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

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Abstract

Background: Previous studies have demonstrated the efficacy of a paging system, Neuropage®, in compensating for memory and planning dysfunctions among people with acquired brain injury (ABI, mainly stroke and traumatic brain injury). We here investigated the degree to which this efficacy is accompanied by a reduced experience of strain among their carers.

Method: In a cross-over design, carers of 99 people with ABI completed a questionnaire concerning strain resulting from the injury at three time-points, before the use of Neuropage®, at the end of a 7 week-period of use, and, for one subgroup, a further seven weeks after withdrawal of Neuropage®.

Results: There were significant reductions in strain reported by carers following the period of Neuropage® use (Cohen's $d = 0.3 - 0.4$). This was true whether the carer was a spouse or a parent. The reduced strain among carers continued even after withdrawal of Neuropage®.

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

Introduction

The occurrence of disability, mental or physical, in a family member who is not institutionalized and lives at home often places a strain on other members of the family who have thereby become carers¹⁻³. Among people who have suffered an acquired brain injury (ABI, e.g. stroke or traumatic brain injury), it is often their difficulties with memory and planning which are the greatest sources of strain to their carers⁴⁻⁷, who need to monitor, and perhaps assist in, the performance of everyday activities.

Electronic technology can considerably improve the performance of people with ABI in their daily tasks, thus reducing their dependence on carers⁸. Particular success has been reported with the Neuropage®, involving an electronic pager worn by the person with ABI and which receives pre-programmed timely reminders to perform tasks – so-called ‘target behaviours’ - which have been specified in advance by that person him- or herself^{9;10}. Typical target behaviours include taking medicine, feeding pets, remembering appointments and remembering to take keys when leaving home.

Using the same subjects who entered the initial studies on the efficacy of Neuropage®⁹⁻¹¹, the purpose of the present study was to examine whether its use also results in a reduction in the strain experienced by carers.

Method

The design of the study was a cross-over involving subjects alternately allocated in blocks of 10 to one of two groups, with measures taken at three time-points over a 16-week period. At time-point 1, both groups underwent a two-week baseline recording of self-identified target behaviours. During this time a carer completed the postal strain questionnaire (the modified

Caregiver Strain Index, mCSI) described below. Group A then used the Neuropage® devices for seven weeks and the target behaviours were measured for the last two weeks, i.e., time-point 2, during which time the mCSI was completed for a second time. Group B were held on a waiting list for the same seven weeks, during the last two weeks of which, i.e. also time-point 2, target behaviour assessment and mCSI data were again collected. At the end of the seven-week period, for Group A the Neuropage® devices were withdrawn, and Group B members correspondingly received them after the seven week waiting period. A further seven weeks followed, again with assessment of the target behaviours and completion of the mCSI during the final two weeks, i.e. 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 Neuropage® study, one carer for each person. The original study involved 143 such people, but adequate carer data across the three time-points were only available for 99 (69%), the attrition being primarily owing to people not having carers. Of the 99, 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 and there were no significant differences between them.

Table 1 Demographic and medical characteristics

	Group A (Neuropage® 1 st)	Group B (Neuropage® 2 nd)
N	62	37
	<hr/>	
	%	%
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
Cerebro-Vascular Accident	25	25
Other (e.g. anoxias, tumours)	27	36
	<hr/>	
	Mean (SD)	Mean (SD)
Age at injury	33 (15)	33 (19)
Age at program entry	38 (13)	37 (16)

Instruments

The questionnaire used to assess carer strain was a modified version of the Caregiver Strain Index developed by Robinson ¹² and concerning “things which other people have found difficult in helping with, after someone comes home from the hospital”, e.g. “Helping takes up a lot of time”. Our 16-item modified version (mCSI) was tailored towards potential stressors of particular relevance in cases of ABI. Responses were to be made on an 11-point scale in which the extreme ratings were labelled as 0 = ‘Never/Not at all’ and 10 = ‘Always/Very much’, a high rating indicated a high degree of strain. A total score was computed 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 for the two groups at the three time-points are shown in Figure 1.

Insert Figure 1 about here

The first issue examined was the test-retest reliability of the mCSI itself. For the seven-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, ($t(36) = 1.46, p > 0.05$).

Group A reported significantly higher levels of strain at initial baseline than 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 to time-point 2 data and for group B, time-point 2 data was compared to time-point 3 data. Thus, in both cases a comparison was made between the immediate pre-Neuropage period with that at the end of the seven 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 ($F(1,97) = 0.4, p > 0.05$). However, 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 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 the median reported strain prior to 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 for carers who were parents ($t(28) = 2.8, p = 0.01$) and the two groups did not differ the degree of reduction ($t(86) = 1.1, p > 0.05$).

A 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, i.e. during Neuropage® usage, with time-point 3,

i.e. seven weeks after it had been withdrawn. As might be expected from the means shown in Figure 1, there is no significant reversal of mCSI ratings following withdrawal of Neuropage® ($t(53) = 0.37$, n.s.).

Discussion

Before considering these findings in detail, some limitations of the study need to be recognized. First, the information gathered here is indirect, being obtained from relatives completing postal questionnaires. Both the internal and test-retest reliabilities are, however, high, suggesting that the questionnaires were carefully and seriously completed by the relatives, whose motivation to be part of the study was generally very high. A second potential limitation arises in that the relatives were not blind to the study design, being necessarily aware of when Neuropage® was in use. However, it seems unlikely that this knowledge would have led to a bias towards favourable responding in terms of their own strain, if Neuropage® use had not in reality resulted in such a reduction. The mCSI could also be criticized for only including negative items, possibly leading to response bias. A further limitation of the study is the lack of randomisation. The baseline difference between the two groups could have been due to the (albeit non-significant) differences in the two groups' composition, e.g. that Group A contained proportionately more males and more persons with TBI. However, both this difference, and the discrepancy between two group sizes, are not critical since the study design does not hinge upon group comparisons.

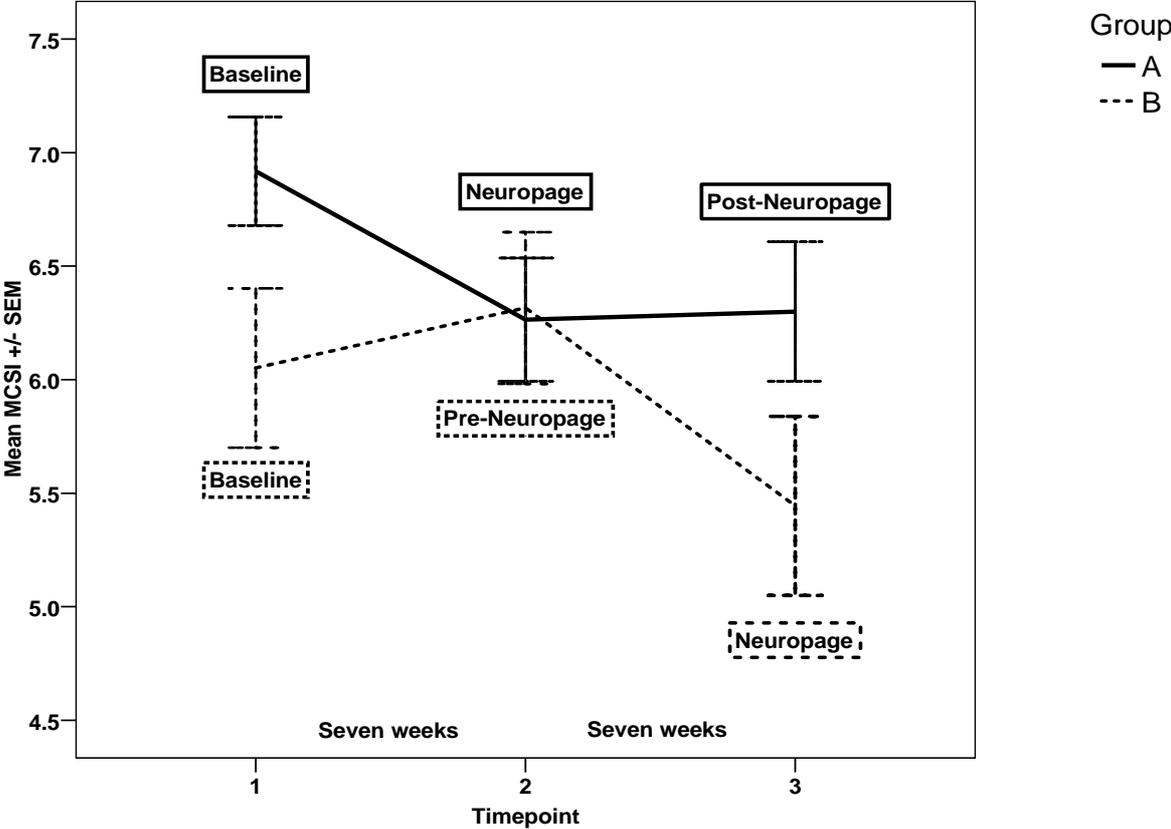
Given the already reported extensive evidence for the efficacy of Neuropage® in assisting people with ABI to cope with, in particular, difficulties of memory and planning,^{10;11} the present confirmation of a reduced strain for the carers, both parents and spouses, is encouraging. The lack of any systematic change in reported strain in the pre-Neuropage® period for group B

further supports the inference that the reduced strain experienced by carers after its use 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 five years post-injury also makes it unlikely that the observed improvements over the seven-week period were unrelated to the use of Neuropage®. Ancillary analyses not presented here showed that the strain relief is reported by carers to people with TBI and with CVA and was greater for carers to persons with ABI who showed significant improvement in attaining targets with Neuropage, themselves an overwhelming majority, than for the remaining small minority 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 acquired brain injury, but that this improvement itself can result in a significant and enduring alleviation of strain among their carers.

Figure 1

Mean (SD) mCSI in relation to group and time-point



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