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**Stroke patients' experiences of weekend days spent on a stroke unit: a
descriptive phenomenological analysis****Rachel Hayden, Farzaneh Yazdani***Buckinghamshire Healthcare NHS Trust; Oxford Brookes University***ABSTRACT**

Large amounts of quantitative data about stroke care are being collected in National Stroke Audits, but at present there is little information about how patients themselves experience this care, information that is important when designing patient-centred services. This study aimed to explore weekend days on a stroke unit from the patients' perspective. In-depth interviews were conducted with four stroke inpatients, and the interview data was transcribed and analysed using a descriptive phenomenological approach. Although each patient's experience was individual, some common themes occurred. The main theme was the perception of inactivity, with various subcategories within this, namely boredom, influence of other people, visitors and needing time to rest. Three other smaller themes were also identified: frustration, a reluctance to criticise ward staff, and changing perceptions of weekend days as patients progressed through their rehabilitation. These results are discussed and implications for practice are suggested.

KEY WORDS: Stroke, inpatient, time-use, phenomenology, patient experience

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INTRODUCTION

A stroke can be a devastating event for an individual, yet with appropriate care and rehabilitation many patients can regain a good quality of life. In a systematic review, stroke units have been shown to be effective in reducing death, dependency and the need for institutionalised care (Stroke Unit Trialists Collaboration, 2007). Much of the focus of stroke unit care is on the multidisciplinary team and yet at weekends some team-members are not present and activity levels are lower (Smith et al, 2008; Bear-Lehman et al, 2001). The aim of this study was to begin to understand how stroke inpatients experience weekend days spent on a sample stroke unit. A deeper understanding from the patients' perspective may aid development of patient-centred services.

LITERATURE REVIEW

There have been several studies into inpatient time-use using behavioural mapping, including specifically with stroke patients. A large study by De Wit et al (2005) in four European rehabilitation centres found that these patients spent 10.1% - 27.7% of the time between the core hours of 7am-5pm in therapeutic activity, and the rest in non-therapeutic activity (De Wit et al, 2005). Studies at weekends demonstrate a further drop in activity levels (Smith et al, 2008; Bear-Lehman et al, 2001) and one study suggested that stroke inpatients spend more time inactive than non-stroke rehabilitation inpatients (Bear-Lehman et al, 2001). The authors observe that stroke patients may have difficulty initiating and engaging in activities independently due to their deficits, which would help explain the differences between the two groups (Bear-Lehman et al, 2001).

Stroke inpatients have also been found to spend a considerable portion of their day alone. Three separate behavioural mapping studies have suggested that over half the working day is spent alone, even on weekdays (De Wit et al, 2005; Bernhardt et al, 2004; Bear-Lehman et al, 2001). However, it is worth considering that some time alone may actually be important, as patients may need time to rest, or to reflect and adjust to their new situation. None of these studies explored patients' perceptions of their time use, so we don't know if patients would want to spend their time differently given the opportunity.

Despite a range of quantitative studies investigating inpatient time use, there is a lack of research into patient perceptions and experiences of this time, which provides justification for this study.

METHODS

The methodology for this study was descriptive phenomenology, the aim of which is to understand and give rich description of the lived experience of the individual subjects interviewed (Creswell, 2007; Moustakas, 1994).

This study was conducted in a UK district general hospital situated in a relatively rural and affluent area. The stroke unit was a comprehensive unit combining acute care with rehabilitation, although patients requiring prolonged inpatient rehabilitation were referred on to a specialist neurological rehabilitation unit. The unit was on a discrete ward with 21 beds, mainly single-sex bays with some individual rooms. Rehabilitation therapy services were provided Monday to Friday. The average length of stay was 20 days.

Purposive sampling was used as it was important that participants had a good knowledge of the phenomenon in question, and were able to discuss in-depth viewpoints. Potential participants were identified by selected members of ward staff who distributed an invitation letter and information leaflet to potential participants, then contacted the researcher if the individual was interested. The researcher then visited potential participants to explain the study and answer questions, then arranged a time to conduct the interview. Written consent was gained just prior to the interview.

Data was collected through individual face-to-face loosely-structured in-depth interviews carried out by the researcher in a private room on the stroke unit and audio-recorded. Individual interview summaries were sent to participants for verification, this was done within two weeks of interview to help avoid the passage of time affecting participants' recollections.

The interviews were transcribed in full by the researcher and then thematic analysis took place. Rigour was achieved by the researcher using the process of "bracketing" throughout data collection and analysis, putting any pre-understanding of the phenomenon in "brackets" to maintain an open mind. The author also kept a reflective diary recalling significant events throughout the research process, which was checked by the researcher to ensure that personal reactions had not unduly influenced the results. Credibility was achieved through participant checks of qualitative studies within two weeks of the interview. To further improve credibility, during the interviews the researcher would often seek clarification of her interpretation of the points informants were making as they arose.

Ethical approval was granted from the Oxford Brookes University School of Health and Social Care Ethics Committee and the Local NHS Regional Ethics Committee.

RESULTS

Six patients were identified for this study. One declined participation, and another was deemed not to have the cognitive ability to participate in an in-depth interview on further assessment. The interviews lasted between 20 and 47 minutes. Participant characteristics shown in Table 1; all were White British.

Table 1: Patient characteristics

Patient	Sex	Age	Marital status	Time since stroke	Main effects of stroke
A	Female	75	Widowed	4 weeks	Right sided weakness
B	Male	56	Married	4 weeks	Left sided weakness and inattention
C	Male	77	Married	3 weeks	Dense left sided weakness
D	Female	89	Widowed	2.5 weeks	Right sided weakness

Three participants responded when sent their interview summaries for verification and were in agreement with their individual summaries.

Cumulative findings

All participants spoke freely about their experiences. The main over-riding theme was inactivity, which has been divided into subcategories, namely boredom, influence of other people, visitors and needing time to rest. Three other separate themes were also identified: frustration, a reluctance to criticise ward staff, and changing perceptions of weekend days as patients progressed through their rehabilitation.

Boredom

Two interviewees expressly mentioned boredom repeatedly and the others spoke of strategies used to try and avoid this state. When unable to relieve the boredom patients would end up dozing off. One subject laughingly summed up her experience of weekend days in a statement illustrating the monotony of the day:

"Well, it seems to me, as though all you have to do is sleep, eat; and sleep, and then eat; and then sleep and then eat; and then go to bed!"
(Pt. D)

Subjects reported that any day as an inpatient seemed to drag. During the week the day was broken up by therapy sessions and visits from healthcare professionals, but these occurred less at weekends, so patients tried to find different ways of breaking up the day, with varying levels of success. The television seemed an important source of stimulation during quieter times for all participants.

One subject was a sports fan and successfully structured his day around sporting fixtures on television, which appeared to give him a more positive experience of weekend days. Another subject occupied himself with reading and small projects he set for himself, such as mastering his new camera. However, the two remaining subjects both reported difficulties with concentration so were unable to use these strategies. The participants generally wished that something more was happening at weekends. Some wished for more therapy, but there was also a common, simpler wish for general stimulation and activity.

"... it would be nice to have something going on, to look forward to, yeah. Not so much strenuous! (laughs)" (Pt. A)

Influence of other people

Lack of interaction was a key factor causing boredom among the interviewees. All the participants were in shared bays and their room-mates had a significant impact on their experience of the weekend. Three subjects had at least one person they could converse with, which helped provide stimulation and pass the time. Despite attending weekday therapy sessions alongside patients from other bays, the patients interviewed did not interact with any patients outside their bay at the weekend. Although there was a small day room on the ward this seemed rarely used. One patient was disappointed that the staff had not initiated using it:

"Perhaps if they could come in here (day room) with people that are able-bodied and they could play bingo, or just... play some quiz, talk about their life, or whatever. Just chat." (Pt A)

This particular patient was in a room with one patient who had a very poor prognosis, and another who was very confused. She reported being unable to get enough rest as one of them kept talking incessantly:

"...gabbles all, on nothing, well nothing you can understand anyway, all the time, all the time. You just can't shut your head off from it, you know. Yeah. And that just makes you feel... I'm going screaming mad". (Pt. A)

When asked how sharing with these particular ladies affected her, she stated emphatically that it made her feel depressed. She was unable to walk independently, so most of her weekend was spent in this room. She was dependent on visitors for interaction and getting out of the room, and referred to trips to the coffee shop as an "escape".

Visitors

Participants gave mixed reports regarding whether the weekend was a busy time for visitors, but in all cases they seemed central in breaking up the day and provided welcome interaction. Visitors also helped the patients to stay connected with the world outside the hospital, and offered them encouragement with their rehabilitation:

"Someone that's in the outside world that can come in and smile, yes. And say to you 'Oh you look better today', and that's encouraging"
(Pt. D)

Visitors were also central in allowing the patients to have a physical change of scene by getting off the ward, a positive event for all participants.

Time to rest

Although most discussions around inactivity were negative, two participants did express that having time to rest at a weekend was helpful. Even the patient who was frustrated with the lack of weekend therapy reported that if more therapy was available he would still want one day off a week, for a variety of reasons:

"...physical, mental and necessity that you couldn't keep on seven days a week, even I couldn't" (Pt. C)

Fatigue was an interesting area, with a wide range of perceptions, from one patient who reported minimal fatigue to another who reported significant levels. Another patient put the fatigue that she experienced at weekends down to inactivity making her lethargic. It is possible that the variance in fatigue may be a direct result of the stroke itself, with some patients being more affected than others. However, it is worth noting that the patient experiencing the greatest fatigue was the one who felt depressed, so her fatigue may have been linked with these negative emotions.

Frustration

All four subjects were keen to return home, and the frustration of being unable to do so seemed more acute at weekends when there was less going on. The other main frustration was lack of therapy, as all subjects saw this as vital to returning to their pre-stroke lives. For the subject with most severe physical weakness the lack of therapy at weekends was a clear frustration and disappointment:

"(The role of a hospital is) ...to put right medical problems; and in the case of the stroke to try as much rehabilitation as you, as you can take.... I

can take it, I want it. Cos my determination is to get back into my life.” (Pt. C)

Three of the four subjects had very little “homework” from the therapists. The one patient who had been given plenty of self-directed exercise did not appear as disappointed about the lack of weekend therapy. He stated that he was still able to do therapy as he was well motivated and had clear tasks to practice.

One subject also reported frustration with a lack of information. When the first weekend arrived he had expected to receive more therapy and reported waiting for something to materialise, which then did not. He felt that more information would have helped him manage his expectations.

Reluctance to criticise staff at a local level

All the participants made it clear that they did not blame staff at a local level for the lack of activity at a weekend. On the whole they were very complimentary about the care they had received and understood that the ward staff were very busy:

“They are under very great pressure. There’s not enough staff.” (Pt. C)

“ The nurses are very good, and, er, they’d do anything for us, so, you know. We shouldn’t grumble should we?” (Pt. D)

The subjects seemed aware that resources were limited, and were keen not to burden staff further by wishing for more therapy or other activity at weekends.

DISCUSSION

The results provided some interesting insights into patient experiences of weekend days on a stroke unit. The perception of inactivity and subsequent boredom was not a great surprise in view of the wealth of quantitative research reporting low activity levels as discussed in the literature review. What was interesting was the difference that individual abilities and coping strategies had on the levels of boredom reported. The findings of this current study suggest that patients who struggle with concentration or have difficulty initiating tasks are less able to manage their own time and are likely to have more negative experiences of weekends. This is an important consideration for staff when trying to improve patient experiences, as a greater level of support and structure may be needed for this patient group.

It is interesting to note that although a couple of participants expressed a definite wish for more therapy at a weekend, there was also a common desire for more general stimulation, with one patient suggesting activities like bingo. Activities such as this may be relatively simple and cost-effective to set up, and provide definite benefits for patients. The informants demonstrated mixed feelings regarding the lack of therapy input at weekends. Regular specialist weekend therapy input is not yet common practice in the UK (NHS Improvement, 2010). As a result of challenging economic times, staff may need to think laterally to increase rehabilitation at a weekend, for example, by empowering patients with more independent task practice or involving family members. Another key finding was the enormous impact that other people had on the patients’ experiences of weekends.

Changing perceptions

All participants reported that their experiences of weekend days had changed from their first weekend to the most recent. During the first weekend in hospital some of the patients interviewed were either unwell or still adjusting to their new situation. This made the experience very different to subsequent weekends:

“...if you feel poorly you take very little notice of what’s going on.” (Pt. D)

Although an increasing awareness of lack of activity at a weekend led to feelings of boredom and frustration, as they were able to do more for themselves the weekends improved slightly.

Summary

The patients all had different experiences of the weekend days, which were affected by factors such as level of disability, coping strategies and the people around them. However, despite these differences, a recurrent theme of inactivity and lack of stimulation emerged. For those who had the ability and resources to effectively fill and structure their day, their experience of weekend days was more positive. For those less able to do this, the weekend was a time of boredom, lethargy and tedium:

Staff should be aware of the potential effects of patients sharing rooms with others with poor prognoses. Therefore, they can offer support, and ideally offer solutions such as spending time away from the room, for example in a day room.

Unsurprisingly, visitors were one of the most positive aspects of the weekend. An interesting finding was that their role in allowing patients to move off the ward environment was so valued. This change of scene was a positive event, and may be an area for ward and therapy staff to explore; in addition to facilitating visitors to take patients out, it might be possible to provide other opportunities for appropriate patients to spend some time in a different environment, which may also increase interaction between patients from different rooms. Participants gave mixed comments about fatigue, highlighting the importance of individualised rehabilitation programs. Patients’ perceptions also changed as they progressed through their rehabilitation. It has been suggested that patients gradually regain their autonomy as they progress through rehabilitation (Proot et al, 2007). If so, it follows that in the earlier stages patients may struggle to self-initiate activity and therefore require more structure at weekends.

Another area of note was the reluctance to criticise ward staff. This may be partially due to unwillingness to discuss negative aspects within the interview situation. Even considering this, participants seemed aware of the pressures that staff were facing and sympathised with them.

Limitations of the study

There are several limitations to this study. The study was carried out on a single site which led to a participant group who were all within a month post-stroke, limiting the transferability of the findings. Although the researcher was experienced in communicating with

stroke patients she was still a novice researcher. Some bias may have occurred as a result of the researcher's clinical role which may have led her to emphasise issues related to therapy, although she tried to minimise bias by "bracketing" prior to data collection and analysis. As this study was part of an MSc program, it was conducted by a single researcher so there was no-one independent to check the analysis.

Conclusions

This study demonstrated that although each participant's experience of weekend days on the stroke unit was unique, there were common themes regarding high levels of inactivity and the subsequent boredom and frustration this brings. Individual coping strategies had a significant effect on the participants' perceptions of weekends, with those able to concentrate and independently fill their time having a more positive experience. Findings showed that other people, particularly other patients and visitors, had a large impact on the informants' experiences.

Key points:

- 1.) Quantitative studies have suggested that stroke patients spend a significant portion of the

weekend inactive and alone. However, patients' experiences of this weekend time had not previously been explored.

- 2.) The common theme among participants in this study regarding their experiences of weekend days on the stroke unit was that of inactivity, which led to boredom and frustration.
- 3.) Individual coping strategies had a significant effect, suggesting that patients who are less able to manage their own time (e.g. due to concentration issues) are likely to require more support at a weekend to improve their experiences.
- 4.) The impact of other patients should not be underestimated; negative interactions with fellow patients can have an enormous impact on individuals. Staff need to be aware of this and offer support as necessary.

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