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# **Psychological and emotional needs, assessment and support post-stroke: a multi-perspective qualitative study**

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## **Abstract**

**Background:** International stroke care guidelines recommend the routine assessment and management of psychological and emotional problems post-stroke. Understanding the experiences of those delivering and receiving these services is vital to improving the provision of psychological support post-stroke.

**Objectives:** To explore patients', carers' and health professionals' experiences of psychological need, assessment and support post-stroke whilst in hospital and immediately post-discharge.

**Methods:** Participants were recruited from seven specialist stroke services in the North of England. Qualitative semi-structured interviews and focus groups were conducted with 31 stroke patients, 28 carers and 66 health professionals. The interviews were recorded and transcribed verbatim, and analysed using thematic analysis.

**Results:** Two central themes emerged Minding the gap: psychological expertise, and Protective factors perceived to reduce the need for formal psychological support. The lack of psychological expertise amongst healthcare professionals working on stroke units was a source of frustration and resulted in other disciplines assuming the role of a psychologist without the required skills and training. Multiple stakeholders discussed the importance of protective factors, including downward social comparison, social support, peer support, communication and information provision, that were perceived to reduce the need for formal psychological support.

**Discussion:** Stroke patients need better access to psychological support, including information, advice and peer or social support. More research is required to establish the effectiveness of alternative options to formal psychological support.

**Key words:** Stroke; Psychology; Clinical psychology; Depression; Guidelines; Qualitative; Thematic analysis

## **Introduction**

Psychological distress after stroke is common. It has been suggested that the stroke experience can be regarded as a psychological transition as a result of its sudden onset and the potential loss of physical functioning which impacts on the individual's social role, requiring adjustment to a new definition of self.<sup>1</sup> Post-stroke depression occurs in more than 50 percent of patients<sup>2</sup> and disorders of mood and cognition have been associated with poor rehabilitation outcomes and reduced participation.<sup>3,4</sup> Two comprehensive reviews of the literature about life after stroke have pointed to loss, social isolation, uncertainty and physical dependence as factors which might contribute to poor psychological outcome.<sup>5,6</sup> Kouwenhoven explored the lived experiences of patients with depression post-stroke, in which patients described the feelings of 'losing oneself' and being 'trapped'.<sup>7</sup>

Despite differences in the ways in which stroke services are organised and provided there is agreement across Europe<sup>8</sup> and the United States<sup>9</sup> that psychological expertise is a vital component of the multidisciplinary stroke team for the assessment and treatment of all aspects of psychological health, including mood disorders and cognitive impairment. In the United Kingdom (UK) the guidance goes further recommending a 'comprehensive approach' to the delivery of psychological care, which encourages holistic practice to address the complex array of post-stroke psychological impairments, and the use of a 'stepped care' model in the delivery of psychological support.<sup>10</sup> The stepped care model is a hierarchical approach originating from mental health services which proposes that most patients will have mild problems with mood or cognition requiring the simplest interventions delivered by members of the stroke team with some training in psychological assessment and support (level 1).<sup>11</sup> Fewer patients will have moderate symptoms that can impact on rehabilitation which should be addressed by

members of the stroke team supervised by clinical psychologists (level 2). The stepped care model proposes that only a small minority of patients with severe disorders of mood or cognition require specialist assessment and intervention, which should be delivered by clinical psychologists or psychiatrists (level 3).<sup>11</sup>

In a bid to increase evidence-based practice and guideline compliance amongst UK stroke services a national stroke audit was introduced in 1998.<sup>12</sup> The audits have shown significant improvements in many aspects of care, including the re-organization of acute stroke care.<sup>12</sup> Such audits have, however, only demonstrated modest improvement in patients' access to clinical psychology services. Despite guidelines stating that psychologists are key members of the multidisciplinary team<sup>10</sup> the proportion of hospitals with access to a clinical psychologist was only 51% in 2015.<sup>12</sup> Guideline compliance for the screening of mood disorders in the UK has improved in recent years<sup>13</sup> as a result of training, education and easy access to screening materials, however, the extent to which this increased compliance has led to improvements in patient outcomes is not known.<sup>14</sup>

A recent NHS Improvement Report recommended that stroke patients' views need to be sought about their experience of psychological care, in order to enhance and improve the provision of psychological support.<sup>11</sup> This multi-perspective study aimed to address this gap in the evidence by exploring patients', carers' and health professionals' experiences of psychological need, assessment and support post-stroke.

## **Method**

### **Design**

This study was part of a wider project exploring the quality of stroke unit care. Participants' perspectives of other aspects of care, including palliative care and accessing acute stroke care, have been discussed elsewhere.<sup>15,16</sup> This study focuses specifically upon stakeholders' experiences of post-stroke psychological need, assessment and support whilst in hospital and their experiences immediately post-discharge. A qualitative study design was adopted for this exploratory enquiry utilising semi-structured interviews and focus groups with patients, carers and health professionals. The multi-perspective approach was chosen to enable the exploration of similarities and differences in the perceptions of patients, carers and health professionals and to help integrate suggestions for improving services.<sup>17</sup>

### **Sample**

Participants were recruited from seven stroke services in the North of England. Services included hyper-acute (n=1), acute (n=3), combined (n=1) and rehabilitation (n=3) stroke units across a large teaching hospital, three district general hospitals and three community hospitals. Patients >18 years with a confirmed stroke diagnosis discharged within the last year were identified from hospital databases. A letter of invitation and information sheet was sent to patients meeting these criteria by a member of the clinical team in each service. Purposive sampling was used to ensure range and diversity in patient participant's experiences,<sup>18</sup> including length of hospital stay and length of time between discharge and interview. Patients with communication and cognitive impairment were invited to take part in the study providing they could contribute meaningfully to the interview and give informed consent. Patients' understanding was

established using a consent support tool to determine whether they could comprehend three information carrying words in a sentence.<sup>19</sup> If the patients had an informal carer they were also invited to take part.

The research team, in collaboration with senior medical and nursing staff, invited stroke unit staff to participate in focus groups and individual interviews at each of the stroke units. Staff were purposively recruited from a variety of disciplines and grades. Ethical approval was granted by Bradford Research Ethics Committee and all participants provided written informed consent prior to participation.

### **Data collection**

The interviews and focus groups were conducted by two researchers (MH, CG) trained in qualitative research methods. Semi-structured, face-to-face interviews were conducted with stroke survivor and carer participants at participants' homes or workplace. The median interview length was 54 minutes (range 34-77 minutes).

Demographic data were collected using a short questionnaire which included a functional outcome measure of recovery and dependency post-stroke.<sup>20</sup> The interview topic guide comprised questions about the patients' stroke journey, starting with the initial question "Where did you have your stroke?" which aimed to elicit the narrative from the time of the stroke to the point at which they were discharged from hospital. Follow-up questions were asked about certain aspects of care including: psychological support, communication, information provision, rehabilitation and discharge.

Health professionals working on stroke units were invited to take part in focus groups. Individual interviews were conducted with senior staff to prevent their presence influencing the opinions other staff members were willing to express. Focus groups and interviews followed the same topic guide which comprised

questions about the quality of all aspects of stroke unit care including psychological support and how well current provision meets the needs of patients and carers. All interviews and focus groups were recorded and transcribed verbatim. The data was collected between July 2011 and April 2012.

### **Data analysis**

A thematic analysis was conducted drawing on the principles of framework analysis and broadly following the five steps of familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation.<sup>18</sup> Social policy researchers developed framework analysis as a pragmatic approach to qualitative data analysis which borrows principles from various epistemological traditions without aligning itself with any; this eclecticism is perceived to be a strength of the approach.<sup>18</sup>

The data collected from staff was analysed separately to the patient and carer data in the first instance. In both cases three researchers (MH, CG, TR) independently familiarised themselves with a subsection of the data (five transcripts) and inductively assigned codes to segments of text. The codes were used to form the initial sub-themes and through the process of constant comparison these were grouped into higher order themes to develop a thematic framework. The three researchers' frameworks were combined and any discrepancies resolved through discussion. The ensuing framework was entered into NVivo 9<sup>21</sup> and the indexing (i.e. identifying portions of text corresponding to a particular theme or sub-theme) of the remaining transcripts was managed using this software. The addition or development of themes and sub-themes during the indexing process was discussed at regular team meetings. Following the initial analysis of the patient and carer data and staff data in isolation, similarities and differences between the datasets were considered during the process of charting the data

by theme and stroke service. The two datasets were merged when similar higher order themes were identified.

A series of feedback events were conducted to relay the early findings of the study and for the purpose of respondent validation. One event was held with stroke survivor and carer participants (n=29) and five feedback events were conducted with staff from six of the seven participating stroke services. These events provided an opportunity for the research team to clarify and validate their interpretation of the data.

## **Results**

### **Participants**

The total sample of 125 participants comprised 31 stroke patients, 28 informal carers and 66 members of staff working on stroke units. Patient and carer dyads took part in 27 joint interviews, whilst four patients and one carer were interviewed alone. Data was not collected about the prevalence of depression and anxiety in the patient sample, but all patients described the psychological distress caused by their stroke. More than half of patient participants described periods of low mood, which most patients referred to as being '*down*' and some reported having been diagnosed with depression. Patient and carer characteristics are shown in tables 1 and 2.

TABLE 1 HERE

TABLE 2 HERE

Staff participants (11 men, 55 women) took part in eight focus groups and nine individual interviews. Staff participant job titles are listed in table 3. The mean (SD) number of participants in each focus group was  $7.13 \pm 1.73$ .

## TABLE 3 HERE

### **Findings**

Two themes emerged from the data: Minding the gap: psychological expertise and, Protective factors perceived to reduce the need for formal psychological support.

#### Minding the gap: psychological expertise

Participants' descriptions of service provision illustrated significant variation between and within services. Formal psychological support was often available in one part of the pathway (e.g. either acute/rehabilitation/community), but which part of the pathway varied. Furthermore, for the most severely affected stroke patients', staff described petitioning other parts of the service in order to get a psychological assessment.

*“If low mood is affecting someone’s behaviour to a point where that’s challenging the service, and causing issues for patients, staff and relatives, then we can sometimes, by begging and grovelling, we can access an assessment at least from the psychologist from the stroke outreach team.”* (Ward manager)

The limited availability of psychological expertise was a source of frustration for all stakeholders and staff expressed a sense of resignation that the situation is unlikely to change.

*“We don’t have formal psychology cover...that is a big gap in the service, but we don’t see any resolution of that in the near future.”* (Consultant)

Staff reported that the lack of availability of formal psychological support can result in a reliance on medication, such as antidepressants, as a first line measure.

*“So if it’s a post-stroke low mood or a post-stroke depression then we will manage it chemically. There’s no talking therapies as such until someone goes home.”* (Ward manager)

Patients and carers described having been, or still being on waiting lists for psychological assessment or support for mood disorders in the community. However, several patients were reluctant to seek help for psychological issues following discharge or found the process of accessing help complicated by concerns that psychological issues were not valid problems post-stroke.

*“The nurse says ‘oh well I’ll refer you to our counselling service’ but then I got a letter from them saying you’re being referred to us and ring this number within 14 days or else we will think you don’t need us, and I just felt, what do I say when I ring them, you know, and it were like more something that I can’t deal with. If they’d have rung me, it would have been alright.”* (Patient)

Staff participants felt that the failure to provide formal psychological support at the early stages in the pathway could have an impact on the amount of rehabilitation patients receive and the recovery they make.

*“Patients are having to wait ‘til discharge home into community or residential home to get any psychological specialist input, which I feel is far too late, we need it earlier on so that they can have the full works and they can take on as much therapy as possible for the best recovery.”* (Occupational therapist)

As a result other disciplines have taken on the role of providing psychological assessment and support on stroke units. However, occupational therapists and nurses described not having the knowledge, skills or experience to provide psychological support to patients with the most severe needs, especially when the team had no input

from a clinical psychologist, thus demonstrating the need for more training, education and supervision.

*“On this unit, the OTs are probably about the nearest you can get to clinical psychology in terms of our knowledge, but it’s still not the same as having somebody that’s got all those expertise there. And I feel, sometimes I feel a bit out of my depth with it, to be honest.”* (Occupational therapist)

One area in which staff participants perceived improvement was the screening of patients for depression and anxiety.

*“Because of the guidelines now we routinely screen everybody for mood which we didn’t do a year ago.”* (Occupational therapist)

However, patients described staff embarrassment when asking screening questions, which demonstrates a need to not only consider what proportion of patients are screened but also how screening tools are delivered and whether staff undertaking this role have received adequate training.

*“Somebody came and quite embarrassed, asked me some questions about did I feel suicidal and things like that.”* (Patient)

Protective factors perceived to reduce the need for formal psychological support  
Individual differences were perceived to mediate the need for formal psychological support and participants described the influence of patients’ personality type and attitude toward the stroke, on psychological outcomes. Patients perceived that ‘self-

*reliance*’, being *‘down to earth*’ and maintaining a sense of control were protective factors.

*“Some people bounce back quite quickly don’t they from a stroke and then others have to go sometimes through like a grieving process.”* (Physiotherapist)

A number of patients utilised downward social comparison as a coping response, making comparison between themselves and other ‘worse off’ patients, which enabled patients to have a more positive outlook on their own situation. One negative consequence was that it made some participants more reluctant for ask for help or information, because they perceived the needs of others to be greater than their own.

*“Because I’ve been not so bad, you know, not a bad one and not so bad, and I see some people that really are bad and I just counted my blessings and think how lucky I am.”* (Patient)

Participants described the psychological benefits of camaraderie and reassurance provided by peer support, particularly through sharing experiences with other stroke patients who were perceived to be on a ‘similar *level*’ in terms of their recovery. Others who did not have the opportunity for peer support felt its absence, and this was echoed by staff who explained that the ward environment is seldom conducive to permitting the congregation of patients.

*“If there had been a patients lounge type of thing where the more active patients could have sat and could talk, exchange experiences...I think that would have been useful.”* (Carer)

Many patients felt that their emotional support needs were met by their families and friends, which diminished the need for input from healthcare professionals.

*“I was offered [psychological support], but obviously with such a close family, you know, I consider, you know, like my wife and my son, you know, if I need to discuss anything, we talk about it, don't we, so, you know, I should imagine somebody who were on their own though would struggle.”* (Patient)

Getting the right information about stroke was often of great importance to patients and carers and aided the processes of reassurance and adjustment. Furthermore, patients and carers often interpreted psychological support as being synonymous with information provision. Staff acknowledged that time constraints and not yet having the information themselves can prevent information from being provided at the most appropriate time for the patient.

*“Anything that could mitigate that feeling of powerlessness and one of those things is being given information.”* (Patient)

*“We're just too busy to actually have the 20/30 minutes to sit down with every single set of patients and relatives and explaining things completely.”*

(Consultant neurologist)

## **Discussion**

This multi-perspective study provides valuable insights into the consequences of a lack of psychological expertise in the stroke care pathway, as well as the protective factors perceived to reduce the need for formal psychological support. These findings can be used to inform service development in an under-resourced and under-researched area of stroke.

UK stroke guidelines state that psychologists are vital members of the multidisciplinary stroke team.<sup>10</sup> However, the findings from this study demonstrate a lack of

psychological expertise throughout the stroke care pathway, which reflects the findings of the national stroke audit.<sup>12</sup> Staff participants from non-psychology disciplines voiced concerns about the increased responsibilities associated with psychological assessment. Furthermore, there was a feeling that this role was being undertaken without the necessary skills, preparation and training required. The UK stroke guidelines recommend a stepped care approach to psychological care after stroke.<sup>10</sup> It is apparent from the data, however, that the potential for such an approach is minimal as psychological expertise is not available to support those patients at most risk and the provision of training and supervision to staff from other disciplines is not available. This raises questions about how staff from other disciplines access training about psychological assessment and support post-stroke when there is a relative absence of psychological expertise. The Stroke Specific Education Framework provides information about competencies required for specific disciplines and endorsed training courses and materials for providing psychological screening, assessment and support.<sup>22</sup> These resources could be utilised by non-psychology staff working on stroke units, in order to increase the capacity of stroke services to provide basic psychological support. The multi-faceted nature of what participants' perceived to be 'psychological support' was reflected in their dialogue about the importance of communication, information provision, peer and social support. Increased recognition of the importance of protective factors, perceived to reduce the need for formal psychological support, might enable resources to be targeted at those without protective factors potentially reducing the burden on staff with psychological expertise. The desire for information as a resource for empowerment and psychological adjustment has been found in many different conditions<sup>23</sup> and is supported by a recent systematic review which demonstrated that information provision post-stroke reduced patient depression.<sup>24</sup> Thus improving

information provision could play a role in reducing the need for more formal psychological support post-stroke. The findings also indicate peer and social support play a vital role in post-stroke psychological adjustment. Evidence has shown that hospital-based peer support groups for stroke patients and carers brought therapeutic gains and perceived benefits including information, advice, making connections and downward social comparison.<sup>25</sup> Volunteer or family member led peer support groups could be a mechanism by which social and peer support could be facilitated post-stroke, particularly in those patients experiencing 'low level' psychological need.

The study is the first of its kind to provide multi-perspective data on psychological care in stroke, however some limitations must be acknowledged. The study took place in one region of the UK so the findings might not be transferable to other regions. The response rate is unknown because the number of invitation letters sent out was not recorded at every site. Patients with significant on-going unmet needs post-stroke might have self-selected not to participate in the interviews, which could result in the data being positively skewed, which might underestimate the extent of need and the range of services required. Furthermore, the staff sample included only one psychologist and the findings need to be interpreted in this context; however this is reflective of the limited psychology input available on the stroke units in this sample. The study is limited to reporting patient's recollections and experiences without data concerning the patient's mood; as a result it is not possible to know what proportion of the patient sample required formal psychological support post-stroke. The interviews and focus groups explored participants experience of all care delivered and received post-stroke, not just psychological assessment and support, which might have impacted on the depth of participant's responses.

The data suggest that patients need better access to psychological support, including formal provision but also information, advice and peer or social support. More research is required to establish the effectiveness of alternative options to formal psychological support, such as information giving and peer support interventions. Moreover, research is needed to explore the organisation of services and the effectiveness of using non-psychology staff to provide psychology services within the stepped care model. Other disciplines from the stroke multi-disciplinary team are taking on the role of providing psychological expertise, but more training and supervision is required to ensure such staff do not feel 'out of their depth' and this will require some degree of psychological expertise to be present within the stroke multi-disciplinary team.

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Table 1. Patient participants' characteristics (n=31)

Mean age (SD)	66.48 ± 8.88 years	
Male	N = 18 (58%)	
Mean length of inpatient stay (SD)	21.52 ± 24.78 days	
Mean length of time between discharge and interview (SD)	171.23 ± 92.43 days	
Recovery outcome measure	Recovered	N = 7 (23%)
	Not recovered	N = 24 (77%)
Dependency outcome measure	Dependent	N = 11 (35%)
	Not dependent	N = 20 (65%)

Table 2. Carer participants' characteristics (n=28)

Mean age (SD)	61.75 ± 13.44	
Male	N = 9 (32%)	
Relationship to patient	Spouse or partner	N = 21 (75%)
	Former spouse	N = 2 (7%)
	Daughter	N = 2 (7%)
	Granddaughter	N = 1 (4%)
	Daughter-in-law	N = 1 (4%)
	Brother	N = 1 (4%)

Table 3. Staff participants' job titles (n=66)

Qualified nurse	N = 22 (33%)
Stroke specialist consultant or registrar	N = 9 (14%)
Physiotherapist	N = 8 (12%)
Occupational therapist	N = 6 (9%)
Speech and language therapist	N = 6 (9%)
Nursing assistant	N = 6 (9%)
Dietician	N = 2 (3%)
Radiologist	N = 2 (3%)
Others *	N = 5 (8%)

\* Other participants included a clinical psychologist, support worker, therapy assistant, orthoptist and personal assistant