Rehabilitation Research Review Making Education Easy

Issue 48 - 2019

In this issue:

- Co-producing self-management support following ABI
- Music listening and mindfulness after ABI
- Australian women's experience
- Recalibrating hope in the year after stroke
- 'Listening in' for subjective interpretations after mTBI
- Participant-led training videos benefit support workers
- Methodological problems in rehabilitation research
- App-based exercise prescription improves inpatient activity levels
- Return to work after major trauma
- Reduced participation in work and activities after injury

Abbreviations used in this issue

6MWT = 6-min walk test 10MWT = 10-min walk test **ABI** = acquired brain injury **mTBI** = mild traumatic brain injury

 $\mathbf{RTW} = \mathbf{return} \ \mathbf{to} \ \mathbf{work}$ **TBI** = traumatic brain injury **TUG** = Timed Up and Go











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Welcome to issue 48 of Rehabilitation Research Review.

In May this year, the New Zealand Rehabilitation Association (NZRA) held its biennial conference in collaboration with the Australasian Society for the Study of Brain Impairment (ASSBI). This issue focuses on six of the presentations from this ASSBI/NZRA Inaugural Trans-Tasman conference, including commentary for four from guest reviewers Dr Felicity Bright and Dr Rachelle Martin.

One of the four remaining papers in this issue discusses 12-month data from the New Zealand Prospective Outcomes of Injury Study (POIS), which found substantial reductions in participation in paid work, unpaid work and activities compared with the range of participation before the sentinel (initial) injury. Experiencing subsequent injury was also found to impact on return to paid work. The study researchers suggest that it may be useful to focus rehabilitative attention on those people experiencing subsequent injuries, to reduce their high risk of participation restrictions that have long-term multidimensional functional consequences.

I hope that you find the research in this issue useful in your practice and I welcome your comments and feedback. Kind regards,

Associate Professor Nicola Kayes

nicolakayes@researchreview.co.nz

COMMENTARY ON SIX OF THE PRESENTATIONS FROM THE ASSBI/NZRA **INAUGURAL TRANS-TASMAN CONFERENCE**

'Feeling less alone': co-producing self-management support following traumatic brain injury

Presenter: Fiona Jones, St George's University of London, London, UK

Summary: This keynote lecture described how co-production methodology and a staged approach was successfully used to develop a shared self-management approach in the acute ABI setting. Fourteen people who had previously been admitted to a major London trauma centre with ABI and their family members participated in a series of activities to co-design books embodying a person-centred approach to self-management. These books incorporate patients' and families' stories, ideas and reflections on life after ABI and provide space for recording hopes, targets, successes and strategies. Supported self-management (SSM) workshops were held with 110 staff from the trauma centre, providing them with training on how to integrate SSM strategies and the new self-management books with patients in acute and rehabilitation settings. Qualitative evaluation revealed that the books were adopted by patients and families and provided staff with a shared mechanism to implement self-management strategies within their everyday work. The lecture described various benefits gained from this participatory process of authentic co-design; reflections were shared from people with ABI, their families, healthcare staff and the project team. The lecture summarised lessons learnt in this process and offered advice for those seeking to engage and involve people with ABI and their families in research and who want to enhance service provision.

Comment (NK): I was really looking forward to hearing Fiona speak and she did not disappoint. Fiona is the founder and director of the Bridges self-management programme (http://www.bridgesselfmanagement. org.uk/) in the UK. While Bridges started in stroke, they have since co-produced versions of the Bridges programme with a range of other people living with long-term conditions. Fiona is a physiotherapist by background and, as such, a lot of her work focuses on building capability for rehabilitation practitioners to embed principles of self-management support into routine practice. In this plenary she talked about her most recent research, which focused on working with patients and practitioners to embed self-management in an acute trauma setting. Acute services are primarily focused on getting people to the point where they are safe to discharge. Primary key performance indicators tend to be service- and cost-driven, with pressure to reduce length of stay. As such, a focus on building capacity for self-management in this setting potentially requires a paradigmatic shift in the way services are delivered and what constitutes a good outcome. I would argue that this is just the kind of paradigmatic shift we need if we are to meet the ever-looming healthcare challenges of the future.

This presentation is related to a paper published in 2019 by Petra Mäkelä and colleagues (including Fiona Jones); Supporting self-management after traumatic brain injury: codesign and evaluation of a new intervention across a trauma pathway.

Music, mindfulness and positive psychotherapy after brain injury

Presenter: Jonathan Evans, University of Glasgow, Glasgow, UK

Summary: This presentation described the development and initial evaluation of Positive Psychotherapy for ABI Rehabilitation (PoPsTAR) and ongoing work evaluating the use of 'character strengths' in goal setting after ABI. It went on to describe how the PoPsTAR programme has used music listening and mindfulness to improve cognitive recovery after stroke. This was supported by data from the MELLO trial, which measured the effects of mindful music listening after stroke and found that cognitive recovery was enhanced and mood was improved early post-stroke.



Comment (NK): This was an excellent presentation that covered a lot! However, I was particularly interested in the ways in which Jonathan and his team have attempted to embed principles of positive psychology into rehabilitation practice. So often we focus on impairment, and what people can't do in rehabilitation. In doing so, we fail to harness people's strengths and appreciate the potential of strategies that focus on building capacity for well-being. In this presentation, Jonathan argues for a primary focus on well-being in rehabilitation. He asks - what would it look like if we drew on well-being from the start? He draws on Martin Seligman (the father of positive psychology) and the PERMA framework in his research. The PERMA framework proposes five domains of well-being, including Positive emotions, Engagement, Positive relationships, Meaning, and Accomplishment. He referred to a pilot trial he has undertaken where they applied positive psychology in Acquired Brain Injury rehabilitation (an intervention he proudly refers to as POPsTAR). Simple strategies for wellbeing included the three things journal (what went well today and why), the gratitude visit, savouring the moment, using the Values in Action Inventory to identify (and use) strengths and much more. These are simple, brief strategies. I challenge you to embed some in your practice today.

This presentation is related to a paper published in 2016 by Breda Cullen and colleagues; *Positive PsychoTherapy in ABI Rehab (PoPsTAR): a pilot randomised controlled trial.*

Tarnished dreams – Australian women's experience of traumatic brain injury

Presenter: Kate O'Reilly, Western Sydney University, NSW, Australia

Summary: This presentation described research that has explored health, activity and participation issues for Australian women post-TBI. Qualitative interviews were conducted with 20 Australian women living with TBI and 97 Australian women completed an online survey seeking to understand their experience of living with TBI. The data were examined within a critical feminist transformative framework. Themes that emerged from the research included a Changing Perception of Self; Sexuality, Sexual and Reproductive Health; Having Tenacity; and Being and Feeling Vulnerable. The research intends to underline the current limitations within the rehabilitation literature, which fails to accommodate the specific experience of women living with TBI. The research also aims to stimulate discussion and inform future directions for research, policy and practice.

Comment (FB): Kate's presentation was fascinating. She skilfully demonstrated how women experience TBI, highlighting that there are important nuances and unique gendered experiences that we need to acknowledge and consider in rehabilitation. I was particularly struck by participants' comments about how the premenstrual syndrome was exacerbated post-TBI. It made perfect sense, but I had never considered it or discussed it when working with women post-TBI. Kate's research highlights the value of developing deep understandings of the needs and experiences of different patient groups. Her work is important in ensuring there is not a 'gender data gap' in brain injury, something evident in a lot of health research.

Recalibrating hope in the year after stroke: a call to move beyond 'realistic' hope

Presenter: Felicity Bright, Centre for Person Centred Research, Auckland University of Technology, Auckland, New Zealand

Summary: This presentation discussed the results from a longitudinal study in which 4 people with aphasia were interviewed at 3 and 12 months after stroke, exploring how they hope and what they hope for, in the year after stroke. Content analysis identified key themes from the data. The patients were largely engaged in the task of reconstructing their lives, (re)engaging in social activities and developing an image of a possible future at 12 months. For these patients, hope was protective and productive, as they actively recalibrated early post-stroke hopes by reflecting on past progress, their current function and what they might be able to meaningfully achieve in the future. The analysis also revealed how other patients struggled to see a possible future. Their hope that "things will be good" acted as a mantra, sustaining them through uncertain times. Crucial to helping them (re)develop hopes for their future included access to social supports and feeling a sense of progress, as well as engagement in meaningful activities and interactions.

Comment (FB): Clearly I am a biased commentator for this presentation! Hope is often a contentious topic with clinicians recognising it is important but often concerned that people be realistic. We argue that we need to trust stroke survivors. Our work suggests they gradually recalibrate their hope over time, revisiting what they hope for in the future. As clinicians, we need to consider how we contribute to creating 'hope-full' environments for clients. This includes prioritising people's social and relational well-being and attending to factors that help people 'be' in the present and look forward to future possibilities.

Independent commentary by Dr Felicity Bright BSLT(Hons), MHSc(Hons), PhD

Felicity is a Senior Lecturer in Rehabilitation and Case Management. She is a speech-language therapist with expertise in neurological rehabilitation. Her research focuses on professional practices in rehabilitation, and has a particular interest in relational aspects of practice and critical examination of clinical practice.



Independent commentary by Associate Professor Nicola Kayes

Associate Professor Nicola Kayes is Director of the Centre for Person Centred Research at Auckland University of Technology. Nicola has a background in health psychology and as such her research predominantly explores the intersection between health psychology and rehabilitation. For full bio CLICK HERE.





Rehabilitation Research Review

'Listening in' for uncertainty during recovery from mild traumatic brain injury: a mixed methods study

Presenter: Deborah Snell, Concussion Clinic, Burwood Hospital, Christchurch, New Zealand

Summary: This case-control study involved 76 people who had or had not recovered after mTBI, 10 of whom participated in a semi-structured interview to explore their recovery experiences in more depth. While the quantitative results revealed a range of differing recovery expectations across both cases and controls, the qualitative results suggested that participants searched for a coherent understanding of their recovery from mTBI, regardless of recovery status. When the researchers used components methods analysis to conduct more in-depth analysis of the threads between the quantitative and qualitative datasets, they identified a superordinate meta-theme suggesting that conflicting knowledge from different sources increased uncertainty and as a result, some participants experienced distress and feelings of invalidation, especially those who had not recovered from their injury.

Comment (RM): How and why people experience recovery differently after a mTBI is complex. This mixed-methods study highlights the importance of providing people with coherent information, but also ensuring alignment with internalised expectations that they may hold about their recovery. Conflicting knowledge from external and internal sources can increase uncertainty, creating potential for distress and feelings of invalidation, especially for those who have not recovered from their injury. This has implications for the way that recovery expectation information is provided to people with a mTBI, with a two-way exchange being required — 'listening in' for subjective interpretations made of information from formal and informal, internal and external knowledge sources. Passively providing information to people, without checking their understanding of this information or how it aligns with their expectations, does not help. . . and may be harmful.

This presentation is related to a paper published in 2019 by Deborah Snell and colleagues; Wrestling with uncertainty after mild traumatic brain injury: a mixed methods study.

Co-design, pilot and evaluation of participant led videos to train support workers

Presenter: Di Winkler, Summer Foundation Ltd., Melbourne, Australia

Summary: This Australian research involved 14 participants: 4 men and 1 woman with ABI (primary participants), 5 close other supporters and 4 staff facilitators. The ABI cohort had ABI-related cognitive and communication impairments and very high support needs. All 14 people were enrolled into a project that set out to co-design, pilot, and document a process for working with National Disability Insurance Scheme (NDIS) participants to produce participant-led training videos (PLVs). These videos are designed to inform disability support workers about how the person with disability wants to be supported. Semi-structured interviews were conducted with all participants at both 1 week and 4 months after the production of the videos, to document multiple perspectives and obtain quantitative and qualitative data. All reported high levels of satisfaction with the PLV process and they enthusiastically endorsed the usefulness of the approach. Primary participants and their supporters recommended the video production process for others; on a scale of 1 to 10, the average score exceeded 8.

Comment (RM): Finding ways to enact practices that support a person's ability to express their wishes, to direct their cares and to feel validated by health professionals and support workers is always challenging. This study evaluated a novel project that co-designed, piloted, and documented a process for working with people with severe cognitive and communication impairments as a result of acquired brain injury. The process involved producing participant-led training videos informing disability support workers about how the person wanted to be supported. However, the process of helping the person to explore their desires, and not just the final video product, contributed to the success of this work. The process of video production allowed people to have a voice and take control in directing their lives. They experienced personal growth through participation and engagement in the planning and production of the videos, and felt validated through the experience. What a lovely example of enacting person-centred relational practices.

Independent commentary by Dr Rachelle Martin, Dip Phys(Otago), MHSc(Otago), PhD(Otago)

Rachelle is a Research Fellow with the Rehabilitation Teaching and Research Unit (RTRU) at the Department of Medicine, University of Otago Wellington, and Rehabilitation and Knowledge Translation Lead at the Burwood Academy of Independent Living, Christchurch. She has worked clinically in the area of acquired brain injury in acute and community rehabilitation settings. Rachelle is particularly interested in exploring outcomes that are considered important by the users of rehabilitation services and she researches how people who experience disability can be supported to live a good life despite ongoing impairments.



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Research Review publications are intended for New Zealand health professionals.

Methodological problems in rehabilitation research. Report from a Cochrane Rehabilitation Methodology Meeting

Authors: Levack WM et al.

Summary: As Cochrane reviews and protocols often cover interventions provided by rehabilitation professionals, the rehabilitation community has a keen interest in the Cochrane Library evidence database. Cochrane Rehabilitation was launched in 2016 to bring this work closer to the global health-related community by creating resources for rehabilitation providers, policymakers and service users, so that they can better use the evidence held by the Cochrane Library and make this database more relevant to their work and lives. This Editorial reflects on how Cochrane Rehabilitation is seeking to provide person-centred rehabilitation intervention and producing evidence most relevant to clinical practice, in an effort to replace the traditional laboratory answers to interventions modelled on scientific practices. Such interventions are of interest to clinicians in specialty areas and do not necessarily respond to the actual needs of patients and their supporters, providers and funders. The Editorial outlines the outcomes from a two-day Cochrane Rehabilitation 2018 workshop held in Paris, France, involving rehabilitation researchers and authors from several countries worldwide. That meeting focused on the results of studies that have interpreted and applied Cochrane methods in rehabilitation reviews, which would support the future development of guidelines for clinical trials examining health-related rehabilitation interventions.

Comment (NK): The Cochrane Collaboration was developed to support the production of highquality, accessible systematic reviews to underpin evidence-based healthcare. Indeed, systematic reviews in rehabilitation are an important source of evidence driving rehabilitation practice. However, rehabilitation is an inherently complex intervention, frequently bringing together a number of interacting (often invisible) components. This in turn adds complexity to trial methodology, and subsequently to the synthesis of evidence in rehabilitation reviews. In July last year, I had the privilege of participating in a Cochrane Rehabilitation Methodology Meeting, which brought together an international group of rehabilitation researchers to critically discuss and contribute to methodological advance in the synthesis of rehabilitation evidence. These discussions underpinned a collection of papers recently published in a special issue of the European Journal of Physical and Rehabilitation Medicine. All papers are of fully open access and downloadable from the following link: https:// www.minervamedica.it/en/journals/europamedicophysica/issue.php?cod=R33Y2019N03

Reference: Eur J Phys Rehabil Med 2019;55(3): 319-21

Abstract

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Rehabilitation Research Review

App-based supplemental exercise during inpatient orthopaedic rehabilitation increases activity levels

Authors: Bui T et al.

Summary: This pilot trial enrolled 20 people admitted to an inpatient private general rehabilitation unit for orthopaedic rehabilitation and randomised them to receive supplemental exercise via an app $(PTPal^{TM})$ on a tablet device additional to usual care (controls; n=10) or usual care alone (n=10) for 4 weeks. The trial sought whether the app-based supplemental exercise programme was feasible and acceptable to the participants and whether it would increase activity levels, as well as improve functional outcomes. The app proved to be highly acceptable; the users completed an additional 549 exercise repetitions (694 supplemental app-based repetitions vs 146 supplemental paper-based repetitions for controls; p=0.02) and an additional 157 min in supplemental exercise during their 4-week stay in the unit (195.3 min vs 38.7 min for controls; p=0.05). Moreover, all functional outcomes (i.e. the 6MWT and 10MWT, TUG and Functional Independence Measure assessments, length of stay) were superior after the app-based intervention compared with those after usual care.

Comment (NK): There is increasing debate about the amount of therapy time people get (or don't get!) during their inpatient rehabilitation stay. It has been argued that while there is an established relationship between dose and outcome, therapy dose routinely falls below recommended guidelines. While apps have been used to support activity engagement in the community, this is the first time I have seen apps used for this purpose in an inpatient rehabilitation setting. While this is a pilot feasibility study (and so results are not definitive) the findings appear promising — with those receiving exercise prescription via an app reporting significantly higher activity levels than controls. It would be interesting to also explore other secondary effects. For example, to what extent does the app signal the expectation that scheduled face-to-face therapy time should be supplemented with an independent exercise programme? To what extent might these expectations remain intact as one navigates rehabilitation in the community following discharge? How does one's experience of safely navigating an exercise programme independently within the safety of a hospital setting increase one's confidence in their ability to do the same upon discharge home?

Reference: Pilot Feasibility Stud 2019;5:47

Abstract

Patterns and predictors of return to work after major trauma: a prospective, population-based registry study

Authors: Collie A et al.

Summary: This study of return to work (RTW) after major trauma (i.e. including any of the following: death after injury; an Injury Severity Score of >12; urgent surgery; or admission to intensive care for >24) analysed records from Australia's Victorian State Trauma Registry to examine the pattern of engagement in paid employment or study over the 48 months (4 years) following injury. A total of 1,086 working-age individuals were included in this analysis; all were in paid employment or full-time education before injury and were followed-up by telephone interview at 6, 12, 24, 36 and 48 months after injury. They were allotted to 1 of 4 groups based on their responses to RTW questions at each interview: (1) early and sustained RTW - the person returned to work at 6 months and was in work at all subsequent follow-up interviews; (2) delayed RTW - the person was not at work initially but later reported returning to work for ≥2 consecutive interviews and was working at all subsequent interviews; (3) failed RTW – any self-reported episode of RTW that was followed by an interview in which the person reported no longer being back at work; (4) no RTW – the person reported not being back at work at all interview time points. A little over half (51.6%) of all respondents belonged to the early and sustained RTW cohort; 15.5% were in the delayed cohort and 13.3% in the failed RTW cohort. Around one-fifth (19.7%) were in the failed RTW cohort. Multivariate multinomial logistic regression analysis found that individuals in a manual occupation and those injured in a motor vehicle accident at higher risk of being categorised in the delayed and no RTW cohorts, compared with individuals in the early and sustained RTW cohort. Older age and receiving compensation predicted both failed and no RTW patterns. Those with a preinjury disability were more likely to be recorded as failed RTW, while individuals with a comorbidity had a higher risk of being recorded as no RTW.

Comment (NK): Exploring predictors of RTW following injury can help to identify subgroups that would benefit from additional, targeted vocational rehabilitation support. This robust prospective cohort study reports findings from a four-year follow-up of people following major trauma using the Victorian State Trauma Registry in Australia. Victoria has third party insurers that are somewhat similar to the Accident Compensation Corporation (ACC), though only for transport- and work-related injury. The findings identify some key subgroups that were significantly more likely to have poorer outcomes (no or failed RTW), including for example those with serious injury involving the brain or spinal cord, older people, and those with comorbidity and/or pre-injury disability. Clearly, existing approaches are failing to meet the needs of these subgroups and more targeted and tailored vocational rehabilitation strategies are needed to address this. It is also worth considering the extent to which the broader attitudinal environment contributes to poor outcomes for these groups who are also likely to be subject to the marginalising effects of normative expectations in the job market and workplace — see Fadyl & Payne (2016) for further discussion on this topic https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5020327/pdf/idre-38-2165.pdf).

Reference: Ann Surg 2019;269(5):972-8

Abstract

Impact of further injury on participation in work and activities among those previously injured: results from a New Zealand prospective cohort study

Authors: Wilson SJ et al.

Summary: These researchers analysed data from 2,282 participants in the New Zealand Prospective Outcomes of Injury Study (POIS), all of whom were recruited after an Accident Compensation Corporation (ACC) entitlement claim injury and completed the 12-month post-injury interview. Three participation outcomes were examined from the 12-month interview: paid work, unpaid work and activities. The researchers also examined whether experiencing ≥1 subsequent injuries predicts reduced participation 12 months after the sentinel (initial) injury. Finally, they examined characteristics of subsequent injuries as potential predictors of reduced participation. At 12 months, 30% of the study cohort had reduced paid work hours, 12% had reduced unpaid work (e.g. housework, gardening) and 25% had reduced activities (e.g. socialising, leisure pursuits) compared with before the sentinel injury event. Sustaining any subsequent injury predicted reduced paid work at 12 months (RR 1.5; 95% CI, 1.2 to 1.8), but not unpaid work or activities. Multivariate analyses identified that participants who had sustained an intracranial subsequent injury were at highest risk of reduced paid work at 12 months (RR 3.2; 95% CI, 1.9 to 5.2). Participants sustaining subsequent injuries at work were less likely to experience reduced paid work at 12 months (RR 0.7; 95% Cl, 0.6 to 1.0) compared with those who sustained only nonwork subsequent injuries. Those who sustaining an assaultive subsequent injury were more than twice as likely to be doing less unpaid work at 12 months compared with those sustaining only non-assaultive subsequent injuries (RR 2.6; 95% CI, 1.0 to 6.8).

Comment (NK): This research drew on data from the Prospective Outcomes of Injury Study (POIS), which is a NZ-based study following people with ACC injury entitlement claims up to two years following injury. Interestingly, some of the predictors of greater participation restriction at 12 months were consistent with those identified in the preceding study by Collie et al. in this issue of Rehabilitation Research Review. For example, among other things, those with comorbidity or still experiencing the effects of prior injury were more likely to have reduced participation in at least two participation areas (e.g. paid work, unpaid work, or other activities). The finding that subsequent injury predicted paid work but not unpaid work or other activity restrictions is interesting. Further work is needed to help make sense of this finding. While more severe subsequent injuries (including those that required hospitalisation or intracranial injuries) were at most risk of contributing to reduced paid work, it may be important to consider the potentially cumulative effects of multiple injury in vocational rehabilitation more generally versus treating each injury as an isolated event.

Reference: Qual Life Res 2018;27(12):3167-78 Abstract









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