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Service users' views of the assessment process in stroke rehabilitation

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Abstract

Objective: To investigate the service users' (stroke survivors and care-givers) experiences and views of the rehabilitation assessment process.

Design: Qualitative data analysis from three focus groups using a content analysis to identify the major themes.

Setting: Participants were recruited from stroke support groups and community rehabilitation services in a large UK city.

Subjects: Seventeen community-dwelling stroke survivors who had completed their rehabilitation within the previous year and six care-givers.

Results: Five themes emerged: understanding the purpose of the assessment; repetition of assessments; feedback about assessments and progress; format of feedback and barriers to feedback. While all participants reported undergoing assessment, some felt their purpose was not always explained and resented unexplained repetitions of tests. Some participants reported a positive experience, but most wanted more information about their progress and predictions of recovery. They wanted regular, consistent, objective information presented in layman's terms; verbally and in writing. Some carers reported difficulty accessing information particularly as a result of confidentiality policies. While some participants accepted these short-comings, others considered them due to staff's disinterest or ineptitude, which undermined their trust in the team.

Conclusions: Stroke service users require clear information about the purpose of assessments and regular, consistent, objective feedback about their progress using layman's language both verbally and in writing.

Keywords

Stroke, rehabilitation, assessment, measurement, qualitative

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Introduction

Comprehensive assessment and the use of objective, standardised measurement tools are a well-established part of stroke rehabilitation, such that they are recommended in clinical guidelines worldwide.[1-4] This is because they are thought to facilitate multidisciplinary team communication, decision-making and treatment planning.[5,6] Professionals' opinions and experiences of using measurement tools as part of the assessment and treatment planning process are well known, particularly the barriers to their use.[7,8] However, the service users' (patients and family/care-givers) perspective has been overlooked. As part of a programme of work to investigate multidisciplinary team work and the use of measurement tools in stroke rehabilitation, we sought stroke service users' views of the assessment process, including the use of standardised objective measurement tools.

Method

A convenience sample of community-dwelling, English speaking stroke survivors who had received stroke rehabilitation within the previous year were recruited through community stroke rehabilitation services, stroke support groups and the Patient and Public Involvement panel of Greater Manchester & Cheshire Cardiac and Stroke Network. Care-givers or family members were also invited to attend with their stroke survivor. Potential participants were identified and approached by the staff from the recruiting organisations. If they expressed an interest in participating, they were provided with a pack of information including a participant information sheet, contact details for further information, ground rules for the discussion and an outline of the questions to be discussed. We did not exclude stroke survivors with communication problems and all attempts were made to ensure the information was aphasia-friendly. Potential participants contacted the research team directly if they wished to attend. We approached the Research Ethics Committee for Manchester for ethical approval, however, this was deemed unnecessary as the study was part of a larger service improvement project.

Focus groups were held in neutral non-clinical settings in locations across the city that were convenient to the participants. At the beginning of each group, the aims and ground rules for the group were reiterated, participants (stroke survivors and care-givers) were given the opportunity to ask questions and informed consent was obtained both verbally and in writing. Two of the authors (LB and AM) facilitated the sessions, one of whom is a stroke speech and language therapist who provided communication support as required. Flipcharts and pens were provided for participants to make notes and those with communication difficulties were encouraged to make use of these resources. One facilitator also recorded themes and notes on a chart for the group's reference, which enabled participants to offer concurrent feedback on accuracy, increased the transparency of the data and facilitated participation for those with communication or concentration difficulties. Each group lasted for approximately two hours. Both facilitators were employed by the Cardiac & Stroke Network to work with the city's stroke services to improve rehabilitation. They had no direct relationship with the participants, who did not know them before the study.

A semi-structured interview schedule was used with verbally presented open and closed questions. These were also tabled for those with communication or concentration difficulties. The questions concerned the participants' experiences and views of the assessments undertaken during stroke rehabilitation; their understanding of the assessments; their relevance and completeness; the explanation and feedback they were given (if any); how progress was monitored and communicated, and how things could be improved.

The focus groups were audio-recorded, transcribed verbatim and anonymised. Data analysis was iterative using conventional thematic content analysis.[9] The authors read the transcripts repeatedly for familiarity and to identify recurring themes. They met regularly to reflect on the data and to discuss their analyses and emerging themes. Two authors (LB and ST) then iteratively coded the transcripts, sentence by sentence, against the emerging themes which, where necessary, were

sub-divided into categories. Relationships between items were explored and discordant opinions highlighted through constant comparison. Any discrepancies in interpretation were discussed and consensus reached. The third author was available to arbitrate if agreement could not be reached.

Results

Seventeen stroke survivors, including three with dysphasia, participated in three focus groups. The mean age of participants was 58 years (sd=15.6, range=19-84) and 11 (65%) were men. Six carers also took part; four women and two men. Five were spouses/partners and one was a stroke survivor's mother. There were 6 to 10 participants in each group.

Although the discussion sometimes merged with a more general discussion about communication between service users and professionals, specific issues regarding assessment emerged in five themes: understanding the purpose of assessments; repetition of assessments; feedback about assessments and progress; the format of feedback and barriers to obtaining feedback.

Understanding of the purpose of assessments

All participants were able to identify some assessments that they had undertaken and appreciated they were necessary for professionals to make a diagnosis, plan treatment and arrange discharge. However, although a couple of participants felt staff had explained the purpose and reason for the assessments, most received little explanation and had a poor understanding. In particular, participants expressed confusion about the reason for psychological assessments. Some supposed staff thought they had dementia rather than a stroke, while others simply could not see the point of them and were not motivated to co-operate:

> *"They never explained really why they were doing it, or what the function of that test* [of cognitive function] *was. Why on earth will I ever want to count backwards in 7s? Please tell me! Please tell me! If you'll explain to me why I will ever have to count backwards in 7s, I'll do it, but until then I'm not doing it."* [stroke survivor 8]

Two participants were puzzled by the content of the assessment and resented being asked if they *"felt like topping themselves"* (which was part of a commonly used assessment of mood). Others described how lack of explanation added to their anxiety:

> *"I mean I'm terrified…… And I'm thinking, "right what's involved with that?"* [having a scan] *Someone said he might put dye in and all that..... I mean obviously they're busy but you get headaches just thinking about it"* [stroke survivor 2].

Repetition of assessments

Related to a lack of understanding about assessments was a problem with their repetition. While some participants were happy to trust the professionals and were confident that they were doing whatever was needed, others were irritated when staff asked *"the same questions all the time"* without explanation. It appeared to them that staff were inept or did not communicate between themselves effectively.

> *"The first question I was asked "Do you smoke?" I've never smoked in my life, and if I've said it once, I must have said it a hundred times ..... At one point, I just said to somebody "have you not read the notes?" ... I find their lack of knowledge of me insulting, like I said, why haven't you read up on me? ..... You're a multidisciplinary team; information is shared and should be combined on to your notes. That's the whole idea of how it works.* [stroke survivor 16, a healthcare professional].

This was also an issue for carers:

> *"The biggest thing to us through all of this has been the lack of communication. There is no liaison whatsoever between all these different people, and like you say, you go through the same thing again and again… At his sheltered accommodation they did an assessment, but that was basically us telling them what he could do and what he couldn't do. But they should've had all that and know this."* [carer 4]

Feedback about assessments and progress

Participants reported more mixed experiences regarding feedback about assessments and progress. Half the participants reported positive aspects of feedback. For example, one stroke survivor had received a written report at the end of an episode of treatment and was told her scores on standardised assessments when the therapists reviewed progress towards her goals, which she found encouraging. Another survivor received feedback on her achievement of rehabilitation goals but without objective measurements and another described how videos had been taken to record his improvements in hand function over time. This demonstrated progress which he had not noticed day-to-day or with subjective feedback and he found the experience very positive. Participants appreciated the time taken to explain the results of assessments so that they had a better understanding of their problems and how this related to their treatment and particularly, to their progress. Family meetings were especially helpful:

> *"We used to have a monthly meeting, the family was brought in and everyone that worked with you was in that meeting, ... and we'd all talk about progress, and if I had any questions or my family had any questions. So we did get lots of feedback .... Good explanation of what they were doing and why they were doing it"* [stroke survivor 1]

However, other experiences were less positive. About half the service users felt they received little or no feedback. Stroke survivor 2 summed up the problem: *"There was plenty of questions, but I needed answers."* The lack of feedback caused a barrier between professionals and service users:

> *"I have no memory of XX having any assessment. He probably did, but we were never told. All we kept being told was 'it just takes time, just takes time…' and that's basically all we could get out of them."* [carer 4]

Stroke survivor 16 felt the lack of feedback was "*dehumanising"* while others felt lack of feedback was demotivating:

> *"You're just like doing endless physio and endless speech, you just think I don't know how I'm doing, am I progressing? Am I getting any better? So yes it would be beneficial if they just spoke to you or spoke to your family"* [stroke survivor 10]

Most participants felt any feedback had to be fought for and that service users had to take the initiative and "*do all the chasing"* or *"hound the staff"* as *"the only time you got to find anything out was if you asked"*. This, they felt, was unreasonable and added to their stress. They felt that staff were *"not bothered with them"* and should proactively feedback the results of assessments and, particularly, progress.

The carers/family members in the groups also felt strongly that they wanted clear objective information about *"what was the prognosis and what was needed for him to improve?"* [carer 4]. Prognosis was in terms of whether the stroke survivor would *"get better"* rather than survival. However, they rarely received such information. Participants complained that feedback, when available, was subjective, vague and unhelpful with phrases such as *"he'll be alright, it just takes time"* or *"everyone is different, we don't know how he will do"* or they were told they (or their relative) were *"doing fine"*, when they felt it was obvious that they were not as they were still experiencing difficulties. Some were content to accept that objective prognostic information was just not available because of the nature of the condition, but most felt that it was because staff were not well enough informed, simply too busy or unwilling to be accountable for sharing such information. They felt frustrated, disregarded and that they needed *"more information regularly"* to support them through the recovery process and manage their expectations.

Format of feedback

As well as the nature of the feedback, both service users and carers were quite clear about the format they would find most helpful. They needed to be given information both verbally and in written format. Staff needed to avoid *"fancy jargon"* and use

"our language, not doctor's." They also needed to be prepared to give the information repeatedly as most stroke survivors were unable to easily take in information, because of memory, concentration or comprehension difficulties but also because of the shock of having suffered a stroke:

> *"Your world's been turned upside down, hasn't it? They're telling you all these things you're like 'what er sorry, I've got all these other things on my mind'"* [stroke survivor 3]

The feedback also needed to be consistent and regular. A few participants received contrasting information and feedback from staff; that everyone had a *"different opinion"* which was confusing and undermined their trust in the professionals.

Most participants felt it would be helpful if their relatives could be involved in discussions about their progress as they would be able to *"translate"* and reiterate the information so they could understand and remember. When this had occurred, participants reported a positive experience. However, not all participants welcomed this. Two actively did not want their relatives to be included in feedback and discussions: one because he felt it was none of their business and the other because she felt it would worry them too much.

There was also some discussion about leaflets. All participants had been given leaflets to describe and explain aspects of their stroke, its impact and the treatment available, but they had a mixed review. The large number of leaflets was a recurring theme. Some found them helpful, had read them and had kept them for future reference, but others found them overwhelming and a poor substitute for personal contact and feedback.

> *"You're given loads and loads of leaflets, 'til they're coming out of your ears but what use is a leaflet? Most people who've had a stroke can't concentrate on reading it"* [stroke survivor 11]

Barriers to obtaining feedback

Several barriers to receiving feedback were highlighted during the discussions. Confidentiality was the most common one, where staff told relatives that they could not discuss the patients' progress because it would breach confidentiality policies. The participants were scornful of this, describing it as *"bollocks"* and *"nonsense."* As stroke survivor 8 explained:

> *"She's* [my wife] *trying to help me and without that knowledge, she can't do the best for me… so don't give me all that nonsense about you're not allowed to say. That really is just detrimental to the whole situation of rehab."*

Other problems were mis-information, inconsistent information and staff being too busy or slow. For example, one participant described how he had been denied access to community-based services as he was told they were unavailable where he lived, which he later found to be untrue. Generally the participants perceived the justifications the staff provided for these difficulties as excuses to avoid interaction with patients and relatives and undermined the professional-patient relationship. However, there were contrasting views. Some felt that giving or preparing feedback would detract from treatment, which was a higher priority.

Discussion

These results show that stroke service users' desire an explanation about the assessments undertaken and feedback regarding their results and progress during stroke rehabilitation. They want specific, regular, consistent and objective information regarding the consequences of stroke and, particularly, their progress. Their overwhelming concern is whether they will 'get better' and they want information about this, for better or worse. To assist with taking in information at a stressful time, service users felt feedback needed to be given repeatedly, both verbally and in writing and most, but not all, wanted their families to be involved. Most felt they had received insufficient explanation and feedback about assessments, although there were examples of satisfaction. They were particularly irritated by the frequent, unexplained repetition of assessments and lack of feedback about the results. This negatively impacted on their trust of the health care professionals and the professional-patient relationship.

To the authors' knowledge, this is the first report of stroke service users' perspective of the assessment process during stroke rehabilitation. There is an extensive body of literature regarding service users' information and education needs (the terms 'educational' and 'information' needs tend to be used interchangeably) particularly around discharge in preparation for 'life after stroke'[10-13] but less investigation of such needs during rehabilitation. However, the findings support previous reports that service users need consistent, individualised information verbally and in writing[12,13] and reiterate that, in the (relatively) early stages of recovery, service users' focus on prognosis and predicted recovery.[10]

In response to the need for information and feedback, there has been an assumption that interventions are needed to increase service users' 'knowledge of stroke'. There is good quality evidence that education and information-giving interventions can increase knowledge, patients' mood and some aspects of satisfaction but do not affect mortality, carers' mood or satisfaction.[11] However, the differences found are small and their clinical significance unclear. It is notable that the interventions rarely include stroke patients' and carers' input during development.

The results of the present study suggest that education-based interventions would not fulfill the needs of stroke service users during rehabilitation where objective, regular, personalised feedback about the nature of their problems, progress and eventual outcome are called for. Some participants had been told that such information and recovery was not possible as *"everyone was different"*. This view does not reflect the evidence; recovery patterns and the likelihood of different levels of recovery have been established for many stroke-related impairments and activity limitations,[14-19] such that it would be possible to give individualised information about patients' likely degree and time scale of recovery.

Further work is needed to explore stroke professionals' views on providing this information and how services can be developed to do so effectively. There is some evidence that stroke professionals avoid giving explanations about recovery because it will, at least sometimes, involve giving bad news which they find uncomfortable and fear may demotivate patients and families.[20-22] Possibly for similar reasons, they also tend to give an overly-optimistic view of recovery once the patient returns home, which can result in great disappointment when the extent of residual disability is realised.[20,23,24] There is substantial literature regarding the giving of bad news in some areas of health care, particularly cancer, but it has received very little attention in stroke; only two papers could be found.[21,22] Nevertheless, several models of delivering bad news and developing the necessary skills have been published which could, potentially, be applied to hospital-based stroke care.[21,25,26]

One way in which stroke service users' information needs could be met during the early stages of recovery (the so-called stabilization and preparation phases[10]) is by using data from assessment with objective measurement tools to explain the nature and severity of stroke survivors' impairments and activity limitations and to demonstrate progress (or lack of it) through changes over time. This has been found to be a useful communication tool in neurological rehabilitation, providing evidence of improvement which is motivating for patients and families and facilitating the giving of bad news by objectifying the professionals' opinion.[5,6]

Our results have clear implications to improve clinical practice; the findings regarding the need to avoid unnecessary repetition and provide for greater explanation of assessments; the nature and format of the feedback, and removal of the barriers to feedback could be implemented immediately. Nevertheless further research is needed to establish how to improve service users' experience and ultimately outcomes. Although there is much research that could be used to inform patients about their expected recovery, work is needed to establish how this can be translated into information that is acceptable and feasible for staff and patients. Models of how to break bad news and support staff development to enable them to be more comfortable with this important communication skill need to be evaluated in stroke care and the impact of using objective measures to feedback information

regarding their problems and progress needs to be tested.

When using these findings to inform clinical services, several limitations need to be considered. Like all qualitative research, there are limitations in the generalisability of the findings. We specifically sought to involve service users who had completed their rehabilitation (so they would be uninhibited by fear of repercussions) relatively recently (so they would be able to recall their experience). However, different results may have been obtained if participants were still receiving rehabilitation or were more than one year after their stroke. We included people from across one of the largest cities in the UK from a range of socio-economic conditions and differing models of stroke service delivery; but we may have had differing results from a different geographical location or an alternative health care system. Nevertheless, the congruence between some of our results and previous reports of aspects of patients' needs and experiences suggest our findings are reasonably representative.

Clinical messages

- Stroke service users reported some good experiences but also negative ones: insufficient information on the nature and purpose of assessment, and inadequate feedback of results.
- They wanted specific, regular, repeated consistent information in layman's language, verbally and in writing.
- Most (but not all) wanted their families to be given information.

Conflict of interest

The author declare there is no conflict of interest.

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References

1. National Audit Office. *Reducing brain damage: faster access to better stroke care*. London: Department of Health, 2005.
2. Care Quality Commission. *Supporting life after stroke*. London: CQC, 2011.
3. National Stroke Foundation. *Clinical guidelines for stroke management 2010*. Melbourne: NMHRC, 2010.
4. Lindsay P, Bayley M, Hellings C, Hill M, Woodbury E and Phillips S. Canadian best practice recommendations for stroke care (updated 2008). *CMAJ* 2008; 179: S1–S25.
5. Tyson S, Greenhalgh J, Long A and Flynn R. The use of measurement tools in clinical practice; an observational study of neurorehabilitation. *Clin Rehabil* 2010; 24: 74–81.
6. Tyson S, Greenhalgh J, Long A and Flynn R. The influence of objective measurement tools on communication and clinical decision-making in neurological rehabilitation. *Journal of Evaluation of Clinical Practice* 2012; 18: 216–224.
7. Fung C and Hays R. Prospects and challenges in using patient-reported outcomes in clinical practice. *Qual Life Res* 2008; 17: 1297–1302.
8. Torenbeek M, Caulfield B, Garrett M and van Harten W. Current use of outcome measures for stroke and low back pain rehabilitation in five European countries: first results of the ACROSS project. *Int J Rehabil Res* 2001; 24: 95–101.
9. Hsieh HF and Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15: 1277–1288.
10. Cameron J and Gignac M. "Timing It Right": A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling* 2008; 70: 305–314.
11. Forster A, Brown L, Smith J, et al. Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews* 2012; 11.
12. Hafsteinsdottir T, Vergunst M, Lindeman E and Schuurmans M. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Education and Counseling* 2011; 85: 14–25.
13. Eames S, Hoffmann T, Worrall L and Read S. Delivery styles and formats for different stroke information topics: patient and carer preferences. *Patient Education and Counseling* 2011; 84: e18–e23.
14. Tyson S, Chillala J, Hanley M, Selley A and Tallis R. The relationship between balance disability and recovery after stroke: Predictive validity of the Brunel Balance Assessment. *Neurorehabilitation and Neural Repair* 2007; 21: 341–346.
15. Kwakkel G, Kollen B, van der Grond J and Prevo A. Probability of regaining dexterity in the flaccid upper limb

impact of severity of paresis and time since onset in acute stroke. *Stroke* 2003; 34: 2181–2186.
16. Kollen B, van de Port I, Lindeman E, Twisk J and Kwakkel G. Predicting improvement in gait after stroke: A longitudinal prospective study. *Stroke* 2005; 36: 2676–2680.
17. Jørgensen H, Nakayama H, Raaschou H, Vive-Larsen J, Støier M and Olsen T. Outcome and time course of recovery in stroke. Part I: Outcome. The Copenhagen stroke study. *Arch Phys Med Rehabil* 1995; 76: 399–405.
18. Pedersen P, Jørgensen H, Nakayama H, Raaschou H and Olsen T. Aphasia in acute stroke: incidence, determinants, and recovery. *Ann Neurol* 1995; 38: 659–666.
19. Hochstenbach J, den Otter R and Mulder T. Cognitive recovery after stroke: a 2-year follow-up. *Arch Phys Med Rehabil* 2003; 84: 1499–1504.
20. Wiles R, Ashburn A, Payne S and Murphy C. Discharge from physiotherapy following stroke: the management of disappointment. *Soc Sci Med* 2004; 59: 1263–1273.
21. Phillips J, Kneebone I and Taverner B. Breaking bad news in stroke rehabilitation: a consultation with a community stroke team. *Disabil Rehabil* 2013; 35: 694–701.
22. Grainger K, Masterson S and Jennings M. 'Things aren't the same, are they?' The management of bad news delivery in the discourse of stroke care. *Commun Med* 2005; 2: 35–44.
23. Hoffman J. "Nothing can be done": Social dimensions of the treatment of stroke patients in general hospital. *Journal of Contemporary Ethnography* 1974; 3: 50–70.
24. Pound P, Bury M, Gompertz P and Ebrahim S. Views of survivors of stroke on benefits of physiotherapy. *Quality in Health Care* 1994; 3: 69–74.
25. Buckman R. Breaking bad news: the SPIKES strategy. *Psycho Oncol* 2005; 2: 138–142.
26. Villagran M, Goldsmith J, Wittenberg-Lyles E and Baldwin P. Creating COMFORT: a communication based model for breaking bad news. *Comm Educ* 2010; 59: 220–234.