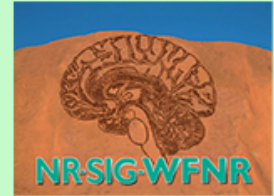




NR-SIG-WFNR Mini Conference - via Zoom
Tuesday 7th July 2020
8.30am - 11.30am UK time
5.30pm - 8.30pm Sydney/Melbourne time



Similarities and differences between bereaved parents and parents of a person with a very severe brain injury.....
Cognitive behavioural therapy for sleep disturbance and fatigue following ABI
Retrieving resiliency: Identity-focused rehabilitation for young people following ABI
Couples living with the consequences of severe TBI: Coping efforts and marital satisfaction
Gotcha! The experiences of creating a digital intervention and trial participation in people with dementia.....
Are single case studies reported in the neurorehabilitation literature methodologically robust?

NR-SIG-WFNR 2020 Mini Conference

7th July 2020

Programme, Abstracts and Speakers bios

- 8.30-8.40 Opening and introduction Satu Baylan
- 8.40-9.10 **Barbara Wilson:** *Similarities and differences between bereaved parents and parents of a person with a very severe brain injury: What can we do to help?*
- 9.10-9.30 **Lucy Ymer:** *Cognitive Behavioural Therapy for Sleep Disturbance and Fatigue Following Acquired Brain Injury*
- 9.35-10.00 **Alison Perkins:** *Retrieving Resiliency: Identity-focused Rehabilitation for Young People following Acquired Brain Injury*
- 10.00-10.05 Short break
- 10.05-10.30 **Jacinta Douglas:** *Couples living with the consequences of severe traumatic brain injury: Coping efforts and marital satisfaction*
- 10.30-10.55 **Catherine Doogan:** *Gotcha!: The experiences of creating a digital intervention and trial participation in people with dementia and their carers. A study of co-design using qualitative methods*
- 10.55-11.20 **Michael Perdices:** *Are single case studies reported in the neurorehabilitation literature methodologically robust?*
- 11.20-11.30 Closing and plans for 2021 Conference – Jennie Ponsford and Tamara Ownsworth

Abstracts

Similarities and differences between bereaved parents and parents of a person with a very severe brain injury: What can we do to help?

Presented by Barbara A. Wilson

Abstract

Wilson, Barbara¹

¹Oliver Zangwill Centre, UK

This opening talk addresses the problems faced by parents whose loved one has died and parents whose loved one has survived a very severe brain injury. There are similarities and differences between the two groups. Both have lost the person they once knew, both grieve, may be filled with regret and/or guilt, face levels of stress and changes in well being and both obtain support from others in the same situation. The main differences are that families with a very severely brain injured person face an ambiguous loss. This is a loss without an end. Their loved one is clearly alive: they have a sleep/wake cycle, they move, make noises and react to stimuli. Despite this, they do not initiate communication or social interaction and may appear unreactive to anything meaningful. They may also appear to be in pain or distress and even show signs of sadness such as shedding tears. Experiencing no interaction, communication or behaviour challenges our understanding of people, behaviour and as some report "life itself". Thus, family members cannot grieve their loss fully; they may constantly be searching for answers and this complicates and delays the process of grieving sometimes resulting in unresolved grief. Help is available to both groups, The Compassionate Friends, for example, supports bereaved parents, grandparents and siblings while the Encephalitis Society

aids those who have lost someone because of encephalitis. The talk ends with some suggestions on how to support and comfort parents of someone with a very severe brain injury.

Cognitive Behavioural Therapy for Sleep Disturbance and Fatigue Following Acquired Brain Injury

Presented by Lucy Ymer

Abstract

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Background and Objectives: Sleep disturbance and fatigue affect over half of the acquired brain injury (ABI) population, significantly impacting functional outcomes, mental health and quality of life. Treatments for these symptoms are limited, although psychological therapies such as cognitive behavioural therapy (CBT) show promise. The efficacy of CBT for sleep disturbance and fatigue (CBT-SF) in ABI has been demonstrated in pilot studies by Nguyen et al. (2017) when compared to standard care. The current study aimed to build on these findings by comparing the impact of CBT-SF with that of an active health education control intervention (HE), to account for non-specific effects of engaging in therapy.

Method: Thirty-two individuals with traumatic brain injury or stroke and sleep/fatigue problems were randomised into an 8-week CBT-SF program, adapted for cognitive impairments ($N=20$, 60% male, mean age=49.2), or an 8-week HE program developed for the study ($N=12$, 66% male, mean age=47.9) at a ratio of 2:1. Participants completed the study either face to face or via tele-health. Sleep quality (Pittsburgh Sleep Quality Index [PSQI]), fatigue (Fatigue Severity Scale [FSS]), and depression (Hospital Anxiety and Depression Scale [HADS]) were measured at baseline, post-treatment and 8-weeks post-treatment.

Results: A one-way ANCOVA controlling for baseline scores revealed significantly greater improvements in the CBT-SF group compared to the HE group on the FSS ($F(1, 29) = 5.56, p < .05$, Hedges $g = .84$), which were maintained at follow up ($F(1, 28) = 4.39, p < .05$, Hedges $g = .75$). Significant differences were not evident on PSQI ($F(1, 29) = 2.27, p = .14$, Hedges $g = .54$) or HADS ($F(1, 29) = 1.97, p = .17$, Hedges $g = .50$), although medium effect sizes were observed on both measures. One-sample t-tests also revealed significant improvements on all measures in the CBT-SF condition from baseline to post-treatment, which were maintained on the FSS and PSQI at follow up ($p < .05$). These gains were not evident on any measures in the HE condition. There were no significant differences in treatment effects between face to face and telehealth modes of delivery.

Conclusions: The current study supports the efficacy of CBT-SF, over and above the non-specific benefits of engaging in therapy, particularly for alleviating fatigue after ABI. There are promising findings for sleep disturbance and depression symptoms, which may become more evident with continued recruitment.

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Retrieving Resiliency: Identity-focused Rehabilitation for Young People following Acquired Brain Injury

Presented by Ali Perkins

Abstract

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Background and Objectives: The sequelae of pediatric acquired brain injury (ABI) are lifelong. In light of this, rehabilitation needs to focus on how young people (YP) adapt to the adversity of TBI, and to promote these adaptive capacities. This abstract presents an area of service development in which rehabilitation for young people with ABI aims to explicitly promote adaptation alongside skill development. This aim was inspired by an audit of our clinical outcomes indicating that resiliency-focused therapies enabled children with ABI to think about their acquired needs. We wished to develop a theoretical model to explain this finding and to provide a conceptual basis through which directly promote adaptation within our pediatric rehabilitation service.

Method: We reviewed the literature on factors influencing the psychosocial outcomes of YP following pediatric ABI, particularly studies describing the views of YP with ABI. We then drew from contemporary models in the literature describing experiential learning, pediatric development of the self-concept, and cognitive behavioural models of adjustment following ABI in adulthood

Result: From these sources we devised a conceptual framework of adaptation after ABI which focuses on the young person's developing identity. Within this framework the YP requires inner resiliency, contextual emotional containment, and information to integrate the consequences of their injury into their self-

concept. The internal resiliency of the child's identity, which needs to be developmentally embedded and environmentally sustained, plays a particularly critical role by regulating the YP's emotions and actions. This enables them to attend to and consider the implications of their injury which threaten the value of their self-concept. We are now integrating the conceptual framework into our multidisciplinary rehabilitation pathway, which has led to service developments in how we provide for the biopsychosocial needs of young people with ABI and their families.

Conclusions: Our work illustrates how an explicit, theoretically based focus on adaptation and resiliency can be introduced into pediatric rehabilitation after ABI. We are now planning how to empirically evaluate the impact of this approach using measures of early adaptation and functional recovery after ABI.

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Couples living with the consequences of severe traumatic brain injury: Coping efforts and marital satisfaction

Presented by Jacinta Douglas

Abstract

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Background and aims: The impact of severe traumatic brain injury (TBI) on partners is well recognised with couples reporting increased levels of stress and strain, and reduced relationship quality and satisfaction. The aim of this study was to explore long term relationship satisfaction and the coping efforts of couples living with the consequences of severe TBI and to compare these outcomes with those of a control group of couples following traumatic injury without injury to the brain.

Method: Participants were 25 couples in which the male partner had sustained severe TBI (post-traumatic amnesia \geq 14 days) and 25 couples in which the male partner had sustained traumatic orthopaedic injury. The groups were matched for duration of relationship pre-injury and at interview, age at injury and interview, and years of education for injured participants and partners. A visual analog scale ranging from 0 (extremely dissatisfied) to 100 (completely satisfied) was used to index relationship satisfaction. Coping efforts were measured using the Marital Coping Inventory (MCI) that identifies types of coping (conflict, introspective self-blame, positive approach, self-interest, avoidance) used to address a recurring problem mutually nominated by both partners.

Results: Couples living with the consequences of TBI were significantly less satisfied in their relationships than couples living with the consequences of traumatic injury without injury to the brain. Partners of men with TBI reported the lowest level of satisfaction. Use of conflict by men in both groups was negatively associated with satisfaction. Coping in TBI couples was characterised by less frequent use of positive efforts by the injured partners, more frequent use of avoidance efforts by the non-injured partners and less frequent positive physical and communicative interactions. Use of avoidance by partners of men with TBI was positively associated with their own satisfaction.

Conclusions: Patterns of coping characterised by avoidance and lack of positive strategies are consistent with relationship vulnerability and indicative of poor outcomes for couples living with the consequences of TBI. Support to enable couples to identify and develop positive coping efforts is an important step in moving towards better outcomes for those who are injured and their partners.

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Gotcha!: The experiences of creating a digital intervention and trial participation in people with dementia and their carers: A study of co-design using qualitative methods

Presented by Catherine Doogan

Abstract

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Background and Objectives: The number of people with dementia in the UK is forecast to increase by 40% over the next 12 years and 156% over the next 38 years (Prince et al., 2014). People with all stages of Alzheimer's disease (AD) report forgetting even very familiar people's names, which patients find annoying

and embarrassing (Werner, 2004). We have developed a digital name-training intervention for people with dementia. We used co-design to produce this digital intervention with people with dementia, their carers and a software company. We wanted to understand how participants experienced co-design of an app, why some people engage in research, and to capture the lived experience of the participants and carers in our clinical trials.

Methods: The participants, their carers, the research team and the software developers attended a series of focus groups with clear objectives. At each focus group the app would be presented, trialled by the person with dementia and discussed as a group. Directly after this focus group semi-structured qualitative interviews were carried out with both the participant with dementia and their carer. For Phase 1 (the co-design phase) semi-structured interviews were carried out with 16 participants. For Phase 2 (the clinical trial) semi-structured interviews were carried out prior to the therapy and on completion of the therapy with both the participants and their carer. Transcripts of these were analysed using the Framework approach.

Results: Pre-focus groups lead to the process adopted to run the co-design focus groups and subsequent interviews. Feedback resulted in many changes being made to the app. Themes from the interviews highlighted their enjoyment of the process and reasons for involvement in research included a desire to help themselves, helping others and doing something meaningful. Themes also highlighted the role of the carer in facilitating involvement in research. Initial results from the pre-post therapy interviews include a desire to get better and keep mentally fit but again highlight the need for a carer to be involved

Conclusion: This co-design project brought together a variety of people with different skill sets. This meant learning new ways of working for the software developers and us as the research team. The interviews gave an insight into the motivations to do research, their expectations of the therapy and what the impact of improving would mean.

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Are single case studies reported in the neurorehabilitation literature methodologically robust?

Presented by Michael Perdices

Abstract

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²John Walsh Centre for Rehabilitation Research, Kolling Institute of Medical Research, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

Background and Objectives: Recent work in the methodology of single-case designs (SCD) has included the development of reporting guidelines, critical appraisal tools, and procedures to classify their methodological rigour (MR). The aims of this study were to critically appraise SCD papers in the neurorehabilitation literature published during the calendar year 2017, to classify their MR using the algorithm developed by Perdices, Tate and Rosenkoetter (2019), and compare it to the MR of SCDs in the applied behaviour analysis literature.

Method: SCD articles (n=18) in 2017 were downloaded from the NeuroBITE database. The sample contained 67 experiments, each of which was critically appraised using the Risk of Bias in N-of-1 Trials (RoBiNT) Scale. Their methodological rigour was then classified. The sample from the clinical psychology and education literature consisted of 46 experiments, published in 2017 in *Behavior Modification* and the *Journal of Applied Behavior Analysis* (Perdices et al., 2019).

Results: The sample consisted of nine A-B-A experiments (and variants), eight multiple-baseline designs, twenty-one A-B designs and twenty-eight B-phase studies. Total scores on the internal validity subscale RoBiNT Scale did not exceed 4 for any experiment. Not surprisingly, MR was generally poor. None were classified as having Very High, High or Moderate MR. While only 7.5% and 9% were respectively classified as Low and Fair MR, the majority (83.5%) were classified as Very Low MR. By contrast, MR for experiments from the applied behaviour analysis literature was significantly better: Very High=4.3%, High=30.3%, Moderate=10.9%, Fair=4.3%, Low=4.3%, and Very Low=45.7% (Kendall's Tau-b=-0.225, Z= -6.4, p< .001).

Conclusion: SCDs are eminently suited as research and clinical tools in neurorehabilitation. Our findings from this sample strongly indicate that they are not being used to their full potential. Their MR is poor (and generally below that of behavioural research in other fields). Threats to internal validity are not adequately controlled and, consequently, it is difficult for such studies to demonstrate credible causal relationships between the intervention and changes in the target behaviour.

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SPEAKERS

Professor Barbara Wilson is a clinical neuropsychologist who has worked in brain injury rehabilitation for 42 years. She has published 31 books, 203 peer reviewed papers, 123 chapters and 8 neuropsychological tests. She has won many awards for her work including an OBE from the Queen in 1998, for services to rehabilitation; five lifetime achievement awards, one from the British Psychological Society, one from the International Neuropsychological Society, one from the National Academy of Neuropsychology, one from the Encephalitis Society and one from the NHS 70 year anniversary parliamentary awards where she was regional champion for the Midlands and East Region. In 2011 she received the Ramon Y Cahal award from the International Neuropsychiatric Association. In 2014 she received an honorary degree from The University of Cordoba, Argentina. Also, in 2014 she received the M.B. Shapiro award from The Division of Clinical Psychology (affiliated to The British Psychological Society) for Distinguished Contributions to Clinical Psychology. In 2019 she received the annual award from the Spanish Clinical Neuropsychological Society. She is editor of the journal "Neuropsychological Rehabilitation" which she founded in 1991 and in 1996 she established the Oliver Zangwill Centre for Neuropsychological Rehabilitation. A rehabilitation centre in Quito, Ecuador is named after her. She is president emeritus of the UK Encephalitis Society and is on the management committee of The World Federation of Neuro Rehabilitation. The UK Division of Neuropsychology has named a prize after her, the 'Barbara A Wilson prize for distinguished contributions to neuropsychology'. She is a Fellow of The British Psychological Society, The Academy of Medical Sciences and The Academy of Social Sciences. She is honorary professor at the University of Hong Kong, the University of Sydney and the University of East Anglia. She has held 30 research grants. Her work has resulted in changes in clinical practice. For example, as a result of a randomised control trial evaluating a paging system to improve the everyday functioning of people with memory and planning problems, the local health authority set this up as a health care system for people throughout the United Kingdom.



Ms Lucy Ymer is a Doctor of Clinical Neuropsychology Candidate at Monash University in Melbourne, Australia. She completed a Bachelor of Psychology (Honours) at Deakin University, graduating with First Class Honours. Her doctoral research at Monash University is being conducted in conjunction with the Monash Epworth Rehabilitation Research Centre at Epworth Hospital. She is currently the trial co-ordinator of an Australia-wide randomised controlled trial investigating the efficacy of Cognitive Behavioural Therapy for sleep disturbance and fatigue following acquired brain injury. In 2017, she was one of two recipients of the Moving Ahead NH&MRC Centre for Research Excellence in Brain Recovery Small Seed Grants and presented her research at the University of New South Wales. Throughout her candidature she has had clinical training in assessment, diagnosis and management of individuals with neurodegenerative conditions, acquired brain injury, and psychiatric and neurological conditions.



Ms Alison Perkins is a principle clinical psychologist who has worked for many years within the field of paediatric acquired brain injury (abi). She practises as part of a multidisciplinary team at The Children's Trust, Tadworth, which provides neuro-rehabilitation for children with a severe abi and their families. Within this role she has witnessed many young people take on the challenge of adapting to their severe brain injury. She has a keen interest in how rehabilitation can help young people integrate the impact of their injury into their everyday lives and developing identities



Professor Jacinta Douglas holds the Summer Foundation Chair of Living Well with Brain Injury at La Trobe University in the Living with Disability Research Centre. Jacinta's qualifications span the disciplines of speech pathology, clinical psychology and neuropsychology. Her research contribution has advanced knowledge in the domains of interpersonal communication and psychosocial functioning following brain injury. Jacinta is a Fellow of the Australasian Society for the Study of Brain Impairment and the Speech Pathology Association of Australia and is



founding co-editor of the multidisciplinary journal *Brain Impairment*. She has published more than 140 peer reviewed papers in international journals and authored 12 book chapters.

Dr Catherine Doogan is a Clinical Psychologist who has been working in field of neuro-rehabilitation for the last ten years. She has a specialist interest in generating novel therapeutic approaches to help people with cognitive impairments caused by stroke or Dementia. Through her NIHR funded post-doc work at UCL, she has co-created two digital neuro-interventions; one for people with post-stroke aphasia, and one for people with proper-name anomia and dementia. She is also working on an immersive virtual reality stimulation paradigm for people with acute, post-stroke neglect. A particular interest, that she will explore in her talk, is how patients and carers experience being involved in co-design and the variety of expectations and experiences they have of participating in neurorehabilitation-based research.



Dr Michael Perdices is a clinical neuropsychologist with 30 years' clinical and research experience, and over 50 publications. His clinical work primarily involves assessment and diagnosis of acquired brain injury in a broad spectrum of neurological conditions. Evidence-based practice and single-case methodology have been his main research interests for the past 20 years. In terms of the latter, he has co-authored (with Professor Robyn Tate) a text book, three book chapters and multiple articles in the field.

