Exploring the Utility and Accessibility of non-pharmacological interventions for mood and emotion problems following stroke

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Thesis Portfolio Abstract

Background: Anxiety, depression, and emotionalism frequently arise following a stroke. Often, demographic and social factors can impact the accessibility and the helpfulness of interventions to support those with post-stroke mood conditions.

Aim: This thesis aimed to explore the reporting of protected characteristics known to impact health equity in non-pharmacological intervention research for post-stroke anxiety and/or depression to understand what characteristics are considered and analysed in research. Additionally, the thesis aimed to explore the contextual factors which can impact the accessibility and utility (helpfulness) of non-pharmacological interventions for post-stroke anxiety, depression, and/or emotionalism.

Method: Firstly, a systematic scoping review was conducted to investigate the reporting of protected characteristics in randomised controlled trials exploring the effectiveness of non-pharmacological interventions for post-stroke anxiety and/or depression. The review also aimed to highlight any studies which explored whether any differences in outcomes were identified based on participant's protected characteristics. Secondly, an empirical paper aimed to identify the opinions of healthcare professionals and researchers on the helpfulness of post-stroke emotionalism (PSE) non-pharmacological interventions and understand the contextual factors that can impact the accessibility of interventions. The study aimed to reach a consensus regarding the helpfulness of these interventions using the Delphi Method and to explore the context regarding the barriers to accessibility by running mini-focus groups.

Results: The systematic scoping review identified that many protected characteristics are not included in RCTs focusing on post-stroke anxiety and/or depression. Furthermore, there is not enough research to suggest whether certain interventions may be accessible or helpful to certain groups based on their protected characteristics. In the empirical paper, providing education to the patient and family were found to be the most helpful interventions, whilst

offering reassurance, asking the patient to take a deep breath, and acknowledging the PSE and then continuing with their current activity were identified as the most accessible. A content analysis of the mini-focus groups' transcripts revealed two themes: "barriers to the accessibility of PSE non-pharmacological interventions" and "suggestions to manage barriers".

Conclusion: This thesis portfolio highlights the need for research to consider reporting the protected characteristics of participants to support clinicians in their decision-making regarding use of non-pharmacological interventions to support people with post-stroke anxiety and depression. Furthermore, services should consider applying a person-centred approach when supporting those with PSE and consider whether a protocol needs to be created to identify who should be supporting those with PSE across the stroke pathway.

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Chapter One: Introduction to Thesis Portfolio

Introduction to Thesis Portfolio

More than 15 million people in the United Kingdom live with long-term health conditions, of which more than 4 million also have mental health conditions (Naylor et al., 2012). Furthermore, in England, a 19-year gap in healthy life expectancy exists between the most affluent and least affluent areas, with people in the most deprived neighbourhoods, certain ethnic minority groups, and certain health groups developing multiple long-term health conditions 10-15 years earlier than those in the least deprived communities (Barnett et al., 2012). Before COVID-19, health inequalities cost the National Health Service (NHS) £4.8 billion a year (Public Health England, 2021). The impact demographic and social factors can have on health outcomes have been mirrored in global studies on the prevalence and burden of stroke (Feigin et al., 2021).

Where health inequity has been acknowledged by health services and governments, an understanding of what characteristics can impact health equity have been investigated (World Health Organisation; WHO, 2022). The United Kingdom (UK) government set out a list of characteristics in the Equality Act (2010) which are considered to impact various areas of one's life such as health and vocation (Equality Act, 2010). These demographic and social factors, referred to as protected characteristics, include age, sex, race, sexual orientation, marital or civil partnership, pregnancy and maternity, gender reassignment, religion or spiritual belief, and disability (Equality Act, 2010). Furthermore, Cochrane have identified demographic and social factors that are known to impact health equity and created the PROGRESS- Plus framework for researchers to consider when reporting their research findings (place of residence/housing, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital, personal characteristics associated with discrimination, features of relationships, and time-dependent relationships; O'Neill et al., 2014).

Stroke Prevalence and epidemiology

Stroke is the second leading cause of death globally and the third leading cause of death and disability combined globally (Feigin et al., 2021). Around 100,000 people in the UK experience a stroke each year (Stroke Statistics, 2021) and in 2019 there were an estimated 12.2 million people expected to have experienced a stroke globally (Feigin et al., 2021). Prospective studies have evaluated the risk factors associated with stroke and have found that age, gender/sex, socio-economic status, living alone, prior health conditions, and level of education are all known risk factors (Addo et al., 2012; Hosseinzadeh et al., 2022; Lindenstrøm et al., 1993; Peters et al., 2014). Older adults, those coming from a lower socio-economic status or country, those who live alone, those with a lower level of education, and those having experienced other physical health conditions, such as diabetes, are also more likely to experience a stroke in their lifetime (Addo et al., 2012; Hosseinzadeh et al., 2022; Lindenstrøm et al., 1993; Peters et al., 2014).

Emotional consequences and evidence base post-stroke

Following a stroke, survivors often experience physical disabilities, cognitive impairment, and disorders of mood and emotion (Sackley et al., 2008). Research has reported that up to 31% of stroke survivors experience depression within five years of their stroke (Hackett et al., 2014; Kim, 2017), and 50% experience depression during the acute phase (Hackett et al., 2014; Robinson & Spalletta, 2010). Furthermore, a systematic review showed that 24% of stroke survivors experience anxiety symptoms following a stroke (Knapp et al., 2017) and 20% experience post-stroke emotionalism (Gillespie et al., 2016). Therefore, it is apparent that anxiety, depression, and emotionalism are all common following a stroke (Gillespie et al., 2016; Medeiros et al., 2020; Rafsten et al., 2018). Furthermore, research suggests that anxiety following a stroke is associated with increased severity of depression and that anxiety and depression are more prevalent in women and younger adults (Burvill et

al., 1995; Schultz et al., 1997). Additionally, post-stroke emotionalism (PSE; pseudobulbar affect, emotional incontinence) symptoms are linked to increased levels of anxiety and depression (Andersen et al., 1995). UK stroke guidance featured assessing mood as part of the advised matched care model (NICE, 2016). Therefore, as anxiety and depression are also known to impact cognition, rehabilitation and quality of life (Cheong & Kang, 2021; Kim, 2017; Rafsten et al., 2018), it is imperative that following a stroke, an assessment for anxiety and/or depression takes place to ensure stroke survivors are provided with the opportunity to engage in interventions to support their mood (Kim, 2017).

Interventions for Mood conditions following a stroke

Pharmacological interventions, such as various forms of anti-anxiety medication or antidepressants, have been found to have a positive impact on mood following a stroke (Castilla-Guerra et al., 2020; Knapp et al., 2017). Furthermore, research into non-pharmacological interventions for anxiety and/or depression following a stroke have identified the benefits of various interventions in managing mood, such as cognitive behavioural therapy, psychoeducation, and physical exercise (Allida et al., 2020; Gillespie et al., 2020; Hadidi et al., 2017; Knapp et al., 2017; Melin et al., 2018). Additionally, there is low quality evidence of the use of antidepressants for PSE symptoms (Allida et al., 2019; Platz, 2020). Despite PSE being common following stroke (Gillespie et al., 2016; House et al., 1989), very few studies of non-pharmacological interventions have been undertaken (Gillespie et al., 2020), with currently no evidence-based approaches.

The potential for health inequalities regarding stroke interventions

Despite the understanding that healthcare services and researchers have regarding the impact social circumstances can have on the ability to access or engage with healthcare services and/or interventions (NHS, 2019), there is limited research regarding the impact protected characteristics have on the accessibility and effectiveness of interventions for mood

or emotion disorders following a stroke, particularly for non-pharmacological interventions. Systematic reviews regarding the outcome of post-stroke anxiety and/or depression in relation to certain health inequalities, such as experiencing aphasia (which is considered a disability and known to impact health equity), have previously been undertaken (Ahrens et al., 2022). Some reviews identified differences in access to stroke services based on ethnicity, socioeconomic status, and place of residence (Bhaskar et al., 2019; Sandel et al., 2009) and the effectiveness of cognitive behavioural therapy for post-stroke depression and non-pharmacological interventions for post-stroke anxiety (Knapp et al., 2017; Wang et al., 2018). However, scoping reviews identifying what protected characteristics are included in the reporting globally of outcome data in non-pharmacological interventions post-stroke, such as those from randomised controlled trials, have not been undertaken. Therefore, it is uncertain how representative stroke research has been when suggesting appropriate non-pharmacological interventions to use in healthcare services to support mood or emotion disorders following a stroke.

Presented Work

The work described in this thesis portfolio focuses on the context surrounding non-pharmacological interventions for mood and emotion disorders following stroke. The systematic scoping review investigated what protected characteristics were collected and reported in randomised controlled trials of non-pharmacological interventions for post-stroke anxiety and/or depression using the PROGRESS-Plus framework as a rating of the quality of the paper's reporting of demographic data (O'Neill et al., 2014). The empirical study used the Delphi Method and mini-focus groups to better understand experts' views on the accessibility and helpfulness of non-pharmacological interventions used within research and healthcare services for post-stroke emotionalism (Gillespie et al., 2016). The empirical study also used the protected groups from the UK government's Equality Act (Equality ACT, 2010), to

explore healthcare professionals' opinions on the impact demographic and sociocultural factors can have on the accessibility (the ability to engage with and use) and helpfulness (the impact on supporting individuals to cope with PSE symptoms) of PSE interventions. The portfolio also includes a bridging chapter, an extended methods chapter, and a critical evaluation and discussion chapter.

Both the systematic review and empirical paper were prepared for submission to the journal *Disability & Rehabilitation* (Appendix A).

Chapter Two: Systematic Review

Prepared for submission to the journal of Disability and Rehabilitation

Author Guidelines are available in Appendix A

Investigating the reporting of participant characteristics relating to health equity in randomised controlled trials of non-pharmacological interventions for post-stroke anxiety and/or depression: A systematic scoping review

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Abstract

Purpose: The systematic scoping review aims to identify what characteristics are reported in randomised controlled trials for the non-pharmacological management of post-stroke anxiety and/or depression and if there is evidence about outcomes for such groups.

Methods: A comprehensive systematic search was completed of five databases: CINAHL, Medline, PsychInfo, Web of Science, and The World Health Organisation. Google Scholar was also accessed. The reporting of participant characteristics was assessed by adapting the PROGRESS-Plus framework.

Results: 19 papers (participants n = 2187) were included. Across all studies, there was generally poor reporting of certain characteristics associated with an increased likelihood of post-stroke anxiety and/or depression. All studies reported the gender/sex, most reported the age of participants, and 11 studies reported the lesion location. However, none of the studies reported any pre-existing disabilities participants experienced or participants' sexual orientations.

Conclusion: There was variation in the reporting of protected characteristics. Future research should follow a health equity framework to ensure that they are reporting protected characteristics to support clinicians in identifying whether the proposed interventions are relevant to their stroke population. Research should consider sub-group analyses where appropriate regarding the effectiveness of post-stroke anxiety and/or depression non-pharmacological interventions.

Keywords: anxiety; depression; mood; stroke; systematic review; health equity

Data availability statement: The data that supports the findings of this study are available from the corresponding author upon reasonable request.

Impact for rehabilitation:

- Supporting the understanding of the effectiveness of non-pharmacological interventions for post-stroke anxiety and/or depression across subgroups
- Identification of which characteristics should be reported in services and in stroke rehabilitation research.
- Furthering the consideration of health equity in stroke rehabilitation research

Introduction

Stroke remains the third-leading cause of death and disability in the world with one in four people experiencing a stroke in their lifetime (Feigin et al., 2021). Whilst the incidence of stroke increases significantly with age, over 60% of strokes happen to people under the age of 70 and 16% to those under 50 years (World Stroke Organisation; WSO, 2023). Along with physical difficulties that stroke survivors can face (Cheng et al., 2018), mood and emotional conditions, such as anxiety and depression, are common (Schöttke & Giabbiconi, 2015).

Anxiety is one of the most common emotional consequences of stroke (Knapp et al., 2020). A study found that 51.3% of their participants experienced anxiety three months following their stroke (Khazaal et al., 2021), whereas other studies have found that around 8% of stroke survivors continue to experience clinical levels of anxiety post-stroke (Rafsten et al., 2018). Factors such as gender, marital status, and place of residence (e.g., living at home vs in a care home) increase the likelihood of a stroke survivor experiencing post-stroke anxiety (Sanner et al., 2019), with women, those who live alone or are single, divorced, or widowed being more likely to experience anxiety following their stroke (Sanner et al., 2019). Furthermore, left hemisphere lesions and levels of physical and cognitive impairment can all impact whether a stroke survivor is more likely to experience anxiety, with those experiencing a higher level of disability being more likely to experience anxiety (Barker-Collo, 2007).

Additionally, a high prevalence of depression has been found in people with stroke (Medeiros et al., 2020), with 76.1% of the participants experiencing depression three months following their stroke (Khazaal et al., 2021) and 31% experiencing depression one year following their stroke (Hackett et al., 2014). Factors such as stroke severity and lesion location have been linked with post-stroke depression (Guo et al., 2022), with research

suggesting that those who have experienced a lesion in their left hemisphere are more likely to experience post-stroke depression, even a year following their stroke (Robinson & Price, 1982; Robinson et al., 1984). However, other reviews have countered this and have either found links to post-stroke depression with right hemisphere lesions (Wei et al., 2015), or have identified no increased likelihood based on lesion location (Carson et al., 2000). Therefore, there appears to be some uncertainty regarding the link between post-stroke depression and lesion location.

Social and demographic factors associated with the risk of depression following a stroke have been investigated. There seems to be conflicting findings regarding the impact of age with some systematic reviews concluding older adults are more likely to experience post-stroke depression (Cheng et al., 2018), and others concluding younger adults are more susceptible to post-stroke depression (Barker-Collo, 2007). Although some research has suggested that women are more likely to experience post-stroke depression (Cheng et al., 2018), a systematic review concluded that there is still an ongoing debate due to the number of studies which have not identified any significant gender differences in post-stroke depression risk (De Ryck et al., 2014). Stroke severity and level of disability following a stroke have also been identified in systematic reviews as risk factors for post-stroke depression (Guo et al., 2022; Hackett et al., 2014). Being single, divorced or widowed, living alone, social isolation, and having a lower level of education have also been identified as risk factors for depression following a stroke (Backhouse et al., 2018; Liu et al., 2017; Northcott et al., 2016; Shi et al., 2017).

Furthermore, it is apparent that the prevalence of post-stroke anxiety and/or depression differs based on various demographic and social factors, such as age and gender (Northcott et al., 2016). Additionally, research has also identified that stroke incidence, service access, and outcomes have been linked to age, ethnicity, education, gender, location,

marital status, prior disability, and/or socioeconomic status (Bhaskar et al., 2019; Reshetnyak et al., 2020; Sandel et al., 2009; Wang & Langhammer, 2018). Additionally, mental health research has shown that the beliefs around mental health conditions are influenced by one's demographic and social factors, such as gender and ethnicity, and the accessibility and engagement of psychological interventions related to mood (Leis et al., 2011; Liddon et al., 2017; Ward et al., 2009; World Health Organisation, 2022).

Due to the impact personal characteristics can have on the accessibility of stroke services and non-pharmacological interventions for post-stroke anxiety and/or depression, it is important to better understand whether research has reported and considered participant characteristics when reflecting on the clinical implications. Especially considering the impact anxiety and depression can have on the quality of life of stroke survivors and their level of engagement in rehabilitation (Cheong & Kang, 2022; Khazaal et al., 2021; Rafsten et al., 2018), which in turn can impact mood (Carod-Artal & Egido, 2009). Therefore, research has focused on identifying helpful pharmacological and non-pharmacological interventions to support those with anxiety and/or depression following a stroke (Kim, 2017).

Whilst it is known that demographic and social factors can increase the likelihood of experiencing post-stroke anxiety and/or depression, what is not known is the extent to which these characteristics are reported in randomised control trials (RCT) for the non-pharmacological management of post-stroke anxiety and/or depression. The present review therefore scopes stroke literature to summarise what demographic and sociocultural factors are being reported in non-pharmacological RCTs for post-stroke anxiety and/or depression and to summarise potential differences in outcomes across characteristics. The secondary aims of the review were to establish what recruitment strategies were used, what outcome

measures were used, and what non-pharmacological interventions were found to be effective in reducing anxiety/depression after considering the protected characteristics mentioned.

Methods

Study Design

A systematic scoping review was conducted. The review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA SCr) extension for scoping reviews guidelines (Tricco et al., 2018; Appendix B).

Literature Search

A reference librarian at the University of East Anglia was consulted to develop the search strategy. Search terms were compiled and tested repeatedly to produce sensitive searches and capture potentially relevant publications. The search was conducted on the following databases, CINAHL, Medline, PsychInfo, Web of Science, and The World Health Organisation (WHO). Google Scholar was also used as a supplement to the main search. Further, the reference lists of retrieved reviews and RCTs were manually searched for trials that may have been previously missed. Searches were conducted on the 20th of December 2022 and refreshed on the 24th of February 2023. There were no date constraints on searches for studies to include in the review.

Keywords used in the literature search to retrieve articles included: stroke, mood disorders, randomised control trials, and psychological therapy (see Appendix C for a list of specific keywords and exact search strategies).

Eligibility Criteria

Participants and Classification of Characteristics

Studies of adults, aged 18 years and older, with stroke and without significant neurological co-morbidities, such as dementia, were included. Additionally, studies which recruited participants who were considered to experience any form of anxiety and or depression post-stroke, regardless of whether it reached the clinical threshold were included. Participants who presented with cognitive impairment alongside mood disorder following a

stroke were included. Studies focusing on interventions where carers and/or family members were the participants were not included.

Interventions

Studies were included if they reported on non-pharmacological interventions that targeted the management of anxiety and/or depression symptoms or disorders as a primary aim. Preventative studies, as well as medical and drug interventions (which included medication, traditional medicines, transcranial magnetic stimulation, etc.) were excluded.

Outcomes

Studies with original data and anxiety and/or depression as primary outcomes, as measured using a validated tool(s), were included.

Design

RCTs were included in the review including pilot RCTs and feasibility RCTs.

Study Characteristics

Studies originally published in English or translated into the English language and peer-reviewed were included.

Data Extraction, Summarising and Reporting Findings

Data extracted included: participants (sample size, place of residence/housing, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital, age, disability, relationships, diagnosis), interventions (type), anxiety/depression outcome measures (valid measures used), recruitment methods, and results. The primary researcher was responsible for identifying whether published studies met the eligibility criteria for the scoping review and for the data extraction, summarising, and reporting of findings.

Quality Assessment

Although not viewed as essential to a scoping review (Arksey & O'Malley, 2005;

Tricco et al., 2018), the methodological quality of the papers included in the review were assessed using the Critical Appraisal Skills Programme (CASP; CASP, 2020) tool to determine any risk of bias and to ensure appropriate statistical analyses were used. A quality assessment took place using the CASP for RCT's to identify how robust results were if studies differentiated outcomes according to participant subgroups. The CASP RCT checklist has been updated to consider the Consolidated Standards of Reporting Trials (CONSORT 2010; Schulz et al., 2010) guideline which applies a health equity lens in assessing the quality of RCTs and includes 11 items (see Appendix E; CASP, 2020). The primary researcher assessed the quality of all the studies included in the review and randomly selected 12 of the 19 studies to be assessed independently by an external reviewer. Where there were differences in responses, a discussion was held until a consensus was reached to appropriately respond to the item. While developers of the CASP checklist do not suggest a scoring system, as it is suggested to be a tool to make researchers think about aspects of studies systematically, an arbitrary scoring system was used for this review to analyse the inter-rater reliability (Yes = 2, No = 1, and Can't tell = 0).

Assessing the Reporting of Protected Characteristics

To evaluate the evidence of demographic and sociocultural factors reported in published papers, the primary researcher extracted the data in line with the protected characteristics which are known to impact health equity and are included within the PROGRESS-Plus framework (O'Neill et al., 2014). PROGRESS-Plus is a framework that captures several socially stratifying factors understood to influence health opportunities (O'Neill et al., 2014). The framework includes place of residence (housing), race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital (living arrangements and marital status), and plus refers to additional

factors associated with discrimination, (such as age, disability, and sexual orientation; O'Neill et al., 2014).

Definition of all PROGRESS-Plus protected characteristics (such as, race/ethnicity/culture/language) were based on the definition and interpretations by the authors of the included studies in their measure of demographic and sociocultural characteristics. This was to ensure that studies were included based on their own interpretation of reporting demographic and sociocultural factors and to prevent the primary researchers own definitions and/or potential biases from influencing the decision.

This study followed the guidance from Campbell and Cochrane Equity Methods Group (O'Neill et al., 2014) and adapted the PROGRESS-Plus framework to better represent the papers published globally and the topic area in which it is being used, as seen in Plastow et al.'s (2021) review on the reported protected characteristics in research for post-stroke mood conditions in Africa. Therefore, along with the previously mentioned characteristics from the PROGRESS-Plus framework, the adapted framework for this review also includes stroke characteristics (location, time since stroke, and type of stroke; Plastow et al., 2021). Papers were given a score of 1 for each participant characteristic reported by the authors, based on the adapted PROGRESS-Plus framework and the guidance from the mentioned systematic review, with a total score of 15 being possible (O'Neill et al., 2014; Plastow et al., 2021).

Synthesis of results

Systematic scoping reviews do not typically present syntheses relating to the results, therefore the results from this review are descriptively summarised in line with the PRISMA SCr guidelines (Tricco et al., 2018). The results were summarised regarding which participant characteristics were reported in research, the results of trials across participant

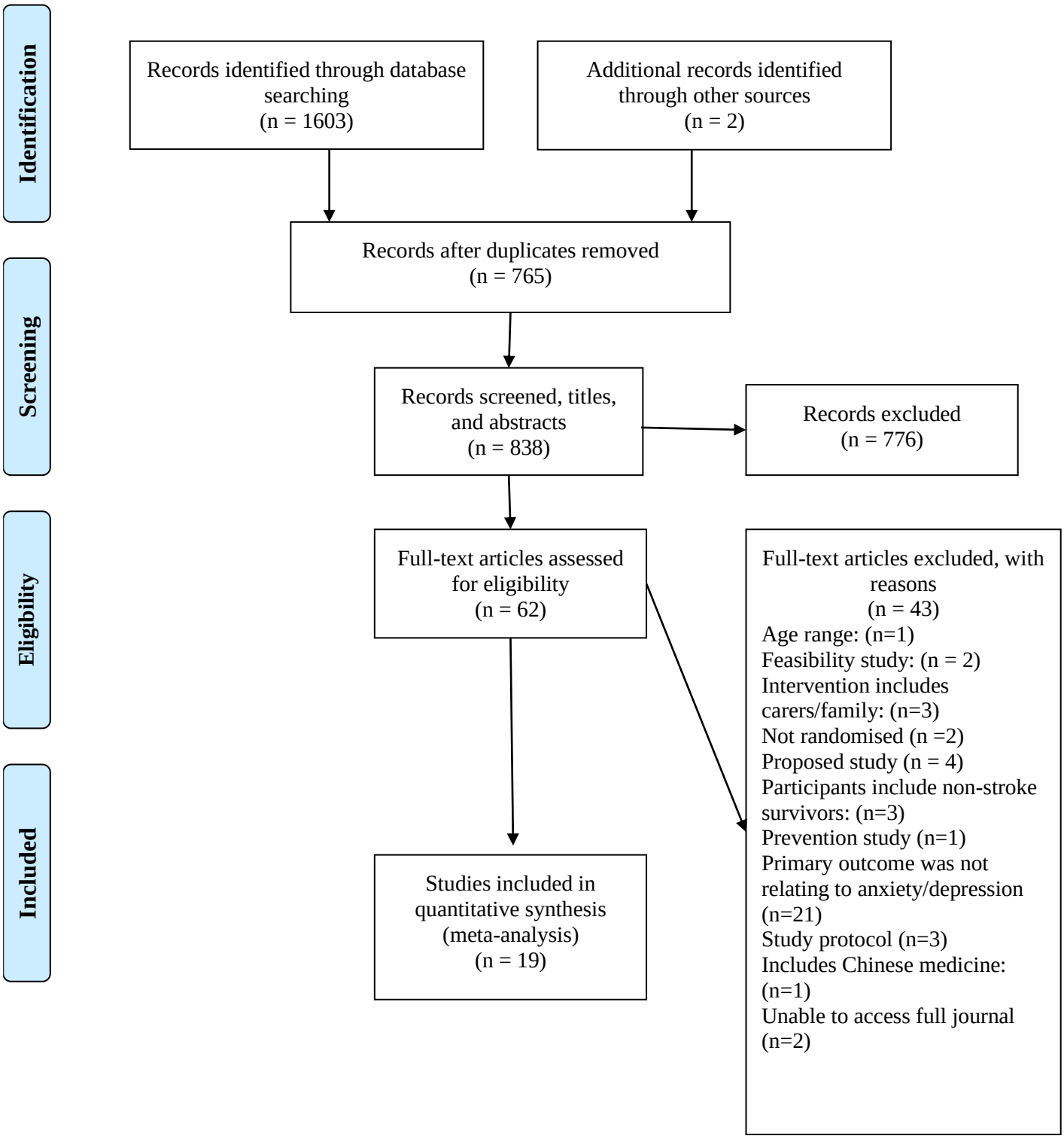
characteristics, the recruitment strategies used by researchers, the location of the research projects, the interventions investigated by researchers, and the outcome measures used.

Results

The number of records that were included/excluded at each stage of the systematic review process is detailed in the PRISMA flow diagram (Figure 1). 1603 records were initially identified, and 62 records reviewed at the full-text stage with 19 being retained for review.

Figure 1

PRISMA Flow Chart



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-Analys
PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Study characteristics

Key characteristics of the studies are presented in the study characteristics table (Table 1).

Design

All studies employed a RCT design, with three of these being pilot RCTs (Chan et al., 2012; Golding et al., 2016, 2018; Hoffman et al., 2015).

Sample size and Recruitment

Across all studies, a total of 2187 participants were recruited into either an intervention or control condition. Twelve projects recruited participants from Hospitals (Bragstad et al., 2020; Chen et al., 2019; Choi & Kim, 2022; Hoffman et al., 2007; Hoffman et al., 2015; Ihle-Hansen et al., 2014; Kongkasuwan et al., 2015; Lincoln & Flannaghan, 2003; Lin et al., 2020; Peng et al., 2015; Raglio et al., 2017; Thomas et al., 2012; Watkins et al., 2007; Wang et al., 2020). One project recruited participants via an advertisement in stroke survivor groups, in national stroke survivor publications, and stroke rehabilitation centres (Golding et al., 2016, 2018). One project advertised their project but did not disclose where (Kootker et al., 2017), and another did not disclose how they recruited participants (Lin et al., 2019). The smallest sample size was 15 participants (Chan et al., 2012) and the largest was 411 (Watkins et al., 2007).

Location of Research

Four studies took part in the United Kingdom (Golding et al., 2016, 2018; Lincoln & Flannaghan, 2003; Thomas et al., 2012; Watkins et al., 2007), two in Taiwan (Chen et al., 2019; Lin et al., 2020), three in Australia (Chan et al., 2012; Hoffman et al., 2007; Hoffman et al., 2015), two in Norway (Bragstad et al.,2020; Ihle-Hansen et al., 2014), two in South Korea (Choi & Kim, 2022; Lin et al., 2019), two in China (Peng et al., 2015; Wang et al., 2020), one in Bangkok (Kongkasuwan et al., 2015), one in Italy (Raglio et al., 2017), one in

the Netherlands (Kootker et al., 2017), and one in Nigeria (Olukolade & Osinowo, 2017).

Funding

Five studies did not disclose whether they received funding (Choi & Kim, 2022; Ihle-Hansen et al., 2014; Kootker et al., 2017; Lin et al., 2020; Olukowade & Osinowo, 2017). Four studies explicitly stated they received no funding for their studies (Chen et al., 2019; Golding et al., 2016; Lin et al., 2019; Raglio et al., 2017). All other studies reported that they received funding from government bodies, healthcare services, universities, and/or charities (Bragstad et al., 2020; Hoffman et al., 2007; Hoffman et al., 2015; Kongkasuwan et al., 2015).

Interventions

Studies included the following interventions: active music therapy (Raglio et al., 2017), augmented CBT (Kootker et al., 2017), behavioural therapy (Thomas et al., 2012), CBT (Hoffman et al., 2015; Lincoln & Flannaghan, 2003), CBT with bilateral limb training (Choi & Kim, 2022), cognitive rehabilitation therapy (Olukolade & Osinowo, 2017), a computer-generated tailored written education programme (Hoffman et al., 2007), creative art therapy (Kongkasuwan et al., 2015), dialogue based therapy (Bragstad et al., 2020), early rehabilitation combined with virtual reality training on muscle strength, mood state, and functional status (Lin et al., 2020), mind-body interactive qigong (Chen et al., 2019), mindful-based CBT (Wang et al., 2020), motivational interviewing (Watkins et al., 2007), multifactorial risk factor intervention program (Ihle-Hansen et al., 2014), neuro-linguistic programming brief therapy (Peng et al., 2015), psychoeducation (Olukolade & Osinowo, 2017), virtual reality training (Lin et al., 2020), Yoga and exercise (Chan et al., 2012), self-help relaxation training (Golding et al., 2016, 2018), and social support & health education (Lin et al., 2019).

Outcome Measures

The most frequently used primary outcome measure was the Hospital Anxiety and Depression Scale (HADS) which was used in eight of the studies (Chen et al., 2019; Golding et al., 2016, 2018; Hoffman et al., 2007; Ihle-Hansen et al., 2014; Kootker et al., 2017; Kongkasuwan et al., 2015; Lin et al., 2020; Raglio et al., 2017). In addition to the HADS, studies included as measures of anxiety the State-Trait Anxiety Inventory-Korean YZ (STAI-KYZ; Choi & Kim, 2022) and the State Trait Anxiety Inventory (STAI: Chan et al., 2012), and for depression, Beck's Depression Inventory scale (BDI; Olukolade & Osinowo, 2017; Lincoln & Flannaghan, 2003) and the Center for Epidemiologic Studies Depression Scale (CES-D; Wang et al., 2020), or general mental health or quality of life measures, such as the McGill Quality of Life Questionnaire (Raglio et al., 2017) and the General Health Questionnaire-28 (GHQ-28; Bragstad et al., 2020; Watkins et al., 2007). One of the studies included three measures of mood for people affected by aphasia, the Stroke Aphaisic Depression Questionnaire, the Visual Analog Mood Scales 'sad' item, and the Visual Analog self-esteem scale (Thomas et al., 2012).

Table 1

Study characteristics

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Bragstad et al., (2020)	Norway	Internally from hospital wards	322	Dialogue based intervention (n=166)	Usual care (n=166)	General Health Questionnaire -28 (GHQ-28)	No statistical difference between groups in psychosocial wellbeing at 12 months ($p>0.05$)	Not reported
Chan et al., (2012)	Australia	Database of stroke participants (Centre for Physical Activity in Ageing)	15	Yoga and exercise (n=9)	Exercise only (n=6)	Geriatric Depression Scale (GDS15) and State Trait Anxiety Inventory (STAI)	Significant difference within groups on pre and post outcome measure scores ($p<0.05$). No significant difference in scores between groups.	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Chen et al., (2019)	Taiwan	Recruited from medical and rehabilitation wards, Taiwan	72	Mind-body interactive qigong (physical exercises and meditation; n =36)	Standard Care (n=36)	Hospital Anxiety and Depression Scale (HADS)	Significant difference between groups regarding anxiety ($p=0.04$) but not depression ($p>0.05$)	Not reported
Choi & Kim, 2022	South Korea	Recruited internally from hospital	20	CBT with Bilateral limb training (n=10)	30-min conventional occupational therapy and bilateral limb training (n=10)	The State Trait Anxiety Inventory-Korean YZ (STAI-KYZ), Korean Depression Scale (KDS)	Significant decrease between groups ($p<0.01$) for anxiety and depression. Statistically significant differences within groups regarding anxiety and depression ($p<0.001$)	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Golding et al., (2016, 2018)	United Kingdom	Advert circulated on stroke survivor groups in the UK and in national stroke survivor publication	21	Self-help relaxation training (n=11)	CD given 3 months after (n=10)	HADS	Significantly more likely to report reduced anxiety since screening (month 1, 2, & 3), compared to those in the control group (p=0.001)	Not reported
Hoffman et al., (2007)	Australia	Recruited on admission to stroke unit.	133	Computer-Generated tailored written education programme (n=67)	Provided with Stroke Fact Sheets produced by Stroke Association Queensland (n=66)	HADS	Anxiety scores improved slightly more in favour of the control group (no significant differences)	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Hoffman et al., (2015)	Australia	Recruited on a consecutive admission basis from the stroke unit of a large ter-tiary hospital in Brisbane, Australia	33	Coping skills (n = 11) Self-management (n=12)	Usual care (n=10)	Montgomery and Asberg Depression rating scale (MADRS), HADS, Self-efficacy questionnaire, the stroke knowledge questionnaire	No significant difference found between or within groups for anxiety/depression	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Ihle-Hansen et al., (2014)	Norway	Recruited from Hospital	195	Multifactorial risk factor intervention program (n=98)	Usual Care (n=97)	HADS	Significant between group differences in anxiety and depression (p=0.044) in favour of intervention group.	Not reported
Kongkasuwan et al., (2015)	Bangkok	Recruited from stroke rehabilitation ward, Bangkok	118	Creative art therapy (n=59)	Conventional physical therapy only (n=59)	HADS	Significant difference between groups in depression scores (p<0.001) in favour of the intervention group not between anxiety (p=0.123).	Not reported
Kootker et al., (2017)	Netherlands	Recruited from rehabilitation centers	61	Augmented CBT (n=31)	Computer Cognitive Training (n=30)	HADS	Mixed model analyses showed a significant and persistent time effect for HADS-D (p<0.001)	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Lincoln & Flannaghan, (2003)	United Kingdom	Hospital register	123	CBT (n= 39)	No Intervention (n=41) Attention Placebo (n=43)	BDI, Wakefield Depression Inventory	No significant difference between groups	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Lin et al., (2019)	South Korea	N/A	62	Social Support & Health Education (n=31)	Routine Rehabilitation (n=31)	Depression scale (from the "Taiwan Longitudinal Study on Aging"	A significant difference was found between groups after social support for 8 weeks, in favour of the intervention group	There was a significant correlation between depression and the economic status of the patients with chronic stroke, satisfaction in leisure, the presence or absence of caregivers, and the duration of stroke.

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Lin et al., (2020)	Taiwan	Recruited from neurological care ward, Taiwan	143	Early Rehabilitation combined with virtual reality training on muscle strength, mood state, and functional status (n=38)	Conventional physical therapy only (n=114)	HADS	significant decrease in anxiety and depression compared to control group (p=0.047)	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Olukolade & Osinowo, (2017)	Nigeria	Health Care Centre (University HospitalI	20	Cognitive rehabilitation therapy (CRT; n =10) Psychoeducation (n=10)	Usual care (n=10)	Beck's Depression Inventory (BDI)	Significant differences in depression scores within intervention groups and control. Significant difference between groups in depression scores (CRT difference and control being the greatest).	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Peng et al., (2015)	China	Recruited from Hospital	180	Neuro-Linguistic Programming (NPL) brief therapy (n=90)	Usual care (n=90)	Hamilton-17 Depression Scale and Hamilton Anxiety Scale	Significant difference between groups in the prevalence of anxiety ($p=0.016$) depression and ($p=0.003$) after intervention. Not after 6-month follow-up ($p>0.05$).	Not reported
Raglio et al., (2017)	Italy	Recruited from hospital rehabilitation ward following stroke	38	Active Music Therapy (n=19)	Standard Care (n=19)	HADS, Italian version of the McGill Quality of Life Questionnaire	No significant difference between control and music therapy. Significant decrease in anxiety and depression scores within experimental group ($p=0.016$)	Not reported

Author (Year)	Country	Recruitment strategy	Sample size (N)	Intervention	Control	Outcome measures	Main findings	Analyses regarding differences in outcomes based on demographics
Thomas et al., (2012)	United Kingdom	Recruited from hospital wards	105	Behavioural therapy (n=54)	Usual Care (n=51)	Stroke Aphaisic Depression Questionnaire, Visual Analog Mood Scales 'sad' item, and Visual Analog self-esteem scale	significant difference at 6 months between control and intervention group (p=0.02)	Not reported
Wang et al., (2020)	China	Recruited from Hospital	134	Mindful based CBT (n=67)	Stress management education (n=67)	Center for epidemiologic studies depression scale (CES-D)	Significant differences in depression score in intervention group.	Not reported
Watkins et al., (2007)	United Kingdom	Recruited from hospital wards	411	Motivational Interviewing (n=204)	Usual Care (n=207)	GHQ- 28	Significant difference between groups (p=0.03).	Not reported

Appraisal of Quality of RCTs

Overall, we found that all RCT studies included in the analysis had a focused objective and appropriate steps were taken to reduce bias through randomisation during group allocation (CAPS-2020). Furthermore, all studies used appropriate statistical tests to analyse their data. From the 12 studies assessed by the primary researcher and external researcher, 100% agreement was met on 7 items of the CASP RCT (items 1, 2, 3, 4, 5, 10 and 11), there was 96% agreement on 2 items (items 6 and 7), 88.89% on item 8, and 80% on item 9. The overall agreement rate for the quality assessments between researchers was 97% (n=12) and the inter-rater reliability (Cohen's kappa) for overall quality was substantial, k = 0.94.

Appraisal of the Reporting of Protected Characteristics

Using the augmented PROGRESS-Plus framework (O'Neill., 2014; Plastow et al., 2021) to assess the reporting of protected characteristics, the highest rating given to the included studies was 9/15 (Peng et al., 2015) and the lowest rating given was 2/15 (Olukolade & Osinowo, 2017), see table 2. Age and Gender were the most reported and Sexual Orientation was the least reported, see figure 2. Despite the potential links to post-stroke anxiety and/or depression, less than half the studies reported the marital status of participants (Bragstad et al., 2020; Chen et al., 2019; Hoffman et al., 2015; Lin et al., 2020; Peng et al., 2015; Thomas et al., 2012; Wang et al., 2020). None of the studies reported whether participants experienced any pre-morbid disability. However, five studies reported the inclusion of participants with aphasia (Bragstad et al., 2020; Hoffman et al., 2007; Hoffman et al., 2015; Raglio et al., 2017; Thomas et al., 2012). Of these, four reported the number of participants with aphasia who took part in their studies (Hoffman et al., 2007; Hoffman et al., 2015; Raglio et al., 2017), with one study including aphasia as an inclusion criterion (Thomas et al., 2012). Two studies reported the number of participants with a physical impairment

(Chen et al., 2019; Lin et al., 2020) and two studies reported the number of participants with vision and visual perception impairments (Hoffman et al., 2007; Hoffman et al., 2015).

What protected characteristics have been reported in non-pharmacological intervention studies in stroke research?

Place of residence

Two studies reported the place of residence (e.g., care home vs home) of the participants (Lincoln & Flannaghan, 2003; Thomas et al., 2012; See Table 3), with most participants residing at home. However, within-group differences were not explored in relation to the participant's place of residence.

Race/ethnicity/culture/language

Two of the 18 studies included demographic information regarding ethnicity and/or language (Chen et al., 2019; Wang et al., 2020). Chen et al. (2019) reported that most of their participants' primary language was Mandarin (compared with Taiwanese and Hakka). Wang et al. (2020) reported that the majority of their participant's ethnicities were Han. Additionally, none of the authors reported information regarding the cultural background of the participants, other than the location of where the study took place.

Occupation

Five studies included information as to whether participants who took part in the project were employed (Chen et al., 2019; Kootker et al., 2017; Lin et al., 2019; Peng et al., 2015; Wang et al., 2020). Across these studies, most participants were unemployed. Again, the number of individuals in the control group and intervention group who were employed/unemployed was shown in the study characteristics table in these studies, but any differences within groups were not explored by any of the authors.

Gender/sex

All 19 studies included information regarding the gender of participants who took part in their study. The number of males and females in each intervention and control group were expressed in tables. However, no studies explored the differences between gender and primary or secondary outcomes. Furthermore, there was no description of whether sex was equated with gender or whether any participants identified as non-binary or transgender or if participants were provided with these options to choose from. All studies reported a mix of male and female participants.

Religion

One study reported the preferred religion of the participants who took part in their study (Chen et al., 2019). With most participants being reported as having an "Other" religion (compared to Buddhism or Taoism). However, within-group differences were not explored based on religion and mood measure outcomes.

Education

Ten studies included information regarding the participant's level of education (Chen et al., 2019; Hoffman et al., 2015; Ihle-Hansen et al., 2014; Kongkasuwan et al., 2015; Lin et al., 2019; Lin et al., 2020; Olukolade & Osinowo, 2017; Peng et al., 2015; Raglio et al., 2017; Wang et al., 2020) but did not explore within-group differences on outcome measure scores. The majority of participants had at least attended elementary (primary) school, with a minority of participants having completed degree level education.

Socioeconomic status

Two projects reported the economic status of participants (Lin et al., 2019; Peng et al., 2015). The studies appeared to have a mix of participant from different socioeconomic backgrounds or perceived sufficiency of financial satisfaction. However, only one project explored within group differences in the intervention group regarding the economic status

and outcome measure scores (Lin et al., 2019). The researchers found that those from a lower socioeconomic status were less likely to experience a significant change in mood following taking part in the intervention group.

Social Capital (marital status, living arrangements including caregivers, networks and engagement in the community)

Only one study reported information regarding engagement in the community, with the researchers reporting participants' perceived level of satisfaction within a community (Lin et al., 2019). Marital status and living arrangements are considered a feature of a relationship (O'Neill et al., 2014) and the review found that seven studies reported data regarding whether participants were married and/or reported on living arrangements (Bragstad et al., 2020; Chen et al., 2019; Hoffman et al., 2015; Lin et al., 2020; Peng et al., 2015; Thomas et al., 2012; Wang et al., 2020). Most participants across all studies were married, lived with another person, and/or lived in independent housing. One study reported whether participants had caregivers (Lin et al., 2019). It was uncertain whether Chen et al. (2019) reported whether participants were primary caregivers or had primary caregivers. Projects were not given additional scores for including both marital status and living arrangements.

The only study which explored subgroup differences relating to caregivers and social capital, was Lin et al.'s (2019) study. Social factors such as whether participants had caregivers were found to have an impact on the likelihood of experiencing depression following stroke at different points of the project (Lin et al., 2019). Additionally, Lin et al. (2019) found that in the intervention group who received social support, there was a significant difference in mean depression scores in favour of those with social support. However, no other studies explored the impact social capital can have on the accessibility/effectiveness of post-stroke anxiety/depression interventions.

Plus (additional factors associated with discrimination)

Age. 18 studies included the mean age of the participants in the data analysis. However, no exploration regarding differences in age and outcome measure scores on the targeted intervention took place in any of the studies. The mean (M) age of participants across all these studies were over 60 and under 76 years of age. One study did not include the age of participants (Olukolade & Osinowo, 2017).

Disability/Stroke Characteristics. None of the 19 studies reported whether participants experienced any pre-stroke disability. Five studies explicitly stated that they included participants with a form of aphasia/language impairment (Bragstad et al., 2020; Hoffman et al., 2007; Hoffman et al., 2015; Raglio et al., 2017; Thomas et al., 2012). However, those with severe expressive aphasia were not included in most of these studies (Bragstad et al., 2020; Hoffman et al., 2007; Hoffman et al., 2015; Raglio et al., 2017). Of these, three reported the number of participants with Aphasia (Hoffman et al., 2007; Hoffman et al., 2015; Raglio et al., 2017). Only one study included participants with severe communication difficulties and set communication difficulties as an inclusion criterion (Thomas et al., 2012). All other studies included in the review cited the ability to verbally communicate as being an inclusion criterion to take part in their study.

Two studies reported the level of physical disability required to take part in their studies (Chen et al., 2019; Lin et al., 2020) and two studies reported the number of participants with vision and visual perception impairments (Hoffman et al., 2007; Hoffman et al., 2015).

None of the studies reported the number of participants with cognitive impairment included in their studies.

Eleven of the 19 studies reported the location of participants' strokes (Bragstad et al., 2020; Chan et al., 2012; Choi & Kim, 2022; Hoffman et al., 2007; Hoffman et al., 2015; Ihle-Hansen et al., 2014; Kongkasuwan et al., 2016; Kootker et al., 2017; Peng et al., 2015; Raglio

et al., 2017; Thomas et al., 2012). Five studies reported the time since participants had had a stroke (Chan et al., 2012; Golding et al., 2016, 2018; Lincoln & Flannaghan, 2003; Peng et al., 2015; Thomas et al., 2012), and 10 reported the type of stroke participants had experienced (Bragstad et al., 2020; Choi & Kim, 2022; Hoffman et al., 2007; Hoffman et al., 2015; Ihle-Hansen et al., 2014; Kongkasuwan et al., 2016; Kootker et al., 2017; Peng et al., 2015; Raglio et al., 2017; Watkins et al.,2007).

Sexual Orientation. None of the 19 studies reported the sexual orientation of those who took part in their research.

Figure 2

The number of included papers per country which reported protected characteristics across adapted PROGRESS-Plus items

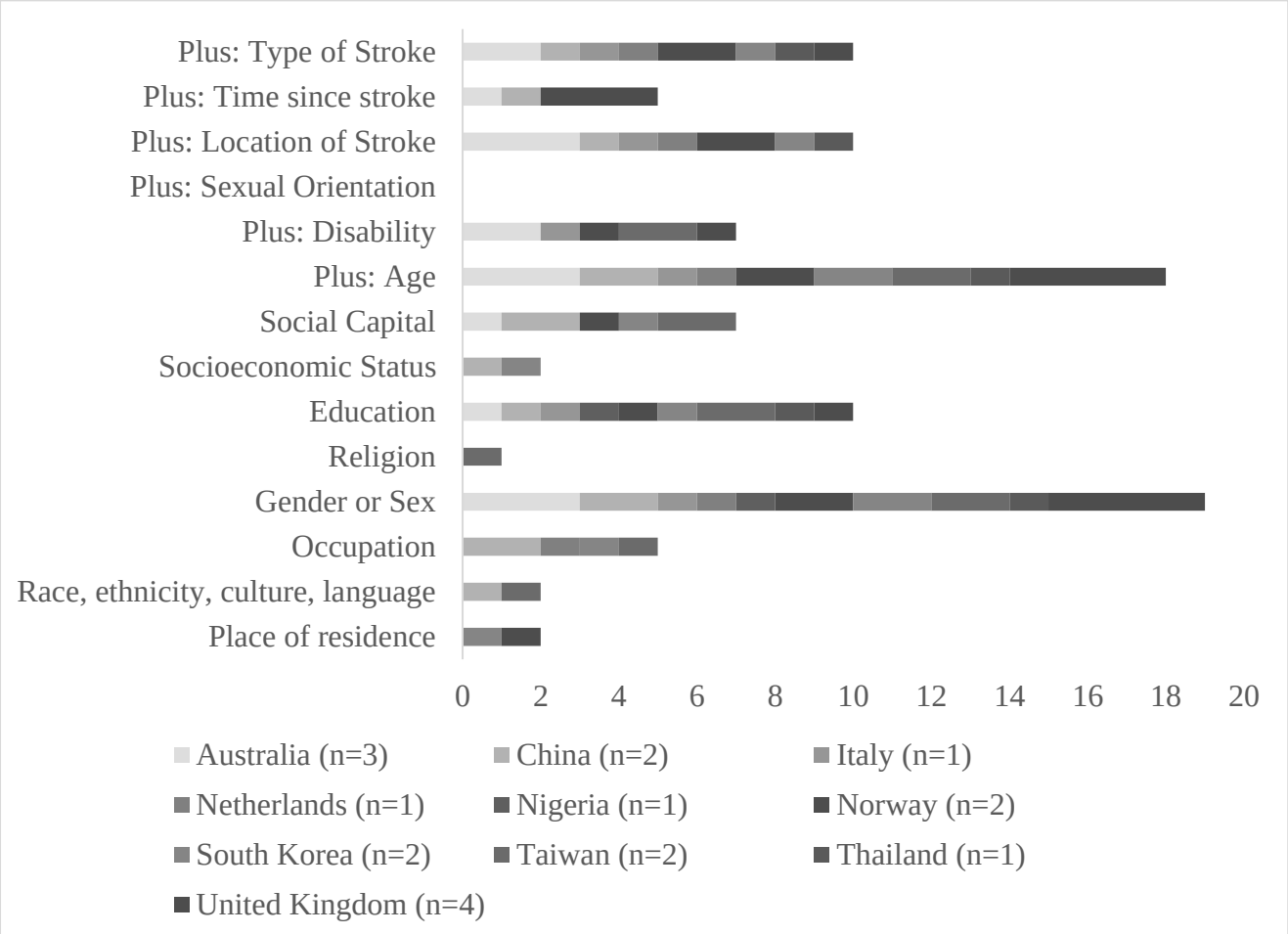


Table 2

Appraisal of reporting adapted PROGRESS-Pluss characteristics

Author	Demographic Characteristics reported in project	Personal characteristics reported in project	Features of relationships reported in project	Stroke Characteristics reported in study	Total Score (n/15)
Bragstad et al., (2020)	Gender/Sex, Disability	Age	Marital Status or living arrangements	Location, Type of Stroke	6
Chan et al., (2012)	Gender/Sex	Age	Not reported	Location, Time since stroke	4
Chen et al., (2019)	Race or ethnicity or culture or language, Occupation, Gender/Sex, Religion, Education, Disability	Age	Marital Status or living arrangements,	Not reported	8
Choi & Kim, (2022)	Gender/Sex	Age	Not reported	Location, Type of Stroke	4

Author	Demographic Characteristics reported in project	Personal characteristics reported in project	Features of relationships reported in project	Stroke Characteristics reported in study	Total Score (n/15)
Golding et al., (2016, 2018)	Gender/Sex	Age	Not reported	Time since stroke	3
Hoffman et al., (2007)	Gender/Sex, Disability	Age	Not reported	Location, Type of stroke	5
Hoffman et al., (2015)	Gender/Sex, Education, Disability	Age	Marital status or living arrangements	Location, Type of stroke	7
Ihle-Hansen et al., (2014)	Gender/Sex, Education,	Age	Not reported	Location, Type of stroke	5
Kongkasuwan et al., (2016)	Gender/Sex, Education	Age	Not reported	Location, Type of stroke	5
Kootker et al., (2017)	Occupation, Gender/Sex	Age	Not reported	Location, Type of stroke	5

Author	Demographic Characteristics reported in project	Personal characteristics reported in project	Features of relationships reported in project	Stroke Characteristics reported in study	Total Score (n/15)
Lincoln & Flannaghan, (2003)	Place of residence, Gender/Sex	Age	Not reported	Time since stroke	4
Lin et al., (2019)	Occupation, Gender/Sex, Education, Socio-economic status	Age	Satisfaction in community	Not reported	6
Lin et al., (2020)	Gender/Sex, Education, Disability	Age	Marital Status or living arrangement	Not reported	5
Olukolade & Osinowo, (2017)	Gender/Sex, Education	Not reported	Not reported	Not reported	2
Peng et al., (2015)	Occupation, Gender/Sex,	Age	Marital Status or living arrangements,	Time since stroke, Location, Type of stroke	9

Author	Demographic Characteristics reported in project	Personal characteristics reported in project	Features of relationships reported in project	Stroke Characteristics reported in study	Total Score (n/15)
	Education, Socio-economic status				
Raglio et al., (2017)	Gender/Sex, Education, Disability	Age	Not reported	Location, Type of stroke	6
Thomas et al (2012)	Place of residence, Gender/Sex, Disability	Age	Marital Status or living arrangements	Time since stroke, Location	7
Wang et al., (2020)	Race or ethnicity or culture or language, Occupation, Gender/Sex, Education	Age	Marital Status or living arrangements	Not reported	6
Watkins et al., 2007	Gender/Sex	Age	Not reported	Type of stroke	3

Discussion

This systematic review scoped the reporting of protected characteristics in non-pharmacological intervention studies for post-stroke anxiety and/or depression. The pooled analysis of the 19 studies revealed a range of differences in the reporting of demographic information of participants in stroke research.

Using the augmented PROGRESS-Plus framework (O'Neill., 2014; Plastow et al., 2021) to assess the reporting of protected characteristics, the highest rating given to the included studies was 9/15 (Peng et al., 2015) and the lowest rating given was 2/15 (Olukolade & Osinowo, 2017). Age was the most reported protected characteristics and Sexual Orientation was the least reported (see Table 2).

The majority of the studies reported the recruitment process for those taking part in their research, with one study being more ambiguous as to where the project was advertised (Kootker et al., 2017). Furthermore, the projects were transparent regarding the outcome measures used, at what time points participants were asked to complete the measures, and what interventions were used to support post-stroke anxiety/depression.

Despite the understanding that protected characteristic can impact the accessibility of healthcare services and research (WHO, 2022), many papers in the present systematic scoping review reported few protected characteristics regarding the participants who took part in their research. Other reviews analysing the consideration of the exploration of protected characteristics in health-related research also reported similar findings (Madani et al., 2022; Plastow et al.,2021). Several studies reported as little as three or four protected characteristics of their participants with none including information regarding the sexual orientation of their participants (Choi & Kin, 2022; Golding et al., 2016, 2018; Kongkasuwan et al., 2016).

Although, understandably, all papers may not feel the need to disclose all the

characteristics outlined in PROGRESS-Plus (Attwood et al., 2016), it was worrying to notice that key clinical characteristics relating to stroke and health inequity were missed by some papers, such as the location, type of stroke, and time since the stroke had occurred. Furthermore, considering that along with age and gender, ethnicity, health history, living alone, marital status, place of residence, and socioeconomic status are all known to impact the likelihood of stroke (Addo et al., 2012; Bhaskar et al., 2019; Hosseinzadeh et al., 2022; Lindenstrøm et al., 1993), accessibility to services (Bhaskar et al., 20019; Sandel et al., 2009), and perceived quality of life of stroke survivors (Wang & Langhammer, 2018), it is surprising that these demographic and social factors are not reported in many of the reviewed studies. Most papers in their inclusion/exclusion criteria did disclose the time frame in which participants sustained their stroke and whether those with cognitive impairment, language deficits, or physical disabilities were eligible to take part. However, it would have been beneficial to gain a better understanding of specific stroke characteristics, such as lesion location, of those taking part as well as any other disabilities or mental health conditions (outside of anxiety/depression) as these are known to impact the likelihood of experiencing anxiety or depression following a stroke (Medeiros et al., 2020; Rafsten et al., 2018).

Furthermore, only eight studies reported the marital status or living arrangements of stroke participants (Bragstad et al., 2020; Chen et al., 2019; Hoffman et al., 2015; Lin et al., 2019; Lin et al., 2020; Peng et al., 2015; Thomas et al., 2012; Wang et al., 2020) and only 9 of the studies reported the level of education of the participants (Chen et al., 2019; Hoffman et al., 2015; Kongkasuwan et al., 2015; Lin et al., 2019; Lin et al., 2020; Olukolade & Osinowo, 2017; Peng et al., 2015; Raglio et al., 2017; Wang et al., 2020). As some research suggests that marital status, living arrangements, and level of education have a great impact on post-stroke anxiety and/or depression (Northcott et al., 2015) and on adherence to post-acute rehabilitation (Duncan et al., 2002), this would seem like an important characteristic to

include when reporting the characteristics of participants and when assessing the effectiveness of interventions.

By reporting the context of who is taking part in post-stroke anxiety/depression non-pharmacological research, services and clinicians can gain a better understanding of what interventions may be accessible for those in their care (Attwood et al., 2016). Here, only one non-pharmacological intervention paper investigated subgroup differences in outcome measures (Lin et al., 2019). The researchers found that those from a lower socioeconomic status or without social support were less likely to experience a positive outcome following the intervention (Lin et al., 2019). As there are many factors which can impact an individual's ability or willingness to engage in an intervention (National Healthcare Service, 2019; WHO, 2022), by providing these additional analyses, fellow researchers and clinicians would be provided with a greater understanding of the context in which the intervention may be more or less accessible.

A strength of this systematic review is that it is the first to examine the reporting of protected characteristics in non-pharmacological stroke research for post-stroke anxiety and/or depression, globally. Further strengths of the review include the use of a quality tool (CASP, 2020) in order to assess the robustness of findings, despite Scoping reviews not being required to check for quality. Furthermore, the use of a protected characteristics framework (PROGRESS-Plus; O'Neill et al., 2014), which incorporates the demographic and social factors considered to impact stroke likelihood, access to services, and outcomes, adds to the strength of the review.

Limitations include that the search for papers was limited to those written in English. Several RCT papers investigating the effectiveness of CBT interventions for post-stroke anxiety and/or depression identified in Wang and Langhammer's (2018) review were thus not included, and others not known to the authors may also have been missed. Furthermore, only

studies which investigated post-stroke anxiety/depression as a primary goal were investigated, therefore, other non-pharmacological RCT studies investigating the impact of interventions on anxiety/depression as secondary outcomes were not included. Additionally, the review solely focused on the reporting of demographic and social factors in RCTs, which could be a potential source of bias. A further limitation to the current review is that it is not known what characteristics researchers gathered for their studies but did not report, or whether subgroup analyses was originally planned in their protocol. Therefore, the review is unable to reflect on whether the intentions of reporting and analysing subgroup data by the researchers differed to what was then reported.

Despite attempting to extract data, due to the limited number of studies exploring sub-group differences on outcome measure scores, we have not been able to advance our understanding of what non-pharmacological interventions may be more effective to whom. To reduce health disparities, we must better understand what may work and what may not work for different subgroups, based on researchers' analyses and explanations of their results. Future studies focusing on the use of non-pharmacological for post-stroke anxiety and/or depression should consider using the PROGRESS-Plus framework when reporting participant characteristics (O'Neill et al., 2014). This would allow researchers and healthcare professionals to know who is currently taking part in stroke research, whether stroke research is representative of the population being treated, and how effective the various non-pharmacological interventions are, across subgroups (Madani et al., 2022). It is understandable that subgroup analysis may only sometimes be possible. Barriers to performing such analysis may be restricted to the data itself. If the study becomes underpowered when analysing subgroup data, the data analysis may no longer be of interest to other researchers and will be considered to have weak methods (Petticrew et al., 2012). However, regardless of this, demographic and social factors known to impact the likelihood

of stroke, access to stroke services, and stroke outcomes, should be reported in relevant research.

Conclusion

In summary, the majority of the RCTs included in the study reported some of the protected characteristics most relevant to the non-pharmacological management of post-stroke anxiety and/or depression. However, only one of the included studies detailed relevant analyses to enable us to determine which population subgroups may find the specified non-pharmacological interventions to be more accessible and/or beneficial. Future research should focus on including the relevant protected characteristics of their participants and analyse any sub-group differences in anxiety and/or depression measures where sample size allows.

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References

Addo, J., Ayerbe, L., Mohan, K. M., Crichton, S., Sheldenkar, A., Chen, R., Wolfe, C. D. A., & McKevitt, C. (2012). Socioeconomic Status and Stroke. *Stroke, 43*(4), 1186–1191.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a Methodological Framework. *International Journal Social Research Methodology. 1*(8),19–32. doi: 10.1080/1364557032000119616.

Attwood, S., van Sluijs, E., & Sutton, S. (2016). Exploring equity in primary-care-based physical activity interventions using PROGRESS-Plus: A systematic review and evidence synthesis. *International Journal of Behavioral Nutrition and Physical Activity, 13*(1), 60. https://doi.org/10.1186/s12966-016-0384-8

Backhouse, E. V., McHutchison, C. A., Cvoro, V., Shenkin, S. D., & Wardlaw, J. M. (2018). Cognitive ability, education and socioeconomic status in childhood and risk of post-stroke depression in later life: A systematic review and meta-analysis. *PLoS One, 13*(7), e0200525. https://doi.org/10.1371/journal.pone.0200525

Barker-collo, S. (2007). Depression and anxiety 3 months post stroke: Prevalence and correlates. *Archives of Clinical Neuropsychology, 22*(4), 519–531. https://doi.org/10.1016/j.acn.2007.03.002

Bhaskar, S., Thomas, P., Cheng, Q., Clement, N., McDougall, A., Hodgkinson, S., & Cordato, D. (2019). Trends in acute stroke presentations to an emergency department: implications for specific communities in accessing acute stroke care services. *Postgrad Med J, 95*(1123), 258-264. https://doi.org/10.1136/postgradmedj-2019-136413

Bragstad, L. K., Hjelle, E. G., Zucknick, M., Sveen, U., Thommessen, B., Bronken, B. A., Martinsen, R., Kitzmüller, G., Mangset, M., Kvigne, K. J., Hilari, K., Lightbody, C. E., & Kirkevold, M. (2020). The effects of a dialogue-based intervention to promote psychosocial

well-being after stroke: A randomized controlled trial. *Clinical Rehabilitation*, *34*(8), 1056–1071. https://doi.org/10.1177/0269215520929737

Carod-Artal, F. J., & Egido, J. A. (2009). Quality of life after stroke: The importance of a good recovery. *Cerebrovascular Diseases (Basel, Switzerland)*, *27 Suppl 1*, 204–214. https://doi.org/10.1159/000200461

Carson, A. J., MacHale, S., Allen, K., Lawrie, S. M., Dennis, M., House, A., & Sharpe, M. (2000). Depression after stroke and lesion location: A systematic review. *Lancet (London, England)*, *356*(9224), 122–126. https://doi.org/10.1016/S0140-6736(00)02448-X

Chan, W., Immink, M. A., & Hillier, S. (2012). Yoga and exercise for symptoms of depression and anxiety in people with poststroke disability: A randomized, controlled pilot trial. *Alternative Therapies in Health and Medicine*, *18*(3), 34–43.

Chen, C.-H., Hung, K.-S., Chung, Y.-C., & Yeh, M.-L. (2019). Mind–body interactive qigong improves physical and mental aspects of quality of life in inpatients with stroke: A Randomized Control Study. *European Journal of Cardiovascular Nursing*, *18*(8), 658–666. https://doi.org/10.1177/1474515119860232

Cheng, L.-S., Tu, W.-J., Shen, Y., Zhang, L.-J., & Ji, K. (2018). Combination of High-Sensitivity C-Reactive Protein and Homocysteine Predicts the Post-Stroke Depression in Patients with Ischemic Stroke. *Molecular Neurobiology*, *55*(4), 2952–2958. https://doi.org/10.1007/s12035-017-0549-8

Cheong, M. J., Kang, Y., & Kang, H. W. (2021). Psychosocial Factors Related to Stroke Patients' Rehabilitation Motivation: A Scoping Review and Meta-Analysis Focused on South Korea. *Healthcare*, *9*(9), Article 9. https://doi.org/10.3390/healthcare9091211

Choi, S. E., & Kim, D. J. (2022). Effects of combining cognitive behavioral therapy with bilateral upper limb training in stroke patients: A randomized controlled trial. *Occupational Therapy International*, *2022*, 1–9. https://doi.org/10.1155/2022/4688113

CONSORT-Equity | Cochrane Equity. (n.d.-a). Retrieved 14 January 2023, from https://methods.cochrane.org/equity/consort-equity

Critical Appraisal Skills Programme (CASP; 2020). CASP Randomised Controlled Trial Checklist 2020 [Available from: https://casp-uk.b-cdn.net/wp-content/uploads/2020/10/CASP_RCT_Checklist_PDF_Fillable_Form.pdf.

De Ryck, A., Brouns, R., Geurden, M., Elseviers, M., De Deyn, P. P., & Engelborghs, S. (2014). Risk factors for poststroke depression: Identification of inconsistencies based on a systematic review. *Journal of Geriatric Psychiatry and Neurology*, *27*(3), 147–158. https://doi.org/10.1177/0891988714527514

Feigin, V. L., Stark, B. A., Johnson, C. O., Roth, G. A., Bisignano, C., Abady, G. G., Abbasifard, M., Abbasi-Kangevari, M., Abd-Allah, F., Abedi, V., Abualhasan, A., Abu-Rmeileh, N. M., Abushouk, A. I., Adebayo, O. M., Agarwal, G., Agasthi, P., Ahinkorah, B. O., Ahmad, S., Ahmadi, S., &Murray, C. J. L. (2021). Global, regional, and national burden of stroke and its risk factors, 1990–2019: A systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Neurology*, *20*(10), 795–820. https://doi.org/10.1016/S1474-4422(21)00252-0

Golding, K., Kneebone, I., & Fife-Schaw, C. (2016). Self-help relaxation for post-stroke anxiety: A randomised, controlled pilot study. *Clinical Rehabilitation*, *30*(2), 174–180. https://doi.org/10.1177/0269215515575746

Golding, K., Fife-Schaw, C., & Kneebone, I. (2018). A pilot randomized controlled trial of self-help relaxation to reduce post-stroke depression. *Clinical Rehabilitation*, *32*(6), 747–751. https://doi.org/10.1177/0269215517741947

Guo, J., Wang, J., Sun, W., & Liu, X. (2022). The advances of post-stroke depression: 2021 update. *Journal of Neurology*, *269*(3), 1236–1249. https://doi.org/10.1007/s00415-021-10597-4

Hackett, M. L., Köhler, S., O'Brien, J. T., & Mead, G. E. (2014). Neuropsychiatric outcomes of stroke. *The Lancet Neurology*, *13*(5), 525–534. https://doi.org/10.1016/S1474-4422(14)70016-X

Hoffmann, T., McKenna, K., Worrall, L., & Read, S. J. (2007). Randomised trial of a computer-generated tailored written education package for patients following stroke. *Age and Ageing*, *36*(3), 280–286. https://doi.org/10.1093/ageing/afm003

Hoffmann, T., Ownsworth, T., Eames, S., & Shum, D. (2015). Evaluation of brief interventions for managing depression and anxiety symptoms during early discharge period after stroke: A pilot randomized controlled trial. *Topics in Stroke Rehabilitation*, *22*(2), 116–126. https://doi.org/10.1179/1074935714z.0000000030

Hosseinzadeh, N., Ala, A., Rahnemayan, S., Sadeghi-Hokmabadi, E., Milani, A. G., Asenjan, M. R., & Vahdati, S. S. (2022). Demographic information and risk factors of stroke patients younger than 65 years old. *Frontiers in Emergency Medicine*, *6*(1), Article 1. https://doi.org/10.18502/fem.v6i1.7676

Ihle-Hansen, H., Thommessen, B., Fagerland, M. W., Øksengård, A. R., Wyller, T. B., Engedal, K., & Fure, B. (2014). Multifactorial vascular risk factor intervention to prevent cognitive impairment after stroke and TIA: A 12-month randomized controlled trial. *International Journal of Stroke: Official Journal of the International Stroke Society*, *9*(7), 932–938. https://doi.org/10.1111/j.1747-4949.2012.00928.x

Khazaal, W., Taliani, M., Abou-Abbas, L., Sadier, N., Boutros, C., Hosseini, H., & Salameh, P. (2021). Psychological Complications at 3 Months Following Stroke: Prevalence and Correlates Among Stroke Survivors in Lebanon. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.663267

Kim, J, S. (2017). Management of Post-Stroke Mood and Emotional Disturbances. *Expert Review of Neurotherapeutics 17*(12)1179–88. https://doi.org/10.1080/14737175.2017.1395281.

Kootker, J. A., Rasquin, S. M. C., Lem, F. C., van Heugten, C. M., Fasotti, L., & Geurts, A. C. H. (2017). Augmented cognitive behavioral therapy for poststroke depressive symptoms: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation*, *98*(4), 687–694. https://doi.org/10.1016/j.apmr.2016.10.013

Kongkasuwan, R., Maneechai, P., Boonin, J., Kuptniratsaikul, V., Voraakhom, K., & Pisolayabutra, P. (2016). Creative art therapy to enhance rehabilitation for stroke patients: A randomized controlled trial. *Clinical Rehabilitation*, *30*(10), 1016–1023. https://doi.org/10.1177/0269215515607072

Knapp, P., Dunn-Roberts, A., Sahib, N., Cook, L., Astin, F., Kontou, E., & Thomas, S. A. (2020). Frequency of anxiety after stroke: An updated systematic review and meta-analysis of observational studies. *International Journal of Stroke*. https://doi.org/10.1177/1747493019896958

Leis, J. A., Mendelson, T., Perry, D. F., & Tandon, S. D. (2011). Perceptions of mental health services among low-income, perinatal African-American women. *Women's Health Issues*, *21*(4), 314–319. https://doi.org/10.1016/j.whi.2011.03.005

Lin, F.-H., Yih, D. N., Shih, F.-M., & Chu, C.-M. (2019). Effect of social support and health education on depression scale scores of chronic stroke patients. *Medicine*, *98*(44), e17667. https://doi.org/10.1097/MD.0000000000017667

Lin, R. C., Chiang, S. L., Heitkemper, M. M., Weng, S. M., Lin, C. F., Yang, F. C., & Lin, C. H. (2020). Effectiveness of Early Rehabilitation Combined With Virtual Reality Training on Muscle Strength, Mood State, and Functional Status in Patients With Acute Stroke: A Randomized Controlled Trial. *Worldviews on Evidence-Based Nursing*, *17*(2), 158–167. https://doi.org/10.1111/wvn.12429

Lincoln, N.B. and Flannaghan, T. (2003) Cognitive behavioral psychotherapy for depression following stroke: A randomized controlled trial. Stroke, 34, 111-115. doi:10.1161/01.STR.0000044167.44670.55

Lindenstrøm, E., Boysen, G., & Nyboe, J. (1993). Risk factors for stroke in Copenhagen, Denmark. I. Basic demographic and social factors. *Neuroepidemiology*, *12*(1), 37–42. https://doi.org/10.1159/000110297

Liddon, L., Kingerlee, R., & Barry, J. (2017). Gender differences in preferences for psychological treatment, coping strategies, and triggers to help-seeking. *British Journal Of Clinical Psychology*, *57*(1), 42-58. https://doi.org/10.1111/bjc.12147https://doi.org/10.1111/bjc.12147

Liu, R., Yue, Y., Jiang, H., Lu, J., Wu, A., Geng, D., Wang, J., Lu, J., Li, S., Tang, H., Lu, X., Zhang, K., Liu, T., Yuan, Y., & Wang, Q. (2017). A risk prediction model for post-stroke depression in Chinese stroke survivors based on clinical and socio-psychological features. *Oncotarget*, *8*(38), 62891-62899. https://doi.org/10.18632/oncotarget.16907

Madani, M. T., Madani, L., Ghogomu, E. T., Dahrouge, S., Hébert, P. C., Juando-Prats, C., Mulligan, K., & Welch, V. (2022). Is equity considered in systematic reviews of interventions for mitigating social isolation and loneliness in older adults? *BMC Public Health*, *22*(1). https://doi.org/10.1186/s12889-022-14667-8

Medeiros, G. C., Roy, D., Kontos, N., & Beach, S. R. (2020). Post-stroke depression: A 2020 updated review. *General Hospital Psychiatry*, *66*, 70–80. https://doi.org/10.1016/j.genhosppsych.2020.06.011

National Collaborating Centre for Methods and Tools (2015). *PROGRESS framework: Applying an equity lens to interventions*. Hamilton, ON: McMaster University. (Updated 01 September 2017) Retrieved from http://www.nccmt.ca/resources/search/234.

National Healthcare Service (NHS). (2019). *NHS Long Term Plan*. NHS choices. Retrieved March 6, 2023, from https://www.longtermplan.nhs.uk/online-version/.

Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, *30*(8), 811–831. https://doi.org/10.1177/0269215515602136

Olukolade, O., & Osinowo, H. O. (2017). Efficacy of Cognitive Rehabilitation Therapy on Poststroke Depression among Survivors of First Stroke Attack in Ibadan, Nigeria. *Behavioural Neurology*, *2017*, 4058124. https://doi.org/10.1155/2017/4058124

O'Neill, J., Tabish, H., Welch, V., Petticrew, M., Pottie, K., Clarke, M., Evans, T., Pardo, J. P., Waters, E., White, H., & Tugwell, P. (2014). Applying an equity lens to interventions: Using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *Journal of Clinical Epidemiology*, *67*(1), 56–64. https://doi.org/10.1016/j.jclinepi.2013.08.005

Peng, Y., Lu, Y., Wei, W., Yu, J., Wang, D., Xiao, Y., Xu, J., & Wang, Z. (2015). The Effect of a Brief Intervention for Patients with Ischemic Stroke: A Randomized Controlled Trial. *Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association*, *24*(8), 1793–1802. https://doi.org/10.1016/j.jstrokecerebrovasdis.2015.04.009

Petticrew, M., Tugwell, P., Kristjansson, E., Oliver, S., Ueffing, E., & Welch, V. (2012). Damned if you do, damned if you don't: Subgroup analysis and equity. *Journal of Epidemiology and Community Health*, *66*(1), 95–98. https://doi.org/10.1136/jech.2010.121095

Plastow, N. A., van Niekerk, L., Cloete, L., & Leibbrandt, D. (2021). The effect of interventions to support mental health post-stroke in Africa: A systematic review. *Human Functioning, Technology and Health*, 133–169. https://doi.org/10.4102/aosis.2020.bk85.04

Rafsten, L., Danielsson, A., & Sunnerhagen, K. S. (2018). Anxiety after stroke: A systematic review and meta-analysis. *Journal of Rehabilitation Medicine*, *50*(9), 769–778. https://doi.org/10.2340/16501977-2384

Raglio, A., Zaliani, A., Baiardi, P., Bossi, D., Sguazzin, C., Capodaglio, E., Imbriani, C., Gontero, G., & Imbriani, M. (2017). Active music therapy approach for stroke patients in the post-acute rehabilitation. *Neurological Sciences*, *38*(5), 893–897. https://doi.org/10.1007/s10072-017-2827-7

Reshetnyak, E., Ntamatungiro, M., Pinheiro, L. C., Howard, V. J., Carson, A. P., Martin, K. D., & Safford, M. M. (2020). Impact of multiple social determinants of health on incident stroke. *Stroke*, *51*(8), 2445–2453. https://doi.org/10.1161/strokeaha.120.028530

Robinson, R. G., Kubos, K. L., Starr, L. B., Rao, K., & Price, T. R. (1984). Mood disorders in stroke patients. Importance of location of lesion. *Brain: A Journal of Neurology*, *107 (Pt 1)*, 81–93. https://doi.org/10.1093/brain/107.1.81

Robinson, R. G., & Price, T. R. (1982). Post-stroke depressive disorders: A follow-up study of 103 patients. *Stroke*, *13*(5), 635–641. https://doi.org/10.1161/01.str.13.5.635

Sandel, M. E., Wang, H., Terdiman, J., Hoffman, J. M., Ciol, M. A., Sidney, S., Quesenberry, C., Lu, Q., & Chan, L. (2009). Disparities in stroke rehabilitation: Results of a study in an integrated health system in northern California. *PM & R: The Journal of Injury, Function, and Rehabilitation*, *1*(1), 29–40. https://doi.org/10.1016/j.pmrj.2008.10.012

Sanner, J., Casameni Montiel, T., Cron, S. G., Ancer Leal, A., Baltazar, N., Hinojosa, E., Okpala, M., Savitz, S., & Sharrief, A. Z. (2019). Identifying and Understanding Factors Associated with Post-Stroke Anxiety. *Stroke*, *50*(Suppl_1), ANS7–ANS7. https://doi.org/10.1161/str.50.suppl_1.NS7

Schöttke, H., & Giabbiconi, C.-M. (2015). Post-stroke depression and post-stroke anxiety: Prevalence and predictors. *International Psychogeriatrics*, *27*(11), 1805–1812. https://doi.org/10.1017/s1041610215000988

Schulz, K. F., Altman, D. G., Moher, D., & Group, C. (2010). CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. *BMJ*, *340*, c332. https://doi.org/10.1136/bmj.c332

Shi, Y., Yang, D., Zeng, Y., & Wu, W. (2017). Risk Factors for Post-stroke Depression: A Meta-analysis. *Frontiers in Aging Neuroscience*, *9*, 218. https://doi.org/10.3389/fnagi.2017.00218

Su, Y., Yuki, M., & Otsuki, M. (2020). Prevalence of stroke-related sarcopenia: A systematic review and meta-analysis. *Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association*, *29*(9), 105092. https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.105092

Thomas, S. A., Walker, M. F., Macniven, J. A., Haworth, H., & Lincoln, N. B. (2012). Communication and low mood (calm): A randomized controlled trial of behavioural therapy for stroke patients with aphasia. *Clinical Rehabilitation*, *27*(5), 398–408. https://doi.org/10.1177/0269215512462227

Tricco A.C., Lillie, E., Zarin, W., O'Brien, K.K., Colquhoun, H., Levac, D. et al. (2018). PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. *Ann Intern Med*,169, 467–473. doi: 10.7326/M18-0850.

Wang, R., & Langhammer, B. (2018). Predictors of quality of life for chronic stroke survivors in relation to cultural differences: A literature review. *Scandinavian Journal of Caring Sciences*, *32*(2), 502–514. https://doi.org/10.1111/scs.12533

Wang, X., Li, J., Wang, C., & Lv, J. (2020). The effects of mindfulness-based intervention on quality of life and poststroke depression in patients with spontaneous intracerebral

hemorrhage in China. *International Journal of Geriatric Psychiatry*, *35*(5), 572–580. https://doi.org/10.1002/gps.5273

Ward, E. C., Clark, L. O., & Heidrich, S. (2009). African American Women's beliefs, coping behaviors, and barriers to seeking mental health services. *Qualitative Health Research*, *19*(11), 1589–1601. https://doi.org/10.1177/1049732309350686

Watkins, C. L., Auton, M. F., Deans, C. F., Dickinson, H. A., Jack, C. I. A., Lightbody, C. E., Sutton, C. J., van den Broek, M. D., & Leathley, M. J. (2007). Motivational interviewing early after acute stroke: A randomized, controlled trial. *Stroke*, *38*(3), 1004–1009. https://doi.org/10.1161/01.STR.0000258114.28006.d7

Wei, N., Yong, W., Li, X., Zhou, Y., Deng, M., Zhu, H., & Jin, H. (2015). Post-stroke depression and lesion location: A systematic review. *Journal of Neurology*, *262*(1), 81–90. https://doi.org/10.1007/s00415-014-7534-1

World Health Organisation (WHO). (2022) Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022.

World Stroke Organization (WSO): Global stroke fact sheet 2022. (2022). *International Journal of Stroke*, *17*(4), 478–478. https://doi.org/10.1177/17474930221080343

Chapter Three: Bridging Chapter

Bridging Chapter

This chapter outlines the connection between the systematic review and the empirical paper and presents a rationale for how the research questions for the empirical paper were developed.

The systematic review investigated the reporting of relevant demographic and social factors known to impact health equity, the likelihood of stroke, access to stroke services, and post-stroke outcomes, using the PROGRESS-Plus framework (O'Neill et al., 2014) in the non-pharmacological management of post-stroke anxiety and/or depression. The review highlighted the variation of protected characteristics reported in randomised controlled trials (RCTs) globally. Furthermore, the review highlighted how studies did not explore the effectiveness of non-pharmacological interventions within-groups, such as whether there were differences in outcomes based on age, gender, ethnicity, etc. The review emphasised the need for future research to report the protected characteristics of participants to support healthcare professionals in identifying whether there may be variations in the accessibility and helpfulness of interventions based on the characteristics of their stroke population. Furthermore, it limits our ability to understand whether the findings from RCTs are implementable across diverse populations.

Another common sequela of stroke pertaining to mood and emotional functioning, is post-stroke emotionalism (PSE; Gillespie et al., 2016). PSE, often referred to as pseudobulbar affect or emotional incontinence, refers to sudden and uncontrollable outbursts of crying or laughing (House et al., 1989). Often, those with PSE find the symptoms of PSE to be distressing, with studies citing those with PSE experiencing anxiety, depression, and at times post-traumatic stress disorder (Andersen et al., 1995; Eccles et al., 1999). Despite the prevalence of PSE, there remains little data regarding its non-pharmacological treatment.

Studies have shown that non-pharmacological intervention strategies are being used by healthcare professionals and by stroke survivors (Fitzgerald et al., 2022; Gillespie et al., 2020). However, the perceived helpfulness and accessibility of such interventions from the perspective of stroke healthcare professionals and PSE researchers is not well understood. Moreover, it remains unclear as to how and in what ways demographic and social factors might impact the perceived helpfulness and accessibility of such non-pharmacological interventions.

The empirical study was inspired by Gillespie et al.'s (2020) earlier work which explored healthcare professionals' and researchers' perspectives of the effectiveness of post-stroke emotionalism interventions in the UK. The current study aimed to better understand the ratings of the perceived level of helpfulness and accessibility to PSE interventions globally, by healthcare professionals and researchers. To support the consideration of the impact health inequalities can have on PSE interventions, the study also included questions regarding the impact that demographic and social factors, described as protected characteristics from the UK government's Equality Act (2010), may have on the accessibility (either access or engagement) to PSE interventions. Questions regarding service impacts, such as waiting list times or staff numbers, on the accessibility of PSE interventions were also investigated.

The original design of the study followed Delphi methodology. Participants were recruited through social media, email advertisements to specialist interest groups, and direct email, to complete a first round of a questionnaire and then an adapted and personalised second questionnaire based on data from the first questionnaire. To gain a better understanding of contextual information regarding the decisions around the scores given by participants from the Delphi method, a focus group was added to the procedure of the study. Therefore, participants who took part in the second round of the Delphi study were also

invited to take part in a focus group.

Chapter Four: Empirical Paper

Prepared for Submission to Disability and Rehabilitation

Author Guidelines are available in Appendix A

Reaching consensus to suggest guidelines for the non-pharmacological management of post-stroke emotionalism using the Delphi Method and mini-focus groups

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Abstract

Purpose: To identify the opinions of healthcare staff and researchers globally regarding the helpfulness and accessibility of non-pharmacological post-stroke emotionalism (PSE) interventions.

Method: Thirty-eight healthcare professionals, including clinical psychologists/neuropsychologists (n=24), medical professionals (n = 1), and allied healthcare professionals (n = 4), and/or clinical academics/researchers (n = 9) completed the first round of the Delphi method, 19 the second round. Eight participants then completed one of three mini-focus groups. Data were summarised in line with Delphi methods with content analysis of the mini-focus group data.

Results: "Ask the patient to take a deep breath", "Provide education for patient", "Acknowledge the PSE and then continue current activity", and "Teach distraction techniques" were rated as the most helpful and accessible interventions, and with the highest level of consensus reached. Content analysis revealed uncertainties about assessment and diagnosis, the roles of multidisciplinary team members, and factors impacting the delivery of PSE interventions as barriers to interventions. Sensitivity to context and maximising support provided to the changing nature of PSE over time were expected to maximise the accessibility and helpfulness of interventions.

Conclusion: Clinical services should consider the most appropriate ways of identifying and responding to PSE depending on service context. This could include developing a PSE assessment protocol, developing a range of non-pharmacological interventions and consideration of case complexity/time since stroke and the appropriate staffing/skill mix to deliver these.

Keywords: post-stroke emotionalism, stroke, non-pharmacological interventions, mood changes, Delphi-method, mini-focus groups.

Data availability statement: The data that supports the findings of this study are available from the corresponding author upon reasonable request.

Impact for rehabilitation:

- Supporting the understanding of the perceived helpfulness of non-pharmacological interventions for post-stroke emotionalism
- The study identified barriers for PSE individuals in accessing support for PSE symptoms.
- The development of a suggested pathway for PSE individuals in stroke services.
- Considerations of demographic and social factors which can impact the accessibility of non-pharmacological interventions for PSE.

Introduction

Post-stroke emotionalism (PSE) is an under-researched neurological disorder of emotional expression characterised by sudden, involuntary, uncontrollable episodes of crying or laughing, representing a change from pre-stroke functioning (House et al., 1989). PSE occurs in around 17-20% of post-acute stroke cases (Gillespie et al., 2016; House et al., 1989). Emotional episodes may be congruent to an individual's underlying emotional state, such as crying after a distressing event, or incongruent such as laughing at an inappropriate time (McAleese et al., 2019). Although tearful emotionalism is often confused with depression, it is a separate disorder (Allman, 1991).

The understanding that there is a high prevalence of PSE and that the symptoms can negatively impact an individual's mood led to the development of validated measures to identify PSE, such as the Testing Emotionalism After Recent Stroke-Questionnaire (TEARS-Q; Broomfield et al., 2020). This is the first reliable and valid measure of emotionalism after a stroke (Broomfield et al., 2020; Broomfield et al., 2021). Often, post-stroke survivors diagnosed with PSE experience anxiety, embarrassment, or shame concerning their sudden outbursts of crying and/or laughter (McAleese et al., 2019). Moreover, there is evidence that people with PSE may be left with symptoms similar to post-traumatic stress disorder, most notably intrusive thoughts regarding their stroke (Eccles et al., 1999). All these emotions can negatively impact mood and lead to behaviour changes, such as social avoidance and social isolation (Fitzgerald et al., 2022).

If taking a cognitive behavioural therapy approach, we can suggest that this might lead to symptoms of anxiety/depression associated with PSE being maintained over time (Johnstone & Dallos, 2014). Research has identified for example that participants with a negative emotionalism experience describe more significant social

avoidance and mood problems (McAleese et al., 2019).

Although research has identified pharmacological interventions for managing PSE (e.g., Selective Serotonin Reuptake Inhibitor anti-depressant medicines), Cochrane review of the evidence base for these interventions reported that it was of low quality, with just a small number of low-quality clinical trials (Allida et al., 2019). Additionally, people with PSE may not wish to rely on medication to improve symptoms due to potential side effect risks, or they may wish to find alternative, non-pharmaceutical support methods to manage their condition.

To improve stroke survivors' experience of emotionalism and longer-term outcomes, we therefore need to better understand the non-pharmacological interventions currently offered through the United Kingdom's National Health Service (NHS). Besides the low-quality findings for pharmacological interventions relating to the management of PSE, there are particular gaps in research regarding non-pharmacological interventions to support people with PSE. Currently, there are no evidence-based non-pharmacological treatments, which is problematic for a condition common among the stroke population (Allida et al., 2019).

Gillespie et al. (2020) completed a survey investigating stroke health professionals' usual practice regarding non-pharmacological interventions currently offered to people with PSE. Their paper consulted data from journals, PSE-related focus groups, stroke-related textbooks, and online training resources to construct a comprehensive list of non-pharmacological PSE interventions routinely offered. Healthcare professionals then rated how often the interventions were used and how effective they felt they were. Offering reassurance, talking to the patient about their goals, acknowledging the PSE and then continuing with the current activity, and providing education for the patient and family were considered the most effective non-

pharmacological treatments by healthcare staff.

Whilst from Gillespie et al. (2020) it appears that non-pharmacological interventions are being deployed to support people with PSE, it is not yet known how experts in the field and stroke health professionals view these interventions and their levels of helpfulness beyond providing ratings. The current study's first aim was to establish expert consensus on the helpfulness and accessibility of non-pharmacological interventions to support people who experience emotionalism after a stroke.

Additionally, whilst numerous factors can impact stroke survivors' access to interventions within healthcare services, such as ethnicity and socioeconomic status (Bhaskar et al., 2019) it is unclear whether current non-pharmacological interventions for PSE consider the preferences of people from various demographic and socio-cultural groups and whether particular non-pharmacological PSE interventions are deemed more acceptable to people from these groups.

To the best of our knowledge, no research to date has focused on the impact PSE has on stroke survivors based on demographic and sociocultural factors, such as age, ethnicity, gender, and/or socioeconomic status, or the association of these factors to PSE treatment accessibility and preference. There is an understanding that demographic and sociocultural factors can impact the accessibility of services and the sensitivity of interventions in the broader stroke context. Tjokrowijoto et al. (2021), for example, identified that age, isolation, and previous mental health history all impacted stroke survivors' access to mental health services for post-stroke anxiety and/or depression. Furthermore, research has found that factors such as disability can impact help-seeking behaviour, impacting stroke survivor ability to access support for anxiety and depression (aphasia; Ryan et al., 2022).

Due to criticism regarding the lack of consideration of demographic and social factors in contemporary psychology and psychotherapy, policy changes regarding adapting interventions have been developed across countries (Bernal & Rodriguez, 2012), with a focus on considering the individual and their own personal and social context (Rathod et al., 2019). Research has identified that personal factors like age, gender, ethnicity, and socioeconomic status can impact how service users think about mental health conditions and intervention styles (Leis et al.,2010; Liddon et al., 2017; Ward et al., 2009). Stroke incidence has been linked to ethnicity, education, socioeconomic status, and prior disability (Bhaskar et al., 2019; Reshetnyak et al., 2020), stroke service access to ethnicity, gender, and location (Bhaskar et al., 2019; Sandel et al., 2009) and post-stroke outcome and quality of life to age, gender, marital status, education level, and socioeconomic status (Wang & Langhammer, 2018). Therefore, it is important to consider how these factors may impact stroke survivors' accessibility, engagement, and opinions of interventions regarding PSE (and potentially their outcome in coping with emotionalism). This was a second aim of the present study.

Aims and Research Questions

The present study aimed to reach a consensus amongst stroke healthcare workers and researchers regarding expert opinion of PSE non-pharmacological interventions in terms of helpfulness (the interventions impact on supporting individuals to cope with PSE symptoms) and accessibility (PSE patients' ability to engage with and use the interventions). The study further aimed to understand any nuances or variations in the consensus in relation to variations in demographic and social contexts through mini-focus groups with the participants.

- What are the opinions of experts regarding the helpfulness and accessibility of current non-pharmacological interventions for PSE?

- What contextual factors may impact the accessibility and helpfulness of non-pharmacological interventions for PSE?

Methodology

Design

The project used a mixed-methods concurrent design, and a critical realist approach was taken to apply a contextual lens to the opinions of participants (Bhaskar, 2020). Quantitative and qualitative data were analysed simultaneously throughout each stage of the project. The project used the Delphi method (Linstone & Turoff, 1975) to identify whether consensus could be reached in identifying helpful and accessible non-pharmacological interventions for PSE. The Delphi method involves a set of structured communication techniques to facilitate a consensus of opinion among experts, or an "expert panel", on specified content areas, developed by the researchers, through a series of questionnaires/meetings combined with controlled feedback (Dalkey, 1969).

The Delphi Method has been applied in various stroke research studies previously, including the development of a list of effective motivational strategies based on consensus among rehabilitation experts (Fisher et al., 2013; Hepworth & Rowe, 2018; Oyake et al., 2020; Philp et al., 2013). It is considered to be an effective method to develop a consensus among panellists, including the development of guidelines with healthcare professionals (Nasa et al., 2021). Delphi method was chosen rather than the nominal group method, which requires face-to-face group rounds, as it is less time-consuming and includes a higher number of panellists (McMillan et al., 2016). Thus, the Delphi method was used to gain an understanding of the opinions of a wider range of healthcare professionals regarding PSE interventions (McMillan et al., 2016). Furthermore, three mini-focus groups were run to gather additional in-depth data and insight regarding the context and nuances surrounding the helpfulness and accessibility of PSE interventions.

Participants

Researchers suggest that at least 15 panellists should take part in Delphi studies, however larger panels are often used (McMillan et al., 2016; Witkin & Altschuld, 1995). Following the first round of surveys, researchers suggest that it is essential for the expert panel to include a minimum of three knowledgeable participants involved in the previous round (Ogbeifun et al., 2016).

Healthcare professionals who work/have worked within stroke services and researchers involved in clinical research into PSE with stroke survivors were invited to take part in the project as study panellists. To recruit as many appropriate individuals as possible globally to take part, the study was advertised on social media (Twitter, Facebook, LinkedIn, and Research Gate; Appendix F) and advertised by Specialist Interest Groups to their members (OPSYRIS, Division of Neuropsychology British Psychological Society, South Thames specialist interest group in Neuropsychology, Neuropsychologists in Australia, and BRAINSPan; multi-disciplinary community of practice for clinicians/researchers in the brain impairment field). Furthermore, clinicians and researchers known via professional networks were invited via email to take part in the study.

Ethical Considerations

The study was approved by the Faculty of Medicine and Health at the University of East Anglia (ETH2223-0913; Appendix G). Participants were provided with Information Sheets and Consent forms (Appendix H & I) at the start of each stage of the project and informed consent was obtained from all participants at each stage.

Measures

Surveys were developed for the initial stage of the project and hosted on an online platform “Online Surveys”. Non-pharmacological PSE interventions were

identified from the Gillespie et al. (2020) paper (see Appendix J). As all interventions were rated as having been used by healthcare professionals, they were all included in the current project as interventions to be rated. Demographic and social factors, which are defined as protected characteristics in the UK government's Equality Act (2010), were used to investigate the accessibility of accessing post-stroke emotionalism interventions. Furthermore, a topic guide for the mini-focus groups following the second round was developed and can be seen in the Appendix K.

Procedure

Delphi method

Jünger et al. (2017) highlights how varied the literature regarding Delphi Methodology procedures is. However, what is clear is that some form of feedback is provided to panellists through statistical means, for example by providing the median score, and/or through a summary of qualitative comments (Jünger et al., 2017). By providing panellists with the statistical aspects of the previous round as well as summarised comments to provide context towards the ratings of interventions/demographic groups, they are supported in gaining a better understanding of the wider group reasoning behind the scores (McMillan et al., 2016). McMillan et al. (2016) provide detailed and helpful guidance in their in-depth narrative of Delphi methodology including a proposed structure in how feedback should be presented, commentary on the usefulness of feedback on descriptive statistics from round 2 and providing a summary of qualitative comments. In the current study we opted to closely follow their guidance on how to structure and run Delphi rounds.

For the present study, the Delphi method was conducted between July 2022 and January 2023. In the first round, panellists were asked questions regarding their demographics, educational and professional background. They were then presented with the list of non-pharmacological PSE interventions per Gillespie et al. (2020) and asked to identify

which ones they had previously used and then rank them based on their preference of use. Furthermore, they were asked to rate each intervention's level of both helpfulness and accessibility using a 7-point Likert scale, as well as the impact demographic and social factors may have on the accessibility of PSE interventions, also using a 7-point Likert scale (Cantrill et al., 1998; see Appendix L for example questions).

The second round of the questionnaire was sent to all panellists who completed the first round. Panellists were provided with their previous rating on each question, the group's median scores, and a summary of the comments previously left by all (see Appendix M for example; Aljamal et al., 2016). After reviewing the results of the previous round, all panellists were asked to reconsider their previous ratings and to rate each item again to establish a consensus with other participants. Questions regarding whether participants changed their ratings, and why, were included as part of the second round.

Being a critical realist and driven to understand the nuances and variations surrounding what the findings of the Delphi method could bring, it felt appropriate to then run a focus group to explore the context around the helpfulness and accessibility of PSE interventions (Canessa et al., 2022).

Mini-focus Groups

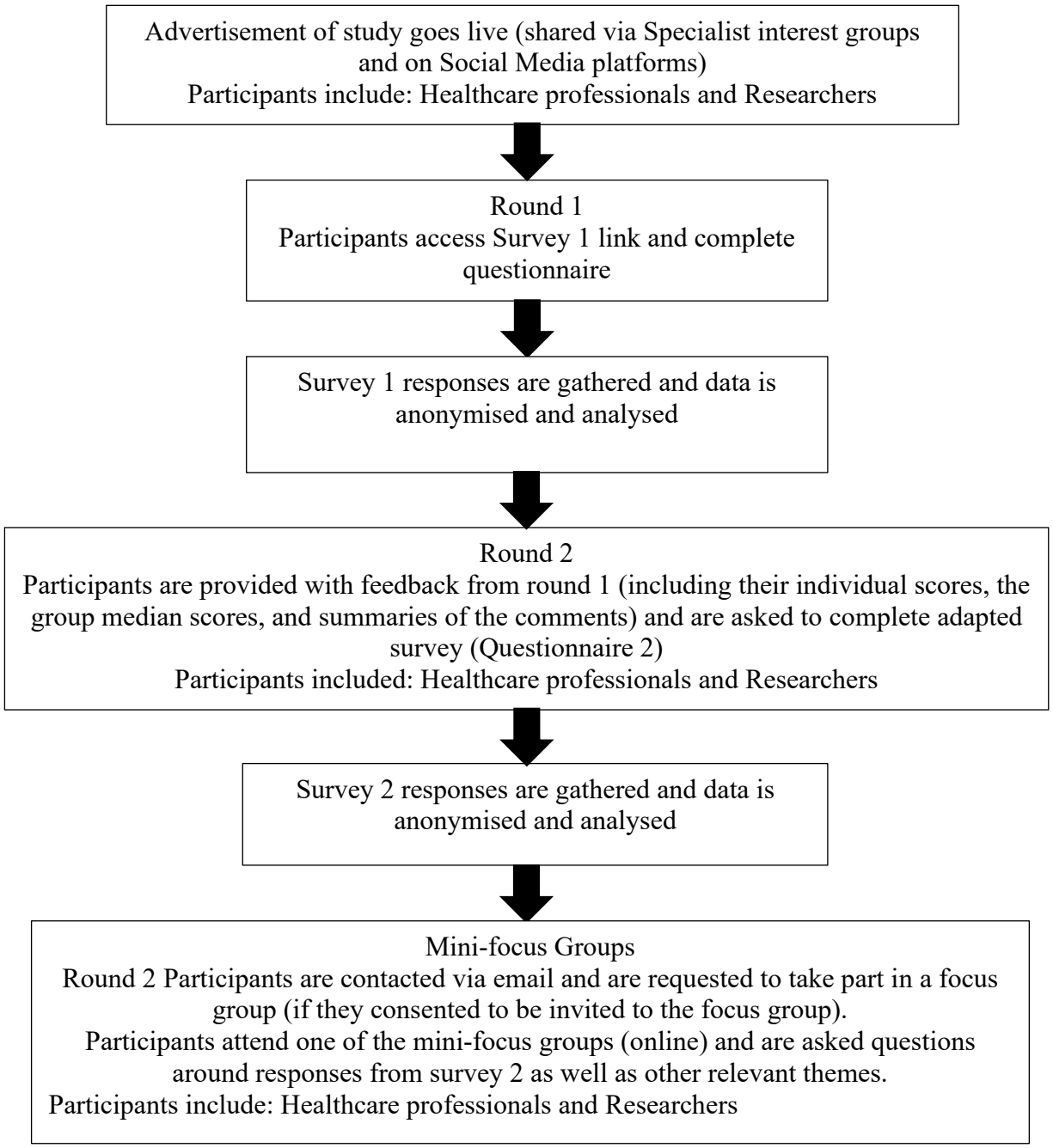
Following completion of the second round of questionnaires, three mini-focus groups were scheduled. We had intended to run one, but due to difficulties of managing a time for all participants to attend a group, three were set up (Morgan, 2012; Sewpaul et al., 2021). Participants who agreed to be invited to take part in the online focus group were contacted to attend one of three mini-focus groups in January 2023. Participants were sent an email giving them the option to choose which date to attend. On entering the online focus group meeting, participants were welcomed with consent obtained regarding the recording of the group and the creation of a transcript. Collaborative ground rules were developed (agreement to respect

each other's opinions and the process if a participant needs to leave early or suddenly leaves the call), and participants introduced themselves to the group. Participants were asked again to give verbal consent for recording and transcript to take place. Pre-developed questions were then delivered by the primary researcher regarding the assessment of PSE and the accessibility and helpfulness of the PSE interventions uncovered in the Delphi round of questionnaires (see Topic Guide in Appendix K). Discussions were guided by the primary researcher and the secondary supervisor of the project. The secondary supervisor attended the mini-focus groups to moderate the impact of researcher bias (Noble & Smith, 2015).

Although the questions in the topic guide were addressed in each group, as a critical realist where there is an understanding that there are multiple perspectives to the observable world (Stutchbury, 2021), it felt appropriate to be flexible in the sequence of questioning and exploration of additional related topics raised in the focus groups. Therefore, the time spent on each question in the topic guide and the surrounding discussion differed across groups. Once the group concluded, the participants were thanked and encouraged to contact the researcher should they wish to learn about the results of the project (see Figure 1 for procedure).

Figure 1

Diagram of the procedure



Data Analysis.

Delphi Method. Descriptive statistics were used to calculate responses about the participants' demographics, assessments used to identify PSE, interventions previously used

for PSE, and areas where barriers to accessing PSE interventions have been identified. A careful review of the Delphi Methodology literature guided decision making around the level of question agreement required for 'consensus' to have been reached. Whilst researchers typically set a consensus level of between 50% - 97% using the Delphi method (Diamond et al., 2013; Fisher et al., 2011; McGrath et al., 2019; Setkowski et al., 2020), systematic review indicates that most studies set a consensus level of between 75% or 80% (Jünger et al., 2017), with studies that set a higher level generating a stronger consensus (Linstone & Turoff, 1975). Accordingly, it was agreed that consensus for helpfulness study questions would be reached if 80% of participants or more responded within one of three categories on the 7-point Likert scale (Very Unhelpful to Slightly Unhelpful, Neither Helpful or Unhelpful, or Slightly Helpful to Very Helpful). With the same 80% threshold relied upon for treatment accessibility (Very Inaccessible to Slightly Inaccessible, Neither Accessible or Inaccessible, or Slightly Accessible to Very Accessible).

As the topic of consensus is mixed throughout Delphi methodology, it felt appropriate to use an additional form of identifying consensus to strengthen the validity of any consensus findings. Therefore, for round 2, if 80% of participants responded within one of the three categories, and the interquartile range (IQR) was found to be 1, the consensus was deemed to be "strong", as demonstrated in other Delphi-methodology studies (De Vet et al., 2005; Von det Gracht, 2012).

All data from the surveys were transferred and analysed using Excel.

Mini-Focus Groups. A conventional inductive content analysis was completed for the qualitative data from the mini-focus groups (Erlingsson & Brysiewicz, 2017; Leung & Chung, 2019). For the coding process, Excel spreadsheets were used to structure all steps of the content analysis. The number of codes were not analysed. The focus lay on aggregating information or meaning of units from the transcripts (e.g., short phrases), assigning codes to

label the key thoughts/ideas of the participants, grouping the codes into sub-categories, grouping the sub-categories into categories, and grouping the categories into meaningful themes (Hsieh & Shannon, 2005). All three transcripts were analysed by the primary researcher. However, to attempt to counter inter-rater reliability issues, an independent researcher reviewed a randomised part of 33% of the codes created by the primary researcher (Elliot et al., 1999). The independent researcher also sub-categorised, categorised, and themed the randomised part of the data using the concept developed by the primary researcher. Any differences in opinion regarding the coding and categorising of data were discussed and a consensus was reached.

Results

Participants

The demographics of the panellists that participated in the project are described below (Table 1). In the first round, 38 individuals completed the Delphi survey. Nineteen participants took part in the second round, and eight in total took part in the three mini-focus groups (two groups of three participants and one group of two).

Table 1

Study characteristics

Demographics	Round 1 (n = 38) (n (%))	Round 2 (n = 19) (n (%))	Focus Group (n=8) (n (%))
Age			
21-30	6 (15.9)	3 (15.8)	0 (0)
31-40	15 (39.5)	6 (31.6)	3 (37.5)
41-50	13 (34.2)	6 (31.6)	3 (37.5)
51-60	1 (2.6)	1 (5.3)	1 (12.5)

Demographics	Round 1 (n = 38) (n (%))	Round 2 (n = 19) (n (%))	Focus Group (n=8) (n (%))
61-70	2 (5.2)	2 (10.5)	0 (0)
Unknown	1 (2.6)	1 (5.3)	1 (12.5)
Gender			
Female	23 (60.5)	10 (52.6)	3 (37.5)
Male	15 (39.5)	9 (47.4)	5 (62.5)
Ethnicity			
Asian	2 (5.3)	1 (5.3)	0 (0)
White	34 (89.5)	18 (94.7)	8 (100)
Mixed/Multiple ethnic groups	2 (5.3)	0 (0)	0 (100)
Religion			
Christian	7 (18.4)	2 (10.5)	0 (0)
Buddhist	2 (5.3)	1 (5.3)	0 (0)
No religion	28 (73.3)	15 (78.9)	7 (87.5)
Prefer not to say	1 (2.6)	1 (5.3)	1 (12.5)
Continent of where participants studied			
Australia/Oceania	6 (15.8)	1 (5.3)	0 (0)
Europe	30 (78.9)	17 (89.5)	7 (87.5)
North America	1 (2.6)	1 (5.3)	1 (12.5)
South America	1 (2.6)	0 (0)	0 (0)
Level of Education			
Bachelor’s degree (e.g., BA, BSc)	4 (10.5)	1 (5.3)	0 (0)
Master’s degree (e.g., MA, MSc, MEd)	3 (7.9)	1 (5.3)	0 (0)
Doctorate (e.g., PhD, EdD)	30 (78.9)	16 (84.2)	7 (87.5)

Demographics	Round 1 (n = 38) (n (%))	Round 2 (n = 19) (n (%))	Focus Group (n=8) (n (%))
Other from comments (Psychiatrist)	1	1	1
Continent where most experienced gained working with PSE			
Asia	1 (2.6)	1 (5.3)	0 (0)
Australia/Oceania	6 (15.8)	1 (5.3)	0 (0)
Europe	30 (78.9)	17 (89.5)	8 (100)
South America	1 (2.6)	0 (0)	0 (0)
Occupation			
Clinical Academic/Researcher	9 (23.7)	6 (31.6)	2 (12.5)
Medical	1 (2.6)	1 (5.3)	1 (12.5)
Clinical Psychologist/Neuropsychologist	24 (63.2)	10 (52.6)	5 (62.5)
Allied Healthcare Professional	4 (10.5)	2 (10.5)	0 (0)

Which non-pharmacological PSE interventions did experts consider helpful to support stroke survivors?

The results of the Delphi surveys on the helpfulness of each non-pharmacological PSE intervention are shown in Table 2., In the first round, consensus was reached regarding four of the interventions. “Provide education for the family”, “Acknowledge the PSE then continue the current activity”, “Provide education for the patient”, and “Instruct how to tense facial muscles”, were all rated within the “Helpful” category.

Table 2

The rated helpfulness of non-pharmacological PSE interventions by Healthcare Professionals during the Delphi method

Type of PSE Intervention	Median (IQR) round 1	Median (IQR) round 2	%
Provide education for patient	6 (1)*	7 (1)**	100
Acknowledge the PSE then continue current activity	6 (1)*	5 (0)**	94.7
Talk to the patient about their goals in relation to PSE	5 (2)	6 (1)**	94.4
Teach distraction techniques	5 (1)	5 (1)**	94.4
Provide education for family	6 (1)*	6 (1)**	90
Normalise the condition	6 (2)	6 (2)*	88.2
Ask the patient to take a deep breath	5 (1)	5 (1)**	82.4
Modify beliefs about the PSE	5 (1)	5 (1)	78.9
Teach relaxation techniques	5 (2)	5 (2)	72.2
Offer Reassurance	5 (1)	5 (1)	68.4
Distract the patient during a PSE episode	4 (1)	5 (1)	68.4

Type of PSE Intervention	Median (IQR) round 1	Median (IQR) round 2	%
Identify the triggers for PSE (so they can be avoided)	5 (2)	5 (3)	55.6
Ignore the PSE and continue with current activity	3 (3)	4 (3)	29.4
Move the patient to another setting/location	4 (1)	4 (1)	27.8
Encourage patient to use a diary to record feelings	4 (0)	3 (1)	21.1
Suggest altered posture (e.g., shoulder back)	4 (0)	4 (0)	11.1
Instruct how to tense facial muscles	4 (0)*	4 (0)	5.6

Note. Values are presented as the group median (IQR) on the 7-point Likert scale. The 7-point Likert scale ranges from 1-7, from very unhelpful to very helpful, respectively. The percent column denotes the percentage of panellists who scored the PSE intervention within the "Helpful" category in round 2.

Key: *signifies consensus was reached, **signifies that a "strong" consensus was reached in round 2.

In the second round, a strong consensus (where it reached 80% consensus level and IQR was 1 or below) was reached for three of the four interventions where consensus was reached in round 1, "Teach distraction techniques" and "Ask the patient to take a deep breath". A consensus (where 80% consensus level was reached but IQR was above 1) was

also reached for “Normalise condition”. For the six interventions where any level of consensus was reached, panellists rated the interventions within the “helpful” category. A consensus was no longer reached for “Instruct how to tense facial muscles”.

Which non-pharmacological PSE interventions did experts consider accessible to support stroke survivors?

The results of the Delphi surveys on the accessibility of each non-pharmacological PSE intervention are shown in Table 3.

In the first round, consensus was achieved regarding six of the interventions. “Offer reassurance”, “Provide education for the family”, “Acknowledge the PSE then continue the current activity”, “Normalise the condition”, “Provide education for the patient”, and “Ask the patient to take a deep breath” were all rated within the “Accessible” category.

Table 3

The rated accessibility of non-pharmacological PSE interventions by Healthcare Professionals during the Delphi method

Type of PSE Intervention	Median (IQR) round 1	Median (IQR) round 2	%
Offer Reassurance	6 (2)*	7 (1)**	100
Ask the patient to take a deep breath	6 (2)*	6.5 (1)**	100
Acknowledge the PSE then continue current activity	6 (2)*	6 (1)**	94.4
Provide education for patient	6 (2)*	6 (1)**	94.4
Normalise the condition	6 (2)*	6 (1)**	88.9

Type of PSE Intervention	Median (IQR) round 1	Median (IQR) round 2	%
Provide education for family	6 (1)*	6 (1)**	88.9
Talk to the patient about their goals in relation to PSE	5 (1.25)	6 (1.25)*	83.3
Teach distraction techniques	5 (1)	5 (1)**	83.3
Identify the triggers for PSE (so they can be avoided)	5 (2)	5 (0.25)**	83.3
Teach relaxation techniques	5 (1)	5 (1)	78.9
Distract the patient during a PSE episode	6 (1)	5 (2)	72.2
Ignore the PSE and continue with current activity	5 (3)	5 (2)	61.1
Suggest altered posture (e.g., shoulder back)	4 (1)	5 (1)	52.9
Modify beliefs about the PSE	4 (3)	4 (1.25)	50
Instruct how to tense facial muscles	4 (0.5)	4 (0.25)	22.2
Move the patient to another setting/location	3 (2)	3 (1)	16.7
Encourage patient to use a diary to record feelings	3 (2)	3 (0)	11.1

Note. Values are presented as the group median (IQR) on the 7-point Likert scale. The 7-point Likert scale ranges from 1-7, from very inaccessible to very accessible, respectively.

The percent column denotes the percentage of panellists who scored the PSE intervention within the “Accessible” category in round 2.

Key: *signifies consensus was reached, **signifies that a “strong” consensus was reached in round 2

In the second round, a “strong” level of consensus was reached for all six interventions where consensus was reached in the first round and for “Teach distraction techniques” and “Identify the triggers for PSE (so they can be avoided)”. A consensus (where 80% consensus level was reached but IQR was above 1) was also reached for “Talk to the patient about their goals in relation to PSE”.

Panellists rated all interventions where consensus was reached at round 2 within the “accessible” category.

Most helpful and accessible non-pharmacological PSE interventions

A “strong” level of consensus where interventions were rated both within the helpful category and accessible category were “Ask the patient to take a deep breath”, “Provide education for patient”, “Acknowledge the PSE and the continue current activity”, and “Teach distraction techniques”. Moreover, consensus (where 80% consensus level was reached but IQR was above 1) was also reached where interventions were rated within the helpful category and accessible category for “Talk to the patient about their goals in relation to PSE” and “Normalise the condition”.

Which demographic factors did experts deem to influence the accessibility of non-pharmacological PSE interventions?

The results of the Delphi surveys on whether PSE interventions are accessible to all groups based on demographic factors suggest that a consensus was only reached with “Gender Reassignment” where participants rated the accessibility of PSE interventions as

being neither accessible nor inaccessible, see Table 4. Participants reached a consensus that regardless of whether an individual has gender reassignment, the PSE interventions should not be more or less accessible to them. In other words, most demographic factors were viewed as not having an impact on the accessibility of PSE interventions, apart from Disability. The results suggest that the level of accessibility of PSE interventions could be impacted if an individual with PSE also has a disability as the median score (3) rated by participants falls under the "inaccessible" category.

Table 4

The accessibility ratings of Demographic factors by healthcare professionals and researchers during the Delphi method

Demographic Factor	Median (IQR) round 1	Median (IQR) round 2	%
Age	4 (2)	4.5 (1)	44.4
Relationship status	4 (1)	4 (1)	43.8
Ethnicity	4 (2)	4 (1)	41.2
Religion/Belief	4 (2)	4 (1)	35.3
Gender	4 (1.75)	4 (1)	35.3
Socio-economic status	4 (1)	4 (1)	35.3
Pregnancy	4 (2)	4 (0.25)	23.5
Sexual Orientation	4 (1.25)	4 (0.25)	23.5
Gender Reassignment	4 (1.25)	4 (0)**	20.0
Disability	3 (1)	3 (1)	16.7

Note. Values are presented as the group median (IQR) on the 7-point Likert scale. The 7-point Likert scale ranges from 1-7, from very inaccessible to very accessible, respectively.

The percent column denotes the percentage of panellists who scored the PSE intervention within the “Accessible” category, scores between 5-7, in round 2.

Key: *signifies consensus was reached, **signifies that a “strong” consensus was reached in round 2.

Which service factors did experts consider impact the accessibility of non-pharmacological PSE interventions?

The results of the Delphi surveys found that staff numbers and waiting times could impact the accessibility of PSE interventions, with participants rating service factors making PSE interventions inaccessible, see Table 5. Therefore, suggesting that the staff numbers and waiting times can lead to PSE interventions being inaccessible. However, a consensus was not reached for this.

Table 5

Service factor ratings of accessibility by healthcare professionals and researchers during the Delphi method

Service Factor	Median (IQR) round 1	Median (IQR) round 2	%
Staff Numbers	3 (2)	3 (1.25)	12.5
Waiting times	3 (1)	3 (2)	5.9

Note. Values are presented as the group median (IQR) on the 7-point Likert scale. The 7-point Likert scale ranges from 1-7, from very inaccessible to very accessible, respectively. The percent column denotes the percentage of panellists who scored the PSE intervention within the “Accessible” category, scores between 5-7, in round 2.

Qualitative Data from Mini-focus groups

A total of eight participants were involved in the mini-focus groups, including five males and three females. Five of those who took part in the groups were clinical psychologists, two were clinical academics/researchers, and one was a medical doctor. Seven of the participants were known professionally to the primary researcher and/or supervisors. Data was themed according to general domains covered in the topic guide upon analysing the data, with the specific content being categorised inductively within each domain (see Appendix N). Uncertainties about assessment and diagnosis, the roles of multidisciplinary team members, and factors impacting the delivery of PSE interventions were raised inductively regarding the barriers in accessing PSE interventions. Whereas sensitivity to context and maximising support provided to the changing nature of PSE over time were raised regarding maximising the accessibility and helpfulness of PSE interventions**.**

Barriers in accessing PSE interventions

Uncertainties about Assessment and Diagnosis

Participants discussed the barriers in assessing and diagnosing patients with PSE. Assessing for PSE was considered to be a complex process, due to the potential for misdiagnosis, the diagnostic overlap with depression, and the limitations of outcome measures to assess the impact PSE has on patients' daily lives.

The existing knowledge of staff, those with PSE, and their family members, were also discussed as having an impact on the assessment and diagnosis of PSE. Whether individuals can identify PSE symptoms and differentiate PSE symptoms from a normal response following a stroke, were all perceived as impacting the likelihood of people with PSE being assessed. Participants cited that PSE is often addressed if the patient, family, or other staff members explicitly raise and state their concerns about it.

Additionally, staff's professional background, their experience of assessing and diagnosing PSE, whether their service assessed or diagnosed PSE, and whether it was deemed appropriate to assess or diagnose patients for PSE were all reported as barriers. A particular point was made regarding staff that, especially in the acute setting where PSE symptoms are more prevalent, being uncertain as to the need to diagnose PSE patients or provide an intervention beyond "normalising" or "providing education" as "we'll just kind of wait this out it might…it might kind of resolve itself" would act as barriers.

Participants also discussed how there were not always opportunities to diagnose those with PSE due to the time-limited nature of sessions, with some staff being limited to "10-minutes" to complete a full (medical) assessment of stroke survivors. Furthermore, reliance to identify PSE symptoms as being placed on the patient, family, or other staff members stating their concerns around PSE was considered a further barrier.

The age, gender, and cultural background of patients and their family members was also considered by participants to impact help-seeking behaviours based on perception of mental health conditions "I guess most challenging in a way is kind of working with family members where there's not a lot of emotional literacy in the family anyway." There were also discussions around how some patients may struggle to seek help due to their own perceptions and biases around seeking support.

Roles of multidisciplinary team members

During the mini-focus groups, participants discussed the confusion amongst some staff regarding who was responsible for assessing and diagnosing PSE and who was responsible for supporting and intervening. One example thus read: "I certainly think that most stroke [professionals] would think it's not their responsibility." Similarly, one participant commented how people with PSE "do fall through the cracks a bit" as various professions would see it not as their responsibility to support the individual regarding their

PSE. Furthermore, it was noted if PSE is noticed too late in the stroke pathway, then there was a risk of patients being missed in primary care or other services, such as Improving Access to Psychological Therapies (IAPT), due to the general lack of knowledge around PSE. In addition, staff's ability to manage distress and uncertainty were found as barriers to the accessibility of PSE interventions, as staff can feel overwhelmed when faced with PSE symptoms.

Factors impacting the delivery of PSE interventions

Participants explored at what point PSE should be managed and whether it needed to be managed or whether appropriate initial responses to PSE should simply be a caring response rather than an "intervention", especially due to its prevalence in the acute stage. Therefore, participants were uncertain whether they should label certain strategies such as "normalising PSE symptoms" or "provide education to patient" as interventions.

The importance of prioritising support, in relation to their PSE symptoms, increased if the PSE symptoms were perceived as complex by staff if they were impacting the patient's rehabilitation and/or functioning and based on the length of time the patient had experienced symptoms. Regarding relationships, PSE symptoms were perceived as complex if they impacted on individual's their relationships, if relatives' behaviours were unhelpful, or if the family raised concerns. Where family members raised concerns of PSE, patients were more likely to receive support in relation to their symptoms: "I have tended to find that the actual patient is less bothered by them, by it, than say a family member". However, the helpfulness and accessibility of interventions, such as "provide education for family" was dependent on the family context, such as whether the family were involved, or based on the family member's perception of emotion with one participant citing. Additionally, the perceived severity of PSE was impacted based on what was competing with the symptoms "Well, what's it competing with? In turn, it sounds a bit brutal this, but it's the matter, isn't it?" and

"If PSE symptoms were competing with other conditions which are prioritised, then PSE are not considered essential to focus on."

Furthermore, participants discussed how people with disabilities in the context of PSE, such as language or cognitive impairments, may also struggle to engage in helpful or accessible interventions, with one participant citing "if somebody has aphasia or communication difficulties" as a factor impacting the accessibility of PSE interventions. Furthermore, the reliance on family members for support in implementing PSE interventions was noted, with one participant stating, "they may need to rely upon the family member, a family member, to be able to implement some of these interventions". Focus group participants also mentioned how due to having had limited experience of working with diverse populations, there was a level of uncertainty as to the impact personal characteristics can have on accessibility and helpfulness of interventions.

Maximising the accessibility and helpfulness of PSE interventions

Sensitivity to Context

Participants also discussed what considerations they make when supporting people with PSE. Reference to Royal College of Physicians (RCP; 2016) stroke guidelines for supporting people with post-stroke anxiety/depression, in relation to using distraction techniques, were briefly discussed. There was a disagreement regarding the helpfulness of distraction as an intervention as it was viewed by some participants as maintaining anxiety and/or depression under some contexts. However, it was named by a participant as the only intervention mentioned in the RCP guideline.

Participants also kept bringing back to the conversation the importance of applying a person-centred approach. As PSE management is context specific, participants mentioned that there is "always a need to adapt interventions", and to consider "cultural backgrounds" when working with stroke survivors.

Additionally, participants discussed the resources used to inform stroke survivors about PSE and to support implementation of interventions. For patients and their families, they were: provide education, provide materials, support family involvement, provide a variety of "tools" for a patient to develop a toolkit, and use pharmacological approaches. The discussion around providing education was recurrent throughout the focus group, in line with the consensus ratings regarding perceived level of helpfulness and accessibility.

From the discussions, it appeared essential to provide education to the patient and that this should occur when symptoms appear. Additionally, participants spoke about how helpful providing a variety of tools/interventions is, as not often does one intervention fit for all patients based on their own context. Therefore, despite some items appearing as highly helpful or accessible, there were some which although rated as "neither helpful or unhelpful", such as "take a deep breath", participants felt could be helpful to some patients in some contexts. Additionally, participants discussed how staff should be supported via provision of education around PSE, using pre-prepared leaflets and other materials to educate patients and their families. In this regard, it was felt that staff should hold responsibility in supporting those with PSE in the acute stage where PSE symptoms are more common (Gillespie et al., 2016).

Matching support provided to the changing nature of PSE over time

When exploring pathways for supporting people with PSE, participants discussed steps to ensure involvement of key staff, when psychological support is needed, and what interventions are most helpful depending on the time point in the stroke pathway, "where the things we have been talking about, maybe the complexity of the emotionalism, how far down the the, the line it it is".

Step one would include all MDT staff providing patient and family with education regarding PSE, normalising the condition, and offering a human response to distress as

“normal human beings acknowledge when somebody starts crying in front of them". Furthermore, it was thought that all staff could be involved in supporting individuals with PSE during this step. With one participant stating, “Step one is something that everybody who works in clinical practice ought to be able to do”. Participants reflected that potentially, step one could take place during the acute or post-acute stage of a patient’s pathway.

Step two would include more specialised staff exploring the impact PSE is having on the individual’s rehabilitation, socialising, and relationships although without an intervention but including assessment of whether an onward referral to psychology would be necessary. One participant cited “Step 2… Yeah, you might… I certainly, I'm still not in intervention frame of mind here” and “Only the patient can tell you if it is affecting their function. It's our job to ask the right questions and to get them to consider it”. Where “if it comes up in a way that it's there's a bit of time and it seems really important, we have haven't got on to how you decide when it's so important that you've got to find time to do it and think about referral”.

Step three occurs when the PSE is more complex, severe, occurring at a later stage in the stroke recovery pathway, “it might be more of a problem if you're seeing someone sort of six months and beyond that sort of a year and emotionalism is still a real problem” or having a higher impact on the patient’s life. Additionally, this might be where psychologists would be expected to be involved in supporting people with PSE “if there is distress as a result of the PSE that is difficult to manage and that's having an impact on rehabilitation that might be a clearer pathway for a psychologist to become more involved”. One participant cited step three as “stage three would be, ok, now we're starting to think more formally about whether there's something to formulate and try as a more specific intervention”.

Discussion

In summary, this study took the first step towards suggesting recommended, helpful, and accessible non-pharmacological interventions for people with PSE. We gathered data

from PSE clinical experts working in stroke services and academic experts by research regarding perceived levels of helpfulness and accessibility of current non-pharmacological interventions for PSE. We also identified whether demographic or sociocultural factors might influence healthcare professionals' and researchers' opinions of the interventions they may have encountered. We then reached data consensus using the Delphi method on the most helpful and accessible intervention options which are/can be offered within stroke services, both publicly (e.g., in the UK National Healthcare Service; NHS) and privately (Dalkey, 1969) and on what factors may impact access to healthcare services/interventions for these interventions. Finally, we used mini-focus groups comprising the same clinicians and researchers to gather in-depth data regarding the context surrounding the helpfulness and accessibility of PSE interventions.

The present study found that the interventions considered most helpful and accessible and where the consensus was also deemed "strong", were "Ask the patient to take a deep breath", "Provide education for patient", "Acknowledge the PSE and then continue current activity", and "Teach distraction techniques". Content analysis of the transcript revealed the emergence of two themes. These were barriers to accessing PSE interventions and maximising the accessibility and helpfulness of PSE interventions.

To the best of our knowledge, this is the first study which draws upon the variations and nuances of the accessibility and helpfulness of non-pharmacological interventions. Furthermore, it is believed to be the first study focusing on the impact of demographic and social factors on the helpfulness and accessibility of PSE interventions. The study used the Delphi method and followed guidance to ensure robust findings (McMillan et al., 2016). Additionally, the study's sample size was within the recommended range of over 15 and under 50 participants (McMillan et al., 2016).

Interestingly, most PSE interventions were rated as neither accessible nor inaccessible when considering demographic or social factors. However, age, gender, ethnicity and socio-economic status can influence an individual's perception of mental health conditions and impact their access to treatment (Leis et al., 2011; Liddon et al., 2017; Ward et al., 2009; WHO, 2022). Therefore, it was surprising that this was not found in the results of the Delphi method. However, upon discussion in the mini-focus groups, participants identified how age, disability, gender, and cultural background could impact the accessibility and helpfulness of PSE interventions. Specifically, they noted that adaptations to interventions based on the context of the individual are essential. Accordingly, in clinical practice in the UK frameworks, such as the Stroke-Specific Education Framework (SSEF; Department of Health, 2007; Watkins et al., 2009), the need to adapt assessments and interventions to fit the understanding and needs of patients is prominent. UK clinical guidance and research findings advise clinicians to consider the contextual factors surrounding a patient when assessing and implementing interventions for mood and emotion changes post-stroke (NICE, 2013; RCP, 2016; Watkins et al., 2009). The findings from the study support current guidance concerning best practices when supporting stroke survivors.

Issues regarding the complexity of the assessment and diagnosis of PSE by patients, family members, and staff also mirror previous Care Quality Commission stroke review's (2011) findings detailing similar issues relating to post-stroke depression. Staff's professional background and experience in assessing and diagnosing PSE were identified as barriers in the UK national project for improving access to psychological care after stroke (NICE, 2012), along with the perceived levels of importance staff place on PSE symptoms. This raises a concern that some stroke survivors may fall through the gaps if they do not ask staff for support (Sauvé, 2016).

It was felt by participants in the current study that the responsibility of assessing and supporting those with PSE should be shared, which is supported by research (Clarke & Forster, 2015). If it is complex or severe PSE, responsibility should fall under psychology. These findings align with the recommendations from NICE (2013) guidelines and the SSEF (Department of Health, 2007; Watkins et al., 2009). Although these recommendations have been suggested across UK services, based on participants' discussions in the mini-focus groups, shared responsibility may not currently occur across all stroke services.

During the Delphi-Method, healthcare professionals and researchers outside of Europe also completed the questionnaire, which provides valuable insight into the perceived helpfulness and accessibility of non-pharmacological interventions globally. Additionally, the trustworthiness of the data following content analysis was managed by including an external researcher (Elliot et al., 1999). Whilst there is no formal model to rate the quality of Delphi method research, the "stepwise" model has been recommended in healthcare (Nasa et al., 2021). To improve the quality of the Delphi method, some researchers suggest keeping rounds open to allow the stability of results (Linstone & Turoff, 1975; Nasa et al., 2021). Due to time limitations for the project, this was not possible. However, there appears to be some stability in the results as most of the ratings did not shift from one category to another between the first and the second round.

It is common to have under 50 participants in the Delphi method research. However, the sample size of the present study is a potential limitation as it would have been beneficial to gather information from a broader scope of professionals globally. Most of the participants who took part in the Delphi method were psychologists, meaning we mostly gathered opinions from individuals more likely to have encountered emotionalism in their clinical practice. Furthermore, there was not a variety of participants across different ethnic or religious groups, with most participants ethnicities being white and considering themselves

non-religious. Neither was there a large range of participants from a range of continents, with most having studied and worked in Europe, and having had little experience of working with diverse populations. Moreover, a relatively small number of participants attended the mini-focus groups, eight in total. Therefore, the contextual information gathered from the mini-focus groups is limited as all participants worked in the UK and a limited number of demographic and social groups were represented, with all members of the mini-focus groups being white and over the age of 30 and with some having mentioned their own inexperience of working with diverse populations in stroke services. Research suggests that the demographic and sociocultural factors of healthcare professionals and that of their patients can influence healthcare professionals' clinical decision making (Boissoneault et al., 2016). Thus, critical contextual factors impacting patients and services around and outside of the UK may not have been addressed in this study as participants own demographic and social characteristics may have influenced the results (Conforti et al., 2018). This may explain why "disability" was the only demographic factor considered to have an impact on the accessibility of PSE interventions during the Delphi method as the participants own biases and experiences may have influenced whether they saw other demographic and social factors, such as ethnicity, as influencing it. Finally, seven of the eight focus group attendees were known to the primary researcher and/or supervisor, which may have potentially introduced bias. Further research attempting to replicate the study on a wider scale or aiming to gather the opinions of those with lived experience of PSE and/or their family members/carers, could mitigate these limitations by using different recruiting channels and reaching different groups (e.g., charities) where there may be a greater representation of different demographic and social groups. Furthermore, collaborating with different Universities globally could also support the recruitment of a more diverse participant sample.

The findings from the study are in line with the Gillespie et al. (2020) study, which reported that “educate patient” and “educate family” were considered the most effective interventions. However, the study adds the strength of consensus having been reached by professionals and researchers in the field, in addition to considering the accessibility of the interventions and the contextual information around the quantitative results from the mini-focus groups (Canessa et al., 2022; Sewpaul et al.,2021). Furthermore, the study complements research investigating the opinions of individuals regarding their PSE symptoms (Fitzgerald et al., 2022; McAleese et al., 2019). The findings from the current study also propose a stepped/mapped care model, which considers who may support the use of PSE interventions and what interventions are provided at each stage, which can incorporate considerations for the use of interventions “in the moment”, their general “coping”, and for the long term “impact” of their PSE symptoms (Fitzgerald et al., 2022). Furthermore, the present study supports the importance of education regarding PSE symptoms early in a stroke patient’s pathway (McAleese et al., 2019).

It is appropriate to suggest that education about PSE to staff is essential to support the assessment and diagnosis of PSE. Especially as research and national guidance have highlighted how vital providing education is concerning supporting individuals with other mental health conditions, such as anxiety or depression (Butow et al., 2015; Melin et al., 2018; NICE, 2012). Participants in this study reported a gap in knowledge regarding PSE in healthcare services and primary care, which could be due to the relatively small amount of research regarding PSE (Fitzgerald et al., 2022; McAleese et al., 2019). However, a suggestion by participants was to manage barriers to PSE interventions by providing education regarding PSE to staff, patients, and family members. Participants also perceived non-psychology staff as having difficulties managing the perceived levels of distress by patients and being uncertain regarding what to do when someone presented with PSE

symptoms. Similar findings were reported in the previously mentioned UK national project regarding improving access to psychological care for stroke patients concerning distress (NICE, 2012). Therefore, acute and post-acute stroke services could consider whether specialised staff, such as clinical psychologists/neuropsychologists, with experience and knowledge regarding PSE need to provide training to MDT staff when new staff take-up their role or if any gaps in knowledge within the team are found regarding PSE, the non-pharmacological interventions to manage PSE, and the services' PSE pathway.

Furthermore, it has been found across studies that adapting the implementation of interventions, rather than the content, for depression can result in effective changes in mood (Chowdhary et al., 2013). As it is common to experience cognitive impairment, language difficulties, and physical disabilities following a stroke, considering adaptations based on these deficits is in line with NICE guidelines relating to mood conditions following a stroke and should be part of usual practice (NICE, 2013). In turn therefore, considering patients' demographic and social factors is essential when assessing and supporting those with PSE. This is especially the case when also considering the impact demographic and social factors have on the incidence rate of stroke, patients' access to health services, and the perceived quality of life post-stroke (Bhaskar et al., 2019; Reshetnyak et al., 2020; Wang & Langhammer, 2018, Sandel et al., 2009). Common considerations of what healthcare professionals should be involved in across a PSE patient's pathway and the complexity and severity of symptoms led to the creation of a proposed pathway in this study. Participants detailed the importance of, (i) including all staff in the assessment of PSE, normalising PSE, and providing PSE patients and their families with education regarding PSE, (ii) having more specialised staff supporting those with PSE, and (iii) a referral to psychology occurring due to the complexity and severity of PSE symptoms, where the patient is in the stroke pathway, and where more formalised interventions are suggested.

Such a stepped-care model for supporting stroke survivors concerning anxiety and depression has been developed in the NHS (NICE, 2011). Therefore, services could follow the proposed model from the NHS to guide how they develop a PSE pathway. Furthermore, educating participants on a variety of PSE interventions so that they may develop a "tool kit" allows patients to access interventions based on their current need, as seen in anxiety/depression studies (Becker-Haimes et al., 2017).

By raising awareness of PSE in services, stroke health professionals should be better placed to understand their responsibility in assessing and supporting those with PSE, as seen in the project conducted by NICE (2012) focusing on psychological care. Furthermore, providing education to staff and developing a pathway for services should decrease uncertainty in managing those with PSE. It is known that providing education to staff has reduced uncertainty in other healthcare settings (Dodd-McCue et al., 2005). Therefore, stroke services should consider developing a stepped-care pathway for assessing and supporting PSE patients, which can reduce levels of stress and uncertainty in team members and ensure those who seek or require support can access it (Dodd-McCue et al., 2005).

Conclusion

The interventions which were considered most helpful and accessible were "Ask the patient to take a deep breath", "Provide education for patient", "Acknowledge the PSE and then continue current activity", and "Teach distraction techniques". Stroke services should consider how best to support patients with PSE and interventions might differ according to where the person with PSE is in the stroke pathway. Furthermore, services should consider developing a protocol for how they assess and support those with PSE, including which staff are involved and what interventions are appropriate based on the complexity and severity of PSE symptoms and the time since experiencing a stroke.

References

Aljamal, M. S., Ashcroft, D., & Tully, M. P. (2016). Development of indicators to assess the quality of medicines reconciliation at hospital admission: An e-Delphi study. *International Journal of Pharmacy Practice*, *24*(3), 209–216. https://doi.org/10.1111/ijpp.12234

Allida, S., Patel, K., House, A., & Hackett, M. (2019). Pharmaceutical interventions for emotionalism after stroke. *Cochrane Database Of Systematic Reviews*. https://doi.org/10.1002/14651858.cd003690.pub4

Allman, P. (1991). Depressive disorders and emotionalism following stroke. *International Journal Of Geriatric Psychiatry*, *6*(6), 377-383. https://doi.org/10.1002/gps.930060608

Becker-Haimes, E., Franklin, M., Bodie (Stump), J., & Beidas, R. (2017). Feasibility and Acceptability of a Toolkit to Facilitate Clinician Use of Exposure Therapy for Youth. *Evidence-Based Practice in Child and Adolescent Mental Health*, *2*. https://doi.org/10.1080/23794925.2017.1383867

Bernal, G., & Domenech Rodríguez, M. M. (2012). Cultural adaptation in context: Psychotherapy as a historical account of adaptations. In G. Bernal & M. M. Domenech Rodríguez (Eds.), *Cultural adaptations: Tools for evidence-based practice with diverse populations* (pp. 3–22). Washington, DC: American Psychological Association.

Bhaskar, R. (2020). Critical realism and the ontology of persons. *Journal of Critical Realism*, *19*(2), 113–120. https://doi.org/10.1080/14767430.2020.1734736.

Boissoneault, J., Mundt, J. M., Bartley, E. J., Wandner, L. D., Hirsh, A. T., & Robinson, M. E. (2016). Assessment of the influence of demographic and professional characteristics on health care providers' pain management decisions using virtual humans. *Journal of Dental Education*, *80*(5), 578–587. https://doi.org/10.1002/j.0022-0337.2016.80.5.tb06118.x

Broomfield, N., West, R., House, A., Munyombwe, T., Barber, M., & Gracey, F. et al. (2020). Psychometric evaluation of a newly developed measure of emotionalism after stroke

(TEARS-Q). *Clinical Rehabilitation*, 026921552098172. https://doi.org/10.1177/0269215520981727

Broomfield, N., West, R., Barber, M., Gillespie, D. C., House, A., & Walters, M. (Accepted/In press; 2021). Practical guidance on use of TEARS-Q to diagnose post-stroke emotionalism. *Clinical Rehabilitation*. https://doi.org/10.1177/02692155211024801

Butow, P., Price, M. A., Shaw, J. M., Turner, J., Clayton, J. M., Grimison, P., Rankin, N., & Kirsten, L. (2015). Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines. *Psycho-Oncology*, *24*(9), 987–1001. https://doi.org/10.1002/pon.3920

Canessa, C., Vavvos, A., Triliva, S., Kafkalas, I., Vrachioli, M., & Sauer, J. (2022). Implementing a combined Delphi and Focus Group qualitative methodology in Nexus research designs—The case of the WEFE Nexus in Apokoronas, Crete. *PLOS ONE*, *17*(7), e0271443. https://doi.org/10.1371/journal.pone.0271443

Cantrill, J. A., Sibbald, B., & Buetow, S. (1998). Indicators of the appropriateness of long-term prescribing in general practice in the United Kingdom: Consensus development, face and content validity, feasibility, and reliability. *Quality in Health Care: QHC*, *7*(3), 130–135. https://doi.org/10.1136/qshc.7.3.130

Care Quality Commission (2011) Supporting Life after Stroke. A Review of Services for People who have had a Stroke and their Carers. Care Quality Commission, London. http://tinyurl.com/4qws5lo

Chowdhary, N., A. T. Jotheeswaran, A. Nadkarni, S. D. Hollon, M. King, M. J. D. Jordans, A. Rahman, H. Verdeli, R. Araya, and V. Patel. 'The Methods and Outcomes of Cultural Adaptations of Psychological Treatments for Depressive Disorders: A Systematic Review'. *Psychological Medicine* 44, no. 6 (April 2014): 1131–46. https://doi.org/10.1017/S0033291713001785.

Clarke, D.J., & Forster, A. 'Improving Post-Stroke Recovery: The Role of the Multidisciplinary Health Care Team'. *Journal of Multidisciplinary Healthcare* 8 (31 December 2015): 433–42. https://doi.org/10.2147/JMDH.S68764.

Conforti, F., Pala, L., Bagnardi, V., De Pas, T., Martinetti, M., Viale, G., Gelber, R. D., & Goldhirsch, A. (2018). Cancer immunotherapy efficacy and patients' SEX: A systematic review and meta-analysis. *The Lancet Oncology*, *19*(6), 737–746. https://doi.org/10.1016/s1470-2045(18)30261-4

Dalkey, N. (1969). An experimental study of group opinion. *Futures*, *1*(5), 408-426. doi: 10.1016/s0016-3287(69)80025-x

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

De Vet, E., Brug, J., De Nooijer, J., Dijkstra, A., & De Vries, N. K. (2005). Determinants of forward stage transitions: A Delphi study. *Health Education Research*, *20*(2), 195–205. https://doi.org/10.1093/her/cyg111

Diamond, I. R., Grant, R. C., Feldman, B. M., Pencharz, P. B., Ling, S. C., Moore, A. M., & Wales, P. W. (2014). Defining consensus: A systematic review recommends methodologic criteria for reporting of Delphi studies. *Journal of Clinical Epidemiology*, *67*(4), 401–409. https://doi.org/10.1016/j.jclinepi.2013.12.002.

Dodd-McCue, D., Tartaglia, A., Veazey, K. W., & Streetman, P. S. (2005). The impact of protocol on nurses' role stress: a longitudinal perspective. *The Journal of nursing administration*, *35*(4), 205–216. https://doi.org/10.1097/00005110-200504000-00010

Eccles, S., House, A., & Knapp, P. (1999). Psychological adjustment and self reported coping in stroke survivors with and without emotionalism. *Journal Of Neurology, Neurosurgery & Psychiatry*, *67*(1), 125-126. https://doi.org/10.1136/jnnp.67.1.125

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), Article 3. https://doi.org/10.1348/014466599162782

Equality Act. (2010). *Equality Act 2010.* https://www.legislation.gov.uk/ukpga/2010/15/part/2/chapter/1

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, *7*(3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001

Fisher, R. J., Gaynor, C., Kerr, M., Langhorne, P., Anderson, C., Bautz-Holter, E., Indredavik, B., Mayo, N. E., Power, M., Rodgers, H., Rønning, O. M., Widén Holmqvist, L., Wolfe, C. D. A., & Walker, M. F. (2011). A Consensus on Stroke. *Stroke*, *42*(5), 1392–1397. https://doi.org/10.1161/STROKEAHA.110.606285

Fisher, R., Walker, M., Golton, I., & Jenkinson, D. (2013). The implementation of evidence based rehabilitation services for stroke survivors living in the community: the results of a Delphi consensus process. *Clinical Rehabilitation*, *27*(8), 741-749. https://doi.org/10.1177/0269215512473312

Fitzgerald, S., Gracey, F., & Broomfield, N. (2022). Post-stroke emotionalism (PSE): A qualitative longitudinal study exploring individuals experience with PSE. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2021.2002439

Gillespie, D. C., Cadden, A. P., Lees, R., West, R. M., & Broomfield, N. M. (2016). Prevalence of Pseudobulbar Affect following Stroke: A Systematic Review and Meta-Analysis. *Journal of Stroke and Cerebrovascular Diseases*, *25*(3), 688–694. https://doi.org/10.1016/j.jstrokecerebrovasdis.2015.11.038

Gillespie, D. C., Cadden, A. P., West, R. M., & Broomfield, N. M. (2020). Non-pharmacological interventions for post-stroke emotionalism (PSE) within inpatient stroke settings: A theory of

planned behavior survey. *Topics in Stroke Rehabilitation*, *27*(1), 15–24. https://doi.org/10.1080/10749357.2019.1654241

Hepworth, L. R., & Rowe, F. J. (2018). Using Delphi methodology in the development of a new patient-reported outcome measure for stroke survivors with visual impairment. *Brain and Behavior*, *8*(2), e00898. https://doi.org/10.1002/brb3.898

House, A., Dennis, M., Molyneux, A., Warlow, C., & Hawton, K. (1989). Emotionalism after stroke. *BMJ (Clinical Research Ed.)*, *298*(6679), 991–994. https://doi.org/10.1136/bmj.298.6679.991

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), Article 9. https://doi.org/10.1177/1049732305276687

Johnstone, L., & Dallos, R. (2014). *Formulation in psychology and psychotherapy making sense of people's problems*. Routledge.

Jünger, S., Payne, S. A., Brine, J., Radbruch, L., & Brearley, S. G. (2017). Guidance on Conducting and Reporting Delphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliative Medicine*, *31*(8), 684–706. https://doi.org/10.1177/0269216317690685

Leis, J. A., Mendelson, T., Perry, D. F., & Tandon, S. D. (2011). Perceptions of mental health services among low-income, perinatal African-American women. *Women's Health Issues*, *21*(4), 314–319. https://doi.org/10.1016/j.whi.2011.03.005

Leung, D. Y., & Chung, B. P. M. (2019). Content Analysis: Using Critical Realism to Extend Its Utility. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 827–841). Springer. https://doi.org/10.1007/978-981-10-5251-4_102

Liddon, L., Kingerlee, R., & Barry, J. (2017). Gender differences in preferences for psychological treatment, coping strategies, and triggers to help-seeking. *British Journal*

Of Clinical Psychology, *57*(1), 42-58. https://doi.org/10.1111/bjc.12147https://doi.org/10.1111/bjc.12147

Lincoln, N., Kneebone, I., Macniven, J., & Morris, R. (2012). *Psychological management of stroke*. Wiley-Blackwell.

Linstone, H. A., & Turoff, M. (1975). *The Delphi method: Techniques and applications*. Addison-Wesley Pub. Co., Advanced Book Program

McAleese, N., Guzman, A., O'Rourke, S., & Gillespie, D. (2019). Post-stroke emotionalism: a qualitative investigation. *Disability And Rehabilitation*, *43*(2), 192-200. https://doi:10.1080/09638288.2019.1620876

McGrath, M., Lever, S., McCluskey, A., & Power, E. (2019). Developing interventions to address sexuality after stroke: Findings from a four-panel modified Delphi study. *Journal Of Rehabilitation Medicine*, *51*(5), 352-360. https://doi.org/10.2340/16501977-2548

McMillan, S. S., King, M., & Tully, M. P. (2016). How to use the nominal group and Delphi techniques. *International Journal of Clinical Pharmacy*, *38*, 655–662. https://doi.org/10.1007/s11096-016-0257-x

Melin, E. O., Svensson, R., & Thulesius, H. O. (2018). Psychoeducation against depression, anxiety, alexithymia and fibromyalgia: A pilot study in primary care for patients on sick leave. *Scandinavian Journal of Primary Health Care*, *36*(2), 123–133. https://doi.org/10.1080/02813432.2018.1459225

Morgan, D. (2012). Focus Groups and Social Interaction. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The sage handbook of interview research: The complexity of the craft* (pp. 161–176). essay, SAGE.

Nasa, P., Jain, R., & Juneja, D. (2021). Delphi methodology in healthcare research: How to decide its appropriateness. *World Journal of Methodology*, *11*(4), 116–129. https://doi.org/10.5662/wjm.v11.i4.116

NHS. (2019). *NHS Long Term Plan*. NHS choices. Retrieved March 6, 2023, from https://www.longtermplan.nhs.uk/online-version/

National Institute for Health and Care Excellence. (2011). *Common mental health problems: identification and pathways to care* (NICE Guideline CG123). Available at: https://www.nice.org.uk/Guidance/CG123

National Institute for Health and Care Excellence. (2012). *Improving access to psychological care after stroke.* Available at: https://www.nice.org.uk/sharedlearning/improving-access-to-psychological-care-after-stroke

National Institute for Health and Care Excellence. (2013). *Stroke rehabilitation in adults* (NICE Guideline CG162). Available at: https://www.nice.org.uk/guidance/cg162/chapter/1-recommendations

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, *18*(2), 34–35. https://doi.org/10.1136/eb-2015-102054

Ogbeifun, E., Agwa-Ejon, J., Mbohwa, C., & Pretorius, J. (2016). The Delphi technique: A credible research methodology. In *International Conference on Industrial Engineering and Operations Management* (pp. 2004-2009). Malaysia; IEOM Society International. Retrieved 5 June 2021, from http://ieomsociety.org/ieom_2016/pdfs/589.pdf.

Oyake, K., Suzuki, M., Otaka, Y., Momose, K., & Tanaka, S. (2020). Motivational Strategies for Stroke Rehabilitation: A delphi study. https://doi.org/10.1101/2020.03.15.20036764

Philp, I., Brainin, M., Walker, M. F., Ward, A. B., Gillard, P., Shields, A. L., & Norrving, B. (2013). Development of a Poststroke Checklist to Standardize Follow-up Care for Stroke

Survivors. *Journal of Stroke and Cerebrovascular Diseases*, *22*(7), e173–e180. https://doi.org/10.1016/j.jstrokecerebrovasdis.2012.10.016

Rathod, S., Phiri, P., & Naeem, F. (2019). An evidence-based framework to culturally adapt cognitive behaviour therapy. *The Cognitive Behaviour Therapist*, *12*, 1–15. https://doi.org/10.1017/s1754470x18000247

Reshetnyak, E., Ntamatungiro, M., Pinheiro, L. C., Howard, V. J., Carson, A. P., Martin, K. D., & Safford, M. M. (2020). Impact of multiple social determinants of health on incident stroke. *Stroke*, *51*(8), 2445–2453. https://doi.org/10.1161/strokeaha.120.028530

Royal College of Physicians (RCP). (2016). National clinical guideline for stroke. https://www.strokeaudit.org/Guideline/Full-Guideline

Ryan, B. J., Clunne, S. M., Baker, C. J., Shiggins, C., Rose, M. L., & Kneebone, I. I. (2022). A systematic review of non-drug interventions to prevent and treat anxiety in people with aphasia after stroke. *Disability and Rehabilitation*, *44*(18), 4997–5006. https://doi.org/10.1080/09638288.2021.1925752

Sandel, M. E., Wang, H., Terdiman, J., Hoffman, J. M., Ciol, M. A., Sidney, S., Quesenberry, C., Lu, Q., & Chan, L. (2009). Disparities in stroke rehabilitation: Results of a study in an integrated health system in northern California. *PM & R: The Journal of Injury, Function, and Rehabilitation*, *1*(1), 29–40. https://doi.org/10.1016/j.pmrj.2008.10.012

Sauvé, W. M. (2016). Recognizing and treating pseudobulbar affect. *CNS Spectrums*, *21*(S1), 34–44. https://doi.org/10.1017/S1092852916000791

Setkowski, K., van Balkom, A. J. L. M., Dongelmans, D. A., & Gilissen, R. (2020). Prioritizing suicide prevention guideline recommendations in specialist mental healthcare: a Delphi study. *BMC psychiatry*, *20*(1), 55. https://doi.org/10.1186/s12888-020-2465-0

Sewpaul, R., Crutzen, R., Dukhi, N., Sekgala, D., & Reddy, P. (2021). A mixed reception: Perceptions of pregnant adolescents' experiences with health care workers in Cape Town, South Africa. *Reproductive Health*, *18*(1), 1–12. https://doi.org/10.1186/s12978-021-01211-x

Stroke statistics. Stroke Association. (2021). Retrieved 15 June 2021, from https://www.stroke.org.uk/what-is-stroke/stroke-statistics.

Stutchbury, K. (2021). Critical realism: An explanatory framework for small-scale qualitative studies or an 'unhelpful edifice'? *International Journal of Research & Method in Education*, *45*(2), 113–128. https://doi.org/10.1080/1743727x.2021.1966623

Tjokrowijoto, P., Stolwyk, R. J., Ung, D., Kilkenny, M. F., Kim, J., Dalli, L. L., Cadilhac, D. A., & Andrew, N. E. (2023). Factors associated with mental health service access among Australian community-dwelling survivors of stroke. *Disability and Rehabilitation*, *45*(3), 504–511. https://doi.org/10.1080/09638288.2022.2032413

Von det Gracht, HA. (2012). Consensus measurement in Delphi studies: Review and implications for future quality assurance. *Technological Forecasting and Social Change 79*(8), 1525-1536. https://doi.org/10.1016/j.techfore.2012.04.013

Wang, R., & Langhammer, B. (2018). Predictors of quality of life for chronic stroke survivors in relation to cultural differences: A literature review. *Scandinavian Journal of Caring Sciences*, *32*(2), 502–514. https://doi.org/10.1111/scs.12533

Ward, E. C., Clark, L. O., & Heidrich, S. (2009). African American Women's beliefs, coping behaviors, and barriers to seeking mental health services. *Qualitative Health Research*, *19*(11), 1589–1601. https://doi.org/10.1177/1049732309350686

Watkins, C., Jenkinson,D., Scoular, P., Williams, J., Fletcher, M., Roffe, C., Leathley, M.,& Golton, I. (2009) on behalf of the UK Forum for Stroke Training Stroke-Specific Education Framework (SSEF).

Witkin, B. R., & Altschuld, J. W. (1995). Planning and conducting needs assessments: A practical guide. Thousand Oaks, CA: SAGE Publications, Inc

World Health Organisation (WHO). (2022) Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022.

World Stroke Organization (WSO): Global stroke fact sheet 2022. (2022). *International Journal of Stroke*, *17*(4), 478–478. https://doi.org/10.1177/17474930221080343

Chapter Five: Extended Methodology

Word count:1980

Extended Methodology

This chapter provides further details in relation to the methodology of the empirical paper which could not be included due to the suggested submission word count for empirical papers. The rationale for using the Delphi method, the description, the rationale for the qualitative methodology used, and the transcription process are considered.

Rationale for the use of Delphi Method

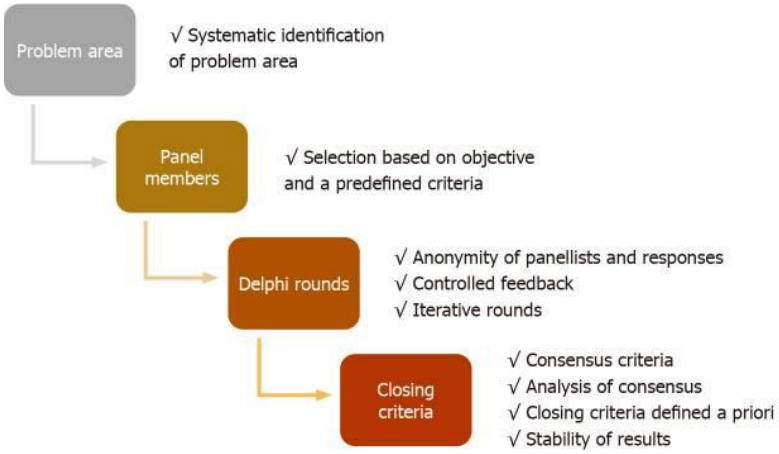
The Delphi method is considered a consensus method used in research to problem-solve or determine priorities (Delbecq et al., 1976). The Delphi method is a highly structured interaction between group (panel) members via questionnaires rather than in-person communication (McMillan et al., 2016). Where a nominal group technique (face-to-face group meetings) or focus group rely on the facilitator to control participation by group members, the Delphi method is a more balanced approach as it allows responses from all participants (McMillan et al., 2016). Therefore, there were many benefits of using the Delphi method as the initial method to gather participant opinions on the helpfulness and accessibility of non-pharmacological PSE interventions, as it allowed for a greater sample size and representation of the sample. Whereas, if we used the nominal group technique, a smaller sample size would have been used due to the format of running rounds of focus groups and there would have been constraints on participants engaging in the study, such as due to time differences. By completing the Delphi method online, we gathered the responses from experts in other continents, where time zone differences would have made face-to-face or video call meetings difficult (McMillan et al., 2016). However, a limitation of the Delphi method was the work and time needed to conduct such a project, especially as multiple rounds could be completed (McMillan et al., 2016). Considering the benefits of reaching a wider number of individuals regardless of location, the Delphi method was still considered the preferred method to reach a consensus regarding the preferred non-pharmacological

interventions for PSE. However, one thing which the Delphi method does not necessarily provide is the contextual information around the responses, which is where the use of qualitative elements, such as a focus group, can be added as an additional part of the study outside of the Delphi method (Linstone & Turoff, 1975) or following the rounds of questionnaires (Canessa et al., 2022).

Currently, there are no reported quality frameworks for Delphi method projects (Nasa et al., 2021). However, researchers have recommended the stepwise quality assessment of Delphi studies in healthcare research (Nasa et al., 2021; see figure 1). Following the approach, the empirical paper addresses each point on the stepwise model. Researchers have argued against having a set number of rounds due to the impact this can have on the stability of results (Linstone & Turoff, 1975), where a set shift can occur between one round and the next (Dajani et al., 1979). However, due to the time limitations of the project, it was not feasible to open the rounds. Upon examination of the Delphi results, there appears to be a level of stability among the ratings as most PSE interventions were rated within the same category (e.g., unhelpful, neither helpful or unhelpful, or helpful) across both rounds. Furthermore, a major part of the study was on the contextual information surrounding the results from the Delphi method, resulting in time needing to be allocated to run the focus groups.

Figure 1

Step wise quality assessment of Delphi studies (Nasa et al., 2021)



Approach to qualitative methodology

As philosophical approaches influence the research process, including the methodology and interpretation of results, it is viewed as essential for researchers to identify early on what ontological and epistemological approach they align with (Jackson, 2013; Ramazanoglu & Holland, 2002). Ontology positions relate to the interactions between the world and our human interpretations and practices (Braun & Clarke, 2013). Epistemology refers to the theory of knowledge (Ramazanoglu & Holland, 2002). There are different continua of ontologies from realism to relativism, as there are for epistemology from constructivism to empiricism (Braun & Clarke, 2013). Where realism (realists) assumes a knowable world made sense of through empirical research, relativism argues there are many realities (Braun & Clarke, 2013; Nightingale & Cromby, 1999).

Furthermore, where positivism assumes an easy and understandable relationship between our perception of the world and the world itself, constructionism approaches question whether knowledge is a reflection of reality, but instead, that how we make sense of the world is tied to our social world (Braun & Clarke, 2013). Critical realists sit in the middle, distinguishing between the ‘real’ world and the ‘observable’ world (Braun & Clarke, 2013)

and combine a realist ontology (that there is a knowable world) with a relativistic epistemology (social context will influence our knowledge and how we make sense of the world; Stutchbury, 2021).

At the initial stage of the project, I (the primary researcher) identified that my ontological and epistemological perspective aligns with a critical realist approach, where the exploration of underlying mechanisms to seek explanations was deemed essential; in this case the context around the results of the second round of the Delphi method (Vincent & Mahoney, 2018). My position of following a critical realist approach shaped the research questions for the project. One of the main aims was to explore the context around non-pharmacological PSE interventions. In line with critical realism, the aim was explored whilst acknowledging that explanations are subjective and up to interpretation from others (Leung & Chung, 2019).

Rationale for content analysis

A mixed methodology was adopted for the empirical paper to gather varying layers of data to make sense of the opinions of experts regarding the accessibility and helpfulness of non-pharmacological PSE interventions (Maxwell., 2012). Research has found that following a critical realist approach whilst conducting content analysis for qualitative data can have many benefits, it can extend interpretation from the surface level of information to a deeper level of understanding (Leung & Chung, 2019). Therefore, based on the critical realist approach I was taking with the project, it seemed appropriate to use content analysis to analyse the data as I was able to investigate the differences in opinions among participants (Hsieh & Shannon, 2005).

There are three main types of content analysis, these include summative, directed, and conventional (Hsieh & Shannon, 2005). Conventional content analysis is considered by researchers to provide a comprehensive picture of a “phenomenon”, through new insight

exclusively grounded in the data (Hsieh & Shannon, 2005). Although the frequency of codes and themes can be explored through content analysis, such as by using a summative approach, it felt useful to focus on what themes, categories, and codes were spontaneously identified (Hisieh & Shannon, 2005). Furthermore, by focusing on what is brought up rather than the frequency, the importance of all participants' opinions during the mini-focus group could be shared. Additionally, rather than following a directed content analysis approach, where themes are already identified, I was able to immerse myself in the data to allow new insights to emerge (Kondracki & Wellman, 2002). This meant I gained direct information from the participants without any pre-conceived themes impacting the analysis of results (Hsieh & Shannon, 2005). Thus, allowing for relevant theories to be addressed in the discussion section (Hsieh & Shannon, 2005).

Researchers have referred to the quality of qualitative data as the level of trustworthiness it holds (Stenfors et al., 2020). Five broad domains are considered important to consider regarding the rigor of qualitative research, these include credibility, dependability, conformability, and transferability (truth value, applicability, consistency), and neutrality (Lincoln & Guba, 1994). The credibility relates to the openness of the researcher in describing the data and participants who took part in the paper whilst the dependability refers to the stability of data over time and with different participants (Elo et al., 2014). The current study reported the participant characteristics of all participants who took part in all stages of the empirical project. Lincoln & Guba (1985) stated the importance of describing the inclusion and exclusion criteria as well as the participant characteristics to strengthen the credibility and dependability of one's study. Furthermore, techniques, such as taking notes in the mini-focus groups, recording the groups, peer debriefing, and focusing on the topic of study (in this case through the topic guide), are considered techniques to increase the

credibility of the research (Elo et al., 2014). Confirmability refers to there being congruence amongst researchers regarding the data.

To support the trustworthiness of the data to present congruent data, an external researcher was brought in to reduce researcher bias when handling the data. They were asked to code, sub-categorise, categorise, and identify themes from one third of randomly selected quotes from the transcripts. The independent researcher followed the process outline by the researcher for 33% of randomly allocated data to determine whether they arrived at similar findings and any disagreements were discussed until a consensus was reached. Transferability refers to whether the findings can be applied to other contexts, settings, or groups (Noble & Smith, 2015). Where the empirical paper focused on understanding the contextual factors around PSE interventions, a theme throughout the paper was holding the opinion that the helpfulness and accessibility of PSE interventions would depend on demographic, social, service, and organisational factors. Therefore, the applicability of the study may not be relevant as a criteria, as there is an understanding that the experiences across services globally will be different (Stenforths et al., 2020).

Analytic Process of the mini-groups

The mini-group transcripts were originally developed from the Microsoft Teams recordings. A transcript is provided once the recording stops. However, following this, the transcript was anonymised, and the content was cross checked and altered based on what was discussed in the recording. Following this, quotes from the transcript were placed in an excel document. Sentences relating to the assessment and diagnosis, helpfulness of interventions, and accessibility of PSE interventions were considered text to include in the excel document. To move towards identifying themes, I worked across the excel columns, following Erlingsson & Brysiewicz (2017) guide to content analysis, where “condensed meaning units”,

"codes", "sub-categories", and "categories" were developed (see Appendix Q for an example).

Condensed meaning units refer to shortening the text derived from the transcript to preserve the core meaning. Following this, a code can be created as a label for the condensed meaning unit. Following completion of all the codes for the condensed meaning units, the codes were then sorted in alphabetical order to analyse whether any sub-categories or categories began to emerge. Codes were then grouped together based on how they related to each other through their content or context (Erlingsson & Brysiewicz, 2017). From this, I was able to work towards the developments of sub-categories. The same step was then taken in relation to developing categories and themes (Erlingsson & Brysiewicz, 2017). However, content analysis is a reflective process, which means that the steps towards themes occur multiple times, with researchers being required to go back to the transcripts, condensed meaning units, codes, sub-categories, categories, and themes to reflect on the initial analysis.

Where the approach followed an "inductive" analysis, allowing for spontaneous data to emerge from the transcripts, it is important to note that my understanding, previous knowledge, and the set questions asked in the Topic guide would have influenced my analyses. For example, the emergence of the category "Uncertainties about Assessment & Diagnosis" within the theme of barriers to accessing PSE interventions was appropriate as a question surrounding assessment and diagnosis was asked. However, as previously stated, content analysis is a reflective process where the researcher must continue to reflect on their assumptions, opinions, and personal beliefs to prevent them unconsciously steering the analysis process (Erlingsson & Brysiewicz, 2017). In argument, as a critical realist, where it is known that contextual factors will impact the direction of the research process and analysis, being aware of this and reflecting on this during content analysis may simply be enough.

Chapter Six: Extended Discussion and Critical Evaluation

Word count: 3831

Extended Discussion and Critical Evaluation

This chapter summarises findings from the systematic review and empirical paper. Findings of each are summarised and discussed in relation to previous research and literature in the field. Additionally, the strengths and limitations of the thesis portfolio, the theoretical and clinical implications, and suggestions for future research are outlined.

Overview of results

The thesis portfolio explored the contextual factors impacting the accessibility (ability to engage with and use) and utility (the helpfulness to support coping with symptoms) of non-pharmacological interventions for mood and emotion disorders following a stroke. The systematic review investigated the reporting of protected characteristics in non-pharmacological interventions for post-stroke anxiety and depression. The empirical paper explored the opinions of healthcare professionals and researchers on non-pharmacological interventions to support those with post-stroke emotionalism (PSE) using the Delphi method and mini-focus groups.

Systematic review

The review identified what protected characteristics have been reported in non-pharmacological RCT intervention studies for post-stroke anxiety and depression globally using the framework PROGRESS-Plus (O'Neill et al., 2014). All papers reported the gender of their participants, with none including information regarding the sexual orientation of their participants. Furthermore, most studies did not include stroke characteristics (e.g., the type and location of the stroke, and time since the stroke occurred). Only one study investigated within-group differences regarding education, living circumstances, and whether caregivers were at home. Currently, it is difficult to analyse who has taken part in research due to studies not reporting the range of demographic and social characteristics of their participants. Taken together the findings from the review suggest that studies should consider what

characteristics are reported as this information is critically relevant for healthcare services and clinicians when considering what non-pharmacological interventions may be accessible to their population. From this, researchers and clinicians will be better informed as to who has been included in non-pharmacological intervention research for post-stroke anxiety and/or depression. Furthermore, future research should also consider whether exploring within-group differences in outcomes is appropriate to understand better what contextual factors may impact the accessibility and utility of non-pharmacological interventions for those with post-stroke anxiety and/or depression.

Empirical paper

The quantitative aspect of the project (the Delphi method) aimed to reach a consensus regarding the ratings of the accessibility and helpfulness of known PSE non-pharmacological interventions by stroke healthcare professionals and researchers. The qualitative aspect of the project explored the contextual factors which can impact the helpfulness and accessibility of non-pharmacological PSE interventions. The project found that “providing education for patient”, “talking to the patient about their goals concerning PSE”, and “providing education for family” were rated as the most helpful interventions. Whereas “offering reassurance”, “asking the patient to take a deep breath”, and “acknowledging the PSE and then continuing current activity” were rated as the most accessible.

The mini-focus groups provided much-needed additional context surrounding the implementation of these interventions, such as considering the barriers that can impact the accessibility and helpfulness of PSE interventions. These included the demographic and social factors of patients and the staff’s understanding of their roles in supporting the use of PSE interventions. Similar concerns have previously been identified concerning supporting stroke survivors in accessing psychological care (NICE, 2012). Frameworks in the UK have been created to help staff in better understanding their roles and responsibilities in assessing

and supporting those with emotional or mood conditions following a stroke (Department of Health, 2007; Watkins et al., 2009). However, the experiences of the focus group members suggest uncertainty regarding the use of these frameworks across all services.

Furthermore, certain interventions, such as “normalise the condition” and “provide education” were considered caring or human responses to PSE symptoms rather than interventions. This leads to the consideration that perhaps, based on where the stroke survivor is in their pathway, they may be more likely to have specific interventions suggested to them. Thus, the development of a stepped/mapped approach could be beneficial. Initially, in the acute stage, a caring/human response appears to be more likely to be shown to those with PSE, and then later in the pathway, they may be introduced to other strategies where the PSE may be more severe, complex, or impacting their rehabilitation and/or relationships. Possibly including some form of educational intervention, as suggested by participants, early on in a stroke pathway could also be beneficial to patients and perhaps prevent distress regarding PSE symptoms. Participants identified uncertainties about assessment and diagnosis, the appropriateness of managing PSE symptoms, and the perceived importance of PSE (e.g., based on time since stroke and the severity of symptoms) as essential factors acting as barriers to PSE interventions. Applying a person-centred approach, adapting interventions to the individual, and developing a matched/stepped PSE service pathway, based on identifying which staff are involved in assessing and supporting those with PSE and at what stage of a stroke patients’ pathway they are supported, were all highlighted.

Interpretation of thesis portfolio findings in relation to previous research and findings

Overall, the systematic review supports findings from previous research that a relatively low number of protected characteristics are reported in health-related research (Attwood et al., 2016; Madani et al., 2022; Plastow et al., 2021). For example, the conclusions from the systematic review are mirrored in Attwood et al.’s (2016) study which

identified the difficulty of assessing within group differences in intervention studies due to the impact this can have on statistical power (Petticrew et al., 2012). However, to support health equity, researchers should be reporting the characteristics of their participants, which does not come at the cost of statistical power, as this provides healthcare professionals and services with a higher level of understanding as to the appropriateness of clinical interventions based on the specific and individual characteristics of their stroke population.

There are very few studies exploring the non-pharmacological treatment of PSE symptoms (Fitzgerald et al., 2022). However, the empirical paper supports findings from Gillespie et al.'s (2020) study which identified that offering reassurance, talking to the patient about their goals, acknowledging the PSE and then continuing with the current activity, and providing education for the patient and family were considered the most effective treatments by healthcare staff. Where the Gillespie et al. (2020) study was able to recruit a large number of participants in the United Kingdom (n =220), the current paper brings strength to its findings by aiming to achieve consensus globally regarding the helpfulness of non-pharmacological PSE interventions, whilst also working towards a consensus regarding the accessibility of the interventions.

There is currently limited research on non-pharmacological interventions of PSE. However, a recent study investigated the experiences of individuals' PSE symptoms in order to develop a framework to shape non-pharmacological interventions (Fitzgerald et al., 2022). The proposed model/framework includes themes regarding "in the moment", "ways of coping", and "longer term impact". Participants in this study cited strategies they have used to cope with their symptoms including taking deep breaths, using distraction, avoiding triggers, accepting their symptoms, and seeking support from others (Fitzgerald et al., 2022). Most of these strategies, apart from acceptance and seeking support, were included as interventions within the empirical paper.

The need for discussions around emotionalism to take place early was highlighted in the focus group and in other PSE research (McAleese et al., 2019). McAleese et al. (2019) conducted a qualitative study to explore participant's experiences of emotionalism and how they managed their symptoms. The researchers discussed how early education around PSE symptoms was expected to reduce the likelihood of the development of negative beliefs and unhelpful coping responses to PSE symptoms (McAleese et al., 2019). Considering the findings from this study and from Fitzgerald et al. (2022), it could fit well with the suggested stepped/mapped care model from the empirical paper. Where healthcare professionals consider what type of PSE interventions might be more suited for different stages in the pathway, such as providing education in step one, whilst providing interventions which are in the moment, to support their ways of coping, or to support the long-term impact of PSE (Fitzgerald et al., 2022).

Where the empirical paper identified the impact age, gender, ethnicity, disability, and cultural background have on the accessibility or implementation of PSE interventions, similar findings have been acknowledged in psychological research into mood conditions (D'cruz et al., 2021; Liddon et al., 2017; Ward et al., 2009). These findings support the recommendations for services to consider the personal characteristics of PSE patients when assessing and supporting their symptoms, in line with NICE guidelines relating to mood conditions post-stroke (NICE, 2013). Where it is known that demographic and social factors can impact health equity (WHO; 2022) and stroke outcomes (Reshetnyak et al., 2020), healthcare professionals need to consider the roles they play in supporting access in groups. Although a main aim of the paper was focusing on the demographic and social factors and their interplay with treatment helpfulness and accessibility, the service and clinical contexts of PSE non-pharmacological interventions was raised in the mini-focus groups. Points raised regarding the lack of understanding of roles and responsibilities in relation to the

management of PSE by healthcare staff parallel similar findings in the UK's Stroke-Specific Education Framework (SSEF; Department of Health, 2007; Watkins et al., 2009). Literature regarding the implementation of evidence-based practice identifies the need to take into consideration the service context and organisational and team structure in relation to supporting stroke rehabilitation (Fisher et al., 2019; Horton et al., 2015). Therefore, the empirical paper's findings further support the need for services to consider service context when assessing and providing non-pharmacological support for PSE.

Strengths and limitations

The thesis portfolio presented two novel main papers, which provide insight into the demographic and social factors reported in post-stroke anxiety and depression non-pharmacological intervention research and the recommendations for services in assessing and supporting strove survivors with emotionalism.

In the systematic scoping review paper, PRISMA Scr (Tricco et al., 2018) guidelines were adhered to, ensuring a robust approach and good reporting of research findings (Tricco et al., 2018). Furthermore, the review is the first systematic scoping review to identify what protected characteristics are being reported in RCTs for the non-pharmacological management of post-stroke anxiety and/or depression. Additionally, it presented an important finding, that there is limited research investigating the impact demographic and social factors can have on the effectiveness of non-pharmacological interventions for post-stroke anxiety and/or depression.

A limitation of the systematic scoping review was that the papers included had to have been originally written in, or translated into, English. Therefore, inevitably, some papers would have been missed. As the review focused on the global reporting of protected characteristics in research examining the effectiveness of non-pharmacological interventions for post-stroke anxiety and/or depression, it is a limitation that studies such as several

identified from Wang et al.'s (2018) systematic review, were not included. Had the required resources been available, it would have been beneficial to further explore the databases set in non-English speaking countries. Linking with other researchers who can access such sites and read different languages could have enabled this, given our focus on reporting demographic and social factors globally (described as protected characteristics in the PROGRESS-Plus framework; O'Neill et al., 2014). However, systematic scoping reviews can be used as an approach to identify whether there is enough literature to consider completing a full systematic review of data (e.g., if there is enough data to investigate outcome differences between subgroups following the implementation of non-pharmacological interventions for post-stroke anxiety/depression; Armstrong et al., 2011). Therefore, although it is a limitation, it may not be disadvantageous for this review to have only included research in English.

Regarding the empirical paper, considering the step-wise quality framework suggested by Nasa et al. (2021) for healthcare research using the Delphi method, the empirical paper could potentially have benefited from not setting two rounds for the project but instead keeping the number of rounds open until the results were stable (consistent). Where there is an aim to reach a consensus, researchers have argued that the stability of the results is essential, even if consensus is not reached (Dajani et al., 1979; Linstone & Turoff, 1975). Therefore, if there were no time limitations to the project, opening the Delphi rounds until stability in the results was noticed would have added to the quality of the project.

Concerning the content analysis conducted in the empirical paper, appropriate steps were taken to ensure that the findings were trustworthy, which is a marker of the quality of qualitative research (Elo et al., 2014). With focus groups there is always the potential risk of untrustworthiness in the interpretation of content analytic data (Noble & Smith, 2015). To counter this, an external researcher independently assessed one-third of the condensed meaning units and codes and was instructed to follow the same rules as deployed by the

primary researcher to create sub-categories, categories and themes to increase the reliability and validity of the emergent codes and themes (Ryan, 1999). The data was then compared to the primary researcher's findings, and consensus was reached where there were any differences or where the external researcher felt the rules did not "fit" with the data.

Additionally, the empirical paper could have benefited from a more diverse participant sample, where most participants recruited were Clinical Psychologists/Neuropsychologists and identified their ethnicity as white. Having a more diverse participant sample could have provided additional insight into the impact demographic and sociocultural factors can have on the helpfulness and accessibility of non-pharmacological interventions. Especially, as it has been suggested that a healthcare professionals' own demographic and sociocultural characteristics can influence the trajectory of treatment (Boissoneault et al., 2016). However, although the study was unable to recruit across all demographic and sociocultural groups, participants across the globe were able to take part in the research, which would have provided important insight into the context of non-pharmacological PSE interventions.

The empirical paper provides much needed insight surrounding the contextual demographic, social, and service factors which can impact the helpfulness and accessibility of non-pharmacological PSE interventions. Furthermore, it provides novel insights surrounding the opinions of healthcare professionals and is the first Delphi method project to aim and reach a consensus regarding the helpfulness and accessibility of PSE non-pharmacological interventions.

The use of mini-focus groups in the empirical project to provide contextual information regarding the accessibility and helpfulness of non-pharmacological PSE interventions provided a deeper meaning to the ratings provided by the Delphi method. Although helpful, there are however limitations to running focus groups. One is the impact

researcher bias can have (Noble & Smith, 2015). Bias was moderated by inviting a second researcher to support the running of the groups, thereby further ensuring as best as possible the topic guide was adhered to. Additionally, by including another moderator in the mini-focus groups, the overall running of the group was supported, as time management, the summarising of comments, and checking-in responsibilities could be shared. As the primary researcher, this supported me in feeling more present during the mini-focus groups, as I was able to be present rather than hold all the next steps of the group on my own. Secondly, the sample size of the mini-focus groups was relatively small. Therefore, as previously stated, the data might not be fully representative of stroke services across the UK. However, vital points were raised in the mini-focus groups, which other services can use to reflect on whether similar barriers are noticed in their services.

Additionally, a potential limitation lies with the original aim of the focus groups being to learn more about the role of demographic and social factors on the perceived helpfulness and accessibility of non-pharmacological PSE interventions, but with the topic veering towards service context and models. Although this was not the original aim of the project, the knowledge gained surrounding service context is vital in better understanding how services can support PSE patients. Furthermore, useful information was still gathered regarding the context surrounding the impact demographic and social factors can have on the helpfulness and accessibility of PSE interventions.

It is also important to consider the impact knowing seven out of the eight participants in the mini-focus groups could have had on the delivery of the groups, which could have resulted in conversations moving from the topic to other areas not relevant to the study. However, the topic guide was created prior to knowing who was taking part in the mini-focus groups and the data did not appear to have been influenced by the researchers having had previous experiences with the participants.

Overall, based on the suggested quality framework for the Delphi method and the trustworthiness of the qualitative research, the empirical study is of good quality and provides much needed insight regarding the perceived levels of helpfulness and accessibility to the helpfulness and accessibility of non-pharmacological interventions for PSE and their barriers.

Clinical and service implications

Implementation science refers to research focused on the methods and strategies which can support uptake of evidence-based practice and research into regular use by professionals (Tucker et al., 2021). Where the systematic review highlighted the need for demographic and social factors to be reported in stroke research to improve the understanding of who is taking part in research and to better understand the differences in outcomes, the empirical paper spoke to the considerations stroke services must make to support the assessment and implementation of PSE interventions.

It is well known that demographic and social factors can impact the likelihood of research involvement (Sheridan et al., 2020), with clear differences in participation of research trials based on marital status, pre-morbid function, socioeconomic status, ability to speak the native language and access to equipment and health services (Busija et al., 2013; WHO, 2022). Where most of the studies mentioned in the systematic review recruited participants from health services or via adverts, it would have been helpful to have seen "who" was included in their research. This would allow researchers to better understand how representative study populations are concerning primary outcomes. Furthermore, where the empirical paper highlighted how service context can impact the likelihood of assessment and support for those with PSE, the recommendations suggest that services should develop a pathway relating to PSE to ensure appropriate patient care and support and to ensure the uptake of evidence-based practice in relation to PSE. If adopted, such service initiatives

would more closely follow NICE (2013) guidelines in supporting stroke survivors with mood and emotion conditions following stroke.

Indeed, despite the prevalence of PSE (Gillespie et al., 2016), there is a lack of mention of assessing or supporting PSE patients, with some UK based national guidelines, proposals, or reviews not mentioning PSE despite including information regarding post-stroke anxiety and/or depression (NICE; 2013; RCP, 2016; SSEF, 2007). Implementing a service embedded PSE care pathway would align with NICE guidance on a stepped care model for common emotional or mood conditions (NICE, 2011) and allow services to identify which staff should be involved at what points in the PSE care pathway, in addition to providing the right level of support or intervention based on the complexity of the PSE or the need for support by the patient (NICE, 2011).

From the empirical paper, there is also a highlighted need for services to identify what contextual factors may be acting as barriers within their service, such as the perceived importance of managing PSE symptoms based on symptom severity or the time since PSE onset.

Theoretical Implications

The empirical paper integrated a mixed-method approach to gather multiple perspectives regarding contextual information surrounding quantitative results. Where a critical realist lens was applied to the project, it provided much needed context around the results of the Delphi method regarding the helpfulness and accessibility of PSE interventions. Rather than suggesting a specific approach with PSE patients, the paper sought to better understand the context in which experts suggested the helpfulness and accessibility of certain interventions. Thus, allowing services to consider their context and population when assessing and supporting people with PSE. This supports the promotion of critical realism as an approach to healthcare research as it allows services to hold autonomy in adapting

interventions to better suit their population based on their contextual factors. Especially, when it is known that demographic and social factors and team and organisational factors will impact a patient's outcome(s) post-stroke (Addo et al., 2012; Swiątkowska-Flis et al., 2014; WHO, 2022; WSO, 2022).

Future research

The reporting of protected characteristics of the studies included in the systematic review varied, emphasising the need for further research to provide a higher quality reporting of such characteristics known to impact health equity. Additionally, further research is needed to identify the impact protected characteristics, which are known to impact health equity, can have on the accessibility/helpfulness of non-pharmacological interventions for post-stroke anxiety, depression, and/or emotionalism.

The empirical paper could be extended by exploring the opinions of stroke survivors regarding the accessibility and helpfulness of non-pharmacological interventions for PSE. If a co-design approach was used, service users could add further contextual nuance to what healthcare professionals say. Furthermore, such a project could allow PSE patients to be actively involved in developing material relating to educating other patients, family members, and staff about PSE, and provide opinions regarding what the PSE pathway could look like in a stroke service. This could enrich the gathered data by obtaining the opinions and experiences of PSE patients regarding the contextual factors that can act as barriers to their accessing PSE interventions.

There appears to be a lack of research investigating the effectiveness of PSE interventions on stroke survivors. Therefore, future research should consider developing a pathway for PSE patients and the context surrounding the helpfulness and accessibility of PSE interventions, identifying what staff are involved at what level of care and what interventions may be appropriate based on the individuals' circumstances, their need, and

severity of symptoms. Additionally, there are still no psychological models or theories of PSE (Fitzgerald et al., 2022). Future research including healthcare professionals, stroke researchers, patients with lived experience and their family members, could follow a qualitative design to explore what psychological factors might influence the outcome of stroke survivors with PSE.

Overall conclusion

The thesis portfolio presents an overview of the contextual factors which are reported and can impact the accessibility and utility of non-pharmacological interventions for post-stroke mood conditions. As highlighted throughout the discussion, a range of contextual factors, and individual characteristics can impact the accessibility and helpfulness of non-pharmacological interventions for mood post-stroke. This provides impact into the importance of transparency when reporting participant characteristics in stroke research and the impact service context can have on the types of interventions which are accessible to stroke survivors. Overall, this thesis portfolio provides further understanding and knowledge of the impact protected characteristics and service context can have on the accessibility and utility of non-pharmacological interventions for anxiety, depression, or PSE following a stroke. This thesis provides an initial contribution to better understanding what demographic and social characteristics researchers are reporting in stroke research, and to consider the barriers and recommendations which have been identified to impact the helpfulness and accessibility of PSE non-pharmacological interventions.

Thesis Portfolio References

Addo, J., Ayerbe, L., Mohan, K.M., Crichton, S., Sheldenkar, A., Chen, R., Wolfe, C.D.A., & McKevitt, C. (2012) Socioeconomic Status and Stroke. *Stroke,* 43 (4),1186–91. https://doi.org/10.1161/STROKEAHA.111.639732

Ahrens, J., Shao, R., Blackport, D., Macaluso, S., Viana, R., Teasell, R., & Mehta, S. (2022). Cognitive -behavioral therapy for managing depressive and anxiety symptoms after stroke: A systematic review and meta-analysis. *Topics in Stroke Rehabilitation*, *0*(0), 1–16. https://doi.org/10.1080/10749357.2022.2049505

Allida, S., Patel, K., House, A., & Hackett, M. (2019). Pharmaceutical interventions for emotionalism after stroke. *Cochrane Database Of Systematic Reviews*. https://doi.org/10.1002/14651858.cd003690.pub4

Allida, S., Cox, K. L., Hsieh, C.-F., Lang, H., House, A., & Hackett, M. L. (2020). Pharmacological, psychological, and non-invasive brain stimulation interventions for treating depression after stroke. *Cochrane Database of Systematic Reviews*, (1). https://doi.org/10.1002/14651858.cd003437.pub4

Andersen, G., Vestergaard, K., Ingemann-Nielsen, M., & Lauritzen, L. (1995). Risk factors for post-stroke depression. *Acta Psychiatrica Scandinavica*, *92*(3), 193–198. https://doi.org/10.1111/j.1600-0447.1995.tb09567.x

Armstrong, R., Hall, B. J., Doyle, J., & Waters, E. (2011). 'Scoping the scope' of a cochrane review. *Journal of Public Health*, *33*(1), 147–150. https://doi.org/10.1093/pubmed/fdr015

Attwood, S., van Sluijs, E., & Sutton, S. (2016). Exploring equity in primary-care-based physical activity interventions using PROGRESS-Plus: A systematic review and evidence synthesis. *International Journal of Behavioral Nutrition and Physical Activity*, *13*(1), 60. https://doi.org/10.1186/s12966-016-0384-8

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*, *380*(9836), 37–43. https://doi.org/10.1016/S0140-6736(12)60240-2

Bhaskar, S., Thomas, P., Cheng, Q., Clement, N., McDougall, A., Hodgkinson, S., & Cordato, D. (2019). Trends in acute stroke presentations to an emergency department: implications for specific communities in accessing acute stroke care services. *Postgrad Med J*, *95*(1123), 258-264. https://doi.org/10.1136/postgradmedj-2019-136413

Boissoneault, J., Mundt, J. M., Bartley, E. J., Wandner, L. D., Hirsh, A. T., & Robinson, M. E. (2016). Assessment of the influence of demographic and professional characteristics on health care providers' pain management decisions using virtual humans. *Journal of Dental Education*, *80*(5), 578–587. https://doi.org/10.1002/j.0022-0337.2016.80.5.tb06118.x

Braun, V., & Clarke, V. (2013). Successful Qualitative Research: A Practical Guide for Beginners. London: Sage.

Burvill, P. W., Johnson, G. A., Jamrozik, K. D., Anderson, C. S., Stewart-Wynne, E. G., & Chakera, T. M. (1995a). Anxiety disorders after stroke: Results from the Perth Community Stroke Study. *The British Journal of Psychiatry: The Journal of Mental Science*, *166*(3), 328–332. https://doi.org/10.1192/bjp.166.3.328

Burvill, P. W., Johnson, G. A., Jamrozik, K. D., Anderson, C. S., Stewart-Wynne, E. G., & Chakera, T. M. (1995b). Prevalence of depression after stroke: The Perth Community Stroke Study. *The British Journal of Psychiatry: The Journal of Mental Science*, *166*(3), 320–327. https://doi.org/10.1192/bjp.166.3.320

Busija, L., Tao, L. W., Liew, D., Weir, L., Yan, B., Silver, G., Davis, S., & Hand, P. J. (2013). Do patients who take part in stroke research differ from non-participants? Implications for

generalizability of results. *Cerebrovascular Diseases (Basel, Switzerland)*, *35*(5), 483–491. https://doi.org/10.1159/000350724

Canessa, C., Vavvos, A., Triliva, S., Kafkalas, I., Vrachioli, M., & Sauer, J. (2022). Implementing a combined Delphi and Focus Group qualitative methodology in Nexus research designs—The case of the WEFE Nexus in Apokoronas, Crete. *PLOS ONE*, *17*(7), e0271443. https://doi.org/10.1371/journal.pone.0271443

Care Quality Commission (2011) Supporting Life after Stroke. A Review of Services for People who have had a Stroke and their Carers. Care Quality Commission, London. http://tinyurl.com/4qws5lo

Carota, A., & Calabrese, P. (2013). Post-stroke emotionalism. Neurological Disorders, 4 (1), 928-929.

Castilla-Guerra, L., Fernandez Moreno, M. del C., Esparrago-Llorca, G., & Colmenero-Camacho, M. A. (2020). Pharmacological management of post-stroke depression. *Expert Review of Neurotherapeutics*, *20*(2), 157–166. https://doi.org/10.1080/14737175.2020.1707666

Cheong, M. J., Kang, Y., & Kang, H. W. (2021). Psychosocial Factors Related to Stroke Patients' Rehabilitation Motivation: A Scoping Review and Meta-Analysis Focused on South Korea. *Healthcare*, *9*(9), Article 9. https://doi.org/10.3390/healthcare9091211

Dajani, J. S., Sincoff, M. Z., & Talley, W. K. (1979). Stability and agreement criteria for the termination of Delphi Studies. *Technological Forecasting and Social Change*, *13*(1), 83–90. https://doi.org/10.1016/0040-1625(79)90007-6

D'cruz, M. M., & Chaturvedi, S. K. (2021). Sociodemographic and cultural determinants of mood disorders. *Current Opinion in Psychiatry*, *35*(1), 38–44. https://doi.org/10.1097/yco.0000000000000766

Delbecq, A., Ven, A., & Gustafson, D. (1976). Group Techniques for Program Planning: A Guide to Nominal Group and Delphi Processes. *Glenview, Illinois: Scott Forman and Co*.

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

Eccles, S., House, A., & Knapp, P. (1999). Psychological adjustment and self reported coping in stroke survivors with and without emotionalism. *Journal Of Neurology, Neurosurgery & Psychiatry*, *67*(1), 125-126. https://doi.org/10.1136/jnnp.67.1.125

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis. *SAGE Open*, *4*(1), 215824401452263. https://doi.org/10.1177/2158244014522633

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, *7*(3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001

Equality Act. (2010). *Equality Act 2010.* https://www.legislation.gov.uk/ukpga/2010/15/part/2/chapter/1

Feigin, V. L., Stark, B. A., Johnson, C. O., Roth, G. A., Bisignano, C., Abady, G. G., Abbasifard, M., Abbasi-Kangevari, M., Abd-Allah, F., Abedi, V., Abualhasan, A., Abu-Rmeileh, N. M., Abushouk, A. I., Adebayo, O. M., Agarwal, G., Agasthi, P., Ahinkorah, B. O., Ahmad, S., Ahmadi, S., Murray, C. J. L. (2021). Global, regional, and national burden of stroke and its risk factors, 1990–2019: A systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Neurology*, *20*(10), 795–820. https://doi.org/10.1016/S1474-4422(21)00252-0

Fisher, D. M., Ragsdale, J. M., & Fisher, E. C. S. (2019). The Importance of Definitional and Temporal Issues in the Study of Resilience. *Applied Psychology*, *68*(4), 583–620. https://doi.org/10.1111/apps.12162

Fitzgerald, S., Gracey, F., & Broomfield, N. (2022). Post-stroke emotionalism (PSE): A qualitative longitudinal study exploring individuals experience with PSE. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2021.2002439

Gillespie, D. C., Cadden, A. P., Lees, R., West, R. M., & Broomfield, N. M. (2016). Prevalence of Pseudobulbar Affect following Stroke: A Systematic Review and Meta-Analysis. *Journal of*

Stroke and Cerebrovascular Diseases, *25*(3), 688–694. https://doi.org/10.1016/j.jstrokecerebrovasdis.2015.11.038

Gillespie, D. C., Cadden, A. P., West, R. M., & Broomfield, N. M. (2020). Non-pharmacological interventions for post-stroke emotionalism (PSE) within inpatient stroke settings: A theory of planned behavior survey. *Topics in Stroke Rehabilitation*, *27*(1), 15–24. https://doi.org/10.1080/10749357.2019.1654241

GOV.UK. 'Health Disparities and Health Inequalities: Applying All Our Health'. Accessed 20 February 2023. https://www.gov.uk/government/publications/health-disparities-and-health-inequalities-applying-all-our-health/health-disparities-and-health-inequalities-applying-all-our-health

Hackett, M. L., Köhler, S., O'Brien, J. T., & Mead, G. E. (2014). Neuropsychiatric outcomes of stroke. *The Lancet Neurology*, *13*(5), 525–534. https://doi.org/10.1016/S1474-4422(14)70016-X

Hadidi, N. N., Huna Wagner, R. L., & Lindquist, R. (2017). Nonpharmacological Treatments for Post-Stroke Depression: An Integrative Review of the Literature. *Research in Gerontological Nursing*, *10*(4), 182–195. https://doi.org/10.3928/19404921-20170524-02

Hosseinzadeh, N., Ala, A., Rahnemayan, S., Sadeghi-Hokmabadi, E., Gholami Milani, A., Rahimpour Asenjan, M., & Vahdati, S. S. (2021). Demographic information and risk factors of stroke patients younger than 65 years old. *Frontiers in Emergency Medicine*, *6*(1). https://doi.org/10.18502/fem.v6i1.7676

Horton, S., Lane, K., & Shiggins, C. (2015). Supporting communication for people with aphasia in stroke rehabilitation: Transfer of training in a multidisciplinary stroke team. *Aphasiology*, *30*(5), 629–656. https://doi.org/10.1080/02687038.2014.1000819

House, A., Dennis, M., Molyneux, A., Warlow, C., & Hawton, K. (1989). Emotionalism after stroke. *BMJ (Clinical Research Ed.), 298*(6679), 991–994. https://doi.org/10.1136/bmj.298.6679.991

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), Article 9. https://doi.org/10.1177/1049732305276687

Jackson, E. (2013). Choosing a Methodology: Philosophical Underpinning. *Practitioner Research in Higher Education Journal*, *7*, 49-62.

Kim, J, S. (2017). Management of Post-Stroke Mood and Emotional Disturbances. *Expert Review of Neurotherapeutics 17*(12)1179–88. https://doi.org/10.1080/14737175.2017.1395281.

Knapp, P., Campbell Burton, C. A., Holmes, J., Murray, J., Gillespie, D., Lightbody, C. E., Watkins, C. L., Chun, H.-Y. Y., & Lewis, S. R. (2017). Interventions for treating anxiety after stroke. *Cochrane Database of Systematic Reviews*, *2017*(5). https://doi.org/10.1002/14651858.cd008860.pub3

Leung, D. Y., & Chung, B. P. M. (2019). Content Analysis: Using Critical Realism to Extend Its Utility. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 827–841). Springer. https://doi.org/10.1007/978-981-10-5251-4_102

Liddon, L., Kingerlee, R., & Barry, J. (2017). Gender differences in preferences for psychological treatment, coping strategies, and triggers to help-seeking. *British Journal Of Clinical Psychology*, *57*(1), 42-58. https://doi.org/10.1111/bjc.12147https://doi.org/10.1111/bjc.12147

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. Naturalistic Inquiry, 289(331), 289-327.

Lindenstrøm, E., Boysen, G., & Nyboe, J. (1993). Risk factors for stroke in Copenhagen, Denmark. I. Basic demographic and social factors. *Neuroepidemiology*, *12*(1), 37–42. https://doi.org/10.1159/000110297

Linstone, H. A., & Turoff, M. (1975). *The Delphi method: Techniques and applications*. Addison-Wesley Pub. Co., Advanced Book Program.Madani, M. T., Madani, L., Ghogomu, E. T., Dahrouge, S., Hébert, P. C., Juando-Prats, C., Mulligan, K., & Welch, V. (2022). Is equity considered in systematic reviews of interventions for mitigating social isolation and loneliness in older adults? *BMC Public Health*, *22*(1). https://doi.org/10.1186/s12889-022-14667-8

Maxwell, J. (2012). *Qualitative research design: An interactive approach* (3rd ed). Sage Publications.

McAleese, N., Guzman, A., O'Rourke, S., & Gillespie, D. (2019). Post-stroke emotionalism: a qualitative investigation. *Disability And Rehabilitation*, *43*(2), 192-200. https://doi:10.1080/09638288.2019.1620876

McMillan, S. S., King, M., & Tully, M. P. (2016). How to use the nominal group and Delphi techniques. *International Journal of Clinical Pharmacy*, *38*, 655–662. https://doi.org/10.1007/s11096-016-0257-x

Medeiros, G. C., Roy, D., Kontos, N., & Beach, S. R. (2020). Post-stroke depression: A 2020 updated review. *General Hospital Psychiatry*, *66*, 70–80. https://doi.org/10.1016/j.genhosppsych.2020.06.011

Melin, E. O., Svensson, R., & Thulesius, H. O. (2018). Psychoeducation against depression, anxiety, alexithymia and fibromyalgia: A pilot study in primary care for patients on sick leave. *Scandinavian Journal of Primary Health Care*, *36*(2), 123–133. https://doi.org/10.1080/02813432.2018.1459225

Nasa, P., Jain, R., & Juneja, D. (2021). Delphi methodology in healthcare research: How to decide its appropriateness. *World Journal of Methodology*, *11*(4), 116–129. https://doi.org/10.5662/wjm.v11.i4.116

National Health Service (NHS). (2019). *NHS Long Term Plan*. NHS choices. Retrieved March 6, 2023, from https://www.longtermplan.nhs.uk/online-version/

National Institute for Health and Care Excellence. (2011). *Common mental health problems: identification and pathways to care* (NICE Guideline CG123). Available at: https://www.nice.org.uk/Guidance/CG123

National Institute for Health and Care Excellence. (2012). *Improving access to psychological care after stroke.* Available at: https://www.nice.org.uk/sharedlearning/improving-access-to-psychological-care-after-stroke

National Institute for Health and Care Excellence. (2013). *Stroke rehabilitation in adults* (NICE Guideline CG162). Available at: https://www.nice.org.uk/guidance/cg162/chapter/1-recommendations

National Institute for Health and Care Excellence. (2016). *Stroke in adults* (NICE Guideline CG162). Available at: https://www.nice.org.uk/Guidance/QS2

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). *Long-term conditions and mental health: The cost of co-morbidities*. https://www.semanticscholar.org/paper/Long-term-conditions-and-mental-health%3A-the-cost-of-Naylor-Parsonage/660f6f4f0d3c7180e2f9af403065908cfb21e334

Nightingale, D., & Cromby, J. (1999). Social constructionist psychology, Buckingham: Open University Press

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing, 18*(2), 34–35. https://doi.org/10.1136/eb-2015-102054

O'Neill, J., Tabish, H., Welch, V., Petticrew, M., Pottie, K., Clarke, M., Evans, T., Pardo, J. P., Waters, E., White, H., & Tugwell, P. (2014). Applying an equity lens to interventions: Using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in

health. *Journal of Clinical Epidemiology*, *67*(1), 56–64. https://doi.org/10.1016/j.jclinepi.2013.08.005

Peters, S. A. E., Huxley, R. R., & Woodward, M. (2014). Diabetes as a risk factor for stroke in women compared with men: A systematic review and meta-analysis of 64 cohorts, including 775,385 individuals and 12,539 strokes. *Lancet (London, England)*, *383*(9933), 1973–1980. https://doi.org/10.1016/S0140-6736(14)60040-4

Petticrew, M., Tugwell, P., Kristjansson, E., Oliver, S., Ueffing, E., & Welch, V. (2012). Damned if you do, damned if you don't: Subgroup analysis and equity. *Journal of Epidemiology and Community Health*, *66*(1), 95–98. https://doi.org/10.1136/jech.2010.121095

Plastow, N. A., van Niekerk, L., Cloete, L., & Leibbrandt, D. (2021). The effect of interventions to support mental health post-stroke in Africa: A systematic review. *Human Functioning, Technology and Health*, 133–169. https://doi.org/10.4102/aosis.2020.bk85.04

Platz, T. (2020). Are pharmacological interventions clinically useful to treat emotionalism after stroke? A Cochrane Review update summary with commentary. *NeuroRehabilitation*, *46*(3), 433–435. https://doi.org/10.3233/NRE-209003

Public Health England. (2021). Health Inequalities Dashboard: March 2021 data update. Available at: https://www.gov.uk/government/statistics/health-inequalities-dashboard-march-2021-data-update

Rafsten, L., Danielsson, A., & Sunnerhagen, K. S. (2018). Anxiety after stroke: A systematic review and meta-analysis. *Journal of Rehabilitation Medicine*, *50*(9), 769–778. https://doi.org/10.2340/16501977-2384

Ramazanoglu, C., Holland, J. (2002). *Feminist methodology: challenges and choices / Caroline Ramazanoglu with Janet Holland*. London; Thousand Oaks, Calif. : Sage http://www.loc.gov/catdir/toc/fy022/2002280742.html

Reshetnyak, E., Ntamatungiro, M., Pinheiro, L. C., Howard, V. J., Carson, A. P., Martin, K. D., & Safford, M. M. (2020). Impact of multiple social determinants of health on incident stroke. *Stroke*, *51*(8), 2445–2453. https://doi.org/10.1161/strokeaha.120.028530

Robinson, R. G., & Spalletta, G. (2010). Poststroke Depression: A Review. *The Canadian Journal of Psychiatry*, *55*(6), 341–349. https://doi.org/10.1177/070674371005500602

Royal College of Physicians (RCP). (2016). National clinical guideline for stroke. https://www.strokeaudit.org/Guideline/Full-Guideline

Ryan, G. (1999). Measuring the Typicality of Text: Using Multiple Coders for More Than Just Reliability and Validity Checks. *Human Organization*, *58*(3), 313–322. https://doi.org/10.17730/humo.58.3.g224147522545rln

Sackley, C., Brittle, N., Patel, S., Ellins, J., Scott, M., Wright, C., & Dewey, M. E. (2008). The Prevalence of Joint Contractures, Pressure Sores, Painful Shoulder, Other Pain, Falls, and Depression in the Year After a Severely Disabling Stroke. *Stroke*, *39*(12), 3329–3334. https://doi.org/10.1161/STROKEAHA.108.518563

Sandel, M. E., Wang, H., Terdiman, J., Hoffman, J. M., Ciol, M. A., Sidney, S., Quesenberry, C., Lu, Q., & Chan, L. (2009). Disparities in stroke rehabilitation: Results of a study in an integrated health system in northern California. *PM & R: The Journal of Injury, Function, and Rehabilitation*, *1*(1), 29–40. https://doi.org/10.1016/j.pmrj.2008.10.012

Schultz, S. K., C. S. Castillo, J. T. Kosier, and R. G. Robinson. 'Generalized Anxiety and Depression. Assessment over 2 Years after Stroke'. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry* 5, no. 3 (1997): 229–37. https://doi.org/10.1097/00019442-199700530-00007

Sheridan, R., Martin-Kerry, J., Hudson, J., Parker, A., Bower, P., & Knapp, P. (2020). Correction to: Why do patients take part in research? An overview of systematic reviews of psychosocial barriers and facilitators. *Trials*, *21*(1), 840. https://doi.org/10.1186/s13063-020-04793-2

Stenfors, T., Kajamaa, A., & Bennett, D. (2020). How to … assess the quality of qualitative research. *The Clinical Teacher*, *17*(6), 596–599. https://doi.org/10.1111/tct.13242

Stroke statistics. Stroke Association. (2021). Retrieved 15 June 2021, from https://www.stroke.org.uk/what-is-stroke/stroke-statistics.

Stutchbury, K. (2021). Critical realism: An explanatory framework for small-scale qualitative studies or an 'unhelpful edifice'? *International Journal of Research & Method in Education*, *45*(2), 113–128. https://doi.org/10.1080/1743727x.2021.1966623

Su, Y., D'Arcy, C., & Meng, X. (2020). Research review: Developmental origins of depression – a systematic review and meta-analysis. *Journal of Child Psychology and Psychiatry*, *62*(9), 1050–1066. https://doi.org/10.1111/jcpp.13358

Swiątkowska-Flis, B., Pierzchała, K., & Łabuz-Roszak, B. (2014). The impact of demographic factors on the course and outcome of stroke. *Wiadomosci Lekarskie (Warsaw, Poland: 1960)*, *67*(1), 23–27.

Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K, K., Colquhoun, H., Levac, D., et al. (2018). PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. *Ann Intern Med*.169, 467–473. doi: 10.7326/M18-0850.

Tucker, S., McNett, M., Mazurek Melnyk, B., Hanrahan, K., Hunter, S. C., Kim, B., Cullen, L., & Kitson, A. (2021). Implementation science: Application of evidence-based practice models to improve healthcare quality. *Worldviews on Evidence-Based Nursing*, *18*(2), 76–84. https://doi.org/10.1111/wvn.12495

Vincent, S., & O'Mahoney, J. (2018) Critical realism and qualitative research: An introductory overview. In C. Cassell, A. Cunliffe, & G. Grandy (Eds), *The Sage handbook of qualitative business and management research methods: History and Traditions*, 201-216.

Wang, S.-B., Wang, Y.-Y., Zhang, Q.-E., Wu, S.-L., Ng, C. H., Ungvari, G. S., Chen, L., Wang, C.-X., Jia, F.-J., & Xiang, Y.-T. (2018). Cognitive behavioral therapy for post-stroke

depression: A meta-analysis. *Journal of Affective Disorders, 235*, 589–596. https://doi.org/10.1016/j.jad.2018.04.011

Ward, E. C., Clark, L. O., & Heidrich, S. (2009). African American Women's beliefs, coping behaviors, and barriers to seeking mental health services. *Qualitative Health Research, 19*(11), 1589–1601. https://doi.org/10.1177/1049732309350686

Watkins, C., Jenkinson, D., Scoular, P., Williams, J., Fletcher, M., Roffe, C., Leathley, M., & Golton, I. (2009) on behalf of the UK Forum for Stroke Training Stroke-Specific Education Framework (SSEF).

World Health Organisation (WHO). (2022) Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022.

World Stroke Organization (WSO): Global stroke fact sheet 2022. (2022). *International Journal of Stroke, 17*(4), 478–478. https://doi.org/10.1177/17474930221080343

Appendices

Appendix A: Journal requirements for SR & EP

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Science's Dimensions platform, available at https://app.dimensions.ai **Usage in 2018-2020 for articles published in 2016-2020.

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Example 1: Leprosy
- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis
- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
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Appendix B: Prisma Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	16
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	17
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	19
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	21
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	22
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	22
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	22
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	182
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	22
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	23
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	23
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	23

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	24
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	26
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	28
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	42
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	42
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	42
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	53
Limitations	20	Discuss the limitations of the scoping review process.	56
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	57
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	57

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix C: Search Terms

therapy or therapeutic or “psychotherapeutic*” or “Psychotherap*” or “treat*” or “intervention” or “cognitive behavioural therapy” or “cognitive behavioral therapy” or “behavioural therapy” or “behavioral therapy”

Anxiety or “anxi*” or anxiousness or “panic disorder” or “panic attacks” or “phobic disorders” or agoraphobia or “social phobia” or “emotional disorder” or “emotional disturbance” or “psychological disorder” or “psychological distress

stroke or “transient ischemic attack” or “TIA” or “cerebral infarction” “~~stroke patients~~” Or “CVA” or “cerebrovascular accident”

randomised control trial or “randomized control trial” or “RCT”

OR

therapy or therapeutic or “psychotherapeutic*” or “Psychotherap*” or “treat*” or “intervention” or “cognitive behavioural therapy” or “cognitive behavioral therapy” or “behavioural therapy” or “behavioral therapy”

depression or “depressi*” or “mood disorder*” or “low mood” or “post stroke depression” or “stroke associated depression” or “emotional disorder” or “psychological disorder” or “psychological distress” or “emotional distress”

stroke or “transient ischemic attack” or “TIA” or “cerebral infarction” “~~stroke patients~~”

Or “CVA” or “cerebrovascular accident”

randomised control trial or “randomized control trial” or “RCT”

Appendix D: Papers excluded at the detailed screening phase with reasons

Author(s), (Year)	Reasons for Exclusion
Battersby, M., Hoffmann S., Cadilhac, D., Osborne, R., Lalor, E., & Lindley R. (2009)	Anxiety/Depression not primary outcome
Baylan, S., Haig, C., MacDonald, M., Stiles, C., Easto, J.,Thomson, M., Cullen, B., Quinn, T. J., Stott, D., Mercer, SW., Broomfield, N. M., Murray, H., & Evans, J. J. (2020)	Anxiety/Depression not primary outcome
Chaiyawat, P., & Kulkantrakorn, K. (2012)	Anxiety/Depression not primary outcome
Cullen, B., Pownall, J., Cummings, J., Baylan, S., Broomfield, N., Haig, C., Kersel, D., Murray, H., & Evans, J. J. (2018).	Anxiety/Depression not primary outcome
Renner, C.I. E., Outermans, J., Ludwig, R., Brendel, C., & Kwakkel, G. (2016)	Anxiety/Depression not primary outcome
Smith, J., Forster, A., & Young, J. (2004)	Anxiety/Depression not primary outcome
Hoffman, T., McKenna, K., Worrall, L., & Read, S. J. (2007)	Anxiety/Depression not primary outcome

Author(s), (Year)	Reasons for Exclusion
Cullena, B., Jaycee Pownalla, J, Cummingsa, J., Baylana, S., Broomfield, N., Haigd, C., Kersele, D., Murrayd, H., & Evans, J. J., (2015)	Anxiety/Depression not primary outcome
Eames, S., Hoffmann, T., Worrall, L., Read, S., & Wong, A. (2013).	Anxiety/Depression not primary outcome
Eames, S., Hoffmann, T., Worrall, L., Read, S., & Wong, A. (2013)	
Immink, M. A., Hillier, S., & Petkov, J. (2014)	Anxiety/Depression not primary outcome
Ker, D., McCann, T., Mackey, E., & Wijeratne, T. (2017)	Anxiety/Depression not primary outcome
Lund, A., Michelet, M., Kjeken, I., Wyller, T.B., Sveen, U. (2012)	Anxiety/Depression not primary outcome
Ng, L., Sansom, J., Zhang, N., Amatya, B., & Khan, F. (2017)	Anxiety/Depression not primary outcome
Thomas, S. A., Russell, C., Seed, R., Worthington, E., Walker, M. F., Macniven, J. A., & Lincoln, N. B. (2013)	Anxiety/Depression not primary outcome

Author(s), (Year)	Reasons for Exclusion
van de Ven, R. M., Murre, J. M. J., Buitenweg, J. I.V., Veltman, D. J., Aaronson, J. A., Nijboer, T. C.W., Kruiper-Doesborgh, S. J. C., van Bennekom, C. A. M., Ridderinkhof, K. R., & Schmand, B. (2017)	Anxiety/Depression not primary outcome
van Eeden, M., Kootker, J. A., Evers, S. M. A. A., van Heugten, C. M., Geurts, A. C. H., & van Mastrigt, G. A. P. G. (2015)	Anxiety/Depression not primary outcome
Wolfe, C. D. A., Tilling, K., & Rudd, A. G. (2000)	Anxiety/Depression not primary outcome
Zedlitz, A. M., Rietveld, T. C., Geurts, A. C., & Fasotti, L. (2012)	Anxiety/Depression not primary outcome
Minshall, C., Castle, D.J., Thompson, D.R., Pascoe, M., Cameron, J., McCabe, M., Apputhurai, P., Knowles, S.R., Jenkins, Z., & Ski, C.F. (2020)	Anxiety/Depression not primary outcome and Intervention for stroke survivor and carers
Sansom, J., Ng, L., Zhang, N., & Khan, F. (2015)	Anxiety/Depression not primary outcome
Kang, K., & Li., S. (2022)	Caregiver intervention

Author(s), (Year)	Reasons for Exclusion
Simblett, S. K., Yates, M., Wagner, A. P., Watson, P., Gracey, F., Ring, H., & Bateman, A. (2017)	Efficacy study
Yu, F., Li, H., Tai, C., Guo, T., & Pang, D (2018)	Family member intervention
Bek, J., Brown, M. R., Jutley-Neilson, J., Russell, N. C. C., Huber, P. A. J., & Sackley, CM. (2016)	Feasibility of therapeutic intervention
Sackley, C. Brown, M., Bek, J., & Huber, P. (2017)	Feasibility study
Brittle, N., Patel, S., Wright, C., Baral, S., Versfeld, P., & Sackley, C. (2008)	Focus on care home residents
Wrapson, W., Dorrestein, M., Wrapson, J., Theadom, A., Kayes, N. M., Snell, D. L., Rutherford, S., Roche, M., Babbage, D. R., Taylor, S., & Siegert, R. J. (2020)	Included 16-year-olds in study
Harrington, R., Taylor, G., Hollinghurst, S., Reed, M., Kay, H., & Wood, V.A., (2010)	Included family members/carers
Xie, J., Li, J., Sun, Q., & Cai, J. (2022)	Includes Chinese Medicine

Author(s), (Year)	Reasons for Exclusion
Marchant, N. L., Barnhofer, T., Klimecki, O. M., Poisnel, G., Lutz, A., Arenaza Urquijo, E., Collette, F., Wirth, M., Schild, K., Coll-Padrós, N.,ReyrolleL; Horney D; Krolak-Salmon P., Molinuevo, J. L., Walker, Z., Maillard, A., Frison, E., Jessen, F., & Chételat, G. (2018)	Includes those with cognitive decline
Chalmers, C., Leathema, J., Bennetta, S., McNaughtonb, H., & Mahawish, K. (2019)	Non-randomised trial
Tsai, Su-Ju; Li, Chia-Chi; Tsai, Shu-Mei; Kao, Shu, Chuan; Pai, & Hsiang-Chu., (2022)	Non-randomised trial
Hill, K., House, A., Knapp, P., Wardhaugh, C., Bamford, J., & Vail, A. (2019)	Prevention study
Chan, C. K. P. L, Lo, T. L. T., Wan, A. H. Y., Leung, P. P. Y., Pang, M. Y. C., & Ho, R. T. H (2021)	Proposed study
Li, S., Blumenthal, J. A., Shi, C., Millican, D., Li, X., Du, X, Patel, A., Gao, P., Delong, E., Maulik, P. K., Gao, R., Yu, X., & Wu, Y. (2018)	Proposed study

Author(s), (Year)	Reasons for Exclusion
Pui Kei, C., Mohd Nordin, N. A., Abdul Aziz, A. F. (2020)	Proposed study
Rash, I., Helgason, M., Jansons, D., Mitchell, L., & Sakakibara, B.M. (2022)	Proposed study
Le Danseur, M., Crow, A, D., Sutzman, S., & Villareal, S. (2019)	Requested access
Moustgaard, A.K. (2005)	Requested access
Ryan, T., Enderby, P., & Rigby, A. S. (2006)	Stroke or Hip Fracture patients included
Kootker, J.A., Fasotti, L., Rasquin, S., van Heugten, C.M., & Geurts, A. (2012)	Study protocol
Rauwenhoff, J., Peeters, F., Bol, Y., & Van Heugten, C. (2019)	Study protocol
Vasu, D. T., Mohd, N. N. A., & Ghazali, S. E. (2021)	Study protocol

Appendix E: CASP TOOL

CASP Randomised Controlled Trial Standard Checklist:
11 questions to help you make sense of a randomised controlled trial (RCT)

Main issues for consideration: Several aspects need to be considered when appraising a randomised controlled trial:

- Is the basic study design valid for a randomised controlled trial? (Section A)
- Was the study methodologically sound? (Section B)
- What are the results? (Section C)
- Will the results help locally? (Section D)

The 11 questions in the checklist are designed to help you think about these aspects systematically.

How to use this appraisal tool: The first three questions (Section A) are screening questions about the validity of the basic study design and can be answered quickly. If, in light of your responses to Section A, you think the study design is valid, continue to Section B to assess whether the study was methodologically sound and if it is worth continuing with the appraisal by answering the remaining questions in Sections C and D.

Record 'Yes', 'No' or 'Can't tell' in response to the questions. Prompts below all but one of the questions highlight the issues it is important to consider. Record the reasons for your answers in the space provided. As CASP checklists were designed to be used as educational/teaching tools in a workshop setting, we do not recommend using a scoring system.

About CASP Checklists: The CASP RCT checklist was originally based on JAMA Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL and Cook DJ), and piloted with healthcare practitioners. This version has been updated taking into account the CONSORT 2010 guideline (http://www.consort-statement.org/consort-2010, accessed 16 September 2020).

Citation: CASP recommends using the Harvard style, i.e., *Critical Appraisal Skills Programme (2021). CASP (insert name of checklist i.e. Randomised Controlled Trial) Checklist. [online] Available at: insert URL. Accessed: insert date accessed.*

Study and citation: .....

Section A: Is the basic study design valid for a randomised controlled trial?			

1. Did the study address a clearly focused research question?
CONSIDER:
• *Was the study designed to assess the outcomes of an intervention?*
• *Is the research question 'focused' in terms of:*
  • *Population studied*
  • *Intervention given*
  • *Comparator chosen*
  • *Outcomes measured?*
	Yes ☐	No ☐	Can't tell ☐

2. Was the assignment of participants to interventions randomised? *CONSIDER:* • *How was randomisation carried out? Was the method appropriate?* • *Was randomisation sufficient to eliminate systematic bias?* • *Was the allocation sequence concealed from investigators and participants?*	Yes ☐	No ☐	Can't tell ☐
3. Were all participants who entered the study accounted for at its conclusion? *CONSIDER:* • *Were losses to follow-up and exclusions after randomisation accounted for?* • *Were participants analysed in the study groups to which they were randomised (intention-to-treat analysis)?* • *Was the study stopped early? If so, what was the reason?*	Yes ☐	No ☐	Can't tell ☐

Section B: Was the study methodologically sound?			
4. • Were the participants 'blind' to intervention they were given? • Were the investigators 'blind' to the intervention they were giving to participants? • Were the people assessing/analysing outcome/s 'blinded'?	Yes ☐ ☐ ☐	No ☐ ☐ ☐	Can't tell ☐ ☐ ☐
5. Were the study groups similar at the start of the randomised controlled trial? *CONSIDER:* • *Were the baseline characteristics of each study group (e.g. age, sex, socio-economic group) clearly set out?* • *Were there any differences between the study groups that could affect the outcome/s?*	Yes ☐	No ☐	Can't tell ☐

6.	Apart from the experimental intervention, did each study group receive the same level of care (that is, were they treated equally)? *CONSIDER:* • *Was there a clearly defined study protocol?* • *If any additional interventions were given (e.g. tests or treatments), were they similar between the study groups?* • *Were the follow-up intervals the same for each study group?*	Yes ☐	No ☐	Can't tell ☐

Section C: What are the results?

7.	Were the effects of intervention reported comprehensively? *CONSIDER:* • *Was a power calculation undertaken?* • *What outcomes were measured, and were they clearly specified?* • *How were the results expressed? For binary outcomes, were relative and absolute effects reported?* • *Were the results reported for each outcome in each study group at each follow-up interval?* • *Was there any missing or incomplete data?* • *Was there differential drop-out between the study groups that could affect the results?* • *Were potential sources of bias identified?* • *Which statistical tests were used?* • *Were p values reported?*	Yes ☐	No ☐	Can't tell ☐
8.	Was the precision of the estimate of the intervention or treatment effect reported? *CONSIDER:* • *Were confidence intervals (CIs) reported?*	Yes ☐	No ☐	Can't tell ☐

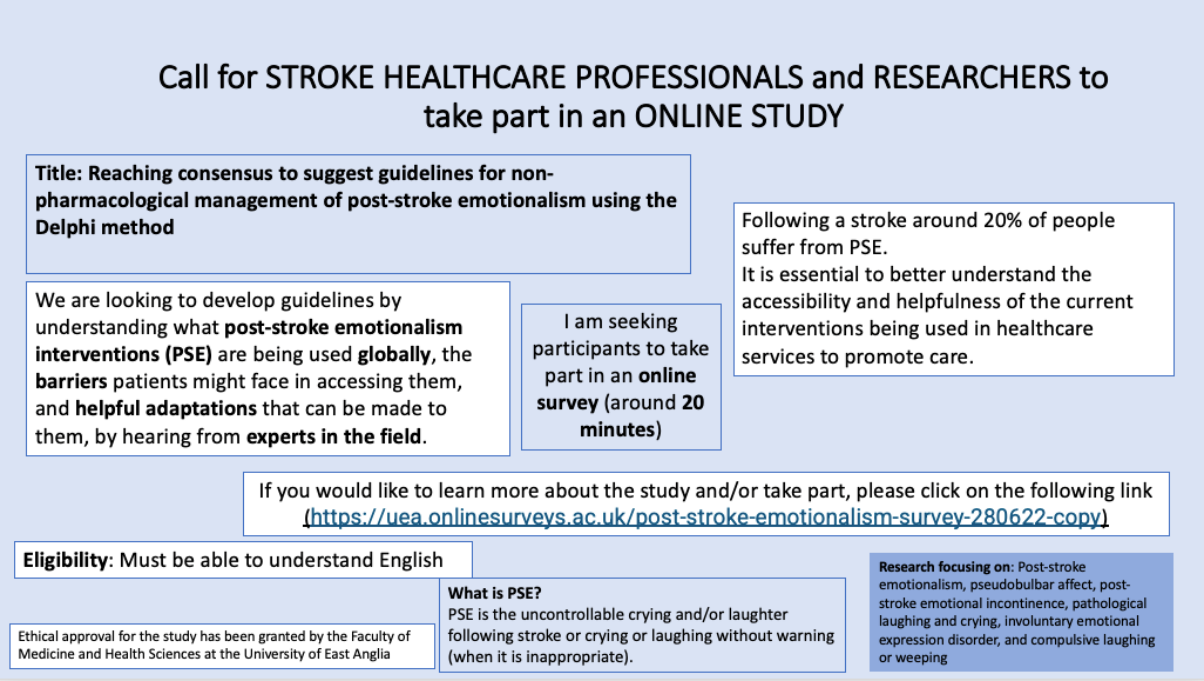
9.	Do the benefits of the experimental intervention outweigh the harms and costs? *CONSIDER:* • *What was the size of the intervention or treatment effect?* • *Were harms or unintended effects reported for each study group?* • *Was a cost-effectiveness analysis undertaken? (Cost-effectiveness analysis allows a comparison to be made between different interventions used in the care of the same condition or problem.)*	Yes ☐	No ☐	Can't tell ☐

Section D: Will the results help locally?

10.	Can the results be applied to your local population/in your context? *CONSIDER:* • *Are the study participants similar to the people in your care?* • *Would any differences between your population and the study participants alter the outcomes reported in the study?* • *Are the outcomes important to your population?* • *Are there any outcomes you would have wanted information on that have not been studied or reported?* • *Are there any limitations of the study that would affect your decision?*	Yes ☐	No ☐	Can't tell ☐
11.	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions? *CONSIDER:* • *What resources are needed to introduce this intervention taking into account time, finances, and skills development or training needs?* • *Are you able to disinvest resources in one or more existing interventions in order to be able to re-invest in the new intervention?*	Yes ☐	No ☐	Can't tell ☐

APPRAISAL SUMMARY: *Record key points from your critical appraisal in this box. What is your conclusion about the paper? Would you use it to change your practice or to recommend changes to care/interventions used by your organisation? Could you judiciously implement this intervention without delay?*

Appendix F: Advert for study



Appendix G: Faculty of Medicine and Health Sciences Ethics Committee Approval

University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsapproval@uea.ac.uk
Web: www.uea.ac.uk

Study title: Reaching consensus to suggest guidelines for non-pharmacological management of post-stroke emotionalism using the Delphi method and a Focus Group (amendment, title)

Application ID: ETH2223-0913 (significant amendments)

Dear Georgina,

Your application was considered on 24th November 2022 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **1st October 2023**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Paul Linsley

Appendix H: First Questionnaire Participant Information and Consent Form

Post-stroke emotionalism survey

Page 1: Information Sheet

Dated 28/06/2022, Version 3

Title of study: Reaching consensus to suggest guidelines for non-pharmacological management of post-stroke emotionalism using the Delphi method

Thank you for considering taking part in this research. Please find more information about the project below.

Definition of Post-stroke emotionalism: uncontrollable outbursts of crying and/or laughing following a stroke, not to be confused with depression or low mood.

Synonyms of Post-stroke emotionalism: pseudobulbar affect, post-stroke emotional incontinence, pathological laughing and crying, involuntary emotional expression disorder, and compulsive laughing or weeping.

What is the study about?

Research suggests non-pharmacological interventions are used to support people with post-stroke emotionalism (uncontrollable outbursts of crying and/or laughing following a stroke), but it is not clear which intervention feels most useful to those who deliver them, what adaptations are considered useful, and what barriers those with post-stroke emotionalism might face to access these interventions. We want to learn more about the current preferences for non-pharmacological (non-medicine) interventions for post-stroke emotionalism by listening to the thoughts and opinions of expert health professionals and researchers who work in this area. We hope that by doing so, we will be able to identify the most potentially helpful nonpharmacological interventions for post-stroke emotionalism, and that further research can then evaluate whether the interventions are feasible and effective.

Who is undertaking the study?

The study will be undertaken by Georgina Ottaway as part of her Doctorate in Clinical Psychology at the University of East Anglia. She is supervised by Professor Niall Broomfield and Dr Fergus Gracey.

Who can take part in the study?

We are seeking the opinions of healthcare workers and researchers who have had experience working with stroke patients with post-

stroke emotionalism or who have experience of researching post-stroke emotionalism. The study is being advertised globally for healthcare workers/researchers all over the world to participate. However, to take part you need to be able to understand English. Therefore, the following Inclusion Criteria apply for the study:

• Experience of working professionally as a clinician or researcher with people who have symptoms of emotionalism following a stroke.

• Access to an electronic device.

• Access to an email address on which to be sent survey links.

• Aged 18 or over.

• Able to understand English.

Why do you want me to take part?

We believe it is essential to be able to get the opinions of those who have close experience with managing post-stroke emotionalism. We believe that by listening to experts in the field, we will be able to suggest guidelines regarding non-pharmacological interventions of post-stroke emotionalism which may better support those with post-stroke emotionalism.

What would I have to do?

The project initially involves the completion of a questionnaire. The survey includes questions regarding your demographics, questions about your experience of working with/researching post-stroke emotionalism, as well as questions around what your opinion of current non-pharmacological interventions, barriers you might have come across for those with post-stroke emotionalism accessing interventions, and adaptations which can be made to support people with post-stroke emotionalism access these interventions. If you consent to participate, you will be asked to complete a questionnaire. This should take around 20 minutes to complete.

Following this, you might be invited to complete second version of the questionnaire once the initial round of data collection has taken place (later this year). To support you in completing this second survey, feedback will be given to you to explain the different responses that other participants gave to the first questionnaire. It would be useful to read the feedback and consider the responses before completing the second questionnaire. This will help people with post-stroke emotionalism cope better with the condition and the impact it has on their lives. Your contribution will also improve our understanding of barriers that people with post-stroke emotionalism may face in accessing non-pharmacological interventions.

Are there disadvantages/risks of taking part?

We have not been able to identify any disadvantages or risks in taking part in the study. However, we are aware that this will take up some of your time and you might find some of the questions difficult to answer. Additionally, we are aware that confidentiality is a topic which many people worry about. Therefore, please read below where we discuss confidentiality in more detail.

Confidentiality

Those who consent to take part in the project will need to provide their email address as they might be asked to complete the second survey. It is important to note that your email address will be removed from any online system used or data software system upon completion/publication of the research. No participant will be identifiable in the paper of any publication. No personal information (such as the email addresses) will be shared with other participants during the study. Solely the primary researcher (Georgina Ottaway) and her supervisors (Professor Niall Broomfield and Dr Fergus Gracey) will have access to the data. Data will be anonymised once data collection has been completed following the second round of surveys.

Participants who no longer want to take part in the study (e.g., when asked to complete the second survey), or who wish to have their responses deleted by the researcher (e.g., following the first survey), can contact the primary researcher (Georgina Ottaway) to opt out of the project. However, it is important to note that once the data is anonymised (where the email addresses are removed), it will be impossible to delete an individual participants data from the project.

Data Management

During the study, the data will be stored in password protected documents in the researcher's encrypted University OneDrive. Only the researcher and supervisors will have access to these files. The anonymised data will be stored by the Data Custodian (Professor Niall Broomfield), for no less than 10 years, in line with UEA data management policy and GDPR guidelines.

Although we are collecting data internationally, data will be stored and remain in the UK, which is where the study originates from.

Who has reviewed the study?

The ethical conduct of this study has been approved by the Faculty of Medicine and Healthcare ethics committee at University of East Anglia.

Raising Concerns

Although UEA protocol states that Professor Niall Broomfield, ClinPsyD Programme Director, can be contacted in the event of any adverse events or complaints, as Professor Broomfield is involved in the project, Professor Richard Meiser-Stedman (email below) can be contacted in his stead.

What do I do next?

If you are interested in taking part in the study, please click the button below to read the consent form, or if you have any additional questions, please contact the primary researcher Georgina Ottaway by email (g.ottaway@uea.ac.uk).

Research Team

Researcher: Georgina Ottaway

Supervisors: Professor Niall Broomfield & Dr Fergus Gracey

If you have any concerns or complaints about the research project, please contact Professor Richard Meiser-Stedman (R.Meiser-Stedman@uea.ac.uk)

Page 2: Consent Page

CONSENT FORM

Title of Project: Reaching consensus to suggest guidelines for non-pharmacological management of post-stroke emotionalism using the Delphi method

Name of Researcher: Georgina Ottaway

By typing "Yes" and clicking on the "next page" button:

1. I confirm that I have read and understand the information sheet dated 28/06/2022 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time.

3. I understand that I will not be named in any research reports, and my personal information will remain confidential.

4. I give consent for you to use my words (with any identifying information removed; amendment) in any research output.

5. Should I decide to withdraw from taking part in the study once I have completed the questionnaire, I agree for my data to be used anonymously.

6. I agree to be contacted to take part in the second round of the survey.

Please type Yes to show you consent then click "next page" to start the study:

Please enter a response that only contains letters.

Appendix I: Second Questionnaire participant Introduction and Consent Form

Post-stroke emotionalism survey: Round 2 [Insert Participant ID number]

Page 1: Information Sheet

Dated 22/11/2022

Title of study: Reaching consensus to suggest guidelines for non-pharmacological management of post-stroke emotionalism using the Delphi method and a Focus group

Thank you for considering taking part in the second round of this research. Please find more information about the project below.

Definition of Post-stroke emotionalism: uncontrollable outbursts of crying and/or laughing following a stroke, not to be confused with depression or low mood.

Synonyms of Post-stroke emotionalism: pseudobulbar affect, post-stroke emotional incontinence, pathological laughing and crying, involuntary emotional expression disorder, and compulsive laughing or weeping.

What is the study about?

Research suggests non-pharmacological interventions are used to support people with post-stroke emotionalism (uncontrollable outbursts of crying and/or laughing following a stroke). However, it is not clear which intervention feels most useful to those who deliver them, what adaptations are considered useful, and what barriers those with post-stroke emotionalism might face to access these interventions. We want to learn more about the current preferences for non-pharmacological (non-medicine) interventions for post-stroke emotionalism by listening to the thoughts and opinions of expert health professionals and researchers who work in this area. We hope that by doing so, we will be able to identify the most potentially helpful nonpharmacological interventions for post-stroke emotionalism and that further research can then evaluate whether these interventions are feasible and effective.

Who is undertaking the study?

The study will be undertaken by Georgina Ottaway as part of her Doctorate in Clinical Psychology at Norwich Medical School, University of East Anglia. She is supervised by Professor Niall Broomfield and Dr Fergus Gracey, Norwich Medical School, University of East Anglia.

Who can take part in the study?

We are seeking the opinions of healthcare workers and researchers who have had experience working with stroke patients with post-stroke emotionalism or who have experience researching post-stroke emotionalism. The study is being advertised globally for healthcare workers/researchers all over the world to participate. However, to take part you need to be able to understand English. Therefore, the following Inclusion Criteria apply to the study:

- Experience working professionally as a clinician or researcher with people who have symptoms of emotionalism following a stroke.
- Access to an electronic device.
- Access to an email address on which to be sent survey links.
- Aged 18 or over.
- Able to understand English.

Why do you want me to take part?

We believe it is essential to be able to get the opinions of those who have close experience with managing post-stroke emotionalism and/or expertise in post-streoke emotionalism. We believe that by listening to experts in the field, we will be able to suggest guidelines regarding non-pharmacological interventions of post-stroke emotionalism which may better support those with post-stroke emotionalism.

What would I have to do?

As you will be aware, the project initially involved the completion of a questionnaire. The survey included questions regarding your demographics, questions about your experience of working with/researching post-stroke emotionalism, as well as questions around your opinion of current non-pharmacological interventions, barriers you might have come across for those with post-stroke emotionalism accessing interventions, and adaptations which can be made to support people with post-stroke emotionalism access these interventions. If you consent to participate, you will be asked to complete a second round of the questionnaire. This should take around 30+ minutes to complete.

To support you in completing this second survey, feedback will be given to you to explain the different responses that other participants gave to the first questionnaire. It would be useful to read the feedback and consider the responses before completing the second questionnaire. This will help our understanding of what may be deemed the most effective non-pharmacological interventions available to support people with post-stroke emotionalism in coping with the condition. Your contribution will also improve our understanding of barriers that people with post-stroke emotionalism may face in accessing non-pharmacological interventions.

Due to the findings from the first round of questionnaires, we have decided it would be helpful to hold an online focus group involving those willing to participate. Therefore, should you consent, following this round of questionnaires, you will be invited to take part in an online focus group, which will take place at the beginning of 2023. On the second consent page, there will be an additional section to sign should you agree to take part in the focus group. We appreciate that your time is valuable, however, if you would be willing to meet with other professionals to discuss post-stroke emotionalism, for up to two hours, it would be much appreciated.

Are there disadvantages/risks of taking part?

We have not been able to identify any disadvantages or risks in taking part in the study. However, we are aware that this will take up some of your time and you might find some of the questions difficult to answer. Additionally, we are aware that confidentiality is a topic which many people worry about. Therefore, please read below where we discuss confidentiality in more detail.

Confidentiality

Those who consent to take part in the focus group will need to provide their email address as they might be asked to attend the focus group online. It is important to note that your email address will be removed from any online system used or data software system upon completion/publication of the research. No participant will be identifiable in the paper of any publication. No personal information (such as email addresses) will be shared with other participants during the study. Solely the primary researcher (Georgina Ottaway) and her supervisors (Professor Niall Broomfield and Dr Fergus Gracey) will have access to the data. Data will be anonymised once data collection has been completed following the second round of surveys.

Participants who no longer want to take part in the study (e.g., when asked to complete the second round), or who wish to have their responses deleted by the researcher (e.g., following the first survey), can contact the primary researcher (Georgina Ottaway) to opt out of the project. However, it is important to note that once the data is anonymised (where the email addresses are removed), it will be impossible to delete an individual participant's data from the project.

Data Management

During the study, the data will be stored in password protected documents in the researcher's encrypted University OneDrive. Only the researcher and supervisors will have access to these files. The anonymised data will be stored by the Data Custodian (Professor Niall Broomfield), for no less than 10 years, in line with UEA data management policy and GDPR guidelines.

Although we are collecting data internationally, data will be stored and remain in the UK, which is where the study originates from.

Who has reviewed the study?

The ethical conduct of this study has been approved by the Faculty of Medicine and Healthcare ethics committee at University of East Anglia.

Raising Concerns

Although UEA protocol states that Professor Niall Broomfield, Head of Clinical Psychology and Psychological Therapies Norwich Medical School UEA, can be contacted in the event of any adverse events or complaints, as Professor Broomfield is involved in the project, Professor Richard Meiser-Stedman (email below) can be contacted in his stead.

What do I do next?

If you are interested in taking part in the study, please click the button below to read the consent form, or if you have any additional questions, please contact the primary researcher Georgina Ottaway by email (g.ottaway@uea.ac.uk).

Research Team

Researcher: Georgina Ottaway

Supervisors: Professor Niall Broomfield & Dr Fergus Gracey

If you have any concerns or complaints about the research project, please contact Professor Richard Meiser-Stedman (R.Meiser-Stedman@uea.ac.uk)

Page 3: Focus Group consent

FOCUS GROUP CONSENT FORM If you consent to be contacted with an offer to take part in the focus group, please provide your email address.

Page 2: Consent Page

CONSENT FORM

Title of Project: Reaching consensus to suggest guidelines for non-pharmacological management of post-stroke emotionalism using the Delphi method

Name of Researcher: Georgina Ottaway

By typing "Yes" and clicking on the "next page" button:

1. I confirm that I have read and understand the information sheet dated 22/11/2022 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time.

3. I understand that I will not be named in any research reports, and my personal information will remain confidential.

4. I give consent for you to use my words (with any identifying information removed) in any research output.

5. Should I decide to withdraw from taking part in the study once I have completed the questionnaire, I agree for my data to be used anonymously.

Please type Yes to show you consent then click "next page"

Please type Yes to show you consent then click "next page" to start the study:

Please enter a response that only contains letters.

Appendix J: List of Interventions from Gillespie et al., (2020)

Type of PSE Intervention
Offer Reassurance
Ask the patient to take a deep breath
Talk to the patient about their goals in relation to PSE
Provide education for patient
Normalise the condition
Provide education for family
Acknowledge the PSE then continue current activity
Distract the patient during a PSE episode
Ignore the PSE and continue with current activity
Teach distraction techniques
Teach relaxation techniques
Suggest altered posture (e.g., shoulder back)
Identify the triggers for PSE (so they can be avoided)
Modify beliefs about the PSE
Instruct how to tense facial muscles
Move the patient to another setting/location

Encourage patient to use a diary to record feelings

Appendix K: Mini-focus group Topic Guide

Format of Focus Group (60-90minutes)

- Welcome the participants
  - Ground rules
  - Discuss what to expect during the focus group (e.g., the time, questions that will be asked, and what to do if you want to leave early).
  - Gain verbal consent for recording and transcript
- Introductions
  - Introduce why we are running the focus group (to complete the project that in turn will potentially inform guidelines in relation to the use of nonpharmacological PSE interventions, while considering the preference, effectiveness, and accessibility of known PSE interventions)
  - Instructions
    - State name and region you are working in

Consent: "The group is now being recorded once the project has been completed, the video will be deleted. Additionally, any information from the transcript that will be completed from the recording will be anonymised. Are you happy for us to proceed?

Exploration of experts' experience working/researching with people with stroke experiencing post-stroke emotionalism

- How difficult do you find it to diagnose PSE?
- Is it easy to gain access to measures?
- How easily understood is PSE by stroke survivors?

Exploration of the effectiveness of PSE interventions, limitations of the interventions

- These were the interventions where consensus was reached "Provide education for patient, acknowledge the PSE the continue current activity, talk to the patient about their goals in relation to PSE, teach distraction techniques, provide education for family, normalise the condition, ask the patient to take a deep breath" and were rated within the Helpful (score of 5-7). The area where all participants scored an intervention within the helpful category was "provide education for patient" and "acknowledge the PSE then continue current activity" and the Median score was 7. talk to the patient about their goals in relation to PSE and provide education for family were in the top three interventions where a high level of consensus was reached and scored highly for helpfulness (Median 6).
  - How much do you agree with providing education for the patient and family and talking to the patient about their goals in relation to PSE as being viewed as the most helpful PSE interventions?
  - Are these the interventions you would/would have offered the most to those with PSE? If not, which would you use most often and why?

- From this list, which one do you use most often?
- Do any demographic factors, such as those from the Equality Act influence the helpfulness of the top three rated interventions?
- What would you do to adapt for other groups?
- Does waiting times or staffing numbers impact the helpfulness of these interventions?
- Encouraging patient to use a diary to record feelings was viewed as the least helpful (Median score 3) intervention. However, consensus was not reached. Are there situations where you might use this still?

Exploration of accessibility of PSE interventions, what adaptations can be made to make them more accessible based on the demographic factors found to be most impacting accessibility of interventions from Round 2 survey, access issues relating to the demands and supply for psychology, and what adaptations can be made to make them more accessible.

- These were the interventions where consensus was reached "Offer reassurance, ask the patient to take a breath, acknowledge the PSE then continue current activity, provide education for patient, normalise the condition, provide education for family" and were rated as Accessible. The two areas where all participants scored an intervention within the accessible category was "offer reassurance" and "ask the patient to take a deep breath" (100% of respondents scored in this category). Median score of 7 and 6.5 respectively were given.
- How much do you agree with offering reassurance, and asking the patient to take a deep breath as being viewed as the most accessible PSE interventions?
- What makes these two interventions more accessible than others?
- Do any demographic factors, such as those from the Equality Act influence the helpfulness of the top three rated interventions?
- Do waiting times or staffing numbers impact the accessibility of these interventions?

- Open floor to explore challenges of working with PSE survivors
- Confirmation of what was discussed
- Conclusion
- Explanation of what happens next
    - Provide the offer for participants to be contacted for a summary of what was discussed or to be sent an anonymised copy of the transcript to review

Appendix L: Example Question Round 1

Please rate how accessible you perceive the following interventions are to stroke survivors for the treatment of PSE, from very inaccessible (1) to very accessible (7)

Accessibility refers to how well an intervention will be received by the target population and the extent to which the intervention meets the needs of the target population and organisational setting.

For example, if this intervention would work for anyone based on **any** of their characteristics, this would be a highly accessible intervention. If this would **not work** so well for someone based on **any** of their characteristics, this might be considered a less accessible intervention.

This part of the survey uses a table of questions, view as separate questions instead?

Q1

Please don't select more than 1 answer(s) per row.

	1 (Very Inaccessible)	2	3	4 (Neither Accessible or Inaccessible)	5	6	7 (Very Accessible)
Offer Reassurance	☐	☐	☐	☐	☐	☐	☐

Please describe why you gave this score:

Appendix M: Example Question Round 2

Q1 Feedback regarding the rating of the intervention "Offering Reassurance"

A consensus was not reached between participants. This means less than 80% of participants rated the helpfulness of the intervention within the scores of 1-3 (Very Unhelpful to slightly Unhelpful), 4 (neither Helpful or Unhelpful), or 5-7 (slightly Helpful to Very Helpful). Below is the summary of the results, including summarised comments from those who took part in Round 1.

Your previous score: _

Group Median score: 5

Scale = (Very Unhelpful) 1 2 3 4 5 6 7 (Very Helpful)

Responses (n) = 1 1 2 4 17 7 6

Number of respondents giving comments = 38

Summary of comments:

Initially offering reassurance is helpful
Offering reassurance can normalise and validate their experience
Offering reassuracne can be a tool to support knowledge/education around PSE
Offering reassurance can perpetuate embarassment of the emotionalism
It can have a variable effect with individuals
After a while, it is no longer helpful as it can support reassurance seeking and maintain anxiety around the PSE
There was uncertainty as to what offering reassurance as an intervention is
Normalising the experience of emotionalism is more important than offering reassurance
Offering reassurance is helpful in the short-term but not in the long-term

Q1 After reading the summary comments from others, please consider the feedback from Round 1 and your own experiences and re-rate your rating of the intervention:

Please don't select more than 1 answer(s) per row.

	1 (Very Unhelpful)	2	3	4 (Not Helpful or Unhelpful)	5	6	7 (Very Helpful)
Offer Reassurance	☐	☐	☐	☐	☐	☐	☐

Appendix N: Themes and Categories of qualitative data from mini-focus groups

Themes	Category	Sub-Categories
Barriers in accessing PSE interventions	Uncertainties about assessment and Diagnosis	Complexity
		Existing Knowledge
		Experience
		Not diagnosed
		Opportunity during assessment
		Perceived Appropriateness
	Roles of multidisciplinary team members	Responsibility
		Staff managing distress
		Uncertainty
	Factors impacting the delivering of PSE interventions	Importance
		Physical
		Context
Maximising the accessibility and helpfulness of PSE interventions	Sensitivity to context	Guidelines to support PSE
		Applying a person-centered approach

		Resources to support PSE
	Matching support provided to the changing nature of PSE over time	Involvement of staff
		Time in stroke pathway
		Nature of PSE symptoms

Appendix O: Example of Content Analysis Process

Meaning Unit (Direct Script)	Condensed meaning unit	Code	Sub-category	Category	Theme
you have to adapt to the individual person and that assumes adapting to their socioeconomic level and their cultural background and everything else	adapt interventions for the patient	Adapting interventions	Person-centered approach	Sensitivity to context	Maximising the accessibility and helpfulness of PSE interventions
you have to adapt pretty much, it, on the individual basis because. Ah, because it is such an individual thing your relationship with your mind.	adapt interventions for the patient	Adapting interventions	Person-centered approach	Sensitivity to context	Maximising the accessibility and helpfulness of PSE interventions
I've certainly kind of spent a long time with kind of MDT's kind of sitting with the teams being like try this. You know try kind of, you know getting consent from the person to distract them with the team. If the tears kind of don't, don't stop or you know, ask them if they're depressed.	Asking questions to differentiate emotionalism with PSE	Diagnostic overlap	Complexity	Assessment & Diagnosis	Barriers in accessing PSE interventions
I'd be tempted to, temporised or people are because I'm a bit, it's how long people spend in hospital is so variable. Uh, uh. but then I'd be tempted to temporise and, and, and be thinking	assessing if it doesn't resolve spontaneuously or is impacting rehab	appropriateness to diagnose in stroke pathway	Perceived appropriateness	Assessment & Diagnosis	Barriers in accessing PSE

about doing more about it if it, it doesn't resolve spontaneously and it's starting to intrude in people's rehab because they're into social avoidance about it

intervention s

Appendix P: Email inviting participants to the second round of the Delphi Survey

Dear [Insert name],

Thank you for completing Round 1 of the study on post-stroke emotionalism nonpharmaceutical interventions. We have a range of really interesting and informative responses on the ways in which people support those with PSE, thank you for your expert contribution!

I am contacting you now to invite you to take part in Round 2 of the study. For this part of the study, you will find a more recent version of the questionnaire which includes questions which were asked in Round 1 as well as some new questions. The questionnaire also provides feedback from Round 1, including summarised answers from the group regarding the questions which were previously asked. You will be asked to read the feedback for each question from Round 1 and then respond. When you answer the questions, please consider the group's feedback as well as your own beliefs and experiences.

In addition to completing Round 2, there is the option to be invited to attend an online Focus group, to further explore the helpfulness and accessibility of PSE interventions. Please consider consenting to take part in the focus group, this further stage of the study is important and any input would greatly support our understanding of how PSE interventions are delivered.

Please click on the following link to access Round 2:

Please complete the questionnaire by the [Insert Date]. If you are unable to complete the questionnaire by the proposed date or no longer want to take part in Round 2 of the project, please reply to this email.

Yours Sincerely,
Georgina Ottaway, Trainee Clinical Psychologist

Appendix Q: Email inviting participants to attend the focus group

Dear [insert name],

Thank you for taking part in Round 2 of the project relating to post-stroke emotionalism (PSE) nonpharmaceutical interventions. We appreciate the time and effort you have put into taking part in this project so far.

I am contacting you to invite you to take part in the online focus group part of the study. The online focus group will discuss themes and areas previously explored in Round 1 and Round 2 of the project regarding nonpharmaceutical PSE interventions.

The group will take place at [insert time] on the [insert date] on Microsoft Teams. The focus group is expected to take up to 1.5 hours. You will not be expected to provide extensive information about yourself; however, we will invite all group members to briefly introduce themselves (their name, role, and experience with those with PSE). We will also record the focus group although once the project has been completed, the video will be deleted. Additionally, any information from the transcript that will be completed from the recording will be anonymised. Verbal consent will be taken once the recording has started.

Please find the link to join the online focus group here: [insert link]

On the day, should you have any difficulty with joining via MS teams, please email me (g.ottaway@uea.ac.uk). Additionally, should you be unable to attend the focus group or are no longer interested in taking part, please email me.

Yours Sincerely,
Georgina Ottaway, Trainee Clinical Psychologist