy JR et al., 2019)	Software NVivo 11 was used to assist in identifying theme and organizing coder

Appalasamy, Quek, et al. (2020)	Design: A single blind Randomized Controlled Trail (RCT) over 12 months, with control group (hospital standard care) Aim : To investigate the effectiveness of video narratives integrated with Health Belief construct on Medication Understanding and use Self -Efficacy (MUSE(and its associated aspects in stroke survivors Eligibility:	**Sample size:** 216 stroke patients **(**There were almost 20% more men participants than women in both groups) Age in years [Range or mean Ranged from 20 and 90 years old Living conditions Not identified Marital status: Not identified Time since stroke:	**The intervention**: 2 sets of video narratives (in English and Malay language) presented face to face + hospital standard care (such as speech therapy, rehabilitation, medication, and nutritional consultation ,appointment with neurologists and outpatient appointment ,self-monitoring check and information on stroke treatment and medication) Content: Hospital standard care +motivational video narratives of a stroke patient experience in successfully managing the illness and a neurologist perspective on the illness and treatment integrated with behavioral construct of health believe mode to promote stroke survivors' self-efficacy related to medication understanding.	Data collection: Sociodemographic data was collected at baseline Outcomes were administered at baseline(T0), at 6 months (T2) and at 12 months (T4) Quantitative measures: (1) The primary outcomes to detect change in participant's self-efficacy perception in understanding and taking medications measure by MUSE . (2) To evaluate participant's knowledge of stroke and associated treatment measured by the Stroke Knowledge Test (SKT) (3) To assess patient's perception of their illness and belief towards their medications measured by Brief Illness Perception Questionnaire

	Adult aged 18 and over, diagnosed with their first stroke within 6 months of the recruitment phase. Post stroke patients who prescribed antihypertension and antithrombotic medication, had satisfactory level of literacy, and could comprehend English and Malay languages. Post stroke patients with depression symptoms and cognitive impairment were excluded.	Not identified Type/location of stroke More than 90% of participants had ischemic stroke. Employment : More than 50% of participants were un-employed Approximately half of participants exposed to co-morbidity/severity of stroke, hypertension, 60% had diabetes and several had may stroke risk factors and more than 80% were prescribed al least 3 types of stroke preventative medications	The video included motivational and short culturally appropriate messages and quotes that emphasized on self-efficacy in particular self-managing medications and increased awareness of stroke risk factors. Development rational: Based on the idea that self-efficacy is the essential factor that influence positive health behaviors and proactivity. Self-efficacy has been integrated in several educational interventions, however, the interventions had mixed findings due to heterogeneity of the population and methodology. Additionally, due to the lack of emotional and cultural elements.	(BIPQ) and Brief about Medicine Questionnaire (BMQ). Data analysis: IBM SPSS

		Recruitment: selected randomly from outpatient neurology clinic at HKL **County:** Malaysia	On the other hand, narrative stories might offer an effective mechanism in influencing viewers as they actively absorbed with the stories or information presented. Moreover, behavioral modification studies showed that people engage and focus more effectively via visual and hearing stimulus Based on these evidences, the researcher team aimed at investigating the effectiveness of motivational video narratives, integrated with behavioral construct of the health belief model on self-efficacy of medication understanding and use among post stroke patients. .	

			Setting: at Hospital Kuala Lumpur, Malaysia (HKL) Provider: A stroke patient and a neurologist Length:	

			The intervention was offered at baseline (T0), at 3 months (T1) and at 6 months (T2) Cost to participants: The one of the most common causes of declining to participate in the study was fear of increasing stress Tailoring: Not identified Modification: Culturally appropriate messages Provided in both English and Malay langue to mee the need of participants The transcripts were initially written in English and then translated to Malay language. A	

			linguistic expert validated the content of the translated transcript. Additionally, doctors, educational experts, pharmacists and stroke survivors reviewed and edited the transcript and videos several times Fidelity assessed: Validation of the intervention procedures and the content of the video narrative intervention had been assessed in previous study (Appalasamy JR et al., 2019)	

Appendix 6- The Completed 13- item modified COREQ framework (Soundy et al .,(2016) adapted from the 32-item COREQ framework (Tong et al., 2007)

The Completed 13- item modified COREQ framework (Soundy et al .,(2016) adapted from the 32-item COREQ framework (Tong et al., 2007)							
Domain 1: Research team and reflexivity		Hancock (2009)	Morris & Morrisn(2012)	Kirkevold1 et al. (2014)	Kessler et al. (2014)	Clark et al. (2018)	Christensen et al.(2019)
Personal Characteristics	Scoring						
1	Interviewer/facilitator Which author/s conducted the interview or focus group?	If they have identified the individual give a point, if they haven't give 0, if you unclear type U. 0 U Unclear who did the interview	0 U Unclear who did the inte5rview	1 "Members of the research team, who had not delivered the intervention and whom the participants did not know, interviewed the participants without language problems, allowing them to more openly voice criticism and concerns regarding the	0 Unclear who did the interview	1 clear who did the interviews	1 clear who did the interviews

					intervention. For participants with aphasia, the same person conducted both the intervention and the interviews" Page 5 of 12			
2	Experience and training. What experience or training did the researcher have?	Where experience is clearly detailed or a detailed reference to training OR experience is made a point is given. IF unclear or absent give zero.	0 no details of experience or training given	0 no details of experience or training given	1 With regard to the research team, all researchers conducting this study had a nursing background, were women and were trained as qualitative researchers within nursing science. . They had different	0 no details of experience or training given	1 details of experienc e or training given	0 no details of experience or training given

			clinical experiences. Three of the researchers had conducted previous qualitative studies of experiences following a stroke, one specifically focusing on persons with aphasia” Page 6 of 12			
Relationship with participants						

3	Relationship established, Was a relationship established prior to study commencement?	Give a point if details of how the researcher or person who undertook qualitative data collection met individuals, identified any previous relationship. Where this is unclear type U. Where this information is absent type 0.	0 Not mentioned	0 Not mentioned	1 Local recruiters in the hospital or home care service approached potential participants; the recruiters judged whether the patients met the inclusion criteria" Page 5 of 12 "Participants provided written, informed consent to a person outside the research group before being included **"page 6 of 12**	0 U Unclear	1 details of how the researcher or person who undertook qualitative data collection met individuals were given	0 Not mentioned

			Members of the research team, who had not delivered the intervention and whom the participants did not know, interviewed the participants without language problems, allowing them to more openly voice criticism and concerns regarding the intervention". "criticism and concerns regarding the intervention. For participants with aphasia, the same person conducted both the intervention and the interviews			

			Their substantial communication difficulties required continuity in the relationship and familiarity with the intervention process to elicit the participants' experiences and thought" . page 5- of 12			

4	Participant knowledge of the interviewer. What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	A point is scored where information about what the participants knew about the research they were being invited to participate in was mentioned. This includes sending background information and study information sheets. Score zero where this information is absent and U where this	1 "Participants were provided information about the research project through their peer support groups (in meetings or through newsletters) and all participants volunteered their time"(page No.4)	0 Not mentioned	1 "Local recruiters in the hospital or home care service approached potential participants; the recruiters judged whether the patients met the inclusion criteria, provided written and oral information about the study and collected informed consent" page 5 of 12	1 " all the peer supporters and coordinators who were involved in the peer support program and health who worked on the hospital unite where program Offred were informed about the project by the researcher during a scheduled	0 Not mentioned	1 "The group leaders told regular participants when a focus group would be happening as part of their meeting and those who were interested attended. Participation was voluntary, and survivors and caregivers were not required to attend together. Written consent was obtained from all participants after explaining the

information is unclear				meeting and invited to contact the researcher if they were interested in participating “ Page 3 of 9 “all new stroke survivors and their care partner (when present) who received visit as part of peer support program		purpose of the study” page 3

				between February and October 2012 were invited to participate in the study by a peer support during the visit if the professional judged that they met the inclusion criteria” Page 2 of 9		

			0 Not mentioned	0 Not mentioned	1 “All authors are nurses with a clinical interest in stroke rehabilitation” Page 11 of 12 “The authors declare that they have no competing interests” Page 11 of 12	1 “ this study was carried out at the request of the agency providing this service. While member of the research team do not have any direct affiliation with SSAO, 2 have worked with the agency on previous evaluation projects and therefore	1 information about the characteristics of the interviewer, their bias, **interests** or reasons for participating in research are identified “All the semi-structured interviews [35] were conducted by EC	0 Not mentioned
5	Interviewer characteristics. What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Score a point where information about the characteristics of the interviewer, their bias, interests or reasons for participating in research are identified. Score zero where this information is absent. Score u where this information is unclear.						

				do have relationships with the agency and some of its employees. While the research team made a conscious effort to conduct the analyses and present the finding an objective manner, the find may be biased towards more positive outcomes as result of this relationshi	who is a PhD student working within the context of stroke self-management" page 570 "EC is the Trial Manager of this study" Page 575	

				ps" page 8 of 9		
Total Score for Domain 1.	1/5	0/5	5/5	2/5	4/5	2/5
Domain 2: study design						
Theoretical framework						

6	Methodological orientation and theory. What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology	Score a point where the paradigm and methodology are given. Score zero where both aspects are missing. Score U where this information is unclear.	0 Mot mentioned	1 “Seven open-ended questions and an additional 21 Likert-type items taken from the Therapeutic Factors Inventory (TFI [29]) were presented by semi-structured interview (recipients), or questionnaire (peer supporters). The transcripts of recipients and peer supporters were analysed separately, **using inductive thematic analysis** [30], to identify	1 paradigm and methodology are given	1 Methodology was given	1 the paradigm and methodology are given	1 methodology are given.

		superordinate and subthemes encompassing aspects of the participants' experience. The Likert items were analysed descriptively to establish "consensus" by identifying items that most participants rated in the same way. This was performed across all participants since numbers were small. The relationship between the content of these items and the themes emerging from the thematic analysis was then examined qualitatively to determine if the				

				items could be assimilated into the themes. Any such items were reported with the relevant theme" (page no 348)				
7	Non-participation. How many people refused to participate or dropped out? Reasons?	Score a point where the number and the reason or attempts to identify the reason are given (e.g., a point is score if they	0 numbers are not identified with reasons	0 Clear number without reasons	1 Clear numbers are identified with reasons	1 Clear numbers are identified with reasons	1 number and the reason or attempts to identify the reason are given	0 numbers are not identified with reasons

		say participants would not give a reason for non-participation). Score zero where this information is absent and score u where this information is unclear.						
Data collection								
8	Interview guide. Were questions, prompts, guides provided by the authors? Was it pilot tested?	Score a point where testing of the interview script is identified either as a pilot or as a way to determine the content	1 reference to development of the interviews was made. "The framework of the study and the interview questions were informed by stroke research as well as literature concerning	1 "semi-structured interviews with seven open-ended questions: e.g. "Is there anything at all you would have liked to have been different about the groups?"; "How	1 testing of the interview script is identified	1 consideration to the derivation of questions have come from.	1 piloting of the interview script consideration to the derivation of questions have	1 consideration to the derivation of questions have come from

	and accuracy of items used. **Score a point where consideration to the derivation of questions have come from**.	social and peer support”(page no,3)	has your life changed by participating in the groups, if at all?”; “Is there anything you learned in the groups that you are now using?”. Recipients were encouraged to expand on their answers, and this format provided focus whilst allowing individuals to provide detailed, individualised information [31]. There were also 21 Likert-type items taken from the TFI [29] . Page 349 Seven open-ended questions and an additional 21 Likert-type items taken from the Therapeutic Factors			come from	

			Inventory (TFI [29 Page348				
9	Field notes - Were field notes or reflective diary made during and/or after the interview or focus group? Score a point where field notes are identified. Score zero where field notes are not identified. Score U where this information is unclear.	0.No mention of field notes.	0.No mention of field notes.	0 No reflective diary of field note identified during or after the interviews	1 "six interview transcripts and dairies were read by the primary investigator and research assistant". "data collection took place	0.No mention of field notes	0.No mention of field notes.

				over 10 months. A total of 27 acute care visits diaries (5 peer supporter, 2 volunteer program coordinators) were collected. As well, post discharge telephone contact diary record were obtained for 28 stroke survivors Page 4 of 9		

10	Data saturation. Was data saturation discussed?	Score a point where saturation of data is considered. Score a point where another form of sample size reference is made. Score U where this information is unclear.	0.No mention of sample size	0.No mention of sample size	0.No mention of sample size	1 Saturation is considered	1 data saturation mentioned	0.No mention of sample size
Total for Domain 2			1/5	2/5	3/5	5/5	4/5	2/5
Domain 3: analysis and findings								
Data analysis								

11	Description of the coding tree. Did authors provide a description of the coding tree?	Score a point if an audit trail is given. **Score a point if a coding tree is mentioned** or score a point if another technique is mentioned that provides a way to structure the information gained.	0 No detail given	1 Audit trail is given "Several of the transcripts were read by a second member of the research team. This enabled the themes to be discussed, verified and modified and provided an assessment of the validity of the themes [31]. Two themes were merged and another re-labelled as a result of this process"	1 Coding tree mentioned	1 "Document of each stage of analysis were kept to create an adult trail." "analytic grid that used to organise information critical to the research objective". Page 4 of 9	1 coding tree is mentioned	0 No detail given

				Page 349 &Page 350 Coding tree mentioned		coding scheme used		
12	Derivation of themes Were themes identified in advance or derived from the data?	Score a point if data driven or theory driven coding is identified or if it is clear how analysis was determined.	0 Framework not mentioned	1 Framework mentioned	1 Theme driven from data	1 MacPherson and McKie's recommendation for the use of quantitative data in program evaluation were followed "page 4 of 9	1 Framework mentioned	1.Framework mentioned.

Reporting							
13	Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Score a point if there is sub-detail for each major theme. Score no points where this information is absent or u if this information is unclear.	0 Subthemes not given	1 Subthemes given	1.Subthemes given	1 There is sub-details of each major theme	1 Subthemes given in details	0 Subtheme did not given
Total for domain 3			0/3	3/3	3/3	3/3	3/3	1/3
Grand total			2/13	5/13	11/13	10/13	11/13	5/13

Appendix 7- Assessment of the overall risk of bias for quantitative studies (Higgins & Green, 2008)

Assessment of the overall risk of bias for quantitative studies (Higgins & Green, 2008)									
Trial* **and type**	Components of risk of bias/key risk criteria						Summary within trial	Comments on high risk components	Classes of evidence(Burns et al., 2012
	1	2	3	4	5	6			

Gurr (2009) **Mixed methodology, including qualitative themes**	H	H	H	H	L	H	H=5 L=1 U=0	Selection bias No identification of random sequence generation or allocation concealment. Detection/performance bias No blinding of assessors indicated Attrition bias No attempt to follow up on participants and no data on participants who dropped out in the analysis. No intention-to-treat analysis mentioned Other bias No protocol; no sample size identified; unsatisfactory response rate; questionable appropriateness of outcome measure	Level of evidence: IV Risk of bias: High Design classification Case series Criteria High risk because of (a) violation of random sequence generation or allocation concealment; (b) violation of blind or independent assessment; (c) failure to follow up and absence of intention-to-treat analysis

Muller et al. **(2014)** **Pre and post study, with no control group**	H	H	H	H	L	H	L=1 H=5 U=0	Selection bias No identification of random sequence generation or allocation concealment. Attrition bias No follow-up of participants who discontinued group Detection/performance bias No blinding of assessors indicated Other bias No protocol mentioned and sample size not considered	Level of evidence: IV Risk of bias: High Design classification: Case series Criteria High risk because of (a) violation of random sequence generation or allocation concealment; (b) violation of blind or independent assessment; (c) failure to follow up

Corsten et al. **(2014)** **Mixed methods**	H	H	H	H	L	H	H=5 L=1 U=0	**Selection bias:** No identification for sequence generation , or that is was randomised. no allocation concealment identified **Detection/Performance bias:** all quantitative assessments were carried out by a researcher who did not carried out the intervention, however, was not blind to purposes of the assessments. The assessments were self-administered to minimise the influence of the assessor **Attrition bias**: they gave the number of people who dropped out, but reasons were not provided and there was no discussion how this would impact on analysis and result	Level of Evidence: IV Risk of bias: High risk Design classification : case series Criteria : High risk because the following: (a)violation of random sequence generation or allocation concealment;(b) violation of blind or independent assessment;(c) failed to follow up and no intention to treat analysis conducted

								Other bias: : No protocol mentioned, and sample size not considered	

Corsten et al. **(2015)** **Mixed methods**	H	H	H	H	L	H	H=5 L=1 U=0	**Selection bias**: No identification for sequence generation no identification, or that is was randomised. Or no allocation concealment identified **Detection/Performance bias:** all quantitative assessments were carried out by a researcher who did not carried out the intervention, however, was not blind to purposes of the assessments . The Qualitative data was collected by speech therapists who were " neural interviewers(no blinding of assessors mentioned) **Attrition bias** they gave a number of people who dropped out, but reasons were not provided and there was no discussion how this would impact on analysis and result	Level of Evidence: IV Risk of bias: High risk Design classification: case series Criteria : High risk because the following: (a)violation of random sequence generation or allocation concealment;(b) violation of blind or independent assessment;(c) failed to follow up and no intention to treat analysis **conducted**

								Other bias: No protocol mentioned, and sample size not considered	
Chow (2018) **RCT**	L	H	L	H	L	H	H=3 L=3 U=0	Selection bias No identification of allocation concealment Attrition bias Number who dropped out stated, but no reasons provided and no discussion of how this would impact on analysis and results. Other bias Sample size not justified and no protocol.	Level of evidence: II Risk of bias: moderately low Design classification: moderate quality RCT Criteria: Moderate because of (a) violation of allocation concealment; (b) co-interventions applied equally through randomisation; (c) follow-up rate

Masterson-Algar et al. (2020) **Mixed methodology**	H	H	H	L	L	L	H=3 L=3 U=O	Selection bias No identification of random sequence generation or allocation concealment. Detection/performance bias No blinding of assessors indicated Other bias No protocol; however, sample size was considered	Level of evidence: III Risk of bias Moderately high Design classification: Moderate cohort study Criteria Moderate, because of (a) violation of random sequence generation or allocation concealment; (b) violation of blind or independent assessment.

Appalasamy, Joseph, et al. (2020) **Mixed methods research**	L	L	H	L	L	L	H=1 L5	Detection/Performance bias: blind **or** independent assessment for important outcome was not ensured	Level of Evidence: II Criteria : Moderately low risk Design classification: Moderate quality RCT because the following: (a)violation of Blind or independent assessment for important outcomes

Appalasamy, Quek, et al. (2020) **Single blind RCT**	L	L	U	L	L	L	L=5 U=1	Detection/Performance bias: Unclear if blind **or** independent assessment for important outcome was ensured	Level of Evidence: II Criteria : Moderately low risk Design classification: Moderate quality RCT because the following: (a)violation of Blind or independent assessment for important outcomes

Trial* donated by first author.Risk of bias criteria: 1, Selection bias=random sequence generation; 2, selection bias=allocation concealment; 3, Detection/performance bias= blinding of personnel, assessors and participants; 4, Attrition bias=incomplete outcome data; 5, Reporting bias=short-term selective outcome reporting; 6, Other bias=potential threats to validity, e.g. consideration of protocol.

Level of risk of bias: H, high risk of bias ;U, unclear risk of bias ; L,Low risk of bias

Appendix 8 -synthesis stage 1 presenting examples of the qualitative tubulation

Study	Result	Comment by RA
Kessler et al., (2014)	Type of support provided (source of data from all categories) Data collected from the diaries and interviews with the new stroke survivors and peer supporters identified that emotional support was provided during the initial in- hospital visit in the form of hope, encouragement, and re- assurance. Emotional and affirmational support occurred through taking time to listen, sharing of stories and validation of feelings. I honestly didn't want them to leave because I just wanted to continue talking to someone who actually had gone through what I went through. (New Stroke Survivor-Sylvie, initial interview) Informational support was also offered during the initial and telephone visits. Peer supporters provided written as well as verbal information on resources in the community including those offered by SSAO. During the initial visit this information tended to be more general in nature. However, during follow-up telephone calls, information was targeted to the new stroke survivor's or care partner's needs and included information on specific services	1-Emotional support during the **initial on-site visit by the peer supporters** (outcomes for stroke survivors) in from of hope, encouragement and reassurance 2- Affirmation support (Outcomes) during the initial onsite visit by peer supporter Mechanism of psychosocial benefit; (a) taking time to listen and sharing stories, (b) validation of feeling.

	avail- able in the community. Information to assist with both finding and accessing services was provided to six out of the 28 people for whom follow-up diaries were kept. Benefits of peer support for the stroke survivors and their care partners (source of data from all categories) All groups identified benefits for the new stroke survivors and their care partners. The emotional support provided was seen as beneficial at a time when stroke survivors and care partners were feeling overwhelmed by the unknown. The visit from the peer supporters encouraged and motivated the stroke survivors to work towards recovery. After having someone who had gone through a similar experience take time, listen, share experiences, and make a connection, stroke survivors reported feeling validated and less alone. Information received from a peer regarding the experience of living with stroke was generally given more value than that received from a healthcare professional. And they [peer supporters] provided sort of reassurance... and provided a real face. When you're dealing with doctors and nurses they're great.... But they're medical people and they can talk to you about what you've just gone	- Informational support (Outcome s for stroke survivor's s) **during the initial on-site visit and follow up telephone calls**. Form and type of information provided by peer supporter. Form: provided written as well as verbal . Types a) Initially during the on-site visits the type of information was general, b)during the follow up was targeted to meet the needs of new stroke survivors and their carers (outcomes for stroke survivor's and care partner) information included finding and accessing specific service available in the community.

	through, but the chances are more than likely that they haven't... The people in Stroke Survivors, well they have. (New Stroke Survivor-Mike, initial interview) Peer supporters were also seen as a source of inspiration by some stroke survivors who expressed an interest in pursuing a peer supporter role in the future. Care partners also benefitted from the emotional support. They reported feelings of reassurance and decreased isolation particularly from the follow-up phone calls. It reassures me, you know, they ask "How is [name of partner]? Can we do anything for you?" This is very important. (Care Partner-Liz, 6 month interview) A few care partners reported that they had read the in- formation kit and found it helpful. But it's nice to have all those resources [in the SSAO information kit] that you can contact because you're overwhelmed sort of, the person is really ill and you're wondering what they are going to need. (Care Partner-Sue, initial interview) Harms of peer support for the stroke survivors and their care partners (source of data form	visit from the peer supporters encouraged and motivated to work towards recovery (psychological positive outcome for new stroke survivors) **Mechanism of psychosocial benefit** 1- relatedness, 2-taking time tom listen 3- sharing experiences 4 connection, 4- feeling validating 5- belonging (' less alone) Informational support from peer about living with stroke was more value than that provide by health professionals.

	new stroke pt,care partner, health professional, program coordinator_) No specific harms of the visits were identified by the new stroke survivors. However, potential harms were identified by one care partner, one health professional and one coordinator. The care partner felt that her partner was not ready to receive this type of visit because his condition had not stabilized enough for the message of hope to be perceived as realistic. Yeah I thought it was maybe a little bit premature. .. He wasn't sleeping well, he wasn't medically stable... he wasn't really ready for someone to tell him everything was going to be all right because it wasn't all right. (Care Partner-Joanne, initial interview) It is interesting to note that the new stroke survivor in this situation did not voice such concerns. The health professional raised concern about potential harms when patients with mild stroke were visited by peer supporters with more obvious physical disabilities. This health professional and one of the coordinators re-ported receiving feedback from a few new stroke survivors that being visited by someone with a significant visible disability (such as	**Mechanism of this** might be Mechanism might be relatedness and reassurance. Considered as source of inspiration by some stroke survivors (positive outcome for new stroke survivors) and created interest to taking new role in the future. emotional support in particular **during the follow up calls** (positive outcome for care partner)as the feel reassurance and decrease isolation.

	someone using a wheelchair) was up- setting. The Program Coordinator reported that she had received calls to SSAO expressing this concern. Two calls. .. from people that we visited on the acute care floor [informed us] that they did not appreciate a person in a wheelchair coming in for the visit,. ..And to have somebody come in in a wheelchair could make them feel as if they're not going to be able to walk again. (Coordinator-Carol) New stroke survivors and healthcare professionals also expressed concern about the number of peer visitors present during a visit. When there is a new peer sup- porter being trained the number of peer supporters may increase from two to three. Feedback indicated that one- on-one interactions were preferable, having two peer supporters visit was acceptable, but any more could be overwhelming for the stroke survivor. Impact of peer role on the peer supporter (peer/ program coordinator) All peer supporters and coordinators indicated that offering support to fellow stroke survivors was beneficial to the peer supporter. While concern was expressed by program coordinators about the potential emotional im-	**Mechanism** for care partner by offering help. Few care partners found information kit helpful . **Mechanism** : convenience/ available resource to contact when you feel overwhelmed and uncertain about the need of ill relative.

	pact on peer supporters for whom the visit may trigger past feelings related to the initial experience of stroke, none of the peer supporters interviewed described experiencing these types of feelings. A few peer supporters reported concern about their ability to do a good job and be understood, particularly with new stroke survivors who had more severe impairments or significant aphasia. I'm not always comfortable going into a room maybe if somebody has really severe disability, and if they can't talk or they're really upset or... I don't know what else to say. (Peer Supporter-Charles) Some people you go and see, they're so deeply depressed, and some of them that has aphasia that can't speak to you, it makes me feel real sad. (Peer Supporter-Steve) Another concern expressed by one peer supporter was the feeling that since he had no visible disability, he may lack credibility among new stroke survivors who did not believe that he had experienced a stroke. Another, more frequent concern expressed by peer supporters was their ability to remember procedures and routines. Due to the fact that peer supporters may only be scheduled once per month, some peer supporters re- ported	No negative outcome of the visit of peer supporters on newly diagnosed patient No specific harms of the visits were identified by the new stroke survivors. One car partner, one health professional and one coordinator identified potential harm of the visit of the peer supporters **WHY** one care partner felt **a)** the patient was NOT ready (too early) to receive this type of visit (the initial one site visit) and message of hope due unstable condition of the new stroke pt. **b)** Unrealistic

	feeling “bothered” about their ability to remember required details. For me like six weeks is like forever and I just forget the whole, I forget all my training. .. Not all my training but important parts. (Peer Supporter-Charles) Peer supporters who used the local adapted transportation service had the additional frustration of sometimes arriving late and missing the visits. Personal benefits noted by peer supporters included increased social connections, personal growth, enjoyment and the feeling that they had been able to make a difference in the lives of others. Following the weekly visits, the Page 6 of 9 peer supporters would go for coffee which provided an opportunity for social interaction, support, and peer mentoring. Several peer supporters reported that while the visits posed challenges mentioned above, they were able to push themselves, and build coping skills and confidence, all of which contributed to their personal growth. Positive feedback received from new stroke survivors reinforced a sense of purpose - a sense that they had contributed.	However, new stroke survivor in this situation did not voice such concerns. One health professional and one coordinator raise a concern by a few stroke patients with mild or less disability when visited by peer supports with more severe obvious disabilities (e.g. wheelchairs users). Negative outcome for stroke patients (2 calls for complain)= Upsetting regarding on site visit

	Perceived processes required to offer such a program (challenges all categories) The processes involved in setting up the peer support program involved close collaboration with the healthcare team to negotiate the referral process, the type of information to be provided to stroke survivors by the peer supporters, and duration of visits. Processes were put in place to ensure that privacy and confidentiality of patient information were protected, and that safety concerns for peer visitors were addressed. An important facilitator for the peer supporters was that parking costs were covered by the hospital. Commitment on the part of healthcare professionals who were willing to take the time to complete the referrals despite busy caseloads was a **key** program component. These professionals also provided important on- going collaboration to address program challenges and improve service to stroke survivors. While data was being collected both the referring professionals and the program coordinators expressed an interest in developing feedback mechanisms following initial visits. Two important goals for these mechanisms were to ensure that all eligible	Why because the give them a negative message and an anticipation about the future. New stroke patients and health professionals reported that too many peer supporters on one visit at the acute site was not preferable – individual one to one is preferable. 2 peer supporters were acceptable on one visit and more than 2 was overwhelming.

	patients were seen, and to ensure health professionals were aware of any issues brought up during the visits that they could help address. The recruitment, training and orientation of the peer supporters were also identified as critical to program success. Training provided coordinators with a method of ensuring all peer supporters were aware of the pro- gram mandate and procedures. The peer supporters also noted that the training provided them with an opportunity to develop communication skills and start building confidence in their new roles. At first it was new ... I didn't know if I was going to be able to do it [volunteer role], to feel like I could contribute and then I learned that yes I could, that it was good, and that gave me the courage I needed to keep on [volunteering]. (Peer Supporter-Michelle) Common preferred characteristics of peer supporters were identified by all categories of participants. These were being authentic, friendly, confident, a good listener, knowledgeable regarding resources and programs and respectful of the stroke survivor. As noted earlier, visibility of the peer supporter's disability had a negative	positive impact of the role of peer on **All** peer supporters and coordinators and they reported that offering support was beneficial to them. Program coordinators (not being expressed by stroke peer supporters themselves) potential emotional harm on peers **WHY** trigger experience relate to their initial stage of condition. **A few** peer supporters raised concern about the ability to do good job as peer and being understood. **Why** less comfortable and did not known what to do especially when new stroke patient is severely disabled, unable to communicate and deeply depressed ,the peer supporters felt sad.

	impact on some stroke survivors but promoted the feel-ng of shared experience for others. The support offered via telephone calls post discharge from hospital was felt by program coordinators and peers supporters to be an important resource for stroke survivors. However, these follow-up calls posed many challenges. Primary among these was the ability to reach people once they left hospital. Although the coordinators reported reaching 82% of the stroke survivors whom they visited in hospital, they felt that the people they could not contact may have been those most in need of support. Additionally, while it was originally hoped that the peer supporter who visited the stroke survivor in hospital would complete the follow-up call, many of the peer supporters did not feel that they had the knowledge and skills to identify and provide the needed support once stroke survivors left the hospital. As well, the organizational skills required to track calls until each in- dividual was reached were a challenge for peer sup- porters with cognitive deficits. Peer supporters noted that organizing call-backs took a lot of effort and that it was difficult to stay on top of information regarding available services. Coordinators noted the need to re- mind peer supporters to make calls. For this reason, the	**one peer supporter** expressed concern (negative) felt lack of credibility **Why** not having visible disability and new stroke patients might think he or she did have stroke. **more frequent** concern expressed by peer supporters their ability to remember, and feeing bothered to remember details procedure and routine .**Why** only scheduled once a month to dot the onsite visits.

	majority of telephone follow-up visits were completed by the Program Coordinator	
		frustration by peer supports who used the adapted transportation **Why** as they sometimes arrived late and missing the visits.
		Several personal benefits of the weekly on site vists reported by peer supporters including; **1)** increase social connection and interaction, 2**)** increase personal growth **3)** feel of enjoyment **4)** feeling of usefulness 5) peer mentoring

		Several peer supporters while the visits posed challenges, however, **1)** they were able to motivate themselves **2)** build coping skills **3)** build confidence **4)** increase personal growth **5**) positive feedback form the new stroke patients led to reinforce sense of purpose **6)** sense of contribution. **<u>The process of setting up</u>** the peer programs required the following :**1)** close collaboration with the health care professional at the acute setting to negotiate the referral process **2)** type of information to be provided by the peer supporters **3)** duration of the onsite visit **4)** process to ensure the privacy and confidentiality of the patient's information **5)** process to ensure the safety of the per supporters.

		Facilitator of the peer program ;**1)** peer supporters parking cost covered by hospital, **2)** commitment of health care professional despite of their busy load to complete the referral, **3**) health professional also provide ongoing collaboration to address program challenges and improve service to new stroke. referral health professionals and coordinators initiated the follow up calls to **Why** 1) to ensure all the eligible new patients were seen **,2)** to know the feedback of

		on site visit and if there were issues occurred during the visit they could help to address. **4)** training and orientation of the peer support was a critical to program success. WHY help peer to be aware of program mandate and procedures and provide the peer supporters with chance to develop communication skills and building confidence in new role.

		Common preferred characteristics of peer supporters **1)** friendly,**2)** authentic,**3)** knowledgeable of resources and program ,**4)** good listener 5) confident **Hinder: 1)** having no visible disability **6)** peer supporters and coordinators felt that the support offered to new stroke patients by the follow up calls were useful source.

		Hinder:2) peer supporters and coordinators felt that it was challenging to do the follow up calls because people could not reach after being discharged from hospital, although 85% was reached during the follow up it was hoped that all the peer supporters who did the initial visit on site would do the follow up calls however, they was not the cause because **many** felt that they ,**4)** did not have the knowledge and skills to identify and provide support to new patients when the left hospital ,**5)** they did not have the organisation skills to track calls until the each patient reached especially with peer supporters with cognitive disability and it was time consuming and required a lot of effort **,6)** difficulty to be on the top regarding available resources in the community and 7) coordinator noted they need to remind peer to make calls, therefore they majority of the phone calls conducted by coordinator, however when finical stopped, peer need to made the calls

Appendix 9-Synthesis stage 2 an example of the descriptive analysis undertake

Study	Result	Comment by R.A
Chow (2018)	■ Preliminary analyses The demographic information and clinical characteristics of sample participants at baseline shown in **Table 1** reveals that, of the *N*=192 original participants, 33 (17.19%) dropped out throughout the data collection time. More than half the participants in the intervention group (61.46%) and the TAU group (62.50%) were male. The mean age of the stroke survivors in the intervention and TAU groups were *M*=72.49 (*SD*: 7.27) and *M*=72.84 (*SD*: 7.82) respectively. The majority of participants suffered an ischaemic stroke (intervention: 83.72%, TAU: 81.82%). Initial MMSE scores were similar in the two groups (intervention: 26.11%; TAU: 26.24%). No other significant differences between the intervention and the TAU group were found for all clinical characteristics and selected demographic information. All selected outcome variables at baseline showed no significant differences between intervention and TAU groups **(Table 2)**; thus both groups were deemed comparable at baseline. ■ Analyses of intervention and control groups	

	Repeated measures ANOVAs were conducted to compare the patterns of outcome change over time between the two groups. These results are presented in **Table 3**. In the intervention group, significant time effects were demonstrated across all 7 outcome measures. However, for the control group, a significant time effect was only found in the meaning in life (*F* (3, 246)=3.28, *p*=0.02), hope (*F* (3, 237)=3.15, *p*=0.03), self-esteem (*F* (3, 243)= 2.70, *p*=0.49) and stroke knowledge (*F* (3, 234) = 43.35, *p*<0.001). The noted change patterns over time were further investigated in their mean plots, which suggested that the patterns of change over time in the outcome measures across the intervention and the TAU groups were statistically different. Further, many of these positive effects were sustained at 4 months post intervention, in the intervention. Pairwise comparisons revealed that hope, meaning in life, self-esteem and stroke knowledge had significant changes between T0 and T1, T0 and T2, and T0 and T3 **(Table 3)**. To further delineate intervention effectiveness, regression of change between (1) T1 and T0, (2) T2 and T0, (3) T3 and T0 were conducted. These analyses are displayed in **Table 4** and indicate there is a delineated pattern: NT shows a higher improvement in most outcome scores over the conventional psycho-education intervention. Results further indicate that the	Stroke survivors in the intervention showed significant improvements in many psychological outcomes including **meaning of life**, **mastery,** self **-esteem, hope**, and **life satisfaction a**fter participating in the narrative group sessions. Furthermore, most of the positive outcomes in the intervention group sustained up to 4 months post intervention. Stroke survivors in the group did not show similar improvement across most of the outcome measures. Improvement of self-esteem was only significant between interim and baseline in the intervention group *R*2=0.02, *F* (1, 179)=3.60, *p*=0.06 Negative mean differences were noted in the stroke knowledge outcome although insignificant between the intervention group and the control group. This could be

	intervention group significantly improved **in mastery *(R2=0.04, F (1, 174) = 7.12, p = .05), hope*** *(R2*=0.04, *F* (1, 176)=7.24, *p* = .05), meaning of life (*R2*=0.04, *F* (1, 172)=7.04, *p*=0.01) and life satisfaction *(R2*=0.04, *F* (1, 178)=6.72, *p*= .05), at post intervention versus baseline. Improvement of self-esteem was marginally significant between interim and baseline in the intervention group *R2*=0.02, *F* (1, 179)=3.60, *p*=0.06. Regarding stroke knowledge, a negative mean difference though insignificant seemed to be understandable, suggesting the relative effects of NT and the psycho-education group are similar. We posit that the reason is the delivery of psycho-education mainly provides information about stroke during the rehabilitation process. Finally, the results of these analyses support the contention that NT is beneficial in reconnecting the persons' sense of mastery, enhancing self- esteem, and reconstructing meaning of life with hope in one's life, (i.e., ascribing more positive meaning to a critical life event) while having other positive influences on their depression and satisfaction of life Table 2: Means, Standard Deviations and Baseline Differences between Groups of Outcome Variables Over Time (*N*=192).	explained by the control group received psychoeducation intervention which focused on providing informational support related to stroke and recovery form stroke NT group: (T0), M(SD)=3.26(2.15), (T1)=5.05(1.88), (T2)=5.49(2.09), (T3)=5.54(2.17); ontrol group: (T0)= 3.46(2.41), (T1)=5.45(1.90), (T2)=5.76(1.93), (T3)=5.86(2.17) insignificant increase in depression was found form baseline to one month (estimated effect size 0.05). However, a significant reduction at 2 months (estimated effect size 2.24) and four months (estimated effect size 2.04).

Variable Tested	T_0	T_1	T_2	T_3	Baseline Difference Between Groups
Intervention Group	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*t*-test
Hope	6.13 (1.23)	6.62 (1.35)	6.89 (1.28)	6.75(1.58)	*t*(189) = -1.14, *p* = .25
Meaning in Life	3.47 (.65)	3.77 (.62)	3.93 (.59)	4.33 (.71)	*t*(189) = -1.73, *p* = .86
Mastery	3.39 (.85)	3.60 (.77)	3.88 (.86)	3.85 (.77)	*t*(188) = -1.18, *p* = .24
Self-Esteem	2.60 (.44)	2.85 (.44)	2.99 (.32)	2.94 (.48)	*t*(189) = -1.57, *p* = .12
Depression	.32 (.25)	.33 (.27)	-.25 (.26)	-.20(.26)	*t*(190) = 1.44, *p* = .15
Life Satisfaction	.71 (.19)	.78 (.17)	.88 (.15)	.84 (23)	*t*(190) = -.62, *p* = .54

	Stroke Knowledge	3.26 (2.15)	5.05 (1.88)	5.49 (2.09)	5.54 (2.17)	$t(189) = -.89$, $p = .38$	
	TAU Group						
	Hope	6.35 (1.39)	6.52 (1.34)	6.66 (1.44)	6.52 (1.30)		
	Meaning in Life	3.62 (.68)	3.68 (.55)	3.76 (.62)	3.64 (.89)		
	Mastery	3.51(.78)	3.56 (.85)	3.68 (.88)	3.70 (.90)		
	Self-Esteem	2.72 (.45)	2.77 (.36)	2.82 (.44)	2.80 (.41)		
	Depression	.27 (.24)	.27 (.24)	.-26 (.24)	.26(.25)		
	Life Satisfaction	.73 (.16)	.74 (.15)	.75 (.16)	.73 (.18)		
	Stroke Knowledge	3.46 (2.41)	5.45 (1.90)	5.76 (1.93)	5.86 (2.17)		

Table 3: Comparisons of Outcome Measures in Intervention & Control Groups across T0 to T3 (N=192).

Selected Measures Tested	Time effects	Pairwise Comparisons		
		T_0-T_1	T_0-T_2	T_0-T_3
Hope				
Intervention	F (3, 219) = 7.94, p < .001***	p = .01**	p <.001***	p =.04*
TAU	F (3, 237) = 3.15, p = .03*	ns	p =.06	ns
Meaning in Life				
Intervention	F (3, 219) = 12.86, p < .001***	p <.001***	p <.001***	p <.001***
TAU	F (3, 246) = 3.28, p = .02*	P = .07	ns	ns
Mastery				

	Intervention	F (3, 210) = 4.38, p < .001***	ns	p =.02*	p =.03*	
	TAU	F (3, 243) = .81, p = .49	ns	ns	ns	
	Self-esteem					
	Intervention	F (3, 216) = 4.38, p < .001***	p < .001***	p < .001***	p < .001***	
	TAU	F (3, 243) = 2.70, p = .49	ns	ns	ns	
	Depression					
	Intervention	F (3, 222) = 5.91, p = .01**	ns	ns	p = .05*	
	TAU	F (3, 243) = .18, p = .91	ns	ns	ns	
	Life Satisfaction					
	Intervention	F (3, 222) = 4.73, p = .01**	ns	p =.01**	p =.01**	

TAU	F (3, 243) = .86, p = .46	ns	ns	ns
Stroke Knowledge				
Intervention	F (3, 219) = 30.63, p < .001***	p <.001***	p <.001***	p <.001***
TAU	F (3, 243) = 43.35, p < .001***	p <.001***	p <.001***	p <.001***
Note. *p < 0.05. **p <0 .01. ***p <0 .001.				

Table 4: Mean Differences between Intervention and TAU group by Outcome Measures between T_0 and T_1, T_0 and T_2 between T_0 and T_3 (*N*=192)

Outcome Measures Tested	Mean differences between intervention and TAU group (*p-value*)		
	T_1-T_0	T_2-T_0	T_3-T_0
Hope	.07 (.71)	.28 (.05)*	.25 (.04)*
Meaning in Life	.10 (.28)	.26 (.04)**	.28 (.02)**
Mastery	.14 (.26)	.17 (.05)*	.13 (.01)**
Self-Esteem	.18 (.24)	.28 (.06)	.25 (.05)*
Depression	-0.003 (.93)	-.02 (.40)	-0.15 (.04)*
Life Satisfaction	.01 (.61)	.24 (.03)*	.21 (.05)*
Stroke Knowledge	.11 (.73)	.16 (.67)	.32 (.43)

*p <0 .05. **p <0 .01. ***p <0 .001.

Appendix 10-Synthesis stage 3 mid mapping

Outcomes from the intervention	Suggested mechanism which explains positive outcomes
Introducing of the concept of hope and increasing positivity about the future.	Social comparison Speaking with other stroke survivors Take time to listen. Listening to recovery stories of other stroke survivors Platform to sharing stories. similar experiences and situation Felt connected. Relatedness validation of the feeling of suffering

	(affirmation support) Social control The group context created a space for individuals to share and listen to other stories, as well as to observe how other improved and successfully managed difficult situations after their stroke. Using humour
Increasing motivation and creating inspiration	learning from others and sharing various experiences. Meeting other stroke survivors who had positive experiences after stroke. Social comparison :Observing how other stroke survivors succeeded after their stroke was motivating. Social upward comparison Peer pressure

	Interacting with peer supporter, inspired new stroke survivors to purse a new role in the future.
Impact on social well-being	
Decreasing sense of loneliness after stroke	Having time to share, listen and relate to others who had gone through similar experiences .
	Similarity in circumstances decrease sense of loneliness.
	sharing concern and problems created a sense of relatedness and validated suffering.
	Meeting and interview with other stroke survivor was something to occupy their day after stroke.
Developing valuable relationship and increased social interaction	
	The group context created an opportunity to make new friends in common to whom stroke survivors could relate.

	Sense of community that was created in the group could led to develop a long-term valuable relationships , support and network for participants and continued validating the sense suffering outside the group context .
Impact on emotions **Impact on depression** **Impact on fear**	Sharing experiences with other stroke survivors and validating own feelings and experiences Being occupied by attending the peer group. Being in a group of other stroke survivors who had disabilities, yet. showed positive attitudes . Ability to express negative emotions. Peer support Related to positive outcome :

Related to Negative emotions :	Taking time to listen , sharing stories with peers and validating suffering. Understating their stroke assisted in decreasing sense of fear. For stroke survivors :Sharing experiences of stroke. Recalling distressing memories For peers who provide intervention : Reliving the distress related to earlier experiences of stroke.
Enhanced ability to cope and recover	Sharing stories with others who had successful experiences of recovery. Group context created a platform where stroke survivors could provide advice on coping after stroke . A peer motivated an individual to practice self-management skills.

	The dialogue approachenhanced ability to copy by ;1)explaining their coping problems ;2)clarifying their coping choices; 3)encouraging them as they sought various coping approaches and 4)assisted them as explored unexpected situation (9)
Providing informational support **Gaining knowledge and information about stroke, how to recovery from stroke and locating and accessing stroke support services and opportunities in the community**	**Group context** created a platform to ;(1) to shar and listen to other people's experiences and (2) to interact with stroke survivors at various stages of recovery .

Appendix 11-Synthesis stage 4 the thematic development

Theme	Subtheme	Code	Unite
Outcomes from the intervention	Introducing the concept of hope after stork and helped stroke survivors to be positive regarding the future.	Definition of subthemes:: Discussion around how hope was introduced to their lives after the incident of stroke and how participants learned to be positive regarding future .These positive outcomes occurred through several mechanisms which are following; (1) Talking to someone who had gone through a similar situation and taking time to listen and shar stories of others was identified as validating the feeling of suffering (affirmation support) (1) (2) Being in a group with other stroke survivors who were in a similar situation and observing how they improved helped participant to learn to be positive regarding the future (2). (3) The narrative aspect of the intervention (Listening to the recovery stories of other stroke survivors could led to the realisation that a person after stroke could recover which as consequence installed hope that did not exist previously (10). (4) Being in a group with people with similar situation could led to unite the experiences (validate the suffering) (10) that emotional support was provided during the initial in- hospital visit in the form of hope, encouragement and re-assurance .Emotional and affirmational support occurred through taking time to listen, sharing of stories and validation of feelings(1) :I honestly didn't want them to leave because I just wanted to continue talking to someone who actually had gone through what I went through. (New Stroke Survivor-Sylvie, initial interview) (1) I've learnt to stay **positive** by seeing people who were in similar situations who are now a lot better... being with another who had had a stroke was encouraging as she was in my situation... **I feel more**	

		positive for the future..... If I hadn't have attended the group I wouldn't be as **positive as I am now**." [Patient 7]) (2) Eleven participants, 5 recipients and six peer support-, agreed with the item " things seem more **hopeful since joining the group** Seventeen participants, all except one of the peer supporters, agreed with the item " group helps me feel more positive about my future". (2) Just by going and listening to their [other survivors] stories…there is really something to that. Learning the stories of recovery … helped me [learn] people can recover. It gave me hope where I thought through the years that you couldn't recover." –Irene, 5 years post-stroke (10) We're not alone. Everybody else is the same as us. I've learned from coming [to the group] that there is life after stroke." –Tom, 7 years post-stroke (10) There may be limits to the physical comeback that you can make but as far as keeping yourself positive, which is a constant battle … this group and other avenues too: church, your other relationships with people …That's the biggest thing on keeping your mental positive attitude going, and in the final analysis that's almost everything." (7) Viewing the video narratives provided some **hope** and less fear to overcome stroke challenges. The video was an aid to their plight that there was life after stroke.(13) They had a **positive** outlook towards stroke recovery and were willing to do better to improve their health condition.(13)	

		I feel that I have to follow the advice, for example, taking medicine, doing blood test… that have been mentioned… (The videos) seem to **inspire** us to take care of health so that we won't get sick. Perhaps to give encouragement makes me feel that I can recover from stroke if follow all the advice [P5] (13) Usually, if you never had a stroke before, you don't really care about watching the videos. Once you had (a stroke), you'll realize that… health is important… you have to take care of it… watch their story… that's it! [P1] Now I ask my doctor more questions if I don't understand…. [P2](13) The noted change patterns over time were further investigated in their mean plots, which suggested that the patterns of change over time in the outcome measures across the intervention and the TAU groups were statistically different. Further, many of these positive effects were sustained at 4 months post intervention, in the intervention. Pairwise comparisons revealed that hope, meaning in life, self-esteem and stroke knowledge had significant changes between T 0 and T 1 , T 0 and T2, and T 0 and T 3 (Table 3) (6) Intervention group T0-T1: p = .01** T0-T2:p <.001*** T0-T3p =.04* (6) Control group: T0-T1 :ns T0-T2 p =.06 T0-T3: ns (6) NT shows a higher improvement in most outcome scores over the conventional psycho-education intervention. Results further indicate that the intervention group significantly improved hope (R2=0.04, F (1, 176)=7.24**, p = .05),** (6)	
	Increasing motivatio	Definition: Discussion around how stroke survivors were encouraged and empowered by their peers. Motivation was increased through the following mechanisms.	

	n and creating inspiration	(1) Motivation from peers: learning from others and sharing various experiences. (3) (2) Observing how other stroke survivors succeeded after the incident of stroke was motivating. (3) (3) Being in a group with other stroke survivors and observing how they improved helped participant to learn to be motivated to do better (3) (4) Meeting other stroke survivors who had positive experiences of recovery was motivating to new stroke survivors (1) (5) interacting with peer supporter, inspired new stroke survivors to purse a new role in the future (as peer supporters) (1) Motivation from peers was mentioned by a number participants. It was spoken about in relation to vicarious experience or learning from others. Seeing others succeed could be particularly motivating: (3) Sometimes it is peer pressure. You see someone doing well and you want to get better as well so it spurs you on a bit. (Paul) (3) That emotional support was provided during the initial in- hospital visit in the form of hope form of hope and encouragement (1) The visit from the peer supporters encouraged and motivated the stroke survivors to work towards recovery (1) Peer supporters were also seen as a source of inspiration (1) some stroke survivors who expressed an interest in pursuing a peer supporter role in the future.(1) Sixteen participants, all except one recipient and one carer, agreed with the item " is group inspires me about the future". (2) Social upward comparison • SGm: 'Because of realizing that Mister IKTm is better than me I want to get there also' (12) The motivational cues inspired the patients and raised confidence among themselves. … (sharing) someone's experience to change others'mind. Sometimes, we need to listen to their stories for us to make a change [P4] (13)	
		Definition: discussion around how the intervention of interest had positive outcomes on social well-being which were the following: (1)	

	Impact on social well-being Decreasing sense of loneliness after stroke and developing valuable relationships and increased social interaction	decreasing the sense of loneliness following stroke, (2) developing valuable relationship (friendship relationships) and (3) developing long-term social relationships and support which occurred via the following mechanism. • Having time to share, listen and relate to others who had gone through similar experiences decreased the sense of loneliness (1) • Similarity in circumstances decrease sense of **loneliness** (2) • sharing concern and problems created a sense of relatedness , validated suffering and minimised the sense of **loneliness** (7) • Talking to other stroke survivors and sharing similar experiences was identified as validating the suffering and decrease sense of l**oneliness** (3) • Meeting with other stroke survivor was something to occupy their day after stroke (4) • The group context created an opportunity to make new friends in common to whom stroke survivors could relate (2) • Being in a peer support group which based on the group dynamic theory and the social learning theory facilitated opportunities to makes new friendships and increased social interaction inside and outside the group context with people like minded (5) • Sense of community that was created in the group could led to develop a lifelong valuable relationships , support and network outside of the group context that continued validating the sense suffering outside the group context .(7) • Stroke survivors in the group had become like friends because they cared and took time to listen , in contract to other people (10) • Related to decreased loneliness. After having someone who had gone through a similar experience take time, listen, share experiences, and make a connection, stroke survivors reported feeling validated and less alone(1) It made me realise I was not alone, that there are many others in the same position." [Patient peer supporter 2]. (2)	

		shared experience may reduce feelings of loneliness as Paul illustrates (3) That is good if you know there are others in the same position as you. Going, going through the same thing as you. So you don't think you are the only one... It's good talking to other stroke survivors because with their experiences you know you are not alone then. Because it is very demoralising once you have had your stroke. (Paul) (3) -I think partly it was like a day out for her, breaking the monotony, but once her family came back she had something to fill the day. When I had my stroke and was looking for help, anything I was offered I would go for it. For me I was looking for solutions to problems, I was meeting with her to work on solving problems. Her problem was loneliness, so I was the solution. (Peer 2) (4) Participant R2G3 said, "It makes you feel like you are not alone. Like there is someone else out there that is having the same problems and concerns that you do. And how they are dealing with it makes a difference(7) -I think that if I had' t had this course [intervention], I would have felt terribly alone. (Woman, 66 y.o./group intervention).(9) Peer support groups helped survivors not feel alone or isolated. Almost all participants commented on the importance of connecting with other survivors. At least half of the survivors expressed gratitude to have received either a visit in the hospital or a phone call from a stroke survivor. They articulated that the isolation of their stroke seemed somewhat alleviated once they connected with others in a similar situation. "You find you're not alone. [The group] is an extended family	

		who knows what you're going through." –Angela, 11 years post-stroke (10) You don't feel quite so much out on a limb. When you've heard [that] other people have gone through the same procedures you had." **[Patient 6].** (2) "It made me realise I was not alone, that there are many others in the same position." [**Patient peer supporter 2].** (2) Related to developing valuable relationships and increased social interaction it the group has changed my life as I have made friends with other people who have had a stroke." [Patient 7].(2) Member response to post participations survey :5 out 13 reported "strongly agree " that the program helped them to make new friends and 5 out of 13 reported" agree" (5) Descriptive data about social and communication activity outside of the group were tracked on the post group survey. For example, members were asked if they met with anyone socially outside of the group or if they used communication path- ways such as Facebook or texting to socialize/communicate outside of the group. Approximately, half of the individuals (n = 6) reported interaction with another member outside of the group context in various formats including text (n = 2), Facebook (n = 2), met or attempted to meet outside of the group (n = 8), email (n = 5), and talk on the phone (n = 6). (5) Equally, over half of the members (n = 8) reported socialization being their favourite aspects of the group process .example, members reported new friendships and social networking were most beneficial. (5)	

		The social domain The CIQ social domain did not reach significant: Mean pre score: 8.23 Mean post score: 9.08 (5) (*p* value 0.148) (5) The sense of community was unique to the support group experience, and impacted participants' lives beyond scheduled stroke support group meetings. Participant R3G2 noted, "I think this group has become more than a support group once per month. They are almost like family (7) … They have become friends and support outside of the meetings." Additionally, participant R2G1 stated, "We love the relationships that we are building with other people. Even if we are in a store ... it's like, 'oh they are in our stroke group.' It is important that outside of this room even, it reminds you that there are other people experiencing the same reconfiguration of their life that we are." (7) They [other survivors] speak to me and then they'll listen. Some people would say 'oh, I can't be bothered'. They're like friends because they're always willing to help you'" –Lillian, 1.5 years post stroke (10)	

		Negative case : The peers identified that although they had not experienced this difficulty, they could see how there was the potential for the stroke survivor to become attached to the peer: It's hard to meet somebody one to one. To meet them at a personal level and then suddenly, that is it, you are never going to see them again. This could be a problem because if you get the wrong sort of people, the ones that cling on all the time they would be phoning you all the time just for a bit of company. (Peer 1) (4) The facilitators gained a better understanding of the participants as individuals because of sharing stories with the groups As part of the evaluation, the facilitators were asked. to answer the following question by the trainee clinical psychologist: 'How was the Share **Your Story** Group useful for you as therapist?' Responses were written down verbatim and grouped. This resulted in the following categories: (8) ■ Getting to know patients as people (six responses (8)	
	Impact on emotions Depression	Definition: discussion around the impact of the intervention of interest on depression and related emotions Qualitative result related to depression outcome : **Mechanism related to depression outcomes** :sharing experience with other stroke survivors and validating own suffering helped in reducing depression. (7) (10) Many participants shared feelings of frustration, depression, and isolation. These feelings stemmed from fear, lack of strength, and	

		feeling overwhelmed by the challenges of adjusting to a new normal after stroke. However, sharing their experiences in peer stroke support groups was helpful. Participant R2G1 noted, "I felt that I was a little depressed before I came … I found that being around other people that's gone through the same thing helps**."(7)** Mechanism related to depression outcomes. 1. Being in a group of people with similar condition and who had disabilities ,yet had positive attitudes could led to increase spirit and decreased depression (10) 2. Discussion and talking with other stroke survivors and express emotion (negative) lead to validate suffering/ not alone feeling this way+ support =decrease phycological distress (depression) (10) 3. attending the peer support group=lead to occupy patients with something to do every month=lead to elevate the depression (10) Although many survivors experience depression post-stroke, their support group played a role in overcoming depression (10) Of those who experienced stroke, the majority expressed their support group played a significant role in overcoming depression. (10) Only 1 participant did not report depression was a part of their stroke experience. (10) "Being together with such a happy group who had disabilities too helped me keep my spirits up so I don't let myself get down." –Lena, 2.5 years post-stroke (10) "I personally thought about suicide. It's scary. In forums they [survivors] all said we felt depressed…in the beginning it's very normal. I'm not alone feeling that way." – Angela, 11 years post-stroke (10) They [the support group] helped a lot. I talked about depression and why I wanted to commit suicide and they were really supportive." – Tom, 7 years post-stroke (10)	

When I first came home from the hospital I wanted to go home, sit in a corner and cry…..now every month I have something to go to." –Aryln, 7 years post-stroke (10)

Quantitative results regarding depression :

Intervention group: T0(baseline),*M(*SD).32(.25);T1(interim) .33(.27);T2(post intervention),-.25(.26) and T3(4 months)-.20(.26) (6)

Table 2: Means, Standard Deviations and Baseline Differences between Groups of Outcome Variables Over Time (*N*=192).

Variable Tested	T_0	T_1	T_2	T_3	Baseline Difference Between Groups
Intervention Group	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*t*-test
Hope	6.13 (1.23)	6.62 (1.35)	6.89 (1.28)	6.75(1.58)	$t(189) = -1.14$, $p = .25$
Meaning in Life	3.47 (.65)	3.77 (.62)	3.93 (.59)	4.33 (.71)	$t(189) = -1.73$, $p = .86$
Mastery	3.39 (.85)	3.60 (.77)	3.88 (.86)	3.85 (.77)	$t(188) = -1.18$, $p = .24$
Self-Esteem	2.60 (.44)	2.85 (.44)	2.99 (.32)	2.94 (.48)	$t(189) = -1.57$, $p = .12$
Depression	.32 (.25)	.33 (.27)	-.25 (.26)	-.20(.26)	$t(190) = 1.44$, $p = .15$
Life Satisfaction	.71 (.19)	.78 (.17)	.88 (.15)	.84 (23)	$t(190) = -.62$, $p = .54$
Stroke Knowledge	3.26 (2.15)	5.05 (1.88)	5.49 (2.09)	5.54 (2.17)	$t(189) = -.89$, $p = .38$
TAU Group					
Hope	6.35 (1.39)	6.52 (1.34)	6.66 (1.44)	6.52 (1.30)	
Meaning in Life	3.62 (.68)	3.68 (.55)	3.76 (.62)	3.64 (.89)	

Mastery	3.51(.78)	3.56 (.85)	3.68 (.88)	3.70 (.90)	
Self-Esteem	2.72 (.45)	2.77 (.36)	2.82 (.44)	2.80 (.41)	
Depression	.27 (.24)	.27 (.24)	.-26 (.24)	.26(.25)	
Life Satisfaction	.73 (.16)	.74 (.15)	.75 (.16)	.73 (.18)	
Stroke Knowledge	3.46 (2.41)	5.45 (1.90)	5.76 (1.93)	5.86 (2.17)	

Table 3: Comparisons of Outcome Measures in Intervention & Control Groups across T0 to T3 (N=192).

Selected Measures Tested	Time effects	Pairwise Comparisons		
		T_0-T_1	T_0-T_2	T_0-T_3
Hope				
Intervention	F (3, 219) = 7.94, p < .001***	p = .01**	p <.001***	p =.04*
TAU	F (3, 237) = 3.15, p = .03*	ns	p =.06	ns
Meaning in Life				
Intervention	F (3, 219) = 12.86, p< .001***	p<.001***	p <.001***	p <.001***
TAU	F (3, 246) = 3.28, p = .02*	P = .07	ns	ns
Mastery				
Intervention	F (3, 210) = 4.38, p < .001***	ns	p =.02*	p =.03*
TAU	F (3, 243) = .81, p = .49	ns	ns	ns
Self-esteem				
Intervention	F (3, 216) = 4.38, p < .001***	p <.001***	p <.001***	p < .001***
TAU	F (3, 243) = 2.70, p = .49	ns	ns	ns
Depression				
Intervention	F (3, 222) = 5.91, p = .01**	ns	ns	p = .05*

TAU	F (3, 243) = .18, p = .91	ns	ns	ns
Life Satisfaction				
Intervention	F (3, 222) = 4.73, p = .01**	ns	p =.01**	p =.01**
TAU	F (3, 243) = .86, p = .46	ns	ns	ns
Stroke Knowledge				
Intervention	F (3, 219) = 30.63, p < .001***	p <.001***	p <.001***	p <.001***
TAU	F (3, 243) = 43.35, p < .001***	p <.001***	p <.001***	p <.001***
Note. *p < 0.05. **p <0 .01. ***p <0 .001.				

A reduction in the mean, for both anxiety and depression scores was found.

Mean pre group depression approximate just at 8.5 of Hospital Anxiety and Depression Scale (HADS) and Mean of post group depression of HADS approximately just above 7.5 (8)

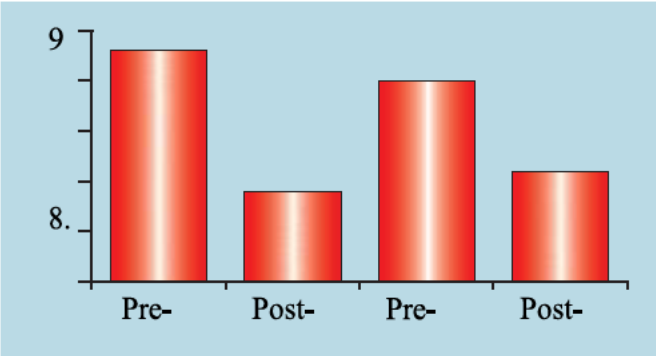


Figure 1. Hospital Anxiety and Depression Scale mean scores pre- and post-group

, but T-test results showed no significant changes in HADS scores before and after the group (n=34) (8)

Affective mood states, measured by the VAMS at the end of the first and the last BNI also changed, as shown in table 4. While **little improvement was demonstrated for the mood state 'happy'** with an increase in the mean T-score from 40.85 to 47.40 (Cohen's d = .25), the mood states 'confused' and 'tense' decreased moderately from 52.96 to 46.23 (Cohen's d = .56) and from 53.52 to 46.50 (Cohen's d = .45), respectively. For all other mood states there were expected trends towards a growth of positive emotions and a reduction of negative emotions. We also conducted **the VAMS at the end of the first and the last GI. Again we found expected trends. The mood state 'tired' decreased from 49.00 to 43.33 (Cohen's d = .30) (12**)

Table 4. Values for mood states VAMS (Stern 1997) at end of the first and the last biographic–narrative interviews (BNI) and group interventions (GI) (12)

	Baseline (end BNI 1)	Post (end BNI 5)	Baseline versus post-test		
	(*n* = 27), mean	(*n* = 26), mean			
Test	*T*-scores (95% CI)b	*T*-scores (95% CI)	***P*-value** (outcome)a	Cohen's *d*	

		VAMS afraid	47.41 (2.61)	46.62 (1.68)	.50	.12
		VAMS confused	52.96 (5.77)	46.23 (2.12)	.01	.56
		VAMS sad	52.37 (6.73)	47.81 (3.25)	.08	.30
		VAMS angry	50.04 (5.10)	47.08 (3.39)	.25	.21
		VAMS energetic	44.37 (5.11)	48.46 (5.02)	.27	.14
		VAMS tired	46.96 (4.00)	46.92 (4.22)	.78	–.03
		VAMS happy	40.85 (5.48)	47.40 (4.52)	.01	.25
		VAMS tense	53.52 (4.42)	46.50 (2.97)	.00	.45
			Baseline (end GI 1) (n = 25), mean T-scores (95% CI)	Post (end GI 7) (n = 24), mean T-scores (95% CI)		
	Fear	VAMS afraid	47.33 (4.73)	46.86 (3.27)	.40	.36
		VAMS confused	48.00 (5.48)	45.35 (2.03)	.40	.58
		VAMS sad	52.96 (8.85)	47.76 (5.24)	.32	.38
		VAMS angry	48.75 (6.54)	45.19 (2.15)	.37	.41
		VAMS energetic	45.25 (6.03)	48.62 (15.17)	.48	–.09
		VAMS tired	49.00 (6.99)	43.33 (11.70)	.00	.30
		VAMS happy	42.88 (6.92)	45.52 (14.92)	.23	–.02
		VAMS tense	51.21 (4.86)	49.86 (11.80)	.93	.18
		Notes: [a]Repeated measures t-test, two-tailed.				

[b] *n* varies because not all participants attended at each session.

TABLE 4

Values for mood states VAMS (Stern, 1997) at end of first and last biographic-narrative interview (BNI) and group intervention (GI) (*n* varies because not all participants attended at each session) (11)

	Baseline (end BNI 1) (n = 17) Mean -t-scores (95% CI)	Post (end BNI 5); (n = 16) Mean t-scores (95%CI)	Baseline vs. Post-test p-values[1] (outcome)
VAMS afraid	48.06 (4.32)	46.38 (2.35)	.30
VAMS confused	54.88 (8.99)	46.50 (3.65)	.03*
VAMS said	52.88 (10.33)	48.13 (5.33)	.12
VAMS angry	52.71 (8.42)	47.44 (5.49)	.20
VAMS energetic	44.35 (7.33)	49.00 (7.11)	.39
VAMS tired	48.65 (6.12)	46.38 (5.47)	.64
VAMS happy	39.00 (7.66)	46.53 (7.13)	.02*
VAMS tense	54.47 (6.59)	46.63 (4.49)	.01**
	Baseline (end GI 1); (n = 14)	Post (end GI 7) (n = 13)	Baseline vs. Post-test

Test	Mean t-scores (95% CI)	Mean t-scores (95% CI) p-values[1] (outcome)	
VAMS afraid	48.00 (4.44)	46.00 (2.70)	.56
VAMS confused	49.43 (5.48)	45.00 (1.53)	.30
VAMS said	51.64 (8.85)	46.23 (3.37)	.42
VAMS angry	49.00 (6.54)	44.69 (1.55)	1.00
VAMS energetic	44.93 (6.03)	47.46 (8.09)	.86
VAMS tired	52.07 (6.99)	45.15 (6.61)	06trend
VAMS happy	42.36 (6.92)	43.92 (8.25)	.46
VAMS tense	49.79 (4.86)	46.23 (5.67)	.44

[1]Repeated measures *t*-test, two-tailed.

Definition :discussion around how the intervention of interest seemed to reduce the sense of fear and instilling a feeling of reassurance

Qualitative result :

Viewing the video narratives provided some hope and **less fear to overcome stroke challenges. I**t's a bit of both worrying and confidence… There is always a worry about what can happen, but it also gives you an idea (on) what to do, and what to be careful, and what to be aware [P3] (13).

		Taking time to listen , sharing stories with peers and validating the suffering felt during the hospitalisation period offered emotional support in the form of reassurance. That emotional support was provided during the initial in- hospital visit in the re- assurance(1) Fear was commonly reported by participants and peer support groups appeared to help to understand the condition, which assisted in overcoming the fear after stroke. far was emphasized as a great challenge in accepting stroke.. [10] When I first had the stroke, I went to my family doctor 3-4 times a week thinking I would be having a stroke. I was always scared," and indicated "**the group helped me overcome my fear."** –Kelly, 4 years post- (10) "Don't be so fearful after you have [had your stroke]. I remember being afraid and that's **where the group helped**." Irene, 5 years post-stroke (10) **Negative case** :There may conversely be some negative impacts of the interventions on emotions of both stroke survivors and peer supporters which might occurred through the following mechanism : • Some aspects of the intervention such as sharing experiences of stroke and recalling distressing memories might led to arise intensive feelings (3). • Hearing and talking about stroke could be "distressing" and "difficult" (3) • Sharing experiences of stroke within a group context might impact negatively on physical and emotions health (increased stress) (3)	

		• The nature of the group (a place where both negative or positive emotions were expressed could be emotionally challenging to some individuals (3). Ability to cope emotionally – "perhaps not everyone can cope" The ability of each individual to cope with the potential emotional demands of a group SMP was discussed by participants. Some aspects of a group may be emotive for some individual's such as, **discussing experiences of stroke and remembering things that are distressing. (**3) Five stroke survivors spoke about how they would cope emotionally when hearing and talking about stroke. Thomas reflects on times he has had to hear about stroke, such as in the paper. He says he does not like it as he finds it both "**difficult**" and "**distressing"** to hear(3) James said he would not want to put himself in a situation in which he might get **stressed as he worries** it would aggravate his atrial fibrillation (3) Margaret, whilst more certain about how she might react emotionally, also sees the experience **as challenging:** (3) "I have found I have got more emotional, I will cry at the drop of a hat, you **know, happy times,** or **sad times.** And erm, if I had somebody who was in a group who was reduced to tears I would be too. ...**it is not a nice feeling I suppose**." (3) The concern that all these participants share is summarized by Ben, who talks about emotional management in relation to group programs: I suppose the danger with rolling it out to everyone, is perhaps not everyone can cope. Because it's not very good news this stuff you are being told. (3) Negative case related peers who provided the intervention : there might be a potential emotional impact of the intention on peers as the intervention might trigger experience relates to their initial stage of stroke.	

		While concern was expressed by program coordinators about the potential emotional impact on peer supporters for whom the visit may trigger past feelings related to the initial experience of stroke, none of the peer supporters interviewed described experiencing these types of feelings (1) Quantitative result : **VAMS** afraid (P=.056) (11) **VAMS** afraid (p= 0.36) (12)	

	enhanced ability to cope and recover	Definition : discussion around how the group context enhanced ability to cope and recovery after stroke which occurred through the following mechanisms. • Through **sharing experiences** and how other stroke survivors **coped** after stroke , an individual picked up ideas on how cope with their own situation (10) • Humour and positivity in groups were also frequently mentioned as important components of effective recovery (10). • Through **hearing how other stroke survivors coped** with their challenges , participant discovered new ways to **cope** with their own difficulties and were able to transfer these experiences and implement them to their day to day lives (action planning) (2) • Through creating a platform where stroke survivors could provide advise on coping after stroke (2) • **A peer motivated** an individual to practice **self-management skills** by setting a goal ,breaking it down into manageable measures and working towards which had a positive effect on his confidence (4) • **The dialogue-based intervention** in both formats (group and individual) according to participants assisted them in cope with their difficulties after stroke. Their difficulties ranged from carrying out daily task and solving practical issues to comprehending and coping with their own emotional response as well as those of families, friend, and co-workers (9**) .This occurred through the following .Mechanism;**1)explaining their coping problems ;2)clarifying their coping choices; 3)encouraging them as they sought various coping approaches and 4)assisted them as explored unexpected situation (9) • By Listening to how other stroke survivors **handled** their situation, , they learned new to address various circumstances (9)	

		"When they [other survivors] talked about their experiences and how they coped…I learned tips on how to get on with it." –Lena, 2.5 years post-stroke (10) Although many of the participants expressed gratefulness for the contributions their support group had brought to their lives and recovery (10) Laughter and being positive were also commonly raised as key components of a successful recovery and of strong peer support groups (10) Fourteen participants, eight recipients and six peer 2supporters, agreed with the item "When I hear how other people are coping with their problems in the group, I often learn new ways to cope with my difficulties".(2) 13 participants, eight recipients and five peer supporters, agreed with the item "I pay attention to how others handle difficult situations in my group so I can apply these strategies in my own life (2) fifteen of the participants, eight recipients and 7 peer supporters, also agreed with the statement "In the group, other members advise me what I should do about difficult situations and life decisions(2) Nine participants, four recipients and 5 peer supporters, agreed with the statement "In the group I get 'how to on improving my life (2) One participant further explained how he was taken out of his comfort zone and was encouraged to identify an initial goal and work towards it	

		by breaking it down into necessary steps. Although challenging, the participant could see the need for this. In his words: (4) So, I think [Peer] was … more goal-orientated than me. I think for me, it was useful to have that structure […] so … it was useful that he was having those. (P4) (4) The participant and peer agreed on a goal which involved the participant being able to take a digital photograph and follow the necessary steps to save it, download it, edit it and finally print it.The participant expressed how he could see the change as the coaching progressed: But as I engaged and went on through the weeks … I know that I was able to …, I could absorb the information and … be able to apply it. (P4) (4) By Session 6 the participant was able to complete the photographic process and he expressed this had a positive impact on his confidence (4) Being supported in their attempts to cope with the situation The participants struggled to cope with their new and unknown situations after the stroke. The issues they struggled with varied widely, from performing daily activities and solving practical problems to understanding and coming to terms with their own emotional reactions and those of their family, friends and colleagues. Facing different social situations within and beyond their family entailed many challenges. (9) The participants reported that the intervention helped them cope with their struggles. Participants in both the individual and group-based interventions emphasised that the dialogues helped them cope by clarifying what their coping challenges entailed, illuminating their coping options, supporting them as they tried different oping strategies and supporting them as they analysed unexpected situations (9) When a traumatic event occurs, such as a stroke , **it is important to be able to share experiences with those** that had been in similar situations (9)	

		The participants in the group-based intervention also reported that by listening to how other stroke survivors managed their situation, they learned new ways to approach different situations: P: I always left [the meetings] a little inspired! I think it is important when a serious thing like a stroke happens, that one may exchange experiences with others who have been in the same situation… . That is what has been most important for me – to be together with people in the same situation. (9) Main theme: Informative and reminder • The videos narratives were a "trigger" toward proactivity and enhanced patients' awareness about stroke and its preventative treatment. (13) They remind us of important medicine… They remind us of the danger of the second stroke… to take medicine well and to have a healthy lifestyle [P7] Helpful….more understanding about stroke [P6] Awareness… before that we were not really concerned about our health. Now, after the advice it's different... like a guide [P4] Patients can recover from stroke and (it) won't recur if we take the medicine prescribed by doctors according to the right schedule on time [P2] (13) Ten of the 13 members reported "agree" or "strongly agree" they were able to identify a new coping strategy, and eight of the 13 members reported they actively used the strategy outside the group. (5) These findings provide preliminary indication that the YESS group had a positive impact on coping strategies after stroke. (5) For example, members were asked if they engaged in volunteer activities, exercise programs, or leisure programs that were presented in the group modules. Over half of the members (n = 8) reported they	

began to engage in various leisure and ADL opportunities outside of the group context. (5)

TABLE 3. Pre and Post group Stroke Impact Scale Domain Scores

Stroke Impact Scale Domain	Median Prescore	Median Postscore	Mean Prescore	Mean Postscore	*p* value
Self-reported recovery score	70 (30–90)	70 (40–95)	62.2	66.2	.196
Strength	50 (25–93.8)	56.3 (25–93.8)	51.9	56.8	.342
Hand function	0 (0–90)	20 (0–100)	28.5	41.2	.138
Mobility	97.2 (52.8–100)	94.4 (55.6–100)	91.7	89.8	.778
ADL/IADL	85 (52.5–100)	90 (44.4–100)	83.2	82.8	.551
Memory	82.1 (57.1–100)	85.7 (60.7–100)	81.9	84	.683
Communication	92.9 (10.7–100)	96.4 (46.4–100)	80	89.8	.214
Emotion	83.3 (50–97.2)	83.3 (44–97.2)	76.9	77.1	1
Handicap	59.4 (37.5–100)	75 (53.1–100)	63.5	75.8	.034*

* Note: $p \leq .05$

TABLE 4. Pre- and Post-group Scores on Community Integration Questionnaire

Domain	Median Prescore	Median Postscore	Mean Prescore	Mean Postscore

					p value
Total score	14.25 (2–19 21.5)	(13.7–14.87 23.75)	18.22	0.028*
Home integration	5 (1–7.5)	5.25 (2.6–10)	4.25	5.99	0.002*
Social integration	8 (2–12)	9 (6–12)	8.23	9.08	0.148
Productivity	2 (1–6)	3 (1–7)	2.69	3.23	0.334

* Note: $p \leq .05$

TABLE 5. Member Responses to Post participation Survey ($N = 13$)

Answer Options	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I have made new friends	5	5	2	0	1

		I provided support to other group members	5	4	3	0	1							
		I learned new ways to cope with issues related to stroke	3	7	2	0	1							
		I am using a coping strategy learned in the group to deal with frustrating or stressful situations	2	6	4	0	1							
		I know more about community and stroke resources	5	5	3	0	0							
		I have gained knowledge to advocate for myself	3	7	3	0	0							
		I feel more hopeful about the future	4	5	4	0	0							
		I know more about opportunities after stroke (i.e., modified leisure, volunteer, or research opportunities)	4	6	2	0	1							
		I am more informed about ways to achieve my goals regarding recovery	4	7	2	0	0							

Table 2 Groups' Comparison at Various Timelines (14)

	Timeline (Month)			Within Group			Between Groups			(Timeline*Group)		
	T0 (SD)	T2 (SD)	T4 (SD)	F	p	η2	F	p	η2	F	p	η2

		MUSE[a]	IC	22.97 (5.17)	27.27 (3.25)	27.81 (2.52)	97.00	<0.001**	0.475	12.41	0.001**	0.055	42.99	<0.001**	0.167
				23.71 (5.44)	24.62 (4.03)	24.42 (4.02)	5.61	0.010*	0.050						
		MUSE[b]	IC	25.00 (5.85)	27.82 (2.96)	28.38 (3.23)	42.05	<0.001**	0.282	5.10	0.025*	0.023	6.91	0.005*	0.205
				24.75 (5.80)	26.29 (4.97)	26.28 (4.88)	14.76	<0.001**	0.121						
		MUSE[c]	IC	25.61 (5.71)	28.88 (3.43)	28.19 (3.18)	49.11	<0.001**	0.315	7.25	0.008*	0.033	12.22	<0.001**	0.195
				25.29 (5.61)	26.39 (5.02)	26.25 (4.73)	8.22	0.003*	0.071						
		Sys/BP	IC	141.68 (20.21)	134.26 (14.96)	135.71 (13.88)	35.67	<0.001**	0.250	0.35	0.552	0.002	8.537	0.001**	0.038
				139.89 (21.31)	137.59 (15.78)	138.11 (15.73)	3.37	0.055	0.031						
		SKT	IC	7.47 (3.40)	9.34 (3.09)	9.79 (3.11)	137.64	<0.001**	0.563	11.54	0.001**	0.051	32.39	<0.001**	0.131
				6.83 (3.59)	7.49 (3.36)	7.81 (3.28)	42.93	<0.001**	0.286						
		BIPQ	IC	52.08 (10.06)	47.44 (9.29)	47.79 (8.81)	53.84	<0.001**	0.335	1.73	0.190	0.008	34.16	<0.001**	0.104
							0.42	0.594	0.004						

		50.76 (12.12)	51.08 (11.89)	51.15 (12.77)									
BMQ	I	51.46 (6.22)	48.22 (6.31)	47.57 (6.15)	51.39	<0.001**	0.324	15.93	<0.001**	0.069	71.76	<0.001**	0.251
	C	50.91 (6.22)	52.76 (7.11)	53.74 (8.00)	23.82	<0.001**	0.182						
BP/Mon	I	2.41 (0.94)	2.76 (0.98)	2.87 (1.04)	27.34	<0.001**	0.204	5.23	0.023*	0.024	12.49	<0.001**	0.055
	C	2.33 (0.89)	2.44 (0.91)	2.44 (0.89)	5.74	0.006*	0.051						

Notes: [a](all medication), [b](antiplatelet), [c](antihypertensive), *The mean difference is significant at $p<0.05$, **Adjustment for multiple comparisons: Bonferroni $p<0.001$. **Abbreviations:** BIPQ, Brief Illness and Perception Questionnaire; BMQ, Belief About Medicine Questionnaire; BP, blood pressure; BP/Mon-BP monitoring; CI, confidence interval; C, control group; I, intervention group; MUSE, medication understanding and use self-efficacy; SKT, stroke knowledge test; Sys/BP-systolic BP; T0, baseline; T2, 6th month; T4, 12th month.

The item of the helpfulness of group " share your story" on a 10-point Likert-type rating was completed by nearly half of the participants (n=37/80) and the result showed an average rating being 7/10.

		The Likert-rating item on helpfulness of the group for the participants' **recovery** was completed. by 37 participants. The ratings of helpfulness of the group showed an average of 7 (range 1–10). (8)	
	Providing informational support and enhanced awareness of stroke and increased	Definition: discussion around how the intervention of interest provided information support regarding stroke, and how to recover form stroke and how to locate and access stroke support service in the community. Theme 1: Survivors and caregivers seek and receive knowledge about stroke and stroke recovery from stroke peer support groups. (7)	

	knowledge	Pursing and gaining information was the initial reason to participate in the groups. Stroke survivors and their carers needed information about the recovery process , but it was difficult to find . Participants shared that they initially attended stroke peer support groups to learn more about stroke and recovery (7) Receiving stroke and recovery related knowledge was important to survivors and caregivers, and difficult to locate. As participant R2G1 stated, "We all go different places and do different things but there is not really a great one source; you just can't go to the kiosk and say, 'I would like to have all of these resources for stroke survivors.' It's just not there." (7) One of the reasons that stroke survivors wanted to continue attended the groups was to learn more about their stroke and rehabilitation process. Receiving knowledge about stroke and recovery is one reason participants continued to attend support groups. Participant R5G1 noted, "I want to continue to recover. I don't want to stop. I want to get stronger each day. I want to get all the knowledge I can possibly get." (7) Participants gained insight by interacting with other stroke survivors at various stage of rehabilitation. Importantly by meeting with other stroke survivors at different stages of recovery, participants gained knowledge from each other and felt empowered by providing help to their peers. Participant R2G4 said, "Each one of us helped somebody that was having a stroke. If we can do what we do and not be doctors, we can make a big difference right here." (7) Via group discussion , participants gained a better understanding of any risk associated d with a stroke diagnosis You discuss things so you can be on the lookout for anything that might be going wrong, or things you need to be looking to get checked out if you are having this symptom or that one that you might not have thought about before(7)	

		Increasing knowledge about stroke not only helped stroke survivors feel more educated but also gave the skills that they could use outside the group context to facilitate recovery process. " In all focus groups, participants reported that the information they received covered multiple stroke-related topics, such as diet, exercise, blood pressure management, stroke prevention and treatment, and stroke research. Having stroke-related knowledge not only made participants feel more informed, but also equipped them with concrete skills they applied at home to further their recovery. As participant R2G2 stated, "We have had different speakers on different subjects … We had a guy who came in and did exercises with us. Of course, we carried that on some at home." Similarly, participant R1G3 noted, "You discuss things so you can be on the lookout for anything that might be going wrong, or things you need to be looking to get checked out if you are having this symptom or that one that you might not have thought about before." Professionals such as physicians, therapists, and dietitians were sometimes invited to share their knowledge at support group meetings, often at the request of group members (7) Informational support was also offered during the initial and follower up telephone visits. Peer supporters provided written as well as verbal information on resources in the community including those offered by SSAO. (1) During the initial visit this information tended to be more general in nature. However, during follow-up telephone calls, information was targeted to the new stroke survivor's or care partner's needs and included information on specific services avail- able in the community. Information to assist with both finding and accessing services was provided to six out of the 28 people for whom follow-up diaries were kept (1).	

		Information about the experiences of coping with stroke provided by peers was valued higher than the information provided by health care professionals. Information received from a peer regarding the experience of living with stroke was generally given more value than that received from a healthcare professional.(1) Peers offered knowledge and information gained from real -life experiences which promoted relatedness. peer supporters] provided sort of reassurance... and provided a real face. When you're dealing with doctors and nurses they're great.... But they're medical people and they can talk to you about what you've just gone through, but the chances are more than likely that they haven't... The people in Stroke Survivors, well they have. (New Stroke Survivor-Mike, initial interview) (1) What did these survivors want new survivors to know about stroke peer support groups? (10) "They can help you and be very helpful with resources." – Kelly, 4 years post stroke (10) Via group discussion , participants gained useful information and guidance about after discharge support programs. Several participants felt that peers provided valuable information and advice about post-hospital support services (2)	

		I've learnt what help you can get when you come home... and how to get it." [Patient 5].(2) Stroke survivors who had a lot of experiences since their stroke thought to be the in the best position to support. Individuals with substantial experience subsequent to their stroke were viewed as being in the best position to be helpful. (2) "that was the ones that I probably got the most benefit from. the ones that had come in that had had strokes probably a year earlier than I had that were further up the road...and you can ask them questions... what do you do in this situation or another situation?" [Patient 6]. (2) Being in a group with other stroke provided an opportunity to share and hear other people's experiences which led to increased awareness about their condition. The strength of being in a group is that you get to share others' experiences … I had never realised that you could get psychological problems after stroke unless I had seen one of the other participants … I found that very enriching. (Woman, 66y.o./group intervention [9] Peer support groups helped survivors understand their stroke (10) Several participants reported that they did not understand their stroke or how to deal with the recovery process at the time of their stroke or during hospitalization period. Many participants indicated that at the time of their stroke and during their hospital stay, they did not feel they adequately understood their stroke or how they could cope with recovery. For a few, they were in a coma or faced challenges with aphasia (trouble with language), <u>but none of the 9 participants</u> indicated feeling their doctor or other hospital staff sufficiently answered their questions about their stroke. (10)	

		Peers helped stroke survivors in learning more about their conditions and how to cope with their lives. We don't learn enough. Doctors never told me anything." –Lillian, 1.5 years post-stroke (10) "I wanted a place to learn more and educate myself more on stroke and how to cope with life." –Richard, 2 years poststroke (10) I didn't understand stroke until I went home and started seeing other stroke survivors." –Tom, 7 years post-stroke (10) The video narrative intervention significantly increased stroke related knowledge. The Stroke Knowledge Test (SKT) substantial mean score differences between groups (F (1214) =11.54, p=0.001, η2=0.051) (F = 11.54, $p < 0.001$) (14) The group enhanced knowledge about stroke support services in the community and opportunities such as voluntary jobs and modified leisure activities. Finally, members identified on the survey that the most useful aspect of the group process was learning about new **information, education, and information** on community re- sources. Thus, results from the survey supported both social engagement and role participation. (5)- TABLE 5. Member Responses to Post participation Survey ($N = 13$) (5)	

Answer Options	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I have made new friends	5	5	2	0	1
I provided support to other group members	5	4	3	0	1
I learned new ways to cope with issues related to stroke	3	7	2	0	1
I am using a coping strategy learned in the group to deal with frustrating or stressful situations	2	6	4	0	1
I know more about community and stroke resources	5	5	3	0	0
I have gained knowledge to advocate for myself	3	7	3	0	0
I feel more hopeful about the future	4	5	4	0	0
I know more about opportunities after stroke (i.e., modified leisure, volunteer, or research opportunities)	4	6	2	0	1
I am more informed about ways to achieve my goals regarding recovery	4	7	2	0	0

Note:1= Kessler *et al.,* (2014);2=-Morris and Morris (2012);3= Clark *et al.,(* 2018);4=-Masterson-Algar *et al.,* (2018);5=Muller *et al.,(* 2014);6=Chow (2018);7= Christensen *et al.,(* 2019);8=- Gurr (2009);9= Kirkevold *et al.*, (2014);10= Hancock, (2009);11= Corsten *et al.*, (2014);12= Corsten *et al.*, (2015);13= Appalasamy *et al.*, (2020a); 14= Appalasamy *et al.*, (2020b)

Appendix 12-The second stage of the thematic development and CerQul Assessment

Theme	Subtheme	Code	CerQul Assessment
Outcomes from the intervention	Introducing the concept of hope and learning to be positive regarding the future after stroke	Definition of subthemes: discussion around how the intervention of the interest in both individualised and group formats, tended to aid in the introduction of the concept of hope following a stroke diagnosis and in assisting stroke survivors to be optimistic about the future which occurred through the following mechanism. 1. Talking to someone who had gone through a similar situation and taking time to listen and shar stories of others was identified as validating the feeling of suffering (affirmation support) (1) 2. Being in a group with other stroke survivors who were in a similar situation and observing how they improved helped participant to learn to be positive regarding the future (2). 3. The narrative aspect of the intervention (Listening to the recovery stories of other stroke survivors could led to the realisation that a person after stroke could recover which as consequence installed hope that did not exist previously (10). 4. Being in a group with people with similar situation could led to unite the experiences (validate the suffering) (10) 5. Stroke survivors were able to share how they effectively handled challenging circumstances following their stroke in a group setting, which helped others to learn how to handle their own situations. (2). (10) and (9) and were able to apply what they had learned in the group to the management of their lives (2)	Methodological limitations: minor concerns. Coherence (fit between studies and review findings: No concerns Adequacy of data (Richness): No Concerns Relevance (applicability to context): No Concerns Confidence in evidence rating: High confidence

		6. Humour and positivity in groups were also frequently mentioned as important components of effective recovery (10). that emotional support was provided during the initial in- hospital visit in the form of hope, encouragement and re-assurance .Emotional and affirmational support occurred through taking time to listen, sharing of stories and validation of feelings(1) :I honestly didn't want them to leave because I just wanted to continue talking to someone who actually had gone through what I went through. (New Stroke Survivor-Sylvie, initial interview) (1) I've learnt to stay positive by seeing people who were in similar situations who are now a lot better... being with another who had had a stroke was encouraging as she was in my situation... I feel more positive for the future..... If I hadn't have attended the group I wouldn't be as positive as I am now." [Patient 7]) (2) Eleven participants, 5 recipients and six peer support-, agreed with the item "things seem more hopeful since joining the group (2)	

		seventeen participants, all except one of the peer supporters, agreed with the item " group helps me feel more positive about my future". (2) Sixteen participants, all except one recipient and one carer, agreed with the item " is group inspires me about the future". (2) Just by going and listening to their [other survivors] stories…there is really something to that. Learning the stories of recovery … helped me [learn] people can recover. It gave me hope where I thought through the years that you couldn't recover." –Irene, 5 years post-stroke (10) We're not alone. Everybody else is the same as us. I've learned from coming [to the group] that there is life after stroke." –Tom, 7 years post-stroke (10) There may be limits to the physical comeback that you can make but as far as keeping yourself positive, which is a constant battle … this group and other	

		avenues too: church, your other relationships with people …That's the biggest thing on keeping your mental positive attitude going, and in the final analysis that's almost everything." (7) Fourteen participants, eight recipients and six peer 2 supporters, agreed with the item "When I hear how other people are coping with their problems in the group, I often **learn new ways** to cope with my difficulties".(2) 13 participants, eight recipients and five peer supporters, agreed with the item "I pay attention to how others handle difficult situations in my group so I **can apply these strategies in my own life (2)** The participants in the group-based intervention also reported that **by listening to how oth**er stroke survivors managed their situation, they **learned new** ways to approach different situations: P: I always left	

		[the meetings] **a little inspired!** I think it is important when a serious thing like a stroke happens, that one may exchange experiences with others who have been in the same situation… . That is what has been most important for me – to be together with people in the same situation. (9) "When they [other survivors] talked about their experiences and how they coped…**I learned** tips on how to get on with it." –Lena, 2.5 years post-stroke (10) Laughter and being positive were also commonly raised as key components of a successful recovery and of strong peer support groups (10) Viewing the video narratives provided some hope and less fear to overcome stroke challenges.	

		The video was an aid to their plight that there **was life after stroke.(13)** They had a **positive** outlook towards stroke recovery and were willing to do better to improve their health condition.(13) I feel that I have to follow the advice, for example, taking medicine, doing blood test… that have been mentioned… (The videos) seem to **inspire** us to take care of health so that we won't get sick. Perhaps to give encouragement makes me feel that I can recover from stroke if follow all the advice [P5] Usually, if you never had a stroke before, you don't really care about watching the videos. Once you had (a stroke), you'll realize that… health is important… you have to take care of it… watch their story… that's it! [P1] Now I ask my doctor more questions if I don't understand…. [P2](13) The noted change patterns over time were further investigated in their mean plots, which suggested that the patterns of change over time in the outcome	

		measures across the intervention and the TAU groups were statistically different. Further, many of these positive effects were sustained at 4 months post intervention, in the intervention. Pairwise comparisons revealed that hope, meaning in life, self-esteem and stroke knowledge had significant changes between T 0 and T 1 , T 0 and T2, and T 0 and T 3 (Table 3) (6) Intervention group T0-T1: p = .01** T0-T2:p <.001*** (6) T0-T3p =.04* Control group: T0-T1 :ns T0-T2 p =.06 T0-T3: ns (6) NT shows a higher improvement in most outcome scores over the conventional psycho-education intervention. Results further indicate that the	

		intervention group significantly improved hope (R2=0.04, F (1, 176)=7.24**, p = .05), (6)** The item of the helpfulness of group " share your story" on a 10-point Likert-type rating was completed by nearly half of the participants (n=37/80) and the result showed an average rating being 7/10. The Likert-rating item on helpfulness of the group for the participants' recovery was completed by 37 participants. The ratings of helpfulness of the group showed an average of 7 (range 1–10).(8)	
	The enhanced the ability to cope	Definition : discussion around how the group context enhanced ability to cope and recovery after stroke which occurred through the following mechanisms : (1) Meeting other stroke survivors who had positive experiences of recovery was motivating to new stroke survivors (1) (2) Increasing knowledge about stroke not only helped stroke survivors feel more educated but also gave the	Methodological limitations: minor concerns. Coherence (fit between studies and review findings: moderate

		skills that they could use outside the group context to facilitate recovery process (10) and (7) (3) This could be aided by a source of self-efficacy. There was a significant increase in self efficacy, when compared to a control group, the intervention group had a higher level of self-efficacy (F = 12.41, p < 0.001) see **Table 2** Groups' Comparison at Various Timelines (14) The visit from the peer supporters encouraged and motivated the stroke survivors to work towards recovery (1) Peer support groups helped survivors understand their stroke (10) Many participants indicated that at the time of their stroke and during their hospital stay, they did not feel they adequately understood their stroke **or how they could cope with recovery.** For a few, they were in a coma or faced challenges with aphasia (trouble with language), <u>but none of the 9 participants</u> indicated feeling their doctor or other hospital staff sufficiently answered their questions about their stroke. (10)	concerns Adequacy of data (Richness): moderate concerns Relevance (applicability to context): moderate concerns Confidence in evidence rating: low confidence

		Having stroke-related knowledge not only made participants feel more informed, but also equipped them with concrete skills they applied at home to further their recovery (7) Ten of the 13 members reported “agree” or “strongly agree” they were able to identify a new coping strategy, and eight of the 13 members reported they actively used the strategy outside the group. (5) These findings provide preliminary indication that the YESS group had a positive impact on coping strategies after stroke. (5) For example, members were asked if they engaged in volunteer activities, exercise programs, or leisure programs that were presented in the group modules. Over half of the members (n = 8) reported they began to engage in various leisure and ADL opportunities outside of the group context. (5)	

		Being supported in their attempts to cope with the situation (9) The participants struggled to cope with their new and unknown situations after the stroke. The issues they struggled with varied widely, **from performing daily activities and solving practical problems to understanding and coming to terms with their own emotional reactions and those of their family, friends and colleagues**. Facing different social situations within and beyond their family entailed many challenges. (9) The participants reported that the intervention helped them cope with their struggles. Participants in both the individual and group-based interventions emphasised that the dialogues helped them cope by **clarifying what their coping challenges entailed, illuminating their coping options, supporting them as they tried different oping strategies and support**ing them as they analysed unexpected situations (9)	

		fifteen of the participants, eight recipients and 7 peer supporters, also agreed with the statement “In the group, other members advise me what I should do about difficult situations and life decisions(2) Nine participants, four recipients and 5 peer supporters, agreed with the statement “In the group I get ‘how to on improving my life (2) Main theme: Informative and reminder • The videos narratives were a “trigger” toward proactivity and enhanced patients’ awareness about stroke and its preventative treatment. (13) They remind us of important medicine… They remind us of the danger of the second stroke… to take medicine well and to have a healthy lifestyle [P7] Helpful….more understanding about stroke [P6] (13) Awareness… before that we were not really concerned about our health. Now, after the advice it’s different... like a guide [P4] (13) Patients can recover from stroke and (it) won’t recur if we take the medicine prescribed by doctors according to the right schedule on time [P2] (13)	

		For example, members were asked if they engaged in volunteer activities, exercise programs, or leisure programs that were presented in the group modules. **Over half of the members (n = 8)** reported they began to engage in various leisure and ADL opportunities outside of the group context. (5) Handicap domain of Stroke Impact Scale (SIS) *p* value= .034 Home integration domain of Community Integration Questionnaire (CIQ) *p* value= .002 (5) the SIS self-perceived recovery domain and the social and productivity integration domains of the CIQ did not reach significance the SIS self-perceived recovery =*p value*=.196 productivity integration domains of the CIQ p value =0.334	

	Impact on loneliness and social interaction	Definition: discussion around how the intervention of interest had positive outcomes on social well-being which were the following: (1) decreasing the sense of loneliness following stroke, Related to decreased loneliness. Related to decreased loneliness. After having someone who had gone through a similar experience take time, listen, share experiences, and make a connection, stroke survivors reported feeling validated and less alone(1)	Methodological limitations: minor concerns. Coherence (fit between studies and review findings: No concerns Adequacy of data (Richness): No Concerns Relevance (applicability to context): No Concerns Confidence in evidence rating: High confidence

		It made me realise **I was not alone**, that there are many others in the same position." [Patient peer supporter 2]. (2) shared experience may reduce feelings of loneliness as Paul illustrates (3) That is good if you know there are others in the same position as you. Going, going through the same thing as you. So you don't think you are the only one... It's good talking to other stroke survivors because with their experiences you know you are not alone then. Because it is very demoralising once you have had your stroke. (Paul) (3) -I think partly it was like a day out for her, breaking the monotony, but once her family came back she had something to fill the day. When I had my stroke and was looking for help, anything I was offered I would go for it. For me I was looking for solutions to problems, I was meeting with her to work on solving problems. Her problem **was loneliness, so I was the solution**. (Peer 2) (4)	

		Participant R2G3 said, “It makes you feel like you **are not alone.** Like there is someone else out there that is having the same problems and concerns that you do. And how they are dealing with it makes a difference(7) -I think that if I had’ t had this course [intervention], I would have felt terribly alone. (Woman, 66 y.o./group intervention).(9) Peer support groups helped survivors not feel alone or isolated. Almost all participants commented on the importance of connecting with other survivors. At least half of the survivors expressed gratitude to have received either a visit in the hospital or a phone call from a stroke survivor. They articulated that the isolation of their stroke seemed somewhat alleviated once they connected with others in a similar situation. “You find you’re not alone. [The group] is an	

		extended family who knows what you're going through." –Angela, 11 years post-stroke (10) You don't feel quite so much out on a limb. When you've heard [that] other people have gone through the same procedures you had." **[Patient 6].** (2) "It made me realise I was not alone, that there are many others in the same position." [**Patient peer supporter 2].** (2) Related to developing valuable relationships and increased social interaction which occurred through the following mechanism: it the group has changed my life **as I have made friends with other people who** have had a stroke." [Patient 7].(2)	

		Member response to post participations survey :5 out 13 reported “strongly agree “ that the program helped them to make new friends and 5 out of 13 reported” agree” (5) Descriptive data about social and communication activity outside of the group were tracked on the post group survey. For example, members were asked if they met with anyone socially outside of the group or if they used communication path- ways such as Facebook or texting to socialize/communicate outside of the group. Approximately, half of the individuals (*n* = 6) reported interaction with another member outside of the group context in various formats including text (*n* = 2), Facebook (*n* = 2), met or attempted to meet outside of the group (*n* = 8), email (*n* = 5), and talk on the phone (*n* = 6). (5) Equally, over half of the members (***n* = 8) reported socialization being their favourite aspects of the** group process .example, members reported new friendships and social networking were most beneficial. (5)	

		The social domain The CIQ social domain did not reach significant: Mean pre score: 8.23 Mean post score: 9.08 (5) *p* value =0.148) (5) The sense of community was unique to the support group experience, and impacted participants' lives beyond scheduled stroke support group meetings. Participant R3G2 noted, "I think this group has become more than a support group once per month. They are almost like family (7) They [other survivors] speak to me and then they'll listen. Some people would say 'oh, I can't be	

		bothered'. **They're like friends** because they're always willing to help you'" –Lillian, 1.5 years post stroke (10) Negative case : The peers identified that although they had not experienced this difficulty, they could see how there was the potential for the stroke survivor **to become attached to the peer: I**t's hard to meet somebody one to one. To meet them at a personal level and then suddenly, that is it, you are never going to see them again. This could be a problem because if you get the wrong sort of people, the ones that cling on all the time they would be phoning you all the time just for a bit of company. (Peer 1) (4) Proposed mechanism behind evidence : (1) Exchanging stories with other stroke survivors who had gone through similar circumstances was identified as essential inspiring and necessary, particularly when dealing with something as severe as the occurrence of stroke. (2) Peers were also seen as a source of inspiration to pursue a peer position in the future, which aided in the growth of **social identity.** (3) The facilitators gained a better understanding of the participants as individuals because of sharing stories with the groups (**8)**	

		(4) Sense of community that was created in the group could led to develop a lifelong valuable relationships , support and network outside of the group context that continued validating the sense suffering outside the group context .(7) When a traumatic event occurs, such as a stroke , **it is important to be able to share experiences with those** that had been in similar situations (9) Peer supporters were also seen as a source of inspiration (1) some stroke survivors who expressed an interest in pursuing a peer supporter role in the future.(1) As part of the evaluation, the facilitators were asked to answer the following question by the trainee clinical psychologist: 'How was the Share **Your Story** Group useful for you as therapist?' Responses were written down verbatim and grouped. This resulted in the following categories: (8)	

		■ Getting to know patients as people (six responses (8) **They have become friends and support** outside of the meetings." Additionally, participant R2G1 stated, "We love the relationships that we are building with other people. Even if we are in a store ... it's like, 'oh they are in our stroke group.' It is important that outside of this room even, it reminds you that there are other people experiencing the same reconfiguration of their life that we are." (7)	
	Impact on emotions Depression	Definition: discussion around the impact of the intervention of interest on depression and related emotions Qualitative results related to depression outcome : Mechanism related to depression outcomes : 1. sharing experience with other stroke survivors and validating own suffering helped in reducing depression. (7) (10)	Methodological limitations: minor concerns. Coherence (fit between studies and review findings: moderate concerns Adequacy of data (Richness): moderate concerns Relevance (applicability to context): moderate concerns Confidence in evidence rating: low confidence

		Many participants shared feelings of frustration, depression, and isolation. These feelings stemmed from fear, lack of strength, and feeling overwhelmed by the challenges of adjusting to a new normal after stroke. However, **sharing their experiences in peer** stroke support groups was helpful. Participant R2G1 noted, "I felt that I was a **little depressed** before I came … I found that being around **other people that's gone through the same thing helps."(7)** 2. Being in a group of people with similar condition and who had disabilities ,yet had positive attitudes could led to increase spirit and decreased depression (10) 3. Participating in a peer support group provided patients with something to do once a month, which helped to alleviate depression. (10) Although many survivors experience depression post-stroke, their support group played a role in overcoming depression (10) Of those who experienced stroke, the majority expressed their support group played a significant role in overcoming depression. (10)	

		"Being together with such a happy group who had disabilities too helped me keep my spirits up so I don't let myself get down." –Lena, 2.5 years post-stroke (10) "I personally thought about suicide. It's scary. In forums they [survivors] all said we felt depressed…in the beginning it's very normal. I'm not alone feeling that way." – Angela, 11 years post-stroke (10) They [the support group] helped a lot. I talked about depression and why I wanted to commit suicide and they were really supportive." –Tom, 7 years post-stroke (10) When I first came home from the hospital I wanted to go home, sit in a corner and cry…..now every month I have something to go to." –Aryln, 7 years post-stroke (10)	

		Quantitative results regarding depression : Intervention group: T0(baseline),*M(*SD).32(.25);T1(interim) .33(.27);T2(post intervention),-.25(.26) and T3(4 months)-.20(.26) (6) A reduction in the mean, for both anxiety and depression scores was found. Mean pre group depression approximate just **at 8.5 of** Hospital Anxiety and Depression Scale (HADS) and Mean of post group depression of HADS approximately just **above 7.5** (8) , but T-test results showed no significant changes in HADS scores before and after the group (n=34) (8)	

Affective mood states, measured by the VAMS at the end of the first and the last BNI also changed, as shown in table 4. While **little improvement was demonstrated for the mood state 'happy'** with an increase in the mean T-score from 40.85 to 47.40 (Cohen's d = .25), the mood states 'confused' and 'tense' decreased moderately from 52.96 to 46.23 (Cohen's d = .56) and from 53.52 to 46.50 (Cohen's d = .45), respectively. For all other mood states there were expected trends towards a growth of positive emotions and a reduction of negative emotions. We also conducted **the VAMS at the end of the first and the last GI. Again we found expected trends. The mood state 'tired' decreased from 49.00 to 43.33 (Cohen's d = .30) (12**)

Table 4. Values for mood states VAMS (Stern 1997) at end of the first and the last biographic–narrative interviews (BNI) and group interventions (GI) (12)

Test	Baseline (end BNI 1)	Post (end BNI 5)	Baseline versus Baseline (*n* = 27),(*n* = 26),post-test mean	mean

			T-scores (95% CI)b	*T*-scores (95% CI)	***P*-value** (outcome)a	Cohen's *d*
		VAMS afraid	47.41 (2.61)	46.62 (1.68)	.50	.12
		VAMS confused	52.96 (5.77)	46.23 (2.12)	.01	.56
		VAMS sad	52.37 (6.73)	47.81 (3.25)	.08	.30
		VAMS angry	50.04 (5.10)	47.08 (3.39)	.25	.21
		VAMS energetic	44.37 (5.11)	48.46 (5.02)	.27	.14
		VAMS tired	46.96 (4.00)	46.92 (4.22)	.78	–.03
		VAMS happy	40.85 (5.48)	47.40 (4.52)	.01	.25
		VAMS tense	53.52 (4.42)	46.50 (2.97)	.00	.45
			Baseline (end GI 1) (*n* = 25), mean	Post (end GI 7) (*n* = 24), mean		

			T-scores (95% CI)	*T*-scores (95% CI)	
		VAMS afraid	47.33 (4.73)	46.86 (3.27)	.40	.36
		VAMS confused	48.00 (5.48)	45.35 (2.03)	.40	.58
		VAMS sad	52.96 (8.85)	47.76 (5.24)	.32	.38
		VAMS angry	48.75 (6.54)	45.19 (2.15)	.37	.41
		VAMS energetic	45.25 (6.03)	48.62 (15.17)	.48	–.09
		VAMS tired	49.00 (6.99)	43.33 (11.70)	.00	.30
		VAMS happy	42.88 (6.92)	45.52 (14.92)	.23	–.02
		VAMS tense	51.21 (4.86)	49.86 (11.80)	.93	.18
		Notes: [a]Repeated measures *t*-test, two-tailed. [b]*n* varies because not all participants attended at each session.				

TABLE 4 Values for mood states VAMS (Stern, 1997) at end of first and last biographic-narrative interview (BNI) and group intervention (GI) (*n* varies because not all participants attended at each session) (11)

	Baseline (end BNI 1) (n = 17) Mean -t-scores (95% CI)	Post (end BNI 5); (n = 16) Mean t-scores (95%CI)	Baseline vs. Post-test p-values[1] (outcome)
VAMS afraid	48.06 (4.32)	46.38 (2.35)	.30
VAMS confused	54.88 (8.99)	46.50 (3.65)	.03*

		VAMS said	52.88 (10.33)	48.13 (5.33)	.12
		VAMS angry	52.71 (8.42)	47.44 (5.49)	.20
		VAMS energetic	44.35 (7.33)	49.00 (7.11)	.39
		VAMS tired	48.65 (6.12)	46.38 (5.47)	.64
		VAMS happy	39.00 (7.66)	46.53 (7.13)	.02*
		VAMS tense	54.47 (6.59)	46.63 (4.49)	.01**
			Baseline (end GI 1); (n = 14)	Post (end GI 7) (n = 13)	Baseline vs. Post-test
		Test	Mean t-scores (95% CI)	Mean t-scores (95% CI)	p-values[1] (outcome)
		VAMS afraid	48.00 (4.44)	46.00 (2.70)	.56
		VAMS confused	49.43 (5.48)	45.00 (1.53)	.30

		VAMS said	51.64 (8.85)	46.23 (3.37)	.42
		VAMS angry	49.00 (6.54)	44.69 (1.55)	1.00
		VAMS energetic	44.93 (6.03)	47.46 (8.09)	.86
		VAMS tired	52.07 (6.99)	45.15 (6.61)	**.06**
		VAMS happy	42.36 (6.92)	43.92 (8.25)	.46
		VAMS tense	49.79 (4.86)	46.23 (5.67)	.44
		[1]Repeated measures *t*-test, two-tailed.			
		Definition :discussion around how the intervention of interest seemed to reduce the sense of fear and instilling a feeling of reassurance			
		Qualitative result :			

		Viewing the video narratives provided some hope and **less fear to overcome stroke challenges. I**t's a bit of both worrying and confidence… There is always a worry about what can happen, but it also gives you an idea (on) what to do, and what to be careful, and what to be aware [P3] (13). That emotional support was provided during the initial in- hospital visit in the re- assurance(1) far was emphasized as a great challenge in accepting stroke.. [10] When I first had the stroke, I went to my family doctor 3-4 times a week thinking I would be having a stroke. I was always scared," and indicated "**the group helped me overcome my fear."** –Kelly, 4 years post- (10) that's **where the group helped**." Irene, 5 years post-stroke (10)	Methodological limitations: minor concerns. Coherence (fit between studies and review findings: moderate concerns Adequacy of data (Richness): moderate concerns Relevance (applicability to context):

		The motivational cues inspired the patients and raised confidence among themselves. … (sharing) someone's experience to change others 'mind. Sometimes, we need to listen to their stories for us to make a change [P4] (13) **Negative case** :There may conversely be some negative impacts of the interventions on emotions of both stroke survivors and peer supporters which might occurred through the following mechanism : • Some aspects of the intervention such as sharing experiences of stroke and recalling distressing memories might be "distressing" and "difficult" (3) • Sharing experiences of stroke within a group context might impact negatively on physical and emotions health (increased stress) (3) **Negative case related peers** who provided the intervention : there might be a potential emotional impact of the intention on peers as the intervention might trigger experience relates to their initial stage of stroke.	moderate concerns Confidence in evidence rating: low confidence

		While concern was expressed by program coordinators about the potential emotional impact on peer supporters for whom the visit may trigger past feelings related to the initial experience of stroke, none of the peer supporters interviewed described experiencing these types of feelings (1) Ability to cope emotionally – "perhaps not everyone can cope" The ability of each individual to cope with the potential emotional demands of a group SMP was discussed by participants. Some aspects of a group may be emotive for some individual's such as, **discussing experiences of stroke and remembering things that are distressing. (**3) Five stroke survivors spoke about how they would cope emotionally when hearing and talking about stroke. Thomas reflects on times he has had to hear about stroke, such as in the paper. He says he does not like it as he finds it both "**difficult**" and "**distressing"** to hear(3)	

		Quantitative result : **VAMS** afraid (P=.056) (11) **VAMS** afraid (p= 0.36) (12)	
	enhanced awareness of stroke and knowledge	Definition: discussion around how the intervention of interest provided information support which enhanced awareness of stroke and increased knowledge One reason to join the group was pursing and gaining knowledge related to stroke (7) and (10)	

		Theme 1: Survivors and caregivers **seek and receive** knowledge about stroke and stroke recovery from stroke peer support groups. (7) Participants shared that **they initially attended** stroke peer support groups to learn more about stroke and recovery (7) "I wanted a place to learn more and educate myself more on stroke and how to cope with life." –Richard, 2 years poststroke (10) The intervention of interest provided useful knowledge about stroke prevention and rehabilitation, as well as identifying and accessing stroke support services in the community, to stroke survivors and their care partners.	

		Informational support was also offered during the initial and follower up telephone visits. Peer supporters provided written as well as verbal information on resources in the community including those offered by SSAO. (1) During the initial visit this information tended to be more general in nature. However, during follow-up telephone calls, information was targeted to the new stroke survivor's or care partner's needs and included information on specific services avail- able in the community. Information to assist with both finding and accessing services was provided to six out of the 28 people for whom follow-up diaries were kept (1). What did these **survivors want new** survivors to know about stroke peer support groups? (10) "They can help you and be very helpful with resources." – Kelly, 4 years post stroke (10)	

		. Importantly by meeting with other stroke survivors at different stages of recovery, participants gained knowledge from each other and felt empowered by providing help to their peers. Participant R2G4 said, "Each one of us helped somebody that was having a stroke. If we can do what we do and not be doctors, we can make a big difference right here." (7) You discuss things so you can be on the lookout for anything that might be going wrong, or things you need to be looking to get checked out if you are having this symptom or that one that you might not have thought about before(7) Several participants felt that peers provided valuable information and advice about post-hospital support services (2)	

		I've learnt what help you can get when you come home... and how to get it." [Patient 5].(2) Information about the experiences of coping with stroke provided by peers was valued higher than the information provided by health care professionals. Information received from a peer regarding the experience of living with stroke was generally given more value than that received from a healthcare professional.(1) And (10) Stroke survivors who had a lot of experiences since their stroke thought to be the in the best position to support. Individuals with substantial experience subsequent to their stroke were viewed as being in the best position to be helpful. (2) "that was the ones that I probably got the most benefit from. the ones that had come in that had had strokes	

		probably a year earlier than I had that were further up the road...and you can ask them questions... what do you do in this situation or another situation?" [Patient 6]. (2) Peers offered knowledge and information gained from real -life experiences which promoted relatedness. peer supporters] provided sort of reassurance... and provided a real face. When you're dealing with doctors and nurses they're great.... But they're medical people and they can talk to you about what you've just gone through, but the chances are more than likely that they haven't... The people in Stroke Survivors, well they have. (New Stroke Survivor-Mike, initial interview) (1) The group enhanced knowledge about stroke support services in the community and opportunities such as voluntary jobs and modified leisure activities. Finally, members identified on the survey that the most useful aspect of the group process was learning about new **information, education, and information** on community re- sources. Thus, results	

		from the survey supported both social engagement and role participation. (5)- See TABLE 5. Member Responses to Post participation Survey (*N* = 13) It was difficult to obtain knowledge about stroke and rehabilitation from stroke, and they and their caregivers valued the ability to learn about these topics from both peers and experts Receiving stroke and recovery related knowledge was important to survivors and caregivers, and difficult to locate. As participant R2G1 stated, "We all go different places and do different things but there is not really a great one source; you just can't go to the kiosk and say, 'I would like to have all of these resources for stroke survivors.' It's just not there." (7)	

		The video narrative intervention significantly increased stroke related knowledge. The Stroke Knowledge Test (SKT) substantial mean score differences between groups (F (1214) =11.54, p=0.001, η2=0.051) (F = 11.54, $p < 0.001$) (14)	

Note:1= Kessler *et al.,* (2014);2=-Morris and Morris (2012);3= Clark *et al.,(* 2018);4=-Masterson-Algar *et al.,* (2018);5=Muller *et al.,(* 2014);6=Chow (2018);7= Christensen *et al.,(* 2019);8=- Gurr (2009);9= Kirkevold *et al.,* (2014);10= Hancock, (2009);11= Corsten *et al.,* (2014);12= Corsten *et al.,* (2015);13= Appalasamy *et al.,* (2020a); 14= Appalasamy *et al.,* (2020

Appendix 13- Information sheet and Consent

Information sheet and Consent form

Stories relating to diagnosis and living with Stroke

Version 1.0

Rana Alawafi,

School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham

Section A: Information sheet

Participant Information

I am a researcher that is interested in the stories people who have had stroke starting from before hospital discharge. This project is one of an extensive range of projects that hopes to further and establish the role, benefit and factors that influence the stories that people tell.

1. Study title

Narratives of Stroke

2. Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The purpose of this study is to explore stories associated with diagnosis and living with stroke.

4. Why have I been chosen?

You have been chosen to take part as you are an individual directly affected by a Stroke and your views, opinions and experiences are vital to constructing an understanding of stories associate with illness at different time .We are interested in obtaining participant from individuals who are over 18 years of age and do not have any cognitive or speech difficulties and would be able to sign a consent form themselves.

5. Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Please be aware that once the data has been published then you will not be able to withdraw.

6.

What will happen to me if I take part?

You will be required to undertake one semi-structured interview via Skype lasting a maximum of 1.5 hours. This means you will be invited to Skype video call by one of our research team. At the start of the interview, we will ask you to confirm some basic demographical information and then proceed with 29 specific questions relating to your illness stories and your experiences of diagnosis stroke and living with stroke.

You will be given a £30-pound voucher to keep once you accept and attend the Skype video interview of whether you complete the interview or have to remove your data.

7. What do I have to do?

You will be required to accept one video call via Skype by one of our research team and allocate no more than 1.5 hours of your time to take part in the interviews. Then, you will answer open questions around your experiences and stories relating to diagnosis and living with stroke.

8. What are the possible disadvantages and risks of taking part?

Giving time to this interview may impact on your day and be a disruption.

9. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. All recordings from interviews will be anonymous and will be kept in a locked office in a secure building at the University of Birmingham and Data Protection Act (2018). This data will be kept for 10 years.

10. What will happen to the results of the research study?

The data will be used for research publications and outputs that accumulate your responses with others to document stories or experiences stated. They will be presented within the university and may be used for conference presentations.

11. Who has reviewed the study?

Contacts for further Information

PhD student: Miss R Al-Wafi

Email [redacted]

OR

Project supervisor: Dr A Soundy

Email: [redacted] Phone: 0121 4148385

Section B :Consent from

Study Number:

Unique Participant number (to be given to participant):

CONSENT FORM/email

Title of Project: Narratives of Stroke

Name of Researcher: Rana Odah Alwafi

Please initial box

I confirm that I have read the information sheet dated 01/10/2020 (Version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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 understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

I agree to take part in the above in the above study ☐

Name of Participant Date Signature

Name of Person Date Signature

Document provided to participants if it is identified that they are distressed or become concerned following the intervention.

Appendix 14 -Pilot interview

Think out loud pilot interviews

Thank you for agreeing to take part in an interview. This interview will take around 20 minutes and is focused on helping us to determine if the proposed interview schedule for our upcoming study is clear and understandable, and if the questions we ask make sense.

Prior to this interview we have provided you with details of the aims and objectives of the study. We hope this information has provided you a background understanding of the study. In this session, the interview questions that are a part of the study will be put to you. We would like to ask you to provide your own thought process and understanding of the questions that are asked. Please speak your thoughts aloud about the following points regarding each interview question posed:

- What did you think the question is asking?
- Is it clear?
- Is any amendment/change needed?
- OR How can we rephrase the question to make it clearer?

If you are happy, can we go through the interview questions that will be asked to community stroke survivors participating in our study.

Appendix 15- The interview schedule

The interview schedules

Section A: Demographical information and Interview schedule

Unique Participant number (to be given to participant):

Demographical information

Please identify the following details:

Age:

Gender:

Diagnosis:

Time since diagnosis (years):

Interview Schedule

Stories are very common ways that people use to share experiences of illness. They are useful because they help others relate to your experience and can aid psychological adjustment and coping when they are shared. We are very interested in the plot of the story associated with illness i.e. a plot could be I want to get back to who I used to be, life couldn't get better now even though this has happened, I am sadden by the event. We would like to examine your stories at a specific time. For the purpose of this study we are interested in stories people tell following stroke just before and after discharge from hospital. Thinking about your own experience and others experience of having Stroke.

Section 1: General information (5 questions)

We are interested in understanding experience, interactions s stories from people around your time at hospital and just after.

Are there any experiences that stick out in your mind as important?

As you look back were there experiences that were difficult?

Were their experiences that were important to you?

Would you want to change any of the experiences? If so how

Section 2: Talking with people before Discharge (within hospital) (14 questions)

How long did it take for you to come to terms with what had happened**?**

Did you perceive a need to talk to people about what had happened to you?

Was there opportunity to talk to people before discharge?

Did you want to see or hear any stories about other people with stroke? if yes, from Whom? Prompt, other stroke survivors or staff.

Was there people you admired? If so who was it and why?

If you went to a hospital what stories would you tell someone before discharge now as you look back?

Were there any stories that influenced you during rehabilitation experience? How and why, can you explain?

Were there experiences that influenced how you came to understand what has happened during your hospital stay?

How did you expectations change over your stay?

What is helpful at that time? Not so helpful? Interactions, experiences.

What were your goals?

What would you do to help people at the start of this process?

Were there stories you didn't want to hear?

Where there any stories you admired?

Section 3: After discharge (when you went home) (6 questions)

Did the experience after discharge challenge you

Looking back at this time was there any stories that would be useful?

Did you want to see or hear any stories about other people with stroke? if yes, from Whom? Prompt, other stroke survivors or staff.

Were there any stories that influenced you at this point? How and why, can you explain?

Did you share your story with others? If so, who did you tell?

Did you story change compared to when you were in hospital?

Section 4: Designing an intervention for stroke (4 questions)

We would like to use stories to help people around the before and after discharge

What stories do you think are important at this time for people to know?

Who (health care professional, peer, family member) should share stories?

Would you have preferred stories from a person with stroke or access to an internet site with stories on?

Appendix 16- individual identification of master plots by participant

Results for participants

Participant 1

The main narratives for Participant 1 were overcoming the monster. He had to overcome an internal barrier and want to be active and part of this was identifying goals and achieving those goals. His story morphed into a quest narrative because he had identified changes that were needed within UK stroke services, as time progressive the goals and objectives were to change health care through research which were largely achieved.

The plot is situated like 'overcoming the monster' the stroke illness threatened the individuals very existence, their psychological well-being, their ability to work and their social identity. The monster was how close he came to destruction. The context from the start meant health care didn't recognise the symptoms of a stroke, but recognising the problems helped the individual identify a need to change what was happening. This recognition began what became like a mission or a quest to help other as he states;

"they investigated me for an upper spinal tract injury because I'd had an RTA [road traffic accident]. They didn't really look at what was in front of them at all, which was classic stroke symptoms. I was put on an observation ward for 72 hours and nothing else was done. And then after three days the on-duty registrar ordered an MRI and that's when the stroke was discovered…. But those mistakes are still being made today. And that's what motivates me to keep getting involved in as much as I can. "

Participant 1 clearly identifies two critical moments post stroke, which were so far removed from how he saw himself. When he identified these moments, in amongst the difficult a challenge or mission was born. The first moment was identify as being at the edge of psychological destruction, told within the context of the hospital ward he was on and influenced by the health care system that surround him;

"I mean hospital; I was on a ward with octogenarian, double incontinent men. It wasn't the most pleasant of experiences. I think it probably, it didn't destroy me, I was on the edge of that. I had told a number of clinical academic colleagues that I've made in the last 15 years, I can remember at one point waking up and this awful stench of urine and faeces just permeating every orifice of my body. And pulling the bedclothes over my head and praying that I'd go to sleep and not wake up. Now, that's not me at all, but that was the effect of that environment. And when I was told by my consultant that they'd actually discussed in a meeting about my psychological welfare being on that ward, and decided that I was coping okay. But nobody had asked me"

Participant 1 had a very supportive family, he acknowledges how 'lucky' he was to have such a supportive family. His wife in particular had a role in pushing him beyond a state of despair during the second critical moment of his story which was when he returned to work, as he states;

"my friends and family could see a horrific deterioration in my psychological state, especially when I tried to go back to work. And they were afraid to talk to me about it because they knew how fragile I was. My wife was amazing in that there were times when I was crying my eyes out, saying I just couldn't do it. I couldn't go back to work. And she knew that if I didn't do it that would be the end."

Following these critical moments, he was able to demonstrate a will and fight to achieve something, these moments provide a clarity and action plan around what he needed to do. Creating possibilities and having hope was central to his action plan, as he identifies a danger with false despair;

"I still think that we have to acknowledge that we must give hope. I don't accept this thing, you may be giving false hope and I answer that now as well, no one talks about false despair. And I think false despair is the evil twin of false hope. By not giving hope we're compelling people into this vortex of false despair, which is far more destructive."

This fight was for independence and taking back ground lost to his former active self as a cyclist and a professional person. It began in hospital, as he recalls;

"I've achieved every goal that I've set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I sort of gave up on that particular one. They started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal. I was fed-up of people I didn't know having to support me in that very, very basic human function."

Participant 1 understand the importance of his action for the greater good, he could see the importance of dignity for people that had experiences of it being lost within the hospital ward and became a key part of his mission for change. In order to create the change he was able to do at the time of the interview he required smaller goals to be achieved. He identified the importance of the word 'improvement' rather than 'recovery', this in his words was '*because I think improvement is infinite and that's what we should be doing in terms of giving people hope*'. This understanding was linked with goals as he states; "*My goals change and as you start to appreciate how you've improved or you can improve, you then can change your goals*."

Very early on he was able to identify goals as a way out of hospital and as a way to a new life, he identifies setbacks, but nothing that stopped his progress, this was the route to 'overcoming' the stroke and something which came naturally to him as he explains;

"As somebody who had been in education, target setting was natural, but I'd never had targets which were so personal or so meaningful as this. The next one I had was to shower independently and I learnt how to do that… Then I had to get my confidence back to go and start that process again, to go and wash independently, which finally the OTs allowed me to do…. Then the next one was to stand up and give my son a hug, my middle son, on his 16th birthday."

A critical change came when attending a conference and listening to a peer talk about their experiences of stroke. This gave him the courage and impetus to become significantly embedded in research, he identifies first national reach then international research and

association with research. He identifies and explains bigger goals which naturally evolve from the small achievements he has made.

Participant 2

Participant 2's identified with a difficult position of being a young mother of 2 children when she experienced her stroke. Her story was one of being isolated and abandoned, the monster for participant 2 was her mental health and which fluctuated for different reasons. Participant 2 provides an account of her stroke, which occurred at a similar time to being pregnant. The main plots of the early story was that of isolation and abonnement. Isolation was due to who she was and by comparing that to others as she identifies "*I was the only young person, 27 year old mum, a pregnant woman who had had a stroke. I didn't know of anybody else*." Isolation was also identified due to the inability to account for her needs, as she states when she reflects on the advice given about attending a day centre for stroke,

"I was told to speak to Help the Aged…I didn't really want to go to a day centre where I could sit other people who have had a stroke…I wanted to be an active mother and [have] active involvement in my baby's life and things as well. So I didn't want to just go off to a day centre and leave them there to."

abandonment by the health care service and isolation. Participant 2 states

"There was talk about help that I would get when I'd come out, help with the baby, help with, because I'd already got a two-and-a-half-year-old, help with that. … But when I actually was discharged, there was none and we kind of had to fight to get help."

Participant 2 describes how her requirements were left because the services couldn't identify who should provide her with support, because of the cost that would be required. As she states "*The adult people were saying no because I'd got a baby and the children's services were saying, well, it's you that had the stroke, so you need the help…I think maybe 12 months later it was the children's services that actually put in a direct payment scheme*"

The story identifies a struggle and further highlights the lack of support and more recently the need to help herself. Part of the story is about the need to reflect back on how stuck she became psychologically and how that was rooted in the challenge she faced, as she says;

" there's always been a bit of me that's quite hard on myself as well. As time has went on, I'm struggling most with why I couldn't hold my baby or I couldn't bath her or things like that. I'd really lay into myself and sort of say to myself; it's a really bad thing. But then, say if I'd ever had a way of, somebody to perhaps talk it through and sort of say, look at it this way, it's okay…"

She recognises the psychological need she had and still has even though time has passed, the way she can get stuck psychological is recognised as something that may endure further;

"I would have liked to have something to have as a support. I do feel that psychologically it can take years for a stroke to kind of, to come to terms with. I'm still struggling now, even though it's like 13 years later, psychologically, who do I talk to? I've had counselling and different things, but they haven't gone really, they haven't really helped. So I'm kind of thinking of ways I can help myself"

The story recognises the need to overcome the psychological difficulties, this could represent the 'monster' from the plot overcoming a monster. That the monster could represented by the negative thoughts and there is a need to overcome them as she states

"I think there's times now where I just get into a bit of a black hole and I think, okay, I need to crawl out of this, I can see myself going bad thoughts and negative thoughts. And I'm thinking,

I need to kind of stop and try and turn this around, so it's not all doom, it's not all bad, it's not all doom and gloom, there are some positive things as well. That's still what, 13 years after the stroke, and whether it'll be, it'll always be an ongoing thing, I don't know. But it kind of, the signs for me were about going to seek help when I couldn't, the negative thoughts, the bad thoughts, oh, I'm fed up, I can't turn this around, I need to go and perhaps talk to somebody."

The story turns from isolation, 12 months following the strokes she found a charity that supports younger stroke survivors. She recognised the value of this and identified the importance of this support early on. She also recognised the value of being able to help others and for a time she supported patients on a stroke ward with art therapist, she says

"I used to do some art therapy in a hospital with an art therapist. And it was all voluntary. We'd go onto a stroke ward and we'd do a bit of art. And I would be there to talk stroke recovery and the art therapist would be there to just provide the art and stuff. And so many people said how they valued that, just because it's something different. And that it was nice to talk to somebody who had had a stroke and managed to get home and live in with the effects of stroke. And it was nice to talk to somebody. But unfortunately, the hospital stopped being helpful in the sense that they didn't want us to go anymore

Participant 3

Main master plots change from restitution to overcoming the monster, the monster in this case was the physical effects of the stroke which were overcome. The participants story following the stroke and for the first 12 months was that of a restitution story and expecting to be restored. As he states

Interviewer: In terms of – did you feel the need to talk to anyone to sort of come to terms with what had happened in hospital or do you think it's a bit too early to try and sort of process what had happened?

Respondent: Oh no… that's the best though. I'm many things but stupid isn't one of them. It was fairly obvious it was changing my – it was a life changer shall we say.

Interviewer: *Yeah?*

Respondent: So, I think that I coped with that quite well because I was naïve enough to think give me three to six months and I'll be back to normal. I did think that. And nobody said I wouldn't be. But then again, they didn't say I would be either. That was just my assumption.

Interviewer: *Right. Right.*

Respondent: You know I've come to terms with it. Well, I've had 12 years now so, yeah, I have come to terms with it, yeah.

The process of coming to terms with the inability to go back to normal was provided in a positive way by stating was identified when he stated "*I mean I've got a lot more… I don't know if the word is movement or what, mobility. I'm 500% on what I was 12 years ago*.". This was the first indication of the story changing to illustrate an overcoming the monster story. Part of overcoming the monster was illustrated by identifying who he wanted to be and who he wanted to avoid being like, as he states

Interviewer: Was there any people that influenced you as you were going through that journey?

Respondent: I quickly realised that, I mean I was only 52, so I was quite young really I think, and I was definitely the youngest one in my group of eight. I quickly realised that a lot of them, and it was an all-male ward, a lot of them wanted everything doing for them and I weren't going to be like that.

During his hospital stay he was given a goal to achieve in order to go home, that provided him with a target. As he states

"They said if I can walk up and down them, I can go home Monday and that was on the Friday. So that was a target. And I chatted to one of the nurses to ask her to help me get dressed on the Monday morning so for when they took me down to the physio. So the one nurse helped me get dressed so I was ready to go. And I found going up the stairs, I'm not going to say easy, but easier than coming down… I couldn't quite manage it but they let me come home."

He was able to reflect on this progression, his determination to progress and overcome, but also a lesson or didactic narrative around understanding what was possible and how change could be uncertain, as he states;

Interviewer: If you were to go into a ward now as you are and offer advice or experience or information, what would you want to tell someone who's just had a stroke?

Respondent: Oh, what would I say to them?

Interviewer: *Yeah.*

Respondent: Well, the obvious thing is don't give up because my main attribute is I'm bloody-minded. See I won't give in to things. I'm still there now. So just – and I did find that if I could do something Monday didn't necessarily mean I could do it Tuesday.

Interviewer: *Yeah.*

Respondent: But it took me a while to figure out that if I could do it once it might go away but it will come back. And so the thing is just because you didn't do it today don't bank on doing it tomorrow. But if you can do it one day you will do it again.

He was able to continue his employment following the stroke and he also was able to attend rehabilitation for 2 years post stroke. In addition to this he identified rehabilitation that he had developed with his wife, the value of this was identified as questionable by a health care professional as he states;

"She'd get my right hand, like a train, the wheels going round. And we'd do this. And that got my arm moving. And the one physio, because I had a home care team come in, used to ask me what I was doing, he goes [health care professional said] it was a pointless movement. But it got my arm going."

He went on to identify other lessons learnt and the didactic narrative for what helped him and what he did, including getting dressed, undertaking activity across year and devising exercises that would help.

He wanted to support others and volunteered at a major UK charity for people with stroke. He hadn't wanted or needed support for his own stroke, he did consider supporting others through a major UK charity, illustrating a quest narrative as he states;

"when I decided to give up my self-employment I was looking for something to do. And I just Googled volunteer work and the [major UK charity] came up. And I thought I'd be an ideal fit. And that's how I go into the [major UK charity]."

Participant 4

Participant 4's narrative was most closes matched with the recovery narrative.

Participant 4 would be honest about his experiences if they. The elements of the narrative which were identified was that the teller want people to listen and are sensitive of being overlooked.

Interviewer: Thinking about sharing a particular story with someone who is in hospital, is there any particular story you think you would share to help them with their experience?

Respondent: I don't know. I would just say the paramedics were very good. Basically I rang 1-1-1, or my daughter did, and they said, "We're sending an ambulance round," which they did do. And the paramedics were very efficient and helpful and seemed very knowledgeable and supportive. They were saying, "It could be Bell's palsy, or it could be a stroke," as we were going in. I suppose ringing 1-1-1 was helpful. …I will say I was 11 hours in A&E before I got a bed, which wasn't great. And also had no food. My daughter had to go and buy sandwiches from the shop. I was on a trolley before I got a bed, until Monday morning. That was unpleasant.

He was stoic and able to put up with symptoms, he was different from past stories as it didn't appear to be self-sufficient. He wanted relationships with HCPS and this was the one aspect that was missing, there appeared to be little willingness to seek out information himself, he looked to others to inform him of what has happened, he would ideally want more information and would like health care professionals to help in this regard. Where possible more information is better and with details.

The relationship and interaction that was valued was a paternalistic relationship with health care professionals and one which would not give any opinions, for instance, he stated;

Interviewer: In terms of what advice you'd give if you went in to talk to somebody who was in hospital right now, what things do you think are important to share with them?

Respondent: One thing, I suppose I've had, they said they'd probably never know why I had a stroke, which I suppose isn't very satisfactory, but it's better to know that. The registrar had written that to the GP. There's an element of, my cholesterol was 4.4. I was moving house, so I suppose I was under stress, so in terms of the causes of the stroke, there was no immediate cause in terms of my blood pressure has always been low. I mean it's probably a bit reassuring to know that it wasn't my fault, if you see what I mean?

He identified an absence of health care professionals to talk to, need to know more information and a want for health care professionals to talk to him, the more the better, for instance he said;

"I had my own room in the hospital, which was very nice. It had a complete, one window of glass, it was a very nice room. But I didn't meet any other people, although it was a stroke ward, I didn't meet any others. It would have been nice for staff to talk to me about my experience, or to put me in contact with someone else in a similar situation in hospital, but that didn't happen."

He identified information he did get but the lack of information or absence of information became a focus of the narrative. At the start this was identified as " *maybe having a better idea earlier on of how long I would be expected to be in there."* In the present he identified

"*although I do feel I've recovered. I suppose I'd like to know why it happened, I probably never will*."

Participant 4 Want to understand what has happened and would use peers to help this process. He identified the value of a local group, stating;

"I did join the [name of group], which that was helpful, sort of, most people worse than me which was, in some ways, made me feel a bit better. But I think hearing other people's stories was quite helpful."

Integrates well into a network and seeks and uses other for information which he will compare against other information given;

Interviewer: Yeah, from talking to others, would you say others have different needs to you? In terms of a recovery perspective, do you think that would influence the needs of people?

Respondent: Some people are very different. The man in my jazz group who has had the stroke, he says, he was told to sleep as much as possible. I wasn't told this, that it was resting for the brain and I was quite shocked when he said he went to bed every afternoon and slept from 2:00 until 6:00. But he was almost told this was, he was told to do this. I think sleep is good, but I was never told sleep was good for me, although I'm sure it is, a normal night's sleep. But I was quite shocked that he was sleeping four hours of the day, on top of a night's sleep.

One of the goals for this person was to go back to an ordinary life, accepting that may not happen and being open about not personally doing enough in some areas

Interviewer: That's useful. Did you have particular goals in mind, after you'd come to terms with what had happened, in terms of what you wanted to do and how it might affect your way of life or what you were doing.

Respondent: Well, I wanted to move house, I wanted to continue with things I was already doing. And I suppose getting back to ordinary life; I'm probably not exercising enough.

Interviewer: Were there any individuals that you think were particularly useful during that period of time, in terms of helping you with advice or information?

Respondent: No. My daughters were quite helpful, but they weren't really giving advice. One of my daughters is a mental health nurse; they weren't particularly giving me information. They were telling me to rest, I suppose, rest as much as possible. Take it easy.

Participant 5

During hospitalisation she reported a need to take responsibility for herself and adjust to what was happening. She identified this experience as being isolated. As she states

Interviewer: Did you feel any need to talk to other people, peers or other people that are in a similar situation at that time, or was it just a case of having to come to terms with it by yourself?

Respondent: It was a case of having to come to terms by myself because I couldn't speak. I couldn't speak, I lost the whole of my left side and I told you I wrote this book afterwards, yes?

This experience was impacted by the health care professionals not getting to know her, but at the same time wanting to be known by the health care team. As she states

"What really sticks out in my mind about that period is the healthcare team not realising…there's a person inside the body and the communication to get to know me, if you like, never occurred. That was the negative side. But there were also a lot of positives, but the negative, which sticks out more in my mind than the positives... The OT especially, did not get to know me. She didn't get to find out what makes me tick, if you see what I mean?"

The hospital experience identified a monster which was being alone and not being able to identify others in a similar situation and feeling like the personal fight and challenge didn't have to be so hard. During the hospital experience, she identified a quick realisation that she had to move on from her old life. This was represented by accepting her 'old life' was over and a new life had to be created:

"My OT didn't, in not communicating with me, or not finding out who the person was inside the body, she didn't realise, she didn't understand, I didn't want to go back to the [name of past job]. And I always remember the first task she gave me was to tell me what you would wear if you were going to a business meeting. No, that life has passed and it's a matter that I reinvented myself as this academic, whatever academic means."

After coming out of hospital very quickly she identified space in the day where she could do something, his was the beginning of overcoming and looking forward, as she states

Interviewer: One thing you said, you didn't want your old life back, how quickly did you realise that you didn't want that old life back? Was it in the hospital, were you like, okay, I've got to look for something new now or?

Respondent: It was when I got home, so I didn't get bored every day. So it was once I was back home, because the hospital kept me busy all day. I was in [hospital name], which has a specialised regional rehab unit, which keeps you occupied all day. So it's when I got home, that then I had to start thinking what was it I wanted to do. And I just wanted to be able to give something back. As you say, something to give back to, for that patient experience, if you like.

This recognition of the need to help others, was demonstrated through various achievements including writing a book, volunteering at a hospital and becoming a counsellor specialising in stroke. For her helping others was the quest, it didn't appear to be about overcoming, rather moving on. This was clearly illustrated when she stated "*quite quickly I came to the conclusion, that's it, life has changed and will never be the same again*." Once this view was established it didn't appear to change as she was determined to continue;

“Interviewer: Did you ever feel like you had to face failure during that time or you had to change view or tact at all?

Respondent: No, I didn’t change view or tact at all. I was just very determined to prove everybody wrong.”

Part of her looking for new challenges was to help others find a new life and seeing there is possibility of taking their own quest narrative. She contrasts this choice against two other narrative master plots with the emphasis on the focus of looking forwarding and doing what is realistic. In the following example she illustrates the importance of overcoming and not looking back or wanting an old life back (a restitution narrative):

“I became a counsellor, specialising in stroke and what I found is that everybody I counselled, all had the same, well, first of all they don’t understand that they’re not alone. They don’t appreciate that, but it’s interesting because they all wanted their old life back, you know, like the good old days. And they didn’t realise that perhaps they weren’t going to get that back, that they were a new person and they had to start understanding the ‘new me’ if you like, or the new norm….it was very difficult for them to understand it. But it’s something that I did get through to them. But it’s interesting, whether they were wealthy or poor; they all wanted their old life back. I must be the only person who didn’t want my old life back “

When the interview considered what advice she would give to others recently diagnosed, she again contrasted the quest narrative to a chaos narrative by stating

“The key thing is that there is life after stroke because a lot of people think their lives are at an end. It’s just a matter of finding what do you enjoy doing? What do you want to do? What can you do at this stage? You’ve got to keep that hope alive.”

She was also sensitive to interactions that were perceived as not helpful or positive. This was because she was solution focused and looked at what was possible rather than what couldn’t be done, this could be identified as she interacted with a doctor, stating;

“What was not helpful was listening to the doctors, to the consultant because he was very negative. His bedside manner was not the best… he didn’t expect me to survive. I mean that was pretty clear from an early stage. Instead of saying, “Now come on, we’re going to get you doing this, we’re going to do this, we’re going to do that,” he was quite negative in his remarks.”

During her volunteering at the hospital she identified how she would help and how physiotherapists would use her to understand patients. This could be seen as part of overcoming the monster, which was the need within the health care interaction. In the following statement she provides an example of understanding the needs of a patient

“there was one elderly lady who enjoyed playing bridge before her accident. And what the OTs didn’t realise, A, that she had a love of playing cards and B, that she had diminished eyesight. So excuse me, don’t give her a pack of playing cards, give her a big pack, not in quantity size, but actual size-wise. Even if she was just to sit there and play snap with herself all day, or patience, at least she would have something to do…So the healthcare professionals would use me to find things out for them that they themselves couldn’t understand which is quite frightening actually.”

During the interview she also identified another moving on to get involved with research and this was a final positive change that offered something new as she states;

“I did get involved with the [Major UK Stroke Charity] and as I say, counselling. But I’ve stopped the counselling now. I’ve pulled away from the [Major UK Stroke Charity] because I want to move on with my life. I don’t want to be kept being pulled back, if you like. So doing research, yes, still keeps me involved, but in a good way”

Participant 6

Participants 6’s story begins with a very challenging situation faced in hospital; she had extremely limited capacity and several significant symptoms including an inability to speak. However, there was improvement in her voice, as she states;

“when I was in hospital I didn’t know much what was happening in the first month. I was in intensive care and then I was in… I just didn’t know. I couldn’t do anything. That was awful. It’s so humiliating in fact because you’re slightly aware but not completely. But afterwards the difficulty I had was with my voice tremendously. I couldn’t – I didn’t make any sound at first, in fact for about a month and a half I had no sound coming out. But I thought I was speaking. And then it got better but it’s very, it’s still, as you can hear, very bad”

Within her story she gave experiences where she faced problems, but within that identified experiences which could be viewed as a setback as something that comes along and can be embraced. Part of her character informed this, when she reflected on who she admired she identified the importance of persistence;

“I read, a man who was, he was some kind of trainer I suppose in the SAS talking about the types of people that they liked. And one of the things he had said was determination to do, to achieve was not enough. It was persistence. Then I have discovered that with persistence – if I don’t do my exercises regularly I go backwards. So that has really helped me that I have to be always persistent…Because if you think of young children, when they like, I remember my children when they were trying to walk they just persisted and persisted. And they didn’t mind falling over because I suppose we all said, “Oh, well done,” and what have you.”

She identified the importance of being independent during this time, and continuing to be independent was overcoming the monster and that had significant value to her, as she explains;

Interviewer: When you were discharged from hospital, was that challenging in any way?...

Respondent: I was fighting all the time and I had wonderful treatment in the hospital. And they offer you all sorts of things. And one of the things I did not ever want to have was a carer.

A major narrative master plot that was integral to much of the interview, was first explored when she explained the uncertainty that was identified around her diagnosis and complex symptoms. She described this uncertainty as something which interested her, she states;

"I was there for nearly three months. And the thing that really bothered me was I had two things wrong. I had a stroke on my right side but my left side was also affected. And that's not possible with a stroke. And they tried to find to what it was but they never could. And that, it still affects me, and that has really interested me. And I often wondered whether any research was ever done into things like that."

The major component of her narrative was identified in the idea of adventure. She identified viewing experiences as adventures, as she states "*I'm still coming to terms with it…. But I don't mind that. I like, it's kind of an adventure to me*." This reflected her ability to view experiences with excitement and benefit and consider the unexpected value that was there to be found. During the interview she is asked to explain when, years before the stroke, she first saw life as an adventure;

Interviewer:Could you just tell me when did you start thinking, "Oh there's some stuff here that's – I can treat it like an adventure."?...

Respondent: Well, I have had the advantage of falling over – this is four years before my stroke. I fell over and I smashed my face. I tripped on a paving stone. And I lost my sight totally in the eye….And from that time on it gave me the advantage of looking at life as learning new things. And in fact I almost wouldn't say, apart from I want to read desperately, apart from that I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating actually…So it programmed me for when I came out of hospital I looked at everything as excitement and people are curious about you when you can't, when you're fuddling around really. And in fact with lockdown, in the beginning of the lockdown, I used to get up very early at about 6:00am. Of course, it was summertime then, it was light. And I would go walking round our cricket field – we've got a cricket field across the road. Four times, an exercise. And then I'd walk around the streets. And one day I was getting very wobbly because I was walking with my stick because there was nobody around. And I was very wobbly, but I could perfectly cope. And a lady saw me from her house and she jumped in her car and, in her pyjamas, which intrigued me, because then stopped and got out and she said, "Oh, I saw you wobbling. I would like to give you a lift," which I refused. But since then she's invited me to have tea with her…. those sort of circumstances, unexpected, makes my life richer because I am now incapacitated in a lot of ways. But I enjoy those sort of things."

This reflects her ability to be open to experience good or bad and identify the value, it is a view that welcomes uncertainty and change and a view that is not dependent on accessing hopes or achieving goals. Difficult experiences were viewed for what could be gained from the experience and what can be gained was exciting and an adventure as it was unknown.

Participant 7

Participant 7 identifies two strokes, leading up to entering the hospital, the first developed symptoms began on one day, but after the initial loss of function, the only symptom that was left was a perception of exhaustion, her mobility returned and she decided to rest at home. The following day she lost the ability to respond to a close family member and was taken to hospital. She explains the action and start of her journey after that, illustrating the will to change with a focus healthy behaviour;

"I then returned home with medication and a low salt diet. I started to working to get low blood pressure and scheduled a visit with my doctor. But then I still continued to get complications from the other stroke. At some time, I thought I was on the journey to recovery…I was, obviously, frustrated and depressed and disheartened as well. I needed motivation to carry on. It's just one of the worst days I had. The best thing I did was make a healthy lifestyle change, stop eating fried food, enjoy your salad each day, vegetarian stuff. I've regained mobility but speech is slightly impaired but I'm still able, you know… yeah, I'm still trying to carry on."

This extract illustrates an early expectation of being restored or recovered, but when this didn't happen a battle against mental health was identified and this could be seen as the 'monster' that needed to be overcome. By herself it appeared that overcoming the monster may not be possible. She repeatedly identified the importance of her daughter on her journey and described herself as a survivor, illustrating the importance of being able to continue, as she states

"I've got a daughter, she's a real inspiration for me. She kept me going and she just brought some joy, which has really enabled me to carry on. I think that's what did it for me, because I think she understood what I was going through. And she became really helpful and encouraging to keep me motivated. And I'm glad I had my daughter to…encourage me to carry on to this day. And that's why I feel I'm a survivor, a real survivor."

Later she identified her motivation to continue was for her daughter as she states "I could sense that she wanted me to carry on. Because it's that relationship, mother and daughter relationship. She didn't want to lose me, I didn't want to lose her, really, because we're very closely bonded together." Her story of overcoming was also focused on healthy choices which help change recovery and a knowing that she needs to be motivated to continue. Her story was about finding a way to continue or as she says finding a way out;

Interviewer: "What would you say to someone who is currently in hospital?"

Respondent: "I think you should carry on and… just tell the people that there is a way out. The best advice I could give you is eat healthy and exercise, drink less alcohol, quit smoking, you know, just try to look after yourself better."

Appendix 17-Information sheet

Study Title: Narrative Vignette:

Dear Participant,

Dear all,

We are interested talking to first and final year physiotherapy students in order to explore your response to the three passages which are based on common real-life stories of people who have suffered stroke. Your responses are incredibly important to help us design a narrative intervention to support stroke survivors in the community. We have identified a short survey to consider your responses to these passages.

PLEASE BE AWARE THAT COMPLETION OF THIS QUESTIONNAIRE MEANS THAT YOU ARE HAPPY TO GIVE CONSENT

The questionnaire considers some background information on you; which includes your age and the year of the studying **Please do not worry about any errors in spelling or language when you are completing the questionnaire.** The most important aspect of this questionnaire is that we get a response. If you are happy to undertake this survey, please click on the following link:

SURVEY LINK

STUDY WITHDRAWAL

IF YOU WOULD LIKE TO WITHDRAW FOLLOWING THE COMPLETION OF THE QUESTIONNAIRE PLEASE EMAIL DR A SOUNDY [redacted] THE WITHDRAWAL DEADLINE IS MARCH 2021. HOWEVER, ONCE RESULTS ARE DISSEMINATED WITHDRAWAL WILL NOT BE POSSIBLE.

PLEASE NOTE THAT RESPONSES ARE ANONYMOUS – IF YOU WISH FOR YOUR RESPONSE TO BE WITHDRAWN PLEASE MAKE SURE YOU ANSWER THE INITIAL QUESTION ON THE QUESTIONNAIRE. WHEN YOU CONTACT DR SOUNDY, THIS CAN BE STATED. WE WILL USE THIS IDENTIFICATION NUMBER TO LOCATE YOU QUESTIONNAIRE AND REMOVE THE DATA.

Thank you for taking the time to consider this survey.

We will send a single reminder after two weeks to enable a higher level of responses. IF you would like feedback please email Dr Soundy on [redacted] and a copy of the findings will be sent to you.

Distress causes by this survey is unlikely. However if this does occur please consider using support services (click on link) like: Samaritans, Hope link UK, CALM, Lifeline, CALL or Breathing space.

Kind regards,

The Research Team

PhD student: Rana Alwafi

Email : [redacted]

Dr A Soundy

Office Tel: [redacted]

Appendix 18- The Narrative Vignette

The Narrative Vignette

Please read the following passage which is a real-life account of an individual who had suffered a Stroke. The individual is describing a particular story plot from their journey following rehabilitation, the story identifies the key challenge they face. Please take a moment to consider the story and then for each story please answer the questions below.

Story (A)

This experience was identified by an individual who had two Strokes the first was 4 years ago.

"I then [following discharge from the Stroke ward] returned home with medication and a low salt diet. I started to working to get low blood pressure and scheduled a visit with my doctor. But then I still continued to get complications from the other stroke… I thought I was on the journey to recovery… and it took an awful long time to come around and understand what happened…I was, obviously, frustrated and depressed and disheartened as well. I needed motivation to carry on…I've got a daughter, she's a real inspiration for me. She kept me going and she just brought some joy, which has really enabled me to carry on. I think that's what did it for me, because I think she understood what I was going through. And she became really helpful and encouraging to keep me motivated. And I'm glad I had my daughter to…encourage me to carry on to this day. And that's why I feel I'm a survivor, a real survivor. I could sense that she wanted me to carry on. Because it's that relationship, mother and daughter relationship. She didn't want to lose me, I didn't want to lose her, really, because we're very closely bonded together."

Story (B)

This experience was identified by an individual who had an Ischemic Stroke 15 years ago.

"they investigated me for an upper spinal tract injury because I'd had an RTA [road traffic accident]. They didn't really look at what was in front of them at all, which was classic Stroke symptoms. I was put on an observation ward for 72 hours and nothing else was done. And then after three days the on-duty registrar ordered an MRI and that's when the stroke was discovered…. But those mistakes are still being made today. And that's what motivates me to keep getting involved in as much as I can….I mean hospital; I was on a ward with octogenarian, double incontinent men. It wasn't the most pleasant of experiences. I think it probably, it didn't destroy me, I was on the edge of that. I had told a number of clinical academic colleagues that I've made in the last 15 years, I can remember at one point waking up and this awful stench of urine and faeces just permeating every orifice of my body. And pulling the bedclothes over my head and praying that I'd go to sleep and not wake up. Now, that's not me at all, but that was the effect of that environment. And when I was told by my consultant that they'd actually discussed in a meeting about my psychological welfare being on that ward, and decided that I was coping okay. But nobody had asked me…I still think that we have to acknowledge that we must give hope. I don't accept this thing, you may be giving false hope and I answer that now as well, no one talks about false despair. And I think false despair is the evil twin of false hope. By

not giving hope we're compelling people into this vortex of false despair, which is far more destructive…"I've achieved every goal that I've set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I sort of gave up on that particular one. They started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal. I was fed-up of people I didn't know having to support me in that very, very basic human function.

Story (C)

This experience was identified by an individual who had an Ischemic Stroke 16 years ago.

"when I was in hospital I didn't know much what was happening in the first month. I couldn't do anything. That was awful. It's so humiliating in fact because you're slightly aware but not completely. But afterwards the difficulty I had was with my voice. I couldn't – I didn't make any sound at first, in fact for about a month and a half I had no sound coming out. But I thought I was speaking. And then it got better but it's very, it's still, as you can hear, very bad…I read, a man who was, he was some kind of trainer I suppose in the SAS talking about the types of people that they liked. And one of the things he had said was determination to do, to achieve was not enough. It was persistence. Then I have discovered that with persistence – if I don't do my exercises regularly I go backwards. So that has really helped me that I have to be always persistent…Because if you think of young children, when they like, I remember my children when they were trying to walk they just persisted and persisted. And they didn't mind falling over because I suppose we all said, "Oh, well done," and what have you…"I'm still coming to terms with it…. But I don't mind that. I like, it's kind of an adventure to me…. Well, I have had the advantage of falling over – this is four years before my stroke. I fell over and I smashed my face. I tripped on a paving stone. And I lost my sight totally in the eye….And from that time on it gave me the advantage of looking at life as learning new things. And in fact I almost wouldn't say, apart from I want to read desperately, apart from that, I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating actually…So it programmed me for when I came out of hospital I looked at everything as excitement and people are curious about you when you can't, when you're fuddling around really."

Appendix 19-The survey

The survey

Instructions for questions

Please answer the following questions and feel free to re-read any parts of the above stories again. There are no right or wrong answers to the following questions as it is your opinions that matter. Therefore, do not feel your replies must fill the spaces provided, or if necessary, please continue your answer on the other side of the paper if you do not have enough space.

Your Identification number (so we can locate your answer an remove if needed)

Please identify a unique number for yourself and retain it: identify a memorable name (send this word to Dr A Soundy or word and add this number to the current date with an underscore e.g., buffalo (YOU detail this)_16/5/2021.

Number: peas_26/7/2021

Before undertaking this survey please confirm (by clicking a tick box) you have read the accompanying information sheet and has opportunity to ask any questions you may want answers to and that you consent:

Tick box ☐

Please indicate your gender (please delete)

- ❍ Male
- ❍ Female

How old are you? (Years)

Year of the studying (please dete one)

- ❍ First year
- ❍ Final year

Have you undertaken a neurological placement?

Yes / No

How many placements have you undertaken?

Number:

Questions applicable to Stories A, B and C

(1) What is your immediate reaction to each story?

Story(**A)**

Story **(B)**

Story **(C)**

(2) list three or more words that describe each story.

Story	Words
Story A	
Story B	
Story C	

Other Questions

(3) What story attracts your attention the most and why?

(4) Which stories do you think is the most common and why?

(5) Which stories do you think is the most unusual and why?

(6) If the stroke incident described above happened to a close relative or friend, which of the three stories (A, B, or C) would you prefer to hear them tell and why?

(7) If you experienced this life-changing disease, which story do you think you would tell and why?

Appendix 20- Immediate reaction to each story

Immediate reaction to story A

Statistics

N	Valid	90
	Missing	0

Immediate reaction to story A		n	%
Valid	Local Support system (friends)	8	8.88
	Family Support	67	74.44
	Uplifting & touching	32	35.55
	Empathy	14	15.55
	Sad	20	22.22
	Care challenges & follow-up issues	25	27.77
	Total	90	100.00

Immediate reaction to story A by cohort

Statistics

N	MSc (pre 1st year)	39
	BSc (1st year)	32
	BSC (3rd year)	19
	Missing	0

Immediate reaction to story A		MSc (1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Local support system (friends)	6	15.38	1	3.12	1	5.26
	Family support	29	74.35	22	68.75	16	84.21
	Uplifting & touching	12	30.76	14	43.75	6	31.57
	Empty	6	15.38	4	12.5	4	21
	Sad	7	17.9	11	34.37	2	10.52
	Care challenges & follow-up issues	9	23	4	12.5	12	63.15
	Total	39	100.00	32	100.00	19	100.00

Immediate reaction to story B

Statistics

N	Valid	90
	Missing	0

Immediate reaction to story B		n	%
Valid	Sad	17	18.88
	Shocking & surprising	9	10
	Unsurprising /realistic story	4	4.44
	Bad and awful experience	4	4.44
	Frustrating & annoying	12	13.33
	Hard to hear /unfair to read	2	2.22
	Angry	5	5.55
	Shameful	4	4.44
	Empathy	28	31.1
	Uplifting	16	17.77
	Shortcomings of HCPs	52	57.77
	Impact of hospital environment /stroke ward	23	25.55
	Provides practical implications for HCPs	16	17.77
	Total	90	100

Immediate reaction to story B by cohort

Statistics

N	MSc (pre 1st year)	39
	BSc (1st year)	32
	BSC (3rd year)	19
	Missing	0

Immediate reaction to story B		MSc (pre 1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Sad	9	23.07	5	15.62	3	15.78
	Shocking to read	3	7.69	3	9.37	3	15.78
	Unsurprising /realistic story	0	0	0	0	4	21.10
	Bad and awful experience	3	7.69	1	3.21	0	0
	Frustrating & annoying	4	10.25	6	18.75	2	10.52
	Hard to hear / unfair to read	0	0	2	6.25	0	0
	Angry	1	2.56	1	3.12	3	15.78
	Shameful	1	2.56	0	0	3	15.78
	Empathy	7	17.9	11	34.37	10	52.63
	Uplifting	5	12.82	7	21.87	4	21.05
	Shortcomings of the HCPs	24	61.53	14	43.74	14	73.68
	Impact of stroke ward/environment on mental health and recovery	10	25.64	7	21.87	6	31.57
	Provides practical implications for HCPs	6	15.38	6	18.75	4	21.05
	Total	39	100.0	32	100.00	19	100.0

Immediate reaction to story C

Statistics

N	Valid	89
	Missing	1

Immediate reaction to story C		n	%
Valid	Inspiring & motivational	18	20.22
	Admiring & impressed	10	11.23
	Hopeful & positive	11	12.35
	Empathy & uplifted	11	12.35
	Sad /hard to read & uplifted	5	5.61
	Surprised & interested	10	11.23
	Individual's traits and characteristics	46	51.68
	Positive outlook/perspective after traumatic /negative event	37	41.57
	Unique perspective /ideology on stroke & life	16	17.97
	Effect of stroke & recovery journey	18	20.22
	Applied & pragmatic story	6	6.74
	Total	89	100

Immediate reaction to story C by cohort

Statistics

N	MSc (pre-1st year)	38	
	BSc (1st year)	32	
	BSc (3rd year)	19	
	Missing		1

Immediate reaction to story C		MSc (pre 1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Inspiring motivational	4	10.52	7	21.87	7	36.84
	Admiring & impressive	3	7.89	6	18.75	1	5.26
	Empathy & uplifted	4	10.52	4	12.5	3	15.78
	Sad /hard to read & uplifted	2	5.26	3	9.37	0	0
	Surprised & interested	1	2.63	1	3.12	8	42.10
	Individual's traits and characteristics	19	50	15	46.87	12	63.15
	Positive outlook/perspective after traumatic/negative event	16	42	18	56.3	14	37.68
	Unique perspective /ideology on stroke & life	3	7.89	5	15.62	8	42.10
	Effect of stroke & recovery journey	10	26.31	4	12.5	4	21.05
	Applied & pragmatic story	3	7.89	1	3.12	2	10.52
	Total	38	100	32	100	19	100

Appendix 21- Words describing each story (A, B and C)

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Words used to describe stories - MSc 1st year; BSc 1st year					
MSc (pre-1st year)			BSc (1st year)		
Words describing story A	n	%	Words describing story A	n	%
Sad	5	12.82	Sad	3	9.67
Disheartened	1	2.56	Painful	1	3.22
Black	1	2.56	Pitiful	1	3.22
Depressed /depressing	2	5.12	Depression	1	3.22
Frustrating	1	2.56	Frustrated/frustration	2	6.45
Trauma	1	2.56	Motivation	7	22.58
Complications	2	5.12	Inspiration/inspirational/inspiring	6	19.35
Unfortunate	1	2.56	Encouragement/encouraged/-ing	4	12.90
Motivation/motivational /motivated	13	33.33	Heartwarming	5	16.12
Inspiring /inspirational	9	23.07	Touching	3	9.67
Encouragement /encouraged	2	5.12	Uplifting	1	3.22
Heartwarming	2	5.12	Cute	1	3.22
Uplifting	1	2.56	Hope/hopeful	5	16.12
Joy	1	2.56	Love/loving & power of love	6	19.35
Sweet	2	5.12	Care	1	3.22
Hopeful	3	7.69	Selfless	1	3.22
Positive	1	2.56	Family	9	29.03
Optimistic	1	2.56	Relational /relationship	2	6.45
Loving/love	4	10.25	Bonding	1	3.22
Caring	1	2.56	Connections	1	3.22
Devotion,	1	2.56	Daughter	1	3.22
Relationships	5	12.82	Support/supportive/supported	6	19.35
Close bond/bond	2	5.12	Helps	1	3.22

Connections	2	5.12	Survivor /surviving	2	6.45
Daughter	1	2.56	Lucky	1	3.22
Support	5	12.82	Determination/determined	3	9.67
Drive	1	2.56	Complaint	1	3.22
Saved	1	2.56	Courageous	1	3.22
Understanding /understood	3	7.69	Pride	1	3.22
Survivor	4	10.25	Warriors	1	3.22
Determination/determined	2	5.12	Strength	1	3.22
Perseverance	2	5.12	Resilience	1	3.22
Hard work	1	2.56	Defiance	1	3.22
Grateful	1	2.56	Achievement	1	3.22
Courageous	1	2.56	Mental health /mindset	2	6.45
Strong/strength	2	5.12	Dependence	2	6.45
Mentality	1	2.56	Recovery	1	3.22
High expectations	1	2.56	Simple in a good way	1	3.22
Meaningful/personal	2	5.12	Real-life/truthful	2	6.45
Total	39	100	Total	31	100.00

Words used to describe stories - BSc 3rd year		
Words describing story A	n	%
Disheartened	1	5.26
Empathetic	1	5.26
Mental strength	1	5.26
Belief	1	5.26
Motivation/inspiration, encouragement	15	78.94
Heartwarming/touching	4	21.05
Love	3	15.78
Joy	1	5.26
Positive/hopeful	2	10.52
Relationship/connection/bound/daughter	4	21.05
Family	7	36.84
Support	5	26.31
Purpose of living	1	5.26
Survival	2	10.52
Transformation	1	5.26
Patience	1	5.26
Vague	1	5.26
Brief	1	5.26
Priorities	1	5.26
Total	19	100

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Words used to describe story B - MSc; BSc 1st year					
MSc (pre-1st year)			BSc (1st year)		
Words describing story B	n	%	Words describing story B	n	%
Sad	8	20.51	Sad	6	19.35
Disheartening	2	5.12	Disheartening	2	6.45
Unpleasant	3	7.69	Pitiful	1	3.22
Stench	1	2.56	Poor	1	3.22
Unfair	1	2.56	Unfair / unfortunate	2	6.45
Heartbreaking	1	2.56	Upsetting	1	3.22
Hard times /difficult	1/1(2)	5.12	Shocking/scary	2/1 (3)	9.67
Humiliated/humiliation/humiliating	3	7.69	Torture/ painful /hurtful	1/1/1 (3)	9.67
Frustrating/frustration	5	12.82	Struggling	1	3.22
Lonely	1	2.56	Loss/dignity/undignified/ self-worth	1/1/1 (3)	9.67
Expecting defeat/failure	1/1(2)	5.12	Frustrating/frustration	4	12.90
Disappointing	2	5.12	Lonely /loneliness /isolation	1/1/1 (3)	9.67
Negative	4	10.25	Destruction	1	3.22
Depressing/depressed	3	7.69	Missed opportunities	1	3.22
Despair	3	7.69	Disappointing/disappointed	3	9.67
Angry	3	7.69	Negative	1	3.22
Vengeful	1	2.56	Depressing/depressed	4	12.90
Mistakes	2	5.12	Pessimistic	2	6.45
Misdiagnosis	1	2.56	Despair	5	16.12
Misunderstood	1	2.56	Anger/bitter	1/1 (2)	6.45
Contemplation/assessment	1/1(2)	5.12	Mistakes	1	3.22
Patient centred care	1	2.56	Mistreatment	1	3.22
Neglect/forgotten/overlooked/ dismissive/abandonment/invisible	4/1/1/1/ 1/1 (9)	23.07	Confusing	1	3.22
Conversation /muted	1/1(2)	5.12	Lack of care	1	3.22

Compelling people	1	2.56	Neglect/overlooked/ abandoned /disregarded	2/1/2/1 (6)	19.35
Trauma	1	2.56	Communication	1	3.22
Unacceptable	1	2.56	Disgust	1	3.22
Disgusting	1	2.56	Doubtful	1	3.22
Lost hope, giving fake or false hope & hopeless	4	10.25	Hope/hopeful	4	12.90
Helplessness	1	2.56	Hopeless	5	16.12
False identity	1	2.56	Unprofessional / ignorance	1/1 (2)	6.45
Demotivation/unmotivated	2	5.12	Powerless	1	3.22
Managing expectations	1	2.56	Motivation	2	6.45
Unknown	1	2.56	Unexpected /surprising	1/1 (2)	6.45
Unexceptional /reality	1/1(2)	5.12	Eye opening	1	3.22
Experience/knowledge	1/1(2)	5.12	Psychological health/ wellness/welfare	1	3.22
Poor mental health state /mental health / psychological welfare/ wellness/welfare	1/2/2/1/ 1 (7)	17.94	Recovery is possible	1	3.22
Emotions	1	2.56	Support	1	3.22
Environment	3	7.69	Strength	1	3.22
Acceptance/coping	1/1(2)	5.12	Determination/determined	3	9.67
Recovery	1	2.56	Goal setting/ setting small goals every time	2	6.45
Uplifting /relief	1/1(2)	5.12	Slow	1	3.22
Strong minded/strong	1/1(2)	5.12	Total	31	100.0
Persistent	1	2.56			
Goals settings /goals	2	5.12			
Achievement /triumph	1/1(2)	5.12			
Spiralling	1	2.56			
Total	39	100.0			

Words used to describe story B - BSc 3rd year		
Words describe story B	n	%
sad	2	10.52
Discontent	1	5.26
empathy	1	5.26
unfairness	1	5.26
Frustration/frustrating	3	15.78
Negativity/negative hospital experience/ negative experience /Hospitals	4	21.05
dark	1	5.26
Neglected/neglect	2	10.52
alone	1	5.26
Disappointing/disappointment	3	15.78
Hopeless /Desperation/desperate/despair	6	31.57
Worrying /scared	2	10.52
Shocking/disgusting	2	10.52
Humiliating /embarrassing	2	10.52
Anger/angry	2	10.52
Depressed	2	10.52
Mental health /emotional		10.52
Patient-centred care/ feel not being taken care of properly	2	10.52
Unawareness /knowledge	2	10.52
Mistake/unprofessional	2	10.52
Bold/strong	1	5.26
Determination	1	5.26
Motivated /self-motivation	2	10.52
Independence	1	5.26
Journey /adventure	2	10.52
Struggle	1	5.26
Failure	1	5.26
primitive	1	5.26
Total	19	100.00

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Words used to describe story C - MSc; BSc 1st year					
MSc (pre-1st year)			BSc (1st year)		
Words describing story C	n	%	Words describing story C	n	%
Positive /positivity	11	28.20	Positive	5	16.12
Inspiring /inspirational /inspiration	6	15.38	Inspiring /inspirational	6	19.35
Hope /hopeful	4	10.25	Hope /hopeful	5	16.12
Optimistic	1	2.56	Optimistic	5	16.12
Good outlook	1	2.56	Motivational/motivating /motivation /self-motivation	5	16.12
Long-term /future	1/1 (2)	5.12	Encouraging /encouragement /encouraged	5	16.12
Motivational/motivating/ motivated /motivation	9	23.07	Driven	1	3.22
Encouraging	2	5.12	Empowered/empowering	2	6.45
Driven	1	2.56	Enlightening	2	6.45
Uplifting	1	2.56	Amiable	1	3.22
Happy	2	5.12	Interesting	1	3.22
Excitement/exciting	3	7.69	Heartwarming	1	3.22
Impressive	2	5.12	Adventure	3	9.67
Adventures	1	2.56	Curiosity	2	6.45
Brave/fearless	1/1 (2)	5.12	Fear	1	3.22
			Confidence	1	3.22
Persistent /persistence	14	35.89	Persistent /persistence	14	45.16
Grit	1	2.56	Determination/self-determining	3	9.67
Determination/determined	5	12.82	Staunch	1	3.22

Dedication/ hard work	1	2.56	Perseverance	1	3.22
Hard work	1	2.56	Challenging	1	3.22
Resilience/resilient	3	7.69	Struggle/struggling	2	6.45
Perseverance	2	5.12	Accomplished	1	3.22
Strength	2	5.12	Nostalgic	1	3.22
Challenge	2	5.12	Journey	1	3.22
Adversity	1	2.56	Review	1	3.22
Overcoming	1	2.56	Experiences /childhood /life	1/1 (2)	6.45
Achievements	1	2.56	Positive mindset/clear minded/mindset	1/1/1(3)	9.67
Journey	1	2.56	Confusion	1	3.22
Evolving	1	2.56	Patience	1	3.22
Growth	1	2.56	Needs	1	3.22
Unaware	1	2.56	Appreciation	1	3.22
Recovery	2	5.12	Opportunities/opportunity	2	6.45
Regularly	1	2.56	Humiliation	1	3.22
Independence	1	2.56	Frustration/frustrating	2	6.45
Physical therapy /rehabilitation /rehab /exercise	1/1/1/1 (4)	10.25	Sad/sadness	2	6.45
Embracement/acceptance	1/1 (2)	5.12	Total	31	100.00
Resistance	1	2.56			
Rebirth/changed	1/1(2)	5.12			
Grateful	2	5.12			
Advantage	1	2.56			
Humiliation/humiliating	2	5.12			
Sad	1	2.56			
Unfortunate	1	2.56			
Shocking	1	2.56			
Speech	1	2.56			
Defining	1	2.56			
Total	39	100.00			

Words used to describe story C - BSc 3rd year		
Words describing story C	n	%
Positive /positivity	6	31.57
Inspiring /inspirational/inspire	6	31.57
Optimistic	3	15.78
Very hopeful	1	5.26
New beginning	1	5.26
Attractive	1	5.26
Motivation/motivational	2	10.52
Encouraging	2	10.52
Self-determination/determination	3	15.78
Persistence	7	
Teaches you the importance of persevering	1	5.26
Resilient	1	5.26
Brave	2	10.52
Strong	1	5.26
Recovery	1	5.26
Adaptable/adapt	2	10.52
Knowing it’s like being a child to learn new things again/learning	3	15.78
Willing to try new things and explore more	1	5.26
Adventure	2	10.52
Perspective / Changed outlook on life	2	10.52
Story /personal	2	10.52
Clarity	1	5.26
Reflective	1	5.26
Happiness	1	5.26
Frustration	1	5.26
Humiliating	1	5.26
Shock	1	5.26
Emotional	1	5.26
Challenging	1	5.26
Total	19	100

Appendix 22- Relative appeal of the stories

Most attractive story
Statistics

N	Valid	89
	Missing	1

Most attractive story	n	%
Story A	18	20.22
Story B	43	48.31
Story C	27	30.33
All but A & C	1	1.12
Total	89	100.0

Most attractive story by cohort
Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Most attractive story		MSc (pre-1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Story A	11	28.20	6	19.35	1	5.26
	Story B	17	43.58	14	45.16	12	63.15
	Story C	10	25.64	11	35.48	6	31.57
	All but A & C	1	2.56	0	0	0	0
	Total	39	100.0	31	100.00	19	100.0

Appendix 23 - Perceived commonness of the stories

Most common story

Statistics

N	Valid	89
	Missing	1

Most common story		n	%
Valid	Story A	42	47.19
	Story B	26	29.21
	Story A & B	5	5.61
	Story A & C	5	5.61
	Story A, B & C	2	2.24
	Story C	9	10.11
	Total	89	100.0

Most common story by cohort

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Most common story		MSc (pre-1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Story A	14	35.89	20	64.51	8	42.10
	Story B	16	41.02	6	19.35	4	21.05
	Story A & B	1	2.56	1	3.22	3	15.78
	Story A & C	3	7.69	1	3.22	1	5.26
	Story A, B & C	0	0.00	0	0.00	1	5.26
	Story C	4	10.25	3	9.67	2	10.52
	Total	39	100	31	10	19	100.0

Appendix 24- The most unusual story

Most unusual story

Statistics

N	Valid	89
	Missing	1

Which story do you think is the most unusual and why?

Most unusual story		n	%
Valid	Story A	3	3.37
	Story B	35	39.32
	B & C	2	2.24
	Story C	47	52.80
	None	1	1.12
	Total	89	100.0

Most unusual story by cohort

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Most unusual story		MSc (pre-1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Story A	2	5.12	1	3.22	0	0
	Story B	13	33.33	17	54.83	5	26.31
	B & C	0	0	1	3.22	1	5.26
	Story C	22	56.41	12	38.70	13	68.42
	None	2	5.12	0	0	0	0
	Total	39	100	31	100	19	100

Appendix 25 - Preferred story to hear

Preferred story to hear

Statistics

N	Valid	89
	Missing	1

Which story is preferable?		n	%
Valid	Story A	39	43.82
	A & C	8	8.98
	Story B	3	3.37
	Story C	39	43.82
	Total	89	100.00

Preferred story to hear by cohort

Statistics

N	MSc (pre-1st year)	39
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	1

Which story is preferable?		MSc (pre-1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Story A	18	46.15	14	45.16	7	36.84
	A & C	7	17.94	1	3.22	0	0
	Story B	2	5.12	1	3.22	0	0
	Story C	12	30.76	15	48.38	12	63.15
	Total	39	100	31	100	19	100

Appendix 26- Preferred story to tell

Preferred story to tell
Statistics

N	Valid	86
	Missing	4

Which story would you like to tell?			
		n	%
Valid	Story A	32	37.20
	Story B	12	13.95
	Story C	31	36.04
	A & B	2	2.32
	A & C	6	6.97
	C & B	2	2.32
	A, B & C	1	1.16
	Total	86	100

: Preferred story to tell by cohort
Statistics

N	MSc (pre-1st year)	36
	BSc (1st year)	31
	BSc (3rd year)	19
	Missing	4

Which story would you like to tell?		MSc (pre-1st year)		BSc (1st year)		BSc (3rd year)	
		n	%	n	%	n	%
Valid	Story A	14	38.88	10	32.25	8	42.10
	Story B	5	13.88	4	12.90	3	15.78
	Story C	12	33.33	14	45.16	5	26.31
	A & B	2	5.55	0	0	0	0
	A & C	1	2.77	3	9.67	2	10.52
	C & B	1	2.77	0	0	1	5.26
	A, B & C	1	2.77	0	0	0	0
	Total	36	100	31	100	19	100

Appendix 27- Initial Email Advertising training for students

Initial Email Advertising training

Subject Title:

The value and benefits of a novel placement supporting people with Stroke; A multi methods study.

Message content for students at the University of Birmingham:

We are looking for student physiotherapists to take part in a unique placement, this will provide you with 2-weeks of unique training. It will require you to complete some shorts on 2 occasions at baseline and post intervention and a self-reported questionnaire at the end regarding your experiences on a novel placement. We would be able to provide you with a voucher as a thank you. You are being contacted to consider if you would be interested in taking part in the research study. Once you have decided to participate in the 2 weeks placement, the study team will email you an information sheet and ask for your consent.

Appendix 28- Information sheet and Consent form for students

Information sheet and Consent form for students

Version 1.0 10/03/2022

School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham

1. Study title

The value and benefits of a novel placement supporting people with Stroke; A multi methods pilot study

2. Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The purpose of this study is to consider the effectiveness and experiences of a two-week novel e-placement to student physiotherapists. You will be taking part in a 2-week training and placement study. You will be asked to complete some forms before the study starts, at the end of the study Also, you will be asked to complete a self-reported questionnaire about your experience at the end of the placement.

4. Why have I been chosen?

You have been chosen to take part because you are a student physiotherapist. We are interested in developing tools to help you communicate and as part of developing communication tools for student we have devised a novel placement to experience. It is essential we understand the value of this work further.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to consent to participate you will keep this information sheet as something to which you might choose to refer back. You will be asked to sign a consent form to say you are happy to take part in the study.

Please note not taking part in this research will have no impact on your degree at all.

You are free to take part or not take part.

If you decide to take part you are still free to withdraw at any time without giving a reason. Please be aware that once the data has been published then you will not be able to withdraw. It is expected the date after which it will not be possible to withdraw will be 1 July 2022. To remove your responses from the research please take a note of your Unique Identification Number written on your questionnaire and email Dr A Soundy [redacted] to have your completed questionnaire removed from the data that is gathered.

6. What will happen to me if I take part?

You will be invited to participate in 4 outcome measure assessments conducted via a survey link which take about 20 minutes to complete and self-reported questionnaire about your experiences of the training you received, the simulation and placement and ways in which we could change it to improve it for future placements.

We will provide you with an amazon voucher at the end of the study as a thank you for participating.

7. What do I have to do?

We would like to undertake a novel placement and then report on it using a survey of forms (20 minutes) on 2 occasions and if you are willing to complete self-reported questionnaire about your experiences of using it (10 minutes maximum).

Please note that taking part in this research is optional, it is research and part of a study **not** part of your requirement as a student. Once you have completed the questionnaire you will be able to keep the vouchers even if you choose to leave during the process.

8. What are the possible disadvantages and risks of taking part?

Giving time to this training may impact on your day. This training is not a core part of your role as a student. No adverse effects have been documented in our pilot work around this process.

9. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. All questionnaires following the session will be confidential and will be kept in a locked office in a secure building at the University of Birmingham or on a secure University computer that is password protected. This data will be kept for 10 years and in accordance with GDPR (2018).

Please be aware that once the data has been published then you will not be able to withdraw. It is expected the date after which it will not be possible to withdraw will be 1 July 2022. To remove your responses from the research please take a note of your Unique Identification Number written on your questionnaire and email Dr A Soundy [redacted] to have your completed questionnaire removed from the data that is gathered.

10. What will happen to the results of the research study?

The results will be presented within the university, used for conference presentations and publications which might include journals or a book. We will prepare a presentation of the results for you to help as part of the training and to give you an idea of the different study outcomes before publication of the work is achieved.

11. Who has reviewed the study?

The University of Birmingham ethics committee has reviewed this study.

Review number: ERN_xx-xxx.

12. Contacts for further Information

Dr A Soundy

Email: [redacted] Phone: [redacted]

Alawafi R

Email : [redacted]

Ethics ID:

Study Number: MEAH02

Participant Identification Number for this trial:_____

CONSENT e-FORM

Title of Project: The value and benefits of a novel placement supporting people with Stroke; A multi- methods pilot study

Name of Researcher:Dr .Soundy A and Alawafi R

Please initial box or place an X in each box.

Statement	Initial
I confirm that I have read the information sheet dated 10/03/2022 (Version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
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 understand the last date for withdrawal of information is 1 July 2022.	
I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers in the team.	
I agree to take part in the above study.	
I agree to take part in a single interview about my experience if required.	
I would like to be contacted and provided with a summary of the study findings	

Name of Participant Date Signature

Name of Person Date Signature

Document provided to participants if it is identified that they are distressed or become concerned following the intervention.

Appendix 29 Questionnaire pack given across email to student physiotherapists

Questionnaire pack given across email to student physiotherapists

Unique Identification Number Generated for you: MEAH 02 A (CHANGED FOR EACH PARTICIPANT)

Please complete this questionnaire which asks specific questions about the course content and your reflections of the value of the course.

PLEASE NOTE BY COMPLETING THIS QUESTIONNAIRE YOU ARE PROVIDING CONSENT FOR YOUR PARTICIPATION. Please contact Dr A Soundy should you want your data removed by 1 July 2022.

Demographics

Age (Years)	
Gender	
Name of Profession (e.g., Nurse, Physiotherapist)	
Type of Course: BSc, MSc	
Year of Course:	
How many placement have you have for people with neurological chronic illness?	

1. Demographics	ANSWERS (CLICK EAC (a pull down menu will ap
Age (years)	
Gender	
Year on Course	
Total number of placements you have been on since arriving on the course (give a whole number)	
Have you had past teaching or experience related to psychological adaptation, hope, emotions or illness stories (narratives)?	
2. Interpersonal Reactivity Index	
Instructions: Please indicate the extent that each statement describes you, using the following scale: 01234	
0 (does not describe me well) 4 (describes me very well)	
When I am reading an interesting story or novel, I imagine how I would feel if the events in the story were happening to me.	
I really get involved with the feelings of the characters in a novel.	
I am usually objective when I watch a movie or play, and I don't often get completely caught up in it.	
After seeing a play or movie, I have felt as though I were one of the characters.	
I daydream and fantasize, with some regularity, about things that might happen to me	
Becoming extremely involved in a good book or movie is somewhat rare for me.	

When I watch a good movie, I can very easily put myself in the place of a leading character.	
Before criticizing somebody, I try to imagine how I would feel if I were in their place.	
If I'm sure I'm right about something, I don't waste much time listening to other people's arguments.	
I sometimes try to understand my friends better by imagining how things look from their perspective.	
I believe that there are two sides to every question and try to look at them both.	
I sometimes find it difficult to see things from the other person's point of view.	
I try to look at everybody's side of a disagreement before I make a decision.	
When I'm upset at someone, I usually try to "put myself in their shoes" for a while.	
When I see someone being taken advantage of, I feel kind of protective toward them.	
When I see someone being treated unfairly, I sometimes don't feel very much pity for them.	
I often have tender, concerned feelings for people less fortunate than me.	
I would describe myself as a pretty soft-hearted person.	
Sometimes I don't feel sorry for other people when they are having problems.	
Other people's misfortunes do not usually disturb me a great deal.	
I am often quite touched by things that I see happen.	
When I see someone who badly needs help in an emergency, I go to pieces.	

I sometimes feel helpless when I am in the middle of a very emotional situation.	
In emergency situations, I feel apprehensive and ill-at-ease.	
I am usually pretty effective in dealing with emergencies.	
Being in a tense emotional situation scares me.	
When I see someone get hurt, I tend to remain calm.	
I tend to lose control during emergencies.	
3. Froehlich Communication Survey	
Instructions: Please complete an answer to each question using this key to provide your response.	
1 Strongly Disagree Much Improvement Needed Disagree Moderate Improvement Needed Agree Some Improvement Needed 10 Strongly Agree Little Improvement Needed	
I can listen without interrupting.	
I can keep my mind free of distractions while listening.	
I can allow for silences.	
When appropriate, I can offer steady eye contact while listening.	
I am aware of body language while listening.	

My posture and facial expression show interest and caring.	
I don’t fidget while listening.	
I can build rapport with others.	
I appropriately maintain confidentiality.	
I can maintain compassion while listening.	
I use open and closed-ended questions to determine someone’s concerns and goals.	
I can effectively use restatement, summaries and clarification in a conversation.	
I can identify, reflect and validate emotional and verbal content in a conversation.	
I can maintain mental focus when listening to someone who is upset.	
I can convey hopefulness.	
I can use humor effectively.	
I can judge when to use touch during conversations.	
I can judge when to redirect someone or help someone get their attention off their distress in a conversation.	
I can judge when someone is ready to hear information or advice.	
I am clear, concise and confident when I speak.	
I can give, receive and solicit constructive feedback including appreciation of others and myself.	

I can be appropriately assertive in interactions with others.

I communicate well on teams by listening to multiple perspectives and sharing mine.

I understand the importance of seeking an interpreter when I don't understand the language of a client.

I can communicate effectively with people from different racial and cultural groups.

5. Open Minds Scale for Health Care Providers (OMS-HC-15)

Instructions: Please read the following questions and click a box as to how much you agree or not with each statement.

I am more comfortable helping a person who has a physical illness than I am helping a person who has a mental illness.

If a colleague with whom I work told me they had a mental illness, I would be just as willing to work with him/her.

If I were under treatment for a mental illness I would not disclose this to any of my colleagues.

I would see myself as weak if I had a mental illness and could not fix it myself.

7-General Self efficacy Scale	
Instructions: Please consider each statement and identify how true each statement is for you.	
I can always manage to solve difficult problems if I try hard enough.	
If someone opposes me, I can find the means and ways to get what I want.	
It is easy for me to stick to my aims and accomplish my goals.	
I am confident that I could deal efficiently with unexpected events.	
Thanks to my resourcefulness, I know how to handle unforeseen situations.	
I can solve most problems if I invest the necessary effort.	
I can remain calm when facing difficulties because I can rely on my coping abilities.	
When I am confronted with a problem, I can usually find several solutions.	



Appendix 30- Qualitative process evaluation questioner

Qualitative process evaluation questioner

Section 1: General questions

Can you tell me about your experience of taking part in the placement?

Was there anything that stood out about it? Can you explain what that was?

Section 2: Perception and experiences of the training, simulation practice and placement

What was good or not so good about the training and simulation you received?

Were there any aspects of this training you would change? Can you explain why?

What was good or not so good about the placement? Can you explain your answers?

Are there any benefits associated with taking the placement? Can you explain what these were OR can you identify why there weren't any?

From the above questions about the intervention, if there were to be changes to the intervention what should these be?

Section 3: Future application of the placement

Do you think the intervention should be used for student physiotherapists more widely? Can you explain why? and when you believe it would be useful?

Do you think the intervention could be integrated into a university course? Can you explain your answer?

Appendix 31- Information sheet for people with Stroke and Consent form

Information sheet for people with Stroke and Consent form

Version 1.0 10/03/2022

School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham

1. Study title

The value and benefits of a novel placement supporting people with Stroke; A multi- methods pilot study

2. Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

The purpose of this study is to understand your experiences of taking part in short interactions with students. This will occur within the Northfield stroke group with your peers, during this time you and your interaction will not be anonymous. We would like to know what you thought of the two interactions you had with the student and group and what and if there were any benefits of it for you. If you participate, we will ask you to give reflections to students following a conversation. The student will complete a brief form to document your comments.

4. Why have I been chosen?

You have been chosen to take part because you are a person with a Stroke who has participate in the student placement. It is essential that your views, experiences and perceptions of intervention are incorporated and help inform future courses or training events.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to consent to participate you will keep this information sheet as something to which you might choose to refer back. You will be asked to sign an e-consent form to say you are happy to take part in the study. If you decide to take part, you are still free to withdraw at any time without giving a reason. Please be aware that once the data has been published then you will not be able to withdraw. It is expected the date after which it will not be possible to withdraw will be 1 July 2022. To remove your responses from the research please take a note of your Unique Identification Number written on your questionnaire and email Dr A Soundy [redacted] to have your completed questionnaire removed from the data that is gathered.

6. What will happen to me if I take part?

You will be invited to participate in one single interview. This that will last 30 minutes . After the interview you will be offered a support list of organizations that can help you if you feel any aspects of the intervention has upset you or caused concern.

7. What do I have to do?

We would ask you to talk to the primary research Dr Soundy online about your experiences of the student placement and any thoughts you have about it.

8. What are the possible disadvantages and risks of taking part?

Giving time to this training may impact on your day. We will ask you about your thoughts of the student placement, however we don't believe this will adversely affect you in anyway.

9. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. All questionnaires following the session will be kept in a confidential way and will be kept in a locked office in a secure building at the University of Birmingham or electronically stored on a password protected university computer. This data will be kept for 10 years and in accordance with GDPR (2018).

10. What will happen to the results of the research study?

The results will be presented within the university, used for conference presentations and publications which might include journals or a book. We will prepare a presentation of the results for you to help as part of the training and to give you an idea of the different study outcomes before publication of the work is achieved.

11. Who has reviewed the study?

The University of Birmingham ethics committee has reviewed this study.

Review number: ERN_xx-xxxx.

12. Contacts for further Information

Dr A Soundy

Email: [redacted] Phone: [redacted]

Alawafi R

Email : [redacted]

Ethics ID: ERN_xx-xxxx

Study Number: MEAH02

Participant Identification Number for this trial:_____

CONSENT e-FORM

Title of Project: The value and benefits of a novel placement supporting people with Stroke; A multi-methods Pilot study

Name of Researcher: Dr A Soundy and Miss Alawafi R

Please initial box or place an X in each box.

Statement	Initial
I confirm that I have read the information sheet dated 10/03/2022 (Version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
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 understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers in the team.	
I agree to take part in the above study and answer brief questions about my experience of it	
I would like to be contacted and provided with a summary of the study findings	

Name of Participant Date Signature

Name of researcher Date Signature

Document provided to participants if it is identified that they are distressed or become concerned following the intervention.

Appendix 32- Questionnaire and short feedback questions given across email to people with a Stroke

Short feedback questions given to people with a Stroke.

Unique Identification Number Generated for you: MEAH 02 A (CHANGED FOR EACH PARTICIPANT)

Please complete this questionnaire which asks specific questions about the you're experience and your reflections of the value of the placement.

PLEASE NOTE BY COMPLETING THIS QUESTIONNAIRE YOU ARE PROVIDING CONSENT FOR YOUR PARTICIPATION. Please contact Dr A Soundy should you want your data removed by July 2022.

Demographics

Age (Years)	
Gender	
Type of Stroke if known	
Years with illness	

Day 2 MEAH questions / Day 4 Storytelling questions

What were your thoughts about the interaction that occurred?

Was there anything that you thought was positive?

Was there anything you found not so positive?

Would you be happy to support students more in this way? (Yes/No; please explain why)

Do you think these questions would be useful for people who have just had a stroke? (Yes/No, please explain your answer)

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