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### Post-stroke emotionalism

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## **Post-stroke Emotionalism: A Qualitative Investigation.**

**Introduction:** Post-stroke emotionalism, outbursts of involuntary crying or laughing, is common after stroke. Little is known about the psychosocial factors associated with this neurological disorder.

**Aim:** To investigate participant's experiences of emotionalism and explore how they managed their symptoms.

**Methods:** A qualitative study that used framework analysis. Participants were recruited across inpatient and outpatient stroke settings. The average time since stroke was 4.3 months.

**Results:** Eighteen semi-structured interviews were conducted. Four themes were identified: (1) *Spontaneous and uncontrollable emotional reactions*; (2) *Incongruence*; (3) *Social reactions* (sub-theme: *The stigma of expressed emotions*) and (4) *Convalescence*. Participants with negative experiences described greater disability, avoidance and mood problems. Positive experiences were shaped by a better understanding of the condition, an increased sense of control, social support and optimism. Few participants knew that their emotionalism was caused by stroke. Embarrassment and social withdrawal were commonly reported and had a detrimental effect on participant's mood and quality of life.

**Conclusions:** Earlier recognition of emotionalism in clinical settings is needed as is promoting discussions about emotional reactions after-stroke. This will reduce the likelihood that patients will develop erroneous beliefs about emotionalism and unhelpful coping responses that may lead to adjustment difficulties in the months that follow their stroke.

**Keywords:** Stroke; Crying; Laughter; Emotionalism; Adaptation, Psychological

### **Introduction**

Stroke is the leading cause of disability worldwide, the fourth leading cause of death and affects over 1.2 million people in the United Kingdom [1]. There are many emotional consequences of stroke but one of the most dramatic is that of emotionalism [2]. Emotionalism is an acute neurological disorder, characterised by sudden, involuntary and uncontrollable episodes of crying or laughing [3]. In some instances, laughter or crying is incongruent to a person's underlying emotional state. On other occasions, the emotional reaction is an exaggerated response to emotional stimuli [4].

The aetiology of emotionalism is strongly associated with cerebral pathology [5]. The disorder arises secondary to a wide range of neurological conditions such as stroke, multiple sclerosis, dementia, amyotrophic lateral sclerosis and traumatic brain injury [6]. There are few well-conducted prevalence studies of post-stroke emotionalism. According to a recent meta-analysis, the incidence of emotionalism is estimated to be between 17-20% at the post-acute phase of stroke (1-6 months) [7].

Studies suggest that emotionalism arises from lesions to the frontal lobes and descending corticobulbar-cerebellar circuits that regulate motor control and the co-ordination of emotional expression [8,9]. Impaired communicating pathways from frontal and cortical motor inputs are thought to disrupt the cerebellum's ability to modulate the motor expression of emotion [10]. Maruzairi and Koh argue that emotionalism arises from dysfunctional serotonergic and glutaminergic neurotransmission in the cerebellum, thought to play an important role in emotion processing [11]. Disrupted neurotransmission is theorised to lead to a loss of, or reduction in, a patient's voluntary control over their emotional expression [10].

It is thought that stroke-related disruption to the pathways between frontal, parietal and brain stem regions result in the involuntary laughter or crying episodes characteristic of the disorder [6]. However, the pathophysiology of emotionalism is not entirely understood and there remains inconclusive links between lesion location and neuropathology [2,10].

The crying variant of emotionalism is frequently mistaken for clinical depression [8,9]. Diagnosis is complicated by the fact that emotionalism can co-occur with mood disorders [2], yet both are distinct conditions. Crying caused by emotionalism is brief and uncontrollable, and there is a relative absence of the depressive beliefs normally associated with crying [6,10,12]. In the case of depression, crying is prolonged and patients report beliefs relating to a sense of hopelessness, worthlessness and despair [13].

Scottish Health guidelines recommend antidepressant medications as the first line of treatment for emotionalism [14] however, the overall effectiveness of medications in symptom

reduction is rather weak [15,16]. Behavioural treatments like competing response training, an intervention that involves learning to anticipate the onset of symptoms and employing movements to counteract symptoms, have shown promising results [17]. Distraction and relaxation training have also been found to reduce the emotional distress associated with symptoms [5]. Despite this, non-pharmacological interventions remain in their infancy in this population and further empirical studies are required.

Our knowledge of factors that contribute to the remission of emotionalism is poor, as is our understanding of what exacerbates symptoms. Similarly, there are few studies measuring the long-term social and functional impact of the condition with existing research relying on cross-sectional case studies [18-20]. Colamonico and colleagues found that emotionalism posed a high burden of illness for patients and their caregivers [6]. 24% of patients reported that emotionalism was the primary reason for becoming housebound. Patients also reported that the condition was at least partly responsible for the need to move to supervised accommodation, divorce or relationship break-down, increased carer burden and job loss. In their qualitative case-study, George, Wilcock and Stanley found that emotionalism negatively affected engagement with post-stroke physical rehabilitation by increasing muscle tone [21]. Emotionalism has been associated with high levels of social disability and a reduced quality of life [11,22-25]. Yet, what leads to these outcomes is not yet understood.

Individuals with emotionalism are at heightened risk of developing mood disorders, most probably due to the socially isolating nature of symptoms [3,26]. To date, the psychological impact of emotionalism is under-investigated. It is not known why some individuals develop mood disorders whilst others do not. It is known, however, that the way a person conceptualises illness can significantly influence their recovery from stroke [27-30]. Research consistently indicates that patient perceptions can predict coping behaviours [31], treatment adherence [32,33], social functioning [34], emotional well-being and quality of life [35] in chronic health populations.

This study hypothesised that a person's beliefs about emotionalism may play a role in how the individual copes with their symptoms. For instance, a person who endorses negative assumptions about emotionalism (e.g. "*crying is weak or childish*") may think critically of themselves, avoid activities that trigger emotional symptoms and withdraw from others for fear of negative evaluation. Avoidance and social isolation are key determinants of poor psychosocial outcomes after stroke [27,36]. Clearly, a greater understanding of the role of patient beliefs is warranted as currently these relationships remain speculative.

### ***Study aims***

There is a paucity of qualitative studies investigating patients' perspectives on emotionalism. This study investigated the experiences of people with post-stroke emotionalism to uncover what it is like to live with this neurological condition.

### **Method**

#### ***Design***

A series of semi-structured interviews were conducted, audio recorded and transcribed verbatim. These were analysed using the framework method. This a form of thematic analysis that focuses on relationships within the data to draw conclusions based on themes [37]. The framework method was chosen due to its systematic approach to data analysis. Its flexible position appealed to the researchers who used a broadly critical realist approach to understanding the personal experiences of living with emotionalism [38]. Flexibility with data analysis also allowed the researchers to combine apriori assumptions based on the literature with data-driven themes to develop the analytical framework. Ethical approval was granted by the West of Scotland Research Ethical Committee (Reference number: 16/WS/0071) and the NHS Lothian Research and Development Department.

### ***Participants***

Participants with emotionalism were recruited across a wide range of ages, stroke classifications and at different stages of recovery.

### ***Inclusion and exclusion criteria***

Participants were included in the study if they had a primary diagnosis of stroke and probable emotionalism as defined by the International Classification of Diseases (ICD-10) diagnostic criteria. Participants were required to have spoken English language skills sufficient to be understood during an interview. The researcher sought this information from the participant's stroke professional in advance of their recruitment to the study. Participants were excluded if they had significant cognitive impairment, which was determined by using a brief screening test of cognitive functioning. Those with severe psychiatric or neurodegenerative disorders were excluded as these conditions would have precluded their ability to fully participate in the interviews.

### ***Screening tools***

In line with the Scottish Intercollegiate Guidelines Network (SIGN) [14], services receiving acute stroke cases routinely screen patients for mood disorders, functional and cognitive impairments. The questionnaires included in the study were routine measures used in NHS Lothian. The Barthel Index (BI) is a 20-item valid and reliable measure of activities of daily living [39,40]. The Addenbrooke's Cognitive Examination (ACE-III), is an established screening measure of cognitive functioning [41]. It is scored out of 100 with higher scores indicating better cognitive functioning. Participants were not eligible to take part if they scored below the cut-off score of 88/100. A score below this point was considered to be indicative of cognitive impairment severe enough that it would interfere with the participant's ability to engage in an interview and reflect on their experiences. The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report questionnaire measuring symptoms of anxiety and

depression [42] that has acceptable psychometric properties in stroke [43]. Information was gathered from routine screening, which was part of the participant's post-stroke treatment, to ensure that they fulfilled the inclusion criteria.

### ***Recruitment procedure***

Participants were recruited via specialist physicians in stroke, Consultant Neurologists, Clinical Psychologists and Nurses from three acute stroke units and one post-acute stroke service.

Members of the stroke teams identified individuals who met the International Classification of Diseases criteria for emotionalism and approached them to introduce the study. If an individual expressed an interest in taking part, they met with the lead researcher who provided them with additional information and the opportunity to ask questions. Potential participants were contacted a week later to ask for their decision and an interview was arranged for those that consented. The researcher obtained written consent before extracting demographic information and the results of the participant's routine screening measures from their medical notes to ascertain that they were functionally and cognitively able to take part. The interviews were conducted during working hours, either at the participant's home or in a visitor room during their inpatient admission on the stroke-ward.

Participants were interviewed by the lead researcher who was not known to them prior to the study. The research team members had a range of experience relating to qualitative research. One researcher completed university training courses in qualitative methodology and the remaining researchers had published a number of papers in peer-review journals using qualitative methods. One researcher had published research using quantitative and mixed methods approaches.

### ***Development of the semi-structured interview guide***

The semi-structured interview guide was based on guidelines by Ritchie and colleagues [44] as well as on previous studies investigating patient beliefs in health populations [45] and in stroke

[46,31]. Given the exploratory nature of the study, the interview guide was used flexibly to avoid constricting participant narratives [46]. Questions were omitted, altered or explored in more detail dependent on the individual. The interview guide was reviewed in consultation with five stroke specialists and amended accordingly. The interview questions were as follows:

- In what way has your ability to control your emotions changed since your stroke?
- How able do you feel that you can control your emotions?
- What do you think are the causes of your emotionalism?
- What impact does emotionalism have on your life?
- How long do you believe that your emotionalism will last for?
- How do you feel when you become emotional?
- What thoughts are passing through your mind when you become emotional?
- How do you cope when you become emotional?
- What do you think that other people are thinking when you're emotional in public?
- Is there anything that you would do but can't because of emotionalism?
- What advice would you give to someone who has emotionalism?

### ***Data Analysis***

Framework analysis was used to explore the experiences of emotionalism. This involved developing a matrix-based method to categorise and organise data according to emergent themes on both an individual and on a group basis [47].

### ***Analysis:***

*Transcription:* All semi-structured interviews were transcribed verbatim by the lead researcher. A reflective diary was kept throughout the interview process to log theoretical ideas, decisions about codes and the dynamics between interviewees and interviewer. This was to provide transparency in the researcher's perspective on the sensitive content of interviews. The diary

was also used to document the researcher's experiences and assumptions about stroke and emotionalism as well as the influence that this had upon their interviewing style and approach to the analytical process.

*Familiarisation:* Listening to the interviews twice reminded the researcher of the emotional tone of the interviews as well as of the severity and duration of participant's emotional reactions. Re-reading transcripts and noting preliminary statements or reflections primed the researcher for the next stage of analysis.

*Identifying a thematic framework:* The first six transcripts were analysed by assigning statements to each line. Multiple theme identification with two members of the research team was used to be transparent with the progressive development of themes and to strengthen the reliability and validity of the analysis process. Codes were initially developed by summarising what each participant was describing [48]. Participants' own words were used in order to stay true to the data at this initial stage [43,49]. Notes as to the reasons why themes were created and reflections on how themes were linked were described in the form of memos and attached to the transcripts. Over time, the process of analysing experiences became more categorical as multiple statements were classified under themes and sub-themes. These analytical themes were clustered into key themes and used to create a coding matrix.

*Developing a working theoretical framework:* Data were charted onto a matrix Excel spreadsheet and categorised based on the framework themes using computerised qualitative software [50]. The themes matrix and interview guide were then used to frame data according to emerging themes. This was an iterative process of constantly refining the framework by clustering participants' passages of text and re-reading transcripts.

*Indexing:* The theoretical framework was initially applied to two transcripts where passages of text were labelled with one or more of the framework themes and then refined as new insights emerged. The final framework was then applied to all subsequent transcripts.

*Charting:* The matrix comprised of one column per participant and one row per framework theme. Conceptual ideas were then abstracted from within each framework theme and between each participant [37]. The final theoretical accounts were summarised using verbatim text.

*Mapping and Interpretation:* At this stage, participants' summary of beliefs and experiences moved beyond descriptive accounts towards a wider understanding of the emotionalism experience. This stage required mapping linkages to similar experiences across participants and developing a framework to interpret emerging themes in the context of living with emotionalism.

## **Results**

A total of eighteen participants met the inclusion criteria and took part in the study. The sample comprised of six males and twelve females (age range=39-81 years,  $M=58.9$  yrs,  $SD=10.4$ ). Six participants were inpatients in a stroke ward and twelve were interviewed in their own homes. The length of time since stroke ranged from 2 weeks to 17 months ( $M=4.3$  months,  $SD=3.7$ ). The sample consisted of four participants with haemorrhagic stroke and fourteen participants with ischemic stroke. Ten were right-sided, three were left-sided and five were bilateral strokes. The functional ability of individuals varied from needing total support for all aspects of daily living (Barthel Index=1) to being fully independent (Barthel Index=20). Three participants scored in the clinical ranges for mild depression and anxiety and were receiving psychological therapy. Two participants were non-UK nationals and for whom English was their second language.

Eighteen semi-structured interviews were carried out. The length of interviews ranged from 12-60 minutes with the duration of interviews being determined, in part, by factors like environmental variables (busy inpatient wards) or the participant's physical ability and inclination to continue.

### ***Emergent themes:***

Four themes and one sub-theme emerged, which represented a mapping of the most salient aspects of participants' experiences. The first theme focused on how participants made sense of and understood emotionalism (*Spontaneous and uncontrollable emotional reactions*). The second theme related to participants disconnect between their internal feelings and external emotional displays (*Incongruence*). The third theme described the social context in response to emotionalism (*Social reactions*) and societal assumptions about the expression of emotions (*Sub-theme: The stigma of expressed emotions*). The last theme emphasised the process of recovery from emotionalism, in particular participants' efforts to cope with their symptoms (*Convalescence*).

### ***Theme 1: Spontaneous and uncontrollable emotional reactions***

Participants attempted to make sense of their emotionalism, by reflecting on their own experience of laughter or crying for little or no reason. Some participants described their symptoms as being exaggerated responses to mildly emotive triggers, citing examples like talking about family members, seeing grandchildren or watching a television programme.

“I get no warning, it just... one minute I'm ok and the next minute I just burst into tears ... it could be a happy thing, it can be a sad thing or it's just for no reason.” (Participant 17, <59 years, 3 weeks post-stroke, Barthel Index:20)

“I laugh or cry for no reason.” (Participant 5, <59 years, 40 weeks post-stroke, Barthel Index:20)

“My emotions would normally work at the right time but now they're just sporadic, it just happens. It could be triggered by a word, triggered by looking at somebody or hearing somebody's name.” (Participant 16, <59 years, 28 weeks post-stroke, Barthel Index:12)

“If I get a nice text or I get a well wish or something. Somebody’s thinking about me, I just burst into tears.” (Participant 4, >59 years, 3 weeks post-stroke, Barthel Index:3)

Most participants seemed to be unaware that their stroke caused emotionalism. In the absence of a medical reason, participants attributed their emotional reactions to different causes. Some assumed that their uncontrollable laughter or crying was a sign that their mental state was deteriorating and understandably, this was distressing for them.

“I thought I had em ... lost my marbles.” (Participant 3, <59 years, 16 weeks post-stroke, Barthel Index:6)

“I thought I was having a nervous breakdown, I thought I was really cracking up.” (Participant 17, <59 years, 3 weeks post-stroke, Barthel Index:20)

For some individuals, their uncontrollable reactions represented a loss of former emotional strength and self-discipline. The impact of this loss varied according to participants’ pre-stroke assumptions about the importance of self-control.

“I feel as though I’ve lost all control of my life. Before, I always felt I knew where I was going, I had my own social life and I was in control of my emotions. I felt I had something to offer.... people would listen to me. But now that I’m emotional, I feel as if I’m ... just overlooked, not here.” (Participant 10, >59 years, 4 weeks post-stroke, Barthel Index:5)

“It’s irritating more than anything else...you’re not in control when you’re overly emotional. You lack discipline.” (Participant 8, <59 years, 64 weeks post-stroke, Barthel Index:20)

Other participants believed that their uncontrollable responses were an unconscious expression of coping and adjusting to stroke. Understanding emotionalism in this way seemed to be less distressing for participants.

“I assumed it was just coming to terms with what I couldn’t do and realising it.” (Participant 14, <59 years, 44 weeks post-stroke, Barthel Index:18)

“I suppose either laughing or crying, it must be me just trying to cope with things. I think that’s a way it comes.” (Participant 7, >59 years, 52 weeks post-stroke, Barthel Index:20)

“I was just told that that’s just what happens when you’ve had a stroke.” (Participant 6, >59 years, 20 weeks post-stroke, Barthel Index:20)

### ***Theme 2: Incongruence***

The contrast between participants’ internal state and their external emotional responses was described as confusing, worrying and strange. In their attempts to identify the reasons for their reactions, participants often experienced confusion and uncertainty.

“There’s nothing emotional... there’s nothing inside me that feels bad, I don’t feel... I don’t feel stressed; I don’t feel any of that kind of thing. I just feel I’m about to cry and

no sort of work up toward it.” (Participant 14, <59 years, 44 weeks post-stroke, Barthel Index:18)

“You know yourself and you know when you come across situations, you know how you’re going to react. You know how your mind works ... but it’s almost like when you’ve had a stroke, you have no control of your mind anymore ... with the giggles or the tears it comes from nowhere, out of character, not the norm and you think ‘oh where has that come from, what’s that all about?’” (Participant 4, >59 years, 3 weeks post-stroke, Barthel Index:3)

Emotionalism seemed to be more distressing for participants who rarely cried before their stroke. They found the discontinuity between their emotional selves before and after stroke to be frightening.

“Tears and everything running down my face... and that’s not me ... I don’t get emotional.” (Participant 2, 59 years, 8 weeks post-stroke, Barthel Index:7)

“It’s scary cause you’re not used to that ... It just isn’t me.” (Participant 6, >59 years, 20 weeks post-stroke, Barthel Index:20)

Participants who strongly valued their sense of autonomy and strength severely criticised their inability to control their emotions. These individuals felt that the expression of emotion was a “sign of weakness” (Participant 10) and that they should be “mentally in control and... disciplined” (Participant 8).

### ***Theme 3: Social reactions***

The symptoms of emotionalism were rarely triggered by internal emotions. Nonetheless, the public respond to participants' emotional responses as though they were genuine. Participants found this incongruence to be intensely embarrassing. Often participants felt ashamed of their inability to control their emotional reactions in public. They voiced many critical beliefs about other people's judgements of them.

“Sometimes you feel really stupid you know, sitting there and tears are falling down (...) and people are all fussing about you because they think there's something wrong and you just keep saying no, I'm absolutely fine I just can't stop crying for some reason or another.” (Participant 14, <59 years, 44 weeks post-stroke, Barthel Index:18)

“They give you this expression, it's like 'oh look at her she's crazy' ... or they're thinking maybe you're high on drugs or something like that because it's not normal (for) a person who has nothing to laugh (at to be) laughing, right?” (Participant 9, <59 years, 68 weeks post-stroke, Barthel Index:20)

“I think people get a different opinion of you because they see it as something wrong with you... that you're not coping with life... and I don't want that to be my life.” (Participant 13, <59 years, 16 weeks post-stroke, Barthel Index:20)

“Other people probably see them as being weak and feeling sorry for themselves. You know eh... not strong.” (Participant 10, >59 years, 4 weeks post-stroke, Barthel Index:5)

The hidden nature of emotionalism was often attributed to be the reason for why people misinterpret their reactions.

"Because I look ok, I don't physically have anything to see from the stroke, folk say 'well you look ok'. God help me if I look ok em... (I) don't look like (I've) had a stroke but em ... I feel that I have had a stroke." (Participant 17, <59 years, 3 weeks post-stroke, Barthel Index:20)

Compassion or empathy from others appeared to exacerbate emotional reactions. Many participants mentioned that they become emotional when people showed concern for their well-being.

"I cry more when somebody says something nice to me... tries to help me...or be kind." (Participant 13, >59 years, 16 weeks post-stroke, Barthel Index:20)

"People tend to rush in to ask you if you're alright, which makes it worse. You just want them to back off so that you can cover it up." (Participant 17, <59 years, 3 weeks post-stroke, Barthel Index:20)

Some participants felt guilty about the impact that emotionalism had on other people and this was salient for individuals who held beliefs about their symptoms distressing others, particularly their friends and family members. Participants engaged in subtle avoidances to cope with the incongruence between their actual emotional state and their symptoms. Examples included only going out with family members, avoiding certain topics in conversation or staying away from busy environments. For some, the incongruence associated with emotionalism felt so disabling that they rarely left their home.

“I don’t want to upset other people and make them feel that they’ve said something wrong.” (Participant 13, >59 years, 16 weeks post-stroke, Barthel Index:20)

“If I’m on my own then nobody thinks I’m crazy.” (Participant 7, >59 years, 52 weeks post-stroke, Barthel Index:20)

### ***Sub-theme: The stigma of expressed emotion***

Multiple references to social stereotypes were made when discussing the public perceptions of those who are emotional. Some participants believed that the older generations (over 65 years) are more sympathetic or compassionate towards tearfulness. These participants believed that older individuals assume that they are grieving and can relate to this better than younger people. Male participants also often referred to societal assumptions about gender and beliefs about how men should not cry.

Participants reflected on how people easily misinterpret their laughing as a sign of humour and will laugh alongside them or encourage further laughter. This was often stressful or anxiety provoking for participants. One individual conveyed the disabling nature of her inappropriate laughter during a time where a passer-by misperceived her laughter and threatened her. She found this event incredibly frightening and consequently avoided public places.

“I was walking and laughing my head off, why I don’t know, [laughs] but the guy behind me, he thought that I was laughing with him or about him and then (he) stopped me and gave me abuse.” (Participant 9, <59 years, 68 weeks post-stroke, Barthel Index:20)

“It’s something that men don’t do... show their emotions. Men were always felt to be the stronger ones.” (Participant 18, >59 years, 8 weeks post-stroke, Barthel Index:6)

#### ***Theme 4: Convalescence***

This theme emerged from the process of participants' recovering from stroke and emotionalism. Participants conveyed the grief associated with their stroke and their struggle in reconciling their new emotional selves with their past identities. This theme further illustrated participants' coping responses and their determination to re-instate a sense of emotional equilibrium. The majority of participants reported noticing gradual improvements in their ability to manage their emotions as they recuperated from stroke. A desire to regain continuity or "getting back to normal" was commonly described by those who were at the earlier stages of stroke. Participants reflected on the challenge of adjusting their expectations when they did not fit with the reality of their recovery.

"It's getting better, it's just not... as good as (I) would've thought it would've been at this stage." (Participant 6, >59 years, 20 weeks post-stroke, Barthel Index:20)

Those who were in hospital with lower functional abilities regarded their physical recovery to be more of a priority than emotionalism.

"I'm thinking how I can get myself better. All the things I can do, physio-wise... this is more physical for me." (Participant 2, 59 years, 8 weeks post-stroke, Barthel Index:7)

The impact of emotionalism became more distressing as individuals progressed in their stroke recovery and experienced a plateau in their functional abilities.

"You're concentrating I think after the stroke on the physical side, you know and getting yourself back and trying to do things and what have you that you... its only after that

that... the emotional side kicks in and you start to realise the different problems it's causing." (Participant 11, >59 years, 32 weeks post-stroke, Barthel Index:18)

Participants developed various methods of coping with emotionalism, some strategies mentioned were humour, distraction or to just simply express it.

"I turn away and look at something or just concentrate on something else. I try to think about something else at that time, it helps." (Participant 16, <59 years, 28 weeks post-stroke, Barthel Index:12)

"We have a joke about it and then it's ok. My family are very good, especially my grandchildren, they tend to help by laughing it off and telling me it's alright."  
(Participant 18, >59 years, 8 weeks post-stroke, Barthel Index:6)

"I've accepted it, I just let it happen. It's easier that way." (Participant 5, <59 years, 40 weeks post-stroke, Barthel Index:20).

Other ways of coping were unhelpful, like self-criticism or avoidance.

"I'm a tearful fool and a blithering (sic) idiot who's just angry at the world."  
(Participant 8, <59 years, 64 weeks post-stroke, Barthel Index:20)

“I spend a lot of time on my own now, you know, pretending I’m alright. I don’t let people see me, it’s stupid I know but that’s just the way I cope.” (Participant 11, >59 years, 32 weeks post-stroke, Barthel Index:18)

The importance of remaining hopeful was strongly emphasised. Those who held a sense of hope and optimism about their continued recovery felt better equipped to manage the difficulties associated with emotionalism.

“Just say to yourself, well look this is just something that’s happened and you know why it’s happening, because of your stroke so you just have to try and ride this bit of the storm and see what you can put in play.” (Participant 14, <59 years, 44 weeks post-stroke, Barthel Index:18)

“Keep trying but be patient because if you lose patience then you lose heart... keep cheerful... Try to find happiness even if the day is dark, tomorrow might be a better day.” (Participant 9, <59 years, 68 weeks post-stroke, Barthel Index:20)

## **Discussion**

The uncontrollable nature of emotionalism was found to be detrimental to participants’ psychological well-being, although those who viewed emotionalism to be a physical consequence of stroke appeared less distressed. Research has demonstrated that individuals who attribute the cause of their illness to be due to psychological factors (i.e. mood, personality, stress or worry) experience greater levels of distress and a poorer quality of life [51].

Many participants reported distress related to their loss of emotional control since the onset of emotionalism, particularly participants who defined themselves as having high self-discipline. This extends on studies finding that those who hold a low sense of control or self-efficacy report greater levels of disability, anxiety and depression post-stroke [36,52].

Additionally, De Castella and colleagues found that those with low self-efficacy beliefs typically engage in more avoidance-based emotion regulation strategies and consequently report greater psychological distress [53].

Loss was common across all of the themes identified which is a well-known issue in adjusting to life post-stroke [54-58]. Participants frequently referred to a loss of emotional strength and of a lost sense of personal or social identity due to emotionalism. According to Dowswell and colleagues, loss occurs as the individual begins to compare their former and post-stroke selves [59]. This was especially challenging for participants who valued emotional resilience as part of their pre-stroke self.

The role that society plays on a person's assumptions about their emotional reactions and the shame attached to these was heavily emphasised (e.g. "*other people think that I'm a weak person who can't cope with life*"). Participants made multiple references to stigma and stereotypes that fit with socio-cultural views of the expression of emotion [60]. Shamir and Travis proposed that societal views of masculinity reinforce shame as crying is seen as a sign of weakness or of inferiority [61]. Many participants referred to the stigma associated with crying. Gillbert and Proctor described the experience of shame as to feel rejectable in the eyes of others, creating a desire to avoid [62]. Participants often reported avoiding others, employing safety behaviours (like always being with a family member) and using humour to minimise shame when they became emotional.

Social compassion and sympathy appeared to exacerbate participants' emotional reactions. As emotional displays are universal behaviours, people instinctively smile when they see others laugh and respond with empathy when they see someone crying [63]. Participants found the incongruence between their internal states (i.e. "*crying and I don't feel sad*") and the responses from others distressing. In addition, emotions shown by others were also likely to elicit exaggerated emotional responses in those with emotionalism (given that it is a disorder of emotional control). Frequent reference was made to the shame, guilt and embarrassment that this caused and of the desire to socially withdraw as a means of escape.

In the last theme, *Convalescence*, participants reflected on their coping mechanisms. Avoidance and social isolation were frequently referred to and are strong predictors of distress post-stroke [28,36]. Avoiding activity can lead to a loss of achievement or a sense of agency, consistent with behavioural models of depression. Similarly, avoiding social contact is likely to maintain a person's anxiety by preventing habituation to the social and cognitive consequences of emotionalism. Positive thinking as well as social and family support was found to have protective effects on participants' mental well-being, findings which are well supported in the stroke literature [15,64].

### ***Clinical implications***

The benefit of investigating patient attributions of illness is recognised in other health populations, though less so in stroke [52]. By focusing on patient experiences, clinicians can understand how patients conceptualise illness, the concerns that they have and in turn, the social or psychological drivers that might be influencing their approach to recovery. To this end, investigating dysfunctional beliefs about emotionalism and their relationship with coping may be the key to understanding individual differences in susceptibility to stroke-related emotional adjustment difficulties.

This study found that few participants understood the causes of their emotionalism, perhaps not a surprising finding as even stroke professionals struggle to identify emotionalism consistently [65]. In acute and non-specialist services, outbursts of emotions are often regarded to be part of a "normal" adjustment process which means that emotionalism is easily missed [22]. This has important clinical implications however, as poor understanding of health conditions is associated with greater social disability [23,30], reduced quality of life [22,58,9] and delay in help-seeking behaviours [66]. Indeed, few participants sought advice or support for emotionalism and it was found to be more distressing to participants in the months following discharge from hospital, as they began adjusting to their life after stroke. Kirkevold [67] argued that the transition from acute services to home is an important milestone, as the person

navigates the discrepancies between their expectations and the reality of their recovery. This is a critical period for patients to receive information and advice to manage emotionalism [68].

Lending support at this time may normalise the person's experiences, mitigate the development of dysfunctional beliefs and encourage them to adopt more realistic expectations about recovery.

Investigating whether individuals are struggling with a sense of lost emotional resilience as a consequence of emotionalism could guide interventions focused on reinstating the person's sense of control and self-efficacy through cognitive reappraisal or the teaching of self-management strategies.

Finally, the social embarrassment caused by emotionalism could be managed by clinicians encouraging their patients to explain emotionalism to others and by supporting them to give others advice about how best to respond to their emotional outbursts.

### ***Strengths and limitations***

Findings from this study contribute to our understanding of the psychological factors that underpin emotionalism. Its strength lies in the recruitment strategy, which covered a wide range of participants across cultures, ages and stages of stroke recovery. The use of Framework analysis meant that there was a systematic method for greater transparency in the generation of themes.

We excluded individuals with significant cognitive or language impairments. The experiences of those with emotionalism and aphasia or cognitive impairment may differ in the way that they perceive the condition, although four participants in the study did have mild communication difficulties. Participants were generally middle-aged from higher socio-economic backgrounds and in employment before their stroke, which may have influenced our findings, given that stroke is known to have a higher incidence and poorer prognosis in those with a lower socioeconomic status [69].

### ***Directions for future research***

Whilst the evidence-base for the efficacy of psychological interventions in emotionalism is lacking, it is a burgeoning area for research [16]. Individual case studies have shown promising preliminary results for reducing the emotional impact of symptoms [5,17]. Should future studies demonstrate that patient beliefs about emotionalism are valid predictors of emotional and social outcomes, then the themes generated from this study may be useful starting points to target or change through intervention. This could result in more meaningful and sustainable interventions being developed in the future.

### **Conclusion**

Emotionalism is poorly recognised and understood, both by professionals and patients themselves. The loss of control and unpredictable nature of symptoms can cause high levels of social embarrassment and psychosocial burden. In this study, isolation, self-criticism and misconstruing emotionalism as a psychiatric disorder were associated with increased emotional distress. Findings emphasise the importance of eliciting patient beliefs about their emotional reactions at the post-acute stages of stroke. Better recognition of emotionalism in clinical settings and earlier discussions could prevent patients from developing erroneous beliefs which may give rise to the development of mood problems later in their stroke recovery. Ultimately, further qualitative studies in this population are needed to improve our understanding. This will guide better healthcare interventions being developed for those living with this neurological condition.

### **References**

- [1] Stroke Association. State of the Nation: stroke statistics. 2018. Available at: [https://www.stroke.org.uk/system/files/sotn\\_2018.pdf](https://www.stroke.org.uk/system/files/sotn_2018.pdf). Accessed November 3<sup>rd</sup>, 2018.
- [2] Carota A, Calabrese P. Post-stroke Emotionalism. *Journal of Neurological Disorders*. 2013;65(6):928-9.
- [3] House A, Dennis M, Molyneux A, Warlow C, Hawton K. Emotionalism after stroke. *BMJ*. 1989;298(6679):991-4.
- [4] House A, Hosker C. Emotional disorders in neurological rehabilitation. *Handbook of Clinical Neurology*; 2013. p.389-398.

- [5] Kasprisin A. Alternative cognitive therapy for emotional instability (pathologic laughing and crying). *Physical Medicine and Rehabilitation Clinics of North America*. 2004;15(4):883-917.
- [6] Colamonico J, Formella A, and Bradley W. Pseudobulbar affect: Burden of illness in the USA. *Advances in Therapy*. 2012;29(9):775-98.
- [7] Gillespie DC, Cadden AP, Lees R, West RM, Broomfield NM. Prevalence of Pseudobulbar Affect following Stroke: A systematic review and meta-analysis. *Journal of Stroke and Cerebrovascular Diseases*. 2016;25(3):688-94.
- [8] Engelman W, Hammond FM, Malec JF. Diagnosing pseudobulbar affect in traumatic brain injury. *Neuropsychiatric Disease and Treatment*. 2014; 10:1903-1910.
- [9] Strowd RE, Cartwright MS, Okun MS, Haq I, Siddiqui MS. Pseudobulbar affect: prevalence and quality of life impact in movement disorders. *Journal of Neurology*. 2010;257(8):1382-7.
- [10] Cummings JL, Arciniegas DB, Brooks BR, Herndon RM, Lauterbach EC, Pioro EP, Robinson RG, Scharre DW, Schiffer RB, Weintraub D. Defining and diagnosing involuntary emotional expression disorder. *CNS spectrums*. 2006;11(6):1-7.
- [11] Maruzairi H, Koh CH. Pseudobulbar affect post stroke. *Brunei International Medical Journal*. 2015;11(1):59-61.
- [12] McCullagh S, Moore M, Gawel M, Feinstein A. Pathological laughing and crying in amyotrophic lateral sclerosis: an association with prefrontal cognitive dysfunction. *Journal of the Neurological Sciences*. 1999;169(1):43-8.
- [13] Leahy RL, Holland SJ, McGinn LK. *Treatment plans and interventions for depression and anxiety disorders*. Guilford Press; 2011. p.26.
- [14] Scottish Intercollegiate Guidelines Network. Management of patients with stroke: Rehabilitation, prevention and management of complications and discharge planning publication. 2010. Available at: <http://www.sign.ac.uk/pdf/sign118.pdf>. Accessed November 3<sup>rd</sup>, 2018.
- [15] Hackett ML, Yang M, Anderson CS, Horrocks JA, House A. Pharmaceutical interventions for emotionalism after stroke. *Stroke*. 2010;41(7):460-1.
- [16] Schneider MA, Schneider MD. Pseudobulbar Affect: What nurses, stroke survivors, and caregivers need to know. *Journal of Neuroscience Nursing*. 2017;49(2):114-7.
- [17] Perotti LP, Cummings LD, Mercado J. Behavioral Treatment of Pseudobulbar Affect: A Case Report. *Perspectives in Psychiatric Care*. 2016;52(2):82-7.
- [18] Bengaline A, Shapiro CM, Sockalingam S, Hawa RJ. Pathological Laughing and Crying Post-stroke: Liaison Psychiatrist Beware. *Journal of Neuropsychiatry*. 2016;2(1):1-12.
- [19] Sacco S, Sarà M, Pistoia F, Conson M, Albertini G, Carolei A. Management of pathologic laughter and crying in patients with locked-in syndrome: a report of 4 cases. *Archives of Physical Medicine and Rehabilitation*. 2006;13(6):353-79.
- [20] Tateno A, Jorge RE, Robinson RG. Pathological laughing and crying following traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences*. 2004;16(4):426-34.
- [21] George S, Wilcock A A, Stanley M. Depression and lability: The effects on occupation following stroke. *British Journal of Occupational Therapy*. 2001; 64(9):455-461.
- [22] Calvert T, Knapp P, House A. Psychological associations with emotionalism after stroke. *Journal of Neurology, Neurosurgery & Psychiatry*. 1998;65 (6):928-9.
- [23] Wei N, Yong W, Li X, Zhou Y, Deng M, Zhu H, Jin H. Post-stroke depression and lesion location: A systematic review. *Journal of Neurology*. 2015;262(1):81-90.
- [24] Ahmed A, Simmons Z. Pseudobulbar affect: prevalence and management. *Therapeutic Clinical Risk Management*. 2013;1(9):483-9.
- [25] Horrocks JA, Hackett ML, Anderson CS, House AO. Pharmaceutical interventions for emotionalism after stroke. *Stroke*. 2004;35(11):2610-1.

- [26] Carota A, Berney A, Aybek S, Iaria G, Staub F, Ghika-Schmid F, Annable L, Guex P, Bogousslavsky J. A prospective study of predictors of post-stroke depression. *Neurology*. 2005;64(3):428-33.
- [27] Taylor GH, Todman J, Broomfield NM. Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological Rehabilitation*. 2011;21(6):808-24.
- [28] Kneebone II, Lincoln NB. Psychological problems after stroke and their management: state of knowledge. *Neuroscience and Medicine*. 2012;3(1):83.
- [29] Campbell Burton C, Murray J, Holmes J, Astin F, Greenwood D, Knapp P. Frequency of anxiety after stroke: A systematic review and meta-analysis of observational studies. *International Journal of Stroke*. 2013;8(7):545-59.
- [30] Twiddy, M. Beliefs about stroke: negotiating shared understandings. Dissertation. University of Leeds. 2008.
- [31] Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*. 2003;18(2):141-84.
- [32] Whitmarsh A, Koutantji M, Sidell K. Illness perceptions, mood and coping in predicting attendance at cardiac rehabilitation. *British Journal of Health Psychology*. 2003;8(2):209-21.
- [33] Petrie KJ, Jago LA, Devcich DA. The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry*. 2007;20(2):163-7.
- [34] Harris C. Return to work after stroke. *Stroke*. 2014;45(9):174-6.
- [35] Foxwell R, Morley C, Frizelle D. Illness perceptions, mood and quality of life: A systematic review of coronary heart disease patients. *Journal of Psychosomatic Research*. 2013;75(3):211-22.
- [36] Van Mierlo ML, Van Heugten CM, Post MW, De Kort PL, Visser-Meily JM. Psychological factors determine depressive symptomatology after stroke. *Archives of Physical Medicine and Rehabilitation*. 2015;96(6):1064-70.
- [37] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013;3(1):117.
- [38] Guba EG, Lincoln YS. Competing paradigms in qualitative research. *Handbook of Qualitative Research*. 1994;2(163-194):105.
- [39] Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *International Disability Studies*. 1988;10(2):64-7.
- [40] Sangha H, Lipson D, Foley N, Salter K, Bhogal S, Pohani G, Teasell RW. A comparison of the Barthel Index and the Functional Independence Measure as outcome measures in stroke rehabilitation: patterns of disability scale usage in clinical trials. *International Journal of Rehabilitation Research*. 2005;28(2):135-9.
- [41] Mioshi E, Dawson K, Mitchell J, Arnold R, Hodges JR. The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*. 2006;21(11):1078-85.
- [42] Zigmond AS, Snaith RP. The Hospital Anxiety and Depression scale. *Acta Psychiatrica Scandinavica*. 1983;67(6):361-70.
- [43] Aben I, Verhey F, Lousberg R, Lodder J, Honig A. Validity of the Beck Depression Inventory, Hospital Anxiety and Depression Scale, SCL-90, and Hamilton Depression Rating Scale as screening instruments for depression in stroke patients. *Psychosomatics*. 2002;43(5):386-93.
- [44] Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. *Qualitative research practice: A guide for social science students and researchers*. 2003; (18):219-62.

- [45] Leventhal H, Meyer D, Nerenz D. The common-sense representation of illness danger. *Contributions to Medical Psychology*. 1980;1(2):7-30.
- [46] Nicholl CR, Lincoln NB, Muncaster K, Thomas S. Cognitions and post-stroke depression. *British Journal of Clinical Psychology*. 2002;41(3):221-31.
- [47] Smith JA and Eatough V. *Analysing Qualitative Data in Psychology*. 2007. p.35-50.
- [48] Gibbs GR. *Analysing qualitative data*. Sage; 2008. p.5.
- [49] Parkinson S, Eatough V, Holmes J, Stapley E, Midgley N. Framework analysis: A worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*. 2016;13(2):109-29.
- [50] MAXQDA software. Available at: <https://www.maxqda.com/products/maxqda-standard>. Accessed on November 3<sup>rd</sup> 2018.
- [51] Hoth KF, Wamboldt FS, Bowler R, Make B, Holm KE. Attributions about cause of illness in chronic obstructive pulmonary disease. *Journal of Psychosomatic Research*. 2011;70(5):465-72.
- [52] Thomas SA, Lincoln NB. Factors relating to depression after stroke. *British Journal of Clinical Psychology*. 2006;45(1):49-61.
- [53] De Castella K, Platow MJ, Tamir M, Gross JJ. Beliefs about emotion: implications for avoidance-based emotion regulation and psychological health. *Cognition and Emotion*. 2018;32(4):773-95.
- [54] Ellis-Hill CS, Payne S, Ward C. Self-body split: issues of identity in physical recovery following a stroke. *Disability and Rehabilitation*. 2000;22(16):725-33.
- [55] Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. *Journal of Rehabilitation Medicine*. 2008;40(8):595-602.
- [56] Sarre S, Redlich C, Tinker A, Sadler E, Bhalla A, McKevitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disability and Rehabilitation*. 2014;36(9):716-26.
- [57] Pluta, A, Ulatowska H, Gawron N, Sobanska M & Lojek E. A thematic framework of illness narratives produced by stroke patients. *Disability and Rehabilitation*. 2015;37(13):1170-1177.
- [58] Crowe C, Coen RF, Kidd N, Hevey D, Cooney J, Harbison J. A qualitative study of the experience of psychological distress post-stroke. *Journal of Health Psychology*. 2016;21(11):2572-9.
- [59] Dowswell G, Lawler J, Dowswell T, Young J, Forster A, Hearn J. Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*. 2000;9(4):507-15.
- [60] Butler EA, Lee TL, Gross JJ. Emotion regulation and culture: are the social consequences of emotion suppression culture-specific? *Emotion*. 2007;7(1):30.
- [61] Shamir M, Travis J. *Boys don't cry? Rethinking narratives of masculinity and emotion in the US*. Columbia University Press; 2002.
- [62] Gilbert P, Procter S. Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*. 2006; 13(6):353-79.
- [63] Keltner D, Gross JJ. Functional accounts of emotions. *Cognition & Emotion*. 1999;13(5):467-80.
- [64] Bronken BA, Kirkevold M, Martinsen R, Kvigne K. The aphasic storyteller co-constructing stories to promote psychosocial wellbeing after stroke. *Qualitative Health Research*. 2012; 22(10):1303-16.
- [65] Picton H. Post-stroke depression (PSD) and post-stroke emotional lability (PSEL): A systematic review of non-pharmacological interventions for PSD and a qualitative study of specialist professionals' conceptualisation of PSEL. 2014. *Edinburgh Research Archive*. Available at <https://www.era.lib.ed.ac.uk/handle/1842/97>. Accessed on November 3<sup>rd</sup>, 2018.

- [66] Stack RJ, Simons G, Kumar K, Mallen CD, Raza K. Patient delays in seeking help at the onset of rheumatoid arthritis: the problem, its causes and potential solutions. *Aging Health*. 2013;9(4):425-35.
- [67] Kirkevold M. The unfolding illness trajectory of stroke. *Disability and Rehabilitation*. 2002;24(17):887-98.
- [68] Burton CR. Re-thinking stroke rehabilitation: The Corbin and Strauss chronic illness trajectory framework. *Journal of Advanced Nursing*. 2000;32(3):595-602.
- [69] Addo J, Ayerbe L, Mohan KM, Crichton S, Sheldenkar A, Chen R, Wolfe CD, McKeivitt C. Socioeconomic status and stroke. *Stroke*. 2012;43(40):1186-91.