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http://hdl.handle.net/11067/1330
https://doi.org/10.34628/1vsn-2769

Metadados

Data de Publicação 2014

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Tipo article

Revisão de Pares Não

Coleções [ULL-IPCE] RPCA, v. 05, n. 1 (Janeiro-Junho 2014)

Esta página foi gerada automaticamente em 2024-10-12T02:31:48Z com informação proveniente do Repositório

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NEUROPSYCHOLOGICAL REHABILITATION FOR YOUNGER PEOPLE: SMALL GROUP AND SINGLE CASE STUDIES EXEMPLIFYING THE ASSESSMENT AND TREATMENT OF COGNITIVE, EMOTIONAL AND BEHAVIOURAL PROBLEMS

REABILITAÇÃO NEUROPSICOLÓGICA PARA JOVENS: EXEMPLOS DE AVALIAÇÃO E TRATAMENTO DE PROBLEMAS COGNITIVOS, EMOCIONAIS E COMPORTAMENTAIS EM PEQUENOS GRUPOS OU ESTUDOS DE CASO

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Abstract: This paper focuses on children, adolescents and young adults who sustained brain damage due to a traumatic brain injury (TBI), encephalitis, stroke or anoxia leaving them with cognitive, emotional or behavioural problems. After presenting the results of a small group study of children recruited to a paging service, recent research to improve working memory in children is described. This is followed by accounts of four young people with: 1) visual object agnosia, 2) Balint's Sydrome, 3) emotional difficulties and 4) behaviour problems. Assessment and rehabilitation procedures for these individuals are described.

Key-words: rehabilitation; memory; perception; emotion; behaviour problems

Resumo: Este artigo centra-se em crianças, adolescentes e jovens adultos que sofreram danos cerebrais devido a um acidente cerebral traumático, encefalite, acidente vascular cerebral ou anoxia que geram problemas cognitivos, emocionais e comportamentais. Depois de apresentar os resultados de um pequeno grupo de crianças, é realizada uma descrição sobre investigações recentes para a melhoria da memória de trabalho em crianças. Esta descrição é acompanhada com quatro estudos de caso com 1) agnosia visual de objectos, 2) Sindrome de Balint, 3) dificuldades emocionais e 4) problemas de comportamento. A avaliação e procedimentos de reabilitação para cada caso são apresentados.

Palavras-chave: reabilitação, memória, percepção, emoção, problemas de comportamento

Introduction

Neuropsychological rehabilitation is concerned with the amelioration of cognitive, emotional, psychosocial and behavioural deficits caused by an insult to the brain. It is not synonymous with recovery (i.e getting back to what one was like before the injury or illness), and it is not synonymous with treatment (treatment is something we *do to* or *give* to people). Rehabilitation is a two way interactive process. The main purposes of neuropsychological rehabilitation are to enable people with disabilities to achieve their optimum level of well being, to reduce the impact of their problems on everyday life, and to help them return to their own most appropriate environments. It needs emphasising that the purpose of neuropsychological rehabilitation is *not* to teach patients to score better on tests or learn lists of words or be faster at detecting stimuli (Wilson, Evans, Gracey and Bateman, 2009a). In terms of rehabilitation for real life issues, Cicerone et al (2011) state that " there is evidence from numerous studies indicating that cognitive rehabilitation is effective during the post acute period, even many years after the initial injury" (2011 p526).

Survivors of any kind of injury or illness affecting the brain are likely to be faced with many problems including motor and sensory deficits, cognitive, behavioural, social and emotional difficulties, and problems with pain or fatigue. These are not mutually inclusive so some people will have many or all of these impairments. Typical cognitive problems seen in rehabilitation involve memory, attention, communication, planning, organisation, reasoning, perception and spatial awareness. The emotional difficulties survivors of brain damage exhibit include anxiety, depression, anger, fear, distress, grief, poor self esteem and lack of confidence. The behavioural consequences are temper outbursts, shouting, swearing, physical and verbal aggression, disinhibition, poor self control and refusal to co-operate. Khan, Baguley and Cameron (2003) report that cognitive and behavioral changes, difficulties maintaining personal relationships and

coping with school and work are reported by survivors as more disabling than any residual physical deficits. All these problems need to be dealt with in rehabilitation.

The NeuroPage system for children and adolescents with neurological deficits

NeuroPage is a reminder system for people with memory and planning problems. It uses radio-paging technology to send messages to a simple device worn by the client. Reminders mostly concern routine events such as taking medication, information about the date, the preparation of meals and other regular chores, but are also used for one-off events such as appointments (Wilson, Emslie, Evans, Quirk and Watson 2009b). Designed for and used by people with memory and/or planning difficulties, NeuroPage can reduce everyday problems and lead to greater independence (Wilson, Emslie, Quirk & Evans 2001). Of the 143 patients who completed all stages of the 2001 study, 12 were school age children, ten boys and two girls aged between eight and seventeen years. Six had sustained a TBI, five had developmental problems and one had sustained anoxic damage at birth. All 12 young people showed significant improvements in carrying out everyday tasks between the baseline and treatment phases.

Parents and children mostly liked the pager. One parent said "I never realised how beneficial the Neuropager was to someone with a head injury. When the study was finished and C had to return the pager I was amazed at how important it had been to him. I also found it gave him more confidence". Another said "It has helped a lot with getting R up in the morning and taking the right things with him to school. It has also helped with his homework which I think is becoming more automatic and he isn't relying on the pager so much. Of course sometimes he resents it and doesn't do what it tells him to but at least he is making a choice. It also takes the pressure off me and I am really pleased with it".

One case illustrates the way the system was used with a 10 year old boy, Peter. His mother contacted the Oliver Zangwill Centre after seeing NeurPage on a television programme. Peter had been diagnosed as dyslexic with short-term memory problems which were becoming more of a problem as he got older and which restricted his independence. His mother said her son's main problems were poor concentration, forgetting to take things to school and remembering to bring them home at night. He also forgot where he was supposed to go after school (sometimes, for example, he was supposed to go swimming). Sometimes when he was supposed to go straight home, he forgot to catch the bus. He also forgot to do his homework and to feed his pets. A two week baseline showed that Peter was forgetting to do what he was supposed to do between 25% and 30% of the time.

Once the pager was given to him, Peter received five messages a day on a school day and two or three on Saturdays and Sundays. On Mondays, for example, his messages were:

1. 7.00 am: Hi Peter, it's 7 o'clock on Monday

2. 8.06 am: Homework, PE kit, sandwiches, bag
3. 3.25 pm: Sandwich box
4. 3.30 pm: Lee Centre today for swimming, wait at school to be picked up
5. 7.55 pm: Feed fish and hamster.

There was a significant improvement between the baseline period and when Peter had the pager ($p < 0.05$). His failures were then in the region of 5%. These improvements were, on the whole, maintained when Peter returned the pager after 7 weeks as there was no difference between the time with the pager and the follow-up. The conclusions to the study using NeuroPage with children are that the pager can help school age children with memory and organisational problems; it makes them more confident and more independent; it will not make children do something if they do not want to and it does not work when there is no family routine (Wilson et al 2009b).

Retraining working memory deficits in children

There is no evidence that we can restore episodic memory deficits (Wilson 2009). Instead we have to help people to compensate for their problems and to help them learn more efficiently (ibid). There is, however, evidence that some restoration of working memory (WM) is possible with healthy adults (Jaeggi, Buschkuehl, Jonides & Perrig 2008; Dahlin et al., 2008), with patients with stroke (Westerberg et al., 2007) and with traumatic brain injury (TBI) (Serino et al., 2007; Lundqvist et al., 2010); as well as with children with poor WM (Holmes, Gathercole & Dunning 2009) and with Attention Deficit Hyperactivity Disorder (ADHD) (Klingberg et al., 2005; Beck et al 2010). There is also evidence of generalization. For example, the Klingberg et al (2005) study reported reductions in parent ratings of ADHD symptoms following WM training. Holmes et al (2009) found that children with poor working memory performance improved on an ecologically valid, classroom-based WM task with training compared to the control group. They also found that at a six month follow-up, the training group had disproportionately improved scores on a Wechsler Objective Number Dimensions task, suggesting that their improved WM enabled children to engage more in lessons or to benefit more from their lessons. In conclusion to the WM training studies, there is good quality evidence in support of computerised WM training from several different studies, from different centres, and from different populations. There is also evidence of generalisation to other tasks or everyday behaviours. The main characteristics of beneficial training procedures include: first, adaptation to participant performance whereby task demands increase as the participant improves; and second, the tasks are varied in terms of modality and cognitive demands.

Visual object agnosia

Visual object agnosia is an inability to recognise objects despite adequate eyesight and naming ability. Thus, in order to diagnose someone with visual object agnosia, it is necessary to exclude poor eyesight, naming difficulties, poor comprehension and failure to cooperate. The case described here is Jenny who was 17 years old when she was involved in a serious horse riding accident (Wilson 1999). Jenny was in a coma/vegetative state for 3 months. Ten months after her accident she was admitted to a rehabilitation centre. She had cerebellar ataxia and dysarthria although she was quite intelligible. She had good understanding of language but could not read (despite being a good reader prior to her accident) or recognise objects. Her errors were unlike those seen in people with language difficulties. For example, when shown a picture of an iron she said it was a shoe; her errors were visually similar to the object being shown. She had less difficulty with real objects than with line drawings and photographs were the most difficult for her to identify. This was probably because photographs contain more shadows to confuse the person with object recognition difficulties. Jenny's eyesight was good, she could see tiny spots but she could not read as she had lost the ability to read alphabetical letters. She could name to description, so if asked, "What is the name of a vegetable that makes our eyes water" she could immediately say, "an onion" but when shown an onion she thought it was an "apple" or "a ball". Jenny could identify objects from sound, so although she thought a matchbox was a "playing card box", when she heard a matchbox being shaken she knew immediately what it was. Again these responses are very different from those seen in people with word finding difficulties.

Jenny received several months of rehabilitation including specific treatment for her reading and object recognition difficulties. She was taught to recognise the individual letters (a process that took many months) and she learned to read to the level of an eleven year old. However, she was always a letter-by-letter reader. Jenny was monitored for several years and she showed some recovery. Her object recognition of real objects improved significantly but she always had difficulty with toys and animals (Wilson 1999). Some people with visual object agnosia can identify manufactured objects but not living things. This was true of Jason (ibid). In his early 20s Jason developed herpes simplex encephalitis. This left him with severe amnesia, surface dyslexia and agnosia for living things. He could identify, describe and draw tools, vehicles and other manufactured things but he could not identify, describe or draw any animals including common ones like cats, dogs or fish.

Balint's Sydrome

Balint's Syndrome is named after a Hungarian neurologist who first reported the syndrome in 1909. There are three components to Balint's Syndrome: first psychic paralysis of gaze or optic apraxia, which is an inability to look voluntarily

into the peripheral field; second, optic ataxia, which is an inability to localise in space or manually point to visually presented objects; and third, simultanagnosia where, despite adequate visual acuity, it is difficult or impossible to process more than one visually presented object at a time. People with Balint's Syndrome do not have an object recognition disorder and can recognise objects although they have difficulty reading because of the simultanagnosia.

Sarah was a young woman who, at the age of 20 years, sustained severe anoxic brain damage some nine months before coming to a rehabilitation centre. The anoxia left her with Balint's Syndrome & Apraxia. She could walk and talk but because she could not localise in space, she was unable to feed herself, she could not drink from a cup, nor could she sit on a chair as she could not orient herself in the right position, and she could not manage her clothes at the toilet. She was severely handicapped in everyday life. The first goal for treatment for Sarah was to drink from a cup alone. Through observations of how Sarah tried to drink, we came up with a plan. The task was broken down into steps as follows:

1. Find the table
2. Put your hand flat on table and slide it forwards
3. Put your thumb through the handle
4. Grasp the handle
5. Lift the cup to your mouth (later we added an extra step, "Put the red coloured rim to your mouth" as Sarah put the far rim of the cup to her mouth so the liquid spilled down her front).
6. Drink
7. Put the cup on the table
8. Open your fingers

9 Take your thumb out of the handle

Each step was scored from 1- 4. Sarah was first asked to drink her coffee. If she found the table she scored one for that step. If that failed she was given a verbal prompt, "Find the table". If she succeeded then she scored 2. If that failed, she was given a slight physical prompt (a nudge toward the table). If she succeeded then she scored 3 and if all else failed, her hand was physically guided to the table in which case she scored 4. The same scoring procedure was used for every other step. Sarah's treatment took place in occupational therapy (OT): hers was a joint programme between the occupational therapist and the clinical psychologist. On the first day, the procedure was followed three times in the morning OT session. At first Sarah needed a great amount of help and her overall score was 30/36 for the nine steps (she could only do step 6, drink, without help). Fifteen minutes later, she had improved and scored 16/36 and fifteen minutes after that, she scored 9/36 which is the best score possible. Over the next three days, she varied a little ranging between 12/36 and 18/36 but always scored much better than she had when the procedure was first introduced. The weekend followed and Sarah was not observed drinking her coffee but the nurses on the ward were asked to follow

the procedure and were shown how to do it. After the weekend Sarah scored 9/36 and from that day on she has been able to drink her coffee alone, albeit in a rather awkward manner. The same procedure was used to teach her to sit on a chair, put on and take off her coat, manage her clothes at the toilet and make a cup of coffee (although she was never allowed to pour the boiling water herself). Sarah learned enough self care skills to ensure that she could return home to her family rather than being admitted to long term care (Wilsonm, 1999).

Emotional difficulties following a TBI

Caroline was studying art when she was attacked on a train by a man with a hunting knife. Because the knife did not enter the brain stem, she did not lose consciousness during the attack and could recall all that happened to her. Evans and Williams (2009) give an account of Caroline's memory of what happened:

"There was a lot of people on [the train]. People got off, and I was alone. I [was] engrossed in a book ...I saw a man go past...he smiled and went to the next carriage. He came back two minutes later ... [& walked past] after 30 seconds I felt pain in my head and weight as if the carriage had fallen onto me. I got up and realized something terrible had happened...I went into the next carriage... another man told me to sit down, and that he would get help, and told me to stay still. I put my hand up and felt the knife. I asked if I had been stabbed, I asked if I was to die. He said no, and he'll get help. At the next stop an ambulance arrived and took me to hospital." (Evans and Williams, 2009 p228)

The hunting knife entered the right parietal area leaving Caroline with cognitive and emotional problems. The cognitive problems were to do with memory and visuo-spatial difficulties, while the emotional consequences were with avoidance, depression and anxiety. Caroline avoided eye – contact, she had post traumatic stress disorder (PTSD) with associated flashbacks and nightmares. She attended groups at the rehabilitation centre as well as having individual therapy and psychological support for her emotional problems. One of the groups, "*Understanding brain injury*" helped her to recognise why she had the particular cognitive and emotional effects she was faced with. She was taught to use a memory compensation system and her PTSD was treated by helping her to imagine the man who attacked her as a cartoon character that she could manipulate and shrink. She was afraid of using public transport so this was addressed by breaking the task into small steps; step one, for example, was to travel one stop on a bus with her psychologist sitting beside her, in step two the psychologist sat in the row behind her, then he sat at the back of the bus. The steps were gradually increased until Caroline could travel alone by train from Ely to Cambridge, a journey of 17 minutes. At the end of the programme, Caroline easily made eye contact, she was more sociable, her PTSD symptoms had reduced, she could travel alone on public transport, she returned to complete her art course and two years later she had her own art exhibition.

Behaviour problems following a TBI

Lisa, a 13 year old girl was knocked off her bicycle by a car. She sustained a severe TBI and a spinal injury. A few weeks later she was admitted to a rehabilitation centre. She had marked physical and visuo-spatial problems but before these could be addressed, it was necessary to deal with her behaviour problems. She screamed, shouted and swore loudly especially in physiotherapy. She was obviously frightened and in pain but she needed physiotherapy to stop or reduce contractures and to make sure she was mobile enough for her parents to help her into the family car and take her home when her time at the rehabilitation came to an end. Lisa's screaming, shouting and swearing was very disruptive, not only to Lisa's own rehabilitation, but to all the other patients at the centre too. A token economy programme (Kazdin, 1982) was introduced whereby if Lisa did not scream, shout or swear for five minutes she was given a large wooden bead which she kept on a necklace. When she had collected 20 beads she could exchange them for something she liked such as an extra trip to the hydrotherapy pool or a telephone call home. The time she was required to resist from screaming, shouting and swearing was slowly increased. Lisa responded well to this programme and liked collecting and exchanging the beads. Within a few weeks, her screaming had stopped, she engaged with her physiotherapy, became more mobile and her parents could take her for home visits or to go shopping.

Conclusions

Children, adolescents and young people, like older people, are likely to face cognitive, emotional and behavioural problems after any kind of illness or injury affecting the brain. Given that how we feel affects how we think, how we behave, and how we interact with others, all three functions need to be addressed in any rehabilitation program. Neuropsychological rehabilitation can reduce many of the problems faced by survivors of brain injury and all should have access to these services. It is important to provide appropriate assessment, treatment and evaluation of all therapeutic interventions. Finally, we need to be informed by a number of models and theories if we are to reduce the everyday problems faced by people who have survived brain injury and not be constrained by any one theory model or framework (Wilson, Winegardner and Ashworth, 2013).

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