Experiences and illness perceptions of patients with functional symptoms admitted to hyper acute stroke wards: A mixed methods study

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Abstract

Introduction

A proportion of patients admitted to acute stroke settings do not have stroke but have conditions mimicking stroke. Approximately 25% of suspected stroke cases are ‘stroke mimics’ and 2% of all suspected stroke are patients with functional symptoms, ‘functional stroke mimics’ (FSMs). This study aimed to explore experiences and illness perceptions of patients with functional symptoms admitted to hyper acute stroke wards.

Methods

This study used mixed methods. Patients with functional stroke symptoms participated in semi-structured qualitative interviews immediately after admission to one of two acute stroke units in London and again two months after hospital discharge. Qualitative data were assessed using thematic analysis. The Brief Illness Perception Questionnaire (Brief-IPQ) measured illness perceptions at admission and at two-month follow-up.

Results

Thirty-six participants completed baseline interviews and 25 completed follow-ups. Six themes emerged: (1) physical symptom experience; (2) emotional and coping responses; (3) symptom cause; (4) hospital experiences; (5) views on the future; and (6) uncertainty after hospital discharge. The mean Brief-IPQ score at admission was 49.3 (SD: 9.9) indicating a moderate-to-high level of perceived illness threat. Participants presented with a range of functional symptoms. At baseline, participants were highly concerned about their symptoms, but this decreased at two-month follow-up. Two months later, many were confused as to the cause of their admission.

Conclusion
This is the first study to examine functional stroke patients’ experiences of acute stroke admission. At admission, patients expressed confusion regarding their diagnosis and experienced high levels of emotional distress and were concerned they were perceived as time-wasting by stroke clinicians. While most participants experienced symptom recovery, there was a significant sub-group for whom symptoms persisted or worsened. A lack of care guidelines on the management of functional stroke patients may perpetuate functional symptoms.

Keywords

Functional stroke symptoms, stroke mimic, unexplained medical symptoms, qualitative research
Introduction

Stroke services have adapted to advances in diagnostic imaging through the creation of rapid admission systems that prioritise swift diagnosis and treatment. In 2010, Hyper-acute Stroke Units (HASUs) were established in London, replacing existing stroke units, leading to improved survival rates and cost-effectiveness (1). There are eight HASUs in London and they are designed to improve the speed of diagnosis and the delivery of stroke treatment through rapid assessment, early treatment and 24 hours a day, seven days a week monitoring and physiological intervention within a high-dependency bed. They are staffed by multidisciplinary teams which include neurologists, neurosurgeons, interventional radiologists, specialist nurses and therapists. Stroke patients arrive at HASUs via a ‘999’ emergency call via ambulance from home or their GP, by arriving at A&E or as an inpatient having stroke on a ward at a district general hospital. They are initially assessed in A&E by an on-call stroke team and receive a Computed Tomography (CT) brain scan and neurological assessment within 30 minutes and transferred to the HASU for immediate treatment. The UK’s Department of Health launched a stroke awareness campaign in February 2009 which brought significant reductions in delays to seeking and receiving medical care after major stroke (2).

A proportion of patients admitted to stroke settings do not have stroke. Approximately 25% of suspected stroke cases are ‘stroke mimics’ and 2% of all suspected stroke cases are patients with functional symptoms, ‘functional stroke mimics’ (FSMs) (3). Patients present with neurological patterns resembling stroke superficially but indicate no specific neurological disorder and have negative findings upon diagnostic testing. FSMs tend to be younger, female and more frequently present with weakness or numbness compared to other stroke mimics (3).

How patients experience and interact with the healthcare system can help predict future health outcomes and can aid in the design of treatment programmes. Previous qualitative research suggests patients with functional symptoms may experience confusion following clinical encounters and can hold negative attitudes towards clinicians (4). Fear of judgement from clinicians is common (5).
Patients with functional motor disorder have described dissatisfaction with clinical explanations and expressed feelings of abandonment and helplessness (6). Such views are of concern as patients may reject advice and seek other medical input (7), potentially leading to iatrogenic harm.

Illness perceptions are an important component of functional disorders as they help predict illness behaviours (8). The Common Sense Model of Self-Regulation (CSM) is a framework to help understand illness self-management (8, 9). It states that individuals construct their own understanding of symptoms which in turn can influence health outcomes. An example of how this may be a belief that a symptom is particularly severe which can result in all-or-nothing behaviour. This behaviour may in turn lead to worsened disability which can then reinforce the initial belief that a symptom is severe.

Such a cycle can perpetuate and worsen symptoms. Dimensions of the CSM model include identity (eg ‘I had a stroke’), timeline (eg ‘I will live with these symptoms for the rest of my life’), cause (eg ‘Psychological stress caused my stroke’), consequences (eg ‘I won’t be able to drive’), control (eg ‘Nothing I can do will change these symptoms’) and coherence (eg ‘My symptoms are confusing’) (10).

The model has been applied in medically unexplained symptom research (11) and to a limited degree within functional disorders. Functional disorder patients often reject psychological factors as a potential symptom cause, blaming external factors (12), although there may be differences according to condition type. For example, patients with functional weakness were less likely to endorse psychological formulations than non-epileptic seizure (NES) patients (13). In neurology outpatient clinics, non-attribution of unexplained symptoms to psychological factors was predictive of poorer outcome (14). Conversely, a meta-analysis of 23 studies found the perception of medically unexplained symptoms as psychological cause was related to negative outcomes (11). Less is known about the other aspects of symptom perception dimensions.

Explorations of functional patients’ healthcare experiences and illness perceptions often come from primary care settings or outpatient settings. No study has explored functional stroke patients’ experiences or illness perceptions within acute settings. Their experiences likely differ to other
functional groups due to stroke medicine’s emphasis on fast diagnosis and treatment, the contextual
effect of observing acutely unwell stroke patients, and the effect of the acute environment on staff
members’ working practices. There is no evidence on the short to medium-term consequences of
stroke admission on functional patients’ symptom perceptions. Improving understanding of illness
perceptions and how these change over time can inform efforts to improve treatments.

The aim of this study was to examine healthcare experiences and illness perceptions of patients with
functional stroke symptoms admitted to HASUs and how these changed over time, using qualitative
interviews and the Brief-Illness Perception Questionnaire (Brief-IPQ). Qualitative research is
particularly useful in understanding complex aspects of subjective experience (15). We utilise the B-
IPQ to quantify illness perceptions within the CSM framework and to achieve methodological
triangulation. By better understanding patients’ own perspectives, we hope to inform the
development of future treatments and care pathways for these patients.

Methods

Study design and setting

This study took place in HASUs in King’s College Hospital and Princess Royal University in South London
between January and October 2016. Additional interviews took place between January and May 2019
and were conducted NOC and AJ. Additional interviews were completed to update data collection and
achieve data saturation.

We used semi-structured interviews to explore the attitudes, experiences and illness perceptions of
FSM patients. Participants were interviewed at their bedside shortly after their admission (baseline)
and re-interviewed two months after discharge via Skype (two-month follow-up). We used the
Consolidated Criteria for Reporting Qualitative Research (COREQ) to guide writing of this study
(Supplementary Material A).
Ethical approval was granted by the Queen Square Research Ethics Committee (REC) (15/LO/1914) on the 6th January 2016 and for the 2019 interviews on 8th December 2018 by the Riverside REC (18/LO/1878).

Sampling and recruitment procedure

We employed total population sampling. Participants were included if they were 18 years or over; communicate in English; and there was no stroke aetiology but there was a functional or psychological explanation for symptoms. Participants were included if they had suspected stroke and had arrived at the hospitals’ A&E (via self-referral, ambulance or GP referral) and had subsequently been admitted to the HASU. We also included patients with stroke who experienced co-morbid functional neurological symptoms. Participants were not robustly clinically-established Functional Neurological Disorder (FND) patients, rather our sample were patients experiencing ‘unexplained stroke symptoms’ or stroke patients with co-morbid functional symptoms. We excluded stroke patients with anxiety or depression only, but who had no functional symptoms as the focus of this study was functional stroke alone.

The researchers attended HASU handover meetings throughout the study period. Patients fitting inclusion criteria were identified by the medical team at these meetings and referred to a study researcher. In all cases, participants had received a full neurological assessment by a stroke physician of at least 5-year post qualification and radiological imaging, commonly brain CT and often MRI. In all cases, the stroke clinician referring the patient to the research team had made a clinical judgement that the patient’s symptoms were either entirely, or partially explained as a functional diagnosis based on their neurological assessment and/or radiological findings. A stroke clinician asked permission from the patient for the researcher to discuss the study who then explained that the study’s purpose was to develop understanding of functional stroke admissions. The researcher provided a study information sheet and consent form. Interviews were recorded using a Dictaphone. Follow-up interviews were conducted via Skype and recorded.
Most commonly, baseline interviews took place after a clinician had seen the patient and radiological tests had been completed. Due to the high turnover on the ward and high demand for beds, functional patients were often discharged quickly after a non-stroke diagnosis. To ensure an interview took place, in a small number of cases it was necessary for researchers to interview patients where a stroke clinician strongly suspected functional symptoms, but radiological results were pending. In only one case did the MRI scan reveal a stroke, contradicting the neurological assessment. This participant’s data were not included in the study.

Data collection

Participants were interviewed at the bedside. The interviewer had no relationship to the participant prior to the study. Interviews were semi-structured and informed by a topic guide (Supplementary Material B). The same topic guide was followed for both sets of interviews, but follow-up interviews explored experiences since discharge rather than experiences on the ward.

The topic guide explored the following issues: (1) admission experiences; (2) history and experience of symptoms; (3) illness beliefs and attitudes; and (4) views on the future. All interviews were transcribed verbatim by NOC and AJ.

Data analysis

Data were analysed using Braun and Clarke’s thematic analysis approach (16). This involved familiarisation through transcription, reading and re-reading of data and the generation of initial codes. NOC and AJ independently coded interviews and discussed the emergence of themes. Themes were reviewed, defined and refined by both authors (see Supplementary Material C for coding framework). Analyses were conducted using NVIVO software. Participants’ names are not presented in this text. All names in the text are pseudonyms. NOC and AJ have backgrounds in psychological research. NOC kept a research diary to interpret and reflect on interviews. The role of potential
researcher bias or observational was discussed by the research team (NOC, AJ, ASD & TC) to aid the qualitative analysis process.

The Brief-IPQ was developed by Broadbent et al (17) and consists of eight items measured on a continuous scale from one to ten (less threatening to highly threatening view of symptoms). Each item assesses a dimension of illness perception. Total scores range from 0 to 80 with higher scores indicating more threatening perceptions. The questionnaire has good psychometric properties (18). Repeated-measures Wilcoxon signed ranks tests compared the mean score of items at baseline with follow-up. We analysed scores using SPSS software (IBM SPSS for Windows, Version 22, Chicago, SPSS Inc.).

Results

We interviewed 36 participants (24 females, 66.7%) at baseline and 26 of those again at two-month follow-up (17 females, 68%). No patient refused to take part and those who were not followed up at two-months were uncontactable, rather than refusing participation. Mean age was 51 years (SD: 15.3). The most common ethnicity was white British (22, 61.1%). Sixteen (44.4%) were employed and eleven (30.6%) unemployed or on medical leave at admission. The 10 participants who did not take part in the follow-up interview had a mean age of 54 years (SD: 14.4); five (50%) were white British and five were unemployed (50%). Table One displays all participants’ symptom profile at admission. Interviews ranged from seven to 65 minutes. Mean number of days between baseline and follow-up was 70 (SD: 16.7).

Twenty-eight participants completed the Brief-IPQ at baseline and 23 completed a follow-up questionnaire. There were no differences in the age or gender of participants completing one survey compared to those completing both baseline and follow-up.
Brief Illness Perception Questionnaire Results

The mean total Brief-IPQ score at baseline was 50.0 (SD: 10.1) and at two-months’ follow-up it fell to 39 (SD: 20.1).

Figure One displays a paired-scatter chart of individual mean scores at baseline and follow-up and Table 3 displays two vignettes describing a patient whose symptoms got worse and a patient whose symptoms improved. We chose these vignettes to highlight the variability in recovery and to illustrate an example of positive recovery and a case where symptoms worsened. There was considerable missing data for total mean scores as many participants did not complete all follow-up questionnaire items meaning individual total scores could not be calculated. Three participants completed all items at both baseline and follow-up.

Table Two presents Brief-IPQ component scores. At baseline, ‘concern about symptoms’ was most highly scored (perceived as threatening) and at two-month follow-up, this was scored as moderate. At baseline the lowest rated component was ‘treatment control’, indicating participants believed treatment would be helpful.

Repeated measures analyses were conducted to assess changes in mean scores over time. Mean perceived consequences ($Z = -3.4, p = 0.001$), identity ($Z = -2.1, p = 0.04$), concern ($Z = -2.7, p = 0.01$) and emotional response ($Z = -2.0, p = 0.05$) decreased significantly.

Qualitative Results

Six themes emerged from qualitative data analysis: (1) physical symptom experience; (2) emotional and coping responses; (3) symptom cause; (4) hospital experiences; (5) views on the future; and (6) uncertainty after hospital discharge.

Physical symptom experience
Symptom onset was commonly marked by feeling faint, disorientated, dizzy or losing balance. The most common symptoms included weakness, numbness, pins and needles, nausea, headache, migraine, pain, visual disturbance, memory loss, loss of speech, disturbed speech, fatigue, and facial droop. Symptoms were rarely discrete, with multiple and varied symptoms often developing between initial onset and admission.

It was this sort of thorough sense of unreality…everything looked out of, slightly out of kilter, slightly swim-y, I could feel the numbness here [gestures to right arm]. I caught the reflection in the mirror, I saw that my eyes had dropped, pins and needles. (Linda, 51)

Participants described an array of chronic pre-existing physical and mental health comorbidities, including anxiety, depression, non-epileptic seizures, irritable bowel syndrome, fibromyalgia, hypertension, diabetes, angina, stroke, migraine, back pain, slipped discs, previous history of breast cancer, prostate cancer, osteoarthritis, Transient Ischemic Attacks, and hernias. Several reported family history of stroke.

Emotional and coping responses

For many, symptom onset and hospital admission was highly upsetting. Participants described feeling shocked, numb, panicked, depressed, scared or frightened. Many were concerned the symptoms represented something serious.

I panicked and I broke down because I didn’t know what was happening…my line manager looked at me, asked if I was okay, I go, “I don’t know what’s happening to me. I can’t use my hands” (Andrew, age unknown)

Participants described varied coping responses. Several felt their physical symptoms were something they would have to endure indefinitely and symptoms were beyond their control. Others described the need to be display resilience for family members.
I do feel little bit [low] but I can’t let the wife see that because I’ve got to be strong for her.

(Noel, 56)

Symptom cause

A significant proportion of participants believed they had had a stroke when first interviewed, although their understanding of what occurred was unspecific. They described a range of possible stroke triggers such as unhealthy behaviours, anxiety, stress, tiredness, heat exhaustion, grief, panic, a virus, medication side-effects, genetics, or co-morbidities like osteoarthritis and cancer. While many endorsed psychological stress as a symptom cause, this was ambiguous as they believed stress had triggered a stroke. In cases where participants did not believe they had had a stroke, they expressed confusion rather than any definitive cause.

I’m assuming it could just be all the stress building up and then the stroke (Emily, 33)

Mentally things like strokes happens if you are worried too much, too much pressure, you know (Marie, 64)

I try to understand it but at this moment in time, I’m just so confused (Kirsten, 21)

Hospital experiences

Participants described receiving fast responses from ambulances, swift admissions, rapid diagnostic testing and receiving intense clinical observation with hourly checks. Many were dissatisfied with the explanation they received from doctors on symptom cause and some felt judged or invalidated by staff.

They said that evening, “Well, we think you’ve had a stroke”...the next day they came back to me and started talking about me weirdly, without even saying hello first...I don’t know what they thought. That I was young, maybe I was on drugs...They weren’t taking it seriously...They just kind of said they don’t think it’s a stroke, it could have been a small stroke but they don’t think that it is...And that was a little bit worrying. (Michael, 23)
I was very angry at first because it’s as if you are putting it on and wasting people’s time but I’m not that sort of person. I don’t like hospitals (Noel, 56)

Views on the future

Participants expressed anxiety that symptoms would reoccur, although there were differences in how participants planned to engage in future work and leisure activities. Some saw their hospital admission as an opportunity to adapt their lifestyle, others decided they required rest, and some were fearful that activity might bring a reoccurrence of symptoms.

If I change my lifestyle completely. I think that will help...I think in terms of eating and exercise (Lucy, 53)

I’ve got to slow down...like my brain goes fast but my body doesn’t move with it...I’ve just got to slow down not get so stressed out and whatever...like it could happen again...so I’m like worried now in case it happens again (Sandra, 62)

Uncertainty after hospital discharge

Two-months post-discharge ten participants (40%) reported no symptom improvement, four (16%) partial improvement, and eleven (44%) reported a complete resolution. For patients with symptom improvement, some reported general health benefits as a result of increased physical activity. For those with persistent symptoms, some had experienced increased intensity or new symptoms had emerged.

I get a really bad headache, I feel sick, I start struggling to breathe. Whether that’s stress or anxiety, I don’t know and then I feel really dizzy...that lasts for about ten minutes and I go into seizure. All I know is that it’s pretty violent (Kirsten, 21)
At follow-up, most participants had been told they had not had a stroke. Some held psychological formulations describing stress, exhaustion, and nerves, while others remained confused. This uncertainty was a source of continued worry for some participants while others learned to accept it.

They suspected that I had mini stroke, but later, when they discharged me, that’s why I’m still confused, they said, ‘No, you have not had a mini-stroke’...it seemed to me that they couldn’t give me the right information and I was discharged without being, without knowing exactly what happened (Marie, 64)

Occasionally I get a little bit anxious about it but not really, not to the point where it stops me living my life. Brains are complex things, that’s the only thing I’d say (Michael, 23)

Discussion

This study examines the healthcare experiences and illness representations of functional stroke patients and how these change at two-month follow-up. Our qualitative findings suggest patients experienced a wide variety of symptoms prior to their admission. The variability in length of interviews reflects this heterogenous sample and symptomatology, with some participants more eager or able to engage with the interview and questionnaire than others. Time spent in hospital was often upsetting and confusing. On the HASU, many participants accepted psychological factors as potential stroke triggers but maintained a biological understanding of symptom aetiology. Two-months later, most understood they had not experienced stroke, but were confused regarding the cause. This uncertainty was a source of anxiety for some, while others accepted the lack of information and reported recovery.

Our Brief-IPQ findings echo the qualitative findings and reflect the intense emotional response and the high degree of concern described. At admission, patients believed there would be severe future consequences, they did not believe they had control over symptoms and were highly distressed. The
mean emotional response score was higher than scores reported in lung cancer and melanoma (19), and heart failure patients (20). The consequences score was similar to mean scores reported in breast cancer (21), lung cancer (22), and patients with depression in advanced palliative care (23).

While the total mean scores indicate that the perception of symptoms as threatening improved at two month’s follow-up, the graphical display of individual scores over time indicates a sub-group of participants’ perceptions worsened. This group who would likely benefit from more targeted intervention within the stroke ward prior to discharge or referral to other interventions (24). The vignettes suggest family support, employment and belief in symptom control are protective factors in recovery.

The sense of not being taken seriously or concern that others believe you are faking symptoms is common in patients with medically unexplained symptoms (5, 25-27) and was observed in this study. This finding is of concern as concordant beliefs between patient and clinician leads to greater satisfaction and better health outcomes (28). Feeling misunderstood or undeserving of clinical care may encourage resistance to future healthcare professionals or healthcare advice with subsequent delays in diagnosis, increased referrals, and seeking of alternative treatments outside the medical mainstream (6). Further, as in the case of Kirsten, it may lead to a worsening of the person’s condition with the accretion of new symptoms (e.g. the onset of seizures). Functional patients could also benefit from the inclusion of their caregivers in follow-up appointments to help carers better understand functional symptoms and provide training or information on how best to support the patient outside the hospital.

Participants’ understanding of symptom cause was similar to qualitative findings from functional motor disorder patients who commonly rejected psychological explanations (6). Stone et al. (29) found patients with functional weakness frequently attributed symptoms to ‘undiscovered physical causes’ or ‘damage to the nervous system’. Patients in this study were happy to endorse psychological factors as a possible organic stroke trigger, but at least at baseline, most believed they had suffered an organic
stroke. Two months after discharge, many remained confused about symptom origins, a similar finding in patients experiencing functional seizures (30). Increased anxiety at two-months may be partially mediated by lower acceptance of diagnostic uncertainty.

Patients’ illness representations are influenced by encounters with their doctors. The confusion about cause is reflective of the lack of clarity provided in the early stages of admission. This is partly a practical requirement as staff wait scan results before giving definitive diagnoses and patients with functional stroke are more likely to receive brain imaging as doctors seek to mitigate risks of false negative diagnoses (3). Ambiguous bedside consultations (31) coupled with the speed of admission, urgency of diagnostic screening and sharing a ward with acutely unwell stroke sufferers may compound initial confusion and lead to purely biological symptom perceptions.

That aetiological confusion continues at two-month follow-up suggests a clinical opportunity has been missed. While there is likely a variety of potential symptom causes, patients with functional symptoms who reject psychological factors entirely may be less likely to address psychological components in recovery which could compound their functional symptoms. We did not examine participants’ hospital records, but instead focussed on self-reported experiences both on the ward and after discharge from the stroke unit. At the two-month follow-up interview, most participants described receiving an outpatient follow-up appointment with a stroke consultant or doctor. One participant describing receiving acute psychiatric inpatient care but none described receiving outpatient counselling for their symptoms – either by hospital, GP or self-referral. There is a need for candid neurological consultation prior to discharge (either by the stroke doctor or the hospital liaison psychiatrist or neuropsychologist if available), greater information provision at stroke follow-up and increased referral or signposting to other services. It is important stroke clinicians engage with the many guidelines on how to address and manage functional symptoms (24, 32, 33).

This study has a number of limitations. These findings represent results from one city with a specific hyper acute stroke model although versions of acute stroke units now exist in most major cities in the
world (3). This qualitative research was designed to understand and explore patients’ experiences and phenomenological accounts of their admission, rather than to elucidate the potential socio-demographic factors that influenced outcomes. This would be a fruitful subject for future research.

We identified a relatively small number of participants. This may be due to the sampling procedure, which relied on doctors to identify and approach participants initially. This study was not an incidence study however, so conclusions on admission rates cannot be drawn. We included a heterogeneous patient sample as well as patients who had experienced stroke but presented with co-morbid functional symptoms (n = 2), and patients with functional symptoms but who had a history of previous stroke (n = 4). While their inclusion has made our sample more diverse, it is a more accurate reflection of the diversity and complexity of functional symptoms and functional symptomatology on stroke wards generally. The definition of functional co-morbidity is relatively unspecific and while it will vary between neurology and stroke consultants, it is commonly deployed, increasing generalisability of our findings. By the same token, our results are less generalisable to specific diagnostic groups, for example well-defined functional neurological disorders. The heterogeneity of symptoms has implications for the interpretation of Brief-IPQ results. A larger sample would have allowed for symptom type to be accounted for in our analysis. We did not include stroke patients with anxiety or depression who did not have functional symptoms. While stroke and anxiety or depression is a well-recognised phenomenon, these patients likely have a separate aetiology and clinical profile compared to functional stroke presentations. We did not have access to participants’ hospital records so could not account for treatment interventions and the possible effect on IPQ scores. One participant with no stroke described receiving thrombolysis at admission, finding the treatment beneficial. Most participants described receiving diagnostic tests however as well as some prescriptions such as blood pressure medication like Warfarin, but no interventional treatments.

This is the first qualitative study of unexplained stroke mimics. Interviews occurred over two time periods, capturing change over time, a rare but powerful qualitative design. Our sample size is large,
allowing us to reach data saturation. By conducting interviews at the HASU, we captured a degree of immediacy in experiences.

Functional symptoms are a persistent presentation to stroke settings. Stroke care has developed a highly interventionist service model since the re-organisation of services. This coupled with public awareness campaigns has led to significant improvements in stroke mortality. The elements of the improved model that have proved effective for stroke patients have most likely led to increased functional stroke presentations. As these patients seek and often fail to find reassurance and diagnostic clarity from their clinicians, these symptoms may become more entrenched and more difficult to treat with time. With no clinical guidelines and the potential for great iatrogenic harm, a clear care pathway is necessary to improve functional patients’ outcomes and to ensure the delivery of high-quality care to this long-neglected patient group.

Acknowledgements

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Disclosure

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article. Part of the results of this study have been previously reported in NOC’s PhD thesis however this has been substantially reworded and contains new data that did not appear in the original thesis.
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**Ethics**

We confirm this study was conducted in accordance with the Declaration of Helsinki. All participants provided informed consent, including publication of their responses and the case details in Figure One. All names given in the document are pseudonyms.

**References**


Table One Clinical characteristics at HASU admission

<table>
<thead>
<tr>
<th>Symptoms at HASU admission</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left sided facial weakness, left arm weakness.</td>
<td>Not known</td>
</tr>
<tr>
<td>Expressive dysphasia.</td>
<td>23</td>
</tr>
<tr>
<td>Facial numbness.</td>
<td>29</td>
</tr>
<tr>
<td>Severe headache and dysarthria.</td>
<td>20</td>
</tr>
<tr>
<td>Frontal bilateral headache; right-sided pain &amp; mild disequilibrium.</td>
<td>65</td>
</tr>
<tr>
<td>Left sided weakness and dysarthria. History of functional seizures.</td>
<td>56</td>
</tr>
<tr>
<td>Left-sided weakness and left visual disturbance and headache.</td>
<td>43</td>
</tr>
<tr>
<td>Light-headed. History of previous stroke.</td>
<td>67</td>
</tr>
<tr>
<td>Left-sided pain.</td>
<td>Not known</td>
</tr>
<tr>
<td>Rotatory vertigo, chronic fatigue and depression.</td>
<td>62</td>
</tr>
<tr>
<td>Left-sided facial droop and slurred speech.</td>
<td>53</td>
</tr>
<tr>
<td>Dysphasia and headache.</td>
<td>33</td>
</tr>
<tr>
<td>Left hand numbness and expressive dysphasia.</td>
<td>64</td>
</tr>
<tr>
<td>Right sided weakness, headache, photophobia. History of bipolar disorder.</td>
<td>Not known</td>
</tr>
<tr>
<td>Several episodes of loss of consciousness with left sided weakness.</td>
<td>21</td>
</tr>
<tr>
<td>Left-sided weakness. History of previous stroke with functional symptoms.</td>
<td>88</td>
</tr>
<tr>
<td>Reduced finger movements in both hands and muddled speech.</td>
<td>Not known</td>
</tr>
<tr>
<td>Sudden onset speech disturbance. History of anxiety.</td>
<td>53</td>
</tr>
<tr>
<td>Left-sided weakness and facial droop.</td>
<td>31</td>
</tr>
<tr>
<td>Left-sided weakness and numbness. History of previous stroke with functional symptoms.</td>
<td>59</td>
</tr>
<tr>
<td>Migraine, left face and arm weakness. History of previous stroke and CFS</td>
<td>38</td>
</tr>
<tr>
<td>Dysarthria, dysphasia, dizziness and posterior headache.</td>
<td>52</td>
</tr>
<tr>
<td>Left-sided weakness and frontal-post headache. Confirmed stroke with functional symptoms.</td>
<td>53</td>
</tr>
<tr>
<td>Left-sided weakness. History of depression.</td>
<td>50</td>
</tr>
<tr>
<td>Hyperventilation and shaking of upper and lower limbs following local dental anaesthetic.</td>
<td>58</td>
</tr>
<tr>
<td>Right-sided weakness. History of PTSD.</td>
<td>55</td>
</tr>
<tr>
<td>Left-facial droop and speech slurring</td>
<td>51</td>
</tr>
<tr>
<td>Left-sided headache, dizziness and diplopia. History of depression and fibromyalgia.</td>
<td>49</td>
</tr>
<tr>
<td>Left-facial weakness, dysarthria and left facial paraesthesia.</td>
<td>49</td>
</tr>
<tr>
<td>Left-facial droop, left arm and face paraesthesia. Confirmed stroke with functional symptoms.</td>
<td>51</td>
</tr>
<tr>
<td>Headache, collapse, dysarthria, blurry vision and left sided weakness.</td>
<td>64</td>
</tr>
<tr>
<td>Confusion, left-sided weakness, slurred speech, swallowing difficulty, horizontal and vertical diplopia.</td>
<td>56</td>
</tr>
<tr>
<td>Slurred speech, lateral gaze diplopia, nystagmus all directions, ataxia upper limbs.</td>
<td>51</td>
</tr>
<tr>
<td>Pain and weakness on right side, bilateral leg weakness, collapse, dizziness, migrainous headache, difficulty swallowing</td>
<td>51</td>
</tr>
<tr>
<td>Right sided weakness, nausea, confusion, speech slow, ataxic, disorientated.</td>
<td>75</td>
</tr>
</tbody>
</table>
### Table Two Brief Illness Perception Questionnaire component results measured at baseline and two-month follow-up

<table>
<thead>
<tr>
<th>Component</th>
<th>Baseline (IQR)</th>
<th>Follow-up (IQR)</th>
<th>Wilcoxon signed ranks</th>
<th>p</th>
<th>d</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequences</td>
<td>8 (6.0 - 10.0)</td>
<td>2.5 (0.0 – 6.25)</td>
<td>-3.4</td>
<td><strong>0.001</strong></td>
<td>1.25</td>
<td>High to low</td>
</tr>
<tr>
<td>Timeline¹</td>
<td>5.83 (2.9)</td>
<td>5.2 (4.3)</td>
<td>0.42</td>
<td>0.68</td>
<td>0.18</td>
<td>Moderate – no change</td>
</tr>
<tr>
<td>Personal control</td>
<td>10 (4.0 – 10.0)</td>
<td>5 (2.0 – 10)</td>
<td>-0.49</td>
<td>0.62</td>
<td>0.21</td>
<td>High to moderate</td>
</tr>
<tr>
<td>Treatment control</td>
<td>2.5 (0.5 – 5.0)</td>
<td>1 (0 – 5.0)</td>
<td>-0.85</td>
<td>0.39</td>
<td>0.22</td>
<td>Low – no change</td>
</tr>
<tr>
<td>Identity</td>
<td>5 (4.0 – 7.0)</td>
<td>3 (0 – 6.0)</td>
<td>-2.1</td>
<td><strong>0.04</strong></td>
<td>0.44</td>
<td>Moderate to low</td>
</tr>
<tr>
<td>Concern</td>
<td>8 (6.25 – 10.0)</td>
<td>5 (0 – 10.0)</td>
<td>-2.7</td>
<td><strong>0.01</strong></td>
<td>0.84</td>
<td>High to moderate</td>
</tr>
<tr>
<td>Understanding</td>
<td>5 (2.0 – 9.0)</td>
<td>5 (0 – 10.0)</td>
<td>-0.47</td>
<td>0.64</td>
<td>0.07</td>
<td>Moderate – no change</td>
</tr>
<tr>
<td>Emotional response</td>
<td>8 (5.0 -10.0)</td>
<td>5 (2.0 – 9.0)</td>
<td>-2.0</td>
<td><strong>0.05</strong></td>
<td>0.69</td>
<td>High to moderate</td>
</tr>
</tbody>
</table>

¹ Normally distributed data so statistic reported here is a t-test

*p values highlighted in bold indicate statistically significant results

Cohen’s *d*: very small: 0.01; small: 0.2; medium: 0.5; large: 0.8; very large: 1.2; huge: 2
**Table Three:** Section A displays a vignette describing a patient whose BIPQ scores deteriorated at two-month follow-up following stroke admission. Section B describes a patient who recovered at two-month follow-up. Some details have been changed to preserve anonymity.

<table>
<thead>
<tr>
<th>A. Vignette describing deterioration</th>
<th>B. Vignette describing improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Admission:</strong> White British male full-time volunteer admitted following several bouts of loss of consciousness with left-sided weakness. <strong>Risk factors:</strong> Childhood asthma, diabetes since 15 and an asymptomatic congenital cerebral cyst. No acute infarction and intracranial appearances were normal. <strong>Symptom onset:</strong> Travelling for holidays, felt unwell and had lost consciousness. <strong>Family history:</strong> Difficult relationship with family, father had recent major surgery. Mother a full-time carer. <strong>Experience on stroke ward:</strong> Did not believe physical functioning would return to normal and expressed belief that symptoms would significantly change his life. <strong>Two-month follow-up:</strong> Patient was referred to psychiatric inpatient ward and received physiotherapy for his leg. Later transferred to a psychiatric inpatient ward closer to home and subsequently discharged to supported accommodation. Continued deterioration in family relationships, reduced function in left leg and had developed fits/seizures. At the time of follow-up the patient had received an appointment for further investigation with neurology to investigate the seizures further.</td>
<td><strong>Admission:</strong> White British female admitted with reduced finger movements and muddled speech with symptoms lasting 30 min before resolving. Symptoms reoccurred later that day and resolved. No neurological deficit. MRI showed no evidence of ischaemia. <strong>Risk factors:</strong> Familial hypercholestrolaemia and arthritis. <strong>Symptom onset:</strong> Cramping and pressure in both hands began during work presentation and following a busy work period. Colleague noticed patient using words out of context. <strong>Family history:</strong> Supportive husband and family who stayed with patient throughout admission. <strong>Experience on stroke ward:</strong> Stroke team explained she had not had a stroke and symptoms likely stress or exhaustion induced. Recommendation she see GP for follow-up to assess symptom in hand. Expressed relief symptoms were not a stroke. <strong>Two-month follow-up:</strong> Continued to experience hand cramping with GP monitoring symptoms. She had taken up running to develop fitness and lose weight. Continued to be busy in work but employers agreed to reduce work-related travelling. She had also begun to develop strategies to help reduce work-related anxiety.</td>
</tr>
</tbody>
</table>
Figure Legend

*Figure One*: Graph showing change in individual total B-IPQ scores between baseline and two-month follow-up. Lower scores indicate symptoms perceived as less threatening.
Figure 1 Graph showing change in individual total B-IPQ scores between baseline and two-month follow-up. Lower scores indicate symptoms perceived as less threatening.