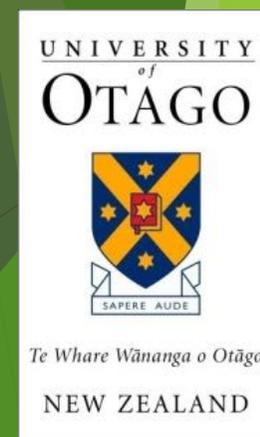


Navigating Ever-Changing Seas: An Emergent Theoretical Model Ageing with Intellectual Disability in the Context of 'Family'



Henrietta Trip, RN, PhD (Otago)
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch, New Zealand
28th PANDDA Conference, Sydney, October 2017

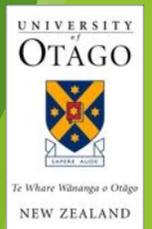


Overview

- ▶ Setting the scene - Background
- ▶ Aim & Methodology
- ▶ Research Findings
- ▶ Discussion & Recommendations
- ▶ Overview:

Navigating Ever-Changing Seas: An Emergent Theoretical Model
(Trip, 2015)

(TRIP, 2017)



WELCOME TO HOLLAND c1987 by Emily Perl Kingsley

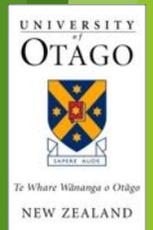


(TRIP, 2017)

Background - The 'Hidden' Population

Individuals who continue to reside with a parent past the age of 40 years have the potential for increased vulnerability regarding service access should the caregiving relationship breakdown

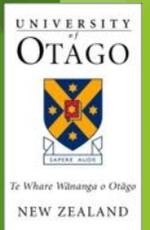
(Dodd, Guerin, Mulvany, Tyrrell & Hillery, 2008)



(TRIP, 2017)

Informal Carers

- ▶ In New Zealand, of ALL informal carers: (Not specific to IDD)
 - 69% are aged 30-64 years
 - 12% are aged > 65 years of age
 - 63% are female (Ministry of Social Development, 2008)
- ▶ Informal carers have their own needs in regards to the impact of age and infirmity (Taggart, Truesdale-Kennedy, Ryan & McConkey, 2012)

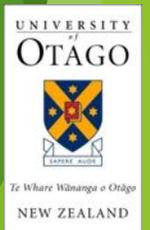


(TRIP, 2017)

(Llewellyn et al., 2003)

*For some older *parents caregiving is virtually a lifelong 'career'... There is a wealth of knowledge... that needs to be made publicly available to inform policy, service development and professional practice.*

*incl siblings, families AND PWIDD

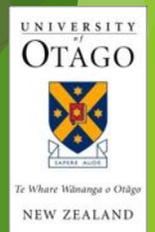


(TRIP, 2017)

AIM



To explore perspectives about ageing &
future planning for people with an
intellectual disability & their family



(TRIP, 2017)



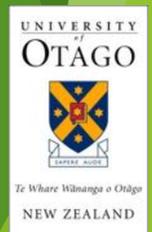
METHODOLOGY

Constructivist Grounded Theory

An interpretive approach in which the researcher ‘co-constructs’ an understanding of experiences alongside participants. (Bryant & Charmaz, 2010)

Individual, historical, cultural & social lenses informs the interaction as it occurs. (Charmaz, 2008)

- ❖ Constant Comparative Process:
Theoretical Sampling + Concurrent Data Collection & Analysis
- ❖ Data Saturation - Theory Building
- ❖ Underpinned by Memo Writing



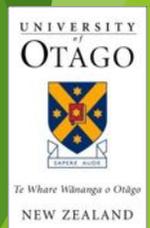
(TRIP, 2017)

Photo Elicitation



“ pictures elicited longer and more comprehensive interviews...
helped subjects overcome the fatigue and repetition of
conventional interviews... it [has an] ability to prod latent memory,
to stimulate and release emotional statements
about the informant’s life...”

(Collier, 1957)



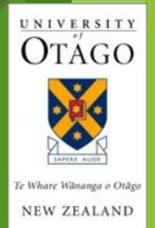
(TRIP, 2017)

Recruitment & Data Collection

- ▶ Non-probability & snowball sampling
- ▶ EOI Form - Informed Consent (Participants with ID)

The above group was invited to bring a photo, image or object to the interview that helped them think about getting older

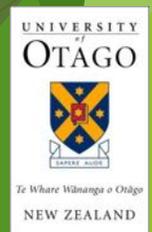
- ▶ Family were nominated by above participants.
- ▶ Interviews occurred simultaneously



(TRIP, 2017)

PARTICIPANTS (n=47)

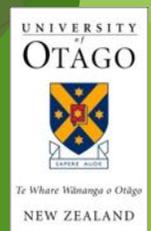
DEMOGRAPHIC	PERSON WITH ID (n=19)	FAMILY/WHANAU (n=28)
Recruitment	Male (n=13) Female (n=6)	Male (n=7) Female (n=21)
Age Range	37 - 58 yrs (means 48yrs)	20 - 83 years old
Co-morbidities	0 - 4	0 - 6



(TRIP, 2017)

RESULTS

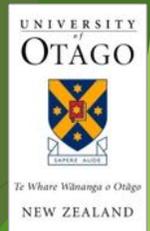
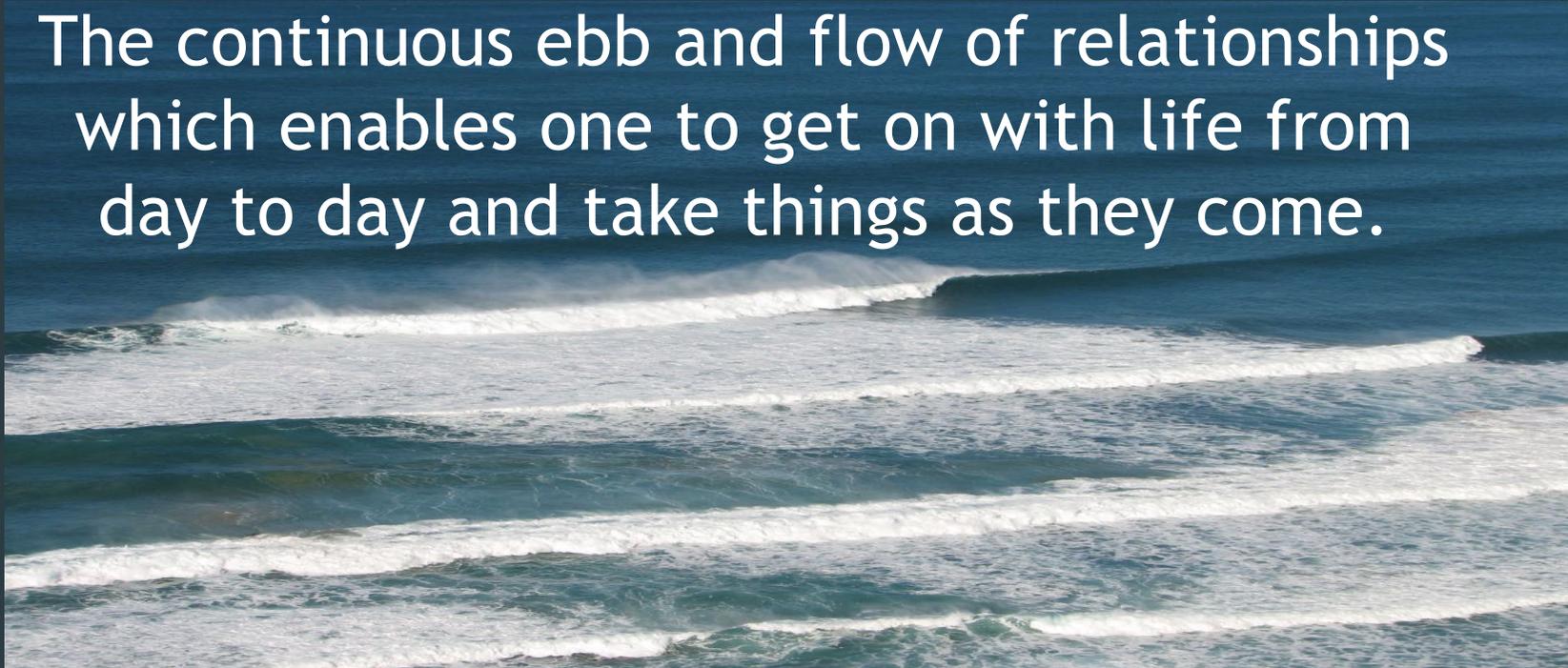
Codes	Category	Concept	Emergent Model
(n=4)	Reciprocating relationships	Riding the Waves	Navigating Ever-Changing Seas
(n=3)	Emerging (in)dependence		
(n=4)	Taking cognisance		
(n=3)	Configuring ageing	Shifting Sands - Changing Tides	
(n=6)	Anticipating change		
(n=3)	Entertaining possibilities	Uncovering Horizons	
(n=2)	Creating a good life		
(n=4)	Mastering decisions		



(TRIP, 2017)

Concept: Riding the Waves

The continuous ebb and flow of relationships which enables one to get on with life from day to day and take things as they come.



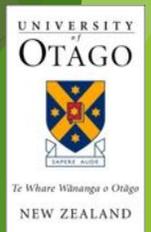
(TRIP, 2017)

Concept: Riding the Waves

“For me I’ve still got a child. I’ll always have a child who is dependent” (Mother)

“...it’s just another role. It is juggling... You become the parent - it evolves...” (Daughter & Sister)

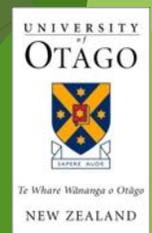
...can't go to the bank and get my money out, she's [sister] got to go with me and sign for it as well...It's a bit harder because sometimes she doesn't turn up... might be 2-3days before she turns up... (Bobby, PWID)



(TRIP, 2017)

Concept: Shifting Sands - Changing Tides

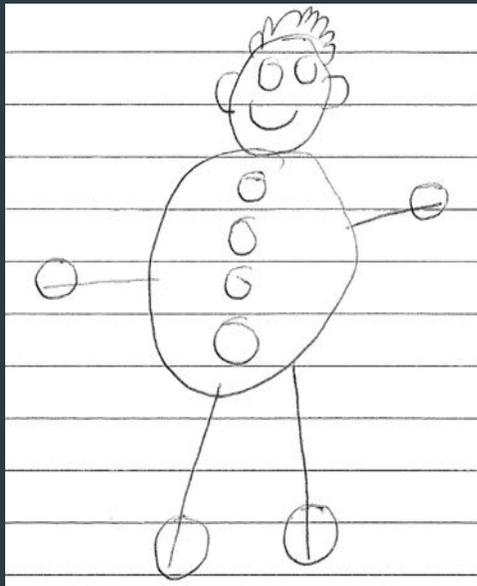
Code	Category	Concept
Defining ageing	Configuring ageing	Concept two Shifting Sands - Changing Tides
Recognising altered function		
Dying is part of living		
Looming responsibilities	Anticipating change	
Limiting factors		
Feeling disillusioned		
Letting go - Enabling others		
Unknowing explorers		
Evolving expectations		



(TRIP, 2017)

Concept 2: SHIFTING SANDS-CHANGING TIDES

Category - Configuring Ageing



“...but it’s [time] too jolly quick...I’d like to have a wand to slow it down but nobody can do that...” (Trevor)



*“That’s me when I’m grown old...
all the hair around there... It grows out” (Lucy)*

Concept: SHIFTING SANDS-CHANGING TIDES

Code: Recognising altered function

“...our bones become brittle... frail and brain becomes weak... [the train] got parts that works by steam and wood to make the engine go and it’s the same with our body parts working...” (Jacob)



....dog is “older than humans sleeps a lot... [and] used to run around like a mad idiot - now not so much. ” (Sam)

Concept: SHIFTING SANDS-CHANGING TIDES

Recognising altered function



“Yes I do [wish he had carried on walking but that was] a long time ago [not an option now]... When in my wheel chair... my body that way... a lean.” (Matt)

Concept: Shifting Sands - Changing Tides

Category - Anticipating change

Code: Looming Responsibilities

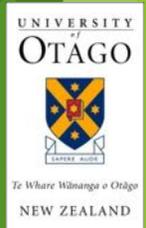
*I'm pretty sure [daughter] would take care of him she wouldn't put him anywhere...
(Maryellen, Mother)*

Code: Limiting Factors

She's very confident. We never leave her... you couldn't quite trust what she'd do in a crisis... (Evelyn, Mother)

Code: Feeling Disillusioned

*I had no help from anyone. I went to the disability people they didn't want to know me...
For almost a year I had [brother] at home... (Teresa, Sister)*



(TRIP, 2017)

Concept: Shifting Sands - Changing Tides

Category - Anticipating Change

Code: Letting Go - Enabling Others

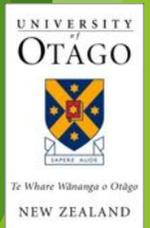
...co-ordinate with us - see what we do... sort of follow on in the lines that we've done... I just want a continuation of what we do... [then] we can just be friends..."

Code: Unknowing Explorers

Honestly don't know what other services are out there... [or] we don't know what to ask for... (Richard, father).

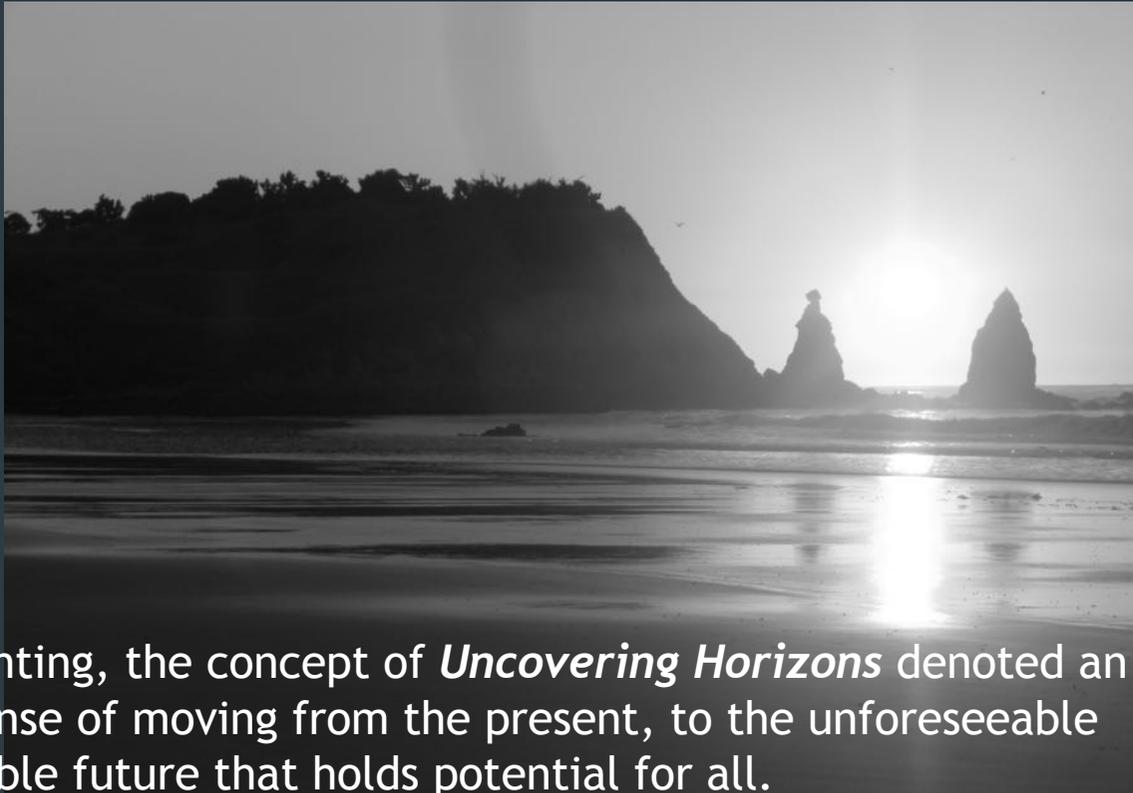
Code: Evolving Expectations

All I know is that ... She'll need someone to help teach her to cook... it maybe selfish but I see that as being [service's] job in a sense (Carmen, mother).

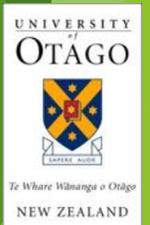


(TRIP, 2017)

Concept: Uncovering Horizons



Whilst daunting, the concept of *Uncovering Horizons* denoted an exciting sense of moving from the present, to the unforeseeable yet inevitable future that holds potential for all.



(TRIP, 2017)

Concept: UNCOVERING HORIZONS

Category - Entertaining Possibilities

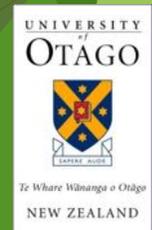
Looking forward



“a bit older [you’ll] have to go and find a flat... It was quite a shock and I felt frightened.” (Kate)

Having an identity

“that was my life as a painter... it was a good life... I liked the job...” (Bob)



(TRIP, 2017)

Concept 3: Uncovering Horizons

▶ **Category: Creating a Good Life**

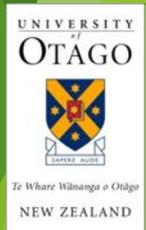
▶ **Category: Mastering Decisions**

Connecting with Others: *“I go to Carer Support sometimes to give Stephanie a break... I quite like it. It’s different people and you get used to stuff. (Sam)*

Knowing the Person: *“...he can judge people and it there’s something about that person I can tell if he doesn’t want to answer a question he’ll change the subject... (Melissa, Aunt)*

Facilitating Ownership: *You kind of have to guide her to the decision... you’re not making the decision for her... how do you feel about it? (Deborah, Sister)*

Engaging the System: *“I swallow a lot of things that come through the system and think well he’s at least got a placement so shut up!”*



(TRIP, 2017)

DISCUSSION

Mutual benefits, social isolation (Parish et al., 2004)

Health status of informal family caregivers cannot be ignored

(Yamaki, Hsieh & Heller, 2009; Taggart et al., 2012)

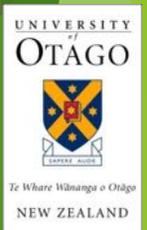
Identity & meaning may be linked to role for family member

(Williams & Robinson, 2001)

The caregiving role between two or more reciprocal parties is often intense and not usually established by choice

(National Advisory Committee on Health & Disability, 2010)

(TRIP, 2017)

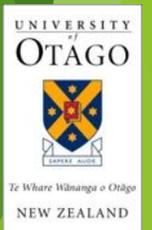


RECOMMENDATIONS

Lifelong planning & collate information:
What would you like others to know to support you
and/or your family member well?

Access to respite care can provide planned breaks, support individuals to develop new skills & may enable opportunity for all parties to seek alternative arrangements.
(Gilbert et al., 2008)

Health & disability systems need to work with families to facilitate planning for compounded caregiving - and the emerging role (or not) of siblings and others considered to be family.

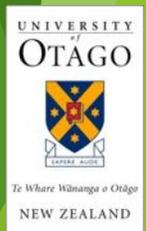


(TRIP, 2017)

Domain	People with Intellectual Disability	Family/Whānau Networks of Support	Health & Disability Systems
Practice	<p>Conversations about ageing in place...</p> <p>Collation of information; life histories...</p> <p>Development of advance-care plans...</p> <p>Edn: Rights & responsibility, life skills</p> <p>Increase flexibility in funding...</p> <p>Assessments which acknowledge and...</p> <p>Information about service access and...</p>	<p>...involving people with intellectual...</p> <p>...update & preferences (bio/psycho/soc)</p> <p>...with each party in caregiving r/s</p> <p>...health literacy & facilitating choices.</p> <p>...and service delivery across the...</p> <p>...respond to the needs of all parties...</p> <p>...delivery is to be provided to individuals</p>	<p>...disability in decision-making</p> <p>...to enable timely planning</p> <p>...across disability & aged care sys</p> <p>Support & enable access.</p> <p>...aged care and disability sectors</p> <p>...in the caregiving relationship</p> <p>...and family across the lifespan</p>
Research	<p>Evaluate Navigating Ever-Changing Seas</p> <p>Develop existing formal & informal</p> <p>Explore opportunities to voice choices &</p> <p>Engagement with photovoice & photo</p>	<p>...across age groups, residential care, SIL</p> <p>...networks of support.</p> <p>...engage person with ID</p> <p>...elicitation. Decrease gatekeeping &</p>	<p>Disability & aged care</p> <p>Evaluation of progs implemented</p> <p>...in future planning</p> <p>... increase inclusive research</p>

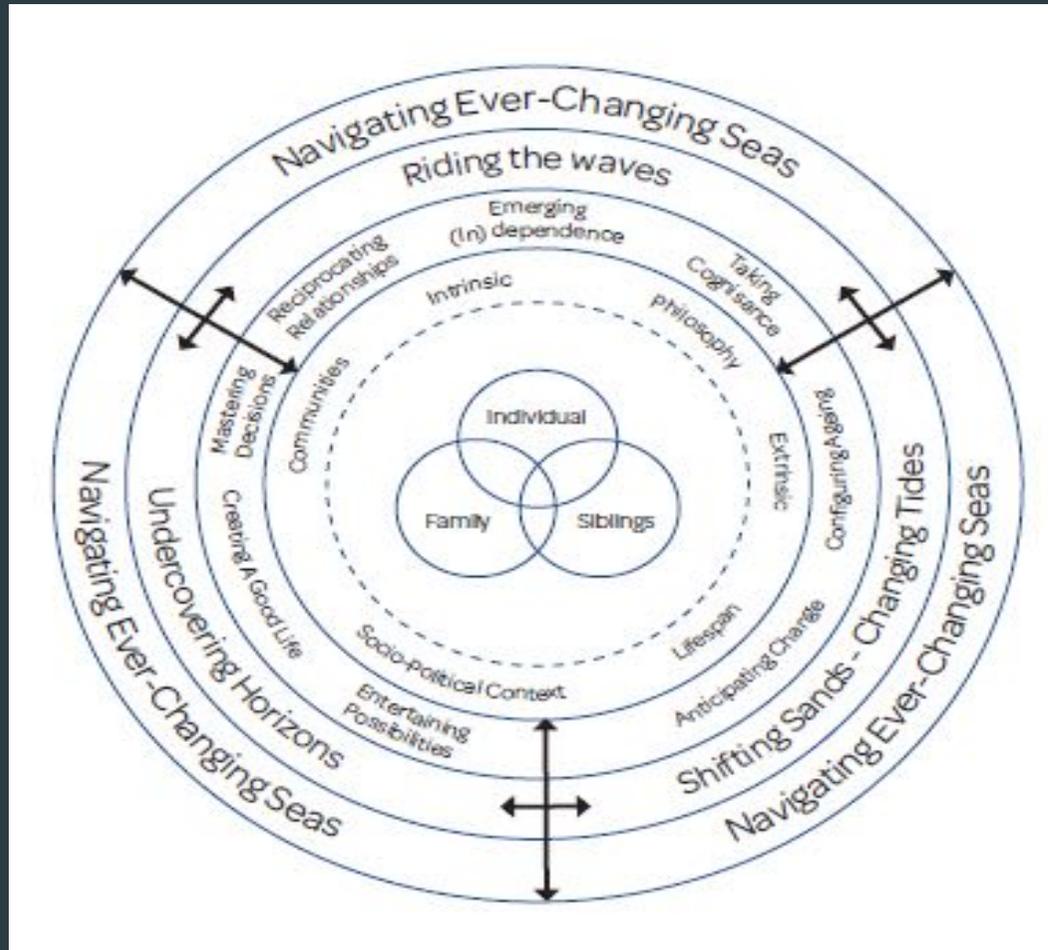
Navigating Ever-Changing Seas: An Emergent Theoretical Model (© Trip, 2015)

*“The map is not the territory”
(Korzybski cited by Bateson, 1973, p. 423)*



(TRIP, 2017)

Navigating Ever-Changing Seas: An Emergent Theoretical Model (© Trip, 2015)



Acknowledgements

To the participants who shared so generously of their lives, their experiences, hopes & realities, past, present and future - which uncovered the dynamics of Navigating Ever-Changing Seas

Professor Lisa Whitehead, RN, PhD

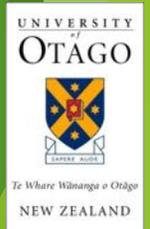
Associate Dean Research, Director, Centre for Nursing, Midwifery and Health Services Research,
Edith Cowan University, Joondalup WA

Honorary Professor of Nursing Research, University of Otago

Professor Marie Crowe, RN, PhD

Centre for Postgraduate Nursing Studies, University of Otago, Christchurch (UOC)

Department of Psychological Medicine, UOC.



(TRIP, 2017)

Thoughts, Comments & Questions...

henrietta.trip@otago.ac.nz

