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EDITORIAL

Welcome to edition 69 issue 2 of the New Zealand Journal of Occupational Therapy

The articles in this issue, which are published in order of submission, offer a range of topics addressing occupational therapy practice. Each one, in its own way, provides practical, hands-on information that is occupation-focused and client-centred.

The first article from Roberts and Robinson, reports the findings of a research project in which Photovoice, a visual method of data collection, was used to explore the perceptions of people with a history of severe mental illness. This novel approach to data gathering is increasingly being used to capture difficult to express issues that could inform approaches to recovery. Responses to the question: What Matters to Me? are enlightening in their simplicity.

Researchers Nyashanu and Nicholson undertook a comprehensive literature review to consider the evidence which frames the Mental Health Recovery Star as an effective outcome measure for determining the functional progress of people experiencing high and complex mental health needs. Furthermore, the authors assessed the value of using John Kotter's 8 Step Change Management Model to implement the Mental Health Recovery Star in practice.

It is a coincidence that these two articles were submitted for review around the same time. Essentially, they highlight the need to consider the ways in which decisions around clinical assessments and interventions are made. There are important lessons to be learned from both of these papers.

The author of the third article, Ann Christie, used a case study to share reflections of working with refugees; this was pioneering work for occupational therapists in New Zealand at the time. The author relates the steps taken to build rapport and includes a detailed account of the reality of being a refugee. This paper, which gives an insight into cultural diversity and ways of being, will be of interest to clinicians who work with refugees and asylum seekers.

Reporting from Australia, Harper et al., used a prospective longitudinal cohort study to investigate the relationships between self-awareness, cognition and function post stroke. Disruption to cognitive processes is a common side effect of stroke and the authors of this article hope that the study findings will encourage clinicians to identify deficits in these areas early, to support rehabilitation, engagement, and outcomes.

Putting clinical governance discourses that shape occupational therapy practice in Aotearoa New Zealand under scrutiny, Orton et al., call on occupational therapists-kaiwhakaora ngangahau to become political actors, and to exercise power, by actively responding to discourses that create practice conflicts. Referred to as 'pinch-points' the authors refer to clinical governance that comes into conflict with the profession's values, and its calls for Te Tiriti responsiveness to achieve health equity for all.

We finish with the abstract from Lizzie Martin's doctoral research which explored the impact of bowel cancer on day-to-day occupations. Aotearoa New Zealand has one of the highest rates of bowel cancer in the world, and many who survive, live with ongoing psychological and physical effects. The information gained in this study could help survivors prepare for life after treatment.

On behalf of associate editor Ema Tokolahi and myself, I hope the articles contained herein will help to refine and expand views of occupational therapy, clinical practice and, of life per se. We look forward to any feedback you may have to offer.

Acknowledgement

Here, I want to acknowledge occupational therapists who have given freely of their time and knowledge to anonymously review manuscripts submitted to the Journal for publication. Over the last year Simon Leadley, Linda Robertson, Ema Tokolahi, Tim Dunn, Annie Baigent, Gilbert Azuela, Lynette Eaton, Katrina Wallis, Amanda Bishop, Shona Paterson, Tamzin Brott, Joy Aiton, Margaret Jones, Roz Sorensen, Kim Henneker, Mary Silcock and Nancy Wright have all responded to my call for help. Furthermore, Editorial Board member Clare Hocking and Associate Editor Ema Tokolahi, are ever willing to share their knowledge and experience. Without this support, the journal could not publish a high standard of peer reviewed articles. Thank-you one and all, I value your input.

A Call for Reviewers

Finally, I would welcome the support of experienced clinicians, researchers, scholars, and educators to undertake anonymous reviews for the New Zealand Journal of Occupational Therapy. Essentially, we are seeking reviewers with knowledge in all fields of practice including:

- Paediatrics, youth & family, community care, communication, culture, mental health, neurology, assessment tools, health promotion, rehabilitation, pain management, adventure therapy, supervision, education, teaching, fieldwork, traumatic brain injury, aged care and palliative care.
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If you are willing to voluntarily give an hour or two of your time to share your knowledge and expertise, please e-mail me at editor@otnzwna.co.nz

The following information would be helpful: (a) contact details (b) statement of interest, (c) institutional / organisational affiliation, (d) education and / or degree, and (e) practice areas and / or research designs in which you are proficient - simply to make sure manuscripts you are asked to review, are within your knowledge base. Usually, reviewers are invited to evaluate one, and very occasionally two manuscripts per year. Practical experience is valued.

Thank-you,

Grace O'Sullivan (Editor)

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Cover photo:

Children playing beside Hamilton Lake at sunset, Frankton

What Matters to Me? Photovoice for People Living With Severe Mental Illness

Louise Roberts¹ and Rita Robinson²

Abstract

This research showcases the multifaceted narratives of four people with severe mental illness, demonstrating their ability to articulate what is important to them.

Methods: Four participants who attend a mental health day service were asked to photograph 'What Matters to Me?' in their everyday life, the photographs formed the basis of individual interviews.

Findings: Home, homemaking, 'doing' and people are what matters. Participants articulated multiple positive identities viewing an illness identity as only a small part of self.

Implications: Access to occupations and the importance of sharing narratives and narrative continuity align with the concepts of occupational justice and 'doing with' and therefore need to be prioritised.

Keywords: Connection, doing, home, hope, identity, occupational therapy

Reference

Roberts, L. & Robinson, R. (2022). What Matters to Me? Photovoice for people living with severe mental illness. *New Zealand Journal of Occupational Therapy*, 69(2), 3-10.

Introduction

More than twenty years after adopting recovery into mental health policy (Mental Health Commission Blueprint, 1998), He Ara Oranga (2018) reported that, despite some progress, recovery services are still developing, and medical services continue to dominate people's lives. For recovery to be achieved it must be self-defined and self-directed by the narratives of people's own experience, rather than professional ideology (Cameron & McGowan, 2013). According to He Ara Oranga (2018) "People with lived experience are too often on the periphery; they should be included in mental health and addiction governance, planning, policy, and service development. Consumer voice and role should be strengthened in DHBs, primary care and NGOs." (p.13)

This study explored the voices of four participants who regularly attend a non-government organisation (NGO) community based mental health day service for people with severe mental illness (SMI). Research suggested this is a vulnerable group, having higher levels of mortality,

poverty, trauma, and comprised physical health (Davidson & Roe, 2007), commonly living alone, with lower levels of education and greater levels of unmet needs (Milbourn, et al; 2014). Photovoice was selected to create space for this 'difficult to engage' group, allowing participants to control the narrative and capture difficult to express issues thus adding to the body of knowledge to inform how service users and professionals can collaborate in the building of recovery services. The question *What Matters to Me?* was a deliberate attempt to usurp the medical paradigm *What is the Matter?*

Literature Review

While an absolute definition of recovery remains elusive, in part due to its individualised and personal nature (Shanks et al., 2013), concepts usually centre around personal responsibility, rebuilding life, developing roles, engaging in meaningful activity (Lloyd, Tse, & Bassett, 2014), inclusion and citizenship (Davidson & Roe, 2007). Davidson and Roe (2007) proposed two concepts 'recovery from' and 'recovery in' mental illness, suggesting that approximately 25% of people diagnosed with SMI will 'recover from,' as consistent with 'cure', or re-establishing life as it was before illness. 'Recovery in' refers to those for whom symptoms and effects of illness persist, making hope, aspirations, autonomy and control in life, the desired outcomes despite illness. Davidson and Roe (2007) also discussed the possibility that 25% of people with SMI are not in recovery and rely on services to survive, a concept that contrasts markedly with advocates who claim that anyone can recover, defined as having the ability to live a meaningful life in the community, provided they have the support of recovery services (Myers et al., 2016).

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Effective recovery services require co-design between service users and providers. While there are some examples of this, more often one person is employed as a 'voice' or 'representative' with varying number of resources and influence (He Ara Oranga, 2018.). Employment along with inclusion in mainstream activities has dominated the recovery dialogue, potentially excluding people who attend day services leaving those most vulnerable subject to the voice of others (Beresford & Bryant, 2008; Bryant, et al., 2010). Efforts to engage people with SMI in co-design are particularly challenged as levels of agency, autonomy, and identity, may have been eroded by long term service use (Hamer, et al., 2014).

For co-design to be successful, a fundamental shift in the attitudes of professionals who have traditionally been in a position of power and maintained service users position as passive recipients of care is required (Lloyd & King, 2003). Professionals must recognise and value the knowledge of lived experience, and accept that service users know more about planning, developing services, and the management of their own care than anyone else (Scholz, et al., 2017).

Research has identified individual and systemic barriers to implementing co-design within a recovery approach. Systemic barriers include tokenism, restricting the amount of power and influence afforded, and deliberately engaging those who are compliant (Meagher, 2011) along with stigma, resistance to change, and an over-reliance on the medical model (Gee, et al., 2016; Linhorst, et al., 2002). Individual barriers include fear of reprisal or censorship (Happell & Scholz, 2018), cognitive impairment, lack of confidence and skills, and difficulty understanding the language (Jansson, et al. cited by Magnusson & Lützén, 2009). Cameron and McGowan (2013) suggested that over time, as people feel unheard or not listened to, they may become silent. People with SMI frequently demonstrate a passive approach to situations, awaiting guidance before responding and adapting their response (Erdner & Magnusson, 2011). As the complexity of different voices begin to be heard, it is important that space is provided for the voices of those living with SMI, as their recovery journey and service needs may differ from those experiencing mild to moderate illness.

Methodology

A qualitative descriptive methodology was used in this small study to provide a rich description of service user's experience. This allowed the researcher to 'stay close to the data' and report it in the language of the participants (Sandelowski, 2010). As the goal was to hear the voices of those previously silenced or marginalised, this methodology, along with photovoice as a tool for data collection, were selected to allow the participants to define and shape the

discussion by taking photographs and interpreting them. This methodology along with the use of photovoice (Wang, et al., 1998) could be more accurately named photovoice-as-method, or photo-elicitation (Baigent, Wilson, & Butler, 2019; Fleming, Mahoney, Carlson, & Engebretson, 2009; Lal, Jarus, & Suto, 2012; Thompson et al., 2008).

Variation of life experiences through purposive sampling techniques considering ethical and cultural background, age, gender, levels of literacy and levels of support (Neergaard, et al., 2009) were considered in the selection of four participants, along with their mental health and likelihood of remaining engaged.

Ethics approval was granted by Otago Polytechnic Ethics Committee (2019), reference number 826, ensuring steps were taken to enable space for a Māori world view as well as mitigate against potential harm of participants or others. As the occupational therapist at the day centre where the research took place, the primary researcher had long term relationships (4-16 years), with all four participants. The researchers membership within the group and the longevity of relationships was considered vital to providing the trust required to work with people who experience SMI (Mcdermid et al., 2014) and including socially excluded participants in the research (Emmel, et al., 2007). To ensure this relationship was not perceived to be coercive, participants were approached by a third party and the voluntary nature of participation was explained at each stage, as was the opportunity to withdraw. Secondary consents were sought prior to publication of photographs, along with individual consent from Fran, peer support worker in photo 7. Pseudonyms are used for each participant (See Table 1).

Disposable cameras were selected so that everyone had the same predetermined number of photos (24) and could be encouraged to use them all, while eliminating the possibility of an unmanageable amount. However, Susan brought her own digital camera (600 shots), to the interview and was dismissive of the disposable camera. To enable Susan to engage and be heard in her own way of choosing, and to maintain congruence by addressing the question, it was agreed to view the printed photos from the disposable camera first and then those from her digital camera. Photographs were developed within 24 hours and interviews organised as soon as convenient to maximise recall and capture data in the present time. Participants could view their photographs and remove or destroy any they chose, before individual interviews in which participants led the discussion by controlling the order and timing of photographs thus maximising narrative agency. Careful attention was given to narrative continuity, narrative agency, countering meta-narratives, and small stories or chit-chat that is recognised as important to building a sense of self (Baldwin, 2005).

Table 1 Participant Characteristics

Name	Age	Gender	Ethnicity	Living situation	No. of photos	Length of interview
Angie	59	Female	NZ European	Living alone. Own home	24	59.16
Susan	55	Female	Māori	Living with partner, supported housing	17 (plus 600)	1.05.24
Peter	58	Male	NZ European	Living alone. Own home	8	40.26
Mike	64	Male	NZ European	Living alone, council flat	11	19.06 break 30.46

Findings

Interviews were recorded and thematic analysis (Braun & Clarke, 2012) was used within a qualitative descriptive framework to develop the following themes. Where Do I Live? What Do I Do? Who am I? A Place to Be Me. Who Do I Love? Hopes and Dreams. These themes are discussed in the following section.

Where Do I Live?

All four participants had taken photographs in and around their home with much of the discussion highlighting the positive aspects of home life. *"I love it, yes, I love it. The centre point of my life"* enthused Susan about the flat she shares with her partner and cat. One of five properties in a small, supported living complex, she is also the participant who spoke most effusively about the neighbours and took photographs to represent the houses and letterboxes around her *"... because it's the neighbour's house it's a neighbourly house."* This contrasted to Mike who although declaring his love for his relatively new home *"Oh I love it"* also highlighted the difficulties of living alone. *"Yea, um it can get lonely, but I just go, and go do something, like go and clean something to take my mind off things. It's hard but it's all good, I'm happy and it's cheap."*

Susan also talked about homemaking revealing a strong sense of pride in her home.

We're gonna have to get new furniture one day, ours is just bloody, it's wrecked. It's ruined. Our leather couch, it's got scratches on with the cats. The leathers peeling off, oh, we need to get a new lazy boy, new couch, and new sofa. The one sofa that we've got beside him goes down deep and the springs are broken yeah.

What Do I Do?

All participants had taken photographs to represent the things they do, often elaborating on the photographs, giving context, demonstrating knowledge, and seemingly enjoying the opportunity to share their passion. Angie used a photograph of sport on TV to express what this meant to her.

Figure 1 Angie: Sport on TV.



I really enjoy my sport, I really do, and I really enjoy cricket and it means a lot to me and, I just really enjoy the competitiveness of it and if it is a close game, it really gets me going. If it's a really close game... you sort of get like an adrenaline rush... that was really good, I was really thrilled about that.

She demonstrated a strong sense of pride and connection when asked about her photograph of the All Blacks doing the Haka. *"I like the Haka. I like the Haka, I like the Haka."* she repeated while smiling. Angie shared not only her extensive knowledge of sport, but informed opinions and memories of games and results. *"it was a draw on the last over and they had to have one over to decide. It was a mad over, so England got 18 runs and we had to get 19 runs to win but England won."*

Peter shared a photograph of his lounge from the viewpoint of his favourite chair, with his laptop and TV clearly visible. He talked about:

following the American political situation, Trump, the current Trump impeachment, ... they haven't passed a single piece of legislation since the Dems, since they have held the house, they have got a drug funding policy sitting there ready to go, and they got the Mexico Canadian free trade agreement sitting waiting to be signed off.

Opportunities for doing varied markedly between participants, Peter had photographed sports equipment, his basement workshop which he talked about renovating, his car, and a reading book, whereas Mike's opportunities for doing seemed limited to walking the streets, visiting friends, and reflecting on life. *"That's my favourite street I like walking up... sometimes I'll go and see a friend. Yeah, it's good, just memories that's all."*

Figure 2 Mike: My favourite street.



Who am I?

Despite having a long history of mental illness and service use, participants only referred to this intermittently, as if mental illness had travelled with them on their journey, a part of who they are, but not the sum of who they are. Susan expressed this clearly: *"I wanted to be known, I wanted my identity to be known and I wanted my friends to know that it is not just one-sided."* After showing a photograph of a rest home where her friend lives, when asked why she had not visited her friend, Susan declared it was because it was an institution, somewhere she refused to return to. Her disengagement from any further dialogue was powerful. She remained silent, averting her eyes to the ground, nodding, and shaking her head in place of verbal responses. At no other point did Susan or any of the participants answer questions using only body language. Her silence was taken as a clear signal that she did not wish to revisit this part of her life.

More commonly, photographs were a catalyst for participants to share memories that portrayed a sense of

self identity other than that of service user, highlighting the possibilities of photovoice. A photograph of a football game on TV prompted Angie to share positive memories.

I remember one game, rugby game, this is going back a few years, me and Mary went. I think she took the afternoon off work and Otago were playing the Springboks and it was teaming down with rain and the students were walking round in diving suits and flippers and it was so funny, and we actually beat them, and we were the only provincial side in New Zealand to beat the Springboks.... it was at Carisbrooke, and they put out a T-shirt Bok Buster... it had a picture of a deer or something and all the Otago players signed it at the back and Mary gave one T-shirt to me and my brother for Christmas and I've kept it. (Angie)

Mike's photograph of the park was also a catalyst for him to share childhood memories and reveal his view of himself as 'special' and being segregated from his peers.

Figure 3 Mike: Childhood Park.



I wish I wasn't kept there, but that used to remind me of when I was younger, when I was very young. I was in hospital when I was a kid, the one where St James is there. There used to be an old house there when I was a young boy, a boarding house for special people and we used to live there and go to the school, drive to the school around town we used to go to, that's when I was very young.

Limited literacy skills and difficulty expressing himself verbally are a part of Mike, and the quote above is the longest he made without prompting, again highlighting the possibilities of photovoice. While he continued to share information about his school memories, this was in response to questions leading to short truncated answers.

Among the myriad of photographs on Susan's digital camera were a collection of photographs taken on her recent trip to Gisborne with her mum and sister. She used one of these photographs to deliver her mihi mihi, expressing her cultural identity and connection to her whakapapa.

Yes, mum's is on her side and dad's is on his side, because both of the maraes, ones on a rise, one on the other side, the mounts up there. There's a big mountain you can go and see but you can't walk up it, you have to be a climber to get out there. Me and Tina tried to get as close as we could, take some photos of Mount Hikurangi, you might have heard of that mountain in Gisborne Waiapu which is our River our tribe is Ngati Porou, yea, a few things anyway.

Figure 4 Susan: Mount Hikurangi.



A Place to Be Me

Mike was the only participant to refer directly to the day service where the research took place leaving no doubt as to how much it mattered to him. *"It's my second home, I love going there, it's the people, it's the people, around you."* Other participant's references to the service were more covert, but connection to daily life was apparent. Items donated to the service, are sold to people who attend for a nominal charge, giving them access to affordable clothing and household goods and Susan had photographed various items in her flat that she has 'bought' at the service. *"the mats I got from here which is outside now. I bought it here yes, bought here, I bought that here years ago."*

Figure 5 Susan: Doormat.



Angie demonstrated the connection between home and the things made at the service even though she did not perhaps feel as included in the making process as she could have or would like to have. *"This one here is a birdfeeder I made... I made that with Stanley but Stanley did most of it, I just sort of painted it, he sort of hung it up."* This example highlights important implications for occupational therapy in the experience of engaging from a client's perspective.

Who Do I Love?

A photograph of a chair highlights the potential of photovoice as Susan used it to articulate the depth and strength of her relationship with her partner, Chris.

Figure 6 Susan: Chris' chair.

This one here is about Chris' life in his chair, the life and soul of the party is when he sits in the corner of his chair. Sleeps in it, rocks in it. It doesn't get moved. That's the only one he likes, loves, and that's probably the only one he will have.

Angie was more direct photographing her sister and left us in no doubt as to the meaning of this relationship. *"She means the world to me Mary. She's very good to me. She can be big bossy sister at times, but she means the world to me."*

Such strong connections were not limited to family and friends with participants expressing not only strong relationships to staff members but evaluating what it was about these relationships that they valued. Mike's photo of Fran, a peer support worker facilitated this conversation.

Figure 7 Mike: Fran.

And what I like about her, we can talk to each other, and it stays there, and she's helped me a lot... she's an amazing person. Not scared of anything, don't seem to worry too much, I like her as a friend... I just feel happier... you know she listens to you. She's an amazing lady.

Connection to staff members and the value in the relationship was also shared by Susan:

Elizabeth is very official, and very therapeutic, and very practical, and very smart, very down to earth,

and a nice person to know and to get on with... happy to help whenever she can, she makes people better, she makes people feel worth it, and says all the right things to hear for your own dignity.

Susan also expressed empathy and a desire to reciprocate or invest in relationships:

Well, I don't see her very much and it's sad to know that she's up there all the time, it would be nice if we could go and see her one day for afternoon tea if she wants up there, if she's well. I'd like to make her something or buy something for her for Christmas?

Hopes and Dreams

Occasionally participants hinted at a different life, one they had hoped for, or still do hope for, the chance to get away, to change a routine or to leave town. Mike shared a dream *"if I'd gotten mechanical minded, I wouldn't have minded being a mechanic yes, things like that enters my head. Yeah I'd have loved to have been doing up cars yeah."*

A weekly lotto ticket is an experience Angie shares with her sister Mary, the ticket sits under the lucky leprechaun, and occasionally they share dreams of winning, looking at houses on the internet.

It's just bit of fun really but if we win it, we'd be oh my God, if we won it, we'd be oh my God, this would be a nice house when we win lotto, when we win lotto this will be a nice house when we win lotto, she gets on the computer, this will be a nice house.

Many of these hopes and dreams seemed beyond the control of individuals, even *"trips we go on each year,"* and *"payday when we get our smokes"* (Susan) were dependent on external factors. Peter implied dreams are of little relevance as *"people live hand to mouth and can't see further than next week."* These findings illustrate how the photographs, the interview narrative, along with previous knowledge and relationships generated the data which is now discussed alongside the literature.

Discussion

From an occupational perspective, private and stable housing, or 'being in place' is necessary for supporting the interconnections between being, belonging and developing a sense of normality (Townley, et al., 2009). All participants were in stable housing at the time of interview and a sense of 'being in place' was apparent as participants had photographs of activities, people and possessions connected with home. Mike often struggled to articulate 'what matters' but did not hesitate to express love when asked about the photo of his flat while Susan described it poetically as central in her being.

As a material resource, home provides meanings such as emotional comfort, security and self-esteem and creates a stage for the 'little things' in everyday life (Borg et al., 2005) such as watching television. In this way, a home may be vital for maintaining a sense of self, and contrasts markedly from the controlled routines of institutional life (Borg et al., 2005).

Homemaking or transforming spaces into meaningful places, and houses into homes (Borg et al., 2005) was illustrated in the findings. Susan talked about her desire to upgrade her furniture, rugs and flowerpots, and Peter talked about renovating his basement and roof. While for some these

activities seemed welcome, for others, they were a chore *"this is something I hate, I hate gardening."*

Occupational therapists working in a service environment need to be mindful of upstream determinants such as housing that impact on an individual's recovery journey and recognise homemaking as a legitimate occupation that can strengthen a sense of place and self.

All participants talked of activities that they chose to do and the meaning they attach to them. For Angie much of 'doing' is watching sport on TV or listening on the radio, as well as occupations that provide opportunity for social connection, personal growth and forming an identity, which facilitate 'being' as she reflects and develops a sense of self. This became evident when asked about the haka.

The activities people choose to do provide meaning, nurture positive identities, and promote empowerment through independent decision making, thus facilitating recovery. These activities can be seated in small everyday acts of living (Davidson & Roe, 2007). The participants in this study used activities such as walking the streets, watching sport on TV, or following politics, to build an identity beyond that of a service user. However, the solitary nature of these activities is also apparent, resonating with research describing how people with SMI spend long periods of time alone engaged in solitary activities such as watching TV and smoking (Milbourn, et al., 2017). Questions remain as to whether the opportunities and choices for doing and being are sufficient, as 'doing' for meaning is often overlooked as self-care, and productivity is traditionally perceived to be more important (Hammell, 2004). "It is the occupation of governments to develop policies that drive occupation within populations" (Wilcock & Hocking, 2015. p. 148), and as meaningful doing is a vital component of well-being, occupational therapists should consider that meaningful doing is no longer a treatment but a human right (WFOT, 2006).

All participants in this study have a long history of mental illness which was acknowledged at various points during the interview process but, in contrast to the literature this did not present as a dominant component of participant's identities (Hamer et al., 2014; Ørjasæter, et al., 2017). For one participant, a historical institutional identity was one she refused to return to, falling silent and disengaging when asked about it. No answer was an answer.

Occupational therapists understand the relationships between occupation, or doing, and health and well-being, recognising that what we do forms our identity. Through doing and being we achieve becoming or who we wish to be, our future self, building hope, and through belonging we achieve connection to people and place (Wilcock, 1998; Hammell, 2004), therefore we are what we consistently do (Christiansen, 1999).

Not everyone views identity through an occupational lens, maintaining that we are essentially narrative beings, our self-identity is the stories we tell ourselves and others, and the stories others tell about us. As stories continue over time our future is influenced by the past, necessitating narrative cohesion, integrating past and future events in stories creates some form of meaningful whole out of the different phases in one's life (Baldwin, 2005). The occupational therapy concept of 'doing with' provides opportunity for therapists to engage in chit-chat collecting stories that build a bridge between occupation and narrative views of identity thereby promoting the development and maintenance of self.

Opinion is divided as to the value of day services (Bryant, et al., 2010) and participants in this research seem to agree with the supporters, reporting that the connection to people, and the things they had made or bought at the service mattered. Angie talked about a bird table she had made at the service and how much it mattered, but she also reflected on the fact that a staff member had done most of the work, valuable feedback about the tension between 'doing with' and 'doing for.' The former providing opportunities for chit-chat, fostering confidence, building skills, and strengthening relationships, the latter potentially undermining these and fostering helplessness and dependency. Thus, photovoice provided Angie with the opportunity to engage in genuine service evaluation.

Connection is well documented as an important part of recovery (Leamy, et al., 2011; Williams, et al., 2012) and maintaining mental health (Jody, et al., 2008). A study of service user views reported that recovery was only possible in the presence of 'kindership': when other human beings - friends, family, and staff - care about you (Cheng et al., 2009). The findings of this study align with this thinking as all participants had taken photos, or photos to represent, family, friends and staff that were important to them. Reciprocity in relationships with the giving and receiving of support has been discussed in the recovery literature and highlighted as an important aspect of recovery, decreasing social isolation, and increasing self-worth (Petros et al, 2016). The concept of reciprocity is pertinent when considering that the essence of a professional relationship is meeting the needs of the service user and does not readily allow the opportunity for reciprocity, yet participants considered those relationships with staff, including peer support workers, mattered.

Hope is defined as the expectation or desire for positive events in the future (Hayes, et al., 2017) and is considered essential to recovery (Schrack et al., 2012). It is directly related to having control over our own destiny, and when people do not feel in control, they lack hope (Chandler cited by Hari, 2018. p.137). Participants appeared to have limited control over the things they desire in the future. According to Hayes et al., (2017) a lack of control creates lower levels of hope for people with SMI making recovery difficult, which has implications for the amount and types of support required. Interventions for improving hope centre around illness management, relationships, peer support, self-directed realistic goals and increased self-esteem (Schrack et al., 2012), yet an individual's reality and socio-political environment can result in loss of hope something individual interventions fail to acknowledge (Thomas & Knight, 2018).

Limitations

This research recruited four participants to explore their experience of what matters. The small sample size selected from a day-based service the participants attend severely restricts transferability of findings. Being the manager of the service and having considerable prior knowledge of the participants brings the primary researchers impartiality into question. However, the strength and longevity of the research participant's relationship underpinned the trust required to ensure full engagement and honest reporting and dialogue. As a Masters' project, this was the first time the primary researcher had engaged in a research project thus increasing the likelihood of oversights or misinterpretation. Both these issues were addressed through a reflexive journal, documented decision making and supervision.

Conclusion

Recovery demands that the lived experience of illness is respected and that people, not professionals are the experts in their own life. This requires the voices of those accessing services to be heard. This research found that people with SMI engaged willingly with photo elicitation and were able to articulate what matters to them and provide insights into recovery focused services.

Key Points

- Connection to place is significant to sense of self and belonging, a platform for recovery providing opportunities for meaningful doing.
- Occupational therapists can play an important role in helping people in recovery build reciprocal relationships.
- 'Doing' and 'doing with' align effortlessly with core concepts of recovery, building identity and facilitating narrative cohesion through sharing stories in 'chitchat'.

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Mental Health Recovery Star: Review of the Evidence and Development of an Action Plan to Improve Practice

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Abstract

This Comprehensive Literature Review set out to consider the evidence which underpins the Mental Health Recovery Star as an effective outcome measure for determining the functional progress of people experiencing mental illness. John Kotter's evidence-based strategies for the implementation of change to practice were also reviewed.

Main results: Findings confirmed the Recovery Star to be effective due to its established recovery model characteristics of being client-centred, collaborative and recovery-focused and having robust psychometric properties. There was also evidence to support the successful use of John Kotter's model for implementing practice change.

Keywords: Literature review, recovery model, psychometric properties, John Kotter's change implementation model, occupational therapy

Reference

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One of the most frequently cited outcome measures in the mental health recovery literature is the Recovery Star, an innovative recovery model-based, patient reported, outcome measure (PROM). The model was developed in the United Kingdom by the Mental Health Providers Forum and Triangle Consulting (Dickens, Weleminsky, Onifade & Sugarman, 2012; Onifade, 2011). According to Burns and MacKeith (2013), the Recovery Star "...focuses on the ten core areas that are critical to recovery: Managing mental health, physical health and self-care, living skills, social networks, work, relationships, addictive behaviour, responsibilities, identity and self-esteem, and trust and hope" (p. 2). Furthermore, the Recovery Star is reported to be useful in monitoring difficulties the service user may experience in each of the ten Recovery Star areas and their progress towards addressing the identified areas of difficulty. These qualities facilitate goals being set to address the difficulties as part of a subsequent intervention thus

enabling the Recovery Star to be used as a key work tool (Burns & MacKeith 2013) (see Figure 1). This review of the Recovery Star is underpinned by Kotter's (1996) eight stages of change model. The purpose of the review was to explore two questions:

1. What is the evidence for the Recovery Star as an effective outcome measure for determining the functional progress of people living with mental illness?
2. What are the effective evidence-based strategies for the implementation of the Mental Health Recovery Star?

Kotter's Stages of Change Model

The eight stages of change model (Kotter, 1996) is frequently cited in literature. According to Stragalas (2010), Kotter's model is directed by broad, albeit prescribed implementation steps within each of the eight stages, all based on extensive research that has helped to transform countless organisations.

The eight stages of change advocated by Kotter are as follows:

1. Establishing a sense of urgency
2. Creating the guiding coalition
3. Developing a vision and strategy
4. Communicating the change vision
5. Empowering broad-based action

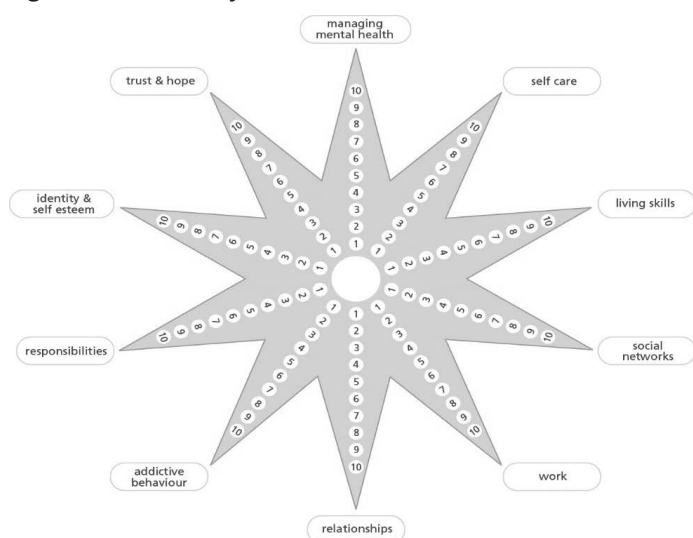
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Figure 1 *The Recovery Star (3rd Edition).*

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 www.outcomesstar.org.uk

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6. Generating short-term wins
7. Consolidating gains and producing more change
8. Anchoring new approaches in the culture. (Kotter, 1996, p. 21)

Project Site

This project was undertaken at a community mental health and addiction service that provides occupational therapy rehabilitation for clients who have high and complex mental health needs. The service's main focus is to enable community participation by building the required functional skills for engagement in meaningful occupations or activities of daily living (ADLs) in the areas of self-care, productivity, and leisure. According to Ikiugu, Hoyme, Mueller and Reinke (2015), "Meaningful occupation is the core construct underlying the practice of occupational therapy" (p. 47). The service strives to achieve this through its three streams of social inclusion, independent living and vocation/work. Social inclusion includes sports and physical exercise programmes that include: basketball, touch rugby, swimming, walking; community gardening, and adventure therapy. The music studio offers 1:1 instrument learning or music beats production and recording sessions, group freestyle music jam sessions, music presentations at community events. Independent living includes bike building, repair, and maintenance for community transportation, computer literacy, gardening, carpentry, budgeting assistance, cooking programme, sensory interventions. Vocation/work includes work skills training programme, time-limited part-time work opportunities in car cleaning, lawn mowing, worksite maintenance, and office and other community premises cleaning.

Methodology

The methodology was a Comprehensive Literature Review (CLR) (Onwuegbuzie & Frels (2016). Described by Onwuegbuzie and Frels (2016), the CLR is a mixed-methods approach to research that can be used as a stand-alone study or as a part of another study. In this project, the CLR was completed as a stand-alone study.

Methods

In this review, the methods section was based on the seven stages outlined within the three phases of the CLR Framework. The main inclusion criteria for this project were;

- literature published in English in the past 10 years related to the use of the Recovery Star and no other outcome star
- articles that relate to change management/ implementation
- secondary information sources (dissertations and theses) were acceptable.

Grey literature, such as unpublished studies, was used for supplementary information and scanning of their reference lists on condition that they also met the inclusion criteria. The main exclusion criteria for this project were:

- literature not using English language
- literature published more than 10 years ago
- literature addressing other outcome stars or other outcome measures.

Data Searches Undertaken

Data collection was in the form of a literature search using electronic databases as shown below;

1. DHB's 'Discovery' search database (Searches across all Library resources)
2. Auckland University of Technology databases
3. Google Scholar.

Most of the selected studies related to question one were identified as retrospective chart audit designs also referred to in other literature as retrospective chart review (RCR) (Sarkar & Seshadir, 2014). Sarkar and Seshadir described RCRs as research that involves the study of pre-collected data which includes summarizing and subjecting the data to sufficient statistical analysis and drawing conclusions based on the evidence and reasoning.

In response to question one, and in keeping with the inclusion/exclusion criteria for the review, 25 articles were identified of which 14 were selected and used as evidence in this project. In response to question two, and in keeping with the inclusion/exclusion criteria, 20 articles were identified of which 10 were selected and used as evidence.

The Critical Appraisal Skills Programme (2018) framework was used in the analysis of all the selected research articles.

Findings: Question One

What is the evidence for the Recovery Star as an effective outcome measure for determining the functional progress of people living with mental illness?

Within the data, a significant number of studies found the Recovery Star to be an effective outcome measure for determining the functional progress of people living with mental illness. This was mainly because the selected studies established that the Recovery Star was underpinned by the mental health recovery model it was derived from. Four themes were drawn from the data that determined the effectiveness of the Recovery Star: client centeredness; collaborative practices (between clients and service providers); recovery model and recovery goal-focused; robust psychometric properties. Each of these themes will now be discussed in further detail.

Client Centredness

Client-centredness emerged as a significant prerequisite to the Recovery Star being acknowledged as an effective outcome measure for determining the functional progress of people living with mental illness. Slade, Adams and O'Hagan (2012) highlighted this when they explained that the implementation of recovery-oriented practice should reflect client-centredness with the deliberate focus of assisting service users to lead a meaningful life. This consequently makes client-centred practice an essential component that underpins the effectiveness of the Recovery Star. Furthermore, McEvoy, Schauman, Mansell and Morris (2012) explained that the recovery model supported client-centredness through its association with a sense of control. Considered a form of personal authority (which is synonymous with client-centredness) a sense of control is needed to determine one's future to pursue a meaningful and productive life and to positively affect societal attitudes towards people living with mental illness. Equally, Burgess, Pirkis, Coombs and Rosen (2011) established the Recovery Star as one of the outcome measures related to personal recovery, which is in keeping with contemporary mental health practice, service delivery and design. Likewise, Burgess et al., (2011) explained that client-centredness is a significant prerequisite for the effectiveness of the Recovery Star as an effective outcome measure for determining the functional progress of people living with mental illness. This is in keeping with Jacob, Munro, Taylor, and Griffiths (2017), who established that the philosophy of client-centredness is underpinned by recovery model oriented practices such as meaningful occupations chosen by the client. Finally, Eisen et al., (2010) argued that the Recovery Star is also a self-report measure "research on patient-centred care supports the use of patient/consumer self-report measures in monitoring health outcomes" (p. 170). Similarly, in their study, which considered service user views regarding mental health outcome measures, Crawford et al., (2011) found evidence of patient support of patient-reported outcome measures as being more relevant and appropriate in practice. Hence the findings by both Eisen et al., and Crawford et al., enhanced the use of the Recovery Star, as an effective outcome measure for determining the functional progress of people living with mental illness. However, it should also be noted that, despite favouring the use of patient-reported outcome measures, the service users in the study by Crawford et al., (2011) did not identify the Recovery Star as a patient-reported outcome measure. Moreover, the authors also stated that the Recovery Star was not created with service user input in concurrence with the study by Sklar et al., (2013). This assertion raised questions regarding the client-centredness of the Recovery Star in contrast to other studies (Dickens et al., 2012; Killaspy et al., 2012; Tickle et al., 2013) that identified the Recovery Star as a patient-reported outcome measure developed with service user input.

Collaborative Practices Between Clients and Service Providers

The collaborative practice theme emerged from the data as another essential factor influencing the effectiveness of the Recovery Star as an outcome measure for determining the functional progress of people living with mental illness. Still, within the data, a significant majority of the selected studies established that collaborative practice enhanced the use and practice of the recovery model principles which underpin the Recovery Star. Data also showed that a significant number of

the selected studies used service users in their research, thus validating client-centredness and collaboration when using the Recovery Star.

On the contrary, a study by Jacob et al., (2017) concluded that the Recovery Star should not be recommended as a routine outcome measure but only used in the facilitation of collaborative care planning. According to Jacob et al., (2017) collaboration is the key to successful recovery-oriented practices. These authors further explained that the multi-dimensional aspect of the recovery-oriented practice requires a multidisciplinary team approach with collaboration and partnership involving the service users, service providers, family members, and policymakers. All of these components underpin the mental health recovery model principles.

There was also evidence of the Recovery Star's collaborative use in Aotearoa New Zealand as shown in the study by Joy-Johnson (2016) who researched the alliance (collaboration) between client and practitioner when using the Recovery Star. Joy-Johnson explained that the Recovery Star had been given recognition for potentially offering a means towards building a positive working alliance (collaboration) between service users and practitioners, and supporting their alliance-building process and recovery principles during interventions. On the contrary, Killaspy, White, Taylor, and King (2012) foresaw the tool facing client/practitioner collaborative challenges when used with service users with significantly severe mental health symptoms that could be a barrier to their engagement in productive discussions that are necessary for rating the Recovery Star's ten domain scales.

Recovery Model and Recovery Goal Focused

Within the data, a significant number of studies demonstrated that the Recovery Star was underpinned by the recovery model and was recovery goal-focused. There was also further evidence of the Recovery Star's adoption in recovery-focused mental health services (Dickens et al, 2012). Recovery model principles were also acknowledged within the data as principles that fed the Recovery Star's natural fit with the model.

Furthermore, the study by Lloyd, Williams, Machingura and Tse (2016), showed clinicians adopting the Recovery Star as a routine outcome measure because it assisted service users in the identification of their key recovery goals whilst also tracking the progress of their recovery journey. Lloyd et al. also concluded that the Recovery Star was able to enhance the service user goal-setting process whilst supporting both the service and organizational goals and enabling practitioners to focus on goals that are important to the service user.

Robust Psychometric Properties

Within the data, approximately half of the selected studies discussed and established the significance of robust psychometric properties as being a contributing factor that influences the effectiveness of the Recovery Star. Some of the psychometric properties validated by the selected studies follow. See Table 1 on the next page.

Table 1 Psychometric Properties Validated by the Selected Studies

Psychometric Properties	Selected Studies That Validated Them
Clinical Utility	Tickle et al., 2013; Killaspy et al., 2012; Placentino et al., 2017; Dickens, Weleminsky, Onifade & Sugarman, 2012; Lloyd, Williams, Machingura & Tse, 2016; Frost et al., 2017; Griffiths, Heinkel & Dock, 2015; Good, 2019.
Responsiveness	Dickens, Weleminsky, Onifade & Sugarman, 2012; Frost et al., 2017; Griffiths, Heinkel & Dock, 2015; Placentino et al 2017; Larsen & Griffiths, 2013; Good, 2019.
Inter - Rater Reliability	Sklar et al, 2013; Killaspy et al. 2012; Placentino et al. 2017; Good, 2019.
Convergent Validity	Frost et al., 2017; Killaspy et al., 2012; Placentino et al., 2017; Good, 2019.
Acceptability	Killaspy et al, 2012; Placentino et al, 2017; Good, 2019.
Temporal Stability	Killaspy et al. 2012; Placentino et al. 2017.
Internal Consistency	Dickens, Weleminsky, Onifade & Sugarman, 2012; Sklar et al, 2013.
Item Redundancy	Dickens, Weleminsky, Onifade & Sugarman, 2012.
Test-Retest Reliability	Killaspy et al, 2012; Placentino et al, 2017.
Face Validity	Lloyd, Williams, Machingura & Tse, 2016.

Clinical Utility. The majority of the selected studies demonstrated good clinical utility of the Recovery Star. Ease of use and acceptability of the Recovery Star was described by both service users and providers. The studies also established that the Recovery Star took a reasonable time to complete, which is essential when working with people who have a short attention span. This component of clinical utility supported the Recovery Star as an effective outcome measure for determining the functional progress of people living with mental illness.

Responsiveness. The Recovery Star's ability to detect change over time was validated by almost half of the included studies. These peer-reviewed studies demonstrated the responsiveness of the Recovery Star to change that takes place during interactions with mental health service providers.

Inter-rater Reliability. The Recovery Star's inter-rater reliability was demonstrated through four of the selected studies. In the study by Placentino et al., (2017), readings from the participating practitioners demonstrated consistency in applying the star scales with a resultant Cohen's kappa coefficient of > 0.7 in all combinations. Cohen's kappa is an index widely used to assess agreement between raters (Tang, Hu, Zhang, Wu & He, 2015). A later

study by Good (2019), also indicated that the Mental Health Recovery Measure by Killaspy (2012) had lower intra-class coefficients of between 0.46 – 0.77 (good – excellent is between 0.6 – 1.0).

Convergent Validity. The Recovery Star's convergent validity was demonstrated through four of the selected studies that used validated outcome measures to assess similar constructs to the Recovery Star. These studies were, namely, the Health of the Nations Outcome Scales (HoNOS), The World Health Organisation's Quality of Life assessment (WHOQOL – BRE), Global Assessment of Functioning and CGI (Placentino et al. 2017); HoNOS, Life Skills Profile (LSP) and the Mental Health Recovery Measure (Killaspy et al. 2012); HoNOS and Kessler Psychological Distress Scales (K10) (Frost et al., 2017). The Life Skills Profile was also reported to be a well-established standardized measure of social functioning (Killaspy et al. 2012).

Acceptability. This was demonstrated to be at the appropriate level by both service users and practitioners (Killaspy et al, 2012; Placentino et al, 2017; Good, 2019). Good emphasized the appropriateness and acceptability of the Recovery Star to culturally and ethnically diverse populations which enhances universal generalizability.

Temporal Stability and Test-retest Reliability. Within the data, evidence of temporal stability was also demonstrated when the Recovery Star was completed within a short time frame set by the researcher (Killaspy et al. 2012; Placentino et al., 2017). In a recent study, Good (2019) concurred with Killaspy et al. and Placentino et al. who established the intra-class coefficient of > 0.7 in all outcome domains confirming good test-retest reliability.

Internal Consistency. The study by Dickens et al. (2012) established the Recovery Star's high consistency of Cronbach's alpha $\alpha = 0.85$ representing very good consistency. Dickens et al. further explained that they found that the Recovery Star appeared to measure an underlying recovery-oriented construct which is in line with the underpinning recovery model that the Recovery Star was developed from. The study by Sklar et al. (2013) also indicated that internal consistency was estimated at $\alpha = 0.85$.

Item Redundancy. The study by Dickens et al. (2012) established the correlation of almost all items with one another at levels that exceeded chance. However, Dickens et al. indicated that no item-item correlation exceeded the 0.7 threshold.

Face Validity. The Recovery Star also displayed high face validity (Lloyd et. al, 2016) which enabled the clinicians to identify service user goals. Consequently, the clear identification of service user goals leads to the improved function of people living in the community with mental illness. Of note, the findings from this CLR are in keeping with a review by Good (2019) who concluded that the Recovery Star's psychometric properties were acceptable and useful such that it produced results that converged with other relevant and validated mental health outcome measurement tools. Good (2019) also found that the recovery star was responsive to change and had temporal stability. Good's review presented initial evidence illustrating that practitioners could consistently apply the scales with the same information (interrater reliability). It must be noted that, at the time of publication, Good was a research analyst at Triangle Consulting, the developers of the Recovery Star, which could have introduced bias as an 'interested party'.

It should be further noted that two of the selected studies (Sklar et al., 2013; Burgess et al., 2011) had findings that contradicted the majority of the selected study's findings, especially regarding the robustness of the psychometric properties of the Recovery Star. In their summary of instrument quality, Sklar et al. stated that in terms of psychometric properties, ease of administration and service user involvement, the Recovery Star did not meet their study's evaluation criteria. Burgess et al., (2011), in reviewing existing recovery outcome measures routinely being used in Australia, concluded that the Recovery Star had not been scientifically scrutinized, did not demonstrate sound psychometric properties, nor promote collaboration between consumers and service providers, or apply to the Australian context and more, was not acceptable to consumers. This is in sharp contrast to the later Australian study (also selected in this review) by Lloyd et al. (2016), which, among other findings supporting use of the Recovery Star, concluded that the Recovery Star was useful as an outcome measure and clinical instrument for a service that is recovery-focused.

Overall, the findings from this CLR have established the Recovery Star as an effective outcome measure for determining the functional progress of people living with mental illness. Additionally, the data also showed that the Recovery Star had robust psychometric properties that enhanced its effectiveness as an outcome measure.

Findings: Question 2

What are the effective evidence-based strategies for the implementation of the Mental Health Recovery Star at a community mental health service in Aotearoa New Zealand?

Within the data, Kotter's model of change (Kotter, 1996) was wholly or partially demonstrated and/or supported by the majority of the selected studies as an effective evidence-based change implementation strategy or model. This was mainly because the selected studies determined that Kotter's model possessed certain essential change implementation elements that enhanced its suitability and appropriateness for the implementation of the Recovery Star at a community mental health service in Aotearoa New Zealand. This section will consider and discuss those elements as themes and/or sub-themes, as follows: successfully used as a whole in active research (direct implementation is well researched); partially used in successful change implementation; found to be highly effective (easy to use, structured, and provided an effective framework to implement a practice change in healthcare); successfully used in tandem/combination with other models.

Successfully Used in Active Research

What emerged from within the data was that half of the selected studies implemented Kotter's model as a whole and reported positive outcomes in terms of its successfully guiding change implementation. The study by Maclean and Vannet (2016) described Kotter's model as a useful guide that had developed services across several health boards and facilitated significant improvements in patient care standards. Also, the successful use of Kotter's model to maximize change impact was established by some studies despite implementation difficulties being reported with some components of the model (Dolansky et al., 2013). However, Dolansky et al., did not complete the eighth and last step of the model and no reason was given for this. Furthermore, Pollack and Pollack (2014) proved Kotter's model to be

effective in change management despite the need for some contextual adaptations.

On the contrary, some studies established that there was mixed support for Kotter's model (Applebaum et al, 2012; Baloh et al, 2018). These studies recommended the model to be used only as an implementation planning tool. Still, the review by Applebaum et. al. established that there is support for most of Kotter's eight steps but highlighted the fact that when the study was completed, there had been no formal empirical studies that had analyzed the whole model. In another study, Applebaum et al. described Kotter's model as a good guideline that does not guarantee success.

Partially Used. Some of the studies demonstrated that change could still be implemented without necessarily completing some of the eight steps in Kotter's change model (Dolansky et al, 2013; Cunningham & Kempling, 2009; Baloh et al, 2018; Applebaum et al, 2012). This is contrary to recommendation that successful business change implementation leaders should complete Kotter's eight stages in the right order (Brisson-Banks, 2010). As described by Kotter (1996), the right order is to sequentially follow his model's eight stages.

The study by Cunningham and Kempling (2009) demonstrated only the first two steps as important. Pollack and Pollack (2014) concurred with this assertion and explained how important Kotter's model's stage one of creating a sense of urgency was. Kotter wrote a whole book entitled "A Sense of Urgency" (Kotter, 2008) which was exclusively focused on this stage alone. Cunningham and Kempling also emphasized the importance of Kotter's Model's stage two of creating a guiding coalition as they asserted that change would falter without a guiding coalition. Similarly, the review by Appelbaum et al. (2012) established support for most and not all of Kotter's Model's eight steps and asserted that there were no studies at that time that had covered the whole model. Furthermore, the study by Baloh et al. (2018), reported unexplainable successful change implementation despite skipping some steps.

Use in Tandem With Other Models in Successful Change Implementation. Baloh et al., (2018) recommended using Kotter's model with other models as they would complement one another. Additionally, the study by Small et al., (2016) reported failure of previous attempts to effect change, in tandem with another model, before Kotter's model was used with success in change implementation being achieved.

Easy to use. Applebaum et al. (2012) established Kotter's model as readily acceptable to use by managers since its basis was the real-life experience and its prescribed eight stages were easy to follow. Some studies explained that this phenomenon was because Kotter's model was popular in varied organizational settings as change managers/agents had embraced its practicality despite there being no empirical evidence supporting its use (Small et al., 2016). The review by Applebaum et al. was reportedly the first thorough review of Kotter's model in the 15 years since its introduction.

Structured. Some studies demonstrated that Kotter's model gave structure to change implementation in terms of providing systematic plans for change (Small et al., 2016). Furthermore, King et al. (2018) established that Kotter's model offered "...a structural framework for analyzing processes of organizational change and identifying areas of deficit in managing these processes" (p, 285).

Provides an Effective Framework to Implement a Practice Change. Half of the studies determined that Kotter's model could be useful as an effective framework for the implementation of practice change. The study by Applebaum et al., (2012) also similarly established that Kotter's model would be at its most beneficial when used as an implementation tool. Also, Baloh (2018) "Reported that Kotter's model has a better fit with implementation... can be a useful guide for nurse manager in implementation change." Small et al. (2016) recommended that Kotter's model be used to provide "...an effective framework to implement a practice change in a health care environment" (p, 307), and King et al. (2018) concluded, "...that Kotter's model could provide a framework within which organizational change can be managed in an iterative process..." (p, 286).

Despite a small percentage of the selected studies' conclusions expressing reservations about either the lack of adequate empirical evidence supporting Kotter's model or only supporting some of Kotter's 8 stages of change, there was a consensus demonstrating full or partial support of this model as appropriate for the implementation of the Recovery Star. These findings consequently led to the development of the Implementation plan presented in the next section.

The Implementation Plan

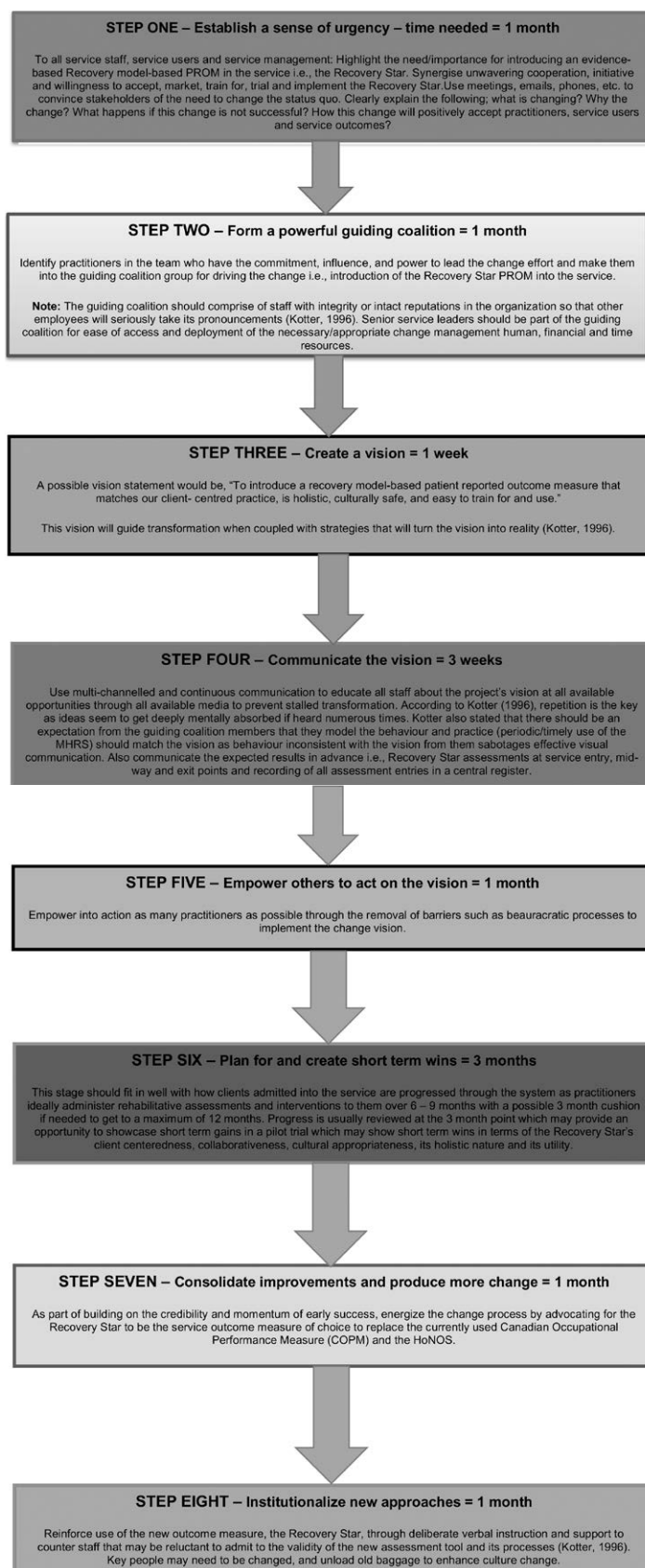
Pulling together the findings from the literature review and the overview of Kotter's Model of change, the Implementation Plan in the Flow Chart in Figure 2 opposite will be used to roll out the Recovery Star in a community mental health service.

Discussion

Across the findings, it was clear that the Recovery Star would be an effective tool to use in practice because it is client-centred, collaborative, recovery-model and recovery-goal-focused and has robust psychometric properties. These qualities consequently meant that the Recovery Star would be a natural fit for use within the recovery model that has been embraced by the Aotearoa New Zealand Mental Health and Addictions Sector. This enhances the Recovery Star's appropriateness and relevance in the Aotearoa New Zealand Mental Health and Addictions Sector which is aligned to universal trends regarding the recovery model's significance in mental health (Osborn & Stein, 2017). This means that, in practice, the Recovery Star's client centeredness can be used with every service user's recovery journey which consequently makes it adaptable to a varied range of services. While there were challenges with accessing Aotearoa New Zealand context data and randomized control trials (RCTs), the client centeredness of the Recovery Star means that a comparative sample is not needed.

The recovery model-oriented multidimensional aspect of collaborative practice, particularly as explained by Jacob et al. (2017), involves the multi-disciplinary team, the service user, service provider, family/whānau, members of the community and policymakers. These consequently enhance and complement the strengths-focused and culturally focused Recovery Star which gives some measured relevance to the Aotearoa New Zealand context. Finally, the established robustness of the Recovery Star's psychometric properties confirms its effectiveness as an outcome measure which consequently makes it valid, reliable and safe for use in a range of contexts, and with people experiencing a range of mental health issues.

Figure 2 The Implementation Plan.



Due to its established client centeredness, collaborative nature, robust psychometric properties, and its being recovery-focused in a recovery model-driven service, the Recovery Star fits nicely alongside other recovery outcome measures in current use. This will consequently afford practitioners a wider choice of outcome measures to use. In addition, this review's validation of the Recovery Star and Kotter's model, which culminated in the development of the implementation plan, is such, that any service could now pick up and implement the plan with some confidence.

As the Aotearoa New Zealand Mental Health and Addiction Services sector's funding is ring-fenced (Ministry of Health, 2019), it is available for essential service needs, such as the introduction of the recovery-focused PROM, the Recovery Star, which will be an enhancement to current service delivery, consequently leading to improved service outcomes. This consequently makes workforce upskilling a priority with regards to funding the training needs of the practitioners and the purchase of the required practice assessment resources. In addition to funding, strong sector leadership and supportive legislation will also support the dynamic service needs in response to the needs of the constantly evolving Aotearoa New Zealand service user population. More importantly, sector leadership will also need to demonstrate the outcomes achieved for the funding received, which the Recovery Star can do.

While it was relatively straight forward to establish the effectiveness of the Recovery Star from the evidence collected/analyzed, it was much more difficult to find out whether the Recovery Star would be useful to include in the Aotearoa New Zealand context. It would be important to understand the Recovery Star from an Aotearoa New Zealand bicultural context and perspective, while also simultaneously being cognizant that Aotearoa New Zealand is a highly cosmopolitan multicultural society. Future studies would do well to explore and address context issues.

Strengths of the Review

One strength of the review was the inclusion of clear guidelines, developed by Onwuegbuzie and Frels (2016), which provided a much-appreciated step-by-step framework for undertaking a comprehensive literature review. Additionally, the use of the CASP (2018) framework (in the analysis of all the selected research articles in combination with the reviewer's green/amber/red colour grading system enabled the systematic and consistent identification of selected research. Green for robust studies, amber for moderately robust studies, and red for poor studies. A further strength of the review was the inclusion of a significant number of quantitative studies that utilized the renowned and established Statistical Package for the Social Sciences (SPSS) in their data analysis which enhanced the validity and reliability of the study results and findings of those selected studies. Also, a significant number of selected studies were Retrospective Chart Audit Reviews (RCARs), whose robustness is enhanced by the fact that they have no chance of data loss due to following up since their cohorts would have been assembled from already available data (Keogh & Stenson, 2014). RCARs' robustness also emanates from their capability to reduce bias during measurements since both the research question and expected outcome would not have been known.

Limitations of the Review

The absence of randomized control trials (the so-called "gold standard" of evidence/literature reviews) in the selected review studies may have compromised the weight of this review's findings. More than half of the selected studies for question one were Retrospective Chart Audit Reviews whose data was from the past of which the researcher has no control over measurement quality, with possibilities of important data having been excluded and being susceptible to the effects of confounding, making causal effects difficult to establish. Most studies in question one used convenience sampling selection which may have introduced selection bias as most studies selected used convenience or opportunity sampling which has the highest likelihood of producing a biased sample as it presents unequal opportunities for potential participation in the research (Taylor, 2007). There are also possibilities that due to the limited scope and timeframe for the project that key research/literature may have been missed.

Conclusion

This project established that the Recovery Star was an effective outcome measure for determining the functional progress of people living with mental illness. This conclusion is significant given the government's priority on mental health, client-centred practice and the measurement of outcomes as stated in He Ara Oranga (2018). As has been noted, the MoH is required to improve, promote and protect the mental health, addiction, and independencies of all Aotearoa New Zealanders (Ministry of Health, 2019) of which the introduction of proven, effective, evidence-based PROMs such as the Recovery Star will play a significant role. Furthermore, with the Aotearoa New Zealand mental health and addictions sector continually striving to achieve better service user outcomes, the above conclusion will enhance the continued accomplishment of acceptable and appropriate service user quality and safety within the sector.

The project also developed an evidence-based nine-month-long implementation plan for introducing the Recovery Star at a community mental health service in Aotearoa New Zealand using Kotter's eight-step model of change. This implementation plan is such that any service within the Aotearoa New Zealand mental health and addictions sector will be able to pick up and use.

Key Points

- The Mental Health Recovery Star is an effective Patient Reported Outcome Measure due to its established recovery model characteristics of being client-centred, collaborative, recovery focused and having robust psychometric properties.
- Kotter's Change Model is recommended to introduce and implement the Recovery Star in any similar service.

Roll out of the Implementation Plan for the Recovery Star at Manaaki Raatonga aa Iwi

The Implementation Plan in Figure 2 was rolled out at Manaaki Raatonga aa Iwi. The first step of synergising unwavering cooperation, initiative and willingness to accept, market, train for, trial and implement the Recovery Star was commenced at the beginning of 2020. All staff members and a significant number of service users were consulted through meetings, emails, phones and in person to advise them of

the need to change the outcome measure of choice to the Recovery Star. A clear explanation was given as to how this change would benefit practitioners, service users and service outcomes.

The Service Manager, who is an occupational therapist, was a key member of the guiding coalition, which comprised all the service's occupational therapists, as described in step two of the Implementation Plan. The Service Manager managed to catalyze the commitment needed through her influence and power to lead the change effort. The Service Manager also managed to organize the financial and time resources needed to enable two occupational therapists to be trained to use the Recovery Star so that they could run a pilot project for a couple of months whilst periodically reporting progress back to the rest of the team.

As per step three, the vision statement used was: "To introduce a recovery model-based patient reported outcome measure that matches our client- centered practice, is holistic, culturally safe, and easy to train for and use." This vision statement aligned very well with our service which is client- centered, holistic and culturally safe - Te Whare Tapa Wha is incorporated at service entry point for Maori service users. The two occupational therapists who were trained to use the Recovery Star in the pilot also reported back that it was easy to train for and to use.

Financial and time resources were then made available to train one of the two occupational therapists to be a Licensed Trainer of Outcome Stars through a company called Unique Outcomes from Australia. This licensed trainer then trained the rest of the service's staff members in use of the Recovery Star. Expected results were communicated in advance. That is, Recovery Star assessments expected to be completed at service entry, mid-way (3 months) and exit points (6 - 9 months). All assessment entries to be recorded in a central register and service users' Waikato DHB official notes online site and copies uploaded onto the Documents section of this site. This and ongoing feedback and communication and removal of any bureaucratic barriers took care of the requirements in step four, five and six of the implementation plan.

The service is now past step seven which is about advocating for the Recovery Star to be the service outcome measure of choice. Most of the practitioners and their clients now use the Recovery Star and report ease of use, client-centredness, cultural appropriateness through its being holistic and relatively short time to complete, approximately 45-60 minutes. This completes step eight at our service as the Recovery Star has become the outcome measure of choice. After a presentation at the Waikato DHB Mental Health and Addictions Services Occupational Therapy Practitioners Forum and based on the reports other practitioners have received from our service, a significant number expressed a desire to train in the use of the Outcome Stars in their areas of practice. The first group was trained in December 2021 and gave positive feedback afterwards.

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Post-traumatic Stress in Children and Adolescent Refugees: An Occupational Therapy Perspective

Elizabeth Ann Christie¹

Abstract

This article shares the reflections of an occupational therapist that was presented with the task of helping refugee families when they arrived in Aotearoa New Zealand from Afghanistan. There were few models of care available at the time and so support strategies were based on professional experience and developed through innovation. The narrative includes a detailed account of the reality of being a refugee, through a compilation of knowledge and experience in this specialist area of occupational therapy. This case study of the family's journey includes a model of care and interventions.

Keywords: Distress, displaced people, mental health, occupational therapy, trauma

Reference

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There can be no doubt that refugees suffer serious mental health issues as a result of living in war torn countries and their journey to safety. Many have experienced severe traumatic events such as torture, rape, and murder of family members in their home countries which results in a high incidence of post-traumatic stress disorder (Chaplin et al., 2020). They do not choose to leave their homeland and flee in response to a crisis and often have little choice about where they will go and how they will travel. They arrive in host countries with few possessions or financial resources and are often debilitated by an encompassing sense of loss, grief, worry, and guilt about family members left behind. Access to community supports ensuring refugees resettle in a host country presents difficulties for both the refugees and the health professionals who support them (Hirani et al., 2015; New Zealand Immigration, 2014). Therefore, it is also important that refugees are enabled to express the mental health distress they have experienced as they attempt to regain their daily occupations, providing opportunities to enter the community, including those involving education, play and leisure. A literature search revealed a paucity of occupational therapy literature that addressed refugees and asylum seekers. Therefore this was pioneering work for occupational therapists in New Zealand.

Afghanistan

Afghanistan is a land locked country, a monarchy until 1973 when a military coup declared it a republic. There followed years of unrest, social change, and invasions by other countries. For example, in 1979 when the Soviet Union caused a full-scale 10 year war, half the population fled to neighbouring countries. Many people were either wounded or killed in civil wars until the Taliban, a hard-line Pakistani-sponsored movement, emerged in 1994. Their harsh and extremist policies deepened poverty and famine. Consequently, Afghanistan remains one of the poorest countries in the world, due to 45 years of war, corruption among high-level politicians, and the recent ongoing Taliban insurgency (Witte, n.d.). It was sometime during this period that the family in this story fled to a refugee camp.

Refugee Camps

Refugee camps are reported to be unsafe places to live, especially for children who are at risk of trafficking, child labour and rape. They are often located in insecure areas, and subjected to cross-border attacks. Approximately 50% of any refugee population are women and girls who, when stripped of protection, are particularly vulnerable and their experiences during flight, in exile and post conflict are significantly different to those of men. Displaced women, such as the mother of this family, try to hold their families together under the most difficult and inhumane circumstances while at increased risk to their personal safety and well-being. Other risks include beatings, torture, hunger, disease and abandonment to name a few. In refugee camps the primary targets are often women and girls. However, young men and boys are also at risk of abduction and they can be subject to forced recruitment by armed groups,

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whether as fighters, for sexual exploitation or other tasks (Ministry of Health. 2012).

The Family

At the heart of this story are a mother, Rohima and four children, a boy, Fazan (19) a girl, Ara (16), and twins, a boy and girl, Kamyar and Hasti (12). Their names are traditional albeit pseudonyms. The whereabouts of their father (Abas), was unknown since he had joined the Afghan Army before they left their home. They were a wealthy family who owned a manufacturing company, had a beautiful home and garden, and all the children were well-educated at local schools. All was lost to them during the Taliban regime.

After passing through New Zealand immigration the family were placed in an Auckland City suburb with a funding allowance (New Zealand Immigration, 2014). The younger children attended the local schools in the area. It was there that a teacher noted that Kamyar (12) demonstrated trauma symptoms when repair men used a nail driving tool to replace broken boards on the school office. The sound of the nail driver caused Kamyar to dive under his desk, crouch, cover his ears and hide his head between his knees and rock. When it was reported that he thought it was gun fire he and his family were referred to a Child Adolescent and Family Mental Health Service.

Service Provision

The two-year funding contract ring-fenced by the service for refugees had a limited criteria, that only extended to mental health intervention and employing interpreters where applicable. On entering the six week immigration programme available at the time, attention focused on learning the language and providing agency supports (New Zealand Immigration, 2014). More traditional occupational therapy intervention would be referred to community therapists as needed.

Occupational Therapy and the Multidisciplinary Team

The Child Adolescent Mental Health philosophy is to take a child and family-centred approach involving two therapists who can collaborate clinically, receive multidisciplinary team support, and hopefully gain co-operation from the family unit. We worked in pairs across all disciplines, understanding each other's roles and expertise, sharing knowledge, performing diagnostic interviews, and making decisions about interventions as a team. My colleague in this instance was a psychologist, whose role was to work with Kamyar while I worked with the remaining family group. Supporting the family as a whole is essential when working in Child Adolescent Mental Health, which helps gain successful therapeutic outcomes. My role included assessment and application of paediatric Occupational Therapy knowledge, gained from specialist training in alternative child and adolescent interventions, such as family systems and therapy, that supported and enhanced occupational therapy intervention. (Christie & Scaletti, 2001; Lougher, 2001). I underpinned my clinical work through the uptake of theoretical knowledge concerning mental health disorders, child and adolescent emotional social development, verbal and non-verbal human behaviour, e.g. understanding body language, for instance.

Clinical Experience

When I first started working with refugees here in Aotearoa New Zealand in 2012, there were no suitable occupational therapy models of care available. Therefore strategies were developed based on professional clinical experience, of working with anxious and depressed children and adolescents, and innovation (Christie, 2007). Over the years I saw many refugees; including unaccompanied children and adolescents, children in the care of unrelated adults, and separated families. Since it can be said that all refugees arrive with mental health issues, those who work with them need to understand post-traumatic stress disorder (PTSD) and its implications in order to help restore them to an acceptable level of health and well-being (American Academy of Child and Adolescent Psychiatry, 2012; Khan et al., 2020; O'Neil, 2020). Equally, it is important to have some knowledge of their country of origin, the culture, customs, and refugee camps, before meeting with a refugee family, and to determine if an interpreter is required. This preparation will allow time to process and theorise what may have happened, and what may still be happening for the family. Interventions built on understanding this information form the basis of therapy to achieve positive outcomes.

Sequentially Planned Integrative Counselling for Children Model

As previously stated, there were no suitable occupational therapy models at the time to guide assessment and interventions with refugee children and adolescents, therefore I sought other frameworks to guide my interventions. Although a westernised model, the Sequentially Planned Integrative Counselling for Children (SPICC), (Geldard, et. al., 2017c; Geldard, et. al., 2019d) I found it to be a useful model and often used it to guide my therapeutic interventions. Both authors are known for their work with children, adolescents and their families.

The model is based on a number of evidenced therapeutic approaches: client-centred psychotherapy; Gestalt therapy; narrative therapy (story telling); cognitive behaviour therapy; and behaviour therapy. Although not precisely occupational therapy models, these approaches have methods or procedures that support the story telling occupation and encourage disclosure. Moreover they enhanced my occupational therapy clinical tool box. Furthermore, I found that positive therapeutic change occurred more quickly, and endured effectively, if the approaches were deliberately and purposefully changed at specific points in the therapeutic process, such as when obvious distress occurred. It was then that I intervened with a relaxing occupation of art or food. This is a useful aspect of the model as it enables individual clinicians, such as occupational therapists, to add their own professional tools and strategies to the process at each stage if and when it would be beneficial. In addition, Giarratano's, (2004a; 2004b; 2004c; 2021) Trauma Trap methods (Fig.1) around relaxation methods, were used along with supporting narrative therapy approaches (Morgan, 2000).

Figure 1 *The Trauma Trap Relaxation Techniques*

Posttraumatic Stress Disorder and Acute Stress Disorder

- The S.U.D. Scale (Subjective Units of Distress Scale)
- The Breath Waltz (Slows down breathing)
- "Buddha Belly" Exercise (Diaphragm breathing)
- Relaxation Monitoring Form

The Trauma Trap (Giarratano, 2004)

Client-centred Interventions

It is important for therapists to work collaboratively with adolescents and their family in any therapeutic process. Creating relationships based on trust, respect and a non-judgemental perspective enables informative conversations and a participatory and reciprocal discourse that can bring about useful and effective solutions to meet the needs of the family (Geldard & Geldard, 2009a; 2009b; 2019; Giarratano, 2004a; 2021). Approaches from the model that appealed to the family and the team were narrative therapy, the integration of story-telling, occupations of art and food, and 'trauma trap' techniques. These were designed to be an approach that would bring about change, alongside cognitive and behavioural techniques. This was when strategies from 'Trauma Trap' (Giarratano, 2004a) such as breathing and self-monitoring techniques (Fig.1) were demonstrated, taught, and accepted by the family. These interventions helped the family to deal with destructive beliefs, e.g., the effect of nightmares on daily living, while reviewing life changes and becoming open to positive options and choices.

Family Background and Story

The family meeting took place in their home. This was usual practice to help offset what may be considered westernised procedures; therefore building trust was our first primary objective. Since Fazan (19) was head of the family, in the absence of his father, he had decided that an interpreter was not required as he and his siblings could speak English. His mother's English was limited; however she acceded to the male authority figure making the decision to translate on her behalf. We later discovered that Fazan declined an interpreter because translators and others who offered help elicited high levels of distrust in Fazan related to post-traumatic stress disorder (PTSD) as a result of his experiences prior to arriving in Aotearoa New Zealand. Such was the family's distrust of the Auckland multicultural population, particularly at schools and in their living environment that they were selective about who came to their home to visit. In addition, they refused an offer of food from the City Mission because that was for 'poor' people. Rohima was educated with a background in law, but had not worked since the twins were born. Furthermore, Hasti was diagnosed with an intellectual disability and to protect her daughter from the community, Rohima had become house bound in Afghanistan because if Hasti's disability was recognised by the Taliban, the family feared she would be killed.

Sometime before they fled, the Taliban attacked the family home due to Abas's political connections. When Abas was injured by gunfire, Fazan carried him to the hospital, an event that caused nightmares. Following this incident, and to protect his family, Abas left home to secretly join the Afghan Army, operating in the hills far from Kabul. The family had no knowledge of his whereabouts or if he was alive, injured or dead. Several months after this incident the family received a message from Abas telling them to escape over the border before Fazan turned eighteen otherwise he would be assigned to the Taliban army. The mother sewed jewels into their clothing and left Kabul to go over the border to Pakistan. At the border, when a suspicious Taliban soldier confronted Hasti, her brother Kamyar stood in front to protect her and suffered a sabre cut down the length of his face. Hasti had not spoken since that incident. After crossing the border into Pakistan they were housed by nationals until they were able to enter a refugee camp also on the border. This was the only way to seek asylum in another country.

Stress Management

Therapeutic observations during the storytelling process considered changes in seating arrangements as distressed body language, with the family members often separating and moving away from the group as they tried to deal with their individual PTSD symptoms. Hasti tended to seek safety with her mother while the others retreated into silence. During this time the nightmares and broken sleep suffered by all family members was revealed, each having their own unspoken personal nightmares. Therefore the family was encouraged use stress management techniques (fig.1) and to share these experiences as an integral part of their ongoing story. Knowing when and when not to intervene as a therapist is important to therapeutic interventions.

The Role of Occupations

Art, food, storytelling or narrative therapy, and play/leisure, i.e. sand play therapy are occupations that cross all cultures and can be used as therapeutic media. When used in mental health settings they can be directive or non-directive in decreasing stress, anxiety, understanding and expressing personal emotional experiences, creating inner reflection, and improving self-esteem (Labovitz, Boik, & Goodwin, 2000; Morgan, 2000; Roesler, 2019; Van Lith, et. al., 2012).

In this instance, we found artistic interventions worked well in establishing rapport and gaining trust with this family (Fortuna, 2017; 2021; Van Lith, et. al., 2012). Their home was sparsely furnished and so the whole family would sit on the floor, along with the clinicians, and use a large sheet of paper and colour pens to draw. Even little Hasti managed to smile when she joined in. Fazan elected to draw a map of Afghanistan, showing where Kabul and their home were located. Surrounding areas of importance to the family were also identified. Each family member added images of relevance to themselves including fruit trees, a school setting, familiar home objects or food preferences, and leisure occupations. Occasionally art was used to elicit representations of their feelings, particularly when silences occurred. This approach was mostly used with Ara and helped reduce stress

With the continued therapeutic interventions, the family responded well to (story telling) and cognitive work, each taking turns to recount incidences foremost in their minds. With help from the occupational therapist they learned to reframe many of their experiences (Morgan, 2000; Geldard & Geldard, 2009b; 2017c; 2019d). Cognitive reframing technique helps shift one's mind-set to view situations, from a different perspective. Of particular importance was the repetitive viewing of a video of their devastated home, sent to them by a family member in Afghanistan. Fortunately, they had escaped just before the Taliban entered and looted their home. The one thing left standing was the boiler in the basement; they could see where the Taliban had fired bullets in an attempt to destroy it. Regularly viewing this video had become a source of story-telling for the family, one that was initially perceived to be destructive due to the reactive responses of Rohima, Fazan and Ara. However, after much critical reflection, research, supervision and support from the team this negative experience was used as a basis for ongoing therapeutic work. It became a 'window of opportunity' that was captured in order to reconstruct (reframe) their story and elicit positive responses, enhance self-perception, self-worth and competency to cope.

Dwelling on thoughts about the loss of their home and

family is a common distortion. Repetition of these negative thoughts can cause people to lose sight of the positive things around them. Using reframing techniques with these negative thought patterns, and focusing on the bigger picture in life, can assist people to move on and to realize that the situation is not their fault, that they have the power to change and become resilient. Goal setting is one way to do this.

It was about this time that we started to share food with the family. Sitting cross legged around a mat on the floor we ate samosas, dried fruit, sweetmeats and coffee laced with cardamom. We chatted about Afghan food practices and preferences, how food is bought at markets, and favourite family festival events. Cross cultural occupations/activities such as this underlined the importance of showing our respect for cultural differences by using an everyday occupation. Positive memories are activated when exploring food through culture. This approach was a way to support the health and welfare (nutrition, relaxation, enjoyment) of the family.

Kammyar joined in the family occupation activities but was having individual therapy in a separate room with the co-therapist, a psychologist. Furthermore, during one of the viewings of the video we noted significant behavioural reactions from the Ara (16) and so she was offered individual therapy sessions, which she was ready to accept. The SPICC process had been beneficial for Ara, starting at the beginning of the cycle, and quickly working through to the Cognitive Behavioural Therapy phase.

Continuing Narrative: Ara's Story

Being proactive means a therapist needs to respond to the cognitive, emotional, somatic, verbal and non-verbal behaviours to allow the freedom within the therapeutic process and to explore and resolve issues (Geldard et.al., 2017c; 2019d).

For Ara and her family, the contrast between their past life and the way of life and culture in a refugee camp was immense. It was an alien environment and their attempts to keep the family unit safe were constantly being challenged. Arrangements for basic activities of daily living, hygiene and sustenance were meagre. Concerns about safety were paramount for both Rohima and Fazan as their funds were now very limited. This became a dilemma for Ara who revealed for the very first time in individual therapy that while in the camp she had been 'given' to man in return for food. She was aged about 14. This was not a marriage.

In Afghanistan, mothers and daughters do not talk about sexual expectations after marriage. We were advised through in-service training that they are told, on the day of marriage, to be a dutiful daughter and to do what their husband asks of them. Ara was given the same instructions while in the refugee camp and subsequently lived with a sense of shame and guilt. The incidents, which were never talked about, gave her nightmares. Therapeutic intervention revealed these traumatic experiences which she tried to deflect with silences, rocking and subdued wailing.

Uppermost in her concerns was how to raise this issue with her mother. Although she was experiencing regular nightmares, she was unsure why she wanted to talk to her mother about sex. Did she want to express her emotions (anger, sadness and guilt), or to be reassured by her mother about her future as a woman living in Afghanistan. The family

were convinced that they would go back home at some point in time, to reunite with Abas.

Therein lay a huge cultural issue for Ara; if she returned home she would no longer be a virgin, which she believed was essential in order to arrange a 'good' marriage. So what did this mean for her future, would she become house bound, a 'damaged woman'? Would she in fact, have a life? She felt her life was completely destroyed by her past experiences. Did she have options and choices? What would her mother think, feel or do?

This is where symbolic or creative strategies, in line with a proactive process, could have been beneficial for Ara. These strategies use art and sand play as part of their therapeutic interactions (Christie, 2014), both of which would have appealed to Ara and would have been an opportunity to rehearse, experiment, and evaluate new behaviours towards/about her dilemma. According to Geldard (2009b; 2017) experimenting with new behaviours and their consequences reinforces adaptive behaviours. However, for unexplained reasons we could not persuade the family to come to the service building where there were two sand play and art rooms available.

The Return Home

Shortly thereafter we arrived at their home for a regular meeting to find Fazan waiting for us outside. He had received a letter from a relative telling him Abas had been found. He had not told Rohima as he believed she would faint and he did not know how to deal with such an event. He wanted us to be present when he shared the letter with mother and the family. This gives an indication of the trust that had developed over weeks of therapy between Fazan, family members, and the two therapists. We looked after Hasti for Rohima and watched as Fazan shared the news with his family. Rohima made an instant decision to return to Afghanistan, the journey being financed by the relative. So our association with the family ended.

Therapeutic Outcomes

The combination of occupations and the SPICC processes as approaches used in therapy revealed improved sleeping patterns, reduction in nightmares, decrease in distrust issues, stress, anxiety, and a return to New Zealand adolescent occupations, e.g., Fazan joined friends fixing car engines which he had never done before. The family learned coping strategies which assisted the healing process without reliving distractive experiences. More importantly for Rohima, who used Trauma Trap techniques as a daily family group activity, was improved family cohesion; the emotional bonding between family members and the degree of autonomy experienced by individuals within the family system.

The Importance of Professional Supervision

It is essential that, when dealing with traumatised children and their families, therapists have access to regular supervision with a professional supervisor. Issues of deflection and resistance can arise when working with refugees. Understanding when deflection, transference and counter transference occurs is fundamental to the therapeutic process (Evans, 2001; Scaife, 2001; Hewson & Carroll, 2016). Therefore supervision from a professional supervisor provides a reflective place to recognise/discuss these issues. Being aware that silence and a display of strong emotions can be a form of resistance is essential to help the family develop

copied strategies. This is a safety and supportive issue for the therapist since transference issues may arise during any intervention session (Scaife, 2001; Evans, 2001) and thus affect the therapist's ability to be impartial.

Figure 2

Recommendations for Occupational Therapists Working with Refugees

- Gain regular supervision from a professional supervisor.
- Understand and recognise transference and counter transference.
- Understand PTSD characteristics.
- Gain knowledge of child and adolescent developmental, emotional/social development and behaviour.
- Apply Art, Food, Storytelling, Play/leisure: traditional cultural occupations.
- Acquire knowledge/information and/or training in sand play therapy (see references).
- Gain an understanding of SPICC, a useful model for children and adolescent with mental health issues (see references).
- Undertake an Interactive drawing course would be useful.
- Investigate and recognise the importance of Art as a therapeutic medium.

Conclusion

Experiential and anecdotal evidence has directed me to an important point, raised in reflection of this case, that trauma permanently changes people. There is no such thing as "getting over it". The five stages of grief model outlines universal stages of learning to accept loss, but the reality of trauma is that a major life disruption leaves a new normal in its aftermath. There is no "back to normal" as people become different, which is not necessarily a negative thing. The goal of intervention is to discover new strengths and positivity to deal with change and in that way to accept the 'new' normal with wisdom and courage. We can only hope that the 'windows of opportunity' found in the intervention process strengthened the family's ability to cope with their new normal and return to everyday occupations.

Key Points

Therapeutic application as a professional occupational therapist was enhanced by:

- Adapting SPICC methods to align them with occupational therapy theory and practice.
- Using Giarratano Trauma Trap techniques were particularly successful and could be used with other trauma or distressful situations.
- Reading and reflecting on literature outside of the occupational therapy knowledge base, while being selective when aligning these to occupational therapy theory and practice

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Examining the Relationship Between Self-Awareness, Function and Cognitive Outcomes in Older Adults After Stroke: A Cohort Study

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Abstract

This prospective longitudinal cohort study recruited 27 stroke survivors and examined the relationship between self-awareness, cognition and function. The Patient Competency Rating Scale, Montreal Cognitive Assessment and motor component of Functional Independence Measure were completed. The PCRS did not significantly change over three-months. The MoCA accounted for 19.7% in the variance of the PCRS at one week and 16.1% of the variance at one month. The mFIM accounted for 13.5% of the variance at one week. Interplay between self-awareness, cognition and function was identified and self-awareness deficits should be identified early to support rehabilitation engagement and outcomes.

Keywords: Awareness, cognition dysfunction, functional status, occupational therapy, stroke

Reference

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Introduction

Stroke represents a leading cause of neurological disability (GBD Stroke Collaborators, 2019). There are approximately 38,000 stroke events per year in Australia (Australian Institute of Health and Welfare, 2020), and 11,000 in New Zealand (New Zealand Institute of Economic Research, 2020). Stroke Foundations recommend people who have suffered a stroke should receive treatment from a specialised multidisciplinary team, including occupational therapy (Stroke Foundation, 2021). Disruption to cognitive processes is a common side effect of stroke, with an estimated 50-78% suffering cognitive impairment (Ekstam et al., 2007), including inflexible and rigid thinking, delayed processing, memory deficits, irritability, impatience, impulsivity and impaired self-awareness (Hartman-Maeir et al., 2002).

Self-awareness deficits following neurological injury have been well documented by clinicians (Ekstam et al., 2007; Hartman-Maeir et al., 2002; Ownsworth & Clare, 2006; Prigatano & Schacter, 1991). Self-awareness can be defined as a highly integrated brain function, encompassing the ability to perceive oneself in relatively objective terms while maintaining a sense of subjectivity (Ekstam et al., 2007; Prigatano & Schacter, 1991). The term 'awareness deficits' is utilised to refer to a lack of recognition of changes to an individual's self and abilities following brain injury (Ownsworth & Clare, 2006). It is believed that awareness of deficits is critical in influencing patient outcomes related to rehabilitation and long term functioning post brain injury (Boosman et al., 2014; Hartman-Maeir et al., 2002; Hartman-Maeir et al., 2003; Hartman et al., 2000; Starkstein et al., 2010). Self-awareness deficit is associated with overestimation of abilities (Fleming & Strong, 1999), the setting of less realistic goals, and achieving poorer results in rehabilitation (Fleming & Ownsworth, 2006). Furthermore, persons with deficits have difficulties using compensatory strategies (Fleming & Strong, 1999; Lindstrom et al., 2013; Toglia & Kirk, 2000).

In previous research Toglia and Kirk (2000) developed a dynamic occupational therapeutic explanatory model to illuminate the complexity of self-awareness and its effect on the execution of activity after stroke (Lindstrom et al., 2013; Toglia & Kirk, 2000). The model describes awareness from two perspectives, the metacognitive knowledge a person has concerning their own capacity which is kept in long-

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term memory, and an “online” awareness activated while the person is active, related to the person’s self-monitoring and self-valuing abilities (Lindstrom et al., 2013; Toglia & Kirk, 2000). Occupational therapists can support patients with self-awareness deficits using activity, the environment, and therapeutic adjustments (Lindstrom et al., 2013). Other studies have focused on strategies to improve self-awareness deficits using metacognitive strategies and exploring rehabilitation experiences of patients with limited awareness after stroke (Kersey et al., 2019; Lindstrom et al., 2013).

However, to identify and provide interventions for these patients, screening for self-awareness deficits is required. Only one other study has explored occupational therapy screening of self-awareness in the acute stages (one week) post stroke as an indicator of patient rehabilitation outcomes (Cameron et al., 2020). There is also limited data to define the relationship between self-awareness and therapeutic outcomes in acute care and on transition to rehabilitation in patients 65 years of age and older. Recent studies have shown that expectations of recovery due to impairments in self-awareness can differ significantly between patients and healthcare providers (Bendz, 2003; Hartigan et al., 2011) leading to discrepant rehabilitation goals (Ellis et al., 2013). As such, this study aimed to examine the relationship between self-awareness, function and cognitive rehabilitation outcomes for older patients three months following stroke. This would allow occupational therapists at an acute tertiary hospital to predict a patient’s engagement in rehabilitation and allocate resources appropriately.

Methods

A prospective longitudinal multicentre cohort study was conducted to determine the relationship between self-awareness, function and cognition as patients following stroke moved from acute care to rehabilitation and discharge home. This study also aimed to collect feasibility data consisting of the recruitment rate and changes in outcome measures to conduct a future definitive study. Reporting adheres to the STROBE statement for observational studies (von Elm et al., 2007).

Patients were recruited from the acute neurology ward of a major metropolitan adult tertiary hospital in Perth, Western Australia throughout 2019-2020. Patients transferred to a secondary older adult rehabilitation hospital when they were deemed medically stable to start rehabilitation and a bed was available for transfer. Patients were then discharged home once the multidisciplinary team and family felt it was safe to do so and inpatient goals were met. Patients were invited to participate in the research if they had an ischemic or haemorrhagic stroke within the last week, were alert, 65 years of age or older and lived within the local rehabilitation catchment area. Patients who had received thrombolysis or undergone clot retrieval from the brain were also eligible for study inclusion as they are provided with standard clinical care in this setting.

Patients underwent two screens completed by a speech pathologist and occupational therapist as part of standard hospital protocol using a non-standardised screening tool. Consent was obtained following these to ensure participants were eligible for inclusion into the study. Patients were excluded if they had moderate-severe expressive, receptive or mixed (expressive and receptive) aphasia, as determined through consultation with the acute speech pathologist based on their clinical examination. This exclusion was

considered essential as the outcome measures selected were language based and as such, required sentence level comprehension and expression in order to be correctly administered. Patients with severe visual or perceptual deficits precluding completion of the written cognitive assessment, as assessed by the acute occupational therapist through completion of a neurophysical assessment, were also excluded. Additional exclusion criteria included patients with a documented diagnosis of dementia, depression, or other mood disorders.

Patients were recruited by an occupational therapist in the acute setting. Participants were advised that non-participation would not result in any adverse consequences or impact on the level of service provided. The researcher and a treating occupational therapist supported the completion of the outcome measures. The treating senior occupational therapist completed the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) as per standard care. The motor component of the Functional Independence Measure (mFIM) (Donaghy & Wass, 1998) and Patient Competency Rating Scale (PCRS) (Prigatano et al., 1986) were completed in addition to standard care at one week post stroke. The participants completed the PCRS with a researcher blinded to the clinician’s or carers responses, when supporting participants to complete the measure. The treating occupational therapist and carers completed the PCRS forms separately and independently of the participant, with no discussion occurring between them.

At approximately day eight post stroke, patients were then transferred to the older adult rehabilitation hospital. In the rehabilitation hospital, a second treating senior occupational therapist, repeated the MoCA, mFIM and PCRS at one month and three months post stroke. This therapist was blinded to the participant’s initial assessment results. If a patient was discharged from hospital before three months post stroke, these assessments were completed in the home setting.

Descriptive Measures

Baseline descriptive measures were recorded including social and medical history, stroke type, discharge destination and hospital length of stay. Additionally the Charlson Comorbidity Index (Charlson et al., 1987) was utilised to measure the burden of comorbid disease in the recruited participants. Seventeen comorbidities are weighted from 1 - 6 for mortality risk and disease severity, and then summed to form the total score (Charlson et al., 1987). Charlson Comorbidity Index scores > 5 have been associated with a 1-year mortality of 85% (Charlson et al., 1987).

Outcome Measures

The Montreal Cognitive Assessment (MoCA) was used to assess cognition and monitor for change (Nasreddine et al., 2005). The MoCA (version 7.1) is a validated cognitive screening tool for use within the stroke population (Abzhandadze et al., 2019; Chiti & Pantoni, 2014) and has been validated for 55-85 year olds. The MoCA includes a 30 point assessment, administrable in approximately 10 minutes, that screens eight cognitive domains (visuospatial/executive skills, naming, memory, attention, language, abstraction, delayed recall and orientation). The measure is scored out of 30, with scores of 18-25 suggestive of mild cognitive impairment, 10-17 moderate cognitive impairment and <10 severe cognitive impairment (Abzhandadze et al., 2019). The MoCA has alternative versions 7.2 and 7.3 which

were utilised at one month and three months to reduce learning effect in test-retest situations.

The Motor Functional Independence Measure (mFIM) is a validated instrument for documenting the severity of disability and assessing the outcome of rehabilitation treatment (Donaghy & Wass, 1998). The motor subscale of the FIM (mFIM) was utilised to assess functional status and improvement. The mFIM was used to examine functional outcomes as this score isolates functional activities from cognitive ratings, which are combined in the total FIM score. The mFIM consists of 13 items measuring activities of daily living (ADLs), transfers, and locomotion, each scored from complete dependence (1) to complete independence (7). A total score out of 91 was calculated indicative of burden of care. A lower score on the mFIM indicates a higher burden of care.

The Patient Competency Rating Scale (PCRS) is a 30 item self-report that asks the person with a brain injury to rank ability to accomplish common daily activities on a five-point scale (Prigatano et al., 1986). Higher scores on the PCRS indicate higher functioning or less perceived functional impairment (Prigatano et al., 1986). The questionnaire was originally designed to measure an individual's self-awareness of their own deficits following brain injury, however it has been recommended for use in the evaluation of the long-term effects of therapy on stroke survivor's recovery (Barskova & Wilz, 2006; Fischer et al., 2004; Noé et al., 2005).

A discrepancy based method is used to compare the patient's self-rating of function with that of an informant, could be a carer or allied health professional (Al Banna et al., 2016). The discrepancy score was calculated by taking the stroke survivor's score on a scale item and subtracting the item score given to that patient by their assigned therapist or carer. The difference represented the degrees to which stroke survivors had over-estimated or underestimated their abilities respectively, relative to their therapist or carer (Cameron et al., 2020; Fischer et al., 2004). A score of zero indicates no discrepancy between the rating of the patient and the therapist or carer. A positive score indicates that the patient rates their ability as higher than rated by the therapist or carer, with higher positive scores reflecting greater deficits in self-awareness (Anson & Ponsford, 2006). Overall, in line with previous research, high self-awareness was considered if the discrepancy score between the patient and therapist or carer was less than 28 (Noé et al., 2005).

Statistical Analysis

Descriptive summaries consisted of frequency distributions for categorical data and medians, interquartile ranges and ranges for continuous data. Linear regression models were used to examine associations of PCRS differences with MoCA and mFIM scores at each time point. Results were summarised as beta coefficients and 95% confidence intervals (CIs), coefficients of determination (R^2) and Pearson's rho correlation coefficients. Linear mixed models including random subject effects and utilising restricted maximum likelihood estimation (REML) were used to estimate mean MoCA, mFIM and PCRS (difference) scores at each follow up from baseline. Results were summarised as marginal means and 95% CIs. MoCA and mFIM scores were compared between PCRS score and score difference categories (mild vs moderate-severe) as per previous research (Prigatano et al., 1986). Sensitivity analysis was completed to manage any participant withdrawals. Statistical analysis was conducted using IBM SPSS Statistics (Version

26.0) and Stata 16.0 (StataCorp, 2019). All hypothesis tests were two-sided, and p values of <0.05 were considered statistically significant. A minimum sample size of $n=30$ would have 95% power ($\alpha=0.05$, two-tailed) to detect a Pearson correlation coefficient of 0.1.

Ethical Considerations

This study was approved by the Human Research Ethics Committee (RGS0000000297). All patients provided written consent and patient data were de-identified and analysed in aggregate form.

Results

Twenty seven participants were recruited with a mean age of 77.6 years over a nine month recruiting period. The study was underpowered due to recruitment difficulties consisting of the exclusion of patients with aphasia and perceptual limitations, however this was acceptable as a feasibility study designed to support future research. Approximately 90 patients were admitted to the hospital following a stroke meeting the inclusion criteria. However, 38% ($n=34$) were excluded due to aphasia and 20% ($n=18$) due to perceptual limitations, resulting in 48 eligible patients. Thirty two patients were approached for inclusion with five declining to participate or being medically unwell. The 27 recruited participants completed the baseline assessments at one week post stroke. Participants were again assessed at one and three months, with seven participants lost to follow up in total (four before the one month assessment and three before the three month assessment, Figure 1). The discrepancy score generally included patient and therapist ratings; four comparisons were made between a carer and patient and due to the low numbers the carer and patient comparisons were not included in the data analysis.

Figure 1 Study Outline Including Patient Recruitment and Management

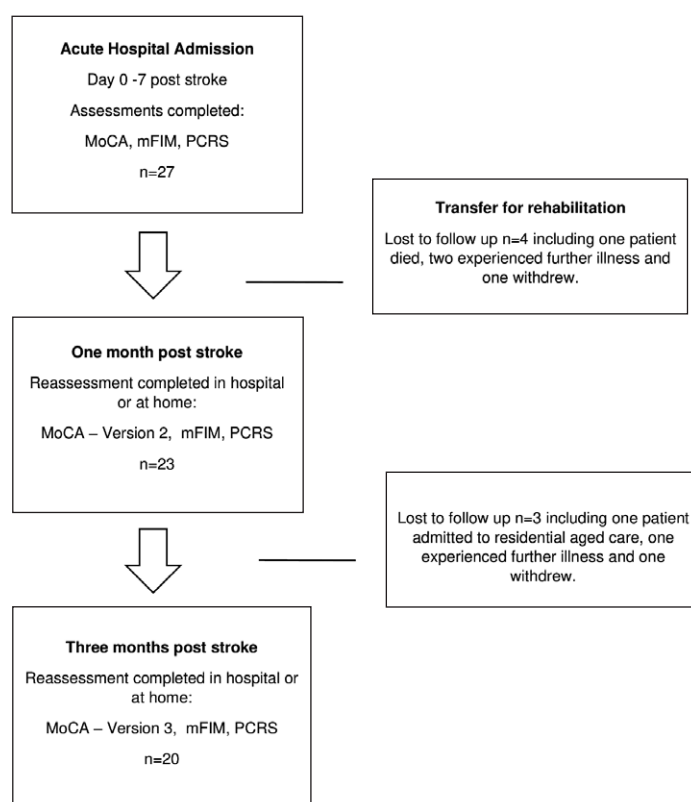


Table 1 outlines the general characteristics of the study population. Recruitment to this cohort study resulted in 11 (40.7%) females and 16 (59.3%) males. Seventy eight percent of participants were admitted with an infarct, most commonly classified as a partial anterior circulation infarct. The average hospital length of stay was 8.4 days in the acute tertiary hospital and 21.4 days in the secondary rehabilitation hospital. This was higher in males who required a longer period of rehabilitation (13.6 days in females versus 26.0 days in males in rehabilitation). Males also had more support at home with 81% (n=13) living at home with a carer or family, compared to 64% (n=7) in females. The Charlson Comorbidity Index ranged from three to 11, with an average of 4.9.

Table 1 Sample Population Descriptive Summaries

Patient Factors	Category	n (%)
Age mean (SD)		77.6 (8.8)
Gender	Female	11 (40.7)
	Male	16 (59.3)
Charlson Comorbidity Index (SD)		4.9 (2.3)
Stroke side	Left	17 (63.0)
	Right	10 (37.0)
Stroke classification	Lacunar cerebral infarct	6 (22.2)
	Partial anterior circulation infarct	17 (63.0)
	Posterior circulation infarct	4 (14.8)
Stroke type	Haemorrhage	6 (22.2)
	Infarct	21 (77.8)
Hospital length of stay median (IQR) [min-max]		14 (11, 22) [5-79]
Social situation	Lives alone	7 (25.9)
	Lives with carer	1 (3.7)
	Lives with partner	13 (48.1)
	Lives with relative	6 (22.2)
Discharge destination	Home alone	7 (25.9)
	Home with carer	14 (51.9)
	Home with relative	3 (11.1)
	Other hospital	1 (3.7)
	Transitional care	2 (7.4)
Follow up	Early supported discharge	17 (63.0)
	Rehabilitation in the home	1 (3.7)
	Stroke clinic	1 (3.7)
	None	3 (11.1)

There was a significant improvement in the MoCA and mFIM measurements at one and three months post stroke from the baseline measurements completed at one week post stroke. Table 2 and Figure 2 outlines the mean longitudinal scores trends for the MoCA, mFIM and PCRS. Overall, the MoCA identified that 52.6% (n=10) of participants assessed at all time points exhibited cognitive impairment (score 24 or lower). The largest MoCA score gains occurred between one week and one month (1.9 points [$p=0.007$]). There was a 34.1 point mean improvement in the mFIM score between admission and three months. Again, the majority of rehabilitation gains reflected by mFIM score improvements were made in the first month (27.9 points [$p<0.001$]). No significant differences between the measures were noted when comparing male and female participants.

Figure 2 Longitudinal Score Trend for the Montreal Cognitive Assessment (MoCA), Motor Component of Functional Independence Measure (mFIM) and the Patient Competency Rating Scale (PCRS)

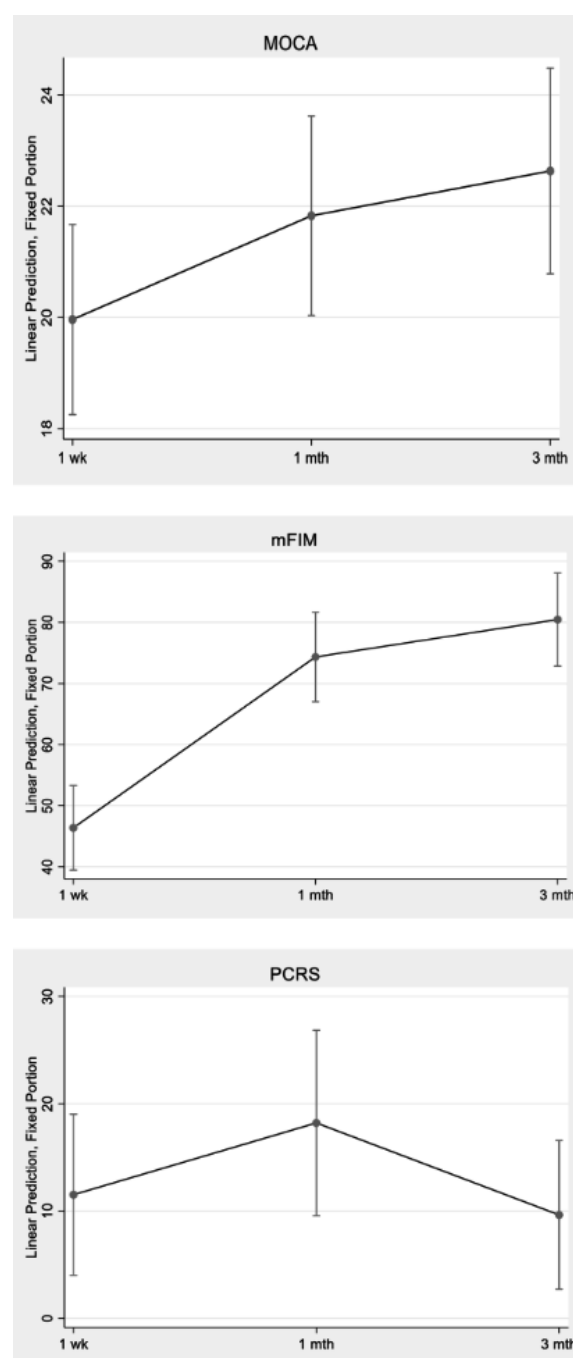


Table 2 Longitudinal Score Trends (Linear Mixed Models) for the Patient Competency Rating Scale (PCRS), Montreal Cognitive Assessment (MoCA) and Motor Component of Functional Independence Measure (mFIM)

	Time post stroke	Est mean (95% CI)	P_diff from baseline	P_diff from 1 month	Female (n=11)	Male (n=16)		P diff between gender (cross-sectional)	P diff between gender (interaction)
					Est mean (95% CI)	Est mean (95% CI)	Est mean diff (95% CI)		
MoCA	1 week	19.96 (18.22 - 21.71)			20.91 (18.15, 23.66)	19.31 (17.03, 21.60)	-1.60 (-5.18, 1.98)	0.382	
	1 month	21.83 (20.00 - 23.66)	0.007		22.47 (19.65, 25.28)	21.42 (18.97, 23.88)	-1.04 (-4.78, 2.69)	0.584	0.701
	3 months	22.64 (20.75 - 24.52)	<0.001	0.280	23.43 (20.48, 26.39)	22.10 (19.60, 24.60)	-1.33 (-5.20, 2.54)	0.500	0.863
mFIM	1 week	46.37 (39.31 - 53.43)			53.00 (42.18, 63.82)	41.81 (32.84, 50.79)	-11.19 (-25.25, 2.87)	0.119	
	1 month	74.34 (66.86 - 81.83)	<0.001		80.68 (69.54, 91.82)	69.56 (59.75, 79.37)	-11.12 (-25.96, 3.72)	0.142	0.991
	3 months	80.46 (72.68 - 88.23)	<0.001	0.071	85.02 (73.19, 96.85)	77.09 (67.03, 87.14)	-7.93 (-23.46, 7.59)	0.317	0.638
PCRS difference	1 week	11.50 (3.83 - 19.18)			9.79 (-1.93, 21.52)	12.73 (2.23, 23.22)	2.93 (-12.80, 18.67)	0.715	
	1 month	18.21 (9.36 - 27.06)	0.146		20.70 (3.94, 37.45)	17.78 (6.94, 28.61)	-2.92 (-22.87, 17.04)	0.774	0.573
	3 months	9.63 (2.54 - 16.72)	0.634	0.058	7.18 (-4.12, 18.48)	11.31 (1.94, 20.68)	4.13 (-10.55, 18.81)	0.581	0.883

Table 3 Associations of the Patient Competency Rating Scale (PCRS) Differences with the Montreal Cognitive Assessment (MoCA) and Motor Component of Functional Independence Measure (mFIM) at Each Time Point (Linear Regression)

	Time post stroke	Beta (95% CI)	p	R ^{2a}	Pearson's CC	p
MoCA	1 week	-0.10 (-0.19, -0.02)	0.020	0.197	-0.444	0.010
	1 month	-0.10 (-0.20, 0.01)	0.064	0.161	-0.401	0.032
	3 months	-0.07 (-0.21, 0.06)	0.262	0.096	-0.310	0.131
mFIM	1 week	0.34 (-0.02, 0.69)	0.059	0.135	0.367	0.030
	1 month	-0.29 (-0.78, 0.20)	0.225	0.073	-0.270	0.112
	3 months	-0.27 (-0.96, 0.43)	0.421	0.050	-0.224	0.211

^aR² Coefficient of determination: measures proportion variance in model attributable to independent variable

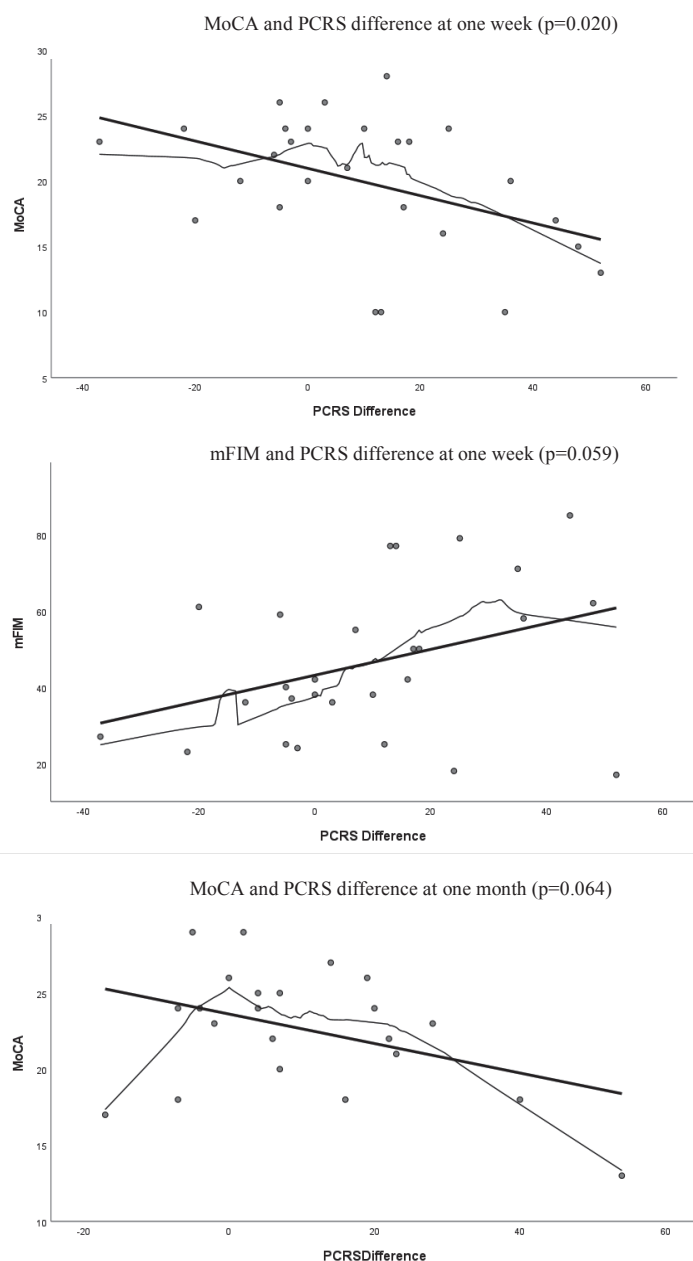
The mean PCRS for participants at one week post stroke was 107 in the acute inpatient setting. This progressed to 116 and 128.6 respectively at one and three months. The mean therapist ratings were overall lower, at 96.1, 100 and 109. The PCRS did not significantly change with measurement at the different time points, however clinical improvements in participant awareness from one to three months were noted by a 1.8 point ($p=0.058$) decrease in difference of scores. The largest difference between patient and therapist ratings occurred at one month (18.2).

Overall self-awareness was significantly predicted by the MoCA in the acute phase. The MoCA accounted for 19.7%

in the variance ($R^2=0.197$, $p=0.01$) at one week and 16.1% of the variance at one month ($R^2=0.161$, $p=0.03$). The mFIM accounted for 13.5% of the variance of the PCRS at one week only ($R^2=0.135$, $p=0.03$) (Table 3). There was a significant linear relationship with the MoCA and PCRS at one week only ($p=0.020$) (Table 3 and Figure 3).

Participants with moderate-severe impairments had poorer motor gains measured via the mFIM. The mFIM change between one week and one month measures for participants with a moderate-severe impairment was five points compared to 44 points for participants with a mild impairment ($p=0.021$) (Table 4).

Figure 3 Linear Regression Relationships Between the Montreal Cognitive Assessment (MoCA), Motor Component of Functional Independence Measure (mFIM) and the Patient Competency Rating Scale (PCRS)



Sensitivity analysis identified the characteristics for those participants who did and those who did not complete the one and three month assessments (Appendix 1). Minor differences were found with participants who completed all assessments being slightly younger (74.4 versus 76.5 years). There were proportional differences in social situations between those who did and did not complete the one and three month assessments: Those who completed all measures mostly lived with a partner. No significant differences were noted in the FIM and MoCA when adjusted for social situation for participants that completed the one and three month assessments.

Discussion

Impaired self-awareness is understood to be a common symptom after stroke and was present in 22% ($n=27$) of our sample at one week post stroke. This is less than other

studies, that have reported up to 51.6% ($n=32$) of their sample (Noé et al., 2005). The hospital length of stay (LoS) was lower than the average rehabilitation hospital LoS (21.44 versus 24 days) for similar patient groups, suggestive of a sample population with milder rehabilitation needs. This may also be explained by our exclusion of participants with aphasia and perceptual deficits and has implications for further research to broaden the eligibility criteria.

Large improvements in function were noted with a near return to full function as indicated by the mean mFIM score of 80.5/91 at three months post stroke. However, the majority of participants continued to exhibit cognitive impairment at this time with mean MoCA score of 22.6. This is similar to another study ($n=567$) in which the mean MoCA was 23.8 for patients with a mean age of 72.7 years (Einstad et al., 2021). Consideration of the long term support these patients may require to manage independently in the community is required.

Overall linear regression analysis revealed that cognitive impairment assessed via the MoCA was influential in the variability of self-awareness. Additionally, a statistically significant relationship was identified between the PCRS and mFIM for participants with moderate-severe self-awareness impairments who failed to make substantial motor and ADL gains one month post stroke. This indicates that patients with moderate-severe self-awareness impairments may have difficulties making motor and ADL gains in early rehabilitation. This is supportive of the current clinical stroke guidelines indicating a need for screening of cognitive deficits including self-awareness prior to discharge from hospital (Stroke Foundation, 2021). In this setting, acute care therapists generally focused on initial assessment and discharge planning. This research has highlighted the benefits of including a self-awareness screening tool to support early identification of deficits. Patients with appropriate perception of their deficits have shown less psychopathological symptoms, better neuropsychological function and higher functional independence (Noé et al., 2005). Interestingly participants with mild impairment in self-awareness had a lower mFIM score of 38 compared to 60 in patients with a moderate-severe impairment, at one week post stroke, indicating that higher self-awareness may also impact on function initially.

Overall, the PCRS was easy to use and assisted in the recognition of self-awareness which is important and is often missed in existing assessments. In our study 40% of the participants overestimated their functional and cognitive ability, despite good functional gains when assessed at three months post stroke. This is similar to other research findings in which half of the patients in a study by Boosman et al. (2014) over-estimated or under-estimated their memory functioning (Fischer et al., 2004). They suggested that over-estimation and underestimation of memory functioning are related to different neuropsychological mechanisms. These findings are in line with previous studies, for example, Giovagnoli (2013) and Carone et al. (2005) suggested that impaired awareness is a specific cognitive impairment directly resulting from brain damage. They reported an association between over-estimation of cognitive performance and impairments in patients with brain injury (Boosman et al., 2014; Carone et al., 2005; Giovagnoli, 2013). Recognition of ongoing cognitive impairment at three months is important and has been independently associated with lower quality of life at 12 months ($p = 0.021$) (Cumming et al., 2014). This has implications for patient and carer education

Table 4 Montreal Cognitive Assessment (MoCA) and Motor Component of Functional Independence Measure (mFIM) for Patients with Mild Versus Moderate-Severe Deficits in Awareness Measured by the Patient Competency Rating Scale (PCRS)

		Actual raw scores			Score changes		
Time post stroke		Mild	Moderate-severe		Mild	Moderate-severe	
		Median (IQR) [min-max]	Median (IQR) [min-max]	p	Median (IQR) [min-max]	Median (IQR) [min-max]	p
MoCA	1 week	23 (18, 24) [10-28]	16.5 (13.5, 22.3) [10-24]	0.058			
	1 month	24 (20, 26) [17-29]	22 (18, 24) [13-26]	0.237	0.5 (-1.5, 3.0) [-5, 14]	2 (0.8, 4.3) [0, 5]	0.261
	3 months	23.5 (20, 27.3) [17-28]	22 (21, 26) [17-27]	0.607	1.0 (-1.0, 2.8) [-5.0, 3.0]	1 (-2.0, 4) [-2, 4]	0.323
FIM	1 week	38 (27, 55) [23-77]	60 (26, 77) [17-85]	0.198			
	1 month	81 (77, 86) [32-89]	65 (60, 90) [32-91]	0.783	36 (16.5, 45.5) [9, 60]	13 (9, 22.3) [6, 32]	0.021
	3 months	83 (72, 89) [62-91]	88 (56, 90) [34-90]	0.864	5.5 (2.3, 8.8) [-4, 12]	2.0 (-1, 19) [-9, 24]	0.701

required and referral and access to follow up services including mental health supports.

With regard to the effect of time measure on self-awareness, stroke survivors in this study saw themselves as more competent in their cognitive and instrumental functioning than did their therapists at one month post stroke. This is different to a study by Cameron et al. (2020) which found the largest difference occurred upon hospital admission. This highlights the need of ongoing assessment of self-awareness and further research to understand the clinical implications on rehabilitation outcomes. Poor self-awareness may lead to patients reduced engagement in rehabilitation, resulting in patients declining rehabilitation services, impacting on their long term recovery and higher rates of patients not attending their outpatient appointments. Additionally, hospital inpatients may engage in risk taking behaviour such poorer use of call bells, higher rates of falls and earlier discharge from hospital due to reduced participation in rehabilitation.

The PCRS has previously demonstrated sound psychometric properties and samples a broad range of functioning, including higher order abilities (Cameron et al., 2020; Smeets et al., 2012). In this study we found the PCRS a feasible tool to implement with patients, therapists and carers to assess self-awareness within the first three months post stroke. Although we did not see significant changes in levels of self-awareness across the different time measures, possibly indicating that the tool does not have the sensitivity to track changes in acute rehabilitation. This may be explained as the PCRS measures intellectual awareness, which may develop in later stages of recovery.

Limitations

A number of limitations were identified in this study. First, it used a small, convenience sample of patients with heterogeneous diagnoses, which may limit the generalisability of our findings to other populations. Patients with severe visuo-spatial deficits and aphasia were excluded despite potentially being a group that may have poor self-awareness. Future studies should consider inclusion of this broader population. The current study recruited 27 patients

identified over a nine month period, resulting in a sample that was underpowered for the analysis, meaning results should be interpreted with caution.

A discrepancy scores was calculated for the PCRS, a comparison between the patient's self-rating and that of a proxy rater (the carer or therapist). As highlighted in other studies, a possible drawback of this method could be rater bias or the inaccuracy of the carer or therapist to estimate the patient's true abilities (Al Banna et al., 2016; Maclean et al., 2000; Wise et al., 2005). Other studies emphasised the importance of using a combination of approaches to measure metacognitive function and could be considered in future research (Al Banna et al., 2016; Wise et al., 2005). Further examination of stroke survivors with poor self-awareness in a larger study is recommended.

Conclusion

The results of this study have explored the relationship between self-awareness, cognition and function and suggest that impaired cognition is associated with poor self-awareness, which can impact on short term functional rehabilitation gains. Methodological and substantive findings from this study will be used to implement a larger, more definitive study of patient insight. Assessment of self-awareness utilising the PCRS was feasible for occupational therapists and provided useful insights into how older patients progress from the acute hospital setting, to rehabilitation and then home. Ongoing assessment of self-awareness by acute care occupational therapists would be recommended to identify patients at risk of poor motor and ADL gains in hospital rehabilitation, impacting on hospital length stay, discharge destination and follow up support needs. It would also support the implementation of intervention strategies in line with clinical guideline recommendations.

Key Points

- Occupational therapy assessment of self-awareness is recommended to identify patients at risk of poor rehabilitation outcomes.

- Patients with moderate-severe self-awareness impairments may have difficulties making motor and ADL gains.
- The PCRS was a feasible tool for use by occupational therapists to assess for early self-awareness deficits after stroke.

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Clinical Governance of Occupational Therapy Practice: Pinch-Points and Political Action

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Abstract

In everyday practice with clients, occupational therapists-kaiwhakaora ngangahau constantly make decisions about their conduct and actions. In this paper, we argue that the clinical governance discourses that were taken up by New Zealand's District Health Boards created practice conflicts, known as 'pinch-points'. These are where organisational pressure for quality, safety, efficiency, professional development and leadership come into conflict with the profession's values and its calls for Te Tiriti responsiveness to achieve health equity for Māori. Drawing on examples of pinch-points recognised by practitioners, we call on occupational therapists-kaiwhakaora ngangahau to become political actors, exercising power by actively responding to pinch-points. Suggestions for action gleaned from current occupational therapy-whakaora ngangahau sources and literature are considered as exemplars of activism within daily practice.

Keywords: Clinical governance, equity, bicultural practice, discourses, subject positions, political actors; Foucault

Reference

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Introduction

This paper emerged from an Occupational Therapy New Zealand - Whakaora Ngangahau Aotearoa ¹ (OTNZ-WNA) online event in November 2021, where the authors presented a discussion entitled 'Clinical governance: Pinch-points within occupational therapy practice'. The 'pinch-points' that we referred to were those events and situations where occupational therapists – kaiwhakaora ngangahau (OT-KNs) were expected to background valued professional practices and concepts in favour of new norms and expectations aligned with a clinical governance framework. At the extreme, pinch-points can be conflicts between the behaviours required of health service employees and clinicians' personal values and professional commitments, such as recommending a ramp to a client's front door but not any emergency egress. When experiencing a pinch-point,

decisions must be made on what action to take based on what is most meaningful and ethically appropriate.

Our discussion focused on the implementation of clinical governance within District Health Boards (DHBs). DHBs have been the primary organisations responsible for delivering publicly funded healthcare in Aotearoa New Zealand since their establishment under the New Zealand Public Health and Disability Act 2000 (Ministry of Health, 2020a). As Gauld (2013) pointed out, each DHB produced its own interpretation of a clinical governance framework, giving rise to multiple variations. Some of that variation in interpretation and uptake of clinical governance may be addressed by the recently announced plans to reorganise the healthcare delivery system, removing the DHBs in favour of a more centralised model, called Health NZ (New Zealand Health and Disability System Review, 2020). Our assumption is that the concept of a clinical governance framework will carry over into the new organisational structure.

In our presentation, a number of pinch-points made visible through analysis of data previously gathered for research were presented and then confirmed via audience experience. Examples include the discomfort therapists feel when 'the system' pushes them to skip over the relationship building phase of engaging with a new client or to deliver less than they believe to be safe. The study referred to was the first author's doctoral thesis, "A Fine Race of Girls": Occupational therapy and clinical governance in the District Health Boards of Aotearoa New Zealand (Orton, 2021). Its goal was to understand how practice has changed since the introduction

¹ Māori are the indigenous people of Aotearoa New Zealand. Whakaora ngangahau is the Māori term for occupational therapy; kaiwhakaora ngangahau refers to occupational therapists.

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of clinical governance frameworks in the DHBs after 2000. For the thesis, data in the form of documents pertaining to clinical governance, occupational therapy – whakaora ngangahau (OT-WN) practice, and Aotearoa New Zealand's political, social, and economic history were gathered. Subsequent analysis was performed through the lens of Foucauldian discourse analysis, which is a research method used to uncover the ideologies behind written and spoken language.

The paper begins by situating our discussion in the governmental commitment to equitable delivery of healthcare, underpinned by Te Tiriti o Waitangi (the Treaty of Waitangi), the contract between Māori and the Crown that is the foundation of Aotearoa New Zealand society. We then provide some background to Foucault's ideas and explain key terminology where relevant. Next, we turn to clinical governance and how that realignment of healthcare leadership is filtering through to create pinch-points in OT-WN practice. To conclude, we urge OT-KNs to step forward as political actors to question and challenge frameworks and practices that compromise the profession's contribution to achieving health equity.

Equitable Delivery of Healthcare Provision

The New Zealand government is bound by an historical treaty, Te Tiriti o Waitangi, to ensure equity of health outcomes for Māori and British settlers. Honouring that obligation is the focus of a recent Ministry of Health (2020b) document, *Te Tiriti o Waitangi and the Health and Disability System*. It asserts that "the Treaty obligations are a foundation for achieving Māori health aspirations and equity for Māori" (p. 2), thereby delivering on the Māori health strategy (He Korowai Oranga). Equity is defined by explaining that "in Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust" (Ministry of Health, 2020b, p. 2), thus positioning health discrepancies as a human rights issue. The document further asserts that "different people with different levels of advantage require different approaches and resources to get equitable health outcomes" (p. 2). In health contexts, therefore, exercising good governance means advocating for outcomes that are equitable and Te Tiriti responsive. Further, no-one working in health is exempted from this responsibility.

To promote health equity for Māori, Te Tiriti o Waitangi is being inserted into DHB clinical governance documents. One influential example is the *Health and Disability System Review - Final Report – Pūrongo Whakamutunga* (New Zealand Health and Disability System Review, 2020), chaired by Heather Simpson and now commonly referred to as the "*Simpson Report*". It identified four key themes: "consumers at the heart of the system; culture change and more focussed leadership; more effective Te Tiriti-based partnerships; integrated system" (p. 3). These themes tie in with the ideologies associated with clinical governance (Health Quality & Safety Commission, 2017) and with the *New Zealand Health Strategy* (Minister of Health, 2016a, 2016b). However, as the Simpson Report made evident, there are still disparities in health outcomes for Māori and inequitable delivery of healthcare needing to be addressed through high level, systemic change to the health delivery structure (New Zealand Health and Disability System Review, 2020).

The OT-WN profession is actively responding to these ideas, conveyed to us via government sponsored reports and new health legislation (Occupational Therapy Board of

New Zealand, 2021). Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa's commitment to Te Tiriti engagement is evidenced by appointment of cultural advisors, who were instrumental in the construction and introduction of the OTNZ-WNA Te Tiriti governance model in 2015 (Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa, 2022). In addition, at a regulatory level, bicultural competencies were included in the Occupational Therapy Board of New Zealand's (OTBNZ) competency framework (Occupational Therapy Board of New Zealand, 2015). (See textbox 2). However, the adequacy of the board's endeavours were judged to be only "fair" in Came et al.'s (2021) review of Te Tiriti o Waitangi compliance in regulated health practitioner competency documents, with an accompanying commentary that "the rightful position of Te Tiriti in health is at the core, not on the periphery" (p. 40).

Textbox 1 OTNZ-WNA Te Tiriti Governance Model

Consistent with Te Tiriti o Waitangi, which recognises Māori as equal partners with the British crown in the governance of Aotearoa New Zealand, the professional association moved to a dual governance model in 2015. Depicted as two houses, it establishes a Māori president, council members, and World Federation of Occupational Therapists delegate in one house and equivalent non-Māori office holders in the other. The co-presidents and Council members are called on to share the decision-making process, working in partnership, participating on an equal footing, and protecting each other's participation and the process of working in partnership. Separate processes are in place for determining who takes up positions on council, as culturally appropriate to each group.

(Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa, 2022)

Textbox 2 OTBNZ 2015 Competency Framework

OTBNZ, the body that registers occupational therapists kaiwhakaora ngangahau in Aotearoa New Zealand, specifies the competencies underpinning safe practice. All practicing therapists are required to have an active professional development plan encompassing all competency areas, and are randomly audited against them. In 2015, practicing in a biculturally appropriate manner was introduced as a specific competency area, alongside applying occupational therapy skills and knowledge, ensuring actions were safe, legal, and ethical; establishing collaborative partnerships; and engaging with and contributing to their profession.

(Occupational Therapy Board of New Zealand, 2015)

Occupational Therapy Board of New Zealand continues in its aim to be "a te Tiriti engaged organisation" (Occupational Therapy Board of New Zealand, 2022b), with the newly introduced Māori Advisory Komiti. The recent refresh of the OT-WN scope of practice, competencies for practice, and Code of Ethics (Occupational Therapy Board of New Zealand, 2021) was a response to the call for health care practitioners to actively recognize and address the requirements of Te Tiriti o Waitangi. Across those guiding documents, OT-KNs are required to actively demonstrate Te Tiriti responsiveness and equitable delivery of healthcare services. That work

continues to open up possibilities and opportunities to extend Te Tiriti responsive knowledge and practices.

The increase in Te Tiriti responsiveness does not, however, operate in isolation. In response to economic discourses about escalating healthcare costs, fiscal and systemic constraints have been imposed by governments internationally, producing ethical tension for frontline healthcare workers (Durocher et al., 2016). For example, standardised protocols embedded in population-based health models can restrict clinicians' ability to respond to the needs of particular groups, such as Māori, youth, or people with obesity, thus jeopardising achievement of equitable healthcare outcomes. Such pinch-points must be carefully considered, giving rise to the idea that OT-KNs should think of themselves as "political actors" (Pollard et al., 2009, p. 31). That is, clinicians ought to challenge restrictions on practice by identifying opportunities to champion what can be done with, and on behalf of clients, with the overall aim of delivering effective, equitable solutions for those experiencing health disadvantages and inequity. In Aotearoa New Zealand, we suggest, that means practitioners acknowledging their role as political actors by advocating for fair and just provision of healthcare approaches and resources to achieve equitable outcomes for Māori. The concept of the 'political actor' is loosely defined as an individual who exercises power in a society, enabling them to engage in purposeful, observable actions, with the intent to influence interventions and outcomes (Page, 1996; Wolfsfeld, 2015).

Foucault and Foucauldian Terms

As mentioned earlier, Foucauldian discourse analysis was the guiding methodology of the study from which insights presented in this discussion were drawn. Michel Foucault, a prominent philosopher and historian, proposed that our understanding of the world in which we live is shaped by social, political, and economic forces (Kelly, 2021). Foucault (1972) argued that understanding these forces and their effect on people's lives requires the analysis of *discourses*: that is, groups of statements that constitute the preferred truth and knowledge in a particular time and space. Multiple discourses circulate in society; some are foregrounded and become dominant and powerful influences on societal beliefs and behaviour, while others are backgrounded and so exercise less influence. Examples include the discourse of biculturalism, now being re-interpreted and foregrounded as Te Tiriti responsiveness across multiple sectors of society, and "being healthy", which is a dominant medical and health discourse in Aotearoa New Zealand. Over time, dominant discourses become construed as "common sense (or popular discourse)" (Purvis & Hunt, 1993, p. 495), and are taken up as societal truths to be acted upon and normalised into daily practices.

Discourses construct *objects, subjects and subjectivities* (Foucault, 1972). *Objects* are entities that appear to be unconscious and passive, and do not act on other things. They are also the phenomena that discourse brings to light. Examples are 'health' or 'occupation'. *Subjects*, on the other hand, are conscious, have agency, and are capable of producing subjectivities that affect their own behaviour. Subjects are able to actively experience and encounter the world through engaging in activities such as reasoning, reflecting, thinking, and feeling. The relevant subjects in this discussion are 'occupational therapists - kaiwhakaora ngāhau' (OT-KNs). *Subjectivities* refer to the beliefs and behaviours taken up by such subjects. For example, the current health discourse produces beliefs that people can and should preserve their health by exercising, eating a

healthy diet, moderating their alcohol intake, not smoking, and during the current pandemic, socially isolating and being the recipients of triple COVID-19 vaccines. People living in this country are expected to take up these discourses, engaging in these behaviours and taking responsibility for preserving their own and others' health. In contrast, the discourses to which OT-KNs subscribe, such as the relationship between meaningful occupation and health and the restorative power of graded occupation, are only present to a limited extent.

The Danger of Discourses

Almost in passing, Foucault warned that "not everything is bad, but everything is dangerous, which is not the same as bad. If everything is dangerous, then we always have something to do" (Foucault, 1982, pp. 231-232). What Foucault is saying is that discourses, in themselves, are neither good nor bad, but that they reflect the preferred knowledge and beliefs of particular moments in time. Furthermore, there can be multiple interpretations, which means that all discourses have the potential to work in both productive and counter-productive ways. He is also warning that we must be vigilant in what we do, and actively ensure we do not engage in behaviour that may be harmful to other individuals.

Heeding Foucault's advice, we would argue that OT-KNs should carefully reflect on clinical governance discourses and use them opportunistically to achieve change, particularly when it comes to equity of occupational engagement and participation. If there is evidence that equitable outcomes will not be achieved due to constraints on practice, therapists should *challenge the barriers limiting practice* such as policy and funding constraints. Inequity should be made visible through careful use and communication of OT-WN reasoning skills, supporting alternative solutions that would be more appropriate in the delivery of equitable health outcomes for Māori.

Clinical Governance Discourses

It is possible to understand clinical governance in Aotearoa New Zealand as a framework of quality, safety, efficiency, professional development, leadership, and management discourses adopted from Britain's National Health Service (NHS) (Sally & Donaldson, 1998). Importantly, multiple DHB clinical governance constructs additionally recognise and include Te Tiriti o Waitangi as a foundation stone of the framework. Clinical governance devolves accountability for the quality of health care from managers to *all* health professionals and gives "everyone ... two jobs: improving the system for providing care as well as providing care" (Davies et al., 2014). Consequently, OT-KNs provide direct clinical interventions to clients and are expected to engage in behaviours that result in indirect accountability and responsibility for the effective and safe delivery of healthcare services.

Clinical governance 'bundles together' discourses that were already circulating in health care, giving them more emphasis and shaping how OT-KNs think about things. Each discourse points to what it makes possible or limits in everyday practice. In New Zealand, clinical governance discourses promote the importance of certain ideas and associated behaviours. These are:

- Quality, safety, and competency of practice
- Efficiency and fiscal prudence
- Active demonstration of self-responsibility and accountability

- Leadership at all levels (distributed across managers and clinicians)
- Te Tiriti o Waitangi obligations and bicultural practice
- Equitable delivery of healthcare
- Ongoing professional development and learning (Health Quality & Safety Commission, 2017).

Analysis of documents published by OTBNZ indicates that the clinical governance discourses named above are present in OT-WN professional competencies (Occupational Therapy Board of New Zealand, 2022a). See Table 1 for examples. These discourses act to both inform practitioners of expected conduct and discipline them into demonstrating specific behaviours via audit of the professional development activities recorded in compliance with OTBNZ's ePortfolio requirements. So, in addition to clinical governance frameworks being visible within DHBs, the discourses contained within them also circulate throughout many organisations linked with healthcare delivery.

Discourses Within DHBs

DHB-related discourses within a clinical governance framework are highly competitive. They can align, cross, conflict, disappear, reappear, be backgrounded or foregrounded or reconstructed into a new, revised concept. It is of concern to OT-KNs that DHB discourses can also conflict with the profession's discourses and subject positions, which poses challenges for practitioners in their every-day practice with clients. Practices and policies driven by clinical governance discourses include:

- Cost reduction initiatives reducing intervention choice
- Healthcare delivery aimed at improving efficiency
- Elimination/minimisation of organisational risk through standardised protocols
- Expectation of engaging in "two jobs" – frontline clinician and participation in quality improvement initiatives (Gauld, 2013).
- Individual responsibility and accountability, underpinned by demonstration of competency.

These dominant economic, quality, and risk reduction discourses (which do have their place) may compete with the subject positions produced by OT-WN discourses:

- Occupation-focused practice
- Prioritization of equitable health outcomes for Māori
- Te Tiriti responsiveness
- Individualised, holistic, humanising, creative, problem-solving practices
- Spending time to establish therapeutic relationships.

When competing discourses meet, practitioners have to make decisions on how to respond. To illustrate that point, we outlined a scenario of the prominent economic discourse of fiscal prudence and cost cutting leading to resources being carefully controlled, which directly affects the subject positions of OT-KNs. For instance, the equipment that can be provided to clients is often limited to a standardised list of equipment, sourced from a Ministry of Health contracted equipment provider. A custom item or solution deemed more appropriate for the way people live their lives is considerably more difficult to prescribe due to strict eligibility criteria. It requires complex negotiation and justification for approval and supply and must be shown to be cost-effective.

Table 1 Examples of clinical governance discourses circulating within OTBNZ Competencies for Registration and Continuing Practice for Occupational Therapists (Occupational Therapy Board of New Zealand, 2022a)

OTBNZ Competencies	Actions and Abilities you must Demonstrate	Clinical Governance Discourses
1. Applying whakaora ngangahau occupational therapy knowledge, skills and values	1.8 Seek feedback from people receiving your services and engage in critical reflection to evaluate and improve your practice.	Quality, safety, and competency of practice
	1.9 Record and justify your intervention and professional reasoning.	Active demonstration of self-responsibility and accountability
2. Responsiveness to te Tiriti o Waitangi	2.7 Provide services reflective of tikanga, manaakitanga and kaitiakitanga as encapsulated in te Tiriti o Waitangi.	Te Tiriti o Waitangi obligations and Te Tiriti responsiveness
3. Developing and sustaining partnerships	3.3 Enable the perspectives and contributions of people, whānau and relevant others to be heard and incorporated into service delivery.	Leadership at all levels (distributed across managers and clinicians)
4. Practising in a safe, legal, ethical, sustainable and culturally competent way	4.11 Keep appropriate records of the services you provide. These records are suitable for evaluating your services, professional performance and business.	Active demonstration of self-responsibility and accountability Efficiency and fiscal prudence
5. Practising responsively and upholding the occupational therapy profession	5.2 Reflect on your competence, knowledge, skills, attitudes and values, then work to enhance your practice through further development activities.	Ongoing professional development and learning (Health Quality & Safety Commission, 2017)

This process can result in longer wait time or even decline, as the non-standardised solution might be considered desirable, rather than an "essential need" (Accessable, 2021, p. 9) by the equipment provider, driven by Ministry of Health requirements (Ministry of Health, 2014a).

Thus, some would argue, practice is constrained by institutional priorities and processes driven by dominant discourses that displace other considerations. Faced with this reality, the available subjectivities range from accepting responsibility to contain costs and gatekeeping the supply of equipment, to resisting such constraints on the basis that what can be offered is inconsistent with the therapist's clinical reasoning based on need or fails to enable occupation. Depending on factors such as the options available, the time and energy required to resist standardised solutions, the possibility of success, and the degree of emotional and ethical tension experienced, this scenario could be described as a pinch-point.

A further example is the emphasis placed on efficiency, which can limit assessment and treatment time spent with clients. This practice is in tension with the alternate discourse of allowing people time to get to know health professionals before commencing interventions, as a necessary basis for effective client/clinician collaboration. Such an approach is an acknowledgement of Te Tiriti o Waitangi, as actively building relationships or 'whanaungatanga' (Berghan et al., 2017) is crucial to the success of the intervention.

Pinch-Points Identified via On-Line Discussion

During the 2021 OTNZ-WNZ event, we invited the audience to think about how clinical governance might be bringing new and old practices into conflict in their setting. We asked them to identify the conflicts or 'pinch-points' experienced in practice, where professional values and beliefs were challenged by DHB or other organisational clinical governance discourses, and the effect they had on clients. Some examples, or conflicts, that were raised in discussion were:

- Being told to administer an assessment to all new clients (efficiency, standardisation) – even without evidence of cultural appropriateness
- An assessment tool developed for palliative clients (standardised protocol) that did not consider tangata whenua issues and needs
- ACC periodically refusing to accept specific aetiologies (standardised protocols) – arguing that some claims are not due to trauma, but to underlying wear and tear of the body, which means that people who need service fall outside the funding remit
- Having to choose equipment off a list and work to justify getting things people really need (cost containment)
- Monitoring systems, such as audits of clinical records or equipment ordering patterns (individual accountability), which remove capacity to be responsive to the individual
- Limited time available for interactions (cost reduction), leading to a requirement to limit interactions to telephone or zoom with an older population (who often have difficulty due to hearing loss)
- High caseloads (fiscal prudence, prioritising efficiency over individualised health care), contributing to staff attrition and limited opportunities to offer student placements or provide breadth of experiences to students
- OT hand therapists not able to sign off ACC45 (standardised protocols), only physiotherapists can.

Occupational Therapists as Political Activists

The examples above, which participants in the discussion readily identified, suggest that there are a range of conflicts

experienced every day in the practice context. Challenging the rules that do not work well for clients is part of the "art of practice... the practitioner's understanding of the process of treatment that is essential to its effectiveness" (Pollard et al., 2009, p. 25) and closely associated with political activism. According to Pollard and colleagues, OT-KNs should "hold political subject positions" (p. 25), where practitioners use political competencies to challenge rules and procedures that limit their ability to respond to client needs. Those competencies lie at the heart of OT-WN practice: effective communication skills, reasoning and reflection, considering the consequences of actions, strategic planning, and decision-making. Further, OT-KNs should engage in networking, lobbying, and debating. Being a political actor means asking questions about knowledge disseminated to health professionals; asking how those ideas and protocols will affect what they do and, more importantly, what they will do to, and for, OT-WN clients (Pollard et al., 2009).

Beyond the rhetoric, what evidence is there that OT-KNs have the competencies required to act when they are pinched by discourses that have become standardised and normalised in practice, yet limit what can be offered, particularly in a Te Tiriti responsiveness context? In an OTBNZ webinar, *Responsiveness to Competency 2* (Pahau, 2021), *kuia* Iris Pahau provided a number of practical examples of what practitioners have done or could do to reduce pinch points in practice. She suggested building relationships by changing the décor and arrangement of the therapeutic space so that it is Māori friendly, as well as enabling Māori clients to lead and, importantly, formally arranging extra time to have meetings with Māori clients and whānau so that *tikanga* (protocol) and *kawa* (expected behaviour) can be acknowledged and implemented. Pahau also suggested challenging systemic practices that do not fit the whānau situation. She provided an example of a practitioner successfully advocating for the supply of a van for a Māori whānau rather than the standard 4-seat vehicle because it was a better fit for their situation. By working in this activist way, practitioners are effectively political actors (Pollard et al., 2009), exercising power to achieve equitable outcomes.

In addition to anecdotal reports, there is a documented history of OT-KNs responding to the clinical governance discourse of clinicians being responsible for the quality and efficiency of health service delivery. That translates to working within organisational parameters to achieve positive change. An early example is Blijlevens and Murphy's (2003) construction and roll-out of an assessment format and accompanying documentation guideline, based on models taken up from Canada. Their initial assessment form was trialled at a metropolitan DHB and then published as *Washing Away SOAP Notes* in the New Zealand Occupational Therapy Journal. While that practice change might have been challenging for some, as it laid bare what they did in their daily practices, over time it became the template for documentation in other DHBs, initially in paper format, and then later developed as an online assessment documentation tool. It is still referenced in the Auckland University of Technology occupational therapy degree curriculum today (Auckland University of Technology, 2021) as an alternative to the long-standing SOAP format of subjective/objective/assessment/plan (Gately & Borchering, 2016).

Another example is Bishop and Brott's (2019) account of conducting a practice review that balanced the need for careful resource use and how healthcare could be delivered in ways that benefit both client outcomes and

the practitioner's professional commitments. The outcome was the construction of a more effective way of managing community referrals, reducing non-face-to-face clinician time while improving the response to referral wait lists. This process was designed to resolve the pinch-point of long waiting lists to receive OT-WN assessment.

As these illustrations attest, clinical governance discourses can open up opportunities for enterprising OT-WN clinicians to propose systems changes. Opportunities to do so were made visible in DHB documents, such as service plans that asked for evidence that quality assurance was being addressed and initiatives constructed in response to government requirements. The Waitematā DHB Annual Plan (Waitemata District Health Board, 2016) is an example. However, systems change is not always easily achieved. For instance, an attempt was made to administer a modified version of the Canadian Occupational Performance Measure (COPM) to everyone admitted into a metropolitan DHB's older adult rehabilitation service (personal observation, first author). The intention was to ensure completion of a patient-led goal setting process to inform team decision making. Although the initiative was meant to be a multidisciplinary collaboration, enthusiasm waned after roll-out and the OT-KNs were left to complete the process. In this case, quality improvement and multidisciplinary teamwork discourses were resisted in favour of established practices.

Discourses are not static, however, with responses to prevalent beliefs at one point in time coming into question as new discourses take hold. Thus, as a Te Tiriti responsiveness discourse comes into prominence, the question arises as to whether there are any pinch-points associated with documentation formats and assessments derived from models developed elsewhere. Recently, Sir Mason Durie suggested that learnings from overseas were helpful but not sufficient for use with Māori, with whom, he argued, an approach that focuses on the whole person, rather than the parts, is required (Tyson, 2022). Durie's perspective raises questions about whether OT-WN models and practices should be revisited to ensure that practice here is applicable to the New Zealand context. Durie's assertion should cause practitioners to reflect on what they do and how they do it; endeavouring to ensure all aspects of practice are compatible with Te Tiriti o Waitangi in the pursuit of equitable health outcomes. In other words, do the overseas models currently used in practice truly serve the needs of Aotearoa New Zealand's diverse population, or is there an underlying pinch-point?

Conclusion

Recent commentators, including Silcock (2020), have asserted that OT-KNs should be vigilant for "opportunities for political activism" (p. 37). Practitioners need to question practice limitations produced from clinical governance discourses, and to uncover opportunities to challenge the normalised practices and outcomes that are not suited to their clients' situations (Pahau, 2021). They should advocate for alternative solutions that emphasise engagement in Te Tiriti responsiveness and achievement of equitable health and wellbeing outcomes. The basis for doing so, as we have described, lies in, and is supported by, Ministry of Health policy in the form of the health strategy and roadmap, Māori health policy documents, and now the health and disability review (Minister of Health, 2016a, 2016b; Ministry of Health, 2014b; New Zealand Health and Disability System Review, 2020).

Members of professional groups are, unavoidably, political actors. History will judge their everyday practice decisions and actions as advancing justice or colluding in the current, inequitable arrangements. As such, OT-WN practitioners are urged to understand the broader impact of the implementation of clinical governance, which is steadily changing healthcare priorities, the way health organisations function, and how clients are perceived. OT-KNs can choose to 'go with the flow' or actively engage in shaping the possibilities open to the profession and the people it serves. For some, the path will be clear. Others will need to find colleagues, within or outside the profession, who are equally troubled by knowledge that the current arrangements in our country's health system serve some people better than others.

No doubt the landscape will change with the nationwide healthcare system restructure (Department of the Prime Minister and Cabinet, 2021), which consolidates health under one organisation (Health NZ) and a Māori Health Authority. Working within Health NZ rather than multiple DHBs will impact OT-WN practice in Aotearoa New Zealand, particularly in relation to equitable delivery of services and resources. Now is the moment for the profession to step up as political actors to challenge pinch-points that impede the achievement of health equity for Māori.

Key Points

- Professional discourses of enabling occupation and addressing inequities for Māori can conflict with organisational pressures for efficiency, standardisation, self-responsibility, and accountability, causing tension in practice.
- Experiencing pinch points requires analysis of their cause and consequences.
- Practitioners are urged to be 'political actors', questioning and challenging standardised policies that constrain practice, in favour of more creative solutions that will achieve culturally appropriate and equitable outcomes.

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The Occupational Impact of Surviving Bowel Cancer

Elizabeth Martin

A thesis submitted in fulfilment of the requirements for a Doctor of Philosophy degree at Auckland University of Technology, Faculty of Health and Environmental Sciences, School of Clinical Sciences, 2022. The full thesis can be viewed at AUT Tuwhera Open Access Theses & Dissertations

Abstract

This study identified and explored the impact of having had bowel cancer on the day-to-day occupations of those impacted by the disease. New Zealand has one of the highest bowel cancer rates in the world, with over 3000 people diagnosed every year. Many of the approximately 60% who survive, live with ongoing psychological and physical effects. Using interpretive description methodology, this research investigated the experiences of a group of survivors. By addressing the period following treatment, the study focused on an area often not prioritised in cancer care with its emphasis on treatment and end of life. Moreover, bowel cancer literature often uses quantitative methods. In contrast, the constructivist approach of this study facilitated the co-construction of knowledge with bowel cancer survivors, thus furthering the existing and emerging body of evidence regarding the life experienced by this population.

The study was conducted over three phases, reported across four manuscripts. The first of these manuscripts, phase one, presents a scoping review designed to gain an understanding of the current state of knowledge regarding bowel cancer and occupations. Six domains of occupation impacted by bowel cancer were identified: social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care. The review also reported on a lack of health professional support after completion of treatment.

Review findings informed the second phase, semi-structured interviews with 15 participants – made up of bowel cancer survivors and some partners – exploring the occupational impact of bowel cancer. Taking an occupational science view of survivors as occupational beings, the second manuscript reports on three themes: “I had to heal myself”, “Life’s too short”, and “The person I’ve become”.

The third phase involved a further round of interviews with three new participants and two involved in the first round. These interviews had a dual focus; 1) to ascertain whether the identified themes resonated with participants and captured their experiences, and 2), to generate participant guidance as to the information needs of bowel cancer survivors. Findings of the second and third phases are reported in two additional manuscripts, the first of which addressed the potential role of a profession currently under-represented in oncology – occupational therapy. Four themes emphasised the occupational impact across multiple aspects of life: changes in eating habits, changes in toileting habits, changes in relationships, and rethinking occupational choices. Findings revealed a possible role for occupational therapists through focused assessments and self-management, making use of peers to provide a credible, relatable voice. The final manuscript explored considerations for content and delivery of information to bowel cancer survivors across four themes: Using a variety of media, the importance of relatability, pressure to conform, and someone who knows.

Hearing accounts of the challenges to everyday life and the practical and attitudinal responses experienced by bowel cancer survivors highlights the significant impact of the disease. Whilst some pre-cancer occupations are surrendered or adapted, others are increased or introduced, with significant variation amongst participants. This information can help survivors prepare for life after treatment, and health professionals understand the unique challenges faced by this population and thus improve health and well-being.

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Books

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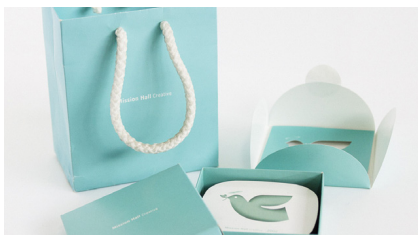
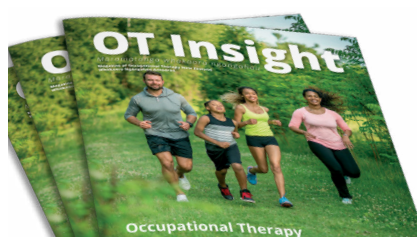
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Multi-C-Air



Tilt-in-Space Rise & Recline Lift Chair

The dual motor Tilt in Space and back recline allows for effective repositioning through 45 degrees with the benefit of increased blood flow and pressure reduction.

- High leg elevation
- Medium to high pressure Care Seat Cushion as standard, additional cushions available
- Optional lateral supports and seat depth adjusters to assist with proper postural support
- 3" built in leg rest extension
- Seat depth adjustability
- Built in vertical lift option, providing a more horizontal and stable platform to those who require it and easier access for either hoist or wheelchair transfers
- Payload of 158kg, leg rest 70kg
- Colour... black



C-Air TIS Bariatric

The dual motor Tilt in Space and back recline allows for effective repositioning through 45 degrees with the benefit of increased blood flow and pressure reduction.

- High leg elevation
- Medium to high pressure Care Seat Cushion as standard, additional cushions available
- Optional lateral supports and seat depth adjusters to assist with proper postural support
- Built in vertical lift option, providing a more horizontal and stable platform to those who require it and easier access for either hoist or wheelchair transfers
- Payload of 222kg, leg rest 70kg (custom mode available to increase leg rest strength up to 140kg)



Multi-Bari Chair

- Conventional dual motor allows for back recline with raised leg rest or the leg rest can be raised independently
- Medium to high pressure Care Seat Cushion as standard, additional cushions available
- Optional lateral supports and seat depth adjusters to assist with proper postural support
- Payload of 255kg with leg rest payload of 160kg



Protac Sensit Chair

- Stimulates the sensory system
- Can be used by all age groups to relieve mental and physical unrest and promote calmness
- Benefits those with ADHD, autism, neurological, mental, sensory processing or developmental disorders.
- 4 side flaps give feeling of safety and security



Madison Mobile Rise & Recline

- The Madison is the mobile version of the Multi-C-Air chair
- The dual motor Tilt in Space and back recline allows for effective repositioning through 45 degrees with the benefit of increased blood flow and pressure reduction.
- High leg elevation
- Optional lateral supports and seat depth adjusters to assist with proper postural support
- Built in vertical lift option, providing a more horizontal and stable platform for ease of hoist transfers
- Seat depth adjustability



Melrose Day Chair

- Manual Tilt in Space
- Push handle and large castors
- Wide range of seat cushions and back support cushions for a range of posture and pressure management
- Seat depth adjustability
- Seat width adjustability
- Ideal for custom fit options