Title:

Emotional adjustment post-stroke:

a qualitative study of an online stroke community

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ABSTRACT

Understanding of emotional adjustment after stroke is limited. Under one-third of stroke survivors reporting emotional problems receive support. The aim of this study was to explore the process of emotional adjustment post-stroke and investigate the role played by participation in an online stroke community. We applied thematic analysis to 124 relevant posts within 114 discussion threads, written by 39 survivors and 29 carers. The contribution of online community engagement to emotional adjustment was explored using the Social Support Behaviour Code.

Stroke survivors share common experiences of emotional adjustment and may not necessarily reach complete acceptance. Positive and negative trajectories of emotional adjustment were identified. Survivors progressed along, or moved between, positive and negative pathways not in a time-dependent manner but in response to 'trigger events', such as physical setbacks or anti-depressant treatment, which may occur at any chronological time. An adapted version of Suhr's 1990 Social Support Behaviour Code showed that support provided through the online community took many forms, including advice, teaching, empathy and normalisation of concerns. Participation in the stroke community was itself deemed to be a positive 'trigger event'.

There is need to improve awareness of emotional adjustment and their 'triggers' amongst stroke survivors, carers and clinicians.

INTRODUCTION

In the UK over 100,000 people suffer a stroke each year[1] and there are over 950,000 stroke survivors aged 45+. This number is expected to increase by 123% by 2035[2]. Whilst the physical impact of stroke has been well documented, the psychological impact is also receiving increasing research attention.[3] Indeed, an accumulating body of evidence suggests that stroke results in a long-term emotional adjustment process, with more than one third reporting unmet needs in this respect and only 27% having their emotional needs addressed within the traditional healthcare system.[4] A recent systematic review including international studies of long-term unmet needs after stroke reports a similar prevalence of unmet needs in the context of emotion/mood (39%, range 3.3- 72.8%).[5]

Psychological interventions that have a good evidence base outside of the stroke population (such as Cognitive Behavioural Therapy) yield at best mixed outcomes post-stroke, with behavioural[6] and motivational interventions[7] showing best effects. The 'stages of loss' model has been applied to summarise emotional effects of stroke in terms of shock and acceptance.[8] Anxiety is also prevalent after stroke,[9] often co-morbid with depression, with standard psychological interventions for anxiety also appearing of limited usefulness post-stroke. It has been suggested that psychological interventions have failed as they have not addressed the variables known to precipitate and prolong distress, or facilitate positive psychological adaptation after stroke.[10,11,12] Research has helped to identify a number of such variables. Qualitative work highlights the background of loss, uncertainty, social isolation and difficulties with developing a 'new self' post -stroke. [13,14] Quantitative studies identify the potential contribution of stroke severity and level of impairment[15] in addition to psychological variables related to appraisals and coping.[16] In particular, these authors found evidence that a combination of personality, illness cognitions, passive or avoidant coping style, acceptance and self-efficacy were key psychological predictors of depression.[17] Degree of self-discrepancy also appears associated with levels of anxiety and depression.[18] Those who are able to maintain their social identities post-stroke also appear to fair better emotionally.[19]

Despite this, rehabilitation approaches that specifically address personal and social identity changes through intervention or outcome measurement are limited.[20] Gracey and colleagues propose models of psychological intervention that seek to address identity changes through a focus on personally significant moments.[12,12,21] In keeping with van Mierlo et al,[17] Taylor et al[22] present a model of post-stroke adjustment to guide intervention which incorporates the appraisals or illness cognitions that arise in response to stroke and its sequelae. These authors argue that a dynamic process arises post stroke where people evaluate and modify their post-stroke appraisals and coping responses over time, resulting in different and changing emotional adjustment status. However, further evidence to support these intervention models is required.[11,18]

Online peer support communities – new opportunities for support

In recent years there has been an increase in the number of online peer support communities, created to support the psychosocial needs of individuals (and their wider networks) who live with a long-term condition. A growing body of evidence has described a range of therapeutic affordances which community members may experience through their online engagement.[23,24] In particular, asynchronous text-based online support communities (e.g. discussion forums) provide individuals the opportunity to share personal stories regarding their illness experience with similar others and to learn how to accept and adjust to life living with a long-term condition. Through the generation and consumption of online content, members of online support communities who have had a stroke, may find engaging with peers through these online platforms a beneficial and supportive activity.[25]

In addition to the psychosocial benefits arising from engagement with online support communities, such discussion forums also provide a rich and extensive repository of illness narratives. Such narratives may represent an important source of data for researchers as they have been generated organically without interference or agenda-setting on the part of the researcher. Furthermore, there is evidence to suggest that individuals may present a more honest and authentic account of their illness experiences online[26] and this may help researchers obtain a fuller account of a particular issue or experience.

In this current study, we aimed to explore post-stroke emotional adjustment through the analysis of online narratives. This in turn would help us understand both the nature of the process of emotional adjustment as well as the role of online peer support communities.

METHODS

Design

We carried out qualitative thematic analysis of stroke survivors' and carers' posts on an online forum.

Setting

Thematic analysis was conducted using the archived 2004-2011 Talkstroke online forum, a UK based moderated online forum hosted by the Stroke Association website. The forum was set up as part of the charity website with the scope of facilitating online communication between stroke survivors and caregivers, sharing information on any aspect of stroke. In total, the archives included 22,173 posts, written by 2,583 unique usernames.[23]

Ethics

The Stroke Association provided access to the archived forum and gave their permission for the data to be used for this research purpose. Talkstroke data were stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS). Users of the forum had previously agreed that their data would become public upon registration within the forum. In order to protect the identity and intellectual property of forum participants, direct quotes have not be used, despite this being normal practice in qualitative research. Summative descriptions of quotes will instead be used throughout the paper. De Simoni et al (2016)[23] reports a detailed description of the ethics linked to the research on the Talkstroke archives.

Identification of study participants

At first, a scoping exercise was undertaken using keywords linked to the terms ‘emotion’ and ‘depression’, which yielded a large number of posts. Familiarisation with the retrieved posts highlighted the string 'come to terms with' as key to selecting posts about emotional adjustment after stroke, written by stroke survivors at various stages of recovery, and those caring for them. Characteristics of stroke survivors including demographics (see Table 1) were retrieved from the usernames linked to the identified posts, taking advantage of data from a previous study.[23,27] The demographics shown after quotes are those of the stroke survivors themselves, as reported by patients themselves or by their caregivers.

Analysis

Relevant posts were then analysed using thematic analysis, as described by Braun and Clarke.[28] Two authors (CJ and FS) read through all posts to become familiar with the data and patient narratives, and to identify characteristics from stroke survivors including demographics, stroke type and residual impairments. One author (CJ) selected the posts about emotional adjustment, which were analysed

using Excel. In order to collate themes of emotional adjustment after stroke, an initial coding framework grounded approach was developed by one author (CJ); this was subsequently adjusted as more posts were analysed. Coding was then performed independently by a second author (FS), overseen by ADS. Coding was discussed until agreement was reached and a final coding framework was agreed.

The same posts were used by FS to explore the role of online forum participation in emotional adjustment after stroke, using the existing model of the Social Support Behaviour Code[29] (SSBC) as a framework to identify types of social support provided through engagement with the online forum. The SSBC has been previously used for the analysis of online community data.[30,31,32] Coding was discussed with ADS until agreement was reached. This resulted in the addition of novel categories and removal of irrelevant categories (i.e. provision of realistic expectations; normalisation; providing comfort; requests for clarification to inform peer support), as seen in Table 2.

RESULTS

Characteristics of forum users included in the study

Out of the 181 posts identified using the string 'come to terms with', 124 focused on the process of emotional adjustment after stroke and were thus deemed relevant to our research question. Posts were classified as irrelevant if 'come to terms with' was used in a different context.

69 participants were identified from the 124 relevant posts. 39 were stroke survivors who posted on the forum themselves, 29 were carers or relatives of stroke survivors, while one was a healthcare professional. 36 participants were male, 26 were female and 6 did not state their gender. The mean age of users (including both stroke survivors and patients talked about by their relatives) was 50.3, ranging from 13-83, median 48.5 (Table 1). 39/69 participants took part in the forum within the first year after stroke, while 14/69 after more than 2 years.

Themes

Themes are grouped according to the two main research objectives: to characterise the process of emotional adjustment after stroke, and to understand the role of online forum engagement in this process.

A number of themes were common to the emotional adjustment of most stroke survivors, divisible into generally positive and negative adjustment trajectories. In some cases users made it clear whether they considered themselves to be moving along a positive or negative trajectory, in others cases this was a subjective interpretation by CJ, FS and ADS, taken in the context of all posts each individual user wrote about emotional adjustment.

The timescales of emotional adjustment differed greatly between individuals. Whilst it could take few months for some stroke survivors to complete the process of emotional adjustment and reach acceptance, some patients still had not reached acceptance by eight years post-stroke. Therefore, fitting themes into specific timeframe boxes was not appropriate. However, it was possible to broadly group emerging themes of emotional adjustment into immediate, intermediate, final or 'ongoing adjustment' experiences, as shown in Figure 1.

Contrary to our expectations, stroke survivors did not necessarily remain on one trajectory throughout their emotional adjustment timeline. Instead, stroke survivors could move between positive and negative trajectories many times throughout their unique timeline of emotional adjustment, as a result of 'trigger events' such as reaching the end of physiotherapy or starting a course of antidepressant medication. Trigger events are outlined in Figure 1, shown between the positive and negative trajectories.

The positive trajectory

Immediate adjustment

Some individuals were seen to almost immediately embark on a positive trajectory of emotional adjustment. Survivors at this stage of adjustment were already making attempts to start their recovery journey.

> *One carer described their relative as being particularly cheerful and optimistic in the immediate aftermath of his stroke, although this later changed. (M, age 52, age at stroke 51, N63)*

The main themes at this stage were of cheerfulness and optimism, along with a new appreciation of life.

> *One survivor described her feelings in the immediate aftermath of her stroke, stating that it wasn't until she had thought that she was going to die that she had begun to appreciate living. (F, age 43, age at stroke 37, N20)*

Intermediate adjustment

Posts belonging to the early and intermediate phases were classified as such when not belonging to the first immediate or long-term adjustment phases, using a 'by exclusion' approach. Posts falling within 'early' and 'intermediate' periods of emotional adjustment were initially analysed separately. Later it became evident that the themes emerged at both early and intermediate stages of emotional adjustment were similar and therefore reported together as 'intermediate adjustment'.

During the intermediate stage, survivors began to make positive changes to their lifestyle and to accept their 'new self' through gained emotional strength and determination.

> *One survivor stated that, four months after her stroke, she no longer lived to work, as the stroke had made her realise what was important. (F, age 46, age at stroke 46, N2)*
>
> *One survivor stated that, after three years, whilst he was still struggling to come to terms with his new fatigue, he was coping well with the physical challenges post-stroke. (M, age 50, age at stroke 47, N46)*

Some survivors maintained their sense of humour, and felt lucky or grateful to be alive.

> *One survivor stated that, 10 weeks on, his stroke was history and that he now needed to accept that it had happened, and to do his best to move on from it. He knew that he was lucky to have survived. (M, age 53, age at stroke 52, N65)*
>
> *One carer stated that, four weeks after suffering from stroke, their relative had not lost her sense of humour, and was coping with the situation brilliantly. (F, age 75, age at stroke 75, N22)*

Through the process of emotional adjustment, survivors developed a sense of perspective on the situation.

> *After 18 months, one survivor made it clear that she realised many people were worse off than herself. (F, age 40, age at stroke 39, N21)*

This was often helped by receiving explanation of the cause of the stroke, which for many provided intense relief.

One survivor had, after three years, met another survivor of the same type of stroke, and described relief at being able to talk to someone who had experienced the same situation. (M, age 50, age at stroke 47, N46)

Acceptance

Intrinsically, acceptance of the stroke meant acceptance of the emotional changes that it had caused. Indeed, after varying lengths of time post-stroke, a number of survivors stated that they had entirely come to terms with their 'new self'.

One survivor described how it took her at least two years to come to terms with the 'new self' after stroke. Once she had done so, her life had improved dramatically. (M, age 67, age at stroke 57, N52)

<u>The negative trajectory</u>

Immediate adjustment

Many survivors began their journey of emotional adjustment on the negative trajectory, describing feelings of shock, confusion, anger and isolation.

A survivor suggested to another user that their relative might be feeling angry and frustrated, as unable to work out what had happened and why it had happened to him. (M, age 55, age at stroke 54/55, N51).

One survivor experienced a delayed diagnosis of stroke, and remembered being overwhelmed by the shock immediately after being told that she had suffered a stroke. (F, age 37/38, age at stroke 36-38, N45).

Drawing on her own experiences, a stroke survivor suggested that patients may feel that they have been left alone to come to terms with their stroke in the immediate aftermath of their diagnosis. (F, age 54, age at stroke 53/54, N59).

These feelings often occurred alongside other warning symptoms that could be associated with depression.

One survivor described feeling miserable and alone immediately after her stroke. (F, age 57, age at stroke unknown, N10).

Survivors wanted to know why the stroke had happened to them, and needed time to come to terms with what had happened. For many, there was an immediate realisation that their life had changed forever.

One survivor remembered asking everyone why it had happened to him, in the first days after his stroke. (M, age 45, age at stroke 42, N44)

One survivor stated that his life had come to a halt immediately after his stroke. (M, age 44, age at stroke 43/44, N60)

Intermediate adjustment

As for the positive trajectory, posts falling in the 'early' and 'intermediate' stages of negative adjustment were initially analysed separately, though it later became evident that similar themes emerged and were therefore reported together as 'Intermediate adjustment'.

By this point in the negative trajectory, many survivors had begun to develop symptoms of mood disturbances.

> *In the year after her stroke, one survivor described low energy levels, a lack of interest in doing anything, loss of appetite and constant nausea. (F, age 46, age at stroke 46, N2).*

Others suffered emotional lability, alongside loneliness, withdrawal and fear.

> *At four months post-stroke, one survivor described finding it very hard to be around other people, and simply wanting to hide herself away. She also stated that she often found herself becoming tearful for no discernible reason. (F, age 46, age at stroke 46, N2).*

Some also showed signs of denial or reported having lost a great deal of confidence.

> *One survivor describes not wanting to admit that she had suffered a stroke for many years after the event itself. (F, age 54, age at stroke 46, N1).*
>
> *Around four months post-stroke, a stroke survivor suggested that another user's relative must have repeatedly suffered blows to his confidence after experiencing fits. (M, age 57, age at stroke 56/57, N36).*
>
> *One survivor described feeling paranoid and vulnerable in the first year post-stroke as she had not been told the cause of her stroke. (F, age 39, age at stroke 39, N28).*

A number felt guilty, either about lifestyle habits which might have led to their stroke, or about the burden they felt their stroke was putting on their loved ones.

> *One survivor describes an intense awareness over the 18 months since her stroke that her family have not found the situation easy. (F, age 48, age at stroke 46, N41).*

These feelings often occurred alongside frustration and anger.

> *One carer described their loved one's frustration after 18 months of living with aphasia. (M, age 71, age at stroke 69/70, N31)*
>
> *One carer described how their relative had, after remaining cheerful and optimistic in the immediate aftermath of his stroke, over the subsequent 18 months become tired, frustrated and angry realising the functions that he had lost. (M, age 52, age at stroke 51, N63)*

As it becomes more apparent that changes are to remain in the long-term, survivors appeared to develop feelings of despair and grief for their 'old self', along with new illusions of worthlessness, ineptitude and demoralisation.

> *Due to the negative reactions of those around her and an unstable social situation, one survivor describes wanting to hide away and cover herself. She stated that her self-esteem was at rock-bottom. (F, age 48, age at stroke 46, N41).*

A carer explained how, 18 months post-stroke, their relative felt increasingly demoralised whenever he met another survivor whom he believed to be recovering at a greater rate. (M, age 71, age at stroke 69/70, N31).

A survivor describes how, for five years after his stroke, he felt worthless and inept, despairing at his situation. (M, age 42, age at stroke 37, N39).

Another survivor describes feeling as if they are living in a stranger's body. After two years, they still did not feel like the person they used to be. (Unknown gender, age 32, age at stroke 30, N67).

Ongoing adjustment

Our analysis showed that survivors could remain on the negative trajectory until they were eventually able to transfer to the positive trajectory by reaching acceptance, at which point their emotional adjustment journey could terminate. The stage of incomplete acceptance could last for many years, with some survivors stating that they would have never come to terms with their situation.

After five years, one survivor described how she remained self-conscious about her aphasia. (F, age 54, age at stroke 46, N1).

One survivor described how they remained reliant upon anti-depressant medication, over six years after suffering a stroke. (M, age 58, age at stroke 57, N53)

One survivor describes how, eight years post-stroke, she has only just come to terms with her stroke. (F, age 54, age at stroke 46, N1)

Trigger events

Moving from the positive to the negative trajectory

A number of 'trigger events' were identified as having the potential to cause a survivor to move from the positive trajectory to the negative trajectory (see Figure 1), thus hindering their journey to acceptance. The prevailing theme of such triggers was a feeling of abandonment, with many survivors describing the ending of their physiotherapy treatment, discharge from hospital or admission to residential care as the triggers which moved their emotional adjustment to the negative trajectory.

One survivor describes feeling like she had been abandoned and left on the scrap heap after her physiotherapy treatment ended. (F, age 42, age at stroke 40, N24).

One carer believed that her relative had felt betrayed after the family had been forced to place him in a residential care home. (M, age 77, age at stroke 76/77, N26).

One carer suggested that their relative had felt something of an anti-climax after returning home from hospital. (gender unknown, age unknown, age at stroke unknown, N32).

Physical setbacks such as new seizures or new loss of function also caused movement of survivors from the positive to the negative emotional trajectory.

One carer stated that his relative was finding physical setbacks very hard to come to terms with, and was withdrawing into himself as a result. (M, age 52, age at stroke 52, N35).

Criticism from family and friends also played a large role in moving survivors from a positive to negative trajectory of emotional adjustment.

> *One survivor described how she had given up on trying to achieve anything because of the negative views she had received from those around her about how much she would be able to manage. (F, age 48, age at stroke 46, N41)*

Moving from the negative to the positive trajectory

Trigger events also had the ability to move a survivor from the negative to the positive trajectory, thus enabling their journey to acceptance. The prevailing trigger was interpersonal support, be this from family, friends, stroke support groups, professional therapy, face-to-face or online peer support.

> *One carer described that their relative had become a lot happier since returning home to be with her family. (M, age 77, age at stroke 76/77, N26).*
>
> *A survivor described how the high number of* [social] *activities taking place in hospital had helped her to come to terms with what had happened. (F, age 42, age at stroke 40, N24).*
>
> *A carer believed that it would have helped her relative to come to terms with his situation if he had been able to meet other stroke survivors through a peer support service. (M, age 71, age at stroke 69/70, N31).*
>
> *Another carer agreed with* [N31]*, stating that it had very much helped to meet other people with aphasia. (M, age 50, age at stroke 50, N38).*
>
> *A survivor stated that she felt inspired by others on the forum. (F, age 25, age at stroke 24/25, N50).*
>
> *One survivor described how he had gained confidence due to support from family and friends. (M, age 43, age at stroke 41, N49).*

Anti-depressant therapies also appear to be of help to several stroke survivors.

> *A survivor explained how antidepressants had given her the strength to pick herself up and come to terms with what had happened to her. (F, age 39, age at stroke 39, N28).*

Provision of a causal explanation of stroke was also an important trigger allowing survivors to finally accept their situation, allowing closure of the emotional adjustment journey.

> *One survivor described how much of a difference it had made to her to know the cause of her stroke. She was now loving life, and taking part in everything. (F, age 39, age at stroke 39, N28).*
>
> *A survivor agreed* [with N28], *suggesting that another user would find it easier to come to terms with the condition once a cause had been found. (F, age 56, age at stroke 50, N43).*

The role of the online forum in emotional adjustment

The role of the online forum in the process of emotional adjustment was examined using Suhr's 1990 model of the Social Support Behaviour Code.[9] This was subsequently amended to more appropriately represent the data within this project, as seen in Table 2. 14 of the 22 support types from Suhr's original

model were retrieved in our analysis, with the exception of loaning, provision of a direct or indirect task, active participation, access, relationship, physical affection, confidentiality and listening. A number of these excluded categories were not relevant to online interaction, due to the style of communication. Four categories were added, as they were deemed to be significantly represented within the forum: provision of realistic expectations, normalisation, providing comfort and requests for clarification to inform peer support.

Posts often contained more than one type of social support. The breakdown of post types within the forum is also shown within Table 2. The majority of support provided within the forum was in the form of prayer or wellwishing (n=23), offering suggestions or advice (n=21), understanding or empathy (n=19) and validation of feelings (n=15).

DISCUSSION

In this study we unpacked the process of emotional adjustment after stroke by applying thematic analysis to the posts written by 69 forum participants, including stroke survivors and patients with stroke described by their carers. Participants took part in the online stroke community at different times and degrees of their emotional adjustment journey after stroke.

The main finding of the study is the non-linear progression of experiences of post-stroke emotional adjustment, which appears to oscillate between positive and negative trajectories as result of trigger events. This is in keeping with the description of 'good and bad days', often reported by patients who suffered from stroke.[33]

Some stroke survivors experienced long-lasting incomplete acceptance of stroke. Trigger events, such as social support, could be positive and take stroke survivors from negative to positive trajectories or allow them to move along the positive trajectory towards acceptance of stroke and their 'new self'. Conversely, negative trigger events such as cessation of physiotherapy could take patients from positive to negative trajectories, thus hindering their progression to acceptance of their stroke.

Our results highlight the role of participation in an online stroke community in providing support. Participation in the forum was itself a beneficial trigger for progression of emotional adjustment along the positive trajectory, or for movement from the negative to positive trajectory, thus aiding progression towards emotional acceptance of stroke. For survivors and carers the online forum provided an open space to ask questions and share thoughts. Participants expressed comfort at reading the stories of other survivors or carers, whilst at the same time stating their gratitude for providing valuable assistance in a time of need.

A strength of this work lies in the self-initiated nature of the data provided by the online stroke community and the potential to analyse patients' perspectives at the time they were actually experiencing issues with post-stroke emotional adjustment.[34] Such data are less likely to be affected by self-presentation, reactivity and recollection biases, or by the influence of the researcher's agenda.[35] In addition, posting a message to peers, i.e. people 'in the same boat', meant being able to get in contact with people who had similar understanding of the process of post-stroke emotional adjustment.

A main limitation of this approach is the inability to ask follow-up questions to participants. Information about participants such as age at stroke and gender was limited to what they chose to reveal within their posts. Forum participants were younger compared to most patients with stroke, therefore the views on emotional adjustment in older patients might be under-represented within this data. For 80% of participants the issues of emotional adjustment discussed within the forum were largely those experienced within the first 24 month post-stroke, therefore may under-represent more long-lasting features of emotional adjustment. The string 'come to terms with' that was used to select

posts and participants may have missed relevant posts. Mood disturbances described within the negative trajectory could explained as clinical sequalae of particular types of strokes rather than emotional adjustment. Similarly, some participants might have initially been following a positive trajectory of emotional adjustment due to lack of full awareness of the effects of their stroke. Oscillations between positive and negative trajectories would have been better documented through analysing messages written by the same participants during their emotional adjustment journeys, tough this was not possible due to the small number of posts available from each individual. Forum data originated either from a population of stroke survivors who were 'computer-literate online forum users' (a selected population of stroke survivors) or from family members or friends of stroke survivors (representing more widely the population of stroke survivors who might not be computer-literate). The posts analysed dated between 2004 and 2011, and support from stroke services received by participants at the time may not reflect current practice. The forum was moderated and some of the posts might have been removed or affected by the moderation process.[19]

Eight of the 22 original Social Support Behaviour Code categories were not represented. This was down to the geographical separation of forum users, limiting social support types requiring face to face interaction such as loaning, provision of tasks and active participation. [36] On the other side, the 'comfortable emotional distance' provided by the forum worked as an enabler for the interaction with peers online.[37] Due to the public nature of posts on the forum, promises of confidentiality were also not possible, despite this being relevant to emotional wellbeing. Therefore participation in an online community may not fully provide emotional support to users.[30]

The results presented are consistent with previous findings, [3,4,13] and with models that highlight how meaning making or appraisals of the stroke and its consequences[22] evolve dynamically over time. The results also provide a novel understanding of the process of emotional adjustment, highlighting how specific moments or 'triggers' (and the meanings or appraisals of them) can move emotional adjustment processes from positive to negative trajectories and *vice versa*.

This study has clinical and research implications. First, it highlights the need of improving awareness of healthcare and rehabilitation professionals of the kinds of 'moments' or 'triggers', with the prevailing trigger for moving from negative to positive being interpersonal support. This knowledge can assist with successful adaptation and meaning-making[38] when consulting patients and their carers. For example, it might be important to make sure that rehabilitation plans include engagement with appropriate opportunities for social connection post-discharge to guard against 'negative triggers' of feelings of abandonment as well as providing opportunities for finding positive meanings. Second, it demonstrates the need of further research exploring the potential of harnessing online peer support as a way to access support, ~~and~~ alternative narratives and discourses and normalisation of experiences[39] that can assist in the emotional adjustment process. Third, our results highlight the role of

antidepressant therapy as a positive trigger for emotional adjustment,[9] which deserves further research attention.

CONCLUSION

This analysis provides novel insight into the process of emotional adjustment post-stroke and highlights the value of engaging with an online community. There is need to improve awareness of themes of emotional adjustment and their 'triggers' amongst stroke survivors, carers and clinicians. Further research is required to understand the effects potential of the integration of online peer support into rehabilitation programmes.

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Conflict of Interest: none.

Table 1. Characteristics of the Talkstroke Online participants as identified in the posts.
M, F, NS stand for Males, Females, not stated.

Sample characteristics	N	Mean		
Total number of participants	69			
Age at stroke		50.3		
Participants' posts				
Number of posts on the forum /participant		136.2		
Number of posts about emotional adjustment /participant		1.8		
Identity person posting		**M**	**F**	**NS**
Stroke survivor	39	15	19	5
Carer	29	22	7	0
Other	1	0	0	1
Time since stroke (months)				
$0 < T \leq 3$	15			
$3 < T \leq 6$	9			
$6 < T \leq 12$	16			
$12 < T \leq 24$	8			
$T > 24$	14			
Not stated	7			

Table 2. Adapted Social Support Behaviour Code *(Adapted from Suhr's 1990 model, additions shown in italics)*

Support type	**Example of support within forum**	**Number of posts**
Informational support		
Suggestion/advice	A recommendation that attending a local stroke club is a good way to come to terms with post-stroke emotional changes.	21
Referral	Redirection of a new member to a forum aimed at younger survivors, where they may receive more tailored support.	3
Situation appraisal	A re-evaluation of the difficulties of being in a wheelchair.	9
Teaching	An explanation of the physiology behind post-stroke changes.	11
Provision of realistic expectations	*A statement of the fact that a survivor may need to come to terms with never knowing the cause of their stroke.*	*8*
Tangible assistance		
Willingness	One user tells another that they are happy to answer any questions that they might have about their stroke.	5
Esteem support		
Compliment	One user compliments other forum users on their bravery, and states that they are an inspiration to her.	4
Validation	One user states that they completely concur with the emotional response of another user.	15
Relief of blame	One user reassures another that they don't need to feel guilty about their negative feelings.	1
Network support		
Presence	One user offers the forum as a place another survivor can come for support from others.	4
Companions	One user tells another that their physical and emotional experiences seem very similar.	7
Normalisation	*One user reassures another that their symptoms are common to most survivors.*	*5*
Emotional support		
Sympathy	One user expresses sorrow at another's story.	2
Understanding/empathy	One user recalls their own story in order to express understanding for another's emotional response.	19
Encouragement	One user reassures another that some are able to see past a disability, and not to give up on trying to find a partner.	14
Prayer/wellwishing	One user wishes another luck with their rehabilitation.	23
Providing comfort	*One user reassures another that they will tolerate an investigation, and explains the process further to relax them.*	*1*

Other		
Requests for clarification to inform peer support (i.e. users asking for more information about another user's problem to ensure that they give the best advice possible)	*One user asks another how their condition has progressed since their original post.*	*4*

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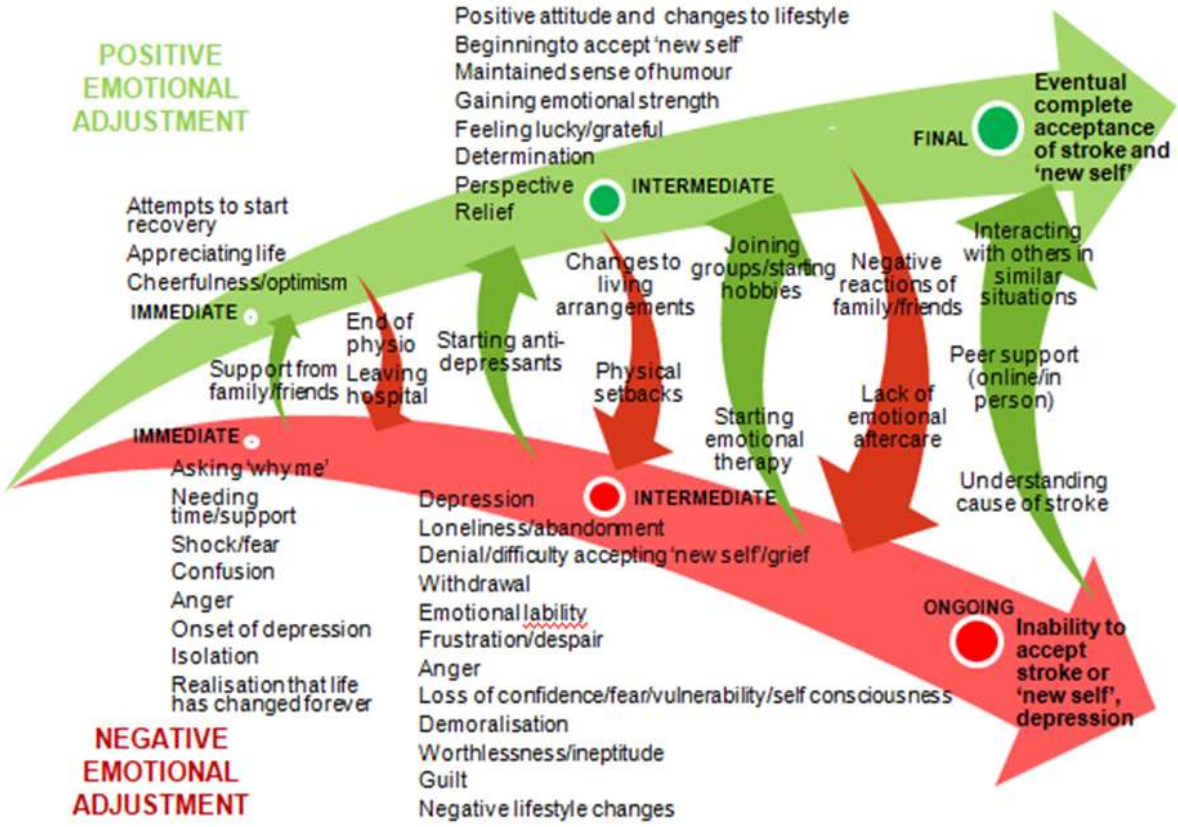

Figure 1. Positive and negative trajectories of emotional adjustment after stroke.

1 References

[1] Stroke Statistics. (2018). *The Stroke Association*. https://www.stroke.org.uk/system/files/sotn_2018.pdf

[2] Current, future and avoidable costs of stroke in the UK. (2017). *The Stroke Association*. https://www.stroke.org.uk/sites/default/files/costs_of_stroke_in_the_uk_report_-_executive_summary_part_1.pdf

[3] Pindus, D.M., Mullis, R., Lim, L., Wellwood, I., Rundell, A.V., Abd Aziz, N.A., & Mant, J. (2018). Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS One*, *21*;13(2):e0192533. doi: 10.1371/journal.pone.0192533.

[4] McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A.R., …Wolfe, C.D. (2011). Self-reported long-term needs after stroke. *Stroke, 42*(5):1398-403.

[5] Chen, T., Zhan, B., Deng, Y., Fan, J.C., Zhang, L. & Song F. (2019). Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open. 19*;9(5):e028137. doi: 10.1136/bmjopen-2018-028137.

[6] Thomas, S. A., Walker, M. F., MacNiven, J. A., Haworth, H., & Lincoln, N. B. (2013). Communication and low mood (CALM): A randomized controlled trial of behavioural therapy for stroke patients with aphasia. *Clinical Rehabilitation*, *27*(5), 398–408. http://doi.org/10.1177/0269215512462227

[7] Watkins, C.L., Auton, M.F., Deans, C.F., Dickinson H.A., Jack, C.I., Lightbody, C.E., …Leathley MJ. (2007). Motivational interviewing early after acute stroke: A randomized, controlled trial. *Stroke*, *38*(3):1004-9 http://doi.org/10.1161/01.STR.0000258114.28006.d7

[8] Kübler-Ross, E. (1969). On Death and Dying, Routledge, ISBN 0-415-04015-9.

[9] Ayerbe, L., Ayis, S. A., Crichton, S., Wolfe, C. D. A., & Rudd, A. G. (2014). Natural history, predictors and associated outcomes of anxiety up to 10 years after stroke: The south london stroke register. *Age and Ageing*, *43*(4), 542–547. http://doi.org/10.1093/ageing/aft208

[10] Broomfield, N. M., Laidlaw, K., Hickabottom, E., Murray, M. F., Pendrey, R., Whittick, J. E., & Gillespie, D. C. (2011). Post-stroke depression: The case for augmented, individually tailored cognitive behavioural therapy. *Clinical Psychology and Psychotherapy*, *18*(3), 202–217. http://doi.org/10.1002/cpp.711

[11] Brands, I. M. H., Wade, D. T., Stapert, S. Z., & van Heugten, C. M. (2012). The adaptation process following acute onset disability: an interactive two-dimensional approach applied to acquired brain injury. *Clinical Rehabilitation*, *26*(9), 840–52. http://doi.org/10.1177/0269215511432018

[12] Gracey, F., Ford, C., & Psaila, K. (2015). A provisional transdiagnostic cognitive behavioural model of post brain injury emotional adjustment. *Neuro-Disability and Psychotherapy*, *3*(3), 154–185.

[13] Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *J Rehabil Med*, *40*(8), 595–602.

[14] Satink, T., Cup, E. H., Ilott, I., Prins, J., de Swart, B. J., & Nijhuis-van der Sanden, M. W. (2013). Patients' views on the impact of stroke on their roles and self: a thematic synthesis of qualitative studies. *Arch Phys Med Rehabil, 94*(6), 1171–1183.

[15] Hackett, M.L. & Anderson, C.S. (2005). Predictors of depression after stroke: a systematic review of observational studies. *Stroke*, *36*(10):2296-301.

[16] Visser, M.M., Heijenbrok-Kal, M.H., Spijker, A.V., Oostra, K.M., Busschbach, J.J. & Ribbers, G.M. (2015) Coping, problem solving, depression, and health-related quality of life in patients receiving outpatient stroke rehabilitation. *Arch Phys Med Rehabil*, *96*(8):1492-8. doi: 10.1016/j.apmr.2015.04.007.

[17] van Mierlo, M. L., van Heugten, C. M., Post, M. W., de Kort, P. L., & Visser-Meily, J. M. (2015). Psychological factors determine depressive symptomatology after stroke. *Arch Phys Med Rehabil*, *96*(6), 1064–1070. http://doi.org/10.1016/j.apmr.2015.01.022

[18] Ellis-Hill, C. S., & Horn, S. (2000). Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clin Rehabil*, *14*, 279–287. Retrieved from http://dx.doi.org/

[19] Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: social identity continuity predicts well-being after stroke. *Neuropsychol Rehabil*, *18*(5–6), 671–691. http://doi.org/789110948 [pii] 10.1080/09602010701643449

[20] Ownsworth, T., & Haslam, C. (2016). Impact of rehabilitation on self-concept following traumatic brain injury: An exploratory systematic review of intervention methodology and efficacy. *Neuropsychological Rehabilitation*, *26*(1), 1–35. http://doi.org/10.1080/09602011.2014.977924

[21] Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A "Y-shaped" model. *Neuropsychological Rehabilitation*, *19*(6), 867–890. http://doi.org/10.1080/09602010903027763

[22] Taylor, G.H., Todman, J., Broomfield, N.M. (2015). Post-stroke emotional adjustment: a modified Social Cognitive Transition model. *Neuropsychol Rehabil, 21*(6):808-24. doi: 10.1080/09602011.2011.598403.

[23] De Simoni, A., Shanks, A., Balasooriya-Smeekens, C., & Mant, J. (2016) Stroke survivors and their families receive information and support on an individual basis from an online forum: descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants. *BMJ Open, 6*:e010501.doi: 10.1136/bmjopen-2015 010501

[24] Coulson, N.S., Bullock, E., & Rodham, K. (2017). Exploring the Therapeutic Affordances of Self-Harm Online Support Communities: An Online Survey of Members. *JMIR Ment Health*, *4*(4):e44. doi: 10.2196/mental.8084.

[25] Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2016). Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. *J Med Internet Res, 18*(3):e61133.

[26] De Simoni, A., Shanks, A., Mant, J., & Skelton, J.R. (2014). Making sense of patients' internet forums: a systematic method using discourse analysis. *Br J Gen Pract*, *64*(620):e178-80. doi: 10.3399/bjgp14X677671

[27] Izuka, N.J., Alexander, M.A.W., Balasooriya-Smeekens, C., Mant, J.& De Simoni, A. (2017). How do stroke survivors and their carers use practitioners' advice on secondary prevention medications? Qualitative study of an online forum. *Fam Pract, 34*(5):612-620. doi: 10.1093/fampra/cmx023.

[28] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qual Res Psychol, *3*(2): 77-101.

[29] Cutrona, C.E.& Suhr, J.A. (1992). Controllability of Stressful Events and Satisfaction With Spouse Support Behaviors. *Communication Research, 19*(2), 154–174. https://doi.org/10.1177/009365092019002002.

[30] Smedley, R., Coulson, R., Gavin, J., Rodham, K., & Watts, L. (2015). Online social support for Complex Regional Pain Syndrome: A content analysis of support exchanges within a newly launched discussion forum. *Computers in Human Behavior. 51*: Part A, 53-63.

[31] Coulson, N.S., Buchanan, H., & Aubeeluck, A. (2007). Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Educ Couns, 68*(2):173-8.

[32] Mo, P.K., & Coulson, N.S. (2008). Exploring the communication of social support within virtual communities: a content analysis of messages posted to an online HIV/AIDS support group. *Cyberpsychol Behav, 11*(3):371-4.

[33] Alaszewski, H.P., Alaszewski, A., Potter, J., Penhale, B., & Billings, J.R. (2003) Life after stroke: Reconstructing everyday life. Project report. Centre for HealthServices Studies, Canterbury. https://kar.kent.ac.uk/7745/1/H.P.Alaszewski_Stroke_Nov_2003.pdf

[34] Jamison, J., Sutton, S., Mant, J., & De Simoni, A. (2018). An online stroke forum as source of data for qualitative research: insights from a comparison with patients' interviews. *BMJ Open, 8:*e020133. doi: 10.1136/bmjopen-2017-020133

[35] De Simoni, A., Mant, J., & Sutton, S. Adherence to medication in stroke survivors dependent on caregivers. *Br J Gen Pract, 65* (640), e789-91. doi: 10.3399/bjgp15X687589.

[36] Smedley, R.M., & Coulson, N.S. (2017) A thematic analysis of messages posted by moderators within health-related asynchronous online support forums. *Patient Educ Couns, 100*(9):1688-1693. doi: 10.1016/j.pec.2017.04.008.

[37] Colineau, N., & Paris, C. (2010). Talking about your health to strangers: understanding the use of online social networks by patients. *New Review of Hypermedia and Multimedia*, *16*:1-2,141-160. DOI: 10.1080/13614568.2010.496131

[38] Park, C. L. (2010). Making Sense of the Meaning Literature: An Integrative Review of Meaning Making and Its Effects on Adjustment to Stressful Life Events. *Psychological Bulletin*, *136*(2), 257–301. doi:10.1037/a0018301

[39] Ch'ng, A.M., French, D. & McLean, N. (2008). Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. *J Health Psychol, 13*(8):1136-46. doi: 10.1177/1359105308095967.