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Kai Tiaki Nursing Research

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- Registered nurses' experiences and perceptions of practising with a disability
- Ngā Manukura o Āpōpō: Sustaining kaupapa Māori nurse and midwifery leadership
- Nurses' experiences of providing care in an environment with decentralised nursing stations
- Anticipatory prescribing in community palliative and end-of-life care: A realist review
- Utility of the Waterlow scale in acute care settings: A literature review
- Influence of a pulmonary rehabilitation education programme on health outcomes for chronic obstructive pulmonary disease (COPD)
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Kai Tiaki Nursing Research

Kai Tiaki Nursing Research is an internationally, double-blinded, peer-reviewed nursing research journal, published by the New Zealand Nurses Organisation. It contains research manuscripts from New Zealand-based nurse researchers (or other researchers where the research can be shown to have relevance to nursing in New Zealand).

Papers in all areas of nursing are welcome. Authors should present original work, or new and original analysis of existing work. Letters to the editor are also published. All articles and manuscripts will be subjected to the same rigorous review process.

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FROM THE EDITOR: **Patricia McClunie-Trust**

Giving voice to nurses' expertise, resilience, endurance and creativity

Tēnā koutou, tēnā koutou, tēnā tatou katoa.

Welcome to the 2021 edition of *Kai Tiaki Nursing Research.* This year has brought further significant COVID-19-related challenges for nurses working in all fields of practice, from clinical settings to education and research. As we know, these challenges have been amplified by the emergence of the Delta strain in community-acquired infections in 2021. Nurses have been core in managing the Aotearoa New Zealand response to the pandemic, across all sectors of the health service. Nurse educators and nurse researchers have flipped teaching and data collection online with skilled determination to overcome the limitations of the social distancing required in their fields. Our postgraduate students have also shown remarkable determination in completing their programmes of learning, albeit with support from their lecturers and supervisors. The pandemic has highlighted nurses' skilful participation in responding to the health needs of our people and their communities.

Maximising the contribution that our existing nursing workforce can make to population health outcomes has been one of the drivers of postgraduate clinical education in Aotearoa New Zealand in recent years (Holloway, 2012). Postgraduate education has enabled nurses to gain advanced knowledge and skills to more capably respond to the demands of rapidly changing and increasingly complex health-care environments, including the COVID-19 pandemic. A capable nursing workforce is the most important factor determining the ability of health services to provide safe and high-quality care (Torabizadeh et al, 2019). Capability describes the expertise, resilience, endurance and creativity of nurses working to the top of their regulated scope of practice, who can respond to challenging, unexpected, unusual and demanding clinical and professional situations. In other words, they can capably work beyond their usual comfort zone, using a complex combination of knowledge, skills and professional self-awareness (O'Connell et al, 2014).

Capability is underpinned by macro-level thinking, or recognition of demographic, epidemiological and social determinants of health that affect a specific client's experience of health. Macro-level thinking – underpinned by research evidence and knowledge about how nurses can respond more ably – is central to widening nurses' thinking about the client and their situation (Hean et al, 2009). Postgraduate education enables nurses to engage with research, both as end users working in evidence-based activities that have direct application to practice, and in conducting research that illuminates nursing's voice in interpreting what nurses know and how they think in practice. Nursing research documents practice knowledge derived from the cumulative integration and synthesis of multiple and challenging care experiences (Tanner, 2006). It is imperative that nurses emerging from postgraduate programmes are supported to publish their research as new voices informing nursing knowledge and practice in Aotearoa New Zealand.

Patricia McClunie-Trust

Nursing workforce

The health and wellbeing of a nursing workforce is core to the effectiveness of any health service. The COVID-19 pandemic has illuminated the work nurses do in health services, but what is less well understood is how it has strained an already stretched nursing workforce (Gottlieb et al, 2021). Gottlieb et al suggest the pandemic has also exacerbated challenges in nursing leadership and had an impact on nurses' agency and autonomy in their practice. Sustaining the nursing workforce within the demands of a pandemic requires nurses to feel empowered at work.

Sustaining the nursing workforce within the demands of a pandemic requires nurses to feel empowered at work.

Nurses' experience of living and working with a disability or impairment was the focus of research by Hughes, Rose and Trip in this issue. The findings of this study suggest nurses are committed to safe nursing practices, but many of the participants in this study did not feel safe to disclose disabilities or know where to seek support. These authors note that more effective support for nurses who have disabilities may help them to remain in the workforce. Moss, Were and Pipi conducted an evaluation of a national Māori nursing and midwifery leadership programme. The key themes from the findings of this evaluation – whakamana, or a sense of empowerment, and ngā manukura, a concept that speaks to starting or progressing leadership journeys – were vital elements of personal, professional and cultural development. The findings of this evaluation also suggest that the kaupapa Māori approach of the programme may help Māori clinical leaders to address future health workforce needs.

Miles, Lea and Ritchie evaluated the experiences of nurses working in decentralised workstations in New Zealand hospitals to understand more about the intersection of the physical environment and its impact on nurses and the delivery of nursing care. The findings of this study suggest that while there were benefits for patients in having nurses close by, nurses experienced isolation from their colleagues, lack of space in the decentralised nursing station, and limited knowledge of other patients on the ward.

Evidence-based nursing practice

Evidence-based practice can be defined as *"the conscious, explicit and judicious use of current best evidence in making decisions about the care of individual patients."* (Aliki & Young, 2019, p. 137).

It involves the interaction of best available evidence, the patient context and preferences, and clinical expertise. The following studies in this section highlight the importance of considering multiple sources of information to inform diagnostic reasoning and clinical judgement. McChesney and McClunie-Trust explored factors influencing anticipatory prescribing in community palliative and end-of-life care. Key themes identified in this meta-synthesis included expertise (knowing when to prescribe and knowing how to prescribe), teamwork and prioritisation. The study concludes that developing and maintaining expertise in primary palliative care, developing better interdisciplinary teamwork, and prioritising anticipatory prescribing practice are key factors underpinning effective palliative and end-of-life care.

The influence of a pulmonary rehabilitation education programme on health outcomes for people with chronic obstructive pulmonary disease (COPD) was the focus of an integrative review conducted by Chiyesu. The findings of this review suggest there is insufficient evidence to demonstrate the influence of this intervention on health outcomes. Further research is required to ascertain whether pulmonary rehabilitation education would be beneficial in the New Zealand context. A literature review by Nadeem and Healee explored the effectiveness and validity of the Waterlow scale in preventing pressure injuries in acute-care settings. The review identified that the Waterlow scale has limited reliability and validity in assessing the risk for pressure injuries in acute-care settings, and further research is needed to test the scale in this context.

Ryan's study on the relationship between health outcomes for rural and urban patients and their proximity to a primary health care provider found that there was little difference between these populations in terms of HbA1c levels for people with type 2 diabetes mellitus. The study found people living rurally were more likely to be diagnosed with depression than those living in urban areas. A meta-synthesis by Harrison and Mercer explored the use of rapid antigen detection tests (RADT) for the diagnosis of group A streptococcus (GAS) for children who have clinical symptoms of pharyngitis. The findings of this review suggest that there are advantages in using RADT for more timely diagnosis and treatment of GAS infections, for reduction in the spread of GAS infection and therefore potential reduction of rheumatic fever hospital admission rates.

Methodology focus

In keeping with the principle of kaitiakitanga (NZNO, 2019) or guardianship of nursing research in Aotearoa New Zealand, fostering emerging researchers is a key responsibility for the *Kai Tiaki Nursing Research* journal. In this edition, two experienced researchers share their methodological "know how", reflecting on their experiences of using methodologies to guide nursing research. Litchfield draws on her long experience in research to offer a rationale for nursing as a paradigm that frames nursing "research as-if practice". Research as-if practice enables nurses, as practitioner researchers, to communicate nursing knowledge and expertise as practice wisdom for the distinctly nursing perspective of health in Aotearoa New Zealand.

In a different, but distinctly practical research approach, MacKenzie used a transdisciplinary research (TDR) methodology to explore some complex issues associated with the position of enrolled nurses in the Aotearoa New Zealand health workforce. Central to the TDR approach is the idea of "wicked problems" that require creative and flexible solutions derived from the perceptions and opinions of stakeholders as participants or key informants in research. The inclusion of viewpoints beyond the assumptions and perspectives of specific disciplines, where diverse voices with unique perspectives on how problems can be solved can be heard, is central to the TDR approach.

Finally, in the last article of the 2021 issue, Stodart and Woods explain how articles in each issue of *Kai Tiaki Nursing Research* are shared with the international world of practice and scholarship, via their inclusion in a range of international research databases. Some limited data is available from one of these databases about which articles are being downloaded and in what quantity, giving a tantalising glimpse of the reach and influence of this research journal.

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REGISTERED NURSES' EXPERIENCES AND PERCEPTIONS OF PRACTISING WITH A DISABILITY

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ABSTRACT

Aims: The aims of this study were to explore the perceptions and experiences of registered nurses (RNs) practising with a disability or impairment, and to describe the strategies they used to support their role as an RN.

Background: Despite the availability of anti-discrimination guidance, nurses practising with a disability or impairment described varying levels of understanding and support available to them from colleagues and managers.

Methods: A descriptive qualitative study allowed us to explore and describe RNs' experiences and perceptions of their interactions with colleagues and managers in clinical practice. This process uncovered what was important to the participants, including strategies they used to ensure they practised safely. Participants took part in a 60-90 minute interview that gathered their experiences and perceptions of working with a disability or impairment as defined by the RN. The semi-structured interview schedule, with one main question and prompt questions, enabled participants to share their individual stories. Thematic analysis was undertaken.

Participants: Ten RNs – nine female and one male – were selected purposively because they identified as living and working with a disability or impairment.

Findings: Four themes were identified. *Impairment or disability?* – Nurse participants preferred to articulate the impact of the disability or impairment on them, rather than defining those terms. *Telling others* captured the decision-making process they went through on whether to disclose their disability or impairment at work. Participants described fear or reluctance to disclose; this decision was also influenced by whether their disability or impairment was visible or invisible. *Getting support* pulled together some of the concerns nurses had about the lack of organisation-wide support. The perceived lack of support affected the nurse's desire to ask for help and often resulted in the nurse organising their own support resources. *Impact in the workplace* – The nurse participants had developed unique strategies to ensure they nursed safely.

Conclusion: For participants, the ability to define the impact of their disability or impairment on their working lives was more important to them than selecting a definition of "disability or impairment". All participants were committed to safe nursing practice. The degree of visibility of the disability or impairment influenced the nurse's willingness to disclose or ask for help. A visible disability was acute or obvious and a less visible disability reflected the post-acute, rehabilitative, or chronic stage. However, overall, because many of the nurses did not feel safe to disclose their disability or impairment, ask for help, or know where to go to access support, accommodations were not made for them in the workplace.

KEYWORDS

Nurse, disability, impairment, disclosure, accommodations

INTRODUCTION

Articles 24, 25 and 27 of the United Nations Convention on the Rights of Persons with a Disability specifically relate to people with disabilities having equitable access to the same resources as others and being able to realise their goals in education, health and employment (United Nations General Assembly, 2007). For nurses practising with a disability, the debate often focuses on their fitness to practise, and the consequences that the disability or impairment has for people wishing to join the nursing profession. This debate is accompanied by a discussion about workplaces making reasonable adjustments or accommodations, and the attitudes of others towards the health worker with a disability (Tee & Cowen, 2012; Griffiths et al., 2010; Storr et al., 2011; Tee et al., 2010; King, 2018).

A review of the literature related to nurses practising with a disability or impairment is timely, as nurse leaders and managers in New Zealand voice concerns over retaining nurses in the workforce in the context of a global shortage of nurses (Matt, 2008; Moloney et al., 2018; Neal-Boylan, 2013, 2019; Report from the National Nursing Organisations to Health Workforce New Zealand, 2014). The review of the literature that follows informs this research study, which is designed to explore the challenges experienced by nurses working with a disability or impairment, the support they would prefer and the strategies they employed at work to practise safely.

BACKGROUND AND LITERATURE REVIEW

Neal-Boylan and Miller (2016) found that many nurses with physical or sensory disabilities left the nursing workforce because they felt discriminated against, and unsupported by nursing colleagues or administrators. Nurse participants in that study were also worried that they themselves could have a negative impact on patient safety. Compounding these concerns, many of the nurses were also unaware of their disability employment rights.

Through a grounded theory study in the United States, Matt (2008) also explored the attitudes of nurse colleagues that did not meet the legislative requirements designed to mitigate employment discrimination. The aim was to identify themes related to the "disability climate" (p.1524), so policies could be designed that supported nurses practising with a disability. Matt's (2008) study identified the impact of an unfriendly environment and the support nurses with disabilities needed from leaders, managers, colleagues and peers to be accepted. This study provided an important snapshot in time, to show how nurse managers could contribute to creating a disability-friendly work environment.

A New Zealand study, which used a qualitative approach, identified the barriers that registered nurses (RNs) experienced due to their impairment, and the strategies they used to overcome them (Korzon, 2011). Seven participants were selected purposively and identified their disability – these included head injury, hepatitis C, fibromyalgia, anxiety, panic disorder and spinal injury. Some of the nurse participants had lived with their impairments from birth, while others had acquired them later. The sometimes disabling attitudes of managers and colleagues had the most impact on the RNs, often leaving them feeling pre-judged (Korzon, 2011). This prevented them from discussing their disability or impairment or asking for support. Korzon's study has contributed to the qualitative literature on RN colleagues whose attitudes "dis-able" nurses with disabilities.

Wood and Marshall (2010) used a study with an exploratory descriptive design to understand the attitudes and concerns of 219 nurse leaders who employed nurses with disabilities in the United States. The study explored the nurse managers' attitudes to work performance, concerns expressed by other staff, perceived abilities of nurses' disabilities, job performance and accommodations made in the workplace. The researchers found the job performance of nurses with disabilities was exceptional. Wood and Marshall (2010) also found a positive correlation between nurse managers' historical experiences of hiring a nurse with disabilities, and willingness to employ in the future. They concluded that further research on the effective recruitment and retention of nurses with disabilities was vital so experienced nurses could be retained, and their skills used.

Similarly, Neal-Boylan (2013) – in a qualitative exploratory study – explored workplace requirements in the United States. Job descriptions of RNs were correlated to the actual work carried out by nurses. Notably, it was found that nurses with disabilities did not generally receive a job description, did not disclose their disability, and therefore did not receive any accommodations in the workplace. Neil-Boylan concluded that nurses were often pre-judged because of their disability and did not feel valued, resulting in them leaving the nursing profession.

While there have been several studies on nursing students with disabilities (Ashcroft & Lutfiyya, 2013; King, 2018; Moodley & Mchunu, 2018; Tee et al., 2010; Tee & Cowen, 2012; Wray et al., 2013), there have been few on graduated nurses who acquired or developed a disability or impairment. Taking into account the global nursing shortage, an ageing nursing workforce (Moloney et al., 2018; Neal-Boylan, 2019; Report from the National Nursing Organisations to Health Workforce New Zealand, 2014), the cost of educating nurses, and legislation that specifically prohibits discriminatory behaviour, it is important to understand the issues and concerns for nurses practising with a disability or impairment.

METHOD

Aims

The aims of this study were to explore the perceptions and experiences of RNs with a disability or impairment and to describe the challenges they faced at work, and the strategies they used to support their role as a nurse.

Design

A qualitative descriptive design was selected to explore and describe nurse participants' experiences and perceptions to answer the research question: How do RNs who live and work with a disability or impairment negotiate their roles and responsibilities in their clinical practice settings? The design was informed by Sandelowski (2000, 2010) who explains that qualitative descriptive studies are useful for exploring and describing a phenomenon, rather than interpreting or penetrating the data.

Ethics

The nurse participants were assigned a pseudonym to ensure confidentiality. Ethical approval for project 1839 was granted by the Ara Human Ethics Committee in April 2019. Confidentiality, privacy and autonomy were maintained throughout the research process.

Table 1. Demographics and disability, impairment or health conditions of nurse participants

Gender	Female	9
	Male	1
	Gender diverse	0
Age	20-29 years	3
	30-39 years	1
	40-49 years	3
	50-59 years	2
	60-69 years	1
Ethnicity	New Zealand European	6
	New Zealander	4
	Māori	0
Disability or impairment	Hearing loss	3
	Autoimmune disease	1
	Chronic pain, neuropathy memory loss	1
	Dyslexia/dyscalculia	1
	Brain injury	1
	Traumatic injury/chronic pain	1
	Dyslexia	1
	Poor vision, back injury, rheumatoid arthritis	1

Notes: The disability, impairment or health condition is as described by the participant. These descriptions have been kept broad to enhance anonymity.

Recruiting participants

Purposive sampling was used to recruit RN participants who met the inclusion criteria. Nurses were eligible to be included if they were registered as a nurse and identified as working with a disability or impairment. They could be employed in any clinical practice setting. A snowballing strategy was also used to recruit participants, whereby prospective participants shared information about the study with colleagues (Polit & Beck, 2012; Valerio et al., 2016).

Ten RNs who met the inclusion criteria were selected, nine female and one male. The demographic characteristics of the participants, including age, gender, ethnicity and type of disability or impairment, are presented in Table 1 (above). Their experience ranged from one to 32 years. Clinical practice settings and years of experience are presented in Table 2 (above, right).

Data collection

Interview questions were sent to participants two weeks before a scheduled face-to-face interview so they could prepare their responses. The main question was: *"Can you please tell me about your experiences of living with a disability or impairment and working as a nurse?"* This was followed by 11 prompt questions that were used as a guide to the information the nurse participant chose to share. The semi-structured interview schedule is provided as Table 3 (see following page). To maintain consistency, the lead researcher carried out every interview. The face-to-face interviews were audiotaped and transcribed verbatim by a professional transcriber. The interviewer wrote field notes and a reflective diary during and after each individual interview.

Table 2. Clinical practice settings of nurse participants and years of nursing experience

Workplace/clinical area		
	Medical/surgical	4
	Medical	3
	Community	1
	Primary health	1
	Mental health	1
Years of experience		
	< 1 year	2
	< 2 years	1
	< 3 years	1
	< 8 years	1
	25-28 years	3
	30-32 years	2

Note: All nurse participants were employed during the study.

Data analysis

Braun and Clarke's (2006, 2012) data analysis process was used as a guide to analyse the data that emerged from the 60-90 minute interviews. The personal stories that emerged from the summary were checked by the other researchers and returned to the participants for comment, deletions, additions or changes. All participants responded to this request and changes were made to three interview summaries. To maintain consistency, the data analysis process was initially undertaken by the lead researcher, then discussed and reviewed with the co-authors.

Colour coding was used to firstly group the data into categories and subcategories, and then to group these into themes within each of the interviews, and between interviews. Verbatim quotes were used to support the themes. The three researchers met again to clarify the names of the themes, as well as their content, evidence and descriptions. The themes identified by the data analysis were: "Impairment or disability?", "Telling others", "Getting support," and "Impact in the workplace".

FINDINGS

Impairment or disability?

While a distinction between disability and impairment is made in government policy documents (Ministry of Social Development, 2016), for the participants in this study, the choice of a term or word such as disability or impairment was not a distinction they felt the need to make. Most of the participants bypassed the definition and described their condition through their diagnosis or the signs and symptoms they were experiencing.

Tammy: *"I have a chronic [auto immune disease[1]]".*

Garry: *"I have a brain injury".*

Pat: *"It's a disability but I don't think of it that way".*

While Jenny had never thought of her hearing loss as a disability,

1) Name of health condition has been kept broad to enhance anonymity.

she felt she was *"disabled without them [the hearing aids]. . . . But it never stopped me doing things"*.

Participants believed it was important to capture the impact of the disability or impairment, rather than defining the terms.

> Cindy: *"It's either or neither. I'm not fussy about what you call it . . . They exist. It's real"*.
>
> Terry preferred the descriptor *"challenges or difficulty rather than using labels such a disability or impairment . . . Like if they asked me, 'Do I have any disabilities?' then I would have said, 'Well I don't define dyslexia as a disability'."*
>
> Emma felt her dyslexia was an impairment, not a disability. *"I just think differently. And because of how things are taught and tested, I'm impaired because of how I must respond."*

Telling others

The "Telling others" theme was informed by two subcategories which exemplified the process of disclosing. These subcategories were: "fear of disclosing", and whether the disability or impairment was "visible or invisible".

Fear of disclosing: The "fear of disclosing" subcategory captured the reluctance many of the participants felt in telling their colleagues and managers about their disability or impairment. Some were reluctant to disclose this information because they were worried it wouldn't be treated confidentially, or they weren't sure they could trust them with the information. For others, this reluctance was linked to their perception that there was a stigma attached to their disability or impairment.

Ellen and Emma did not want to disclose information about their health conditions to prospective managers or colleagues as they felt there was a lack of confidentiality.

> Ellen: *"I haven't really told a whole lot of colleagues. They know I was on treatment. One of them very explicitly asked: 'What problems do you have after treatment?' So, I told her because I trust her.. . . I haven't shared it with my manager. I think it's a trust issue. I don't want to be felt like I couldn't do my job. . . . And I guess that comes to part of the trust issue, that I wouldn't necessarily trust a whole lot of people to, you know, react to it well, or you know, not to be talking about me"*.
>
> Emma: *"I don't know if my colleagues know. I've mentioned it to some of them . . . I honestly don't know if my boss knows whether I'm dyslexic . . . I would probably be more selective in who I approached about it though."*

The degree of stigma associated with the disability or impairment also influenced whether they disclosed.

> Cindy did not disclose any of her disabilities in her job application: *"I didn't disclose my disabilities because I thought that I wouldn't get the job. And I wouldn't have. They didn't ask in the application or the interview . . . I knew I wouldn't have a chance they'd employ me."*
>
> Fear of disclosing was echoed in Garry's interview. He was quite clear – if you disclosed, you were treated unfairly and

Table 3. Interview schedule

The semi-structured questionnaire that guided the interview, including the main question and prompt questions:

Before you come to the interview, you might like to consider some of the questions listed here. Please feel free to write on/beside the questions, bring notes with you or ask for clarification.

Demographic data

- What is your gender?
- What is your age?
- How would you describe your ethnicity?
- How long have you been registered?
- Are you currently employed?

Main question

Can you please tell me about your experiences of living with a disability or impairment and working as a nurse?

Prompt questions

- How would you describe or define your disability or impairment?
- Did you acquire your disability or impairment or was this something you have always lived with?
- Has living with your disability or impairment impacted on your role as a nurse in your workplace?
- Have you always disclosed your disability or impairment to your colleagues and managers? Have you ever hidden it in any way? If so, how?
- Have you ever asked for help for your disability or impairment at your workplace?
- Has a workplace or a colleague ever made any accommodations or adjustments for your disability or impairment?
- Can you describe a situation when a person or workplace facilitated and supported your success as a nurse working with a disability or impairment?
- Can you please describe an experience that illustrates some of the difficulties you may have had as a nurse working with a disability or impairment?
- Were you able to overcome the barriers you identify in the previous question? Please describe.
- What sort of support, strategies or enablers, if any, would you like to see in your workplace?
- What skills and attitudes do you think nurses and managers need to work safely and effectively with nurses with a disability or impairment?

Note: The semi-structured nature of the interview encouraged nurse participants to share the ideas, issues and concerns that were important to them and enabled them to describe their own story.

"discriminated against. . . . Because of my injury I've had to have a significant amount of time off work. You have to disclose that when you go for jobs. I just like don't get interviews! . . . As soon as they ask: 'Have you had any significant time off work?' I think that's a big tick box that says: 'Don't even bother with this person.' "

Tammy also felt there was a degree of unfairness: *"I still feel there's a lot of people that see [my autoimmune disease] and then just [write me off]. Because before that, I used to, you know, I applied for quite a few jobs and that, but I don't even get interviews nowadays. And I never had that. You know? . . . Cos I'm choosing jobs that I think I can do."*

Jenny believed that having a hearing impairment did come with stigma. *"I do [find that]. More than with poor sight. So, nobody thinks twice if somebody's wearing glasses. But if you can't hear what they're saying, people get a bit irritated. And I mean, I don't feel embarrassed. Because I'm old and I don't care now. But I used to feel embarrassed when I couldn't hear what people were saying, you know, before I had hearing aids. . . . I think I've got more confident about speaking up about it as I've got older."*

On the other hand, Pat believed there was no stigma associated with her hearing impairment. She was able to articulate her hearing impairment needs in meetings so she was not disadvantaged, and had the confidence to ask people to face her when they spoke to her so she could lip-read.

"And that kind of leads us to the next question about disclosing. Well it's my managers who found it, so that wasn't an issue. And I've never kept it hidden because there's no gain for me. It's easier for me because it's not an embarrassing thing to mention. I've not done anything stupid. I've not done anything unfortunate. It just is."

Invisible or visible? Disclosure was also dependant on whether the disability or impairment was visible or invisible. A visible disability or impairment was one where the signs and symptoms were overt or obvious, such as the need to use a hearing aid or walking stick, or if the nurse was in an acute stage of their condition. An invisible disability was one where the nurse was in a less acute, less obvious, chronic or rehabilitative stage. When the disability or impairment was overt or visible, this removed the need to re-explain, justify or re-tell their story.

Although Rebecca's experiences of support from management were glowing, her perception was that when her disability was visible, she did not feel guilt when asking for help or receiving it. However, when it became a rehabilitating and chronic situation (and was no longer as overt or visible), she felt a sense of guilt. This led to her re-explaining her condition and feeling the need to justify it more to her manager and others.

"It's interesting. And it's almost like I felt a little bit guilty [as now not so visible], I didn't get as much support as last time. And I wonder if it's the stigma of ACC and the stigma of chronic issues and the stigma of . . . you don't know how long they're going to go for versus 'I've had a traumatic injury, and actually, I can see that I'm improving' and people can see that you're improving".

Tammy described finding other people understanding of acute health issues, but it was the chronic, often unseen, ones that people struggled to see and understand.

"Well, I had some crutches – my mother had a broken ankle. That was my idea as well. I just felt more stable with it. And then I found that people were maybe well . . . a visual aid. Cos [an autoimmune condition] is pretty much an invisible thing. . . . But that's why I use the crutch more too, because people actually go, 'Okay. She may need a little bit of help.' Whereas before that, you didn't get any. Which is kind of funny."

Polly also talked about the visible versus invisible stages of a disability or impairment:

"Especially people with regional pain syndromes – and just back pain . . . I mean, just back pain, that is so disabling. And then the whole mental health stuff. It's nothing visible. I feel really sorry for people with those less visible conditions that you might be embarrassed of or ashamed of or just tired of, kind of thing."

Ellen confirmed this sentiment. *"Yeah. And I guess for me it's, because it's not a very visual thing, it's kind of a blessing and a curse. The fact that I can present as very – no problems at all. Like sometimes I will be sort of limping and things, but, you know, I don't use a crutch. You know, I don't have a very visible thing, or I haven't got a hearing aid. I haven't got, you know, anything that would really identify me as disabled. But then also if I did, I feel like people would be more understanding of my situation."*

Getting support

The "Getting support" theme captured the ideas expressed by the participants relating to organisation-wide help and support, the workplace making accommodations, and the nurse asking for help.

Organisation-wide help and support: Many small and medium-to-large organisations employ a health and safety officer or quality or privacy officer. However the participants in this study did not believe that an office or person existed for employees with a disability or impairment. This led nearly all participants to believe there was a lack of an overall point of contact or organisation-wide support.

Tammy had problem-solved the barriers she encountered each step of the way as her condition deteriorated. She pointed to the human resources (HR) department as a possible support but could not think of any office or person dedicated to supporting or advising employees with disabilities or impairments, although her (new) charge nurse had tried to help.

"I kind of get the feeling that it was just new for her [the charge nurse] and new for me. So we kind of didn't really know where to go from there. . . . But, I mean, you know, she's been trying to find me other work."

Pat could not think of any support offered that was an organisation-wide point of contact:

"I wouldn't know where to go other than occupational health, and to be honest I wouldn't consider it. They're not really set up to help in these situations."

Jenny suggested that the nurses' union could be approached for

support, but was not aware of any other organisation-wide support.

She added: *"There are some good managers . . . And you know they want to look after their nurses. It starts at the top."*

Garry described an immediate manager who was caring, helpful and supportive. He also noted that he had offered his services to senior management, to share his experiences of re-entering the workforce and working with a disability with other employees. However, the organisation had not returned his calls or responded to his offer. Although the organisation had a human resources (HR) division, overall he felt the quality of the information provided to him was variable, and sometimes conflicting. His perception was that there was not enough support for people with disabilities or impairments in his organisation.

The workplace making accommodations: The participants identified some missed opportunities for their workplace to make accommodations for nurses with a disability or impairment. This led to several of them seeking out their own resources and supports.

Sally and Cindy both spoke about their workplaces buying equipment that did not meet the needs of all users. Sally struggled with phones that were old, or not capable of having the volume turned up or down, even though they were newly installed – this was despite nurses with hearing impairments having worked there for several years.

Sally: *"And so, I really struggled with phones. I still really do if it's too noisy. I can't hear anything. And I'm still getting used to that and trying to figure out how it works and what phones work and how to turn them up and things. But they're aware that I won't use the phone unless I really have to . . . Yeah, they [the Cochlear Programme] give me ideas. But, like, all the things they've given me related to phones and stuff wouldn't work with the phones we have [at work] and they're all too old and I can't plug anything in or do anything."*

She was not aware of a specific support person or office within her organisation. Other than the ward suggesting she could get a badge saying, "I'm hard of hearing," which she did not find helpful, Sally had worked on solving her own problems. For example, she had organised her own personal stethoscope which was linked by Bluetooth technology to her cochlear implants. She believed this need to problem-solve for oneself was the same for all employees with a disability or impairment.

Sally: *"My whole Bluetooth thing is new. Before that, I just plugged it in. So, I have my own stethoscope and that is quite good. I can turn the volume up, so it worked out quite well for me . . . There was someone that was a midwife that I met through the Cochlear Implant Programme. And she used that one. Like, she said she'd spent years and years trying to find good ones. Like, she'd bought so many, and this one worked. And so I tried it. I was like, 'Yes, this one's good.' So, I got one. And yeah, it's been really good so far."*

Sally also identified a missed opportunity to help people with disabilities in her workplace. When she started the job, she was replacing someone with a similar impairment. Being able to talk to this outgoing staff member would have been beneficial for her.

"Yeah. Like even kinda finding people like you to feed off ideas. Because, like, before I even started, I was worried about the phones. And, I mean, I was talking to other people but, they had different jobs, so, circumstances were different. But it would have been kinda good to kinda feed ideas off people on how they cope."

Asking for help: Some participants said they were reluctant to ask for help and support.

Ellen did not ask for any help and therefore her workplace had not made any accommodations or adjustments. *"I guess I don't want to be seen as weak. And I don't want to be seen as not doing my dues."*

Terry felt the same. *"I avoid asking my charge nurse [for help] as I feel as though she will think I'm incompetent, it is the charge nurse specialist I go to for help."*

Emma was also hesitant to ask for help because of the experiences she had had. *"And I don't want to ask her . . . Yeah. I definitely know some of my colleagues know. I've mentioned it to some of them. . . . I don't think it's actually changed how they work with me one way or the other."*

She could not name any support services or department within her organisation who she could ask for help.

Conversely, Rebecca had found her manager not only supported her requests, but almost anticipated them. [My manager said]: *"Look, let me know if they pull that [support] out and you still need it. So, she was prepared to pay for taxis for me which is absolutely incredible."*

Cindy's experience differed to this. She described being in a new, purpose-built building that did not have sufficient natural light, which affected visibility. However she was keen to point out that this affected all the staff, not just her. She said support and help had been non-existent in her previous clinical workplace, but when she disclosed her dyslexia in her new workplace, she received extra computer training.

Impact in the workplace

The "Impact in the workplace" theme reflected some of the barriers the participants encountered and the strategies they used to keep themselves and their patients safe. Participants identified barriers such as:

- Phones that were old and lacked volume control.
- A perception of discriminatory thinking and stigma associated with some disabilities or impairments.
- A perception that there was a lack of confidentiality, which led to a lack of trust to disclose.
- Feelings of guilt about being unwell when it was not overt or obvious to others.
- Difficult and similar names of medications or products.
- Small print on medication labels.
- The time-consuming effects of constantly having to clarify information on the phone (when hearing-impaired).
- Lack of an overall organisational point of contact for people with disabilities or impairments.

Participants revealed their own unique ways of coping, via strate-

gies to keep themselves and their patients safe.

Terry always made a special effort to ask a senior RN to double-check her medication calculations to be as safe as possible. This was important to her.

"And it's like if we've got new medication to draw up or something that I'm not familiar with or don't feel that confident with, I'll always grab a senior nurse versus a junior one. . . . for them to educate me and make sure that I'm doing it right and we can have a thorough discussion in regard to what else we need to look for as well as reading the protocol and everything like that."

Emma had taught herself to keep the label attached to dressing products and medications she was using, especially if they had similar names. This gave her confidence that the spelling and information she had documented about the dressing was correct.

"The dressing products, a lot of the names are quite similar. And I sometimes get them muddled. I know exactly what I mean, so I'll often describe it as well as saying the name. And when I'm doing one, I'll take the top bit of the packaging off, and I won't throw it away. I'll put it in my pocket. So, I've got the name written down."

Rebecca had seen a physiotherapist, and educated herself on chronic pain.

"And the first thing that she [physiotherapist] does is educate you a little bit on chronic pain and that biopsychosocial element of it. And then I went on my phone and downloaded a number of apps where I could actually listen to people's stories and listen to some facts and information so that I had extra education on that. And that was actually quite a key changing point for me, actually understanding what I needed to do to get myself well. So, that whole education was a really good tool kit strategy for me in itself."

Garry had learned not to accept night shifts, as the lack of sleep interfered with his ability to concentrate.

"I don't work night shift. My manager has made sure that I don't work night shift, because I said I think I will probably end up in hospital. Cos that's the reality of it, if I don't get decent sleep. So that's about knowing my limits and what I can and can't do."

Tammy had learned that when she used her physical aids more, this acted as a cue to others around her. She also tried a range of shifts and non-nursing roles to see what was more suitable.

"The time that I actually said, 'I have [an autoimmune disease]' to my charge nurse was when I said, 'Look, I just can't do the shifts I'm doing now.' So, then I changed to nights for a while. . . . I knew I could do them okay. . . . I like the work, cos you have to think more when there's not as many people around. It's just the hours that are horrible. . . . And keep the safety going for the patients, but to not be so tiring on myself."

Cindy: *"I'm very fortunate in that, so far, I haven't made any drug errors or any administration errors, probably because of that. And I'm a bit pedantic. I've got a colleague who's a good nurse, but she likes to be fast and speedy at everything. And she did make a mistake purely because of rushing through and not double checking . . . "*

Sally purchased her own stethoscope that was the correct type for hearing impairment and used a Bluetooth connection to her new hearing aids. She also ensured she could see people's faces when they were talking so she could use her lip-reading skills.

"I was trying to listen to them, I was like, 'Oh, I can't understand.' But I was like, yeah, it would be the same for everyone. But then when I tried to, like, focus on their lip movements more, I just found I actually could get what they were saying."

DISCUSSION

While government policy documents clarify the differences between disability and impairment (Ministry of Social Development, 2016), the nurse participants in this study were not interested in distinguishing the terms. They were more concerned about the impact of their disability or impairment on their roles than defining the terms.

Nearly all the participants chose not to disclose their disability or impairment at work, because they believed they would receive unfair treatment if they did. Such reluctance is not a new finding (Ashcroft & Lutfiyya, 2013; Korzon, 2011; Neal-Boylan 2013). However our study made new and detailed findings (although they are not intended for generalising) – that our participants feared that if they disclosed their disability at work it would not be kept confidential; that the degree of stigma attached to their disability influenced whether they would disclose it; and that the visibility or invisibility of their disability affected how colleagues treated them. If we are to retain experienced nurses in the workplace, these findings would benefit from further investigation and research.

Of note, the finding that the nurse's disability or impairment did not prevent them from carrying out their nursing roles and responsibilities, and that it was other people's attitudes towards their disability that affected their ability to do their job, is consistent with the social model of health recommended elsewhere (Ministry of Social Development, 2016; Oliver, 2013). Korzon (2011) also highlighted the disabling attitudes of others, which is in keeping with the intention and understanding of the social model of disability. That is, people may have impairments but are dis-abled by other's attitudes. While Matt (2008) describes how managers can support and help nurses with disabilities or impairments and can play a crucial role in supporting them, two of the nurse participants in this study expressed a reluctance to tell their manager as they lacked sufficient trust to share this information. The decision not to disclose can result in the manager not being aware of the support the nurse needs and thus no accommodation is made for them.

None of the participants we interviewed believed their disability made them unsafe. Rather, they exhibited a strong desire to be very safe. Their strategies are evidence of this heightened awareness and responsiveness to patient safety. While the need to be "double-double" safe or "triple safe" is a new expression of this, the desire to work safely as a nurse has been identified by Neal-Boylan & Miller (2016) and Wood & Marshall (2010).

Participants in this study had developed professional strategies to address the barriers and challenges they experienced, and this information has added to the findings already available (Ashcroft & Lutfiyya, 2013; Korzon, 2011; Matt, 2008; Neal-Boylan 2013,

2016, 2019). While the fact that nurses who work with a disability or impairment experience challenges is not new, the detail in this study about the strategies used to overcome them has provided additional perspectives and evidence. The strategies they developed were unique to each nurse – they had developed these over time to suit their own particular challenges and their individual disability or impairment. Significantly, all the strategies developed by the nurses in this study cost little or nothing.

While some of the participants found there were some helpful and caring individuals in their organisations, there were no dedicated departments or persons charged with supporting, advising or helping nurses with disabilities or impairments. This meant that in some instances nurses had to organise their own resources, and opportunities were missed to prepare new staff to talk with an outgoing staff member with a similar disability or impairment. In addition, the equipment provided in some workplaces, while positively intentioned, did not meet the needs of the person working with a disability or impairment.

This study has provided unique individual insights and detailed experiences and perceptions of RNs who live and work with a disability or impairment. The United Nations Convention on the Rights of Persons with a Disability, Articles 24, 25 and 27 (United Nations General Assembly, 2007) explain that people with disabilities require equitable access to achieve their goals in education, health and employment. This is not consistent with the experience of several of the participants, who expressed a fear of disclosing, a reluctance to ask for help or approach some staff members, the perception that disclosure of the disability or impairment would lead to discrimination, a lack of organisation-wide support and missed opportunities to provide equipment that functioned for everyone. Addressing these challenges and barriers could help retain experienced RNs (Report from the National Nursing Organisations to Health workforce New Zealand, 2014).

IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS

We recommend organisations provide a dedicated staff member to ensure consistent advice and support is available to nurses working with a disability. This role could include dealing with requests for equipment and resources that meet nurses' needs and contribute to a disability-friendly environment, as identified in Matt's (2008) research.

The result of nurses not disclosing their disability or impairment is that accommodations cannot be made to help them (Neal-Boylan, 2013). Providing a designated resource person would address the findings in this study related to a lack of trust and confidentiality, reluctance to approach managers and the perception that disclosing their disability or impairment might disadvantage them. Further research is needed to explore what kind of support nurses with a disability or impairment need to practise well.

In this study, the participants all expressed a desire to be "very safe" nurses. The strategies they developed to be very safe and to overcome the barriers they experienced in clinical practice could be shared within this newly created resource role.

STRENGTHS AND LIMITATIONS

This is a small qualitative descriptive study, with 10 participants. The findings should be interpreted in this context and generalisation is not claimed. A strength of this study was the in-depth descriptions and the individual and unique stories generated. This has provided a detailed picture of the RNs' experiences and perceptions of working with a disability or impairment.

CONCLUSIONS

The nurse participants identified a number of barriers to them performing their job. However, none of them pointed to their disability, impairment or health condition as a barrier. Rather it was the reaction to their disability or impairment that was notable. Participants identified barriers such as phones that were old with non-adjustable volume, a perception of discriminatory thinking about disabilities, a fear of lack of confidentiality which led to a lack of trust to disclose, and a lack of an overall organisational point of contact for people with disabilities or impairments.

The number of nurses who disclosed their disability or impairment at work was low, because they felt it was not safe to do so. It is important to understand the barriers these nurses experience and the strategies needed to overcome them, given the global nursing shortage, the ageing nursing workforce, and legislation that specifically prohibits discrimination against those living and working with a disability. Addressing some of the findings in this study may help retain nurses who are dedicated to being safe practitioners.

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The authors declare there is no conflict of interest.

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NGĀ MANUKURA O ĀPŌPŌ: SUSTAINING KAUPAPA MĀORI NURSE AND MIDWIFERY LEADERSHIP

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ABSTRACT

Aim: The aim of this study was to explore the outcomes of Ngā Manukura o Āpōpō's national Māori nursing and midwifery clinical leadership training programmes and to consider how the kaupapa Māori approach (Māori ways of doing things) has contributed to these outcomes.

Background: In Aotearoa New Zealand, Māori – the indigenous peoples – experience the worst health inequality of any population group. Māori workforce development has long been recognised as key to improving Māori health and wellbeing. Ngā Manukura o Āpōpō is a significant programme designed to enhance the capacity of Māori leaders in the health and disability system. It covers clinical leadership, recruitment and profile raising, professional development and governance. Ngā Manukura o Āpōpō provides a marae-based kaupapa Māori leadership development programme for Māori nurses and midwives in Aotearoa.

Methods: A content analysis and synthesis of findings from Ngā Manukura o Āpōpō evaluation reports to date was undertaken, using inductive strategies to categorise the data.

Results/findings: Whakamana (a sense of empowerment) and ngā manukura (starting or progressing leadership journeys) were key themes identified through the synthesis. These centred on outcomes from the programme relating to personal and professional development, and cultural identity, as well as taking up leadership opportunities and contributing to change. The training also helped retain participants in the health workforce. The kaupapa Māori approach was a key contributor to these outcomes. Challenges that participants faced in their roles – including racism and bridging the Māori and western health paradigms – and their ability to contribute to better health outcomes for Māori, are consistent with experiences of other Māori nurses and midwives, and of indigenous nurses and midwives in other parts of the world.

Conclusions: There is a significant need for Māori clinical leaders in the health and disability sector to help address current and future workforce and population health needs. Ngā Manukura o Āpōpō clinical leadership training can help meet this requirement.

KEYWORDS

Māori, indigenous, leadership, workforce, inequity, policy

INTRODUCTION

In Aotearoa New Zealand, the legacy of colonisation contributes to poorer health statistics, poorer general wellbeing and to injustice for Māori, its indigenous peoples (Anaya, 2011). Māori health workforce development has long been signalled as a critical enabler of good health outcomes (CBG Health Research Ltd, 2009; Douglas, 1996; Ratima et al., 2008). Recent reviews of Aotearoa New Zealand's health and disability system recognise Māori leadership in particular as key (HDSR, 2020; Waitangi Tribunal, 2019). Ngā Manukura o Āpōpō is Aotearoa New Zealand's national Māori nursing and midwifery workforce development programme. It provides a unique and dedicated pathway for Māori leadership for Māori nurses and midwives.

This synthesis aimed to explore the outcomes of Ngā Manukura o Āpōpō's clinical leadership training programmes and to consider how the kaupapa Māori approach (Māori ways of doing things) contributed to these outcomes.

BACKGROUND

Māori comprise nearly 17 percent of the Aotearoa New Zealand population (Statistics NZ, 2020). Te Tiriti o Waitangi (the Māori text) of the Treaty of Waitangi (Te Tiriti) – an agreement between representatives of the British Crown and Māori, signed in 1840 – proposed to protect Māori rights to self-determination and obliged the Crown to ensure that public policy was as effective for Māori as it was for everybody else. However, Māori health status is significantly worse than non-Māori and inequities persist for the majority of health measures (MOH, 2015; MOH, 2019; Waitangi Tribunal, 2019). There is a strong link between health inequity for Māori and the unequal distribution of social determinants of health, inadequate access to services, poorer quality of care and worse health outcomes (MOH, 2015; MOH & University of Otago, 2006).

Māori workforce development and Māori leadership, as means to address these inequities, have been elevated as priorities in health policy and strategy documents since the 1990s (CBG Health Research Ltd, 2009; Douglas, 1996), including The New Zealand Public Health and Disability Act 2000, He Korowai Oranga: The Māori Health Strategy (MOH, 2002), Raranga Tupuake: the Māori Health Workforce Development Plan (MOH, 2006) and the Rauringa Raupa report (Ratima et al., 2008). Despite these strategic directions, Aotearoa New Zealand's health system has not fulfilled its Te Tiriti obligations to provide equitably for Māori.

This failure has recently been affirmed through the Wai 2575 Health Services and Outcomes Kaupapa Inquiry (Wai 2575) (Waitangi Tribunal, 2019) and the Health and Disability Services Review (HDSR, 2019, 2020). They both identified systemic issues such as inequitable funding, under-representation and lack of decision-making functions by Māori at all levels of the system, and inadequate resources for Māori to design services and provide for their own wellbeing. Structural, policy and procedural reforms of the system were called for, including fully incorporating and ensuring the system recognises and supports te ao Māori (Māori world views), Māori authority, mātauranga Māori (Māori knowledge) and expression of Māori cultural identity (HDSR, 2019, 2020; Waitangi Tribunal, 2019). These intentions are being embodied in the establishment of a Māori Health Authority.[1] Whakamaua: Māori Health Action Plan 2020-2025, the most recent roadmap for achieving He Korowai Oranga, also reflects these intentions (MOH, 2020).

Consistent with the findings of the HDSR and Waitangi Tribunal reports, is that Māori are under-represented in the nursing and midwifery sectors (Midwifery Council of New Zealand, 2020; Nursing Council of New Zealand, 2019). Both sectors grapple with systemic issues. There is a lack of Māori-specific workforce, health or leadership strategies; and Māori representation in decision-making, strategic leadership and care model design is either scant or lacking. Generally, in the nursing and midwifery workforce, there are few opportunities to develop governance roles and skills, and leadership programmes are ad hoc, limited in numbers and often have unfair and inequitable access. DHBs tend to favour professional development with significant clinical components, which limits nurses' access to courses with other foci (NZCM, n.d; NZNO, 2018). Limited investment in professional development for nurses, and Māori nurses in particular, is reflected in national workforce development data (Brinkman, 2010; NZNO, 2018).

Ngā Manukura o Āpōpō – Tomorrow's Clinical Leaders (Ngā Manukura o Āpōpō) was established in 2009 in recognition of the issues of Māori participation and retention in the health and disability workforce.[2] As Aotearoa New Zealand's national Māori nursing and midwifery clinical leaders network and workforce development programme, it aims to better position Māori nurses and midwives to improve the quality of health-service delivery. It does so by developing their capacity and capability, in culturally relevant ways, to deliver and re-design health services at all levels of the health and disability system.[3] The programme affirms a need for bicultural praxis in the context of health but also in how leadership is defined, recognising that practising leadership and nursing and midwifery as Māori, are mutually reinforcing and transcend health contexts.

As highlighted by Mead (2006), the traditional Māori system of leadership is based on cultural criteria (eg kinship ties, appropriate whakapapa [genealogy], and spiritual assets such as tapu [sacredness] and mana [agency]) and expectations of and values held about leadership are very broad. Traditional information about expected pūmanawa (talents) of a Māori chief/leader specifies knowing the traditions and culture of one's own people and wider community as a prerequisite for such a role. Reflecting this, Ngā Manukura o Āpōpō clinical leadership training programmes are kaupapa Māori. That is, Māori cultural processes, knowledge and theory are integral to their design, content and delivery. A kaupapa Māori approach is inherently multi-dimensional and collective, as reflected in the whakataukī (Māori proverb): *"Ehara tāku toa i te toa takitahi, engari he toa takimano" ("My strength is not that of an individual but that of the collective").* Ngā Manukura o Āpōpō provides spaces for emerging and experienced leaders to travel together on their leadership journeys.

A key feature of Ngā Manukura o Āpōpō is clinical leadership training. The Foundation Leadership Training[4] is well established in the sector and has been in place since 2010. It consists of four two-day noho marae (live-in) wānanga[5] held over a four-month period, is situated within te ao Māori and underpinned by Māori pedagogy. The training is designed to integrate Māori and mainstream leadership theory and practice to enable participants to develop leadership knowledge and skills in the context of Māori health and disability services. It provides participants with practical tools and critical networks to undertake clinical leadership roles in their own workplaces. Ngā Manukura o Āpōpō is currently exploring follow-on options from the Foundation Leadership Training to create a more comprehensive leadership pathway. KuraWaka was the first such option to be trialled.[6] It was delivered over a 10-month period

1) On April 21, 2021, reforms to strengthen the health system were announced – these included the establishment of a Māori Health Authority (DPMC, 2021).

2) Ngā Manukura o Āpōpō was established in partnership with the District Health Board New Zealand Māori Workforce Champions, a cross-sector reference group of workforce leaders from within district health boards, non-government organisations, health professional organisations, tertiary institutions and the Ministry of Health.

3) Notably, the first Māori nurses in the history of Aotearoa New Zealand to become the Chief Nursing Officer in the Ministry of Health have a background in this programme. See: https://kaitiaki.org.nz/article/new-chief-nurse-seeks-leadership-shift/

4) The Foundation Leadership Training is delivered by Digital Indigenous.Com Ltd.

5) Culturally grounded space of deliberation and learning.

6) KuruWaka was co-designed with the provider, DWS Creative Ltd, Ngā Manukura o Āpōpō leadership group members and Foundation Leadership Group graduates. It was piloted in 2019. Another follow-up option to the Foundation Leadership Training is being trialled at the end of 2021.

Table 1. Evaluation reports

Evaluation report	Method	Key findings	Limitations
King J, Pipi K, Moss M (2014). *Ngā Manukura o Āpōpō Evaluation of Tomorrow's Clinical Leaders training programme – final report*. Julian King & Associates, a member of the Kinnect Group.	Leadership Foundation Training • Interviews with participants/ graduates, employers, presenters, facilitators, advisory group members and other sector stakeholders. • Group interviews with graduates from cohorts 1-8. • Online survey for graduates of cohorts 1-8 (n=35, 22% response rate). • Review of the programme reporting and feedback forms. • Six success cases. • Causality was assessed qualitatively using Bradford Hill Criteria.[7]	The training contributed to: • Strengthened cultural identity and participants feeling comfortable viewing themselves as Māori clinical leaders. • New skills, knowledge and tools, which were being applied in participants' personal and professional lives. • Progression into leadership roles and/or leadership activities. • Participants contributing to wider sector/social/whānau/hapū/iwi outcomes. • Evidence and acknowledgement of learnings being integrated into nationally and internationally disseminated work.	Relied principally on qualitative information and soft data (graduate survey and feedback forms). Did not include longitudinal data on graduate outcomes, or a comparison group.
Wilson, D. (2017). *Ngā Manukura o Āpōpō Programme Evaluation Report: 2015-2016*. AUT: Taupua Waiora Centre for Māori Health Research.	Leadership Foundation Training • Group interviews with graduates from cohorts 10-13. • Review of 6-monthly provider reports. • Survey for graduates from cohorts 1-13 (n=53, 22% response rate).	The training contributed to: • Strengthened cultural identity and pride. • Participants extending them selves and their practice. • Participants feeling ready and well-positioned to undertake leadership opportunities professionally and beyond. • Reignited participants' passion for nursing/midwifery.	None stated.
Pipi K, Were L, Moss, M. (2019). *Ngā Manukura o Āpōpō Programme Evaluation 2019*. Evaluation report FEM 2006.	Leadership Foundation Training • Online survey distributed to graduates (cohorts 1-17; n=49). • Group interviews with graduates (cohorts 15-17). • Online survey distributed to employers/colleagues/whānau of graduates (n=4). • Review of reporting and feedback forms. • The evaluation was underpinned by kaupapa Māori approaches, including pūrākaū[8] and evaluation-specific methodology.	The training contributed to: • Strengthened leadership skills, including technical expertise and practical skills. • Increased confidence, competence and personal development. • Growing networks. • Development of Māori leaders. • More involvement in leadership activities professionally, personally and in the wider community.	Relied principally on qualitative information and soft data. Did not include a comparison group. Low survey response rate (16%; likely due to survey fatigue).

continues next page

7) The Bradford Hill criteria, otherwise known as Hill's criteria for causation, are a group of nine principles that can be useful in establishing epidemiologic evidence of a causal relationship between a presumed cause and an observed effect and have been widely used in public health research.

8) Pūrākaū is used in research and evaluation as a narrative inquiry method, akin to a case study approach. Pūrākaū, in this context, provides a way of representing indigenous knowledge and stories that culturally connects with Māori.

Evaluation report	Method	Key findings	Limitations
Pipi K, Were L, Moss, M. (2020). *Ngā Manukura o Āpōpō Programme Evaluation 2020*. Final Evaluation Report, FEM 2006.	• Observation and engagement during four KuraWaka wānanga. • Interview with KuraWaka participants (n=22) and other stakeholders (n=11). • Online survey for KuraWaka participants (n=21). • Review of KuraWaka reporting. • Follow-up online survey for Leadership Foundation Training graduates to explore leadership in action over time (n=15). • Online survey distributed to employers/colleagues/whānau of Leadership Foundation Training graduates (n=8). • The evaluation was underpinned by kaupapa Māori approaches, including pūrākaū methodology and evaluation-specific methodology.	The training contributed to: • Readiness for leadership. • Internal changes such as increased confidence, cultural identity and pride, feeling inspired, re-energised. • Filling up kete (basket) with indigenous knowledge and skills. • Understanding importance of self-care. • Applying knowledge and tools. • Seeking out clinical leadership opportunities. • Increased leadership involvement in diverse contexts.	Relied principally on qualitative information and soft data. Did not include a comparison group. Timing of KuraWaka evaluation coincided with design, delivery and completion of the programme, limiting exploration of post-programme outcomes. No employer feedback on KuraWaka participant outcomes.

through three two-day noho marae, one regional wānanga, two one-on-one coaching sessions[9] and six online sessions by subject experts. KuraWaka aimed to guide Māori leadership to new levels of excellence, through a kaupapa Māori approach that had an explicit focus on learning journeys. The training immersed participants in te ao Māori, and sought to enable participants to customise their leadership experience and self-direct their learning and its impact. It also ran a concurrent, uniquely Māori hauora (health) component to foster the oranga (wellbeing) of participants.

Between 2010 and 2021, 306 Māori nurses and 42 midwives graduated from the Foundation Leadership Training, across 40 cohorts. Of those graduates, 25[10] completed KuraWaka. Participants of both programmes came from a range of settings such as district health boards, non-governmental organisations, Māori providers, mainstream providers, rural and urban, and also worked across a range of expertise levels – from entry to executive.

METHODS

The aim of this synthesis was to analyse the findings of four evaluation reports to understand more about how Ngā Manukura o Āpōpō's clinical leadership training contributes to leadership development of Māori nurses and midwives. The synthesis was undertaken using a qualitative descriptive design in the form of content analysis. Content analysis is an approach used to analyse text to identify patterns, trends and relationships (Pope et al., 2006; Vaismoradi & Snelgrove, 2019). A descriptive method was employed for the coding and interpretation of data. This interpretation was informed by a realist perspective, assuming data is an accurate representation of reality (Sandelowski, 2010). Content analysis is an approach that can be applied to analyse qualitative text as well as quantify numerical data (Gbrich, 2007). The aim of the data analysis was to describe phenomena in the textual and numerical data which were relevant to the research question, and group them into categories. (Vaismoradi et al., 2019). The research question was: *"What are the outcomes of Ngā Manukura o Āpōpō's clinical leadership training programmes, and how has the kaupapa Māori approach contributed to these outcomes?"*

Data analysis

Data analysis involved using inductive strategies to develop coded categories from textual and numerical data selected from the four evaluation reports commissioned by Ngā Manukura o Āpōpō on the implementation and delivery of the Foundation Leadership Training and KuraWaka. The process for data analysis entailed creating codes from patterns in data, grouping data into categories or topic groups, and conceptualising the categories into descriptive categories.

The characteristics of the four evaluation reports included in the synthesis are set out in Table 1 (previous page and above).

FINDINGS

Two key themes emerged from analysing the outcomes of Ngā Manukura o Āpōpō leadership programmes: "whakamana" – a sense of empowerment, and "ngā manukura" – the process of starting or progressing leadership journeys. The following section presents the findings of the synthesis.

Whakamana: sense of empowerment

The theme "whakamana" indicated that the Ngā Manukura o Āpōpō clinical leadership training contributed to participants' personal and professional development and cultural identity. Markers of personal development included participants feeling more confident (less shy, standing up for beliefs, speaking out more), more assertive and better prepared to respond to and manage challenging situations. Participants felt inspired and re-energised by peers and guest

9) Provided by Rise2025, a coaching leadership agency for indigenous women and girls.
10) This includes five Ngā Manukura o Āpōpō leadership group members, and the Ngā Manukura o Āpōpō KuraWaka project manager (n=5).

speakers, and felt better positioned to consider other roles *("listening to them makes me think, if they can – so can I").*

Further, the training motivated participants to remain in their profession. Some participants had considered leaving the health and disability workforce altogether prior to the training. They struggled with both implicit and explicit racism in their workplaces, including dual expectations because they are Māori (eg to lead cultural activities) while receiving no recognition for doing so. They also felt a constant need to justify Māori ways of doing things. Systemic racism also affected participants' ability to access Ngā Manukura o Āpōpō programmes (being denied study leave to attend, employers not seeing the programmes as a critical part of professional development and non-Māori colleagues questioning the value of the programme and its costs). Ngā Manukura o Āpōpō often contributed pūtea (money) where cost was a barrier to participation in the programme.

The delivery of Ngā Manukura o Āpōpō training helped participants broaden and strengthen their networks. Each Foundation Leadership Training cohort has a network attached to it. These networks provided support, both during and beyond the training, and were particularly valuable when participants experienced racism at work, or faced other challenges that other Māori nurses and midwives could identify with. The advice, encouragement and support from these networks helped sustain participants in their roles, but also helped them progress their leadership journeys.

Markers of professional development included having learnt technical and practical skills and knowledge relating to public speaking, conflict management, change management, writing and submitting proposals, ethics, how to write and deliver project plans and higher strategic thinking. For KuraWaka participants, skills and knowledge gained centred more on te ao Māori, mātauranga Māori (maramataka [lunar calendar], mauri ora [wellbeing] goals, tikanga [customs/protocols] and whakapapa [genealogy]), tools for self-care and how to use coaching to support and sustain leadership. The new knowledge, skills and connections helped boost participants' confidence to take on leadership activities or roles.

Strengthened cultural identity was another element of the whakamana theme, with participants noting a stronger sense of cultural connectedness and pride. They gained a deeper understanding of who they were and where they were from and felt encouraged to further develop their cultural identity to enhance their confidence and effectiveness as Māori clinical leaders. One participant pointed out that KuraWaka had taught her that, *"knowing who you are is what strengthens and creates your ability to be a good leader".* The ways in which cultural identity was influenced varied. Some participants had little or no involvement with their "Māori side" before the training (for whom it was inspiring and supportive of exploration) and others had it integrated to different levels in their personal and professional lives (for whom it offered validation, affirmation, and/or ideas for how to take this further).

KuraWaka provided an opportunity to further intensify immersion in te ao Māori, compared to the Foundation Leadership Training, and participants appreciated this stepped increase in the level of immersion. As a result, they felt further connected to whakapapa and tīpuna (ancestors), to te ao Māori and to the shared kaupapa (agenda) – to facilitate change to improve outcomes for whānau. Participants attributed the use of more te reo Māori (the Māori language), karakia (Māori prayer/chant) and their mihi (Māori ceremonial greeting) in a work environment than before the training. Some had also started te reo Māori classes during the training or post-graduation. The ability to sustain and continue to strengthen cultural identity was supported by the graduate networks. Feeling validated as Māori, having time to reflect, take stock and look to the future as well as having leadership capacity identified and/or re-discovered, helped participants to progress on their leadership journeys. This included having started or returned to post-graduate study. Overall, it was common for participants to describe their participation in the programmes as "life-changing".

Ngā manukura: taking up leadership roles and achieving change

The "ngā manukura" theme centred on the application of new skills, knowledge and confidence gained from participation in Ngā Manukura o Āpōpō leadership training. Participants had completed professional portfolios, written, or contributed to publications, presented at national and international conferences, secured funding for project work, written practice guidelines, and promoted and applied indigenous concepts and tools (eg maramataka for planning, managing meetings and structuring reports). One director of nursing had applied a deepened understanding of te ao Māori, in terms of kotahitanga (collective unity/solidarity), integration, collaboration and reciprocity, when designing a new workforce strategy and attributed this to her participation in KuraWaka.

Participants also reported having progressed into leadership roles and/or taken on key leadership activities. This included securing more senior positions (nurse leader, Māori health manager, charge nurse manager, educator, director of nursing, clinical nurse manager); putting their names forward for national forums (Nursing Council of New Zealand); joining or being a key driver in setting up local boards and governance groups; taking on tuakana teina (a model for buddy systems) roles such as providing mentoring, supervision, support, and education; and getting involved in policy development.

Participation in the training also contributed to increased involvement in leadership activities outside work, including within whānau (extended family), hāpori (community), hapū (subtribe) and iwi (tribe). Graduates did so as chairpersons, trustees, committee members, project coordinators, event organisers, holders of Māori-specific leadership roles and through leading/supporting whānau in health-related kaupapa (matters).

Participants also undertook project work as part of the Foundation Leadership Training, including research/reviews/audits, education/awareness-raising activities and development of tools, education pathways, forums and support groups. Positive sector/social/whānau/hapū/iwi outcomes were demonstrably emerging as a result of these changes. These included free dental health care for 18 to 21-year-old rheumatic fever patients in the Far North, increased understanding and application of tikanga Māori and cultural safety in nursing practice, increased health literacy among whānau, and increased numbers of Māori women undertaking cervical screening.

There were factors that affected the extent to which participants were able to progress their leadership journeys. They were all at different stages in these journeys, had different levels of support (professionally and personally), worked in different types of environments (mainstream/kaupapa Māori; rural/urban), had various levels of cultural identity, as well as different notions of what leadership looked like. They also faced constraints such as institutional racism and implicit bias, lack of opportunities locally, lack

of support from managers/colleagues, family/whānau life and health issues. Change was not always immediate, but continued to occur over time. Further, participants were all at different stages on the leadership continuum and differed in how far along the continuum they wanted to go.

Contribution of the kaupapa Māori approach

The kaupapa Māori approach was consistently identified in the evaluations as a key supportive factor of personal and professional development, strengthening cultural identity and progressing leadership journeys. Grounding content and delivery firmly in te ao Māori supported deep, rich cultural affirmation and learning, ensured safety for participants to be and express who they are – and helped them find their place in the leadership spectrum as Māori. It also ensured the training was culturally meaningful for participants and facilitated connections and networks that provided strong cultural foundations for leadership. Being connected to their Māori peers was considered invaluable in the wider context of working in a western-dominated health and disability system. Opportunities for whanaungatanga (establishing and sustaining relationships) contributed to a sense of belonging, and the ability to develop, maintain and use networks and connections.

The holistic aspect of the kaupapa Māori approach benefited participants spiritually, mentally and physically, and helped them feel stronger and more resilient as leaders. It also facilitated a collective approach that benefited participants and their whānau and wider communities. This was considered to have potential to support a ripple effect of change (eg intergenerational) with more sustainable solutions (rather than as a leader affecting change through a one-off event). Part of what enabled participants to grow in their leadership was that they were part of a collective, a growing network of Ngā Manukura o Āpōpō participants and graduates. This network could provide support, advice and encouragement, particularly when participants were facing challenges such as racism in their workplaces or feeling isolated as Māori in a mainstream setting.

> *"The connections and whakapapa that you make here, and you can only make here, enable us to stay connected, enable us to network. It's probably the best asset ever as a Māori and as a Māori nurse. It's the most important tool I've acquired on my nursing journey so far in terms of Māori and Māori leadership."*
>
> – KuraWaka graduate

The marae setting and noho-marae delivery model are Māori preferences for teaching and learning, and they contributed to a sense of familiarity and safety that allowed participants to absorb new knowledge. The cultural significance of the setting contributed to experiences that reinforced the richness of Māori culture and identity. Delivery by Māori for Māori also contributed to a sense of safety and a deepened understanding of leadership as Māori. This included a better understanding of the expectations that accompany being a Māori nurse or midwife leader (to benefit Māori and whānau users of the health system), and how to effectively walk in and/or between the "two worlds" (Māori and Pākeha) that they operate in. These two worlds were challenging for participants to navigate as they represented two different worldviews and, as such, different views on models of care. The Māori concept of manaakitanga (the process of showing respect, generosity and care for others) was evident in feedback, and involved ongoing contact, mentoring and support by the trainers and Ngā Manukura o Āpōpō – often over and beyond what they were contracted to do. This helped sustain the momentum of participants' leadership journeys, during and beyond the training. Participants noted that Ngā Manukura o Āpōpō's clinical leadership training programmes were the most professional, relevant, useful and worthwhile Māori (and other) professional development programmes they had encountered.

DISCUSSION

The themes identified in this synthesis are congruent with other research that indigenous approaches are necessary for the development of indigenous leadership (Spiller et al., 2015; Turner & Simpson, 2008; Young, 2006). They are also consistent with research that affirms the importance of cultural identity for a strong and effective indigenous health workforce (MOH, 2006; MOH 2020; Waitangi Tribunal, 2019). An increased presence of Māori in health roles may better meet health needs for Māori patients due to improved communication and trust between people of the same culture interacting. Strong and capable Māori leadership within the health workforce is necessary to inspire such change, and subsequently to lead institutions to more equitable and culturally effective health care (Burrel et al., 2005). Kaupapa Māori health and leadership programmes, and national health policy expectations, affirm that dedicated kaupapa Māori leadership development for Māori nurses and midwives is a valuable pro-equity response (HDSR 2020; NZNO, 2018; Ratima et al., 2008). However, there are still many challenges for Māori nurses and midwives that inhibit their ability to contribute to a more equitable system.

Dealing with racism

Institutional racism[11] has been identified as a significant issue for Māori health, in terms of both access and delivery (Came, 2012; Longmore, 2018; Ministry of Health, 2018; Waitangi Tribunal, 2019). The literature on indigenous leadership in nursing and midwifery shares personal experiences of racism faced at work, coupled with the institutionalised racism that manifests in ways in which professions and services are structured, framed and practised (West et al., 2016; Power et al., 2014; Goold, 2011). Power et al. (2014) recognise that *"Being Indigenous in a White profession means being exposed to relentless and frequent episodes of racism both personally as a health professional and vicariously through Indigenous patients"* (p. 145). Power et al. (2014) also articulate the experience of being *"progressively re-defined by western constructs of professionalism"* (p.142) and highlight the dichotomy that indigenous women are naturally accepted as leaders in their communities, but as indigenous nursing leaders they are an oddity in the system. This "peculiarity" goes beyond the small but growing numbers of indigenous nurses and midwives, but more deeply recognises that it is during nursing education that whiteness becomes normalised in the nursing profession. It aligns itself with scientific hegemony that determines which knowledge systems are worthwhile, thus discounting indigenous knowledge. However, Power

11) Institutional racism is defined by claimants in the Waitangi Tribunal's 2019 *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa* as "a pattern of differential access to material resources, cultural capital, social legitimation and political power that disadvantages one group, while advantaging another", and/or as conscious or unconscious "inaction in the face of need" (Waitangi Tribunal, 2019, p. 21).

et al., and others (West et al., 2016; Chamberlain et al., 2015; West et al., 2013; Downing & Kowai, 2011) advocate for the reclamation and reassertion of indigenous history, culture and cultural practices within nursing and midwifery. West et al. (2016), while in reference to the success of Australian Aboriginal and Torres Strait Islander nursing students, put forward strategies to resist racism across nursing and midwifery including *"valuing indigenousness and resisting racism"* (p.351). In doing so, they provide a sense of clarity about the value of the unique experiences and ways of being indigenous peoples bring to the practice and professions of nursing and midwifery.

Bridging two knowledge bases and value systems

Noted by Power et al. (2014) through the personal story of an indigenous nurse, *"there is the expectation that we will be the bridge between our culture and the culture we work within"* (p.143). A Māori leader is expected to be well-versed in mātauranga Māori as well as well-educated and schooled in the Pākehā knowledge of current times. Māori in leadership roles therefore have the challenge of negotiating the dynamic interplay between traditional Māori values and principles and contemporary ways of thinking (Mead et al., 2006, p. 14). The synthesis indicates that Māori nurses and midwives are not always recognised for what they bring as Māori. This has been identified in other Māori nursing and midwifery literature (Hunter, 2018; Longmore, 2018; Ramsden, 1993, 2002). Baker and Levy (2013) note that this concept of dual competency as it relates to the Māori health workforce is now commonly understood as acknowledging both clinical and cultural expertise. However, in the context of Māori and indigenous health, dual competency encompasses a much richer articulation. Sones et al. (2010) highlight that it explicitly recognises indigenous health as a specialised area of practice. A dual-competency framing visibly communicates that Māori have a body of knowledge and skills drawn from te ao Māori which is relevant for the delivery of effective health services for Māori. The synthesis shows that Ngā Manukura o Āpōpō's clinical leadership training helped participants bridge the gap between Māori and Pākehā worlds. The opportunity for Māori nurses and midwives to develop and become effective leaders within the two worlds is considered important (West et al., 2013). Unique cultural experiences such as those provided by Ngā Manukura o Āpōpō enable Māori nurses and midwives to become better positioned to make a difference for Māori health and for equity in their professions (Wilson & Baker, 2012).

Retaining Māori in the workforce

Ratima et al. (2008) report that disillusionment is a reason many Māori leave the health workforce. Wilson (2017) noted in her evaluation report that Ngā Manukura o Āpōpō's Foundation Leadership Training is an intervention and a retention strategy in its own right. The wānanga came at a time when many nurses and midwives were disillusioned with their profession and career prospects, and were considering leaving. Huria et al. (2014) report similar experiences, including racism on institutional and personal levels leading to Māori nurses being marginalised, overworked and undervalued. Tupara and Tahere (2020) also describe how Māori in the maternity sector struggle because of under-resourcing, inadequate remuneration, bullying culture, racism and feeling unheard as individuals and undervalued as a workforce. Research (Health Central, 2016; Ratima et al., 2007; Stewart, 2016) indicates that occupational stress experienced by Māori nurses is different from that experienced by their mainstream counterparts as there are higher expectations of Māori nurses (including cultural) which add to an already demanding profession. This is particularly so in the current climate where health strategies stress the need for more Māori nurses to help counter poor health statistics. There is an ongoing risk of burnout among Māori nurses which could have high consequences for a workforce that is expected to grow to meet government targets and community needs (Huria et al., 2014; Stewart, 2016).

Sustaining diverse Māori leadership

The synthesis demonstrated that leadership progress for Māori nurses and midwives is wide-ranging, not necessarily linear and affected by a range of factors. In particular, the diversity of participants and the contexts in which they operated affected their ability to grow and influence. Day et al. (2009) note that leadership development is integrally related to identity development and a belief that one *can* lead. Ngā Manukura o Āpōpō clinical leadership training has been successful in fostering that belief. However, where that takes participants varies; some progress up the hierarchical ladder, while others remain in their roles, but become more involved in leadership activities at work or in other settings such as whānau, hapū and the wider community.

This suggests that Ngā Manukura o Āpōpō contributes to an increasing number of Māori nurse and midwifery leaders who have influence at different levels of the health and disability system and different parts of society and, perhaps, at different times in their careers. Kenny (2012) notes it is not uncommon for indigenous leaders to prioritise serving their families and communities, rather than having a desire for a position or power. *He Korowai Oranga, the Māori Health Strategy* (MOH, 2002) positions whānau, hapū, iwi and community development as one of four pathways to achieve "pae ora" (healthy individuals, healthy families and healthy environments), the Government's vision for Māori health. The strategy posits that effective Māori leadership is critical to achieving this vision, and that supporting this leadership involves empowering individuals, whānau members, local Māori and iwi leaders, as well as leaders at each level of the health and disability sector.

LIMITATIONS OF THE SYNTHESIS

This synthesis focused on four programme evaluations from two training programmes, and as such is limited in its scope. What is presented would need to be contextualised to understand applicability for other practice contexts. However, this synthesis provides insight into the impact of kaupapa Māori leadership development approaches for Māori nurses and midwives. It also provides avenues for further research.

CONCLUSION

Kaupapa Māori approaches to leadership development play a significant role in enabling Māori nurses and midwives to initiate and/or progress leadership journeys. In particular, they contribute to strengthening cultural identity, which provides the foundation for strong indigenous leadership. The Department of the Prime Minister and Cabinet (DPMC, 2021) has acknowledged the impact Māori leadership can have on achieving equity. Part of its vision for the future is a health and disability system that reinforces Te

Tiriti o Waitangi principles and obligations with rangatiratanga (self determination) shaping care design for Māori. While awaiting the establishment of the Māori Health Authority, *Whakamaua: Māori Health Action Plan 2020-2025* will help lead the way forward. It calls for a shift of cultural and social norms embedded across the health and disability system that will be critical to addressing and eliminating racism and discrimination and achieving equitable health outcomes. Key priority areas of the plan include Māori leadership and workforce development, in both capacity and capability (MOH, 2020). Ngā Manukura o Āpōpo is well-positioned to play a substantial role in fulfilling these directions, none the least through its clinical leadership development pathway which contributes to a growing pool of much-needed Māori clinical leaders.

AUTHORS' REFLECTIONS

As models of health-care delivery change to combat inequities in our health and disability system, programmes to support both clinical leadership and professional development for Māori nurses and midwives must be developed and sustained. The case for this is only stronger with the findings and recommendations from the HDSR and the Wai 2575 inquiry, culminating in the recent health reforms. The current COVID-19 pandemic also emphasises the need for a system more devised by and responsive to Māori, amid concerns that they are likely to experience a disproportionately negative impact of widespread illness (McLeod et al., 2020).

The authors maintain that Ngā Manukura o Āpōpō's national Māori nursing and midwifery clinical leaders' network and workforce development programme is well ahead of its time. It has worked to influence system-level determinants to Māori health and disability workforce participation and retention and increase Māori presence, capacity and capability in the health and disability sector for more than 10 years. However, they face persistent challenges that limit the sustainability and potential impact of their approach. These challenges include a need to keep validating the equity response provided by kaupapa Māori professional development pathways, slim budgets and short funding cycles.

Continued success relies heavily on the goodwill, commitment and dedication of those involved, with the leadership group providing countless voluntary hours to drive the Ngā Manukura o Āpōpō kaupapa (agenda). This reliance on Māori to drive change, often without remuneration or other recognition, is not uncommon (Haar & Martin, 2021). Nursing and midwifery leadership and education has been described as a tangible response to the imperatives of te Tiriti (Chalmers, 2020). Yet the ability for programmes such as Ngā Manukura o Āpōpo's to contribute change rests heavily on the Government stepping up and commissioning Māori professional development programmes adequately and fairly, and committing to sustained, longer-term investment.

RECOMMENDATIONS

- Funding structures for leadership development programmes for Māori nurses and midwives should be reviewed to better enable their contribution to increased leadership capacity and capability.
- Further research is needed on how leadership success might be measured for Māori clinicians, taking into consideration the diversity of Māori leadership and the realities in which they operate.

DISCLOSURES

The authors, Michelle Moss, Louise Were and Kataraina Pipi, declare they have had contractual relationships with Ngā Manukura o Āpōpō Leadership Group via FEM (2006) Limited since 2014 to evaluate their leadership programmes. The authors have received financial payment for the preparation of this article.

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NURSES' EXPERIENCES OF PROVIDING CARE IN AN ENVIRONMENT WITH DECENTRALISED NURSING STATIONS

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ABSTRACT

Aim: This research sought to evaluate the experiences of nurses working with decentralised workstations in New Zealand hospital wards, to explore the intersection between the physical environment and its impact on nurses and nursing care.

Background: The environment in which nurses deliver care is always changing. There has been a shift away from centralised nurses' stations in wards to decentralised satellite workstations. While studies have shown positive aspects of this shift, unintended challenges of this design for nurses have been identified, eg increased physical exertion, feelings of isolation and challenges related to teamwork.

Methods: This exploratory qualitative design collected data by way of two focus groups with nurses who worked in a hospital ward with a decentralised nursing station. Each focus group consisted of seven participants and ran for approximately 30 minutes. The focus groups were audio-recorded and transcribed for thematic analysis.

Findings: The findings showed a dichotomy of experiences and views about decentralised workstations. While there were benefits for patients, such as quicker response to call bells, nurses being in close proximity and more communication with families, for the nurses, there were feelings of isolation which affected teamwork, collegiality and nursing culture. The nurses also faced challenges related to increased walking, less patient visibility, lack of space to document nursing care and limited knowledge of other patients on the ward.

Conclusion: There is a need for well-researched and considered hospital design, with both the patient and the staff considered during the planning process.

KEY WORDS

Decentralised workstation, pod nursing, hospital design, nurse collegiality.

INTRODUCTION

The environment in which nurses deliver care is always changing. In the modern hospital inpatient ward, there has been a step away from the traditional central nurses' station to decentralised nursing stations (DNS). This shift has changed the model of care and had an impact on the nursing workforce (Fay et al., 2017; Gum et al., 2012). The student researcher for this master of health science research study has worked in both centralised and decentralised satellite stations and has experienced benefits and challenges of both models. This research sought to evaluate the experiences of nurses working in decentralised satellite workstations to determine the advantages and limitations of working in this context, as well as explore the intersection of the physical environment and nursing care. The study aimed to identify strategies to support staff working in a decentralised environment and suggest recommendations for hospital management and nursing leaders to formulate strategies to make nursing in a decentralised environment successful for staff and patients.

BACKGROUND

Decentralisation of the nursing station – also known as pod nursing, geographical nursing or modular nursing – is generally defined as several small workstations each located next to a cluster of patient rooms (Bayramzadeh & Alkazemi, 2014). Nurses working in pods usually work with only one other nurse and may not see others unless they are in a shared space such as the medication room.

Decentralising the nursing station and creating geographically positioned pods has become a popular mode of design (Zadeh et al., 2012). The reasoning behind this shift is that by decentralising the nurses' station and placing pods closer to patients' rooms, nurses may spend more time at the bedside. For nurses, there may also be less distractions and noise, less walking and reduced physical burdens, more bench space and access to computers, and reduced infection rates (Gum et al., 2012; Pati et al., 2015; Real et al., 2017).

Strategically placed decentralised nursing stations may decrease physical exertion for nurses if they are closer to their assigned patients and if they can see their patients while documenting care at the satellite station (Hendrich, et al., 2008; Copeland & Chambers, 2017). Studies have shown that nurses working in decentralised stations made more visits to patient rooms (Gurascio-Howard & Malloch, 2007), which has been linked with increased communication with patients and their families and improved patient satisfaction (Real et al., 2018). Extra time at the patient bedside and increased visibility of patients afforded by decentralised nursing stations have also been widely linked to a reduction in falls and quicker response times to call bells (Brewer et al., 2018).

Other reported benefits of the decentralised station for nurses include reduced noise and distractions, and more bench space with improved availability of computers, telephones and equipment (Copeland & Chambers, 2017; Zhang et al., 2015). A decentralised nursing station may also increase staff visibility and therefore remove a perceived physical barrier between staff and the public (Zborowsky et al., 2010). Increased proximity has been shown to be reassuring for patients and their family members (Bosch et al., 2016). An added benefit is that decentralised nursing stations may mean less physical exertion due to less walking. This may encourage nurses to stay longer in the workforce, improve morale, reduce stress and increase staff satisfaction (Friese et al., 2014; Stichler, 2013).

While these reported benefits of decentralised stations are positive, other studies have shown that nurses face challenges in this environment (Becker, 2009). Becker (2007) argued that decentralisation affects staff connections, learning by participation with others, and the flow of information (which in nursing is often opportunistic rather than planned). Becker points out that socialising, while often considered wasted time, is the foundation of teamwork and collaboration, which builds trust and offers direction, mentoring, feedback and learning.

Nurses have also spoken about a lack of shared space in decentralised stations which affects collegiality and mentoring of new or junior staff (Real et al., 2018; Zhang et al., 2015). Informal interactions between nurses gathered at a central station, acts as a conduit for relationships between colleagues and provides an opportunity for junior staff to elicit knowledge and experience from those around them (Hendrich et al., 2008; Real et al., 2017). Similarly, Parker et al. (2012) point out that a centralised hub fosters social interactions and support in a job that is emotionally taxing. These authors argue that the physical environment for nurses should help ameliorate the emotional fatigue, stress and burnout often associated with nursing.

Several studies have shown that decentralising the workstation may have an unintended consequence of nurses feeling isolated (Copeland & Chambers, 2017; Parker et al., 2012; Real et al., 2018; Zhang et al., 2015). These feelings typically arise from not seeing other nurses and therefore being unaware of their workloads (Bosch et al., 2016; Copeland & Chamber, 2017). According to Bosch et al. (2016), if nurses cannot see their colleagues, they are less likely to ask for help and they may not know that their co-workers need help. Whereas being in close proximity to one another allows for co-ordination and co-operation – both hallmarks of a high-functioning, positive team environment (Kalisch & Begeny, 2005). Identifying when nurses are stressed or busy plays an important role in nursing culture, because team members can offer each other physical or emotional support (Parker et al., 2012; Real al., 2017). The geographical separation of the stations may also mean the nurse in charge of the shift is unaware that a nurse requires extra help or guidance (Zhang et al., 2015).

In summary, research shows there are both positive and negative outcomes from the decentralisation of nursing stations. However much of the research has employed quantitative methods or questionnaires, which limits a qualitative understanding of the impact of a decentralised environment for nurses. The aim of this study was to highlight the nurse's voice to explore how ward design works in the New Zealand context. It aims to provide data on the positives and negatives of this design model for nurses working in this environment. Since decentralisation of the nursing station is a design growing in popularity with hospital developers, this research project may help conceptualise the problems and successes of this model and add to the growing knowledge on the topic.

METHODOLOGY

The research design was an exploratory qualitative approach, employing two focus groups to explore the experiences of the nurses who worked in a ward with a decentralised nursing station. Focus groups were chosen as an efficient and effective method to bring nurses together to share their experiences. It was also a method suited to the nurses, who were time poor due to workloads, because the focus group could be conducted on the ward during a scheduled education session.

Potential participants were registered nurses who worked and delivered care in a ward with decentralised satellite workstations. The inclusion criteria were kept broad to include charge nurse managers, clinical nurse educators and clinical nurse specialists, as they could offer different perspectives, creatiing a holistic picture of the decentralised model. The aim was to recruit nurses from two different contexts (an acute hospital setting and a rehabilitation hospital setting). However the COVID-19 pandemic affected recruitment from acute care, and consequently, nurses were recruited from the rehabilitation setting only. The recruitment process consisted of displaying advertising posters as well as a short verbal presentation to the ward on the research project. Participants were asked to express their interest by contacting the researcher, who then emailed them further information about the study.

Two focus groups (seven nurses in each) were conducted at a tertiary-level rehabilitation hospital where the nurses worked. The reason for having two focus groups was due to the number of nurses expressing an interest in participating. The nurses could choose which focus group to attend. Each focus group ran for approximately 30 minutes. The groups were facilitated by the student researcher using a semi-structured interview guide. A second person who signed a confidentiality form was present at the first focus group to observe group behaviours and take notes. The student researcher was unable

to find a suitable note-taker for the second focus group. The questions were pre-planned but were adapted to the flow of the conversation, as well as to seek clarity and obtain detail. Participant demographics were also collected. Examples of the opening questions included:

1) Tell me about the ward layout, ie is your medication room centralised? Are your supplies decanted to your workstations?

2) How does the layout of your ward impact on how you do your job?

3) Does it support or hinder you in providing nursing care?

The set phases outlined by Clarke and Braun (2017), and similarly reinforced by Attride-Stirling (2011), guided the thematic analysis. This process involved becoming familiar with the data and then creating codes based on what the researcher felt was characteristic of a piece of data (Clarke & Braun, 2017). Next, the codes were organised into themes and sub-themes that fed into the primary and overarching themes. The final phase involved reviewing the themes to determine their validity in reflecting the data, ensuring each theme was well supported by data, checking that the appropriate sub-themes and codes were under the main themes, and checking that the themes were distinct from one another (Clarke & Braun, 2017). The student researcher led the analysis, with input and discussion about the emerging themes from the two other experienced researchers. To promote trustworthiness, the themes are illustrated with verbatim quotes from the nurses, so readers can determine if the interpretations make sense.

Table 1. Nurse demographics

Gender					
	Male	**Female**	**Other**		
Group 1	2	5	0		
Group 2	1	6	0		
Total	**3 (21%)**	**11 (79%)**			
Age					
	21-30	**31-40**	**41-50**	**51-60**	**60+**
Group 1	1	1	3	2	0
Group 2	0	3	1	1	2
Total	**1 (7%)**	**4 (29%)**	**4 (29%)**	**3 (21%)**	**2 (14%)**
Ethnicity					
	NZ European	**Māori**	**Pasifika**	**Asian**	**Other**
Group 1	2	0	1	3	1
Group 2	4	0	0	1	2
Total	**6 (43%)**	**0**	**1 (7%)**	**4 (29%)**	**3 (21%)**

Ethics approval for the study was obtained from the University of Otago ethics committee (reference: D20/071) and the hospital in which the nurse participants worked. The researchers were not asked to keep the setting confidential. However they chose to not name the hospital/region in the write-up because New Zealand is small, therefore participants might be identified. The application of tikanga Māori in regard to the decentralisation model and its relationship to partnership with whānau and access to nurses was discussed during consultation with Māori.

FINDINGS

A total of 14 nurses participated in the two focus groups – seven nurses in each group. The majority were female and there was a range of ages. Unfortunately, there was no Māori voice, which would have added to the findings of this research. There were only two nurses working in the ward where this research was conducted who identified as Māori, which may explain why this voice was lacking. Nurse demographics are shown in Table 1 (above).

Drawing on the thematic analysis of the focus group data, a possible dichotomy was identified, in that a decentralised nursing station environment benefited the patients but not necessarily the nurses. This finding is presented in three overarching themes:

1) Benefits for patients and families.

2) Challenges related to the ward design.

3) Feelings of isolation.

Together, these three themes describe the nurses' experiences of working in a ward with pods, as opposed to a centralised nursing station. These findings are presented with excerpts from the focus group data to illustrate. For clarity, unnecessary words and slang have been removed from the quotes presented.

Benefits for patients and families

The nurses discussed several benefits of working in a DNS environment for the patients and their families. A recurrent theme was that open spaces and improved visibility of the nurses created opportunities for communication and interactions between families and nurses. One nurse suggested that because the families could see them, the nurses were perceived as more approachable. The nurses suggested this approachability differed to wards with a centralised nursing station because in that design, the public areas

and the nurses' station may seem separated:

"When we were centralised, it felt like we were quite separate and the families wouldn't come to the door".

"You have more contact with them [patient's families]. You say hello as they come in and goodbye as they go out. In here [a centralised room] we probably wouldn't see them come and go".

The nurses discussed an important benefit of a DNS in regards to patient safety in that their response time to answer call bells was quicker. The main reason for this was that the nursing stations were geographically closer to the patient rooms compared to when they worked in a centralised nursing station. One nurse explained that being able to answer bells promptly meant patients were less likely to try to mobilise without assistance. Several nurses suggested that hearing the nurses moving about, or conversing with others, particularly during the day shift, was reassuring for patients:

"They do say they can hear us, they know we're out there, they can hear people talking . . . so there is some type of reassurance".

"I think bells are acknowledged sooner . . . I think our response time and our timeliness to respond to patients' needs generally, is greater and better".

"Presence of staff in an area where patients were all the time works in theory because ultimately, we base ourselves at a pod . . . We do a lot around the pods".

These examples show the nurses perceived there were important benefits for their patients and families when working in a DNS environment. These benefits aligned with the intended purpose of the DNS which was that nurses would spend more time at the bedside, respond more quickly to call bells and that falls would be reduced (Real at al., 2018). However, there were further discussions in the focus groups that a DNS environment benefited the patients but not necessarily the nurses. The following themes highlight the challenges the nurses in this study experienced when working in a DNS environment.

Challenges related to the ward design

The impact of the ward design on the nurses was discussed in both focus groups. A particular challenge they spoke about was that despite their DNS being close to the patients' rooms, the patients could not see them. This was due to the room configuration, in which the bed was positioned behind the wall. The problem was exacerbated when the glass doors into the rooms that were initially clear, were frosted to protect the privacy of the patients. One nurse explained this was a possible falls risk for patients as they often *"tried to get up and do it themselves"*. The room configuration also meant nurses could not see the patients:

"If you were sitting on the toilet as a patient, everyone coming down the corridor could see you sitting on the toilet so hence why there's now frosting, but that diminishes our ability to have line of sight into the rooms".

"If you stand at the end of the staff station, you can glance and see into patient rooms, but you can't always see their heads or the head of the bed. You can see that they are probably still in their beds at a glance . . . but generally they can't see you either".

The nurses also spoke about the potential effect of the ward design on their working day. The first was that the medication room and kitchen were located at one end of the ward by the entrance. If the nurse was assigned to the DNS furthest away from the entrance, they walked more during their shift. Some of the nurses said they had noticed more patient falls during medication times because they were in the medicine room rather than at their DNS:

"The end pod does a lot more walking with going to the kitchen to get a cup of tea and meds".

"People want to get up and go to the bathroom, yet people aren't around when we've got activities that take nurses away from those patient areas".

The second challenge the nurses discussed was a lack of space in the DNS to write their notes. Space was particularly problematic during the morning shift because the multidisciplinary team often sat at the DNS. The nurses found this lack of space frustrating because they needed to find an alternative space to write patient notes. Examples were given of writing notes standing at the counter, in the patient lounge, or at the kitchen tables, which was not practical or private:

"It's a dining room for the patients, so if you're sitting there with patient notes it's like a confidentiality [issue]."

"We encourage visitors [and the] patients to sit in that area . . . so that's not actually that practical for us."

Feeling isolated

Another challenge of working in a DNS, discussed in both focus groups, was a feeling of *"being on their own"*. The nurses explained that this feeling was especially noticeable when they needed assistance, or later in the evening when they had settled their patients for the night:

"We used to have two nurses . . . so we always knew if they needed help with something, it's not like that anymore, you're normally left on your own".

"One nurse can sit in quite an isolated space and be quite lonely".

"It is quite isolating, especially in the evenings when everyone might be in their rooms with their patients and you can't find anybody".

The nurses also spoke about receiving less support from their colleagues when working in a DNS, largely because the other nurses might not realise how busy they were:

"We don't really know if the nurse in that pod is really struggling unless they tell us that they are actually struggling . . . When we are centralised . . . we huddle together and if that person or nurse is not interacting [because] there's something she's busy doing, we can offer help right away".

"If you're in a big pod all together, you know what your colleagues [are] going through and you're all out there to bat for them . . . it's not like that anymore".

By comparison, working in a centralised nursing station provided the nurses with a hub for social connections and interactions:

"You miss out on the connection point throughout your whole entire duty, apart from your initial handover that you have."

"[When] you were centralised, you saw people in and out so you would be like 'Oh, are you alright?' You would check in with people more."

A new graduate nurse explained that for her, interactions with senior nurses were especially important because these moments provided an opportunity to chat about her patients. Other nurses spoke about less "banter", chatting, debriefing and laughter when working in a DNS, which one nurse described as a loss of camaraderie. The nurses explained it like this:

"We used to have banter at the end of the shift while we wrote our notes and debrief . . . it was all good but there is none of that anymore."

"Patients used to tell me, it's so nice to hear you girls laughing out there. That doesn't really happen too much anymore, which is really quite sad."

"There is not much comradery and some people might not think that's important but I do, [for] your mental health in a workplace".

Similarly, the nurses spoke about the impact of a DNS environment on the ward culture which typically thrived on social interactions. For example, one nurse explained that nurses were *"sociable creatures"*. Various strategies had been implemented to try to overcome isolation such as having "huddles" and catch-ups. However, due to busyness, these strategies were difficult to sustain:

"The ward culture certainly depends on nurses being able to talk to each other . . . we've put everyone into these little cells to work on their own. I do find the feel of the ward certainly changed . . . for nurses and the whole culture of nursing. I think we're actually losing a bit in a way".

"Our staff try and meet together at some point, especially in the afternoon . . . our reasoning [is] that there was an opportunity to catch up about a particular patient, so everyone was aware".

"We do encourage huddles and they are meant to be where you connect with people, but there are varying thoughts on how that occurs."

A related challenge the nurses discussed was that because they worked in geographically separated nursing stations, they had limited information about other patients on the ward. Whereas when they worked together in a centralised nursing station, they often overheard their colleagues discussing their patients. The result was an overall knowledge of what was happening in the ward which was deeper than the handover given at shift change:

"If it's centralised . . . we are able to know all of the patients, rather than just that particular pod".

"You have a brief overview of them but you don't know them well".

"You heard all the conversations as it happened, whereas you probably don't get that [in the pod] because . . . we generally don't talk with the others the same".

The nurses also discussed safety concerns associated with less knowledge about the other patients on the ward. For example, one nurse said there was an increased reliance on the mobility boards above the patient's bed. She explained that if this board was not up-to-date, safe mobilisation might be compromised. Another concern raised by several nurses was that their colleagues might not realise their patient was deteriorating. To alert the other nurses that they needed help, using the emergency bell might be their only option, which was not ideal:

"You are heavily reliant on the bedside boards . . . you really hope that they are up to date".

"I have been involved in situations where a lot can be happening with an individual patient in one pod and the rest of the ward is probably unaware that the patient is deteriorating".

"The nurse is flat out and unless they activate an emergency button or the clinical emergency . . . gets to that point . . . the rest of the ward can remain [oblivious] to the fact that that is happening around them".

DISCUSSION

The findings of this study show that nurses felt that while there were benefits of decentralised nursing stations for patients, the design posed some challenges for nurses. The perceived benefits for patients were having nurses closer at hand and a quicker response time to call bells, both of which have been reported in the literature (Hua et al., 2012; Zhang et al., 2015). This is a positive finding because other studies have shown that responding more quickly to call bells increases patient satisfaction (Hua et al., 2012) and prevents patient falls (Zhang et al., 2015). While data related to patient satisfaction and falls were not collected in this study, the nurses believed working in close proximity to patients enabled them to respond to their patients in a timely manner, which meant patients were less likely to try to mobilise by themselves.

The nurses in this study spoke about increased walking during their working day because of the way the ward was designed. Those working in the DNS furthest away from the medication rooms and kitchen were affected the most. However, the literature highlights conflicting findings about whether working in a DNS increases the amount of walking a nurse does. Some studies have shown that locating a DNS closer to patient rooms results in less walking (Pati et al., 2012; Real et al., 2017). The findings in this study suggest an influencing factor as to how much a nurse walks during their working day, is the location of frequently accessed areas, such as the medication room. This is worth considering during the hospital design process.

Another perceived benefit of a DNS identified by the nurses in this study was that they were more visible, which created opportunities to interact with patients and families. The nurses believed this visibility reassured patients, which is consistent with the findings in other studies (Bosch et al., 2016; Zborowsky et al., 2010). In the context of this study, this finding is important because the nurses worked in a rehabilitation ward with mostly older patients who the nurses said could be quite anxious. Further, visible nurses might be perceived as more approachable and in the New Zealand context, this may

support working in partnership with Māori patients and their families.

On the other hand, increased visibility did not necessarily translate to these nurses being able to see their patients. Some desks were positioned so that nurses faced away from patients and had to turn around in order to see into the rooms. This may not have been the way the original ward design was envisioned but rather an unintended consequence of furniture and door placement. Visibility, and having patients in the nurse's line of sight were high on the list of reasons why DNSs were designed (Jimenez et al., 2019). Therefore this lack of visual access to patients in the ward studied appeared to be out of the norm. While the literature about DNS does not specifically state how to physically design these spaces, it does implicitly state that visibility is key (Hua et al., 2012). There is a potential that this lack of line of sight contributed to what the nurses in this study perceived was an unchanged patient fall rate.

The nurses also identified a lack of space at the DNS which meant they sometimes used public spaces to complete documentation. A lack of DNS space is not reported in the literature; however other hospitals with a DNS model have introduced a hybrid design by including a centralised space for allied health, nurses and medical teams (Copeland & Chambers, 2017; Zhang et al., 2015). The use of the hybrid design (a combination of pods and a shared space to congregate) may address some of the issues with space, as well as providing an opportunity for social connections.

For the nurses in this study, the foremost personal challenge of the DNS model was feelings of isolation which the literature suggests may be the largest unintended consequence of this design (Tyson et al., 2002; Zborowsky et al., 2010; Zhang et al., 2015). For the nurses, isolation affected teamwork, collegiality and ward culture, which were intertwined and interdependent concepts. Isolation may also have an impact on informal mentoring of novice nurses – this is significant because learning by osmosis from experienced nurses is a cornerstone of nursing (Becker, 2007). Similarly, the nurses spoke about receiving less support in a DNS because their colleagues might not have noticed that they were stressed or busy. Zhang et al. (2015) reported a similar finding; however these researchers found that over time, the nurses started to address this issue by actively working on changing their nursing culture, and having "huddles". This finding suggests there is the potential to address isolation if strategies are put in place to bring nurses together.

Another challenge for the nurses this study identified was that working in a DNS could affect collegiality. The nurses spoke about missing laughter, and opportunities to share, bounce ideas off each other, and debrief. According to Gurascio-Howard and Malloch (2007), when working in a DNS, the nurses still actively sought to congregate in communal spaces to interact with colleagues. Collegiality is important because it helps build trust and enables nurses to form bonds, find common ground and relate to one another (Real et al., 2018). It also provides much-needed emotional support in a job that can be emotionally taxing (Zhang et al., 2015). The nurses in this study had not yet consistently used strategies such as "huddles", communication technologies, or rostering an extra nurse in charge, all of which might address some of these challenges.

The nurses suggested isolation was a patient-safety risk because their colleagues could be unaware of what was going on in other pods. This is an international concern with the DNS model (Parker et al., 2012; Real et al., 2018). A participant in a study by Real et al (2018) explained that *"people could be coding, could be sick. You can't hear anything or see anything"* (p.8). This issue might therefore be a global one and not just be specific to the application of the DNS design in the New Zealand context. This is a concerning finding because if nurses do not have enough knowledge about the other patients on the ward, or receive the support they need, patients may be at risk and the stress on nursing staff may increase.

RECOMMENDATIONS

The following recommendations are suggested strategies to support nurses working in DNS and foster a working environment more conducive to providing nursing care.

1) Consider bringing in communication technology that nurses could use to get help if they are working alone, eg a wireless communication tool that the nurses could carry with them.

2) Implement nurse "huddles" at least once a shift so they can connect with each other, discuss their patients and flag any unwell patients.

3) Consider an increase in nurse staffing so a nurse without a patient load can be rostered as an extra each shift. This role could include intentional rounds of all pod stations; support, mentoring and advice for staff; medication checks; and assistance if a patient is deteriorating.

4) Explore whether simple changes are possible in the existing ward layout (room configuration) to increase visibility of the patients for the nurses.

Further research about the experiences of nurses working in the DNS model with a larger sample size, and across other geographical locations and ward settings, would further our understanding of this topic. Studies to investigate the relationship between the DNS model and patient safety, and research into effective strategies for the improvement of the DNS model for nurses would be beneficial.

LIMITATIONS

This research explored the experiences of nurses in a specific DNS environment, therefore the implications and recommendations might be limited. A strength of focus groups is that nurses can interact and share their perspectives; the researchers acknowledge that the voice of confident personalities may overshadow the voice of quieter participants.

CONCLUSION

This research project has highlighted nurses' perspectives of the benefits and challenges of decentralised satellite stations. The main benefit was that open spaces and improved visibility of the nurses created opportunities for communication and interactions between families and nurses. There were some challenges for the nurses, related to isolation and loss of collegiality; however with thoughtful consideration, these challenges might be mitigated. Nurses spend the most time providing hands-on care in the ward environment. Therefore consulting and including nurses in the design stage of the ward layout may lessen some of the challenges these nurses experience.

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ANTICIPATORY PRESCRIBING IN COMMUNITY PALLIATIVE AND END-OF-LIFE CARE: A REALIST REVIEW

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ABSTRACT

Background: Access to community palliative and end-of-life care that is patient-centred, culturally sensitive and responsive is not equitable for all people in New Zealand. There is an opportunity to transform primary palliative care through an anticipatory prescribing approach and an interdisciplinary workforce. Research is needed to inform the development of best practice and give confidence to authorised prescribers.

Aim: This study aimed to identify the factors influencing anticipatory prescribing in community palliative and end-of-life care.

Methodology: A literature search was undertaken of the databases CINAHL Complete, Science Direct, PubMed, Google Scholar, Grey Lit, Open Grey, Mednar and Open Core. Seven relevant primary research studies were selected. A meta-synthesis of the qualitative research was carried out using a critical realist framework.

Findings: Three main themes emerged from the reviewed articles to explain the factors influencing anticipatory prescribing in community palliative and end-of-life care, including *expertise*, *teamwork* and *prioritisation*. Expertise had two subthemes, which were *knowing when to prescribe* and *knowing how to prescribe.*

Conclusions: Developing and maintaining expertise in primary palliative care, developing better interdisciplinary teamwork, and the prioritising of this prescribing practice are the factors underpinning effective anticipatory prescribing in palliative and end-of-life care. There is an ethical responsibility to anticipate the likely deterioration and end-of-life needs of palliative patients, so timely care can be provided and symptoms managed. Anticipatory prescribing should be individualised, approached with an equity lens, and delivered through an interdisciplinary health workforce to effectively meet population needs.

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KEY WORDS

Palliative, end-of-life care, anticipatory prescribing, patient/whānau-centred, interdisciplinary team, community

INTRODUCTION

Interdisciplinary teamwork is integral to the philosophy of palliative care (Brown, 2015). The complexities of whole-person care require the complementary approaches of different team members to work together to meet the needs of the patient and their whānau or family (Dyess et al, 2020; Ministry of Health [MoH], 2012). Relieving physical suffering is an important component of palliative and end-of-life care, an intervention which should not have to be delayed (Rome et al, 2011). Predicting when patients' end-of-life will occur remains a significant challenge to health professionals, however, and responding to acute needs at short notice can present a challenge to general practices in New Zealand.

The approach of anticipatory prescribing for palliative and end-of-life care needs is used overseas (Antunes et al, 2020; Brady, 2016) and has the potential to provide timely and more equitable access to symptom control here in New Zealand. This article reports on a meta-synthesis of qualitative research, applying a realist framework to better understand the factors affecting anticipatory prescribing in community palliative and end-of-life care.

BACKGROUND

Anticipatory prescribing is the approach of prescribing medications ahead of clinical need for symptoms that are likely to occur, so the medications are readily available when they are needed most (National Clinical Guideline Centre, 2015). Anticipatory prescribing is used for end-of-life care to reduce potential distress or suffering. This approach can also be used in the management of long-term and palliative-stage conditions, where providing medication in advance of likely recurrent symptoms can enable treatment to be initiated sooner before a worsening deterioration develops. Meeting people's palliative and end-of-life care needs is internationally recognised as a basic human right (World Health Organization, 2020). The burden of disease and the changes that take place when dying mean that there is potential for suffering, which can often be avoided.

Palliative care aims to improve an individual's quality of life until their death, attending to their physical, psychosocial and spiritual needs in a culturally sensitive way (MoH, 2011). For care to be fairly distributed, patients should have equitable access to care. However, in New Zealand, significant health disparities are known to exist between Māori and non-Māori, including in accessing palliative care (MoH, 2014). Māori have a higher incidence of life-limiting disease, yet their access to palliative care has failed to match their need (Kidd et al, 2018). Despite the principles and obligations under Te Tiriti o Waitangi (The Treaty of Waitangi), to preserve and improve health for Māori, equitable provision of palliative care has not been achieved in New Zealand (MoH, 2019). There are also other inequities in palliative care that are not specific to Māori, relating to non-cancer diagnoses, age, other minority ethnicities, and rural geographical locations, which need to be addressed for care to be fairly distributed (Palliative Care Council of New Zealand, 2010).

The palliative death rate in New Zealand is projected to increase by more than 47 percent over a 22-year period, from 30,500 deaths in 2016 to 45,000 deaths in 2038 (McLeod, 2016; see Table 1, below). The three most common categories of palliative deaths relate to the circulatory system, cancer, and "other" causes, which largely encompasses dementia and frailty (McLeod, 2016; see Table 2, below). By 2038, non-cancer related deaths are expected to reach triple the number of cancer deaths (McLeod, 2016).

As cancer has a more predictable disease trajectory than other palliative diseases, the projected increase in non-cancer related deaths will result in less predictable patterns of illness, including the onset of patients' last days of life (Thomas et al, 2016). Over the coming decades, death rates for Māori are expected to stay constant, but those deaths are projected to occur at much older ages (McLeod, 2016). Considering Māori are currently under-represented in the uptake of palliative care (Kidd et al, 2018), achieving equity will involve matching the current need and increasing resources to match the rising need (MoH, 2016).

International studies indicate that most people prefer to die at home (Grattan Institute, 2014; Nilsson et al, 2017; Pennec et al, 2015; Stanford School of Medicine, 2021). However, in New Zealand, over a third of adults aged 65 and over die in acute hospitals (Broad et al, 2015). Data on place of death suggests that there is poor continuity of care and support being provided at home (MoH, 2016) which can lead to crises (which may involve suffering and harm) and care being provided contrary to the patient's wishes. Furthermore, there are quality and sustainability concerns, which may result in poorer outcomes for patients and families (Health Quality & Safety Commission [HQSC], 2020). These concerns are likely to compound, resulting in significantly strained resources for future palliative patients if not addressed (HQSC, 2020).

Enabling anticipatory prescribing to become a safe and widespread practice would require a true integration of services. For example, anticipatory care plans and prescriptions could primarily be developed by GPs and primary care nurse practitioners (NPs). They could also be initiated by secondary and specialist care providers, with a request for review by the patient's primary provider within a defined timeframe. As outlined in the Resource and Capability Framework for Integrated Adult Palliative Care Services (MoH, 2012), most palliative care would continue to be provided by primary care providers, with support from specialist services. However, the anticipatory care plans and prescriptions could be accessed by other community health-care providers as appropriate, allowing them to provide care whenever needed, according to the patient's wishes and the directives of the primary provider.

Table 1. Projected palliative deaths in New Zealand

Year	Number of deaths	Change
2016	30,500	↑ 47.5% (over 22 years)
2038	45,000	

Table 2. Most common causes of palliative deaths

Year	1 (most common)	2	3
2016	circulatory system	cancer	other (includes dementia, frailty)
2038	circulatory system	other	cancer

METHODOLOGY

The origins of critical realism come from the writings of Roy Bhaskar, who made the distinction between epistemology, a focus on knowledge, and ontology, a focus on reality (Archer et al, 2013; Bhasker, 1975). The underpinning philosophy of realism deals with the truths behind what is unobservable, seeking to understand the causal processes between the context of an intervention and the outcomes (Chakravartty, 2017). Informed by the three domains of reality (see Figure 1, next page), theory or data can be evaluated through four basic forms of logic: deductive, inductive, abductive and metaphoric inference (Eastwood et al, 2014). Retroduction can then be used to conceptualise the hidden causal forces that emerge from these forms of logic. The result (see Figure 1) is a layered approach to explaining the mechanisms that result in particular outcomes within particular contexts.

Applying a realist review approach to a synthesis of the findings of primary research studies can enable a deeper understanding of these causal processes.

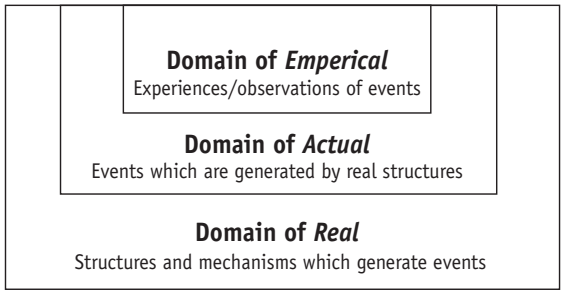

Figure 1. The three domains of reality (Stevens, 2020, adapted from Mingers, 2004).

Realist review approach

The methodological process followed in this review was informed by the realist review stages outlined by Power et al (2019). According to Power et al, there are six active stages in carrying out a realist review.

- **Stage 1:** Setting a clear scope for the review and developing a theoretical framework.
- **Stage 2:** Creating a search strategy.
- **Stage 3:** Selecting and appraising the primary research studies.
- **Stage 4:** Undertaking a process of data extraction.
- **Stage 5:** Data synthesis and analysis processes.
- **Stage 6:** Testing and refining theories that have been developed.

These six stages were adapted to form a basis for the methodology for this study. Elements of the PICO (population, intervention, context and outcome) were identified as authorised prescriber, anticipatory prescribing, community palliative and end-of-life patients, and symptom management respectively, as represented in Table 3 below.

To apply these elements of the PICO to a critical realist framework, the intervention and context were considered as mechanisms, the population viewed as human agency, and the outcome was viewed as an inter-relation of the above, as shown in Figure 2 below.

Search strategy*:*The second stage involved refining and completing the search strategy. The terms from the PICO table were used as a basis for searching databases. The terminology used in other countries was explored to maximise the capture of international findings. The search strategy for PubMed is shown in Box 1 (opposite page), and was adapted for CINAHL Complete, Science Direct, Google Scholar, Grey Lit, Open Grey, Mednar and Open Core.

Study selection: Inclusion and exclusion criteria were applied to the selection of studies. Primary research studies published in the last 10 years were included. Anticipatory prescribing in contexts other than palliative and end-of-life care were excluded. Articles not published in English were excluded unless an English translation was available. Additional relevant articles were handpicked from the reference lists of secondary research studies to add completeness and rigour. The PRISMA process diagram (Figure 3, opposite page) shows the identification of the studies selected at each stage.

Data extraction: Research article titles were screened to indicate whether the topic was potentially relevant, and if so, the abstract was screened. Article titles which included palliative, terminal, dying, last days of life, or symptom management, had their abstracts screened. If articles were found to be exclusive to hospital anticipatory prescribing, prescribing for assisted dying, or involved examining decisions about the administration of anticipatory medications for example, they were excluded. During

Table 3. PICO table

	Key words	Synonyms and other terms
Population	Authorised prescriber	General practitioner, GP, nurse practitioner, NP, nurse prescriber, family doctor, family physician.
Intervention	Anticipatory prescribing	Advanced prescribing, pre-emptive prescribing, just-in-case medications.
Context	Community palliative and EOL patients	Palliative, last days of life, terminal, dying. Home, primary care, community.
Outcome	Symptom management	Symptom relief, "good death" vs "bad death".

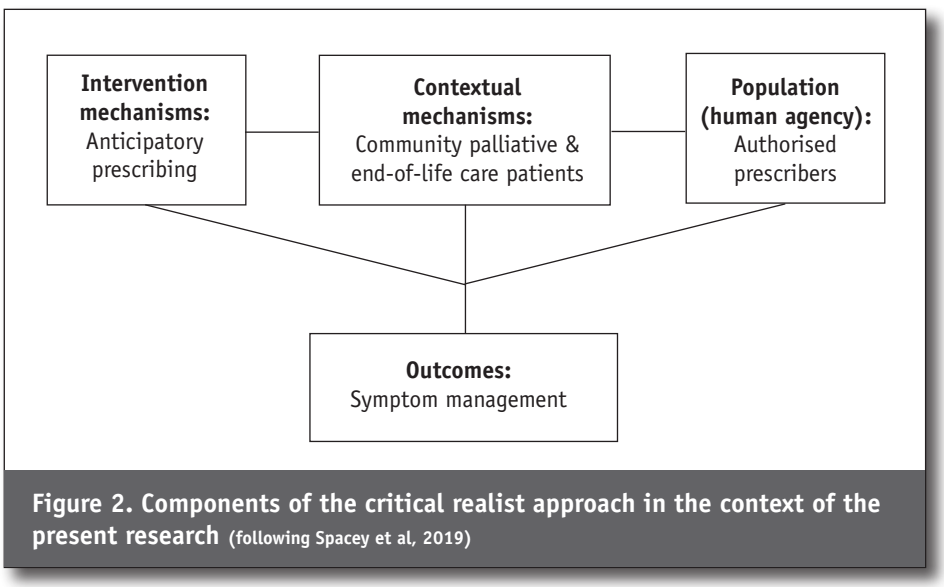

Figure 2. Components of the critical realist approach in the context of the present research (following Spacey et al, 2019)

Box 1. PubMed search strategy

"symptom control" OR "symptom management" OR "symptom relie*" OR "suffering" OR "distress" AND "palliative" OR "end stage" OR "terminal" OR "last days of life" AND
"anticipatory prescribing" OR "anticipatory medication" OR "just in case prescribing" OR "just in case medication" OR "end-of-life prescribing" OR "end-of-life symptom management" OR "end-of life medication" AND "authorised prescriber" OR "authorized prescriber" OR "medical practitioner" OR "general prescriber" OR "GP" OR "nurse practitioner" OR "NP" OR "prescriber" OR "family doctor" OR "family physician"

FILTERS: in the last 10 years

LIMITS: publication year ≥2011, research article/ primary research

EXCLUDES: guidelines, quantitative, secondary research

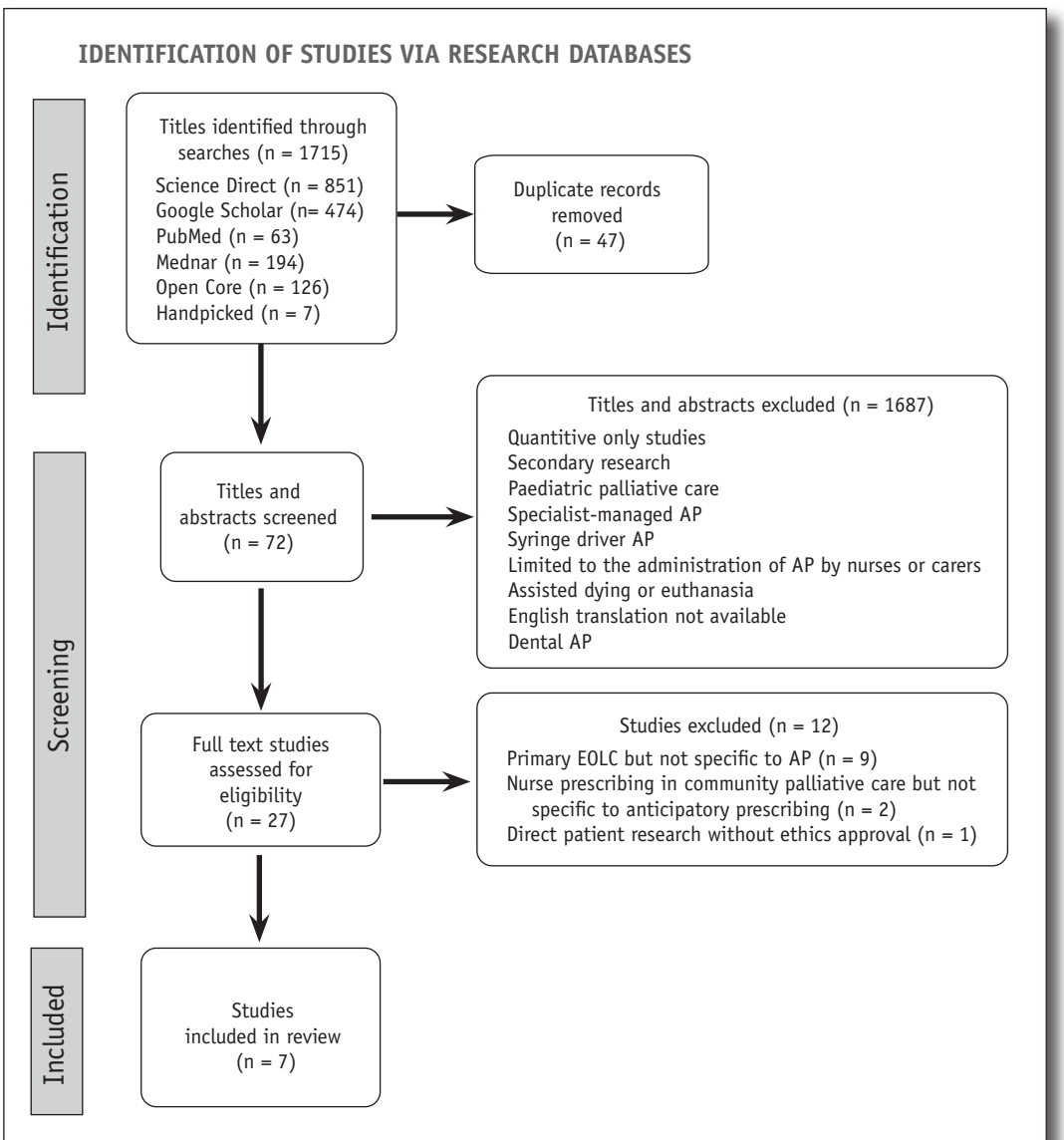

Figure 3. PRISMA diagram (Page et al, 2021)

the full-text review, 11 of the articles were found ineligible on the basis of not directly mentioning anticipatory prescribing.

Quality appraisal: The Joanna Briggs Institute (JBI, 2017) critical appraisal checklist was used as assessment criteria for all seven articles. Three of the 10 appraisal areas highlighted some areas which were lacking strength. Three studies did not locate the researcher culturally or theoretically. Two studies did not address the influence of the researcher and there was a level of uncertainty with two further studies of this being adequately addressed. The final area of potential inadequacy was in two studies which did not provide reader assurance that the voices of the study participants were adequately represented. One article was excluded since it did not demonstrate ethical review in a study involving palliative patients as the population.

Characteristics of the selected studies: The characteristics of the seven studies selected for inclusion in the review are set out in Table 4 (next page). Five of the studies were English, one was Scottish (of note: the National Health System (NHS) in England and Scotland are separate health system bodies). The seventh study took place in Victoria, Australia (Khalil et al, 2021). The community settings had GP or nurse practitioner clinical oversight, with interdisciplinary team involvement. Aged residential care homes were included as a community setting; hospice in-patient units were excluded.

The seven studies were published between 2012 and 2021 in general practice, nursing and palliative care journals. Three study designs were qualitative descriptive, two were ethnographic, one was observational and one was based on grounded theory. Although Bowers et al (2020) note that anticipatory prescribing is encouraged practice for end-of-life symptom management in the United Kingdom (UK), Australia and New Zealand, no New Zealand-based studies were located.

Data synthesis & analysis: The Stepwise Framework (Bygstad et al, 2016) was used to guide the stages of data analysis and synthesis. This framework was chosen for the six-step process it provides with an applied critical realist

Table 4. Study characteristics

Authors	Title	Year	Journal	Country	Setting/demographic	Study design	Aim of study	Inclusion criteria
Bowers, Barclay, Pollock, Barclay	GPs' decisions about prescribing end-of-life anticipatory medications	2020	British Journal of General Practice	United Kingdom	GPs in one English county.	Interpretive descriptive study	To explore GPs' decision-making processes in the prescribing and use of anticipatory medications for patients at the end of life.	On the basis that GPs were being asked to share their views and experiences of anticipatory prescribing for end-of-life.
Khalil, Garett, Byrne, Poon, Gardner, Azar, Craig, Karimi	Mapping end-of-life and anticipatory medications in palliative care patients using a longitudinal general practice database.	2021	Palliative and Supportive Care	Australia	From 25 GP practices where a palliative care referral had been undertaken, over 10-year period.	Retrospective observational study.	To map EOL and the uptake of anticipatory medications through databases, and discuss the results with stakeholders.	A sample of GPs/NPs were asked to share their views on AP practice and supporting resources, the questions of which were derived from the quantitative findings of palliative prescribing in 25 general practices in their region over a 10-year period.
Wilson, Seymour	The importance of interdisciplinary communication in the process of anticipatory prescribing.	2017	International Journal of Palliative Nursing	United Kingdom	Study sites were either community nursing or rest home settings where AP is used. Involved 2 regions in England with mixture of urban and semi-rural.	Ethnographic study.	To study health professionals' perceptions of what facilitates and restricts interdisciplinary communication, by using anticipatory prescribing as an example.	Community health professionals were observed and interviewed to find out the issues that affected anticipatory prescribing in various settings.
Faull, Windridge, Ockleford, Hudson	Anticipatory prescribing in terminal care at home: what challenges do community health professionals encounter?	2013	BMJ Palliative and Supportive Care	England, United Kingdom	Two regions. At least one from each of 6 different nursing services, pharmacy and general practice. Different responsibility levels, experience, practice size, age, experience of out-of-hours care, nurse prescribers and non-prescribers, rural and city clinicians, male and female. Culture and ethnicity not mentioned.	Grounded theory.	To explore the issues that arise for community clinicians in relation to prescribing, dispensing and administering subcutaneous midazolam, and diamorphine or morphine for the anticipated need of end-of-life patients.	Community health professionals were asked to share issues and challenges associated with the process of anticipatory medications for EOLC.
Wilson, Seymour, Seale	Anticipatory prescribing for end-of-life care: a survey of community nurses in England.	2016	Primary Health Care	England, United Kingdom	District and community nurses, palliative care nurses and managers and matrons of nursing homes. Sampled over two regions in England.	Ethnographic study.	To gain insight into the roles and experiences of a wide range of community nurses involved in end-of-life medication decisions.	Community nurses provided some free-text insights to support the main (quantitative) study in relation to their experience and influence in anticipatory prescribing.
Bowers, Redsell	A qualitative study of community nurses' decision-making on the anticipatory prescribing of end-of-life medications.	2017	Journal of Advanced Nursing	England, United Kingdom	Purposive sampling of community palliative nurses and district nurses with direct experience of prescribing AM to individuals with terminal illness.	Qualitative, interpretive, descriptive.	To explore community nurses' decision-making processes on anticipatory prescribing for people who are dying.	Community nurses' insights into anticipatory prescribing and the influencing factors of this practice in EOLC.
Lawton, Towsey, Carroll	What is a 'good death' in the care home setting?	2016	Nursing and Residential Care	Scotland, United Kingdom	After-death care reviews following a government initiative to better integrate palliative care into care homes.	Qualitative descriptive.	To increase the care home staff recognition of the integrated palliative care plan initiative in relation to them providing palliative care.	Anticipatory prescribing was identified as ne of the factors contributing to a 'good death' in care homes and qualitative insights were shared in this.

approach (see Table 5, below).

The first step involved noting the events and issues that lead to anticipatory prescribing from each of the seven studies. The second step involved identifying the key entities that constituted structures with causal powers (Bygstad et al, 2016). By the third step, an exploration of meaning was applied, where through abduction, themes to explain and interpret the events were noted. The fourth step, made up of four sub-steps, involved going through the data with retroductive inference, a process of identifying the circumstances where anticipatory prescribing would not occur. The analysis as part of step five involved explaining the causal properties of the events and how they related to dependent factors and contributed to mechanisms. Finally, in step six, the explanations of the causal properties and mechanisms were tested repeatedly against the theorising already made, and the wording of these was refined until the explanatory power was most effectively explained (Power et al, 2019). Once the explanations had been tested, the coding of data was compiled in a table under the explanatory themes.

Table 5. Data synthesis and analysis

1. Description of events and issues that constitute the phenomenon of interest.
2. Identification of key entities.
3. Theoretical re-description (abduction).
4. Retroduction a) immediate outcomes b) interplay between entities c) the candidate affordances d) the stimulating/releasing conditions
5. Analysis of the set of affordances and associated mechanisms.
6. Assessment of explanatory power.

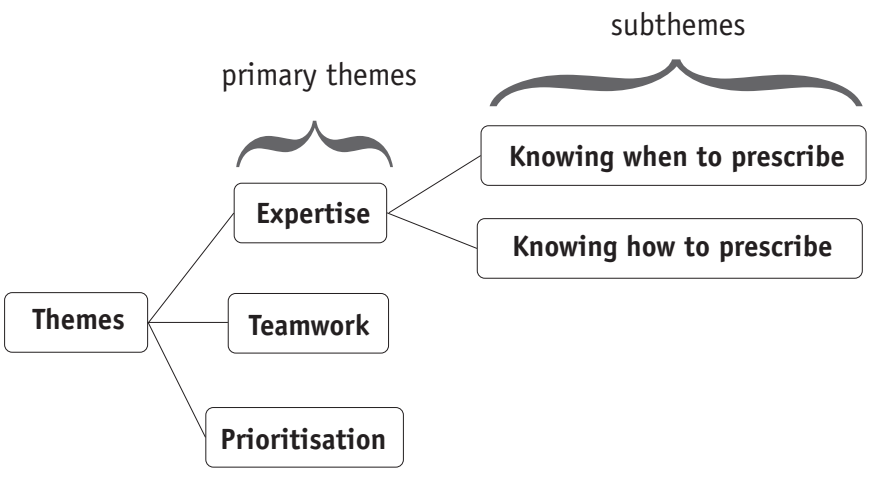

Figure 4. Themes and subthemes of the findings

FINDINGS

Three primary themes emerged from the synthesis, including *expertise*, *teamwork* and *prioritisation*. Expertise has two subthemes, which are *knowing when to prescribe*, and *knowing how to prescribe* (see Figure 4, below).

Expertise

Effective anticipatory prescribing for palliative and end-of-life care needs is underpinned by expertise. This idea of expertise is reflected in the primary research findings referring to *"getting the timing right"* (Bowers et al, 2020); *"knowledge of when to prescribe"* (Khalil et al, 2021); *"awareness of pathways"* (Khalil et al, 2021); *"knowledge of publicly available resources"* (Khalil et al, 2021); *"reflecting on expertise and experience"* (Faull et al, 2013); and in *"reading the situation"* (Bowers & Redsell, 2017). A well-placed confidence to prescribe for palliative and end-of-life care comes from knowledge and experience (Wilson et al., 2016) and through education, such as from local integrated projects for palliative care which include guidance on anticipatory prescribing (Lawton et al, 2016). Knowing "*when"* and knowing "*how"* to prescribe anticipatory medications both require expertise.

Knowing when to prescribe: Knowing when to prescribe anticipatory medications requires the greatest expertise. It is challenging to accurately predict when symptoms will occur, and identifying the right stage to prescribe anticipatory medications is also a challenge and significant barrier to its implementation (Bowers & Redsell, 2017; Khalil et al, 2021). Some prescribers only use anticipatory prescribing for end-of-life. Others prescribe for earlier stages, aware that there are additional benefits and indications for anticipatory prescribing (Khalil et al, 2021). Noticing that a patient is deteriorating is the most obvious indication for which prescribers agree to prescribing anticipatory medications; there will likely be a consensus too, if the practitioner can anticipate the patient's disease deterioration (Khalil et al, 2021). Nurses also make judgements about when anticipatory prescribing may be appropriate, initiating conversations with families and recommending that GPs consider anticipatory prescribing (Bowers & Redsell, 2017; Wilson et al, 2016). These clinical judgements by the nurse may or may not be shared by the prescriber (Wilson et al, 2016). Some GPs, on the other hand, fully rely on nurses to prompt them to consider anticipatory prescribing, particularly in aged residential care (Bowers et al, 2020).

Knowing when to prescribe is a learnt skill (Bowers & Redsell, 2017; Faull et al, 2012). Prescribers need a forward-planning approach and may tie in the timing of anticipatory

prescribing with other care-planning decisions such as resuscitation status and preferred place of care and death (Bowers et al, 2020). Interdisciplinary team meetings provide shared expertise and lead to shared decision-making on when to prescribe anticipatory medications (Wilson & Seymour, 2017). The Gold Standards Framework (GSF), a tool designed to help clinicians develop a more planned approach to life-limiting conditions (Thomas & Noble, 2007), forms the basis and purpose of interdisciplinary team meetings (Wilson & Seymour, 2017).

> *"In our practice, we have regular Gold Standard Framework meetings where we keep up to date on what's happening with the patients. The district nurses normally let me know when anticipatory drugs are needed."*
>
> (GP interview, Wilson & Seymour, 2017, p 131).

This quote provides an example of where patient care is improved by different professions working together. The different lens they bring from their clinical backgrounds, experience and working contexts adds more than an individual practitioner or single-disciplinary team are likely to provide.

Knowing how to prescribe: The skill in knowing how to prescribe has several important elements. Best practice in prescribing dictates that prescribers must know the patient's condition well, have undertaken adequate assessment of the patient's situation, and know that the medications are safe and appropriate for the patient's needs (General Medical Council, 2021; Medical Council of New Zealand, 2020). Most GPs report seeing the patient for themselves following a nurse suggesting anticipatory prescribing, but a minority would prescribe on account of a well-known and trusted nurse (Bowers et al, 2020). Conversations with patients and their families about anticipatory prescribing need skill and sensitivity, tailored at a level that matches their needs (Bowers et al, 2020). Although some patients and families are open to talking about the need for anticipatory prescribing and are believed to be reassured by it being implemented, others have appeared ambivalent. GPs report framing anticipatory prescribing as a clinical recommendation, while giving the patient and family the opportunity to opt out (Bowers et al, 2020). GPs need to know where to find appropriate guidance, otherwise they may be unlikely to prescribe anticipatory medications (Wilson & Seymour, 2017).

A final but significant element of knowing how to prescribe is in the correct completion of prescriptions. Wilson et al's (2016) study of 575 community nurses involved with palliative care revealed that incorrectly prescribed anticipatory medications affected around one fifth of nurses. GPs seemed to lack understanding of the impact of incomplete prescriptions on their interdisciplinary colleagues. What GPs considered small errors in their prescriptions, were in fact legally incomplete prescriptions/documents for pharmacists to dispense or nurses to administer. However, the lack of understanding about these differing responsibilities led to time-consuming processes, delays in access to medications and considerable frustration on both sides. Skill and experience could lead to more accurate prescriptions being written, and improved understanding of professional colleagues' responsibilities.

> *"If we get a form right, it's usually cause for celebration. Just because all of the 'I's and all of the 'T's definitely have to be crossed. I'm not sure they actually definitely have to be crossed but our district nurses feel that they actually have to definitely be crossed".*
>
> (GP interview, Wilson & Seymour, 2017, p 132)

> *'I think sometimes doctors don't seem to understand the importance, the legal requirements of doing a controlled drug prescription. For example, the validity, there's got to be directions, dosage, quantity, they've got to be in words and figures . . . There's times when prescriptions come from surgeries that haven't been signed, where legally you cannot dispense it then".*
>
> (Pharmacist interview, Wilson & Seymour, 2017, p 132).

Inexperience – the opposite to expertise – leads to a reluctance to do anticipatory prescribing and results in variations in practice between prescribers (Faull et al, 2013; Wilson & Seymour, 2017; Wilson et al, 2016). The fears documented about anticipatory prescribing include prescribing opioids, expediating death, misuse, waste, and medication shortages, which lead to reluctance and in turn, less real-world experience of using this approach (Bowers & Redsell, 2017; Faull et al, 2013; Khalil et al, 2021). For more experienced clinicians, misuse and waste are viewed as risks rather than fears, and risks are weighed up against the potential benefits. While there may be risks involved in putting medications in a house too early, the possibility that individuals may not get effective symptom management if left too late is often a greater cause for concern (Bowers & Redsell, 2017). In cases where medications were left in homes for longer periods, experienced GPs would rely on nurses to provide feedback on any concerns they had (Bowers et al, 2020).

Teamwork

The process of anticipatory prescribing is smoother and more successful when health professionals work as a team. Nurses were often the first to identify the need for anticipatory prescribing (Wilson & Seymour, 2017) and GPs typically assumed responsibility for initiating the anticipatory prescribing conversations with the family (Bowers et al, 2020). Nurse prescribers would often take responsibility for both. They initiated conversations both with the family unit and the GP, having the authority to prescribe independently within their scope, but with the aim to act collaboratively (Stenner & Courtenay, 2008).

GPs were reported as being receptive to nurses requesting that they consider anticipatory prescribing, were influenced by them, valued them greatly, and frequently relied on them (Bowers et al, 2020). Specialist and palliative care nurses were considered an asset to GPs, and nurses were aware that they were acting as the eyes and ears of the GPs (Bowers & Redsell, 2017; Bowers et al, 2020; Wilson & Seymour, 2017). However, as non-specialised providers of palliative care, district nurses could feel undervalued and not listened to by GPs, in many cases stemming from hierarchical attitudes and poor understandings of nurses' responsibilities and capabilities (Wilson & Seymour, 2017). Other studies contrasted with this finding, showing that district nurses formed closer relationships with GPs than specialist nurses (Bowers & Redsell, 2017). The reason for this was that GPs and specialist nurses could both attempt to take the lead, and as a result experience conflict. Specialist nurses were also thought to value specialist palliative views over the generalist views

of GPs (Bowers & Redsell, 2017).

In all cases, an adequate nurse-GP (or other prescriber) relationship needs to be established (Bowers & Redsell, 2017). An understanding of differing professional responsibilities is also vital. When these aspects of connection and relationship are properly understood, it can lead to increased communication and trust in the anticipatory prescribing process. In contrast, lack of trust and/or relationship tends to be the weak link in the process of anticipatory medications in the home (Faull et al, 2013).

> *"I offered to meet the out-of-hours doctor, it was a . . . patient who was very, very terminally ill and he said he would, but didn't, and he . . . admitted that patient and she died in the ambulance on the way to hospital and you know, that was – I was quite happy to meet him, to give whatever, but he wasn't interested."*
>
> (Nursing professional, focus group 8, Faull et al, 2013, p 3).

> *"We had a patient who was requiring an awful lot of morphine . . . the breakthrough dosages were very high and were continually being adjusted and because [specialist palliative nurses] were involved I used to give quite a big range actually, because they were women that I worked with . . . and I know and trust, so you give a big range . . . but when you have a [different] nurse going in at night, they were very, very reluctant to give the dose that they had been having and they would tend to go to the lowest dose on the range, which caused difficulty with pain control . . . not knowing the patient, not knowing the family, not knowing me, not knowing the team, and being asked to give what seemed to be a lethal dose of morphine."*
>
> (GP interview 2, Faull et al, 2013, p 4).

The health professionals in these examples appear to have acted independently, rather than as part of a team, highlighting that insufficient links between them prevent a more comprehensive approach to care. Nurses working in aged residential care, in relative isolation from the health-care team, may request admission of palliative patients to hospital, which may later be identified as inappropriate (Lawton et al, 2016). Having one GP allocated to an aged care home has the potential to improve the relationship and trust between members of the health team in this context (Wilson & Seymour, 2017), as it promotes continuity of relationship as well as continuity of care. Nurses advocating for patients in aged care settings have successfully promoted collective discussions about anticipatory medications (Bowers et al, 2020).

Where nurses work well with GPs, they report good access to anticipatory medications (Faull et al, 2013). Being located in the same building enhances relationships; the closer the proximity, the more frequently the informal "corridor" conversations take place (Wilson & Seymour, 2017). When nurses have been overstretched in their workload or split off from GPs geographically, it has made their working relationships, interdisciplinary communication, and the process of anticipatory prescribing more difficult (Bowers et al, 2020). One solution has been having the GP review the shared electronic records where nursing care is documented. Anticipatory prescribing was also reportedly used as a signal to visiting clinicians that symptom control was the priority focus when shared electronic records were not available (Bowers et al, 2020).

Nurses know to provide regular updates to GPs in relation to patients who may need anticipatory medications (Bowers & Redsell, 2017). Yet nurses encounter issues with some GPs when they broach the subject of anticipatory prescribing. Even senior nurses with direct experience in anticipatory prescribing reported *"playing the game"* when negotiating with GPs over what to prescribe. Nurses are documented as having to balance the patient advocacy role with negotiation tactics – compromises, persuasions, suggestions and tailored approaches to individual GPs (Bowers & Redsell, 2017). However, healthy negotiations tend to be valued by nurses, like in the following example.

> *"It's very rare that your suggestions are ignored. The problem is I don't like the doctors that say no to everything and I don't like doctors who say yes to everything, I like the negotiation."*
>
> (Rene, community palliative nurse, Bowers & Redsell, 2017, p 18).

Even when conflicts arise, nurses would work to get the best outcome for the patient.

> *"They don't always agree with me and sometimes you have to choose your battles, but ultimately you have got to do what's right for the patient . . . I'm not afraid to be the advocate and push that forward."*
>
> (Debbie, community palliative nurse, Bowers & Redsell, 2017, p18).

GPs also put their patients' needs above that of concerns within the interdisciplinary team. For example, concern would arise if the GP had no connection with the third party who would be initiating the anticipatory medications. However, the greater concern for GPs was that the patient would not be given the prescribed medication when needed, and that this would result in a bad death (Bowers et al, 2020). Ultimately, health professionals are still navigating interprofessional issues to continue to provide the safest and most effective patient care they can.

Prioritisation

Recognising the benefits of anticipatory prescribing, and acting to prioritise them, is the third theme to emerge from the analysis. The prescribers involved in facilitating anticipatory prescribing were aware of the benefits it could bring to patients and their families; to relieve distressing symptoms when they occurred meant caring for the physical needs of the patient, and offering a sense of control to patients and their families in knowing that these needs could be managed (Bowers & Redsell, 2017).

> *"I like to have those conversations early. To get them out of the way sounds like I'm trying to avoid them, I think get them out of the way for their benefit so that they don't have to, they can, there's a lot to sort out, 'let's get it all sorted out and then enjoy the last time you have'."*
>
> (Dr Matthews, GP and out-of-hours doctor, Bowers et al, 2020, e734).

Anticipatory prescribing was seen as an insurance plan, a way of managing uncertainty and preventing crises, particularly for non-cancer conditions where disease trajectories could be very difficult to predict (Bowers et al, 2020). In these patients, anticipatory prescribing was done while the patient was still stable, and could involve medications to cover end-of-life symptoms as well as earlier

needs (Bowers et al, 2020; Khalil et al, 2021). Only some clinicians used anticipatory medications to manage other stages of late disease and specifically injectable medications in patients for whom oral medications were no longer best, for example, when swallowing issues were present and gastroparesis (Bowers et al, 2020; Khalil et al, 2021). Having a proactive mindset enabled GPs to put anticipatory medications in place before the clinical needs occurred. Knowing the benefits of anticipatory prescribing is the first step in this; prioritising the action is the next, even if the need does not arise for a while.

> *"One or two of the partners said, 'I think it's a problem thinking when to do it'. I said, 'Why? Why can't you just leave it [anticipatory medications] gathering dust . . . why can't you do it early?' "*
>
> (Dr Taylor, GP, Bowers et al, 2020, p3)

While some GPs felt it was the responsibility of out-of-hours services to attend to end-of-life symptomatic needs (Wilson et al, 2016), many other GPs felt anticipatory prescribing was a more optimal approach to covering out-of-hours care needs (Bowers et al, 2020; Bowers & Redsell, 2017). Anticipatory prescribing was therefore put in place to benefit patients and their families, as well as to prevent additional work for their out-of-hours colleagues (Bowers et al, 2020). The risks of leaving medications in homes for months where they could go missing, be misused or expire are well documented, and in some contexts accessing these medications to begin with could be challenging, and the cost could affect patients (Bowers et al, 2020; Faull et al, 2013; Khalil et al, 2021). However, for many GPs these challenges were worked around, whenever the clinical and emotional benefits outweighed the risks (Bowers et al, 2020).

As a result of the anticipatory prescribing approach, many GPs found working in palliative care extremely rewarding, and were willing to work hard to prioritise end-of-life symptom control (Bowers et al, 2020). This willingness cultivated a culture where anticipatory prescribing was encouraged (Bowers et al, 2020). Ultimately there was also agreement on the principle that distressed patients should not have to wait for relief, that without anticipatory prescribing "bad deaths" occurred, and "good deaths" could occur where anticipatory prescribing was present (Faull et al, 2013; Lawton et al, 2016).

> *"Just in case [JIC] drugs used 3 times in the last 24 hours of life – family delighted with the care."*
>
> (Afterdeath review in Care Home, number 12, Lawton et al, 2016, p 496).

Anticipatory prescribing then, can enable "good deaths" to occur in accordance with patient and family wishes.

DISCUSSION

The relevance of international studies for the New Zealand context of community palliative care needs to be considered on various levels. At the most fundamental level, the relevance of anticipatory prescribing is universal, and indeed ethical. The definition and purpose of anticipatory prescribing – that palliative and end-of-life patients in physical distress should not have to wait for relief – remains the same.

Conceptually then, the principles underpinning anticipatory prescribing are universal. However, on a cultural level there are differences between palliative care in New Zealand and in other countries. Despite the cultural diversity that exists in the UK and Australia, through immigration and asylum, and the indigenous populations that live in Australia, culturally safe practices were not discussed in the articles reviewed. In New Zealand, considerable efforts have been put into developing culturally safe practices, particularly for Māori, the indigenous people of New Zealand. Health inequities have persisted for Māori for generations (MoH, 2020a; MoH & University of Otago, 2006), and a commitment to changing these inequities has shaped the education of health-care professionals in New Zealand, underpinned by the Treaty of Waitangi. Relating the concept of cultural safety to the findings of this study, the skills and competencies required for culturally safe practice fit with the *"expertise"* theme. As health-care professionals become more aware of the impact of their own views and biases (Medical Council of New Zealand, 2020), and seek to work with patients and whānau and their differing worldviews, the aim of achieving toi ora (health) could be closer to being realised (Te Rūnanga Hauora Māori o Te Moana a Toi, 2019).

The interdisciplinary approach encouraged by the Gold Standards Framework (2019) speaks to the value of different health professionals playing their part as a team in providing palliative care. Hierarchical attitudes and poor understandings of other professionals' roles exist in New Zealand as well as overseas (Forgues, 2018). The primary care funding model in New Zealand may reinforce these attitudes and prevent more interdisciplinary approaches from occurring (Pullon et al, 2009). The fee-for-service model links payments to tasks, which separates the team into practitioner types, and the biggest revenue stream by far is for the doctors, who tend to work independently (Pullon et al, 2009). This model provides little incentive for a one-team approach in a context where privately-owned practices have fiscally tight margins and alternative ways of working may offer little guarantee of investment return. As for GPs having an interdisciplinary approach with other health professionals outside their practice, such as district nurses and ambulance personnel, the barriers are potentially greater, due to tight scheduling templates, and separate working facilities.

The professional scope of nurses in primary care has been much slower to advance in New Zealand than it has in the UK (Hoare et al, 2012). Community nurses have been able to prescribe injectable medications for end-of-life care since 1994 in the UK (Legislation UK, 1992), and as Bowers and Redsell (2017) reported, these nurses are frequently involved in initiating anticipatory prescribing. Twenty-seven years on, nurse prescribers in New Zealand still cannot prescribe injectable medications for palliative and end-of-life care (New Zealand Legislation, 2016; Nursing Council of New Zealand, 2018). Nurse practitioners working in primary care in New Zealand are able to attend to these end-of-life needs however, including for the anticipatory prescribing approach, and the numbers of these primary nurse practitioners are increasing (MoH, 2020b).

Members of the health workforce who provide palliative and end-of-life care will vary between the UK and New Zealand; indeed this varies within regions of New Zealand. When anticipatory medications are prescribed, it could vary from area to area who would administer them. District nurses, hospice nurses, doctors or ambulance personnel are the most likely members of the workforce to do this. Sometimes family members may be comfortable with carrying this out. Ambulance personnel have an increasing role in end-of-life care, particularly when families need support in the home at relatively short

notice and when someone from their primary health-care team is not available (McCormick & Thompson, 2019).

Until now in New Zealand, anticipatory prescribing has featured more in specialised and residential care settings (Canterbury District Health Board, 2011; MoH, 2009; MoH, 2013), with little evidence of it being used in primary care. In the last few years however, the *Te Ara Whakapiri* documents *Principles and Guidance for the Last Days of Life* (MoH, 2017a) and *Te Ara Whakapiri Toolkit Care in the Last Days of Life* (MOH, 2017b) have encouraged anticipatory prescribing as a means of guiding the care of dying patients across *all* settings in New Zealand, including the home setting (MoH, 2017b). These documents view anticipatory prescribing as integral to planning for end-of-life care needs, responding quickly to symptoms and optimising the care that is delivered. General practice was also represented in the working group for these documents (MoH, 2017a).

LIMITATIONS

Most of the studies included in the meta-synthesis were from the UK, with just one from Australia. The limited availability of New Zealand research on anticipatory prescribing reduces the potential for broader insights. Studies which did not have an English translation were also excluded. Perhaps the most significant issue and limitation emerging from the selected studies, however, was that there was minimal consideration for cultural needs and equitable health care. Although cultural components of the UK and Australia have differences to New Zealand, it would have been useful to have diversity and equity incorporated in the thematic findings of the study.

CONCLUSIONS

This meta-synthesis has revealed that the factors which influence anticipatory prescribing in community palliative and end-of-life care settings fall under the themes of *expertise, teamwork* and *prioritisation.* Authorised prescribers require expertise in *knowing when* and *how* to prescribe anticipatory medications. Possessing the expertise to initiate and guide serious conversations with patients and whānau/family also promotes the anticipatory prescribing approach.

It is readily apparent that a wider team is needed for an optimal anticipatory prescribing approach. An interdisciplinary approach can enable safer and more comprehensive palliative care to be provided, and is facilitated through a clear understanding of differing roles, open communication, relationship, trust and mutual respect. Finally, clinicians need to recognise the benefits of anticipatory prescribing given the unpredictable nature of end-of-life care, and take steps to prioritise it. If anticipatory prescribing is not prioritised, it potentiates patient and family crises, preventable access to and demand for acute services, and ultimately "bad deaths" for these patients and their whānau/families. Limiting the palliative prescribing approach to immediate indications rather than the likely and inevitable symptomatic needs will allow harm and inequities to continue. Anticipatory prescribing should therefore be enabled and embraced whenever possible and appropriate, to provide timely palliative and end-of-life care for patients and their whānau/families, supported by an interdisciplinary workforce.

RECOMMENDATIONS

- Education on anticipatory prescribing needs to be available to prescribers to equip them with the knowledge and skill to do this well, incorporating cultural safety and patient-centredness.
- Interdisciplinary training and education sessions are needed to foster teamwork in the provision of anticipatory prescribing.
- Experienced palliative care clinicians need to be retained to help upskill the existing workforce to be competent in improving timely palliative care in a patient-centred way.
- A nationally adopted tool is needed to improve consistency and equity in palliative care, either using the Supportive & Palliative Care Indicators Tool (SPICT) or the Gold Standard Framework (GSF), as determined through a consultation process.
- New Zealand research is urgently needed to understand the perspectives of patients and their whānau/family regarding anticipatory prescribing.
- Anticipatory prescribing could be added to the nurse prescribing scope in New Zealand, drawing on the experiences of nurses in the UK.

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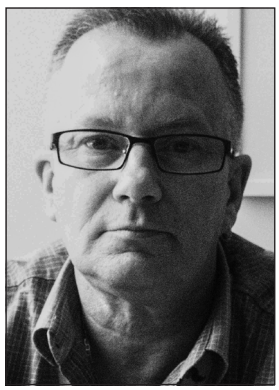

David Healee

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UTILITY OF THE WATERLOW SCALE IN ACUTE CARE SETTINGS: A LITERATURE REVIEW

ABSTRACT

Background: Pressure injuries are an indicator of quality of care, and are associated with decreasing quality of life for patients, and increased recovery time. The Waterlow scale is a recommended tool in many international guidelines for pressure injury prevention.

Aim: The aim of this literature review was to explore the effectiveness and validity of the Waterlow scale in acute care settings for the prevention of pressure injuries.

Method: Six electronic databases were searched: CINAHL EBSCOhost, Ovid Embase, Ovid Emcare, Ovid Medline, The Cochrane Library and Ovid Nursing Database. Eleven studies were identified for inclusion in the review. A thematic approach was used to synthesise the information.

Findings: Three key themes were identified: *"validity and reliability"*, *"clinical judgement"* and *"feasibility and cost implications"*. Ten out of the 11 studies indicated poor reliability and validity. Using this scale in conjunction with clinical judgement is highly recommended for best practice. Although the Waterlow scale was found to be easy to use, it may not be economical due to its tendency to overpredict the risk.

Conclusion: The Waterlow scale shows poor reliability and validity in assessing pressure injury risk in acute settings. It should only be used in conjunction with clinical judgement for initial screening. Educating and training nurses to use it effectively can increase its reliability over time. Despite its limitations, the Waterlow scale is the most widely used scale in clinical practice. Further research is recommended to test the scale in acute care settings.

KEY WORDS

Pressure injury, Waterlow scale, reliability, validity, effectiveness, clinical judgement.

INTRODUCTION

Pressure injuries (PIs) cause significant clinical problems in health-care facilities worldwide, and are responsible for considerable morbidity and mortality (Webster et al., 2010). Although preventable, they have always been present and are an important indicator of quality of care (O'Tuathail & Taqi, 2011; Serraes et al., 2018). Various studies conducted in the United States (US), Canada, and Europe reported the prevalence range of PI from 5 to 26 percent (McInnes et al., 2015). The annual cost of managing PIs is estimated to be UK£2.1 billion in the United Kingdom, A$1.8 billion in Australia, and about US$3.6 billion in the US. In New Zealand, the annual cost is estimated to be NZ$694 million (Rodgers et al., 2020).

In acute settings in an Australian study, the incidence of PI was found to range from 2.9 to 32.4 percent (Webster et al., 2010). Screening patients for risk factors is a long-standing and successful approach to preventing PI (Webster et al., 2010). In clinical areas, risk assessment scales (RASs) such as the Waterlow scale, Braden scale and Norton scale are widely used to measure PI risk and have been subjected to many studies to assess their validity (Anthony et al., 2010). Evidence suggests that RASs such as the Waterlow scale do identify patients at risk (Anthony et al., 2010). However, despite the ability to predict risk, there is not enough evidence showing the Waterlow scale's effectiveness in reducing PI incidence in acute settings (Anthony et al., 2010).

This article aimed to review the literature describing the effectiveness of the Waterlow scale in identifying patients at risk of PI in acute settings.

BACKGROUND

PIs are preventable but are still an ever-growing problem for the health-care sector worldwide. They are caused by *"localized damage to the skin and/or underlying tissue mainly over bony prominences due to constant pressure or shear or both"* (McInnes et al., 2015, p.3), and are known as *"pressure sores, pressure ulcers, bed*

sores, and decubitus ulcers" (McInnes et al., 2015, p.3). From 2016 onwards, the US National Pressure Injury Advisory Panel (NPIAP) staging system replaced the word *"ulcer"* with *"injury"* to reflect the characteristics and aetiology of pressure injuries (Edsberg et al., 2016).

Patients admitted to intensive care units (ICU) are at higher risk of PI, compared to other patients (Kottner & Dassen, 2010). Prevention is the best approach to addressing the problem of growing incidence of PI (Mahalingam et al., 2014). Prevention measures should focus on identifying risk factors and tailoring interventions (Serraes et al., 2018). Assessment is the key. Nurses have an important role in assessing and identifying patients at risk and implementing prevention measures (O'Tuathail & Taqi, 2011). NPIAP, the European Pressure Ulcer Advisory Panel (EPUAP) and the Pan Pacific Pressure Injury Alliance (PPPIA) recommend using a structured approach, tailored to changes in a patient status (Alderden et al., 2020). In clinical settings, risk assessment is performed using screening tools such as the Braden scale, Norton scale or Waterlow scale. However, NPIAP, EPUAP and PPPIA also recommend a risk-based prevention approach rather than solely relying on a screening tool (Alderden et al., 2020). Nevertheless, using tools in PI prevention is crucial due to their ability to screen patients to ensure appropriate care and that measures are taken to alleviate risk (Walsh & Dempsey, 2011).

There are 40 RASs currently in use, based on seminal work from the 1980s. Most of them have not been frequently validated by controlled trials, but are widely used in acute care settings (Kottner & Dassen, 2010; Moore & Patton, 2019; Webster et al., 2010). An ideal RAS should have both good validity and reliability, or inter-rater reliability, to determine if it is suitable to measure a particular variable (Wang et al., 2014). The Waterlow scale is most widely used in clinical practice (Moore & Patton, 2019). It was developed by Judy Waterlow in 1980s (for educational purposes) from a survey undertaken among elderly patients and in acute settings (Webster et al., 2010). In the Waterlow scale, patients can be grouped into three risk categories according to their score – at risk (10-14), high risk (15-19) and very high risk (>20) (Borghardt et al., 2015; Tannen et al., 2010). The higher the score, the higher is the risk of developing a pressure injury (Borghardt et al., 2015; Tannen et al., 2010). A revised Waterlow scale considered factors such as height and weight for body mass index (BMI), skin assessment, continence, mobility, nutrition, medication, tissue malnutrition, neurological deficits, major surgery or trauma, and demographic details (gender, sex, age) (Charalambous et al., 2018).

According to the New Zealand Health Quality and Safety Commission (2018), about four to eight percent of all hospitalised patients develop PIs, with 40 percent of these patients suffering a stage three or stage four PI. Despite continuous efforts to raise awareness and reduce PIs in New Zealand, it was noted that between 2009 and 2016, claims related to PI increased by 63 percent (Accident Compensation Corporation [ACC], 2017).

REVIEW AIM

This review aimed to explore the effectiveness and validity of the Waterlow scale for risk assessment of PIs for patients in acute settings. This may add to the knowledge about the utility of the Waterlow scale, which, in turn, may help to introduce preventive measures early and reduce costs by using available resources appropriately.

METHOD

A search was conducted using CINAHL EBSCOhost, Ovid Embase, Ovid Emcare, Ovid Medline, Cochrane Library and Ovid Nursing databases. Search words included *"pressure ulcers", "pressure sores", "pressure injury", "decubitus ulcers", "risk assessment", "Waterlow scale", "prevention"* and *"effectiveness".* Only peer-reviewed journals were searched, and no limitation was set for type of study. A total of 472 articles were found. From these, 462 remained after removing duplicates; 433 articles were then removed after applying criteria of a 2010-2020 date range and English language. Although limited articles were found related to the review question, date range was not broadened. Systematic reviews were included to increase the amount of information. After reviewing the title, key words and abstracts, 11 articles were included in the review.

A thematic analysis approach, developed by Braun and Clarke (2013), was used to analyse the data. This approach involved six key stages: familiarisation with the data, generating initial codes, searching for themes, reviewing for themes, defining and naming the themes, and producing the report.

FINDINGS

Three themes were generated from the analysis: *"validity and reliability"*, *"clinical judgement"*, and *"feasibility and cost implications"*. These themes, shown in Figure 1 (below), are interconnected.

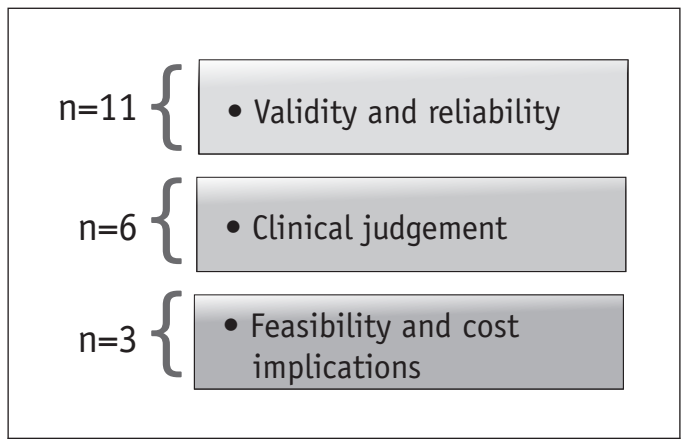

Figure 1. Key themes

Theme one: Validity and reliability

The first theme relates to looking at the validity and reliability of the Waterlow scale to analyse its effectiveness. Three observational studies (Kottner & Dassen, 2010; Tannen et al., 2010; Wang et al., 2014) evaluated the validity and reliability of the Waterlow scale by comparing it with other RAS scales such as the Braden scale, the Norton scale, the visual analogue scale and the care dependency scale. Kottner and Dassen (2010) compared the inter-rater reliability and construct validity of the Waterlow scale and the Braden scale in intensive care units (ICUs) (n=45) in Germany. They recruited 45 patients. The intra-class correlation coefficient (ICC) was used to determine inter-rater reliability. The Waterlow scale sum score, ICC=0.36 (95% CI 0.09-0.63), was lowest among the RASs (Kottner & Dassen, 2010). Variance of 41 percent to 74 percent was found,

suggesting lower inter-rater reliability and validity of the Waterlow scale, compared to the Braden scale (Kottner & Dassen, 2010).

Tannen et al. (2010) collected data through standardised questionnaires across multiple acute settings (n=1053) in Germany, comparing the predictive validity and inter-rater reliability of the Waterlow, Braden and care dependency scales. They showed the Waterlow scale scoring less than 70 percent for specificity and sensitivity, the lowest of the RASs, thus failing to achieve the minimum requirement. With a cut-off point of 8, it also showed poor validity. In contrast, Wang et al. (2014), in their observational study in China across multiple acute care settings (n=23), found inter-rater reliability of the Waterlow scale was substantial, but it still had low reliability for some items on the scale. Wang et al. (2014) recommended development of a new evidence-based RAS and advised caution in using Waterlow in clinical practice.

Two cohort studies (Borghardt et al., 2015; Kumari et al., 2015) compared the predictor validity, specificity and sensitivity of the Waterlow scale with the Braden and Norton scales. Borghardt et al. (2015) evaluated a cohort of patients (n=55) from two different ICUs in the same hospital in Brazil. The receiver operating characteristic curve (ROC) was used to determine the sensitivity and specificity of each scale to determine the predictor validity. The Waterlow scale demonstrated sensitivity of 71 percent and specificity of 47 percent, which was higher than the Braden scale (Borghardt et al., 2015). Most of the patients who developed PIs in their study were identified as "high risk" on the Waterlow scale.

However, the second prospective cohort study (Kumari et al., 2015), conducted in India among surgical patients (n=100), did not recommend the Waterlow scale be used in acute-care settings. The researchers assessed patients admitted within the previous 24 hours without pre-existing PIs with the Waterlow scale, the Braden scale and the Norton scale. On evaluation, the Waterlow scale scored the lowest cut-off point, compared to the Braden and Norton scales (Kumari et al., 2015). The ROC curve plot was used to assess the predictive validity of each scale. The Norton scale showed very high sensitivity of 95.6 and high specificity of 93.5, whereas, the Waterlow scale was the lowest, providing adequate sensitivity of 91.3 and specificity of 84.4 (Kumari et al., 2015). Similarly, a third prospective cohort study (Webster et al., 2010) screened patients (n=23) with the Waterlow scale across acute care in a tertiary hospital in Brisbane. They concluded that the Waterlow scale had poor predictive validity and was not recommended for use in acute care (Webster et al., 2010). They recommended evaluation of the Waterlow scale alongside other RASs and clinical judgement, by randomised controlled trial (RCT), for an accurate and generalisable result.

The above findings are supported by four systematic reviews (Charalambous et al., 2018; Chou et al., 2013; Moore & Patton, 2019; O'Tuathail & Taqi, 2011). These reviews focused on studies assessing the reliability and validity of the Waterlow scale in acute-care settings, mostly in ICUs. They concluded that the Waterlow scale was a weak predictor of PIs for patients in acute care. An RCT (Webster et al., 2011) was conducted in Australia with patients (n=1231) across multiple settings that compared the Waterlow scale (n=410), the Ramstadius scale (n=411) and clinical judgement (n=410) for effectiveness. The main purpose of this study was to assess the incidence of hospital-acquired PIs; however the trial found no evidence that suggested the Waterlow scale was superior in reliability or validity (Webster et al., 2011).

Theme two: Clinical judgement

The second theme relates clinical judgement and its relationship with the outcome of the screening. One observational study (Kottner & Dassen, 2010) and one cohort study (Webster et al., 2010) concluded that assessment skills of nurses were superior to any RAS used in acute care. Kottner and Dassen (2010) created artificial written scenarios to compare nurses' clinical judgement, based on a score from 1-10, with the Waterlow scale and another RAS. Nurses' clinical judgment better matched reference standards than did the standardised scales (Kottner & Dassen, 2010). In addition, Webster et al (2010) demonstrated that basic nursing assessments, such as regular skin checks and monitoring of nutrition and hydration levels, mobility status and friction and shear were the important markers of PI risk. Similarly, results from the Webster et al (2011) study, done in an acute setting, found no evidence that suggested the Waterlow scale was better than clinical judgement in assessing and preventing PIs. They carried out a RCT at a tertiary hospital in Australia among 1231 patients from medical and oncology wards. They recommended assessing for specific PI risks and skin inspections, rather than relying on RASs.

These findings are further substantiated by three systematic reviews (Chou et al., 2013; Moore & Patton, 2019; O'Tuathail & Taqi, 2011) which concluded that the Waterlow scale and other RASs were no better than non-standardised risk assessment based on nurses` clinical judgment.

Webster et al (2010) in their cohort study collected data from patients (n=247) through trained nurses. They found nurses were prepared to modify the final score of the Waterlow scale based on their assessment of what the patient needed. For example, they would judge whether a patient needed a special mattress or overlay on the basis of their mobility, level of activity, skin issues and nutritional status, rather than the Waterlow result. Webster et al (2011) found the poor predictability of the Waterlow scale was due to the inability of nurses to calculate body mass index (BMI) – this was an important component of the Waterlow scale, but was rarely calculated (Webster et al., 2010). Kottner and Dassen (2010), in their correlation study among critically ill patients, found a variation of 60 percent between RAS scores and risk estimates by nurses using their clinical judgement.

Theme three: Feasibility and cost implications

The third theme relates to the feasibility of using the scale in clinical settings. Two systematic reviews, O'Tuathail and Taqi (2011) and Moore and Patton (2019) discussed the cost implications of relying on the Waterlow scale, owing to its poor specificity and sensitivity. Their reviews highlighted the additional burden on health-care costs due to Waterlow over-predicting risk. This resulted in unwarranted allocation of resources and staff time being wasted.

Feasibility was an important factor influencing the use of standardised RASs in clinical settings (O'Tuathail & Taqi, 2011). Two systematic reviews (Charalambous et al., 2018; O'Tuathail & Taqi, 2011) found that the Waterlow scale was easy to use, compared to other RASs. O'Tuathail and Taqi (2011) also noted that the Waterlow scale was ambiguous and time-consuming, as it involved reading patients' charts to obtain scores for some components of the scale. Familiarity with RASs was another factor to consider when assessing ease of use, as some nurses might find a particular scale easier to use due to previous experience with it (O'Tuathail & Taqi, 2011).

DISCUSSION

The purpose of this review was to assess the utility of the Waterlow scale in reducing the incidence of PIs in acute care. This review found the Waterlow scale might not be a reliable screening tool for PI risk assessment in acute-care patients. The three main factors identified included: insufficient validity and reliability, the importance of nurses' clinical judgement, and feasibility and cost implications related to use of the Waterlow scale. Effectiveness of any RAS is assessed in terms of its validity and reliability (Satekova et al., 2017). Walsh and Dempsey (2011) stated that it was highly unlikely for a patient to be assessed by the same nurse each time and variability could also occur due to differing levels of knowledge among different nurses. Therefore, any RAS had to be reliable *"regardless of the assessor"* (Walsh & Dempsey, 2011, p. 201).

In this review, many studies identified the poor predictive validity and reliability of the Waterlow scale (Borghardt et al., 2015; Charalambous et al., 2018; Chou et al., 2013; Kottner & Dassen, 2010; Kumari et al., 2015; Moore & Patton, 2019; O'Tuathail & Taqi, 2011; Tannen et al., 2010; Wang et al., 2015; Webster et al., 2010). Lack of knowledge about the validity and reliability of any RAS has far-reaching implications for clinical practice and patient safety (Moore & Patton, 2019).

The recommendation to use the Waterlow scale in conjunction with nurses' clinical judgment arose often in the reviewed studies. Several studies concluded that nurses often use their clinical judgement when assessing PI risk (Chou et al., 2013; Kottner & Dassen, 2010; Moore & Patton, 2019; O'Tuathail & Taqi, 2011; Wang et al., 2014; Webster et al., 2010, 2011). Nurses' clinical judgment plays a key role in assessing and screening patients for PI risk (Webster et al., 2011). Using clinical judgement is defined as *"knowing why an intervention is needed and how to perform it competently"* (Standing, 2008, p. 125). Using Waterlow and other RASs in conjunction with clinical judgement can predict risk better and reduce the incidence of PIs (Webster et al., 2011).

According to Balzer et al. (2014), nurses consider various patient characteristics and regard some conditions as more important than others for PI risk assessment. Nurses make their assessment based on patient acuity and impairments, which are well-known aetiological factors. However there is a lack of consensus on which variables are more important risk factors, which can vary depending on the clinical settings (Moore & Patton, 2019). Borghardt et al. (2015) argued that the incidence of PIs in ICUs with critically ill patients was significantly higher than in other acute settings due to patient dynamics, leaving little value for the Waterlow scale. Wang et al. (2014) demonstrated, through sub-group analysis, that inter-rater reliability of some elements of the Waterlow scale was poor. For example, activity could not be assessed for orthopaedic and spinal injury patients, nutritional status and continence for neurology and neuro-surgery patients, and assessment of skin type in the cardiothoracic surgical unit (Wang et al., 2014). The complexity of the scoring system and manipulation of the score by nurses on the basis of their clinical judgement reflected its limitations (Webster et al., 2010). Thus, the PI risk status of a patient might be influenced by the clinical judgement of the nurse using this scale (Walsh & Dempsey, 2011). Hence, it is imperative to research nurses' perceptions, to identify which patient characteristics inform their clinical decisions for PI risk assessment.

Literature suggests that the Waterlow scale has a tendency to over-estimate risk (Webster et al., 2010). Consequently, PI prevention interventions are carried out for patients not at risk and conversely, others who need them are not receiving them (Moore & Patton, 2019). This causes pressure on health-care budgets and resources such as staff time and equipment (O'Tuathail & Taqi, 2011; Moore & Patton, 2019). For example, several patients may be given pressure-relieving equipment such as mattresses and cushions for longer than required, with the result that others miss out on these interventions.

Two studies suggested that the Waterlow scale was time-consuming, even though it was easier to use than other RASs (Charalambous et al., 2018; O'Tuathail & Taqi, 2011). Although considerable time and resources are wasted by nurses completing the Waterlow scale and other RASs, any scoring method cannot replace comprehensive nursing assessment, ongoing observation and patient-centred care plans (Borghardt et al., 2015; Moore & Patton, 2019; Webster et al., 2011). Borghardt et al.(2015) suggest using the Waterlow scale only to support documentation of elements favouring PI development. These authors also suggest trialling the scale with larger samples for better determination of its validity and predictability for a chosen population. Using a multi-disciplinary approach is recommended to identify and manage PI risk factors and provide quality care (Moore & Patton, 2019). Nursing assessment is one of the major roles of nurses and using assessment tools correctly is crucial (Bell, 2018). Nurses must be able to understand PI risk factors, know how to use assessment tools and use the right one for acutely ill patients, and implement interventions when risk is identified. Further research is needed comparing the usefulness of the Waterlow scale with other RASs and with clinical judgement in acute-care settings.

CONCLUSION

Prevention of PIs is an important health issue in the current health-care environment. Many PI prevention guidelines recommend using the Waterlow scale for risk screening and assessment in acute care. This review indicates that the Waterlow scale may not be useful as a diagnostic tool, due to insufficient validity and reliability. Instead, it can be used for initial assessment of PI risk, in conjunction with nurses' clinical judgement. Measures such as repositioning patients based on their mobility, use of nutritional supplements and reducing friction and shear from bed surfaces are of greater benefit than screening. The results of this review are consistent with the evidence from the literature. However, limited evidence is available to analyse the effectiveness of the Waterlow scale in acute-care settings.

It is important to rethink whether RASs such as the Waterlow scale are useful for improving patient outcomes. There is no clear evidence that using the Waterlow scale reduces PI incidence, or increases nurses' ability to use their education and training in clinical judgement. Further research is needed to assess this scale in multiple settings. Moreover, exploring nurses' perceptions about the usefulness of the Waterlow scale or other RASs may be an area of interest. There is also a need to continue to educate nurses on PI prevention and management, with a focus on strategies to identify risk factors. This, in turn, may strengthen nurses' clinical decision-making on PI risk assessment when using RASs such as the Waterlow scale.

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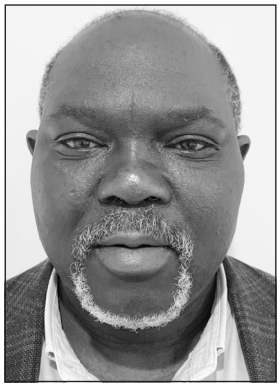
INFLUENCE OF A PULMONARY REHABILITATION EDUCATION PROGRAMME ON HEALTH OUTCOMES FOR CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)



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ABSTRACT

Aim: To explore whether the education component in a pulmonary rehabilitation programme (PRP) influences health outcomes for chronic obstructive pulmonary disease (COPD) patients.

Methodology: An integrative review of literature was employed in the study to allow for narrative integration of results from qualitative, quantitative and mixed-methods articles.

Findings: The research findings from 11 reviewed articles highlighted the following concepts: *"Knowledge of the disease", "knowledge as key to self-management*" (with sub-concepts *"management of symptoms"* and "*management of psychosocial symptoms"*) and "*the relationship between knowledge and education".*

Discussion: Insufficient evidence exists about the importance of education in PRPs. Therefore, health practitioners providing PRPs must consider, as standard practice, evaluating the educational component to highlight evidence of its significance.

Conclusion: The educational component of PRPs for people with COPD is not currently supported by sufficient evidence showing its influence on health outcomes. Robust research is required to investigate the influence of the educational component of PRPs in any setting and to test a suitable measurement tool on people with COPD in New Zealand. Further research is required to evaluate the teaching methods currently being used in any PRP settings where cultural diversity is prominent in New Zealand. This should investigate the relevance of the topics being covered in the current education component from the patient's perspective, and explore the involvement of cultural leaders/peer groups in the delivery of education.

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KEY WORDS

Pulmonary rehabilitation programme, education, COPD, knowledge, self-management.

INTRODUCTION

A pulmonary rehabilitation programme (PRP) is a comprehensive non-pharmaceutical intervention. It includes thorough patient assessment and individually-tailored therapies, such as exercise training, education and self-care interventions aimed at lifestyle changes to improve health (Nici et al., 2009; Paneroni et al., 2013; Zeng et al., 2018). These programmes are intended to improve the physical and psychological well-being of people with chronic obstructive pulmonary disease (COPD) and to promote long-term adherence to health-enhancing behaviours (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2019). International and national guidelines stipulate that exercises and education are the two core elements of PRP.

Exercise interventions have traditionally been the role of physiotherapists. However, in New Zealand, respiratory nurses can lead and support PRPs. Respiratory nurses work alongside the respiratory physiotherapist to provide a complete PRP package which includes providing education. Respiratory nurses are responsible for assessing, developing nursing plans and screening patients appropriate for PRP, as guided by GOLD (2019).

There are evidence-based recommendations for the exercise component, including the prescription of exercises; however there is

no unequivocal scientific evidence on the real learning benefit from a single educational approach in patients with COPD (Crisafulli et al., 2010; Wilson et al., 2007). Participants in previous studies expressed dissatisfaction with their knowledge about COPD (Casey et al., 2011; Sandelowsky et al., 2019), and the development of the educational component has been highlighted as a significant area for research (National Collaborating Centre for Chronic Conditions, 2004).

SIGNIFICANCE OF THE STUDY

COPD is a common, preventable disease characterised by persistent respiratory symptoms and airflow limitations due to airway and/or alveolar abnormalities, usually caused by significant exposure to noxious particles or gases (GOLD, 2019; Vestbo et al., 2013). It is a wide-spectrum disorder, which includes chronic bronchitis and emphysema. The consequences of COPD are usually noticed in people in their late 40s (GOLD, 2019). The number of people with COPD worldwide is expected to rise over the next 30 years due to continued exposure to COPD risk factors and the numbers of people of low socioeconomic status. It is the third leading cause of death worldwide and by 2030, the annual death toll is expected to be 4.5 million (GOLD, 2019; Vestbo et al., 2013).

COPD IN NEW ZEALAND

New Zealand has one of the highest rates of COPD cases in Organisation for Economic Co-operation and Development (OECD) countries (Milne & Beasley, 2015). Milne and Beasley's (2015) study showed that COPD was a major health problem in New Zealand, reflected in high numbers of hospital admissions. In the year 2012/13, there were 12,418 admissions with a principal diagnosis of COPD. The cost per admission was estimated at NZ$4799, costing district health boards (DHBs) a total of NZ$59.59 million in 2012/13 (Milne & Beasley, 2015).

In New Zealand, Māori were reported to have the highest rate of COPD mortality, with 190.7 deaths per 100,000 people per year, which is 2.24 (95% CI 2.04-2.41) times higher than the rate of 85.1 for non-Māori, Pacific and Asian people (Telfar Barnard & Zhang, 2016). COPD is the fourth leading cause of mortality in New Zealand (Milne & Beasley, 2015). The hospital admission rate for Māori is double that of non-Māori but the degree to which this represents a greater COPD incidence among Māori is not known (Milne & Beasley, 2015).

There is a direct relationship between the severity of COPD and the cost of care (Milne & Beasley, 2015). The huge cost spares neither the public health system nor individual patients and their families – eg the cost of hospitalisation and of ambulatory oxygen increase as COPD severity progresses.

Factors leading to high rates of hospital admission include lower socioeconomic status, exposure to smoking, and geographical location. Māori and Pacific people have a higher chance of exposure to the risk factors of COPD, leading to higher rates of hospital admission (Milne & Beasley, 2015). In part, this may be a result of delays in seeking medical help and the variation in care delivered in different settings, especially in rural areas, reflecting inequity in health services (Milne & Beasley, 2015). Telfar Barnard and Zhang (2016) state that COPD mortality rates are directly proportionate to socioeconomic deprivation, with deaths in the NZDep2006 quintile 9-10 (the most deprived) occurring at 2.37 times the rate in quintile 1-2 (the least deprived) (per Figure 65 in Telfar Barnard & Zhang, 2016).

SIGNIFICANCE OF PULMONARY REHABILITATION PROGRAMMES

Alison et al. (2017) stated that attendance at PRPs for people with COPD improved exercise tolerance and health-related quality of life, and reduced hospitalisation. The PRP has proved to be an effective intervention in improving shortness of breath for COPD patients (GOLD, 2018). Pulmonary rehabilitation ranks as one of the most cost-effective treatment strategies, with an estimated cost per quality-adjusted life years of NZ$2000-NZ$8000 (GOLD, 2018).

Blackstock et al. (2014) argued that the benefits directly attributed to the education component remain unclear. These authors further stated that pulmonary rehabilitation education has not been evaluated or clearly defined. There is currently insufficient validated research internationally to demonstrate the importance of the educational programme for COPD patients. There has not been a specific study which has evaluated the role of the educational component without including exercises (Blackstock et al., 2014). Therefore, it is unclear whether any benefits gained by COPD patients which enhance health behaviours, leading to better health-related quality of life, are a result of physical exercise or education (Blackstock et al., 2014).

Current practice models recommend evaluation of improvements in patients' health status and exercise capacity after pulmonary rehabilitation, but the assessment of the educational component is not routine practice (Jones et al., 2008). Jones et al. suggest that COPD knowledge questionnaires are too long and reflect the health-care professional's perspective rather than that of the patient. In addition, there have been no validated tools developed to assess the benefits gained from the educational component of PRP for people with COPD (O'Neill et al., 2012; White et al., 2006).

The purpose of this study is to explore whether the education component in PRPs influences health outcomes for patients with COPD.

METHODOLOGY

An integrative review of results from qualitative, quantitative and mixed-methods research (Whittemore & Knafl, 2005) was undertaken, specifically focused on education of people with COPD. Integrative reviews are broadly used to provide an auditable and robust synthesis of qualitative, quantitative and mixed-methods literature to construct new knowledge (Brady et al., 2019; Neville et al., 2016; Wright-St Clair et al., 2017). Quantitative, qualitative and mixed-methods perspectives are informative when seeking to answer empirical and theoretical research questions.

Philosophical perspective

This integrative review is underpinned by the philosophical dimensions of a post-positivistic approach in which it is argued that there is no best design in developing knowledge, and no reason to assume that qualitative and quantitative methods are incompatible. It allows for the application of diverse methodologies to develop knowledge of a phenomenon (Houghton, 2011). Houghton contended that claims about knowledge must be subjected to wide critical scrutiny to help to expose reality as closely as possible. Post-positivism acknowledges that the outcome of an investigation is an estimation of the truth, rather than truth itself (Grove & Gray, 2018).

METHODS

The specific techniques and procedures for literature search and data analysis were guided by Whittemore and Knafl's (2005) conceptual framework, which offers a rigorous process for the integrative review of relevant literature. The process follows these five stages:

(1) Problem identification, which ensures the research question and its purpose are clearly defined.

(2) Literature search, which incorporates a comprehensive search strategy.

(3) Data evaluation, which focuses on the authenticity, methodological quality, informational value and representativeness of available primary studies.

(4) Data analysis, which includes data reduction, display, comparison and conclusion.

(5) Presentation, which synthesises findings in a model that comprehensively portrays the integration process and describes the implications for practice, policy and research as well as the limitations of the review.

Hopia et al. (2016) appraised the integrative review process to consolidate the methodological approach in accordance with the five stages published by Whittemore and Knafl (2005).

For this study, a comprehensive approach to the search strategy was designed with the support of an experienced librarian, and used electronic academic databases. The databases included: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PubMed, Scopus and Google Scholar.

Keywords employed in the search strategy were: "COPD", "integrative review", "pulmonary rehabilitation programme", "education", "evaluation/assessment tools", "outcome measure*", "self-reporting questionnaire", "psychometric properties" and "measurement tools". Truncations (*) were employed to include spelling variations or similar terms.

Inclusion criteria

Inclusion criteria for the search included peer-reviewed articles using the keywords mentioned above. Only articles in English were reviewed and citation-index searching, which involved references used in published articles, was used. The citation index is highly recommended because it is based on the citing practices of authors, who commonly refer to studies similar to the original citation (Conn et al., 2003). Other high-quality articles on education for COPD patients were considered, including those on the development of structured education programmes for people with a confirmed diagnosis of COPD only. Peer-reviewed articles published in the years 2000 to 2020 were included. To ensure rigour, the peer-reviewed articles were screened by the second author and confirmed for inclusion.

Exclusion criteria

Excluded from this integrative literature review were studies on education for asthma or other chronic airways diseases. One study by Terwee et al. (2007), who outlined a measurement of the properties of a health status questionnaire, was excluded because it was not specifically on COPD.

An outline of the search results is displayed in the Preferred Reporting Item for Systematic reviews and Meta-Analysis (PRISMA) diagram, shown in Figure 1 (above, right). Through the reading and re-reading of the articles' abstracts and full text to ensure the evidence was relevant to the topic, the selected literature was reduced to n=11 articles to be synthesised in this integrative review.

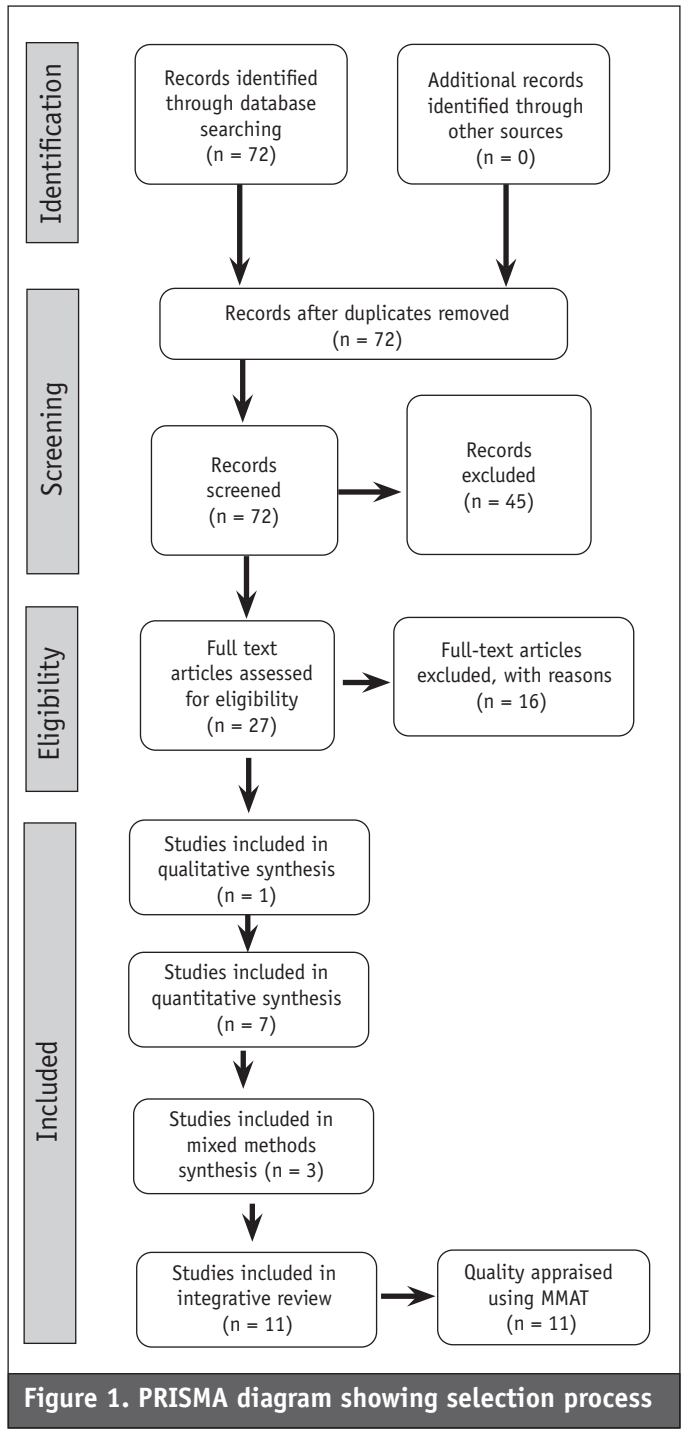

Figure 1. PRISMA diagram showing selection process

Quality evaluation

The quality appraisal tool Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was applied to assess the methodological quality of the studies included. After applying the MMAT screening questions (see Table 1, next two pages), the conclusion was that all 11 studies included in the review were methodologically reliable and met the quality appraisal criteria.

Table 1. Quality evaluation of selected articles using MMAT (Hong et al., 2018)

Quantitative articles	Are there clear quantitative research questions?	Do the collected data address the research questions?	Is the sampling strategy relevant to address the quantitative research question?	Is the sample representative of the population under study?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?	Is there clear mention of ethical approval process in the article?
Blackstock et al., 2014	✓	✓	✓	✓	✓	✓	✓
Crisafulli et al., 2010	✓	✓	✓	✓	✓	✓	✓
de Torres et al., 2002	✓	✓	✓	✓	✓	✓	✓
Jones et al., 2008	✓	✓	✓	✓	✓	✓	✓
O'Neill et al., 2012	✓	✓	✓	✓	✓	✓	✓
Sandelowsky et al., 2019	✓	✓	✓	✓	✓	✓	✓
White et al., 2006	✓	✓	✓	✓	✓	✓	✓
Qualitative articles	Are there clear qualitative research questions?	Do the collected data address the research question?	Are the sources of qualitative data relevant to address the research question (objective)?	Is the process for analysing qualitative data relevant to address the research question (objective)?	Is appropriate consideration given to how findings relate to the context, eg the setting in which the data were collected?	Is appropriate consideration given to how findings relate to researchers' influence, eg through their interactions with participants?	Is there clear mention of ethical approval process in the article?
Wilson et al., 2007	✓	✓	✓	✓	✓	✓	✓

Mixed methods articles	Are there clear research questions?	Do the collected data address the research question?	Is the mixed methods research design relevant to address the qualitative and quantitative research questions, or the qualitative and quantitative aspects of the mixed methods question?	Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?	Is appropriate consideration given to the limitations associated with this integration, eg the divergence of qualitative and quantitative data in a triangulation design?	Is appropriate consideration given to findings related to researchers' influence, eg through their interaction with participants?	Is there clear mention of ethical approval process in the article?
Casey et al., 2011	✓	✓	✓	✓	✓	✓	✓
Hyland et al., 2006	✓	✓	✓	✓	✓	✓	✓
Maples et al., 2010	✓	✓	✓	✓	✓	✓	✓

Ethics

All studies included in the integrative review noted ethical approval.

Data analysis

Eligible articles were read and re-read to work out the key patterns in the primary data. Through an iterative process, headings were conceptualised by re-grouping similar data under the headings, following Whittemore and Knafl's (2005) elements of data analysis. These elements are: noting patterns, seeing plausibility, clustering, contrasting and comparing data. The results from the 11 eligible studies were then integrated, synthesised and conceptualised to interpret the data.

The 11 eligible studies consisted of: seven quantitative studies with a total of 865 participants – this demonstrates a significant number of participants capable of providing robust results; only one qualitative study, which involved 32 participants; and three mixed-methods studies, which recruited a total of 943 participants. The data characteristics of the articles are summarised in Table 2 (following page).

RESULTS

Data characteristics

The studies reported in the 11 included articles were conducted in various countries. Six were from the United Kingdom, one from Italy, one from Sweden, one from Australia and two from the United States.

The 11 articles employed diverse methodologies, namely: quantitative (Blackstock et al., 2014; Crisafulli et al., 2010; de Torres et al., 2002; Jones et al., 2008; O'Neill et al., 2012; Sandelowsky et al., 2019; White et al., 2006); qualitative (Wilson et al., 2007); and mixed methods (Casey et al., 2011; Hyland et al., 2006; Maples et al., 2010).

All 11 articles included in the review were peer-reviewed and reliable. The ages of participants in the studies ranged from 49 to 86 years, which reflects the fact that symptoms of COPD manifest later in life (White et al., 2006). Both male and female genders were included in the 11 studies. The study sizes ranged from Wilson et al. (2007), with n=32, up to Hyland et al. (2006) which had the highest number of participants at n=590.

Data conceptualisation

The data from the studies was summarised and then organised into conceptual categories. Using an iterative approach, this data was eventually consolidated under headings and sub-headings to compare differences and similarities in the 11 articles. The following headings and sub-headings were developed as conceptual terms from the results: *Knowledge of the disease; knowledge as key to effective self-management* (with sub-headings for *management of symptoms* and *management of psychosocial symptoms*); and *relationship between knowledge ↔ education*. These three data conceptualisations covered all studies and incorporated the key findings.

Knowledge of the disease

A key conceptual finding in the reviewed data was COPD patients' knowledge of the disease, which promotes independent self-care (Casey et al., 2007; Maples et al., 2010; O'Neill et al., 2012; Sandelowsky et al., 2019; White et al., 2006; Wilson., 2007). For example, participants in one study reported *"knowing own norms and limits", "knowing when you are in trouble", "knowing what to do",* and *"but I do find when I get the niggling pain in my left lung and sputum changes colour, that I know I'm getting an infection"* (Casey et al., 2011, p. 184). These participants demonstrated pre-existing knowledge and skills for self-management. In contrast, Wilson et al. (2007) argued that there were consistencies in results demonstrating lack of knowledge across all participants in the domain of diagnosis and continued care.

Sandelowsky et al. (2019) suggested that people with moderate COPD who had chest infections reported a significantly higher need

Table 2. Integrated results

Authors	MMAT score %	Study aim	Study design	Participants' age gender & ethnicity	Outcome measure	Educational component results
Blackstock et al., 2014	50%	To compare improvement in COPD PR with and without a structured educational intervention.	Randomised control trial (quantitative).	n=267 people with COPD (mean age 72 years) allocated to exercise plus education or exercise training alone.	Education and exercise, or exercise training alone.	No significant differences between groups.
Casey et al., 2011	50%	To describe the development of a structured education PRP.	Mixed methods.	n=16 COPD patients (age range 44-76) and health-care professionals: GPs (n=9), nurses (n=7), physiotherapists (n=4), respiratory nurse specialists (n=3), dietitian (n=1) and the chair of the national COPD strategy group.	Development of a structured educational programme for PRP.	The SEPRP (Structured Education Pulmonary Rehabilitation Programme) was constructed.
Crisafulli et al., 2010	50%	To assess the learning impact of education session in COPD.	Quantitative.	n=285 COPD patients; completers of education session n=226, compared with control group n=59 (age 69 +/- 8 years).	Education session questionnaire.	This study showed that attending education session as part of PR yielded a specific short-term learning effect during rehabilitation of COPD patients.
de Torres et al., 2002	75%	To investigate the capacity of several of the most frequently used outcome measurements to detect change after PR.	Quantitative.	n=37 patients with severe COPD pre/post PR.	6 minutes walk test, Medical Research Council scale, baseline and transitional dyspnoea index, chronic respiratory disease questionnaire and St-George's respiratory questionnaire.	6 minutes walk test and chronic respiratory questionnaire may be the best practical tools to evaluate responsiveness of PR.
Hyland et al., 2006	75%	To construct information needs questionnaire.	Mixed methods.	Five audiotaped focus groups (n=29 COPD patients). 40 years old and confirmed diagnosis of COPD.	Disease knowledge, medicines, self-management, smoking, exercise and diet.	Lung information needs questionnaire (LINQ) developed.
Jones et al., 2008.	75%	To assess the ability of the LINQ to measure changing information needs pre/post PR.	Quantitative.	n=115 with mean age 69 years; range=45-87 years.	LINQ.	This study demonstrates that the LINQ is a practical tool for detecting areas where patients require education and is sensitive to change post-PR. All domains improved significantly except smoking.
Maples et al., 2010	75%	To develop COPD-Q (COPD Questionnaire).	Mixed methods.	n=22 experts in COPD and n=34 COPD patients.	COPD-Q validated measurement tool.	Readable, reliable low-literacy questionnaire.

Authors	MMAT score %	Study aim	Study design	Participants' age gender & ethnicity	Outcome measure	Educational component results
O'Neill et al., 2012	75%	To develop the Understanding COPD Questionnaire (UCOPDQ).	Quantitative.	n=7 key health-care professionals and n=118 COPD patients.	Psychometric properties: Face and content validity. Internal consistency.	UCOPDQ measures: self-efficacy, effects on understanding of and satisfaction with educational component of PR.
Sandelowsky et al., 2019	75%	To reduce an existing research gap by assessing self-reported needs for information about COPD.	Quantitative.	n=542 COPD patients recruited from 24 primary health care centres.	Lung Information Needs Questionnaire.	Demonstrated greatest need for information about self-management of COPD and diet.
White et al., 2006	75%	To assess psychometric properties of Bristol COPD Knowledge Questionnaire (BCKQ).	Quantitative.	n=53 participants with confirmed diagnosis of COPD, n= 24 health-care professionals.	BCKQ is a comprehensive measurement tool to assess the effectiveness of education and enable comparison of different teaching methods. The results on education can be correlated with other outcome measures following PRP.	Effectiveness of the BCKQ to detect change in knowledge.
Wilson et al., 2007.	50%	To ascertain from patient's perspective what should be included in educational component of PRP.	Qualitative.	n=32 patients with COPD plus n=8 health professional experts in COPD.	Educational content of PRP.	Highlighted greater understanding of patient's educational needs. Creation of format that is acceptable to patient (tailor-made programme).

for information than those with severe disease. However, people with severe disease were highly likely to demonstrate higher levels of knowledge because of several encounters with health-care professionals (Sandelowsky et al., 2019). In contrast, White et al. (2006) suggested *"age, socioeconomic status and disease severity did influence the degree of knowledge"* (p. 129) in people with COPD. They further suggested that a significant proportion of participants had inaccurate knowledge about COPD and that it might be difficult to accurately ascertain people's knowledge, even using verified tools, where factors other than knowledge shaped behavioural responses (White et al., 2006).

Knowledge as a key to effective self-management

Many of the studies highlighted the importance of knowledge and understanding if people with COPD were to effectively manage their own health and well-being. Understanding of one's body was important to adapting health behaviour to improve the quality of life (Casey et al., 2011; Hyland et al., 2006; White et al., 2006; Wilson et al., 2007). The application of knowledge about COPD by individuals and families can be regarded as effective self-management strategies. For instance, Casey et al. (2011) stated that participants acknowledged that the provision of information and knowledge related to COPD was important for enhancing self-management.

The results from the studies by Crisafulli et al. (2010), Hyland et al. (2006), Jones et al. (2008), O'Neill et al. (2012), Sandelowsky et al. (2019) and Wilson et al. (2007) showed that knowledge was the key to self-management. Wilson et al. (2007) had similar results, demonstrating that knowledge about pulmonary conditions could influence patients' behaviour in managing their symptoms. Crisafulli et al. (2010) stated that COPD patients' knowledge contributed substantially to reduced hospital admission rates, and that they retained knowledge over two years. For instance, education session total and partial scores significantly changed (p=0.001) for participants who completed pulmonary rehabilitation (Crisafulli et al., 2010).

Self-management is a key concept in the care of people with chronic conditions worldwide. Self-management is defined in the reviewed literature as the ability of people with chronic conditions to apply acquired knowledge and skills to independently self-care (Blackstock et al., 2014; Crisafulli et al., 2010; Jones et al., 2008). However, Sandelowsky et al. (2019) found that participants lacked

knowledge about diet and self-management, highlighting the need to provide education on COPD related to nutrition and self-care.

The following sub-sections separate findings on the management of symptoms from those on the management of psychosocial symptoms.

Management of symptoms: Some of the studies (Casey et al., 2011; Crisafulli et al., 2010; Sandelowsky et al., 2019; Wilson et al., 2007) demonstrated that early recognition of the signs and symptoms of an exacerbation of the disease, and being able to navigate support through health-care services, is significant for self-management. It is through exposure to the educational component of a PRP that people with COPD acquire the knowledge and skills to self-administer these therapeutic interventions without daily supervision by health-care professionals. For example, participants in Casey et al.'s (2015) study recognised changes in their bodies *"and straight away I act by ringing the team and going into hospital"* (p. 184). Crisafulli et al. (2010) stated that education led to a substantial reduction in hospitalisation rates over a period of two years. Despite self-management being key to managing chronic conditions, the concept often takes a narrow focus of recognising the signs and symptoms of an exacerbation of COPD. Other strategies also need to be included for holistic care (Jones et al., 2008; Sandelowsky et al., 2019).

Management of psychosocial symptoms: Knowledge as a key to self-management will be incomplete if other disabilities which manifest as a result of chronic illness are not considered. Some of the studies identified anxiety and depression as correlated with COPD; increased knowledge, however, could help reduce anxiety and depression after exposure to pulmonary rehabilitation (Jones et al., 2008). Sandelowsky et al. (2019) found similar results, showing that lower levels of education about COPD were a significant risk factor for anxiety and depression. Therefore, addressing self-management should incorporate input from a health psychologist.

Knowledge ↔ education

The last data category is "knowledge ↔ education". The symbol between the two words indicates there is a relationship between knowledge and education where each concept is distinct from the other while also related to the other. The relationship between education and knowledge is not static and assumptions that education improved knowledge were not substantiated.

Many clinicians believe that educating patients translates into the knowledge needed to make lifestyle changes and thus to improve health. However, the results demonstrate that knowledge and education may not be interpreted as the same thing (Maples et al., 2010; Sandelowsky et al., 2019; White et al., 2006). Maples et al. (2010) suggested that participants with or without prior knowledge of COPD scored similar post-intervention results (p>0.001). These studies demonstrated that even without exposure to an education intervention, people with a confirmed diagnosis of COPD had prior knowledge of the disease.

The data showed participants possessed knowledge even before any formal education through a PRP. Maples et al. (2010) suggested participants had prior knowledge about COPD on their first contact with health-care professionals in a PRP. Sandelowsky et al. (2019) showed that, in the domains of medication and smoking, participants demonstrated prior knowledge. However, while most participants had pre-existing knowledge on the effects of smoking, it was unclear whether participants had knowledge on smoking cessation. Knowledge can be acquired through lived experience or through an education programme related to a particular chronic condition (Sandelowsky et al., 2019). White et al. (2006), for example, showed that education related to COPD did lead to significant improvements in knowledge. Jones et al. (2008) demonstrated that education clearly improved knowledge in most domains except for smoking, on which participants had prior knowledge. Education related to COPD led to improved knowledge (White et al., 2006). However, Wilson et al. (2007) suggested that participants with COPD who engaged in pulmonary rehabilitation reported "dissatisfaction with COPD knowledge [and] were unclear about the aetiology of COPD" (p. 1706). This highlighted that improved knowledge is not the same as having adequate knowledge related to COPD. The comments quoted above referred to dissatisfaction following an education intervention in pulmonary rehabilitation, as opposed to being satisfied with their existing knowledge. It is unclear whether the results which captured this dissatisfaction with knowledge were incidental or reflected an inability by individuals to understand the educational content and the way it was delivered.

Findings from Hyland et al. (2006) showed participants were satisfied with the structure and process of the educational component of PRP, rather than their knowledge related to COPD. For example, 21 percent of the participants did not know the name of their disease, 3 percent reported non-compliance and 8 percent were confused about their inhalers. Despite participants attending an educational programme, they still had inaccurate knowledge about COPD. For instance, most respondents seemed to misunderstand the meaning of "chronic", thinking it meant "severe" rather than "longterm" (White et al., 2006).

Researchers have applied validated measurement tools to demonstrate the place of *exercise* in PRP. Therefore, the significant impact of exercise in improved health outcomes must be accepted. For instance, O'Neill et al. (2012) applied UCOPD to demonstrate the efficacy of the educational component in PRP. Education informs pulmonary rehabilitation in the sense of creating an awareness of the benefits of the programme. It is at this stage of contact in PRPs that a measurement tool can be employed to inform the educational component of pulmonary rehabilitation with the information needs of people with COPD.

Sandelowsky et al. (2019) stated that participants (68 percent) who had no contact with health-care professionals had a high perceived need for information, unlike those who had contact with health-care professionals. These results showed that health-care professionals provided some form of information about COPD in each encounter, but it cannot be extrapolated to say how that occurs or whether the increased knowledge is adequate for COPD patients to effectively self-manage their health signs and symptoms.

DISCUSSION

There is insufficient evidence of the contribution made by the educational component of PRPs in New Zealand, when compared to the exercise component. This could partly be a result of insufficient research on validated assessment tools to evaluate the impact of the educational component (Blackstock et al., 2014; Crisafulli et al., 2010; White et al., 2006). Therefore, the place of the educational component of PRPs remains unclear. By comparison, in other chronic conditions such as diabetes mellitus and heart failure, education is known as the cornerstone of interventions to influence lifestyle

changes for improved self-management (Peterson et al., 2011; Steinsbekk et al., 2012; Strömberg, 2005).

Knowledge of the disease

Health-care professionals have used the traditional didactic method of presenting information and advice to COPD patients, assuming that knowledge will enhance behavioural change (GOLD, 2018). Enhancing patients' knowledge is a major step towards behaviour change (GOLD, 2018). Whether this knowledge translates into changed behaviour depends on the individual patient, the mode of delivery and the content of the education package (GOLD, 2018). However, the susceptibility of certain behaviour to being transformed must be assessed, and the impact of different theory-based educational techniques must be included to bring about the anticipated change (Harris et al., 2008). Education helps COPD patients to understand their chronic pulmonary condition and may increase their ability to take action to seek medical help in a timely manner (Omachi et al., 2013). Although pulmonary rehabilitation improves physical function, most studies did not show that education alone improved health-related quality of life (Blackstock et al., 2014; Monninkhof et al., 2003). Monninkhof et al. (2003) suggested that early education intervention with newly diagnosed COPD participants showed benefits in the self-management of their symptoms. There is, however, little evidence to suggest that knowledge is retained over time.

Knowledge as a key to effective self-management

Casey et al. (2011) suggested that participants acknowledged that accessing information and knowledge related to COPD was significant for promoting self-management. Crisafulli et al. (2010) highlighted that education was a precursor which substantially lessened hospital admissions in participants with COPD over a period of two years. Jones et al. (2008) argued that although participants showed no improvement in self-management after taking part in a PRP educational session, this was in part due to individual participants' inability to acquire knowledge. Thus the health-care professionals needed to review the content and delivery of the educational intervention.

To provide holistic care to people with COPD, their physical and psychosocial symptoms need to be addressed. In the studies conducted by Jones et al. (2008) and Sandelowsky et al. (2019), the authors suggested a low level of COPD knowledge was associated with anxiety and depression. Anxiety and depression are common in people with COPD as the disease progresses (Gudmundsson et al., 2005). Although this was not the focus of the present study, these results showed that a lack of knowledge related to COPD predisposed respondents to scoring more in the domain of anxiety and depression. Jang et al. (2019) showed that the incidence of anxiety and depression was significantly reduced following short-term education, which encouraged awareness and advised on coping strategies.

Knowledge ↔ education

The conceptualisation of *knowledge ↔ education* reflects the fact that knowledge and education are evident in the data; however, they are correlated rather than equivalent. Past work experiences of health-care professionals suggested that any health education improved knowledge (White et al., 2006). This implies that participants with COPD had prior knowledge. However, education improved knowledge related to the disease. Jones et al. (2008) stated that education clearly improved knowledge, but not in the domain of smoking because participants had prior knowledge on smoking as a predisposing factor of COPD. Even if participants presented with pre-existing knowledge, this did not apply in all areas being measured. The uptake of information varied between individual patients and, as a result, some respondents scored high for non-medication related elements of self-management. Sandelowsky et al. (2019) also maintained that participants showed the least need for education in the areas of medication and smoking. This may suggest that health-care professionals provided more information on medication and smoking, compared to other aspects of self-management. White et al. (2006) further stated that, regardless of a participant's involvement in the educational part of a PRP, they still had inaccurate knowledge about COPD. For example, the word "chronic" was interpreted by respondents as referring to the severity of the disease instead of its long-term nature. This suggests health educators needed to revisit the structure of their education programme and the tools used to assess it.

Teaching methods

To optimise the effects of health education, the content must be appropriate for people with COPD (Hyland et al., 2006; White et al., 2006). Further, the method of transmitting the health education programme must suit COPD patients. The COPD-X Plan (Yang et al., 2018) suggested that interactive sessions were more effective than lecturing. It is through interactive discussions on various topics that real meaning and understanding is developed over time.

This type of education session encourages full participation and offers opportunity to engage in the lessons. This also helps participants remember the information, yielding benefits over the long term. Pictures and other visual aids can reinforce the lessons. There were some participants who felt uncomfortable about certain issues being discussed in a group setting, for instance living wills and end-of-life. The consensus was that such issues should be addressed in individually tailored discussions (White et al., 2006).

LIMITATIONS

The primary author is a respiratory clinical nurse specialist involved in providing a health education programme to people with COPD. This could have led to bias in the results, especially where the author may have anticipated certain results, leading to a tendency to influence them. To mitigate against this risk, the work was frequently checked by the second author.

Employing a range of studies, underpinned by diverse methodological perspectives, poses challenges in data analysis and integration of results. The heterogeneous interventions reported in the reviewed articles may have limited the results because of the lack of consistency. Also, the study population of the reviewed literature was not limited to one specific ethnicity, presenting a higher chance of this variation affecting the results. Finally, for the benefits of a health education programme to be significant, the follow-up time used in the published research studies needed to be at least one year post-programme. Unfortunately, in most of the studies discussed here, the follow-up was within six months (White et al., 2006). This led to a failure to demonstrate the long-term efficacy of the educational intervention in PRPs.

RECOMMENDATION FOR FUTURE RESEARCH AND CHANGE OF PRACTICE

Health professionals providing PRPs in any setting must consider evaluating the educational component to establish its significance in the programme. The evaluation of a programme will highlight areas of improvement and those requiring change. Knowing the attributes of the educational intervention in a PRP will help health professionals shape the structure of the intervention. As much as the exercise component in PRPs was highly appreciated in the reviewed literature, more emphasis should be focused on research to investigate the significance of education to complement the benefits of exercise. There is a need for mixed-methods research to help health-care professionals select validated measurement tools to evaluate the educational component.

Early education intervention after diagnosis of COPD has the potential to show the influence of the intervention in the management of symptoms. Therefore, education should be provided to people with COPD upon being diagnosed and during the progression of the disease.

The population of people with COPD in Aotearoa New Zealand includes higher proportions of Māori and Pacific people (Winnard et al., 2015). As noted earlier, Māori have the highest rate of COPD mortality, 190.7 deaths per 100,000 people per year, which is 2.24 (95% CI 2.04-2.41) times higher than the rate of 85.1 for non-Māori, Pacific and Asian (Telfar Barnard & Zhang, 2016). COPD is the fourth leading cause of mortality in New Zealand (Milne & Beasley, 2015). Therefore, the education component of PRP must be culturally safe to meet the needs of people with unique cultural backgrounds. It is also pivotal to translat learning materials into different languages. PRP in New Zealand must prioritise Māori and Pacific populations to provide equitable quality health services.

CONCLUSION

A PRP is a comprehensive non-pharmaceutical intervention which includes a thorough patient assessment and the use of exercises to enhance health outcomes. Most recent studies reviewed support the argument that a PRP is beneficial in improving quality of life on completion of the programme. The educational component of a PRP for people with COPD is not supported by sufficient evidence for it to claim its place in such a programme. Further research is needed to investigate the place of the educational component of PRPs in any setting and to test the measurement tools on people with COPD in New Zealand.

Further research is required to:

- measure whether education does influence health outcomes in COPD patients in New Zealand;
- evaluate the teaching methods currently being used in any PRP settings where cultural diversity is prominent in New Zealand;
- investigate the relevance of the topics being covered in the current education component from the patient's perspective; and
- explore involvement of cultural leaders/peer groups in the delivery of education.

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Research brief

COMPARING HEALTH OUTCOMES OF RURAL AND URBAN DIABETES PATIENTS: AN AUDIT OF A MĀORI HEALTH PROVIDER

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Key words

Diabetes, Māori, health care centre, rural, urban.

Aim

THE AIM of this study was to explore whether diabetes management is influenced by proximity to health-care providers for rural and urban patients with either type 1 or type 2 diabetes mellitus. There is no internationally recognised definition of a "rural" area; however traditionally, rural is defined as an area where people reside which is not included in the definition of urban (Stats NZ, 2020). For the purpose of this study, the definition of rural is where patients live outside a 5km radius from their health-care provider.

Introduction

The health-care centre providing the context for this study is a charitable trust Māori health provider. The centre has four general practitioners (GPs), registered nurses (RNs), community health workers and administration support staff. It administers several community district health board (DHB) contracts. This Māori health provider serves an enrolled population identified as being 91 percent high needs – high needs being defined as Māori, Pacific and/or of quintile 5 deprivation (Crampton et al., 2020). Of the enrolled population, 78 percent are Māori, 5 percent Pacific, and 17 percent are other ethnicities (Lane, 2016).

The health centre has a contract to support patients with type 1 and type 2 diabetes mellitus. The nurses' role in this service model allows for resource flexibility in organising care support under a kaupapa Māori framework (Kapuaahiwalani-Fitzsimmons, 2015). The role involves annual diabetes reviews, goal-setting with patients and whānau, home visits and working closely with other kaupapa agencies such as Te Arawa Whānau Ora and Tāne Takitu Ake programmes.

Background

The prevalence of diabetes in New Zealand is projected to increase by 70-90 percent over the next 20 years, with those from deprived areas affected the most (Diabetes New Zealand, 2021). For New Zealand Māori, the prevalence of diabetes is twice that of non-Māori (Ministry of Health, 2018). Also Māori often have more co-morbidities and long-term conditions than non-Māori (Ministry of Health, 2015). This trend is a recognised equity concern in the New Zealand health system (Sharples et al., 2018). While it may be argued that access to health care is less equitable for rural populations, rurality in itself does not necessarily lead to rural-urban disparities (Smith et al., 2008). As Smith et al. note, rurality may increase the effect of other disparities such as ethnicity, socio-economic factors, lack of transportation and distance from health services. As health professionals, it is always important to take stock of current practice and to regularly assess whether there are any barriers in the way health care is delivered.

Primary care has an important role in diabetes management and in addressing inequities in health care. Research suggests the use of primary care combined with community services is linked to a reduction in hospital admissions (Hiscock et al., 2008). A New Zealand study by Lawrenson et al (2010) showed the main source of education on diabetes is general practice. Access to quality health services and education is imperative to good health and wellbeing. However, for the population of New Zealand and in particularly for Māori, there are still barriers in accessing health services (Ministry of Health, 2019). This study will evaluate if proximity to health centres could be a barrier for patients.

The locational proximity or travel time to a health provider can influence health-service delivery and engagement of health users. Research has shown that distance from a health-care provider can influence patients' health outcomes (Blattner et al., 2020). Patients living in urban settings are more likely to experience cardiovascular disease, asthma, arthritis and cancer than rural patients (Sharples et al., 2018). While there is no difference between diabetes prevalence, rural males are less likely to access general practice services except for cases of accidents or poisoning (Sharples et al., 2018). It is thought rural patients may experience barriers to accessing a health centre due to their social deprivation, the travel time, transport, financial constraints or work commitments. These barriers can have an impact on healthy self-management.

Methods

A quantitative audit was undertaken in an urban Māori health-care provider. Clinical records of 372 patients with type 1 or type 2 diabetes (as defined in accordance with the New Zealand Group Guidelines [Ministry of Health, 2012]) were examined and data retrospectively collected from a 12-month period. Information collated included diabetes type, gender, age, year of diagnosis, visits to their primary Māori health provider and hospital visits, including referrals to other primary-care services. The patients' records were also checked for incidence of depression, gout, cardiovascular risk and chronic obstructive pulmonary disease (COPD), or other respiratory conditions. Bio-marker data such as medications, blood pressure and HbA1c levels was gathered. Geographical and general information collated included deprivation quintile, whether the patient was a community services card user and their proximity to the Māori health provider.

Data were analysed using Chi-square testing and likelihood ratios.

The average age of people whose clinical records were included in the study was 57 years, with 54 percent male and 46 percent female. Of this group, 74 percent lived in urban areas and 26 percent lived rurally. The majority, or 69.6 percent, lived in quintile 5 (Crampton et al., 2020). Proximity to the health-care provider was divided into two categories – those who lived 0 to 4.9km from the provider (urban) and those who lived further than 5km away (rural). Data were then analysed for a difference between the two groups in terms of diabetes management (using the above bio-markers), clinical interventions and degree of social deprivation. Because this study was an audit of clinical records, ethical approval was not required. All patient information was anonymised to protect patient privacy.

Results

The results showed approximately a quarter of the patients with diabetes registered with the service lived in rural areas, with the rest living in urban areas. The HbA1c bio-marker of 64mmol/L or less is used to indicate suitable management of diabetes (Ministry of Health, 2012). There was only a marginal difference in HbA1c levels between the rural and urban patients. Interestingly, those patients with an HbA1c of greater than 100mmol/L lived less than 5km from the health provider, ie were urban patients. This suggests that, for those living close to this health centre, proximity does not greatly influence their management of uncontrolled HbA1c levels.

There was no statistical difference between cohorts for those prescribed insulin, statins and angiotensin-converting-enzyme inhibitors, which would indicate prescribed medications are used equally between the cohorts. Looking at visits to allied health professionals by the rural and urban groups, 1 percent more of the urban patients had had their retinal screen appointments, but more patients from the rural cohort visited the podiatrist. It could therefore be argued that those living rurally were no less deprived than the urban population. However other health indicators showed that twice as many patients were diagnosed with depression in the rural sector than the urban sector.

Discussion

People with diabetes experience poorer health outcomes and have higher unmet health needs (Ministry of Health, 2019). Māori, Pacific and Asian ethnic groups are at even higher risk. Resources to manage and treat diabetes are a substantial cost to the New Zealand health system. Some studies have found differences in health outcomes between urban and rural populations. For example, Obertova et al. (2016) identified that men from rural areas in Midland region health-care practices were less likely to be screened with a prostate specific antigen (PSA) test, and more likely to present with an elevated PSA result. Therefore, when working with rural patients, it is important health professionals assess what is working well and what areas need improving.

While this study shows patients living rurally were able to access the health provider and allied community health services, they were more likely to have a diagnosis of depression than those patients living in urban areas. This result contradicts the findings of other studies regarding outcomes for those living in rural areas. (For example, Mavoa et al [2019] found evidence of a possible link between natural environments and the emotional health of adolescents.) Further research into how rural patients cope with depression could prove valuable for health professionals.

Deprivation was greatest for those patients living closer to the Māori health provider, yet there was little difference between the rural and urban cohorts in overall diabetes management. It could be argued that the closer cohort, living within a reasonable distance to their general practitioner services, should have better health outcomes than their rural equivalents due to better access (Reid, et al., 2016). It could also be argued that distance may not be as relevant to better health outcomes and therefore other factors that improved health outcomes may need to be investigated. This study shows some positive outcomes in biomarkers between both cohorts, suggesting that distance from patient to health-care provider is not in itself an indication of potential disparity, but distance may exacerbate the impact of other disparities (Smith et al., 2008).

Recommendations

This study showed there was minimal difference in health outcomes between rural and urban diabetes patients, but did highlight areas for further research and recommendations. These should include:

- A follow-up study to examine why there is little difference between the urban and rural cohorts.
- Further research into levels of healthy literacy in the two cohorts in relation to health outcomes.
- An exploration of possible improvements to the current diabetes health-care delivery models in primary care.

Conclusions

Primary health care services are obliged to assess the effectiveness of their service delivery. This study indicates access to a health-care centre, in terms of distance, is not necessarily a barrier to diabetes management and good health outcomes. Perhaps a greater barrier to health outcomes is social deprivation and health literacy. The findings of this study identify possible areas for further exploration – firstly, assessing the patients' health literacy pertaining to diabetes management and secondly, researching how distance may exacerbate other disparities such as ethnicity, socio-economic factors, and access to transportation. Exploring these recommendations may help health professionals improve service delivery and ensure that the patient is at the centre of care.

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Conflicts of interest

The author declares no conflict of interest in this research.

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Research brief

RAPID ANTIGEN DETECTION TESTING FOR DIAGNOSIS OF GROUP A STREPTOCOCCUS (GAS) IN CHILDREN

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Keywords

Group A streptococcus (GAS), pharyngitis, rapid antigen detection testing (RADT), rheumatic fever.

Aim

THE AIM of this study was to evaluate the use of rapid antigen detection tests to provide timely service for diagnosis and treatment of group A streptococcus (GAS) positive results for children experiencing pharyngitis symptoms. Using rapid antigen detection testing for GAS, as part of diagnostic screening, may be an effective intervention to reduce rheumatic fever hospital admission rates in Aotearoa New Zealand.

Background

Rheumatic fever is an autoimmune disease evolving from a GAS pharyngitis infection (Sika-Paotonu et al., 2017). It is a serious, potentially life-threatening illness and is preventable with early detection and intervention. The most severe complication of rheumatic fever is rheumatic heart disease, which can cause inflammation and scarring of the heart valves (Sika-Paotonu et al., 2017). The Ministry of Health is concerned about rates of rheumatic fever among Māori and Pacific children, which result from the complications of untreated or undiagnosed GAS pharyngitis (Ministry of Health, 2019).

Current practice test for GAS testing involves taking throat swabs from students with sore throats, which are sent to the nearest laboratory for culture. The advantage of sending a throat culture to the laboratory is the ability to detect GAS from small amounts of bacteria on the swab. A limitation of this approach is the waiting time for results, which can take three to five days (Cohen et al., 2013). The waiting time for throat-swab results puts the student and close contacts at risk of spreading GAS pharyngitis infection. In most cases, by the time the results have been received, it is inevitable the infection has spread to close contacts and household family members. School principals are also concerned about the spread within classrooms to classmates and teachers. To reduce transmission, some schools in South Auckland have adopted a policy (guided by the Ministry of Health [2018] recommendations) that students are excluded from school until well and have received antibiotic treatment (from their general practitioner or Mana Kidz Nurse) for at least 24 hours before returning to school.

Bringing in an alternative diagnostic tool such as a rapid antigen detection test (RADT) could improve service delivery and the treatment regime. RADT detects the presence of strep A antigen on a throat-swab specimen and provides GAS results within five to 25 minutes (Ngaio Diagnostics, 2019). Ngaio Diagnostics (2019) argues the RADT has high sensitivity (correctly detecting 95.1 percent of patients with infection) and specificity (correctly detecting 97.8 percent of patients who do not have an infection), and that it has overall accuracy of 97.1 percent. The use of point-of-care testing allows for the best treatment decisions to be made at the time of the consultation, thus saving time, reducing referrals and increasing the efficiency of patient care (American Academy of Paediatrics, 2012; WHO, 2017).

Methods

For this study, meta-ethnography was the approach used to synthesise the findings of published research on this subject. Meta-ethnography uses an interpretive approach to research synthesis, combining and translating the findings of primary studies in ways that preserve the context and concepts in the original studies, but at the same time offers new interpretations of them (Lockwood & Hannes, 2011).

Primary qualitative research articles were searched using key search terms “RADT”, “GAS pharyngitis”, “throat culture”, “streptococcal infection”, “diagnostics and antibiotic prescription”, “rheumatic fever”, and “children”. Search phrases included “point-of-care tests”, “pharyngotonsillitis”, “acute sore throat”, “strep throat”, “pharyngitis”, “streptococcus pyogenes”, “respiratory tract infection”, “rheumatic heart disease”, “acute rheumatic fever microbiology test”, “bacteriology”, “paediatrics” and “child/teens”. Infants (birth to 23 months) and adults (19-plus years) were excluded to target the age range where rheumatic fever is predominant. The articles sourced for the synthesis were published in the Scopus, Medline (OVID), PubMed, Science Direct, Cochrane, Gale, CINAHL, Google Scholar, BMJ, Clinical Key and DOAJ databases.

Using the CASP critical appraisal tool for qualitative studies, the articles selected were evaluated to determine eligibility for inclusion. Twenty-nine studies met the inclusion criteria. The lead researcher then read and evaluated each article to follow France et al’s (2019) process of finding themes in the research studies, translating them into concepts then amalgamating these to reach new interpretations of the material.

Findings

This review found there were advantages to using RADT for GAS infection – these included reducing the spread of GAS infection and reducing rheumatic fever admission rates. The synthesis of the studies identified three key elements: *closure of time gaps*; *antibiotic stewardship*; and *quality assurance*.

Closure of time gaps

RADT reduces time gaps in GAS testing and treatment. The optimised time period to treat a GAS infection safely with antibiotics is nine days before the possible onset of rheumatic fever (Clerc & Greub, 2010). Studies from the United States (US) (Gieseker et al., 2003), Turkey (Küçük et al., 2014), Poland (Stefaniuk et al., 2017), and New Zealand (Upton et al., 2015) found that using RADT reduces the incidence of rheumatic fever through rapid turnaround in detecting GAS-positive pharyngitis. Transmission rate is thus reduced in school classrooms, homes and community settings (Ehrlich et al., 2002). RADT proved a suitable alternative for young, uncomplicated clients who had difficulty accessing their GP at the time of symptom onset (Papastergiou et al., 2018).

RADT testing is more cost-effective than throat swabbing, with fewer processing steps, which reduces service costs (Edmonson & Farwell, 2005; Ehrlich et al., 2002). Internationally, physicians acknowledged that using RADT reduced the waiting time for diagnosis and treatment as results were gained in one consultation (Gieseker et al., 2003; Orda et al., 2016). However, a small minority of practitioners said consultation times were lengthy, because they had to carry out a diagnostic test, physical assessment and treatment all in one consultation (Bourbeau, 2003). Bulk throat swabbing for RADT was not an option as each test needed to be acted on before the child left the clinic (Bourbeau, 2003). Practitioners noted the test was reasonably simple to use and, with practice, they would become more proficient in its use, which would reduce consultation time (Bourbeau, 2003).

Antibiotics stewardship: The need to accurately prescribe antibiotics is essential to antibiotic stewardship (Al-Najjar & Uduman, 2007), and RADT helps general practitioners accurately prescribe antibiotics (Alp et al., 2018; Bulut et al., 2020; Ehrlich et al., 2002). Misuse of antibiotics can contribute to bacterial resistance, therapeutic failure and adverse effects, such as drug toxicity and drug interaction (Llor et al., 2014). Having visual results from the RADT also helped reinforce to practitioners when antibiotic treatment was not required, and helped them reassure clients of this more quickly, than if they were relying on clinical signs and symptoms alone (Al-Najjar & Uduman, 2007). However, some prescribers were reluctant to use the RADT as a differential diagnostic tool, and gave antibiotics based on their own clinical assessment (Leydon et al., 2013), or their judgement that all bacterial infections should be treated with antibiotics (Gröndal et al., 2015; Hedin et al., 2014).

The stopping and starting of antibiotic treatment can create a culture of overuse and misuse (Llor et al., 2014). RADT can prevent this by confirming a result at the time of the initial consultation.

Quality assurance: Quality assurance measures include the implementation of appropriate clinical policies and procedures to ensure RADT tests are used for the right person at the right time and in the right context (Luo et al., 2019). Quality assurance is essential to ensure RADT is used as recommended. Barakat et al (2019) observed that children who have been treated for recent GAS pharyngitis might give a false positive RADT that is rarely seen in children not recently treated. The false positive RADT may be caused by the presence of non-degraded antigenic proteins that stay even in the absence of viable GAS in the pharynx (Barakat et al., 2019). This study found children five years and under had significantly higher false positives than older children. It concluded that RADT testing should be reserved for children who had not been treated for a GAS infection in the previous 28 days (Barakat et al., 2019).

Gieseker et al (2003) said that RADT GAS-negative results in children should be backed up with laboratory throat culture to ensure an accurate result. The American Society of Infectious Diseases (American Academy of Paediatrics, 2012) recommends all RADT GAS-negative results in children should be followed up with laboratory testing.

The need for space to perform RADT testing is critical to its introduction and success in practice (Gazzano et al. 2016). The development of RADT training workshops for practitioners is beneficial, as the person performing the test is a crucial to its success and accuracy (Gazzano et al. 2016). According to Gazzano et al, practitioners agreed that training was essential to ensure competency. RADT training should align with the manufacturer's diagnostic guidelines (Bourbeau, 2003).

Conclusion

This synthesis of research studies found that RADT testing improved outcomes for children with illness associated with GAS infection. It also decreased the severity of illness by allowing early intervention with antibiotics. The introduction of RADT testing may help reduce some of the barriers that exist in the current throat-swabbing practice, and in turn may reduce overall rheumatic fever rates. These findings suggest rheumatic fever programmes need to be realigned to support RADT pilots, as part of public health sector modernisation and change. RADT testing in primary health care settings, especially in areas of high deprivation, would best support the Ministry of Health strategy of reducing rheumatic fever.

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NURSING IS – AND HAS – A METHODOLOGY: A NURSING VOICE

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Abstract

Access to nursing is at the core of health care in civilised societies. This paper is about naming, framing and claiming nursing's contemporary significance for health and people's lives through research. I argue that a nursing paradigm, with its historial ethos of caring and humanness, identifies and differentiates nursing's perspective on health, reframing the paradigm of practical expertise. Drawing on my experience in research, I establish my rationale for nursing as a paradigm that frames "research as-if practice", as participatory. Through research, each nurse, as practitioner/researcher, evolves and presents findings as practice wisdom: the coherence of the knowing and the doing aspects of nursing. The significance of nursing is explained as being its knowledgeable practitioners – their methodology is not deterministic, and involves "what can be" for all participating. The nursing voice comes from the collective. The need for kōrero, and for a succinct phrase indicating the distinctly nursing perspective of health in Aotearoa/New Zealand as a reference point are emphasised.

Key words

Nursing knowledge, methodology, perspective of health, nursing voice, technology, practical expertise, practice wisdom.

Introduction

I was challenged to write this paper to bring some coherence to my career-long efforts to say what it is about nursing that is essential to the health, health care and lives of people here in Aotearoa/New Zealand. Early in my career, I worried about what I should know as a nurse tutor. Through my academic studies to find out, I became convinced that nursing is a discipline in its own right, but I couldn't explain it. So, many years ago, I drew a diagram (Figure 1, opposite page) that would serve to focus conversations with nurses. I have continued to elaborate (and question) my thinking and language with reference to the diagram. I present it here with my explanation – to date – to bring the focus to research and methodology.

What we as nurses know, from experience, about the significance of nursing cannot be explained as just an adjunct of another discipline. There is a vast literature published around the world by nurses as scholars and researchers that has offered a myriad viewpoints of this since Florence Nightingale. My diagram and explanation echo many; it is part of the global and evolving dialogue that has sustained nursing through its history. In one of her editorials, Sally Thorne (2018), Canadian editor of the journal *Nursing Inquiry*, cited a number of authors using a similar metaphor to mine to distinguish nursing's *"unique and distinctive"* perspective. Wrestling with many of the same concerns, she wrote: *"This 'angle of vision' depicts a particular stance toward the universe of interest, shaped by certain ways of knowing and perceiving".*

This is a diversion from the current emphasis on analyses of workforce. I present a view of research as concerned with "what can be" when the significance of nursing as "practice wisdom" is acknowledged. It is a step back from the current "what is" concerns with nurse roles and positions: nurses being "fit-for-purpose" in the health services that employ them. I see nurses as knowledgeable practitioners whose significance for health and people's lives is recognised directly in the design and delivery of health-care systems – not defined by those systems. Practice, in its methodology, is at the core of nursing's paradigm where, through research, we bring coherence to the knowing and the doing aspects of nursing.

With reference to the diagram (Figure 1), I address each of the components before eventually reaching the topic of research and methodology. I have to first establish my rationale for nursing as a distinct practice discipline, significant because of its "unique and distinctive" perspective on health: what knowledgeable nurses pay attention to, what they do about it, and what is achieved by it. A definitive methodology for nurses in the conventional sense should not be expected.

I refer to nurses as those who have been credentialed with the legally protected title of nurse when entered on that register (RNs). They might be practising directly with patients/consumers, educators or managers. The profession refers to the bodies representing RNs and those in allied nurse roles. The perspective that gives nursing its contemporary social purpose is a professional matter.

The 'health' focus

"Health is everybody's business".

Bee Salmon, NZ nursing academic pioneer, speaking to Auckland nurses in 1971 (Salmon, 1983).

"Nurses, individually and collectively, are responsible for representing ourselves as expert capable members of a profession that is the core of NZ's health system".

Patricia McClunie-Trust, nursing educator, scholar and research leader; editor of *Kai Tiaki Nursing Research* (McClunie-Trust, 2021)

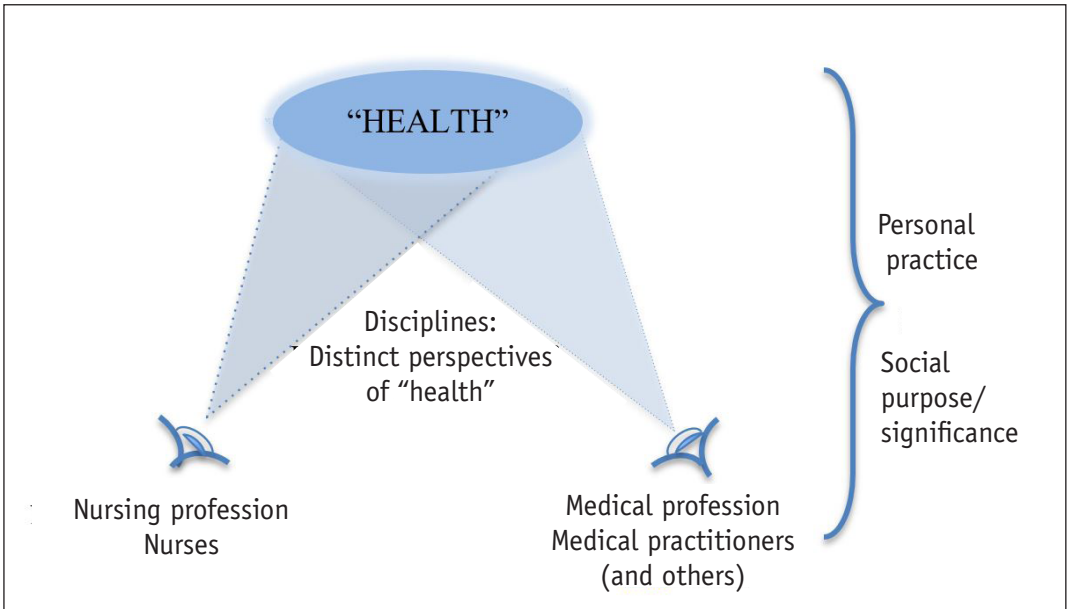

Figure 1. Perspective of 'health', differentiated and complementary in the social purpose of the respective practitioners

The starting point is "health". This is our overall sphere of interest. In my diagram, "health" is in inverted commas to convey that although it is a word familiar in the conversations of our everyday lives, it is packed with a complexity of meanings that have evolved through time; it has been explored, defined and debated in the literature. It is accepted globally as a vital facet of life and living at the centre of government in civilised societies. The World Health Organization (WHO) has repeatedly led international collaboration to redefine it for relevance in contemporary contexts, to urge the international sharing of information and experience and inspire whatever action each nation state decides will improve the quality of life of its citizens. As such, "health" is a **reference point** for international dialogue that we must participate in – from our own national and nursing standpoints.

In Aotearoa/New Zealand, we know that cultural perspectives vary the meaning of "health" – this is vital to how we live in our world and experience our nationhood. We know the conventions of health care shaped by the historically-dominant western perspective have not benefited citizens equitably. But also we are part of the growing public consciousness that the meaning of "health" that drives health care should include other perspectives. Recognising Te Tiriti o Waitangi as the foundation of our nationhood, metaphors for "health" and te reo Māori have shaped how our nation addresses it: Mason Durie's Te Whare Tapa Whā and Te Pae Māhutonga (Ministry of Health, 2017a), and Rose Pere's Te Wheke (Ministry of Health, 2017b). Irihapeti Ramsden (1990) introduced "kawa whakaruruhau" (cultural safety) to embed culture and equity as fundamental to "health". And, of course, every one of us has our own meaning for "health", elaborated through living and chatting together, being exposed to the media and experiencing health care.

Nurses bringing their own perspective to "health" and research must take into account these current renderings and debates around them – but not be confined by them. The relevance of the perspective is personal for practitioners/researchers, and is also framed by the collectives that assert the professional social purpose of their discipline.

Complementary perspectives of 'health'

"Experience teaches me that nursing and medicine must never be mixed up. It spoils both."

A letter from Florence Nightingale to a medical academic friend, 1869 (Baly, 1997, p.77)

In the diagram, I use eyes to represent the sources of two perspectives giving "health" its meaning, according to separate disciplines. Particularly important for understanding the diagram and the following discussion is that the discipline perspectives are discrete: the perspectives do not merge (a two-dimensional diagram can't show this). When recognised as distinctly different, disciplines can then be considered complementary in addressing "health" matters. This provides for a more inclusive kōrero and a richer conceptualisation as foundation for health-service systems.

Medicine is the discipline for comparison with nursing. When we talk about health care being inter- and multi-disciplinary, we must assume that nursing *is* a discipline – essential alongside medicine, and with its own identifying social purpose. But as noted above, the predominant perspective of "health" has determined the conventions of health care. The discourse expresses the highly-respected social purpose of medicine: the amazing potential of discoveries in medical science and technology. Medical research produces the form of knowledge considered the core of health care; its assumptions of "health" deeply convincing as the hegemony of contemporary service systems, its conventions resilient and self-reinforcing. The methodology is science, empirical – objectifying, to be prescriptive. This is the loudest voice of health-care. Importantly, the methodology developing the discipline of medicine is philosophically consistent with the methodology of its practitioners.

To differentiate perspectives of "health", we look for relevant language for the distinct social purpose of each. For the medical perspective, I have taken the definition of medicine from the succinct and widely accessible English dictionary on my computer (www.

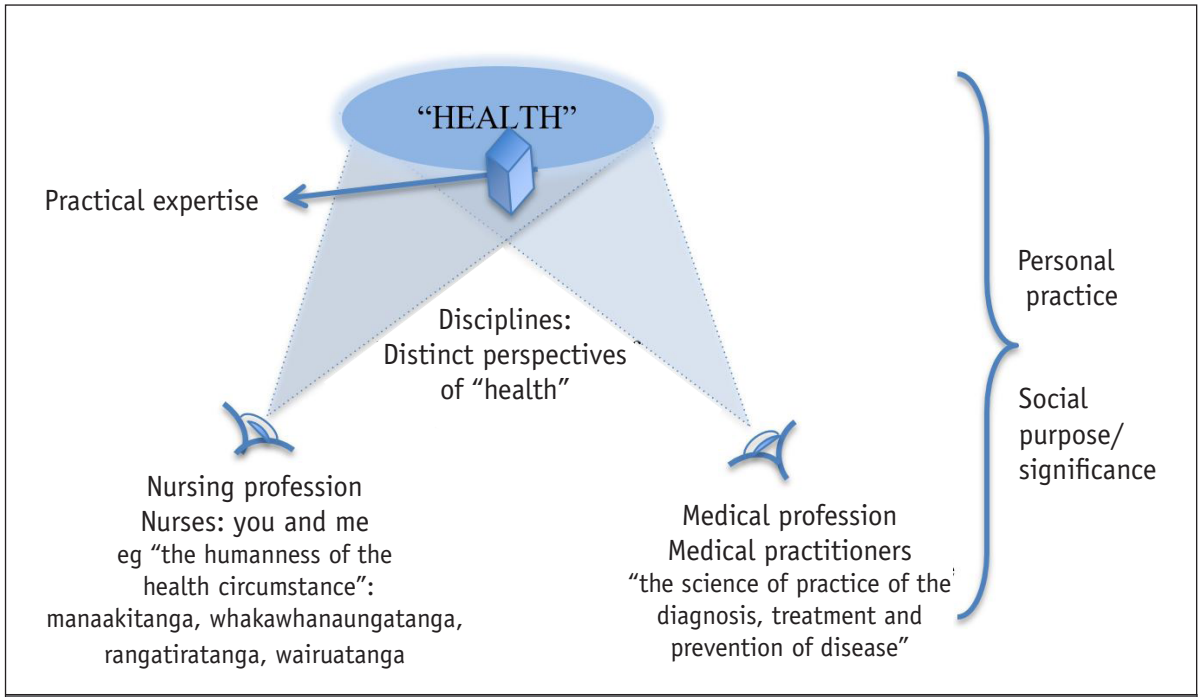

Figure 2. The nursing perspective of 'health' determines the use of practical expertise

lexico.com: Powered by Oxford. Retrieved 25.10.21): *"The science or practice of the diagnosis, treatment, and prevention of disease".* I extrapolate from this: the practitioners of medicine give "health" its everyday meaning in terms of the cure and control of disease, assuming its scientific methodology.

For nurses, it has been difficult to similarly convey "a professional practice", to find the language for its social purpose in terms of direct significance for health and people's lives. It is not medicine and is not just what anyone can "do". To people without the qualification and experience of a nurse, nursing is commonly referred to in terms of support for the predominant "health" purpose, that is nurses as part of the generic "medical workforce". This is emphasised by Canadian journalists Buresh and Gordon (2013), who urged nurses to broadcast what they do. But given the hegemony of our health system, the workforce is constructed (or minimised) around quality and economic decisions, according to the medically-oriented social purpose of the system.

In this light, we need to consider the "doing" work defining the workforce, before looking at what "health" benefit comes from the nursing perspective.

Practical expertise

> *"We are on the brink of a period of fundamental and irreversible change in the way that the expertise of . . . specialists is made available in society. Technology will be the main driver of this change. And, in the long run, we will neither need nor want professionals to work in the way that they did in the twentieth century and before."*
>
> Susskind & Susskind, academics of Oxford University, 2017, p.1

Irrespective of perspective of "health", there are many activities now not exclusive to any one workforce group or profession. I have inserted a three-dimensional box into my diagram (Figure 2, above) to symbolise the collection of all the actions and skills used in the provision of health care. They include procedural tools and instruments (including assessment formats), checklists, decision-supports, flow-charts, guidelines, protocols, algorithms. They are the substance of evidence-based competencies, developed, modified and improved through research. Around them, training and quality control programmes have been constructed, inter- and multi-disciplinary.

I have taken the term "practical expertise" from the book by the Susskind father and son duo of Oxford University, in the United Kingdom: *The Future of the Professions: How technology will transform the work of human experts* (2015). They observe a transformation underway in the production and distribution of the knowledge and expertise once held in the mandated realms of professions: they say the future will be in artificial intelligence, robots and the internet. Having analysed the trend in their own professions of law and economics, and explained this as "dismantling", they observed the same trend in the other traditional professions. Now *" . . . we cannot afford them, they are often antiquated, the expertise of the best is enjoyed only by a few, and their workings are not transparent."* (p. 3).

The Susskinds argue that *"today's professions should and will be displaced by feasible alternatives"* (p. 3). Professional work, they observe, is being demystified and gatekeeping bypassed. Drawing on extensive research, they depict the trend as a *"decomposition of professional work"* – from the personalised, bespoke craft of professionals in the past, to routinised and increasingly standardised packages of expertise that are being digitised, built into systems and then liberated into the internet to be available in the public arena. Through this process, expertise is extracted and allotted to whomever is best suited. Given the financial incentive associated

with the delegation of practical expertise, in parts, down the line of cost containment, the process is "commodification". Eventually and inevitably, the items of practical expertise reach the realm of increasingly capable machines.

It is not difficult to see this trend in our health sector, with nurses major players. Professional practices are changing as components of their jobs are delegated to, or claimed by, others no longer needing the full depth and breadth of knowledge and competency once believed essential. With technology expanding, our health workforce has been diversifying into specialisms, opening new roles for health-care workers with their own protocols, credentialing, job descriptions etc (eg delivering meal trays to hospital patients; hysteroscopy). Discoveries are in the media daily and marvelled at in everyday conversations. The box of practical expertise is expanding unstoppably. For now, it is confined by and reinforcing the hegemony of the health system.

The Susskinds (2015) are confident that people will be better placed to access, afford and benefit from the advances in science and technology. But we see the impact of the increasing fragmentation of the health-care people receive, and envisage the growing vacuum where the human face and human touch used to be, when the practical expertise becomes an end itself. And unrest comes from the competition around who does – or should – do what tasks. In my diagram (Figure 2), the box is set within the perspective spheres of both nursing and medicine. We often "do" the same tasks. However, we know nursing is more than just the practical expertise. So nurses, like others in the workforce, are called to convincingly articulate why, because of their nursing perspective of "health", they should usefully incorporate items of practical expertise in practice.

The nursing perspective

> *"The humanness of life is the natural setting for nursing . . . the nurse brings to a situation a language of herself, her peculiar wit and skill and comprehension of things."*
>
> Bee Salmon, in her keynote address to the 1968 ICN Congress, Montreal, Canada (Salmon, 1983)

> *"Cultural safety requires that nurses care for people* ***regardful*** *of those things which make them unique". (emphasis original)*
>
> Irihapeti Ramsden (Ngāi Tahu, Rangitāne), nurse educator and consultant, author of *Kawa Whakaruruhau: Guidelines for Nursing & Midwifery Education* (Papps & Ramsden, 1996, p.491)

> *"I would love to see more nurses initiate real conversations with focus on the person in their care, rather than referring them on to somebody else. What we say as a nurse is like sowing a seed – every opportunity matters."*
>
> Isabelle Sherrard, RN, letter to the editor, *Kai Tiaki Nursing New Zealand,* October 2021

Whereas nurses readily engage with medical colleagues (and others in the health workforce) about the medical aspects of patient care, we know there is so much more to nursing that is unsaid and unacknowledged. So here I differentiate a nurse's perspective of "health", which is just as essential: to name and claim it as complementary so that "health" is addressed holistically.

To start, I again refer to my computer dictionary for a succinct definition of nursing that is publicly recognised and commonly accessed: *"The profession or practice of providing care for the sick and infirm"* (www.lexico.com: Powered by Oxford. Retrieved 25.10.21). These dictionary definitions of nursing and medicine (see above) are closely matched in words and syntax, which makes them useful for comparison. Both are understood as practice professions. Nursing is concerned with care, in place of science, and focused on the sick and infirm, in place of disease. I take from this that nursing is seen as attending to people's "health"-related predicaments as an emotional engagement; medicine is defined by its scientific knowledge used in a practice that is deterministic, its purpose the cure and control of disease. The ethos differs: process vis-à-vis outcomes. The perspective of "health" differs – the perspective that determines what practitioners primarily pay attention to, and how they address it (and what funding there is for it). .

The word "caring" to identify the nursing ethos is familiar to us. It became an explicit connector for international conversations among nurses, bringing solidarity and a sense of professional identity. In New Zealand, from the 1960s, "caring" was used to identify and define nursing in core statements of the New Zealand Nurses' Association (NZNA): *". . . nursing is a specialised expression of caring . . .".* (NZNA, 1976, 1985). New Zealand nursing scholar and educationist Bee Salmon had earlier worded the nursing ethos as *"warmth, understanding and compassion . . . the well springs of the profession we represent"* in her keynote to the 1969 International Council of Nurses (ICN) congress in Montreal, titled *What Comes from the Heart Goes to the Heart* (Salmon, 1983). Much earlier, Grace Neill (Neill, 1961), who wrote and implemented the 1901 Nurse Registration Act, in her keynote to the international gathering of nurses that was the precursor to ICN, said of the nurse: *"upon her patience, skill and gentle tendency rest the comfort and well-being . . . "* This is our history, of an enduring ethos which is the source of our identity and social purpose as "nurses" today (albeit framed in ways and in language relevant for the day): he tangata; it is people. However, the usefulness of the word "caring" has been fading. It is no longer adequate for conveying either a distinct nursing perspective or what nurses do in today's context (Allen, 2014; Buresh & Gordon, 2013). So now we look for some wording for contemporary relevance, that each of us can identify with, and to spark the kōrero to connect us.

In 2006, my friend and colleague Helga Jónsdóttir, professor in the School of Nursing, University of Iceland, and I collaborated on a publication to contribute to the debate on the focus of the discipline of nursing. We agreed on a phrase: *"the humanness of the health circumstance"* (Litchfield & Jónsdóttir, 2006). As a phrase this was just a reference point in common, with enough meaning for each of us to prompt reflection on our own work, and to advance our respective agenda.

Here is my "take" on the phrase, coming from my research experience and academic study. The words were adequate; the syntax was what gave it meaning for the way I saw nursing. I could see in it the historically consistent trend of ethos. As a reference point for "health circumstance", it allowed me to take account of the knowledge of what is currently considered "health" from the predominant perspective and also the complexity of its contexts. What I wanted to acknowledge as the uniqueness of experience, everyday living with disease and disability, practice as relational and contingent, could be elaborated for nursing. And also, to consider

the presence of the nurse *in* the partnership, genuinely engaging with people about what matters to them. I thought it would draw practitioners, educators and managers into the kōrero with researchers, with their various "takes" on nursing's social purpose and what needs to be done.

This wording would give a focus for discussion of nursing education, practical expertise, and how nurses work with advancing technology. It would help to challenge habitual thinking, inspire study and innovation for new roles, irrespective of service and sector divisions, and the divisions of personal and population health-care. It surely would give a pointer to a person-centred model of care.

The phrase draws our attention to values and language. In Aotearoa/New Zealand, te reo and English give vitality to the relational and contingent nature of partnership. Personal values in my work that I saw represented in the phrase were: a sense of belonging and of *"the presence of past and future"* (Litchfield, 1999). Partnership, participation and protection represent "regardful" values we all want for our bicultural nationhood and a "culturally safe" multicultural society. Manaakitanga, whakawhanaungatanga, rangatiratanga, wairuatanga are particularly meaningful for explaining *"the humanness of the health circumstance"*; they do not need definitions to connect us into kōrero about nursing in Aotearoa/New Zealand. This is the language of the current NZNO definition of nursing for its work (Clendon, 2011).

I have found the phrase useful when I talk with nurses about the significance of their practice. I have asked them to explain what they do. I have seen them somewhat startled by the strangeness of both the question and the language; they pause and concentrate hard to find wording for their work. (Nurses are more used to talking about what they do in terms of the medical discipline and workforce roles; to escape from it requires mental effort and overcoming the fear and embarrassment of not having a ready answer.) But also I have repeatedly seen the great and unexpected pleasure of insight when they realise how important their nursing has been – for health and people's lives. This is foundation for engaging in nursing research. And isn't it the educative/learning process?

I write about the phrase here, in my words, not to justify or persuade. Rather it is to emphasise that a phrase is essential as a reference point for the kōrero and for the research through which we explain practice and create the nursing voice we need and want: to focus our efforts to articulate nursing. To be inclusive, the phrase must have as few words (meaning-laden) as possible, to accommodate the diversity and uniqueness of personal practice. It must also have the syntax that helps us give a distinctive *nursing* meaning to the words, our "mindful" (non-deterministic) ethos, the wairua and aroha of cultural safety. Vitally, it must come readily to our minds anywhere we talk to others about nursing. It must be primarily meaningful for the people of Aotearoa/New Zealand, but also for us to engage in the international nursing community. That is, to be readily recognisable, in its essence, as the nursing people need, want and can see as practicable.

I have been deliberate in arguing that we use a phrase – without a verb. How we understand knowledge involves how we use it in practice. This is the issue to be addressed in discussion of distinctly nursing research and its methodology.

The nursing paradigm of research and methodology

"Nursing research is undertaken by nurses. It is a process of systematic enquiry, the purpose of which is to contribute to the shaping of nursing practice within its changing context."

NZNA Statement on Nursing Research, 1990

"It behoves us [nurses] not to be told by other people what we should be doing – listen certainly – but to define and develop our own practice through research".

From a 2007 interview with Bernie King, first New Zealand RN to earn a PhD (1981), later senior research officer in NZ Department of Health (Litchfield, 2009, p.16).

"Cultural Safety theory . . . in essence puts the nurse as the focus of insight and change, not the patient . . . It is essential that . . . we value and respect our own experience . . ."

Irihapeti Ramsden, RN (Ngāi Tahu, Rangitāne) (2001, p.24).

In my diagram, there are two paradigms for the research relevant to nursing. One is the box of practical expertise substantiated through research and assuming the methodologies of science framed by the dominant medically oriented perspective and purpose; it is the foundation for evidence-based/informed activities. The other is the nursing paradigm, its discipline created by the perspective of nurses as individual human beings and as a professional collective.

If "humanness" identifies a nurse's perspective of "health", then it is the relational, contingent – and dialogic – core of nursing practice, personalising practical expertise, that is to be studied as nursing knowledge. As nursing researchers, our interest is the practice partnership: our personhood – who we are and what we know – coming together with the personhood and health predicament of others, as the nursing endeavour (Jónsdóttir et al., 2004). This differentiates the perspectives as paradigms.

In the literature, there are many thoroughly-explored renderings of two paradigms for nursing research. Here I cite Afaf Meleis (2017) who, every five years since 1985, has intensively reviewed the literature to describe trends in the discipline of nursing in her widely-cited book *Theoretical nursing: development and progress*. In her most recent edition, she envisaged an emergent generation of nurses researching from *"two possible models"* that will continue into the foreseeable future. She hasn't named them, but how she has contrasted them seems to fit with the paradigms I am conveying in my diagram. However, like others, Meleis presents her models as quite discrete paradigms, their methodologies used in parallel as options for researchers in their respective cadres. Rather, in my diagram, I point to nursing as a paradigm itself: one paradigm with its methodology bringing fresh meaning to the box of practical expertise already embedded in the many methodologies of competency. The following is a very condensed rationale.

Practical expertise paradigm

Knowledge is underpinned by the conventional methodologies, both quantitative and qualitative. They are definitive and prescriptive, to produce the form of knowledge required for the workforce to achieve the desired outcomes of the "health" service: to do better. The findings of researchers are made available to be operationalised by practitioners and others; to be confirmed, refuted or modified and built on in new research; methodology and its products are legitimised through the conventions of critique. A whole academic field of "knowledge translation", and a career role as "knowledge broker" have emerged. This form of knowledge is depersonalised and its use self-reinforcing in trends: it's a 'hard boundary' between

knowledge and its application/use in "health" practices.

Nurses have contributed voluminously to the contents of this box of practical expertise; they have structured research and teaching programmes around them. People have benefited from the proficiency of nurses and others in the workforce drawing on the evidence to inform their work. Nurses must continue with this essential contribution, using whatever methodology serves their practical expertise intent. But a nurse's research from a nursing paradigm reframes the interface of this form of knowledge and its relevance in people's lives.

The nursing paradigm

As for other disciplines, distinctly nursing research calls for methodology to express the premises of the nursing perspective of "health". The significance of nursing lies in **a relational, contingent form of practice focused on people's lives**, so the methodology is the way we develop knowledge as it evolves in the reality of our practice experience, along with all the participants (Jónsdóttir et al., 2004, Litchfield, 1999): the humanness/mindfulness of partnership as practice.

To give our methodology a genre that links it into the wider research literature, I refer to it as participatory (Litchfield & Jónsdóttir, 1999). Philosophical foundations for a range of participatory methodologies emerged in the social science literature a long time ago and the relevance for nursing was quickly recognised, although not without controversy. US nurse theorist Margaret Newman (1991, p.100) explained to a sceptic: *"research is practice"* means *"the **form** that nursing research takes is the **form** of practice: a real relationship between nurse (researcher-practitioner) and client focusing on a real concern of nursing practice"* (emphasis original). Nursing research requires our own rendering.

So in the nursing paradigm, identified by its "health" perspective with social purpose, research is the process by which the methodology itself is the findings. Presented as a narrative of process, this is practice wisdom. It is what happened through the process and what eventuated, not predetermined: the humanness of the partnership (Litchfield, 1999). *"The nurse (is) the focus of insight and change"* (Ramsden, 2001, p.26). In this paradigm, the box of practical expertise is re-construed as a library of current conventions, "items" critiqued for usefulness as part of the uniqueness of the partnership, in context. Here, practical expertise is actually integral to the *"health circumstance"* that is partnership. It is personal practice, a nursing process that is opportunity for "health" to be understood as "what can be": what is to be done by any and all participants.

Since "research" takes its contemporary meaning and legitimacy within established ethics guidelines, committee approval, funding, publication, conference presentations etc, I emphasise that this endeavour is "research", not to be dismissed as the expected everyday development of practice: it is *"research as-if practice"* (Litchfield, 1999; Jonsdottir, 2007). Of course, as such it needs "research" design parameters.

However, the presentation of a nurse researcher's narrative of practice wisdom – which is personal – does not itself develop the discipline. It is when the narratives of practice wisdom are brought into the collective dialogue that the discipline evolves. The **nursing discipline is a dialogue.** It is through our kōrero as knowledgeable nurses, here and now, that we can seek the unity of diversity for a nursing voice substantiated though research. In our hui and forums, we do the mahi on the meaning of Te Tiriti for "health", on Kawa Whakaruruhau *and* Cultural Safety in Nursing (Ramsden, 1990; Roberts, 2019), we question our ethics and develop confidence.

Conclusion

So, nursing does have a methodology. It is the way nurses become knowledgeable, bringing coherence to "knowledge" from all sources and the experience of nursing. It cannot be defined like the conventions of research in the health field. In this sense, nursing *is* methodology. Nursing is a paradigm.

The conceptualisation I have diagrammed is embedded in our Aotearoa/New Zealand nursing turangawaewae, but the thinking echoes through international nursing literature. Meleis (2017) referred to the same elements and their significance as she pondered the future of nursing theory and research: *"By being clear about our mission, our values and the models we choose to use for knowledge development, we are empowering ourselves to empower our consumers."* (p.426). From my stance presented here, I add that nurses and consumers are simultaneously empowered through the process of research-as-if-practice.

I acknowledge the twist of mind involved in looking at nursing research in this way. There is much to be questioned and new ideas to be developed. My explanation is necessarily pared down and superficial. And I am writing as just one reflecting academic-at-large, using my language as best I can, here and now. I hope the diagram prompts kōrero useful to substantiate the vital voice of nursing in health care – where knowledgeable nurses should be free to nurse in new ways in response to changing need, and to claim the conditions required for it. But, for this, there is real need for hui and forums where we can collectively settle on and repeatedly review a phrase, simple and brief, as an identifying reference point for our individual and collective efforts.

Nursing research, when we see that it is and has a methodology with social significance, gives us our voice. Canadian Sally Thorne (2018) reminded us: *"a shared voice is fundamental to our public trust".* Our research is how NZNO's belief about the future can be realised: *"Nurses will shape the future of health in this country, we will be recognised for the difference we make in people's lives, and we will work together as a profession to achieve this".* (Clendon, 2011).

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USING TRANSDISCIPLINARY RESEARCH TO EXPLORE SOLUTIONS TO 'WICKED PROBLEMS'

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Abstract

Transdisciplinary research (TDR) was the methodological approach used to explore challenges and opportunities for enrolled nursing in the contemporary health workforce in New Zealand. The question considered in this TDR study was how the contribution of enrolled nursing might become more visible and better understood in terms of its contribution to the health workforce. TDR was chosen as the methodological approach to enable exploration of potential innovations through a collaboration between a variety of stakeholders in a health-care delivery community.

Key words

Transdisciplinary research (TDR), methodology, 'wicked problems', collaboration, partnership.

Introduction

Transdiciplinary research (TDR) is a methodological approach that enables researchers to examine complex problems in collaboration with a wide variety of stakeholders. This article presents some practical insights from my experience of using TDR to explore the challenges and opportunities of enrolled nursing in the contemporary health workforce. The central ideas of the TDR approach are explained, including "wicked problems", definitions of TDR, the involvement of stakeholders in partnership and collaboration, and the relevance of reflection in the process of conducting a TDR study.

Wicked problems

In considering the notion of complex societal problems, the phrase "wicked problems" emerges (Mobjörk, 2010, p. 869). These "wicked problems" are complex and require a multi-faceted approach by a variety of stakeholders to find creative and flexible solutions. Roberts (2000) identified four features of "wicked problems". Firstly, Roberts asserts there is no definite statement of a problem but more of a broad disagreement of what it could be. Secondly, the exploration of solutions is unrestricted and dependent upon stakeholder points of view. The third characteristic is the problem-resolving process is multifaceted due to limitations such as resources or politics. Finally, Roberts identified that these limitations also change as stakeholders change, fail to communicate, or change the parameters by which the problem must be solved (p. 1).

The "wicked problem" for this study came from anecdotal stories relayed by enrolled nurse (EN) students and graduates. They discussed their difficulties with employment and an apparent lack of understanding by other health professionals about the EN scope of practice. ENs practise under the direction and delegation of a registered nurse (RN) or nurse practitioner (NP). They deliver nursing care and health education across the lifespan to health consumers in community, residential or hospital settings. ENs contribute to nursing assessments, care planning, implementation and evaluation of care for health consumers and/or families/whānau, while the RN maintains overall responsibility for the plan of care (Nursing Council of New Zealand, 2019). For me, having participated in successful community-wide projects in the 1990s, transdisciplinary research and innovative methodology appealed, when considering furthering my studies. It seemed timely, then, to take a formal approach to these anecdotal stories.

I considered the challenges for enrolled nursing to be "wicked problems" due to their complexity, the variety of stakeholders and viewpoints involved and the impact of resources and politics. As identified by Dorst (2018), organisations facing complex problems need to become more flexible in the way they respond to them. Dorst suggests a design-based approach which creates a framework for mixing practices, creating new insights and *"action in the space between established professions"* (p. 60). The TDR methodology was chosen because it enabled a variety of viewpoints to be considered, using a research approach that focused on "real-world" issues.

Transdisciplinary research

In preparing to conduct the research, I needed a workable definition of TDR. Westberg and Polk (2016, p. 385) define TDR as a way to *"address the complexity of societal problems through the exchange of knowledge and expertise across diverse groups of societal actors".* Similarly, Wickson et al (2006) determine TDR as focusing on complex and multi-dimensional problems and involving and developing shared methodology with multiple disciplines. Hoffmann-Riem et al (2008) define TDR as ranging from a diffuse conceptual term involving individual disciplines to any research involving stakeholders. Academic literature uses the terms "actors" interchangeably with "participants", "stakeholders" and "non-academic actors" to describe the individuals who work within the TDR framework (Hoffmann-Riem et al., 2008; Mauser et al., 2013; Wickson et al., 2006). Other writers suggest the critical difference

between transdisciplinarity and interdisciplinarity is the deliberate collaboration and intentional involvement of stakeholders in the identification of problems and the co-creation of solutions (Mobjörk, 2010; Thompson Klein, 2004; Wickson et al., 2006). I learnt from my enquiry that TDR involves the collaboration of a diverse number of interested people, focusing on a complex societal problem, and co-creating innovative sustainable solutions.

Partnerships, stakeholders and collaboration

TDR involves various actors/stakeholders from outside academia focussing on real-world issues (Binder et al., 2015). Therefore research on how enrolled nursing might become more visible and better understood in terms of its contribution to the health workforce, involved collaboration with various stakeholders in the Waikato Tainui region and other regions of Aotearoa New Zealand. Participants in the study included non-academic partners or actors in research (Belcher et al., 2016; Binder et al., 2015; Hospes et al., 2017; Schauppenlehner-Kloyber & Penker, 2015; Smith, 2007; Westberg & Polk, 2016).

The inclusion of partners from outside a research context and/or science discipline allows a more holistic viewpoint to be developed. Scholz and Steiner (2015) identified societal actors as having differing world views. Some have goals to improve their business or manage actual issues. In contrast, other researchers/scientists seek to grow theoretical knowledge, contributing to a better understanding of the real world. Klein (2008) recognised the importance of having experts from the *"problem space"* because the group as a whole form an *"appropriate interdisciplinary epistemic community"* (p. 121). I felt this aspect of TDR was significant for the study as the research involves and impacts upon nurses, health providers and academics. Through the lens of TDR, diverse voices could be heard.

Positive outcomes from TDR partnerships include network building, trust in others, understanding of others, community identification due to involvement in a TDR project, and knowledge generation and sharing (Walter et al., 2007). Through the TDR framework, mutual and transformational learning occurs – learning that *"leaves a legacy"* (Mitchell et al., 2015, p. 93). TDR is a long-term process and work-in-progress for those working with the societal problem. I concluded that this would be the case for this study, due to the complex nature of the problem, the diversity of potential stakeholders and subsequent innovations.

The project methodology

An essential consideration in TDR is that each "wicked problem" will have its own distinctive methodology, researchers and detailed solution or solutions. In essence, there is no "one size fits all'. Bergmann et al (2012) state that if researchers want to apply the methods of one transdisciplinary problem to any other transdisciplinary problem, the methods must be *"de-coupled or de-contextualised"* (p. 20). The selected strategy must also be reassessed frequently and revised, if needed, throughout the research process. Bergmann et al (2012) describe this as the principle of recursiveness, as each step of the process is subject to iteration – the repetition of a process to create a series of outcomes. Each step requires review, given the diversity of people involved, ensuing discussions held, and alterations made. Vilsmaier and Bergmann (2017) further examine the fundamental concepts of TDR and its methodology – integration, collaboration, mutual learning, problem-framing, co-production of solutions, and bringing the solution to fruition.

Bergmann et al (2012) examine three dimensions of integration. Firstly, the cognitive-epistemic dimension explores individual differences and similarities of science and practice and the development of new methods together. Secondly, the social and organisational element considers the varying interests and activities of the research group, focusing on leadership, mutual understanding and the group's willingness to learn. Finally, communication links various communication styles, expressions and practices to find a common understanding (Bergmann, 2017).

Binder et al (2015) describe practical elements in establishing a TDR project and propose three phases:

1) Problem-framing and team-building
- Team members clarify their perspectives, problems and expectations and agree on a common set of goals for the project.

2) Project partners focusing on project work
- Individual participants focus on various components of the project and may involve participants outside the group.

3) Co-generation of knowledge and knowledge integration
- Outcomes of the research are identified for the groups of participants – practitioners look to solve societal problems or see transformations; scientists look for new knowledge regarding theory or methodology.

This last phase is the process for making the results useful for all parties. It facilitates understanding of the problem and the processes needed for developing a sustainable solution for all (p. 546).

Pohl and Hadorn (2008, p. 35) also identified the three phases of TDR as problem identification and structuring, problem analysis, and bringing results to fruition. Roodt (2020) describes TDR as a recursive process, whereby existing knowledge is combined with new concepts to co-create an updated construct. In unravelling the intricacies of the societal problem, I needed a logical approach to frame, analyse and process the area of concern, as suggested by Pohl (2011). Pohl and Hadorn (2008, pp. 431-432) identified three types of knowledge that are part of a TDR project, including systems, target and transformational knowledge. Firstly, systems knowledge identifies the problem and the difficulties with transforming the problem and concept into a workable solution. Target knowledge looks at the need for change, potential outcomes and improved practices. Transformational knowledge looks at cultural, ethical, technical, sustainable, political and social components when transforming current practice into improved practices.

Several frameworks and processes describe the transformation of problems into solutions in TDR research (Bergmann et al., 2012; Binder et al., 2015; Hoffman-Riem et al., 2008; Pohl, 2011). Wickson et al (2006) add to the picture by declaring that methodologies used in TDR need to respond to and reflect the problem and situation under investigation (p. 1049). They say *"transdisciplinarity is characterized by an interpenetration of epistemologies in the development of methodology"* and the *"dissolution of disciplinary boundaries is necessary for the construction of novel or unique methodologies tailored to the problem and its context"* (p. 1050).

Other literature revealed it was acceptable to use traditional forms of research methods in TDR projects: mixed-method (Thompson et al., 2017), and quantitative and qualitative methods (Claasen et al., 2015; Krettek & Thorpenberg, 2011). The most reassurance was

provided by Leavy (2016), who stated *"any TDR design can use any method in pursuit of the research objective"* (p. 54) and methods were only tools for data collection. Leavy provides a sense of comfort that researchers can still use traditional methods, as it is more the philosophy and process that defines transdisciplinary research.

Reflection in transdisciplinary research

Researchers have highlighted the importance that reflection plays in TDR (Finlay, 2002; Palaganas et al., 2017; Patnaik, 2013). The need to reflect, review and reiterate the research process is essential to producing solutions that are fit for purpose and meaningful to the context. Reflection and reiteration are equally important at the group and individual levels: the group level when participants are together considering the project and the individual level when considering a researcher's involvement.

Reflection for researchers is therefore essential, as the researcher's worldview and potential areas of bias may have an impact on the understanding of the problem, the research method, the design and the solutions (Wickson et al., 2006). This reflection contributes to the deconstruction of current knowledge and the rebuilding of new group and individual bodies of knowledge (Wickson et al., 2006, p.1053-1054). This deconstruction and co-creation of knowledge is further elaborated by Popa et al (2015), who proposed four main characteristics of reflexivity related to TDR:

- collaborative deliberation to develop a shared understanding of a problem;
- the social relevance of the problem-framing;
- social experimentation and collective learning processes;
- critical and transformative character of the research agenda.

Reflection is therefore required in all stages of TDR, from discussing the problem and its societal relevance, formulating the action plan, and reviewing learning outcomes to the contribution of the research and transformation of the problem (p. 3). With the diversity of worldviews and knowledge in the stakeholder group, reflection is essential for each member to understand each other and the "wicked problem". Roux et al (2010) propose the idea of co-reflection by the entire stakeholder group – and support the aspirations of individuals, sub-groups and research funders. Roux et al (2010) introduced the need for a facilitated workshop at the start of the research and then regularly after that to enable *"learning by doing"* (p. 735). This co-reflection offers opportunities for stakeholders to understand each other's worldviews better, while working collectively towards a *"defined social purpose or aspiration goal"* (p. 737).

Group reflections for this project centred on updates on research progress and discussion among the stakeholder group on the role of the EN. The discussions initially centred on the methodology of the project and potential areas of inquiry, processes involved, ethics approval, and updates from group members on the topic from their perspective. Many participants have an active role in the development or employment of ENs, particularly in the Waikato district, but also from a national or regional perspective. Other participants were involved with health-service delivery, and while might not necessarily work or employ ENs, they could see the potential for the development of this role. Group reflection focused on the development of the research project and then later on the findings. Discussions were noted in my portfolio and stakeholders were followed up by email or as part of regular meetings. An email update for stakeholders was disseminated to participants towards the end of the research to discuss the progress and findings.

I found the involvement of the stakeholders to be invaluable for my own understanding of the issues and how the problems affected a variety of people from different parts of the health sector. The group also guided me on my research journey, offering suggestions and opportunities for reflection with kanohi-ki-te-kanohi (face-to-face) discussions. The group has specialised knowledge of the wicked problems being addressed. It could now be likened to *"communities of practice",* as proposed by Lave and Wenger (1991), where people form a group with a common interest in a particular area and share knowledge and experiences.

Iteration was a fluid process; it was incorporated throughout the research project and occurred at many stages. This included the development of the "wicked problem", the ethics application process, construction of the survey questions, dissemination of the surveys and project information-sharing. Mutual learning occurred as group participants took part in ongoing discussions and knowledge-sharing about the development of the role and the broader socio-political and health workforce influences that affect the EN. Participants were able to share developments, trends and strategies that were in place for the role of the EN, and also discuss further challenges or opportunities that they had noted as part of their day-to-day roles.

Networking with stakeholders was also a key component of the TDR methodology. This occurred either in groups or with individuals, and relationships developed over time. Participants pledged support and ongoing contribution to the project and are keen to be a part of future knowledge-sharing, research outcomes and development of the role. Mutual learning transpired for the participants from their involvement in the research, information-sharing, networking and discussions held during the process. As participants come from a variety of backgrounds, they were able to share their knowledge in their collective groups and learn from each other about developments of the role and how to consider moving forward with potential innovations. The group had evidence of the difficulties faced by ENs, both present and historical (Gibson & Heartfield, 2005; Ministry of Health, 2019; Nursing Review, 2017; Prinsloo, 2014).

In summary, the TDR process is underpinned by a fluid research methodology involving integration and collaboration, responding to people, problems and the context in which the research is conducted. TDR methodology evolves due to many factors: wicked real-world problems that may in themselves be evolving, a range of stakeholders including academic and non-academic actors, varying epistemologies, knowledge and practice, and reflection and iteration.

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HOW INTERNATIONAL DATABASES TAKE *KAI TIAKI NURSING RESEARCH* TO THE WORLD

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When a new researcher is first published in *Kai Tiaki Nursing Research (KTNR),* it is understandable if they ask: Who will read my article? Where does it go? The point of having research published is for it to be read, and hopefully by as many as possible. For what is the point of nursing research if not to share knowledge and improve practice.

KTNR was launched in 2010, as a sister publication to the New Zealand Nurses Organisation (NZNO) monthly magazine *Kai Tiaki Nursing New Zealand.* Its purpose was to add to the professional services provided by NZNO, by supporting and encouraging nursing researchers and the dissemination of nursing knowledge.

It is an annual peer-reviewed hard-copy journal. Once an issue is printed, copies are posted to its subscribers – individuals and institutions mainly in New Zealand. These institutions include the National Library and the libraries of universities, polytechnics and district health boards, making the content accessible to staff and students at these institutions.

Some time after its print release, the contents of *KTNR* are then released to a much wider international audience through their inclusion in several online academic databases. Through these listings, the audience a *KTNR* author potentially reaches increases exponentially.

Since 2010, KTNR articles have been included in three databases: Cengage Gale – Academic OneFile, and RMIT Publishing (Australasia)'s Informit Health Collection and Informit New Zealand Collection. More recently, from the 2013 issue onwards, the journal has been listed in the massive Ebsco Publishing – CINAHL Complete database.

Cengage Gale – Academic Onefile

Gale, a Cengage company, has worked with libraries around the world for more than 60 years to share knowledge on a huge range of topics.

Its main database for periodicals (publications that come out with new editions on a regular schedule), Gale Academic OneFile, lists millions of articles from more than 17,000 scholarly journals and other authoritative sources. This wealth of material also includes videos from BBC Worldwide Learning, thousands of podcasts and transcripts from CNN. It includes more than 11,000 peer-reviewed journals, more than 8000 of them in full text.

RMIT Publishing (Australasia) – Informit Health Collection

The Informit Health Collection is, as its name suggests, a specialist health database for authoritative nursing and allied health content. It includes research articles, reports and case studies of practical use to anyone studying or working in therapeutic, diagnostic and preventative health roles.

Much of the content in this collection is unavailable elsewhere online – it includes journals dedicated to specialist and topical subjects, including ageing and aged care, child health and breastfeeding, indigenous health and mental health and rehabilitation.

RMIT Publishing (Australasia) – Informit New Zealand Collection

Much of New Zealand's best research remains undiscovered or difficult to find online. The Informit New Zealand Collection was developed to provide easy, affordable access to full-text content publishing in, or of relevance to, New Zealand. Multidisciplinary in scope, this database will benefit anyone looking for research which explores New Zealand culture and society in-depth. Its content includes many authoritative Australasian journals which are unique to Informit.

Ebsco Publishing – CINAHL Complete

From the 2013 issue onwards, KTNR has been included in Ebsco Publishing's CINAHL Complete database which specialises in nursing and allied health literature. It is one of the largest and most in-depth nursing research databases (ANMF, 2021). CINAHL (Cumulative Index of Nursing and Allied Health Literature) Complete contains 424 active, full-text, non open-access journals; and 3604 active indexed and abstracted journals, 3112 of which are peer-reviewed. Subject headings in CINAHL help users search and retrieve information, following the structure of the medical subject headings (MeSH) used by the National Library of Medicine.

Most New Zealand libraries subscribe to the Cengage Gale databases, making *KTNR* content widely available in this country. Institutions and organisations worldwide subscribe to these databases, which means anyone who is employed by these institutions can access *KTNR* articles and download them as a PDF.

The New Zealand Nurses Organisation library also subscribes to these databases and they are made available to all current NZNO members via the NZNO website (NZNO, 2021).

So why is it important for *KTNR* content to be included in these databases? Having *KTNR* listed in internationally accessed and credible research databases is vital for the journal and its authors**.** Sharing and promoting *KTNR* articles forms an important part of research, in terms of fostering the exchange of scientific information in your nursing field and allowing your paper to contribute to wider scientific progress.

It provides international exposure and enhances the visibility of

each individual author, of the journal and of NZNO. It can pave the way for collaboration and coordination in different areas of research so that researchers can keep abreast of the latest developments in their areas of interest.

When *KTNR* was launched, NZNO library staff approached various international database providers to see if they were interested in listing *KTNR* material. The response was positive, with some saying there was a lot of demand for New Zealand content. NZNO receives modest royalties based on the usage of each article.

No data is available on how often *KTNR* articles are cited in international research or who accesses the articles. But Ebsco Publishing – CINAHL Complete does provide NZNO with usage data which shows how many times a particular *KTNR* article was downloaded and at which institution.

This usage data shows the journal is very popular at universities and state colleges in the United States (US). It is interesting to look at which particular articles have been downloaded the most.
For example, Wintec educator Jenny Song's case study in the 2018 issue, *Ethics education in nursing: Challenges for nurse educators,* (Song, 2018) was popular at three different US universities. At Chamberlain University – a specialist nursing and health care university with campuses across the US – there were 224 full-text downloads of this article. At Grand Canyon University, Song's article was downloaded in full text 375 times, and at Northern Kentucky University, 44 times.

Also popular was Monina Gesmundo's 2016 article, *Enhancing nurses' knowledge on catheter-associated urinary tract infection (CAUTI) prevention* (Gesmundo, 2016), which was downloaded in full text 564 times at Western Governors University.

Costantinos Tabakakis, Margaret McAllister and Julie Bradshaw's cross-sectional survey, *Burnout in New Zealand registered nurses: the role of workplace factors,* in the 2020 *KTNR* issue, was downloaded 94 times, again at Grand Canyon University in the US.

Again at Chamberlain University, there were 63 full-text downloads of *Does simulation add value to clinical practice? Undergraduate student nurses' perspective,* by Jeanette Briscoe, Bev MacKay and Thomas Harding, publishing in KTNR's 2017 issue.

Closer, in Australia, at the Holmesglen Institute in Melbourne, Sarah Winship and Patricia McClunie-Trust's article, *Factors influencing hand hygiene compliance among nurses: an integrative review,* from the 2016 issue, was downloaded in full-text 60 times.

This is just usage data from one of the databases *KTNR* is stored in. And it is impossible to know even from this CINAHL data, exactly what these *KTNR* articles were being used for. Bulk downloads possibly suggests these articles are being used as recommended course reading material.

Individual downloads, where a researcher is using a KTNR paper to help background or inform their own research, cannot be quantified, and so remain unknown.

But the data we do have does give a fascinating glimpse of how the inclusion of KTNR content in international databases spreads the work of New Zealand nurse researchers around the world, raising the profile of nursing in this country, and adding New Zealand knowledge to the international pool of nursing wisdom.

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