Research for Rehabilitation and Resilience Person-Centred Rehabilitation A Learning & Development Package for Rehabilitation Teams Delena Amsters, Ray Quinn, Melissa Kendall, Sarita Schuurs Division of Rehabilitation, Metro South Health



Person-centred rehabilitation (PCR) means treating each service user undergoing rehabilitation as an individual.
 There is a strong and committed drive to provide this type of rehabilitation both nationally and internationally.
 To help rehabilitation teams improve their ability to deliver person-centred rehabilitation a training package was developed.

Package Objectives

Package Outline

- Create a shared understanding of PCR in your service context.
- 2. Gain awareness of tools to grow PCR in your service context.
- 3. Consider how to assess PCR in your service context.
- 4. Ideas for sustaining PCR in your service context.

Four sessions of 45 minutes | Short exercises during sessions | Homework Session 1. Understanding PCR Session 2. Critical reflection and PCR Session 3. Empowerment | Shared decision making | Dealing with difference Session 4. Evaluating & sustaining PCR

The package is designed to be undertaken in teams.
The sessions will be delivered by a trained facilitator.
Some examples of package content appear below.

Exercise: Personhood profile

Take five minutes to think about a current client. From your knowledge of the client write one sentence about each of these influences on them as a person. Leave any blank that you don't know about. Emotional disposition Spirituality Psychological status Life experience Family situation Culture History Self concept Relationships Perceived future

Discussion: Personhood profile

1. Was this a challenging task?

- 2. How did you find out these things about your client? Is it part of initial assessment? Does it emerge over time? Is it implicit or explicit?
- 3. Are there gaps in your knowledge about the client?
- 4. How comfortable would you be to ask questions of your client

How to reflect critically

Move beyond superficial Established model versus individualised approaches Individual and group approaches

A model of critical reflection to start you off (Based on Johns 1994)

1. Tell

2. Reflect

- 3. Contextualise
- 4. Assess
- 5. Resolve

Dealing with difference

PCR <u>does not</u> require people to agree with each other. It <u>does</u> require practitioners to try to understand client perspectives, what matters to them, and how their views have been formed.

Dealing with difference – tips (1)

Rather than **telling** a client what treatment or intervention you believe to be best, **explain** to them **why** you believe it to be best. Explain your view as a person rather than a professional.

Put a <u>reflexive lens</u> on the situation – What are the factors underpinning your views? Are they driven by rock solid clinical evidence or are they influenced by your values and beliefs?

ABIOS



Key Sources:

Cott, C., 2004. Client-centred rehabilitation: client perspectives. Disabil. Rehabil. 26, 1411–1422.

Elwyn, G., Frosch, D.L., Kobrin, S., 2016. Implementing shared decision-making: consider all the consequences. Implement. Sci. IS 11, 114.

Hewitt-Taylor, J., 2015. Developing person-centred practice: a practical approach to quality healthcare. Macmillan Education/Palgrave, London.

Johns, C., 1994. Nuances of reflection. J. Clin. Nurs. 3, 71–75.

O'Toole, G., 2017. Communication: core interpersonal skills for health professionals. Elsevier Health Sciences, Chatswood.

Development of this package was supported by The Hopkins Centre.



Rehabilitatio

Research for Rehabilitation and Resilience

Introduction

With an ageing population and improving acute care, increasing numbers of Australians are surviving stroke¹. However, b 87% of stroke survivors face limitations to their activities of daily living², and over 30% are under 65 years of age³, and potentially face decades living with the effects of their stroke.

Self-management skills after stroke: What is the role of the hospital stroke team? Kylie Bower & Carly Gomura Princess Alexandra Hospital Adjunct Research Fellows, Griffith University

Purpose

A program of research is planned to explore how self-management is conceptualised in a hospital service, which elements are currently evident, and whether there is value or feasibility in incorporating any other aspects of self-management. The links between these self-management components and those existing in community services will also be considered.





Planned studies

Acute

Rehab

Day

Hospital

MDT

interviews

MDT

interviews

Study one: staff perspectives across hospital stroke services

To help stroke survivors navigate life after stroke, Stroke Guidelines recommend the use of generic or stroke-specific selfmanagement programs in the community⁴. However, there is currently little literature exploring the impact of incorporating aspects of self-management into hospital services. Recent research recommends that: 'Research is required to explore a new model of stroke self management which is integrated across secondary, primary and community care and adopts a whole systems approach.' (Parke et al 2015, p 20)

Methods

A descriptive, qualitative design will be used across 2 studies.

Purposive sampling will be used to recruit staff (study 1), stroke survivors and carers (study 2) across three hospital stroke programs at the Princess Alexandra Hospital: the acute stroke unit, geriatric and rehabilitation unit, and the day hospital service.

Semi-structured focus groups and interviews will explore elements of selfmanagement represented in figure 1. Interviews will be recorded, transcribed and thematic analysis will be used to identify key themes.

How do / could you impart this?

What is self-management?

How do / could you impart this?

What is self-management?

What is self-management? MDT interviews How do / could you impart this?

Study two: patient / carer perspectives across hospital stroke services

> Reflections on self-management interventions in the acute service.

 Reflections on self-management interventions in acute and inpatient rehabilitation services.

Reflections on self-management interventions in acute, rehabilitation and day hospital services.

Reflections on self-management interventions across hospital and community experiences.

Progress

Partnership developed with Griffith

University School of Occupational Therapy.

Ethics application commenced for study

Medical self management

e.g. adherence to medication

behaviours

Emotional self management behaviours We expect to better understand how hospital stroke services contribute to a stroke survivor's self-management journey.

Expected Results

We also hope to identify whether any changes to the hospital stroke services could optimise self-management outcomes for stroke survivors.

(Parke et al, 2015) Acquisition of core self-management skills **Provision of**

Figure 1: Model of self-management to be explored in study 1 and 2

effective selfmanagement support

Problem solving Decision making Resource utilisation 3. Forming a patient/professional relationship 4. Taking action 5.

Enactment of skills mediated by self-efficacy

e.g. managing depression

Role self management behaviours

e.g. adopting new, realistic hobbies

Feedback from behaviours can modify feelings of self-efficacy and skill utilisation

Literature Cited

- 1. Australian Institue of Health and Welfare. (2013). Stroke and its management in Australia: An update.
- 2. Stroke Foundation. (2016). *National Stoke Audit*, Rehabilitation Services Report.
- 3. Deloite Access Economics. (2013). The Economic Impact of Stroke in Australia.
- 4. Stroke Foundation. (2017). *Guidelines for stroke management 2017*.
- 5. Parke, H., Epiphaniou, E., Pearce, G., Taylor, S., Sheikh, A., Griffiths, C., Pinnock, H. (2015). Selfmanagement support interventions for stroke survivors: A systematic meta-review. PLoS ONE, 10(7).

Acknowledgement

We wish to acknowledge the contributions of Ms Amelia Greenway (honours student), Professor Louise Gustafsson, and Ms Kim Walder (Lecturer) of the Occupational Therapy Department, Griffith University, in the commencement of study one.

The Workplace factors that contribute to nurses' wellbeing in tertiary mental health care: Hopkins A scoping review Centre Carolyn Ehrlich, Emma Haggvist, Kate Knudsen The Hopkins Centre and Mid Sweden University Research for Rehabilitation and Resilience

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Introduction

Responsive, integrated, safe and effective (i.e., quality) care depends on individual nurses' professional practice together with the practice environment (Stallings-Welden & Shirey, 2015).

A sense of personal wellbeing, shared decision-making, leadership, safety, quality and professional development are six service standards that support quality nursing care (Dans, Pabico, Tate & Hume, 2017).

Wellbeing has been linked with job satisfaction, personal assessment of own health, and measures of work engagement. Nurses' wellbeing was identified by mental health nurses as a priority area for action within tertiary services.

Research Question

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What workplace factors contribute to nurses' wellbeing in tertiary mental health care?

Method

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Scoping review as per Arksey and O'Malley (2005) and as refined by Colquhoun, Levac et al (2014).



References

al journal of social re ology, 8(1), 19-32 Colquhoun, H. L., Levac, D., O'Brien, K. K., Straus, S., Tricco, A. C., Perrier, L., ... & Moher, D. (2014). Scoping reviews: time for clarity in definition, methods, and reporting. Journal of clinical epidemiology, 67(12), 1291-1294.

Dans, M., Pabico, C., Tate, M., & Hume, L. (2017). Understanding the New Pathway to Excellence® Standards. Nurse Leader, 15(1), 49-52.

Stallings-Welden, L. M., & Shirey, M. R. (2015). Predictability of a professional practice model to affect nurse and patient outcomes. Nursing administration guardenty, 39(3), 190-210

N = 2572 1 306 records excluded due to: non English language, books, book section, thesis, dissertation abstract, dissertation, book review, film review, editorial, published before 1998 N = 1054 included ∇ 7 706 records excluded due to: study population (consumers, n rs nursing students other health professionals or unclear study population), incomparable cultural context (i.e. non-Western), MHN N = 748 included role or prescriptive power, description of non-organisational influences on wellbeing, individual narratives, papers with no study component, literature 30 records excluded due to: fter title and abstract N = 42 included ame criteria as listed abov N = 252 N = 12 includer 225 records excluded due to same criteria as listed above

Figure 2: syste matic selection of studies for inclusion

Results

N = 39 included in qualitative synthesis

cords afte

Structuring care provision:

Mental health nurses working in acute care environments appear more stressed than nurses working in other contexts. The way that care is organised within the system creates more or less possibilities for healthy and sustainable workplaces that do or do not support nurses' wellbeing.

articles as

N = 27 included

ed for eligibilit

Practice environment

Five factors in the practice environment that influence nurses wellbeing were identified: (1) Scope and clarity of nurses' roles; (2) Managerial leadership style; (3) Communication and appropriate flow of information; (4) Working conditions (staffing, pay, work hours, regulations, administration and opportunities for career advancement); and (5) Interdisciplinary relationships (i.e., strength of relationship, level of conflict, efficacy of teamwork).

Caring work

Identified factors that influence wellbeing and are associated with nurses' care work include: (1) Patient characteristics; (2) Occupational violence; (3) Workload; and (4) Social support.

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Discussion/Conclusion

Managerial support is key for optimising wellbeing outcomes of nurses. A transformational leadership style is encouraged.

A sense of being supported is important for nurses within organisational and direct care contexts. Appropriate personal and social support that extends beyond organisational and care contexts is necessary. Therefore, nurses need easy access to multiple support systems if their wellbeing is to be optimised.

The Hopkins Centre Research for Rehabilitation and Resilience

CONSUMER ENGAGEMENT IN HEALTH SERVICES ACROSS QUEENSLAND

What roles doWhat impactconsumers anddoes Health Consumerscarers currentlyQueensland (HCQ) havehave in healthon consumer engagementservices?in Queensland?

WHAT DID PEOPLE TELL US ABOUT THEIR INTERACTIONS WITH HCQ?



WHO DID WE GET FEEDBACK FROM?

via interview



WHO ARE THE CONSUMER & CARER REPRESENTATIVES?

"HCQ have made an enormous impact"

WHAT DID PEOPLE TELL US ABOUT THE IMPACT OF HCQ?





Interesting result

Attending networking sessions and webinars was perceived to be most useful by people who were from an Aboriginal and Torres Strait or culturally and linguistically diverse background

"HCQ helps me to connect a lot of dots"

The more that HCQ helped individuals prepare for their role, the more likely they were to report higher levels of selfefficacy in their role.

"HCQ have been really instrumental"



Requests for HCQ services: HCQ staff reported increasing requests for their services.

Value for consumer engagement: Consumers reported feeling valued and validated by health service organisations.

Type of consumer engagement: Consumer engagement occurred on a continuum from simple passive activities to more meaningful and influential activities.

Renumeration of consumers and carers: is inconsistent and contested. A statewide policy for renumeration is required.

Depth of consumer engagement: Some qualitative evidence suggested that there were positive shifts in knowledge and use of consumer engagement in health services.

Accessibility of consumer engagement: Qualitative evidence showed that remuneration of consumer and carer representatives was one policy area that was inconsistent and contested.

Embedded consumer engagement: There was no consistent evidence to conclude that authentic consumer engagement was embedded in the health service system as standard practice.

Assoc. Professor Carolyn Ehrlich, Dr Maddy Slattery, Ms Kelsey Chapman and Prof. Elizabeth Kendall HCQ = Health Consumers Queensland



Integrating an Evidence-based Clinical Exercise Physiology Service Model into a Comprehensive Multiprofessional Rehabilitation Service for People with Brain Impairment: An Integrated Knowledge Translation Approach.

Clanchy, K., Tweedy, S., Kennedy, A., Jeffrey, S., Gainforth, H.

Introduction

Research for

Rehabilitation and Resilience

Investment in healthcare research continually produces significant breakthroughs for methods of treatment and care which can yield significant benefits for patients, financial value gains and returns on investment [1]. There are significant barriers to translating evidence into

clinical practice including differences in the implementatio environments, time and resource limitations of practitioners, insufficient training, lack of feedback and incentives for use of evidence-based practices, and limite organisation infrastructure to support translation [2].

Integrated Knowledge Translation (IKT) is a theory informed approach for knowledge translation that is characterised by the ongoing and collaborative involvement of stakeholders and the tailoring of knowledge to the needs of the individuals and organisations who will be implementing it [3, 4].

Purpose

The Acquired Brain Injury Transitional Rehabilitation Service (ABI-TRS) is currently developing its clinical Exercise Physiology service arm which requires the integration of current evidence regarding physical activity promotion in adults with an acquired brain injury in order to facilitate a best-practice model. The Adapted Physical Activity Program (APAP) is a physical activity promotion intervention that has been demonstrated to increase physical activity adoption in adults with brain impairment [5].

The aim of this project is to use an IKT approach to increase the prospects of successfully translating the APAP into ABI-TRS.

Methods

IKT has two components: 1) knowledge creation which includes the evaluation of an innovative idea and the synthesis of research findings into useable tools/ products; and 2) action cycle including adaptation to the local context and assessing barriers and facilitators related to knowledge adoption. This information is used to develop a plan for the translation of knowledge into clinical practice [3]. The application of the IKT framework for the development of a plan for the translation of the APAP into ABI-TRS is presented in Figure 1.

	Establishment of the Adented D	hysical Activity Translation Crown
Γ	Establishment of the Adapted P	
	Step 1a Refinement of the APAP	Step 1b Understanding the ABI-TRS Context
	γγ	
	The information gained from Step 1a and Step 1b will and facilitate the intervention workshop (Step 2b). Preli plan will also be undertaken at this point.	e used to adapt the APAP to the local context (Step minary work regarding the development of a translat
	Step 2a Adaptation of the APAP to the ABI- TRS Context	
	Step 2a Delivery of Intervention Workshop	Step 2b Focus Group with ABI-TRS Sta
	context and progress the development of the translation Step 2c Continued Adaptation of	further adapt the APAP for delivery in the ABI-TRS n plan. the APAP to the ABI-TRS Context
	context and progress the development of the translation Step 2c Continued Adaptation of Step 2d Design of an Integrated and 0	further adapt the APAP for delivery in the ABI-TRS n plan. the APAP to the ABI-TRS Context Collaborative Framework for Translation
,	context and progress the development of the translation Step 2c Continued Adaptation of Step 2d Design of an Integrated and 0 Step 2e Design of an integrated Protocol for th ABI	further adapt the APAP for delivery in the ABI-TRS n plan. the APAP to the ABI-TRS Context Collaborative Framework for Translation e Evaluation of the Translation of the APAP in -TRS
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	context and progress the development of the translation Step 2c Continued Adaptation of Step 2d Design of an Integrated and Q Step 2e Design of an integrated Protocol for th ABI The outcomes of processes undertaken in Step 2c, 2c workshop and evaluated through the use of a focus g Step 2f Implementation Workshop	further adapt the APAP for delivery in the ABI-TRS n plan. the APAP to the ABI-TRS Context Collaborative Framework for Translation the Evaluation of the Translation of the APAP in -TRS d and 2e will be presented in an implementation roup. Step 2g Focus Group with ABI-TRS Stakeholders and Clients
	context and progress the development of the translation Step 2c Continued Adaptation of Step 2d Design of an Integrated and C Step 2e Design of an integrated Protocol for th ABI The outcomes of processes undertaken in Step 2c, 2c workshop and evaluated through the use of a focus g Step 2f Implementation Workshop The outcomes of processes undertaken in Step 2g will implementation.	further adapt the APAP for delivery in the ABI-TRS n plan. the APAP to the ABI-TRS Context Collaborative Framework for Translation e Evaluation of the Translation of the APAP in -TRS d and 2e will be presented in an implementation roup. Step 2g Focus Group with ABI-TRS Stakeholders and Clients be used to finalise the proposed translation plan for

including: the willingness of stakeholders from multiple settings to adopt the APAP; the perceived fit of the APAP into ABI-TRS; and the ability of ABI-TRS staff to implement key components of the intervention in routine clinical practice [2]. This translation plan will be implemented in January 2019

The effectiveness of the translation of APAP into ABI-TRS will be evaluated using the RE-AIM (<u>Reach, Efficacy, A</u>doption, <u>I</u>mplementation and <u>M</u>aintenance) Framework [6].

Literature Cited

- 1. Kristensen et al BMC Health Services Research, 2016. 16(48): p. 1-10.
- 2. Glasgow et al American Journal of Public Health, 2003. 93(8): p. 1261-1267.
- 3. Gagliardi et al Implementation Science, 2016. 11: p. 38-50.
- 4. Field et al Implementation Science, 2014. 9(172): p. 1-14.
- 5. Clanchy et al Neurorehabilitation and Neural Repair 30(9): 854-865.
- 6. Dzewaltowski et al Annals of Behavioural Medicine, 2004. 28(2): p. 75-80.

Disclosure

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Integrating technology into a new acquired brain injury rehabilitation service

- Gisela Brittain¹, Elizabeth Beadle¹, Elizabeth Spitzer¹, Areti Kennedy^{1,2}
- - The Hopkins Centre, Division of Rehabilitation & Griffith University, Brisbane, Australia

Introduction

Method



The ABI TRS aimed to implement evidence-based technology to enhance rehabilitation for clients with ABI into a new community transitional rehabilitation service.

delivery, including telehealth, tablets and smartphones; and (ii) utilizing technology-enabled therapy, including web-based interventions and social media platforms.

The Acquired Brain Injury Transitional Rehabilitation

provides interdisciplinary community rehabilitation for

Service (ABI TRS) commenced in Brisbane in 2017 and

Clinician skill, knowledge and experience of use of technology was also explored

Results

clients with a brain injury.

Identified area of need: Recent systematic reviews^{1,2} identified several benefits of technology-based rehabilitation including; 1. Intensity: clinicians can provide patients with a greater intensity of sessions; 2. Client-centred treatment: Technology allows the clinician to tailor the tasks to clients impairments and goals for a more personalized rehabilitation program³; 3. Improved rehabilitation outcomes: studies have shown various degrees of improvement and greater independence for clients with cognitive¹ and communication^{2,3} impairments .

Clinician skill, knowledge & experience: Team survey revealed that clinicians had skill and knowledge of technology usage, however lacked experience of using technology in a community rehabilitation setting. To address this barrier, clinical processes, training and education were provided and technology items have been successfully embedded within the community rehabilitation program.

TRS team consultation: Through ABI TRS service review, along with the results of the literature review, a need for internet usage in home and smart devices for therapeutic use was identified. Three iPads (2 with data) were purchased. Individual disciplines were consulted with regards to evidence based apps for: compensatory strategies (e.g., diary, communication aids); skill building (e.g., language therapy); education (e.g., brain information); leisure (e.g., games, music); support building (e.g., circles of support); and client safety /independence (e.g., GPS tracking; supported emergency calls). Additional dongles were purchased in order to access the internet when using laptops. Review of dongle use is underway.

Benchmarking: Community rehabilitation and inpatient services were consulted on their technology usage and resources. Community rehabilitation services reported using service laptops (each staff member) and otherwise the clients own devices, and inpatient services reported using service laptops, internet, and iPads.

In the last 12 months over 60% of ABI TRS clients have received technology based rehabilitation using service devices



Conclusion

- · Technology was successfully implemented into a new transitional rehabilitation service.
- Technology has enabled clinicians enhance client's rehabilitation through using alternative modes of treatment and providing a tailored treatment program.
- Future research is needed in to how technology is being used by the interdisciplinary team with clients (e.g., specific apps and therapy treatment targets), as well as how clients use technology to enhance their recovery and wellbeing after injury. There is also a need to review both clinician and client confidence and experience with technology use.

References

Bogdanova, Y., Yee, M. K., Ho, V. T., and Cicerone, K. D. (2016). Computerized cognitive rehabilitation of attention and executive function in acquired brain injury: a systematic review. J. Head Trauma Rehabilitation. 31, 419–433.
 Brunner M, Hemsley B, Togher L & Palmer S. Technology and its role in rehabilitation for people with cognitive-communication disability following a traumatic brain injury. Brain Inj. 2017;31(8):1028–43.
 Des Roches CA and Kiran S (2017) Technology-Based Rehabilitation to mprove Communication after Acquired Brain Injury. Frontier in Neurosciences. 11:382.
 Gartland, D (2004) Considerations in the selection and use of technology with people who have cognitive deficits following acquired brain injury. Neuropsychological rehabilitation. 14, 61-75
 Cicerone, K. D., Langenbahn, D. M., Braden, C., Malec, J. F., Kalmar, K., Fraas, M., & Ashman, T. (2011). Evidence-based cognitive rehabilitation: Updated review of the literature from 2003 through 2008. Archives of Physical Medicine and Rehabilitation. 92(4), 519–530.
 Agency for Clinical Innovation, NSW Health. (2013). Understanding the process to develop a Model of Care: An ACI Framework. www.aci.health.nsw.gov.au/__data/assets/pdf_file/0009/181935/HS13-034_Framework-DevelopMoC_D7.pdf



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Research for Rehabilitation and Resilience

Fostering self-management within an upper limb therapy group for stroke survivors and their caregivers

Carly Gomura & Kylie Bower Princess Alexandra Hospital

Introduction

Self-management is recommended in the Australian Clinical Guidelines for Stroke Management 2017. It aims to help stroke survivors adopt **strategies** to manage changes in physical and cognitive ability, relationships, and to better participate in their community. 1

Opportunities exist for self-management care planning to commence within the acute inpatient episode of care, to best prepare stroke survivors and their caregivers to manage their chronic condition for the longer-term. ^{2,3}

Purpose

Existing models outline a process for which self-management behaviours may be developed and adopted.⁴

This process requires the provision of effective therapeutic interventions to allow stroke survivors to acquire self-management skills and the self-efficacy to put these skills into practice.

Our project explored the impact of therapeutic interventions in imparting self-management skills, behaviours and self-efficacy for upper limb management post-stroke.

Methods

A stroke-specific upper limb education group in an inpatient rehabilitation setting was redesigned to target the development of self-management skills through the provision of the following interventions which are supported in the literature ^{3,4} :

Goal setting: impairment, activity and participation goals are set in collaboration with stroke survivors and their caregivers, as part of an established joint Occupational Therapy/Physiotherapy upper limb management proces

These goals are incorporated into education and exercise, and goal performance is monitored at each aroup

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Acknowledgements

wish to acknowledge the combined efforts of the PA Hospital GARU Occupational Therapy team and students for their work towards this project outcome over 2017-2018.

Active information provision: the group commences with education and discussion on a rotating list of topics, using an education resource that adopts a self-management approach. A variety of multimedia tools are incorporated, such as the EnableMe website.

te is an injury to an area of your brail stop or change: our your brain sends messages to yo o jike telling a muscle to move; and ge your brain understands message o jike understandig what somethin

Shoulder joint probl

Changes in feeling ('s

Swelling D Mussle I

Difficulty paying attention to one arr

ulty using your arm or hand

ages from your

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 like



Involving carers: caregivers are encouraged to attend the group, to develop their own knowledge-

base and to develop skills to support the stroke survivors ongoing self-management care plan.



Emotional / social focus: attendees are encouraged to share their experiences with managing their upper limb throughout their recovery. This is supplemented with a targeted

education topic addressing basic social and emotional aspects to upper limb changes after a stroke.

Evaluation of the upper limb education group was conducted via pre-post survey of participants, measuring their perceived knowledge, skills and confidence in caring for their stroke-affected upper limb

A separate cohort of stroke survivors not involved in a targeted self-management approach to upper limb recovery were also surveyed for comparison.

Literature Cited

oke Foundation. Clinical Guidelines for Stroke Management 2017. Melbourne;

Warner G, Packer T, Villeneuve M, Audulv A & Versnel J (2015) A systematic review of the effectives of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors, Disability and Rehabilitation, 37:23, 2141-2163



Participants demonstrated improved selfratings of knowledge, skill and confidence in upper limb self-management following participation in the group.

Oueensland

Government



Participants identified a continued practice of upper limb self-management behaviours following completion of the group, and the benefit of peer support and encouragement that the group provided.

"[we] continued with the forward reaching...and developed on that to enable using a wheelie walker

"group support and encouragement, doing some activities together [was helpful]"

The separate cohort of stroke survivors not involved in this group displayed high levels of perceived knowledge, skills and confidence in caring for their stroke-affected upper limb.

This outcome may represent the discrepancy between perceived and attained knowledge.

This gap has been demonstrated to lead to ineffective self-management behaviours within stroke literature. 6

	Perceived knowledge				
	no yes				
yes	They don't know they know.	They know they know.			
	They don't know they don't know.	They know they don't know.			

Conclusion

A self-management framework can be successfully incorporated into a group setting to foster self-management knowledge, skills and the efficacy to translate these into ongoing selfmanagement behaviours. A group setting provides an opportunity for peer support amongst participants, and can be an appropriate setting for consolidating selfmanagement skills.

Parke HL, Epiphaniou E, Pearce G, Taylor SJC, Sheikh A, Griffiths CJ, et al. (2015) nt Support Interventions for Stroke Survivors: A Systematic Meta-R Self-Manar PLoS ONE 10(7): e0131448 Website accessed 3/11/18: http://joh

Bower K, Gustafsson L, Hoffmann T & Barker R (2012) Self-Management of Upper Limb Recovery after Stroke: How Effectively Do Occupational Therapists and Physiotherapists Train Clients and Carers? British Journal of Occupational Therapy, 75(4) 180-187

Research for Rehabilitation and Resilience

Staff Experiences of Concerning, Complex and Challenging Behaviour in Rehabilitation Settings: Supporting Our Frontline Workforce

Karleigh Kwapil^{a,b}, Courtney Wright^b, Jacinta Colley^b, Rob Moloney^{a,b}, Carolyn Ehrlich^b, Michael Deen^{a,b}, Kate Wood^{a,b}, & Tim Geraghty^{a,b}

^aDivision of Rehabilitation, Princess Alexandra Hospital; ^bThe Hopkins Centre, Griffith University

Introduction

Adults undertaking rehabilitation for an acquired brain injury (ABI), spinal cord injury (SCI), or persistent pain (PP) condition (and their families) can experience a range of emotions and behaviours during the process of injury and adjustment, some of which may be experienced as concerning, confronting, or challenging for rehabilitation clinicians (Behaviours of Concern; BOC).

BOC have been widely examined in emergency, mental health and aged care settings [1, 2] however there is limited research regarding the type of BOC and their impact on staff working in frontline rehabilitation settings. An understanding of these issues is a necessary first step in developing local approaches for ensuring an environment in which rehabilitation professionals feel supported in working with clients and families who exhibit BOC.

Research Overview

As part of a larger program of research, a systematic review **(Study 1)** was conducted to identify and synthesise existing rehabilitation research with attention to determining the specific types of client and family BOC reported by rehabilitation clinicians and their impact.

Systematic Review Method

Four databases (Pubmed, CINAHL, Psycinfo, and Web of Science) were systematically searched for eligible studies. Studies were included in the review if they:

- Reflected original, peer-reviewed research published between 2000 and 2018;
- Described the views of in-patient and/ or community-based rehabilitation professionals working with adults with ABI, SCI, or PP conditions on one or more of the following:
- (1) Client or family BOC,

(2) The impact of client or family BOC on rehabilitation staff

19 eligible studies were included in the review.

Systematic Review Results

The majority of included studies focussed on clients with ABI (n=17), with very few studies examining BOC for SCI (n=1), PP (n=1), and families (n=4).

1) Client / family BOC for rehabilitation staff:

		_		
Behaviours of Concern	No. studies	ABI	SCI	PP
Client behaviours:				
Language / communication difficulties	7	~		
Expressed emotion (e.g., emotional lability, non-expression of emotions, grief)	6	~	~	
Aggression (e.g., physical, verbal or gestural)	5	~	~	
Cognitive impairment (e.g., lack of awareness, impaired memory/ attention / concentration)	5	~		
Non-compliance/ resistance to therapeutic approach	4	~	~	
Impulsive, erratic or disinhibited behaviours	4	~		
Denial / minimising of limitations	2	√		
Lack of motivation	2	~		
Agitation	1	√		
Absconding	1	~		
High demand on staff	1	~		
Suicidal behaviours	1	~		
Not taking feedback seriously/ making excuses for performance	1	~		
Fatigue	1	~		
Fixed ideas about injury/ rehabilitation (e.g., difficulty accepting that psychological factors influence pain experience)	1			~
Family behaviours:				
Intrusive behaviours	3	~		
Expression of grief	1	~		
Need for continual reassurance and explanation	1	~		
Verbal abuse	1	✓		
Presence of drug paraphernalia in the home	1	~		
Inappropriate behaviour	1	√		
Presence of family member triggers challenging client behaviour	1	~		
Lack of support/ involvement	1	~		

2) Impact of BOC on rehabilitation staff:

Perceived Impact	No. of studies	Examples
Emotional	9	Feelings of disappointment, frustration, helplessness, stress, anxiety, fear, overwhelm
Physical	2	Physical health risk, bruises, scratches, fractured bones, sore muscles
Loss of productivity / workforce	1	Sick leave, consider leaving / leave job

Interpretation

From the included studies (n=19):

- The majority of studies reported on BOC within the ABI setting with very few studies reporting on BOC in the SCI or PP setting.
- The majority of studies focussed on client behaviour, with fewer studies reporting on BOC experienced from families.
- 15 categories of client BOC and 8 categories of family BOC were identified.
- The majority of studies appeared to focus on 'active' or 'overt' behaviours (i.e, physical/ verbal aggression), with fewer studies reporting on 'passive' or 'covert' behaviours (i.e, self-neglect).
- 10 studies reported on the impact of BOC on staff. Emotional and psychological impacts were frequently reported with physical health impacts and reduced work productivity also described.

Conclusion

The current study has identified existing gaps in the rehabilitation literature and highlights the important need for continued research to inform service development and resourcing for supporting rehabilitation clinicians in working with clients and families who exhibit BOC following injury and adjustment.

Future Directions

As part of a wider program of research, further qualitative (Study 2) and quantitative (Study 3) studies are planned to examine the beliefs and expectations of rehabilitation clinicians in working with individuals who demonstrate BOC. It is anticipated that this research will further inform the development of local approaches for ensuring an environment in which frontline rehabilitation professionals feel supported in working with clients and families who exhibit BOC.

References

- Wyatt, R., Anderson-Drevs, K., & Van Male, L. M. (2016). Workplace violence in health care: A critical issue with a promising solution. *Journal of the American Medical Association*, 316(10), 1037-1038. doi:10.1001/jama.2016.10384
- Rose, J. L., & Cleary, A. (2007). Care staff perceptions of behaviour and fear of assault. *Journal of Intellectual and Developmental Disability*, 32(2), 153-161. doi:10.1080/13668250701351816

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Research for Rehabilitation and Resilience

Introduction

Disability support services that provide advocacy, information, and health and social care are integral to the health and wellbeing of people with disability.

Research indicates that such services are essential in addressing individual comorbidities by linking clients with additional health services [1], improving community participation [2] and education and training outcomes [3], and supporting self-directed decision making [4].

It is important that disability support services are proximately available. In Australia, the proximate availability of services has been questioned, even for those in metropolitan settings [5].

Purpose

Recent research has established that areas in South-East Queensland with high proportions of people with disability are underserviced in terms of allied health services [6].

Only a small fraction of research has focused on the use of Geographic Information System (GIS) technologies to clarify the geographic dispersion of disability services in relation to people with disability.

The current study aimed to:

- Use spatial analysis to identify priority regions in Queensland with a significantly high number and proportion of people with disability.
- . Use spatial analysis to estimate travel times from localities within these regions to disability services.

Methods

The numbers, and proportions of people with disability across Queensland SA2 regions was sourced from the 2016 Australian Bureau of Statistics (ABS) census data. Localities within SA2 regions was sourced from the ABS, 2016 Urban Centre & Locality classification. The location of disability services in Queensland was provided by Health Direct.

Identifying the dispersion of disability services

in Queensland priority areas

Lakhani, A.*, Parekh, S., Grimbeek, P., Gudes, O., Watling, D.P.

Harre, P. & Stocker, J.

ons relating to this study please contact Dr Ali Lakhani

- A Hot Spot Analysis (Getis-Ord Gi*) within ArcGIS was conducted to ascertain SA2 regions with significantly high numbers and percentages of people with disability in Queensland.
- The travel time between localities and disability service organisations was calculated via the network analysis feature in ArcGIS.

Findings

- Thirty-eight SA2 regions in Queensland were identified as having a high number and proportion of people with disability. These regions are presented in Figure 1. Sixty-two urban centre localities were located within these regions.
- Descriptive statistics relating to the travel time (in minutes) to three types of disability services has been included in the table below.

Service Type	Mean	SD	Min.	Max.
Aids and Equipment	32.47	17.56	1.92	69.67
Information and Referral	22.53	16.76	0.90	70.34
Support and Advocacy	42.24	25.45	4.53	96.49

 On average, the greatest travel time for localities within priority areas was to Support and Advocacy services. The shortest travel time was to Information and Referral services.

Findings Continued...

- Friedman's test (non-parametric equivalent to repeated measures ANOVA) was used to examine the extent of differences in travel time to the three types of disability services.
- The three travel times were significantly different. When the service with the shortest travel time (Information and Referral), was excluded, the travel times to Support and Advocacy services turned out to be significantly greater than travel times to Aids and Equipment services.

Friedman Test	Chi-	Df	Asymp. Sig.
Comparing three services	53.79	2	0.00
Comparing Aids and Equipment	6.45	1	0.01

Points for Consideration

- The findings are consistent with travel times to Support and Advocacy disability support services for localities within priority areas being greater than the two other types of disability services, and consequently this type of service has the least proximate accessibility for localities considered.
- While travel time is important, the proximate availability of specific disability services might have less impact on access when telehealth or home/site visits are available as options.
- Furthermore, there are potentially services which have not been listed, and thus not included in the analysis.



References

- Brown, M., et al., Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perc and intellectual disability services. Journal of Intellectual Disability Research, 2017. 61(5): p. 435-449.
- Chenoweth, L. and N. Clements, *Participation Opportunities for Adults W* Policy & Practice in Intellectual Disabilities, 2011. 8(3); p. 172-182.
- Abreu, M., et al., Student Experiences Utilizing Disability Support Services in a University Setting. College Student Journal, 2016. 50(3): p. 323.
- Bigby, C., M. Whiteside, and J. Douglas, Providing support for decision making to adults with intellectual disability: Perspectives of family mer support services. Journal of Intellectual & Developmental Disability, 2017: p. 1-14.
- 5. Digiacomo, M., et al., 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services. BMC Health Services

ities Provided by Disability Se

Research, 2013. 13(1): p. 326-326. Gao, F. M. Foster, and Y. Liu, Disability concentration and access to rehabilitation services: a pilot spatial assessment applying geographic information system analysis Disability And Rehabilitation. 2018: p. 1-9. Figure 1: Areas with significantly high levels of disability in Queensland

Research for Rehabilitation and Resilience

How is this working for you? Early insights from a masterclass to advance frontline rehabilitation nursing research

Letitia Burridge¹, Alison New², David Lewis³, Jenny Kohlhardt³, Tracey Tattam², Michele Foster¹, Melissa Legg¹

Navigating the research process: from here to here

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Background

- Nurses more than ever have higher education^{1,2}, but are under-engaged with research vs. other health professionals³.
- Nurse-led research is impeded by lack of experience, knowledge or skills, lack of insight into the complexity of the research process,

- and the perennial problems of being time-poor and having inadequate resources and support⁴.
- Stronger research capacity and culture can enable nurse-led, practice-relevant research and its dissemination ^{5,6,7}.

Rationale

Nurse-led research can improve the quality of rehabilitation care, and showcase rehabilitation nursing as a specialty.

Purpose

To assess the value and impact and experience of a research masterclass program for rehabilitation nurses.

Method

Mixed methods, pre-post evaluation.

Sample and setting

11 rehabilitation nurses practising within Metro South Health, Queensland, Australia

The Masterclass

1-day interactive workshops: foundation (April 2018), advanced (October 2018). Between workshops: informal peer-group mentoring, supported by experienced mentor. *Foundation workshop topics:* barriers to research, pitching an idea, applying for ethical clearance, research planning templates, research methods, next steps. *Advanced workshop topics:* mentee presentations, expectations and experience with mentored research process, mentees' future plans.

Early results



Provisional conclusions

- The workshop evaluations suggest the Masterclass supports a keen pre-existing interest in and desire for nurse-led rehabilitation research.
- Participants remained highly interested in research, and their experience, confidence and opportunity increased between the workshops.
- Participants remained committed to their research goals in a landscape that included opportunities for colleagues and their practice specialty.

References

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Dependent on Foconomic C-Separation and Development: Health Workforce Pélodes in OECD Countries: Therefs in Naming Education in Automatical DECCD, 2016 (Available Intern. <u>Firsty Annual Academic Academ</u>

Research for Rehabilitation and Resilience

Partnering with Consumers: Development of a Consumer Engagement Strategy

Mandy Nielsen, Delena Amsters, Ray Quinn, Sarita Schuurs The Hopkins Centre and Division of Rehabilitation, Metro South Health

Introduction

Consumers of rehabilitation services (also known as service users) have a valuable role to play in the development and delivery of rehabilitation services and in conducting and translating rehabilitation research.

How to meaningfully partner with consumers in these activities is an important issue for the Division of Rehabilitation (DoR) and a key focus of The Hopkins Centre (THC).

The DoR and THC recognised that an appropriate and coherent strategy was required to effectively engage and partner with service users. A 12-month Consumer Engagement Strategy Project is in process.

The Project aims to design, plan and document a sustainable consumer engagement strategy which embeds into clinical, management, education and research activities of the DoR and THC.

Defining Consumers & Engagement

A **consumer** is someone who is using or has used a DoR service. Consumers are also referred to as **service users.**

Consumers can also be **family members or carers** of people using or who have used DoR services.

Consumer Engagement is meaningfully involving people (consumers) who have used DoR services in the **planning**, **delivery & evaluation** of DoR services & research.

Different Levels of Consumer Engagement¹

X

٩.

The IAP2's Public Participation Spectrum ² is often used as the standard to define the consumer role in engagement processes. Different roles are appropriate for specific activities.

EMPOWER	 Users of a rehabilitation unit suggest changes to the existing service model in feedback provided to the hospital. Staff follow up on the feedback & ask the users to partner with them to develop a consumer-centred service model.
COLLABORATE	 A rehabilitation unit puts together a steering committee including staff members, researchers & service users to oversee the development of a new model of care. The steering committee is involved in all aspects of the decision making.
INVOLVE	Staff from a rehabilitation unit put together a focus group of consumers who have used the unit to consider their concerns and preferences prior to the development of a new model of care. This information is incorporated into the new model.
CONSULT	 A rehabilitation unit has designed a new service for the region. They ask the hospital consumer advisory committee for feedback, some of which is evident in the final service model.
INFORM	A hospital produces a fact sheet to let the community know about a new service being offered in the rehabilitation unit.

Methods

The Project involved four interconnected phases:

Initiation & Planning

- Develop project planEstablish Reference
- Committee
- Obtain ethics approval & governance authorisation
- Scan existing QH strategies
 Rapid literature review
 Stakeholder consultation – staff, researchers & service

users

Scoping &

Stakeholder Consultation

Strategy Development

 Develop draft strategy
 Identify staff & consumer training needs Evaluation

Next step

Stakeholder Consultation Outcomes

- Level of interest in being involved in consumer engagement activities >70% for all stakeholder groups.
- High level of agreement regarding important Consumer Engagement Strategy attributes.
- Staff & researchers identified skill areas to build, including: procedures & processes, communication skills, activity planning & partnering for service co-design & evaluation.

· Identified facilitators of consumer engagement included the following:

Consumers:

Staff:

2

- Allocated time
- Awareness of opportunitiesTraining / Education
- Accessibility & flexibility
 Understandable & timely information
 - Training for effective participation
 - Feedback on engagement outcomes

Contribution is valued & respected

Emerging Strategy Domains

The literature review & consultation outcomes have contributed to 6 potential 'strategy domains'. Build & SUSTAIN CAPACITY COMMUNICATE & INCENTIVE & RESEARCH & TRANSLATION SERVICE MPROVEMENT

http://www.hcq.org.au/for.consumer-representatives/resources/ International Association for Public Participation (AP2 Public Participation Spectrum https://www.iap2.org.au/About-Its/Ahout-IAP2-Australasia-Spectrum



Introduction

and Resilience

The Acquired Brain Injury Transitional Rehabilitation Service (ABI TRS) is a 5-year pilot which aims to facilitate early community reintegration for individuals with acquired brain injury (ABI) and their families.

This service was established to address an identified unmet need in the continuum of ABI rehabilitation in Queensland. Funding for the pilot was received from the Motor Accident Insurance Commission (MAIC) in July 2016, with clinical services commencing in January 2017.

To determine the impact of ABI TRS on community re-integration, funding included an embedded service evaluation for the duration of the pilot.

Methods

People with ABI (n=71) completed the 12 week ABI TRS community-based program, comprising an intensive, individualised, goal directed program using an interdisciplinary, client-centred approach. Self and/or practitioner-rated measures were completed at 0 (baseline) and 3 months. Results were compared to a quasi-control (CON) where no transitional service existed. Data were analysed using linear mixed models in a Bayesian framework.

- Results Baseline ratings in all outcome measures were statistically worse for ABI TRS clients compared to CON i.e. the ABI TRS cohort was more impaired than the CON group at the first time point.
- 2. There were statistical improvements in measures of global function (MPAI-4¹) and psychological wellbeing (DASS-21²) compared to CON.
- Community integration (MPAI-4) ABI TRS CON Significant other Key worker Differences at baseline (d = 5.08 - 7.28, large)On average, clinical improv for ABI TRS in total and ability (mode ABI TRS ↓ (improv) on all indices at 3 months (d = -2.57 to -4.00, large) Psychological wellbeing (DASS-21) Health related QOL (EQ-5D) ABITRS CON ABI TRS clients † (worse) dep at baseline (d = 1.93, large) ABI TRS trend ↓ (improv.) stress & total at 3 months = -1.56 & -1.16) CON trend ↑ (worse) dep & stress at 3 months (d = 2.78 & 1.61) ABI TRS 1 (improv) total mean score at 3 months
- Psychosocial function (SPRS-2³) and health-related quality of life 3. (EQ-5D⁴) were statistically improved at 3 months compared to baseline.



Division of Rehabilitation Metro South

Health

Conclusions

Motor Accident Insurance Commission

ABI TRS clients demonstrated statistically improved or matched outcomes at 3 months compared to the quasi-control group.

 Λ

The ABI TRS sees a clinically diverse range of individuals, and early results indicate that clients generally exhibit superior outcomes following program completion.

 Λ

¹Mayo Portland Adaptability Inventory-4; ²Depression Anxiety Stress Scale 21; ³Sydney Psychosocial Reintegration Scale-2; ⁴EuroQuol Health Questionnaire

Addressing Client Needs Through Interdisciplinary Multi-site Groups in **Acquired Brain Injury Transitional Rehabilitation**

Nina Wegener¹, Sarah Jeffery¹, Sarah Kekki¹, Elizabeth Beadle¹, Kerrin Watter ^{1,2}, Areti Kennedy^{1,2} ¹Acquired Brain Injury Transitional Rehabilitation Service, Division of Rehabilitation, MSH, Brisbane Australia ²The Hopkins Centre, Division of Rehabilitation & Griffith University, Brisbane, Australia

Introduction

Transition from hospital-to-home is a critical time for people with acquired brain injury (ABI) and their families¹. Recognised issues include changes to physical, cognitive and communication skills, which impact independence, reintegration and community access^{1, 2}. The Acquired Brain Injury Transitional Rehabilitation Service (ABITRS) is a new service that provides time limited community-based rehabilitation to people with ABI discharging home from hospital.

The ABI TRS identified the clinical need to implement a new therapeutic model of care (MOC), which would:

- increase therapy intensity
- practise rehabilitation skills in real-life situations
- improve clients' rehabilitation access in the community
- address clients' goals of reintegration and independence
- assist with community participation & reintegration

Group-based rehabilitation was identified as a MOC that would address these areas. This included providing a tailored program with contextually relevant activities to address an individual's goals. Group-based rehabilitation for adults with ABI has been shown to enhance learning experience, motivation and mood through peer interaction as well as being a cost-effective means of utilising health resources and increasing intensity in rehabilitation programs³⁻⁵. Emerging research also identifies that clients perceive group intervention to be beneficial for sharing experiences, reducing isolation, receiving help and feedback, and assisting with adjustment and adaptation to life after TBI². Having an emphasis on interventions targeting functional 'real world' activities in group settings should benefit people following TBI².

Method

The Agency for Clinical Innovation (ACI) framework⁶ was used to develop a new model of care i.e., interdisciplinary group rehabilitation.



Themes: Week 1. Social Connections Week 2. Leisure Week 3. Vocation Week 4. Family and Community Roles Week 5. Family and Client Education (Medical and AHP)

• Group running order • Group program content • Local offsite group • Telehealth

Results and Conclusion

The new MOC has been successfully integrated into ABI TRS. Consumer and stakeholder feedback has influenced ongoing program development and acknowledged the clinical benefit of the program. Using a service delivery model that involves the whole interdisciplinary team should support the ongoing implementation and translation to clinical practice and the long-term sustainability of the program.

"Being around a group of supportive peers motivates and pushes you"

> "Learning about new challenges and being able to create a strategy to help in the situation"

An interdisciplinary group program was developed, with the following components:

Clinical content:

- functional goal-focussed activities;
- utilising expert clinician delivery;
- targeting psychosocial, physical, cognitivecommunication,

Service Delivery:

- group-based intervention,
- use of telehealth for isolated clients;
- implementation of offsite groups to encourage local community access;
- delivered across the interdisciplinary team.

"I particularly enjoyed having a say and that everyone contributes and participates"

"I enjoyed hearing how others are dealing with their injuries and discussing how others are going"

References

self-management and education.

In the first year of implementing the interdisciplinary group program:

- 39 clients attended two or more sessions of group program
- 22 clients attended the entire group program
- 1 client attended entire program via telehealth
- 1 offsite group run in clients' local community



"Liked the

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Nalder E et al. (2012). Identifying factors associated with perceived success in the transition from hospital to home after brain injury. Journal of Head Trauma Rehabilitation, 27, 143-153.

- Patterson, F., Fleming, J. & Doig, E. (2016). Group-based delivery of interventions in traumatic brain injury rehabilitation: a scoping review, Disability and Rehabilitation, 38:20, 1961-1986.
- Hamond F.M., et al. (2015). Group Therapy Use and Its Impact on the Outcomes of Inpatient Rehabilitation After Traumatic Brain Injury: Data From Traumatic Brain Injury: Data Fr
- Drum, D., Swanbrow Becker, M. & Hess, E. (2011). Expanding the application of group interventions: Emergence of groups in health care settings. The Journal for Specialists in Group Work, 36, 247–263.
- Bertisch, H., Rath, J. F., Langenbahn, D. M., Sherr, R. L. & Diller, L. (2011). Group treatment in acquired brain injury rehabilitation. *The Journal for Specialists in Group Work*, 36, 264–277.
- Agency for Clinical Innovation, NSW Health. (2013). Understanding the process to develop a Model of Care: An ACI Framework. www.aci.health.nsw.gov.au/__data/assets/pdf_file/0009/181935/HS13-034_Framework-DevelopMoC_D7.pdf 6.

We care about you Poster produced by Patient Safety & Quality Unit, Princess Alexandra Hospital, 2018



Princess Alexandra Hospital BRISBANE • AUSTRALIA

MAIC Motor Accident Insurance Commission

Online Education Resources for Spinal Cord Injury



Michael Todorovic^{1,2}, Matthew Barton^{1,2}, Steven Bentley³, Jenny Ekberg^{1,2}, James St. John^{1,2}

1. Menzies Health Institute Queensland, Griffith University, Gold Coast, Australia 2. Clem Jones Centre for Neurobiology and Stem Cell Research, Brisbane, Australia 3. Griffith Institute for Drug Discovery, Griffith University, Brisbane, Australia

We conducted a survey of 100 Australians within the SCI community...



What online resources are most important for people with SCI?

Equipment

11%

Physiology 4.9%

Education

Resources

Community Resources/ Services

11%

"Your" Injury

34.1%

What treatment 01 options are available for specific injury-type?

What bodily changes 02 to expect after specific injury-type?

What structure/ affected by the injury?

POINTS OF INTEREST

51.2% OF PARTICIPANTS COULD NOT FIND INFORMATION ONLINE

• REGARDLESS OF DEMOGRAPHIC, EDUCATION RESOURCES ON "YOUR" INJURY ARE THE MOST IMPORTANT

 SPECIFICALLY, TREATMENT OPTIONS DIRECTED AT A SPECIFIC INJURY-TYPE ARE NEEDED

WHAT'S NEXT?

Research for Rehabilitation and Resilience

Refugees in Pain: A Retrospective Chart Audit

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Introduction

Refugees often have experiences of violent and psychological trauma ^{1,2} leading to prevalence of mental health issues,. physical disabilities, and persistent pain.

Management of persistent pain for refugees is complex as a result of cultural interpretations of pain, language barriers and distrust of formal health systems ^{3,4,5.}

In some cultures, persistent pain is considered to be a natural part of life² resulting in failure to seek treatment.

Clinicians at the Persistent Pain Clinic at Princess Alexandra Hospital sought to identify factors impacting on refugees using this service adequately.

Aim

The aim of our study was to conduct a retrospective chart audit to gain an understanding of the characteristics of the refugee population attending the Persistent Pain Clinic at Princess Alexandra Hospital as a first step towards providing optimal pain management to refugees.

Methods

- Retrospective chart audit of medical records of refugees who attended the clinic was conducted (2015-2017).
- Adapted Minnesota Complexity Assessment Method ⁶ (MCAM) used.

Data Collected

- Demographics
- DASS21 & (Brief Pain inventory) BPI pre and post scores
- Attendance details: No of appointments booked, No of Appointments kept, Failure to Attend (FNA)
- Discharge Information
- · Information about Pain & Trauma
- · Social context family & networks

Sample

N=37 (17 M, 20 F); Mean age: 44.7 years

Mean years in Australia: 9.4 years

- 29 patients required use of an interpreter.
 8 Patients had functional use of English
- 8 Patients had functional use of English.

Work status: 18 unemployed, 3 working, 7 on Disability Support Program, 2 home duties, 4 studying English.

Results

Pain Duration: Mean 8.6 years

Most patients had PTSD (n=22) or PTSD Symptoms (n=11), often contributing to pain.

MCAM Measures:

- Very high levels of pain interfering with functioning;
- Very high levels of distress, distraction, preoccupation;
- Less than half displayed readiness to engage in treatment options;
- Almost all patients had restricted participation in social networks; modal interference in 2 domains.

Self-report measures:

 About two thirds completed questionnaires of intake & one third completed at end of treatment.

Discharges:

- 27 patients discharged
- 8 patients improved with treatment, especially in functioning.
- Other discharges equally split into active and passive withdrawal by patient, and doctor initiated discharge.

Issues that may lead to less than optimum pain management:

- Very high levels of pain, distress, and interference with functioning in refugee patients.
- Communication difficulties with clinicians despite use of interpreters.
- Inability to use functional English is a significant factor affecting attendance, completion of selfreport measures and engagement in group programs.
- Cultural issues, including differing cultural views of pain, may interfere with patient treatment.

References

1. Australian Institute of Health and Welfare (AIHW), Canberra. (2011). Australia's Welfare 2011 in Brief (Australian Welfare No. 10. Cat No. AUS 145). Retrieved June 19, 2018, from http://www.aihw.gov.au/publication-detail/?id=10737420536

2. Sonne, C., et al. (2016). Psychosocial predictors of treatment outcomes for traumatised refugees. Doi : 10.3402/ejpt.v7.30907 PMCID: PMC4889772

 Lin, I. B., et al. (2013) Disabling chronic low back pain as an iatrogenic disorder: A qualitative study in Aboriginal Australians. DOI: 10.1136/bmjopen-2013-002654
 Schulz, T., et al. (2012). Health issues in the refugee population. *Medicine Today*, 13 (3), 79-85.

5. Burton, A, B., et al. (2015). Pain management programs for non- English speaking black and minority ethnic groups with long-term chronic pain: Literature review. *Musculoskeletal Care*, 13, 187-203.

6. Minnesota Complexity Assessment Method (2009). University of Minnesota Department of Family Medicine & Community Health, 4/23/2009.

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Research for Rehabilitation and Resilience

Energy needs in people with spinal cord injury undergoing surgical repair of chronic pressure injuries

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Introduction

Consensus Dietetic guidelines for people with spinal cord injury (SCI) who have pressure injuries (PIs) recommend an increased energy intake to meet demands of wound healing, but evidence to support this is limited. The impact of PI surgical repair on energy needs is also unknown.

Purpose

The aims of this study were to:

- 1. Determine the resting energy needs of people with SCI admitted to hospital with established chronic PIs
- 2. Investigate the energy burden of PI surgical repair and healing.
- 3. Observe weight change from pre-surgery until discharge from hospital.

Methods

Data was collected at the bedside following an overnight fast of ≥8 hours. Resting energy expenditure (REE) was measured using indirect calorimetry (canopy hood) for ≥20 minutes one week pre-surgery, one week post-surgery, on removal of stitches and on return to unrestricted wheelchair sitting with complete wound healing (at discharge). Weight was measured one week pre-surgery and at discharge. Clinical energy prescription during admission was based on measured REE.

Preliminary findings

To date, 12 individuals have undergone surgery to repair stage four PIs (100% male, median age 52 years [range 27-72 years]; C4-T10 AIS A-B, n=1 spina bifida).

Pre-surgery, dietetic guidelines for energy prescription overestimated energy requirements by 30-70% in nine out of ten individuals (Figure 1).

There was no change to REE across time points (<10%) variation), with the exception of two individuals who experienced a clinically significant (>10%) increase in REE at different time points post-surgery (Figure 2). This may be due to an infection for one individual, and a combination of autonomic dysreflexia and spasticity for the other. Despite energy prescription individualised to REE, weight gain between 2-17kg was observed in three quarters of individuals.

Conclusions

The presence of chronic PIs, surgical repair or subsequent healing do not appear to impact the energy needs of people with SCI and weight gain is common. Current guidelines recommending increased energy prescription conflict with these findings and may increase risk of unintentional weight gain over the course of healing.

Research for Rehabilitation and Resilience

Understanding patient engagement in outpatient cardiac rehabilitation programs using the Model of Therapeutic Engagement

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Introduction

Engagement is a construct that can inform our understanding of intention, attendance and participation in rehabilitation. A proposed model of therapeutic engagement during cardiac rehabilitation (CR) was introduced by Lequerica and Kortte (2010) 1, and where the construct of therapeutic engagement is explicitly defined, by identifying a series of sub-models that explain to intention to engage in cardiac rehabilitation (CR), preparation for engagement in CR, initiation of cardiac rehabilitation, and cardiac rehabilitation evaluation and maintenance. This complex model can facilitate our understanding of the variables and processes that play a role in determining participation in, and benefit from, rehabilitation.

Method

- Participants: 217 patients eligible for outpatient cardiac rehabilitation programs from the Cardiology ward at Gold Coast University Hospital
- Design of this study: a prospective study
- Data collection: paper surveys over three time intervals to cover all stages of the Model of Therapeutic Engagement.
- Statistical method: Structural equation modeling to test the hypotheses proposed
- Nine hypotheses have been tested based on the Model of Therapeutic Engagement in Rehabilitation (significant relationships showed in red).

Results

Path analysis was carried out by ascertaining the significance of path (p-value).

For stage 1, results revealed significant relationships between perceived need and patient intention to engage in CR programs ($\beta = 0.43$; B = 0.63; SE = 0.29; p = 0.03), and perceived self-efficacy and patient intention to engage in the CR program ($\beta = 0.23$; B = 0.24; SE = 0.13; p = 0.05).

For stages 2 and 3, there were significant relationships between:

Intention to engage in the CR program and CR preparation ($\beta = 0.37$; B = 0.28; SE = 0.09; p = 0.001), CR Initiation and Engagement ($\beta = 0.68$; B = 0.20; SE = 0.03; $p \le 0.001$); Engagement and Analysis of Experience ($\beta = 0.381$; B = 0.38; SE = 0.08; $p \le 0.001$); Analysis of Experience and Maintenance ($\beta =$ -0.58; B = -0.30; SE = 0.05; $p \le 0.001$); and Maintenance and Engagement ($\beta =$ 0.20; B = 0.56; SE = 0.29; p = 0.05).

Purpose

The overall aim of this project was to examine the Model of Therapeutic Engagement in Rehabilitation (Lequerica & Kortte, 2010) to advance understanding about patient engagement in outpatient CR programs. The specific objectives of the study were to:

- Explore, measure and validate the components of the Lequerica-Kortte conceptual model of therapeutic engagement in rehabilitation.
- Examine the way in which the components of this conceptual model interact with each other, when empirical data is used to understand patient engagement.
- Use these findings to inform future patient engagement interventions.

SEM path analysis with standardized regression coefficients

Note: *** $p \le 0.001$. R-squared represented the explained variance of the outputs at each stage of the <u>Model of Therapeutic Engagement</u>.

Expected Results

The Model of Therapeutic Engagement moves the field toward a more complete understanding of the process of engagement in cardiac rehabilitation programs and contributes knowledge about how to make this process more effective. It is suggested to embed this model broader into socioа environmental context to have a comprehensive understanding of patient engagement cardiac rehabilitation programs.

Literature Cited

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Lequerica, Anthony H, & Kortte, Kathleen. (2010). Therapeutic engagement: a proposed model of engagement in medical rehabilitation. American journal of physical medicine & rehabilitation, 89(5), 415-422.

Tomarken, A. J., & Waller, N. G. (2005). Structural equation modeling: Strengths, limitations, and misconceptions. Annu. Rev. Clin. Psychol., 1, 31-65.

Disclosure

Financial support for this study was received from Griffith University.

Conflict of interest The authors declare no conflict of interest for this study.

Research for Rehabilitation and Resilience

Health Status after Motor Vehicle Accidents: Results from a survey in Queensland

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Introduction

- Self-rated health is an established marker of general health status and predicts long term morbidity and mortality.
- After Motor Vehicle Accidents, patients experience challenges with self-efficacy and return to work that extend well beyond the immediate time frame of discharge from acute health care.
- There is an abundance of literature on health during Acute Care or while receiving Rehabilitation after trauma. Information on longterm health status after Motor Vehicle Accidents for patients within the community, especially in Australia however is limited.
- In this context, we examined factors associated with general health status after Motor Vehicle Accidents from a survey of community dwelling Compulsory Third Party (CTP) insurance claimants in Queensland, Australia.

Purpose

Examine the association between demographic, injury related variables and general health status as assessed by responses to questions based on dimensions (i.e. health states) of the EuroQoI-5D (EQ-5D).

Methods

Study Population

- Participants from a survey conducted by the Centre of National Research on Disability and Rehabilitation Medicine (CONROD), Griffith University and the Motor Accident Insurance Commission (MAIC).
- Mail-in-surveys distributed to a random sample of 2500 claimants. Criteria for inclusion: age ≥18 years, completion of claim payments and noncritical injuries (fatalities, AIS categories 5 &6 excluded).
- Responses were returned within 2 months, a draw for a \$500 shopping voucher was provided as incentive.
- A total of 426 responses (17%) were received. Those with unusable information (n=216), missing IDs (n=1) and non-specific injuries (n=4) were additionally excluded. Final analytic sample comprised of 205 participants (8.2%).

Methods

Study Variables

 We examined age, gender, marital status, country of birth, spoken language, education level, employment status, income, injury severity, time since injury and whether participants received funded rehabilitation care.

Outcomes: EuroQoI-5D (EQ-5D) Health States

 Responses to the 3-level EQ-5D health states including: Mobility, Self-Care, Usual Activities, Pain or Discomfort and Anxiety or Depression.

Results

Table 1. Descriptive characteristics of the	Sample (N=205)
Variables	Mean + SD or N (%
Age, years	48.4 ± 14.2
Gender	
Men	78 (38.1%)
Women	127 (61.9%)
Marital Status	
Single/Never Married	33 (16.1%)
Married/De facto	129 (62.9%)
Separated/Divorced/Widowed	43 (21.0%)
Spoken Language	
From English speaking country	180 (87.8%)
From Non-English speaking country	23 (11.2%)
Employment status	
Unemployed	81 (39.5%)
Employed	122 (59.5%)
Abbreviated Injury Scale categories	
Minor injuries	160 (78.0%)
Moderate injuries	33 (16.1%)
Serious/Severe injuries	12 (5.9%)
Time since Accident, years	3.4 ± 1.3
Received Rehabilitation Care	
Yes	117 (57.1%)
No	71 (34.6%)
Mobility	
No Problems with Mobility	137 (66.8%)
Have problems with Mobility	68 (33.2%)
Self-Care	
No Problems with Self-Care	166 (81.0%)
Have problems with Self-Care	37 (18.1%)
Usual Activities	. ,
No Problems with Usual Activities	86 (41.9%)
Have problems with Usual Activities	118 (57.6%)
Pain or Discomfort	. ,
No Pain or Discomfort	51 (24.9%)
Have Moderate to Extreme Pain or Dis	comfort 152 (74.1%)
Anxiety or Depression	
No Anxiety or Depression	119 (58.0%)
Have Anxiety or Depression	86 (41.9%)
EQ-5D, 3 level Index	0.77 ± 0.18
†Data	- /0/)
*statis Health status b	y Gender
90	Men Women
80 -	
e 60	
eg 50 -	
0 40	
20	
10	
0	
Mobility Self-Care Usual A	Activities Pain or Anxiety or
	Discontion Depression
Health status by Co	untry of Birth
100 1	

Results

Participant Factor	Odds Ratio(95% CI)
Brobloms with Mobility	UT WEATT I SE '
Gender	
Man	1 (referent)
Momon	
n volue	0.42 (0.20, 0.09)
p-value Employment status	0.02
Employment status	1 (referent)
Employed	
Unempioyed	2.35 (1.13, 4.89)
p-value	0.02
Time since injury, years	1.50 (1.13, 2.00)
p-value	0.005*
Problems with Self-Care	
Employment status	
Employed	1 (referent)
Unemployed	2.90 (1.22, 6.88)
p-value	0.01*
Time since injury, years	1.38 (1.01, 1.88)
p-value	0.04*
Problems with Usual Activities	
Time since injury, years	2.38 (1.68, 3.38)
p-value	< 0.0001*
Pain or Discomfort	
Time since injury, years	1.89 (1.31, 2.73)
p-value	0.0007*
Anxiety or Depression	
Country of Birth	
Australia	1 (referent)
Other countries	0.33 (0.15, 0.71)
p-value	0.0005*
Employment status	
Employed	1 (referent)
Unemployed	1.93 (0.97, 3.86)
p-value	0.06
Time since injury years	1.35 (1.03, 1.77)
n-value	0.03*
EQ-5D Index (3-level)	0.00
Employment status	
Employed	(referent)
Linemployed	0 10 ± 0.02
n value	-0.10 ± 0.03
Time since injung years	0.0003
nine since injury, years	-0.03 ± 0.01
p-value	0.0009"

*Adjusted for age, gender, country of birth, education, employment, injury se

Conclusion

- Gender, country of birth, employment status and time since injury were associated with individual health states of the EQ-5D.
- Employment and time since injury were consistently associated with overall health status (EQ-5D index score).
- Future prospective studies with larger representative samples are required to confirm our findings.

The Housing for people with an acquired brain or spinal injury: Hopkins Mapping the Australian funding landscape Centre Research for Dr Courtney Wright^a, Dr Jacinta Colley^a, Ms Kate Knudsen^a, & Prof Elizabeth Kendall^a Rehabilitation ^aThe Hopkins Centre, Menzies Health Institute Queensland, Griffith University and Resilience ∇ Background Method Due to several personal and systemic factors, individuals with an acquired brain injury (ABI) or spinal A scoping review of available grey literature was cord injury (SCI) are often unable to afford the extent of support required to address their housing needs. conducted. For the purpose of this review, funding related Funding is often sought from National or State/Territory-based insurance schemes to assist a person with to housing was broadly defined as funding that supported ABI or SCI to make changes to their housing situation and improve their quality of life. people to live as independently as possible in their home and participate in their community. **Research Aim** Two researchers independently and systematically Given the crucial role of insurance schemes in contributing toward housing improvements for individuals searched the NDIS, interstate NIIS and national / with ABI and SCI, this research interstate workers compensation scheme websites for for people who have sustained an ABI or SCI for the relevant information. Data extraction was also performed following schemes: independently by two researchers using a standardised National Disability Insurance Scheme (NDIS); data extraction form to ensure consistency. A narrative • Interstate National Injury Insurance Schemes (NIIS); and synthesis was used to describe the data extracted from

Results

National and interstate workers compensation schemes.

This review identified 20 major insurance schemes across Australia that provide housing-related funding to individuals who have sustained a moderate, severe, or profound ABI, or SCI resulting in incomplete or complete paraplegia or tetraplegia. The funding contributions of the 20 relevant schemes toward three main categories of housing support (i.e., infrastructure, tenancy, and service delivery) following ABI or SCI are outlined below:

Home Modifications Modifications New Builds (New Builds (New Builds (New Builds) (New Builds) (N	Attendant (Personal) Care	Household Services	sumables quipment	nunity ss & pation	es ment	ports	
Home Modifications Modifications (weed by individual) Home Purchases (owned by individual) Vehicle Modifications Short-term Accommodatio Costs Maintaining a Costs	Attendant (Personal) Car	Household Services	sumables quipment	nunity ss & pation	e ment es	por	0
			Con ⊗	Comn Acce Partici	Case Managei Servic	Family Sup	Assistance Animals
National Schemes							
NDIS X Y X Y Y	× -	 Image: A second s	×	 Image: A second s	 Image: A second s	1	 Image: A second s
Seacare	×	1	1	۸	۸	٨	^
Comcare	× -	 Image: A second s	1	1	۸	٨	^
DVA Scheme X ✓ A X ✓ A	×	×	×	×	 Image: A second s	×	 Image: A second s
State/Territory-based Schemes							
Queensland							
	× -	×	× -	1	۸	 Image: A second s	^
WorkCover (QLD)	۸	۸	 Image: A second s	 Image: A second s	۸	۸	^
New South Wales							
icare Lifetime Care X X X X X X X	× -	×	1	1	۸	1	^
icare Workers Care	× -	×	×	۸	۸	٨	^
Australian Capital Territory							
Lifetime Care and Support Scheme 🗸 🗶 X 🗶 🗸 🔨 🔨 X 🗸 🗸	× -	1	1	1	۸	۸	^
Workers Compensation (ACT)	۸	۸	1	۸	۸	٨	^
Victoria							
Transport Accident Compensation Scheme 🗸 🖌 🖌 🗶 🖌 🖌 🖌 🖌	×	1	 Image: A second s	×	 Image: A second s	1	 Image: A second s
WorkSafe (VIC)	× -	 Image: A second s	 Image: A second s	 Image: A second s	 Image: A second s	1	^
Tasmania							
Motor Accidents Insurance Scheme 🗸 🔥 A 🔥 🗸 🗸 A A A	1	1	 Image: A second s	۸	^	1	^
WorkSafe (TAS)	1	 Image: A second s	 Image: A second s	۸	^	۸	^
Northern Territory							
Motor Accidents Compensation Scheme 🗸 🔥 A	×	1	 Image: A second s	۸	۸	۸	^
WorkSafe (NT)	× -	1	۸	۸	^	1	^
South Australia							
Lifetime Support Scheme 🗸 🗶 X X 🗸 🗸 🗸 X ^ /	1	 Image: A second s	 Image: A second s	 Image: A second s	^	1	 Image: A second s
ReturnToWork (SA)	1	1	 Image: A second s	 Image: A second s	^	1	^
Western Australia							
Catastrophic Injuries Support Scheme 🖌 🔥 🔥 🔨 🔥 🔥 🔥	1	 Image: A second s	 Image: A second s	۸	^	 Image: A second s	۸
WorkCover (WA) Image: A mark and an	^	۸	 Image: A second s	۸	^	۸	۸

Putning provided, x-tuning not provided, x-no tuning described (i.e., not clear whether funding provided of hot).
DVA=Department of Veterans' Affairs; NDIS=National Disability Insurance Scheme; NIISQ=National Injury Insurance Scheme Que

Implications for Consumers

The findings highlighted the extent of missing information regarding funded housing supports across the NDIS, NIIS, and workers compensation schemes. Individuals with an ABI or SCI, and their families, may use this information to inquire about particular housing supports they may need to live as independently as possible at home and participate in the community, and that have not been mentioned in scheme guidelines, fact sheets, or other public documents. The review findings may therefore empower individuals and their families to pursue information about housing supports they may be entitled to, in order to improve their housing situation.

Implications for Policy-makers

the relevant sources

The review identified inconsistencies across the 20 schemes regarding funded housing supports and eligibility criteria to access particular housing supports. This inconsistency raises equality issues that must be considered by policy-makers, particularly if individuals with ABI or SCI are unable to access the housing support they require from other government or non-government schemes. The development and communication of a unified, evidence-based framework for housing support that is tailored to ABI and SCI may inform future decision-making in this area and improve housing outcomes for consumers.

Research for Rehabilitation and Resilience Introducing the *My Accessible Home* resource: A technological platform to assist consumers in making important housing decisions

Dr Courtney Wright The Hopkins Centre, Menzies Health Institute Queensland, Griffith University

Problem

After a life-changing injury or illness, people often need to modify their home or find an alternative place to live. This is because their previous home is no longer suitable or equipped for their high level physical, mental, or support needs [1-4]. Despite the clear nature and extent of the problem (1.3 million Australians have a severe / profound disability requiring daily support) [4], many people remain in unsuitable living environments for years or are moved to institutional group homes or nursing facilities in an attempt to 'solve' the problem [2,5].

While there are some housing resources currently available to help consumers modify their homes, they are limited in scope (i.e., focused solely on physical accessibility design) and substance (i.e., static information mediums: websites, Microsoft Word© documents, or PDF documents simply listing information).

There is no resource currently available to systematically and comprehensively assist consumers in designing or re-designing their own home

<u>Solution</u>

The "*My Accessible Home*" resource (see https://www.myaccessiblehome.com.au/) is a comprehensive, online decision tool (with the potential of being a 'one-stop-shop') for people with disability and their families to access relevant housing information and plan for the future.

Importantly, the information provided includes, but is not limited to, physical access considerations. In contrast to other housing resources currently available, the *My Accessible Home* tool prompts consumers to not only think about functional design, but to also think more broadly in terms of what they would like their home to include, and where and how they would like to live.

For the first time, consumers are able to navigate through a comprehensive and detailed resource, watch informative videos, browse pictures, and collate (save) their ideas in a virtual space representing 'My Dream Home'. The resultant report may then be shared with individuals in a position to help the person improve their housing situation (e.g., friends, family, advocates, architects, designers, builders, occupational therapists) via print form, email, or social media. Importantly, the information comprising the technological platform is evidence-based and informed by consumers' voices.

<u>Impact</u>

Traditionally, consumers have not had the financial capacity to build, buy, or modify their own home unless they had been able to access compensation, inheritance, or grant funding. This situation changed in 2016, when the National Disability Insurance Scheme (NDIS) and National Injury Insurance Scheme (NIIS) commenced in Queensland (and has also been rolled-out across Australia).

The individualised funding packages provided to consumers through these schemes have enabled consumers to invest in their housing situation, subsequently compelling the sector to respond to a new consumer market. The user-friendly, interactive nature, and comprehensive information provided by the *My Accessible Home* resource will empower consumers to make important decisions in early design (or purchase) processes.

It is anticipated that the resource will improve housing suitability and liveability for people with complex disability, reducing the number of forced relocations of people into group homes and nursing facilities.

References

- [1] The Senate Community Affairs References Committee (2015). Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia: Report. Canberra, ACT: Commonwealth of Australia.
- [2] Wright, C. J., Muenchberger, H., & Whitty, J. A. (2015). The choice agenda in the Australian supported housing context: A timely reflection. *Disability & Society*, 30(6), 834-848. doi:10.1080/09687599.2015.1038336
- [3] Ahmed, N. (2013). Paralympics 2012 legacy: Accessible housing and disability equality or inequality? *Disability & Society*, *28*(1), 129-133. doi:10.1080/09687599.2012.739367
 [4] PricewaterhouseCoopers. (2011). *Disability expectations: Investing in a better life*, a
- stronger Australia. Australia: PwC. Available from http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf [5] Quarterly Brain Injury Services Meeting Group (2013). A comprehensive service
- [5] Quarterly Brain Injury Services Meeting Group (2013). A comprehensive service system for Queenslanders with brain injury: Positioning paper. Available from http://synapse.org.au/media/89778/qbism_position_paper_-_final_september_12.pdf

Acknowledgements

The *My Accessible Home* resource was produced by a collaborative partnership between The Hopkins Centre (Menzies Health Institute Queensland, Griffith University) and Youngcare. The original idea for the resource was conceived by Dr Courtney Wright.

- Dr Wright's PhD thesis informed the resource content. The partnership sincerely thanks Elizabeth Ainsworth (Occupational Therapist; Access Consultant) for her additional intellectual contributions and Winning Media for developing the website. The partnership are also grateful for the financial contributions of Perpetual through the 2016 IMPACT Philanthropy Program and acknowledge the Recover Injury Research Centre (The University of Queensland) for their support.
- Dr Wright's PhD thesis (cited below) was supervised by Prof Heidi Zeeman and Prof Elizabeth Kendall: Wright, C. (2016). Likes, dislikes, must-haves, and must-nots: An exploratory study into the housing preferences of adults with neurological disability (Doctoral dissertation). Brisbane, Queensland: Griffith University.

The *My Accessible Home* resource would not have been possible without the people who shared their stories so willingly in the research. Dr Wright's deepest thanks are extended to the research participants who gave so generously of their time.

Participants were asked to explain their reason/s for their multiple choice response. Data was thematically analysed using a text analysis software package, Leximancer (Version 4.5, 2016), to identify a full list of emerging concepts. Following the software-supported text analysis, a manual thematic analysis was completed by two researchers to develop overarching themes and limit interpretation bias.

Qualitative Findings Theme 1: Right to choice, autonomy and participation

The majority of participants were in favour of mandating Livable Housing Design standards. Participants believed that mandating Livable Housing Design in all new builds would ultimately promote the physical, psychosocial, and emotional health and quality of life of individuals and families. These benefits were perceived to relate to all Australians (either now or in the future) since "we are all ageing as well as vulnerable to illness, accidents or injuries which could lead to incapacity of varying degrees at any age or stage of life" (Response 0324). Participants therefore suggested that mandating Livable Housing Design features would prepare individuals well for when (rather than 'if') their circumstances or needs change. Livable Housing Design was considered to be a human right, based on equality and anti-discrimination principles.

A smaller number of participants suggested that mandating Livable Housing Design would infringe on peoples' right to choose their housing design and features: "Socially boring!!! ... Lack of human-rights for individuals to choose to live in the built environment they prefer" (Response 0036).

Theme 2: Perceived financial impact of change

Participants' perceptions regarding the financial impact of mandating Livable Housing Design standards varied. Several participants believed that implementing livable design features following regulation would cost little or no more than current housing options since changes would be made during the design stage. Others believed that implementation would cost a lot more than current housing designs. As one person suggested, more space is needed regardless and "space costs money" (Response 0369). Others noted "the initial cost of changing from current designs and learning how to do things differently" (Response 0674). However, most participants believed that mandating Livable Housing Design standards would come with an initial cost, but that the cost would be outweighed by social benefits and/or recovered over time.

[Mandating Livable Housing Design] would be of economic benefit to society - in the mid- to long-term. It would save money on expensive retrofitting. It would save on potential injuries caused by inappropriate housing. It would reduce the cost associated to people who have mobility issues having to stay in hospital due to having no accessible home to which to return" (Response 1344).

Conclusion

The majority of participants considered mandating Livable Housing Design in all new builds a cost-effective venture for Australia's housing future. The research findings indicated that any cost-benefit exercise must go beyond the immediate impacts on the housing industry and the housing market, to consider the public interest in Australia's housing infrastructure in the long-term, and the significant Government investment to assist people to be socially and economically included and to participate in family and community life. The results also highlighted the perceived need for a comprehensive education and awareness strategy to accompany regulation, so that all stakeholders understand why the regulation of Livable Housing Design is important for them, their businesses, and for a more inclusive Australian society.

References

[1] National Dialogue on Universal Housing Design (NDUHD). (2010). Strategic plan. Retrieved from https://www.dss.gov.au/sites/default/files/documents/05_2012/national_dialogue_strategic_plan.pdf

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