Plan Overview

A Data Management Plan created using DMPonline

Title: The lived experience of people with post-stroke emotionalism and those who live with them: a dyadic interpretative phenomenological analysis

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Project abstract:

Post-stroke emotionalism (PSE) is a common neurological sequalae of stroke arising from lesions that disrupt the pathways of communication between emotional experience and expression, such that individuals with PSE may express emotion that is greater than the magnitude of emotion experienced or incongruent with the emotion experienced. PSE is associated with greater psychological distress and poorer stroke rehabilitation outcomes and this is hypothesised to be a result of self-critical cognitions regarding emotionalism that may lead to social avoidance and decreased engagement with activity that is associated with better rehabilitation and mental health outcomes in stroke survivors. Models of secondary psychological distress in emotionalism suggest a role for carer distress in perpetuating secondary psychological distress due to PSE. Additionally, previous qualitative studies have taken a theory-driven approach to data analysis rather than a purely inductive approach, meaning that some aspects of the lived experience of PSE may have been missed. This study proposes to use Interpretative phenomenological analysis (IPA) of interviews with people with PSE and their carers.

The research questions are:

Principle Research question

How do those with post-stroke emotionalism and partners or family members who live with someone experiencing post-stroke emotionalism understand and make sense of post-stroke emotionalism?

Secondary Research Objectives

To explore the perceptions and understandings of psychological distress in those with post-stroke emotionalism and partners or family members who live with someone experiencing post-stroke emotionalism understand and make sense of post-stroke emotionalism.

To explore coping and adjustment to emotionalism in those with post-stroke emotionalism and their partners or family members who live with someone experiencing post-stroke emotionalism understand and make sense of post-stroke emotionalism.

Qualitative data will be generated from interviews with consenting participants who have completed or dropped out of the intervention. Interviews will be recorded face to face or remotely using the NHS NearMe platform by the Principal Investigator. Audio will be recorded for both in-person and remote interviews using an encrypted audio recorder belonging to NHS Lothian.

The qualitative data will be audio recordings of interviews, verbatim transcripts of interviews and demographic data which, while collected individually, will be reported at the "group" level rather than individual level (i.e. reporting on percentage of male and female participants, the average ages of participants etc).

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Copyright information:

The lived experience of people with post-stroke emotionalism and those who live with them: a dyadic interpretative phenomenological analysis

Administrative Information

1) School or Institute

- CAHSS - School of Health in Social Sciences

NHS Lothian will also be involved with the project. The PI's field supervisors are employees of NHS Lothian.
The University of Edinburgh will be the study sponsor.

2) Name and Contact details of supervisor(s)

Academic supervisor:
Dr Sue Turnbull, Sue.Turnbull@ed.ac.uk
Clinical Supervisors:
Dr David Gillespie, David.Gillespie@nhslothian.scot.nhs.uk

3) Project start date

2025-06-02

4) Project end date

2026-06-30

Data Collection

5) Data Collection

No existing datasets will be used; all data within the study will be generated for the purposes of answering the research questions.
The study proposes 12-16 participants (i.e. 6-8 couples) from whom data will be generated and collected following the same protocol for each participant.
The first “point of contact” in recruitment of potential participants will be the stroke clinician (either a stroke nurse, clinical psychologist or allied health professional in NHS Lothian neuropsychology stroke rehabilitation services) currently working with the participant. These clinicians will henceforth be referred to as the "mediating clinician".

The researcher will provide mediating clinicians with details of inclusion and exclusion criteria, a single-sheet poster for potential participants introducing the study aims, a “confirmation of verbal consent to approach” form to be completed by the clinician, and a “suitability conformation” form to be completed by the clinician.

This mediating clinician will be asked to provide potential participants with a brief summary poster of the study. This poster will also give the researcher’s contact details. Potential participants may then directly contact the researcher to express interest in the research, or they may ask their clinician to let the researcher know they are interested in participating.

Where potential participant dyads contact the researcher directly, they may do so by email or phone call. If only one set of contact details are provided, the researcher will ask for a contact telephone number for each member of the dyad. The researcher will contact each member of the dyad separately by phone. They will ask each member of the dyad for their postal address and explain that they will send a document pack containing a detailed participant information sheet, consent form, stamped addressed envelope for returning consent forms, and a cover letter explaining each document in the pack. The researcher will then arrange to contact each member of the dyad by telephone two weeks after the date of initial contact so that they have had time to receive and read through the participant information sheet. The researcher will conduct this process separately for both the person with PSE and their partner.

Where potential participant dyads ask their mediating clinician to express their interest to the researcher, the mediating clinician will request verbal consent from each person to provide the researcher with the contact details (phone number, address, name) of each person, and verbal consent for the researcher to contact each person (“consent to approach”).

The researcher will then contact the potential participants by phone to thank them for their interest, and to explain that they will be sending potential participants the same document pack outlined above in step 4a. The researcher will arrange a second phone call with the potential participant two weeks after this phone call so that they have had time to read through the participant information sheet. The researcher will conduct this process separately for both the person with PSE and their partner.

During recruitment, the only personal data collected will be participant names, telephone numbers and postal address.

Demographic information (gender, age) and stroke-specific information (stroke location, time since stroke, time since emotionalism onset) will be collected and reported. Ethnicity and socio-economic status will also be recorded with participant’s consent to determine how representative participants are of the population of people with PSE. Socio-economic status will be recorded using the Scottish Index of Multiple Deprivation, derived from participant’s post code. Participants will therefore be informed that during the recruitment and consent process that their postcode will be used in this way. Given that anti-depressant medication can change the frequency or intensity of emotionalism and may even be prescribed for management of emotionalism, participants will also be asked if they are currently prescribed anti-depressant medication.

The researcher will collect the above demographic information immediately prior to conducting the recorded interview once written consent to participate has been provided and confirmed.

Participants will be informed that they do not have to provide this information. These data will be stored in a password-protected csv file in a separate password-protected folder to the consent forms. Participant data will be de-identified through provision of a unique identifier (e.g. “P1”, “P2”…). The researcher will generate a “key” in a separate password protected csv file accessible only to the researcher. This will contain ONLY participant initials in one column, and their corresponding identifier (“P1”, “P2” etc.) in an adjacent column. The key document will be stored in a separate password-protected file to the demographic information file.

Raw qualitative data

Raw qualitative data generated for each participant will comprise:

- The researcher will keep a reflexive journal starting at the point that the study is initiated. This will not contain identifiable information about participants. This journal will be stored as a

password-protected .docx file in a password protected folder on a secure NHS network drive. When completed, the journal will be converted to .txt format for long-term storage and accessibility.
- Audio recorded 45-60 minute interview- this will be recorded on an AES-256 bit encrypted audio recorder owned by NHS Lothian. Following the interview, the device will remain on the person of the researcher or kept in a locked filing cabinet in the researcher's office on an NHS site (Astley Ainslie Hospital Department of Neuropsychology). The researcher will upload interviews by USB connection to a password protected folder on an NHS network drive. Recordings will then be deleted from the audio recording device. Audio recordings will be kept until the end of the analysis phase of the study. Each audio recording file name will be pseudonymised using the unique identifier described above in the "key file". The file name will be the unique identifier for that participant with the suffix "_audio" (e.g. the participant identified as "P1" would have their transcript named "P1_audio.mp3").
- Verbatim transcript of each interview- this will be made and stored electronically as a password protected Microsoft word ".docx" file. All identifying information will be removed from the transcript (e.g. names, places). The file name will be the unique identifier for that participant with the suffix "_transcript" (e.g. the participant identified as "P1" would have their transcript named "P1_transcript.docx"). The file will be stored in a separate password-protected folder to the audio recordings. The researcher will also print a copy of the transcript for the analysis stage because interpretative phenomenological analysis requires a stage of exploratory note-making and annotation. Physical copies of transcripts will be kept on the person of the researcher or in their line of sight when in use. When not in use, they will be stored in a locked filing cabinet in the researcher's NHS site office. The researcher's field supervisor and/or an NHS Lothian neuropsychology assistant psychologist will be asked to check a random selection of transcripts for fidelity. The field supervisor and this additional assistant psychologist would therefore also have access to the transcripts and audio recordings on the NHS Lothian neuropschology drive.

Output qualitative data

Output qualitative data will be the results of interpretative phenomenological analysis. There are four "levels" of analysis:

- Personal experiential themes from each participant's interview.
- Dyad experiential themes obtained from cross-case analysis of each member of a couple (i.e. a stroke survivor and their partner).
- Sub-group level experiential themes obtained from cross-case analysis of three sub-groups: people with PSE, partners of people with PSE, and dyads.
- Overarching group level experiential themes obtained from cross-group analysis of the experiential themes from each sub-group.

Output data from the analysis will comprise:

- Personal experiential themes for each participant. These will be organised as a table in a password protected .docx file. The table will comprise three columns: "experiential statements", "Participant experiential themes" and "Supporting quote(s)". The file name will be the unique identifier for that participant with the suffix "_PETs" (e.g. the participant identified as "P1" would have their file named "P1_PETs.docx"). When the study is completed, this document will be converted to .txt format for long-term storage and accessibility.
- Dyad experiential themes for each couple (i.e. person with PSE 1 and their partner). These will be organised as a table in a password protected .docx file. The table will comprise three columns: "Personal experiential themes", "Dyad experiential themes" and "Supporting quote(s)". The file name will be the unique identifiers for the participants in the dyad with the suffix "_DETs" (e.g. the couple comprising the participants identified as "P1" and "P2" would have their file named "P1P2_DETs.docx"). When the study is completed, this document will be converted to .txt format for long-term storage and accessibility.

- Group experiential themes for each sub-group of analysis (i.e. the subgroup of all participants with PSE, the subgroup of all the partners, the subgroup of all the dyads). These will be organised as a table in a password protected .docx file. The table will comprise two columns: "Personal experiential themes" and "supporting quote(s)". The file name will be the designation of that subgroup with the suffix "_GETs" (e.g. the subgroup of "people with PSE" would have their file named "PeoplewithPSE_GETs.docx"). When the study is completed, this document will be converted to .txt format for long-term storage and accessibility.
- Overarching group experiential themes (i.e. the comparison of all subgroup experiential themes). These will be organised as a table in a password protected .docx file. The table will comprise five columns: "Group experiential themes for those with PSE", "Group experiential themes for partners of those with PSE", "Group experiential themes for dyads", "Over-arching group experiential themes", and "supporting quote(s)". The file name will be the designation of that subgroup with the suffix "_GETs" (e.g. the subgroup of "people with PSE" would have their file named "PeoplewithPSE_GETs.docx"). When the study is completed, this document will be converted to .txt format for long-term storage and accessibility.
- The researcher will keep a reflexive journal starting at the point that the study is initiated. This will not contain identifiable information about participants. This journal will be stored as a password-protected .docx file in a password protected folder on a secure NHS network drive and accessible only to the researcher. When the study is completed, excerpts from the journal will be converted to .txt format for long-term storage and accessibility.

Documentation & Metadata

6) Documentation & Metadata

A .txt file containing anonymised transcripts.

A .txt file containing reflexive journal entries.

A .txt file containing personal experiential themes and supporting quotes.

A .txt file containing dyad experiential themes, supporting personal experiential themes and supporting quotes.

A .txt file containing subgroup-level experiential themes, supporting personal experiential themes/dyad experiential themes and supporting quotes.

A .txt file containing overall group experiential themes, supporting subgroup experiential themes, supporting personal experiential themes and supporting quotes.

A .txt file README containing an explanation of each of the data files kept in long-term data storage for other researchers to access.

Ethics & Legal Compliance

7) Ethics & Legal Compliance

Audio recording of in-person and remote interviews will ONLY be made using an NHS Lothian AES-256 bit encrypted digital audio recorder.

Participants will be de-identified as outlined in the data collection section. The key document used to link responses to participant unique IDs will be securely deleted at the end of the study. Therefore in the longer term each participant's de-identified responses will be differentiated only by the unique identifier they were assigned ("P1", "P2", etc.).

Sensitive data will only be stored, analysed and transformed within the NHS Lothian IT network accessible by VPN only by the researcher.

De-identified transcripts that have been printed physically for annotation and analysis will be kept within the researcher's office at all times and kept in a locked filing cabinet in that office when not in use.

Storage and Back-Up

8) Where will your data be stored and backed-up during the project?

Data will be stored within the NHS Lothian IT system. Additionally, fully anonymised interview transcripts will be shared by the researcher with their academic supervisor via NHS email. The academic supervisor will store these transcripts in their personal research network drive on the University of Edinburgh computer network. The academic supervisor will securely delete these transcripts at the end of the study.

Data stored on the NHS Lothian IT system will follow this structure:

NHS Neuropsychology drive

Overarching folder: "CH Project"

Subfolders: "Consent forms", "Demographic data", "Recordings", "Transcripts", "Reflexive journal", "Analysis", "Key"

Data will be considered sensitive because they pertain to participant’s health, contain demographic information and can be considered directly or indirectly identifiable. The identifiable information would include client's names, ages, stroke lesion location, gender, ethnicity and whether the participant uses anti-depressant medication (regardless of whether it has been prescribed for PSE or not). It is necessary for the researcher to be able to link these data to participants in the analysis phase to account for potential divergence between personal experiential themes during cross-case analysis. It is also necessary for analysis to know whether a response is from a person with PSE or the partner of a person with PSE, and which person with PSE and which partners are in the same couple. Data will therefore be pseudonymised through assigning each participant a unique identifier; this will require a "key" document where initials for each participant will be provided alongside their unique identifier. This will comprise four columns: "person with PSE initials", "Person with PSE unique identifier", "Partner initials", "Partner Unique identifier". This key document will be necessary during data collection, storage and analysis in the active phase of the project so that data can be correctly analysed. The key document will be stored in a separate folder to any files containing any data from participants. Therefore, the entire data-set, while protected somewhat against identification of individual participants, is not truly anonymised during the data collection and analysis phase. Data will therefore be considered sensitive data and therefore will not leave the NHS Lothian IT ecosystem.

Following conclusion of the analysis phase, it will no longer be necessary to link demographic information to individual participants and so these will be de-identified and aggregated as group data with no identifiers. It will also no longer be necessary to link unique identifiers to participant initials and so the key document will be securely deleted. Therefore transcripts and tables of experiential themes will no longer be linkable to participant initials.

Following conclusion of the analysis phase, it will also no longer be necessary to retain the audio recordings of interviews and so these will be securely deleted.

The researcher will make a weekly backup of data and store this in a password-protected folder labelled "PSE_backup" in their individually allocated network drive on the NHS Lothian IT system.

Selection and Preservation

9) Where will the data be stored long-term?

At completion of research, data can be fully anonymised. Individual cases no longer require linking to initials and so the unique identifier can be used. Demographic information is collected for the purposes of demonstrating the relative heterogeneity/homogeneity of the group as a whole and so details such as gender, ethnicity and stroke lesion location do not need to be linked to any individual in publication and reporting or long-term data storage. Therefore there is insufficient information from which patients could be directly or indirectly identified in the dataset.

The anonymised dataset will therefore be stored in the researcher's academic supervisor's University of Edinburgh Data Store provision for a period of 10 years.

10) Which data will be retained long-term?

Raw data that will be stored:

De-identified digital transcripts of interview (.txt file)

Table of aggregated demographic information (mean age, percentage males with PSE, percentage females with PSE) (.csv file)

Output data that will be stored:

Table of personal experiential themes and supporting quotes (.txt file)

Table of dyad experiential themes and supporting quotes (.txt file)

Table of sub-group experiential themes and supporting quotes (.txt file)

Table of over-arching group experiential themes and supporting quotes (.txt file)

Metadata that will be stored:

Readme .txt file explaining each file in storage

Data Sharing

11) Will the data produced from your project be made open?

- No: go to 13

13) Please explain why your data cannot be made open.

Data will not be made open because of the increased risk of participants being identifiable from

qualitative data. Additionally, interviews may contain information that is sensitive to participants. Interested parties may apply for access to data through the University of Edinburgh if they are researchers affiliated with an academic institution AND

- They wish to replicate the analysis
- OR they wish to analyse the data for another study on post-stroke emotionalism.
- AND they can provide a clear rationale and protocol that indicates the data collected by this study is the most appropriate way that they can answer their research question.

Responsibilities & Resources

14) Who will be responsible for the research data management of this project?

The principal investigator (PI) will be responsible for the research data management of this project.

15) Will you require any training or resources to properly manage your research data throughout this project?

The principal investigator will complete MANTRA training for data management, the data collection and management module of the NIHR's Introduction to good clinical practice elearning, and will complete modules on NHS LearnPro relevant to data handling and storage.