



Alleviation of carer strain during the use of the NeuroPage device by people with acquired brain injury

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Received 15 September 2008

Revised 23 January 2009

Accepted 27 January 2009

Published Online First

25 February 2009

ABSTRACT

Background: Previous studies have demonstrated the efficacy of a paging system, NeuroPage (Cambridgeshire Primary Care Trust Corporation, Fulbourn, Cambridgeshire, UK), in compensating for memory and planning dysfunctions in people with acquired brain injury (ABI; mainly stroke or traumatic brain injury). In this study, the degree to which this efficacy is accompanied by a reduced experience of strain among carers of patients with ABI was investigated.

Methods: Carers of 99 people with ABI completed a questionnaire concerning strain resulting from caring for the injured individual. The questionnaire was completed at the following three time points: before the use of NeuroPage, at the end of a 7-week period of use, and, for one subgroup, a further 7 weeks after withdrawal of NeuroPage.

Results: There were significant reductions in strain reported by carers following the 7-week period of NeuroPage use (Cohen's $d = 0.3$ – 0.4). This finding persisted when the carer was a spouse or a parent. The reduced strain among carers continued even after withdrawal of NeuroPage.

Conclusion: The efficacy of the NeuroPage paging system for people with ABI appears to result in reduced strain for their carers.

The occurrence of disability, mental or physical, in a family member who is not institutionalised and lives at home often places a strain on other members of the family who have become carers.^{1–3} People who have suffered an acquired brain injury (ABI; e.g. stroke or traumatic brain injury) often have difficulties with memory and planning. It is these impairments that are the greatest sources of strain to carers,^{4–7} who need to monitor, and perhaps assist in, the performance of everyday activities.

Electronic technology can considerably improve the performance of daily tasks in people with ABI, thus reducing their dependence on carers.⁸ Particular success has been reported with NeuroPage system (Cambridgeshire Primary Care Trust Corporation, Fulbourn, Cambridgeshire, UK), which involves an electronic pager worn by the person with ABI. The pager receives preprogrammed timely reminders to perform tasks—so-called ‘target behaviours’—that have been specified in advance by the patient.^{9–10} Typical target behaviours include taking medicine, feeding pets, remembering appointments and remembering to take keys when leaving home.

Using the same patients who took part in the initial studies on the efficacy of NeuroPage,^{9–11} the

present study examined whether the use of this device also results in a reduction in the strain experienced by carers.

METHODS

This study used a cross-over design that involved alternately allocating patients in blocks of 10 to one of two groups, with measurements taken at three time points over a 16-week period. Time point 1 was during a 2-week baseline period in which both groups recorded self-identified target behaviours. During this time, a carer completed the postal strain questionnaire (the modified Caregiver Strain Index, mCSI), as described below. Group A then used the NeuroPage devices for 7 weeks and target behaviours were measured for the last 2 weeks of this period—time point 2—during which time the mCSI was completed by the carers for a second time. Group B were held on a waiting list for the same 7 weeks, during the last 2 weeks of which (also time point 2) target behaviour assessment and mCSI data were again collected. At the end of this 7-week period, NeuroPage devices were withdrawn from patients in Group A and assigned to members of Group B. For both groups, the study continued for a further 7 weeks, in which target behaviours were assessed and the mCSI completed during the final two weeks—time point 3. Further details of the study design have been reported elsewhere.^{9–10}

Participants

Participants in this report were primary carers of the people with ABI who had been recruited to the original NeuroPage study, one carer for each person. The original study involved 143 patients with ABI, but adequate carer data across the three time points were only available for 99 (69%) patients, the attrition primarily due to people not having carers. Of the 99 patients with ABI, 62 had been allocated to Group A and 37 to Group B, the discrepancy arising from the block allocation of subjects and the practical constraints of completing the study. Demographic and medical characteristics of the two groups are shown in table 1. There were no significant differences between the two groups at baseline.

Instruments

The questionnaire used to assess carer strain was a modified version of the Caregiver Strain Index, which was developed by Robinson¹² and concerns

Table 1 Demographic and medical characteristics of the patients with acquired brain injury

	Group A (n = 62)	Group B (n = 37)
Gender (%)		
Male	79	70
Female	21	30
Carer (%)		
Spouse	61	57
Parent	24	38
Other	15	5
Type of Injury (%)		
Traumatic brain injury	48	39
Cerebrovascular accident	25	25
Other (e.g. anoxia, tumour)	27	36
Age at injury (mean in years (SD))	33 (15)	33 (19)
Age at program entry (mean in years (SD))	38 (13)	37 (16)

“things which other people have found difficult in helping with, after someone comes home from the hospital”. Our 16-item modified version was tailored towards potential stressors of particular relevance in cases of ABI. Responses were made on an 11-point scale of strain ranging from 0 (lowest) to 10 (highest). A total score was computed by averaging the 0–10 response across the 16 items. The internal reliability of the total score was high (Cronbach’s $\alpha = 0.91$).

The study complied with the Declaration of Helsinki and was approved by 11 regional ethics committees around the United Kingdom.

RESULTS

Means and standard errors of the mCSI scores for the two groups at the three time points are shown in fig 1.

The first issue examined was the test–retest reliability of the mCSI itself. During the 7-week period between time point 1 and time point 2, there were no systematic changes in circumstances for the 37 people in Group B. The intra-class correlation

between mCSI ratings for the two time-points was 0.86 ($p < 0.01$), indicating a high level of test–retest reliability. The mean mCSI score did not change significantly for Group B between time point 1 and time point 2 ($t(36) = 1.46$, $p > 0.05$). Carers in Group A reported significantly higher levels of strain at baseline than did those in Group B ($t(97) = 2.11$, $p = 0.04$).

The overall effect of the introduction of NeuroPage was assessed by combining data from the two groups. For group A, data from time point 1 was compared with time point 2 data and for group B, time point 2 data was compared with time point 3 data. Thus, in both cases a comparison was made between the immediate pre-NeuroPage period and the end of the 7 weeks of NeuroPage usage. A mixed-model analysis of variance was performed, with group as a between-subjects factor and time point as a within-subjects factor. There was no overall difference between groups A and B ($F(1,97) = 3.1$; $p > 0.05$) and there was no significant interaction between groups and time point ($F(1,97) = 0.4$; $p > 0.05$). On the other hand, the main effect of time point was highly significant ($F(1,97) = 24.1$, $p < 0.001$). The effect sizes for groups A and B can be estimated, using Cohen’s d effect size calculation,¹³ as 0.33 and 0.39 respectively, which can be considered as small to medium. For both groups, over two-thirds of carers reported lower levels of strain following use of NeuroPage than before its use.

In separate matched-pairs t -tests, the reduction in strain was found to be significant for both carers who were spouses ($t(58) = 3.3$; $p = 0.002$) and carers who were parents ($t(28) = 2.8$; $p = 0.01$). The degree of reduction in strain was similar in these two groups ($t(86) = 1.1$; $p > 0.05$).

The final issue addressed was the extent to which the now demonstrated beneficial effect of NeuroPage was maintained after the device was withdrawn. This was examined by comparing the mCSI ratings for Group A at time point 2—during NeuroPage usage—with those from time point 3—7 weeks after the device had been withdrawn. As might be expected from the means shown in figure 1, there was no significant reversal of mCSI ratings following withdrawal of NeuroPage ($t(53) = 0.37$; $p > 0.05$).

DISCUSSION

Before considering these findings in detail, some limitations of the study need to be recognized. First, the information here was gathered indirectly, being obtained from relatives completing postal questionnaires. Both the internal and test–retest reliabilities are high, however, suggesting that the questionnaires were carefully and seriously completed by the carers. In addition, the motivation among carers to be part of the study was generally very high. A second potential limitation is that the relatives were not blind to the study design, being necessarily aware of when NeuroPage was in use. It seems unlikely, however, that this knowledge would have led to a bias towards favourable responding in terms of their own strain; that is, if NeuroPage use had not in reality resulted in such a reduction. The mCSI could be criticized for only including negative items, possibly leading to response bias. A further limitation of the study is the lack of randomisation. There was a baseline difference between the two groups in the level of strain initially reported by carers, which could have been due to the (albeit non-significant) differences in the two groups’ composition (i.e. Group A contained proportionately more males and more persons with traumatic brain injury). Both this difference and the discrepancy in group sizes are not critical, however, because the study design does not hinge upon group comparisons.

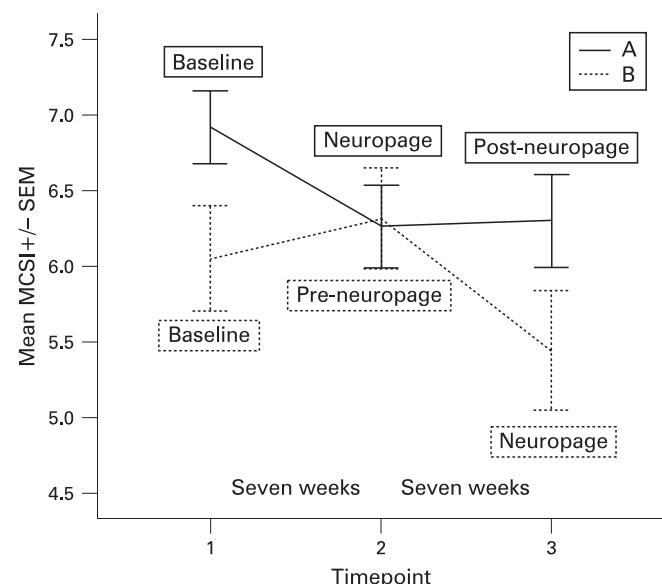


Figure 1 Mean (\pm SEM) modified Caregiver Strain Index score relative to group (A or B) and time point. MCSI, modified Caregiver Strain Index.

Given the already reported extensive evidence for the efficacy of NeuroPage in assisting people with ABI to cope with, in particular, difficulties of memory and planning,^{10 11} the present confirmation of a reduced strain for carers, both parents and spouses, is encouraging. The lack of any systematic change in reported strain in the pre-NeuroPage period for group B further supports the inference that the reduced strain experienced by carers after the introduction of the device is indeed a direct consequence of that use, rather than being some other function of the passing of time. The fact that the people with ABI in this study were on average about 5 years postinjury also makes it unlikely that the observed improvements over the 7-week period were unrelated to the use of NeuroPage. Ancillary analyses not presented here showed that the strain relief reported by carers to people with traumatic brain injury or cerebrovascular accident was greater for carers to persons who showed significant improvement in attaining targets with NeuroPage, themselves an overwhelming majority, than for the patients who did not.¹¹

In summary, the present results suggest that not only does the use of NeuroPage improve the performance of everyday tasks among people with ABI, but that this improvement itself can result in a significant and enduring alleviation of strain in their carers.

Competing interests: None.

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Information for patients from JNNP

Using technology to ease the strain on carers

When someone has a brain injury, either from a head injury or from an illness such as a stroke or a brain tumour, they're not the only one affected. Partners, parents, and children often find their own lives change too, as they become carers for their family member at home. Caring for someone with a brain injury can be a tough job, so anything that helps ease the strain is good news.

What do we know already?

People with brain injuries frequently have memory problems and difficulties with planning. These two issues can make life very difficult for their carers. For example, people with brain injuries may forget to take their medicines unless prompted. And they may have difficulty making and keeping appointments, or they may leave the house without remembering to take their keys.

Researchers have been investigating ways of using technology to help people with brain injuries better manage everyday life. The technology being tested in this study is called NeuroPage. It's a small pager that can be worn by the person with brain injury. The pager can be programmed to send reminders when it's time to carry out tasks such as taking medicine. Previous studies show it can help some patients with memory and planning problems.

What does the new study say?

The new study looks at the effect of the NeuroPage device on carers of people with brain injuries. It says that, overall, carers have a small to medium reduction in their stress levels, measured by questionnaire, after the person they care for has used the pager for seven weeks. About two-thirds of carers had lower stress scores after use of the pager.

Perhaps surprisingly, the reduction in stress lasted even after the pager had been taken away.

How reliable are the findings

This is a fairly small study, involving just 90 people.

In the most reliable type of study, researchers compare a treatment with an inactive but identical version of the same treatment (often called a placebo), to find out whether it's really the treatment that makes the difference. That's easy

to do with medicines, but not with devices like pagers, as people need to know whether the pager is being used. Instead, the researchers divided the people in the study into two groups: one group got the pager straight away, while the other group waited seven weeks before using the pager. In both groups, the carers filled out questionnaires about their stress levels before and after using the pagers. Stress levels stayed the same while people were waiting for the pager, but reduced during the seven weeks that it was being used. This suggests that it was the pager, not just being in a study, that helped reduce stress.

Where does the study come from?

The study was carried out several hospitals and universities, in the UK and in Denmark.

What does this mean for me?

If you are caring for someone with a brain injury, and find that memory and planning are causing problems, this study suggests using a technology such as the NeuroPage device may help. However, the effect on your stress levels may not be that big. Average stress scores reduced by 1 to 2 points, on a 10-point scale.

Most people in the study had been affected by a head injury, not a stroke. Their average age was 33 at the time of their brain injury. So we don't know from this study how well the pager device would work for older people with brain damage.

What should I do now?

If you are struggling to cope with stress from caring for a relative or partner with brain injury, you might want to talk to their doctor about assistive technologies. That's the general name for technology that helps people get on with their lives, despite problems such as memory loss or difficulties thinking or planning. There are a number of different assistive technology devices available, and the doctor may be able to help you find one that is suitable for the person you are caring for.

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Teasdale TW, Emslie H, Quirk K, *et al.* Alleviation of carer strain during the use of the NeuroPage device by people with acquired brain injury. *J Neurol Neurosurg Psychiatry* 2009;**80**:781-83. <http://jnnp.bmj.com/cgi/content/full/80/7/781>

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