

Rehabilitation Research Review

Making Education Easy

Issue 14 – 2010

In this issue:

- *Rehabilitation and the Māori experience*
- *Does objectivity mean good science*
- *Models of rehabilitation*
- *Experience of recovery and outcome post-TBI*
- *The productive partnerships framework*
- *SCIRehab conceptual model*
- *Vocational integration in severe mental illnesses*
- *Value for money*
- *Evaluating the quality of medical care*

Welcome to the fourteenth issue of Rehabilitation Research Review.

May 2010 saw a special issue of *Disability and Rehabilitation* (Outcomes in Rehabilitation: values, methodologies and applications) published. Each of those papers seems particularly relevant to RRR readership and so – here is a corresponding special issue of RRR! Only some of the papers are referred to here because of space, so if the range of topics interests you, it may be one issue to have a browse through in your local hospital/university library. Thanks to the many people (including colleagues from around New Zealand) who collaborated on the special issue forum back in July. I hope you enjoy this issue of Rehabilitation Research Review and I welcome your comments and feedback.

Kind regards,

Kath McPherson

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Rehabilitation and indigenous peoples: the Māori experience

Authors: Harwood M

Summary: This paper discusses existing health inequities and rehabilitation outcomes as experienced by Māori, the indigenous peoples of New Zealand. A comprehensive rehabilitation strategy is proposed to address disparities and achieve the aspirations of Māori, so that they may live the promise of a healthy nation.

Comment: The fact that there are disparities between Māori and Pakeha in health is not new information, albeit it is disappointing and – unacceptable – that this continues. Matire Harwood's paper is not a reiteration of these disparities; rather it is a challenge for all involved in rehabilitation provision regarding what we think is a good outcome and how that fits (or doesn't) with He Korowai Oranga (the Māori Health Strategy) and other recent research about what matters most for Māori. I enjoyed this paper, was challenged by it and, suspect I will refer to it many times over the coming months.

Reference: *Disabil Rehabil.* 2010;32(12):972-7.

<http://informahealthcare.com/doi/abs/10.3109/09638281003775378>

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Measuring what matters: does 'objectivity' mean good science?

Authors: Kayes NM, McPherson KM

Summary: These researchers (ah . . . including me) argue that we need both 'objective' measures and subjective rating scales in rehabilitation research and practice. Preferring objectivity is inappropriate and misguided, they say, as it ignores the truth that there are scientific limits to objective measures and that they may be subject to flaws, similarly to self-report measures. They argue that instead of focusing on objectivity, we should discern whether or not a measure is fit for purpose and makes mathematical sense. In some cases, it may be that we will only *truly* capture the phenomenon of interest by including both an 'objective' measure and a subjective rating scale. After all, they are likely both measuring important, albeit distinct, aspects of a construct, the paper's authors surmise.

Comment: This paper provides data (i.e. more data!) challenging the value of simplistic answers when it comes to considering and evaluating outcome in rehabilitation, which is frequently – by definition – complex. The continued relative weight that seems attached to 'objective' measurement data compared with so-called 'subjective measures' (largely self-report questionnaires) is intriguing, given the rhetoric in most quarters about the importance of patient perspectives. Although I hate to say 'read the paper' . . .

Reference: *Disabil Rehabil.* 2010;32(12):1011-9.

<http://tinyurl.com/2u6bbyr>

Models of rehabilitation – commonalities of interventions that work and of those that do not

Authors: Cameron ID

Summary: This paper reviews models of rehabilitation and considers factors that influence a model's effectiveness or ineffectiveness. It argues that the effectiveness depends on how any particular model is interpreted by a person with disability. Those models that are more likely to work and are more likely to be accepted by the people involved are those rehabilitation models that use a complex intervention paradigm, with rehabilitation operating at the level of activity and participation, as defined by the WHO International Classification of Functioning, Disability and Health. The paper posits that we have yet to define what works in rehabilitation and also detect the crucial components that influence effectiveness.

Comment: There were a number of things I liked about this paper (again it is dealing with complexity as to whether things do/don't work *or* whether research has just failed to be definitive). In addition to this paper though, it highlighted another discussing the update to the MRC's framework for evaluating complex interventions. One of the authors of that paper (Paul Dieppe) has a background in rehabilitation so perhaps it is not surprising that both papers (the latter is freely available at BMJ@sphsu.mrc.ac.uk) hit the spot if you are trying to work out just what works – and more importantly – why.

Reference: *Disabil Rehabil.* 2010;32(12):1051-8.

<http://informahealthcare.com/doi/abs/10.3109/09638281003672377>

Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research

Authors: Levack WMM et al

Summary: This investigation into the lived experience of recovery following traumatic brain injury (TBI) acquired during adulthood used qualitative metasynthesis to interpret data from 23 studies published between 1965 and June 2009. The authors identified eight inter-related themes describing the enduring experience of TBI: 1) mind/body disconnect; 2) disconnect with pre-injury identity; 3) social disconnect; 4) emotional sequelae; 5) internal and external resources; 6) reconstruction of self-identity; 7) reconstruction of a place in the world; and 8) reconstruction of personhood. The paper concludes that outcome measures exist for some but not all of the issues identified in qualitative research on surviving TBI. They suggest that new outcome measures may be required to evaluate experiences of loss of personal identity, satisfaction with reconstructed identity, and sense of connection with one's body and one's life following TBI.

Comment: Whilst you may feel faint at the mention of the word 'metasynthesis' – don't! It is (sort of) the qualitative version of meta-analysis – where multiple studies investigating the same issue are integrated and interpreted. There are many novel features to this paper, far too many to go into here – but findings include pointing to the fact that there are now many hundreds of qualitative papers about the experience of living life post-TBI and many of those indicate a major concern to this population is the ongoing challenge it brings to one's sense of self, who you/we are. This raises the spectre of not only a possible core component to consider in rehabilitation interventions (if they are to get at what matters most), but also how we might evaluate success. 'Watch this space' for more on this topic over the coming months.

Reference: *Disabil Rehabil.* 2010;32(12):986-99.

<http://informahealthcare.com/doi/abs/10.3109/09638281003775394>

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The productive partnerships framework: harnessing health consumer knowledge and autonomy to create and predict successful rehabilitation outcomes

Authors: Verkaaik J et al

Summary: This paper examines the role of power distribution in partnerships between health consumers and professionals in determining successful desired outcomes, and the contributing role of consumer knowledge and autonomy. The researchers contend that we currently lack practical tools that could be used to facilitate consumer and professional perspectives and help create productive partnerships. They propose prototype tools that can be shared between health consumer and professional, enabling them to identify the strength of their cumulative power and giving them a choice of power contexts for the partnership to operate within, and a simple method for testing alignment to a common goal. The paper argues that through this approach, it is possible to establish robust working relationships between health professionals and consumers.

Comment: One of the nice things about putting together a special issue of a journal is that you can do things slightly differently and as a result, one gets papers like this one. It is an idea. It is an attempt to operationalise integration of consumer knowledge into the health/consumer partnerships. Evidence of its utility and effectiveness? Not yet, but – it's an idea shared for thinking about how to do what we all talk about doing.

Reference: *Disabil Rehabil.* 2010;32(12):978-85.

<http://informahealthcare.com/doi/abs/10.3109/09638281003775386>

SCIRehab: a model for rehabilitation research using comprehensive person, process and outcome data

Authors: Whiteneck G, Gassaway J

Summary: These researchers present a comprehensive conceptual model of the SCIRehab project, which merges the International Classification of Functioning, Disability, and Health (ICF) focus on outcomes with the Practice-Based Evidence (PBE) research design, which focuses on process and also quantifies person and outcomes details. The paper discusses the SCIRehab methodology, its implementation of the most data-intensive study of spinal cord injury to date, and how this comprehensive research approach may complement RCTs in rehabilitation research.

Comment: When the co-editor of the D&R special issue (Will Taylor) commented on this paper in a meeting recently, his words were *'This paper may be one of the most important papers about spinal cord injury rehabilitation in many years'*. I think he is probably right. The methodology is innovative (I first read of it in the work of Gerben Dejong about stroke in *Archives of Physical Medicine and Rehabilitation Volume 86, Issue 12, Supplement, Pages 1-126 2005*) and offers an alternative to where the randomised clinical trial may not be appropriate. There are big issues in doing PBE (it needs collaboration across multiple centres), but maybe we could prioritise some of the key questions for NZ where other research designs let us down and work together to find some useful answers.

Reference: *Disabil Rehabil.* 2010;32(12):1035-42.

<http://informahealthcare.com/doi/abs/10.3109/09638281003775584>

Outcome, recovery and return to work in severe mental illnesses

Authors: Pachoud B et al

Summary: Recently, the focus in psychiatry has shifted from a traditional medical notion of "disease outcome" to a wider perspective that incorporates "functional outcome", the fate of the person and its determinants. Recovery, rather than cure or remission, is regarded as the good outcome, with its own underlying factors. This paper acknowledges that return to work, as a vocational outcome, represents in research one of the good functional outcomes. Return to work is generally regarded to be a sign of social recovery, with the disease sufficiently under control as to allow the person to resume 'normal life'. Nevertheless, the paper's authors consider that the first goal of recovery remains what makes sense for each person. While several theoretical and empirical arguments look upon work as a privileged way toward recovery, it is not the only way, the paper concludes.

Comment: This topic is hugely important just now... The Australian College of Physicians has just released a position statement titled Realising the Health Benefits of Work and our Minister of Social Development has just called together a Welfare Working Group to examine ways forward in the face of the rising numbers of long-term beneficiaries (including people on a long-term sickness and disability benefit). Pachoud and colleagues capture what seems the enormous potential for work to be 'therapeutic' but at the same time, reflect on the wide-ranging and very 'human' issues that consideration of work for people with complex needs entails.

Reference: *Disabil Rehabil.* 2010;32(12):1043-50.

<http://tinyurl.com/32k2t6q>



Independent commentary by Professor Kath McPherson, Professor of Rehabilitation (Laura Fergusson Chair) at the Health and Rehabilitation Research Centre, AUT University in Auckland.

Kath has been at AUT since 2004 and has been building a research, teaching and consultancy programme focused on improving interventions and outcomes for people experiencing disability.

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Value for money – recasting the problem in terms of dynamic access prioritisation

Authors: Taylor WJ, Laking G

Summary: These researchers propose a system that is ethically just in the context of allocation of scarce health care resources; an approach that achieves value for money in rehabilitation based on dynamic prioritisation of access to services according to individual capacity to benefit. They argue that using this approach will lead to greater transparency in the decision making around access to inpatient rehabilitation services.

Comment: None of us really like to think that choices have to be made about who gets what treatment (other than based on need) but ... the truth is that choices and prioritisation are a daily occurrence – sometimes implicit, sometimes veiled in language that belies what is really going on such as plateau (see *Demain et al Disabil Rehabil. 2006 Jul 15-30;28(13-14):815-21*). Taylor and Laking explore an approach to thinking about this that would make the decisions explicit and based upon joint decision making. Whilst this is a novel approach, and still needs lots of ironing of wrinkles and testing, it is a useful reminder that how we utilise our limited resources is getting more and more important.

Reference: *Disabil Rehabil. 2010;32(12):1020-7.*

<http://tinyurl.com/35dqv73>

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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VINTAGE PAPER

Evaluating the quality of medical care

Authors: Donabedian A

Summary: This paper evaluates the medical care process at the level of physician-patient interaction. It discusses approaches to the assessment of medical care: it advises using discrimination when employing outcomes as criteria of medical care, as they do not allow an insight into the nature and location of the deficiencies or strengths to which the outcome might be attributed. Secondly, the paper advises that one must examine the process of care itself rather than its outcomes; whether “good” medical care has been applied. Thirdly, the paper notes that we should study the settings in which care takes place and the instrumentalities of which it is the product. The paper goes into a comprehensive discussion of the various sources and methods of obtaining information (clinical records, direct observation of the physician’s activities, ratings and rankings that estimate the quality of care), sampling and selection, measurement of quality standards and measurement scales, the reliability of assessments, bias and validity. Issues and concerns are discussed as to the traditional indices concerning the quality of medical care. The paper concludes that the process of evaluation itself needs further study. Suggestions are proposed that are intended to help us better understand the medical care process itself, as opposed to being preoccupied with evaluating quality. We should be asking what is going on, rather than trying to determine what is wrong and how it can be improved. We will then recognise and maintain the necessary distinction between values, and elements of structure, process or outcome, says Donabedian.

Comment: Having produced a series of papers about outcome it feels only reasonable that one of the most influential papers about the topic be referred to as the vintage paper. Alvedis Donabedian is a name I think any student I have ever worked with has heard. He was the father of modern approaches to ‘quality’ and proposed (very usefully) that any healthcare episode was made of three components: structures (the *service hardware* like staff, staffing mix, documentation, etc); processes (the things we do, the ways of working like goal setting, communication, other interventions or ways of working with patients and clients); and outcomes (the end result of any health care episode). He proposed they were linked and that failure to see them as linked was responsible for a failure to improve quality. Not a bad thing to be reminded of.

Reference: *Milbank Mem Fund Q. 1966 Jul;44(3):Suppl:166-206.*

<http://www.jstor.org/pss/3348969>

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