The
New Zealand
Medical Journal
Te ara tika o te hauora hapori

Published by the Pasifika Medical Association Group

Vol 136 | No 1581 | 2023 August 25

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PMA PASIFIKA MEDICAL ASSOCIATION Group

Publication information

published by the Pasifika Medical Association Group

The *New Zealand Medical Journal* (*NZMJ*) is the principal scientific journal for the medical profession in New Zealand. The *Journal* has become a fundamental resource for providing research and written pieces from the health and medical industry.

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ISSN (digital): 1175-8716

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The New Zealand **Medical Journal**
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Publication information

published by the Pasifika Medical Association Group

Further information

ISSN (digital): 1175-8716
Publication frequency: bimonthy
Pubication medium: digital only

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Patients' and clinicians' views on shared decision making in cancer care: a qualitative study of Aotearoa New Zealand patients' and clinicians' perspectives

Karol J Czuba, Rachel Owens, Pieta Brown, Te Hao Apaapa-Timu, R Matthew Strother, Ryan P Radecki

Our team wanted to understand how we can use digital health tools to enable patients to exercise their right to self-determination/rangatiratanga of health and wellbeing. We talked to 31 participants, including patients with cancer and clinicians. Their stories revealed a broad range of experiences in relation to SDM, highlighting a gap between the SDM expectations and its practice. Patients and whānau want to participate in making decisions about their care, to hold authority in this process and to have their needs and preferences considered beyond the biomedical model. However, there are multiple barriers that limit patients' engagement in SDM, including lack of clinical time and resources, patient and clinician attitudes, inherent healthcare system constraints, and the overall uncertainty surrounding cancer care. Our findings contribute to building Te Tiriti responsiveness across the cancer care and other healthcare settings; for example, by recognising patients' preferences for treatments such as rongoā (traditional Māori healing) and that Māori approaches to health and wellbeing are holistic and encompass concepts of collectivism rather than individualism. Future work should focus on key content and design features of decision tools, supporting SDM processes, improving information transfer and comprehension, and facilitating equitable experience and outcomes of cancer care for all patients.

Caregiver experiences of racism and child mental health outcomes: cross-sectional analysis from Aotearoa New Zealand

Rebekah Jaung, Chao Li, Ricci Bernette Harris, Sarah-Jane Paine

Caregiver experiences of racism (indirect racism) may impact on children's perception of the world as being fair and just, thus negatively impacting on their sense of mental wellbeing. This study aimed to measure how common indirect racism in New Zealand is and investigate the association between this indirect racism and diagnosed child mental health conditions. Data from 2,989 child–caregiver pairs showed that almost 20% of caregivers had experienced "any" racism ever. Children in Māori, Pacific and Asian ethnicity groupings experience significantly higher exposure to indirect racism than those in the European/Other grouping. Multiple experiences of indirect racism are associated with increased chance of diagnosed child mental health conditions. These results, alongside existing research about racism as a determining factor for health, should be received with concern about the damaging effects of racism, colonisation and white supremacy on health, and provide strong motivation for health system and whole-of-society action.

Equity of Māori access to the orthopaedic rehabilitation service of the Bay of Plenty: a cross-sectional survey

Lachlan John Cate, Nigel Giles, Bert van der Werf

We surveyed all patients in the Bay of Plenty who underwent knee replacement surgery in 2021. They were asked to document the rehabilitation they accessed before and after surgery, as well as the location at which they accessed this rehabilitation. On average, Māori patients accessed more rehabilitation (9.75 total hours) than non-Māori patients (8.34 total hours). This was in large part driven by a significant home-based component of their rehabilitation. We suggest that breaking down transport barriers is an effective method of promoting access to health services for Māori.

Administration of Routine Antenatal Anti-D Prophylaxis (RAADP) in Wellington, Aotearoa: is our practice equitable?

Zoe Lahood, Judy Ormandy

Routine Anti-D injections are given to Rhesus-negative pregnant people to prevent isoimmunisation. Isoimmunisation causes significant pregnancy complications. Hospital guidelines for Anti-D administration were not followed and there was evidence of inequity. People cared for by a private obstetrician, living closer to hospital, and birthing at a tertiary hospital were more likely to have received routine Anti-D.

Endometrial cancer diagnoses prompted by routine cervical cytology: a retrospective case study

Rhiannon CE Mertens, Peter H Sykes, Carrie R Innes, Bryony J Simcock, Simone Petrich

This study aimed to estimate the number of women who have diagnoses of endometrial cancer prompted by an abnormal cervical screening test as part of the National Cervical Screening Programme (NCSP). This is important to understand because soon the cervical screening test will test for the human papillomavirus (HPV) and not look at cells. It was found that 26 of the 334 women (7.8%) in the study had their endometrial cancer prompted by abnormal endometrial cells picked up on the cervical cell test. The disease characteristics in these cases were most often classified as less aggressive. It remains unclear what the impact of delayed diagnosis will be for these women; however, as most have less aggressive disease it is unlikely to be severe.

Low risk of variant Creutzfeldt-Jakob disease transmission from blood transfusions in Aotearoa New Zealand suggests donor exclusion policies can be relaxed

David T S Hayman, Michael G Baker

Aotearoa New Zealand excludes potential blood donors who lived in the United Kingdom for six months or more between 1980 and 1996. This policy is due to the “mad cow disease” epidemic in cattle there causing variant Creutzfeldt-Jakob disease (vCJD) in humans who could potentially pass on this infection through blood transfusions. As a result, 10% of New Zealand’s active blood donors were excluded, contributing to periodic shortages of some blood products. Cases of vCJD peaked 23 years ago in 2000 and are declining, with no new cases since 2019. Only three confirmed cases have ever been linked to a blood transfusion. We calculated the risk of relaxing these restrictions to lead to approximately 1 in 1 billion risk per year nationally, similar to a recent 1 in 1.45 billion estimate for Australia. This calculation suggests that relaxing current blood donation restrictions, like Ireland and Australia’s recent policy changes, would lead to an extremely low risk of vCJD transfusion-transmission in New Zealand. This change would increase the supply of blood products for multiple medical needs.

Cryptorchidism in a young man with learning disabilities returns as advanced testicular cancer

Morgan J Bressington, Lodewikus Vermeulen

Our case explores the story of a young man with learning disabilities who presents with an aspiration pneumonia. Investigations show this to be sequalae of an abdominal mass stemming from an advanced primary seminoma. We discuss why men with learning disabilities demonstrate a higher incidence of testicular cancer, as well as worse outcomes, and identify ways to reverse this phenomenon.

Impact of a non-medical switch from tocilizumab to upadacitinib in a cohort of patients with rheumatoid arthritis in routine clinical practice

Douglas White, David Poppelwell

In New Zealand, some adults with rheumatoid arthritis, a disease that causes inflamed joints, had their medication switched from an intravenous injection (tocilizumab) to a tablet (upadacitinib). This study looked at the effect of this. Following the switch, 6 months later most patients stayed on upadacitinib. Their rheumatoid arthritis was controlled, and they found upadacitinib convenient.

Seen and unseen work: the intensity of service provision for individuals with type 2 diabetes in a high-needs population

Christine Barthow, Nadine Kuiper, Bryan Betty, Ioana Viliamu-Amusia, Linda Bryant, Dipan Ranchhod, Erin Millar, Eileen McKinlay, Jeremy Krebs

Funding and sustainability of primary healthcare are urgent priorities to address if the recent health reforms are to achieve equitable health outcomes for all New Zealanders. Services operating as Very Low-Cost Access general practices provide care to populations with disproportionately high health and social needs; however, the complexity, volume and nature of work done by these practices is poorly understood. This case note review analysed the care provided to adults with diabetes attending a Very Low-Cost Access practice over a year and found these individuals had multiple health conditions, used many medications and multiple different types of staff were involved and provided very frequent care for most of the group. Findings highlighted the hidden, as well as the visible, complexity of work for such patients and extremely low fee-for-service invoiced to individuals when contrasted with the intensity of services provided and current funding models.

The rise (and possible fall) of ketamine treatment in New Zealand

Ben Beaglehole, James Foulds, Roger Mulder

Existing treatments for depression have limitations, including side effects and inadequate response rates. Thus, the recent interest in new treatments such as ketamine and psychedelic medications is not surprising. The use of psychedelics such as psilocybin for depression has been much hyped, but the evidence base for ketamine is more robust. In this editorial we outline the current status of ketamine in the treatment of mental illness in New Zealand and how we see it is evolving.

Ketamine treatment of mental illness has been the subject of formal research since the 1990s. By 2021, the rapidly expanding literature included more than 29 randomised trials and other non-randomised studies.[1] Most studies evaluated treatment-resistant depression and reported that ketamine treatment is associated with large short-term improvements in depression symptoms.[1] Key features of this research include the predominant use of parenteral dosing, marked dissociative symptoms at the time of dosing, and high rates of relapse when treatment ends. Additionally, there are concerns about the abuse potential of ketamine and other adverse factors including ketamine-associated cystitis, and possible memory side effects.

New Zealand research is making a significant contribution in this area. Researchers in the University of Otago have evaluated the pharmacokinetics and dosing of ketamine,[2] predictors of ketamine response and cross-diagnostic indications for ketamine treatment,[3] and the role of adjunctive psychotherapy.[4] The University of Auckland's research includes a focus on the challenges associated with expectancy and blinding with ketamine and psychedelic research,[5] qualitative aspects of ketamine associated antidepressant response[6] and neuroimaging.[7]

A key challenge for clinicians is translating the evidence for ketamine treatment of depression into usual care. The Royal Australian and New Zealand College of Psychiatrists (RANZCP) position statement[8] suggests restricting use to treatment-resistant depression (outside of research settings) and ensuring its use only occurs in services where clinicians are familiar with the drug and support structures are in place.

In New Zealand, ketamine use for psychiatric indications is off-label, although Esketamine (the S-enantiomer of ketamine) nasal spray is approved for use in treatment-resistant depression in combination with a conventional antidepressant. Esketamine is not funded by Pharmac and can only be administered in an appropriate clinic, making it expensive. The RANZCP mood disorder guidelines also report that Esketamine has not been compared directly with ketamine, most Esketamine data stems from industry-sponsored trials and longer-term outcomes are unknown.[9] To date, ketamine use in New Zealand has mainly occurred in research settings, although we are aware of limited use by publicly funded speciality services and, recently, treatment being offered by private providers.

A recent trial published in the New England Journal of Medicine showed ketamine to be non-inferior to electro-convulsive therapy (ECT) for outpatients with non-psychotic treatment-resistant depression.[10] In that study, the response rate was 55.4% in the ketamine group compared to 41.2% in the ECT group, while ketamine was better tolerated. However, a prior meta-analysis of inpatient studies drew differing conclusions.[11] Consequently, ECT should still be considered the treatment of choice for severe inpatient depression, but ketamine may be more desirable for outpatients and should be considered prior to ECT for community treatment-resistant depression.

Psychiatric disorders are chronic conditions. Longer courses of psychoactive medications are often utilised to reduce risk of relapse. Over time, neuroadaptation with some medications contributes to a number of phenomena, including fading benefits over time, discontinuation symptoms, physiological dependence and risk of broader substance disorder. While short term efficacy of ketamine is established, several questions about its longer-term role are unanswered. What is the role of maintenance ketamine treatment for enduring mood and anxiety disorders? Will factors such as reduced effectiveness over time,

dose escalation and tolerance/withdrawal emerge as issues? Despite striking short-term efficacy in most studies, how will ketamine perform given the longer-term issues often faced by patients with mental illness such as childhood adversity, discrimination and socio-demographic disadvantage?

This history of psychiatry includes treatments such as diazepam that are heralded with strong initial enthusiasm followed by overuse, re-evaluation, and recalibration of use after better awareness of the risk–benefit profile. This profile resembles the recent opiate epidemic in the United States and elsewhere. A key concern is the influence of pharmaceutical companies on consumer and doctor-led demand.

The desire for greater use of ketamine for depression is not just led by clinicians. In Australia, the Therapeutic Goods Administration has down-scheduled psilocybin and MDMA in response to intensive lobbying, despite advice from experts. This has promulgated therapeutic use of these agents despite a lack of evidence and expertise.[12] A further context in the demand for new treatments for depression is increasing rates of psychological distress in the community. We predict that the mislabelling of distress as depression will fuel demand for perceived "quick fixes" such as ketamine. We are also concerned that greater ketamine use may not be impactful, since the underlying drivers of psychological distress include early childhood adversity, poverty, and disadvantage, rather than a lack of antidepressant treatment.

Ketamine is known as "K", "special k", "ket" and "jet" by recreational users. Most ketamine consumed by recreational users in New Zealand is produced offshore. At this stage, prescribed ketamine is unlikely to contribute much to the pool of recreational ketamine. However, lessons learned from methylphenidate, benzodiazepines and opiates suggest there will be some misuse and diversion of prescribed ketamine. Careful patient selection and monitoring for these adverse outcomes will be needed.

Despite these reservations, we believe that greater availability of ketamine for treatment-resistant depression is desirable, but do not support a large-scale rapid increase in ketamine use. At present, ketamine treatment is best initiated by specialty services for the primary indication of treatment-resistant depression, although careful attention to equity of access is required. The management of relapse following courses of ketamine treatment will challenge clinicians. Adjunctive psychotherapy should be considered and there may be a role for general practitioners in selected individuals in which longer-term courses are indicated. Greater use of oral ketamine will assist management. This is currently limited to liquid ketamine for injection sipped over 30–60 minutes to reduce dissociation, but long-acting tablet formulations are in development. Clinical audit and service oversight are needed to support monitoring of outcomes and side effects. In conclusion, the potential offered by ketamine is exciting, but history suggests tempering our enthusiasm given lessons learned from other exciting treatments in our past.

COMPETING INTERESTS

Dr Beaglehole researches the impact of ketamine on mood and anxiety disorders using public funding. Prof Mulder has served on the data safety monitoring committee of a ketamine trial sponsored by Douglas Pharmaceuticals. The other author does not have any relevant conflicts of interest to declare.

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Patients' and clinicians' views on shared decision making in cancer care: a qualitative study of Aotearoa New Zealand patients' and clinicians' perspectives

Karol J Czuba, Rachel Owens, Pieta A Brown, Te Hao Apaapa-Timu, R Matthew Strother, Ryan P Radecki

ABSTRACT

AIMS: Oncology stakeholders' view on shared decision making (SDM) in Aotearoa New Zealand is not well described in the literature. This study aimed to explore the perspectives of patients, clinicians and other cancer care stakeholders on shared decision making, and how and why shared decision making in cancer care can be viable and appropriate for patients and healthcare providers.

METHODS: Non-random, purposive sampling, combined with advertisement and snowball recruitment identified patient, whānau and healthcare provider participants for qualitative interviews. One-hour, semi-structured interviews were conducted to elicit perspectives on SDM. Data was analysed using Directed Content Analysis.

RESULTS: Thirty-one participants were interviewed. SDM conceptualisations primarily concerned the sharing of information. Participants' stories highlighted patients' and whānau willingness to participate in making decisions about their care, to hold authority in this process, and to have their needs and preferences considered beyond the biomedical model. Patients and clinicians identified a range of factors moderating the extent of SDM, creating a gap between SDM expectations and practice.

CONCLUSIONS: These data highlight the complexity of information needs in cancer care, and the discrepancy between patients' and their whānau and clinicians' views. This study increases our understanding of cancer stakeholders' expectations of SDM by highlighting various views on the meaning of SDM, informational needs and decision making engagement level. These findings can aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing. Future work should explore approaches and implementations of SDM to facilitate an equitable experience of cancer care.

Shared decision making (SDM) is the collaboration between patients and healthcare providers to make care decisions based on the available medical evidence in accordance with patients' values and preferences.[1–3] Critical to patient-centred care, SDM can be used across all healthcare settings and patient populations, and allows patients and their support network to actively participate in making decisions about the care they receive.[4–6] SDM is also considered an indicator of care quality, and may contribute to improved equity of health outcomes in Aotearoa New Zealand.[3,7,8] The positive impacts SDM offers include whole of system benefits, such as improved healthcare utilisation and cost savings.[9] However, despite these benefits and patients' overall preference for SDM, the integration of SDM into clinical practice has not improved much over time.[10]

Cancer is the second leading cause of death worldwide, with an estimated ten million deaths in 2020 globally.[11] This number includes 9,500 deaths in Aotearoa New Zealand,[12] with new cancer registration rates much higher for Māori patients than for non-Māori (411.5 versus 328.8 per 100,000, respectively). Medical decision making in cancer care is a multi-stage process involving complex concepts, often without clear optimal choices. Cancer care is often comprised of surgery, radiation and chemotherapy, with each therapeutic modality presenting uncertainty around risks, side effects, benefits and long-term consequences.[10,13] In spite of this complexity, studies show that patients with cancer expect to be actively involved in their treatment decision-making and enabled to make informed decisions, with subsequent benefits including increases in patient engagement without significant increases

in consultation time, and reductions in decisional conflict and decisional regret.[4,13,14] However, a recent study of decision making in cancer care in Aotearoa New Zealand observed clinicians often made direct and preferred recommendations during clinical consults, limiting patients' ability to exercise their self-determination rights.[15] This highlights the continuing discrepancy between recognition of the benefits of SDM versus implementation in clinical practice.[10]

Providing patients with informative and relevant contextual information to support decision making is essential to SDM.[1] Patient-facing decision aids (PDAs) enable these essential aspects of SDM. PDAs are designed to help patients make deliberate decisions that are congruent with their personal values and preferences.[10,16] A PDA can be developed as a booklet, app, video/audio recording, or static/interactive information dashboard to present complex medical information, including treatment options, risks, and benefits.[16] Examples include: a booklet for prevention of breast cancer for women with BRCA1 or BRCA2 mutations containing information about breast cancer risks, preventive options, guidelines, studies, and comparisons;[17] a web-based breast cancer application with the following content tailored to individual patients: breast anatomy, breast cancer definition and types, tumour grader and markers, types of treatments and associated risks, benefits and recovery timelines.[18] PDAs can help patients make high-quality decisions within their cancer journey.[19]

Recent reports published by Health Informatics New Zealand and Manatū Hauora – Ministry of Health call for increased focus on digital solutions to enable better consumer choice, flexibility and decision-making in aid of reducing healthcare access and outcome inequities.[20,21] Addressing these needs in Aotearoa New Zealand presents several unique challenges: the disproportionate cancer burden experienced by Māori patients, which is in breach of Te Tiriti o Waitangi provisions; the large disparity in treatment options via public versus private funding; continuing poor health system integration; and significant resource constraints with limited time for decision making.[22] Importantly, an increased understanding of patients' SDM expectations is necessary to aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing.[23] As part of the development of a PDA to facilitate SDM in cancer care in Aotearoa New Zealand, we conducted a study exploring cancer care stakeholders' perspectives on the use of SDM, when decisions are made in cancer care, and key considerations when making these decisions.

Methods

Study design and location

In this Qualitative Description study,[24] we explored the perspectives of oncology patients, clinicians, and other stakeholders. The study was conducted in Aotearoa New Zealand between June and September 2022. Ethical approval for the study was received from the Health and Disability Ethics Committees of Aotearoa NZ 2022 EXP 12168.

Participant selection

Participants were oncology stakeholders, defined as: patients and their whānau, clinicians and other (e.g., patient advocates, digital health solutions developers, etc.). They were recruited using non-random, purposive sampling,[25] combining advertisement and snowball recruitment at cancer support organisations across Aotearoa New Zealand. Those who responded to the initial invitation were emailed the participant information sheet, which described the study purpose and expectations for participation. We prioritised equitable participation of Māori in this study by contracting a Māori researcher who developed a culturally appropriate flyer, and offered a "by Māori, for Māori" approach to recruiting and interviewing Māori participants. To reflect the totality of the treatment population, we recruited participants from a range of socio-demographic backgrounds, specifically seeking diversity of ethnicity, age and variation in place of residence (city, town, or rural). All participants received a $50 grocery voucher as an acknowledgement of their contribution to this study.

Participants were eligible for inclusion if aged 18 years old or older, displayed capacity for informed consent, lived in Aotearoa New Zealand, and were in one of the following groups: diagnosed with breast or prostate cancer in the last 5 years, or whānau of a breast or prostate cancer patient; clinicians working with patients who have cancer; currently involved in work related to provision of oncology services, for example: patient advocates, researchers, staff at organisations such as the Cancer Society, healthcare software developers. Participants had to have sufficient capacity to complete the interview in English or Te Reo Māori. Breast and prostate cancer were specifically pursued as these are

among the most prevalent cancers in Aotearoa New Zealand, with several possible treatment pathways leading to complex decision pathways and relatively high five-year survival rates.[26]

To achieve adequate information power[27] we aimed to recruit approximately 20–30 participants, including: 5–10 patients with breast cancer, 5–10 patients with prostate cancer, and 5–10 oncology clinicians/researchers/patient advocates. Our sample size expectation was based on Malterud et al. guidelines[27]: 1) broad aim (the overall experience of SDM in cancer care), 2) high quality of dialogue (semi-structured, in-depth interviews), 3) well-defined analytical focus (prespecified categories for data analysis), 4) cross-case analysis (exploring the range of experiences), and 5) specific sample (patients with breast or prostate cancer, cancer clinicians).

Data collection

Participants took part in one-off, semi-structured, face-to-face interviews (primarily via Zoom, with two interviews conducted in person at the participants' request). We used two interview guides (a patient and whānau, and a clinician and other stakeholder version; Appendices 1 and 2) to explore participants' perspectives on several prespecified categories: the meaning and experience of SDM, factors moderating SDM, when decisions were made in cancer care, and decisional considerations. The interviews lasted between 30 and 90 minutes. They were audio recorded and transcribed semi-verbatim. Participants were invited to have their whānau/family/support people present at the interview and were also given the option to review their transcripts for accuracy before analysis. There were three interviewers: Te Hao Apaapa-Timu (female; speaking English and Te Reo Māori; Master of Public Health; experienced in qualitative research), Karol Czuba (male; English; PhD; experienced in qualitative research), and Rachel Owens (female; English; Master of Data Science; experienced in qualitative interviewing). Participants were able to indicate with whom they wanted to be interviewed. Participants and interviewers involved in the study did not have any prior personal or professional familiarity.

We also collected standard demographic information (sex, age, ethnicity) for all participants. We asked them about their location (rural vs urban), cancer type, stage, and time since diagnosis (patients), and their role in relation to provision of oncology service (non-patient participants).

Data analysis

Participants' demographic data were summarised descriptively. Interviews were analysed using Directed Content Analysis,[28] employing primarily a deductive approach and focusing on the prespecified categories. Coding of all transcripts in QSR NVivo was conducted by KC, who read the transcripts multiple times to become immersed in the data. Initially ten transcripts were coded inductively, and the resulting codes were then linked to the prespecified categories, providing a refined coding framework. This framework was then used to code all 31 transcripts. The resulting codes, subcategories, and categories were reviewed at the project team's fortnightly progress meetings. KC, RO, PB, and RR discussed the emerging findings and the two coders' interpretations of the participants' reports.

Deidentified quotes (*in italics*) from participants' transcripts are presented to support our interpretations of the data. Each study participant was allocated an alphanumeric identifier (e.g., PB1) representing their background: 1) PB—patient with breast cancer, 2) PP—patient with prostate cancer, 3) C—clinician, and 4) O—other stakeholder.

Results

Forty-nine potential candidates responded to the study invitation. Four were not eligible to take part (not breast/prostate cancer [n=3] and diagnosed over 20 years earlier [n=1]). Nine people who enquired about the study did not respond to our follow-up emails. Five people were eligible, but enquired late in the recruitment at which time we were seeking participants of non-European ethnicity to ensure diversity of participants.

Thirty-one participants were interviewed. No whānau/family/support persons were formally interviewed; however, in several instances they were present in the same space as the participant (e.g., in the background when participants were being interviewed via Zoom). Initial recruitment was halted after 28 participants were interviewed, followed by recruitment of three additional stakeholders to balance the research cohort. Following these last three interviews, the study sample was deemed to hold adequate information power.[27] Nineteen participants took part as patients who had cancer, seven as clinicians (of whom three had a current cancer diagnosis), and five as "other" (of whom three had a current cancer diagnosis). Table 1 presents a summary of the participants' demographic characteristics.

Overall, participants expressed definitions of SDM ranging from informed acceptance of clinicians' recommendations to desire for detailed in-depth discussion related to cancer treatment. Most patients wanted to be involved in decision-making; however, there were some who wanted to only "do what they are told". Clinicians expressed support for SDM but noted significant variation in practice. They also expressed an element of hesitancy to utilise SDM, concerned the process may introduce further uncertainty into decision making. Several factors appearing to moderate the practice of SDM were identified: patient and clinician characteristics, patient–clinician relationship, time and space to make decisions, healthcare system constraints and the uncertainty surrounding cancer care. In the following sections, we report the findings for each of the prespecified categories, along with tables presenting the subcategories and participant quotes.

Meaning of SDM: from accepting care recommendations to deliberating every nuance

Participants shared their perspectives on what SDM meant to them and what it looked like in practice. Overall, both patients' and clinicians' definitions of SDM revolved around provision and sharing of information about the available cancer care options. The extent of SDM depended on a range of moderating factors.

Patients' views on SDM: "I want to have a say and contribute to the decision making process"

The minimum expectation regarding SDM was that anything to do with cancer care had to "*be agreed*", or accepted, by the patient. In some cases, as explained by PP8, it may mean agreeing to do "*what he was told, as he was trying to be a good person*", especially when patients were primarily focused on facilitating expediency in making care-related decisions. Other patients, like PB10, wanted to know about all possible treatment options, all potential side effects and "*all the facts and figures*", and be able to ask questions about anything that broadly related to their cancer care. Table 2 outlines the subcategories and representative quotes for "patients' views on the meaning of SDM".

Although for a few patients the relationship with their treating clinician seemed mostly unidirectional with no room for deliberation, most patients expected a much more "consultative" SDM process. Furthermore, with cancer impacts extending beyond the diagnosed patient, some participants highlighted the importance of including their whānau and family in SDM. This appeared particularly important to Māori patients, for whom collective decision making is often more acceptable than individual decision practices.[29]

The above-mentioned expectations around SDM were also reflected in patients' care experiences. Some patients reported that not much consultation was needed between them and their clinician. Others, for example PB1, were involved in deliberating "*every single nuance of every treatment*". However, patients' satisfaction with how much SDM occurred appeared to depend less on the extent of SDM itself, and more on their preferences and expectations.

When asked about the most important aspects of SDM, patients talked specifically about provision of information, and wanting to know as much as possible about their condition and options. Some postulated that "*information is power*", and given the uncertainty accompanying cancer, having sufficient information provided a sense of control. This sense of control, in turn, contributed to maximising patients' autonomy, and empowered them to make decisions about their care.

> *"I think the biggest thing around cancer is that you need to give patients the feeling they may have some control over something that seems so uncontrollable. Even if that control is only that my oncologist and I are going to do the best that we can to monitor me, and give me the best drugs, and help me on my journey—then I've got control of that."* (O2)

Clinicians' views on SDM: SDM can be beneficial, but challenging in practice

Clinicians had a similar understanding of SDM, proposing that SDM involved sharing information about treatment options and outcomes to help patients understand their situation and make informed decisions regarding their cancer care. However, clinicians tended to focus more than patients on the realities of SDM, specifically, on the difference between the ideal SDM and implementation in clinical practice. Table 3 outlines the subcategories and representative quotes related to this category.

As C2 reflected, the nature of clinician–patient

Table 1: Demographic characteristics of the participants.

	Patients with breast cancer (n=11)	Patients with prostate cancer (n=8)	Clinicians (n=7)	Other (n=5)
Age (years); median (range)	51 (38–74)	70.5 (55–74)	37 (28–72)	63 (39–85)
Gender (F:M)	11:0	0:8	5:2	4:1
Ethnicity				
European	7	6	5	5
Māori	4	2		
Asian			2	
Place of residence[1]				
City	4	5	7	4
Town	6	2		1
Rural	1	1		
Cancer diagnosis type[2]				
Breast	11			2
Prostate		8	1	
Bowel			2	
Brain				1
None			4	2
Cancer stage[2]				
Stage 1	2	1	NA	NA
Stage 2	3	2		
Stage 3	4	3		
Stage 4	1			
Not reported	1	2		
Time since diagnosis[2] (median [range])	7 months (3–24)	36 months (7–60)	NA	NA

Table 1 (continued): Demographic characteristics of the participants.

	Patients with breast cancer (n=11)	Patients with prostate cancer (n=8)	Clinicians (n=7)	Other (n=5)
Role	NA	NA	Anaesthetist – 1 GP – 1 Haematologist – 1 Medical oncologist – 2 Pathologist – 1 Radiation oncologist – 1	Patient advocate – 2 Digital solutions developer – 2 Cancer support volunteer – 1
[1]City—any urban area with a population of at least 100K; town—any other urban area; rural—any area not included under city or town. [2]Patient-reported data				

Table 2: Subcategories and quotes for: patients' views on SDM.

Do what the doctor suggests
"I don't like messing around—the clinician explained things really well, made me feel comfortable about it and I wanted this thing (cancer) zapped out of me." (PP6)
"They came at it in a fairly professional way, you know, just the hard, cold, facts. There wasn't any … any warmth or any sort of feelings. Either 'this' or 'that', 'take it or leave it—what do you want to do?' sort of thing. They didn't discuss it through much, they just said 'you can either cut it out or you can have the other treatment. Here's some books for you to decide, let us know'." (PP4)
Be involved in every single decision
"It never occurred to me that it could be any other way until I spoke to this other person, and she was like: 'what? You are doing this?' And it seemed like their oncologist had made some decisions without consulting her. It was only then that I realised that I actually had been privy to every single nuance of every treatment, and it all has been run by me." (PB1)
"What it should look like is that the healthcare professional describes the options and the pluses and minuses of all of the options. I can then question for more details, for example, statistics around appropriateness of the treatment for my situation, or survival statistics for a particular treatment plan. From there, I get to choose what treatment I would like to have." (PB3)
Provide information to foster empowerment
"I think the biggest thing around cancer is that you need to give patients the feeling they may have some control over something that seems so uncontrollable. Even if that control is only that my oncologist and I are going to do the best that we can to monitor me, and give me the best drugs, and help me on my journey—then I've got control of that." (O2)

Table 3: Subcategories and quotes for: clinicians' views on SDM.

SDM is about being on the same page with patients
"Shared decision making is about sitting down with the patient and having all the same information, having a talk about their diagnosis and various options for testing and treatment, and then talking about their goals and what they wish as well, and what their priorities are for their health. Then talk about the options of what we've got and using their wishes to guide or inform which ultimate choice we end up going for in terms of treatment and further testing or investigations. It's about me presenting them with some information, them asking questions, and making sure that it's all understood, that whatever we choose is with their input and wishes in mind." (C7)
SDM in practice varies widely
"Traditionally it's very hierarchical, so, it was the doctor, the lead consultant saying, 'this is what we're going to do' and everyone went with it. Nowadays, we take a lot of people's opinion into account and it's a shared decision. So, most importantly the patient, the multidisciplinary team members, nursing staff, junior doctors. The outcome for the patient is much more autonomous and it's more fair as well because a lot of people have input in it." (C2)
"I think my role is to interpret the information/knowledge/experience I have in a way for patients to understand that allows them to make the best decision for them." (C3)
Too many options can increase feelings of uncertainty
"It's obviously a good thing and the patients feel happy if they can be involved rather than, I think, years ago, doctors were like 'God' in what they said, and patients went along. Things have changed a lot. I think people expect more collegial decision making … you give them all the options, but don't give them too many options; otherwise, they tend to get confused." (C1)

Table 4: Subcategories and quotes related to: factors moderating SDM.

Patient characteristics
"Just from my experience with this exercise so far, if you're not tenacious, there's a good chance you won't get the care that you'd get if you are tenacious. Which is a very sad thing." (PB3)
"I asked 'where is your model of Te Whare Tapa Whā?'—'What's that?'—I said, 'Oh my goodness. You disappoint me'. That's where it lacks a lot, that's where a consumer misses out. We fall through the cracks. You get so exhausted in trying to teach them. You give up." (PB10)
Clinician characteristics
"What was perhaps useful, was my clinician's complete understanding of the situation, because her husband had been through something similar and was just coming through the other end. So, she'd been through that, she could understand the heartbreak, the worry, the stresses that we were going through." (PB1)
"You put your trust in the medical profession. And if there are other things available, whether they think that you can afford it or not, they can't judge anybody by just walking into the office and saying they can afford this drug or not." (PB2)
Patient–clinician relationship
"I think my clinician is very personable. Easy for me to relate to. Similar age. Similar stage of life. She understood where I was coming from. And what the things were that were important to me." (PB1)
"Traditionally medicine has been a very hierarchical profession, even among its members. So, how we were taught at medical school was definitely very different to how older doctors were taught and what they were exposed to. The way we practise is quite different." (C2)

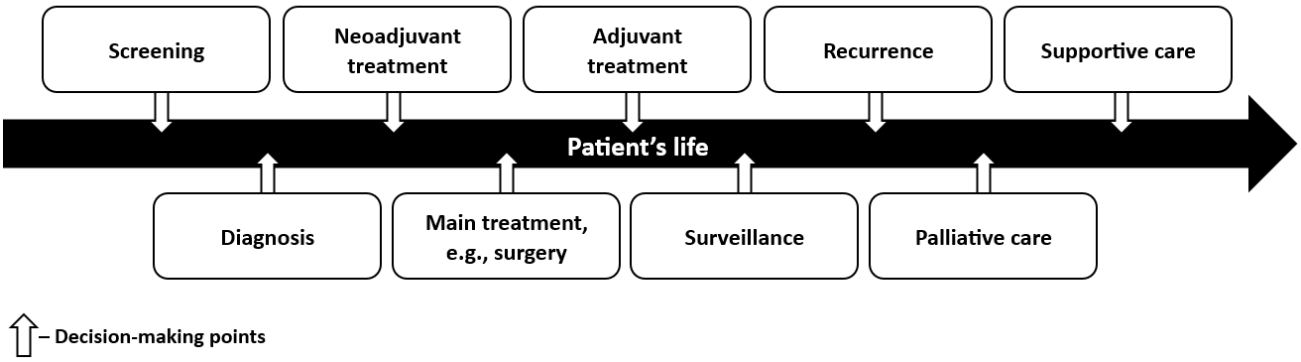
Table 4 (continued): Subcategories and quotes related to: factors moderating SDM.

Time and space to make decisions
"Me and my daughter listened to it in the comfort of our own home, our own surroundings and took in the information and made decisions that we felt, that I felt good with because I was in my own surroundings. Not in a clinical setting." (PB10)
"What really helped was we had a whole family meeting, with about five of her children and their partners came and we also got the kaumatua, or the Māori liaison support worker to come and help us. That was the most successful interaction she'd had about talking about her cancer and making her wishes expressed at that point so we could actually move forward. Prior to this, she'd had a number of consultations where we weren't able to achieve very much or make any leeway." (C2)
Healthcare system constraints
"The standard port of call for the oncologist is to go through the standard protocol and you never get fired for that. And so initially they're a little bit reticent to do statins, metformin, stuff like that. But after a while, they realise that, you know, this is a patient who will give it a go. And so, they get more experimental." (O5)
"I had my first appointment in the public sector before I decided I was definitely going private. Man, that waiting room was chocka-block full of people, they were half an hour behind schedule by the time I had my appointment. I just don't think they have time to have these really open-ended, challenge-everything discussions." (O4)
Uncertainty surrounding cancer care
"Sometimes a little knowledge is better than too much because you really don't know what you're in for. You don't understand, no matter how much you read and how much you hear from people, you don't really appreciate what you're up for." (PP6)
"You don't know whether chemotherapy is needed until after they've had surgery and then they'll see me and I'll go 'yeah, you need chemo and you need radiation' but I've got no idea whether it's four weeks or three weeks or five weeks." (C7)

Table 5: Subcategories and quotes related to: decisional considerations.

Complexity of cancer care
"My typical presentation for a decision, for when we're discussing a treatment with a patient and requiring a decision regarding treatment would be a broad outline of the cancer in general, tying that back to their specific situation. So, what are the expected outcomes; outcomes from treatment; if this is a life-shortening illness, what a typical life expectancy might be, because decisions about treatment that may have high-ish toxicity and relatively low efficacy, I don't think can be readily made in the absence of that context. There's some discussion about baseline prognosis. Then, some estimate of what the likely benefit of treatment might be, you know, on average, based on clinical studies to the degree that they apply to you and your individual situation, what's the likely lifespan extension? Then, secondarily, what are the toxicities of treatment, what's the cost in terms of … well, fiscal financial cost, if there is one, but more generally speaking, just cost in terms of time. Then, an exploration with the patient about how they perceive that, how they perceive those things to be … to measure up against one another." (C5)
Diagnosis-related considerations
"Their underlying comorbidities or past medical history is really important, because there are certain things that we can't treat if they've already had certain conditions. But their functional status is very important; I need to know that at the moment they are able to mobilise by themselves, they're able to shower, dress and toilet themselves—so we know, at baseline, that they'll be able to tolerate the treatments and we can yield the good improvement with the treatments too." (C2)
"My surgeon that I've got now, she said 'Oh, there's no harm in getting a second opinion'. Everybody should have a second opinion. But there's still oncologists and surgeons out there that don't think like that. So, I think it's allowing people an opportunity to do that. And encouraging them to do so, to be your self-advocate. Knowledge is power and that's what you need at that point." (PB2)
"For example, there are these skull caps which send electric waves through your head and could give you another two months. But do you want the quality of life walking around looking like a robot? No..." (O5)
Treatment-related considerations
"Because some of these treatments have some big down sides. I thought, I'm not going to put up with all that crap just to get another three months." (PP6)
"Quality of life does not really come into that. You're just trying to take, do whatever you can, the best possible you know ... to kill the cancer is what you're trying to." (O5)
"There's definitely the odd thing, like sometimes some reactions to the radiation treatment, the lymphedema. One that my own GP has to manage for me having no bowel is diarrhoea, and that's just life now." (C6)
"I reckon that should be an option, having tohunga, having the option of mirimiri. Not everyone wants mirimiri, not everyone likes honohono, but having those options … and romiromi, and rongoā—the Māori medicine from the plants." (PB10)
Psychosocial-related considerations
"Having a cancer diagnosis is utterly terrifying and life changing. Facing this sort of existential crisis is no small thing. And generally, even if you are the most confident and worldly person, you're brought to your knees." (PB7)
"Unfortunately, the best way to do that was to give my breast. And that was, you know, I've got three children and I breast fed all of them. And thankfully I've finished with that stage, my kids are old enough and I don't want to have any more kids. So, in that respect my breasts have done their purpose and are not needed for this important job of feeding my children anymore." (PB4)
"Most people want to be heard, and I think when you open up the conversation like that, most people are happy to be able to have a say and contribute to those decision making processes." (C2)

Figure 1: Potential decision making points in cancer care.



relationship often dictates how much SDM occurs. She noted that the more "*traditional clinicians*" tended to be quite authoritarian with their patients, while many others focused more on maximising their patients' autonomy in making decisions. C6 argued that patients often want to be told what to do, rather than being presented with all their possible choices as it can be "*too hard, too overwhelming*". Additionally, as noted by C5, some patients may have "*unrealistic*" expectations of treatment efficacy, potentially limiting patients' ability to engage in "*fully informed decision making*".

Regardless of the extent of information sharing, it appeared that an effective SDM process may offer benefits to both the patient and their clinician. As C7 reflected, SDM supports patients in deliberating their options and selecting the most appropriate treatment: "*I think the sharing of information is really important, both for patients and me, to get the right decision for them at the end of the day*".

Factors moderating SDM: the gap between expectations and clinical practice

Several factors moderating the extent of SDM were identified. Table 4 presents a summary of the moderating factors and examples of quotes supporting them.

Patient and clinician characteristics were highlighted as having a major impact on the alignment between their expectations of SDM and the actual experience. Patient characteristics included personality traits (e.g., assertive, agreeable), level of empowerment and engagement, coping skills, educational attainment, overall health status, values and beliefs, cancer diagnosis and prognosis, treatment expectations, and individual preferences. Clinician characteristics included clinicians' attitudes towards and training in SDM, their ability to tailor information for patients, and their degree of empathy. Importantly, participants noted the many biases held by clinicians and patients, including prior experiences with the healthcare system, not offering treatments to patients who do not seem able to afford them, and making decisions based on incomplete information. These biases can affect the extent of SDM that occurs in practice.

> *"It actually never occurred to me that it could be any other way. Until I spoke to this other person, and she was like, what? You are doing this? And it seemed like their oncologist had made some decisions without consulting her. It was only then that I realised that I actually had been privy to every single nuance of every treatment, and it all has been run by me." (PB1)*

The patient–clinician dyad was also noted as an important SDM moderator. Some clinicians were described by participants as "*quite authoritarian*", noting this was preferred particularly by those patients who wanted to be told what to do next. Other patients preferred a more collaborative relationship, as they found the ability to ask questions reassuring. One clinician argued the authoritarian style was more prevalent among clinicians who were trained in the previous century, while more recently trained oncologists tended to foster more collegial relationships with their patients. In this context, it

appeared that a "*good match*" personality-wise can facilitate patients' satisfaction with SDM. Participants also noted effective communication was key to building trust and understanding, which are essential for successful SDM. However, some clinicians commented that it is challenging to communicate to patients the uncertainty surrounding cancer treatments, with no clear "best" choice based on available evidence. In this context, as C6 argued, some patients want the clinician to tell them exactly what to do, rather than practise SDM.

Participants also deliberated on several moderating factors related to the broader healthcare system in Aotearoa New Zealand. A range of inequities, for example, inequitable access to information, were noted as impeding patients' ability to make shared decisions. PB10, who is Māori, noted the lack of recognition of her cultural background negatively impacted her care experience, where she struggled to engage with clinical staff and was left feeling poorly informed about her care options. She recalled multiple encounters when she felt disrespected and disempowered, and it furthered her mistrust towards the healthcare system. Additionally, C2 argued the limited choice of publicly funded cancer treatments in Aotearoa New Zealand may be further deepening the health outcome inequities. Some participants even noted the lack of choice may render SDM unnecessary. Furthermore, staff shortages, resource-related constraints and system fragmentation were named as barriers to SDM. These constraints, as noted by C5, can contribute to clinicians only presenting the information that they consider most critical. Finally, many patients noted the importance of having sufficient time and being in an appropriate space to deliberate treatment options. Some argued being able to discuss these options with their family and whānau would help them make decisions truly reflecting their preferences and needs, and as noted by PB10, it could also help their whānau understand the specific implications of their relatives' cancer diagnosis on themselves.

Cancer care decisions and considerations: arriving at *"a clear decision that the patient is comfortable with"*

Participants reflected on a broad range of decisions patients may have to make throughout their cancer journeys. Figure 1 presents an example of the potential decision making points in cancer care identified by participants; the specific stages and sequence in which they occur can vary.

They included decisions related to screening, diagnosis, care team selection and changes, treatments (including types, order, funding, changing goals) and post-treatment procedures. These decisions were emotional and complex, involving elements of uncertainty, risk, and compromise, often in the context of urgency and varying patient preferences. Participants also identified a number of important considerations for making the above-mentioned decisions. We grouped these considerations into three subcategories: 1) diagnosis-related, 2) treatment-related, and 3) psychosocial-related considerations. Table 5 presents the subcategories and representative quotes related to this category.

First, a good understanding of cancer diagnosis is crucial in helping patients to choose the most appropriate treatment plan and develop realistic expectations about their care and outcomes. C2 noted underlying comorbidities, medication, past medical history and functional status play a critical role in determining the best course of treatment, with the evolving nature of cancer adding further complexity. Some comorbidities, for example diabetes or heart disease, may make certain treatments more risky or unsafe for patients. Additionally, as reported by PB2, the option of seeking a second opinion may play an important role in building trust and enabling effective SDM; however, not all clinicians support this practice. Indeed, as argued by O1, disagreeing with the initial diagnosis and seeking a second opinion is part of the cancer journey for some patients, who "*stay with the original person*" but become better informed.

Second, participants reflected on several aspects of the treatment decision making, including treatment options, goals and aims, effectiveness, costs, side effects, timelines and alternative treatments. In many participants' stories, eliminating cancer appeared to be the primary driver for treatment decisions. PP7 simply wanted "a peace of mind" and to know the cancer is gone. However, some participants with the more advanced stages of cancer postulated the treatment's impact on their quality of life and functional independence were key determinants. Some participants also expressed interest in non-standard treatments. PB10 argued for more recognition and consideration of traditional approaches, like rongoā Māori. PB2 was interested in combining radiation with evidence-based, non-standard treatments like sauna, but her clinician "*was like: Pffft!*". At

the other end of the spectrum, O5, whose cancer was diagnosed as terminal and was treated via the private sector, appreciated his ability to discuss standard and non-standard treatment with his clinician. Significant consideration was also given to side effects such as incontinence, erectile dysfunction, diarrhoea and lymphedema. Side effects were alternatively seen as necessary trade-offs and treatment deterrents. In this context, as PP6 described, "*seeing other people's stories and information as best as you can was highly valuable*".

Finally, some participants felt considerations relating to the psychosocial domain do not get acknowledged enough in the clinical context. The emotional impact of receiving a cancer diagnosis, which is often unexpected, was reported by most as significant and impacting a patient's ability to engage in SDM. For example, PB7 described her diagnosis as "*utterly terrifying and life-changing,*" and emphasised the need to cope with emotions before making treatment decisions. For PB4, the diagnosis was isolating and she "*did not know what to do with her emotions*". She sought a community of similar people and found knowing how patients felt in similar situations helped her cope with emotions. Participants' stories also highlighted the need for consideration of whānau and family: their preferences and how cancer diagnosis and treatment may affect these groups. For some participants, treatment decisions were dictated by the extent of support they might require from relatives. Their roles within their family and whānau, and also more broadly, were also considered. For PB4, losing her breast in mastectomy did not concern her as much as it would have, had she wanted to breastfeed her, now older, children. However, knowing her sexuality and self-image were affected by the procedure made her wonder if opting for a more conservative treatment would have fit her preferences better.

> *"How do you see the pros and cons or the benefits and all that? How does one weigh up against the other? How does it affect your urinary function? How does it affect your sex life? What bits do they take out? How do they take it out? How do I manoeuvre my way through this thing and actually come out the other end with a clear decision that I'm comfortable with?" (PP5)*

Discussion

Participants' reflections of SDM in cancer care revolved around the sharing of information and collaboration between patients and clinicians. The context within which care decisions are made is characterised by significant complexity, compounded by the volume of potential decisions and limited foresight, and cancer being an evolving disease. Participants' stories suggest perceptions about the right level of information varies between patients, and also between clinicians. In light of the complexity of cancer care, wide range of SDM expectations' and variability of informational needs, it is clear a "one size fits all" approach is unlikely to succeed in providing optimal healthcare to cancer patients. Furthermore, it appears that the current processes for supporting SDM may be insufficient, with patients often wanting more time and space to deliberate options with their whānau, express preferences and have their concerns addressed. Participants recounted several areas patients consider during their cancer care experience, focusing on diagnosis, treatment and specific psychosocial aspects.

Our findings suggest practising SDM may be particularly beneficial in the Aotearoa New Zealand context, with the increased focus on upholding Te Tiriti o Waitangi and the implementation of the Pae Ora (Healthy Futures) Act 2022. The Act involves explicit attention to the ongoing effects of colonisation on Māori, including a range of social and health inequities.[30] Fortifying responsiveness to Māori in designing SDM platforms also honours the other two articles of Te Tiriti, as it facilitates Māori to exercise Tino Rangatiratanga (Article 2, Authority) and forms pathways towards achieving Ōritetanga for Māori (Article 3, Equity). In the current study, Māori participants' stories highlighted patients' willingness to participate in making decisions about their care and to feel empowered to hold authority in this process and have their needs and preferences considered beyond the biomedical model. Importantly, most non-Māori patients also shared this view. These findings can contribute to building Te Tiriti responsiveness across the cancer care and other healthcare settings, for example, by recognising patients' preferences for treatments such as rongoā (traditional Māori healing) and that Māori approaches to health and wellbeing are holistic and encompass concepts of collectivism rather than individualism.[30] Indeed, both Māori and non-Māori participants in this study recommended more focus on including

whānau/family/support persons in SDM. These notions, as well as cultural dynamics, should be incorporated into health technologies,[31] such as PDAs, to foster patients' agency in decision-making. Input from Māori stakeholders to this process will be imperative for responsiveness to a range of cultural nuances, such as whakamā or shyness, and to ensure high usability of these new technologies.[31]

While participants appeared to generally agree on what SDM involves, some discrepancies were noted regarding how it should be enacted in practice. Specifically, there appears to be a gap between how much patients want to know and what clinicians deemed to be feasible or beneficial for the patient. This observation is consistent with prior publications of SDM in cancer settings: e.g., in cancer care in Aotearoa New Zealand,[15] in surveillance imaging for lung cancer,[32] surgical options for breast cancer,[33] or surgery or chemotherapy in breast cancer.[34] The existence of this gap may be driven by a common underlying assumption that provision of more information leads to better outcomes and more satisfaction with decisions.[35] As argued by Peters et al.,[35] for this assumption to be true, the provision of information should be accompanied by other forms of support or interventions providing a structure for using this information, for example goal setting or decision frameworks. Moreover, Peters et al.[35] also note that there exist between- and within-individual differences in desired levels of information across multiple domains. These differences were also evident in the current study, where the participants' SDM expectations appeared more important to their overall care experience than the level of SDM actually occurring. Thus, tailoring the information being given to patients, including its format, breadth and depth, appears critical to SDM, as it may prevent such unintended consequences in patients as increased anxiety or poorer decision making. Additionally, the differences in SDM expectations pose a challenge to building reliable clinical heuristics, which could be overcome by PDAs assisting clinicians to quickly decide the appropriate level of engagement and kind of information for each specific situation.[10]

Finally, our research identifies several factors moderating the level of SDM, some of which are fixed and some of which may be amenable to interventions. The fixed characteristics—e.g., personalities, education level, time constraints, available drugs—may be mitigated by interventions expediting information transmission, maximise the available options in the clinical interaction while also supporting self-directed learning in other options, and offer a range of presentations to transmit complex concepts for better comprehension. Furthermore, some of the moderating factors are likely correctable. For example, a clinician bias in presenting information can be mitigated by standardised patient decision supports, giving all patients access to the same information and saving clinicians' time. This time could be potentially spent on exploring patient values, rather than on, e.g., prostate anatomy, which can be done more efficiently presented in a PDA. PDAs can play an important role in mitigating patient, provider and system constraints to achieving ideal SDM.

Limitations

Our findings present a spectrum of perspectives and experiences of cancer care stakeholders. Limitations include a lack of representation of key ethnic groups, particularly from Māori clinicians. As non-Māori are overrepresented within the clinical workforce, we aimed to balance this by recruiting more Māori patients and/or patient advocates. However, during the initial recruitment phase we were only able to interview one participant who identified as Māori. We then focused specifically on recruiting Māori patients (we engaged a Māori interviewer, developed a flyer and liaised with Māori cancer support organisations) and managed to recruit another five Māori patient participants. With Māori as Te Tiriti o Waitangi partners who experience excessive inequities in health outcomes, there is an urgency to develop strategies that support a responsive health system constructed to effectively engage Māori at all levels, in pursuit of attaining health equity for all. Prioritising a focus on whānau engagement in SDM in future research would be one way of honouring Te Tiriti in future strategies.

In this study we focused specifically on patients with breast or prostate cancer. There is at least some overlap between the two selected cancer types and the other cancer types in terms of how shared decision making is enacted in practice. In that regard, we believe that our findings are largely transferable to other populations of patients with cancer. However, further research is required to ascertain whether there are any specific differences between breast and prostate cancer and other cancer populations that may impact patients' and clinicians' attitudes to SDM.

Conclusion

This qualitative evaluation describes patients' and clinicians' accounts of SDM in cancer care in Aotearoa New Zealand. Participants described a broad range of experiences in relation to SDM, highlighting a gap between the SDM expectations and its practice. Several factors were identified appearing to contribute to this gap, making it more challenging to achieve optimal outcomes for patients. These findings increase our understanding of cancer stakeholders' expectations of SDM to aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing. Future work should focus on key content and design features of PDAs, supporting SDM processes, improving information transfer and comprehension and facilitating equitable experience and outcomes of cancer care for all patients.

COMPETING INTERESTS
Nil.

ACKNOWLEDGEMENTS
We would like to acknowledge Dr Judy Blakey, MZNM, for providing feedback on the study protocol and patient interview guide.
We would like to acknowledge the following organisations for support with participant recruitment (listed alphabetically): Arohamai Mai Cancer Support Services, Breast Cancer Foundation, Cancer Society of NZ, Nga Kete Matauranga Pounamu Charitable Trust, Orion Health, Precision Driven Health, Prostate Cancer Foundation, ProstFit NZ.

FUNDING
This study was funded by a grant from Precision Driven Health, reference number: 1411.

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Appendix 1: Patient and whānau interview guide.

Potential questions and prompts

- Where are you currently in your cancer journey?
- What does shared decision making mean to you?
- What has SDM looked like for you in your (your whānau member's) cancer journey so far? How did you and your clinician decide on your treatment? What information did you use (also through own research)? What aids/tools did you use? What visual aids? Did you discuss how your symptoms may develop over time? Care timeline/trajectory? Did you talk to anyone else?
- How important is shared decision making (SDM) to you? When do you feel that you are/are not included in the decision making?
- Were there many treatment options to choose from? How did you decide? What factors did you consider? How did you consider potential benefits vs harms? How was the risk around treatment communicated to you? How did it make you feel? Would you prefer it was done differently?
- What kinds of information are/would have been helpful to you when making decision about your (your whānau member's) cancer care?
- How were your choices/wishes/culture/values/needs/preferences/personal circumstances identified and considered by the clinician? What about the treatment's impact on your (your whānau member's) life/whānau? Your (your whānau member's) other responsibilities? On your (your whānau member's) quality of life?
- What would you (or did you) do if you and your clinician had differing opinions regarding your (your whānau member's) treatment?
- If your oncologist tells you that you (your whānau member) should get a treatment that is not included in the guidelines (not standard or usually recommended), how would you react? What questions would you ask?
- What are some key considerations when it comes to trusting/mistrusting your clinician's advice/recommendations?

Appendix 2: Clinician and other stakeholder interview guide.

Potential questions and prompts

- Could you please tell me a little bit about your role in relation to the topic of this research study?
- What does shared decision making mean to you? What is its role in your practice? What do you usually do to engage your patients in that process?
- Thinking about the decision making flows and key decision points—what is your usual approach to developing a care plan for your cancer patients? Can you talk me through that process step-by-step?
- What information do you use to discuss care/treatment decisions with your patients? What do your patients want to know when discussing care/treatment options? What tools/aids do you use and how? How do you know if they are available to your patient?
- When making a treatment decision, what are the most important factors to you when making treatment choices?
- How do you consider your patients' choices/wishes? Life/family situation? Logistics/costs of treatment? Cultural factors? Are there any particular cultures or groups who you would find these tools particularly helpful for?
- How do you explain to your patients what the important considerations are, what the different risks are? How did you discuss potential benefits vs harms? How do you help your patients decide?
- How do you incorporate clinical guidelines into your decision making process and discussions with your patients (thinking about 'recommended' treatment vs alternatives)? How do you know if the guidelines are appropriate for your patient? Which guidelines do you use (e.g., ASCO or ESMO; NCCN)?

- What about other/alternative treatment options, e.g., via clinical trials—how do you find out if your patient could take part in a trial?
- How do you approach discussing your patients' treatments options, prognosis, predicted survival/mortality rate?
- What do you do if there is a disagreement between you and your patient regarding next steps?

Caregiver experiences of racism and child mental health outcomes: cross-sectional analysis from Aotearoa New Zealand

Rebekah Jaung, Chao Li, Ricci Bernette Harris, Sarah-Jane Paine

ABSTRACT

AIMS: This study aimed to estimate the prevalence of vicarious racism experienced by children (0–14 years) in Aotearoa New Zealand and investigate the association between vicarious racism and diagnosed child mental health conditions.

METHODS: Adult and child 2016/2017 New Zealand Health Survey data were merged to create child–caregiver dyads. Multivariable logistic regression models were used to investigate the association between the caregiver experiences of racism (exposure) and diagnosed child mental health conditions (outcome), adjusting for confounders and exploring potential pathway variables.

RESULTS: Looking at 2,989 dyads, the prevalence of "any" vicarious racism was higher for Māori (28.1%; 95% CI 24.2–31.9), Pacific (23.2%; 95% CI 17.9–28.5) and Asian (29%; 95% CI 23.6–34.5) children compared to European/Other children (12.5%; 95% CI 10.2–14.8). A statistically significant association was identified between >2 reports of vicarious racism and the outcome (OR= 2.53, 95% 1.18–5.43). Adding caregiver psychological distress reduced this association (OR= 1.92, 95% 0.91–4.08).

CONCLUSIONS: Children in Māori, Pacific and Asian ethnicity groupings experience higher exposure to vicarious racism than those in the European/Other grouping. Multiple experiences of vicarious racism are associated with increased odds of diagnosed child mental health conditions in a dose–response distribution.

Alongside personal experiences of racism, racism can be experienced indirectly or vicariously through the experiences of other individuals or groups. Vicarious racism is proposed to impact on children's perception of the world as being fair and just, thus negatively impacting on their sense of mental wellbeing (mental and socio-emotional health).[1]

Direct experiences of racism have been strongly associated with poor child mental health outcomes;[2] however, the evidence supporting a relationship between vicarious racism and child mental health is less definitive. Associations have been identified between a number of socio-emotional health outcomes and post-birth, caregiver-mediated vicarious racism exposure.[1] However, only a minority of studies examining the association with mental health outcomes have reported significant results.[1]

Local research has demonstrated that children who had any exposure to vicarious racism had poorer mental health, and that greater exposure was associated with worsening child emotional wellbeing.[3] Caregiver mental health and socio-economic position have been identified as important potential pathway variables for the impact of vicarious racism.[1,3,4]

Considering vicarious exposure to racism acknowledges that racism can have a collective, as well as individual, impact. This is particularly relevant for marginalised communities who have experienced a disproportionate amount of collective trauma from processes like colonisation and imperialism. In the context of child health, this conceptualisation stands apart from approaches which silo child health outcomes from the relationships and environments in which children are embedded.

This study aimed to estimate the prevalence of child exposure to vicarious racism in Aotearoa New Zealand and examine the association between this exposure and child mental health outcomes. We hypothesised that exposure to vicarious racism would be associated with having an increased odds of reporting a diagnosed childhood mental health condition.

Methods

Responsiveness to Māori

This research was aligned with Kaupapa Māori theory (KMT) (carried out according to

KMT but undertaken by a non-Māori researcher with supervision from Māori researchers).[5] A full responsiveness to Māori statement is available as appendix 1. In short, this study was led by senior Māori public health academics with subject matter expertise and sought specifically to improve Māori health. We sought to expose the distribution of power and privilege when examining racial oppression in Aotearoa, and started from the position that Māori children have a right to health and wellbeing, free from the harm of racism.

Study overview

Ethical approval for the study was obtained from The University of Auckland Human Participants Ethics Committee (023851), and access to the New Zealand Health Survey microdata was approved by the Statistics NZ Microdata Access Manager (CURF2020-02).

This quantitative, cross-sectional observational study involved secondary analysis of data collected by Manatū Hauora – Ministry of Health as part of the 2016/2017 New Zealand Health Survey (NZHS). The NZHS includes separate questionnaires for children (0–14 years) and adults (15 years and over), and experience of racism is currently only measured in the adult questionnaire.

This study analysed data collected from a sample population of children aged 0–14 years living in Aotearoa New Zealand who were included in NZHS 2016/2017 and had a primary caregiver who was selected to answer the NZHS adult questionnaire.

Dyad formation

In the NZHS, child questionnaires are completed by proxy by the adult primary caregiver in face-to-face interviews, but not all adult primary caregivers are selected for the adult survey. This restricted inclusion in our analysis to children whose questionnaires were completed by their primary caregiver. Confidentialised unit record files (CURF) data that were obtained from children's questionnaires completed by a non-primary caregiver adult were excluded (n=551).

Child questionnaire responses to questions about mental health, adult questionnaire responses to the racism module, and mediating factors such as socio-economic position and adult mental wellbeing were combined to create child–caregiver dyads for data analysis (Figure 1).

A full description of the NZHS variables and how they were translated into study variables are outlined in appendix 2. For the exposure variable, responses other than "yes" or "no" were treated as missing data, and included responses were used to create binary ("any" experiences of racism ever: yes/no) and categorical (number of "yes" responses) variables for data analysis as in previous studies by the research group.[3,4] The categorical variable was expressed as: no experiences, one experience, or two or more experiences.[5]

The outcome measure collated responses to questions about children's diagnoses of depression, anxiety disorder, and attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD). The "yes" and "no" responses to these questions were examined by condition and then used to create the composite binary variable "any diagnosed mental health condition".

Ethnicity

Child ethnic groupings are selected by the caregiver in the NZHS. Ethnicity data were aggregated into Māori, Pacific, Asian and European/Other groupings, and could not be disaggregated for analysis. According to 2006/2007 NZHS data, the European/Other group is predominantly European, with approximately 1% of this group identifying with an ethnicity in the "Other" category;[3] it can be considered a comparator or reference population when examining the prevalence of experiences of racism in the other ethnic groups.[7]

Potential pathway variables

The potential pathway variables included in this study were informed by previous studies of vicarious racism and child health using NZHS data.[3,4] Caregiver socio-economic position was measured using highest educational qualification (none vs secondary school qualifications or higher) and neighbourhood level deprivation (New Zealand Deprivation Index, NZDep 2013, quintile 1=least deprived and quintile 5=most deprived).[8]

Caregiver mental health status was measured using the 10-item Kessler Psychological Distress Scale (K10), which is a screening tool measuring psychological distress.[9–10] The range for K10 scores is 10–50 points, and this was analysed both as a continuous variable and a categorical variable with a cut-off at 12-points (low=K10 <12 and high=K10 >12).

Figure 2 displays the hypothesised relationship between the exposure, outcome, and potential pathway variables.

Data analysis

Data analysis was performed using StataIC

Figure 1: Illustration of how adult and child datasets are merged to create child–caregiver dyads.

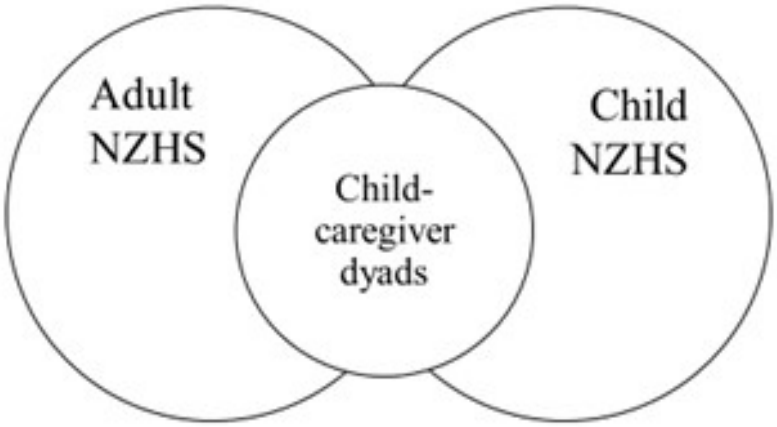

Figure 2: Hypothesised relationship between exposure, outcome, and potential pathway variables.

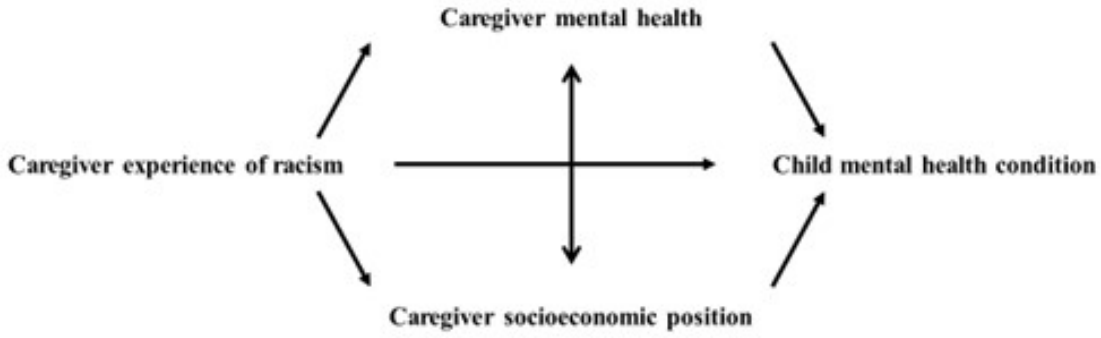

Table 1: Weighted percentage of vicarious racism by child's ethnic grouping (prioritised ethnicity).

	Child ethnic grouping							
	Māori (1,074)		**Pacific (395)**		**Asian (432)**		**European/Other (1,269)**	
	N (unweighted %)	Weighted % (95% CI)	N (unweighted %)	Weighted % (95% CI)	N (unweighted %)	Weighted % (95% CI)	N (unweighted %)	Weighted % (95% CI)
Any racism (ever)	327 (30.5)	28.1 (24.2–31.9)	107 (27.9)	23.2 (17.9–28.5)	125 (28.9)	29 (23.6–34.5)	192 (15.13)	12.5 (10.2–14.8)
Level of exposure								
One experience	222 (20.7)	19.9 (16.4–23.3)	77 (19.5)	17.1 (12.5–21.7)	91 (21.1)	20.3 (15.2–25.5)	160 (12.6)	10.5 (8.4–12.6)
Two or more experiences	105 (9.8)	8.2 (6.4-10.1)	30 (7.6)	6.1 (3.7–8.6)	34 (7.9)	8.7 (5–12.4)	32 (2.5)	2 (1.1–3.0)

CI = confidence interval.
*Māori, Pacific and Asian ethnic groupings are reported as total response and the European/Other grouping is a mutually exclusive comparator.

Table 2: Association between vicarious racism ("any" racism and level of racism exposure) and diagnosed child mental health conditions, models adjusted for caregiver binary gender, age group and ethnic grouping.

		Any diagnosed mental health condition OR (95% CI)
"Any" racism		1.4 (0.9–2.2)
Level of racism	1 report	1.1 (0.7–1.8)
	2+ reports	2.5 (1.2–5.4)*

*Statistically significant (p <0.05).

Table 3: Association between vicarious racism and diagnosed child mental health conditions, with findings presented for: unadjusted models (M0); models additionally adjusted for confounding variables of age, gender, ethnicity (M1); and potential pathway variables (M2 and M3).

		Any diagnosed mental health condition OR (95% CI)
Model for "any" racism		
M0: unadjusted		1.3 (0.8–2.0)
M1: caregiver ethnic grouping, binary gender and age		1.4 (0.9–2.2)
M2: caregiver neighbourhood deprivation, highest educational qualification		1.5 (0.9–2.2)
M3: caregiver psychological distress (continuous variable)		1.1 (0.7–1.8)
Model for level of racism		
M0: unadjusted	**1 report**	1.1 (0.7–1.7)
	2+ reports	1.9 (0.9–4.1)
M1: caregiver ethnic grouping, binary gender and age	**1 report**	1.1 (0.7–1.8)
	2+ reports	2.5 (1.2–5.4)*
M2: caregiver neighbourhood deprivation, highest educational qualification	**1 report**	1.1 (0.7–1.8)
	2+ reports	2.6 (1.2–5.8)*
M3: caregiver psychological distress (continuous variable)	**1 report**	0.9 (0.5–1.6)
	2+ reports	1.9 (0.9–4.1)

*Statistically significant (p <0.05).

(version 16, StataCorp, College Station, TX) by two study investigators (Chao Li and Rebekah Jaung) and reviewed by all investigators.

Descriptive summaries of caregiver and child demographic and other characteristics, weighted prevalence of caregiver experiences of racism/vicarious racism and weighted prevalence of child mental health variables were analysed by total response ethnicity. Child–caregiver dyads with missing exposure or outcome data were excluded from further analysis.

Multivariable logistic regression models were generated to examine the association between child mental health outcomes and caregiver experiences of racism/vicarious racism, with adjustment for covariates. The role of potential pathway variables in the relationship between caregiver experiences of racism/vicarious racism and child mental health was then examined by building several models where covariates were added sequentially:

1. Baseline model (M0)
2. Add confounding caregiver characteristics: (age, prioritised ethnicity, binary gender), (M1)
3. Add caregiver SEP measures: highest educational qualification and NZDep13 (M2)
4. Add caregiver psychological distress (M3)

Results of logistic regression were reported as odds ratios (OR) and 95% confidence intervals.

Results

A total of 2,989 child–caregiver dyads were included in the analysis, out of the 4,668 children (64%) and 13,598 adults (22%) who participated in the child and adult 2016/2017 NZHS. Demographic data and characteristics for the children included in the analysis are displayed in appendix table 1.

Vicarious racism

Overall, 19.7% (95% CI 17.9–21.4) of caregivers reported experiencing "any" racism ever. The prevalence of vicarious racism ("any" exposure to racism experienced by caregivers) was higher in Māori (28.1%; 95% CI 24.2–31.9), Pacific (23.2%; 95% CI 17.9–28.5) and Asian (29%; 95% CI 23.6–34.5) children when compared to European/Other children (12.5%; 95% CI 10.2–14.8) (Table 1). This pattern of exposure is more pronounced when looking at multiple experiences of racism, with 2% (95% CI 1.1–3.0) of caregivers of European/Other children reporting two or more experiences of racism compared with caregivers of Māori (8.2%, 95% CI 6.4–10.1), Pacific (6.1%; 3.7–8.6) and Asian (8.7%, 95% CI 5.0–12.4) children.

Child mental health outcomes

The overall prevalence of any diagnosed mental health condition was 5.4% (95% CI 4.0–6.7).

The outcome variable (any diagnosed mental health condition) is markedly lower in Pacific and Asian groupings, as is condition-specific prevalence (appendix tables 2A and 2B). Looking at missing outcome data by ethnic grouping, there did not appear to be major differences in child or caregiver ethnic grouping associated with missing mental health outcome data (appendix table 3).

Potential pathway variables

Examining caregiver socio-economic position, 11.1% (95% CI 9.0–13.3) of European/Other children had caregivers living in the most deprived neighbourhoods (NZDep13 quintile 5) compared to the Māori 40.5% (95% CI 35.2–45.7), Pacific 56.2% (95% CI 47.4–65.1) and Asian 18.9 % (95% CI 14.1–23.7) children. Māori and Pacific children were less likely to have caregivers who reported secondary school qualifications or higher (Māori 66.0%, 95% CI 62.4–69.5; Pacific 76.9%, 95% CI 71.5–82.2) compared with children of the mutually exclusive European/Other group (90.4%, 95% CI 88.3–92.6). Compared to European/Other children (7.8%, 95% CI 5.8–9.8), Māori (10.1%, 95% CI 7.7–12.6) and Pacific (12.0%, 95% CI 8.3–15.9) children were more likely to have caregiver who reported a high K10 score, while Asian children had caregivers who were less likely to have a high score (3.1%, 95% CI 1.0–5.2).

Relationship between child mental health outcomes and caregiver experiences of racism

Table 2 presents multivariable logistic regression models used to examine the association between vicarious racism and child mental health conditions which have been adjusted for caregiver binary gender, age group and ethnic groupings. While we did not find a significant association when looking at the "any" racism exposure variable, the OR point estimates are suggestive of increased risk of diagnosed mental health condition if the children were exposed to "any" vicarious racism via their caregivers (OR=1.4, 95% CI 0.9–2.2).

For the level of racism exposure (Table 2),

while there was no association for a single report, again the OR point estimate is suggestive of an increased risk. With two or more reports of vicarious racism the model was statistically significant (OR 2.5, 95% CI 1.2–5.4), indicating a higher risk of their child having a mental health condition with this level of vicarious racism exposure. Viewed together, these point estimates are suggestive of a dose–response.

Table 3 summarises the findings from a series of logistic regression models used to explore whether the association between vicarious racism and child diagnosed mental health conditions operate via two potential pathway variables: caregiver socio-economic position (M2) or caregiver psychological distress (M3).

Inclusion of the potential pathway variable of SEP for the "any" racism exposure variable had minimal impact on the OR point estimate between M1 (OR=1.4, 95% 0.9–2.2) and M2 (OR=1.5, 95% 0.9–2.2). Additional adjustment for caregiver psychological distress (M3) had a larger attenuating effect on the OR point estimate (from OR=1.5 [95% CI 0.9–2.2] to OR=1.1 [95% CI 0.7–1.8]). This suggests that caregiver psychological distress is also a contributing factor to child mental health outcomes, resulting in a lower OR point estimate for our model.

Inclusion of the potential pathway variable of socio-economic position had minimal impact on the association between 2+ reports of vicarious racism and child mental health outcomes (M2; OR= 2.6, 95% 1.2–5.8). However, adjusting for caregiver psychological distress had a larger attenuating effect on this association (M3; OR= 1.9, 95% 0.9–4.1).

An independent association was not identified between "any" vicarious racism and child diagnosed mental health conditions; however, our modelling sequence demonstrated some consistent effects related to the potential pathway variables. The series of models from M1 to M3 for both "any" and level of racism exposure (Table 3) illustrate the contribution of the different caregiver variables to the association between caregiver experiences of racism and child mental health, with the addition of caregiver socio-economic position (M2) having a negligible effect on M1 and psychological distress leading to a drop in the odds ratio (M3). This observation adds to our understanding of caregiver psychological distress as a potential pathway variable, in terms of the direction and magnitude of impact that it may have on the relationship between vicarious racism and child mental health outcomes.

Discussion

Using data from the most recent NZHS, which included the racism module (2016/2017), we have demonstrated an association between two or more caregiver experiences of racism and increased odds of diagnosed mental health outcomes in children. This association was reduced by caregiver psychological distress, suggesting that the latter may be a potential pathway variable through which caregiver experiences of racism impacts child mental health.

This work builds on existing analyses that have identified associations between vicarious racism and child health-related quality of life, mental health, behaviour and self-esteem scales,[3] and healthcare utilisation.[4] Previous quantitative studies investigating the association between vicarious racism and child health outcomes using earlier NZHS data have identified that children from Māori, Pacific and Asian groupings are exposed to much higher levels and a greater frequency of vicarious racism when compared to children in the European/Other grouping.[3,4] Our analysis also supports the pattern of exposure to vicarious racism by child's ethnicity grouping that has been identified in earlier studies and indicates that the prevalence of vicarious racism has not decreased, and "any" experience of racism may have increased slightly since the last time racism was measured in the NZHS in 2011/2012.

Our analysis found that caregivers of Māori children were four times more likely to report two or more experiences of racism than caregivers of children in the Other/European grouping, which suggests that Māori children may disproportionately experience the health consequences of vicarious racism. Pacific and Asian children are also more likely to experience the detrimental effects of vicarious racism than their Other/European counterparts. These findings add to the limited but growing pool of evidence highlighting the impact of vicarious racism on wellbeing, in addition to the harm of direct racism.

Our findings that suggest caregiver mental health as a potential pathway variable are consistent with previous analyses of NZHS data looking at the impact of vicarious racism on child health. Caregiver psychological distress reduced the association between vicarious racism and unmet need for healthcare,[4] and reduced child health-related quality of life.[3] Similar observations were made in an American context, whereby parental mental health, but not socio-economic position,

mediated the effect of caregiver-reported racism on child mental health outcomes.[11,12] Caregiver mental health has also been identified as a contributing factor for child mental health outcomes outside of the framework of vicarious racism,[13–15] which supports our conceptualisation of caregiver psychological distress as a potential pathway variable.

A key strength of this study is that it utilises a nationally representative dataset to demonstrate an association between high exposure to vicarious racism and the prevalence of diagnosed mental health conditions in children. It generates estimates of the prevalence of children's experience of vicarious racism for the major ethnic groupings in Aotearoa New Zealand, using methodology which is consistent with the existing evidence base for this population. Our analysis also includes multiple measures of socio-economic position, which is a way of acknowledging the ways in which institutional racism structures resources and opportunities by ethnicity in Aotearoa New Zealand, as another form of racism that may be associated with our study outcome. This study also adds new knowledge to the growing body of local and global literature on the impact of vicarious racism on child health,[1–16] highlighting anti-racism work as a priority for health.

This study also contains some important limitations. Firstly, the cross-sectional design of the NZHS limits our ability to comment on causal relationships based on our findings or conduct formal mediation analyses.

The use of diagnosed mental health conditions as an outcome is highly likely to underestimate the true prevalence of these conditions, particularly in Indigenous and minoritised ethnic communities. Diagnosis of mental health conditions is dependent on access to healthcare, the ability of health workers to provide appropriate and high-quality services, and cultural and institutional norms that are privileged by health services.[17–19] Furthermore, the difference in rates of diagnosis are thought to be due to underdiagnosis of children from minoritised ethnic groups rather than overdiagnosis of children from the dominant ethnic group,[20] and appear to continue throughout adult mental healthcare services.[21]

The incidence of mental health conditions is also influenced by the differential exposure to deprivation and hardship that children of different ethnicities experience as a result of historical trauma, coloniality and systemic racism.[22] Longitudinal data from Aotearoa New Zealand observed differences in the incidence of mental health conditions and in internalising and externalising behaviours between Māori and non-Māori adolescents, and identified relationships between these outcomes and childhood deprivation and family adversity.[23]

The use of dyads of linked child and adult NZHS data is another limitation that contributes to reduced study power and may introduce bias. As the racism module is only included in the adult questionnaire of the NZHS, our study population was restricted to children who had a primary caregiver who was also a participant in the adult survey. This may introduce selection bias, as children who are part of larger households with more adults are less likely to have a primary caregiver selected to take part in the survey. Aggregate ethnic groupings such as Asian and Pacific are also of limited utility when examining the phenomenology of racism, which is experienced and enacted in highly contextual and specific ways.

NZDep is an area-level measure of relative socio-economic deprivation that has limitations when applied to individuals. It has also been critiqued for lacking in political analysis and for upholding hegemonic conceptualisations of deprivation.[24] This is particularly relevant to our analysis of the impact of racism. There are still important benefits of including an area-based measure of deprivation, since we conceptualise and understand differences in NZDep by ethnicity to reflect processes of structural racism.[25] Our model also included caregiver education qualification as an individual measure of socio-economic status.

Measuring vicarious racism using only the limited range of self-reported caregiver experiences of racism that the NZHS includes is likely to underestimate the true extent of exposure. As the NZHS is cross-sectional, these self-reported measures may be subject to recall bias, will not measure racism which is not recognised by respondents, and responses may be influenced by factors such as social desirability, which is most likely to operate in a way that discourages the reporting of racist experiences.[26]

Previous racism in health research using NZHS data observed that there were differences in how racism was experienced according to binary gender categories, with men being more likely to experience personal (verbal and physical attacks), and women more frequently experiencing unfair treatment by a health professional.[7] Given that between 60–80% of caregivers included in our analysis were women, there is likely to be a

significant difference in the lived experiences captured in this dataset compared to one that is gender-balanced and utilises a more robust gender data collection methodology.

Conclusion

This study adds to the expanding body of knowledge about the impact of vicarious racism on the health and wellbeing of children in Aotearoa New Zealand and internationally. Our analysis indicates that a third of Māori, Pacific and Asian children in Aotearoa New Zealand have experienced vicarious racism, that there is an association between greater exposure to vicarious racism and the odds of having a diagnosed mental health condition, and that there may be a dose–response association with multiple exposures. Specifically, caregivers of Māori children were four times more likely to report two or more experiences of racism than caregivers of children in the Other/European grouping. This pattern of vicarious racism remains unchanged across multiple instances of the NZHS and suggests a status quo that is an infringement of the rights of Māori children as Indigenous people to be free from discrimination and of the rights of all children to optimal health and wellbeing.

These results, in tandem with existing research about the impact of vicarious racism on child health and racism as a determinant of health, should be received with concern about the damaging effects of racism, coloniality and white supremacy on health and wellbeing, and provide strong motivation for health system and whole-of-society action. In Aotearoa New Zealand, this requires us to not only discard white supremacy as a dominant ideology and eliminate racism, but to support the transformation of our society into one that honours Te Tiriti o Waitangi, breaks down the restrictions to Māori autonomy and wellbeing caused by the historical and ongoing harm of colonisation, and enables Māori children to flourish on a land where their rights as Indigenous people are upheld.

COMPETING INTERESTS
Nil.

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Appendices

Appendix 1: responsiveness to Māori.

This research was aligned with Kaupapa Māori theory (KMT) (carried out according to KMT but undertaken by a non-Māori researcher).[1] This was actualised in the following ways:

- Located in the context of tino rangatiratanga, with Māori at the centre. Although the primary investigator was non-Māori, this research was carried out within a Māori research group and with guidance from senior Māori supervisors.
- Sought to specifically improve Māori health. This research project sought to identify the impact of racism on the mental health of Māori children.
- Took a right to health rather than a health needs approach. This research acknowledged that Māori have a right to health and that health inequity represents a breach of those rights.
- Took a strength-based rather than deficit-analysis approach. This research examined the impact of racism—a structural determinant of health—on mental health outcomes, acknowledging that negative health outcomes are not due to failures at an individual level.
- Exposed privilege. Racism disadvantages Māori and people of colour and privileges Pākehā. This research project sought to examine the extent of this inequity within the limits of the study question.
- Centred Māori as the norm. This research acknowledged Māori cultural models and conceptualisations of health, which incorporate mental and spiritual wellbeing, collective and generational wellbeing, and relationships with the natural and spiritual environment.

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Appendix 2: New Zealand Health Survey variables.

Exposure variables

In the NZHS 2016/17 adult questionnaire, experiences of racism were measured with the following questions:[1]

- Have you ever been a victim of an ethnically motivated attack (verbal or physical abuse to you or your property) in New Zealand?
- Have you ever been treated unfairly (each of the three items below) because of your ethnicity in New Zealand (for example, kept waiting or treated differently)?
    - by a health professional (that is, a doctor, nurse, dentist, etc.)
    - at work or been refused a job
    - unfairly when renting or buying housing.

The range of possible responses were: "Yes", "No", "Don't know", "Refused" and "Not applicable". Responses which were "Don't know", "Refused" or "Not applicable" were categorised as missing in this present study. These questions were used to create binary (*"any" experiences of racism ever*: yes/no) and categorical (number of "yes" responses) variables for data analysis, as in previous studies by the research group.[2,3] The categorical variable was expressed as: No experiences, One experience, or Two or more experiences.[4]

Outcome variables

The main outcome measure of interest was any child-diagnosed mental health condition. This was categorised through responses to the following questions that were part of the child questionnaire:[5]

- Have you ever been told by a doctor that [Name] has depression/?
- Have you ever been told by a doctor that [Name] has an anxiety disorder/? This includes panic

attack, phobia, post-traumatic stress disorder and obsessive-compulsive disorder.
- Have you ever been told by a doctor that [Name] has attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD)?

Possible response to these questions were: "Yes", "No", "Don't know" and "Refused", of which only one could be selected for each question. "Don't know" and "Refused" responses were treated as missing. The responses to these questions were examined by condition and then used to create the composite binary variable "*any diagnosed mental health condition*".

Appendix 2 references

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Appendix Table 1: Socio-demographic profile of children included in child–caregiver dyads.

		N (total = 2,989)	Unweighted %
Age group			
	Group 1 (0–4 years)	1,139	38.1
	Group 2 (5–9 years)	960	32.1
	Group 3 (10–14 years)	890	29.8
Binary gender	Female	1,492	49.2
Ethnic grouping*			
	Māori	1,074	35.9
	Pacific	395	13.2
	Asian	432	14.5
	European/Other	1,270	42.5
Caregiver area deprivation (NZDep13 Index)**			
	Quintile 1	363	12.1
	Quintile 2	442	14.8
	Quintile 3	570	19.1
	Quintile 4	686	23
	Quintile 5	928	31.1

*Māori, Pacific, and Asian ethnic groupings are reported as total response, and the European/Other grouping is a mutually exclusive comparator.
**NZDep13 = New Zealand Deprivation index (Quintile 1 = least deprived, 5 = most deprived).

Appendix Table 2A and 2B: Prevalence of child mental health outcomes by total ethnic grouping.

Table 2A: Prevalence of any diagnosed mental health conditions.

2A	**Any diagnosed mental health condition (any condition)**	
	Yes (146)	Weighted % (95% CI)
Child ethnic grouping*		
Māori	173	7.6 (5.2–10.0)
Pacific	35	2.7 (0–0.6.1)
Asian	83	0.8 (0.1–1.6)
European/Other	232	5.9 (3.9–8.0)

Table 2B: Prevalence of depression, anxiety, and ADD/ADHD.

2B		**Any diagnosed mental health condition (condition-specific)**		
		Yes	**Unweighted %**	**Weighted % (95% CI)**
Depression		21	0.7	0.5 (0.2–0.8)
	Māori	10	1.1	0.7 (0.1–1.3)
	Pacific	0	0	0
	Asian	0	0	0
	European/Other	11	1.1	0.6 (0.1–1.1)
Anxiety		89	3.0	3.2 (2.2–4.3)
	Māori	42	4.6	4.5 (2.5–6.6)
	Pacific	3	0.9	1.8 (0.0–0.1)
	Asian	3	0.9	0.3 (0.0–0.7)
	European/Other	45	4.3	0.4 (0.2–0.5)
ADD/ADHD		78	2.6	2.7 (1.9–3.6)
	Māori	40	4.4	4.5 (3.0–5.9)
	Pacific	4	1.2	1.0 (0.0–2.1)
	Asian	4	1.2	0.6 (0.0–1.3)
	European/Other	33	3.2	2.9 (1.5–4.3)

*Māori, Pacific and Asian ethnic groupings are reported as total response, and the European/Other grouping is a mutually exclusive comparator.
CI = confidence interval.
ADD/ADHD = Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder.

Appendix Table 3: Proportion of child–caregiver dyads with missing outcome data by child and adult prioritised ethnic grouping.

	N (Total = 523)	Unweighted %
Child ethnic grouping*		
Māori	173	16.1
Pacific	35	13.8
Asian	83	21.2
European/Other	232	18.3
Adult ethnic grouping*		
Māori	134	15.8
Pacific	36	14.1
Asian	76	20.1
European/Other	277	18.4

*Māori, Pacific, and Asian ethnic groupings are reported as total response, and the European/Other grouping is a mutually exclusive comparator.

Equity of Māori access to the orthopaedic rehabilitation service of the Bay of Plenty: a cross-sectional survey

Lachlan Cate, Nigel Giles, Bert van der Werf

ABSTRACT

AIMS: Examine the access to the Bay of Plenty rehabilitation service for Indigenous Māori patients undergoing total knee arthroplasty (TKA). Identify structural aspects of the rehabilitation service which promote or restrict access for Māori.

METHODS: All patients who underwent TKA in publicly funded Bay of Plenty hospitals in 2021 were retrospectively supplied with a survey. Participants were asked to self-report demographic information and to complete a structured record of the duration, type, and location of their pre and post-operative rehabilitation.

RESULTS: Māori patients accessed more rehabilitation (mean = 9.75 total hours) than non-Māori patients (mean = 8.34 total hours). This was in large part driven by a significant home-based component of their rehabilitation (42.9% of Māori respondents received at least some of their rehabilitation at home, compared to 16.4% of non-Māori).

CONCLUSIONS: Once engaged with the orthopaedic service and having undergone TKA, rehabilitation access for Māori is comparable to if not greater than that of non-Māori. This is in large part driven by home-based rehabilitation. Practical facilitators which negate transport and financial barriers are an effective method of promoting access to health services for Māori.

Rehabilitation after total knee arthroplasty (TKA) has manifold benefits. It improves knee range of motion, minimises pain, and betters functional mobility over the short term.[1,2] The burgeoning emphasis on the interdependence of structured, health professional-led rehabilitation and positive functional TKA outcome is thus unsurprising.[3,4] In spite of this emphasis, there remain considerable disparities in rehabilitation protocols locally and abroad.[5,6,7] It has been suggested internationally that access to rehabilitation is unequal between ethnic groups, although the small number of studies which examine this remain incongruent.[8,1]

To date there has been one Aotearoa New Zealand study into the extent of rehabilitation access after total joint arthroplasty.[9] Notably, the study elucidated a trend toward poorer rehabilitation access in rural areas. It was proposed that the predominance of hospital outpatient clinic as a rehabilitation setting established geographic and socio-economic barriers to access. The authors thus hypothesised that a diversification of rehabilitation setting and increased opportunities for home and community-based rehabilitation would promote access for minority groups. Conclusions regarding any difference in rehabilitation access between Māori and non-Māori were not drawn from this sample in which the Māori population was greatly underrepresented compared to population and localised orthopaedic registry data.[10]

In 2013, it was documented in a local piece of literature that in the Bay of Plenty of Aotearoa, Māori experience worse arthroplasty outcomes than non-Māori.[10] The aforementioned groundbreaking 2013 study pointed to poorer functional gains after surgical intervention in Māori compared to non-Māori. Rehabilitation after TKA has remained non-protocolised in the Bay of Plenty since this research. Although there otherwise remains a paucity of data pertaining to Māori outcomes after arthroplasty, the need to identify and rectify the influences on any ongoing disparity is pressing.

More broadly, Māori remain alienated from an array of health services in Aotearoa and continue to have worse health outcomes overall.[11,12] This is a foreseeable consequence of longstanding structural and individualised racism. As the health landscape in Aotearoa continues to rapidly evolve, emerging discourse centres on facilitators to

healthcare access for Māori.[13,14] A recent literature review proposed five themes that encompassed potential facilitators for Māori accessing health services: practical facilitators, whakawhanaungatanga, whānau, manaakitanga, and cultural safety.[13] Subsequently, there is active interest in evidencing factors which improve Māori access to continuing care, both within and beyond the orthopaedic realm.

In the Bay of Plenty, rehabilitation regimes after TKA are influenced by surgeons, patients, and rehabilitation providers. They are thus individualised for each patient. This service, being individual as opposed to guideline driven, therefore provides a unique opportunity to assess structural influences on care.

This present study aims firstly to identify disparities between Māori and non-Māori in rehabilitation access after TKA that may be contributing to poor functional gains after surgery. Secondly, it aims to detail the extent to which the structure of rehabilitation service provision affects access for Māori.

Methods

Study design and recruitment strategy

Before conducting research activities, we consulted with the local Māori health agency Te Pare ō Toi to assess how our project could best assist with their ongoing research efforts. A formal protocol was then developed which was endorsed by Manukura – Executive Director Toi Ora on behalf of the 17 iwi of Mai i Ngā Kuri a Whārei ki Tihirau/Bay of Plenty District Health Board (2902 26072022).

Participants were recruited from local Bay of Plenty surgical databases. All patients undergoing primary elective TKA in the publicly funded Tauranga and Whakatāne Hospitals during 2021 were deemed eligible.

Over a period from December 2021 to January 2022, all eligible patients were given an invitation to complete an anonymous cross-sectional questionnaire regarding the rehabilitation they accessed before and after primary TKA. Questionnaires were available for completion either in person on attendance at outpatient surgical clinic follow-up, by funded return mail, or online, as per the preference of each participant. Return of the survey constituted informed consent for participation in the study. Multiple methods of survey return were offered in order to maximise uptake. Patients who did not return the survey were not followed-up with due to the anonymous nature of the survey.

Ethnicity was self-reported using a prioritised reporting system in accordance with Manatū Hauora – Ministry of Health guidelines in place at the time of the survey. Other demographic indicators including age and highest level of qualification were collected concomitantly to assess the breadth of the sample. Respondents were asked to complete a structured report concerning the timing of pre- and post-operative rehabilitation. Participants were also asked to report whether this rehabilitation took place in the hospital, their home, or other centres e.g., community practices. Timing and location of rehabilitation was determined by a combination of patient preference and availability of local services. Information regarding rehabilitation access was collected based on patient recall as it is not centrally collected elsewhere.

Statistical analyses

Logarithmically transformed values for "average hours of rehabilitation" were analysed with a linear model with the explanatory variables' ethnicity, location and type of rehabilitation. The logarithmic transformation was used to meet the analysis' requirements, homogeneity of variances and normality of the residuals. The full model contains all two-way interactions. The marginal estimates are calculated using the parameter estimates and their (co) variances derived from the model. Marginal means, in the case of the location and ethnicity table, a model with equal weights for each level of type. That way, the differences are shown correctly. Only the data were used where there was a non-missing value for "average hours of rehabilitation".

All calculations were done with R version 3.[15] The lme4 package was used to calculate the regressions. The assumptions for the analysis were checked with the package DHARMa.

Results

In total there were 145 eligible patients who underwent TKA in a public hospital in the Bay of Plenty in 2021. Seventy-five eligible patients completed and returned the questionnaires (a 51.7% response rate). Sixty-six patients returned the survey via mail, five responded in clinic and four submitted the online survey.

This sample comprised 18.7% Māori and 81.3% non-Māori. This is comparable to the arthroplasty demographic in the Bay of Plenty, which has

previously been reported as 13.8% Māori.[10] (For reference, the Bay of Plenty population is estimated 29.1% Māori and 70.9% non-Māori, as per 2018 national Census data).[16] Forty patients underwent TKA at Tauranga Hospital and 35 at Whakatāne Hospital. The median age of Māori respondents was 63 and that of non-Māori was 74.

On average, Māori (9.75 hours) received more rehabilitation after TKA compared with non-Māori (8.34 hours). Māori were also more likely to have a home component to their rehabilitation than non-Māori (42.9% of Māori, 16.4% of non-Māori). Māori accessed a greater average amount of rehabilitation when their regime included a home component (10.33 hours) than when it did not (8.86 hours).

There was minimal discrepancy in access to rehabilitation between patients who underwent surgery at Tauranga Hospital (8.42 hours per patient) and Whakatāne Hospital (8.88 hours per patient).

On sub-analysis of ethnicity and location of rehabilitation, Māori had significantly more average rehabilitation time than non-Māori (p-value 0.002) when receiving treatment exclusively in their own home. Conversely, non-Māori received significantly more rehabilitation when rehabilitation was carried out only in hospital, as opposed to exclusively in their own home (p-value 0.0001).

Discussion

These new data point to a comparable provision of knee rehabilitation between Māori and non-Māori in the Bay of Plenty. This is incongruous with existing local literature, which highlights outcome inequality for Māori after TKA.[10] It is possible that advances have been made toward equality of outcome as a whole, or that Māori require an even greater provision of rehabilitation to achieve equality of outcome. It is also, of course, likely that drivers of surgical outcome other than rehabilitation, including timeliness of first surgical intervention, are of considerable influence. Of note, the initial research highlighting worse post-operative function for Māori at 1 and 5 years after surgical intervention also evidenced that Māori have worse pre-operative function. It is known that this corresponds to worse functional gain after surgery.[17] Hence it may be that barriers to first access are more profound than those to rehabilitation.

Our data are also incongruous with the over-whelming ethnic disparity in healthcare access in

Table 1: Average total rehabilitation time after TKA in the Bay of Plenty as a function of patient ethnicity, hospital of arthroplasty and patient educational attainment.

	Māori		**Non-Māori**		**Total**	
	Number of participants	**Average hours of total rehab**	**Number of participants**	**Average hours of total rehab**	**Number of participants**	**Average hours of total rehab**
Tauranga Hospital	4	10.00	36	8.24	40	8.42
Whakatāne Hospital	10	9.33	25	8.70	35	8.88
Tertiary qualification	5	6.40	27	9.56	32	9.06
Secondary qualification	7	13.00	28	6.78	35	8.02
No formal qualification	2	7.00	6	8.00	8	7.75
Total	**14**	**9.75**	**61**	**8.34**	**75**	**8.61**

Table 2: Logarithmically transformed average hours of patient rehabilitation after TKA as a function of patient ethnicity and setting of rehabilitation. Statistically significant differences in rehabilitation time between combined groups of ethnicity and rehabilitation setting are highlighted.

		Hours of rehabilitation per patient			Logarithmic conversion of rehabilitation time per patient				p values from logarithmic conversions							
									Māori				Non-Māori			
Ethnicity	Location of rehabilitation	Median	Lower 95	Upper 95	Estimate	Variance	Lower 95	Upper 95	Home	Hospital	Hospital & home	Other	Home	Hospital	Hospital & home	Other
Māori	Home	25.49	6.14	105.83	3.24	0.50	1.81	4.66	1.000	0.365	0.113	0.490	0.002	0.137	0.083	0.037
	Hospital	14.05	5.07	38.90	2.64	0.26	1.62	3.66	0.365	1.000	0.341	0.253	0.005	0.346	0.230	0.086
	Hospital & home	7.51	2.27	24.82	2.02	0.36	0.82	3.21	0.113	0.341	1.000	0.100	0.079	0.897	0.670	0.364
	Other	41.04	5.64	298.47	3.71	0.98	1.73	5.70	0.490	0.253	0.100	1.000	0.011	0.117	0.076	0.002
Non-Māori	Home	2.07	0.88	4.87	0.73	0.18	-0.13	1.58	0.002	0.005	0.079	0.011	1.000	0.0001	0.095	0.490
	Hospital	8.18	4.63	14.46	2.10	0.08	1.53	2.67	0.137	0.346	0.897	0.117	0.0001	1.000	0.391	0.148
	Hospital & home	5.29	1.70	16.49	1.67	0.32	0.53	2.80	0.083	0.230	0.670	0.076	0.095	0.391	1.000	0.554
	Other	3.33	0.87	12.77	1.20	0.45	-0.14	2.55	0.037	0.086	0.364	0.002	0.490	0.148	0.554	1.000

Aotearoa that results from systemic inequity.[12,18] Cost, location, and opening times of services greatly impact access and impose a relatively large barrier on Māori.[19,20] We theorise that the comparable access in the context of this study corresponds, at least in part, to the very high rate at which Māori receive rehabilitation in their own home (42.9% compared to 16.4% among non-Māori). The logarithmically transformed data show that rehabilitation being exclusively carried out in the home has a significantly positive effect for Māori. Hence, we opine that negating location barriers, actively involving whānau, and facilitating autonomy for Māori regarding the structure of their healthcare has an overwhelmingly positive impact on access.

This research adds to the emerging picture regarding the age at which Māori undergo TKA. The median age of Māori respondents in this study was 11 years younger than that of their non-Māori counterparts. This is in line with a 2013 study which evidenced that Māori undergoing total hip and knee arthroplasty in the Bay of Plenty were on average approximately 7 years younger than non-Māori.[10] We hypothesise this ongoing difference evidences a high burden of disease among Māori. This would add further emphasis to the already highlighted importance of equitable care.

On the whole, these data validate continued work promoting equity for Māori, suggesting that emerging strategies and zeitgeists are of great benefit. They evidence that when structurally acceptable access to care is provided for Māori, engagement and continued participation is strong. We note that emerging Indigenous literature points toward a need for cultural critical consciousness, with the obligation for health professionals extending from critique of one's own practice to critique of wider structures as well.[21,22] It thus is paramount that moving forward we ensure that both our systems and ourselves give all patients a fair, timely pathway to wellbeing.

In addition to equal access for Māori, we found no discrepancy in access between the Western Bay of Plenty population serviced by Tauranga Hospital and the Eastern Bay of Plenty population serviced by Whakatāne Hospital. Of note, however, existing Aotearoa data elucidated a rural deprivation of access to rehabilitation after TKA.[9] We suggest that home-based rehabilitation is thus likely a strong driver toward equal rehabilitation access for rural patients also. This would be in line with international literature in the realms of cardiac and stroke rehabilitation.[23,24,25] Said literature demonstrates that home rehabilitation is equally if not more effective and much more accessible for patients compared to centre-based programmes. The practical facilitation of in-home rehabilitation evidently promotes access for rural communities and is transferable across many realms of the wider health service.

Limitations

This population sample is limited in size, response and generalisability. The geographic localisation of this study controls many factors which would confound a more widespread investigation, but limits the number of patients who are eligible to participate and reduces generalisability. The response rate for this survey risks non-representation.

We note, importantly, that engagement and access go hand-in-hand; it is plausible that non-respondents are also likely to be less engaged with ongoing rehabilitation. It would be prudent for future investigators to recruit proactively during the TKA process to promote response. The surgical process requires ongoing engagement for planning, execution and follow-up, which could be interlinked with research. In addition, this study presents only quantitative data, and the written survey method does not allow whakawhanaungatanga between researchers and patients. We intend this data to be partnered with emerging qualitative data obtained in hui with patients in order to form a holistic picture.

This study was designed to investigate access to rehabilitation services and how this may affect outcomes after TKA, but not to directly assess TKA outcome. Ongoing evaluation of outcomes for Māori after arthroplasty is required to determine the extent to which practical facilitators are driving equal outcomes. We note that whakawhanaungatanga, whānau, manaakitanga, and cultural safety have also been identified as facilitatory factors that are imperative to ensuring health services are accessible and effective for Māori. Validating the effectiveness of interventions in these realms is of ongoing importance.

Conclusion

Access to rehabilitation for Māori undergoing TKA in the Bay of Plenty region is comparable to that of non-Māori. This is in large part driven by home-based rehabilitation. The advantage of an individualised service in which patients and health practitioners can tailor their care to their perspectives and locations is apparent. Moving forward, continued emphasis on equitable holistic care is highly prudent.

COMPETING INTERESTS
Nil.

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Administration of Routine Antenatal Anti-D Prophylaxis (RAADP) in Wellington, Aotearoa: is our practice equitable?

Zoe Lahood, Judy Ormandy

ABSTRACT

AIM: To assess local compliance with Routine Antenatal Anti-D Prophylaxis (RAADP) guidelines and to determine if its administration is equitable in Wellington, Aotearoa New Zealand.

METHODS: A retrospective 6-month audit of people birthing in Wellington maternity units. Rhesus-negative people were identified and electronic heath records reviewed.

RESULTS: Two hundred and nine out of 1,881 (11%) of people birthing were Rhesus-negative. Two hundred and five people were included in the audit. Three people were excluded as they birthed prior to 28 weeks, and one was already isoimmunised. One became isoimmunised during pregnancy. Eighty-three out of 205 (40%) received RAADP as per guidelines. Factors that made it more likely for people to receive RAADP were private obstetrician care (78% versus 34%, $p<0.01$), living closer to hospital ($p<0.01$) and birthing in Wellington Hospital (43% versus 11% in a primary unit, $p<0.01$). There is no evidence that management was influenced by ethnicity, mode of birth, parity, age or attendance at a hospital antenatal clinic.

CONCLUSION: RAADP guidelines are not being followed and some subgroups are disproportionately affected. There is evidence of harm, with one person becoming isoimmunised during pregnancy. Simplifying local protocols, establishing more sites for RAADP administration such as pharmacies or primary units and improving staff and patient education could help to address these inequities.

Pregnant people who have a Rhesus-negative blood type are at risk of developing antibodies against Rhesus-positive foetal red blood cells (sensitisation), if there is crossover of foetal cells into the maternal circulation. This can result in a condition called haemolytic disease of the newborn (HDN), causing symptoms ranging in severity from foetal anaemia to hydrops foetalis, stillbirth or neonatal death.[1] This can affect the baby in the current pregnancy or in future pregnancies. Provision of Anti-D for Rhesus-negative people both during sensitising events in pregnancies (such as terminations, amniocentesis or abdominal trauma) and, postnatally, significantly reduces the risk of sensitisation and subsequent effects on the baby.[1]

Routine Antenatal Anti-D Prophylaxis (RAADP) is now internationally recommended to protect from potential silent sensitising events. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and New Zealand Blood Service (NZBS) guidelines have recommended RAADP be given at 28 and 34 weeks gestation since 2016.[2,3] This further reduces sensitisation from 1% to 0.3%.[4] Capital and Coast District Health Board (CCDHB) has recommended RAADP since August 2018, although the policy also notes that RAADP is not yet given routinely across Aotearoa New Zealand.[5] Wellington Hospital has run a dedicated Anti-D clinic since April 2020 where lead maternity carers (LMCs) can refer pregnant people for RAADP. RAADP can also be administered in general antenatal clinics. Written information should be given to the pregnant person to supplement the recommendation of RAADP given by their LMC, with pamphlets provided by the NZBS. Anecdotally, however, RAADP administration is variable across the Wellington Region.

Methods

All people who birthed between 1 January 2021 and 30 June 2021 at CCDHB birthing units were retrospectively identified through the Perinatal Information Management System (PIMS). Medical App Portal (MAP) was used to confirm Rhesus status. People were excluded

from analysis if they were already known to be isoimmunised (i.e., had already developed Anti-D antibodies) or if they birthed prior to 28 weeks gestation. The NZBS provided data linked by NHI for Anti-D doses administered to our cohort anywhere in Aotearoa and all sensitising, RAADP and postnatal doses of Anti-D were evaluated.

For each Rhesus-negative pregnant person, information was obtained from MAP and PIMS on maternal age, parity, ethnicity, address of residence, attendance at a hospital secondary antenatal clinic, type of LMC, midwife or private obstetrician, and whether they birthed in a secondary hospital or a primary birthing unit. Distance lived from hospital was calculated using their address of residence and Google Maps. Each of these factors were analysed in the context of whether RAADP was given as per guidelines or if guidelines were not met. Given as per guidelines was classed as either one double dose of 1250IU, or two 625IU doses at approximately 28 and 34 weeks. A single dose of 625IU or no RAADP was classed as guidelines not being met.

Data were entered into Microsoft Excel Version 16.61.1. In order to assess for a relationship between each LMC type, ethnicity, place of birth and antenatal clinic attendance and whether or not RAADP was administered as per guidelines, Chi-squared independence tests were used, with a p-value of <0.05 used to indicate statistical significance. Independent sample t-Tests (equal variance not assumed) were used to compare age and parity with administration of RAADP, with $p<0.05$ regarded as significant. A Mann–Whitney U test was used to compare distance from hospital with adherence to Anti-D guidelines, as these data were skewed.

Approval for the audit was obtained from the CCDHB Women's Health Service Audit Committee. Ethics approval was not required as this project was classed as a clinical audit.

Results

During the 6-month period, 1,881 people birthed at CCDHB maternity units. Of these, 209 were Rhesus negative. Two hundred and five people were included in the audit. Three people were excluded from our analysis as they birthed prior to 28 weeks and one person was excluded as they were already isoimmunised.

Only 40% (83/205) of Rhesus-negative people received RAADP as per RANZCOG and NZBS guidelines. Postnatal Anti-D was indicated for 136 people in our cohort as their baby was Rhesus positive and 133 (98%) received it.

One person in the cohort was identified as having become sensitised in their third trimester, as there was evidence of passive transmission of antibodies to their baby. They had not received any RAADP.

Tables 1 and 2 show patient characteristics and the associated proportion of RAADP administration.

Statistical significance was not reached when comparing proportions of RAADP administration by age, parity, ethnicity or attendance at a doctor-led hospital antenatal clinic.

There were higher numbers of RAADP given to people under the care of a private obstetrician, compared to those under the care of a midwife (78% versus 34%, $p<0.01$). People who birthed at a secondary hospital were more likely to receive RAADP as per guidelines than those who birthed at a primary maternity unit (43% versus 11%, $p<0.01$). Pregnant people who lived further from hospital were less likely to receive RAADP as per guidelines ($p<0.01$).

Discussion

This audit has identified that RAADP for Rhesus-negative pregnant people in the Wellington Region is not being administered as recommended by national guidelines. There is evidence of harm, with one person becoming isoimmunised during their pregnancy. The administration of RAADP is inequitable by type of maternity carer, place of giving birth and geographical location, with people living further from hospital having significantly lower rates of RAADP prophylaxis.

No statistically significant differences in administration of RAADP were identified by ethnicity. However, as rates of Rhesus negativity are lower in Māori, Pasifika and Asian people, it is likely that the sample size was not sufficiently powered to detect any differences that may exist.

A limitation of the audit was that we were unable to obtain data of people who birthed at home. In 2020, 4% of CCDHB parturients birthed at home.[6] A strength is that we have been able to identify Rhesus status in 100% of our cohort and were able to link these people to all Anti-D doses administered anywhere in Aotearoa.

While we have not addressed the reasons for low rates of RAADP provision, possible reasons include lack of clinician awareness of policies, insufficient capacity at the Anti-D clinic, difficulty accessing the clinic due to lack of transport or parking, inability to access Anti-D at satellite maternity

Table 1: Patient factors and associated adherence to RAADP guidelines.

Variable	Number (%total)	RAADP administered as per guidelines (%)	
Ethnicity			
Māori	16 (8%)	3 (19%)	
NZ European	170 (83%)	70 (41%)	
Asian	13 (6%)	6 (46%)	
Other (Pasifika, Latin American, Middle Eastern, African)	6 (3%)	4 (67%)	*p=0.17*
Lead maternity carer			
Private obstetrician	32 (16%)	25 (78%)	
Midwife (independent and hospital midwives)	173 (84%)	58 (34%)	*p<0.01*
Place of birth			
Secondary hospital	187 (91%)	81 (43%)	
Primary birthing unit	18 (9%)	2 (11%)	*p<0.01*
Attendance at hospital antenatal clinic (*n=32 excluded as under private obstetrician)			
Attended secondary clinic	82	33 (40%)	
Did not attend secondary clinic	91	40 (44%)	*p=0.62*

Table 2: Patient factors and associated adherence to RAADP guidelines.

Variable	RAADP administered as per guidelines	RAADP not administered as per guidelines	
N	**83**	**122**	
Age (years) M±SD	33.2 ±3.9	32.5 ± 5.1	p=0.33*
Parity M±SD	0.5±0.8	0.7±0.6	p=0.12*
Distance lived from hospital (km) Mdn, (IQR)	13.5 (22.3)	24.8 (IQR 38.25)	p<0.01 **

*t-Test
**Mann–Whitney U test

units, clinicians not recommending RAADP or patients declining. As we had no access to independent midwifery or private obstetrician notes, we were unable to assess if there was a clinical reason for people not requiring RAADP, such as the partner known to be Rhesus negative and paternity certain. With such successful uptake of Anti-D administration postnatally (98%), it appears that patients find administration of Anti-D acceptable, though the reason for the discrepancy between antenatal and postnatal uptake is unknown. It is likely that barriers to RAADP are not unique to CCDHB and are present in other regions of Aotearoa. Rurality has previously been identified as a likely barrier to RAADP, with a study showing that fewer than one in five women received any antenatal Anti-D in Southland, New Zealand.[7] Badami et al. found that the rates of sensitisation in Christchurch are three times higher than would be expected if RAADP was given as per guidelines, and this is likely due to poor adherence to local guidelines for RAADP.[8]

In order to facilitate implementation of changes to practice, the barriers to the administration of RAADP to all eligible people need to be identified. Once further information around these barriers has been identified, initiatives can be put in place to improve RAADP rates.

Currently, for pregnant people to access the local Anti-D clinic, a referral is required from their LMC. An automatic digital referral to an Anti-D clinic at booking, once Rhesus status is determined from early antenatal blood tests, would reduce the need for LMCs to independently refer to the clinic and may improve administration rates. Those who decline RAADP after appropriate counselling could opt out of the clinic rather than opting in.

Accessibility is also a barrier, with people who live further from hospital having lower rates of RAADP—therefore, the development of more Anti-D clinics at satellite locations may improve this. Accessibility has been addressed uniquely in other regions of New Zealand, including by Counties Manukau District Health Board who have introduced an initiative whereby pharmacists can administer Anti-D to their Rhesus-negative population free of charge, in an effort to improve access to care and reduce the traffic of patients into hospital.[9]

Concerningly, 60% of Rhesus-negative pregnant people attending a secondary antenatal clinic at the hospital did not receive RAADP as per the guidelines, despite having face-to-face interactions with a clinic midwife and an obstetric doctor. Factors that could have contributed to this include people being seen at variable gestations outside of recommended RAADP administration, a broad range of experience among clinic doctors and the absence of a central documentation system that is accessible by both the hospital team and private or independent LMCs. Regardless of cause, this rate of administration needs to improve. A complete electronic record of all perinatal care, such as BadgerNet with integrated alerts for Rhesus status and when Anti-D is due, has the potential to improve uptake in this population.

The current CCDHB protocol for Anti-D gives the options of two doses of 625IU of Anti-D or a single dose of 1250IU. Consideration of recommending a single dose of 1250IU could improve uptake as it reduces the number of visits required and would therefore increase capacity of the current Anti-D clinic. There is some evidence that a single dose of Anti-D prophylaxis is not as effective as 2 doses.[10] However, it is associated with higher compliance, lower cost and greater convenience in overseas jurisdictions.[11] Given that only 40% of pregnant people are currently receiving RAADP in CCDHB, it could be argued that there would be greater overall population benefit to having larger numbers of people receiving a single dose.

This audit has demonstrated significant deficiencies in the administration of RAADP within the CCDHB population, with evidence of harm in the development of isoimmunisation. There is inequity with people living closer to hospital, or people under the care of a private obstetrician, being more likely to have been administered RAADP. While this study has been undertaken at CCDHB, it is feasible that this deficiency is reflected in other district health boards. These inequities need to be urgently addressed to provide high-quality maternity care for all pregnant people.

As a result of this audit, a multitude of changes were made to improve uptake of RAADP in this population. The RAADP policy was simplified to give only two dose options—single doses at 28 and 34 weeks or a one-off double dose around 32 weeks. Providers (doctors and midwives, both public and private) were re-oriented to the policy with the changes outlined. In addition, a second Anti-D clinic was opened in one of the satellite units in October 2022, in an effort to improve accessibility for this population. Re-auditing this process will be essential in determining if these changes do improve rates of RAADP administration in the region.

COMPETING INTERESTS
The authors of this article have no competing interests to declare.

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Endometrial cancer diagnoses prompted by routine cervical cytology: a retrospective case study

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ABSTRACT

AIMS: Endometrial cancer is the commonest gynaecological cancer in New Zealand. Some women have their diagnosis of endometrial cancer prompted by an abnormal cervical cytology screening test. When high-risk human papillomavirus (hr-HPV) testing becomes the primary test for cervical screening, this avenue of incidental diagnosis will be reduced. Therefore, our aims were to estimate the proportion of women whose diagnosis of endometrial cancer follows incidental detection on routine cervical cytology, and to understand the clinicopathologic characteristics of these cases.

METHODS: Retrospective analysis of patient medical records from women of cervical screening age diagnosed with endometrial cancer between 2015–2019 in the South Island of New Zealand.

RESULTS: Of 334 women, 26 (7.8%) had endometrial cancer diagnosis prompted by abnormal cervical cytology. Most women had low-grade (17/26, 65.4%), low-stage (18/26, 69.2%) disease of endometrioid histologic subtype (21/26, 80.8%). The small cohort prevented significant correlations with clinicopathologic characteristics and outcomes. Overall, cervical cytology had low sensitivity (32.3%) for the detection of endometrial cancer in the 6 months before diagnosis.

CONCLUSIONS: A small number of women currently have diagnoses of endometrial cancer prompted by routine cervical screening with cytology. However, the undefined clinical benefit from and poor sensitivity of cervical cytology for detecting endometrial cancer does not justify its use in screening, or opposition to hr-HPV cervical screening.

Endometrial cancer is the fifth most common cancer among New Zealand women overall, and is the most common gynaecological malignancy.[1,2] Its incidence is further increasing with rates of obesity, diabetes and an aging population.[1,3,4] The current and projected burden of endometrial cancer hence emphasises an unmet need in its early diagnosis: to date, no specific and cost-effective screening method has been established. Rather, diagnosis depends on reporting of clinical symptoms or incidental detection. Clinical symptoms include abnormal uterine bleeding, discharge and pain. Symptomatic reporting is certainly unreliable in its timeliness, and delayed diagnosis predisposes to worse clinical outcomes.[5]

The purpose of the New Zealand National Cervical Screening Programme (NCSP) is to detect abnormalities of the cervix by 3-yearly screening utilising liquid-based cytology. However, it has also had a role in the incidental diagnosis of endometrial cancer. Three types of endometrial cells can be reported: normal endometrial cells (NEMCs), atypical endometrial cells (AEMCs) and endometrial carcinoma cells (EMCCs).[6,7] As NEMCs may reflect physiological exfoliation related to menstruation, they are only reported in women older than 40 years, for whom the likelihood of malignant endometrial pathology is significant.[7]

Compared with cytology, high-risk human papillomavirus (hr-HPV) testing has been shown to offer greater protection against cervical cancer.[8–10] The NCSP therefore plans to action routine utilisation of primary hr-HPV testing in place of cytology. This change to primary hr-HPV testing will reduce routine cervical cytology as an incidental diagnostic avenue for endometrial cancer. Only women who have a positive hr-HPV result will go on to have cytology. Existing literature confirms that cervical cytology can detect abnormal endometrial cells in women with endometrial cancer, albeit with low sensitivity and predictive value.[11–17] Presence of abnormal endometrial cells on cervical cytology has also been correlated with unfavourable clinicopathologic disease characteristics.[17,18] Nevertheless, there is a dearth of evidence specifically addressing the role of routine cervical cytology in prompting diagnoses of endometrial cancer.

This retrospective observational study

reviewed the cervical cytology histories of women in the South Island of New Zealand who were diagnosed with endometrial cancers between 2015 and 2019. The primary aim of the study was to quantify the proportion of women with endometrial cancer that were diagnosed following incidental finding on routine cervical screening by cytology. Secondary aims were to determine whether ethnicity, grade and stage of disease at diagnosis, histological tumour type and 12-month mortality differed significantly for women diagnosed following routine cervical cytology, compared with women who presented symptomatically.

Methods

A retrospective review of hospital clinical records was conducted for women with endometrial cancer diagnosed between 2015–2019, who were managed by New Zealand southern regional gynaecological cancer services and retained in their clinical databases. Inclusion required confirmed histological diagnosis between January 2015–December 2019, and being of cervical screening age (25–69 years) at the time of diagnosis. Data relevant to the primary and secondary outcomes were obtained through manual review of electronic clinical records and transcribed to a Microsoft Excel database. Ethical approval for the study was obtained from the University of Otago Human Research Ethics Committee (approved 23 September 2020, reference number: HD20/076).

Prompt for diagnosis was reported as any one of: abnormal cervical cytology, clinical symptoms, other incidental or unclear. Where the prompt for diagnosis was abnormal routine cervical cytology, this was usually specified in a referral letter to specialist services. A prompt for diagnosis was unclear if there was an absence of clarifying clinical information in the hospital record.

Results of cervical cytology in the 36 months preceding endometrial cancer diagnosis were recorded to a maximum of the 3 most recent results prior to diagnosis date. Endometrial abnormalities were reported as NEMCs, AEMCs and EMCCs, as per NCSP and Bethesda system resources for cytologic diagnoses.[6,7] The sensitivity of cervical cytology for the detection of endometrial cancer was estimated from those cytology results in the 6 months pre-diagnosis.

A cervical cytology sample taken in the 6 months prior to diagnosis was classified as routine if it was taken at, or just beyond, the routine screening interval for that person (i.e., 12 months or 3 years, depending on what was advised on the preceding cervical cytology result), and there were no coincident clinical symptoms. If clinical symptoms were explicitly reported prior to cytology (i.e., not reported after an abnormal result), the investigation was considered to have been done for clinical work-up of symptoms. A cytology sample taken earlier than required for routine screening, and/or by a specialist, and/or in conjunction with other investigations (e.g., high vaginal or endocervical swabs, pipelle biopsy) was also classified as being part of clinical work-up. The indication for cytology was categorised as unclear when a cervical cytology sample was taken in a primary care facility, its timing fell at or beyond a woman's routine screening window and there were no available notes to confirm or refute its use in work-up of coincident symptoms. From this categorisation, the proportion of women participated in routine cervical screening was estimated.

Ethnicity was reported as total response ethnicity, whereby every ethnicity recorded for a woman is counted independently. Hence, numbers of ethnicity-related events exceed the number of women in the study cohort.

12-month mortality was measured using date of death, cause of death (if available on electronic record, otherwise deemed unclear) and date of last contact with any medical service.

Data were analysed using STATA (nptrend StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StatCorp LP).

Results

From 512 women identified with a diagnosis of endometrial cancer between 2015 and 2019, the final study population comprised 334 women (Figure 1). The median age at diagnosis for the cohort was 60 years (range 36–69). Eighty-seven percent of women identified as NZ European. And, most had low-grade, low-stage endometrioid disease: 69.8% had grade 1, 65.3% FIGO stage 1A and 90.1% had endometrioid type disease.

The prompt for diagnosis was abnormal routine cervical cytology for 26/334 women (7.8%). The majority of diagnoses were prompted by presentation with clinical symptoms (283/334, 84.7%), or other incidental findings (19/334, 5.7%). Diagnostic prompts for six women were unclear (1.8%).

Figure 1: Study cohort after eligibility criteria applied, and their diagnostic prompts.

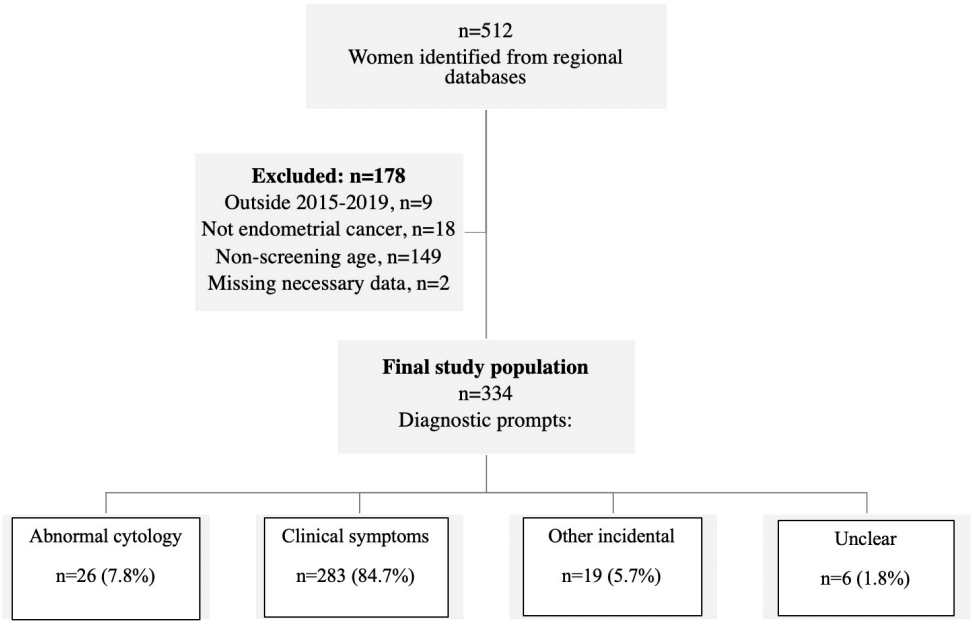

Table 1 shows disease characteristics by diagnostic prompt. Low-grade and low-stage disease was present in >65% and >57% of cases across all diagnostic groups. Seventeen out of 26 (65.4%) women diagnosed following abnormal routine cervical cytology had FIGO grade 1 disease, and 18/26 (69.2%) had FIGO stage <IA disease. This was comparable to proportions of low-grade (198/283, 70.0%) and low-stage disease (185/283, 65.4%) in the group of women whose diagnostic prompt was clinical symptomatology.

For analytic purposes, all endometrial carcinomas were classified as either endometrioid or non-endometrioid histologic subtypes. Non-endometrioid carcinomas included serous carcinoma, clear cell carcinoma, undifferentiated carcinoma, mixed type and carcinosarcomas. Most carcinomas were of endometrioid histologic subtype (301/334, 90.1%) as compared with their non-endometrioid counterparts. This was true across all diagnostic prompts. Twenty-one (80.8%) of the abnormal routine cervical cytology group and 258 (91.2%) of the clinical symptoms group had endometrioid endometrial carcinomas. However, 15% (5/33) of women with non-endometrioid tumours, as opposed to 7% (21/301) of women with endometrioid type, had abnormal cytology as a diagnostic prompt.

Data pertaining to age and ethnicity are not shown. There was no substantial deviation of median diagnostic age for any diagnostic prompt group. The median age at diagnosis was 60 years (range 47–65) for the abnormal cytology group, 59 years (range 31–69) for the clinical symptoms group, 65 years (range 36–69) for the other incidental group and 62.5 years (range 41–66) for the group whose diagnostic prompt was unclear.

For every total response ethnicity group, clinical symptomatology most frequently prompted diagnosis (248/292 [84.9%] Europeans, 15/19 [79.2%] Māori, 12/12 [100%] Pacific, 19/24 [79.2%] Asian, 22/25 [88%] Other). Twenty-three European (7.9%), three Māori (15.8%), two Asian (8.3%) and two Other (8.0%) were diagnosed following abnormal cytology. Fifteen (5.1%) European, one (5.3%) Māori, three (12.5%) Asian and one (4.0%) Other had other incidental diagnostic prompts. Only six (2.1%) Europeans had an unclear diagnostic prompt.

Of the 334 women who met inclusion criteria, 299 (89.5%) had cervical cytology results from the 36 months antecedent to their endometrial cancer diagnosis. Total cytologic results are summarised in Table 2. One hundred and sixty-nine out of 299 (56.5%) women had one documented cytologic result in the 36-month pre-diagnosis period, 115 (38.5%) had two results and 15 (5.0%) had three

Table 1: Pathologic disease characteristics by diagnostic prompt.

Diagnostic prompt						
Disease characteristic		**Abnormal cervical cytology (n=26) n (%)**	**Clinical symptoms (n=283) n (%)**	**Other incidental (n=19) n (%)**	**Unclear (n=6) n (%)**	**All (n=334) n (%)**
FIGO grade	1	17 (65.4)	198 (70.0)	14 (73.7)	4 (66.7)	233 (69.8)
	2	3 (11.5)	33 (11.6)	2 (10.5)	1 (16.7)	39 (11.7)
	3	6 (23.1)	52 (18.4)	3 (15.8)	1 (16.7)	62 (18.6)
FIGO stage	≤IA	18 (69.2)	185 (65.4)	11 (57.9)	4 (66.7)	218 (65.3)
	≥IB	8 (30.8)	98 (34.6)	8 (24.1)	2 (33.3)	116 (34.7)
Histological type	Endometrioid	21 (80.8)	258 (91.2)	17 (89.5)	5 (83.3)	301 (90.1)
	Non-endometrioid	5 (19.2)	25 (8.8)	2 (10.5)	1 (16.7)	33 (9.9)

Table 2: All cytology results (to a maximum of three) for 299/334 women with endometrial cancer that had available cytology in the 36 months before their diagnosis.

Cytologic result	No. (%) results from 0–36 months before diagnosis
Abnormal cytology	
Glandular (n=83, 18.7%)	
NEMC≥40	16 (3.6%)
AEMC	45 (10.1%)
EMCC	21 (4.7%)
AGC	1 (0.2%)
Squamous (n=14, 3.2%)	
HSIL	3 (0.7%)
LSIL	3 (0.7%)
ASC-US	8 (1.8%)
ASC-H	0 (0%)
NILM (n=347, 78.2%)	
Normal	341 (76.8%)
Reactive cellular change	3 (0.7%)
Unsatisfactory	3 (0.7%)
Total	444 (100%)

NEMC≥40 = normal endometrial cells in woman over 40 years; AEMC = atypical endometrial cells; EMCC = endometrial carcinoma cells; AGC = atypical glandular cells; HSIL = high-grade squamous intraepithelial lesion; LSIL = low-grade squamous intraepithelial lesion; ASC-US = atypical squamous cells of undetermined significance; ASC-H = atypical squamous cells – cannot exclude high-grade squamous intraepithelial lesion; NILM = negative for intraepithelial lesion or malignancy.

Table 3: Corresponding disease characteristics (FIGO grade and stage, histological type) for cervical cytology results nearest cancer diagnosis for those sampled.

Cytology result nearest diagnosis		Disease characteristic						
		FIGO grade			FIGO stage		Histological type	
		1 (n=213) n (%)	2 (n=34) n (%)	3 (n=52) n (%)	≤IA (n=200) n (%)	≥IB (n=99) n (%)	Endometrioid (n=270) n (%)	Non-endometrioid (n=29) n (%)
Glandular	NEMC≥40 (n=14)	12 (5.6)	2 (5.9)	0 (0)	11 (5.5)	3 (3.0)	14 (5.2)	0 (0)
	AEMC (n=41)	29 (13.6)	7 (20.6)	5 (9.6)	27 (13.5)	14 (14.1)	39 (14.4)	2 (6.9)
	EMCC (n=21)	7 (3.3)	5 (14.7)	9 (17.3)	7 (3.5)	14 (14.1)	13 (4.8)	8 (27.6)
	AGC (n=1)	1 (0.5)	0 (0)	0 (0)	0 (0)	1 (1.0)	1 (0.4)	0 (0)
	Any glandular (n=77)	49 (23.0)	14 (41.2)	14 (26.9)	45 (22.5)	32 (32.3)	67 (24.8)	10 (34.5)
Quamous (n=6)		3 (1.4)	1 (2.9)	2 (3.8)	2 (1.0)	4 (4.0)	6 (2.2)	0 (0)
NILM (n=216)		161 (75.6)	19 (55.9)	36 (69.2)	153 (76.5)	63 (63.6)	197 (73.0)	19 (65.5)

or more. Most women that had a cytology sample taken in this period only yielded results negative for abnormality (211/299, 70.6%). Two hundred and thirty-two out of 299 (77.6%) women had at least one cervical cytology sample taken in the 6 months preceding diagnosis. Among these 232 women, 159 (68.5%) had cytology samples taken for clinical work-up for symptoms, while 66 had samples taken for routine screening. Seven had an unclear indication.

Approximately 228/334 (68%) women underwent routine cervical screening in the 36 months before their diagnosis. The proportion of screened women whose diagnosis was prompted in the same way was 11.4% (26/228).

AEMCs were detected on 16/26 (61.5%) cervical cytology samples that prompted a diagnosis of endometrial cancer. EMCCs were detected in 5/26 (19.2%), as were NEMCs≥40 (5/26, 19.2%). The sensitivity of cervical cytology for the detection of endometrial cancer based on results most antecedent to diagnosis in the 6-month pre-diagnosis was 32.3%, given 75/232 women returned an abnormal related result (40 AEMC, 21 EMCC, 13 NEMC ≥40, one AGC) in this interval.

Cervical cytology results most antecedent to diagnosis (and not exceeding 36 months) (n=299) were analysed with regard to the pathologic characteristics of a corresponding woman's disease (Table 3). Irrespective of the FIGO grade, FIGO stage and histological type of disease, >55% of cytology results nearest diagnosis were negative for intraepithelial lesion or malignancy (NILM). Fourteen out of 52 (26.9%) women with grade 3 disease, and 49/213 (23.0%) women with grade 1 disease, had a glandular abnormality on cervical cytology prior to their diagnosis. Thirty-two out of 99 (32.3%) women with ≥IB stage disease returned a glandular abnormality, as did 45/200 (22.5%) women with ≤IA stage disease. Glandular abnormalities on cervical cytology ahead of diagnosis were recorded for 10/29 (34.5%) women with non-endometrioid type cancers, and for 67/270 (24.8%) those with endometrioid types.

14 women died in the 12 months following their diagnosis of endometrial cancer. All deaths were ascribed to end-stage endometrial cancer, or were of unclear cause (none definitely died from an unrelated cause). No women for whom cytology prompted diagnosis died within 12 months.

Discussion

This retrospective study is important as it quantifies the active role of cervical cytology in incidental diagnoses of endometrial cancer, which appears not to have been previously estimated. In this study, at least 7.8% (26/334) of women eligible for cervical screening had their endometrial cancer diagnoses prompted in this way. Excluding women who appear not to have taken part in cervical screening, the proportion of women whose diagnostic prompt was abnormal cervical cytology becomes 11.4%.

In terms of diagnostic accuracy, cervical cytology has already been designated an overall poor sensitivity for the detection of endometrial cancer.[12–17] Discordant estimates range between 28.1–88.3%, reflecting the heterogeneity of the studies producing them.[12–17] Thirty-two point three percent of women who had cervical cytology within 6 months of their diagnosis had an abnormal result in this study. This aligns with that of past literature, which deems cervical cytology an unreliable screening test for endometrial cancer.[12–17]

Glandular abnormalities on cervical cytology have previously been correlated with endometrial cancer of higher grade, higher stage and worse prognoses.[14,17,18] When considering cytology nearest to cancer diagnosis irrespective of diagnostic prompt, the results of the present study were consistent with those of preceding studies. Specifically, glandular abnormalities (AEMC, EMCC, NEMC ≥40, AGC) were more often detected by cervical cytology nearest to cancer diagnosis in women with higher FIGO grade (14/52, 26.9% grade 3 vs 49/213, 23.0% grade 1) and stage (32/99, 32.3% stage ≥IB vs 45/200, 22.5% stage ≤IA) of disease. Glandular abnormalities were also detected more often in women with non-endometrioid histological tumour types (10/29, 34.5% vs 67/270, 24.8% endometrioid). However, diagnoses prompted by abnormal glandular results on cervical cytology were not correlated with worse clinicopathologic characteristics of disease: most had low FIGO grade (17/26, 65.4%) and stage (18/26, 69.2%) disease, and endometrioid tumour histologies (21/26, 80.8%). This is likely because the majority of women in the study had low-grade and low-stage disease, regardless of diagnostic prompt. Due to the small study size, correlation with worse disease characteristics cannot be excluded.

Mortality was the clinical outcome of interest in this study, but was also a rare outcome (14/334). This was probably augmented by the short 12-month follow-up period. Although there were no cases of 12-month mortality in the group diagnosed following abnormal cytology, the study is again too underpowered for correlation.

The incidence of endometrial cancer is 19.6 per 100,000 Māori women and 40.9 per 100,000 Pacific women, notably higher than for non-Māori/non-Pacific women (12.6 per 100,000 women).[4] Compared with non-Māori, Māori women are also nearly twice as likely to present with advanced stage endometrial tumours[22] and have a 56% higher mortality rate (age- and sex-adjusted cancer-specific excess mortality).[23] Again, small numbers of Māori and Pacific women in this study deem correlations with ethnicity unreliable. However, matters of equity in relation to endometrial cancer are evidently of utmost importance. Further research including more Māori and Pacific women is required to better postulate the impact of the NCSP change on these groups.

Results of this study indicate that with the introduction of cervical hr-HPV screening, diagnosis for at least a small proportion of women with endometrial cancer may be delayed. In 2019, there were 686 women diagnosed with endometrial cancer in New Zealand.[24] By extrapolation of figures from this study, approximately 35 women a year would therefore have their diagnosis of endometrial cancer delayed by the change in NCSP policy. Here, the impact of delay is undefined, as the interval between incidental detection on cytology and onset of symptoms cannot be studied outside of real practice. Concern is reduced by this study, as the majority of women detected by cytology had low-grade disease, such that delay may not result in a significantly worse outcome.

The increasing burden of endometrial cancer is well documented. This study identifies that endometrial cancer can be detected in some asymptomatic women. Respondent to this are efforts to develop screening tests with the necessary elements of early detection and easy dissemination across clinical contexts. Some progress has been made with combining molecular testing and non-invasive sampling techniques. Genomic, epigenomic and proteomic approaches have shown potential in leveraging the sensitivity of numerous specimens (e.g., cervical cytology, cervical scrapings, cervicovaginal secretions, tampons) for detection of endometrial cancer, to 70–90%.[25–27] These approaches may meet the growing diagnostic need in this area, but research is ongoing. For disenfranchised Indigenous Māori and Pacific populations in New Zealand that have higher incidence of endometrial cancer, culturally sensitive and equitable screening strategies are needed.

This research is most limited by its retrospective design and small regional cohort. Although the cohort is a relatively complete representation of women with endometrial cancer in the Southern Region of New Zealand, it has reduced applicability to other populations. For example, Māori and Pacific populations were significantly under-represented in this study. Small cohorts also undermine statistical power, which has not been formally analysed in this study.

In conclusion, endometrial cancer can be detected in asymptomatic women by cervical cytology. Seven point eight percent of women eligible for cervical screening in this study had their endometrial cancer diagnoses prompted this way. The implementation of hr-HPV screening will reduce this pathway to diagnosis. It is important to acknowledge the women who will consequently have their diagnoses delayed, as the true clinical impact of these delays is undetermined. The poor sensitivity of cervical cytology for endometrial cancer does not justify its continued use as the primary cervical screening test in New Zealand; nor does it support a potential role in endometrial cancer screening. Research exploring screening modalities and potential benefits for endometrial screening in asymptomatic and disenfranchised Indigenous women is justified.

COMPETING INTERESTS
The authors of this paper have no conflicts of interest (relational, financial or otherwise) to report.

ACKNOWLEDGEMENTS
Dr Adele Hanna, for time spent verifying some classifications of routine versus non-routine screening.

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Low risk of variant Creutzfeldt-Jakob disease transmission from blood transfusions in Aotearoa New Zealand suggests donor exclusion policies can be relaxed

David T S Hayman, Michael G Baker

ABSTRACT

Aotearoa New Zealand currently excludes potential blood donors who lived in the United Kingdom (UK) for 6 months or more between 1980 and 1996. This action is due to the potential for variant Creutzfeldt-Jakob disease (vCJD) following blood transfusions from pre-clinical vCJD cases, who themselves mostly developed disease from the consumption of cattle with bovine spongiform encephalopathy (BSE) during this period, or from those incubating the misfolded prion proteins that cause disease. This donor exclusion policy led to 10% of New Zealand's active blood donors in 2000 being excluded, and it remains today despite periodic shortages of some blood products. Globally there have been 232 vCJD cases recorded—178 in the UK—with no new cases since 2019 and the peak numbers 23 years ago in 2000. Only three confirmed cases have been linked to blood transfusion. Here, we aimed to estimate the annual risk of vCJD from blood transfusion in New Zealand after restriction removal. We used UK case numbers, population estimates, and donor and recipient transfusion numbers to calculate the risk to the New Zealand public. We calculated the risk, based on approximately 131,000 transfusions a year and accounting for multiple transfusions, might lead to 0.005 cases annually, or approximately one in one billion nationally, and comparable to recent one in 1.45 billion estimates for Australia. Our analyses suggests that relaxing current blood donation restrictions, like Ireland and Australia's recent policy changes, would lead to an extremely low risk of vCJD transfusion-transmission in New Zealand. This policy change would help increase the supply of blood products for multiple medical needs.

On 23 February 2023, the Aotearoa New Zealand blood service urgently needed blood. This shortage came after the service estimated in 2022 that it required 40,000 more donors in 2023 to meet demand;[1] yet, currently, New Zealand excludes potential donors who lived in the United Kingdom (UK) for 6 months or more (cumulative time) between 1980 and 1996 due to the potential for these people to be infected with variant Creutzfeldt-Jakob disease (vCJD). This exclusion led to 10% of New Zealand's active blood donors in 2000 being excluded.[2]

vCJD is a very rare but deadly degenerative brain disorder leading to dementia and death, caused by an infectious prion originally derived from eating contaminated beef and beef products.[3] It occurs against a backdrop of the far more common Sporadic Creutzfeldt-Jakob disease in humans (sCJD), which has a worldwide rate of 1–2 per million population per year and occurs spontaneously without a defined source.

The vCJD prion, PrP^{Sc}, causes bovine spongiform encephalopathy (BSE) in cattle, and this was likely derived from cattle being fed scrapie-infected sheep, another prion disease. Due to possibly long incubation periods, a lack of non-invasive tests (but see [4,5] for developments) or ways to fully remove them from products,[6] precautionary principles emphasising caution in the absence of scientific knowledge have been applied by countries to avoid any risk of vCJD from blood transfusions. However, since the first vCJD case there have only been 232 cases recorded globally, with 178 (76%) of those in the UK.[3] Further, there have been no new cases in the world since 2019, the last in UK in 2016, and the peak was in 2000, 23 years ago.[3] No new cases of transfusion-related vCJD have been reported since 2007 and there have only been three confirmed cases linked to blood transfusion ever, with a further two pre-clinical, asymptomatic cases of PrP^{Sc} detection in the spleen attributed to blood products.[3]

Due to these low numbers, countries have begun lifting restrictions on donors with potential

exposure to BSE. Ireland lifted its ban in 2019 and Australia has allowed the same demographic to donate blood from 25 July 2022.[7] Australia's exclusions were the same as New Zealand's, yet only resulted in the exclusion of 5.3% of all blood donations (50,100 donations in 1998),[8] so its impact was less than in New Zealand. The annual number of Australian blood donations made by donors potentially infected with vCJD was estimated to be 1.15 (range 0.02–31.1, based on the uncertainty in the UK prevalence estimate).[8] Indeed, recent modelling of the risk in Australia estimated the overall risk of vCJD transmission (infection) from blood, based on prior residency in and travel to the UK from 1980–1996, to be one in 389,000,000 and clinical cases one in 1,450,000,000.[9] There is no reason to believe New Zealand's will be substantially different.

If we assume the overall prevalence of vCJD among all 251,652 reported UK-born New Zealanders[10] is the same as it would be for the 176 total UK cases using the UK population in 1980 (56,310,000,[11] so, smaller than today, giving a high prevalence than larger population sizes would) then the prevalence would be 3.1×10^{-6} and we would expect fewer than one UK-born person to be a vCJD case in New Zealand (0.79). However, not all people donate blood. The New Zealand Blood Service reports 86,710 donors in 2020,[12] and initial restrictions on donors present in the UK between 1980–1996 reduced donors by 10%—so let's assume there might be 8,671 donors excluded. Using the same logic, this would mean fewer than 0.03 donors might be cases. We can assume the risk of vCJD transmission is 0.448 via blood transfusion, given 3 cases from 67 exposures.[3] Thus, 0.001 infections might take place in New Zealand per year. However, on average the 30,316 recipients received 131,308 transfusions,[12] so (accounting for multiple transfusions) infections could rise to 0.005 cases, or one in 967 million or approximately one in one billion, annually.

More rigorous, data-driven analyses, such as age-structured analyses following McManus et al.,[9] would provide more robust evidence; however, this annual risk estimate of about one in one billion is of a similarly small risk to McManus et al.'s estimates of one in 389 million for transmission and one in 1.45 billion for clinical cases for Australia that it seems unnecessary. We did not account for non-UK-born donors who might have spent 6 months or more in the UK in the prevalence estimates potentially lowering the prevalence among donors, but equally we assumed all UK born at risk, potentially increasing the prevalence among UK-born donors. By assuming all excluded donors (the 10%) from the 2020 decision were UK born potentially balances these, as some will not have been UK born. Moreover, we assumed all recipients to be at similar risk of developing vCJD, which is unlikely due to age structure at least.

A concern is there could be a second epidemic of vCJD, due to prolonged vCJD incubation periods and the number of people with sub-clinical vCJD, which is unknown.[3] In the UK one in 2,000 people are thought to carry abnormal prions; the importance of which is not known, but genetic testing for the genotype at prion protein gene (PRNP) codon 129 found most were valine homozygous in the normal population compared to methionine homozygous in vCJD cases.[13] Concerns were raised over a potential second wave from different genotypes (e.g., PRNP codon 129 MV genotype) with longer incubation periods possible after a case in the UK was detected in 2016, but such a surge has not been observed.[3] The age structure of New Zealand's blood transfusion recipients is strongly skewed, with 65% of the recipients of all New Zealand's blood component transfusions being ≥55 years old, including 20.3% aged 65–74, 19.5% aged 75–84 and 12.1% aged 85+ years in 2020.[12] Prolonged incubation periods among recipients in these age classes are less likely to be important, due to natural mortality rates from other causes and the immediate- and intermediate-term need for blood products likely being more important.

The strongest evidence of a risk from transfusion, apart from the three vCJD cases, comes from studies in sheep, where blood products have been shown to be infectious.[5] However, sCJD seems unlikely to be transmissible via blood (though iatrogenic transmission can occur via contaminated human growth hormone, dura mater and corneal grafts or neurosurgical equipment).[14,15] Moreover, there has been no second vCJD wave in the UK, which had 76% of cases, and evidence suggests extended incubation is rare in other human prion diseases, Kuru and iatrogenic CJD.[3] Modelling studies suggested a secondary blood transfusion-derived UK vCJD epidemic would be biologically implausible, with hundreds of cases considered an extreme worst case.[16] Further, the UK's own government assessment reported that future infections are expected to range from 0–62 due to 90 million transfusions spread over 50 years for red blood cells, 0–31 due to 14 million transfusions spread over the next

50 years for plasma and 0–84 due to 19 million transfusions spread over the next 60 years for platelets.[17]

In conclusion, while the risk is not zero and acknowledging the need for ongoing surveillance and that vCJD is a terrible, fatal disease, the risk of vCJD through blood transfusion in New Zealand seems extraordinarily low. Given the need for blood, and that less than 4% of the New Zealand population currently donate blood,[18] it seems time for New Zealand to revisit its own restrictions. Public health regularly requires preventative measures that carry potentially higher, but still extremely low risk. It seems timely to follow Australia and remove the restriction on donors potentially exposed to BSE in the UK in the 1980s and 1990s.

COMPETING INTERESTS
Nil.

ACKNOWLEDGEMENTS
Alex James and Mike Plank, both University of Canterbury, for early discussions. Royal Society Te Aparangi Grant RDF-MAU170 and The Percival Carmine Chair in Epidemiology and Public Health for funding.

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Cryptorchidism in a young man with learning disabilities returns as advanced testicular cancer

Morgan J Bressington, Ludewikus Vermeulen

Testicular abnormalities in men with intellectual disabilities is reported to be as high as 10.8%.[1] These same men are much less likely to present early with testicular cancers and have been demonstrated to have poorer prognoses.[2]

Case report

Our case describes the story of man in his twenties who first presented to hospital with an episode of choking while eating at home. On admission, aspiration pneumonia was diagnosed and an examination in the emergency department revealed a large, firm abdominal mass.

After recovery from the pneumonia, further history and examination was possible. The patient's medical history consisted of cerebral palsy, learning disability, epilepsy and previous aspiration episodes. The only abdominal history involved an undescended testicle that had first been identified 4 years ago and planned for orchidopexy, but, unfortunately, this had been lost to follow-up. Examination confirmed only one testicle in the scrotal sac and a large abdominal mass, causing distention from the pubis to just above the umbilicus.

Further investigations were organised in the form of computed tomography (CT) imaging, tumour markers and biopsy. The CT scan demonstrated mass effect from the abdominal mass, compressing the right ureter (Figure 1, A) and inferior vena cava (Figure 1, B) with enlarged para-aortic nodes. Tumour markers demonstrated an alpha-fetoprotein (AFP) of 3.0ng/mL (0–15), a beta-human chorionic gonadotrophin (βhCG) of 210mIU/mL (0–5) and a lactate dyhydrogenase (LDH) of 1,490U/L (120–250) and histology confirmed a diagnosis of pure seminoma.

After diagnosis was confirmed, the patient proceeded to theatre. He underwent midline laparotomy and excision of a large abdominal seminoma (Figure 3). Surgery was a success, and 3 days later the patient was discharged from the acute hospital, completing recovery in a smaller district general hospital, with return home 10 days after surgery. Follow-up continues with the medical oncologists.

Discussion

Testicular cancer is atypical in that it becomes less common as men get older. It represents the most common cancer in men aged between 15–49, although only 1% of total male cancers.[3] Risk factors include undescended testicles (cryptorchism), family history, microlithiasis and previous personal history.[4] Most men present having made an incidental discovery of a unilateral testicular lump on self-examination.[5]

Considering undescended testes being a major risk factor, and self-examination being the major method of discovery, education around examination of the genitals is of paramount importance. Men with intellectual disabilities are more likely to have cryptorchidism and are less likely to self-examine.[1] This means they're less likely to identify that a testicle is missing from the scrotum or maintain surveillance on present testicles. As such, men with intellectual disabilities are more likely to have testicular cancer and are more likely to present late.[1]

In addition to presenting late, our case highlights the issue of loss to follow-up. Maintaining relationships with patients with learning difficulties is known to present multiple challenges, and research exists suggesting methods to overcome these barriers.[6,7] Active involvement of caregivers and clear communication allow for more effective long-term relationships and could well help with following up this cohort.

A large cohort study by Afshar et al.[2] reviewed the notes of over 150,000 men with learning disabilities. This study highlights the significantly increased risk that patients with learning disabilities face from testicular cancer. They concluded that more

needed to be done in the education of patients and carers so that early identification and improved outcomes could be achieved.

Fortunately for our patient, surgical management was a success, and following continued care under our colleagues in medical oncology, a complete recovery can be expected. However, an earlier detection could well have avoided the need for such drastic surgery. As such, in addition to the conclusions of Afshar et al., we would emphasise the importance of robust follow-up in patients with learning disabilities. Following the identification of an undescended testicle, prompt fixation should be planned, and inclusive, transparent communication had with both patient and caregiver to ensure effective follow-up.

Figure 1: Axial CT slice.

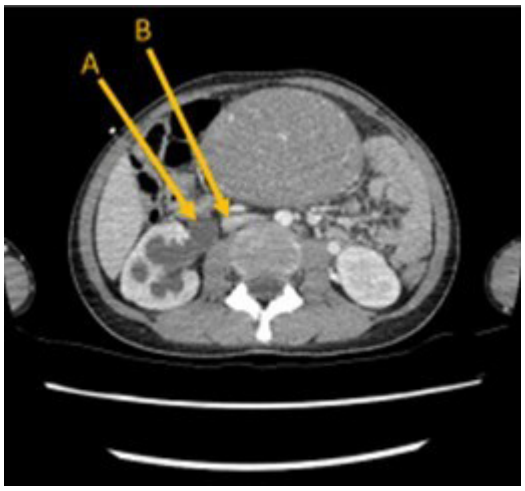


Figure 2: Coronal CT slice.

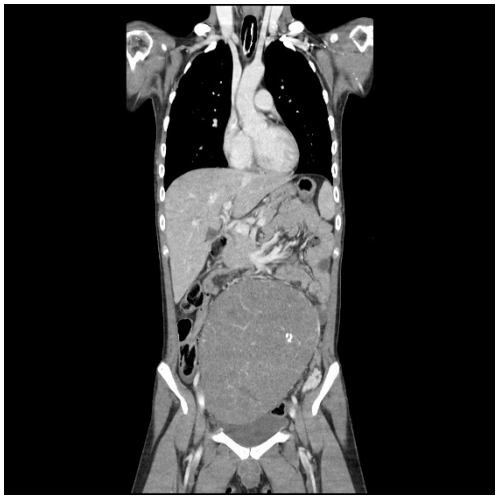
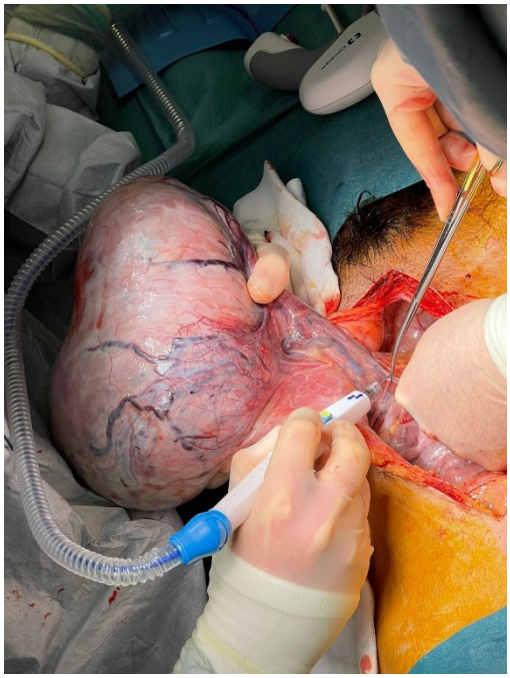


Figure 3: Excision of large seminoma.



COMPETING INTERESTS
There are no potential conflicts of interest.

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Impact of a non-medical switch from tocilizumab to upadacitinib in a cohort of patients with rheumatoid arthritis in routine clinical practice

Douglas White, David Poppelwell

The COVID-19 pandemic caused significant disruption in medicine supply lines. From 1 October 2021 in New Zealand, publicly funded access to the only available IL-6 receptor inhibitor, tocilizumab (administered intravenously in New Zealand), was widened to treat moderate-to-severe cases of COVID-19.[1] In order to preserve the remaining tocilizumab stock for patients at highest risk, prescribers were asked to transition their patients with rheumatoid arthritis (RA) from tocilizumab to upadacitinib from 1 October 2021.[2] Prescribers were given just 2 weeks' notice to begin making the switch.

Upadacitinib is a selective and reversible inhibitor of Janus kinase (JAK) 1. In New Zealand, upadacitinib is indicated for the treatment of adults with moderately to severely active rheumatoid arthritis (RA).[3] Approval was based on the results from a comprehensive clinical trial programme assessing efficacy and safety across a range of patient types and treatment strategies in patients with RA, including patients with inadequate response or intolerance to prior biologic disease-modifying antirheumatic drugs (bDMARDs).[4–9] However, the effectiveness and safety of a direct non-medical switch (NMS) to upadacitinib, defined as a switch for reasons unrelated to patient health, has not been investigated in these bDMARD-experienced patients.

This study therefore represents a unique opportunity to address a significant data gap where no data currently exist—to investigate the impact of a non-medical switch from tocilizumab to upadacitinib on outcomes in a cohort of patients with RA in routine clinical practice.

Methods

This was a non-interventional, observational, single-centre cohort study with a retrospective phase and a prospective phase.

1) Retrospective phase

The medical records of adults with RA receiving tocilizumab prior to 1 October 2021 who have attended the Rheumatology Clinic at Waikato Hospital, Hamilton, New Zealand were reviewed for the data extraction period, defined as 6 months after the initiation of upadacitinib. For a patient's records to be considered for inclusion in the study, the initiation of upadacitinib must have occurred after 1 October 2021. The date of initiation of upadacitinib was recorded as the index date. Upadacitinib was prescribed in accordance with the approved New Zealand Datasheet and in line with expectations of the government agency responsible for managing access in this situation.

2) Prospective phase

Six months from the index date, a small number of questionnaires related to secondary outcomes were provided to patients and the treating physician.

Health and Disability Ethics Committee approval was obtained (2022 EXP 11553). This study was a low-risk observational study.

The primary outcome was treatment persistence, defined as the proportion of patients continuing therapy with upadacitinib at 6 months. Key secondary outcomes assessed at 6 months included: reasons and time to permanent discontinuation of upadacitinib for any reason, change in Physician Global Assessment of disease activity (PhGA) on 100mm visual analogue scale (VAS), maintenance of Remission/Low Disease Activity at 6 months after switch from tocilizumab in the physician's opinion, change in disease control (notably better/no change/notably worse) in the physician's opinion, Patient Global Assessment of disease activity (PtGA) on 10cm (100mm) visual analogue scale (VAS; scores range from 0 to 10, higher scores represent a higher

level of disease activity) and patient treatment satisfaction using the abbreviated Treatment Satisfaction Questionnaire for Medication (TSQM-9).[10–11] The TSQM-9 provides a validated score for three subscales: effectiveness, convenience and global satisfaction. Scores range from 0 to 100, with 0 representing complete dissatisfaction and 100 maximum satisfaction.

The primary outcome was estimated as a proportion with corresponding two-sided 95% confidence interval (CI) using the Clopper–Pearson exact method. Data description and analyses used IBM SPSS version 29.

Results

Baseline demographics of the 43 patients receiving tocilizumab for RA are detailed in Table 1. The median age of those receiving tocilizumab was 56 years, with a range of 43 to 89 years. Mean (SD) disease duration was 15 (12) with a range of 1 to 68 years. As anticipated, patients had long-standing disease recalcitrant to multiple previous treatments.

The decision to switch to upadacitinib was made for 26 patients. Twenty proceeded with the medication change and six elected not to (Figure 1). Reasons given were concern about adverse effects, wondering whether they would be all right without treatment, resentment at the treatment change being forced upon them and feeling they needed more time to consider their options. Five of the six elected to start upadacitinib at a later date and are excluded from further discussion here. Upadacitinib was therefore used following 1 bDMARD in 1 patient, 2 bDMARDs in 4 patients, 3 bDMARDs in 10 patients and 4 bDMARDs in 5 patients.

The number of patients who continued treatment with upadacitinib after 6 months was 17/20, a proportion (95% CI) of 85% (62 to 97). (Primary outcome: Figure 1).

In the 3 patients who discontinued, primary non-response was the reason; all were transitioned back to tocilizumab with resumption of supply. Mean time to discontinuation was 92 days with a range of 31 to 139 days.

The PhGA at 6 months following a switch from tocilizumab to upadacitinib was felt to be improved in 4 of 20 cases. Maintenance of Remission/Low Disease Activity at 6 months after switch from tocilizumab, in the physician's opinion, was reported in 17/20 cases (85%; Figure 2). Only in the 3/20 cases (15%) where lack of efficacy was reported was loss of Remission/Low Disease Activity noted. For change in disease control (notably better/no change/notably worse), in the physician's opinion, corresponding patient numbers were 4/13/3 (20%/65%/15%).

Patient treatment satisfaction data was available for 15 of the 17 participants remaining on upadacitinib: mean (SD) TSQM-9 scores were 82.7 (17) for effectiveness, 89.5 (14.3) for convenience and 75.3 (24.8) for global satisfaction. The median PtGA at 6 months was 2 with a range of 1 to 5. One adverse event (sinus infection) was reported among the 20 participants.

Discussion

Upadacitinib treatment persistence was high following a switch from tocilizumab in this cohort of RA patients in routine clinical practice. Disease control following the switch was maintained in the majority of patients. Satisfaction with upadacitinib treatment was excellent and felt to be effective and convenient.

Not all those patients receiving tocilizumab at Waikato Hospital were transitioned to upadacitinib. There are likely to be several reasons for this. Firstly, some switch decisions were made by the physician before the availability of upadacitinib was announced. In six cases, the patient prescribed upadacitinib had reservations and elected not to start treatment. Since many of the consultations took place by telephone during the prevailing COVID-19 restrictions and the need to contact many patients urgently, it is likely there was less opportunity to discuss and explore these reservations than during a standard face-to-face consultation.

There were some limitations to our study. Waikato DHB experienced a cyberattack in May 2021 which hampered access to records and the ability to record formal disease activity measures prior to the loss of supply of tocilizumab. Assessment of disease activity was based on subjective outcomes that may be influenced by self-presentational and recall biases.

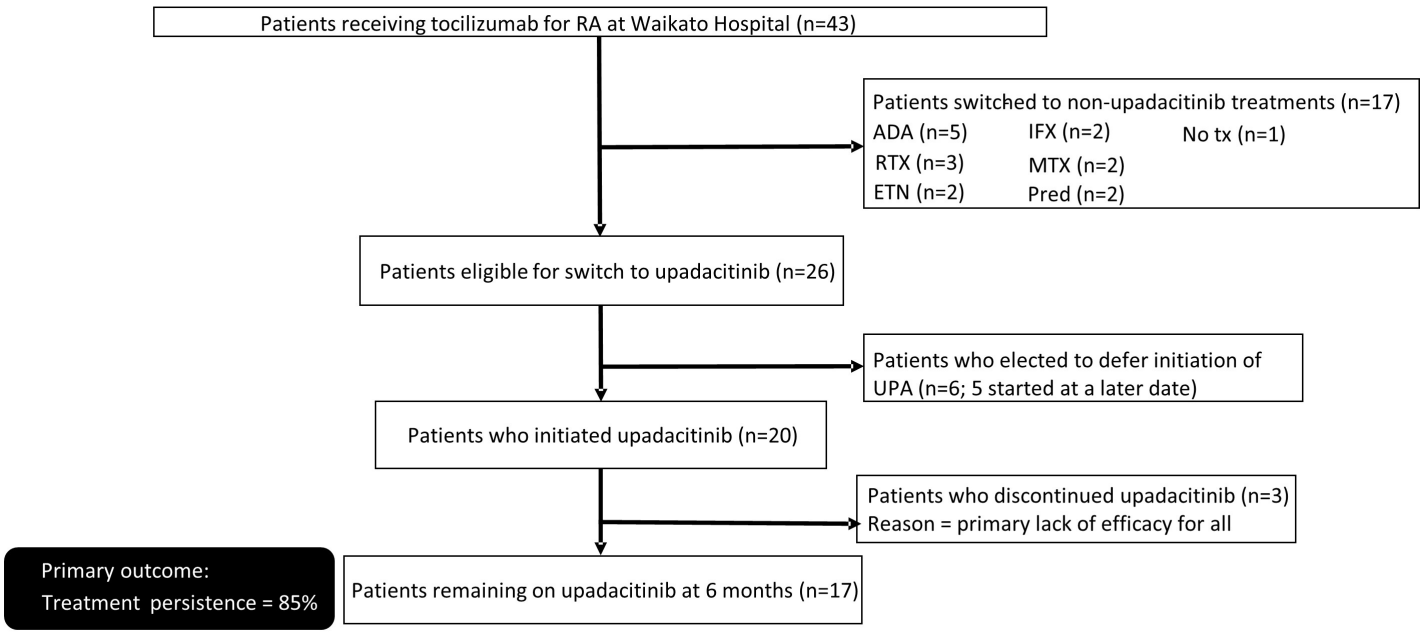
Our study showed that a non-medical switch from tocilizumab to upadacitinib is effective in a cohort of patients with RA in routine clinical practice.

Table 1: Patient demographics of RA Cohort at Waikato Hospital.

Demographics, n (%)	**n=43 (complete cohort)**	**n=20 (cohort starting UPA)**
Age, median (range)	56 (43 to 89)	55.5 (48 to 89)
Female, n (%)	36 (84)	16 (80)
Ethnicity, n (%)		
NZ European	37 (86)	20 (100)
Māori	4 (9)	
Indian	1 (2)	
Tongan	1 (2)	
Mean disease duration, years (SD)	15 (12)	17.05 (15)
Rheumatoid Factor positive, n (%)	32 (74)	14 (70)
Anti-CCP positive, n (%)	29 (67)	13 (65)
Number of prior csDMARDs (median, range)	4 (3 to 5)	4 (3 to 5)
Prior biologic, n (%)		
Tocilizumab	43 (100)	20 (100)
Adalimumab	25 (58)	14 (70)
Etanercept	24 (56)	16 (80)
Rituximab	9 (21)	7 (35)
Infliximab	3 (7)	0
Golimumab	1 (2)	0
Tocilizumab as 1L/2L/3L/4L biologic	9(21) / 14(33) / 13(30) / 7(16)	0 / 5(25) / 10(50) / 5(25)

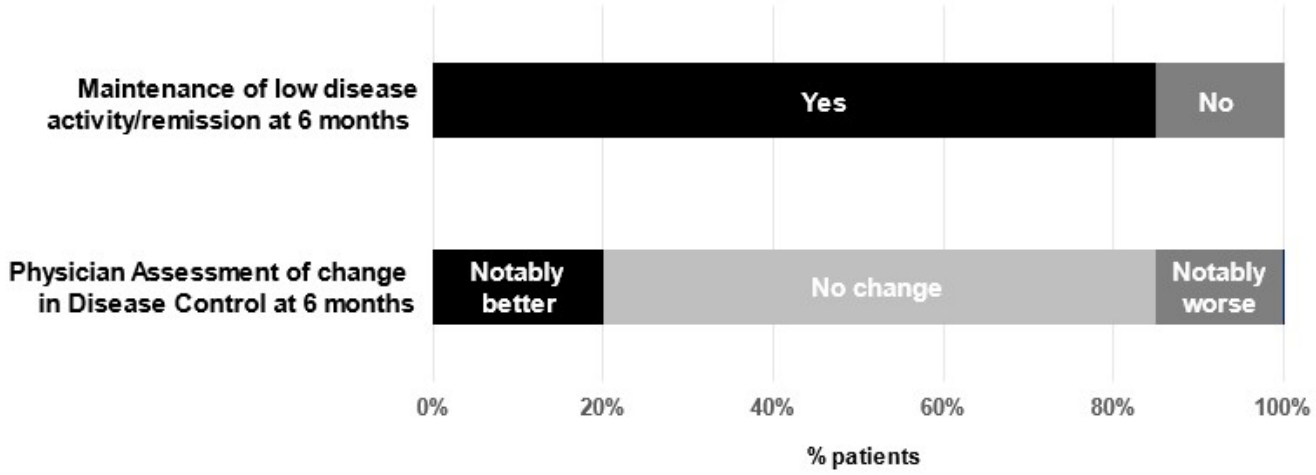
CCP, Cyclic Citrullinated Peptide; csDMARD, Conventional synthetic DMARD; DMARD, Disease Modifying Anti Rheumatic Drug; L, Line; UPA, upadacitinib.

Figure 1: Patient flow and primary outcome.



ADA, adalimumab; ETN, etanercept; IFX, infliximab; Pred, Prednisone; RTX, rituximab; UPA, upadacitinib.

Figure 2: Disease control: physician assessment at 6 months.



COMPETING INTERESTS

AbbVie participated in the study design, interpretation of data, reviewing and approval of the publication. All authors had access to relevant data and participated in the drafting, review and approval of this publication. No honoraria or payments were made for authorship. D White has served as a consultant to AbbVie and has received research funding and speaker fees from AbbVie. D Poppelwell is an employee of AbbVie and owns AbbVie stock.

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Seen and unseen work: the intensity of service provision for individuals with type 2 diabetes in a high-needs population

Christine Barthow, Nadine Kuiper, Bryan Betty, Ioana Viliamu-Amusia, Linda Bryant, Dipan Ranchhod, Erin Millar, Eileen McKinlay, Jeremy Krebs

The funding and sustainability of primary healthcare are urgent priorities that must be addressed if the recent health reforms are to achieve the goal of equitable access and outcomes for all New Zealanders. This is particularly critical for services where large proportions of the enrolled population have high health needs and/or multiple social disadvantages. Providing adequate services to such groups is recognised as challenging,[1,2] and long-term under-funding of these services is recognised.[3] These populations have higher rates of multi-morbidity, more frequently utilise health and other social services and have higher unmet needs than other groups.[4–7] This results in high concentrations of complexity[6] and the need for evidence-based interprofessional collaborative models of care,[7] including a diverse range of regulated and unregulated workers.[8] However, current data detailing the extent of work and the range of skills and workers needed within practices serving these populations are limited.[9]

Within a practice serving a high-needs population, this exploratory study aimed to ascertain the complexity of individuals with type 2 diabetes (T2D) and the volume of work undertaken by members of the practice team providing healthcare to these individuals over 1 year.

Context

Porirua Union Community and Health Service (PUCHS) operates as a Very Low Cost Access (VLCA) practice and serves a population of 7,189, comprising 48% Pacific Peoples, 21% Māori and 9.2% Refugee (many with English as a second language). Overall, 89% of this population live in the most deprived areas (quintile five) and many have multi-morbidity. Within PUCHS, 9.3% (n=657, including 20 individuals aged 14–29 years) have T2D, compared with 4.7% overall in the primary health organisation (PHO) that PUCHS operates within. Similarly high proportions have pre-diabetes; PUCHS 8.8% (n=627, including 36 aged 14–29 years), PHO overall 4.4%. In return for higher capitation and equity funding than other practices, caps are placed on co-payments charged to individuals attending VLCA practices.[10] PUCHS utilises a wide range of staff to address the enrolled population's needs, including general practitioners (GPs), nurses, health coaches, healthcare assistants, and a practice-based prescribing pharmacist, podiatrist, dietitian, counsellor, health improvement practitioner (HIP), cross-cultural worker and community health worker. Many of these staff are culturally matched and live within the local community.

Methods

Ethical approval was provided by the University of Otago Human Ethics Committee (Health) (HD23/003). To ascertain the practice work, we collected anonymised clinical records and data extracts from the MedTech practice management system for eight individuals with T2D, purposefully selected to include a range of ages, genders and ethnicities. Table 1 describes the data and analysis.

Results and discussion

A summary of the findings is presented in Table 2. The mean number of recorded long-term conditions (LTC), unique items prescribed and daily record entries per case/year were high, confirming the complexity of these cases.[11] Nevertheless, these numbers alone under-represent complexity. Case 7 had only seven daily record entries; however, this individual was worryingly unengaged in healthcare, difficult to locate and the HIP was actively but unsuccessfully

Table 1: Description of data and analysis.

Data, explanation and analysis
Demographic data Data: age, ethnicity, gender and community service card status.
Read code classifications Data: Read code classifications for the individual's entire enrolment with the practice. Definition: LTC were defined as any ongoing condition warranting ongoing monitoring or management, or any disabilities, likely to increase the complexity of care delivery. Classified[a] LTC present across all cases: Asthma, atopic dermatitis/eczema, bipolar affective disorder, chronic obstructive pulmonary disease, chronic renal failure, coronary artery disease, depression, diabetes mellitus, disability (intellectual), gastro-oesophageal reflux, gout, habit and impulse disorders, hypertensive disease, mixed hyperlipidaemia, obesity, obstructive sleep apnoea, osteoarthritis, polycystic ovaries, psoriasis, smoker or ex-smoker, transient ischaemic attack Classified complications: Diabetic nephropathy, diabetic retinopathy or diabetic maculopathy, microalbuminuria
Prescriptions covering 1 April 2022–31 March 2023 Data: All individual items prescribed over a 1-year period. Analysis: The total number of individual items (including repeat prescriptions for the same item) and the total number of unique items prescribed over the year were calculated.
Daily records covering 1 April 2022–31 March 2023 Data: These records document healthcare actions directly with or in relation to each patient. These typically include face-to-face or phone consultations, prescription reviews and prescribing and other patient-related queries or tasks and their outcomes. Some providers, particularly those whose work is not invoiced to the individual receiving care, did not routinely enter notes into the daily records. Analysis: For each case all entries into the daily record were coded according to staff provider type and counted. Entries with provider name only and no comment were excluded from counts. Then, to enable a more contextual analysis of each case, factors likely to impact the intensity of service use or case complexity and that were not evident in the classification coding were identified by reading the content of the notes and recorded in each case summary.
Outbox and inbox transactions covering 1 April 2022–31 March 2023 Data: Outbox entries captured investigation requests, referrals and certificates. Inbox entries captured incoming correspondence including investigation results and other service providers reports. Analysis: Entries were coded according to broadly similar categories and counted. To avoid over-estimation of work volume, entries by a health improvement practitioner or health coach that were recorded in the inbox and daily records were removed from inbox/outbox counts and represented in the daily record counts only.
Invoices covering 1 April 2022–31 March 2023 Data: Due to the complex nature of funding streams, not all care is directly invoiced to the individual receiving care. Analysis: The total co-payment directly invoiced to each case was calculated and coded according to provider type.

LTC = long term conditions.
[a] Some records used alternative read code terminology for the same condition; for simplicity only one condition for each category is reported.

Table 2: Summary data.

	Individual case data								Summary data	
	Case 1	**Case 2**	**Case 3**	**Case 4**	**Case 5**	**Case 6**	**Case 7**	**Case 8**	**Mean**	**Range**
Demographics										
Age range	40–50	60–70	30–40	60–70	50–60	20–30	20–30	60–70		
Gender	Female	Male	Female	Female	Female	Other	Male	Male		
Ethnicity	Māori	Māori	Samoan	Tokelauan	Middle Eastern	Cook Island Māori	Māori	South Asian		
CSC holder	Yes	Yes	Yes	No	Yes	Yes	Yes	No		
Read code classifications										
Number of read coded LTC	10	5	10	9	7	3	3	4	8.5	3 to 10
LTC complications	3	2	1	3	1	0	1	1	2.0	1 to 3
Medications[a]										
Number of individual items prescribed within 1 year	77	57	41	58	49	25	4	29	56.7	4 to 77
Number of unique items prescribed within 1 year	29	15	19	27	18	14	3	14	23.2	3 to 29
Daily record entries by staff provider type										
GP	17	7	11	23	9	16	1	12		
Nurse	9	22	3	11	7	12	2	1		
Practice-based prescribing pharmacist	3	8	2	0	2	3	0	1		
Dietitian	0	0	0	0	0	1	0	0		

Table 2 (continued): Summary data.

Counsellor	2	0	0	0	0	0	0	0		
Podiatrist	2	1	0	0	0	0	0	0		
Health improvement practitioner	0	0	0	0	0	2	4	0		
Health coach	11	0	0	0	0	0	0	0		
Other workers[b]	0	0	0	0	0	0	0	0		
Total entries daily records	**44**	**38**	**16**	**34**	**18**	**34**	**7**	**14**	**25.6**	**7 to 44**
Outbox transactions										
Lab/radiology request	4	4	5	6	5	4	2	5		
Certificates[c]	2	2	0	3	0	8	0	0		
Referral/special authority request/other forms	3	2	1	6	3	5	3	3		
Total outbox interactions	**9**	**8**	**6**	**15**	**8**	**17**	**5**	**8**	**9.5**	**5 to 17**
Inbox transactions										
Hospital/specialist/other service	12	8	8	24	3	17	1	7		
Labs/investigation results	26	12	15	35	7	16	0	16		
Preventative care—screening	1	1	0	1	1	0	0	3		
Total inbox interactions	**39**	**21**	**23**	**60**	**11**	**33**	**1**	**26**	**26.8**	**1 to 60**

Table 2 (continued): Summary data.

Patient invoices[d]										
Total co-payment invoiced directly to the patient	$100	$68	$88	$110	$67	$51	$0	$60	$68	$0 to 110
Total number of non-zero invoices to patient	8	10	8	17	9	8	0	5	8.1	0 to 17
Non-zero invoices by provider type	7 GP, 1 pharmacist	3 GP, 5 pharmacist, 2 podiatrist	7 GP, 1 pharmacist	17 GP	7 GP, 2 pharmacist	8 GP	N/A	4 GP, 1 pharmacist		

LTC = long-term conditions; CSC = community service card holder; GP = general practitioner.
[a] An item refers to a single prescribed medication or device (such as insulin needles etc).
[b] Other unregulated staff providers include healthcare assistant, community health worker and cross-cultural worker; some data from this type of worker was missing from daily records.
[c] Includes off-work, medical and Work and Income (WINZ) certificates.
[d] Funding for VLCA practices comes through multiple streams, and therefore not all interactions are directly invoiced to the patient.

2023 Aug 25; 136(1581). ISSN 1175-8716
https://journal.nzma.org.nz/

trying to engage them. This highlights the hidden complexity of work when care is recognised as not optimal but remains invisible if relying solely on services provided as an assessment of future service requirements.

Outbox and inbox interactions predominantly undertaken by GPs contributed a large work volume and require timely attention to ensure safety and quality are maintained. Given the number of LTC, coordinating referrals and responding to incoming results and communications is likely more complex than other population groups.

The range of workers contributing to service provision is notable. While GP and nurse work are expected, the practice-based prescribing pharmacist role in primary care is relatively new[12] and well utilised, as were the growing use of the newer HIP and health coach roles. Both HIP and health coach roles are funded centrally through the PHO; however, HIP services are shared between practices. Given the nature of diabetes and the socio-economic status of the population, there are likely to be opportunities for more intense work by dietitians and there was no involvement from a social worker; these workers' input is limited by funding.

Work completed by nurses, HIPs, health coaches and community health workers is not charged to the individual and is therefore financially invisible and only seen if documented in the daily records. The low value of invoices compared with the high volume of work represented in the daily records by GPs and the pharmacist and podiatrist whose work was directly invoiced to the individual is particularly striking. Total daily record entries from these providers (n=118) divided by the total directly invoiced to all individuals ($612) gives an average of $5.19 per daily record entry for these workers alone. This does not include non-contact time for outbox and inbox transactions, following up on referrals or trying to contact patients. GPs are allocated 15-minute appointments; however, the complexity of care required in this population frequently requires longer consultations,[2] which could not be accounted for in this analysis.

Conclusion

This study demonstrates the amount of work staff in a VLCA practice provided over 1 year to a purposefully selected sample of individuals with T2D, and highlights the complexity of these cases with multiple LTCs and high medication use. It reveals the range of workers and the work volume involved in caring for this population with complex needs. Lack of invoicing aside, work may be under-represented and under-valued if entries by workers are missing from daily records, and it was impossible to quantity the time taken for work completed and the real cost of each health transaction. Time required for care delivery is particularly pertinent in populations where social disadvantage impacts engagement in healthcare. The extremely low fee-for-service invoiced to individuals for care compared to current VLCA practice funding[10] highlights problems with funding models and service sustainability. Together these data highlight factors that require consideration in future funding and resourcing arrangements. Further research is required to holistically examine the nature and intensity of this type of interprofessional work in culturally diverse high needs and other practices, the current funding received, the financial and workforce resourcing requirements and the health outcomes achieved.

COMPETING INTERESTS
Nadine Kuiper, Bryan Betty, Ioana Viliamu-Amusia, Linda Bryant and Erin Millar are practising clinicians at PUCHS. They contributed to the study design, data interpretation and review of the manuscript; however, they did not analyse the study data.

ACKNOWLEDGEMENTS
The authors thank Professor Tony Dowell and Associate Professor James Stanley for advice on study design. This study was funded by the Health Research Council (HRC 21/1008/A).

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Case of traumatic rupture of the pregnant uterus

NZMJ, 1923

By Archer Hosking, M.B.

The case here described occurred in the practice of *Dr. Johnston*, of Carterton, by whose consent I am enabled to publish the details of an uncommon condition.

Mrs. X., aged 35 years, a healthy woman, and mother of six children, was injured by the overturning of a motor car. She was struck violently over the right abdomen and her clothing torn off. She was at this time six months pregnant. She suffered from shock, and complained of pain on right side of abdomen, most marked in upper segment. She was driven 15 miles in a motor car to the nursing home: on arrival her clothing was found to be wet, and there followed a slight blood-stained discharge. P.V. the parts appeared normal. She rallied quickly, and in three days was feeling well except for pain under ribs on right side.

For 15 days her general condition improved. Temperature rose daily to 100deg. F. and pulse 100. On the 16th day temperature was 101 F. Feeble labour pains set in and os was softening. Under an anæsthetic *Dr. Johnston* dilated the cervix. She was given pituitrin, and, though irregular pains continued, there was no result. On 18th day there was some loss of blood with heavy odour, and temperature rose to 104deg.

I saw her in consultation, after pains had persisted over 48 hours. Her temperature was then 101deg. F. Examination showed dullness in right flank extending to the ribs. Under anæsthetic membranes were found protruding from a soft and easily dilated cervix. Placenta, low and detached, was removed, a foul smelling blood discharge following. The hand entered the uterus easily: A foetal leg was brought down, but the body resisted gentle traction. Exploration revealed head and body protruding through a rent in right side of uterus. There was no serious hæmorrhage, but patient showed signs of shock. A towel was packed in the cervix, and patient returned to bed, saline being injected with adrenalin. Two hours later, assisted by *Dr. Tweed*, and *Dr. Johnston* giving the anæsthetic, I opened the abdomen in the middle line. A much-macerated foetus was found completely outside the uterus except for one leg. It lay in a space formed by adherent bowel and omentum, and more or less walled off in right flank. It was easily removed after disentangling from its surroundings. Blood clot filled the right kidney pouch. The uterine tear extended from above the external os in front of the right broad ligament. A hand was easily passed to remove the packing towel from the cervix.

The patient's condition was now very serious and hysterectomy out of the question. Blood clot was cleaned up, and some adhesions being freed from the fundus, the uterus contracted fairly firmly. A drain was placed in flank to right kidney pouch. A long strip of gauze was introduced through the rent into the uterus, then in front of the broad ligament, and behind it into Douglas' pouch. This was brought up to the abdominal wall, and the wound partly closed, but leaving a free opening in the lower end for the gauze packing to come through. Patient returned to bed collapsed. She was given 1/2c.c. of pituitrin three-hourly for the next 24 hours. She rallied well. There was free discharge from vagina, and through gauze packing and tube to kidney pouch. On the fourth day after operation I removed the gauze pack. It was foul smelling but dry. A lesser quantity was replaced, drainage being quite satisfactory. After operation the temperature remained at about 103deg. F. for a week, gradually coming down till it reached normal at the end of a month. The patient made steady progress and a month later was attending to some of her household duties.