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Citation: Moss, B., Northcott, S., Behn, N., Monnelly, K., Marshall, J., Thomas, S., Simpson, A., Goldsmith, K., McVicker, S., Flood, C. & et al (2021). ‘Emotion is of the essence. … Number one priority’: A nested qualitative study exploring psychosocial adjustment to stroke and aphasia. International Journal of Language & Communication Disorders, 56(3), pp. 594-608. doi: 10.1111/1460-6984.12616

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Link to published version: https://doi.org/10.1111/1460-6984.12616

‘Emotion is of the essence. … Number one priority’: A nested qualitative study exploring psychosocial adjustment to stroke and aphasia

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First published: 07 April 2021 https://doi.org/10.1111/1460-6984.12616

Supplementary file 1: COREQ checklist

Item	*Section and paragraph*
Domain 1: Research team and reflexivity	
Characteristics	
1 **Interviewer/facilitator**: which author(s) conducted the interviews/focus groups?	Methods, Procedures
2 **Credentials**: what were the researcher’s credentials e.g. PhD?	Methods, Procedures
3 **Occupation**: what was their occupation at the time of the study?	Methods, Procedures
4 **Gender**: was the researcher male or female?	Methods, Procedures
5 **Experience and training**: what experience and/or training did the researcher have?	Methods, Procedures
Relationship with participants	
6 **Relationship established**: was there a relationship established prior to commencement of the study?	Methods, SUPERB study design and methods
7 **Participant knowledge of the interviewer**: what did the participant know about the researcher? E.g. personal goals, reasons for doing the research	Methods, SUPERB study design and methods Methods, Procedures
8 **Interviewer characteristics**: what characteristics were reported about the interviewer/facilitator? E.g. Bias, assumptions, reasons and interests in the research topic	Methods, Procedures
Domain 2: Study design	
Theoretical framework	
9 **Methodological orientation and theory**: what methodological orientation was stated to underpin the study? E.g. grounded theory, discourse analysis, ethnomethodology, phenomenology, content analysis	Methods, Analysis

Participant selection	
10 **Sampling**: how were participants selected? E.g. purposive, convenience, consecutive, snowball	Methods, Participants
11 **Method of approach**: How were participants approached? E.g. face to face, telephone, email, mail	Methods, Setting and participants
12 **Sample size**: How many participants were in the study?	Methods, Nested qualitative study
13 **Non-participation**: How many people refused to participate/dropped out? Reasons?	Results, first paragraph
Setting	
14 **Setting of data collection**: Where was the data collected? E.g. home, clinic, workplace	Methods, Setting and participants
15 **Presence of non-participants**: Was anyone else present apart from the participants and researchers?	Results, second paragraph
16 **Description of sample**: What are the important characteristics of the sample? E.g. demographic data, date	Results, first paragraph. Supplementary files 4 and 5
Data collection	
17 **Interview guide**: Were questions, prompts, guides provided by the authors? Was it piloted?	Supplementary files 2 and 3
18 **Repeat interviews**: Were repeat interviews carried out? If yes, how many?	No
19 **Audio/visual recording**: Did the research use audio or video recording to collect the data?	Methods, Procedures
20 **Field notes**: Were field notes made during or after the interview or focus group?	Methods, Procedures
21 **Duration**: What was the duration of the interview or focus group?	Results, second paragraph
22 **Saturation**: Was data saturation discussed?	Methods, Participants
23 **Transcripts returned**: Were transcripts returned to participants for comment and/or correction?	No. Methods, Procedures
Domain 3: Analysis and findings	
Data analysis	

24 **Number of data coders**: How may coders coded the data?	Methods, Analysis
25 **Description of the coding tree**: Did authors provide a description of the coding tree?	Results headings and subheadings
26 **Derivation of themes**: Were themes identified in advance or derived from the data?	Results, third paragraph
27 **Software**: What software, if applicable, was used to manage the data?	Methods, Analysis
28 **Participant checking**: Did participants provide feedback on the findings?	No
Reporting	
29 **Quotations presented**: Were participant quotations presented to illustrate the themes/findings? Was each quotation identified e.g. participant number?	Results, throughout
30 **Data and findings consistent**: Was there consistency between the data presented and the findings?	Results, throughout
31 **Clarity of major themes**: Were major themes clearly presented in the findings?	Results, third paragraph
32 **Clarity of minor themes**: Is there a description of diverse cases or discussion of minor themes?	Results, throughout

Supplementary file 2: Interview topic guide for people with aphasia

[Items in **bold** reported here, other items reported elsewhere]

Objectives:

1. Explore their experiences of the study, including study procedures (recruitment and consent procedure, assessment protocol) and intervention (those who received it); explore suggestions for how study protocol could be improved
2. **Explore what has helped (both formal and informal help) with: emotional needs; adjusting to life with stroke/'getting on with life'; confidence; feeling hopeful for the future**
3. **Explore what has been unhelpful/missing in terms of 'getting on with life post-stroke**

Pre-interview: reaffirm consent; tape recording

Thank yous: for their time and taking part in the project

Reassurances: confidential; can stop/take a break; no right or wrong answers, their perspective

Time: 1 to 1½ hours

Aim of interview: (1) explore how they found taking part in the study (what worked well, what was less good, experiences of peer befriending); **(2) explore what has helped them feel better/ adjust to living with stroke and aphasia**

Aphasia: provision of pictures, key words, scales and other communicative supports to scaffold conversation as appropriate.

Background preparation prior to interview: **interviewer to find out GHQ-12 score; severity of aphasia; living arrangements; mobility at baseline; ethnicity;** knowledge of whether they received befriending and any issues that may have arisen. **Interviewer also to have access to social case history and CSRI (where possible).** Interviewer to take with them: photos of research team (to help prompt discussion on trial protocol); Participant Information Sheet(s) (to prompt discussion of consent processes); name/ photo of befriender (as appropriate).

1. Background information

Introduce section: check got details correct (nb: should know the answer to these questions from case history, service use questionnaire etc – purpose of these questions is that they are 'easy' to answer/ to create a 'map' to refer to)

1.1 **Who living with; how long lived there**
1.2 About their involvement with project: who RA was, and (where applicable) who befriender was (show photos)
1.3 **Map out services/ support they currently receive through asking about a typical week *(may have this info from CSRI).***
- stroke and other groups
- therapies
- paid care
- (peer befriending, where applicable)

2. Whether anything has helped their adjustment/ emotional needs following their stroke

Interested in what helps people adjust/ get on with life post stroke; what helps them with emotional needs/ feelings (may be helpful to point out that many people find it distressing/

difficult). Clarify OK to talk about peer befriending/ taking part in the project, or anything else that's been helpful, such as doctor, nurse, stroke groups, or more informal (e.g. friends and family).

2.1 General (open questions on whether anything has been helpful)

Specific areas to cover:

2.2 emotions
2.3 getting on with life following the stroke (potentially including work)
2.4 confidence
2.5 **feeling there is a future/ feeling hopeful for the future (i.e. has anything helped them to keep going, helped them to not give up)**
Note: the focus of the interview is not emotions/ confidence etc but what has helped with emotions/confidence etc. Still, may be useful to preface by asking them to reflect on how they are (e.g. 'what about your confidence after the stroke, how's that been? Has anything helped you with your confidence?')

Possible prompts: more formal/ organised help

- **NHS (doctor, nurse, SLT etc)**
- **Other professional/ paid worker (e.g. home carer; social worker)**
- **Community groups and services**
- **Stroke groups**
- **Stroke Association/ other charity (e.g. advice; groups; one to one support)**

Possible prompts: less formal help

- **Family**
- **Friends**
- **Activities/ getting out**
- **Self**

3. Stroke services and well-being post stroke/ psychological care/ help with their feelings

Note: we are interested in what they have experienced as helping their psychological well-being during their stroke care. This is likely to be specific people (e.g. nurses, doctors, therapists), e.g. conversations they may have had, things the health professional did, or the way they did them. It may also be services (e.g. stroke groups). *Where relevant, compare and contrast professional support with peer befriender support.*

3.1 On their stroke journey, what was experienced as helpful– in the context of well-being (what they found most helpful/useful)
(e.g. 'It can be a very distressing time when you're in hospital. Did anything help you/ make it a bit better for you? Made it worse?' – use participant's words where possible, e.g. stuck, overwhelmed etc)
Track their stroke care (particular emphasis on longer term):
- in hospital
- leaving hospital
- longer term
3.2 What was not helpful/ useful/ necessary

3.3 How services could be improved/ perceived gaps in services (support they wished they'd had and why)

4. Experiences of taking part in the project/ befriending

4.1 *Overall impression* of taking part in the project
- how they experienced the project
-what worked well (if any)/ worked less well
- what they'd change
- what difference it's made to them to take part (if any)

4.2 *Peer befriending* (for those that received it – note this will likely form part of 4.1 conversation)
- overall impression of intervention
- map out what sorts of things they did with their befriender (and explore how they experienced these)
- relationship with the befriender (how they got on; how they negotiated the types of activities they did together; the significance, if any, of befriender having aphasia)
- what worked well (if any)/ perceived as useful (if any)
- what didn't work well/ unhelpful
- impact of the intervention, if any, on their lives (may come up in section 2)/ what difference it's made to them
- what difference it makes that the befriender has stroke/aphasia (if any)
- timing –best time to receive befriending in stroke journey
- how does it compare to receiving support from a health professional (may come up in section 2)
- logistics (number, spacing, how it was arranged, process of being 'matched' and introduced, timing of befriending post stroke)
- qualities of a good befriender/ what makes a good befriender
- ending of the befriending
*** suggestions for change ***

4.3 Recruitment procedure/ initial contact
- Initial contact
- Initial information about project ('participant information' session where researcher explained about project; consent process; two stage consent process for those in intervention arm; knew what to expect)
- Factors that made them decide to take part; any reservations
  *** suggestions for change***

4.4 Assessments/ questionnaires
- overall: their experience of the assessment sessions/ answering questions
- the right questions? (ie measuring the most meaningful areas?)
- Easy to understand?
- Length of assessment sessions/fatigue?
*** suggestions for change***

5. Suggestions/ overall comments

[Signpost coming to end of the interview; chance to say any last comments]

On their experiences of taking part in the project:

5.1 Final comments
5.2 [Would they recommend befriending to someone who's just had a stroke?/ best thing about befriending?]
5.3 One thing to improve stroke services to help people with their feelings after the stroke?

Provision of any relevant information

Discuss with them their next visit

Reassurances about confidentiality/ what will happen next

Thank yous!

Supplementary file 3: Interview topic guide for significant others

[Items in **bold** reported here, other items reported elsewhere]

Objectives:

1. Explore their experiences of the study, including study procedures (recruitment and consent procedure, assessment protocol) and intervention (for those in the intervention arm); explore suggestions for how study protocol could be improved
2. **Explore impact of stroke and aphasia on them and family life**
3. **Explore perspectives of care received in terms of helping them with their well-being/adjusting to being a carer**
4. Explore impact of peer befriending on their life (for those in intervention arm)

Pre-interview: reaffirm consent; tape recording

Thank yous: for their time and taking part in the project

Reassurances: confidential; can stop/take a break; no right or wrong answers, their perspective

Time: 1 to 1½ hours

Aim of interview: (1) explore how they found taking part in the study (what worked well, what was less good, experiences of peer befriending if appropriate); **(2) explore what has helped them feel better/ adjust to living with stroke and aphasia**

1. Background information

Introduce section: check got details correct (nb: should know the answer to these questions from case history, service use questionnaire etc – purpose of these questions is that they are 'easy' to answer/ to create a 'map' to refer to)

1.1. About their involvement with project: who RA was, and (where applicable) who befriender was (show photos)

Map out services/ support they currently receive as a family – both PwA and what they have received as carers *(may have this info from CSRI)*
- stroke and other groups
- therapies; paid care
- (peer befriending, where applicable)

2. Experiences of taking part in the project

Want to understand their experiences, so can improve the project. Helpful to hear: what's working, what we should change.

2.1. overall impression of taking part in the project

-how experienced
- what worked well (if any)/ less well
-what they'd change
-what difference it's made to them to take part

2.2 peer befriending (where applicable – likely this will interleave with section 2.1)

- overall impression of intervention
- map out what sorts of things their partner did with their befriender (and how the carer experienced these)

- impact of befriending on carer's life
- what worked well (if any)/ perceived as useful (if any) – for carer
- what didn't work well/ unhelpful – for carer
- what difference it makes that the befriender has stroke/aphasia (if any)
- logistics (number, spacing, how it was arranged, process of being 'matched' and introduced)
- ending of the befriending

*** suggestions for change ***

2.3 Recruitment procedure/ initial contact

- Initial contact
- Initial information about project ('participant information' session where researcher explained about project; consent process including two stage process where appropriate)
  *** suggestions for change***

2.4 Assessments/questionnaires (their experiences of answering questions)

- overall: their experience of completing the assessments
- the right questions? (ie measuring the most meaningful areas?)
- Easy to understand?
- Length/ number of assessments?

*** suggestions for change***

3.Impact of stroke and aphasia on them/ family life

Explain interested to know about how the stroke has affected them, and their day to day life.

General question - impact of stroke/ aphasia on them

Probe following areas:

3.1 Their relationship with person with aphasia/ stroke

3.2 Family relationships
3.3 Friends/ social activities
3.4 Day to day life (incl. fatigue)
3.5 Emotional well-being / sense of who they are

3.6 Thoughts about the future/ making plans

4. What has helped their emotional well-being following their stroke

Interested in what helps family members of people with stroke adjust/ get on with life; what helps them with emotional needs.

4.2 General (open questions on what they've found helpful over previous 4 months)

Specifics: revisit areas 2.1 to 2.6 - explore whether anything has helped *[nb – may be that what helps will flow from your above conversation naturally – e.g. talk about exhaustion in day to day life, then what helps with that etc).*

4.3 Explore what services they have found helpful for carer's emotional well-being/ adjustment
(e.g. NHS, charities like Stroke Association)
- how services could be improved/ perceived gaps in services (support they wished they'd had and why)
- what was not helpful / useful/ necessary

- ‘ideal’ service (if they were in charge of services, and had lots of money…)

5. Suggestions/ overall comments

[Signpost coming to end of the interview; chance to say any last comments]

On their experiences of taking part in the project:

5.2 Final comments

5.3 [How they would describe peer befriending to someone who has just had a stroke – *only applicable for intervention group*]

On stroke services:

5.4 One thing that stroke services should do to help carers adjust to living well with stroke?

Provision of any relevant information

Discuss with them their next visit

Reassurances about confidentiality/ what will happen next

Thank yous!

Supplementary file 4: Characteristics of participants with aphasia (*n* = 20)

Pseudonym	**Severity of aphasia (mild v moderate-severe)***	**Lives alone (Yes/No)**	**Gender (Male/ Female)**	**Mobility (Wheelchair user Yes/No)**	**GHQ-12 score (>3 Yes/ No)**	**Ethnicity**	**PEER / USUAL arm of trial**
Samson	Mild	No	Male	No	No	Black	PEER
James	Mild	Yes	Male	No	Yes	White	PEER
Jonathan	Moderate-Severe	Yes	Male	Yes	No	Black	PEER
Trevor	Moderate-Severe	No	Male	Yes	No	White	PEER
Betsy	Moderate-Severe	No	Female	Yes	Yes	Black	PEER
Marilyn	Mild	No	Female	No	Yes	White	PEER
Ivy	Mild	No	Female	No	No	Black	PEER
David	Mild	Yes	Male	No	Yes	White	PEER
Rose	Mild	No	Female	No	No	Black	PEER
Elizabeth	Moderate-Severe	No	Female	Yes	No	Mixed race	PEER
Peter	Mild	No	Male	No	No	White	USUAL
Kofi	Moderate-Severe	No	Male	Yes	No	Black	USUAL
Christine	Moderate-Severe	Yes	Female	No	No	White	USUAL
Susan	Mild	No	Female	No	Yes	White	USUAL
Judy	Mild	No	Female	No	No	White	USUAL
Maureen	Moderate-Severe	No	Female	No	Yes	White	USUAL
Katherine	Mild	No	Female	Yes	Yes	White	USUAL
Bashiir	Mild	No	Male	Yes	Yes	Black	USUAL
Santiago	Mild	No	Male	No	Yes	Asian	USUAL
Sayid	Moderate-Severe	No	Male	Yes	No	Asian	USUAL

*Determined by Western Aphasia Battery AQ score, where 0-50 = severe, 51-75 = moderate and 76 and above = mild.

GHQ-12: General Health Questionnaire – 12 item version; PEER: usual care + peer-befriending; USUAL: usual care

Supplementary file 5: Characteristics of significant others (*n* = 10)

Pseudonym	**Relationship to participant with aphasia: Spouse/Partner or Child/Other**	**Participant with aphasia interviewed (Yes/No)**	**Ethnicity**	**Gender**	**GHQ-28 score** **(>5, Yes/ No)**	**PEER/USUAL arm of trial**
Ivy's daughter	Child/Other	Yes	Black	Female	No	PEER
Elizabeth's daughter	Child/Other	Yes	Mixed race	Female	Yes	PEER
Benjamin's wife	Spouse/Partner	No	White	Female	No	PEER
Enid's husband	Spouse/Partner	No	White	Male	No	PEER
Marcellino's daughter	Child/Other	No	White	Female	Yes	PEER
Peter's wife	Spouse/Partner	Yes	White	Female	Yes	USUAL
Christine's granddaughter	Child/Other	Yes	White	Female	No	USUAL
Judy's husband	Spouse/Partner	Yes	White	Male	No	USUAL
Claire's husband	Spouse/Partner	No	White	Male	No	USUAL
Bashiir's sister	Child/Other	Yes	Black	Female	Yes	USUAL

GHQ-28: General Health Questionnaire – 28 item version; PEER: usual care + peer-befriending; USUAL: usual care