

Rehabilitation Research Review™

Making Education Easy

Issue 27 – 2013

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Welcome to the twenty-seventh issue of Rehabilitation Research Review.

My obsession with goals continues with the first paper (Stevens et al) highlighting that of all currently available patient-specific goal setting instruments, none can be singled out and recommended specifically. All have unique strengths and weaknesses during the various phases of the goal setting process. The study authors recommend applying a combination of the strengths of the available instruments, tailored to the individual patient.

Physician Nortin Hadler has released a new book called "The citizen patient", which argues that reforms to health care are necessary for the sake of the patient and to improve the health of the populace. Although embedded in the American system, this book challenges patients and policy makers worldwide to think about how medical treatment, health care finance and attitudes surrounding health, medicine and disease play out in broad social and political settings.

I hope you find the papers in this issue useful in your practice and I welcome your comments and feedback.

Kind regards,

Kath McPherson

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The use of patient-specific measurement instruments in the process of goal-setting: a systematic review of available instruments and their feasibility

Authors: Stevens A et al.

Summary: These researchers examined the feasibility of the currently available patient-specific measurement instruments used in the process of goal setting. A total of 11 instruments were identified, all of which can be used for goal negotiation, goal setting and evaluation. The thematic analysis revealed that each instrument has unique strengths and weaknesses during the different phases of the goal setting process. All instruments shared objective feasibility data including administration time, instruction, training and availability. Subjective feasibility was limited to the Canadian Occupational Performance Measure, Goal Attainment Scaling, Self-Identified Goal Assessment and Talking Mats. The Canadian Occupational Performance Measure and Goal Attainment Scaling were time consuming and difficult for patients with cognitive problems, but they facilitated goal setting in a client-centred approach. Talking Mats was especially feasible for patients with cognitive and communication impairments.

Comment: Given the rather ubiquitous nature of goals and goal setting, it is on the surface rather odd we don't yet have an instrument that works well. However – it is not really that odd. Parallel work identifies that the purposes and mechanisms of goals are incredibly variable and other literature tells us that goals themselves are problematic for patients and professionals alike. So – it is unsurprising that the tools are similarly. My hunch is that rethinking what we do with goals is a central question in Rehabilitation and wider healthcare and that as the well-known phrase goes – what you measure is what you do. So - better tools for goals and goal setting – yes please. This is the topic of a book edited by NZ'ers Richard Siegert and Will Levack due to be published later this year or early 2014 – keep your eye out for that.

Reference: *Clin Rehabil* 2013;27(11):1005-19

<http://cre.sagepub.com/content/27/11/1005.abstract>



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Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury

Authors: Knox L et al.

Summary: This review of the literature sought to identify factors that determine how clinicians provide support and influence opportunities for individuals with acquired brain injury (ABI) to participate in decision making across the rehabilitation continuum. The intention of this review is to raise professional awareness of how these factors may impact upon post-injury rehabilitation and living. A range of factors may influence the decision-making support provided by clinicians and, ultimately, shape lifetime outcomes for individuals with ABI. The study researchers suggest that a multidimensional framework may assist clinicians to identify hidden assumptions on their part that influence their decision-making support.

Comment: This is one of two papers focusing on communication at the pointy end of healthcare in this issue – i.e., involving people with cognitive impairment (or learning impairment in relation to the paper by Rossignol) in decisions about their care and rehabilitation. In essence, this review indicates we: a) make assumptions about people's ability to make decisions (and therefore can be wrong) and b) we seem very (dare I say 'over') cautious about the risks. Some useful ideas in here about how we might do this better – first point being to recognise there are risks to our assumptions.

Reference: *Disabil Rehabil* 2013;35(22):1926-32.

<http://informahealthcare.com/doi/abs/10.3109/09638288.2013.766270>

Rehabilitation Research Review

Independent commentary by Professor Kath McPherson.

Kath McPherson is Professor of Rehabilitation (Laura Fergusson Chair) at the Health and Rehabilitation Research Centre, AUT University in Auckland. She completed a PhD at the University of Edinburgh exploring how individuals and their families recover and adapt after moderate to severe brain injury. From 1997-2001, Kath worked at the Rehabilitation Teaching and Research Unit at University of Otago - Wellington, then taking up a post as Reader in Rehabilitation at the University of Southampton. She returned to New Zealand (AUT) in 2004 building a research, teaching and consultancy programme focused on improving interventions and outcomes for people experiencing with disability. Current projects are funded by the Accident Compensation Corporation, the Health Research Council, the UK-NHS and a number of charitable organisations.



Disclaimer: This publication is not intended as a replacement for regular medical education but to assist in the process. The reviews are a summarised interpretation of the published study and reflect the opinion of the writer rather than those of the research group or scientific journal. It is suggested readers review the full trial data before forming a final conclusion on its merits.

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An exploratory study of knowledge brokering in hospital settings: Facilitating knowledge sharing and learning for patient safety?

Authors: Waring J et al.

Summary: This exploratory study explored the structural position and roles of four types of intra-organisational knowledge broker working within three large acute hospitals in the English National Health Services. The paper explains how formal role, location and relationships shape how these people share and support the use of knowledge across organisational and occupational boundaries. It suggests those occupying hybrid organisational roles, such as clinical managers, are often best positioned to support knowledge sharing and learning because of their 'ambassadorial' type position and legitimacy to participate in multiple communities through dual-directed relationships.

Comment: Our own group is increasingly looking at ways to help findings get into practice more speedily than happens by chance (multiple generations it seems from Teasell's work in stroke). The idea of Knowledge Brokers is not new with the most successful model seeming to be operationalising having 'champions' for research within healthcare organisations. My sense is that this is indeed the model that seems to work best – researchers alone can't do transfer – people 'within' organisations are key. Could it be time for all services to identify their Knowledge Broker? I think it could be...

Reference: *Soc Sci Med* 2013;98:79-86

<http://linkinghub.elsevier.com/retrieve/pii/S0277953613005029>

Reporting disability in the age of austerity: the changing face of media representation of disability and disabled people in the United Kingdom and the creation of new 'folk devils'

Authors: Briant E et al.

Summary: These researchers describe a significant change in the way that disability is reported in the UK since the election of the Coalition Government in 2010. Radical restructuring of disability-related benefits have been called for, on the justification that the financial crises of 2007/08 make these necessary. In comparison with a similar period in 2004/05, newspaper coverage of disability has become less sympathetic and more likely to report articles that focus on disability benefit and fraud, with a greater tendency to use pejorative language to describe disabled people. The article notes that an audience reception study suggests that this coverage is negatively impacting the way that people think about disabled people.

Comment: This paper caught my eye because I had just read another by Devotta et al. in *Disability & Rehabilitation* Vol. 35, No. 22 (2013) suggesting a change for the better in Canada on exactly this topic. So what is the reason for the difference? Some would suggest welfare reform and how it has been managed, which is of interest, given NZ's focus on such reform also. Diversity Works recently undertook a survey concerning media representation of disabled people (particularly on the screen) and it would seem NZ'ers are more on side with the Canadians in perspective although the 'quantity' of representation of disability on screen is still pretty low. See <http://unique-extras.co.nz/campaign/> for more details.

Reference: *Disabil Soc* 2013;28(6):874-89

<http://www.tandfonline.com/doi/abs/10.1080/09687599.2013.813837#.UI2ySRAs-d4>

Disorders of consciousness: outcomes, comorbidities, and care needs

Authors: Whyte J, Nakase-Richardson R

Summary: An evolving understanding of disorders of consciousness (DOC) in recent years calls for a reconsideration of appropriate models of care, in the face of findings demonstrating a surprisingly positive prognosis for functional recovery early after injury, particularly in those with traumatic aetiologies; that meaningful recovery proceeds for longer intervals than previously appreciated; and that such individuals are often medically complex and challenging to manage. Despite this change in thinking, access to intensive specialty rehabilitation is limited for most individuals with DOC in the USA. This collection of articles provides insight into the functional recovery of individuals with DOC, new tools for assessing prognosis, and the patterns of comorbidity that complicate the recovery process. It also presents American and European models of care that attempt to address the needs of patients as well as their caregivers.

Comment: It's not that long since many patients with DOC were described as being in a 'persistent vegetative state' or a variant with an implication that no change or improvement was possible. However, data has shown that with appropriate input (care responding to their medical and nursing complexity along with an early rehabilitative approach), better outcomes than we may have accepted in the past may occur. Whilst prognostic accuracy remains a bit of a black box, advance is under way and this paper is a most useful update.

Reference: *Arch Phys Med Rehabil* 2013;94(10):1851-4
<http://tinyurl.com/l86ga43>

Examining the evidence about psychological treatments for chronic pain: Time for a paradigm shift?

Authors: Morley S et al.

Summary: This paper argues that a paradigm shift is essential and long overdue concerning the way in which we design treatments for chronic pain and study their effectiveness. It calls for an improvement in study quality, access to data at an individual patient level and access to larger data sets on community studies. Systematic reviews must become explicit and transparent about trial entry. Grading of evidence will recognise the influence of bias in individual trials, and innovative methods of portraying the results of comparative effectiveness studies to different stakeholders will improve their relevance.

Comment: This paper is a reminder that 'more' is not necessarily 'better'. Knowledge advance is not only less likely, but more complicated when a field becomes over-run by multiple small studies with multiple big problems. I really like the idea here that authors are promoting for a 'within large trial' evaluation of 'individual patient level data' to add value and information about how and why individual people respond differently even to those interventions that are 'effective' for total populations. For me, some of the best trials (i.e., the most informative for practice) are those that include qualitative data on such issues, and funders are seemingly welcoming such designs. Meantime – let's think about how many small trials we undertake or support – the cost benefit of the effort being dubious at best.

Reference: *Pain* 2013;154(10):1929-31

[http://www.painjournalonline.com/article/S0304-3959\(13\)00291-1/abstract](http://www.painjournalonline.com/article/S0304-3959(13)00291-1/abstract)



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3RD AUSTRALASIAN COMPENSATION HEALTH RESEARCH FORUM

10 - 11 October 2013
 Sydney, Australia

In October, Sydney hosted the 3rd Australasian Compensation Health Research Forum. Following on from two successful events held in 2011 and 2012, the forum brought together international and experts, policy makers, political figures and researchers in the fields of injury compensation and rehabilitation.



ACC is proud to be a joint convener of the forum along with The Institute for Safety, Compensation and Recovery Research (a joint initiative of WorkSafe Victoria, the Transport Accident Commission and Monash University).

The forum is the only gathering of its kind putting compensation health, a multi-billion dollar part of the workforce and economy, at its centre.

The focus of this year's forum was 'New Directions, Health, Work and Disability'

The programme boasted an enviable list of speakers including:

- Terry Bogoy, former Director of Corporate Strategy, WorkSafe, British Columbia, Canada
- Professor Nortin Hadler, Professor of Medicine at the University of North Carolina, USA
- Professor Kathryn McPherson, Professor of Rehabilitation and Director of the Person-Centred Rehabilitation Centre at the Auckland University of Technology, New Zealand
- John Walsh, Partner Price Waterhouse Coopers and NDIS champion
- Dr Margaret Macky, Accident Compensation Corporation, New Zealand

Further information about this forum is available at: www.achrf.com.au

How do children with autism spectrum disorders express pain? A comparison with developmentally delayed and typically developing children

Authors: Rattaz C et al.

Summary: Outcomes are presented from an investigation into the facial, behavioural and physiological reactions of 35 children with autism spectrum disorders (ASD) during venipuncture in comparison with the reactions of 32 children with an intellectual disability and 36 non-impaired control children. The children were videotaped during venipuncture and their heart rate was recorded. Facial reactions were assessed using the Child Facial Coding System and behavioural reactions were scored using the Noncommunicating Children's Pain Checklist. Children's reactions increased between baseline and venipuncture and decreased between the end of venipuncture and the recovery period. While there was no significant difference between groups regarding the amount of facial, behavioural and physiological reactions, behavioural reactions seemed to remain high in children with ASD after the end of the venipuncture, but not in the other groups. Pain expression decreased significantly with age in non-impaired children, whereas no such effect was seen among children with ASD.

Comment: A neat design to test a tricky question – pain perception in children with impairment (developmental delay or autistic spectrum disorders) compared to healthy children. Of course, findings beg the question as to how best to support children with impairment who have pain (and their family/whanau and the professionals working with such children in pain situations). The paper stimulated me to look a bit wider in the literature and despite there being some interesting research on this – there wasn't much... An important area for investment perhaps.

Reference: *Pain* 2013;154(10):2007-13

[http://www.painjournalonline.com/article/S0304-3959\(13\)00317-5/abstract](http://www.painjournalonline.com/article/S0304-3959(13)00317-5/abstract)

The citizen patient: reforming health care for the sake of the patient, not the system

Author: Hadler NM

Summary: This book takes a critical view of how medical treatment, health care finance, and attitudes about health, medicine, and disease play out in broad social and political settings. The author describes a vision of a new, shared understanding of the primacy of the relationship between doctor and patient – essential for improving the health of the populace. He argues that rational health care is far less expensive than the irrationality of the status quo.

Comment: Many people in NZ will know of Nortin Hadler for his work on back pain and the debunking of myths associated with OOS/RSI and a number of other 3-letter acronyms of the 1990s. Nortin has written a series of books for the lay public (I am currently reading 'Rethinking Ageing' and it's a fascinating read with a thought-provoking synthesis of research evidence on treatment, survival and quality of life). This is his new book and whilst US-oriented, it has some interesting observations on how we harness the potential of our patients, and indeed of ourselves as professionals. He writes mainly about 'doctor-patient' factors but many of the points are relevant it seems to me to other health professionals.

Reference: *The University of North Carolina Press. Published: April 2013.*

http://uncpress.unc.edu/browse/book_detail?title_id=3262

Empowering patients who have specific learning disabilities

Authors: Rossignol LN et al.

Summary: This US-based Viewpoint discusses ways in which clinicians can respond when a child or adult with a learning disability or cognitive impairment seeks care. It describes how Individual Education Program (IEP) plans might be used to address the different types of disabilities that can influence patient education and how IEP plans can be integrated into clinical practice. The paper discusses aspects that help to create a supportive learning environment.

Comment: In a way this is related to the Australian work mentioned in this issue (Knox et al.), and the work by Hadler (although that was at a more macro level and not specifically relating to people with intellectual difficulty). I was delighted to see this paper for a number of reasons. Firstly – it's in JAMA and to see mainstream medicine discussing such issues is very exciting indeed. Secondly – it suggests that structural supports from education and educationalists (in this case the Individual Education Plans) might be helpful for healthcare (the caveat being they need to be accurate). Healthcare has been slow to take on board lessons from education even though much of rehabilitation is about 'learning'. Lastly – the authors note that clinicians can (and arguably should) ask people with intellectual impairment the best way for them to be given and act on information. The elephant often stated in the room is that 'this all will take too long' but the opportunity cost of not setting things up this way might be that everything else is null and void. That's not good for anyone.

Reference: *JAMA* 2013;310(14):1445-6

<http://jama.jamanetwork.com/article.aspx?articleid=1740740>

Improving the interface between informal carers and formal health and social services: a qualitative study

Authors: McPherson KM et al.

Summary: This study was conducted in the community setting and included urban and rural areas of New Zealand. It set out to explore the connection between informal and formal carers and identify how a positive connection or interface might be developed and maintained. The 70 participants (informal carers, formal care service providers and representatives from carer advocacy groups) participated in 13 focus groups and 22 individual interviews. Content analysis identified four key themes: Quality of care for the care recipient; Knowledge exchange (valuing carer perspectives); One size does not fit all (creating flexible services); and A constant struggle (reducing the burden that services impose). The paper proposes an optimum interface to address these key areas.

Comment: I rarely include a paper by our own team in RRR and even more rarely do I include a paper if I am the first author, to avoid a sense that I am pushing my own agenda (although I guess I am doing that no matter whose papers I refer to!). Anyway – I mention this one because I have been grappling with how we might better support informal carers in their important role. The big issue from our data was that we – services and professionals – make it worse for many people. The big solution? Well, we don't claim to have that but maybe a small solution for starters: to truly, actively listen to what carers have to say; to acknowledge they have expertise to bring to the table. Having recently become lead carer for an elderly relative, I have experienced at firsthand how when this happens; it is an incredible relief amidst the many difficulties that one faces. It doesn't take much – but it does matter.

Reference: *Int J Nurs Stud* 2013 Aug 5. [Epub ahead of print]

[http://www.journalofnursingstudies.com/article/S0020-7489\(13\)00220-4/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(13)00220-4/abstract)

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