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What do stroke survivors think about the evidence-based stroke care they receive? Learning from insights at the “*periphery*”.Cherry Kilbride MSc PhD MCSP^a, Rhoda Allison MSc MCSP^b and Philip H Evans MPhil FRCGP^c

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Abstract

Rationale and aim of study: While exploring the experience of stroke survivors of secondary stroke prevention as part of a wider patient and public involvement service initiative, study participants willingly shared insights on other aspects of care that mattered to them. This is important as little is known about patients' preferences for care.

Methods: Data was generated from focus groups and semi-structured interviews that were held with 38 stroke survivors or their proxy respondents as part of an action research study. A framework analysis was used to examine data.

Results: Our findings largely support current knowledge about the benefits of receiving evidence-based stroke care. Although patients broadly appreciated being on a specialist unit, unexpectedly and contrary to best practice some expressed the wish to be treated elsewhere as they found the experience of being on a stroke unit difficult. Other findings included the need for more local peer support and difficulties surrounding transfer from hospital to home. Resultant actions included awareness training for staff about sensitively managing people's perceptions about being on the stroke unit, development of shared computer-based (IT) resources, and the establishment of a volunteer peer support system.

Conclusion: The evidence base for the benefits of stroke unit care is unequivocal; however, this model of care presents challenges for some. Involving patients in service development can inform small but key changes in practice that can help address inherent tensions in delivering evidence based services that are sensitive to patient preference.

Keywords

Evidence-based stroke care, patient preference, person-centered medicine, stroke, stroke unit

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Introduction

Stroke is the second largest cause of death in adults and the principal cause of long-term severe adult disability worldwide [1–3]. For those who suffer a stroke one-third die, a third will make a good recovery and the remainder will be left with enduring impairments and disabilities [4]. Specialist intervention delivered in an in-patient stroke unit has been shown to save lives, lessen lasting disability in those surviving the initial insult and improve quality of life [5, 6].

Post discharge from the specialist acute stroke service, those with residual disability require ongoing input from health and social services as determined by their individual needs [7]. Substantial progress in delivering hospital-based

stroke services has been clearly shown [8]. However, advances in post-hospital support for stroke survivors and their families remains problematic. For example, access to early supported discharge (ESD) teams, specialist stroke rehabilitation, peer support and a paucity of relevant information after leaving hospital are areas requiring further improvement [9–12]. These service delivery issues are all the more important given that the physical and psychological aftermath of stroke is often most profoundly experienced when the stroke survivor is discharged from hospital. Here they experience the full impact of their disabilities within the neighbourhood and home environment, which may result in their becoming socially isolated, a factor associated with post-stroke depression [13–15].

The rhetoric of policy development for those with long-term disability and chronic illness such as stroke, emphasises the importance of personalised care and listening to the voice of the patient. While the benefit of evidence-based stroke care is unequivocally proven, little is known about patients' preferences for care, especially in the acute setting. This paper presents the experiences of people receiving specialist stroke care; findings are drawn from an action research study that looked at secondary prevention for stroke and was undertaken as part of a wider patient and public involvement service initiative [16]. During the study, participants willingly shared unsolicited remarks about other aspects of their treatment that mattered to them during their journey across the stroke pathway; these are the focus of this paper.

Methods

A qualitative approach was taken to explore the participants' experience of receiving evidence-based stroke services. The study took place in South Devon across a stroke care pathway that spanned acute, rehabilitation and community settings. The service has a strong ethos of partnership working and received a national accolade from the Department of Health for Improving Access in 2006.

Stroke survivors registered in one of three Primary Care Trusts in South West England were invited to participate, along with their carers who acted as proxy respondents for people who had communication or mild cognitive impairments. Potential participants were identified from hospital records using the International Classification of Diseases (version 10) codes [17] for stroke. The sample was purposively selected to ensure a variety of patients were approached, including individuals characterised by a range of age, gender, time since stroke and impact of stroke (identified using the proxy of hospital length of stay).

One hundred and thirty people were invited to take part in the study, 38 people agreed to participate. Twenty-five semi structured interviews and 4 focus groups were undertaken (by RA). The methods were chosen to seek a range of individual perspectives and joint constructions respectively. In line with client-centred practice, participants could choose if they wished to attend a community-based focus group, or be interviewed at home.

Data from the focus groups and interviews were audio-taped and transcribed *verbatim*. Data were analysed using framework analysis [18-20] and followed a step-wise method including familiarisation of data, identification of thematic framework, generation of codes to label transcript passages, revision of themes and coding as data accumulated, code application to the final dataset and exploration and mapping of theme relationships both within and between participants. Data related to the primary research question regarding secondary stroke prevention is reported elsewhere [16].

All 29 transcripts were analysed by the principal investigator (RA). To strengthen the validity and trustworthiness of findings one-third of the transcripts were also scrutinised by a second researcher (CK) providing triangulation through multiple analysis [21]. Themes and supporting data were further reviewed by a Primary Care Clinician to enhance credibility (PHE). Researchers planned to resolve any differences in interpretation through discussion, but this proved unnecessary as there was strong agreement between identification of codes and themes.

Ethical considerations

Ethical approval for the study was obtained from the South Devon Ethics Committee (REC: 06/Q2104/14).

Results

There were 25 people with stroke and 13 carers who acted as proxy respondents over the study period of 11 months. Nineteen of the participants were women and 19 were men. The mean age was 69 years (standard deviation of 14 years) and a mean duration of time since stroke of 8 months (standard deviation 5.7 months).

Three main themes related to the experience of stroke emerged from the data; the highs and lows of stroke unit care, difficulties with the transition from hospital to home and isolation.

Highs and lows of stroke unit care

Patients treated on a stroke unit where interventions are delivered by a specialist multidisciplinary team with expertise in stroke have better outcomes than those managed elsewhere [6]. Thus, it follows that best practice guidance calls for all stroke patients to receive this gold standard care [22,23]. Indeed the majority of patients in the present study received their care on a stroke unit and were able to experience first hand the benefits of the staff specialist skills and knowledge.

"...I was bewildered, frightened, no doubt about that...and yet the care there [stroke unit]...you felt in safe hands...right from the start

Participant 24 (age 53, 6 months post-stroke)

Patients drew some comfort and confidence from knowing they were receiving specialist care although the impact of the stroke was still undeniable. In contrast, the three stroke patients interviewed that were admitted to general medical wards described the negative effect they felt this lack of specialist input had on their care:

"We never had a discussion with any doctors there because he wasn't in the right ward to start with..."

Proxy respondent 11 (age 76, 6 months post-stroke)

The positive evidence for stroke unit care is well documented and findings from this study lend further support to this concept. Conversely, there appears to have been little attention to any negative perceptions of patients receiving this form of espoused care. Nonetheless, this under-reported matter emerged as a strong theme from this study's participants who described a number of differing problems associated with this specialist care. Being with people who were more affected by stroke than themselves was evident in the data:

"The worst thing they did was put me in the stroke ward ... people that can't talk and are incontinent and can't do a thing for themselves is very depressing for the people walking around and trying to make a go of it"

Participant 12 (age 68, 5 months post-stroke)

"...it is a bit depressing (on the stroke unit) because of the other people... hoping it's not going to happen to you what's happen to them"

Participant 7 (age 70, 9 months post-stroke)

Likewise it was hard for the family members to observe the effects of severe stroke in others;

"We sat in the dayroom most of the time because I didn't want to sit on the ward looking at others in terrible situations..."

Proxy respondent 6 (age 65, 5 months post-stroke)

Although stroke unit care is the only proven treatment option for acute stroke that reduces mortality [6], a third of stroke patients still die from the initial event [4]. Bearing witness to others dying from a health event the same as your own is understandably hard:

"The reason I wanted to get home is that the chap in the bed next to me died the night before and it was very off putting..."

Participant 17 (age 57, 6 months post-stroke)

Part of the remit of the UK National Stroke Strategy [24] was to establish a coordinated network of stroke care across the patient journey. This has led to a variety of service configurations, often with acute care centralised in larger regional hospitals with local care providing ongoing stroke rehabilitation. Whilst it is necessary to bring specialists together in stroke centres to maximise effectiveness of care and improve outcomes to develop expertise of care [25], these findings suggest this can have a personal price for the stroke survivor and their families. Because of exactly this, one participant chose not to remain on the stroke unit preferring instead to transfer his care to a local community hospital. His wife was unable to

drive and this presented considerable difficulty in being together at this difficult time:

"My whole object really was (my wife) doesn't drive and we were adjusting to new circumstances – my object was to get me into our local hospital as quickly as possible"

Participant 23 (age 79, 6 months post-stroke)

It is a misconception that stroke is a disease of older people as people of all ages including babies can be affected [26]. Nonetheless, some of the younger stroke survivors found it problematic to be alongside people who were mostly older than them. One participant described how being on the stroke unit made him feel;

"...it was actually demoralising in truth because as a relatively young person, essentially people around you are old and you recognise their symptoms...its actually depressing...it was frightening...you think you are going to die...that was scary..."

Participant 2 (age 46, 24 months post-stroke)

Notwithstanding difficulties such as these, the appreciation of the broader clinical need to be on a specialist stroke unit was still evident. For example, one younger participant said:

(I didn't mind being on the stroke unit) "because I knew what was happening ...I suppose you put it down to life experience I suppose it didn't bother me because even Dr. S said are you bothered about going on to the stroke ward and I said no because I knew how severe – how deadly it [stroke] could be"

Participant 18 (age 37, 3 months post-stroke)

Difficulties with the transition from hospital to home

The second key theme to arise from this study centre on difficulties surrounding the transition from hospital to home. The prominence of this topic is not altogether surprising given the improvements in acute care, so more people are surviving stroke to return to the community with significant residual impairments [27]. Moreover, the aftermath of stroke is most profound when the stroke survivor returns home and experiences the full impact of their disabilities within the context of their home and social environment [28]. Returning home was cited as being stressful for more than a third of the participants in the present study findings.

"...coming home was daunting – because I wasn't prepared – ... the thought of being in the house with all these stairs on my own, and cooking..."

Participant 9 (age 64, 24 months post-stroke)

These feelings of worry were exacerbated when seemingly straightforward aspects of follow-up services were not clear:

“When I left hospital I had to fight for my own physiotherapy... I was put under the community physiotherapy team... I had to ring up before they visited... they didn’t contact me immediately so I didn’t know what was happening”

Participant 4 (age 68, 10 months post-stroke)

This corroborates the findings of Murray et al [29] that patients and carers felt ill-prepared for discharge. A number of studies have found that people feel they do not receive sufficient therapy after hospital discharge [30] and that staff do not always make onward referrals for therapy even when patients feel they may benefit [31]. As such, this could be seen as calling into question the clinical judgement of the healthcare professionals that have been responsible for their care and who is best placed to decide if more treatment is needed. Moreover, stroke survivors have reported feeling resigned to having to accept passive roles in their interactions with professional staff due to the loss of control over their circumstances [32], expressing disappointment that they are not informed of follow-up arrangements for their care [33].

Isolation

Reports of isolation post-stroke are well documented in the literature [7,28], with the findings of this study providing further support for this. People described feelings of missing their previous lives, loneliness and being cut off from professional help, the latter being more pronounced when community services began to be withdrawn.

“Friends came and even then I still felt very isolated – life had changed so much”

Participant 5 (age 70, 12 months post-stroke)

“Once you came out of hospital you see the Dr. for the INR but that’s it... what else is there”

Proxy respondent 7 (age 75, 9 months post-stroke)

In particular, stroke survivors have articulated their difficulty in explaining their experiences to other people who cannot imagine how it is to live with a stroke [34]. Over half of the participants in this study articulated the desire to talk to others who had survived a stroke. This ranged from wishing to talk to someone while still in hospital to wanting to attend peer support groups in the community:

“I think a lot of things came out of that (peer group in community) – they did give advice on if you had got problems they could point me in the right direction”

Participant 19 (age 52, 4 months post-stroke)

“I think that makes one heck of a difference because I can’t always share how I feel”

Participant 24 (age 63, 5 months post-stroke)

Provision of peer support has been shown to have positive benefits in some areas of healthcare including management of post-partum depression [35] and breastfeeding [36], but its value is less well established in the management of long term conditions.

Discussion

The evidence base for the benefits of stroke unit care is unequivocal; people have better outcomes [6,23]. Hence, it is not surprising that stroke units as the general method of care delivery has gone largely unchallenged. Nonetheless, our findings showed that some people found the experience of being on a stroke unit very difficult, especially sharing space with others more severely affected than themselves. Some younger patients had discussed transfer to the stroke unit with a consultant prior to this taking place and felt this had been helpful in preparing them for the move and what to expect. Given the increasing call for direct admission to hyperacute stroke units (first 72 hours) with a view to increasing the percentage of those with ischaemic stroke receiving intravenous thrombolysis [24,37], it is less likely that opportunities for a pre-admission consultation will continue to present itself. However, this increasing technicalisation of stroke care which is improving outcomes for some [38] must not be at the expense of losing the “human dimensions of care” [39]. However, as Todres et al [40] found in an earlier study looking at the intensive care situation, patients do understand the need for staff to concentrate on the technological requirements at this stage in their treatment. Nonetheless, staff should make the time to help prepare stroke survivors psychologically for the following stages of stroke care and remain mindful to the challenges this may present to some.

Although findings indicate patients broadly valued being on a specialist stroke unit some felt their feelings prompted them to seek earlier discharge home. Although not suitable for all, the evidence for early supported discharge (ESD) in stroke is favourable [41]. As the majority of patients and carers expressed a need for a smoother transition between hospital and home with frustrations centred on when they would have contact with the community team, the model of ESD may be welcomed by many. However, not all patients are considered suitable for the criteria for ESD so the local service has implemented a process where the community services share available appointments with the stroke unit. Consequently, ward staff can pre-book therapy follow-up appointments before the person leaves hospital so that patients and carers are informed when these visits will

occur. Even for people not considered for ESD, follow-up is made within 72 hours. In addition, all patients receive a copy of their stroke unit discharge summary which details all follow-up arrangements and contact telephone numbers following discharge.

Our findings also indicated that patients and carers wanted to be able to access peer support both immediately and in the longer term. While the former could be seen as contrary to the earlier reported discomfort provoked by being alongside others with stroke, it was ultimately perceived as a means of dealing with longer-term issues and the isolation felt. This led to action being taken to develop a volunteer peer support role on the stroke rehabilitation unit where people who have recovered from stroke are recruited to come into the unit to offer one-to-one support for current inpatients and their carers.

Although the aim of the initial action research study was to involve stroke survivors and carers in service development about secondary stroke prevention [16], the results described in this paper show how findings seemingly peripheral to the primary area of interest can also be transformational. None of the aforementioned examples of changes made to the local stroke service can be described as large-scale, but nonetheless they have positively impacted on the experience of stroke care. This suggests that *less* really can be *more* and further research into the small things that matter to patients is required [42]. It may be precisely this “devil in the detail” that will help to weave the best of evidence-based practice with person-centred care [43].

Arguably, the use of action research with its participatory and democratic ethos enabled practitioners to engage with and better understand the needs and wants of the service users. Thus, the developments are firmly embedded within the patient perspectives. While some may argue that action research is research with a small *r*, given that it has user participation at the centre of its approach, it can help providers address the paradox of delivering evidence-based services that are also sensitive to the preferences of the patient.

The limitations of the study were that the average age of participants with stroke was 69 years, which is lower than the average age of someone experiencing stroke in the UK and the relatively small number of participants. Previous patient and public involvement work in the local health community suggests that many people have difficulty engaging with service reviews and development in the first few years after stroke, possibly because they are still recovering.

Further research needs to be undertaken to ensure that people with stroke have an effective voice in the development and delivery of stroke services. However, it must be remembered that despite the general move away from the paternalistic approach to healthcare, there does remain an ethical dilemma in heeding patient choice in every situation and indeed it may be contrary to commonsense and even detrimental to their care [44].

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