Tōpūtanga Tapuhi
Kaitiaki o Aotearoa
NEW ZEALAND NURSES
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Kaitiaki NURSING RESEARCH

Researching in a virtual world

November 2025

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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

Researching in a virtual world

Kia ora koutou. Welcome to the 2025 edition of *Kaitiaki Nursing Research.* As this edition marks our first fully online production, I am reminded that much of our nursing research is now undertaken virtually and in collaboration with other researchers, enabled by digital tools that allow us to work across institutional and international boundaries (McClunie-Trust et al., 2022).

Scholarly information is abundant, in both quantity and quality, available through a wide range of subscribed and open-source digital repositories. Gusenbauer (2021) reports that more research has been published so far this century than in the preceding 100 years. This abundance of information means that researchers need to develop sophisticated methods for searching databases and digital repositories, and to engage librarians as information experts in framing searches and evaluating what they find (Gusenbauer, 2021). Online tools for storing research data and integrating multiple researchers into research projects, such as Microsoft Teams, the Open Science Framework (2025), and Covidence (2023), have increased collaboration potential, enabling researchers to work together virtually in real time (McClunie-Trust et al., 2022).

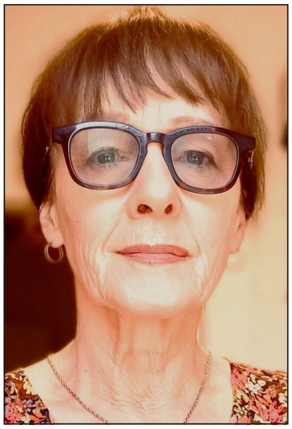
Facilitating collaboration

Research collaborations are an effective way to develop knowledge, improve patient outcomes, and foster innovation. Collaborations can leverage the skills and other capabilities of like-minded researchers (McClunie-Trust et al., 2022), expand researchers' networks, and offer opportunities to share expertise and resources. Collaborations often lead to greater productivity on more complex research projects (Abramo et al., 2017). Collaborations among nurse academics, nurse clinicians and health-care organisations promote the translation of research into practice, ultimately improving health-care delivery and patient safety. They lay the groundwork for innovative solutions in response to the cultural and clinical requirements of nursing education, practice and research in Aotearoa New Zealand.

Collaborations with communities and researcher colleagues that incorporate a Māori worldview put cultural values and identity to the fore in research in a way that expands knowledge and understanding (Durie, 2004). Blending Māori values and Western science offers a transformative approach for nurse researchers to address equity issues in Māori health (Rolleston et al., 2022). Positioning research within te ao Māori enables Māori researchers to take an approach informed by Te Ara Tika — a framework for Māori research ethics which includes the four principles of "whakapapa (relationships), tika (research design), manākitanga (cultural responsibility), and mana (justice/equity), which draw from mātauranga Māori and tikanga Māori" (Woods et al., 2025, p. 4).

Māori men in nursing education

In this year's edition, the researched viewpoint by Hughes et al. presents reflections on the experiences of two Māori male nurses working in nursing education. Seamus Hughes and John Hiakita note that the Nursing Council of New Zealand's Te Tiriti o Waitangi policy (NCNZ, 2023) and guidelines for cultural safety in nursing education and practice (NCNZ, 2011) mandate obligations for nurses to foster cultural safety in order to address health inequities. The challenge for nurses is to create an authentic, embodied nursing practice grounded in cultural safety and Māori values. Hughes and Hiakita explain how their experience as Māori men and nurse educators underpins a powerful pedagogy, weaving together a unique blend of cultural perspective, professional experience and personal identity to enrich the cultural and learning environment in nursing education.



Patricia McClunie-Trust

Perceptions of rongoā

Bowlin and Song's research used a qualitative survey method and thematic analysis to explore third-year bachelor of nursing students' perceptions of rongoā Māori. A traditional Māori healing system, rongoā encompasses Māori knowledge and wisdom, including the interconnectedness of land, plants, family, spirituality, and physical well-being (Mark et al., 2017). The standards of competence for registered nurses (NCNZ, 2025) require all nurses to support Māori health equity, advocate for patient preferences, and uphold kawa whakaruruhau (cultural safety). The findings of this study suggest that while bachelor of nursing students have positive attitudes toward rongoā Māori, cultural and systemic barriers are major factors in successfully integrating it in practice. The authors highlight the need for nursing students to learn about holistic Māori healing systems and to ensure the safe integration of rongoā knowledge into clinical care settings and nursing education programmes.

The lived experience of gout

Jack and McClunie-Trust conducted a meta-ethnography to synthesise the findings of 20 qualitative research studies that explored the lived experience of people with gout. The findings of this review suggest that the ripple effect of gout flares impacts every aspect of a person's life, disrupting work and family life and contributing to a sense of helplessness due to the intensity of pain. Misconceptions about gout as a chronic disease often resulted in missed opportunities for effective management of symptoms for participants in the studies. Study participants also related how they negotiated their lives with gout, finding a sense of agency through effective self-management of the disease and its symptoms. Recommendations from this review suggest that educational approaches that align with patient preferences and health literacy, address treatment barriers, and incorporate relevant cultural support are most effective. These strategies support optimal disease management and foster a sense of agency in living with gout.

Screening tools for perinatal depression

The researched viewpoint by White examined screening tools for perinatal depression, which is defined as severe depressive episodes during pregnancy (antenatal) and within 12 months postpartum. While screening for perinatal depression is widely practised across the world, there are ethical issues associated with the use of screening tools, which may result in more harm than benefit, particularly in over- or under-identifying perinatal depression or degrees of emotional distress. White explores the efficacy of identified screening tools in relation to the ethical responsibilities of nurses, midwives, and other health practitioners when making decisions about health care for women in pregnancy and childbirth.

Staff perceptions of palliative care

The integrative review by Michael and Mercer examined staff perceptions and experiences of palliative care provision in aged residential care facilities. Staff working in these facilities must possess expertise in delivering care to enhance the quality of life for people with advanced palliative and end-of-life care needs. The feasibility of receiving preferred palliative care in these facilities is limited by available resources. Palliative care requires an integrated, responsive staff familiar with providing end-of-life care (Moberly et al., 2023). The findings of this review indicate that palliative and end-of-life care are essential elements of service in aged residential care facilities. However, health policy and funding need to reflect the increasing demand for these services in aged residential care and provide adequate resourcing to meet those needs.

NZNO's nurse researchers

In the final section of this year's edition, we have included a report from Lorraine Ritchie on NZNO's Nursing Research Section Te Wāhanga Rangahau Tapuhi (NRS). The section is committed to upholding the principles of Te Tiriti o Waitangi. It works to honour this commitment through meeting kaupapa, the scholarships made available to NRS members, and the inclusion of researchers using indigenous kaupapa Māori research methodology at research forums. The NRS golden jubilee will be held in October 2026, celebrating 50 years since the section was inaugurated to promote nursing's professional voice through research.

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RESEARCHED VIEWPOINT:

Seamus Hughes, John Hiakita, Anna Tiatia Fa’atoese Latu

Reflections on Māori male nurses’ experiences working in nursing education

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Nursing education in Aotearoa New Zealand is at a pivotal point. With a clear mandate to foster cultural safety and address persistent health inequities for Māori, teaching methods must evolve beyond traditional frameworks. The Nursing Council of New Zealand’s *Guidelines for Cultural Safety, Te Tiriti o Waitangi/the Treaty of Waitangi and Māori Health in Nursing Education and Practice* (Nursing Council of New Zealand [NCNZ], 2011) make it clear that nurses must be prepared to work with Māori in a way that is respectful and effective. The challenge, however, lies in moving from theoretical understanding to authentic, embodied practice. A powerful model for this is found in the lived experiences of a small but growing group: Māori male nurses. They bring a unique blend of cultural perspective, professional experience and personal identity that enriches the learning environment. This article explores the teaching philosophies of two such educators, John, a nurse of 27 years, and Seamus, a nurse of 12 years, both from the University of Waikato. By examining their personal and professional journeys, we aim to show how they translate their experience into a powerful form of pedagogy that not only teaches foundational nursing concepts but also normalises te ao Māori within the curriculum.

John Hiakita, Seamus Hughes and Anna Tiatia Fa’atoese Latu

Te ao Māori and whanaungatanga

Te ao Māori is a holistic and interconnected worldview that provides the foundation for Māori culture, identity and nursing practice in Aotearoa New Zealand (Durie, 2012; Ministry of Business, Innovation and Employment, 2025). It is essential to recognise the unique position of Māori as the Indigenous people of Aotearoa and the impact of colonisation on their health and societal outcomes (Reid & Robson, 2006; Wilson et al., 2022). Of the 2023 estimated resident population of New Zealand, Māori constitute 17.1 percent, with a total count of 914,400 people (Stats NZ, 2024). Despite this significant and growing presence, Māori experience considerable disparities in health, education and economic indicators compared to non-Māori, which is a direct consequence of historical and ongoing colonisation (Came et al., 2019; Durie, 2012; Reid & Robson, 2006). A critical factor that needs to be tackled in addressing Māori health inequities is the significant under-representation of Māori in nursing. Although Māori make up more than 17 percent of the population, they are only 7 percent of the nursing workforce (Heyes, 2024; Wilson et al., 2022). An increased Māori workforce is considered a “critical enabler” for reducing health disparity (Wilson et al., 2022). The ability of Māori nurses to understand and integrate te ao Māori concepts such as whanaungatanga (connectedness) and manaakitanga (care for others) into health care enables them to help address systemic inequities and foster culturally safe and effective care (Carlson et al., 2016; Lacey et al., 2011).

In nursing literature, the therapeutic use of self refers to the way a nurse can intentionally use their relationship with the patient (Kingston & Greenwood, 2020). They can use the therapeutic relationship to find out what knowledge whānau lack and help fill those gaps, and to use identified strengths and motivational interviewing to enhance the health of patients and their whānau (Erkayiran & Aslan, 2025; Kingston & Greenwood, 2020).

Te ao Māori concepts intertwine with the therapeutic use of self, or therapeutic relationship-building, and then go above and beyond into whanaungatanga (Carlson et al., 2016). Whanaungatanga is the art of connectedness (Carlson et al., 2016; Lacey et al., 2011) which can be reflected in both informal and formal engagements between people. It involves an expectation of meaningful, purposeful engagement, grounded in mutual respect and caring (Lacey et al., 2011).

An example of this process is the use of tikanga Māori during formal engagements such as the pōwhiri ceremony (Opai, 2023). It helps to understand that the word "pōwhiri" (formal welcome) is made of two words, "pō" meaning "night" and "whiri" meaning "weaving". Joining these two meanings, the word pōwhiri indicates the process of weaving distinct peoples together, including their time shared and the ancestors of each party (Opai, 2023). The meaning of "manuwhiri" (guests) enhances this understanding — birds (manu) come to a place for a time and weave (whiri) with the people who are there. A pōwhiri begins with a karanga (calling). The word "karanga", again, strengthens the understanding of the process of connectedness. It derives from "raranga" (to weave), and indicates the start of the weaving of ancestral connections between hau kāinga (local people) and manuwhiri. Whaikōrero (oratory) and waiata (singing) follow after the two groups have come together and sat down. "Whaikōrero" is made up of the words "whai" (to follow) and "kōrero" (speech). Speakers from each side of the paepae (speakers' line) take turns at speaking, ie "following the speech". This further emphasises the process of connectedness. At the conclusion of speeches, the two parties become "one" with the use of hongi, pressing noses together and sharing the breath of life. This is followed by the sharing of kai (food) to whakanoa (make normal) and manaaki (take care of) all involved (Opai, 2023).

The common theme through this ceremony is weaving, using strands to create a strong korowai (cloak) that is bound together tightly and securely with whakapapa, shared experiences and connectedness. Time is spent weaving these strands together under the same roof. The weaving metaphor, which describes how the pōwhiri process builds whanaungatanga, the "art of connectedness", can also be applied to the way the therapeutic nursing relationship works.

The history of cultural safety in nursing

From the late 1980s through to 1990, meetings were held between education, health and nursing leaders to discuss two alarming and interconnected issues — the health needs of Māori, and the education needs of Māori nursing students, too many of whom were dropping out of their undergraduate courses (NCNZ, 2011; Ramsden, 2002; Richardson & Carryer, 2005; Wilson et al., 2022). During one of these meetings, a Māori nursing student voiced their concern about nursing education, saying they did not feel safe within the curriculum (Ramsden, 2002). A connection was then made to how Māori may feel when accessing health care in a dominant colonial culture (Richardson & Carryer, 2005). Led by nurse educator Irihapeti Ramsden, the concept of cultural safety — providing an environment in nursing education and in the health service in which Māori could feel culturally understood and free from racism and judgment — was introduced into nursing education and in 1990 became established as part of the Nursing Council of New Zealand nursing competencies (NCNZ, 2011; Ramsden, 2002). The concept was originally known as kawa whakaruruhau, but was renamed "cultural safety" in the 1990s due to racist social backlash, and was used to apply broadly to all cultures (Wilson et al., 2022). Kawa whakaruruhau is often used interchangeably with cultural safety, but via the Māori worldview it has a particular meaning of practice (kawa) and of protection (whakaruruhau) from discrimination (Wilson et al., 2022). Since the development of cultural safety/kawa whakaruruhau in nursing education and practice, there have been many different ethical, legal and professional documents and guidelines developed to guide and translate the concept into practice. It is currently guided by the Nursing Council's Standards of Competence for Registered Nurses (NCNZ, 2024b), Code of Conduct (NCNZ, 2012), and Guidelines for Cultural Safety, the Treaty of Waitangi and Māori Health in Nursing Education and Practice (NCNZ, 2011); also by the New Zealand Nurses Organisation Code of Ethics (NZNO, 2019) and the Health and Disability Commissioner Act 1994 Code of Rights" (2024). Te Tiriti o Waitangi — the document signed by Māori leaders and representatives of the British Crown in 1840 — is referenced in all these documents and holds professional and ethical practice by nurses accountable to the articles or principles of Te Tiriti.

Men's experiences in nursing

Historically, there has been a slowly increasing acceptance of women entering male-dominated professions. The opposite, however, is not true (Jamieson et al., 2019). In March 2023, it was reported that 10 per cent of the nursing workforce was male (NCNZ, 2024a). Male nurses bring diverse perspectives and unique strengths to the profession, challenging traditional gender norms and enriching patient care through their presence. The dominant western culture, characterised by misogyny, patriarchy (Came et al., 2022) and cis-heteronormativity (Cui, 2024), has negatively affected men entering female-dominated professions (Lazzaro-Salazar, 2020). This has been compounded by the common misconception that nursing is a "caring profession", and that men do not carry the appropriate "caring qualities" to be a nurse (Lazzaro-Salazar, 2020). Men working in the nursing profession must navigate these gendered stereotypes — the tensions between expectations of masculinity and femininity — ultimately leading to strain, gender discrimination and isolation (Hodges et al., 2017). On the other hand, men in the nursing workforce can have their career fast-tracked and promoted more than women (Lazzaro-Salazar, 2020), keeping in line with the gendered narrative of the colonial culture in Aotearoa.

Māori nurses' experiences in nursing

Māori nurses represent approximately 7 percent of the nursing workforce (NCNZ, 2024a) despite Māori comprising 17.1 percent of the population (Stats NZ, 2024). This is a consequence of Aotearoa's colonial history and its legacy of racism and discrimination (Came et al., 2019; Wilson et al., 2022). The under-representation of Māori in the nursing workforce, due to historical and current racism and discrimination, is tightly linked with the experiences of Māori nurses in the workforce. Experiences of racism and discrimination are still all too common for Māori nurses, which facilitates and perpetuates their under-representation in the nursing workforce (Wilson et al., 2022). Improved Māori representation in the nursing workforce is believed to be a key contributor to Māori achieving health equity (Wilson et al., 2022). This is due to the unique worldview Māori bring to the profession, their dual role as a Māori and a nurse, and their lived experiences of racism (Wilson et al., 2022).

Life experience as a tool for teaching

In two separate conversations, nurse educators John and Seamus articulated a shared philosophy: the most powerful teaching tool is one's own lived experience. They have both found unique ways to translate their personal journeys into lessons that resonate with students, to better prepare them for the realities of nursing in Aotearoa.

John's narrative:

> *I began my journey in nursing as a young Māori man in a largely female-dominated profession. At over six feet tall, I quickly realised my physical presence could be intimidating to people I was trying to care for. I knew I had to find a way to connect with people who might hold biases about me. I had to find ways that I could use the way that I look, the way that I stand, the way that I talk, my body language.*
>
> *With over 27 years of nursing experience, I've had time to master the therapeutic use of self. One of the first things I learned was to sit down. I never read that in any nursing manual. It was something I had been taught while working in acute mental health. It was an essential skill, especially if the person I was nursing were Pākehā, female and were very small. This simple act of lowering myself to their level was a form of communication that often helped to build trust. It's a lesson I now teach our male nursing students, showing them that their best resource is themselves, and that care is about meeting the patient where they are.*
>
> *My background in mental health and forensic services also gave me a unique perspective. I'd seen firsthand the effects of colonisation on Māori, not just in a historical sense, but in the systems and policies that continue to cause harm. Having worked to help develop a Māori forensic service, I've seen the dilemma of nursing up close: how do you provide wellness and optimal health for Indigenous peoples when the very systems we are in can be restrictive and harmful?*
>
> *This is why I believe that teaching manaakitanga is so important. For me, it is the ultimate expression of trustworthiness, a value I learned from my parents. My father, to put it in context, was from Tuhoe, and he came from Te Waimana Valley close to Opotiki. He was very self reliant ... we could always trust that he would always do right by us. Our mother, who is from Whatawhata in the Waikato, also exemplified these values. Their unwavering reliability is what I strive to provide for my students. I want them to trust that I will be a consistent presence in their learning journey and that I will honour their decision to come to me for help.*

Seamus's narrative:

> *I am a second-generation male nurse, with both my father and uncle working as registered nurses. My father graduated in the early '90s and my uncle in the early 2000s, so being a male nurse has not been a foreign concept for me and has in fact been normal for my entire life. With 12 years of nursing experience and a second generation male nurse in my whānau, my teaching focuses on applied sciences and pharmacology. It might seem like a rigid, scientific field, but I believe it is a perfect place to normalise te ao Māori and te reo. My ultimate goal is that te reo becomes a normalised, conversational language in Aotearoa. I do this by interjecting Māori words and concepts into my lectures. I'll be talking about pharmacokinetics and then introduce concepts like manaakitanga or whanaungatanga and explain how they apply. I am showing students how these two worlds, Western science and te ao Māori, can intersect and grow together.*
>
> *I also believe that my teaching is about more than just delivering content; it's about building trust and connection. My approach is to be as relatable as possible, so that students can come to me with any question, no matter what it is. I had two Pacific students who came to me for assistance with medication calculations and technology. They needed more than a lecture, they needed personalised support to help them understand how to find reliable information online.*
>
> *I believe that my role is to break down the power dynamics that can exist between students and teachers. Reflecting on my own student experience, when I see students today, I make myself available and approachable, ensuring they know that I am more than just a lecturer. I want them to know who I am, a father, a husband, a person to help break down those barriers. It is this authentic connection that allows students to feel comfortable enough to ask for help outside of class time.*

Shared perspective and implications

In both conversations, a powerful and unified philosophy emerged. John and Seamus are fundamentally committed to teaching cultural safety in an authentic and relational way. They demonstrate that Indigenous pedagogy is not an abstract theory but a living practice. By embodying the principles they teach, they empower their students to do the same.

They are also vital role models. By simply existing as Māori male nurses in academia, they challenge stereotypes and provide a counter-narrative to traditional perceptions of the nursing profession. They show their students that a nurse can be a protector, a leader, a scientist, and a cultural facilitator, all at once, making their lessons more compelling and helping to create a more inclusive learning environment for all.

The lessons from John's and Seamus's stories offer clear, actionable takeaways for all nurses and educators. Their approach challenges us to move beyond superficial training to embrace a more authentic, heart-centred practice.

- **For male nurses:** Tuakana teina (mentoring) — support other male nurses in the profession and male students aspiring to become nurses. Your experience as a male in a female-dominated profession provides valuable insights on how to nurture others into the role.
- **For educators:** Use your own life experiences as a teaching tool. Be authentic and vulnerable with your students, as this builds trust and makes learning more meaningful. Normalise the use of

te reo and te ao Māori in your everyday teaching, regardless of the subject.

- **For the nursing profession:** Recognise the immense value of manaakitanga. Actively recruit and support more Māori nurse educators, as their unique perspectives are crucial for a curriculum that is truly fit for purpose in Aotearoa.
- **For all nurses:** Embody the principles of whanaungatanga and manaakitanga in your daily practice. Approach every patient interaction with a commitment to building a trusting relationship and providing care that is culturally safe and based on authenticity.

Conclusion

The narratives of John and Seamus are a powerful testament to the value of Indigenous pedagogy in nursing education. Through their unique journeys as Māori men in nursing, they have forged a new path for teaching cultural safety, grounded in lived experience, building relationships, and a deep commitment to their students. Their shared philosophy demonstrates that to prepare nurses for the complexities of health care in Aotearoa, we must move beyond the confines of traditional teaching and embrace educators who model the very principles they seek to instill. In doing so, we not only honour the past, but also create a healthier and more equitable future for all.

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Perceptions of rongoā Māori among third-year nursing students in Aotearoa New Zealand

ABSTRACT

Background: Rongoā Māori is an Indigenous system of healing in New Zealand which reflects Māori knowledge and wisdom. Given that rongoā Māori contributes to the well-being of Māori and is a significant health practice among the Māori population, there is a need to increase awareness of it among health-care professionals. However little is known about third-year nursing students' knowledge and perceptions of rongoā.

Aims: The purpose of this study was to examine third-year nursing students' attitudes and beliefs about rongoā Māori.

Methods: This descriptive qualitative study was conducted at a tertiary education institution in New Zealand using an anonymous online questionnaire. Qualitative data collected from open-ended questions were analysed using thematic analysis.

Results: A total of 187 students enrolled in the third year of a nursing degree programme at a tertiary education institution were invited to participate, of whom 73 completed the survey (response rate 39 percent). Key themes emerged, including positive attitudes towards rongoā Māori, uncertainty about rongoā, and barriers to integrating rongoā into care.

Conclusion: Although nursing students value the cultural significance of rongoā in supporting Māori tino rangatiratanga in health, they see cultural and systemic barriers to its implementation into the health service. They see the lack of policies about rongoā Māori reflecting broader cultural and systemic barriers where Indigenous knowledge systems are undervalued and marginalised within a Western-dominated health-care system.

KEYWORDS

Rongoā Māori, culture, nursing students, education, nursing practice

INTRODUCTION

In Aotearoa New Zealand, the role of the Waitangi Tribunal is to investigate claims brought by the Indigenous Māori population related to government actions or inactions in relation to the Treaty of Waitangi (signed by Māori leaders and the British Crown in 1840). Reporting in 2011 on the WAI 262 claim, the tribunal highlighted the need for government institutions to support and protect traditional Māori knowledge and practices, including rongoā (Waitangi Tribunal, 2011). Rongoā is a system of healing based on Māori tikanga (customs and traditional wisdom), incorporating herbal remedies, physical therapies such as mirimiri (massage), and spiritual healing. In February 2025, the Nursing Council of New Zealand (NCNZ) redeveloped its nursing competency framework. The revised standards of competence for registered nurses (RNs) require all RNs in Aotearoa New Zealand to incorporate knowledge of both tangata whenua (people of the land, ie Māori) and tangata tiriti (people of the Treaty, ie non-Māori New Zealanders) into practice (NCNZ, 2025). This competence framework aligns with contemporary nursing practice and emphasises that all nurses must support Māori health equity, advocate for patient preferences, and uphold kawa whakaruruhau (cultural safety) in their nursing practice.

Rongoā is an Indigenous system of healing, grounded in mātauranga Māori (Māori ways of knowing) and is a legitimate expression of tino rangatiratanga (self-determination) under Te Tiriti o Waitangi (Jones, 2000; Mark et al., 2019). As a traditional medicine, it reflects Māori cultural values, beliefs and ways of life, highlighting the interconnectedness of land, plants, family, spirituality and physical well-being (Jones, 2012; Jones, 2000; Mark et al., 2017; Thompson et al., 2025). For centuries, Māori people have benefitted from this holistic and cultural healing practice, which involves physical treatment, herbal remedies and the spiritual dimension of healing (Jones, 2012). Rongoā practice is guided by Māori tikanga (customs and practices), and advice from the New Zealand Nurses Organisation (NZNO, 2011) suggests the role of nurses, in providing culturally informed care, is to advocate for rongoā where appropriate and refer patients to rongoā practitioners. The Nursing Council of New Zealand makes it clear in its standards for competence of registered nurses (2025) that RNs are required to recognise cultural preferences for complementary treatment, such as rongoā, and support their integration into client care. However a survey of staff at Auckland's Waitemata District Health Board, published in 2020, which investigated the potential integration of rongoā in hospital systems in Aotearoa New Zealand, found only 46 percent of respondents were familiar with rongoā, and just a third were willing to support it in their practice (Koea & Mark, 2020). Researchers argue that various barriers, including misunderstanding of rongoā, the context-specific nature of traditional health practices, and a lack of knowledge, have hindered health professionals from supporting the integration of this Indigenous therapy into the health service (Ahuriri-Driscoll et al., 2008). They have also argued that culturally bound and Indigenous knowledge systems are potentially marginalised in the Western-dominated health-care system (Te Huia & Mercer, 2019).

Given that rongoā contributes to the well-being of the Māori population and is a significant health practice in improving Māori health, there is an urgent need to increase awareness of it among health-care professionals. Little is known about third-year nursing students' attitudes and perceptions regarding rongoā Māori. Their beliefs, knowledge and attitudes are likely to shape how confidently and competently they support rongoā Māori in their future nursing practice. As tertiary students' understandings of rongoā Māori have not previously been investigated in Aotearoa New Zealand, this study seeks to answer the question: *"What are third-year nursing students' attitudes and beliefs about rongoā Māori?"*

METHOD

Design

This descriptive qualitative study was conducted at a tertiary education institution in New Zealand and aimed to investigate the attitudes, understandings and perceptions of third-year nursing students regarding rongoā Māori. The researchers developed an anonymous online questionnaire using Qualtrics survey software. A total of 10 questions were developed, covering demographic information and understandings and attitudes towards rongoā. The survey included open-ended questions, which allowed participants to respond in their own words rather than choosing from pre-defined answer options. These open-ended questions helped elicit more descriptive qualitative data (Hansen & Świderska, 2024).

This study included participants who met the following criteria: third-year nursing students, currently enrolled in a bachelor of nursing programme leading to RN registration, at a tertiary education institution in New Zealand. A matrix barcode (QR code) was generated using Qualtrics survey software, which was distributed to all third-year nursing students at the institution.

ETHICAL CONSIDERATIONS

This qualitative survey was conducted after receiving ethics approval (approval number: WTLR03030325) from the Human Ethics in Research Group (HERG) of a tertiary education institution in New Zealand. The survey's information section provided participants with a full explanation of the study's purpose and assured them of the survey's anonymity. To confirm the reliability of the online survey, the questionnaire was piloted and sent to a co-researcher for verification of its content before distribution. To minimise potential coercion, the researchers made an explicit statement on the first page of the survey that participation was completely voluntary. Participants could decline the survey by clicking the answer "No" on the first page of the survey if they did not wish to participate. No identifiable information was collected, which helped protect participants' privacy and ensured confidentiality.

DATA ANALYSIS

The open-ended questions in the survey aimed to explore participants' perspectives and feelings about rongoā Māori. Data collected from these questions were analysed using thematic analysis. This is a research method that has been widely used to investigate qualitative data, such as interview transcripts and survey responses (Braun & Clarke, 2021). Thematic analysis typically involves the following steps: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, interpreting themes and producing the analysis (Braun & Clarke, 2021).

FINDINGS

The online survey was live for participants to complete from April 23 to August 1, 2025. It took participants 15-20 minutes to answer all the questions. The demographic section of the survey asked for the participants' age, gender and self-identified ethnicity. A total of 187 students enrolled in the third year of the undergraduate nursing degree programme were invited to participate, of whom 73 completed the survey (respondent rate 39 percent). As shown in Table 1, of the 73 participants who completed the survey, 82 percent (n=60) were female, and 18 percent (n=13) were male. Through analysing the data, key themes emerged, including positive attitudes towards rongoā Māori, uncertainty about rongoā, and barriers to integrating into practice.

Positive attitudes towards rongoā Māori

Participants were asked about their feelings or attitudes towards the integration of rongoā into health care. Comments from participants

Table 1. Characteristics of participants

	Number (n=73)	Valid %
Gender		
Female	60	82%
Male	13	18%
Age		
Under 25	28	38%
25-35	26	36%
36-45	13	18%
46 and over	6	8%
Ethnicity		
Māori	9	12%
Pacific Islander	5	7%
NZ European	20	27%
Asian	27	37%
Other	12	16%

showed positive attitudes towards rongoā. Some participants stated that rongoā supports appropriate and holistic care, as reflected in the following direct quotes.

> *I feel that is important to have awareness of rongoā as a nurse in the New Zealand context. Like any traditional medicine, there are benefits to its simplicity and values of achieving a holistic wellness.*

> *It helps nurses understand how to care for our Māori/ Indigenous communities.*

> *I do think it will be hard to integrate rongoā into modern practices. How long we've been practising Western medicine? The benefits of incorporating these traditional practices are obvious, such as improving the outcomes of our Māori patients, building trust and improving well-being.*

> *Benefits include improving health outcomes, building rapport and working in partnership with Māori patients.*

Some participants saw rongoā as a traditional cultural heritage which should be embedded into client care in Aotearoa New Zealand.

> *Rongoā should be integrated into modern nursing practice because it would allow patients to have a second option in terms of their health. In my culture, rongoā, or herbal medicine, is very common for people to use as an alternative for medicines. I think this would empower patients to have control over their health and as well as connect to their culture.*

> *This will make sure that the future generations will become acquainted with the traditional healing methods.*

> *Rongoā provides not only physical remedies but allows a space for spirituality and cultural ... practice.*

Some participants linked rongoā Māori to culturally safe nursing practice.

> *Integrating rongoā into nursing supports holistic, culturally safe care, but it must be done respectfully and collaboratively.*

> *We are trained in Aotearoa New Zealand, where culturally safe practice is required, which means that we need to understand Māori and other Indigenous cultures in health practice.*

> *It's a vital cultural consideration for Indigenous clients, to complement health care dominated by biomedicine.*

Other participants mentioned that rongoā could be complementary to Western medicine.

> *I think rongoā would be a great incorporation for modern nursing practice especially in regard to Māori patients being able to connect back with their own healthcare remedies rather than westernised medications which may not be beneficial for them.*

> *It should be available for all people who would like it alongside western care.*

> *I support its integration in modern nursing practice because currently, the practices are based on western traditions. The integration would allow Māori to feel safer in engaging with healthcare.*

> *I perceive rongoā to be a great intervention in ways that modern medicine may not be. It's not as invasive and detrimental to the body systems as Western medicine does.*

Uncertainty regarding rongoā Māori

While the majority of participants held positive attitudes about rongoā Māori, some expressed feelings of uncertainty about this traditional Māori health practice. One participant argued that,

> *It may be beneficial in cases where pharmaceutical methods of healing are ineffective, but I'm not sure.*

Some participants were hesitant about the integration of rongoā into client care due to uncertainty about the potential benefits and side effects. They argued that it would be challenging to promote rongoā without scientific evidence. For example, some participants argued that

> *I, myself, have to know a lot, needing a lot of research regarding it, if I am to recommend or suggest to the patients.*

> *I don't have the knowledge, I would need to learn more, to be able to utilise this approach in nursing practice when needed.*

> *We don't understand the contraindications and side effects*

> *of rongoā.*
>
> *They have been taught evidence-based practice but have not been given scientific evidence on rongoā Māori.*

Barriers to integrating rongoā Māori in practice

Participants reported the potential challenges they saw to the integration of rongoā Māori into the current health-care system, including cultural barriers and system barriers.

Cultural barriers

Some participants noted that international nursing students have had no exposure to Māori culture, and therefore it would be difficult for them to understand and support rongoā Māori in their nursing practice.

> *As an international student, I have never heard about this, and don't know what to do with it.*
>
> *People have different beliefs and worldviews regarding traditional health practice, especially when studying as an international student.*
>
> *Not many modern healthcare workers could be interested or open to the idea of incorporating rongoā into their practice.*
>
> *Health practitioners may not want to prescribe or put their registration on the use of it as they may have their own bias or unwillingness to support the use of rongoā.*
>
> *Some health professionals might not believe in a holistic approach so it might be challenging to get people like that on board with integrating it.*

Some participants reported their concern about potential racist views about rongoā Māori.

> *I feel that racism is still very present and therefore some may be hesitant or resistant to learning about rongoā or even to completely understand, as even though some wish to embrace rongoā, it's only on surface level.*
>
> *I've found lots of complaints from other students asking why certain parts was relevant but not fully understanding the concepts completely, which is unfortunate. As most western medicines are so destructive on the human body whereas rongoā can be less harmful and a therapeutic approach to clinical treatment (in the right settings).*
>
> *I am not properly well equipped therefore would need adequate education to incorporate it. But health professionals might not be open to this practice — especially in the current political climate in NZ.*

Systemic barriers

Participants also reported systemic barriers as being likely to place some limits on integration of rongoā Māori into the health service. These could include a lack of clear policies and access to resources, the shortage of Māori in the health workforce, and limited understanding and education opportunities regarding these traditional health practices.

> *There are no clear policies regarding treatment options, and it would be challenging to obtain informed consent and navigate regulatory and institutional policies.*
>
> *Benefit would be improvement in mental and physical well-being of Māori. However, there are not many Māori colleagues who understand and support rongoā.*
>
> *Challenges are that many people dismiss rongoā as being ineffective or getting in the way of traditional western healing. Also, many healthcare professionals don't understand how rongoā works and have never learnt about it.*
>
> *Many people lack awareness of rongoā, including doctors and nurses, they have no knowledge about rongoā Māori.*
>
> *Access to resources may be challenging within a hospital setting and we don't know where to find useful resources regarding rongoā Māori .*

DISCUSSION

Rongoā Māori, a traditional healing process, has been a way of living for Māori for centuries. It benefits the Māori population by providing a holistic approach to health and well-being. This study was designed to investigate third-year nursing students' attitudes and beliefs about rongoā Māori. In this study, participants reported positive attitudes towards rongoā Māori, including its unique cultural wisdom, holistic healing process, and connections to whakapapa and te ao Māori. These findings correspond with scholarly work which contends that the use of rongoā is an important aspect of health care for Māori as it represents whakapapa and culture grounded in Māori worldviews (Durie, 2010; Jones, 2012; Mark et al., 2017).

Rongoā is an essential element of the traditional Māori healing process, and is commonly used as a complementary and alternative medicine (CAM) by the Māori population of Aotearoa New Zealand. Researchers have argued that the value of traditional knowledge is increasingly accepted, and Indigenous and holistic understandings of rongoā are being recognised as having "a newfound contemporary significance" (Ahuriri-Driscoll et al., 2008, p. 6). The international landscape also supports this approach. The World Health Organization (WHO) notes that of 194 member states, 170 report the use of traditional or complementary medicines, and many developed countries have recognised and integrated traditional medicine into their health systems (WHO, 2023). The WHO's Western Pacific member states have shown strong acknowledgement of traditional complementary medicine (TCM), with 93 percent of them using TCM as part of traditional healing, and for illness prevention and treatment (WHO, 2021). In Aotearoa New Zealand, some nursing education providers have shown small movement towards integration of rongoā into curricula, despite the lack of formalised legislation for traditional medicine (Te Huia & Mercer, 2019).

A positive finding of this study was that participants were able to link rongoā Māori to culturally safe practice, which is required of nurses by the Nursing Council of New Zealand. The Nursing

Council's Standards of Competence for Registered Nurses framework strongly emphasises the rights of Māori as tangata whenua and requires nurses to incorporate knowledge of cultural safety into practice (NCNZ, 2025). The New Zealand Nurses Organisation (NZNO) has clearly outlined the role of nurses in rongoā Māori and complementary therapies, encouraging nurses to understand the relevance and cultural foundations of rongoā (NZNO, 2011).

While participants in this study expressed positive attitudes about, and understanding of, rongoā, they also raised what they saw as significant potential barriers to the integration of rongoā into the health service. Uncertainty about rongoā was one of the concerns raised by participants. Some said health practitioners' lack of knowledge about rongoā and limited educational opportunities to learn about traditional Māori healing practices were barriers to culturally responsive care. In New Zealand, rongoā is regulated by tikanga and kawa, rather than a regulatory body. The NZNO rongoā guidelines state that the nurse's role is to advocate for patient preferences by referring patients to rongoā practitioners and supporting the integration of rongoā into client care (NZNO, 2011). Clarity about the role of nurses as advocates can enhance student nurses' confidence about their role in an interdisciplinary approach to holistic care.

The ability of health-care professionals to advocate for rongoā for a person who chooses this complementary health treatment can be undermined by lack of understanding and knowledge of indigenous cultural health practices. This study found that although third-year nursing students who participated might value rongoā traditions, some of them might not understand its significance or be confident about advocating for it in their future nursing practice. The literature also suggests that a lack of knowledge may limit people's understanding of the relationship between rongoā and conventional health practices, despite many health professionals expressing a desire to learn more about it (Mark & Koea, 2021). In this study, some participants felt hesitant that they would be able to promote rongoā without robust clinical research to support its benefits and safety, commenting that "it's not evidence-based practice". Rongoā Māori is culturally bound and requires knowledge of Māori tikanga, which may not always align with Western clinical trials. The notion of evidence-based practice has been criticised for amplifying empirical data without balancing it with cultural context and patient values and beliefs (Kumah et al., 2022). The Nursing Council's (2025) standards of competence require RNs to engage in evidence-informed practice that is underpinned by critical thinking and high-quality current evidence, and to take greater account of culture and patient values in providing safe nursing care.

The findings of this study highlight policy gaps that stand in the way of integrating rongoā Māori into the current health-care system. Participants thought that cultural and systemic barriers were major contributing factors for ineffective integration of rongoā into health services. Some pointed out the lack of regulatory and institutional policies on rongoā. The literature agrees, asserting that the lack of supporting policies is a major barrier to integration of rongoā (Mark & Koea, 2019; Thompson et al., 2025). Existing health policies often neglect Indigenous knowledge systems, which limits the ability of health-care professionals to incorporate rongoā Māori into treatment plans. The absence of clear policies that promote collaboration between rongoā practitioners and health services has been identified as a critical gap that requires urgent attention (Thompson et al., 2025). Political gaps are evident where legislative and Treaty provisions do not align, and where the law does not accommodate Indigenous cultural preferences or rights (Waitangi Tribunal, 2011).

In this study, participants reported concerns that prejudice, framed as "racism", might stand in the way of further integration of rongoā. A lack of understanding of Indigenous medicine can lead to scepticism or even dismissal of rongoā as a complementary healing methodology (Mark & Koea, 2019). In New Zealand, Western health approaches are the mainstream, with a focus on pathological processes. Some health professionals may hold prejudices about the effectiveness of traditional Māori healing practices. By raising awareness of rongoā Māori, nurses can challenge these ideas and improve culturally appropriate care. Educational initiatives should incorporate both practical applications and the philosophical foundations of rongoā, helping raise awareness of rongoā Māori and bridging the gap between traditional healing practices and modern health care (Mark & Koea, 2021). Collaboration between rongoā practitioners and conventional health-care professionals could help create a collective understanding of both practices (Thompson et al., 2025).

CONCLUSION

While nursing students in our study may recognise the cultural significance of rongoā in promoting Māori health and well-being, they can see there remain cultural and systemic barriers to its implementation into general health care. These barriers include a lack of policies related to rongoā, reflecting the undervaluing and marginalisation of Indigenous knowledge systems in the Western-dominated health-care system. This study emphasises the need for systemic adaptation. Providing clarity about rongoā Māori by further developing regulatory guidance, training programmes and stronger interdisciplinary partnerships can help equip health-care professionals with the skills to incorporate rongoā Māori into culturally safe practice.

CLINICAL IMPLICATIONS

Nurses represent the largest group in the health-care workforce in Aotearoa New Zealand. This study highlights the need for nurse educators to provide education on holistic Māori healing systems and the safe integration of rongoā in clinical care settings.

LIMITATIONS OF THE STUDY

The limitations of the research are related to the relatively small sample size and the use of only one tertiary education institution as the study site, which limits the generalisability of the research findings. Given this constraint, it would be useful to conduct a larger national study to understand nursing students' perspectives and attitudes related to rongoā Māori.

Another limitation of this study is that it does not have a comparative analysis with nursing programmes that are deeply embedded in Māori culture and practices. Therefore, further comparative studies with nursing programmes are recommended to strengthen nurses' understanding of cultural preferences and support the integration of rongoā into care.

Conflicts of interest

No conflicts of interest.

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Appendix A: Glossary of Māori terms

Aotearoa – The Māori name for New Zealand, which translates as “the land of the long white cloud”.

Kawa whakaruruhau – A nursing framework that ensures nurses deliver care in a way that is respectful of Māori and Tiriti o Waitangi obligations.

Mātauranga Māori – A body of knowledge originating from Māori ancestors, including the Māori world view, values, and ways of knowing.

Pou – Literally “post” or “pillar”. In this context, a guiding standard or principle (as in the Nursing Council competency pou).

Rongoā Māori – Traditional Māori healing system encompassing herbal medicine, massage (mirimiri), spiritual healing, and other culturally grounded practices.

Tangata Tiriti – People of the Treaty. Those in Aotearoa New Zealand whose rights to be here derive from Te Tiriti o Waitangi, who are usually non-Māori.

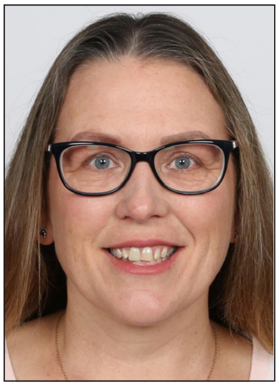
Tangata whenua – People of the land; Māori as the Indigenous people of Aotearoa New Zealand.

Te Tiriti o Waitangi – The Treaty of Waitangi, signed in 1840 between representatives of the British Crown and many Māori chiefs; considered New Zealand’s founding document and a cornerstone for Māori-Crown relationships.

Tino rangatiratanga – Self-determination, sovereignty, or the authority to make decisions and control resources; a key concept in Māori rights and governance.

WAI 262 – A significant Waitangi Tribunal claim lodged in 1991 concerning Māori rights to indigenous flora, fauna, cultural knowledge and intellectual property.

Whānau – Extended family or community of related families who share a common ancestor.



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The lived experience of gout: A qualitative meta-synthesis

ABSTRACT

Background: This meta-synthesis explores the lived experiences of individuals as they navigate their journey with gout. Nurses must recognise gout as a highly treatable condition, enabling them to deliver high-quality, relevant care to those affected.

Objective: To explore the lived experiences of people with gout.

Methods: A qualitative meta-synthesis was undertaken using meta-ethnography. Electronic databases searched included CINAHL Plus, PubMed and Medline. Qualitative studies published in English that reported rich descriptions of the lived experiences of people with gout were sought for inclusion. No date limiters were applied.

Findings: Twenty primary research studies were selected for inclusion in this review. The overarching theme that emerged from the synthesis was the ripple effect from gout flares impacting a person's entire life. Three subthemes and storylines were identified: Disrupted lives (Pain is disruptive), Misconceptions about gout (Misunderstanding and missed management), and Finding a sense of agency (Negotiating how to live with gout).

Conclusion: People living with gout are confronted with challenges in the physical, mental, emotional and social aspects of everyday life. They are sometimes reluctant to seek treatment because of the assumption that it is self-inflicted and therefore should be silently endured. Nurses need to understand the lived experience of gout and the opportunities for providing optimal support, enabling individuals to manage their condition more effectively and increase their own agency over their bodies, thereby reducing the impact that gout has on overall well-being.

KEYWORDS

Gout, chronic disease, lived experience, pain, stigma, sense of agency

INTRODUCTION

This meta-synthesis explores the lived experiences of individuals with gout as a chronic condition. Gout is the most prevalent and uniquely curable form of inflammatory arthritis worldwide (Doherty et al., 2012; Kuo et al., 2015). Although it is treatable, sub-optimal treatment is widespread globally. Gout is notorious for acute, sporadic and debilitating episodes known as gout flares, resulting in severe pain and causing progressive disfigurement (Sivera et al., 2022). This pain can limit physical activity, leading to increased time off work, which affects earning capacity, reduces socialisation and affects mental health (Smith et al., 2011). The review question was framed as: *What are the lived experiences of people with gout?*

BACKGROUND

Nurses need insight into the prevalence and lived experience of gout to provide good health care (Dehlin et al., 2020). The prevalence of gout worldwide ranges from 1 percent to 10 percent, depending on population demographics (Galassi et al., 2024). A greater prevalence is found in men and older populations, as well as in certain ethnic groups, suggesting a genetic predisposition (Galassi et al., 2024; Kuo et al., 2015). Oceanic countries, particularly those with significant populations of Taiwanese, Aboriginal, Pacific and Māori descent have the highest prevalence of gout. Along with ethnicity, other demographic factors also affect gout prevalence, including age and gender (Dehlin et al., 2020; Sivera et al., 2022).

For instance, the prevalence of gout in New Zealand is among the highest internationally, affecting approximately 6 percent of the total population aged over 20 years (Dalbeth et al., 2018; BPACnz, 2021). The prevalence of gout among Māori is double that of European and other ethnicities, and the incidence of gout in Pacific peoples is triple that of European and other ethnicities (Gout, 2019).

People who experience the intial stages of gout are often unaware of the potential for it to develop into a chronic, disabling disease, which can affect their quality of life and become permanently disabling (Wertheimer et al., 2013). People living with chronic disease have complex needs, requiring a range of health-care services, which necessitate empowering the individual to self-manage their disease. Understanding the lived experience of people with chronic diseases such as gout empowers and motivates nurses to engage in patient-centred health-care management strategies. (Nolte, 2008).

As a chronic disease, gout progresses through four stages, starting with asymptomatic hyperuricemia and progressing to chronic pain and loss of function (Ragab et al., 2017). In the first stage, signalled by high levels of uric acid in the body, people have no symptoms (Afzal et al., 2025). In the second stage, the uric acid starts to form urate crystals which often collect in the joints, causing sudden, severe pain, swelling and heat, also known as a gout attack, or flare. While symptoms usually improve within two weeks with the use of anti-inflammatory medication or steroids, over time these flares may increase in frequency, severity and duration (Dalbeth et al., 2016; Smith & Karakashian, 2018; Wertheimer et al., 2013). During the third stage, people are mostly asymptomatic, and the condition appears to be resolved. However, the deposit of crystals from persistent hyperuricemia continues to build (Afzal et al., 2025). This stage is also referred to as inter-critical gout (Smith & Karakashian, 2018). The fourth stage is chronic tophaceous gout, which develops approximately 10 years from the first presentation, where earlier stages have been insufficiently treated (Afzal et al., 2025). This stage can destroy bones and joints, causing severe deformity and probable renal impairment (Smith & Karakashian, 2018).

The fact that gout is a chronic disease requires clear communication with patients to prevent misinterpretation that may hinder treatment (Talaat et al., 2021). Implementing a treatment plan formulated between the individual and the nurse involves educating individuals about how to monitor and manage symptoms by addressing underlying causes, and recommending both pharmacological and non-pharmacological treatments (Benn et al., 2018). Supporting people in managing the greater impact of gout involves educating them about a health-promoting lifestyle and making informed nutritional choices (Regan-Smith et al., 2022; Rimler et al., 2016). Clinical guidelines recommend long-term management with urate-lowering drug therapy, such as allopurinol, probenecid and febuxostat (Gill et al., 2020) to control gout. Initiating urate-lowering therapy using a dose-escalation strategy, combined with prophylactic low-dose anti-inflammatory therapies or colchicine, can reduce gout flares and is effective in achieving treatment targets (Dalbeth et al., 2019).

Education includes highlighting to the person with gout the likelihood that they are genetically predisposed to the condition to remove any perception that it is self-inflicted (Benn et al., 2018). Health practitioners must be cautious about enforcing unrealistic lifestyle and dietary modifications that may evoke feelings of self-blame (Pillinger & Mandell, 2020). There are effective and readily accessible treatments for gout. However, the disease burden of gout is increasing worldwide and is associated with significant morbidity (Meyappan et al., 2021).

METHODS

Study design

The design of this study is qualitative meta-synthesis, informed by meta-ethnography. Meta-ethnography is one of the most developed methods for synthesising qualitative research studies on a particular topic (Hannes & Lockwood, 2012). It is an inductive approach that seeks to interpret multiple studies by integrating their findings (Sattar et al., 2021) to develop broader analytical insights, enabling a deeper understanding of a phenomenon. Meta-ethnography is particularly appropriate for developing conceptual models and theories, and can be used in health care to generate evidence and inform policy. France et al. (2019) propose that meta-ethnography can offer new insights into how patients perceive their health conditions, affect their adherence to treatment and enhance understanding of the effectiveness of interventions. There are seven phases in conducting a meta-synthesis using meta-ethnography (France et al., p. 2), as shown in Table 1.

Table 1. The seven phases in meta-ethnography

Phase 1	Identifying a phenomenon of interest that qualitative research might inform
Phase 2	A systematic review of the literature
Phase 3	Reading the studies
Phase 4	Determining how the studies are related
Phase 5	Translating the studies into one another
Phase 6	Synthesising translations
Phase 7	Expressing the synthesis

Identifying a phenomenon

The phenomenon of interest was identified as the lived experience of gout, and the review question was framed using the PICo (Population, Phenomenon of Interest, Context) framework. The population consisted of adults, the phenomenon of interest was their lived experiences, and the context was gout.

Systematic review of the literature

A systematic search for peer-reviewed published qualitative studies on people's experiences of living with gout was implemented with the assistance of an expert librarian. Electronic databases searched included CINAHL Plus, PubMed, MEDLINE, ScienceDirect, DOAJ, CORE, OVID and Cochrane, without date limiters, up to the final search date. Table 2 summarises the PICo structure used to frame the search for primary qualitative studies in response to the review question. The CINAHL search string is outlined in Table 3, and was adapted for use in the other database searches. The search strings

Table 2. PICo table

	Key words	Synonyms
P – Population	Adults	Adults
I – Phenomenon of Interest	Lived experiences	Experience, perceptions, thoughts, feelings, opinions, attitudes, beliefs or emotions
Co - Context	Gout	Gout, hyperuricemia

Table 3. Search terms

Qualitative studies: The lived experience of gout		
	Concepts	**Additional key words**
Population	Adults	Adult* OR age* OR geriatric OR “old person” OR “elderly person” OR “middle age” OR senior OR “young adult”
Phenomenon of interest	The lived experiences	Experience OR “lived experience” OR “patient experience” OR “personal experience” OR perception* OR thought* OR feeling* OR opinion* OR belief* OR attitude OR “attitude* to illness” OR emotion*
Context	Gout	Gout OR “gouty arthritis” OR hyperuricemia

table is set out in Supplementary File 1.

The electronic database references were exported and duplicates removed using citation management software (Zotero) before being imported into Covidence Systematic Review Software (Veritas Health Innovation, 2023) for screening. A hand search of the reference lists of the included studies was also undertaken to identify any additional articles that were not found through database searches.

Study selection

Two reviewers, PM and TJ, undertook a two-stage blind screening process in Covidence. The reviewers independently screened title and abstract records, followed by full-text screening of records that potentially met the inclusion criteria. Conflicts in screening were resolved through consensus by the two reviewers.

Critical appraisal

The included studies were critically appraised in duplicate (TJ & PM) using the JBI 10-item critical appraisal checklist for qualitative research studies (Porritt et al., 2024). A quality appraisal was undertaken to assess and report the methodological quality, including ethical review (Munn et al., 2018), and the results were tabulated and reported. All subsequent studies then proceeded to data extraction, tabulation and narrative summary. The critical appraisal table is included as Supplementary File 2.

Data extraction

Two reviewers (TJ & PM) independently extracted data into the predetermined fields of the data extraction framework in Covidence. The extraction fields included publication details, study design and objectives.

Data synthesis

Phase 3 marks the beginning of the synthesis (Sattar et al., 2021), during which researchers become familiar with key concepts and metaphors in each study by repeatedly reading the studies (Sattar et al., 2021). Phase 4 involves determining how the studies are related to “put them together” (Noblit & Hare, 1999, p.111). This phase involves determining how the different studies relate to one another (France et al., 2019) and formulating themes, concepts and metaphors to compare and contrast them (Atkins et al., 2008). Phase 5 involves translating the studies into one another (Noblit & Hare, 1999), which entails a meticulous comparison of the meanings of concepts and metaphors across different studies to determine the range of concepts. The key to translation is interpreting meaning (France et al., 2019). Reciprocal translation involves directly comparing and combining studies to gain a deeper understanding. Refutational translation occurs when the studies oppose one another. Phase 6 is the second-level synthesis, where translations from the previous phase are further developed by comparing them to identify similar concepts and form interpretations that extend beyond the findings from individual studies (France et al., 2019). The findings (Phase 7) are set out in the following section.

RESULTS

Search strategy

The electronic database search produced 365 studies; 43 studies proceeded to full-text review, and 20 studies met the inclusion criteria. The search, screening and selection process is set out in Figure 1.

Characteristics of the included studies

Twenty studies met the inclusion criteria for this meta-synthesis. All studies were published in English between 2011 and 2024. The studies were all primary studies, with two being original research and 18 published in journals. Studies originated from the United Kingdom, Australia, Spain, New Zealand, British Columbia, Canada, China, Singapore, the United States and the Netherlands. Seven of these studies were from New Zealand. Interviews were conducted in various settings, including primary and secondary care, people’s homes and workplaces. Most interviews were face-to-face, while some were conducted over the phone. The study designs were all qualitative; most studies were descriptive and explorative, two used a grounded theory approach, and one used a mixed-method approach. The characteristics of the included studies are summarised in Table 4.

Figure 1. The search and screening process

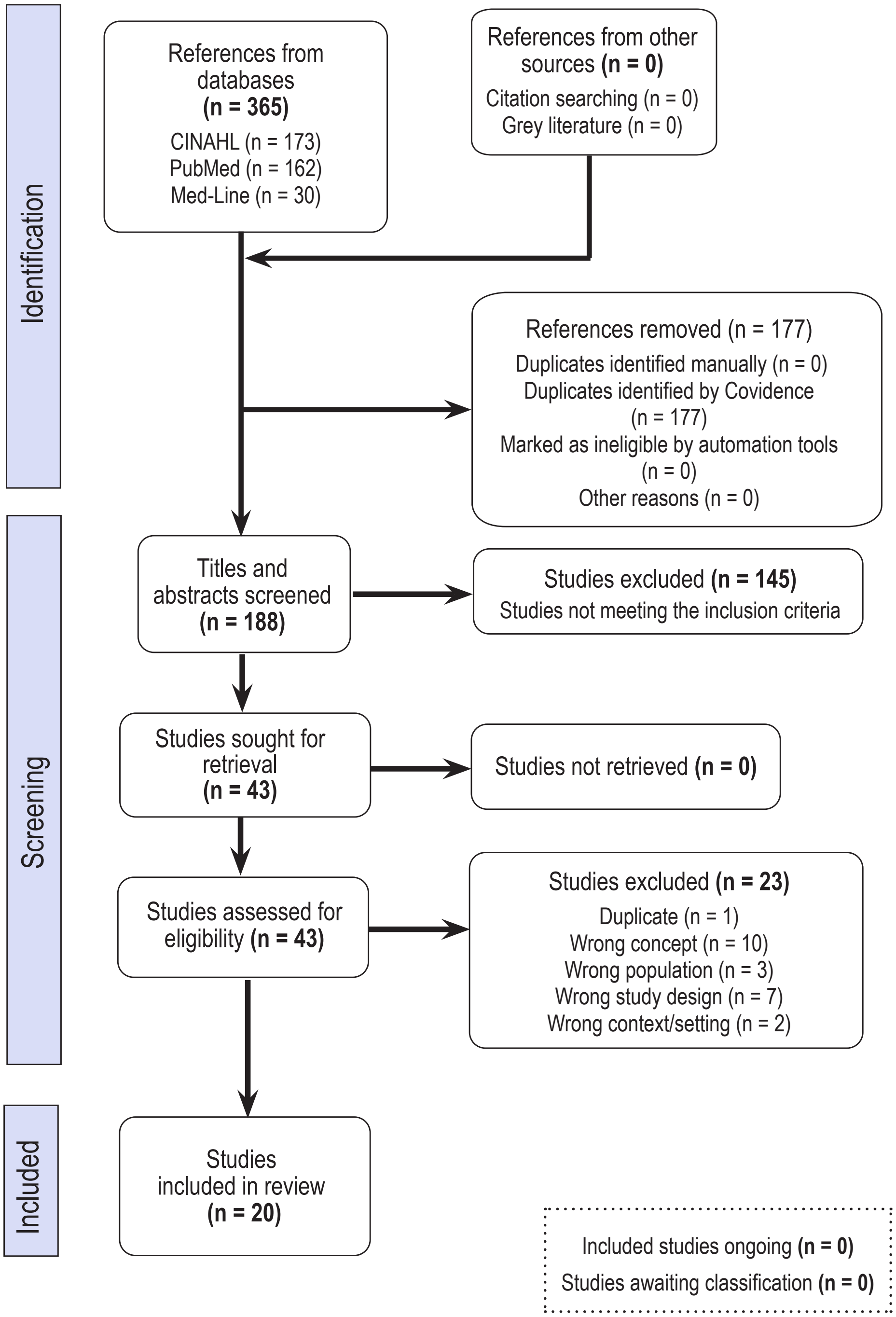

Table 4. Characteristics of studies

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Objectives
Chandratre, P., Mallen, C. D., Roddy, E., Liddle, J., Richardson, J.	"You want to get on with the rest of your life"	2016	Clinical Rheumatology	United Kingdom	Mixed primary and secondary care settings	Qualitative study Thematic analysis	Examine the impact of gout and its treatments on health-related quality of life (HRQOL) using focus group interviews.
Coleman, W., Spencer, D., Wong, P., Manolios, N.	An enquiry into the crippling gout affecting Pacific Islander and Māori men in Western Sydney	2021	International Journal of Rheumatic Diseases	Australia	Westmead Hospital and the homes of the participants	Thematic analysis 'Grounded theory' approach	Although the high prevalence and increased severity of gout in this cohort has been well documented, there has been little qualitative research undertaken in Australia into the lived experience of this group of people. It is this gap in the research that this study aimed to address.
Coulshed, A., Nguyen, A. D., Stocker, S. L., Day, R. O.	Australian patient perspectives on the impact of gout	2020	International Journal of Rheumatic Diseases	Australia	1-on-1 interviews, either in person or by telephone	Qualitative study Thematic analysis Semi-structured interviews	Explore the perceptions of patients on the impacts of gout, in an Australian context.
Diaz-Torne, C., Pou, M. A., Horne, A., Gasteiger, C., Dalbeth, N.	'Gout was like the boss'	2024	Rheumatic and Musculo-skeletal Diseases	Spain and New Zealand	University of Auckland, or at the Hospital de la Santa Creu i Sant Pau, Barcelona	Qualitative study Semi-structured interviews	This study aimed to understand the impact of gout on employment.
Frecklington, M., Williams, A., Dalbeth, N., McNair, P., Gow, P., Rome, K.	The footwear experiences of people with gout	2019	Journal of Foot and Ankle Research	New Zealand	Either at the Auckland University of Technology or their home	Qualitative, descriptive methodological approach Semi-structured interviews	The aim of this study was to carry out an exploration of the footwear experiences of people with gout.
Garcia-Guillen, A., Steward, S., John-Taylor, W., Gaffo, A., Dalbeth, N., Su, I., Gott, M., Slark, J., Horne, A.	Gout flare severity from the patient perspective	2020	Original article	New Zealand	Private room at the University of Auckland Clinical Research Centre	Reflexive thematic approach	This qualitative study examined what factors contribute to the severity of a flare from the patient perspective.

Table 4. Characteristics of studies (continued)

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Objectives
Howren, A., Cox, S. M., Shojania, K., Rai, S. K., Choi, H. K., De Vera, M. A.	How patients with gout become engaged in disease management	2018	Arthritis Research and Therapy	British Columbia, Canada	Telephone	Qualitative study Semi-structured interviews Constructivist grounded theory	To use patients' perspectives to construct an explanatory framework to understand how patients become engaged in the management of their gout.
Kong, D., Sturgiss, E., Raj, A. K. D., Fallon, K.	What factors contribute to uncontrolled gout and hospital admission?	2019	BMJ	Australia	Hospital inpatients with patient and telephone interview with GP	Qualitative study using thematic analysis Semi-structured interviews	To provide deeper insight into why patients are admitted to hospital with gout and discover potential targets for better disease control.
Li, Q., Liu, T., Zhang, S., Miao, X.	Illness perception and treatment experience in patients with gout	2022	Clinical Rheumatology	China	Face-to face in rheumatology clinics	Descriptive qualitative approach Semi-structured interviews	To explore the illness perception and treatment experience of gout patients in China.
Liddle, J., Roddy, E., Mallen, C. D., Hider, S. L., Prinjha, S., Ziebland, S., Richardson, J. C.	Mapping patients' experiences from initial symptoms to gout diagnosis	2015	BMJ Open	United Kingdom	Face-to-face in homes or workplace	A qualitative exploration Semi-structured interviews	To explore patients' experiences from initial symptoms to receiving a diagnosis of gout.
Lindsay, K., Gow, P. Vanderpyl, J., Logo, P., Dalbeth, N.	The experience and impact of living with gout	2011	Journal of Clinical Rheumatology	New Zealand	Primary care	Qualitative grounded theory approach In-depth semi-structured one-to-one interviews	This study aims to understand the experience of men living with chronic gout using a qualitative grounded theory approach.
Morris, C., Macdonald, L., Stubbe, M., Dowell, A	"It's complicated" — talking about gout medicines in primary care consultations	2016	BMC Family Practice	New Zealand	Primary care	Qualitative, exploratory, descriptive study using an inductive qualitative analysis	Greater understanding of communication between patients and health-care professionals is one way of improving management of gout. This paper describes communication about gout medicines and treatment between patients and primary-care health professionals during routine consultations.

Table 4. Characteristics of studies (continued)

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Objectives
Richardson, J. C., Liddle, J., Mallen, C. D., Roddy, E., Prinjha, S., Ziebland, S., Hider, S.	"Why me? I don't fit the mould … I am a freak of nature"	2015	BMC Women's Health	United Kingdom	Face-to-face interviews	Qualitative research design Semi-structured interview	Little is known about women's experience of gout and the impact it has on their lives. It is important for practitioners to be aware of these areas, given the increasing numbers of women with gout they are likely to see in the future. This study aimed to explore women's experiences of gout.
Rolston, C. J., Conner, T. S., Stamp, L. K., Neha, T., Pitama, S. Fanning, N., Janes, R., Judd, A., Hudson, B., Hegarty, R. M., Treharne, G. J.	Improving gout education from patients' perspectives	2018	Original scientific paper	New Zealand	Outpatient settings	Focus group methodology Thematic analysis Semi-structured focus groups using nominal technique	To explore gout patient education in primary care from the perspectives of Māori and Pākehā people with gout.
Seow, L., Jiao, N., Wang, W., Holroyd, E., Teng, G. G., He, H.-G.	A qualitative study exploring perceptions of patients with gout	2020	Clinical Nursing Research	Singapore	Rheumatology clinics	Descriptive qualitative study Individual face-to-face semi-structured interview	The aim of this study was to explore the perceptions of living with gout of patients with gout in Singapore.
Singh, J. A.	Facilitators and barriers to adherence to urate-lowering therapy in African Americans with gout	2014	Arthritis Research & Therapy	United States	Outpatient clinics	A qualitative study Nominal group technique	The aim of this study was to examine the facilitators and barriers to adherence to urate-lowering therapy (ULT) in African Americans with gout.
Tatlock, S., Rüdell, K., Panter, C., Arbuckle, R., Harrold, L., Taylor, W., Symonds, T.	What outcomes are important for gout patients?	2017	Original research	United States	Primary care and rheumatology clinics	A qualitative, non-interventional interview study	To explore the symptoms and impacts of gout, and assess the content validity of existing patient-reported outcomes.

Table 4. Characteristics of studies (continued)

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Objectives
Te Karu, L., Bryant, L., Elley, C.	Māori experiences and perceptions of gout and its treatment	2013	Original scientific paper	New Zealand	Most interviews conducted at participants' homes, except for three participants who chose to be interviewed at the clinic.	Qualitative general inductive approach Semi-structured interviews	This study explores the perceptions, understanding and treatment of gout among Māori.
ten Klooster, P. M., Vonkeman, H. E., Voshaar, M., Bode, C., van de Laar, M.	Experiences of gout-related disability from the patients' perspective	2014	Clinical Rheumatology	The Netherlands	Outpatient settings	Qualitative study Semi-structured interviews and a cross-sectional survey	To explore disability issues in patients with gout and to examine the content validity of the health assessment disability questionnaire index in this patient group.
Van Onna, M., Hinsenveld, E., de Vries, H., Boonen, A.	Health literacy in patients dealing with gout	2015	Clinical Rheumatology	The Netherlands	Outpatient settings	Qualitative study Semi-structured interviews	To explore the health literacy of patients dealing with gout and to understand perceptions that might account for non-adherence to urate-lowering therapy (ULT).

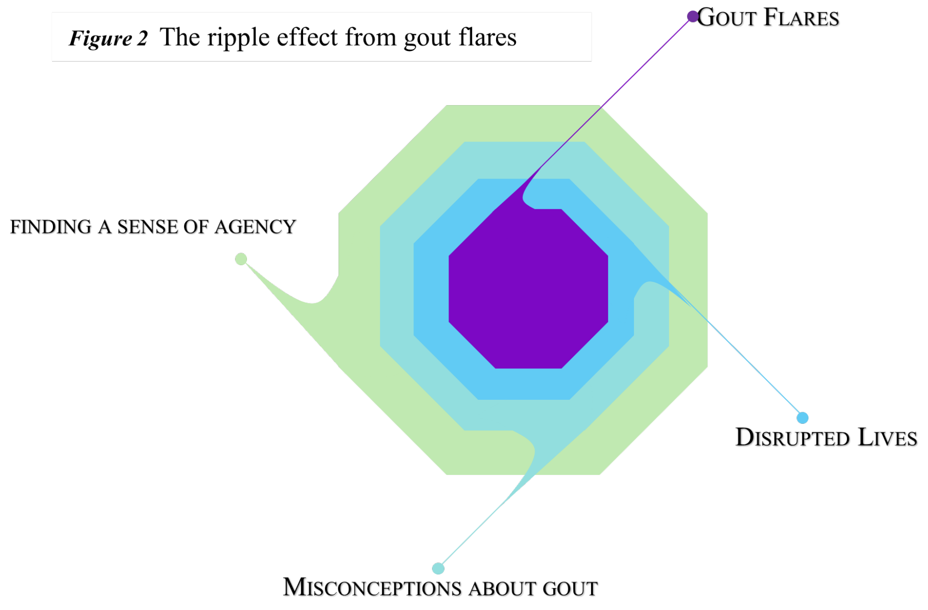

Figure 2 The ripple effect from gout flares

NARRATIVE PRESENTATION OF FINDINGS

The overarching theme developed from the analysis was "The ripple effect from gout flares impacting on a person's entire quality of life." Three subthemes identified from the synthesis include: 1. Disrupted lives, 2. Misconceptions about gout, and 3. Finding a sense of agency. Figure 2 illustrates the ripple effect from gout flares.

Theme 1: Disrupted lives

Narrative storyline — Pain is disruptive

Severe pain from gout flares has a disruptive effect that leads to a sense of helplessness, due to loss of control. The ripple effect from severe pain caused by repeated gout attacks is multifaceted, negatively affecting the person's quality of life. Participants in the studies described the all-consuming nature of severe gout in terms of its impact on perceived quality of life (Coleman et al., 2021). *"The worst thing ever, man, gout. It's just taken over my life, I can't do anything"* (Participant not identified, Coleman et al., 2021, p. 1398). Participants could recount their first experience of gout pain with vivid descriptions of the worst pain ever experienced, comparable with birth pains and heart attacks. Pain significantly affected their physical lives (Garcia-Guillen et al., 2020; Te Karu et al., 2013). *"It just feels like the area is inflamed...cooking. I mean it is hot, a real hot sensation…it feels like the flesh is trying to rip your outside…like it is going to burst…"* (P7, Lindsay et al., 2011, p. 2).

The severity of pain was dependent on the stage of gout, varying from a mild warning twinge settled by treatment to a severe debilitating flare that led to days bed-bound (Te Karu et al., 2013). *"I just couldn't move. The pain was that bad, you just wanted to cut your foot off. You can't touch it, you can't walk. You lose your appetite. You can't work. It makes you miserable"* (P9, Te Karu et al., 2013, p. 217). The impact of pain from chronic gout is evident in every step of daily life, having a disruptive effect on activities such as walking, preparing food and self-care (Coleman et al., 2021; Garcia-Guillen et al., 2020).

Participants with mild flares did not report the same degree of disruption to their lives. *"It [gout] doesn't [affect my life], it's a bit uncomfortable for the first day, but you know it doesn't stop me from doing anything"* (P13, Coulshed et al., 2020, p.1376). However, other participants reported problems with activities associated with daily living, which negatively affected their sense of self-worth (Coulshed et al., 2020; Garcia-Guillen et al., 2020). *"When it's at its worst... it was difficult to even just get out of bed… shower, toilet. All those daily things, it was… very difficult."* (P19, Garcia-Guillen et al., 2020, p. 18). Sleep was a luxury for some participants due to unrelieved pain during an acute attack (Garcia-Guillen et al., 2020). *"When it hits hard, you can't even put a sheet over because it hurts at night. And if you move at night, it just hurts, so you keep waking up"* (P12, Garcia-Guillen et al., 2020, p. 18).

Sleep disruption can increase mood disorders, reduce quality of life and increase stress responsivity. Participants also felt they were a burden during a gout attack (Coulshed et al., 2020; Tatlock et al., 2017). *"I can't hack the pain, but I need to go pay these bills. And if I don't hack the pain, and I don't go to work, my family doesn't eat"* (P7, Lindsay et al., 2011, p.2). The ripple effect of a gout attack led to an inability to work, loss of income and economic burden for the participant and their family. In contrast, a few participants in less physically demanding jobs experienced less impact, as one stated, *"No [it doesn't affect my productivity], because I work with my head, not with my feet"* (P15, Coulshed et al., 2020, p. 1375).

Most participants described forced lifestyle modifications. The severity of pain dictated the level of modification, specifically in terms of exercise, hobbies and travel (Li et al., 2022; Te Karu et al., 2013). *"To go to the toilet, you're crawling on the floor"* (P1, Te Karu et al., 2013, p. 217). *"I rely on my hands, and I can't play the piano anymore … from the gout"* (P2, Coulshed et al., 2020, p. 1376). In contrast, a small subset of participants reported no gout-related limitations between attacks (Coulshed et al., 2020; Ten Klooster et al., 2013).

"When I'm not having an attack, I don't notice my gout or arthritis at all" (P4, Ten Klooster et al., 2013, p. 4). This lack of noticing demonstrates the possibility of gout being optimally managed, which in turn improves quality of life. The most prominent emotional impact experienced by participants was continuous worry about impending gout flares (Coulshed et al., 2020; Kong et al., 2019). *"…it's like living in a little box that you're just waiting when is the hurricane coming?"* (P6, Kong et al., 2019, p. 3). This sense of waiting also affected self-esteem: *"I'm disappointed with my body. I'm disappointed that I'm not free, that I could at any time get a gout attack"* (P2, Coulshed et al., 2020, p. 1375). The inability to anticipate a gout attack affected the participants' ability to feel they had control, and negatively affected their emotional well-being.

Theme 2: Misconceptions about gout

Narrative storyline – Misunderstanding and missed management

The second theme, misconceptions about gout, illuminates how participants navigate living with gout when surrounded by common misconceptions about it coming from themselves, the community and health practitioners. These negative misconceptions undermined their access to the best treatment. Participants' narratives included preconceived notions about gout being self-inflicted or trivialised, and the permanence of a lesser quality of life (Seow et al., 2018; Te Karu et al., 2013). *"You just accept it, don't question."* (P4, Te Karu et al., 2013, p. 217). *"I don't regret [that] I can't do this; I resigned to the fact [that] I have this problem"* (P10, Seow et al., 2018, p. 61). *"I don't share all my sufferings, so I just take care of myself. I confine [it] within me"* (P3, Seow et al., 2018, p. 61). These ways of thinking about living with gout contributed to misconceptions and delayed participants from seeking care.

Some participants believed gout was an unimportant, nuisance illness (Chandratre et al., 2015). *"I don't think it's perceived to be life-threatening, whereas cancer and heart attacks are."* (P not identified, Chandratre et al., 2015, p. 1201). Another misperception that affected seeking treatment was that gout could not be treated (Lindsay et al., 2011). *"I think I have accepted the fact that there is no cure, because I haven't talked to anybody who has had it and says they don't get it anymore."* (P7, Lindsay et al., 2011, p. 4).

Misunderstandings about gout between participants and their own family also contributed to suboptimal gout management, especially the idea that gout was self-inflicted (Richardson et al., 2015; Te Karu et al., 2013). *"I thought it was all my fault"* (P4, Te Karu et al., 2013, p. 218). *"[Name] [wife] goes [expletive] nuts at me. She looks at me and says, '[Expletive] here we go again.' "* (P9, Te Karu et al., 2013, p.218). Stigma also contributed to a sense of shame and embarrassment (Chandratre et al., 2015; Lindsay et al., 2011). *"They asked me what was wrong with it, and I said, 'Maybe I got poisoned'. They relate gout with all the negative stuff with it, it took me a long time to actually admit the fact that I did have this sickness".* (P2, Lindsay et al., 2011, p. 4). Stigma creates an unnecessary sense of shame. Participants suggested that stereotyping and stigmatisation also originated from some health practitioners, influencing their reluctance to seek treatment (Coleman et al., 2021; Kong et al., 2019). *"He [senior doctor] said, `What gives gout?' The young fella [junior doctor] said, `Oh, too much rich living, too much rich food'.* (P2, Kong et al., 2019, p. 4). *"I'm only young, I'm not that old, and that's what the surgeon said, at your age you shouldn't have this disease"* (P7, Kong et al., 2019, p. 4).

Participants felt some health practitioners saw gout as a nuisance illness and that some of them misunderstood the reality of gout (Te Karu et al., 2013). *"These doctors need to have a bash of gout and see what it feels like to them, then they would see what it's really like. I think they have no idea".* (P9, Te Karu et al., 2013, p. 219). *"I came here to see a doctor to find out whether my uric acid level and other data are normal. I had a lot of questions, but before I could ask, the doctor called the next patient and urged me to leave."* (P16, Li et al., 2022, p. 5). Some health practitioners may lack knowledge about the presentation of gout symptoms (Chandratre et al., 2015; Diaz-Torne et al., 2024; Liddle et al., 2015). *"I went to the A&E […] I saw a doctor ... he thought I'd been bitten on the foot. It was just really a shot in the dark, so my medical advice then was not geared towards gout."* (Henry, 63yrs, Liddle et al., 2015, p. 3).

Where health practitioners failed to provide good care to gout patients, whether from lack of knowledge or other reasons, this resulted in some participants living with pain for sustained periods of time without adequate management, and lacking understanding that gout is a treatable disease.

Theme 3: Finding a sense of agency

Narrative storyline – Negotiating life with gout

This theme highlights how participants navigate their pathway to self-management and develop a sense of agency in managing to live with gout. Some participants' understanding of gout was limited to their own experience and what they observed from other "gout sufferers". Other participants sought information from sources such as family members, nurses and other health professionals, educational resources and fellow participants (Howren et al., 2018; Li et al., 2022). *"I did not know about gout until I was diagnosed with it. I just have joint pain and do not have any other symptoms of gout. But I saw the tophi and joint damage of other patients, I realised that gout is such a serious disease."* (P12, Li et al., 2022, p. 4).

Processing their feelings about the diagnosis of gout and understanding the disease are the first steps people need to take to navigate it. This understanding can lead to lifestyle choices that help them manage their own symptoms (Howren et al., 2018). For one patient, having gout was not too concerning, as he already had many other health issues. *"I've got so many other things going on [health issues] … at the moment it, what's one more little [gout], yeah, nothing to worry about".* (P11, Kong et al., 2019). A diagnosis of gout brought a sense of relief to some participants who worried what the severe pain might mean. Some doubted the accuracy of their diagnosis (Liddle et al., 2015). *"Main concern was that he [patient] was going to lose a toe basically, rather than it being gout, so he's actually, if anything, relieved that it was gout as a diagnosis."* (GP 1, Kong et al., 2019, p. 4). *"I often doubt, I think, 'Oh have they got it wrong?' You know, because I don't speak to anybody who's got it, especially my age, […] they're not women".* (Georgina, 41yrs, Liddle et al., 2015, p. 4).

People who recognise the common traits of gout can adapt to living with it. This adaptation involves making lifestyle modifications, such as adjusting their diet, identifying personal triggers and making practical changes in clothing, as well as adapting to pain (Coulshed et al., 2020; Li et al., 2022). *"Since I knew I had gout, I began to adjust my lifestyle, not staying up late, drinking less carbonated drinks, less alcohol, and not eating high purine foods"* (P18, Li et al., 2022, p. 6). Some participants found that their gout-related diet changes had a positive impact on their health, although others found it harder to adapt (Li et al., 2022). *"It is very painful not to eat seafood or drink. Because, after all, I have to attend some alcoholic drinking occasions ... It is not easy to quit [alcoholic drinks]."* (P17, Li et al., 2022, p. 6).

Some participants felt comfortable enough to adjust their diet and medication during an asymptomatic period (Howren et al., 2018). *"Because I hadn't been having flare-ups, I felt I could indulge a little bit more in some of the foods that I knew were triggers"* (P8, Howren et al., 2018, p. 3). They felt empowered to try different things when they felt well, and being organised helped them to self-manage (Coulshed et al., 2020; Garcia-Guillen et al., 2020; Howren et al., 2018). *"… my gout is part of my planning"* (P3, Coulshed et al., 2020, p. 1375). *"Well, I'm on other medications, so I've got a very regimented schedule when I take a medication."* (P1, Howren et al., 2018, p. 4). This participant made their medication regimen part of their daily routine.

Motivation to seek health care increased when participants felt a sense of agency in living with gout (Diaz-Torne et al., 2024; Howren et al., 2018). *"That pain and discomfort that I had from gout was inhibiting. And so that was the main point that made me decide to seek treatment and knowledge on gout"* (P2 Diaz-Torne et al., 2024, p.7). *"If I don't take my medication, I don't want to get sick, right, because I've got to take care of my family and my husband and my housework too"* (P3, Howren et al., 2018, p. 3). Taking control refers to the journey that participants undertake as they assume responsibility and become proactive in their self-management (Díaz-Torne et al., 2024; Howren et al., 2018). *"I mean the bottom line is, I'm the patient and know my body so ultimately it becomes my responsibility"* (P12, Howren et al., 2018, p. 3). *"I've got one of those little kits that you use. I wanted to understand my own disease and manage my own disease, so I calibrated my monitor with the blood test. At some points, I titrated my own dose of Allopurinol"* (Adam, 41yrs, Liddle et al., 2015, p.5).

Optimal management of gout is achievable with urate-lowering drug therapy. Participants who achieve medication adherence experience improved quality of life and a reduction in gout flares.

DISCUSSION

This meta-synthesis endeavoured to journey with participants through their lived experiences with gout. Twenty studies on the reality and impact of living with gout were explored. The findings of this synthesis reveal the potentially devastating effects of poorly treated gout on every aspect of life.

The pain that disrupts lives is a dominating factor in participants' accounts of living with gout. Therefore, optimal management must be a key focus. Management of pain in gout involves two key elements: managing acute flares and using urate-lowering drug therapy, which is the cornerstone of gout treatment. Evidence-based management guidelines, such as the 2020 American College of Rheumatology Guideline for the Management of Gout and the National Institute for Health and Care Excellence guidelines, should guide all health-care professionals in the optimal management of gout (Fitzgerald et al., 2020; NICE, 2022). These guidelines provide direction for clinicians and patients on managing acute gout flares and incorporating options for the individual complexities patients face in terms of their preferences, comorbidities and tolerances.

Approximately half those living with chronic illness experience stigma. Stigma may be internalised and anticipated personally, as well as experienced in health-care and social contexts (Earnshaw & Quinn, 2011; Pearl et al., 2024). Stigma can involve negative stereotyping, being labelled as different, separation and discrimination. In any form, it poses a barrier to optimal management of chronic disease (Link & Phelan, 2001; Pearl et al., 2024). Internalised stigma creates a barrier to accessing health care, as the person believes they do not deserve care. Patients with chronic illness can experience stigma in the health service, if the health professional believes the person is to blame for their poor health, leaving them with the feeling that they are a nuisance and that the health practitioner is frustrated with them (Pearl et al., 2024).

The stigma associated with gout has a significant influence on whether people seek help to manage their condition, and also affects practitioners' treatment of gout. One source of stigma can be the unhelpful attitudes and myths about gout within families and the community (Liddle et al., 2015). Stigma is a barrier to a person receiving timely and appropriate medical care for their gout — and withoutf urate-lowering therapy, this can lead to them suffering constant gout (Liddle et al., 2015). Distorted perceptions of the nature of gout have a marked negative effect on patients' attitudes to their condition and its treatment (Doherty et al., 2012). Poor knowledge about gout and lack of interest among doctors also negatively affects health outcomes (Doherty et al., 2012). The well-being of individuals and populations can improve by lessening the stigma attached to gout. De-stigmatisation efforts can include the dissemination of knowledge by medical experts, cultural advocates and the media, publicly advocating for the worth of people with gout, and removing blame. Reducing stigma requires transforming beliefs and behaviours among individuals, the public and the health sector (Clair et al., 2016).

Having a sense of agency can involve feeling empowered to make choices and manage the consequences (Moore, 2016). Chronic conditions, although each unique in their pathology, share management challenges. Individuals can improve their health by developing skills to take responsibility for the daily management of their own chronic condition. Self-management programmes can equip individuals with these skills (Grady & Gough, 2014). Nurses are central members of the multidisciplinary team supporting people with long-term conditions. Their role in helping people with gout to develop a self-managing toolkit involves developing a partnership with the individual, their family and their community, as well as following a systematic, individualised approach with each person (Dineen-Griffin et al., 2019). Nurse-led, individually focused care, involving education and disease management, improves long-term adherence to treatment, potentially reducing gout flares (Fuller et al., 2020). Further research is needed to assess the impact of nurse-led services on improving quality of life and well-being for people with gout, given that the prevalence of gout in New Zealand is among the highest internationally.

RECOMMENDATIONS

Best outcomes for gout patients require a multifaceted, patient-centred approach, incorporating education methods that align with the patient's preferences and health literacy (van Onna et al., 2014). This approach requires identifying the gaps in the patient's knowledge and barriers to treatment. A multidisciplinary team approach to care is best, including nurse-led and marae-based strategies, with cultural supports to ensure effective communication and education. For patients to successfully manage their own condition, they need effective education (Fields & Batterman, 2018). This leads to optimal disease management and fosters a sense of agency in the person living with gout. Recommendations from the findings of this review include:

- Referrals to rheumatologists from primary care should be timely so patients can live well with gout and manage complications that may affect their daily activities.
- Education on gout for health-care providers is needed. The Gout Guide NZ is a dynamic, must-have resource for GPs, nurses, pharmacists, health coaches and all health-care teams in Aotearoa New Zealand.
- De-stigmatise gout by improving health literacy and raising awareness of gout as a chronic condition. Clinics should display A4 posters — gout is more than a pain in the toe. Patient and whānau resources, such as information booklets and postcards with information about educational videos, should be readily available. (In New Zealand, these are available from Gout Guide NZ and Arthritis NZ.) To improve the quality of life of this expanding population, a better understanding of the stigma attached to chronic illness in health services will be increasingly important.
- Patients and their families should have access to multidisciplinary care, via nurse-led gout clinics. Raising awareness of the diversity of people living with gout should improve cultural awareness and decrease stigma attached to the condition.
- Gout management may improve if uric acid targets were included in the national health targets, and gout was specifically included as an aspect of formal qualification in the education of health-care practitioners.

LIMITATIONS

This meta-synthesis sheds light on the experiences of individuals with gout. However, only qualitative studies were included in this review. Quantitative studies may enable a broader understanding through measuring experience, eg cohort studies that show the trajectory of gout and its impact on function.

CONCLUSION

This meta-ethnography identified and synthesised the findings of 20 qualitative studies on the lived experience of people with gout. Storylines evolved from these studies, which demonstrated the ripple effect that pain from gout flares has on an individual's quality of life. The studies shed light on the trials and tribulations of navigating life with gout, while surrounded by misconceptions and negative stigmas, and on the way people with gout can achieve self-management through learning about their condition. A potentially debilitating disease such as gout does not have to be tolerated in silent suffering and stoicism. These powerful and vulnerable narratives enable us to briefly envision what it means to walk a mile in someone's shoes, living with gout as a long-term condition. There are ways for people with gout to significantly improve their quality of life through effective self-management of the condition, and nurses play a key role in this.

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Supplementary File 1. Search strings

Search #	Field tag	CINAHL
1	Title or abstract	Adult* OR elderly OR age* OR "old person" OR "middle age*" OR senior OR "young adult*"
2	Main Heading (MH)	Adult OR frail elderly OR "young adult"
3		S1 OR S2
4	Title or abstract	Experience* OR "lived experience*" OR "patient experience*" OR "personal experience*" OR perception* OR thought* OR feeling* OR opinion* OR belief* OR "life experience*" Or "attitude* to illness" OR emotion*
5	Main Heading (MH)	
6		S4 OR S5
7	Title or abstract	
8	Main Heading (MH)	
9		S7 OR S8
10		S3 AND S6 AND S9
	Filters	No date filter, remove full text limiter

Supplementary File 2. Critical appraisal of the included studies

Author (year)	Title	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Dependability
Chandratre et al, 2016	“You want to get on with the rest of your life”: a qualitative study of health-related quality of life in gout.	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate
Coleman et al, 2021	An enquiry into the crippling gout affecting Pacific Islander and Māori men in Western Sydney.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Coulshed et al, 2020	Australian patient perspectives on the impact of gout.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Diaz-Torne et al, 2024	‘Gout was like the boss’. A qualitative study exploring the impact of gout on employment.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Frecklington et al, 2019	The footwear experiences of people with gout: a qualitative study.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Garcia-Guillen et al., 2020	Gout flare severity from the patient perspective: a qualitative interview study	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Howren et al, 2018	How patients with gout become engaged in disease management: a constructivist grounded theory study	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Moderate
Kong et al, 2019	What factors contribute to uncontrolled gout and hospital admission? A qualitative study of inpatients and their primary care practitioners.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Li et al, 2022	Illness perception and treatment experience in patients with gout: a descriptive qualitative study.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Liddle et al, 2015	Mapping patients’ experiences from initial symptoms to gout diagnosis: a qualitative exploration.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Lindsay et al, 2011	The experience and impact of living with gout: a study of men with chronic gout using a qualitative grounded theory approach.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Morris et al, 2016	“It’s complicated” — talking about gout medicines in primary care consultations: a qualitative study.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Richardson et al, 2015	“Why me? I don’t fit the mould … I am a freak of nature”: a qualitative study of women’s experience of gout.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate

Supplementary File 2. Critical appraisal of the included studies (continued)

Author (year)	Title	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Dependability
Rolston et al, 2018	Improving gout education from patients' perspectives: a focus group study of Māori and Pākehā people with gout.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Seow et al, 2020	A Qualitative Study Exploring Perceptions of Patients with Gout	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Singh, J A, 2014	Facilitators and barriers to adherence to urate-lowering therapy in African-Americans with gout: a qualitative study	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Tatlock et al, 2017	What Outcomes are Important for Gout Patients? In-Depth Qualitative Research into the Gout Patient Experience to Determine Optimal Endpoints for Evaluating Therapeutic Interventions.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Te Karu et al, 2013	Māori experiences and perceptions of gout and its treatment: a kaupapa Māori qualitative study.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
ten Klooster et al, 2014	Experiences of gout-related disability from the patients' perspective: a mixed methods study.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
van Onna et al, 2015	Health literacy in patients dealing with gout: a qualitative study	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate

Notes:

Quality appraisal tool questions:

1) Congruity between the stated philosophical perspective and the research methodology;
2) Congruity between the research methodology and the research question or objectives;
3) Congruity between the research methodology and the methods used to collect data;
4) Congruity between the research methodology and the representation and analysis of data;
5) There is congruence between the research methodology and the interpretation of results;
6) Locating the researcher culturally or theoretically;
7) Influence of the researcher on the research, and vice-versa, is addressed;
8) Representation of participants and their voices;
9) Ethical approval by an appropriate body;
10) Relationship of conclusions to analysis, or interpretation of the data.

Dependability was scored by the number of "yes" votes for questions 2, 3, 4, 6 and 7; can be scored overall as High, Moderate, Low or Very low (Munn et al., 2014).

RESEARCHED VIEWPOINT:

Gillian White

Screening tools: Challenges identifying perinatal depression in primary care

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This researched viewpoint focuses on screening to assess perinatal emotional distress or depression in primary health. Perinatal depression, defined as severe depressive episodes during pregnancy (antenatal) and within 12 months postpartum (postnatal) represents one of the most ubiquitous complications of a woman's reproductive life (Yang et al., 2022). In perinatal health care, the aim is to provide the best possible start for mothers, partners and their babies, physically and emotionally. Historically, we have prioritised the physical, have improved obstetric and midwifery care, and reduced the maternal mortality rate by 40 percent between 2000 and 2020 in the Western world (World Health Organization, 2021).

Antenatal and postnatal depression share similar prevalence rates to prevalence rates for depression in the general population, with estimates ranging from 12-20 percent and a commonly reported estimate of 13 percent (Mitchell et al., 2023; Wang et al., 2021; Yin et al., 2021). While physical perinatal healthcare has improved and maternal mortality rates have decreased, emotional healthcare (which includes socio-cultural and spiritual aspects) remains a global problem, making oversight of accurate assessment a clinical ethical issue. Screening for perinatal depression (both ante and postnatal) is widely practised across the world. A systematic review and meta-analysis of 589 studies and outcomes of 61,6708 women from 51 countries by Mitchell et al. (2023) indicated the prevalence of perinatal depression to be 10 to 20 percent in developed countries and one in four women (24 percent) in underdeveloped countries.

Perinatal depression or distress can be both under-diagnosed, and over-diagnosed, neither of which is helpful to women. The former can lead them to missing out on the mental health support they need, and the latter to over-testing and feeling stigmatised, with root causes unexamined. On the one hand, perinatal emotions are often normalised, suggesting a potential gap in the current diagnostic criteria of distress or depression, and making oversight a clinical ethical issue. A significant number of women do not meet the criteria for a maternal mental health diagnosis due to the perceived lack of severity in their symptoms. On the other hand, a recent literature review (White et al, 2024) to identify current research into ante and postnatal distress and perinatal depression for a maternal mental health study in primary health highlighted various screening tools used, which may be contributing to the rising prevalence of perinatal depression, where the actual root cause persists and is left untreated.

Various ethical issues are associated with screening tools, which can result in more harm than benefit (Yong et al., 2022). The sole reliance on screening tools over or under-identifies perinatal depression or degrees of emotional distress. As reported in this article, standard screening scales used are not of acceptable quality for the perinatal period and do not identify specifics where assistance may be of help, to avoid a diagnosis of depression or perinatal emotional distress. This is because they lack robust validity and cultural nuances.


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Screening for health issues is generally cast in a favourable light when promoted to the public, but screening tests are not "risk free" as their use has potential harm. The possible harm from screening for perinatal mental health arises from the validity and accuracy of the self-reported tests; the cut-off used; cultural inappropriateness, being developed in a Western model; rising prevalence rates for minority cultures; the tendency to treat based on the test; and stigmatisation and fear of the baby being taken away. Zubaran et al. (2010) highlighted the challenge of existing screening scales being developed based on the English language, posing complications of local interpretations, cultural relevance, semantics and sensitivity. Highet et al. (2023) also questioned the specificity and sensitivity in screening for perinatal depression, and Wang and Kroenke et al. (2021) emphasised the importance of screening with efficient and evidence-based measures. False positives can generate psychological distress and often result in further investigations to determine if the condition of concern is present.

A literature search was conducted on the major perinatal screening tests used, accessing Scholar One, Semantic Scholar, Google Scholar, PubMed and PsycINFO. In addition, the notes of pregnant and postnatal women attending two local primary health care clinics in a medium-sized, low socio-economic urban area in New Zealand were reviewed over a retrospective period from March 2022 to March 2023. The purpose of reviewing the notes was to ascertain which screening tools were commonly being used and the interventions recommended, to provide a foundation for the literature review and critique.

Both practices inform patients that their notes may be subject to review for research purposes when they register with the practices and have given permission. The women's notes were reviewed by senior practitioners. Individuals were given codes; no names were recorded, and the data collected were amalgamated for descriptive statistics.

Seven tools investigated

Seven screening tools commonly used around the world in primary health to test pregnant and postnatal women for depression or anxiety were identified and investigated.

1) Edinburgh Postnatal Depression Scale (EPDS) (Cox, 1987)

Inspired by Brice Pitt, who published a seminal paper, ' "Atypical" depression following childbirth', in the *British Journal of Psychiatry* (1968), John Cox carried out a controlled study of perinatal psychiatric morbidity in 263 rural women in Uganda. Later he undertook a prospective study in Edinburgh – each followed by the Structured Psychiatric Interview (as described in Pitt,1968). Cox found that the existing scales lacked criterion and face validity for postnatal depression. Hence, a short self-report questionnaire acceptable to mothers and health professionals, with satisfactory psychometric properties, was required. Collaborating with his team and exploring existing depression scales such as the Hospital Anxiety and Depression Scale (HAD), General Health Questionnaire (GHQ), and Beck Depression Inventory (BDI), Cox rejected somatic symptoms attributed to postnatal physiological changes. Drawing insights from his Edinburgh study, he developed the Edinburgh Postnatal Depression Scale (EPDS) through iterative testing for validation. Omitted items, however, included social and domestic circumstances of the peripartum period. Cox emphasised that the EPDS should be administered by a trained health professional to identify women with a "false negative" score, potentially indicating severe retarded depression or psychotic symptoms. Cox noted that the EPDS did not offer a differential diagnosis, as a score above the cut-off could occur in mothers with post-traumatic stress disorder or an anxiety disorder. Despite its ease of use (and potential misuse), the EPDS is widely employed by doctors, midwives and other health professionals for both antenatal and postnatal depression screening. While it is rarely accompanied by a Structured Psychiatric Interview, Loney and Frick (2003) and Cox et al. (1987) recommended using it as a starting point for further discussion with the mother about her symptoms. This approach allows for clarification of the nature of the underlying psychiatric condition and determination of the impact on the infant and extended family. Following a systematic review to assess the appropriateness of the EPDS, Highet et al. (2023) found it showed high certainty (sensitivity and specificity) for major depression in both the antenatal and postnatal periods, in multiple languages and populations. The authors strongly recommended its use to screen women for possible perinatal depressive disorder with a strong proviso that women with a cut-off score of >13 should be further assessed.

2) Kessler Psychological Distress Scale (K10)

The K10 is a questionnaire for patients to complete. It is a measure of psychological distress (Kessler et al., 2002). About one in four patients seen in primary care will score 20 and over (mild mental disorder) with 13 percent of the adult population scoring 20 and over (Highet et al., 2023). This is a screening instrument, and practitioners should make a clinical judgment whether a person needs treatment. The development of the Kessler scales was based on a review of psychopathological screening scales by Dohrenwend et al. (1980), based on a probability sample of 200 adults, through interviews, drawn from heterogenous sex, class, and ethnic groups in New York City (Andrews & Slade, 2001). It has never been validated for perinatal women, yet is used by some New Zealand practitioners. Indeed, the K10 was found to have low certainty for its adequacy in screening for major perinatal depression. Highet (2023) does not recommend its use.

3) Patient Health Questionnaire (PHQ-9)

Developed by Kroenke et al., (2001), the PHQ-9 is a nine-item component of a larger self-administered Patient Health Questionnaire (PHQ), but can be used as a stand-alone instrument. The PHQ is a depressive symptom scale and diagnostic tool introduced in 2001 to screen adult patients in primary care settings (Spitzer et al., 1999). The diagnostic validity of the PHQ/PHQ-9 was established in two studies involving 3000 patients in eight primary care clinics and 3000 patients in seven obstetrics-gynaecology clinics. The findings, however, did not differentiate perinatal women. The PHQ-9, popular among health practitioners, also includes a functional health assessment, including how any emotional difficulties or problems impact work, life at home, or relationships with other people. If the responses indicate difficulties, the suggestion is that the patient's functionality is impaired. According to Highet et al. (2023), the specificity and sensitivity in screening for perinatal major depression using the PHQ-9 is low, and very low for minor depression, and therefore it is not recommended. However, Wang and Kroenke et al. (2021) found during a systematic review that the PHQ-9 appeared to be a viable option for perinatal depression screening with operating characteristics like the EPDS, with the proviso that depression should never be diagnosed, or excluded, solely based on a PHQ-9 score.

4) General Anxiety Disorder 7 (GAD-7) and General Anxiety Disorder 2 (GAD-2)

General Anxiety Disorder 7 (GAD-7) was based on DSM-IV (American Psychological Association, 1994) criteria for anxiety, PTSD and social anxiety. General Anxiety Disorder 2 (GAD-2) uses only the first two of the core anxiety symptoms: feeling nervous, anxious or on edge; not being able to stop or control worrying. The scale was published in 2006 by Spitzer et al. and was originally developed to be used with adults (aged 18+); however it has also been validated for use with adolescents (aged 14-17) with generalised anxiety, as GAD-7 scores can support the assessment of anxiety symptoms and help differentiate between mild and moderate anxiety in youth. Using GAD, the current prevalence of general anxiety disorder is

2-3 percent, with a lifetime prevalence of over 5 percent. It is the most prevalent anxiety disorder encountered in primary care with an estimated prevalence of 8 percent. An estimated 4 percent of the global population currently experience an anxiety disorder (WHO, 2023), making anxiety disorders the most common of all mental disorders. Prevalence varies widely across countries and populations and estimating a worldwide prevalence rate is challenging due to varied study methods, cultures and access to health services (Mossman et al., 2017). Thus, validated within a generalised population in the United States, many of the symptoms would be quite normal in a pregnant or postnatal population. However, a systematic review by Sinesi et al. (2019) clearly points out how evidence regarding the screening performance of anxiety scales for use in pregnancy remains insufficient.

5) Beck's Depression Inventory (BDI)

The Beck Depression Inventory (BDI, BDI-1A, BDI-II) was developed by Aaron Beck (1996) as a tool to measure the severity of depression in a quantifiable manner. The current version, BDI-II, is intended for individuals aged 13 years and above. It consists of various items that assess symptoms of depression such as hopelessness and irritability, thoughts and beliefs related to guilt or feeling punished, and physical symptoms like fatigue, weight loss and decreased interest in sex. The BDI-II has been validated with the general population and college students in the United States, but it is also commonly used by health-care professionals to screen perinatal women for depression.

6) Perinatal Depression Inventory (PDI-14)

The Perinatal Depression Inventory (PDI-14) was developed using Modern Measurement Theory (MMT) computer-assisted item response (Brodey et al., 2016). Most measures used to assess depression in the perinatal period in this tool are designed to assess general depression (White et al., 2024). Tests using one-word Likert responses have been criticised for being confusing and idiosyncratic; some tests are too long, and none were developed and calibrated for context and universality. After stringent comparative testing, all instruments in current use, including the PDI-14, are based on the criteria for antenatal/postnatal/perinatal depression, as defined by DSM-IV (White et al., 2024). White et al.'s study on emotional distress in pregnancy and post-birth concluded that the primary goal of the PDI is to assess the severity of perinatal depression more accurately and precisely to inform treatment decisions.

7) DuKe assessment (DASI)

The DuKe assessment (Hlatky, 2024) is a generic self-report instrument containing six health measures (physical, mental, social, general, perceived health and self-esteem), and four dysfunction measures (anxiety, depression, pain and disability).

In the two primary care clinics whose records were examined, assessments showed women dealing with a range of highly stressful personal situations during the perinatal period, in which it would be quite valid to feel a high level of emotional distress. These included drug and alcohol use, post-traumatic stress disorder (PTSD) after witnessing the suicide of loved ones, traumatic birth experiences, sexual and physical assault, family violence, miscarriages, terminations, struggles with relationships and transient living situations, struggles with relationships and living situations some of which are unsafe, family violence, childhood abuse, medical conditions eg diabetes, and psychological conditions eg bipolar, schizophrenia. Inappropriate screening tests may allocate these women high scores and thus a diagnosis of depression, when the reality is they are distressed and in need of support due to intense external or health-related pressures.

Postnatal Depression Screening Scale (PDSS)

The Postnatal Depression Screening Scale (PDSS), which is not used in New Zealand, is a screening tool developed after an extensive research process by Beck and Gable (2000) that began with women providing crucial insights into what health professionals needed to know about postnatal depression. Derived from qualitative data, the PDSS underwent testing across various countries and languages via the backtracking process and was validated through rigorous analysis. Comprising 35 self-administered survey items, the PDSS categorises responses into seven domains, each with its cut-off point. The domains are: sleeping and eating, anxiety, mental confusion, emotional lability, loss of self, guilt and shame, and suicide ideation. This approach allows health professionals to target interventions based on specific domains (with symptoms), rather than relying on a singular diagnosis of depression. A thoroughly tested and validated shorter 14-item screening scale is available.

Summary

The EPDS had high certainty for major perinatal depression with a cut-off score of >13. The Kessler 10 is not validated for perinatal women, having low certainty. The PHQ-9 appears to be viable, although there was disagreement among researchers. Evidence for the GAD-7, validated within a general population, is lacking as the symptoms are normal in pregnancy and postnatal women. The primary goal of the PDI is to assess the severity of perinatal depression, and the DuKe is too generic.

All tests have a proviso that positive results are not diagnostic. The ethical principle of informed consent to be screened, predicated on the principle of autonomy, can also be challenged if the test being used has not been validated for the presenting demographic, perinatal women. The results may suggest follow-up, specialist consultation, and further testing, causing further stress to women and additional costs to the national health service, setting up an unjust cascade of emotional distress. The perinatal screening scales examined have all been developed from a westernised medical approach to mental health and illness. There is no allowance for ethnic and cultural beliefs and values concerning pregnancy, childbirth and parenting.

While the PDSS demonstrates specificity and sensitivity for perinatal depression, its use is limited by cost, as it has to be purchased. However, identification of the domains that are problematic for the individual is very useful, in that nurses, midwives, or health improvement practitioners can explore each one with the woman and find the root cause(s) or significant factors contributing to her emotional distress. Health-care ethics involves questions about what is right and what we ought to do, and it is essential to consider these ethical issues when making decisions about health-care improvement. Ethical analysis includes whether we treat people in acceptable ways, do not harm, do good, work in ways that embody assets, and foster social and cultural strengths.

Pregnancy and childbirth are not medical conditions. Despite the widespread availability of perinatal depression and distress screening scales, they may not be in a woman's best interests if used diagnostically without an exploration of the root causes or significant factors that can be found in exploring the domains. Management may result in medications and stigma if a woman is afraid her children will be taken from her due to a "mental illness". Even more significant if the root cause of the emotional distress is not established and appropriately managed, it can become worse, eventually leading to a full-blown depression.

Clinical findings raise many issues for perinatal women that are specific to their context and outside the range of non-perinatal experiences. The state of being pregnant and having a child involves unique physiological/hormonal changes, specific mental concerns, social worries, and existential or spiritual reflections. Perinatal women may exhibit emotional distress, misdiagnosed as depression.

Pregnant and postpartum women have complex and labile emotional reactions to their experiences. To be assessed as depressed by an inappropriate screening tool exacerbates existing distress without exploring the root cause. Different perinatal depression tests have varying levels of scientific evidence. Resources directed toward screening for perinatal depression based on unvalidated screening tools are also inequitable and uneconomical.

Clinicians should consider reframing perinatal depression as emotional distress. Exploring the domains of emotional distress shifts the focus from a broad diagnosis of depression to managing emotional distress, which is both person-centred and respectful of women and their families experiencing pregnancy and childbirth. A small percentage will have physiological and/or psychological disease; however, for most, pregnancy and childbirth will follow a normal pattern accompanied by normal day-to-day anxieties.

Is perinatal anxiety a distinct condition? A question worth exploring.

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RESEARCH BRIEF

Staff perceptions and experiences of palliative care in aged residential care facilities

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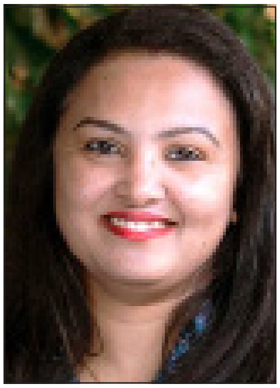

Remya Michael

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Introduction

Nations with an ageing population, including New Zealand, have growing end-of-life and/or palliative care needs for their people. Historically, aged residential care (ARC) facilities have not been acknowledged as locations where palliative and end-of-life care is provided (Phillips et al., 2015). However, there are challenges to incorporating specialised palliative care services into aged-care facilities and residents' end-of-life care (Luckett et al., 2014). This integrative review explores the perceptions and experiences of staff working in, or associated with, ARC facilities about the provision of palliative care in these settings. The terms "patient" and "resident" are deliberately used in this research brief. "Patient" describes a person who has been admitted to the facility for palliative, end-of-life care. A "resident" is someone who was admitted to the place of residential care and, as their health deteriorates, may need palliative care.

Background

The higher levels of multi-morbidity, dementia, frailty and other life-limiting conditions among those in ARC facilities can be very challenging, and complex palliative care may be required for months or possibly years prior to death. Therefore, providing care at this level requires more resources, including an appropriate level of staffing (Hawley, 2017). Staff working in these facilities must possess expertise in delivering care to enhance the quality of life for individuals with complicated co-morbidities and complex needs for advanced palliative and end-of-life care (Frey et al., 2019). Furthermore, the model of palliative care delivered in ARC is different to that provided to cancer patients (Boyd et al., 2019), warranting an integrative review of literature that focuses on the provision of palliative care in ARC.

Methodological approach

This study followed the six-step integrative review framework based on Whittemore and Knafl's original work, subsequently elaborated by Toronto and Remington (2020). An integrative review brings together diverse perspectives to foster a deeper understanding of a specific phenomenon (Whittemore & Knafl, 2005).

A PCC (Population – any health professional working in the aged-care sector; Concept – palliative care or end-of-life care; Context – long-term residential care) framework was used to construct the review question, stated as: *"Staff perceptions and experiences of palliative care in aged residential care facilities"*. Primary qualitative research studies were searched using key search terms "palliative care", "end-of-life", "terminal care", "aged care", "long-term care" and "geriatric care". Search phrases included the key terms and variations of "experiences", "perspectives", "perceptions", "thoughts", "attitudes" or "feelings ".

The databases searched included CINAHL, PubMed, and Journals@Ovid.

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Staff working in aged-care facilities above 18 years of age and providing palliative care	Staff providing palliative care in the community, hospice and private/public hospitals
Staff experiences and perceptions about palliative care in aged-care facilities	Staff experiences regarding other levels of care, including dementia and behaviour management
Review of primary research published between 2011 and 2024	Abstract only articles
Published research articles	Non-English primary research
All types of primary research based on the topic	Palliative care study based on hospital and community settings
	Palliative care studies on children

Findings

Of the 348 records identified, 53 were screened, and 38 studies were excluded due to wrong setting, outcome, study design, population, time frame and language. Fifteen met the inclusion criteria for the review. Publications were from eight countries: New Zealand (n=2), Australia (n=4), Canada (n=1), Belgium (n=1), the United Kingdom (n=2), the United States (n=1), Italy (n=1) and Ireland (n=3). For the purposes of developing this research brief, two articles (one from the UK and one from Ireland) were excluded as they both focused on additional constraints of providing end-of-life care during the COVID-19 pandemic. The studies included in this review were published between 2011 and 2024.

Three key themes emerged from the analysis: Understanding palliation in ARC; transitioning through palliative/end-of-life care; and resourcing palliative care in ARC.

Understanding palliation in ARC

Findings from this review revealed a palliative approach is multi-faceted, requiring a balance between physical, emotional and "quality" care (McVey et al., 2014). Cable-Williams and Wilson (2017) found that despite a great deal of palliative care being provided in nursing homes, and one in three residents dying yearly, some staff objected to calling this work palliative care. Therefore, a shared understanding of the philosophy of palliative care is of upmost importance to facilitate the delivery of appropriate care, especially if the patient has been discharged to the ARC facility for end-of-life care (Hill et al., 2018; McKinlay et al., 2019; Omori et al., 2022).

> *…everybody just thinks it's just death straight up and you're only here to look after them for two weeks and they'll die. I think it's not. It's ensuring that their life is lived to the fullest and as independently as they can and for as long as possible.* (Personal care assistant, McVey et al., 2014, p.204).

In addition, the concept of palliative care should be raised with the patient and family on admission to the long-term care facility (Hill et al., 2018; McKinlay et al., 2019). This means that families need to be informed that the patient has been admitted for comfort care, rather than active care to cure the condition that has resulted in them being transferred to residential care.

> *"…they [the family] don't really understand what it [palliative care in ARC] means...the family hasn't been explained what that means"* (Geriatrician, Omori et al., 2022, p.690).

> *[We have] … a discharge summary from the hospital saying this person is palliative, but then when we go to start the conversations, both the patient and the family have got a totally [different] idea.* (ARC RN clinical manager, McKinlay et al., 2019, p.23).

Timely, comforting, caring and meaningful communication is pivotal in providing palliative care (Albers et al., 2014; Borbasi et al., 2021; Gonella et al., 2020; McVey et al., 2014), with Omori et al. (2022) reporting staff believed it was important to use "caring" words, rather than blunt terms such as "terminal", to prepare the family for the fact that their loved one is dying.

> *…you say, 'We're not going to make your mum, or your dad, or your husband any better, but we can make sure that they're very comfortable, that you're with them when you want to be.'* (Interview, senior manager/director, residential/nursing home, Lee et al., 2017, p.7/19)

Transitioning through the stages of palliative end-of-life care

The second theme that emerged from this review is the transition from active care, through palliative care and end-of-life care. Care that is consistent with the resident's documented preferences is one of the top-ranked quality indicators for palliative-oriented care (Gonella et al., 2020). This is more successful where advance care planning has already been established (McKinlay et al., 2019). Providing care aligned with the patient's wishes, negotiating the relationship between staff, family and patient, and being attentive to the patient's care needs is challenging in the absence of such documentation (Albers et al. 2014; Gonella et al., 2020; McKinlay et al., 2019; Muldrew et al., 2019).

Poor communication between staff and families can lead to the family having unrealistic expectations that the resident will receive active care when they need palliative care (Omori et al., 2022). Staff note subtle changes that indicate a resident's condition is deteriorating, but families, who have not been fully informed, may be struggling to understand the significance of the declining health (Muldrew et al., 2019; Omori et al., 2022). The use of futile or aggressive treatment in the absence of advance care planning creates ethical tension for staff, as they experience conflict between what they feel is right and their duty of care (Muldrew et al., 2019). For example,

> *[A person with dementia] had three hospital admissions, he'd had five lots of different antibiotics but all different doctors and when I actually sat down and spoke to the family and said 'I think he's dying', nobody had actually just sat them down and made that decision.* (Interview, nurse, primary care, Lee, et al., 2017, p.9/19).

Staff want to provide the best possible care to the patient. However, the significant change in the patient's care needs during end-of-life care, and the lack of space in their rooms, puts pressure on staff to meet those needs, testing staff capabilities and staffing levels (McVey et al., 2014).

Resourcing palliative care in ARC

Clinical staff in aged-care facilities need to develop skills in identifying and managing symptoms such as pain, breathing difficulties or terminal secretions, thus avoiding unnecessary hospitalisation (Lamppu & Pitkala, 2021). Added to the complexities of multi-morbidities, findings from this review also reveal that limited resources and low staffing levels in ARC facilities compromise their ability to meet residents' palliative care needs (Cable-Williams & Wilson, 2017; Frey et al., 2020; Gonella et al., 2020; Hill et al., 2018; McKinlay et al., 2019; McVey et al., 2014; Muldrew et al., 2019). Resources include staffing levels, access to specialist medical services and other medical equipment, and availability of on-site GP services. Compared to public hospitals or hospices, the staff at ARC admitted that they did not possess the same comprehensive range of specialised equipment or specialised roles such as palliative clinical nurse specialist, or counsellor (Gonella et al., 2020; McKinlay et al., 2019).

> *It's the resource thing... families [think] ... hospice and hospital are free ... I ... say to them ... the hospital gets $2000 a day for a bed ... [but] ARC gets $130 and they are supposed to provide the same level of care."* (GP, McKinlay et al., 2019, p.20).

Providing high-quality palliative care is fundamentally more time-consuming since challenges in communication make it harder to assess the resident's needs effectively. Additional time is required to comfort the resident and create a peaceful atmosphere (Cable-Williams & Wilson, 2017; Hill et al., 2018).

> *In the afternoon it's very difficult, sometimes you get three palliative cases, they all have syringe drivers; three syringe drivers to be monitored by one nurse. And sometimes one syringe driver plays up and sometimes the other syringe driver needs to be recalibrated. That's already three patients and how about my 30 patients who need their regular medications? And family members visit in the afternoon waiting for you. And you want to sit with this patient who is actually dying…* (RN, McKinlay et al., 2019, p.20).

In addition, staff in ARC, undertaking these new and more challenging responsibilities, are directed to comply with financial limitations (Midtbust et al., 2018). Consequently, they are torn between their obligation to provide effective palliative care for residents and their growing workload (Musto et al., 2015).

Conclusions and recommendations

The findings of this review indicate that the provision of palliative and end-of-life care is expected as part of the services delivered in ARC. However, barriers have been identified for providing effective care for residents and their families. Staff and families need to understand the philosophy of palliative care — it involves providing quality care to a patient through the complex stages of frailty and end-of-life. The concept of palliative care needs to be raised with the patient and their family on admission to the ARC facility, and the patient, family and staff must all be involved in advance care planning. Finally, policy-makers need to make a substantial effort to recognise the increasing demand for palliative and end-of-life care in aged-care facilities and provide adequate resourcing to meet those needs.

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NZNO nurse researchers plan celebration to mark 50 years of the research section

'We hope to honour and pay our respects to the nurse leaders who paved the way for a culture of nursing research in Aotearoa New Zealand to grow and enrich the profession of nursing.'

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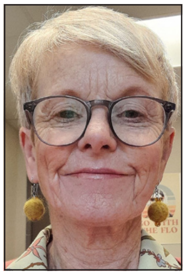

Lorraine Ritchie

THE NZNO NURSING RESEARCH Section Te Wāhanga Rangahau Tapuhi (NRS) has around 380 members, with an overall goal, as stated on NZNO's website, to "raise the profile of research in all areas of nursing by inspiring and encouraging nurses in research".

Section members are nurses from all over New Zealand — many are educators and researchers, while others have a particular interest in research and research methodologies. We are committed to the principles of Te Tiriti o Waitangi, and endeavour to honour this commitment through our meeting kaupapa, the scholarships we make available and the inclusion of researchers using indigenous kaupapa Māori research methodology at our research forums.

Research presentations

The section held its biennial general meeting in Christchurch in October 2025, which included three research presentations:

- Chey Ratima, nurse educator Māori at Te Whatu Ora — MidCentral, presented her research on cultural safety, titled *Kawa Whakaruruhau: A framework for enabling culturally safe practice with Māori.*
- Wintec nurse educator Patricia McClunie-Trust (who is also an NRS committee member) spoke on her research into graduate-entry nurses, *Graduate-entry nursing students' development of a professional nursing self*.
- Isaac Amankwaa (also a committee member) spoke on his research into assisted dying: *Evolving nursing roles in assisted dying: Insights for an ideal service model.*

These presentations generated stimulating discussion and we are very grateful to those who presented and fortunate to have such experienced researchers in the committee and section.

At the October meeting, the section committee looked ahead to next year to plan activities for the membership. Many ideas were discussed, including a mentorship model for members seeking mentors for their research journey, and "how to get published" workshops, where researchers on the NRS committee could give helpful suggestions and inside knowledge on the sometimes daunting task of turning a thesis or study into an article ready for publication. This would include which journal is the most appropriate to send an article to, how to condense a thesis into 4000-or-so words and how to respond to reviewers' feedback. To confirm which activities would be most helpful, the committee wants to consult the membership — a survey will be sent to all members seeking their views and suggestions on what they would like to see from the committee.

One event which is already in the planning stage is the NRS golden jubilee, to be held in October 2026. This celebration will be a two-day forum marking the section's 50th anniversary. The section (then known as the nursing research special interest section) officially began its life in 1976. Prominent nurse leaders and academics came together to form a group which was interested in the development and promotion of a professional nursing voice through the medium of research.

From the late 1950s through to the 1970s, prominent nurse leaders had to go overseas to pursue academic degrees, which were not available in New Zealand at that time. Many studied in universities in the United States and returned home with fresh ideas, influences and vision on how the profession of nursing could be advanced in New Zealand.

The profession becoming more 'professional'

Nursing was moving into a more professional space on an international level and New Zealand followed this lead. Many changes were taking place in society and in nursing, such as the shift of nursing training from apprenticeship-style, hospital-based training to polytechnic or other tertiary education bases from 1973 onwards. This move emphasised the transition of nursing from a more task-focused, service-driven role into a profession with its own identity and body of knowledge. This meant that nursing would also develop its own research culture, rather than it being an adjunct to medical research.

In her history of the section, Merian Litchfield summarises the context: “The international professional movement, the social forces shaping it in New Zealand, the structuring of the health sector and the resources of NZNA [now NZNO] together formed the setting of radical change in which the Section came into being in the mid-1970s” (Litchfield., 2009).

The section was officially inaugurated in April 1976 and immediately started planning for its first seminar, held in September 1976, titled, “A Forum for Nursing Research”. The early years of the section were exciting and formative ones. The current committee’s intention is to honour the mahi of these visionary nurse researchers of the past, to foster contemporary research in Aotearoa, and to look foward to research possibilities in the future.

A busy year of planning lies ahead of us. The golden jubilee will be held in Auckland in October 2026. The venue and programme is yet to be confirmed and will be advertised as the year progresses. We hope both NRS members and other nurses will join us at this exciting and historic gathering of nurses who have a passion for research. We also hope to honour and pay our respects to the nurse leaders who paved the way for a culture of nursing research in Aotearoa, New Zealand to grow and enrich the profession of nursing.

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