Equity is the new black—and black lives matter

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Politicians and Physicians
How is dementia portrayed in New Zealand newsprint media? Causes, effects and moral evaluation
Sarah Cullum, Rachael Simpson, Farzana Gounder

Dementia in New Zealand is expected to triple in the next 30 years at which point 170,000 people and their families will be affected. The media play an important role in not only disseminating information to the public but also shaping opinions and behaviours towards families living with dementia. We examined New Zealand’s three largest daily newspapers and found that dementia is still largely portrayed from a victimhood viewpoint. Up to 40% of dementia is potentially preventable and positive media representation could empower the public regarding attitudes towards dementia.

Patient characteristics and predictors of completion of a pulmonary rehabilitation programme in Auckland, New Zealand
Sarah Candy, Nicola Jepsen, Christin Coomarasamy, Jonathan Curry, Grace Dodson, Joe Pomelile, Mitchel Versey, Julie Reeve

Pulmonary rehabilitation (PR) for people living with a long-term respiratory illness is an effective intervention which can reduce symptoms and improve health-related quality of life. Despite the compelling evidence for this intervention, attendance and completion of PR worldwide is low. Our study identified predictors to completion of a PR programme in Counties Manukau, New Zealand. Being of an older age group, having a higher exercise capacity and of European ethnicity was found to be independent predictor of completion in this cohort. Future service improvements in the provision and delivery of PR programmes in New Zealand need to ensure we are providing accessible options for younger participants, supporting those with lower exercise tolerance and ensure services are engaging for all ethnicities.

A feasibility study investigating the impact of a dietitian-led low in fermentable oligosaccharide, disaccharide, monosaccharide and polyols diet group education programme with irritable bowel syndrome
Dorcas Chan, Paula Skidmore, Leigh O'Brien, Sally Watson, Richard Gearry

Many people have irritable bowel syndrome (abdominal pain with diarrhoea, constipation). Treatments are limited but a special diet called low FODMAP diet can help. Usually a dietitian needs to teach this one on one with the patient, but this study has shown that it is feasible to teach this in a group setting.

Are over-the-counter fish oil supplements safe, effective and accurate with labelling? Analysis of 10 New Zealand fish oil supplements
Julia J Rucklidge, Ian C Shaw

The study shows that 90% of the most popular fish oil supplements sold in New Zealand are true to label based on the stated capsule omega fatty acid content. All of the products studied indicated benefits across heart, brain and joint health. Based on studies published in scientific journals, 30% of the products would result in benefits across heart, brain and joint health when taken at the top dose recommended on the label. Mercury was not found in any of the samples analysed; therefore, even if some of the products might not confer health benefits at the recommended doses, they are all safe to consume.
Hui: a partnership in practice in familial hypercholesterolemia
Jocelyne Benetar, Tara Elville, Helen Wihongi, The Whanau
Genetic mutations causing very high cholesterol levels that lead to premature heart disease is
the most common genetic disorder and occurs in 1 in 250 people. The incidence in Māori is not
known and New Zealand has no systematic way of screening and managing these patients.
This paper describes a large whanau who have endured many tangihanga as a result of
premature heart disease caused by a gene mutation. It describes establishing a partnership
with whanau so they hold all the information on this disorder to empower all members,
ensuring appropriate screening and treatment no matter where they live.

Lessons from a system-wide response to a measles outbreak,
Canterbury, February–April 2019
Daniel Williams, Meik Dilcher, Hongfang Dong, Bridget Lester, Kerry Marshall,
Ramon Pink, Debbie Smith, Jimmy Wong
New Zealand is at ongoing risk of measles outbreaks, due to sub-optimal vaccination coverage.
Canterbury experienced a measles outbreak from February to April 2019. Canterbury's whole-
of-health-system response helped contain the outbreak to 38 cases. A systematic primary
care-based measles vaccination catch-up campaign could prevent future measles outbreaks.

Medication dispensing for attention-deficit/hyperactivity
disorder to New Zealand youth
Stephanie D’Souza, Nicholas Bowden, Sheree Gibb, Nichola Shackleton,
Richard Audas, Sarah Hetrick, Barry Taylor, Barry Milne
Over a 10-year period, medication dispensing prevalence for attention-deficit/hyperactivity
disorder (ADHD) almost doubled in young New Zealanders aged 1–24 years. Medication was
more common in males and in those between 7–17 years old. Strong socioeconomic differ-
cences in medication were not apparent when looking at the youth population as a whole but
were more noticeable within specific ethnic groups, with different patterns observed across
ethnic groups. Dispensing prevalence increased as area deprivation level increased in Euro-
peans only, but the opposite trend was generally apparent in Pasifika youth. These results
suggest that healthcare disparities may exist within certain ethnic groups.

Knowledge and perspectives about the use of cannabis as a
medicine: a mixed methods observational study in a cohort of
New Zealand general practice patients
Karen Oldfield, Allie Eathorne, Ingrid Maijers, Richard Beasley, Alex Semprini,
Irene Braithwaite
This study explored what a group of GP patients knew and had experienced regarding the use
of cannabis as a medicine. The majority of patients reported being comfortable discussing
medicinal cannabis use with their doctors and were willing to use prescribed medicinal
cannabis products. When considering their own medical conditions, just under half thought
that medicinal cannabis may be helpful; primarily for pain relief. Few patients had talked to
their doctors regarding medicinal cannabis use. Patients have expressed that they would like
information about medicinal cannabis from their doctors that is in keeping with what would
be conveyed regarding regular prescribed medications.
Why dizziness is likely to increase the risk of cognitive dysfunction and dementia in elderly adults

Paul F Smith

Dizziness related to inner ear dysfunction of the balance organs (the ‘vestibular system’) causes memory impairment, independently of hearing loss, by disrupting the function of neurons in brain regions responsible for remembering places in the environment. It is therefore possible that dizziness related to vestibular dysfunction increases the risk of dementia, including Alzheimer’s disease. Vestibular rehabilitation, a non-invasive form of exercise, may reduce the risk of dementia.

A pragmatic diagnostic approach to myocardial infarction with non-obstructive coronary arteries

Ammar J Alsamarrai, Jocelyne R Benatar, Eun Soo Chung, Jithendra B Somaratne

A heart attack is usually caused by a blockage in the arteries that supply the heart. However, some people who suffer a heart attack have rather normal looking heart arteries. In these cases, it can be difficult to figure out what caused the heart attack. We propose a simplified algorithm (originally designed by the American Heart Association) to help heart specialists decide which tests to do in patients with heart attacks and normal looking heart arteries.

The assessment of testamentary capacity

Jane Casey, Anthony Grant

People are living longer with chronic medical conditions including cognitive impairment and with increased wealth. Recent New Zealand Court decisions will likely result in more demand for contemporaneous medical assessments of the capacity to make a will. This paper outlines the clinical assessment and the legal test. Careful assessments could protect the older adult and minimise the risk of a contested will after death.

Computers, confounding, clusters, consent, cost, COVID and consultation: how the Health and Disability Code impedes the learning health system

Mark Webster, Ralph Stewart

The Health and Disability Code, resulting from the Cartwright Inquiry and protecting patient rights, precludes any research without participant consent. Comparative effectiveness studies—a cornerstone of the learning health system—compare well-established drugs/procedures/practices used for the same condition. Randomisation is the only way to ensure that the comparison is reliable. Some comparative effectiveness studies cannot practicably be undertaken with participant consent. The Code needs carefully considered updating, to improve patient healthcare delivery.
Management of personal protective equipment in New Zealand during the COVID-19 pandemic: report from the Auditor-General

Elizabeth Fenton

In June 2020 the Office of the Auditor-General released its report on the management of personal protective equipment (PPE) in New Zealand during the COVID-19 pandemic. This viewpoint article addresses three issues of ethical concern raised in the report: inadequate stock, inequity and complacency. It highlights the importance of healthcare worker trust in the institutions they work for, and investment in a robust public health system. Acting on the report's recommendations is a critical step in strengthening New Zealand's preparedness for future public health crises.

New Zealand doctors and euthanasia—legal and practical considerations of the End of Life Choice Act

Bruce CH Tsai, David B Menkes

New Zealanders will be voting on the End of Life Choice Act in the upcoming referendum in October. This paper examines what this would mean for doctors, patients and families based on experience in countries where euthanasia is already legal. By putting the New Zealand Act in context and comparing it with legal frameworks overseas, we identify what doctors and others need to know. We also highlight issues that still need to be worked through and clarified to ensure that end-of-life choices are informed, settled and free from coercion, and provide examples that may assist determination of this.

A model respiratory personal protective programme for the New Zealand healthcare industry

Chris Walls, Geraint Emrys, Siobhan Gavaghan, Des Gorman, David McBride, Dave McLean

In the absence of advice from the workplace regulator these Doctors with workplace experience in healthcare offer a model respiratory protection programme for healthcare institutions to consider and adapt to their requirements.
Could comprehensive cancer centres improve cancer outcomes and equity in New Zealand?

Frank Frizelle, Murray Brennan

In the midst of the present Covid pandemic it is easy to forget that we have an ongoing cancer pandemic that will not be ameliorated by a generic vaccine. Globally, based on 2013–2015 data approximately 40% of men and women will be diagnosed with cancer during their lifetime, meaning that most of us can be expected to be affected by cancer, either directly or indirectly.1

In New Zealand, cancer is now the leading cause of death, with cancer deaths making up 30.2% of all deaths, ischaemic heart disease 15.8% and cerebrovascular disease 7.8% in 2015.2 More people are developing cancer in New Zealand, mainly because the population is growing and ageing. In 2016, 24,086 people in New Zealand were diagnosed with cancer; an increase of 21% since 2007.3 By 2040, the number of cancer diagnoses is predicted to double to around 52,000, or 142 people a day.1 The cancer burden is not evenly distributed in any community with a disproportional effect on indigenous people and those on lower incomes. In New Zealand, Māori are 20% more likely to get cancer than non-Māori, and nearly twice as likely as non-Māori to die from cancer.5

Internationally, survival trends for cancer are generally improving, with New Zealand’s five-year survival rates, similar to those of the US, Canada, Australia, Finland, Iceland, Norway and Sweden.7 New Zealand does have a lower cancer survival compared to our neighbour Australia, and this difference is increasing.8,9 For example, Australia showed significant improvements (6% in men, 3% in women) in comparing the periods 2000–05 and 2006–10, while New Zealand had only a 1.8% increase in cancer survival.

Figure 1: Provisional New Zealand cancer mortality rates, 2016, selected cancers, Māori vs non-Māori, non-Pacific.6
survival in men and 1.3% in women. The five-year survival rates for these common cancers for Australia and New Zealand are, respectively: colorectal: 70.9% (Australia), 65% (New Zealand); lung: 19.4%, 15.3%; breast (women) 89.5%, 87.6%; prostate: 94.5%, 90.3% and melanoma: 92.9%, 91.8%, from 2000–05 to 2006–2010. Differences in cancer survival trends are thought most likely to, due to healthcare-related factors such as early diagnosis and optimum treatment. This demonstrates that our survival rates from cancer are now falling behind those of our comparable countries and has not been improving at the same rate as elsewhere. The impact as measured by disability adjusted life years lost by cancer is illustrated below.

Figure 2: Provisional New Zealand cancer registration rates, 2017, selected cancers, Pacific vs non-Pacific, non-Māori.

Figure 3: Age-standardised disability-adjusted life years lost per 100,000, all neoplasms, both sexes, selected countries, 1990–2016.
In response to the increasing demand for cancer treatment, the Ministry of Health has developed the New Zealand Cancer Action Plan 2019–2029 to provide a pathway to improve cancer outcomes. On 1 December 2019, the Government launched the Cancer Control Agency (Te Aho o Te Kahu) to lead the implementation of this plan. Key priorities for the agency include providing accountability, coordination of various agencies involved in cancer, and working to implement the Cancer Action Plan. Te Aho o Te Kahu has been charged with working closely with people impacted by cancer, including their whānau and healthcare professionals, as well as with Māori and Pacific leaders to ensure that they inform them on how best engage with them to meet their needs.

The New Zealand Cancer Action Plan 2019–2029 sets out the four main goals required over the next 10 years to ensure better cancer outcomes:

• New Zealanders have a system that delivers consistent and modern cancer care
• New Zealanders experience equitable cancer outcomes
• New Zealanders have fewer cancers
• New Zealanders have better cancer survival, supportive care and end-of-life care.

This plan has a strong focus on achieving equity of outcomes and contributing to wellness for all, and recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes. The plan states that it is guided by four overarching principles:

• Equity-led
• Knowledge-driven
• Outcomes-focused
• Person and whānau-centred.

Given that Māori have the poorest overall health status in New Zealand, have higher rates of most cancer and worse outcomes for most stages than others and are significantly disadvantaged in terms of health inequities, it is essential that we ensure the rights and meet the needs of Māori people; new approaches to the diagnosis and delivery of cancer care is needed to be considered with the integration of research and especially clinical trials into clinical practice in a manner that promotes support. Māori involvement at all levels is critical to improving the cancer outcomes for all New Zealanders.

The present model has led us to where we are today and continuing the delivery care in the same model will likely keep the disparity in outcomes growing. A change, not just in philosophy (which we have seen) but in the model we use to deliver care is required. The integration of clinical practice and research is well established as providing better outcomes across a range of outcome measures, including survival with comprehensive cancers centres across the world.

The Comprehensive Cancer Centre (CCC) model, initially established by the US Government was developed to improve cancer outcomes. A hallmark of a CCC— comprehensive and multidisciplinary care—means that specialists from different medical disciplines collaborate to plan, evaluate and deliver accurate cancer-specific diagnosis treatment, with integration of basic and clinic research pushing to improve outcomes. CCCs are places of excellence for cancer management and have now been adopted at least in part in most developed countries. In the UK The Maggie cancer centres have developed as a charity independent of the NHS, yet linked to the provision of care to provide the support and care needed to help patients with cancer. This culturally appropriate integration of comprehensive multidisciplinary clinical care, research and psychosocial support is a model that may meet the needs of New Zealand to achieve its cancer outcome goals and help close both the outcome and the equity gap.

Below, New Zealand’s most famous cancer surgeon (Professor Sir Murray Brennan) tells his perspective of working in such a centre and how this might work in New Zealand.

From a New York perspective

I have spent almost 40 years at one of the most visible cancer centres in the world, Memorial Sloan Kettering Cancer Center in New York City. If I did not believe in the mission, the achievements and the relevance, I would never have stayed.
In the 1880s, J Marion Sims was the person who originally proposed the idea of a cancer centre in New York City: “...a cancer hospital (should be built) on its own foundation, wholly independent of all other hospitals... Its medical board ought to be men who go in to it with zeal, determined not only to give temporary relief to human suffering, but to do something toward discovering better methods for treatment...”

A visionary, Sims’ interest grew from the difficulty of women with gynaecological cancer to be treated in general hospitals in the mid-to-late 19th century. No paragon, Sims was a controversial figure having left New York at the time of the American Civil War to avoid fighting for his home in the North or his birthplace in Alabama. Imminently successful in Europe, he returned to New York with zeal for his work. President of the American Medical Association, he was honored by his peers and a statue erected in his name in Central Park. This statue was recently removed as it represented a symbol of a man who performed surgery on African American slaves in the 1840s without consent and in the absence of anaesthesia—a conflicting story of competing ethics.

Sims died in 1883 aged 70, before the Memorial Hospital was opened in 1884 with benefaction from the rich and famous of the day, including John Jacob Astor III and his wife Charlotte, Elizabeth H Cullum, John E Parsons and other prominent New Yorkers.

But what has happened in the 136 years since the opening of what is now MSKCC? The buildings and the staff have proliferated across the upper East Side and on out to the suburbs, with a total staff approaching 20,000 with 1,000 volunteers, and an education programme that embraces almost 2,000 residents and clinical fellows, and an operating revenue which would have reached $5 billion in 2020 had not COVID-19 brought that to a halt or at least a slow walk.

Across the US there are 71 cancer centres, 51 comprehensive, 13 clinical and seven basic—a cancer centre for every 2.5 million people, a comprehensive centre for every six million people. Australia has an admirable institute built on clinical care—the Peter MacCallum Cancer Centre. Founded by Peter MacCallum, a Scottish-born oncologist raised in childhood by his New Zealand father in Christchurch! One might conjecture it was the relative ill health of Peter MacCallum from exposure to nitrogen mustard gas in 1918 that led him to a career in research and pathology. Ironically, it was nitrogen mustard that was the first cancer therapeutic used in the management of leukaemia and lymphoma because of its hematopoietic toxicity.

What are the real and potential benefits of such a disease-specific focus? The original mission of excellence in clinical care, research and education are embodied in the MSK logo—Research, Treatment, Education. For MSK this statement has been recently modified to read “To lead in the prevention, diagnosis, treatment, and cure of cancer through programs of excellence in research, education, outreach, and cost-effective patient care” to reflect and address the socioeconomic problems of healthcare in the US.

The pyramidal building of a cancer centre begins with integrated patient care, integrated from diagnosis to demise. Few appreciate how difficult it is to embrace the idea that cancer is not one but a myriad of diseases. When asked how many cancer types there are, I answer obliquely that “one day there will be as many different cancers as there are different people with cancer.” With rapid evolution and characterisation of the human genome we know the genetic variation that calls us each a person. With molecular diagnosis we know, at least in part, the ever-evolving genetic definition of each cancer, and as we put your cancer into you, we have that unique identifier. But that demands a high degree of research which, you will say, belongs in the basic labs of any university or research facility. I would argue that that challenge can be admirably met by juxta-positioning the patient and the science in the one place. “Know then thyself, presume not God to scan; The proper study of mankind is man.”

Again, that is no reason for a cancer centre alone. Any competent clinical facility with a translational research arm can do that. In many places that is how an institution, clinic, hospital or university division begins and evolves into a designated cancer centre.

Outcomes for cancer patients treated at varying sites have been long studied. A multitude of studies have demonstrated that for surgical outcomes, volume, especially for
complex cancers, improves with centralisation.\textsuperscript{13,14} Not all cancer patients will benefit from referral centres; such a concentration is neither necessary nor realistic. We are in the process of deciding how many is enough for complex cancers to get results comparable to those best available.

But do cancer centres deliver better comprehensive cancer care, better long-term survival outcomes?

It is now clear that not only short-term but long-term survival can be improved if patients are treated from diagnosis at focused referral cancer centres.\textsuperscript{15,16}

And what of the benefits in research and education? Research, both clinical and basic, are integral to any progress in the management of the cancer patient. Without a fundamental understanding of the etiology, initiation, progression and the metastatic process, ultimate control and cure is impossible.

New Zealand has a remarkable resource in their National Health Care data bases. The utilisation of such a data base is a potential rich source for identifying variations in the delivery of healthcare by variables such as site, race and ethnicity. As in other societies, the use of such data is often limited not by the value of the information but by the political ramifications of transparency.

The newly formed New Zealand National Cancer Programme is focused on “access to high quality screening and care”. Without access to screening and early diagnosis for potential cure it is hard to improve cancer outcomes for all citizens. The focus by the New Zealand National Cancer Programme on regional networks would allow such screening programmes to translate to expedited timely care. While many cancer centres do focus on screening, the majority do not, as that is better left to the community with selective referral to regional centres, reserving complex and less common cancers to be referred to a comprehensive cancer centre. Despite not having the benefit of screening programmes, cancer centres do have better short- and long-term outcomes, corrected for all stages.

Cancer centres cannot survive only on integrated cancer care; they must provide innovation and progress. That cannot occur without sound basic and translational research and opportunities to educate the brightest and the best.

The rapid adoption of telemedicine brought about by the Covid-19 pandemic has opened a new opportunity for cancer centres. Clinical trials and clinical research are no longer necessarily confined to cancer centres. It is progressively clear that the former mandatory relocation to a centre to participate in a clinical trial may not be necessary. With telehealth, clinical trial oversight will allow trials to be extended with remote patient participation. That requires a centralised cancer centre infrastructure but could portent an option for New Zealand to participate and initiate clinical trials on a national and international platform.

Financing of all cancer centres is a challenge. The Peter MacCallum is Australia’s only public hospital dedicated to cancer care. In the US, cancer centres rely predominately on revenue from patient care, albeit often private insurance rather than federal support by programmes such as Medicare and Medicaid. All centres rely on philanthropic and competitive grant support to advance their research mission. This is different from what I understand of the New Zealand health system; however, support from research grants and healthcare are not that different. When I look at our own financial base, with a $4.9 billion operating revenue, 80% is derived from patient care revenue, 7% from grants and contracts, 12% from contributions, investment income and royalties.

So, is it time for New Zealand to consider a national cancer centre? The building blocks of the new cancer programme would suggest that could be the next step. No doubt there are unique challenges in New Zealand that I have not appreciated. However, great the challenges, the benefits for the cancer patient, the physicians, the research scientists and the public are real.
Competing interests:
Nil.

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Health equity matters: it is the right thing to do and the rights thing to do. It is of significance that all main political parties during election campaigning have indicated the importance of health equity as a necessary measure of success of our health system. Along with the recent Heather Simpson Health & Disability System Review, there now appears to be a societal consensus that equitable healthcare is a must.

Given we Kiwis like to think of ourselves as fair-minded, and equity is—at its heart—about fairness, this is perhaps not surprising. Although this is an encouraging place to find ourselves, saying something is important and then actually achieving it are quite different end-points. We must all do what we can within our personal and professional spheres of influence to ensure equity becomes reality.

Late last year the Medical Council of New Zealand (Council), in partnership with Te Ohu Rata O Aotearoa (Te ORA), released its Statement on Cultural Safety and He Ara Hauora Māori: A Pathway to Māori Health Equity. These statements set Council’s expectations of doctors and healthcare organisations in the delivery of culturally safe practice. In Aotearoa New Zealand, cultural safety is key to achieving equitable health outcomes for Māori—a right under Te Tiriti o Waitangi.

The move away from only the ‘cultural competence’ of the doctor, towards achieving ‘cultural safety’ for patients is deliberate and indicates a shift in thinking away from acquiring knowledge about the ‘other’, towards a focus on how patients receive their care. Research shows that simply learning about another’s culture does not result in positive change or improved health outcomes.

Doctors (and other health professionals, and indeed the health system at large) have moral and professional obligations to strive for health equity in our practice. In order to do so, we need to understand the contributing factors to health inequity and our role in it.

The New Zealand Medical Council has just released an independent report on the state of cultural safety and health equity relating to doctors practicing in Aotearoa New Zealand and patients receiving care. The Report places Māori patients’ experiences front and centre; however, many of the challenges and solutions are applicable to other communities and populations who experience inequitable healthcare.

Findings from the Report show there is a strong need to acknowledge the systemic racism and privilege that prevails in the health sector. Doctors must reflect on their own cultural views and biases as a first step, then work to influence and support the places they work in and those they interact with, to improve how patients receive their care. Examples of racist beliefs and practices that proliferate in the health system were discussed in the last NZMJ editorial, and show there is considerable work to be done.

Significant structural barriers are also shown to impact patient care and cultural safety. These include short appointment times and a focus on only the immediate presenting needs, which limits the ability...
to build relationships and partner with patients and whānau.

Many patients and whānau feel disempowered, that their knowledge is underestimated, and that they are not involved in decision-making. This can lead to whānau feeling distanced from both the doctor and healthcare team, and from their own health. One of the intended outcomes of the Ministry of Health’s Whakamaua: Māori Health Action Plan 2020-2025 is that iwi, hapū, whānau and Māori communities can exercise their authority to improve their health and wellbeing. This is an important focus for collective action.

The Health and Disability System Review found that “improving equity and wellbeing for Māori requires immediate improvements in the way the system delivers for Māori, a growth in the range and distribution of kaupapa Māori services, enhancements to rangatiratanga and mana motuhake”, and our findings support this. We need a diverse, culturally safe health workforce which reflects the communities we serve. This begins through selection into medical school, and continues through the training continuum to vocational specialisation.

Māori doctors often experience additional cultural demands on top of their day-to-day work. There is little evidence that such cultural activities and training of others is acknowledged and recognised in job descriptions or as a key element of professional development. Council is working with our partners to better support the Māori health and disability workforce and increase Māori leadership and participation in governance and decision making. Where representation is low, it requires being bold and courageous when highlighting issues for Māori.

There is overwhelming evidence of inequities in health outcomes for Māori—you need look no further than the previous issue of NZMJ or the Wai 2575 Māori Health Trends Report. COVID-19 also presents a concern for the likely disproportionate impact on Māori.

Council encourages all doctors, employers, training and professional organisations to consider the findings in the cultural safety Report, draw on the data, and use this as a basis for achieving long-term, positive change for the benefit of all patients and whānau.

While the Report offers an insight into current practice, it is only the first step on a long journey. It sets a baseline for ourselves and our stakeholders to use when developing programmes, strategies and policies that support us to drive change.

We are already seeing excellent work from the Medical Schools in selecting for medical workforce diversity, and the next generation of physicians in training will be “equity natives”. The specialist medical colleges, here and in Australia have Indigenous health and health equity embedded in their training and recertification programmes. Cultural safety training is increasingly (but far from universally) available, as is education on Te Tiriti within workplaces such as district health boards.

In exerting ourselves to success, we are reminded of the words of Tā Mason Durie, Māori doctor and academic, who writes “The potential within the Māori population has never been greater ... the potential to face the future with both the freshness of youth and the wisdom of age”. We should also be encouraged by the well-known whakatauki or tauparapara of Tā James Henare “Kua tāwhiti kē to haerenga mai, kia kore e haere tonu. He nui rawa o mahi, kia kore e mahi tonu”.

Council encourages all doctors, employers, training and professional organisations to consider the findings in the cultural safety Report, draw on the data, and use this as a basis for achieving long-term, positive change for the benefit of all patients and whānau.
Competing interests:
Nil.

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REFERENCES:


How is dementia portrayed in New Zealand newsprint media? Causes, effects and moral evaluation
Sarah Cullum, Rachael Simpson, Farzana Gounder

ABSTRACT
AIMS: To evaluate how New Zealand newsprint media shapes discourse about dementia through its framing of the causes, effects and solutions, and who bears responsibility for the disease.

METHODS: Using New Zealand’s three largest daily newspapers, we examined i) the coverage of dementia between 2012–2016, ii) the framing of causes and effects of dementia, and iii) the most frequent associations of causes and effects of dementia. We integrated the findings to assess the moral evaluation of dementia in New Zealand newsprint media.

RESULTS: Of the 361 articles extracted all presented effects of dementia, 35% discussed causes and 7% mentioned solutions for dementia. Medical causes dominated over health behavioural and societal causes, and effects were mostly the negative impact on the individual, family and society. Modifiable medical causes were more likely to be associated with adverse outcomes for society whereas non-modifiable medical causes were more likely to be associated with adverse outcomes for the individual and/or their family.

CONCLUSIONS: Between 2012–16 New Zealand newsprint media largely portrayed dementia from a ‘powerless victim’ frame. Further research is required to assess whether, since 2016, there has been a shift towards media framing of dementia as potentially preventable and a social justice issue.

As the world’s population ages, dementia is increasingly recognised as a global public health priority. There are estimated to be approximately 50 million people worldwide currently living with dementia and this is projected to reach 150 million by 2050. The prevalence in New Zealand is currently estimated to be around 70,000 and expected to reach 170,000 by 2050. As a public health challenge, dementia requires a public health response and a major element of this response are mass media campaigns that raise public awareness and understanding about dementia. The media play an important role in not only disseminating information to the public but also shaping opinions and behaviours towards families living with dementia.

For many years dementia has been viewed as a disease driven by genetics and aging, factors over which people have no control. However, recent research indicates that approximately 35% of late-onset dementia can be attributed to modifiable risk factors, including education, midlife hypertension, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking and social isolation, whereas non-modifiable genetic risk factors, such as inheritance of the apolipoprotein E4 allele account for very little of the overall risk. Many of these risk factors are highly determined by individual health behaviours, which, if controlled, may mitigate or delay the onset of dementia. Dementia is also increasingly being presented as a social justice issue, as its rapid increase in prevalence, particularly in low and middle income countries, has an associated economic impact on families and society in general. Thus societal solutions for dementia may also start to be considered in the media. The
power of media on health perceptions and outcomes in these areas is important, not only as a potential influence on our health behaviours and the chances of developing dementia, but also how we choose to attempt to address the societal challenges ahead.

The media selects which health issues and perspectives are given prominence, thus playing an essential role in the public’s consideration of the importance of health issues. This also shapes consideration of how problems at individual and public policy levels should be resolved. Media frames are a method of selecting salient information regarding health issues and creating pathways to think about the issue’s news value in terms of causality, effects and solutions. Frames define a problem, suggest causality and consequences of the issue, and provide solutions. Through these perspectives, frames can influence the public, and policy-makers, on how to respond to health issues.

Frames are a cultural construct and thus moral evaluations come into play when considering the responsibility attributions of causality and effects. When causality for an issue is attributed to individuals’ behaviours, the solution is also seen as the responsibility of those same individuals. Likewise, when causality is attributed to societal factors, the solution lies in the modification of social determinants. For instance, Iyengar10 analysed audience attributions of causal responsibility for poverty and found that when the audience was exposed to more individualised media frames depicting individuals living in poverty, the audience assigned responsibility to those people as being the cause of their poverty. However, when the audience was exposed to more societal media frames, the audience assigned responsibility for poverty to society rather than the individuals. Iyengar’s study demonstrates how audience attributions, shaped through media framing, influences political opinions and ideas. As a result, media framing of responsibility has powerful implications beyond purely the definition of the problem.

Research into dementia representation in media discourse is relatively sparse when compared to other public health issues such as cancer, obesity and HIV. While dementia coverage is positive in certain areas, such as sympathetic photographic depictions of people living with dementia,11 overall the literature suggests that the prevailing image of dementia in media is pessimistic, created through substantially negative frames, with an emphasis on stereotypically ageist depictions,12 but attribution of responsibility for the disorder has rarely been addressed.

The aim of our research is to evaluate how New Zealand newsprint media shapes discourse about dementia through its framing of the causes, effects and solutions, and who bears responsibility for the disease. We investigate this through examining i) the coverage of dementia between 2012–2016; ii) the framing of specific causes and effects of dementia; and iii) the association between specific causes and effects of dementia. Integrating the findings of the above three research questions, we discuss the moral evaluation of dementia through the lens of New Zealand newsprint media.

Methods

The study analyses dementia discourse across New Zealand’s three largest metropolitan daily newspapers: The New Zealand Herald, The Dominion Post and The Press between 1 January 2012 to 31 December 2016. Readership for the 2016 period were as follows: 423,000 for The New Zealand Herald, 159,000 for The Dominion Post and 157,000 for The Press. Our inclusion of the three newspapers takes into consideration geographical readership coverage: The New Zealand Herald is published in Auckland and has its largest audience-base in the upper North Island, The Dominion Post, published in Wellington, has highest readership in the lower North Island, while The Press, published in Christchurch, is the leading newspaper in the South Island.

Data extraction

We used ‘dementia’ as a search term on the academic database Newztext. Articles were restricted to those that were at least 150 words, in order to ensure articles were of sufficient length to develop themes and responsibility discussions. Articles that fell outside these criteria were: letters to the editor, advertisements, events, obituaries, duplicates within the newspaper, reports that were not about dementia in humans (as in articles discussing animal dementia) and items that mentioned dementia in passing.
Data analysis

We conducted the research in three phases of content analysis. We firstly developed thematic codes and their attributed reasoning devices of cause, effect and solution. Using Ward's hierarchical clustering, we distributed codes under thematic categories. We categorised the thematic codes under the three generic frames identified as being the dominant theme in the health discourse: medical, health behavioural and societal. For each article, we also identified the dominant theme mentioned as a cause, effect or solution, and we marked it as being present once per document under that attribution regardless of how many times the theme and its associated reasoning device was reiterated within the article.

Once we had exhausted all possible codes within the cohort of news stories and the wider literature, we then developed and implemented the coding matrix. The coding matrix consisted of cause, effect and solution along the y-axis and medical, health behavioural and societal frames along the x-axis (see Table 1), similar to that recently developed for the framing of diabetes.

---

Table 1: Coding matrix for framing of dementia by New Zealand newsprint media.

<table>
<thead>
<tr>
<th>Causes</th>
<th>Medical</th>
<th>Health behavioural</th>
<th>Societal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-modifiable:</td>
<td>Personal attitudes:</td>
<td>Personal attitudes to dementia</td>
<td>National level:</td>
</tr>
<tr>
<td>Biological aging</td>
<td>Personal attitudes</td>
<td>Personal beliefs about dementia</td>
<td>Laws and policies</td>
</tr>
<tr>
<td>Genetic predisposition</td>
<td>Personal knowledge about dementia</td>
<td>Government initiatives</td>
<td></td>
</tr>
<tr>
<td>Amyloid plaques and proteins</td>
<td>Lifestyle factors:</td>
<td>National higher education access</td>
<td></td>
</tr>
<tr>
<td>Traumatic brain injury:</td>
<td>Health behaviours</td>
<td>Local level:</td>
<td></td>
</tr>
<tr>
<td>Head trauma</td>
<td>Diet</td>
<td>Workplace factors</td>
<td></td>
</tr>
<tr>
<td>Concussion</td>
<td>Lack of exercise</td>
<td>Healthcare resources</td>
<td></td>
</tr>
<tr>
<td>Modifiable risk factors:</td>
<td>Recreational drug use</td>
<td>Geographical determinants</td>
<td></td>
</tr>
<tr>
<td>Hearing loss</td>
<td>Alcohol consumption</td>
<td>Socioeconomic determinants</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular risk factors</td>
<td>Smoking</td>
<td>Access to higher education</td>
<td></td>
</tr>
<tr>
<td>Obesity</td>
<td>Inadequate sleep</td>
<td>Community-based:</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Unhealthy lifestyle</td>
<td>Community-based activities</td>
<td></td>
</tr>
<tr>
<td>Vitamin deficiencies</td>
<td></td>
<td>Community-level beliefs</td>
<td></td>
</tr>
<tr>
<td>Thyroid abnormalities</td>
<td></td>
<td>Social networks’ influence on</td>
<td></td>
</tr>
<tr>
<td>Medication side-effects</td>
<td></td>
<td>behaviours and attitudes</td>
<td></td>
</tr>
<tr>
<td>Effects</td>
<td>Physical impairments:</td>
<td>Quality of life:</td>
<td>National level:</td>
</tr>
<tr>
<td>Slower gait</td>
<td>Ability to self-care</td>
<td>Laws and policies</td>
<td></td>
</tr>
<tr>
<td>Poorer balance</td>
<td>Loneliness</td>
<td>National economy</td>
<td></td>
</tr>
<tr>
<td>Lower coordination</td>
<td>Conducting daily activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weaker muscles</td>
<td></td>
<td>Local level resources:</td>
<td></td>
</tr>
<tr>
<td>Cognitive impairment:</td>
<td>Behavioural changes:</td>
<td>Workforce</td>
<td></td>
</tr>
<tr>
<td>Memory loss</td>
<td>Recklessness</td>
<td>Healthcare resources</td>
<td></td>
</tr>
<tr>
<td>Confusion and wandering</td>
<td>Aggression</td>
<td>Residential care resources</td>
<td></td>
</tr>
<tr>
<td>Word-finding difficulties</td>
<td>Mood swings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personality changes</td>
<td>Depression</td>
<td>Community response:</td>
<td></td>
</tr>
<tr>
<td>Death</td>
<td></td>
<td>Physical abuse and neglect</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Financial abuse</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social ties within family</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family caregiver burnout/stress</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reduced finances of family</td>
<td></td>
</tr>
</tbody>
</table>
Finally, we used measures of association to examine the foremost cause-effect relationships within dementia discourse in New Zealand newsprint media.

We used MAXQDA Analytics Pro for the qualitative coding scheme development and content analysis, and its statistics module for statistical analysis to make inferences about measures of association between cause and effect themes.

**Intercoder reliability**

Two of the authors (FG, RS) independently coded 75 articles (20%) to assess inter-coder reliability. An acceptable level of agreement for Krippendorff’s $\alpha$ is $\alpha=0.8$ (Krippendorff, 2004:241). Our study achieved $\alpha=0.851$ across all codings. For each of the three frames, alpha scores were similar: medical frame $\alpha=0.881$, societal frame $\alpha=0.861$, and behavioural frame $\alpha=0.874$.

**Results**

**Framing of dementia in New Zealand newsprint media (2012–2016)**

Using the word ‘dementia’ as a search term on the academic database Newztext resulted in a total of 800 articles: 242 articles from *The New Zealand Herald*, 285 articles from *The Press* and 273 articles from *The Dominion Post*. 439 articles did not meet the inclusion criteria; 361 articles were included in the study. All 361 articles presented the effects of dementia, 35% discussed causes and 7% mentioned solutions for dementia.

Table 2 presents the frequency of media framing for the years 2012–16 and shows an increase in coverage over that time period.

Table 3 presents the causes and effects of dementia as reported through medical, national, local, and community-based levels.

<table>
<thead>
<tr>
<th>Solutions</th>
<th>Medication</th>
<th>Health behavioural prevention:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical advancements</td>
<td>Personal attitudes to dementia</td>
<td>Personal beliefs about dementia</td>
</tr>
<tr>
<td></td>
<td>Personal knowledge about dementia</td>
<td>Health behaviours</td>
</tr>
<tr>
<td></td>
<td>Health diet</td>
<td>Adequate exercise</td>
</tr>
<tr>
<td></td>
<td>Adequate sleep</td>
<td>Healthy lifestyle</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>National level:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laws and policies</td>
</tr>
<tr>
<td>Government initiatives</td>
</tr>
<tr>
<td>National higher education access</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Local level:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workforce</td>
</tr>
<tr>
<td>Healthcare resources</td>
</tr>
<tr>
<td>Support for caregivers</td>
</tr>
<tr>
<td>Housing requirements</td>
</tr>
<tr>
<td>Residential care</td>
</tr>
<tr>
<td>Socio-economic determinants</td>
</tr>
<tr>
<td>Access to higher education</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community-based:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based activities</td>
</tr>
<tr>
<td>Community-level beliefs</td>
</tr>
<tr>
<td>Social networks’ influence</td>
</tr>
<tr>
<td>Caregivers’ responses</td>
</tr>
<tr>
<td>Family responses</td>
</tr>
<tr>
<td>Formal carers’ responses</td>
</tr>
<tr>
<td>Social networks’ response</td>
</tr>
</tbody>
</table>

Table 1: Coding matrix for framing of dementia by New Zealand newsprint media (continued).
behavioural and societal frames in New Zealand newsprint media. As solutions were rarely presented (7%) and mostly described existing medication or potential medical advances available for dementia, these were not included in the table.

Framing the causes of dementia
Framing of causality mostly used the medical frame (83%). Within medical framing, 72% of the topics discussed were potentially modifiable causes of dementia (rugby-related head trauma and concussion, hearing loss, medication use, cardiovascular risk factors and obesity), but only nine percent of medical causes were presented as a result of lifestyle or health behaviour. One quarter of medical frames were attributed to non-modifiable causes such as biological ageing and genetic factors, and eight percent identified societal causes of dementia, for example the impact of air pollution or aluminium in the water supply.

Framing the effects of dementia
The framing of the effects of dementia were mainly represented by the societal frame (n=196, 54%). Within this frame, 70% of articles reported the adverse societal consequences of living with dementia, such as potential financial abuse, physical abuse and neglect, the effect on family relationships and caregivers’ stress and burnout. The remaining 30% in the societal frame addressed dementia’s impact on society including health and social care resources, the national economy, workforce, laws and policies.

The medical frame for effects of dementia was the second most utilised (n=119, 33%). As with the societal frame, the emphasis was on living with dementia. Within the medical frame, articles were more likely to identify dementia’s cognitive impact including memory loss, confusion and wandering, word-finding difficulties and personality changes.

<table>
<thead>
<tr>
<th>FRAMES</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAUSE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>10</td>
<td>15</td>
<td>9</td>
<td>22</td>
<td>50</td>
<td>105</td>
</tr>
<tr>
<td>Health behaviour</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Societal</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>19</td>
<td>11</td>
<td>26</td>
<td>55</td>
<td>127</td>
</tr>
<tr>
<td>EFFECTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>19</td>
<td>11</td>
<td>9</td>
<td>23</td>
<td>57</td>
<td>119</td>
</tr>
<tr>
<td>Health behaviour</td>
<td>10</td>
<td>8</td>
<td>6</td>
<td>10</td>
<td>12</td>
<td>46</td>
</tr>
<tr>
<td>Societal</td>
<td>41</td>
<td>35</td>
<td>29</td>
<td>45</td>
<td>46</td>
<td>196</td>
</tr>
<tr>
<td>Total</td>
<td>70</td>
<td>54</td>
<td>44</td>
<td>78</td>
<td>115</td>
<td>361</td>
</tr>
<tr>
<td>SOLUTION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Health behaviour</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Societal</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>8</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>90</td>
<td>75</td>
<td>57</td>
<td>112</td>
<td>179</td>
<td>513</td>
</tr>
</tbody>
</table>
Table 3: Causes and effects of dementia via medical, behavioural and societal frames in New Zealand newsprint media.

<table>
<thead>
<tr>
<th>Causes mentioned in news articles</th>
<th>N</th>
<th>%</th>
<th>Effects mentioned in news articles</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical frame</td>
<td>105</td>
<td>83%</td>
<td>Medical frame</td>
<td>119</td>
<td>33%</td>
</tr>
<tr>
<td>Non-modifiable:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic predisposition</td>
<td>14</td>
<td>11%</td>
<td>Memory loss</td>
<td>40</td>
<td>11%</td>
</tr>
<tr>
<td>Biological aging</td>
<td>13</td>
<td>10%</td>
<td>Confusion and wandering</td>
<td>33</td>
<td>9%</td>
</tr>
<tr>
<td>Amyloid plaques</td>
<td>3</td>
<td>2%</td>
<td>Word finding difficulty</td>
<td>14</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Personality changes</td>
<td>29</td>
<td>8%</td>
</tr>
<tr>
<td>Modifiable:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Traumatic brain injury/concussion</td>
<td>49</td>
<td>39%</td>
<td>Death</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>4</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>16</td>
<td>13%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obesity</td>
<td>5</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication side-effects</td>
<td>1</td>
<td>1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health behaviour frame</td>
<td>12</td>
<td>9%</td>
<td>Health behaviour frame</td>
<td>46</td>
<td>13%</td>
</tr>
<tr>
<td>Lifestyle factors</td>
<td>9</td>
<td>7%</td>
<td>Quality of life:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal attitude</td>
<td>3</td>
<td>2%</td>
<td>Ability to self-care</td>
<td>15</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Loneliness</td>
<td>10</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Conducting daily activities</td>
<td>9</td>
<td>2%</td>
</tr>
<tr>
<td>Behavioural changes:</td>
<td></td>
<td></td>
<td>Behavioural changes:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood swings</td>
<td>9</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Aggression</td>
<td>2</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Recklessness</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Societal frame</td>
<td>10</td>
<td>8%</td>
<td>Societal frame</td>
<td>196</td>
<td>54%</td>
</tr>
<tr>
<td>Pollutants</td>
<td>5</td>
<td>4%</td>
<td>National level:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influence of social networks</td>
<td>3</td>
<td>2%</td>
<td>National economy</td>
<td>20</td>
<td>5%</td>
</tr>
<tr>
<td>Community-level activities</td>
<td>2</td>
<td>2%</td>
<td>Laws and policies</td>
<td>15</td>
<td>4%</td>
</tr>
<tr>
<td>Local resources:</td>
<td></td>
<td></td>
<td>Community responses:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workforce impact</td>
<td>13</td>
<td>4%</td>
<td>Physical abuse and neglect</td>
<td>54</td>
<td>15%</td>
</tr>
<tr>
<td>Strain on healthcare resources</td>
<td>7</td>
<td>2%</td>
<td>Financial abuse</td>
<td>31</td>
<td>8%</td>
</tr>
<tr>
<td>Strain on social care resources</td>
<td>7</td>
<td>2%</td>
<td>Social ties within family</td>
<td>24</td>
<td>7%</td>
</tr>
<tr>
<td>Community responses:</td>
<td></td>
<td></td>
<td>Family caregiver stress and burnout</td>
<td>25</td>
<td>7%</td>
</tr>
<tr>
<td>Total causes</td>
<td>127</td>
<td>100%</td>
<td>Total effects</td>
<td>361</td>
<td>100%</td>
</tr>
</tbody>
</table>
The health behavioural frame was referred to least in discussions of dementia effects (n=46, 13%). Within this frame, the majority addressed reduced quality of life for people living with dementia due to the loss of independence in self-care, daily activities and feelings of loneliness. A few articles also mentioned behavioural changes, such as mood swings, and increased aggression and recklessness.

Association between medical causes and societal effects in New Zealand newsprint media

Table 4 presents the medical causes and societal effects that were most frequently mentioned together in the same article (p<0.0001). Modifiable medical causes (eg, concussion and cardiovascular risk factors) were more likely to be associated with adverse outcomes for society (eg, residential care resources), and non-modifiable medical causes (eg, biological ageing and genetic) were more likely to be associated with adverse outcomes for the individual and/or their family (elder abuse, caregiver stress and burnout, and impact on social ties). Figure 1 presents examples of quotes from articles to illustrate the associations made between medical causes and societal effects of dementia.

Discussion

Our study is the first to examine media framing of dementia and its associated moral evaluations using a coding matrix that consists of cause, effect and solution along the y-axis and thematic categories by medical, health behavioural and societal frame along the x-axis, extending the work by Gounder et al, 2018.16 We found that, between 2012 and 2016, New Zealand newsprint media largely attributed the causes of dementia to medical causes, whereas the effects focused on the negative impact of the disorder on individuals, families and society. Modifiable medical causes were more likely to be associated with adverse outcomes for society whereas non-modifiable medical causes were more likely to be associated with adverse outcomes for the individual and/or their family.

Causes and effects of dementia

Recent epidemiological evidence suggests that approximately 35% of late-onset dementia can be attributed to modifiable risk factors.5 Many of these are related to lifestyle choices and therefore important to target for health promotion and prevention of dementia. Between 2013 and 2016, 35% of the articles about dementia in New Zealand

<table>
<thead>
<tr>
<th>Medical cause</th>
<th>Societal effect</th>
<th>Measure of association (Chi-square)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Modifiable: Cardiovascular risk</td>
<td>Residential care</td>
<td>$\chi^2(1)=185.99, p&lt;0.0001$</td>
</tr>
<tr>
<td>Cardiovascular risk</td>
<td>Family caregiver’s stress and burnout</td>
<td>$\chi^2(2)=20.99, p&lt;0.0001$</td>
</tr>
<tr>
<td>Concussion</td>
<td>Residential care resources</td>
<td>$\chi^2(1)=92.25, p&lt;0.0001$</td>
</tr>
<tr>
<td>Non-modifiable: Biological aging</td>
<td>Residential care</td>
<td>$\chi^2(1)=15.55, p=0.0001$</td>
</tr>
<tr>
<td>Biological aging</td>
<td>Abuse and neglect</td>
<td>$\chi^2(1)=32.99, p&lt;0.0001$</td>
</tr>
<tr>
<td>Genetics</td>
<td>Family caregiver’s stress and burnout</td>
<td>$\chi^2(1)=45.374, p&lt;0.0001$</td>
</tr>
<tr>
<td>Genetics</td>
<td>Social ties within family</td>
<td>$\chi^2(6)=60.98, p&lt;0.0001$</td>
</tr>
</tbody>
</table>
newsprint media emphasised the medical causes of dementia. Almost half of these described rugby-related head injuries and concussion, but medical causes were rarely presented as lifestyle choices or health behaviours. This framing might suggest to readers that there is little that they can do to prevent dementia, or that it is rugby players who are most at risk.

New Zealand newsprint media also placed great emphasis on the effect of dementia on the individual. These were often described in negative, even catastrophic terms (see Figure 1). The effects were commonly reported as a loss of personhood, judgement and autonomy, resulting in a vulnerability to abuse from others, and the likelihood of ending up in a care home. In this respect, little has changed in the last 14 years: in 2006 Kirkman18 similarly reported that New Zealand newspaper articles between 1998 and 2002 represented people living with dementia as “powerless victims of their disease, victims of their carers and victims of health and social care services”. Likewise, in the UK print media, disproportionate negative emphasis on the effects of dementia, in addition to the ageing demographic, has been described. Peel (2014) concluded that “the high level of emphasis on the lack of personal control over the cause of dementia and the widespread detrimental effects on society creates a public discourse about dementia that is pessimistic and contributes to stigma around the disease”, as well as being a significant contributor to

<table>
<thead>
<tr>
<th>Causes</th>
<th>Societal effects of dementia</th>
</tr>
</thead>
</table>
| **Non-modifiable causes:**                  | Most of us know someone with one of these insidious diseases that select at random but can run in families. Not that anything can necessarily be done to prevent it; one just starts drifting away, or the lights go out, one after the other. The mothers or fathers of several people I know are in that twilight zone, unable to recognise their own children.  
...she said the same things over and over again, was an unbearable torment. But he was old school, took the “in sickness and in health” bit to the letter of the marital pact battling on with this strange person living alongside him feeling more and more alone.  
When the elderly couple moved in with their daughter, they last an hour of domestic assistance and a medication prompt. “Because I was here, they got what I feel was the bare minimum.”  
Her husband was advised to quit his job as he would eventually become her full-time carer. “I was told by my doctor to give a whole lot up. It wasn’t even logical.”  
The recurring themes are family taking advantage of older people or even helping themselves to the person’s money; commission salespeople or scammers duping them; and carers abusing them financially.  
Other examples included a man suffering dementia who was regularly tied to a chair when his wife went out of the house. She felt it was “okay” to tie him up due to his confused mental state.  
...the Baby Boom generation suddenly arriving at its retirement, and there is the added worry of how society is going to be able to afford our care. A cost crunch must be coming, so how grim could those last years be?  
...health boards are already having to plan ahead and reconsider how they will cope as dementia rates start to soar.  
...already a worrying shortage of dementia beds and a “huge” lack of funded community services of people with dementia and their carers in this country. |
| **Modifiable causes:**                      | ...is 86 now, in care on Auckland’s North Shore. “When you play more than 190 first-class games, the chances you got concussed at some point are pretty high.”  
“A link seems likely between serious head-knocks and dementia and the strain rugby-related injuries could put on the health system will be monitored”, (the) Health Minister said.  
“Life expectancy is growing much faster than health expectancy, so a third of our newly gained extra years look likely to be sickly ones. … We are going be riding motorbikes longer but also spending longer in hospitals and dementia homes.” |

![Figure 1: Examples of associations between medical causes and societal effects of as portrayed in New Zealand newsprint media.](image-url)
societal "dementia-panic". In a more recent examination of news articles about dementia published in the British press between 2012 and 2017, the biomedical emphasis was noted, in particular the reliance on pharmaceutical treatments as the only possible solution to prevent dementia.

Moral evaluation
We found that non-modifiable medical causes were more likely to be associated with adverse outcomes for the individual and/or their family. These findings replicate previous research which has shown that if the frame attributes dementia to non-modifiable medical causes (or ‘fixed attributes’) such as genetics and biological aging, these are perceived as being outside the control of the individuals, having adverse consequences on an individual’s lifestyle resulting in ‘social death’ with loss of self and personhood, independence and quality of life. The person (and their family) are seen as victims of the disease. While the medical frame distances individuals from blame for their disease, it also decreases their agency to alter their health outcomes. This reinforces the idea of individuals living with dementia as blameless victims of their circumstances, and powerless to alter their prognosis, contributing to the victimhood frame.

In contrast, we found that modifiable medical causes of dementia (such as rugby-related head injuries) were less likely to be associated with adverse consequences for the individual, and more likely to be associated with adverse outcomes for society, such as the effect on the use of scarce health and social care resources. This might suggest a shift away from victimhood and a possible move towards blaming the victims and their lifestyle choices for the impact that dementia has on society.

Victimhood or victim-blaming?
In recent years, the UK news media has begun to shift its emphasis to health-related behaviours and dementia, in areas such as diet, exercise and lifestyle, and what people can do to “stave off” dementia. A similar shift has been observed in Australian news media where a causal relationship between engaging in preventative behaviour and individuals’ risk of cognitive decline and dementia has been emphasised. While this might be construed as empowering people to have control over their disease, it might also be viewed as problematic if individuals are presented as being morally deviant in their health behaviours. The authors of the Australian study argue that health advice given in newspaper articles is often accompanied by underlying moral claims regarding audiences’ obligation to commit to dementia preventative activities. Those that do not take preventive measures might be seen as being responsible for causing their disease, and possibly for the societal consequences of dementia such as the effects on the public purse, thus shifting the frame from victimhood to victim-blaming.

The topics of lifestyle choices and health behaviours in dementia have not received the same level of attention in New Zealand media. This lack of attention may be perceived by some as problematic, as it may add to the anxiety around dementia as an incurable and untreatable disease (victimhood). On the other hand, unhelpful victim-blaming for perceived unhealthy lifestyle choices has long been recognised in various chronic diseases such as obesity and diabetes, and particularly so among Māori in New Zealand. The scarce research evidence available in New Zealand suggests that Māori and New Zealand Pacific Islanders may be at greater risk of dementia and that this may be due to higher rates of risk factors such as diabetes, obesity and cardio-vascular disease compared with New Zealand Europeans. Thus dementia could become yet another chronic disease that is more common in socially disadvantaged peoples, who are then made responsible for developing the disease and morally judged for their assumed unhealthy lifestyle choices and health-related behaviours having an impact on society as a whole.

Strengths, limitations and implications
This study provides a comprehensive analysis of the national media coverage of dementia, but the findings from this study are limited due to the homogeneity across mainstream New Zealand newsprint media due to merged ownership: the Australian media company APN News & Media owns The New Zealand Herald, while Fairfax owns
The Dominion Post and The Press. Newspaper readership globally is on the decline but remains popular in New Zealand. In 2019 over three million (77%) of New Zealanders read or accessed newspapers in an average seven-day period via print or online (website or app) platforms, so New Zealand newsprint media still enjoys substantial influence on public perception and therefore policy development. However, as other media sources are increasingly used by the public to educate themselves, these will also require examination in future research in this area.

As the prevalence of dementia changes rapidly, so too does the portrayal of the disease. In addition to its recent portrayal as a potentially preventable disorder, dementia is also increasingly presented as a social justice issue. This frame represents dementia as a public and social health crisis through depiction of the effect of dementia across family, community and wider society. Dementia as a societal issue, with adverse social and financial consequences, will require societal solutions such as social inclusion, a public health approach to risk reduction and support for families who provide most of the care. This approach has been adopted by the World Health Organization with the production of a global action plan on the public health response to dementia, calling on its 194 member states, including New Zealand, to produce a national dementia plan or strategy for 2017–2025. Our study examined newspapers from 2013 to 2016 prior to the introduction of the concept of dementia as potentially preventable and/or a social justice issue. Consequently, an update of our research findings is already required to assess whether there has been change in the New Zealand media framing of dementia since 2016 which will contribute to this new public health approach.

Conclusion
Dementia is a complex issue as a result of it having both modifiable and non-modifiable origins and shaped by its multilayered effects on individuals and society and a current lack of solutions for prevention or cure. Dementia remains a highly stigmatised disorder in many countries, so it is important that information about the disease is disseminated accurately and responsibly. From a human rights perspective, there is perhaps a moral obligation for media to choose words carefully and to not portray people with dementia as powerless, child-like, vulnerable, dependent and a burden. By portraying people using a personhood model the focus is on the human being rather than the disease. From a social justice perspective, the New Zealand media has an important role to play in promoting an inclusive society that champions the rights of individuals and families living with dementia, rather than reinforcing a culture of victim-blaming and stigma. This approach would contribute to engaging the public in addressing the inevitable social and financial consequences of the expected ‘tsunami’ of dementia and help to address potential inequities for people and families living with dementia in New Zealand.
Competing interests:
Nil.

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Patient characteristics and predictors of completion of a pulmonary rehabilitation programme in Auckland, New Zealand

Sarah Candy, Nicola Jepsen, Christin Coomarasamy, Jonathan Curry, Grace Dodson, Joe Pomelile, Mitchel Versey, Julie Reeve

ABSTRACT

AIM: Chronic respiratory diseases, such as chronic obstructive pulmonary disease, are a worldwide public health problem. Pulmonary rehabilitation is a gold-standard intervention for these diseases, yet attendance and completion rates are poor. Counties Manukau Health, in Auckland, New Zealand, has a high prevalence of chronic respiratory disease and a culturally diverse population, comprising large numbers of Māori and Pacific Island people, who are known to be disproportionately affected by chronic respiratory disease. The aim of this study was to investigate patient characteristics affecting engagement with the Counties Manukau Health pulmonary rehabilitation programme and identify factors predicting completion of the programme.

METHODS: Investigators performed a retrospective analysis using routinely collected data of 2,756 patients invited to attend the pulmonary rehabilitation programme at Counties Manukau Health. Data were analysed to compare demographic and clinical outcomes of patients who completed, did not complete or did not attend the programme, and identified factors predicting completion.

RESULTS: Significant differences were found between groups in demographic and clinical characteristics. Increasing age, higher six-minute walk test distance at programme commencement and European ethnicity were significant predictors of completion of the PR programme.

CONCLUSIONS: Compared to European people, Māori were 52% less likely and Pacific Island people were 40% less likely to complete the programme. These findings are significant for the Counties Manukau Health population. Further work needs to focus on determining how to make programmes more engaging to different cultures and how we can aim to reduce health inequities in these populations.

Chronic obstructive pulmonary disease (COPD) was the third leading cause of death in 2016 and resulted in more than three million deaths worldwide in 2015. In New Zealand, the population prevalence of COPD is estimated to be 14.2%. The disease is associated with a significant burden on the healthcare system. Internationally, COPD disproportionately affects people living in developing countries and indigenous people in developed countries. In New Zealand, COPD is more prevalent among Māori, Pacific Island people and those living in more deprived areas.

Pulmonary rehabilitation (PR) is an evidence-based, multi-disciplinary programme, comprising exercise and education for people with chronic respiratory disease. It is an essential component of therapy for COPD. Pulmonary rehabilitation has been shown to improve exercise capacity, dyspnoea and health-related quality of life, reduce hospital readmissions and mortality. Despite this, rates of attendance at, and completion of PR programmes are poor; internationally, up to 50% of people referred to PR programmes fail to attend and rates of non-completion have
been reported between 9.7% and 31.8%. One New Zealand-wide study estimated that only 0.9% of people over 40 with COPD were offered PR per year, and of those, only 56% completed the programme. Another PR programme in New Zealand found their programme enrolled less than 2% of the region’s population with COPD.

Counties Manukau Health (CMH), in the Auckland region, is one of 20 district health boards in New Zealand. Better Breathing is a PR programme, which runs at four different sites in CMH—one acute care facility and three community-based sites. Patients attend a one-off initial assessment, then attend the exercise and education-based PR programme twice-weekly for eight weeks. The population at CMH is culturally diverse, with 16% Māori, 21% Pacific Island, 24% Asian and 38% New Zealand European/other. The population has a distinct socioeconomic makeup, with over 36% of people living in the most deprived deciles, based on the New Zealand Deprivation Index [NZDep2013]. Within CMH, the prevalence of chronic respiratory disease is high especially among Māori, Pacific Island people and those living in deprived areas. With guidelines widely recommending PR as a gold-standard intervention, it is important to consider factors impacting upon engagement with PR in the context of contemporary practice in culturally and socioeconomically diverse populations, such as CMH.

The primary aim of this study was to identify and compare the key factors in predicting patients who complete and those who did not complete the PR programme. The secondary aim was to compare the characteristics of those who attended and those who never attended the PR programme.

**Methods**

Investigators performed a retrospective analysis of routinely collected health information data of 2,756 patients invited to attend the Better Breathing PR Programme, run across the four sites at CMH. We evaluated data from all patients who were invited to attend between 1 January 2010 and 31 December 2015. Patients were divided into four groups:

1. ‘Never-attenders’—who did not attend either the initial assessment or programme;
2. ‘Initial assessment-only attenders’—who attended an initial assessment but did not commence the programme;
3. ‘Non-completers’—who completed less than 75% of the programme;
4. ‘Completers’—who completed at least 75% of the programme.

Data for extraction and analysis were determined prior to commencement of the study and were extracted from routinely collected data from the CMH electronic patient information system by a Senior Analyst at Health Intelligence and Informatics at CMH and two researchers (NJ and SC). Following data extraction, retrieval of missing data was undertaken by two members of the research team (NJ and SC), who used the hospital’s patient information systems to extract any available missing data. Data collected included demographic characteristics (age, gender, self-reported ethnicity, marital status, smoking status, occupation, spoken language, level of deprivation) and clinical characteristics (referral source, percent predicted forced expiratory volume in one second (FEV1%), Hospital Anxiety and Depression Scale (HADS) score, Medical Research Council Dyspnoea Score (MRC), Body Mass Index (BMI) and six-minute walk test (6MWT) distance). The clinical data were taken at the initial assessment and therefore only available for those who attended at least an initial assessment.

Data were analysed in four ways:

1. To compare the characteristics of those who did not attend the programme (never-attenders and initial assessment-only attenders) to those who did attend the programme (completers and non-completers);
2. To compare the characteristics of never-attenders to initial assessment-only attenders;
3. To compare the characteristics of completers to non-completers;
4. To identify factors predicting completion of the programme.
Chi-square, two-sample t-tests and Kruskal-Wallis tests were undertaken to assess associations between demographic and clinical characteristics between the groups. Univariate and multiple logistic regression were carried out to test for significant factors that were associated with completion of the programme. To identify significant predictors in the model after accounting for the demographics variables, three model selection techniques were used, such as forward, backward and stepwise procedures, in SAS version 9.4. For those variables with more than 20% of missing data, the variables were not included for model selection. The model with the smallest Akaike Information Criterion was selected and variables that were deemed significant were kept in the model. A p-value < 0.05 was considered statistically significant. Sensitivity analysis was also carried out by using a single imputation method and compared to the complete cases using likewise deletion. This involved replacing the missing values for the continuous variables by the median.

The New Zealand Health and Disability Ethics Committee stated ethical review was not required. Approval for the study was granted by CMH Research Committee on 21 April 2016 (Research Application Numbers 5 and 6).

**Results**

Of the 2,756 patients that were referred to the Better Breathing programme, 1,028 (37%) never attended and 33 (1%) attended the initial assessment only. The remaining 1,695 (62%) patients commenced the programme; 1,040 (61%) of those were completers and 655 (39%) were non-completers (see Figure 1). This shows that, of all referrals to the Better Breathing programme, 1,716 (62%) never attended or did not complete the programme.

**Figure 1**: Flow chart showing the numbers of referrals to, attendance at and completion of the Better Breathing Pulmonary Rehabilitation programme between 2010 and 2015.
Characteristics of those who attended the programme (completers and non-completers combined) and those who did not attend the programme (never-attenders and initial assessment-only attenders combined) are summarised in Table 1. There were significant differences between these groups in marital status (p=0.001), deprivation index (p=0.021), smoker (p<0.001), distance from home to PR site (p<0.001) and site location

Table 1: Demographic characteristics by group—attenders (completers and non-completers combined) and non-attenders (never attenders and initial assessment-only attenders combined).

<table>
<thead>
<tr>
<th></th>
<th>Attenders n=1,695</th>
<th>Non-attenders n=1,061</th>
<th>P value</th>
<th>Missing proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>898 (62.1)</td>
<td>549 (37.9)</td>
<td>0.53</td>
<td>0%</td>
</tr>
<tr>
<td>Male</td>
<td>797 (60.9)</td>
<td>512 (39.1)</td>
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<td></td>
</tr>
<tr>
<td>Ethnicity</td>
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</tr>
<tr>
<td>Asian</td>
<td>102 (68.5)</td>
<td>47 (31.5)</td>
<td>0.44*</td>
<td>1.1%</td>
</tr>
<tr>
<td>European</td>
<td>824 (61.0)</td>
<td>526 (39.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>395 (60.1)</td>
<td>262 (39.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Island</td>
<td>334 (62.0)</td>
<td>205 (38.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>18 (60.0)</td>
<td>12 (40.0)</td>
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<tr>
<td>Marital status</td>
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</tr>
<tr>
<td>Married/partnered</td>
<td>956 (64.2)</td>
<td>533 (35.8)</td>
<td>0.001*</td>
<td>4.6%</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>161 (61.5)</td>
<td>101 (38.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>221 (59.2)</td>
<td>152 (40.8)</td>
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<td>Widowed</td>
<td>275 (54.4)</td>
<td>231 (45.7)</td>
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<td>Smoker</td>
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<td></td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>968 (62.4)</td>
<td>584 (37.6)</td>
<td>&lt;0.001</td>
<td>5.0%</td>
</tr>
<tr>
<td>Smoker</td>
<td>247 (52.6)</td>
<td>223 (47.5)</td>
<td></td>
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<tr>
<td>Non-smoker</td>
<td>394 (66.2)</td>
<td>201 (33.8)</td>
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<td>Language spoken</td>
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<td></td>
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<tr>
<td>English</td>
<td>1,465 (61.8)</td>
<td>906 (38.2)</td>
<td>0.75*</td>
<td>5.7%</td>
</tr>
<tr>
<td>Other</td>
<td>144 (62.9)</td>
<td>85 (37.1)</td>
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</tr>
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<td>Site location</td>
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<tr>
<td>Acute Care Facility</td>
<td>962 (64.1)</td>
<td>540 (36.0)</td>
<td>&lt;0.001*</td>
<td>0%</td>
</tr>
<tr>
<td>Community</td>
<td>733 (58.4)</td>
<td>521 (41.6)</td>
<td></td>
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<tr>
<td>Employment status</td>
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</tr>
<tr>
<td>Not working</td>
<td>427 (61.8)</td>
<td>264 (38.2)</td>
<td>0.96*</td>
<td>6.2%</td>
</tr>
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<td>Retired</td>
<td>733 (61.3)</td>
<td>463 (38.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>431 (61.8)</td>
<td>266 (38.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>66.8 (11.0)</td>
<td>67.0 (12.1)</td>
<td>0.64*</td>
<td>0%</td>
</tr>
<tr>
<td>Age range</td>
<td>19–92</td>
<td>21–93</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distance from home – PR site (kms)</td>
<td>4.0 (1.9–7.1)</td>
<td>4.9 (2.4–9.9)</td>
<td>&lt;0.001¹</td>
<td>0%</td>
</tr>
<tr>
<td>Deprivation index</td>
<td>Median (IQR)</td>
<td>9 (6–10)</td>
<td>9 (7–10)</td>
<td>0.021</td>
</tr>
</tbody>
</table>

*The parametric p-value is calculated by two sample t-test for numerical covariates and chi-square test for categorical covariates.

¹The non-parametric p-value is calculated by the Kruskal-Wallis test and Mann-Whitney-U test for numerical covariates and Fisher’s exact test for categorical covariates.

KEY: kms, kilometres; IQR, inter quartile range; n, number; PR, pulmonary rehabilitation; SD, standard deviation.
There were no statistically significant differences between attenders and non-attenders in age (p=0.64), gender (p=0.53), ethnicity (p=0.44), language spoken (p=0.75) or occupation (p=0.96).

Comparison between demographic characteristics of those who never attended (n=1,028) and initial assessment-only attenders (n=33) showed a statistically significant difference in ethnicity (p=0.001), with never-attenders having a larger proportion of European and Māori patients. The initial assessment-only group also had a significantly higher proportion of patients who did not speak English as a first language (22% vs 8%, p=0.02) and a larger proportion of married/partnered patients (80% vs 52%, p=0.03) compared to the never-attenders. The small sample size in the initial assessment-only group limits the significance of these findings.

When comparing demographic and clinical characteristics between the completer and non-completer groups, there were statistically significant differences between the two groups in all characteristics except for gender, distance from home to PR site and site location (Table 2). Furthermore, for each year increase in age, patients were 4% more likely to complete the programme (OR 1.04 95%CI 1.02–1.05, p=<0.001). For every 10m extra that a patient walked in their 6MWT at programme commencement, they were 3% more likely to complete the programme (OR 1.03, 95%CI 1.02–1.04, p=<0.001). Compared with Europeans, Māori were 53% (OR 0.47, 95% CI 0.35–0.65, p=<0.001) and Pacific Island people were 46% (OR 0.64, 95% CI 0.44–0.92, p=<0.001) less likely to complete the programme. Results of the univariate and logistic regression model predicting completion of the better breathing programme are displayed in Table 3. Results of multivariate logistic regression models for both complete and imputed cases can be seen in Table 4.

**Discussion**

Data were collected on 2,756 patients referred to the Better Breathing programme in the period under investigation; this data set is larger than those previously described in other New Zealand studies. Our study has shown that 62% of all patients referred to the Better Breathing programme either do not take part in the programme at all, or do not complete the programme. An older study exploring attendance at a PR programme in an Auckland clinic reported that 41% of patients either did not attend, or failed to complete the programme. A more recent study in a different New Zealand region showed that 46% of those referred to PR completed the programme. Our results compare poorly with this, whereby only 38% of all patients referred completed the Better Breathing programme. In a review of 11 international studies, non-completion rates were reported to be up to 32%, so it is of concern that our non-completion rates in those who commenced the Better Breathing programme (39%) appear to be higher than those reported elsewhere.

When comparing the characteristics of those who attended with those who did not attend, significant factors included distance travelled, site location, deprivation index and marital status. Other studies investigating reasons for non-completion of PR have cited transport and the distance from home to PR site as problematic. While we found that the distance from home to PR and the location of PR was significantly different between attenders and non-attenders, once patients commenced the programme, distance and location were no longer a significant factor influencing attendance. This suggests that factors relating to the running of the PR programme itself may be more important than geographical location when considering completion rates.

Some studies have demonstrated that people with lower socioeconomic status may find it harder to access transport and parking costs associated with attending primary healthcare services and these factors have also been linked to poor attendance at PR programmes. A widely used measure of social deprivation in New Zealand was used to investigate whether social deprivation affected completion rates at the Better Breathing programme. Even though there was an indication of deprivation index being a significant risk factor (Table 3), after accounting for other characteristics, the deprivation index was not strongly correlated. However, it should be noted that the univariate results indicate that for every one unit increase in deprivation index, the likelihood of completing the programme reduces by 8%.
Table 2: Demographic and clinical characteristics by group—completers vs non-completers.

<table>
<thead>
<tr>
<th></th>
<th>Completers n=1,040</th>
<th>Non-completers n=655</th>
<th>P value</th>
<th>Missing proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>536 (59.7)</td>
<td>362 (40.3)</td>
<td>0.13*</td>
<td>0%</td>
</tr>
<tr>
<td>Male</td>
<td>504 (63.2)</td>
<td>293 (36.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>61 (59.8)</td>
<td>41 (40.2)</td>
<td>&lt;.001*</td>
<td>1.3%</td>
</tr>
<tr>
<td>European</td>
<td>595 (72.2)</td>
<td>229 (27.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>184 (46.6)</td>
<td>211 (53.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Island</td>
<td>173 (51.8)</td>
<td>161 (48.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>14 (77.8)</td>
<td>4 (22.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>593 (62.0)</td>
<td>363 (38.0)</td>
<td>0.002*</td>
<td>4.8%</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>84 (52.2)</td>
<td>77 (47.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>116 (52.5)</td>
<td>105 (47.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>181 (65.8)</td>
<td>94 (34.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>605 (62.5)</td>
<td>363 (37.5)</td>
<td>0.018</td>
<td>5.1%</td>
</tr>
<tr>
<td>Smoker</td>
<td>130 (52.6)</td>
<td>117 (47.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-smoker</td>
<td>240 (60.9)</td>
<td>154 (39.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>908 (62.0)</td>
<td>557 (38.0)</td>
<td>&lt;.001*</td>
<td>5.1%</td>
</tr>
<tr>
<td>Other</td>
<td>69 (47.9)</td>
<td>75 (52.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site location</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute Care Facility</td>
<td>449 (61.3)</td>
<td>284 (38.7)</td>
<td>0.94</td>
<td>0%</td>
</tr>
<tr>
<td>Community site</td>
<td>591 (61.4)</td>
<td>371 (38.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distance from home to PR site (kms)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>3.8 (1.9–7.2)</td>
<td>4.1 (1.5–7.0)</td>
<td>0.28‡</td>
<td>0%</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not working</td>
<td>227 (53.2)</td>
<td>200 (46.8)</td>
<td>&lt;.001*</td>
<td>3.4%</td>
</tr>
<tr>
<td>Retired</td>
<td>480 (65.5)</td>
<td>253 (34.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>251 (58.2)</td>
<td>180 (41.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>68.3 (10.1)</td>
<td>64.3 (12.0)</td>
<td>&lt;.001*</td>
<td>0%</td>
</tr>
<tr>
<td>Deprivation index</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>9 (6–10)</td>
<td>9 (7–10)</td>
<td>&lt;.001‡</td>
<td>0%</td>
</tr>
<tr>
<td>BMI</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>28 (24–34)</td>
<td>31 (25–39)</td>
<td>&lt;.001‡</td>
<td>3.4%</td>
</tr>
<tr>
<td>MRC</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>3 (1.2)</td>
<td>3.3 (1.2)</td>
<td>&lt;.001‡</td>
<td>6.0%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>N 878</td>
<td>421</td>
<td>&lt;.001‡</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>6 (3–9)</td>
<td>7 (4–10)</td>
<td>23.4%</td>
</tr>
<tr>
<td>Depression</td>
<td>N 876</td>
<td>420</td>
<td>0.005‡</td>
<td>23.5%</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>5 (3–7)</td>
<td>5 (3–8)</td>
<td></td>
</tr>
<tr>
<td>FEV1%</td>
<td>N 994</td>
<td>553</td>
<td>&lt;.001*</td>
<td>8.7%</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>51.5 (18.9)</td>
<td>47.8 (17.7)</td>
<td>6.00%</td>
</tr>
<tr>
<td>6 MWT (m)</td>
<td>N 1,030</td>
<td>563</td>
<td>&lt;.001*</td>
<td>6.00%</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>336.5 (107.2)</td>
<td>304.8 (116.6)</td>
<td></td>
</tr>
</tbody>
</table>

*The parametric p-value is calculated by two sample t-test for numerical covariates and chi-square test for categorical covariates.
‡The non-parametric p-value is calculated by the Kruskal-Wallis test and Mann-Whitney-U test for numerical covariates and Fisher’s exact test for categorical covariates.
KEY: BMI, body mass index; FEV1, forced expiratory volume in one second; IQR, inter quartile range; kms, kilometres; MRC, Medical Research Council Dyspnoea Scale; n, number of patients; PR, pulmonary rehabilitation; SD, standard deviation, 6MWT, 6 minute walk test distance.
**Table 3**: Results of univariate logistic regression model showing variables predicting completion at the Better Breathing Pulmonary Rehabilitation Programme.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Levels</th>
<th>Odds ratio (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female</td>
<td>0.84 (0.67–1.06)</td>
<td>0.15</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Asian</td>
<td>0.60 (0.36–0.99)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Māori</td>
<td>0.34 (0.26–0.46)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1.29 (0.27–6.14)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pacific Island</td>
<td>0.44 (0.33–0.60)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>European</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>Married/partnered</td>
<td>1.50 (1.06–2.11)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Separated/divorced</td>
<td>0.90 (0.56–1.43)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>1.95 (1.27–2.98)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>Ex-smoker</td>
<td>0.94 (0.71–1.24)</td>
<td>0.218</td>
</tr>
<tr>
<td></td>
<td>Smoker</td>
<td>0.73 (0.50–1.06)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-smoker</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td>1.50 (1.01–2.25)</td>
<td>0.046</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Site location</td>
<td>Community</td>
<td>1.02 (0.81–1.29)</td>
<td>0.872</td>
</tr>
<tr>
<td></td>
<td>Acute care facility</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td>Retired</td>
<td>1.56 (1.18–2.06)</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td>Working</td>
<td>1.06 (0.78–1.45)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not working</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Per year increase</td>
<td>1.04 (1.03–1.05)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Distance from home to PR site</td>
<td>Per km increase</td>
<td>0.99 (0.97–1.01)</td>
<td>0.414</td>
</tr>
<tr>
<td>Deprivation</td>
<td>Per unit increase</td>
<td>0.92 (0.88–0.96)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>BMI</td>
<td>Per unit increase</td>
<td>0.97 (0.96–0.99)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>MRC</td>
<td>Per unit increase</td>
<td>0.86 (0.78–0.95)</td>
<td>0.002</td>
</tr>
<tr>
<td>FEV1 (%pred)</td>
<td>Per 1% increase</td>
<td>1.01 (1.01–1.02)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>6 MWT</td>
<td>Per 10m increase</td>
<td>1.03 (1.01–1.04)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
In comparing participants who completed with those who did not complete the PR programme, many factors were significantly different between the groups. However, when all variables were included in a fully adjusted model, only three factors were identified as independent predictors of completion of PR: age, distance walked on 6MWT and ethnicity. Consistent with other literature, the results of our study found that patients had a greater likelihood of completing the programme as age increased. It is possible that this is related to work schedules. The Better Breathing programme, which runs during normal working hours, may be less accessible to the working population. Māori and Pacific Island people tend to develop COPD at an earlier age (the average age of onset of COPD in New Zealand is 70.3 years, but for Māori and Pacific Island people it is 62.6 and 62.5 years respectively), so these populations may be more severely impacted by timing of PR programmes. An increase in flexibility of services including: offering classes outside of working hours, a home-based service and/or a telehealth based programme may allow younger participants, who may be working or looking after dependents, the opportunity to complete PR.

### Table 4: Results of multivariate logistic regression model showing variables predicting completion of the Better Breathing Pulmonary Rehabilitation Programme for the complete and imputed cases.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Complete cases (n=1,296)</th>
<th>Single imputed cases (n=1,508)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds ratio (95% CI)</td>
<td>P value</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0.97 (0.75, 1.26)</td>
<td>0.83</td>
</tr>
<tr>
<td>Male</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>0.84 (0.46, 1.51)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Māori</td>
<td>0.47 (0.35, 0.65)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1.23 (0.25, 6.16)</td>
<td></td>
</tr>
<tr>
<td>Pacific Island</td>
<td>0.64 (0.44, 0.92)</td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>1.09 (0.75, 1.59)</td>
<td>0.22</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>0.74 (0.45, 1.21)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1.21 (0.75, 1.97)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>0.99 (0.72, 1.35)</td>
<td>0.87</td>
</tr>
<tr>
<td>Smoker</td>
<td>0.91 (0.6, 1.37)</td>
<td></td>
</tr>
<tr>
<td>Non-smoker</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>1.52 (0.93, 2.49)</td>
<td>0.09</td>
</tr>
<tr>
<td>Other</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Site location</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>0.95 (0.74, 1.22)</td>
<td>0.71</td>
</tr>
<tr>
<td>Acute care facility</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>1.03 (0.75, 1.42)</td>
<td>0.76</td>
</tr>
<tr>
<td>Working</td>
<td>1.13 (0.81, 1.59)</td>
<td></td>
</tr>
<tr>
<td>Not working</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Per year increase</td>
<td>1.04 (1.02, 1.05)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>6 MWT</td>
<td>1.03 (1.02–1.04)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

**KEY:** m, metre; 6MWT, 6-minute walk test distance.
Patients who walked further in their 6MWT at commencement of our programme were also more likely to complete the programme; this is consistent with other literature.\(^{26-28}\) 6MWT distance correlates with MRC dyspnoea score and pulmonary function testing.\(^{29,30}\) and our study found that non-completers had significantly greater dyspnoea and disease severity. These factors may make exercise more challenging, potentially increasing the likelihood of non-completion. Potential strategies to overcome this challenge for participants may involve; increased time spent on orientation to PR including strategies to manage breathlessness, starting exercise at lower intensities and ensuring increased levels of supervision and/or support for people with lower exercise capacity. The location of PR, including access to the building and close parking facilities may also facilitate completion for this group.

An important finding of this study is that Māori and Pacific Island patients are significantly less likely to complete the programme compared with European patients, supporting the findings of others in New Zealand.\(^{11}\) Ethnicity was not significantly different when comparing attenders to non-attenders \((p=0.44)\), but became significant when comparing completers to non-completers \((p=0.001)\). When all variables were accounted for, ethnicity was found to be an independent predictor of completion of PR. This finding is important because the CMH population comprises large numbers of Māori and Pacific Island people in the community, who are disproportionately affected by chronic respiratory diseases in New Zealand.\(^{3}\) The results of this study, therefore, show that the people who may potentially benefit from PR the most are those who are least likely to complete the programme. Differences in attendance between people of various ethnicities may be related to differences in the culture of attendees or of the programme itself. Cultural factors appear to play an influential role in how well PR programmes are able to engage with Māori and Pacific Island people. Levack et al\(^{31}\) found that when the cultural needs of Māori attending PR were not addressed adequately, patients were less willing to attend those PR programmes.\(^{31}\) To our knowledge, two New Zealand-based studies\(^{31,31}\) are the only other studies to have specifically explored the influence of ethnicity on participants' engagement with PR. We encourage others undertaking PR programmes with ethnically diverse populations to further explore issues with engagement and completion of PR programmes and identify factors that may improve these. Levack et al\(^ {31}\) have suggested that indigenous-led PR programmes may overcome barriers for indigenous and minority participants and the feasibility of this requires further investigation. Other factors such as the venue in which PR programmes are held—such as a Marae—could be important for many Māori participants. Future research should ensure collaboration with cultural experts, and participants who have attended PR, to work towards co-design of culturally responsive PR programmes.

In our cohort, there was a significant difference in completion rates between English and non-English speaking participants. Indeed, in comparing the characteristics of never-attenders with initial assessment-only attenders, a large proportion of participants who reported English as a second language attended only the initial assessment and did not go to further attend or complete the programme. Additionally, while in our multivariate regression modelling, language was not found to be significant in predicting completion, following data imputation speaking English as a first language became statistically significant, suggesting this may be a relevant factor in completion of PR. Attention should be given to whether the delivery of programmes in different languages might improve completion rates in non-English speakers, and this together with how language aligns with delivering culturally relevant programmes should be considered.

**Limitations**

It should be noted that during the period of the study, we implemented several changes arising from quality improvement initiatives to the PR programme that may have influenced interpretation. During this period, the service expanded and the hospital outpatient programme moved from the hospital site to four community venues, which we considered may better fulfil the needs of our population. It is feasible that
these changes may have impacted on the results of this study, particularly regarding distance from home to PR. However, because distance from home to PR was calculated using each individual’s home address and their closest PR site, we believe that this measure will account for these location changes.

The nature of the data collection and retrieval meant that not all data was available for all groups. For example, data from those who attended the PR programme was more extensive than those who did not attend, due to extensive assessment and monitoring undertaken during the PR programme. Even following completion of the programme, some data was missing on retrieval, e.g., HADS. Reasons for some of this missing data could be spoken language/literacy issues, assessment burden or clinician or administration error. Where data were known to be missing, imputation of the continuous variables into the statistical modelling for analysis was carried out and compared with complete cases. Furthermore, we acknowledge a prospective matched cohort study could have improved the ability to account for the effect of confounding variables in our analyses, increasing the confidence regarding the impact of each of the different variables individually.

Conclusion

Of everyone referred to CMH Better Breathing PR programme during the period of our study, only 38% completed the programme. Considering that less than 2% of people with COPD in New Zealand are referred to a PR programme, it is problematic that so few patients are completing this gold-standard intervention. Age, 6MWT distance at commencement of PR and ethnicity were important predictors of completion of PR in this population. Strategies to make PR more engaging must be considered for varying age groups, those with poorer exercise tolerance, and, importantly, in different ethnic groups.

Competing interests:
Nil.

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A feasibility study investigating the impact of a dietitian-led low in fermentable oligosaccharide, disaccharide, monosaccharide and polyols diet group education programme with irritable bowel syndrome

Dorcas Chan, Paula Skidmore, Leigh O’Brien, Sally Watson, Richard Gearry

ABSTRACT

AIMS: To investigate the feasibility and effectiveness of dietitian-led education on using the low fermentable oligosaccharide, disaccharide, monosaccharide and polyols (FODMAP) diet in adults with irritable bowel syndrome (IBS) in Christchurch, New Zealand.

METHODS: Patients with IBS (n=25) were referred by their general practitioner to attend a group education programme. The number recruited and subsequent attendance were used to evaluate feasibility. The Structured Assessment of Gastrointestinal Symptoms (SAGIS) questionnaire and Hospital Anxiety and Depression Scale (HADS) were compared at baseline and at follow-up. Semi-structured telephone interviews assessed the acceptability of the education programme.

RESULTS: Of the 25 recruited participants, 17 attended the group education programme. The SAGIS score decreased significantly (p<0.05) between baseline (mean 1.844) and follow-up (mean 0.607). Similarly, there was non-significant trend of lower HADS anxiety and depression scores from baseline to follow-up. Symptomatic improvement was reported by 13 participants (76.5%), while two participants (11.8%) did not improve and two others (11.8%) had not implemented the diet. Overall, participants were positive and grateful for the improvement the diet had made to their symptoms.

CONCLUSIONS: A dietitian-led low FODMAP group education programme in Christchurch adults with IBS was found to be both feasible and effective.

Irritable bowel syndrome (IBS) is a common functional gastrointestinal disorder (FGID) that affects 10–20% of the Western population. IBS has peak incidence in those aged 25–54 years who experience symptoms such as abdominal pain, diarrhoea and constipation that lead to significant morbidity and reduced quality-of-life. FGIDs are one of the most common causes for presentation to general practice and therefore have significant direct and indirect healthcare costs.

Food has been identified as a symptom trigger by 70–80% of IBS patients. National Institute for Health and Care Excellence (NICE) suggest general healthy eating guidelines such as having regular meals, adequate fluids and reducing intake of caffeine and
alcohol to improve the management of IBS. A study by Eswaran et al found that 40–50% of IBS predominant diarrhoea patients (n=92) reported adequate symptom relief with the low fermentable oligosaccharide, disaccharide, monosaccharide and polyols (FODMAP) diet or a diet based on the modified NICE Guidelines. However, the low FODMAP diet led to greater improvement in bloating and abdominal pain. There is strong evidence that a diet low in fermentable oligosaccharides, disaccharides, monosaccharides and polyols (FODMAPs) is effective for the management of IBS. The mechanism by which FODMAPs contribute to IBS symptoms are well described. FODMAPs are poorly absorbed in the small intestine and rapidly fermented in the colon. This leads to increased delivery of fluid to the colon, luminal distension and abdominal pain. Observational and randomised controlled trials have shown that approximately 70% of patients experience significant symptom improvement after implementation of a low FODMAP diet led by a dietitian.

The low FODMAP diet is traditionally taught in a one-to-one setting by a dietitian using a three-phase approach. First, patients are given in-depth dietary education on FODMAP restriction followed by dietary elimination of FODMAPs for up six weeks. Patients who achieve symptomatic improvement are then instructed on how to reintroduce individual FODMAPs into the diet while their symptoms are monitored. The overall aim of the low FODMAP diet is to identify the specific FODMAPs that trigger IBS symptoms while achieving a diverse and nutritionally adequate diet. Due to its restrictive nature, unguided implementation of the low FODMAP diet has the potential to develop restrictive eating behaviours, nutrient deficiencies and cause problems in specific populations such as vegetarians and pregnant women.

Given the restrictive nature of the diet, the high prevalence of IBS and the increasing popularity of the low FODMAP diet, dietetic capacity in the public health system to guide individuals through the diet is unable to meet demand. To address this problem, King’s College (London) implemented and evaluated a dietitian-led low FODMAP group education programme, that showed such an approach was clinically effective and more cost effective than traditional one-to-one education of patients. However, the study did not assess quality-of-life or psychometric measures, which are important aspects of IBS management.

In New Zealand, it is estimated that IBS affects approximately 10–20% of individuals. The aim of this study was to determine the feasibility and effectiveness of a dietitian-led low FODMAP diet group education programme in a community setting in adults with IBS in Christchurch, New Zealand. The objectives of the study were: 1) examine the practicalities and feasibility of dietitian-led low FODMAP group education, 2) assess patients’ gastrointestinal symptoms and psychological status before and after attending the education sessions and 3) record patients’ experiences with the low FODMAP diet.

### Methods

#### Participants and recruitment

The primary outcomes of the study were the number of referrals to the education programme, types of recruitment method(s), attendance rates, and participant acceptability of the FODMAP diet and perceived changes in IBS symptoms. The study was a prospective observational design of 25 participants recruited to attend one or two education sessions nine weeks apart. Baseline characteristics including age, sex, IBS subtype, weight, height and body mass index (BMI) were recorded at baseline. The study was approved by the Human Ethics Committee of the University of Otago in March 2018 and all participants gave written informed consent before entering the study.

The study was undertaken with the assistance of the Canterbury Initiative (http://www.cdhb.health.nz/about-us/key-projects-and-initiatives/canterbury-initiative/). Initially, the study recruited participants from the community using general practices in the surrounding areas of the proposed venues. However, only a small number of referrals were received from these practices. However, further referrals were received following promotion of the study on Canterbury DHB websites including Community HealthPathways and HealthInfo Canterbury (http://www.cdhb.health.nz/...
Inclusion criteria for the study were aged 18 years or older, a diagnosis of IBS predominant diarrhoea (IBS-D) or IBS predominant constipation and diarrhoea (IBS-M) made by a physician using the ROME IV criteria and negative coeliac markers.17 Participants were excluded if they had inflammatory bowel disease, IBS with constipation only, diabetes mellitus, history of bowel resection, BMI ≤18.5kgm$^2$ or ≥35kgm$^2$, unintentional weight loss, limited comprehension of English, living in residential care and previous dietetic supervision on the low FODMAP diet.

Group education sessions
A New Zealand registered dietitian with experience in IBS dietary management led the education sessions. The initial 90-minute sessions focused on eliminating high FODMAP foods from the diet for six weeks and included discussion around how to overcome common challenges encountered on a low FODMAP diet. Opportunities for engagement between the participants was encouraged during the session including a label reading group activity. Validated questionnaires including the Assessment of Gastrointestinal Symptoms (SAGIS)16 and Hospital Anxiety and Depression Scores (HADS)17 that measured gastrointestinal and psychological symptoms, respectively were completed prior to the intervention and six weeks later. The SAGIS questionnaire uses a five-point rating scale to assess the severity of symptoms (no problem=0, mild=1, moderate=2, severe=3 and very severe=4), while the HADS questionnaire utilises a 4-point rating scale of 14 items divided into two domains, anxiety and depression.

A semi-structured interview was performed by telephone after six weeks to assess the group education sessions and resources provided and record the participant’s acceptability and attitudes towards following a low FODMAP diet. All the interviews were transcribed and a thematic inductive approach used to identify broad themes in the responses.18

If the patient’s symptoms had improved by ≥50%, they were invited to attend a second group education session. Participants with no improvement in symptoms were referred back to their GP. These 60 minute follow-up sessions were held nine weeks after the first and focused on how to safely and correctly challenge for each FODMAP group. Participants were advised to gradually introduce food containing each FODMAP, starting with small amounts and then increasing intake, and allow days between each challenge in order to monitor symptoms and determine their tolerance to the specific FODMAP. In both sessions the class was taught using a PowerPoint presentation on a screen projector and given written information to take home. Participants were also encouraged to visit websites and web apps for meal and recipe ideas such as ‘A Little Bit Yummy’ and the Monash University low ‘FODMAP Diet app.19,20

Statistical analysis
The SAGIS and HADS data were analysed using the statistical software programme; IBM SPSS Statistics 25 (1998, 2017, US). The SAGIS questionnaire scores were analysed using paired t-tests, while the HADS scores were stratified into their domains, anxiety and depression an analysed using chi-square and paired t-tests. The study was not designed, or adequately powered to test clinical significance, but only numerical significance (p<0.05).
Figure 1: Disposition of participants.

Results

Attendance

The flow of the patients from referral to attendance at the two education sessions is shown in Figure 1. Of the 25 referrals, three individuals reported they could no longer proceed with the referral, leaving 22 who were sent a booking for the first education session (elimination phase). However, only 17 of these individuals attended the first education session (attendance rate 77%). Those who did not attend were contacted regarding why they could not attend; one participant had not received any information or appointment, one could not take time off work, and another participant who was called into work unexpectedly. The baseline characteristics of the 17 participants who attended the first education session participants is shown in Table 1. All 17 participants were contacted by a member of the research team seven to eight weeks after the first education session who carried out a semi-structured interview. This showed 13 participants (76%) had a ≥50% improvement in their IBS symptoms, while two participants reported no improvement (12%) and two had not implemented the diet (12%). The 13 participants with symptomatic improvement were then given a booking for the second education session (Reintroduction phase), although only 11 attended.
Table 1: Baseline characteristics of study participants.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of participants n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years)</td>
<td>34.5</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>17</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>22</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td>Body Mass Index (BMI)*</td>
<td></td>
</tr>
<tr>
<td>Normal (18.5–24.9 kg m(^{-2}))</td>
<td>7</td>
</tr>
<tr>
<td>Overweight (25.0–29.9 kg m(^{-2}))</td>
<td>7</td>
</tr>
<tr>
<td>Obese Class I (30.0–34.9 kg m(^{-2}))</td>
<td>5</td>
</tr>
<tr>
<td>Obese Class II (35.0–39.9 kg m(^{-2}))</td>
<td>0</td>
</tr>
<tr>
<td>IBS subtype(^{b})</td>
<td></td>
</tr>
<tr>
<td>IBS with predominant diarrhoea</td>
<td>10</td>
</tr>
<tr>
<td>IBS with diarrhoea and constipation</td>
<td>9</td>
</tr>
<tr>
<td>Other conditions(^{c})</td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td>15</td>
</tr>
<tr>
<td>Chronic fatigue</td>
<td>6</td>
</tr>
<tr>
<td>Back pain</td>
<td>9</td>
</tr>
<tr>
<td>Depression</td>
<td>10</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>9</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>11</td>
</tr>
<tr>
<td>Referral</td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>20</td>
</tr>
<tr>
<td>Other health professional</td>
<td>2</td>
</tr>
</tbody>
</table>

n; number, BMI; body mass index (weight (kg) divided by height squared (m\(^{2}\)))  
* n=19. Three participants did not have heights recorded for BMI to be calculated.  
\(^{b}\) n=19. Three participants were unable to be contacted to determine IBS subtype.  
\(^{c}\) n=18. Based on the SAGIS questionnaires answers completed by participants who returned the first questionnaire.

Semi-structured interviews to assess improvements in symptoms

Results from the telephone interviews showed a range of benefits in group education and the general response from participants about the low FODMAP diet were positive. Most participants felt that the information provided at the session was sufficient for them to implement the low FODMAP diet for six weeks. Table 2 shows a summary of the main and sub themes identified.

Participants expressed a change in their relationship with food and eating; one expressed that they “definitely changed some of my thinking” and another “I’m more aware what I’ve been eating but also how I’ve been eating”. More effort into meal planning was reported by the participants. Most of participants had used the ‘A Little Bit
Table 2: Summary of themes derived from semi-structured interviews.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>A new way of eating</td>
<td>Meal planning</td>
</tr>
<tr>
<td></td>
<td>Time to prepare and plan meals</td>
</tr>
<tr>
<td></td>
<td>Regular meal pattern</td>
</tr>
<tr>
<td></td>
<td>Monitoring FODMAP intake</td>
</tr>
<tr>
<td></td>
<td>Cooking from scratch</td>
</tr>
<tr>
<td>Replacement of foods</td>
<td>Replacement of high FODMAP foods with low FODMAP alternative</td>
</tr>
<tr>
<td></td>
<td>Using alternative flavourings instead of garlic and onion</td>
</tr>
<tr>
<td>Eating out</td>
<td>Maintaining social norms</td>
</tr>
<tr>
<td></td>
<td>Uncertainty of FODMAP content in meals eaten away from home</td>
</tr>
<tr>
<td>Social support</td>
<td>Understanding from family and friends</td>
</tr>
<tr>
<td></td>
<td>Reinforcement and encouragement from partners/spouse</td>
</tr>
<tr>
<td></td>
<td>Group education and other participants</td>
</tr>
<tr>
<td>Resources</td>
<td>Using a readily available app on the go (ie, MONASH low FODMAP app)</td>
</tr>
<tr>
<td></td>
<td>Using websites (eg, A Little Bit Yummy) for recipe ideas</td>
</tr>
<tr>
<td></td>
<td>Low FODMAP take home resources provided at the session</td>
</tr>
<tr>
<td>Label reading</td>
<td>Ease of reading and interpreting nutrition information</td>
</tr>
<tr>
<td></td>
<td>Aids to label reading—Monash low FODMAP diet app</td>
</tr>
</tbody>
</table>

Yummy' website, while some had purchased the Monash app and found its accessibility and convenience to be very helpful: “I downloaded the app, the FODMAP app, it sort of gave me enough products on there to give me an idea”. Most participants agreed that finding low FODMAP alternatives for foods that they often ate was really helpful.

Behavioural change proved to be the biggest challenge for most participants. One participant expressed that “It was harder at the beginning but towards the end it was quite simple now really”, while another reported that “(it was) really just changing my habits”. Another common challenge faced by the participants included social gatherings and eating out, with one stating that she “just wanted to fit in with other people” and another saying “they were distracted more than anything, conversations happen”. “The garlic and onion scenario” was a common challenge that participants experienced both at home and eating out.

**Symptom-related questionnaires**

A total of 32 SAGIS questionnaires and 31 HADS questionnaires were collected throughout the study. Participants were excluded from final data analysis if they had not attended the first education session or had not implemented the low FODMAP diet for a minimum of six weeks.

Table 3 summarises the mean scores of the 24 variables in the SAGIS questionnaire before and after the group low FODMAP diet intervention. There was a significant reduction ($p<0.05$) in scores for 19 of the 24 variables. The symptom with the greatest improvement was bloating ($p<0.0001$), while scores for belching, dysphagia, early satiety, loss of appetite and vomiting showed a non-significant improvement.

Anxiety and depression was measured using the HADS. For both anxiety (11.2 [SD 4.3] vs 8.17 [SD 4.2], $p<0.001$) and depression (7.7 [SD 1.9] vs 5.3 [SD 1.8], $p<0.001$) there was a significant reduction in the total scores following the low FODMAP intervention. However, when analysing these results categorically (using predefined ‘normal’ [≤7], ‘borderline abnormal’ [8–11] and ‘abnormal’ [≥12] categories) there was no significant change ($p>0.05$).
Conclusions

To our knowledge, this is one of the first studies to formally evaluate the feasibility and effectiveness of a dietitian-led low FODMAP group education programme for dietary management of IBS. Our results support those of Whigham et al and demonstrate that dietitian-led low FODMAP group education in a community-based setting is effective and feasible in the management of IBS.

Our initial recruitment method was similar to that currently used in clinical practice with GPs referring patients directly to dietitians. However, we achieved greater success when using a combination of recruitment strategies such as websites, clinic visits, and e-newsletters. The attendance rate of 77.3% for the first session and 85% for the second session are positive indicators that participants were willing to attend and were satisfied with the education they received. Seventy-six percent of participants reported ≥50% improvement in their IBS symptoms, whereas the remaining participants did not experience any improvement or did not start the diet.

Table 3: Changes in gastrointestinal symptoms following group low FODMAP diet intervention.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Before low FODMAP diet</th>
<th>After low FODMAP diet</th>
<th>Δ</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain before BM</td>
<td>2.45 (0.93)</td>
<td>0.91 (0.83)</td>
<td>1.55</td>
<td>0.001*</td>
</tr>
<tr>
<td>Pain after BM</td>
<td>2.30 (1.06)</td>
<td>0.80 (0.79)</td>
<td>1.50</td>
<td>0.01*</td>
</tr>
<tr>
<td>Difficulty to empty BM</td>
<td>1.91 (1.22)</td>
<td>1.00 (0.89)</td>
<td>0.91</td>
<td>0.04*</td>
</tr>
<tr>
<td>Constipation</td>
<td>1.73 (1.19)</td>
<td>0.64 (0.67)</td>
<td>1.09</td>
<td>0.01*</td>
</tr>
<tr>
<td>Hard BM</td>
<td>1.55 (1.21)</td>
<td>0.45 (0.52)</td>
<td>1.09</td>
<td>0.03*</td>
</tr>
<tr>
<td>Loose BM</td>
<td>2.73 (1.27)</td>
<td>1.09 (0.83)</td>
<td>1.64</td>
<td>0.003*</td>
</tr>
<tr>
<td>Incontinence</td>
<td>0.91 (0.94)</td>
<td>0.09 (0.30)</td>
<td>0.82</td>
<td>0.01*</td>
</tr>
<tr>
<td>Urgency to empty BM</td>
<td>2.82 (1.17)</td>
<td>1.27 (0.65)</td>
<td>1.55</td>
<td>0.001*</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>2.18 (1.40)</td>
<td>0.91 (0.54)</td>
<td>1.27</td>
<td>0.01*</td>
</tr>
<tr>
<td>Abdominal cramps</td>
<td>2.09 (1.14)</td>
<td>0.73 (0.79)</td>
<td>1.36</td>
<td>0.01*</td>
</tr>
<tr>
<td>Bloating</td>
<td>3.00 (0.9)</td>
<td>1.09 (0.70)</td>
<td>1.91</td>
<td>0.000*</td>
</tr>
<tr>
<td>Excessive gas</td>
<td>2.64 (1.03)</td>
<td>0.82 (0.98)</td>
<td>1.82</td>
<td>0.002*</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>0.73 (1.10)</td>
<td>0.27 (0.65)</td>
<td>0.46</td>
<td>0.14</td>
</tr>
<tr>
<td>Sickness</td>
<td>1.09 (1.04)</td>
<td>0.27 (0.47)</td>
<td>0.82</td>
<td>0.02*</td>
</tr>
<tr>
<td>Nausea</td>
<td>0.73 (0.91)</td>
<td>0.09 (0.30)</td>
<td>0.64</td>
<td>0.01*</td>
</tr>
<tr>
<td>Vomiting</td>
<td>0.27 (0.47)</td>
<td>0.00 (0.00)</td>
<td>0.27</td>
<td>0.08</td>
</tr>
<tr>
<td>Excessive belching</td>
<td>1.36 (1.12)</td>
<td>0.18 (0.41)</td>
<td>1.18</td>
<td>0.01*</td>
</tr>
<tr>
<td>Belching</td>
<td>0.55 (0.69)</td>
<td>0.18 (0.41)</td>
<td>0.36</td>
<td>0.17</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>0.18 (0.12)</td>
<td>0.09 (0.09)</td>
<td>0.09</td>
<td>0.34</td>
</tr>
<tr>
<td>Fullness</td>
<td>1.64 (0.81)</td>
<td>0.73 (0.79)</td>
<td>0.91</td>
<td>0.01*</td>
</tr>
<tr>
<td>Early satiety</td>
<td>0.73 (0.2)</td>
<td>0.36 (0.51)</td>
<td>0.36</td>
<td>0.17</td>
</tr>
<tr>
<td>Postprandial pain</td>
<td>1.45 (0.93)</td>
<td>0.55 (0.69)</td>
<td>0.91</td>
<td>0.02*</td>
</tr>
<tr>
<td>Epigastric pain</td>
<td>1.55 (1.04)</td>
<td>0.36 (0.51)</td>
<td>1.18</td>
<td>0.01*</td>
</tr>
<tr>
<td>Retrosternal discomfort</td>
<td>0.91 (0.94)</td>
<td>0.27 (0.47)</td>
<td>0.64</td>
<td>0.05</td>
</tr>
</tbody>
</table>

*p<0.05.
participants who do not experience any improvement were referred back to their general practitioner or health provider for their individualised IBS care. We anticipated that not all patients would improve with a low FODMAP diet, as similar to other dietary therapies, there is evidence that this diet does not work for every individual.21

Results from the telephone interviews showed that participants were generally positive and found the group education programme enhanced their understanding and acceptability of the low FODMAP diet. Our results are consistent with other IBS or non-IBS group dietary interventions, which demonstrated that group settings increase patients’ acceptability of the treatment through sharing of experiences as well as comradery with other patients.13,22,23 Furthermore, suitable educational resources as well as references to websites and apps also increased adherence and acceptability of the low FODMAP diet, a finding consistent with published literature.25,26 Websites and web apps such as ‘A Little Bit Yummy’ and the ‘Monash University Low FODMAP Diet App’ are increasing in popularity as they provide a fast and accessible platform for FODMAP friendly meals and products. However, the increase in web-based education creates uncertainty and vulnerability for evidence-based advice on low FODMAP diets, with individuals without the necessary expertise possibly delivering misleading information. More research is therefore warranted on the efficacy and safety of emerging web-based platforms.

Participants who did not start the diet after attending the initial session, expressed that they had personal reasons for not doing so. Suggesting it was not due to the delivery of intervention, but rather personal reasons. Screening for those suitable for one-to-one delivery rather than group delivery should be of importance when delivering a group education programme. Whigham et al employed a triage system using a telephone screening clinic to allocate participants’ suitability for group versus one-to-one education.21 Anecdotal feedback from a dietitian-led low FODMAP group education session at Christchurch Public Hospital also emphasised the need for a more vigorous screening process. Although our study employed strict exclusion criterion, telephone screening may be more useful for identifying those participants suitable for group education.

Significant improvements were observed in most gastrointestinal symptoms in our participants, supporting the findings of Whigham et al.13 In their study, 54% of participants were satisfied with their gut health following the intervention. Comparatively, our study found that 87% (13/15) of participants who implemented the diet were satisfied with their symptomatic improvement at the end of intervention. Our study also found similar symptomatic improvement comparative to that of traditional one-to-one education. Improvements in abdominal symptoms such as bloating, loose bowel motions, stool consistency and flatulence in our study were found to be consistent and significant similar to studies that used the traditional one-to-one pathway.26,27

A positive effect of the group low FODMAP education programme on psychometric and psychosocial measures was also observed in this study. There is limited literature regarding the impact of IBS group education on anxiety, depression, and health related quality-of-life. Some studies suggest that individualised dietary education and counselling improves patients’ understanding of IBS and their dietary management of IBS and hence their overall mood and quality-of-life.28–30 However, Whigham et al did not measure psychometrics and health-related quality of life. In our study, between 45–50% of participants reported having anxiety or depression symptoms prior to entering the study. Although the anxiety and depression scores did not improve significantly, the nature of the intervention, pre-existing psychological disorders, and the small number of participants would not have been expected to provide the study with sufficient statistical power to investigate these changes. Long-term behavioural therapy, medications and other strategies besides dietary management and a longer follow-up period may possibly demonstrate more positive changes in mental health and hence HADS scores.

The mixed methods design of our study meant it was possible to assess both the feasibility and practicality of a low FODMAP group education programme. Our quantitative data needs to be viewed with caution and interpreted in context with the
limitations of the study. There was also no comparator group and participants were not blinded to the intervention, although this is extremely difficult for a whole diet study. Despite these limitations, the results are promising with clinical improvement being seen across a wide range of relevant gastrointestinal symptoms.

Given that this study has demonstrated that low FODMAP group education in a community setting is feasible in a New Zealand context, future research should investigate the efficacy of low FODMAP group education in terms of reintroduction and diet modification. Efficacy in a range of ethnicities and IBS phenotypes should also be examined. Clinical trials powered to determine whether low FODMAP group education is effective at improving gastrointestinal and psychological symptoms in patients with functional gastrointestinal disorders such as IBS in a cost-effective way are warranted.

In conclusion, a dietitian-led low FODMAP diet group education programme in adults diagnosed with IBS-D or IBS-M is an effective and feasible intervention. A dietitian-led low FODMAP group education programme is worthy of consideration in routine clinical practice.

Competing interests:
Dr Gearry reports grants from Zespri, grants from AbbVie, outside the submitted work. Ms Watson reports personal fees from Canterbury DHB and personal fees as a self-employed dietitian, outside the submitted work.

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Are over-the-counter fish oil supplements safe, effective and accurate with labelling? Analysis of 10 New Zealand fish oil supplements

Julia J Rucklidge, Ian C Shaw

ABSTRACT

AIM: Fish oil supplements are regulated in New Zealand under the Dietary Supplement Regulations (Section 42, Food Act 1981) and therefore are not subject to the same level of scrutiny and regulations as medicines. We investigated accuracy of labelling, stated health benefits of fish oil supplements sold in New Zealand, and risks relating to possible mercury content.

METHOD: The amounts of omega-3 fatty acids contained per capsule were determined by an independent laboratory using gas chromatography on 10 of the most popular over-the-counter fish oil supplements sold in New Zealand and were compared with amounts stated on product labels. Information on doses recommended to achieve a specific health benefit were taken from the 10 labels as well as the company websites. These recommended doses were compared with published recommended doses identified as being effective in those health areas stipulated on the labels, based on either systematic reviews, meta-analyses and/or consensus statements. Mercury was analysed by an independent laboratory using inductively coupled plasma mass spectrometry.

RESULTS: The actual amounts of EPA and DHA per capsule in 90% of the over-the-counter fish oil supplements analysed were within 10% of the amount stated on the product labels. Only one product was greater than 10% below the stated dose on the label. All products suggested benefit across heart, brain and joint health and all but two products stated a range of capsules required to achieve that health benefit (eg, 2–6 capsules). Based on the maximum number of capsules recommended (which ranged from 3–6 capsules), only three products would likely confer the dose identified as optimal for achieving a health benefit across all three health areas. Only two products recommended doses that would likely confer a health benefit both at the minimum and maximum number of capsules. More products would likely benefit brain and heart health than joint health. Mercury was not detected in any sample.

CONCLUSIONS: It is reassuring that the doses of 90% of the products were accurate and that mercury was not detected in any sample; however, less than a third of the supplements would likely confer all the health benefits stated, even at the highest recommended daily doses. This paper has highlighted the ongoing challenges associated with the regulation of “health claims” associated with dietary supplements in New Zealand. Indeed, the literature on health effects is contradictory at best. Clearer definitions of the types of health statements that can be made and the research necessary to support them requires regulatory clarification.

Fish oil supplements are among the most popular dietary supplements on the global market, with use having increased dramatically over the last decade. In a biochemical context, the omega-3 fatty acids, docosahexaenoic acid (DHA) and eicosapentaenoic acid (EPA), play crucial roles in brain development, cell signalling and gene regulation; they are essential (ie, required in the diet) fatty acids (EFAs) because they are not biosynthesised in human cells.
There has been an enormous body of research exploring the health benefits (note that “health benefit” is not being used with any legal or regulatory meaning) of EFAs for both physical and mental health. There have been hundreds of clinical trials, reviews and meta-analyses documenting the potential benefits of omega-3 fatty acids in medical conditions, including treatment of migraine, cardiovascular health post-myocardial infarction, rheumatoid arthritis, post-operative immune function and treating type 2 diabetes. Other studies have shown no clinical benefit, such as in the treatment of postoperative arrhythmias, postoperative atrial fibrillation, dementia or acute lung injury.

Research over the last decade demonstrating the importance of fish oil for mental health and supplementing the diet with EFAs has emerged as a promising therapy for the management/treatment of psychiatric disorders, both as a monotherapy and as adjunct to medications, to reduce the risk of developing psychosis, treat attention-deficit/hyperactivity disorder (ADHD), anxiety and assist with the management of mood disorders. On the other hand, no effects have been observed for the treatment of symptoms associated with autism and tics.

Fish oil supplements in New Zealand are regulated by the Dietary Supplement Regulations 1985 under the Food Act 2014. As part of these regulations as well as the Consumers Guarantees Act 1993, supplements must be true to label. However, a study published in 2015 indicated that many fish oil supplements sold in New Zealand did not contain the amounts of active ingredients stated on labels (only 3 of 32 brands tested contained label amounts of omega-3 fatty acids), raising concern that supplements are poorly regulated in New Zealand. Further, the majority of the fish oil supplements (83%) analysed by Albert et al exceeded recommended oxidation levels, meaning they were highly oxidised, likely due to the oxidative susceptibility of double bonds in the fatty acid chain. The implication for consumers is that the actual daily intakes may be too small to confer health benefits.

In considering health benefits, the form of the EFAs is important. In fish oil supplements, the omega-3 fatty acids are either as triglycerides or ethyl esters (Figure 1). Ethyl esters are more common probably because they are cheaper to produce. Following a refinement process, the fatty acids may be present as free fatty acids, ethyl esters or re-esterified triglycerides, which leads to

Figure 1: Conversion of omega fatty acid ethyl esters to triglycerides by gut bacteria.

![Conversion of omega fatty acid ethyl esters to triglycerides by gut bacteria.](image)

Triglycerides are well absorbed in the gut, but ethyl esters are poorly absorbed. For high omega fatty acid supplements: R = omega fatty acid (eg, ALA); the R groups in a triglyceride might be different (eg, ALA, DHA).
questions about the quality and bioavailability of this highly refined and ostensibly synthetic product.

EFA ethyl esters are manufactured by trans-esterification of natural EFA triglycerides. The resulting ethyl esters are distilled at low pressure (molecular distillation) to enhance the omega-3 ethyl ester content by removing short chain fatty acid ethyl esters. However, research has shown that EFA ethyl esters are less well absorbed than natural EFA triglycerides, as they must be reconverted to triglycerides to enable intestinal absorption.25,26 Poor absorption has important implications for the bioavailability of fatty acids derived from fish oil and supplement effectiveness.

In addition to actual EPA and DHA capsule content, whether the consumed dose will confer a stated health benefit is important and has not been systematically researched for accuracy. Labels on fish oil supplements typically provide information on the recommended daily dose to give a health benefit. The most common benefits on labels of fish oil supplements are improved heart, joint and brain health—DHA and EPA doses are particularly important for these health benefits. By law, the label cannot stipulate a therapeutic claim (as that would make it a medicine) and therefore, interpretation of the intention of the stated health benefit is obscured. However, the only way to learn about potential health benefits and optimal doses would be through published clinical trials, systematic reviews and meta-analyses.

EPA and DHA doses used in clinical trials vary considerably with concomitant effect discrepancies; however, published recommendations have been made on optimal doses for conferring benefit for specific health conditions. For example, a 2017 meta-analysis27 and 2018 review7 identified 1.0g/day EFAs (EPA+DHA) as more likely to be helpful for improving cardiovascular health post-myocardial infarction (MI). Two meta-analyses have identified that ingestion of EFAs (EPA+DHA) at a dose ≥2.7–3.0g/day is more effective in improving painful and/or tender joints compared with <2.7g/day.8,28 For brain health, the greatest amount of positive evidence is for mood disorders and ADHD.29 A 2019 consensus paper identified that the optimal dose for the treatment of depression should be 1–2g of net EPA daily, from either pure EPA or an EPA/DHA (>2:1) formula.30 A 2018 meta-analysis concluded that the dose of EPA should be ≥0.5g/day to be most likely to confer benefit for the management of ADHD symptoms.16

In addition to health benefits, it is also important to consider health risks. In the case of fish oil consumption, the most significant toxicological risk relates to organic mercury (eg, methyl mercury—CH₃Hg⁺) contamination—organic mercury is neurotoxic and lipid soluble and so concentrates up the food chain particularly into oily fish.21 Oily fish species (eg, sardines, pilchards) are often used for fish oil manufacture.

We are aware of only one study that investigated mercury in over-the-counter fish oil supplements.32 Analysis by cold vapor atomic absorption spectrometry revealed that all five supplements studied contained insignificant amounts of mercury with levels ranging from <6µg/L to 12µg/L.32 However, it is the form of mercury that is toxicologically important. Organic mercury (eg, CH₃Hg⁺) is far more toxic than inorganic mercury (Hg⁺ or Hg²⁺) because it forms a cysteine complex which mimics methionine and crosses the blood brain barrier.33 Inorganic mercury is less neurotoxic as it is unable to efficiently cross the blood brain barrier.34

The aims of the current research were to investigate whether the EPA and DHA content of the top 10 dietary fish oil supplements sold over-the-counter in New Zealand are accurate (as determined through analysis of fatty acid composition), contain low mercury levels, and whether the recommended daily doses for a health benefit are consistent with the doses determined to be effective based on meta-analyses, systematic reviews and/or consensus statements.

**Methods**

**Selection of the top 10 fish oil supplements sold in New Zealand**

A fish oil dietary supplement for the purpose of this study was defined as any product consumed orally that was labelled ‘fish oil’, ‘odourless fish oil’ or ‘omega-3 fish oil supplement’ and contained EPA and DHA from the bodies of deep-water fish (ie, sardines, pilchards, anchovies, mackerel, tuna) or farmed salmon. Marine oils from
alternative sources (eg, krill, calamari, algae) were omitted due to their compositional differences. Similarly, plant sources of omega-3 (eg, flax, chia seeds, walnuts, rapeseed) fell outside the scope of the current study.

All fish oil supplements that were available over-the-counter in supermarkets, pharmacies and health stores in New Zealand were eligible for inclusion in the study; however, we asked for assistance from local companies (Foodstuffs New Zealand Ltd, Progressive Enterprises Ltd, Green Cross Health Ltd, and Health 2000 Retail Ltd) to determine the top 10 best sellers based on sales information from these companies. Fish oil supplements were purchased over-the-counter from stores owned and operated by Foodstuffs New Zealand Ltd and Green Cross Health Ltd, including Life Pharmacy, Amcal, and PAK’n SAVE supermarket. Products with a use by date between 15 and 35 months from the date of purchase were selected.

The ingredients and recommended daily dosage to confer health benefits for each supplement were recorded, including the batch number and country of origin. Possible health benefits were based on the label statements as well as statements on the manufacturers’ New Zealand websites, and the range in the number of capsules recommended for each health benefit was noted. These stated health benefits and doses were confirmed as up-to-date as of 24 November 2019.

Collection, storage and analysis of fish oil samples

Fish oil supplements were purchased in April 2015, they were stored in the dark at <30°C to minimise oxidative and light-induced changes. Three capsules from each fish oil package were analysed within three months of purchase. The samples were coded so that the analyst did not know the product identity.

Analysis of fish oil supplement samples for omega-3 fatty acids

The contents of three fish oil capsules were pooled and an aliquot analysed by gas liquid chromatography (GLC) for EPA and DHA using AOAC Official Method 991.39 by AsureQuality Ltd, Auckland, a New Zealand Good Laboratory Practice (GLP) accredited laboratory approved by International Accreditation New Zealand (IANZ). This accreditation denotes that the analytical methodology has been validated to determine between sample and within sample analytical variability, and that all quantitative laboratory equipment (eg, balances) is regularly calibrated in accordance with approved Standard Operating Procedures and that readings (eg, mass) variability is within pre-defined acceptable limits.

In brief: approximately 0.025g of fish oil from each capsule was accurately weighed into a glass vial containing 25mg hexacosanoic acid (C23:0) methyl or ethyl ester (internal standard) in 2,2,4-trimethylpentane. Samples were derivatised to methyl esters, separated on a capillary GLC column, and peaks detected by a flame ionisation. GLC peaks were identified using EPA and DHA authentic standards; retention times were expressed relative to the internal standard for identification purposes. Peak areas were used to determine EPA and DHA concentrations. Results were expressed as amount (mg) of EPA and DHA per capsule (ie, taking account of different fish oil weights per capsule for different products). Individual samples were analysed (ie, no replicates); however, each batch of analyses included at least one sample in duplicate to check within sample variability. All duplicate samples analysed fell within AsureQualitys repeatability criteria.

Analysis of mercury in fish oil supplement samples

Mercury was determined by inductively coupled plasma mass spectrometry (ICP-MS) by Hill Laboratories Ltd (GLP accredited, IANZ approved). The American Public Health Association (APHA) Standard Method 3125B was used. In brief: fish oil samples were acid digested (nitric acid + hydrochloric acid, 85°C, 1 h) and the acid extract analysed directly by ICP-MS.

Results

Top 10 over-the-counter fish oil supplements sold in New Zealand

The top 10 fish oil supplements sold in New Zealand were identified (brand names are not reported here for commercial reasons) and purchased.
Analysis of omega-3 fatty acids in the top 10 fish oil supplement samples

The analytical laboratory (AsureQuality) carried out in batch and between batch replicates of samples to determine analytical variability. Their results are as follows: repeatability ±5%, reproducibility ±12%, and uncertainty of measurement ±7.2%. The limit of detection of the analytical method is 6mg/100g, and the limit of quantification is 10mg/100g.

Table 1 shows the label amounts of EPA and DHA and the actual amounts based on our analyses. The percentage differences between actual amount and label amount of EPA and DHA range from 2.8% above the label amount to 11.1% below the label amount for EPA, and no difference to 12.5% below the label amount for DHA. All fish oil supplements analysed contained greater amounts of EPA than DHA. Using 10% as an accepted range of error (this also accounts for the analytical method’s uncertainty of measurement of 7.2%, and is consistent with TGA regulations on standards for capsules and tablets that state they must be above 90% of the stated content), using this definition, 90% of the products were true to label in terms of capsule EPA and DHA content.

Recommended daily doses of the 10 supplements for conferring a health benefit

To determine whether doses contained within the supplements are comparable to those doses identified in the published literature as most likely to achieve a health benefit, we calculated the doses of EPA and DHA below the label amount for DHA. All fish oil supplements analysed contained greater amounts of EPA than DHA. Using 10% as an accepted range of error (this also accounts for the analytical method’s uncertainty of measurement of 7.2%, and is consistent with TGA regulations on standards for capsules and tablets that state they must be above 90% of the stated content), using this definition, 90% of the products were true to label in terms of capsule EPA and DHA content.

Table 1: Doses (label and actual) of 10 supplements (brands) sold in New Zealand and daily doses for health benefit based on label recommendations.

<table>
<thead>
<tr>
<th>Brand</th>
<th>EPA Label mg cpsl</th>
<th>EPA Actual mg cpsl</th>
<th>EPA Label-Actual Diffa</th>
<th>DHA Label mg cpsl</th>
<th>DHA Actual mg cpsl</th>
<th>DHA Label-Actual Diffb</th>
<th>Label recommended daily dose for health effects</th>
<th>Total recommended dose rangec mg</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Heart EPA+DHA</td>
<td>Joint EPA+DHA</td>
<td>Brain (mood) EPA only</td>
<td>Brain (ADHD) EPA only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>180</td>
<td>181</td>
<td>+0.6</td>
<td>120</td>
<td>114</td>
<td>-5.0</td>
<td>1–3 1–3 1–3</td>
<td>300–900 300–900 180–540 180–540</td>
</tr>
<tr>
<td>2</td>
<td>180</td>
<td>184</td>
<td>+2.2</td>
<td>120</td>
<td>119</td>
<td>-0.8</td>
<td>3–6 6 3–6</td>
<td>900–1,800 1,800 540–1,080 540–1,080</td>
</tr>
<tr>
<td>3</td>
<td>270</td>
<td>273</td>
<td>+1.1</td>
<td>180</td>
<td>171</td>
<td>-5.0</td>
<td>2–4 4 2–4</td>
<td>900–1,800 1,800 540–810 540–810</td>
</tr>
<tr>
<td>4</td>
<td>270</td>
<td>266</td>
<td>-1.7</td>
<td>180</td>
<td>174</td>
<td>-3.3</td>
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<td>177</td>
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<td>120</td>
<td>118</td>
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<tr>
<td>6</td>
<td>360</td>
<td>352</td>
<td>-2.2</td>
<td>240</td>
<td>228</td>
<td>-5.0</td>
<td>3 5 3</td>
<td>1,800 3,000 1,080 1,080</td>
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<tr>
<td>7</td>
<td>275</td>
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<td>185</td>
<td>175</td>
<td>-5.3</td>
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<td>210</td>
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</tr>
<tr>
<td>10</td>
<td>360</td>
<td>360</td>
<td>0.0</td>
<td>240</td>
<td>240</td>
<td>0.0</td>
<td>3 5 3</td>
<td>1,800 3,000 1,080 1,080</td>
</tr>
</tbody>
</table>

Number of products likely to be effective for health benefit based on published recommended doses.

**Bold:** Doses likely to be effective based on comparison with published recommendations on dose across heart (≥1g EPA+DHA27), joint (≥2.7g EPA+DHA28) and brain (≥1g EPA for mood30 and ≥500mg EPA for ADHD16). Actual amounts have been rounded to the nearest whole number.

Grey boxes identify those two products that recommend a daily dose within the same ranges as those identified as effective in the published literature across heart, joint and brain.

a Label-Actual/Label x 100%

b Label dose x number of capsules recommended. Range based on number of capsules recommended on product labels.

c Example: (180mg+120mg)x3=900mg

Abbreviations: cpsl = capsule, diff = difference
and DHA based on the number of capsules recommended. The daily dose was determined by using both the lowest and the highest recommended daily dose given on the specific labels (eg, if the label stated take 2–4 capsules for brain health, we used two capsules and four capsules as the daily lowest and highest number of capsules for ‘brain’ respectively) and was calculated based on label content of omega-3 fatty acids per capsule. EPA dose alone was also calculated as EPA dose alone is relevant for supporting symptoms associated with mood and ADHD.

The health benefits stipulated across the 10 supplements were similar, with all of them reporting promotion of heart health, joint health and brain function on the labels and/or manufacturer websites. Stated benefits varied from “assists in the maintenance of healthy brain function” to “helps during times of stress and emotional upset” to “keeping your heart healthy” to “easing many kinds of inflammation, including joint swelling and stiffness”. As of 24 November 2019, none of the labels or company websites referred to specific research that supported the stated health benefit; however, this is not a regulatory requirement for dietary supplements.

All products taken at the highest recommended daily dose contained more than 500mg of EPA and as such could support symptoms associated with ADHD,16 50% of them taken at this highest dose would contained the minimal dose (≥1g EPA)30 identified for supporting mood, 80% of the products had doses comparable to the recommended dose for heart health (≥1g EPA+DHA),27 and 30% contained the optimal dose for assisting with joint health (≥2.7g EPA+DHA).8,28 Based on the lowest recommended daily doses, 50% were in the range necessary to confer a benefit for symptoms associated with ADHD, 20% were in the dose range for heart health and mood, and 30% were in the dose range for joints. At the highest recommended dose, three (Brands 6, 9 and 10) of the products (30%) would confer a health benefit across all three areas of function. Only two products (Brands 6 and 10—Table 1) recommended doses that matched research doses identified as necessary in order to confer a health benefit both at the minimum and maximum number of capsules (Table 1).

Amounts of mercury in fish oil supplements

Measurement of mercury showed no mercury above the limit of detection (LoD); 0.010 mg/kg; ie, not detected. Therefore, the mercury levels were below WHO provisional tolerable weekly intakes.38

Discussion

Label vs actual content of omega-3 fatty acids in fish oil supplements

The actual amounts of EPA and DHA per capsule in all but one of the over-the-counter fish oil supplements analysed were within 10% (which takes account of the analytical uncertainty of measurement of ±7.2%) of the amount stated on the product labels. A single product had EPA/DHA doses greater than 10% below the stated dose on the label. Only one sample was analysed per product; therefore, it is not possible to determine within brand variance.

These results are not consistent with the results of Albert et al,23 in that 90% of the products were true to label versus 10% of those tested by Albert et al.23 This also means that there was likely very much less oxidation in our samples (although we did not measure it). It is possible that in the intervening year since the Albert et al23 study was published, the industry addressed the labelling issues. It is also possible that the popular brands that we studied were not on the shelf for as long as other less popular brands that might have been included in the Albert et al study,23 allowing for less time for oxidation to occur. Indeed, two more recent studies39,40 showed that Australian and New Zealand fish oil products did meet the stated doses on their labels for EPA and DHA content, and were not oxidised, although the methodology used has been challenged.41

It is possible that omega-3 fatty acids might be lower than those stipulated on the labels because unsaturated fatty acids are vulnerable to oxidation due to the double bonds in the fatty acyl chain23 which can undergo an ultra violet light catalysed oxidative free radical reaction. Indeed Albert et al23 explained the discrepancy between label and actual omega-3 fatty acid levels in their study by the presence of oxidation products. In addition, the legislation requires data from a pooled sample of
20 capsules, whereas we analysed three individual capsules from the same purchased container. Bearing this in mind, in our study we found only one product (Brand 8; Table 1) with marginally lower EPA and DHA than stated on the label and therefore we do not think it necessary to consider the toxicological implication of unsaturated fatty acid oxidation products in the context of the top 10 fish oil supplements sold in New Zealand.

**Health benefits**

We investigated whether the recommended doses on labels of these 10 over-the-counter supplements are in line with the amounts shown to provide optimal health benefits based on research. Based on the highest recommended daily doses, the doses of all 10 products are within the ranges used in clinical studies that have been effective in treatment of symptoms associated with ADHD (≥0.5g EPA) but only half contained doses recommended for supporting mood (≥1g EPA). Eighty percent of products sampled used doses recommended for support of cardiovascular health (1g EPA+DHA/day) whereas 30% contained the dose identified to be of benefit for joint health (≥2.7–3g EPA+DHA). However, for the lowest recommended daily dose, 50% would be adequate for ADHD, 20% for cardiovascular health and mood, and 30% for joints. Therefore, in order for the consumer to increase the opportunity for a health benefit to occur, it would be best to consume at least the highest number of capsules recommended, albeit in some cases, this would mean taking up to six fish oil capsules per day.

In interpreting these health benefits, it is important to note based on the published literature we reviewed and cited that there is large variability in doses and measures used in clinical research across the conditions investigated. It is important to recognise that the conditions studied (heart, joint, brain) cover myriad health problems and therefore it is difficult to identify optimal effective doses for specific disorders. Indeed, it is equally difficult to define the broad disorders covered; for example ‘joint’ could refer to osteo- or rheumatoid arthritis or other non-arthritic disorders, ‘heart’ could mean prevention of cardiovascular infarction, lowering high blood pressure, modifying cholesterol levels, and ‘brain’ could mean improved cognitive function or mood or reduce anxiety. Therefore, this aspect of our discussion is indicative and not definitive. Further, the samples range from children to adults and a dose that may confer a health benefit for an adult may not necessarily apply for children and vice versa.

Even the results on a specific dose are mixed with some studies showing benefit and others not. For example, a 2017 meta-analysis did not find a significant benefit of a dose ≥2.6g/day for assisting with the reduction of arthritic symptoms, but the authors admit significant discrepancies between the individual studies used in their analysis. Further, their analysis showed that EFAs are effective in pain reduction in rheumatoid arthritis, but not in osteoarthritis. A much higher dose may be required to be effective in the management of hypertension, highlighting the difficulty in determining effects and effective doses. There is also disagreement on overall health benefits across meta-analyses; for example, a 2018 meta-analysis identified that omega-3 capsules do not reduce heart disease, stroke or death, while a 2019 meta-analysis identified that marine omega-3 supplementation does lower risk of myocardial infarction and other cardiovascular outcomes. What is clear is that the EFA/health benefits interface is a minefield of conjecture.

The effective dose of ≥0.5g EPA for ADHD symptoms does not reflect the fact that many of the studies have included DHA in their formulae which may also be important. Further, the positive effect of EFAs for ADHD has only been observed for parent ratings not ratings by teachers. Lower doses than those identified in the literature as optimal may confer a benefit, although the opportunity for benefit diminishes the further the dose is away from that identified as optimal. However, one observation that is consistent across all three health areas we explored (brain, heart, joint) is that there appears to be a linear dose-response relationship between omega-3 supplementation and outcome. As such, the doses we identified through the literature appear reasonable targets to optimise the opportunity of a health effect to occur.
Importantly, the doses used in the research were at least of the same magnitude as those recommended in the daily doses of the over-the-counter supplements we studied. Previously, we found that B vitamin doses from over-the-counter products are significantly below the therapeutic doses used in clinical studies for the treatment of mental health conditions in children. It is reassuring that this is not the case for EFAs.

This research highlights the challenges of labelling for supplement manufacturers in terms of health benefits and exposes that the law as it stands, encourages vague statements that are very difficult to substantiate and tie to any specific clinical literature. The most common and simplest way to determine whether a product has conferred a health benefit is to study people who have a disease and then track whether that disease improves following supplement consumption. A “health benefit” could relate to prevention of a disease developing, reduction of mild symptoms or improvement in those with no disease or symptoms. Definitive efficacy studies for prevention are very challenging to conduct and to verify proof of an effect. Investigations of healthy populations typically result in null effects due to participants having no room for improvement. As a result of this difficulty, the interpretation that a health benefit results from research on people with symptoms is reasonable. Further, the field is moving so quickly such that health benefits observed in early trials are not always replicated in later trials, making it a challenge to keep up with the research underpinning the statements and leaving it open for dispute as to what constitutes a reasonable health benefit. Better regulation of “health claims” for dietary supplements and the research necessary to support these statements is clearly overdue. A starting point could be for manufacturers to list on labels and websites the source of the evidence to support any stated health benefit.

**Risks**

Our studies showed that mercury levels in fish oil supplements analysed were <0.010mg/kg (ie, LoD). Thus, there is no or negligible risk of mercury toxicity from over-the-counter fish oil supplements.

**Conclusion**

This study suggests that the majority of the 10 most popular fish oil supplements sold in New Zealand are true to label based on dose but mixed in terms of potential health benefits they might confer. Overall, if maximum recommended daily doses of supplements are taken (as recommended on the label), most products may confer health benefits for brain and heart health, but probably not joint health. In this respect, only two products were true to label and would likely confer a health benefit across heart, joint and brain across both minimum and maximum daily dose. However, mercury was not found in any of the samples analysed which suggests that the risk of mercury toxicity is negligible and therefore, while they may not all confer a health benefit, they are safe to consume.
Competing interests: Nil.

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Familial hypercholesterolemia (FH) is the most common dominant genetic disorder in humans and causes premature heart disease and death. The incidence of heterozygous FH in the general global population is 1:250; however, rates in Māori are not known. It is characterised by very high-level low-density lipoprotein-cholesterol (LDL-c), systemic manifestation of cholesterol deposition (tendon xanthoma, xanthelasma and arcus cornealis). Three clinical definitions for FH are used to identify people with possible FH; the most commonly used are the Dutch Lipid Clinic and Simon Broome criteria. Early detection and treatment of individuals with this disorder is important to prevent the early development of cardiovascular disease. Current guidelines recommend screening of high-risk individuals, and then cascade screening of family members in childhood. Cascade screening using the genetic test is recommended once the proband for DNA testing is identified. Studies have shown that 15–20% of family members are incorrectly classified based on cholesterol testing alone. Treatment of gene positive offspring is recommended to start at the age of 8–10 years with the aim of reaching a target LDL-c <3.5mmol/L or to less than 50% if the target is not achievable. Early identification of FH in children is vital as children with FH can have normal life expectancies if treatment is started early. The most common mutation causing FH is in the LDL receptor, identified in ~90% of cases. The LDL receptor mediates endocytosis of LDL-c into cells including hepatocytes.

A number of medications are recommended to treat FH; intensive statin therapy, ezetimibe and protein convertase subtilisin/kexin type 9 (PCSK9) inhibitors. At present, New Zealand has a limited range of drugs to treat hypercholesterolemia. For example, rosuvastatin, the most potent statin, or PCSK9 inhibitors are not funded for FH, limiting choice in individuals at very high risk of premature heart disease (See Figure 1, patient experience). Studies suggest that
expensive medications like PCSK9 inhibitors are cost effective as they significantly reduce cardiovascular events in FH.\textsuperscript{10}

**LDLR:c.2312-3C>A splicing mutation**

A specific mutation in the LDL receptor, LDLR:c.2312-3C>A splicing mutation, was described in a Māori man who was working in western Australia who presented with coronary artery disease in his 30s. He had a strong whānau (extended family) history of premature death from heart disease.\textsuperscript{11} He described a whānau blighted by premature heart disease and death and a whānau legend of “a white woman” who had married their Māori ancestor at the turn of the 20th century who had “brought a curse on them”. The gene has been traced back to whānau with origins in Valencia (in eastern Spain), with an ancestor moving to northern France during the 1600s. Descendants then migrated to England, and subsequently to New Zealand whereupon one ancestor married a Māori man and then moved to in a remote area of New Zealand. This union resulted in a very large whānau afflicted with premature heart disease and death. Endocrinologists visited this remote area and tested a number of members of the whānau and confirmed the presence of this mutation. However, no systemic screening and treatment was initiated as no national system was in place to manage this.

In 2018, three members of the extended whānau presented to the cardiology department at Auckland City Hospital with very high LDL-c; one male in his early 30s with significant atherosclerosis requiring stents and two females in their 20s with tendon xanthomata. They all told a story of a large extended whānau affected by premature heart disease with high rates of premature death. They remembered the endocrinologists that had visited the whānau about 15 years earlier who had taken samples, but they were not sure of the diagnosis. Contact was made with the Christchurch Laboratory who had records of an identified LDL-c receptor mutation in this whānau. Confirmation of the presence of the same mutation was made in the three index patients. This revealed issues in the health system in terms of systemic screening and treatment of whānau now scattered across the country and the world.

The consequence of a lack of a national strategy for FH has resulted in a fragmented and disparate service for patients (Figure 2, practice nurse experience). There are pockets of experts in some places, but there is also little awareness of how to treat and manage this condition in the general medical community. For example, few clinicians without a specific interest in FH understand that genetic testing and treatment needs to be implemented in childhood (Figure 3, patient experience).

There was no prospect of a national service in the near future; however, a solution for this whānau was needed urgently.

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**Figure 1: Patient experiences.**

I am a very physically active and fit woman in my early 30s. My cholesterol levels were well controlled on the atorvastatin and ezetimibe tablets, but I had extreme fatigue and a ‘cloudy mind’. I would sleep from 3pm to 6pm, eat my dinner and sleep right through the night. If I exercised it would take my body two days to recover from fatigue. I was experiencing short-term memory loss consistently every day. At first I thought it was lack of sleep or ‘mummy brain’. I was unable to hold conversations with people because my mind couldn’t keep up. A lot of conversations went over my head.

Because of all these symptoms I decided to try Rosuvastatin, which is not funded. I had none of the previous symptoms; however, I experienced difficulty with the monthly price. And because the price kept increasing and I was unable to afford this. I stopped it altogether after the second month.

Unfortunately, my cholesterol levels were high, so I restarted rosuvastatin. Realistically because of the price, I probably will eventually end up back on atorvastatin and it scares me. I’m afraid of what it’s going to do with my brain as I age.
Methods
Consultation with a broad range of invested stakeholders was undertaken to determine how to best ensure that the whānau were empowered to manage this condition across generations and geography. Initial consultation was with index whānau and then kaumātua (elders). Then broader consultation was with the national genetic services, the paediatric metabolic department and the director of Māori Health Research at the Waitemata and Auckland District Health Boards (DHB) Dr Helen Wihongi. The discussion with Dr Wihongi focused on how to ensure that tikanga Māori (custom, ethics) was taken into account especially around the issues regarding taking

Figure 2: Rural nurse experience.

I have been here for 35 years and was aware from the start that some research had been done by a cardiologist at the University Of Auckland School Of Medicine in the late 1970s. Therefore, as health providers we knew that it was likely a heredity gene (even though it was prior to the possibility of genetic mutation identification). We were constantly reminded of the impact of this mutation on the family by photos and in discussion about husbands, children, aunts and uncles who had suffered a sudden and catastrophic cardiac event at an early age. We considered every Tangihanga to be a health system failure.

Therefore, in primary care the families have always been a target for us, but we struggled with secondary care response and with compliance with statins due to the high doses required and follow on side effects. We had found that atorvastatin worked better than simvastatin and then at one stage Pharmac took atorvastatin off the subsidised list which was a frustration. As well most of the patient information focused on healthy food choices resulting in some erroneously believing that if they made dietary changes then medication would be unnecessary.

It has also been difficult when the family are no longer registered with us and their new GP does not understand the condition. One example was that I had a man in his 50s who had very high LDLs up until the age of 50 and would not take statins—he moved to Auckland and over the last five years has been compliant with medication. I wrote to his GP and asked if he would refer him to cardiology and explained why—his response was to send me a photo of his normal lipid profile—he did not understand that it was likely that 50 years of very high lipids had already caused significant damage—he did not refer—we are afraid of an unnecessary event at some stage as he ages.

The identification of the genetic variant has instilled us with renewed confidence that we will be able to play a part in improving health outcomes for this family. The willingness of the secondary care provider to visit the Marae to provide education and develop a culturally appropriate plan of care has been very effective. We no longer feel that we are fighting the battle on our own. The health system taking a family centred approach has resulted in an effective referral and treatment pathway for this extended family that will certainly save lives.

Figure 3: Patient experience.

I have the genetic mutation and my 13-year-old son has very high cholesterol levels. My GP referred him to the hospital paediatric department for testing and surveillance. I had to take two days off work specifically for an appointment because of the distance to the hospital. When we arrived the doctor told us she didn’t know why he was there because he has no existing heart disease. I proceeded to tell them about familial hypercholesterolemia and how we now know the specific mutation and its great news for our family. I explained that my son is on a statin, even though he is a young boy and our understanding was that he needs to have his heart health and progress monitored very closely. I also said that he needed blood tests for the gene. The doctor looked at me dumbfounded and was embarrassed. She apologised, arranged a blood test and booked another appointment with another specialist. I had to take another two days off work for the second appointment. This specialist told us everything we already knew, and sent us on our way with pamphlets. It felt like a waste of time.
and storing of blood, as well as who owned the data. We reviewed the current consent form used by the genetic services to ensure this explained that blood samples may be stored and that this may have implications for the whakapapa (genealogy). The form also explains that the samples are kept in New Zealand and are not given to third parties. There is currently no national genetic database for FH in New Zealand so no one currently holds the data other than the treating physician and laboratory. We also discussed how to balance the needs of the extended whānau and the privacy of the individual. The genetic and metabolic services provided support for cascade screening and were happy to be part of the hui. The local general practice was also consulted to assess their needs and opinions on how best to move forward.

Hui

A hui (social gathering) was organised to inform the whānau about the genetic mutation and discuss how best to manage this to ensure access to testing and treatments. This was attended by the whānau, kaumātua, doctors and nurses from the local health practice, the national genetic services, a doctor from ADHB and a health science student.

On arrival at the marae (meeting ground) there was a pōwhiri (formal welcome), which included a karanga (call) to the manuhiri (guests), and a response. After a number of speeches and songs by the men, we all introduced ourselves. After a mihi (introduction) and waiata (song) the doctor gave a talk that centred on what FH is, what age to screen and treat FH, how the gene is transmitted, how to organise testing and risks and benefits of treatment. The geneticists then explained genetic and cascade testing and how it is undertaken. The formal presentations by the doctors and geneticists lasted two hours, and the rest of the hui was comprised of open discussions. There was also a need to acknowledge the past. The whānau felt used and let down by previous doctors who had visited and taken samples but gave no information on how to prevent further deaths. This had to be acknowledged by the medical team. The pace of discussions was driven primarily by the needs of the whānau. For example, when the doctor spoke too fast or used medical terms, the whānau backtracked by asking questions. There was a strong feeling that decisions on how to manage this issue could not be made in haste, and that we were all in this together (He waka eke noa (A canoe which we are all in with no exception)). There was agreement that for any solution to work, it needed to be acceptable to everyone and according to the Kaupapa Māori principles of self-determination, involvement of the whānau and āta (respectful relationships).

Issues discussed were:

- Who should have access to the information and how to balance the rights of the individual vs the rights of the whānau?
- How to cascade screen whānau and ensure this is done in perpetuity?
- How to ensure whānau members living in other counties access the information?
- How to ensure whānau is updated on new information regarding treatment?
- How to access novel agents shown to work in FH?
- Can PHARMAC be approached for access for new medications for this whānau under Te Tiriti o Waitangi obligations?
- How to manage blood samples, ethical issues with privacy and storage of blood?

Results

A whānau member was nominated to run a closed social media page for the whānau that includes a family tree. The closed social media page can only be accessed by members and Facebook administration. The Facebook administrators monitor closed sites only to “promote safety and security on and off of our products”. Data is not given to third parties. The whānau member acts as a gatekeeper so that new posts can be sent to them and can only be uploaded by them. All extended whānau are invited to be part of this Facebook site, and the addition of the genetic test result to the family tree is completely up the individual. A printable letter to show health professionals was created with general information about FH, diagnosis and treatment, the proband identified and steps for genetic testing (Figure 4).
Your patient belongs to a family who carry a mutation on gene LDLR c.2312-3C>A. This causes a medical condition called ‘familial hypercholesterolaemia’ (FH). The key to preventing premature heart disease and death is early diagnosis and treatment to achieve normal life expectancy. Individuals of this whānau who have the mutation develop heart disease in their 20s and 30s. Life expectancy in untreated individuals is approximately 30–40 years for heterozygous individuals (HeFH). Homozygous individuals (HoFH) manifest cardiovascular diseases in childhood or adolescence.

1. **What is familial hypercholesterolaemia?**

   FH is an autosomal dominant disorder that leads to premature coronary heart disease and atherosclerosis.

   • Mutations result in markedly reduced hepatic capacity to clear atherogenic cholesterol-rich lipoproteins (LDL) from the blood resulting in LDL cholesterol (LDL-C) accumulation in arteries from childhood (extreme cases have LDL-C exceeding 13mmol/L).

   • The sustained exposure of the arterial wall to elevated LDL-C levels accelerates cholesterol deposition and vascular inflammation leading to stroke, atherosclerosis and CHD.

2. **Treatment—the key is early diagnosis and treatment**

   • A healthy lifestyle (smoking cessation, high fruit/veg diet, exercise)

   • Genetic screening of children for the gene mutation should be done at ages 8–10 years (or diagnosis). There is a 20% chance that you will miss a gene mutation if you base your decision to do a genetic test based on cholesterol levels only.

   • Aim to reduce LDL by 50% or to <3.5mmol/L for children and <2.5mmol/L for healthy adults and <1.8mmol/L if someone already has heart disease or diabetes. If this cannot be achieved aim to reduce LDL-c by 50%.

   • Pregnancy/ breastfeeding—do not prescribe statins in pregnant/breast feeding woman—restart statins once able.

   • Medication dosage must be prescribed at the highest possible tolerated dose for that patient:
     - Statin (atorvastatin, rosuvastatin): 58–60% LDL decrease
     - Ezetimibe: 10–15% LDL decrease
     - PCSK-9 inhibitors: twice monthly injection decreases LDL by 50–60%
     - Bempodic acid: 30–40% LDL decrease (currently unavailable in New Zealand)
     - Inclisiran: twice yearly—in clinical trials decreases LDL-c buy 54%

3. **Blood testing for gene mutation**

   There is a 50% chance of children of FH carriers inheriting the mutated genes.

   • All children of FH individuals should be genetically tested/cascade-based screening to identify LDLR mutation carriers.

   • Cascade-based screening is more effective and provides earlier diagnoses than lipid-profile testing which can give hard to interpret results and is based on cholesterol levels which fluctuate with age.

4. **Steps for genetic testing**

   1. Fill out attached consent and lab form with blood sample.
   2. Send to National Genetic Screening Services in Christchurch and email them in advance to raise this sample to their attention.
   3. Begin treatment once mutation is confirmed.

For more information contact Jocelyne Benatar on 021893886 or jbenatar@adhb.govt.nz

Nga mihi,

Jocelyne Benatar and the whānau
A consent form for testing and a pre-filled laboratory form with the proband are also available. The consent form is the standard consent form used by the National Genetic Services for New Zealand. It requires specific and separate consent for storage of samples. As new treatments become available, the ADHB doctor sends the information to the gatekeeper who then uploads this to keep extended whānau informed of latest treatments. The clinician has no access to the Facebook page but is in close contact with the moderator to address concerns, misinformation and misconceptions about FH and treatments to lower cholesterol.

This whānau social media page will also engage with whakahaekengar (descendants) within the whānau in the long term. This will allow all to make informed decisions on the need to be tested, especially if no data is available about their immediate whānau.

At present, the social media page is active with a number of whānau members active on it. As a direct result, genetic testing and appropriate treatment has been initiated in 17 whānau members. Intensive statin treatment has been initiated in two children and a couple of young adults; this has the potential to ensure they reach normal life expectancy. The hope is that testing will be extended to all young children when they reach the age of eight. Only one surviving whānau member over the age of 50 has been found to have the mutation; however, this LDL-c is lower than others with the mutation.

Results of genetic tests are known only to the testing laboratory, the treating physician and the person tested. Results of genetic tests are only sent to the ADHB doctor if this is specifically requested by the patient. No data is centrally held by genetic services at this point as there is no national genetic service for FH. This ensures data for and about this Māori whānau can be safeguarded and protected from parties who are not directly involved with their care.

Discussion

The experience of this whānau underscores a number of issues. The first is that there is no systematic national approach to FH in New Zealand. It is not possible for clinicians to test and treat families from other DHBs or refer them to a national screening service as none exists. In this particular instance, testing was undertaken by clinicians from another DHB for research purposes, but there was no ability to refer for clinical follow up, cascade screening or appropriate treatment. A missed opportunity resulted to prevent premature cardiovascular events and led to an injustice perpetrated on the whānau. This resulted in inequity though three pathways; ongoing exposure to a modifiable and potent risk factor for CVD, difference in the quality of care received and differential access to healthcare. Had the whānau lived within the researchers’ DHB, they would have been appropriately managed. A priority of the hui was acknowledging that there had been an injustice and that that this had led to ongoing harm. The whānau wanted assurances it would never happen to them again and that measures were put in place to ensure that the whānau had ownership and control of their health information.

A second issue is that the system prioritises the needs and privacy of the individual over the whānau. This Westernised approach to health ignores the cornerstone of health; taha whānau (family health). In this instance, if one person misses testing, other members of the whānau further down the ‘cascade stream’, such as children will not be tested. This may be useful in societies where the needs of the individual are paramount, but not where the collective is just as important.

Despite calls over a number of years for a national screening registry for FH, none has eventuated. The argument for a registry is that it will allow for efficient screening and treatment of gene positive children and young adults to prevent future cardiovascular events. The argument against this is that it is a common genetic disorder picked up by a cheap lipid test, and that gene testing may be prohibitively expensive for the country. This approach ignores the benefits of cascade screening and treating gene positive children. It has resulted in a haphazard approach to FH with disparity in care across the country. For this whānau it has led to ongoing hurt caused by young family members developing often fatal premature heart disease.
Conclusion

FH is the most common dominant genetic disorder in humans and causes premature heart disease and death. Current approaches in New Zealand are dependent on index patients presenting for cascade screening and do not incorporate the needs and views of the extended whānau. Establishing a partnership with the whānau and giving back control of health information is crucial to ensure equity. A national systematic programme is also needed to manage this condition with important health outcomes that can be averted if treated from a young age.

Competing interests:
Nil.

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Lessons from a system-wide response to a measles outbreak, Canterbury, February–April 2019

Daniel Williams, Meik Dilcher, Hongfang Dong, Bridget Lester, Kerry Marshall, Ramon Pink, Debbie Smith, Jimmy Wong

Measles is a highly contagious airborne virus which affects both children and adults and can be life-threatening. Furthermore, measles infection can cause immune memory loss, increasing susceptibility to other infections for up to three years and contributing significantly to childhood non-measles infectious disease mortality. In New Zealand, people born before 1969, when vaccination was introduced, are likely to be immune due to past measles infection. The measles, mumps and rubella (MMR) vaccine is effective at preventing measles in 95% of people after one dose, and 96% of people after two doses. Reports of previous New Zealand outbreaks have identified important gaps in community immunity.

New Zealand achieved measles elimination in October 2017. However, cases continue to be introduced to New Zealand from overseas. Canterbury experienced measles outbreaks in 2009 (126 confirmed and 43 probable cases), 2011 (three cases), 2017 (one case) and 2018 (February, three cases; April, nine cases plus seven linked cases elsewhere in the South Island). There are currently large measles outbreaks in a number of overseas countries. From mid-2019 a large Auckland-centred outbreak grew rapidly and resulted in cases in many other parts of New Zealand and in neighbouring Pacific countries.

The purpose of this paper is to help inform measles control in New Zealand and elsewhere by describing a contained measles outbreak in Canterbury in early 2019 and reflecting on lessons learnt from our system-wide response.

ABSTRACT

Despite New Zealand’s “measles elimination” status, the risk of measles outbreaks persists, due to ongoing measles importation and sub-optimal vaccination coverage, including specific sub-populations with higher proportions of susceptible people. From February to April 2019, Canterbury experienced a measles outbreak with 38 local cases and an unidentified index case. The outbreak strain was linked to a large outbreak in the Philippines. The whole-of-health-system response included active case and contact follow-up by public health and hospital staff, and a prioritised vaccination campaign in primary care. Important features of a measles outbreak response in an “elimination” context include cross-system liaison, co-ordination of communications, careful prioritisation of use of available resources, and support for households affected by isolation and/or quarantine requests. Closer analysis of the effectiveness of outbreak control measures would help prioritise use of scarce public health and health care resources during outbreaks. Future measles outbreaks could be prevented by a systematic primary care-based MMR catch-up campaign.
Methods

The Health Act 1956 requires health practitioners to notify confirmed or suspected cases of measles to the medical officer of health. Canterbury Community Health-Pathways provides a generic electronic notification form or a measles-specific fax form, as well as advice on laboratory testing. Staff at Canterbury District Health Board (DHB)'s public health unit, Community and Public Health (CPH) follow up notifications using Ministry of Health case and contact definitions and laboratory confirmation criteria, and obtain further information from cases and contacts.

At the National Measles and Rubella Laboratory (CHL Christchurch), nucleic acids were extracted from nasopharyngeal swab samples and analysed via a CDC-developed screening real-time PCR. A second measles genotype A-specific real-time PCR developed by the Regional Measles and Rubella Laboratory at VIDRL/Melbourne was used to identify the measles vaccine strain in people who had recently been vaccinated and developed measles symptoms. Further genotyping of positive measles cases was done via a conventional RT-PCR targeting the N gene and sequencing of the terminal 450 nucleotides. Serum samples were analysed for Measles IgM via a manual ELISA using a WHO-recommended Siemens Enzygnost kit. Measles IgG were detected using a Euroimmun kit on an automated Triturus platform.

Outbreak description

In the last week of February 2019, CPH was notified of five unrelated confirmed cases of measles. One case had been an inpatient at Christchurch Hospital before and during the incubation period. The other four cases were from Rangiora, a town just north of Christchurch. Cases had been in contact with large numbers of people, including in schools and healthcare facilities. A further 33 confirmed cases were notified during March (see Figure 1), bringing the total number of cases meeting our operational case definition to 38 (one additional case had been in Thailand during their incubation and initial symptomatic periods and so was not included in the outbreak total). Sixteen cases were hospitalised and one case was admitted to ICU. No cases died. Cases ranged in age from four months to 54 years, with a median age of 23 years (see Table 1). Thirty-one cases (81.6%) were European, six (15.8%) were Māori, and one (2.6%) was Asian. Although most lived in Christchurch, cases came from as far north

Table 1: Age distribution of confirmed measles cases of the February 2019 Canterbury outbreak.

<table>
<thead>
<tr>
<th>Age group</th>
<th>&lt;15 months</th>
<th>15 months–4 years</th>
<th>5–28 years</th>
<th>29–50 years</th>
<th>50+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
<td>5 (13.2%)</td>
<td>2 (5.3%)</td>
<td>16 (42.1%)</td>
<td>13 (34.2%)</td>
<td>2 (5.3%)</td>
</tr>
</tbody>
</table>
as Waiau (see Figure 2). Identified exposure settings included households, education settings (pre-school, primary and secondary school, and university), a hospital and two medical centres (see Figure 3). However, half of the cases (19 cases) did not have any identified exposure to measles. Nineteen cases (50%) were unimmunised, 11 (29%) had only received MMR1, four (10.5%) had received MMR1 and MMR2, and four (10.5%) were of unknown vaccination status. One case was a general practitioner and six cases were hospital staff members. Two of the infected healthcare workers had received MMR1 and MMR2, two had received only MMR1 (both vaccinated overseas), two were unvaccinated and one's vaccination status was unknown.

One case was exported to Dunedin and subsequently infected one other person there, and another case was exported to Auckland. Both exported cases were linked to this outbreak with a 100% identical B3 sequence but have not been included in the outbreak total as they did not meet our operational case definition. Case 11 was overseas during his incubation period and was subsequently confirmed as having a non-outbreak measles strain (D8). However, as he became symptomatic in Christchurch he met our operational case definition and was followed up as part of the outbreak.

Of the 38 cases of this outbreak, the genotypes of 13 cases were determined at the National Measles and Rubella Laboratory at Canterbury Health Labs (CHL) in Christchurch and for eight cases genotyping was done at the Regional Measles and Rubella Reference Lab at VIDRL, Melbourne. The genotype of this outbreak (OB-19-108048-CH) was B3, but the strain of this outbreak was not previously reported in New Zealand. It shows 100% sequence identity to a measles B3 sample from the Philippines from epidemiological week 17 in 2018 (MV/47.18) and no exact matches to MeaNS named strains. A phylogenetic comparison with genotyped measles samples from 2018 and 2019 also shows a close relationship of the Canterbury B3 strain to other B3 importations from the Philippines (see phylogenetic tree in Figure 4).
During the period of the outbreak from 21 February (date of first sample) until 31 March (date of last sample) the measles vaccine strain (genotype A) was detected in 16 additional suspected cases from Canterbury. In the same time period, four more importations of different B3 strains (from Afghanistan, Philippines, China [originally from the Philippines] and an unknown source) as well as two more D8 importations (from the UK and Thailand) have occurred in New Zealand (see Figure 4).

**Outbreak control**

**Community and public health**

Initially all community cases and contacts were followed up by CPH staff according to in-house protocols. Cases were asked to stay away from early childhood services, school, work and close contact with unexposed people for five days after the appearance of the rash, with airborne precautions recommended in healthcare facilities for the same period. Susceptible contacts who met the contact definition were asked to avoid attending school, early childhood services or community gatherings, and to avoid contact with other susceptible individuals, including in higher-risk work settings, from seven days after first exposure until 14 days after last exposure to the infectious case. However, contacts who had previously received one documented dose of MMR and then received their second dose of MMR within 72 hours after first exposure and contacts who received IG within seven days after first exposure were considered safe to...
Figure 4: Phylogenetic tree of genotyped measles samples 2018–April 2019.
return to school or work. All contacts were advised to seek early medical attention (telephoning ahead) if symptoms developed. Institutions and families were provided information on the disease risk and advised that all unimmunised children should receive MMR. The use of Health Act directions to individuals, requiring exclusion, was considered, but was not required.

Due to the large number of cases and contacts during the second week of the outbreak CPH staff moved to “focused public health management”, continuing to follow up household contacts but asking the case, institution or healthcare setting to provide a tailored “contact letter” to other contacts. Full follow-up by CPH staff resumed later in the outbreak as case numbers fell. A total of 799 contacts were recorded as followed up by CPH staff. Many more contacts were identified but not formally recorded. Seventeen contacts were referred for MMR vaccination within 72 hours of their exposure.

A Coordinated Incident Management System (CIMS) structure ran from 22 February until the outbreak was declared over on 16 May, and included up to 30 staff from multiple CPH teams and other organisations as the outbreak progressed. Daily situation reports and regularly updated incident action plans were shared with all stakeholders.

Christchurch Hospital

The response to DHB patients and staff who had been exposed to measles at Christchurch Hospital and/or who developed measles was overseen by the Canterbury DHB Infection Prevention and Control Executive Committee. The committee included infection control nurse specialists, infectious disease physicians, laboratory and communications staff, and senior hospital management. Its focus remained on the hospital, the key objectives being to contain measles infection and spread, and to minimise impact on business as usual activities. Over 200 staff who had been exposed to measles cases in hospital were followed up using CPH protocols. Staff members who had been exposed to measles but whose immune status was uncertain were offered serological testing to guide advice about quarantine. In addition, vaccination records for all staff working in areas designated as “high risk” (including cleaning staff employed by a contractor) were reviewed, and if there was no record they were contacted and offered vaccination. Over 130 staff were vaccinated by the Occupational Health Service.

Contacts from the emergency department waiting room who had been discharged home were followed up by CPH staff.

Primary care

The Canterbury Primary Response Group (CPRG) is tasked by the Canterbury DHB with leading the region’s primary care emergency planning, response and recovery. It includes general practice, nursing, pharmacy, and emergency planning expertise, and can call on a wider group of health sector representatives to provide a whole-of-health response to health emergencies. CPRG became involved when a measles vaccination campaign was proposed as part of the response, and contributed to the campaign’s planning and implementation, including providing co-ordination and communication with primary care.

Planning and funding

Canterbury DHB’s Planning and Funding division became involved as vaccine supply issues arose due to increased demand, and led modelling of priority group volumes and expected demand and co-ordinated vaccine supply for the remainder of the outbreak.

Vaccination campaign

It was quickly clear that the early cases had exposed large numbers of people to measles and that further spread was likely. Canterbury has relatively high recent measles, mumps and rubella vaccine (MMR) coverage, with 93% of both two and four year-olds fully vaccinated for their age. However, there was concern about those in the community who were susceptible to measles because they:

• were too young for their first MMR (given at 15 months)
• were too young for their second MMR (given at four years)
• had declined or not sought MMR in the past
• were aged between 29–50 years old and may have only had one MMR based on the vaccination schedule when they were young.
as well as concern about health or education professionals who worked with vulnerable populations.

Initial public communications emphasised the importance of all people born after 1969 having two MMR vaccinations. The resulting public demand placed considerable pressure on general practices and on the vaccine supply. An Immunisation Programme Team was formed by representatives from CPH, Ministry of Health, and Canterbury DHB Planning and Funding, who worked closely with PHARMAC and the Canterbury Primary Response Group, and on 13 March identified the following priorities for vaccination:

**Priority 1:** Children aged 12 months to 13 years who have never been vaccinated

**Priority 2:** Children and adults aged 14 years to 28 years who have never been vaccinated

**Priority 3:** Caregivers and close contacts of children aged less than 12 months or those who cannot be vaccinated.

**Priority 4:** Continue with the routine immunisation programme (15 months and 4 years)

**Priority 5:** Occupational groups who have frequent contact with children, such as EEC, primary, and secondary school teachers, residential care and healthcare workers, who have never been vaccinated.

Planning and Funding estimated vaccine requirements for each priority group (a total of 20,000 vaccines for the five priority groups), produced daily uptake reports based on National Immunisation Register (NIR) data, and in conjunction with the immunisation co-ordinators managed vaccine supply to practices. The Immunisation Programme Team met regularly, and liaised with CPRG.

Between 4 March and 24 March, 13,578 MMR doses were recorded on NIR, with greatest uptake in under-five-year-olds. Another 4,500 MMR doses were administered to 14–50-year-olds but could not be linked to NIR. As more vaccine had become available, the vaccination strategy was reviewed, and a “phase two” four-week campaign agreed from 28 March to 26 April, delaying the start of the seasonal influenza vaccination campaign, and targeting first or second MMR for:

- all those aged 12 months to 28 years
- caregivers of infants aged up to 12 months
- those between 29 and 50 who work with children (teachers or healthcare workers)

In total, over 31,000 vaccines were distributed to general practice during the response, and over 22,000 vaccination events were recorded on the NIR. At its peak, general practices vaccinated over 1,950 people in one day, with individual practices vaccinating up to 850 people each over the six weeks of the outbreak. Fifty-three percent of vaccines were delivered to under-five-year-olds. Two thirds of these were MMR2 delivered early to 1–3-year-olds. Five to 29-year-olds received 14% of vaccines. The remaining third of vaccines were delivered to people aged 30 and over. Almost all of the vaccines delivered to people aged five and over were MMR1 (see Figure 5). The recorded ethnicity of those vaccinated was European 67%, MELAA 15%, Maori 8%, Pacific 3% and Other 7%.

**Liaison**

A CPH medical officer of health undertook liaison with hospital, primary care and Ministry of Health groups, to help coordinate activities and ensure good communication.

CPH’s Māori Relationships Manager liaised with and provided information to local rūnanga, Mana Whenua ki Waitaha, and local Māori providers.

One of the Ministry of Health’s Deputy Directors of Public Health was based at Community and Public Health for much of the outbreak, facilitating linkages to the Communicable Diseases Team in the Ministry as well as to PHARMAC, who were responsible for vaccine supply.

**Communications**

The Canterbury DHB Communications Team were engaged early in the outbreak to ensure consistent and accurate information was relayed through the DHB, other health sector organisations and the community. Media interest remained high for much of the outbreak, often requiring daily media briefings which were live-streamed via Facebook, and interpreted by a sign language interpreter. The footage from daily media
briefings was posted on the Canterbury DHB's Facebook page, and elicited large volumes of comments, shares and likes. Throughout the outbreak, the Communications Team received a large number of private messages via Facebook from concerned members of the public requesting updates on the latest priority groups for vaccinations, vaccine availability, whether it was safe for parents to take unvaccinated young children and babies out in public, and latest updates on case numbers. The medical officers of health fronted media briefings and were consulted on any clinical queries from members of the public.

The initial focus for communications was to advise the public on the risks and actions they should take, and keep them updated as the situation evolved. Communications staff were also involved with communications to primary care and the wider health system, and with liaison with the Ministry of Health.

Community information was provided through print media, radio, television and Canterbury DHB's website and social media. Press releases were produced daily during the height of the outbreak and fact sheets and FAQs were translated into multiple languages (te reo Māori, Samoan, Farsi, Tongan, Tagalog, Hindi, Simplified and Traditional Chinese) and circulated through community channels.

Education settings were identified as priority audiences for communication and information. Updated measles information was distributed to all Canterbury early childhood centres and schools. Information was also distributed to affected workplaces, community organisations and Christchurch International Airport.

Discussion

Source

As the index case of this outbreak could not be identified, no information about importation was directly available. The measles strain of this outbreak had been previously identified in The Philippines but had not been previously reported in New Zealand.

The Philippines were experiencing a very large measles outbreak that started in December 2017, with mainly B3 genotypes circulating. Canterburys Filipino population at the 2013 census was 4,887 (approximately 1% of the then Canterbury population, 516,360). Between January and March 2019, 2,471 passengers arrived at Christchurch Airport carrying Philippine passports.

The cases with the earliest onset of symptoms and rash onset in this outbreak were the first Dunedin case, an 18-year-old, and case 7, a 42-year-old from Christchurch, who both developed their first symptoms on 14 February and a rash on 16 February. The Dunedin case was likely to have been infected while staying in Rangiora. Most other cases early in the outbreak appeared in Rangiora or had been inpatients at Christchurch Hospital. On this basis, it was hypothesised that the unknown index case had visited Christchurch Hospital as well as moving around the community in Rangiora while infectious.
Ongoing risk of importation

Globally, analyses of 2012 and 2013 data suggested that measles incidence is typically highest in less-developed nations. WHO preliminary global data in August 2019 showed that reported cases of measles rose by 300 percent in the first six months of 2019, compared to the same period in 2018. Many countries were in the midst of sizeable measles outbreaks, with all regions of the world experiencing sustained rises in cases.

Travel to New Zealand by non-New Zealanders is dominated by Australia, followed by China, UK, Japan and the US. Australia is also the most common travel destination for New Zealanders. However, outbreaks in other countries with strong links to New Zealand or significant immigrant or resident populations here may pose a particular risk.

Vaccination

Despite New Zealand’s immunisation programme having achieved endemic measles elimination in 2017, outbreaks continue to occur in response to imported cases. The World Health Organization estimates that interruption of measles transmission can be achieved by herd immunity when approximately 95% of the population is homogeneously immune to measles. In New Zealand, not only is overall population immunity lower than 95%, but significant pockets of susceptible, non-immune population remain. As a result, New Zealand outbreaks still largely affect school-aged children, young adults and children under two years of age. Modelling suggests that supplementary measles immunisation would be economically beneficial in the New Zealand population.

Heightened media and public interest in measles during this outbreak provided a potential opportunity to promote vaccination widely, in order to improve community immunity, and reduce measles spread during the current and future outbreaks. However, the limited amount of vaccine available at short notice necessitated identification of priority groups for vaccination.

Canterbury DHB Planning and Funding led the vaccine prioritisation process, working with CPH, Ministry of Health, PHARMAC and primary care. At the start of the outbreak Canterbury DHB had been achieving MMR coverage of 92–95% at ages two and five for the previous five years, so was confident that children aged 2–10 years were well protected. Unfortunately, vaccination coverage data for the years before introduction of the NIR in 2005 are incomplete. Based on local experience, adults born between 1969 and 2005 were assumed to have mostly had one dose of measles vaccine and some would have also received a second dose in their teenage years. Coverage may have been lower for current secondary school-aged children, whose vaccination ages coincided with public discussion of the now-discredited “Wakefield” paper. However, a substantial measles outbreak in Canterbury in 2009 had also raised awareness of measles, and widespread publicity of the recommendation for early MMR1 and MMR2 for Canterbury children may have increased vaccination uptake at that time.

Challenges for the vaccination campaign included uncertainty about vaccine supplies, general practice capacity to deliver large numbers of additional vaccinations within a short time frame, and difficulty accessing prior vaccination history for people vaccinated before the introduction of the National Immunisation Register. Unfortunately, adults who would otherwise have been eligible for a second MMR who sought vaccination during the outbreak had to be turned away if they did not belong to a priority group.

Over one third of the vaccinations administered during the outbreak were MMR2 delivered early (to 1–3-year-olds). While these vaccinations improved protection for an important vulnerable group during the outbreak, they will not improve population immunity in the longer term. The number of people in Canterbury born since 1969 who have not received full vaccination against measles is unknown. Many of these people are not aware that they have not been fully immunised. A systematic campaign offering vaccination to all these people through recall and/or opportunistic vaccination in general practice could substantially reduce the future risk of measles outbreaks in Canterbury.
Isolation and quarantine

Isolation of measles cases while infectious is universally recommended. Recommendations for quarantining of susceptible contacts vary between jurisdictions, but while there is limited evidence for its effectiveness, there are good arguments for its use in elimination settings, particularly in the very early stages of an outbreak.\(^\text{13}\)

Although the Health Act (1956) provides for medical officers of health to require compliance with isolation or quarantine restrictions by issuing a direction or by applying for a public health order, in practice these provisions are time-consuming and difficult to enforce. The use of directions was discussed by the response team in this outbreak, but was not considered necessary. Cases and contacts generally appeared receptive to public health advice, and appeared willing to comply with isolation and quarantine requests.

Nevertheless, the burden on individuals and families of staying away from work or study, or keeping children away from school or early education for extended quarantine periods can be substantial. CPH is continuing to develop relationships with other agencies which can provide support to households affected by isolation or quarantine advice, including primary healthcare providers and non-government organisations in our region.

Equity, hauora Māori, and culturally and linguistically diverse groups

Current “fully vaccinated” rates for Māori in Canterbury are 91% for two-year-olds and 89% for five-year-olds, and for Pacific people in Canterbury are 97% for two-year-olds and 98% for five-year-olds (CDHB 2018/19 Q4 data). The ethnicity of measles cases in this outbreak was recorded and did not suggest a disproportionate burden in any one ethnic group. Although the outbreak measles strain suggested the current Philippines measles outbreak as the most likely source of this outbreak, no cases were identified in Filipino people.

No specific cultural or support needs were identified for the six Māori cases. The response team maintained links with and provided advice to local rūnanga (tribal councils), Mana Whenua ki Waitaha (the representative body of the local tribe Ngāi Tahu in Canterbury for health issues) and local providers.

The potential for isolation and exclusion advice to place a disproportionate burden on poorer families was noted, and plans were made to engage social support for households requiring it. However, the extent to which households were willing or able to comply with isolation and exclusion advice is not known, as the response team had limited capacity to follow up individual households once advice had been provided, and the team did not become aware of any households where social support was required.

More recent Canterbury measles cases have highlighted the importance of isolation and exclusion advice that matches the expectations and needs of the households and families involved, and CPH is pursuing closer working relationships with Māori and Pacific health and social service providers to ensure that public health advice is accompanied by appropriate support.

Prioritising public health resources

Public health follow-up of measles cases is labour-intensive, and capacity for individual contact follow-up by public health staff is quickly overwhelmed in a large outbreak. In this outbreak, planning for “focused public health management” commenced early, based on strategies developed and generously shared by Auckland Regional Public Health Service. The “focused management” phase recognises that household contacts are at highest risk, and they continue to be followed up by public health staff. For other contacts, public health staff provide a tailored letter to the case, and to any institution or health care setting where exposure has occurred, with a request for the letter to be passed on to any identified contacts. The effectiveness of this approach compared to individual contact follow-up by public health staff is unknown.

Follow-up of waiting-room contacts is labour-intensive for healthcare settings, and can be at least partially avoided by clearly instructing possible measles patients to phone ahead for advice.

In this outbreak only 17 contacts were advised to receive post-exposure MMR within 72 hours of their contact with a measles case. Post-exposure prophylaxis...
is a proven control measure in measles outbreaks. However, measles cases are commonly notified too late for post-exposure MMR to be effective. Encouraging health practitioners to notify measles cases on suspicion is an important component of outbreak communications.

Recent research has suggested that “breakthrough” measles infections in vaccinated patients produce a lower viral load, and are associated with a reduced risk of onward transmission. In this outbreak 11 of 38 cases had previously received MMR1 and four of 38 cases had previously received both MMR1 and MMR2. None of the seven instances of identified transmission from one case to another in this outbreak resulted from fully vaccinated cases. Further discussion of the extent of follow-up required for breakthrough cases could support prioritisation of limited public health resources in large measles outbreaks.

Healthcare workers
Exposure of healthcare workers to measles is inevitable in any outbreak. In this outbreak, there was substantial measles transmission in the hospital environment. Nosocomial transmission of measles by healthcare workers is costly and preventable, as is quarantine of susceptible healthcare staff after workplace exposure to measles. All staff in healthcare settings should have their vaccination history recorded, and susceptible staff should be offered measles vaccination.

Communications
A substantial measles outbreak response is a complex event involving many players, with inevitable public and media interest. In the early stages of this outbreak, variations in messaging, particularly concerning priority groups for vaccination, provided challenges for the public and for primary care staff delivering MMR. Early collaboration between public health, primary care, the Ministry of Health and PHARMAC on vaccination strategy development is recommended to avoid confusion. Alignment of key messages across all agencies is essential, and can be facilitated by early establishment of regular interagency meetings, early development and adoption of a formal communications plan, and by including an on-the-spot communications advisor in the public health response team.

Impact of mosque murders
The 15 March Christchurch mosque murders occurred in the middle of this outbreak. Potential implications for the outbreak considered by the response team included reduced capacity at Christchurch Hospital, the potential for re-importation of measles by people travelling to New Zealand in response to the event, and the potential for measles spread at mass gatherings and among the communities affected by and responding to the event. Public communications in the aftermath of the event emphasised that anyone who was unwell should stay away from others, and particularly from mass gatherings or community events. Media coverage of the outbreak, which had been intense, decreased markedly following the event. In retrospect, no effect of the event on measles transmission could be detected.

Lessons learnt
Despite New Zealand’s “measles elimination” status, measles continues to pose a risk to New Zealanders due to ongoing importation and sub-optimal immunisation coverage, including specific sub-populations with higher proportions of susceptible people. This outbreak, which involved substantial spread before it was detected, and in which the index case was never identified, highlighted that risk, which the subsequent much larger 2019 Auckland-centred outbreak has reinforced.

Canterbury mounted a substantial whole-of-health-system response to the outbreak, and along with apparently relatively high background population measles immunity, this appears to have limited its size. Important features of a measles outbreak response in an “elimination” context include cross-system liaison, co-ordination of communications, careful prioritisation of use of available resources, and support for households affected by isolation and/or quarantine requests.

In view of the ongoing risk of measles outbreaks, review and prioritisation of strategies for measles prevention and control is important at both national and local levels. Maintaining high childhood vaccination rates, vaccination of healthcare workers, and immunisation advice for travellers to countries with outbreaks are obvious strategies to
Competing interests:
Nil.

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Medication dispensing for attention-deficit/hyperactivity disorder to New Zealand youth

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ABSTRACT

AIMS: Global trends show an increase in medication dispensing for attention-deficit/hyperactivity disorder (ADHD) in young people over time. The current study aimed to examine whether similar trends were observed in New Zealand youth over the period of 2007/08 to 2016/17.

METHODS: We estimated the prevalence in ADHD medication dispensing using national pharmaceutical data for each fiscal year from 2007/08 to 2016/17 in approximately 2.4 million New Zealand youth aged 1–24 years. We also examined whether trends varied by sociodemographic factors.

RESULTS: The total dispensing prevalence almost doubled from 516 per 100,000 to 996 per 100,000 over the study period. Males had a consistently higher dispensing prevalence relative to females. Young people aged 7–17 years had the highest dispensing prevalence. The most deprived quintile had a slightly lower dispensing prevalence relative to other quintiles. Ethnic differences in dispensing prevalence were apparent, with deprivation differences also existing within most ethnic groups.

CONCLUSIONS: Overall, our study showed an increase in ADHD medication use by young people in New Zealand, similar to international findings. Further research is needed into why disparities in dispensing prevalence occur across ethnic and socioeconomic groups.

Attention-deficit/hyperactivity disorder (ADHD) is a childhood-onset neurodevelopmental disorder characterised by symptoms of hyperactivity/impulsivity and inattention. It is more common in males than females, with symptoms decreasing with age. The disorder is associated with adverse health, academic and social outcomes and an increased risk of comorbidity with oppositional defiant disorder, conduct disorder and substance abuse.

ADHD has an estimated worldwide prevalence of 3.4%. Varying diagnosis rates across countries and regions may reflect different diagnostic criteria rather than actual differences in disorder prevalence. For example, European countries generally show lower prevalence than other regions, as the more stringent International Classification of Diseases (10th edition; ICD-10) is used for diagnosing ADHD (referred to as hyperkinetic disorder). In contrast, other regions (including New Zealand) use the Diagnostic and Statistical Manual of the American Psychiatric Association (5th edition; DSM-V).

Treatment for ADHD consists of a combination of talk therapy and behavioural interventions for child and parent, lifestyle changes and medication. For preschool children, behavioural intervention is recommended as the first line of treatment, with medication given only when intervention alone is unsuccessful in improving symptoms. For older children and adults, it is recommended that a combined approach is used (ie, medication and behavioural intervention/therapy). Internationally, medications for ADHD include stimulants, such as methylphenidate and amphetamines, and non-stimulants, such as atomoxetine, clonidine and guanfacine.
methylphenidate hydrochloride, dexamphetamine sulphate, atomoxetine and modafinil are publicly funded for clinical use as stimulants (for stimulant medication) and in the treatment of ADHD.\textsuperscript{13}

International studies using administrative databases have shown that the prevalence of ADHD medication prescription and dispensing is increasing. Bachmann et al examined the trends in ADHD medication prescription in children aged 0 to 19 years across five regions (Denmark, Germany, the Netherlands, the UK and the US) between 2005 to 2012.\textsuperscript{6} They found that while prevalence in ADHD medication varied across regions, it increased across all areas ranging from 10.7\% in the US to 302.7\% in Denmark. Raman et al also observed similar trends across Asia, Australia, North America, and Northern and Western Europe between 2001 to 2015.\textsuperscript{14} Given that there is no evidence of an increase in disorder prevalence, the rise in ADHD medication use has led to concern about medication over-prescription.\textsuperscript{5}

To date, one study by Barczyk et al has examined dispensing prevalence and trends for ADHD medication, alongside other psychotropic medication, in New Zealand.\textsuperscript{15} Using national administrative records on pharmaceutical dispensing, the study found that the prevalence of ADHD medication increased from 0.75\% in 2011 to 1.06\% in 2016 (an increase of 41.33\%) in 0- to 17-year-olds. The authors also observed that the dispensing prevalence for all psychotropic medication was much lower for Māori. However, the study did not calculate the dispensing prevalence for other demographic groups (other than ethnicity and sex) nor the group-specific dispensing trends over time.

This study aimed to investigate the prevalence and trends in ADHD medication dispensing in young New Zealanders, similar to Barczyk et al.\textsuperscript{15} However, we extended the observation period from 1 July 2007 to 30 June 2017, focused on individuals aged 1 to 24 years, and examined prevalence and trends by sex, age, ethnicity and area-level deprivation. We hypothesised that there will be:

1. Increasing dispensing prevalence over time, consistent with trends observed in other studies.\textsuperscript{6,14,15}
2. Higher prevalence of dispensing among males than females, given the higher ADHD prevalence in males.\textsuperscript{2,3}
3. Lower dispensing prevalence for young children (1–6 years) and young adults (18–24 years) relative to middle childhood and adolescence (7–17 years), given that ADHD symptoms reduce with age and medication of preschool children is discouraged.\textsuperscript{5}
4. Lowest dispensing prevalence in the highest socioeconomic deprivation quintile. This is based on observed socioeconomic disparities in the dispensing of other medications in New Zealand.\textsuperscript{16} For example, Bowden et al found that antidepressant dispensing to young people was lower in deprived areas, despite depression prevalence being similar.\textsuperscript{16,17} They speculated that this could be due to access barriers.
5. Higher dispensing rates for New Zealand Europeans, with lower rates for other ethnic groups. New Zealand Health Survey (NZHS) results indicating highest ADHD prevalence in European/Other and Māori children and lowest in Pasifika and Asian children.\textsuperscript{16} However, studies of youth antidepressant prescribing have indicated that the European/Other ethnic group has a higher antidepressant dispensing prevalence than Māori, despite having similar depressive disorder rates.\textsuperscript{16,17} Barczyk et al also reported a lower psychotropic medication dispensing prevalence for Māori.\textsuperscript{15}
6. Different socioeconomic patterns in dispensing prevalence for different ethnic groups, indicating socioeconomic barriers to accessing medication for some ethnic groups.

Methods

Study population

Data for this study were obtained from Statistics New Zealand’s Integrated Data Infrastructure (IDI), a large database of de-identified administrative and survey data about people and households linked at the individual level. A detailed description of the IDI can be found elsewhere.\textsuperscript{18}
The study population consisted of repeated cross-sections of all New Zealand residents aged between 1 to 24 years, taken for each fiscal year between 1 July 2007 to 30 June 2017 (see Table 1 for population counts). The combined study population across all fiscal years was 2,395,209 individuals. This time-period represents when reliable data are available for this study. The resident population is identified based on activity in health, tax, education, and injury claims datasets and falls within 2% of official resident population estimates.\(^19,20\)

### ADHD medication dispensing

Information on ADHD medication dispensing was obtained by linking data from the Ministry of Health community pharmaceutical dispensing collection to the study population. The pharmaceutical collection contains information about subsidised prescription drugs dispensed by community pharmacists.

For each fiscal year, individuals were classified as obtaining a dispensing if they received at least one dispensing of a publicly funded stimulant/ADHD medication: atomoxetine, dexamphetamine sulphate, methylphenidate hydrochloride (immediate- and extended-release), and modafinil.\(^13\) In addition, clonidine, typically prescribed for hypertension in adults, is used off-label to treat ADHD in the New Zealand paediatric population and was therefore also included.\(^12\)

### Sociodemographic information

Age was calculated at the end of each fiscal year (ie, 30 June) and categorised into the following four bands: 1–6, 7–12, 13–17 and 18–24 years.

Ethnicity was measured in total response format; that is, individuals could belong to one or more ethnic groups, as it is common for children in New Zealand to identify with multiple ethnicities.\(^21\) We focused on six ethnic groups, using Level 1 Statistics New Zealand categorisation: European; Māori; Pasifi ka; Asian; Middle Eastern, Latin American and African (MELAA); Other.\(^21\)

The NZDep2013 Index was used to capture area-level deprivation. The NZDep2013 Index assigns each meshblock a deprivation decile value from 1 (least deprived) to 10 (most deprived), based on socioeconomic indicators from the 2013 New Zealand census.\(^22\) Meshblocks are evenly distributed across each deprivation level. For the current study, deprivation scores were converted into quintiles.

Table 1 presents the count of individuals in the study population within each fiscal year, by age and sex. Table 2 presents the count of individuals in the study population by fiscal year, stratified by total response ethnicity and area-level deprivation.

### Data analysis

Dispensing prevalence rates were calculated for each fiscal year by dividing the

### Table 1: Population counts per fiscal year and stratified by age bands and sex.

<table>
<thead>
<tr>
<th>Fiscal year</th>
<th>Total population</th>
<th>1–6yrs</th>
<th>7–12yrs</th>
<th>13–17yrs</th>
<th>18–24yrs</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/2008</td>
<td>1,441,674</td>
<td>348,471</td>
<td>356,280</td>
<td>317,352</td>
<td>419,568</td>
<td>738,837</td>
<td>702,834</td>
</tr>
<tr>
<td>2008/2009</td>
<td>1,455,660</td>
<td>356,754</td>
<td>354,468</td>
<td>313,989</td>
<td>430,449</td>
<td>746,367</td>
<td>709,290</td>
</tr>
<tr>
<td>2009/2010</td>
<td>1,468,593</td>
<td>363,885</td>
<td>353,088</td>
<td>311,220</td>
<td>440,400</td>
<td>754,248</td>
<td>714,345</td>
</tr>
<tr>
<td>2011/2012</td>
<td>1,468,284</td>
<td>369,765</td>
<td>348,477</td>
<td>303,342</td>
<td>446,700</td>
<td>754,725</td>
<td>713,559</td>
</tr>
<tr>
<td>2012/2013</td>
<td>1,466,064</td>
<td>369,945</td>
<td>346,275</td>
<td>301,296</td>
<td>448,551</td>
<td>754,209</td>
<td>711,855</td>
</tr>
<tr>
<td>2013/2014</td>
<td>1,475,529</td>
<td>370,479</td>
<td>349,962</td>
<td>300,906</td>
<td>454,182</td>
<td>759,831</td>
<td>715,695</td>
</tr>
<tr>
<td>2014/2015</td>
<td>1,489,050</td>
<td>368,178</td>
<td>358,218</td>
<td>300,288</td>
<td>462,366</td>
<td>769,122</td>
<td>719,928</td>
</tr>
<tr>
<td>2015/2016</td>
<td>1,501,488</td>
<td>366,984</td>
<td>367,329</td>
<td>300,501</td>
<td>466,674</td>
<td>776,106</td>
<td>725,382</td>
</tr>
<tr>
<td>2016/2017</td>
<td>1,509,429</td>
<td>363,873</td>
<td>376,521</td>
<td>303,123</td>
<td>465,912</td>
<td>779,124</td>
<td>730,305</td>
</tr>
</tbody>
</table>
number of young people dispensed an ADHD medication within that year by the number of resident New Zealand youth in that year, and presented as ‘per 100,000 population’. These counts were random rounded to base 3 to reduce disclosure risk, as per the confidentiality rules of Statistics New Zealand. This method was used to calculate the dispensing prevalence for the total population, by sex, age, ethnicity, and deprivation quintiles and for each ADHD medication type. All data management and analyses were conducted using SAS version 7.1.

Table 2: Counts per fiscal year, stratified by total response ethnicity and NZDep2013 quintiles.

<table>
<thead>
<tr>
<th>Fiscal year</th>
<th>Asian</th>
<th>European</th>
<th>Māori</th>
<th>MELAA</th>
<th>Pasifika</th>
<th>Other</th>
<th>Quintile 1</th>
<th>Quintile 2</th>
<th>Quintile 3</th>
<th>Quintile 4</th>
<th>Quintile 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/2008</td>
<td>162,066</td>
<td>995,313</td>
<td>352,434</td>
<td>41,871</td>
<td>175,023</td>
<td>18,792</td>
<td>240,330</td>
<td>256,377</td>
<td>270,855</td>
<td>300,312</td>
<td>362,412</td>
</tr>
<tr>
<td>2008/2009</td>
<td>168,396</td>
<td>1,000,572</td>
<td>355,344</td>
<td>41,235</td>
<td>179,586</td>
<td>19,125</td>
<td>244,422</td>
<td>258,978</td>
<td>272,619</td>
<td>301,302</td>
<td>365,928</td>
</tr>
<tr>
<td>2009/2010</td>
<td>174,126</td>
<td>1,005,000</td>
<td>360,567</td>
<td>39,912</td>
<td>184,116</td>
<td>19,122</td>
<td>247,446</td>
<td>261,285</td>
<td>274,662</td>
<td>302,073</td>
<td>369,528</td>
</tr>
<tr>
<td>2010/2011</td>
<td>180,789</td>
<td>1,002,462</td>
<td>362,451</td>
<td>37,431</td>
<td>186,936</td>
<td>19,131</td>
<td>250,500</td>
<td>262,971</td>
<td>275,373</td>
<td>302,484</td>
<td>371,994</td>
</tr>
<tr>
<td>2013/2014</td>
<td>201,543</td>
<td>992,001</td>
<td>363,132</td>
<td>32,802</td>
<td>189,690</td>
<td>19,062</td>
<td>256,524</td>
<td>266,679</td>
<td>275,967</td>
<td>299,037</td>
<td>368,928</td>
</tr>
<tr>
<td>2014/2015</td>
<td>214,425</td>
<td>991,083</td>
<td>366,120</td>
<td>33,450</td>
<td>192,222</td>
<td>18,771</td>
<td>258,078</td>
<td>267,939</td>
<td>276,990</td>
<td>298,785</td>
<td>370,134</td>
</tr>
<tr>
<td>2016/2017</td>
<td>234,885</td>
<td>986,130</td>
<td>371,514</td>
<td>33,921</td>
<td>196,782</td>
<td>18,210</td>
<td>263,304</td>
<td>272,250</td>
<td>280,287</td>
<td>297,000</td>
<td>376,377</td>
</tr>
</tbody>
</table>

Table 3: Annual dispensing prevalence (per 100,000 population) overall and by sex.

<table>
<thead>
<tr>
<th>Fiscal year</th>
<th>Overall</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/08</td>
<td>516</td>
<td>802</td>
<td>216</td>
</tr>
<tr>
<td>2008/09</td>
<td>566</td>
<td>878</td>
<td>237</td>
</tr>
<tr>
<td>2009/10</td>
<td>617</td>
<td>952</td>
<td>265</td>
</tr>
<tr>
<td>2010/11</td>
<td>652</td>
<td>1,003</td>
<td>282</td>
</tr>
<tr>
<td>2011/12</td>
<td>708</td>
<td>1,081</td>
<td>313</td>
</tr>
<tr>
<td>2012/13</td>
<td>780</td>
<td>1,176</td>
<td>362</td>
</tr>
<tr>
<td>2013/14</td>
<td>826</td>
<td>1,241</td>
<td>385</td>
</tr>
<tr>
<td>2014/15</td>
<td>876</td>
<td>1,302</td>
<td>420</td>
</tr>
<tr>
<td>2015/16</td>
<td>928</td>
<td>1,378</td>
<td>446</td>
</tr>
<tr>
<td>2016/17</td>
<td>996</td>
<td>1,472</td>
<td>488</td>
</tr>
<tr>
<td>% Change</td>
<td>93.0</td>
<td>83.5</td>
<td>126.6</td>
</tr>
</tbody>
</table>

Results

The period prevalence for ADHD medication dispensing between 2007/08 and 2016/17 was 1.18%. The dispensing prevalence almost doubled from 2007/08 to 2016/17, increasing from 516 per 100,000 to 996 per 100,000 (Table 3). The dispensing prevalence for both males and females increased over time, with the prevalence for males being consistently 3–4 times higher than females (Table 3). However, the rate of increase was far greater for females.
(127%) than for males (84%) from 2007/08 to 2016/17. As indicated in Figure 1A, 7–17-year-olds had the highest dispensing prevalence over the entire study period, followed by 18–24-year-olds and then 1–6-year-olds. Rates increased over time for all age groups, with the greatest increase for 18–24-year-olds (152%) and lowest for 7–12-year-olds (84%).

Figure 1B stratifies dispensing prevalence by ethnicity. The European and Other ethnic groups generally had the highest dispensing prevalence across fiscal years. The Asian ethnic group had the lowest dispensing prevalence, with the Pasifika ethnic group second lowest. All groups showed an increase in dispensing prevalence over time. Rate increases were greatest for Asian
(190%) and Pasifika (144%) followed by Other (132%), Māori (105%), then European (99%). The MELAA group had the lowest rate increase over the study period (39%).

Dispensing prevalence increased over time for all NZDep quintiles (see Figure 1C). Quintile 5 generally had the lowest dispensing prevalence, although differences in dispensing prevalence between quintiles were small. Increases over time were greater in less deprived quintiles. Quintiles 1 and 2 approximately doubled in dispensing prevalence (126% and 101%, respectively). Quintiles 3 and 4 had the next highest rate increase (both at 88%), with Quintile 5 showing the lowest rate increase (83%).

We also examined whether the dispensing prevalence trends for NZDep quintiles differed across ethnic groups. For the European group, dispensing prevalence was greater with increasing deprivation (Figure 2B). The least deprived quintile had the highest dispensing prevalence from 2009/10 for Pasifika and from 2013/14 for the Asian population (Figures 2E and 2A, respectively). The most deprived quintile generally had the lowest dispensing prevalence for Māori and Pasifika (Figures 2C and 2E, respectively). For the MELAA group, there appeared to be a separation in dispensing prevalence between quintiles from 2014/15 (Figure 2D); The least deprived quintile had the highest dispensing prevalence, followed by quintiles 2 and 3, and the most deprived quintiles (quintiles 4 and 5) had the lowest dispensing prevalence. For the Other ethnic group, quintiles 4 and 5 had had a slightly higher dispensing prevalence relative to other quintiles (Figure 2F).

Table 4 shows the dispensing prevalence for each ADHD medication type. The prevalence for methylphenidate hydrochloride, atomoxetine and clonidine increased from 2007/08 to 2016/17, whereas the rates of dexamphetamine sulphate and modafinil remained consistent over time. Methylphenidate hydrochloride had a much higher
dispensing prevalence than the other medications, with a rate 9–11 times greater than
the next most prescribed drug (clonidine). Modafinil was the least prevalent drug,
with prevalence ranging from <1–1 per
100,000. Dispensing prevalence for Atomoxetine increased quickly between 2007/08 to
2016/17, though prevalence was still low.

**Discussion**

Using administrative data on community
pharmaceutical dispensing, we investigated
the dispensing trends of ADHD medication
to New Zealanders aged 1–24 years. Between
1 July 2007 and 30 June 2017, the prevalence
of ADHD medication dispensing to young
people increased by 93%. These results are
consistent with our hypothesis and findings
in New Zealand, although the increase in
prevalence was greater than that observed
by Barczyk et al (41.33%). This difference
in prevalence rate increase is likely due to a
variety of factors including the different age
ranges and study periods.

Our results also support the findings
by Bachmann et al and Raman et al, who
observed that ADHD medication use was
increasing over time across different
regions worldwide. Specifically, meth
ylphenidate hydrochloride, clonidine and
atomoxetine all increased in prevalence
over the study period. The rapid increase in
prevalence for atomoxetine from 2007/08
to 2016/17 is likely due to its subsidisation
as a prescription drug for ADHD in 2009.

Similar to other countries, methylphenidate
hydrochloride was the most commonly
prescribed medication within our study
and considerably more prevalent than
other ADHD medications. This is unsur-
prising as it is recommended as the first-line
medication for treating ADHD. Modafinil
was the least prevalent medication, likely
due to a lack of recommendation for its use
in children and adolescents with ADHD.
International guidelines typically state that
methylphenidate, amphetamines, atomox-
etine, clonidine or guanfacine could
be prescribed for the pharmacological
treatment of ADHD in children.

As noted previously, there is no evidence
of an increase in the prevalence of ADHD
diagnoses. Polanczyk et al reported that,
throughout 1985 to 2012, ADHD prevalence
did not vary over time; rather, variability
in ADHD prevalence could be explained
by methodological differences between
studies. Therefore, the increase in ADHD
medication prevalence over time is likely
not due to an increase in the prevalence of
ADHD. While our study cannot elucidate
what may be underlying the increase in
medication prevalence, potential explana-
tions could be increased access to healthcare
and medication, greater awareness, and
changes to clinical practice. It is important
to note that the dispensing prevalence at
the end of our study period (1% in 2016/17)

<table>
<thead>
<tr>
<th>Fiscal year</th>
<th>Methylphenidate hydrochloride</th>
<th>Clonidine</th>
<th>Dexamphetamine sulphate</th>
<th>Atomoxetine</th>
<th>Modafinil</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007/08</td>
<td>462</td>
<td>50</td>
<td>36</td>
<td>&lt;1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>2008/09</td>
<td>507</td>
<td>51</td>
<td>33</td>
<td>12</td>
<td>&lt;1</td>
</tr>
<tr>
<td>2009/10</td>
<td>555</td>
<td>50</td>
<td>28</td>
<td>28</td>
<td>&lt;1</td>
</tr>
<tr>
<td>2010/11</td>
<td>586</td>
<td>52</td>
<td>26</td>
<td>28</td>
<td>&lt;1</td>
</tr>
<tr>
<td>2011/12</td>
<td>638</td>
<td>57</td>
<td>28</td>
<td>31</td>
<td>01</td>
</tr>
<tr>
<td>2012/13</td>
<td>703</td>
<td>66</td>
<td>29</td>
<td>35</td>
<td>01</td>
</tr>
<tr>
<td>2013/14</td>
<td>744</td>
<td>70</td>
<td>30</td>
<td>37</td>
<td>01</td>
</tr>
<tr>
<td>2014/15</td>
<td>790</td>
<td>79</td>
<td>32</td>
<td>39</td>
<td>01</td>
</tr>
<tr>
<td>2015/16</td>
<td>834</td>
<td>89</td>
<td>31</td>
<td>42</td>
<td>01</td>
</tr>
<tr>
<td>2016/17</td>
<td>899</td>
<td>98</td>
<td>34</td>
<td>46</td>
<td>01</td>
</tr>
</tbody>
</table>
remained below the pooled worldwide prevalence of the disorder (3.4%), indicating that the medication is probably not over-dispensed. However, this does not mean that medicating every child with a diagnosis of ADHD should therefore be encouraged. The choice to medicate should depend on what is best for the child and family preferences, with particular consideration given to the benefits of going on medication against the potential risks associated with medication side effects.11

Consistent with our hypothesis, we found a higher dispensing prevalence in males than females. This mirrors the sex difference in ADHD prevalence, which has a male to female ratio of 3–4:1.3 However, the relative increase in dispensing prevalence over time was much greater for females than males. ADHD has historically been harder to detect in females than males, as females tend to show primarily inattentive symptoms rather than more disruptive hyperactivity and impulsivity symptoms. The greater relative increase in dispensing prevalence for females may reflect increased recognition of ADHD in this group.25 Nevertheless, the rate still remains consistently higher for males relative to females.

We observed the highest prevalence in ADHD medication dispensing in 7–12 and 13–17-year-olds, followed by a notably lower prevalence in 18–24-year-olds. The lowest dispensing prevalence was for very young children (1–6-year-olds). These findings also support our age-specific hypothesis. As noted previously, pharmacological treatments are not encouraged in pre-school children unless symptoms are severe, likely explaining the very low prevalence observed in this age band.3 The lower prevalence for 18–24-year-olds could be due to the reduction in the severity of ADHD symptoms.3 It may also be due to caution on the part of the prescriber over concerns regarding stimulant misuse and abuse. International guidelines do recommend that healthcare professionals monitor adolescents and adults receiving ADHD medication for signs of stimulant abuse.6 However, the 18–24-year-old age group also had the greatest relative increase in ADHD dispensing prevalence (152%). One explanation for this could be improved detection of ADHD in adults.

Our results did not support our deprivation-specific hypothesis (ie, that dispensing prevalence would increase with deprivation level, except for the most deprived quintile which would show the lowest prevalence rates over time). While the most deprived quintile generally had the lowest dispensing prevalence for ADHD medication, this disparity was small. Furthermore, there were no clear differences in dispensing prevalence between quintiles 1–3. However, more deprived areas showed a smaller relative increase in dispensing prevalence. This suggests that there may be differences in access to medication over time for different socioeconomic groups, with more deprived areas having less access.

Consistent with our hypothesis, the European and Other ethnic groups showed the highest dispensing prevalence while Pasifika and Asian groups showed the lowest prevalence (though the greatest relative increase in dispensing prevalence). These disparities are similar, but do not exactly mirror ethnic differences in ADHD diagnosis. In the NZHS, the prevalence of parent-reported doctor-diagnosed ADHD was found to be highest in European/Other and lowest in Pasifika and Asian children.16 However, the diagnosis prevalence for Māori children (2.4%) was similar to the diagnosis prevalence for European/Other (2.7%). This finding was not replicated in our study, where the dispensing prevalence for Māori children is lower than European or Other. Barczyk et al similarly observed lower dispensing prevalence among Māori for all psychotropic medication.15

This difference in relative disorder prevalence and relative dispensing prevalence for Māori may be due to barriers in accessing medication. Our results did indicate that for Māori, those in the most deprived quintile generally had the lowest dispensing prevalence, suggesting that financial barriers to access may play a role. However, cultural choices regarding treatment may also underly the lower dispensing prevalence. Indeed, whānau or community-based models of treatment are dominant in Māori culture and may be preferred over pharmacological interventions.26,27

For the European and Other ethnic groups, greater dispensing prevalence was observed for more deprived quintiles...
(though these differences were small). In contrast, the least deprived quintile within Asian, MELAA and Pasifika groups had the highest dispensing prevalence by the end of the study period. These differences were small for the Asian and MELAA group but particularly pronounced for Pasifika. Additionally, those in the most deprived quintile generally had the lowest dispensing prevalence among Pasifika. While we did find that both Pasifika and Asian groups showed the greatest relative increase in dispensing prevalence over time, these results suggest that this increase may be driven by those from low deprivation areas. Overall, these results imply that there may be a barrier to accessing healthcare for certain groups, particularly Pasifika who come from more deprived regions. As such, these groups may need targeted support in the management of ADHD.

It is important to note that as we allow for the identification of multiple ethnicities, caution is advised when comparing one group to another. However, multi-ethnic identification represents the reality of many New Zealand children. Given that we are not running inferential statistics but describing general trends, we do not believe that this impacts the fidelity of our results. Caution is also advised when interpreting findings relating to the MELAA, Asian and Other groups, given their ethnic and cultural heterogeneity. Additionally, it is worth noting the considerable increase in Asian youth across the study period (Table 1), likely due to increased immigration. It may be of interest to investigate whether immigration status influences medication use for this group, particularly for psychotropic medication.

Our selection of medications for this study was primarily based on what is publicly funded for ADHD treatment in New Zealand (ie, methylphenidate hydrochloride, dexamphetamine sulfate, atomoxetine and modafinil). However, we are also aware that clonidine is internationally recommended for ADHD treatment and appears to be used “off-label” for ADHD in New Zealand. This is supported by our results, which show a doubling of the clonidine dispensing rate from 2007/08 to 2016/17. Furthermore, its dispensing prevalence is consistently higher than that of both dexamphetamine sulphate and atomoxetine combined. This suggests that it may be beneficial to subsidise clonidine for the treatment of ADHD in New Zealand.

In addition, a review of the most recent ADHD assessment and treatment guidelines is needed in New Zealand. Guidelines were last published by the New Zealand Ministry of Health in 2001 and do not mention all currently publicly funded medications in New Zealand (eg, atomoxetine), let alone internationally approved and recommended ADHD medications such as clonidine and guanfacine. These guidelines also align with outdated diagnostic criteria from the DSM-IV rather than the current DSM-V. Any updated New Zealand guidelines should also consider the ethnic and socioeconomic disparities apparent in ADHD medication use, and take these into account in their recommendations so that equitable health outcomes can be achieved.

A limitation of this study is the absence of information on why the medication was dispensed. In some cases ADHD medication can be prescribed for narcolepsy, or hypertension. Therefore, not all children dispensed a medication may have a diagnosis of ADHD. However, given that narcolepsy and hypertension are rare in children, we believe that non-ADHD prescribing will be rare in our sample.28 While our results suggest that over-dispensing is likely not of concern in New Zealand, we cannot conclude whether New Zealand prescribing practices for ADHD medication are appropriate without complementary information on non-pharmacological treatments. Furthermore, the IDI only provides information on medication dispensings (ie, filled prescriptions), which may not reflect the total number of prescriptions given. However, despite these data limitations, the availability of a national dataset on pharmaceuticals that is linkable to sociodemographic data is an important strength. As a result, we were able to estimate the dispensing prevalence of ADHD medication for all New Zealand children and young people as well as subgroups. The availability of data over 10 years also allowed us to examine temporal trends in dispensing prevalence.
This study demonstrates that the dispensing of ADHD medication to children and young people is increasing over time in New Zealand but remains lower than the worldwide pooled prevalence of the disorder. There is evidence of differences in dispensing prevalence across ethnic and socioeconomic groups, suggesting disparities in ADHD medication use. To ensure that equitable health outcomes are achieved, investigating the reasons underlying these disparities is important. Further research that incorporates diagnostic and treatment information would also help determine whether current prescription practices are appropriate.

Statistics New Zealand Disclaimer
Access to the data presented was managed by Statistics New Zealand under strict micro-data access protocols and in accordance with the security and confidentiality provisions of the Statistic Act 1975. Our findings are not Official Statistics. The opinions, findings, recommendations, and conclusions expressed are those of the researchers, not Statistics NZ.

Access to the anonymised data used in this study was provided by Statistics NZ under the security and confidentiality provisions of the Statistics Act 1975. Only people authorised by the Statistics Act 1975 are allowed to see data about a particular person, household, business, or organisation, and the results in this paper have been confidentialised to protect these groups from identification and to keep their data safe.

Careful consideration has been given to the privacy, security and confidentiality issues associated with using administrative and survey data in the IDI. Further detail can be found in the Privacy impact assessment for the Integrated Data Infrastructure available from www.stats.govt.nz.

Competing interests:
Dr Gibb, Dr Hetrick and Dr Bowden report grants from University of Auckland via National Science Challenge MBIE grant outside the submitted work. Dr Taylor reports grants from NZ Ministry of Business and Enterprise, from null, during the conduct of the study. Dr Gibb and Dr Bowden report grants from Janssen Cilag Pty Ltd outside the submitted work.

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URL:
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Knowledge and perspectives about the use of cannabis as a medicine: a mixed methods observational study in a cohort of New Zealand general practice patients

Karen Oldfield, Allie Eathorne, Ingrid Maijers, Richard Beasley, Alex Semprini, Irene Braithwaite

ABSTRACT

AIM: To determine what patients presenting to general practice (GP) understand about the use of cannabis as a medicine, beliefs of how this may impact their medical conditions and interactions with doctors.

METHOD: An in-person survey of 134 GP patients from four GP practices throughout the North Island of New Zealand undertaken from November 2018 to October 2019.

RESULTS: Fifty-five percent of the sample were female, with 40% of all participants aged 60 years plus. Ninety-one percent of participants indicated they would use a prescribed medicinal cannabis product while 45% reported they believed it may be of some benefit to their medical condition. Of those who believed it beneficial, 71% indicated they thought it useful for pain relief. Participants indicated comfort discussing medicinal cannabis use with GPs and specialists (92% respectively); however, less than 10% had done this.

CONCLUSIONS: Just under half of patients surveyed believe that medicinal cannabis products may be helpful to their condition, and while the majority report willingness, few have discussed this with their GP or specialist. There is need for accessible, accurate information regarding the use of cannabis-based medicine for patients and doctors alike to guide the patient-doctor consultation and decrease barriers to open discussion.

In December 2018 the New Zealand government introduced the Misuse of Drugs (Medicinal Cannabis) Amendment Act, allowing patients with a palliative diagnosis a statutory defence against the use of illicit cannabis in the management of their symptoms. It also legislated the development of a medical cannabis scheme that would enhance access to quality medicinal cannabis products. This regulatory scheme came into effect in April 2020 and allows general practitioners (GP) to prescribe approved medicinal cannabis products without the need for specialist approval.

This recent legislative change reflects a growing worldwide trend towards the use of cannabis as a medicine, a trend which tends to outstrip the available supporting evidence. This results in a misalignment between public expectations and the medical/scientific regulatory bodies that are charged with developing guidelines and/or following regulations. For example in November 2018 a change in government legislation allowed the prescription of medicinal cannabis products in the UK; however, the recommendations to prescribers from the National Institute for...
Health Care and Excellence (NICE) guideline [NG144] for Cannabis-based medicinal products\(^3\) recommended the use of only three pharmaceutical-grade products for specific medical conditions and ran counter to the public expectations of the legislation, which they expected would allow the wider use of cannabinoid-based products for medicinal purposes.\(^2,4\)

In a study of GPs in New Zealand, 77% had reservations about prescribing medicinal cannabis products, citing insufficient evidence of safety and efficacy and lack of understanding of the prescribing process.\(^5\) However, the majority stated they would be likely to prescribe such products that had been manufactured in accordance with good manufacturing practice (GMP) and shown efficacy through a similar process to all other approved medicines.\(^5\) This outlook is consistent with studies from Ireland,\(^6\) Australia\(^7\) and the US\(^8\) demonstrating that healthcare professionals are somewhat cautious in their approach to the use of medicinal cannabis products while they sit outside the usual evidence-based approach to the development of medicines.\(^9\)

The general population appears more supportive of the medical applications of cannabis. In the UK, a 1998–2002 survey indicated that a third of patients with chronic illness had used cannabis for medicinal purposes, with 68% reporting efficacy.\(^10\) In New Zealand, the majority of medicinal cannabis users surveyed in 2019 reported an overwhelming belief in symptom improvement.\(^11\) Despite 63.5% discussing their use with their doctor, only 14% had requested a prescription, primarily due to lack of faith in doctors prescribing, bureaucracy and cost.\(^11\) A recent study of current cannabis users in the US showed disparity between beliefs in the effectiveness of cannabis as a medicine and the available evidence; and that those who sought and received information from their primary care provider about medicinal cannabis had better knowledge of effectiveness.\(^12\) The drivers for patient expectations and willingness to use cannabis as a medicine may relate to the high mainstream and social media profile of cannabis,\(^12\) distrust in the pharmaceutical industry\(^13\) and the growing wellness culture associated with products that are perceived as natural.

In this study we asked patients visiting their GP about their current understanding regarding the use of cannabis as a medicine. The primary outcome was patient beliefs about the potential impact that medicinal cannabis may have on their medical conditions. Secondary outcomes included; proportions of participants that had undertaken discussions with a GP or specialist about medicinal cannabis products; if they had used medicinal or illicit cannabis for a medical condition in the past; what information patients wanted from their GP about medicinal cannabis and how they wished this to be communicated. We hypothesised that patients would have expectations of medicinal cannabis that exceed current scientific evidence, with limited knowledge about the specific pharmaceutical medicinal cannabis products available. We anticipated that a small proportion of patients would have discussed medicinal cannabis with their GP or specialists.

### Methods

A mixed methods prospective observational study design was used.

Recruitment was through four GP practices located within the North Island of New Zealand (Wellington, Hutt Valley, Wairarapa and Bay of Plenty) occurring between November 2018 and October 2019. GP practices were included if they were part of the Medical Research Institute of New Zealand GP Research Network, and the GPs themselves had participated in a related study of healthcare practitioners' knowledge of the use of cannabis as a medicine.\(^5\)

Approval for the research was obtained from the Victoria University of Wellington Human Ethics Committee (Reference: #25835).

### Participants

Participants were eligible for inclusion if they attended the GP practice for an appointment on a day when the study investigator was present in the practice and were 18 years or older. If the primary appointment holder was a child less than 18 then their parents or guardian were not eligible. Patients were not required to have a specific diagnosis to participate in the study.
Recruitment
Eligible patients were asked by the practice reception staff or attending GP if they were interested in completing a questionnaire and those expressing interest were given a participant information (PIS) sheet to read. Patients were then referred to the on-site study investigator who fully discussed the study and answered any questions. Participants were given the option to complete the questionnaire via iPad or paper. The study-investigator was available to clarify any questions during survey completion. Implied consent was obtained by the submission of the questionnaire to the study investigator.

Questionnaire
The questionnaire was developed with the assistance of a patient advocate and contained the following domains (Appendix):

- Patient demographics
- Beliefs around the use of medicinal cannabis in relation to their medical conditions
- Patient knowledge of pharmaceutical grade medicinal cannabis products, particularly Sativex® (the only approved pharmaceutical grade medicinal cannabis product in New Zealand), including cost per year and availability in New Zealand
- Willingness to take a prescribed medicinal cannabis product
- Interactions with their GP and/or specialists about the use of medicinal cannabis
- Previous use of recreational/illicit cannabis to treat medical symptoms; perceived effectiveness of this treatment
- Information they would seek from a healthcare professional about the use of medicinal cannabis and preferred method of delivery of this information

For the purposes of the study, medicinal cannabis was defined as “any use of cannabis plants and/or medications derived from cannabis that have been used by a patient to treat a medical condition”.

Questions allowed a mixture of Yes/No, Multiple choice and Free-text answers.

Data entry and analysis
All data was entered into REDCap (Research Electronic Data Capture). Partially completed questionnaires were included for analysis. Single missing data points such as a blank space in a table where all other information had been input were treated as a ‘Don’t know’ answer and contributed to the denominator. All other blank fields were treated as ‘No answer given’ and were removed from the analysis for that question. Free-text answers were grouped into related categories in NVivo14 to be reported numerically, with supporting quotes used in the results as required.

Ethnicity data was prioritised to level two according to the Health Information Standards Organisation.

Statistics
Descriptive statistics were used to calculate percentages with exact 95% confidence intervals (CI) reported where appropriate. Percentages and CIs were calculated using Microsoft Excel and SAS® software, Version 9.4 Copyright © 2013. The proportion denominator was determined by the number of participants answering that specific question within the questionnaire. The sample size represents a convenience sample, accounting for the central limit theorem that proposes that in sample sizes greater than 30 the distribution of the sample population mean will reflect that of the normal population.

Results
Across the four practices, 360 potential participants were approached by receptionists to read the participant information sheet relating to the survey, of which 160 accepted (44.4%). Of these, 134 participants undertook the questionnaire (83.8%) with an overall response rate for the survey of 37.2%. Participant demographics are shown in Table 1. The median age-band was 50–59 years and the age-band distribution may be seen in Figure 1.

The most common reasons for GP attendance were hypertension (n=27), health check-ups (n=17), depression (n=15), anxiety (n=15) and musculoskeletal problems (n=11). The most commonly reported classes of patient medications were anti-hypertensives (n=45), anti-depressants and anti-anxiety.
Table 1: Patient demographics.

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>60</td>
<td>44.8</td>
</tr>
<tr>
<td>Female</td>
<td>74</td>
<td>55.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>20–29</td>
<td>11</td>
<td>8.2</td>
</tr>
<tr>
<td>30–39</td>
<td>23</td>
<td>17.2</td>
</tr>
<tr>
<td>40–49</td>
<td>17</td>
<td>12.7</td>
</tr>
<tr>
<td>50–59</td>
<td>28</td>
<td>20.9</td>
</tr>
<tr>
<td>60–69</td>
<td>24</td>
<td>17.9</td>
</tr>
<tr>
<td>70–79</td>
<td>21</td>
<td>15.7</td>
</tr>
<tr>
<td>80+</td>
<td>8</td>
<td>6.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity (prioritised to level 2)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ European</td>
<td>106</td>
<td>79.1</td>
</tr>
<tr>
<td>Māori</td>
<td>5</td>
<td>3.7</td>
</tr>
<tr>
<td>Pacific</td>
<td>3</td>
<td>2.2</td>
</tr>
<tr>
<td>Chinese</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Indian</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>12.7</td>
</tr>
</tbody>
</table>

Figure 1: Age-band distribution of participants.
medications (n=22), non-steroidal anti-inflammatory agents (NSAIDs) (n=19), cholesterol lowering agents (n=14) and proton pump inhibitors (n=10). Seven participants were taking opioid medications.

Patient beliefs about medicinal cannabis prescriptions

Patient beliefs about medicinal cannabis products are shown in Table 2. When asked if they would take a prescribed medicinal cannabis product, 91.0% (95% CI: 84.8 to 95.3) reported ‘Yes’. Most participants (71.2%) who thought their condition may be helped believed it may be useful for pain relief. Those participants who believed they would NOT benefit from medicinal cannabis products could be grouped into five categories: not relevant to current condition (n=26), belief that cannabis is useful for pain only (n=18), not knowing if it would help (n=15), satisfaction with current medication regime or not currently taking any medications (n=6), and belief that the mode of consumption, eg, smoking, would exacerbate other problems (n=2).

Patient knowledge of medicinal cannabis products

Overall, 43 participants (32.3%) stated awareness of at least one prescription medicinal cannabis product, though the majority of those were not aware of specific pharmaceutical-grade products (Table 3). Of 38 participants who answered about specific products, eight were aware of Sativex®; with one participant aware it was a combination of tetrahydrocannabinol and cannabidiol, five believing it to be a cannabidiol only product and two not supplying answers. Five participants estimated the annual cost to patients of Sativex®, with responses ranging from $1,600 to $1,000,000.

Interactions with healthcare professionals

Participants indicated they would be happy to discuss medicinal cannabis products with the healthcare professionals involved in their care: GP (91.7% (95% CI: 85.7–95.8)), specialist (92.1% (95% CI: 83.6–97.0)), however less than 10% reported doing this (Table 4).

Table 2: Beliefs about medicinal cannabis products.

<table>
<thead>
<tr>
<th>Belief</th>
<th>n</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you take a prescribed medicinal cannabis product?</td>
<td>Yes</td>
<td>121/133</td>
<td>91.0</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72/133</td>
<td>55.0</td>
</tr>
<tr>
<td>Do you believe a medicinal cannabis product would be helpful for your condition?</td>
<td>Yes</td>
<td>59/131</td>
<td>45.0</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72/131</td>
<td>55.0</td>
</tr>
<tr>
<td>If Yes, why? (more than one answer can be supplied)</td>
<td>Symptom control</td>
<td>14/59</td>
<td>23.7</td>
</tr>
<tr>
<td></td>
<td>Pain relief</td>
<td>42/59</td>
<td>71.2</td>
</tr>
<tr>
<td></td>
<td>Decrease anxiety</td>
<td>28/59</td>
<td>47.5</td>
</tr>
<tr>
<td></td>
<td>Cure my condition</td>
<td>5/59</td>
<td>8.5</td>
</tr>
<tr>
<td></td>
<td>Other reasons</td>
<td>5/59</td>
<td>8.5</td>
</tr>
</tbody>
</table>

a: Nausea n=4, Fatigue n=2, Appetite n=1, Blood pressure n=1, Calmed state of mind n=1, Chemotherapy associated side effects n=1, Confusion n=1, Joint inflammation n=1, Muscle relaxant n=1, Sleep related disorders n=1, Spasticity n=1, Vomiting n=1.

b: Sleep related problems: n=3, Don’t know n=2, General support of management n=1, Nausea n=1, Nutritional support n=1.
Table 3: Knowledge of medicinal cannabis products.

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants indicating awareness of prescribed products</td>
<td>43/133</td>
<td>32.3</td>
<td>24.5–41.0</td>
</tr>
<tr>
<td>Recognition of named products in those who indicated they were aware of prescribed products</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nabiximols (Sativex®)</td>
<td>8/38</td>
<td>21.1</td>
<td>9.6–37.3</td>
</tr>
<tr>
<td>Dronabinol (Marinol)</td>
<td>8/38</td>
<td>21.1</td>
<td>9.6–37.3</td>
</tr>
<tr>
<td>Nabilone (Cesamet)</td>
<td>3/38</td>
<td>7.9</td>
<td>1.7–21.4</td>
</tr>
<tr>
<td>Epidiolex®</td>
<td>4/38</td>
<td>10.5</td>
<td>2.9–24.8</td>
</tr>
</tbody>
</table>

Table 4: Interactions with healthcare professionals about medicinal cannabis.

<table>
<thead>
<tr>
<th></th>
<th>GP</th>
<th>Specialist</th>
<th>GP</th>
<th>Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy to discuss with healthcare provider?</td>
<td>n</td>
<td>%</td>
<td>95% CI</td>
<td>n</td>
</tr>
<tr>
<td>Yes</td>
<td>122/133</td>
<td>91.7</td>
<td>85.7–95.8</td>
<td>70/76</td>
</tr>
<tr>
<td>Don't have a specialist</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>57/133</td>
</tr>
<tr>
<td>If Yes, have you discussed medicinal cannabis products?</td>
<td>6/122</td>
<td>4.9</td>
<td>1.8–10.4</td>
<td>6/70</td>
</tr>
<tr>
<td>Did you feel informed?</td>
<td>2/6</td>
<td>33.3</td>
<td>4.3–77.7</td>
<td>3/5</td>
</tr>
<tr>
<td>Were you prescribed a product?</td>
<td>1/6</td>
<td>16.7</td>
<td>0.4–64.1</td>
<td>-</td>
</tr>
<tr>
<td>If not happy to discuss, why not?</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1/6</td>
</tr>
<tr>
<td>Stigma</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1/6</td>
</tr>
<tr>
<td>Legal implications</td>
<td>5/11</td>
<td>45.5</td>
<td>16.8–76.6</td>
<td>2/6</td>
</tr>
<tr>
<td>Cost</td>
<td>2/11</td>
<td>18.2</td>
<td>2.3–51.8</td>
<td>-</td>
</tr>
<tr>
<td>Other a</td>
<td>5/11</td>
<td>45.5</td>
<td>16.8–76.6</td>
<td>3/6</td>
</tr>
</tbody>
</table>

a: GP: Dislike any type of drug n=2, Not aware of how it would help me n=1, Not interested n=1, No answer n=1
Specialist: No need n=1, Satisfied with condition currently n=1, No answer n=1.

Table 5: Use of recreational/illicit cannabis for medical symptoms.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of recreational/illicit cannabis to treat medical symptoms</td>
<td>15/134</td>
<td>11.2</td>
<td>6.4–17.8</td>
</tr>
</tbody>
</table>

Mode of consumption

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking (pure)</td>
<td>12/15</td>
<td>80.0</td>
<td>51.9–95.7</td>
</tr>
<tr>
<td>Smoking (with tobacco)</td>
<td>2/15</td>
<td>13.3</td>
<td>1.7–40.5</td>
</tr>
<tr>
<td>Vaped</td>
<td>2/15</td>
<td>13.3</td>
<td>1.7–40.5</td>
</tr>
<tr>
<td>Oil</td>
<td>5/15</td>
<td>33.3</td>
<td>11.8–61.6</td>
</tr>
<tr>
<td>Edibles</td>
<td>1/15</td>
<td>6.7</td>
<td>0.2–32.0</td>
</tr>
<tr>
<td>Other</td>
<td>1/15</td>
<td>6.7</td>
<td>0.2–32.0</td>
</tr>
<tr>
<td>Did you find it effective?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13/15</td>
<td>86.7</td>
<td>59.5–98.3</td>
</tr>
<tr>
<td>Did you reduce your prescribed medications?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8/12</td>
<td>66.7</td>
<td>34.9–90.1</td>
</tr>
</tbody>
</table>
Use of recreational/illicit cannabis for medical symptoms

Recreational/illicit cannabis had been used for symptom relief of medical conditions by 15 (11.2%) participants, of whom the majority (80.0%) smoked cannabis (Table 5). Thirteen (86.7%) found it to be effective for their symptoms, with eight indicating they had reduced other regular medications. The primary symptoms that participants reported using recreational cannabis for were pain (n=8), insomnia (n=5) and anxiety (n=4).

Information communication from healthcare professionals

Participants wanted a wide range of information about medicinal cannabis from their healthcare professionals, with 82.8% (95%CI: 75.4–88.8) indicating that they would like further information. Emergent themes were benefits and side effects, efficacy in specific conditions and how that compared with other medications, dosage and administration—including long-term use, addiction information and impact on functioning, work and driving. Supporting quotes from participants are shown in Figure 2.

The majority of participants wished to access information about medicinal cannabis from their provider through a website (68.7% (95% CI: 60.1–76.4)) or a pamphlet (45.5% (95% CI: 36.9–54.4)).

Discussion

In this study over 90% of patients would use medicinal cannabis products if prescribed by their GP or specialist and a similar proportion would be happy to discuss medicinal cannabis products with their practitioners. Most (70%) thought it would be best used for pain, and just under half thought it might be helpful for their specific condition. Despite this, awareness of approved medicinal cannabis products was low and less than 10% of patients had actually approached their doctor about medicinal cannabis. Those who did not want to discuss with their practitioners were concerned about legal implications and reported a dislike of ‘drugs’ in general.

A small number of patients reported using recreational/illicit cannabis to treat medical symptoms, primarily through smoking, with...
the majority of these finding it effective, and two thirds indicating a reduction in use of other prescription medications. Less than half of this group stated that they had discussed medicinal cannabis with their doctor. The majority of patients wanted to know more about cannabis as a medicine from their doctor, either through accessing websites or being given pamphlets.

There are many possible reasons that may impact why patients display willingness to discuss medicinal cannabis but do not follow through with it. These include being happy with their current treatment, concerns around stigma, cost, bureaucracy, lack of trust and the fact that patients rarely initiate treatment discussions.11,17 While a ‘concordance’ approach to undertaking a medical consultation,17 where the patient and doctor have equal input into the discussion about medications is considered ideal, this does not always happen in practice, as patients may not be confident in asking about a treatment the doctor has not suggested for fear of upsetting them.16,19 Without this patient input, the limited evidence of efficacy combined with the current illicit status of recreational cannabis may make it less likely that a GP will bring medicinal cannabis up in a consultation without a conscious plan to add this in to their usual practice.

There may also be an inherent appreciation of the apparent misalignment between progressive legislation and evidence-based medical practice. Patients’ expectations are that doctor prescribed medicinal cannabis products are effective, ‘approved’ and safe. The Medical Cannabis Scheme guidelines in New Zealand, where products may need to meet a minimum standard based on GMP, have no requirements for clinical trials prior to being available to doctors on prescription.20 Such products will be ‘unapproved’ by Medsafe, New Zealand’s regulatory authority, but will be able to be prescribed as an exception to the Medicine’s Act.21,22 The Medical Council of New Zealand’s Good Prescribing Practice guidelines23 which identify strict rules for when unapproved medications may be prescribed, highlights the difficulties that doctors face if choosing to prescribe such medications.22 Similar dichotomy is seen in the UK, where the NICE guidelines limit applications of the recent law changes2,3 and Canada, where despite law changes patients found it difficult to find physicians to support access of non-pharmaceutical medicinal cannabis due to lack of evidence for use compounded by its ongoing controversial status.19,24,25

It was expected that participants would not be aware of specific medicinal cannabis products. Although New Zealand is one of only two countries in the world that allows direct-to-consumer advertising of medications,26 medicinal cannabis products are excluded. As a result, patients can only increase their awareness through media reporting, accessing internet fora and discussions with healthcare professionals. It is of interest that of those who stated they were aware of Sativex®, nearly all of them stated that they thought it was a CBD only, suggesting that the public perception may be that ‘medicinal cannabis’ is synonymous with cannabidiol and does not contain the perceived harmful substance delta-9-tetrahydrocannabinol (THC).

It is of interest that the majority of the group who believed medicinal cannabis may be beneficial indicated that it is primarily helpful as a pain relief, with a number of whom believed it was only useful for pain, highlighting the widespread belief of its efficacy despite patchy medical evidence for this. Currently an internet search by a patient using the terms ‘cannabis for pain relief’ will provide over 13 million results, many of which extol its virtues through ‘medical news’ websites. However, there is no peer-reviewed evidence for the use of medicinal cannabis in acute pain conditions with only low-moderate evidence of efficacy in chronic neuropathic pain.27,28 Despite this, ongoing patient belief in the efficacy of cannabis for pain management will likely result in GPs seeing increased patient enquiries and prescription requests as the use of medicinal cannabis continues to be normalised.

Encouragingly, 83% of participants reported wanting information about the use of medicinal cannabis in the same way that their healthcare provider would recommend any medicine. This indicates that patients in New Zealand will be generally receptive to professional recommendations as to medicinal cannabis use as products become more widely available.
Strengths and limitations

The overall sample size provides reasonable confidence in the outcomes derived from questions with high response rates with the quality of data enhanced by the availability of a study investigator allowing for clarification of questions during survey completion. Two participants posted in their answers as they were unable to complete the questionnaire due to time constraints, with 98.5% of responses recorded in the presence of an investigator. For the primary outcome, the proportions of participants amenable to use prescribed medicinal cannabis products and willing to discuss this with their GP or specialist were in excess of 90%, with lower confidence interval boundaries of 85% suggesting a relatively precise estimation of current opinion in a GP practice patient population.

There are also some methodological limitations. Time-pressured patients may be less likely to complete the questionnaire at the end of a consult, resulting in selection bias toward those who are time rich. Response rates varied depending on reception staffing levels on the days investigators were present and the limited geographical representation limits national generalisability. Despite this, the overall response rate of 37.2% is within the expected range when compared with GP patient surveys undertaken in New Zealand, the UK and Canada, which range from 19.8–55.9%.29–31 Responder bias is likely in such a polarised topic, with those who have strong opinions about cannabis more likely to respond, and while comparative GP patient surveys regarding medicinal cannabis use in the general practice population were not identified, overseas studies in oncology patient populations have reported response rates of 27.4–63%.32–34 Non-response bias was unable to be assessed due to the anonymous nature of initial recruitment for the survey. While the availability of an investigator aimed to minimise confusion between medicinal cannabis use and the upcoming referendum about the legalisation of recreational cannabis, participant concerns around illegality of cannabis, distrust of cannabis companies, previous convictions and anti-drug sentiment may have negatively impacted the response rate. Due to the length of the recruitment period, it is acknowledged that attitudes towards medicinal cannabis may have altered, however this is unable to be tested.

While the proportion of males in this sample was less than that of the general population, it is consistent with males attending GP consultations 30% less often than females.36 There was overrepresentation of the elderly, which may be consistent with the population group who typically visit their GP.36 In this sample Māori were under-represented (4%), where 8–11% of all consultations in targeted age ranges would be expected,37 likely due to the geographic location of the general practices involved and the demographics of the practice population. This under-representation is in keeping with previous New Zealand research undertaken in the general practice population, where Māori were more likely to be under-represented in the initial recruitment and subsequent completion of questionnaires.38 This limits the generalisability of the results, and identifies an area in which future research could be undertaken.

Conclusion

This study suggests a not insignificant number of patients presenting to general practice believe that medicinal cannabis may provide them clinical benefit; however, few have actively discussed this with their GP or specialist. The gap between those expressing a willingness to discuss medicinal cannabis with their healthcare professional and those who actually do is a concern and likely multi-factorial in nature. It is important that patients feel comfortable discussing cannabis in general, both illicit and medical use, with doctors facilitating these discussions. There is need for accurate and accessible information about the use of cannabis as a medicine to guide patient-doctor consultations in the context of the current evidence base and legislative status in New Zealand.
Appendix

Medical cannabis—patient experience questionnaire

1. Are you aware of any prescribed medical cannabis products?
   Yes ☐ No ☐ - go to question 3

2. If yes, have you heard of any of the following medications?

<table>
<thead>
<tr>
<th>Aware of product? (Y/N)</th>
<th>Primary constituents (tick all that apply)</th>
<th>Available in NZ? (Y/N)</th>
<th>Estimated cost per year to patient* (NZ $ amt)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>THC*</td>
<td>CBD*</td>
<td></td>
</tr>
<tr>
<td>Dronabinol (Marinol)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nabiximols (Sativex)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nabilone (Cesamet)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epidiolex</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*THC = delta-9-tetrahydrocannabinol, CBD = cannabidiol.

3. Would you take a prescribed medication made from medical cannabis?
   Yes ☐ No ☐

4. Please can you state what medical conditions you see your doctor for:

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

5. Please list the prescribed medications you take for your medical conditions:

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

6. Do you believe that medical cannabis products may be helpful for your medical conditions?
   Yes ☐ - go to part a) No ☐ - go to part b)

   a) If yes, what benefits do you think medical cannabis products will give you (tick all that apply)?

   ○ Symptom control (eg, spasticity, nausea/vomiting) (please list specific symptoms)

   ○ Pain relief
   ○ Decrease anxiety
   ○ Cure my condition
   ○ Any other benefits (please list)
b) If no, why not?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

7. Have you ever used recreational cannabis to treat a medical condition or symptom?
   Yes ☐ No ☐ - go to question 8
a) If yes, what medical condition or symptom did you treat?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

b) How did you take it?
   ○ Smoked (pure)
   ○ Smoked (with tobacco)
   ○ Vaped
   ○ Oil
   ○ Edibles
   ○ Other (please specify)
__________________________________________________________________________________

7. Have you ever used recreational cannabis to treat a medical condition or symptom?
   Yes ☐ No ☐ - go to question 8
a) If yes, what medical condition or symptom did you treat?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

b) How did you take it?
   ○ Smoked (pure)
   ○ Smoked (with tobacco)
   ○ Vaped
   ○ Oil
   ○ Edibles
   ○ Other (please specify)
__________________________________________________________________________________

7. Have you ever used recreational cannabis to treat a medical condition or symptom?
   Yes ☐ No ☐ - go to question 8
a) If yes, what medical condition or symptom did you treat?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

b) How did you take it?
   ○ Smoked (pure)
   ○ Smoked (with tobacco)
   ○ Vaped
   ○ Oil
   ○ Edibles
   ○ Other (please specify)
__________________________________________________________________________________

7. Have you ever used recreational cannabis to treat a medical condition or symptom?
   Yes ☐ No ☐ - go to question 8
a) If yes, what medical condition or symptom did you treat?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

b) How did you take it?
   ○ Smoked (pure)
   ○ Smoked (with tobacco)
   ○ Vaped
   ○ Oil
   ○ Edibles
   ○ Other (please specify)
__________________________________________________________________________________
b) If No, why not (tick all that apply)?
○ Stigma
○ Worried about legal implications
○ Cost of product
○ Other (please specify)

9. Would you feel comfortable discussing medicinal cannabis (whole plant and/or medical product) with your specialist(s)?
   Yes ○ - go to part a) No ○ - go to part b) I don’t see a specialist ○ - go to question 10

a) If yes, have you discussed medicinal cannabis (whole plant and/or medical product) with your specialist(s)?
   Yes ○ No ○ - go to question 10
   i) If yes, did you feel you were informed about the evidence for/against use as well as any possible side effects associated with use of medicinal cannabis (whole plant and/or medical product)?
      Yes ○ No ○
   ii) Did your specialist prescribe a medical cannabis product for you?
      Yes ○ No ○
   iii) Did you fill your prescription? How much did it cost you per month?
      Yes ○ No ○
      Cost (NZ$) ____________________________________________________________________
   iv) Have you found it effective?
      Yes ○ No ○ - go to question 10
   v) If effective, have you decreased the amount of your other prescribed medications for your medical condition?
      Yes ○ No ○

b) If no, why not (tick all that apply)?
○ Stigma
○ Worried about legal implications
○ Cost of product
○ Other (please specify)

10. What information from your doctor would you like about cannabis as a medicine and medical cannabis products?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

11. What would be the best way we could communicate this information?
○ Website
○ Pamphlet
○ Poster
○ Podcast
○ Social media (Facebook/Twitter/Instagram)
○ Other (please specify)
12. Demographic information

**Age (years):**
- Under 20
- 20–29
- 30–39
- 40–49
- 50–59
- 60–69
- 70–79
- 80+

**Gender:**
- Male
- Female
- Other (please specify) ________________________________________________________
- Prefer not to disclose

**Ethnicity: Which ethnic group do you belong to? (Tick all that apply)**
- NZ European
- Māori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- Other (such as Dutch, Japanese, Tokelauan). Please state: ____________________________

Source: SNZ, 2001 Census


NVivo qualitative data analysis software. 2018.


Medicines Act.; 1981.


Why dizziness is likely to increase the risk of cognitive dysfunction and dementia in elderly adults

Paul F Smith

ABSTRACT
Dementia is recognised to be one of the most challenging diseases facing society, both now and in the future, with its prevalence estimated to increase substantially by 2050. The potential contributions of age-related sensory deficits have attracted little attention until recently, when a landmark study suggested that hearing loss could be a greater risk factor for dementia than hypertension, obesity, smoking, depression, physical inactivity or social isolation. Over the last decade, evidence has been gradually accumulating to suggest that the other part of the inner ear, the balance organs or ‘vestibular system’, might also be important in the development of cognitive dysfunction and dementia. Increasing evidence suggests that dizziness associated with vestibular dysfunction, a common reason for patients consulting their GPs, increases the risk of cognitive dysfunction, including dementia, and our understanding of the basic neurobiology of this sensory system supports this view. This paper aims to review and critically evaluate the relevant evidence.

Dizziness is reported to be one of the most common reasons for patients consulting a general practitioner. Although not all consultations regarding dizziness are related to the vestibular system, for example, they can be due to cardiovascular dysfunction, approximately 20–50% are believed to be due to balance disorders related to the peripheral vestibular system (see Table 1). Recent studies have estimated that 35% of US adults over the age of 35 years suffer from vestibular disorders, increasing to 85% aged 80 and over. Unfortunately, no reliable statistics are available on the prevalence of vestibular disorders for New Zealand. However, the Health Quality and Safety Commission reported that even between January and March, 2020, there were 65,893 fall injuries reported to the ACC, of which 8,544 were classified as serious. Overseas, impairment of the vestibular system has been estimated to increase the odds of falling by over 12-fold, and nearly 30% of adults aged 65 and over fall each year. In 2016, the mortality rate associated with falls in the US was estimated to be 122.2 per 100,000 persons.

The impact of vestibular dysfunction on loss of balance and falls is due both to its effects on brainstem vestibular reflex pathways as well as higher cognitive processing of self-motion signals from the vestibular system. The vestibular system (Figure 1) senses head movement (strictly speaking ‘head acceleration’ or change in head velocity) in different planes, as well as linear acceleration by gravity. The three semi-circular canals in each inner ear sense angular rotation of the head, and the two otoliths, the utricle and the saccule, sense linear movement. This linear movement not only includes movement of the head, forward and backward, and left and right, but linear acceleration of the head by gravity; the saccule, in particular, senses linear acceleration by gravity (Figure 2 for explanation). The utricle and saccule detect linear acceleration as a result of...
‘otoconia’ (calcium carbonate crystals) that generate an inertial force on the hair cells during head movement, causing a change in electrical potential (see Figure 2). In this respect, it is important to note that the most primitive form of the otoliths (‘statoliths’) are estimated to have evolved approximately 670 million years ago, and they exist in invertebrates such as jellyfish. This is their only means of detecting upright, which is necessary for survival. Therefore, given their evolutionary age, the otoliths might be expected to have developed major contributions to balance in humans. The vestibular system, through short-latency brainstem pathways, generates rapid eye movements that compensate for the unintentional movement of the head, eg, movement of the head due to the pulse beat (the vestibulo-ocular reflexes or VORs) and maintains the stability of the visual image of the world on the retina. The vestibular system also generates rapid vestibulo-spinal reflexes (VSRs) which adjust posture for unintentional movement, enabling us to keep our balance. Without a normal vestibular system, vision would become blurred (a condition known as ‘oscillopsia’) and balance and locomotion become disrupted.

Information about angular and linear head movement is also transmitted to higher centres of the brain, where it contributes to the conscious experience of moving through the environment and to cognitive processes such as memory. As we move through the environment, the vestibular hair cells in the semi-circular canals and otoliths detect every head movement, and transmit this information to areas of the brain such as the hippocampus, where it is assimilated and stored to provide a spatial map of our movements. This information is integrated with other sensory information, such as that from the visual, auditory, tactile, olfactory and proprioceptive systems, and formulated into mathematical maps of the spatial world, allowing us to navigate through it more effectively. In the 1970s, specific neurons were discovered in the hippocampus that selectively discharged in response to specific areas of the environment. These became known as ‘place cells’. In the 1990s, related cells were discovered in the medial entorhinal cortex, known as ‘grid cells’, which discharged in response to multiple areas in the environment.

In 2014, the Nobel Prize in Medicine or Physiology was awarded to John O’Keefe, Edvard Moser and Britt-Mayer Moser for these discoveries, which have become known as the brain’s ‘global positioning system’. Since then, both place cells and grid cells have been demonstrated to rely on vestibular information from the inner ear. Therefore, one reason why vestibular-related dizziness contributes to falls, is that not only does it impair fast vestibular reflexes such as the VORs and VSRs, but it impairs the ability of the brain to integrate self-motion information and to navigate through the spatial environment and form spatial memories. Information from the vestibular system is distributed widely throughout the central nervous system and is involved in higher cognitive function. There is increasing evidence that the otoliths may be important for cognitive processing independently of the semi-circular canals; this is one reason why the evolutionary age of the otoliths is of interest.

In recent years, a substantial amount of epidemiological evidence has been published to support the idea that age-related hearing loss is a risk factor for dementia. For example, in a seminal study published in the Lancet, it was reported that the contribution of hearing loss to the incidence of dementia was greater than hypertension, obesity, smoking, depression, physical inactivity and social isolation. This result seemed surprising, because sensory systems had never been considered particularly important to dementia, except perhaps for olfactory function as a potential biomarker. It is important to note that the Livingstone et al study was based on data from high-income countries and the evidence from low-to-middle income countries is less convincing in this respect. Over the last several years, further evidence in support of the importance of hearing loss for the development of dementia has been published, although it is not entirely consistent.

Less attention has been given to the other part of the inner ear, the vestibular system (see Figure 1); however, evidence is mounting that age-related vestibular disorders could also be a significant risk factor for the development of cognitive dysfunction and dementia, along with
hearing loss. The vestibular system is known to degenerate with age, as with other sensory systems, with decreases in hair cells in the semi-circular canals and otoliths, a reduction in the number of neurons in the vestibular nerve and brainstem vestibular nucleus, and a deterioration of vestibular reflex responses. As shown in the Iceberg model in Figure 3, clinical presentation of age-related vestibular symptoms usually includes ‘presbystasis’ (the imbalance of disequilibrium) or ‘presbyvertigo’ (vertigo), or both, possibly with a decrease in vestibular perception; however, it is possible for age-related vestibular symptoms to be sub-clinical and therefore harder to detect.

Animal studies supporting the role of the vestibular system in cognitive function

The literature relating the vestibular system to cognitive function, especially spatial memory, dates back to the 1960’s. Numerous studies have reported evidence

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peripheral vestibular</td>
<td>20–50%</td>
<td>Benign paroxysmal positional vertigo (BPPV), labyrinthitis, vestibular neuritis</td>
</tr>
<tr>
<td>disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>10–30%</td>
<td>Arrhythmia, congestive heart failure, vasovagal conditions (eg, carotid sinus hypersensitivity)</td>
</tr>
<tr>
<td>Systemic infection</td>
<td>10–20%</td>
<td>Systemic viral and bacterial infections</td>
</tr>
<tr>
<td>Psychiatric conditions</td>
<td>5–15%</td>
<td>Depression, anxiety, hyperventilation</td>
</tr>
<tr>
<td>Metabolic disturbances</td>
<td>5–10%</td>
<td>Hypoglycemia, hyperglycemia, electrolyte disturbances, thyrotoxicosis, anemia</td>
</tr>
<tr>
<td>Medications</td>
<td>5–10%</td>
<td>Anti-hypertensives, psychotropic drugs</td>
</tr>
</tbody>
</table>

Table 1: Common causes of dizziness in primary care practice. From Agrawal et al1 with permission.
Figure 2: (A) Schematic representation of the plates of the otolithic receptors (the utricular and saccular maculae). The arrows show the preferred polarization of the hair cell receptors across the maculae. The dashed lines are lines of polarity reversal (lpr). The striola refers to a band of receptors on either side of the lpr. Schematics of type I (B,D) and type II receptors (C,E) show how linear acceleration acts on the otoliths and so deflects the hair bundles of individual receptors. From Curthoys et al7 with permission.
that unilateral or bilateral lesions of the peripheral vestibular system impair spatial memory in various maze and foraging tasks.\textsuperscript{14,29–31} In some cases, these have been conducted even 14 months after bilateral vestibular lesions (BVL) in rats, and the spatial memory deficits remain.\textsuperscript{32} A variety of potentially confounding factors have been controlled for, including vision, degree of motor activity, anxiety and auditory function, and the results have been consistent.\textsuperscript{29–32} BVL has been demonstrated to impair the function of neurons in the hippocampus that encode places in the environment (‘hippocampal place cells’),\textsuperscript{11,12} EEG activity in the theta frequency range,\textsuperscript{33–35} which is thought to regulate place cell function, and theta EEG activity among grid cells of the entorhinal cortex.\textsuperscript{13} Neurons in the thalamus which encode head direction (‘head direction cells’), are also dysfunctional following BVL.\textsuperscript{36} Together, these abnormalities in the function of place cells, grid cells and head direction cells, are likely to underlie the spatial memory deficits observed in animals.\textsuperscript{14,15} Furthermore, transgenic mice without otoconia and therefore without otolith function (‘otolith deficient tilted mice’), but with normal semi-circular canal function, have been shown to have aberrant hippocampal place cell and head direction cell activity.\textsuperscript{36,37} In addition, a variety of neurochemical changes have been documented in the hippocampus following BVL, including changes in the N-methyl-D-aspartate (NMDA) subtype of glutamate receptor and muscarinic acetylcholine (ACh) receptors,\textsuperscript{38–40} both of which are implicated in hippocampal learning and memory processes.
Taken together, the data from animal studies strongly indicate an important role for the vestibular system in spatial cognition. Although the specific pathways through which vestibular information reaches areas of the brain such as the hippocampus, are yet to be fully elucidated, projections from the vestibular nucleus and cerebellum are likely to transmit information via multiple routes, particularly the thalamus (see Figure 4). It is speculated that there is a ‘theta pathway’, which involves projections from the brainstem vestibular nucleus complex (VNC) to the pedunculopontine tegmental nucleus (PPTg), then via various nuclei to the medial septum, which releases ACh into the hippocampus; a ‘head direction pathway’, from the VNC via head direction cells of the anterodorsal nucleus of the thalamus (ADN) to the medial entorhinal cortex (MEC), to the hippocampus; a major thalamic pathway which transmits vestibular information to the parietal cortex and then on to the MEC and hippocampus; and a transcerebellar pathway. The detailed pathways are depicted in Figure 4.

**Figure 4:** ADN, anterodorsal nucleus of the thalamus; DTN, dorsal tegmental nucleus; Interpositus N, anterior and posterior interpositus nuclei; LMN, lateral mammillary nuclei; MEC, medial entorhinal cortex; MG, medial geniculate nucleus; NPH, nucleus prepositus hypoglossi; Parietal C, Parietal cortex; PaS, parasubiculum; Perirhinal, Perirhinal cortex; PoS, posterior subiculum (i.e. dorsal part of the presubiculum); Post HT, posterior hypothalamus; Postrhinal, postrhinal cortex; PPTg, pedunculopontine tegmental nucleus of Gudden; Pulv, pulvinar; RPO, reticularis pontis oralis; SUM, supramammillary nucleus; ViM, ventralis intermedius nuclei of the thalamus; VLN, ventral lateral nucleus of the thalamus; VNC, vestibular nucleus complex; VPL, ventral posterior inferior nucleus of the thalamus; VPM, ventral posterior medial nuclei of the thalamus. From Hitier et al. with permission.
Vestibular contributions to cognitive function in humans

Consistent with the studies in animals, many studies conducted over the last two decades have demonstrated that vestibular disorders are associated with the impairment of cognitive function in otherwise normal healthy adults.44–53 The studies reviewed were identified using a Pubmed search between 1989 and 2020, using ‘vestibular’ and ‘cognition’ as key words. All of the studies were included; they consisted of two main types: survey and epidemiological studies; and clinical experimental studies (Table 2). Among the symptoms that have been reported are difficulty concentrating, deficits in attention and spatial memory, verbal fluency, mental rotation, and dyscalculia and other forms of numerical cognition (see Table 2). Although some 51 such studies have been published since 1989, only a subset of them (21) have controlled for hearing loss, either by excluding patients with hearing loss or by controlling for it statistically in the analysis of the data.54–69 Table 2 provides a summary of the studies that have controlled for hearing loss and therefore where the deficits can be considered to be mainly vestibular in origin. Dobbels et al70 have argued that few of the studies reporting cognitive deficits in humans with vestibular disorders, have controlled for hearing loss. However, a careful review of the literature suggests that is not the case. Of course, there are cases in which vestibular and auditory symptoms present together, for example, in Meniere’s disease, in which case they are both likely to contribute to cognitive deficits. Beyond controlling for hearing loss, the major weaknesses of the epidemiological studies are that they often include ‘heterogeneous vestibular disorders’ (bilateral vestibular loss, unilateral vestibular loss, vestibular neuritis, benign paroxysmal positional vertigo (BPPV), etc.) and do not include the same controls as the experimental studies (see Table 2). The available experimental studies are based on samples of patients with different vestibular disorders, but each one of them includes a sample of patients which is compared to a control group without vestibular dysfunction (see Table 2).

Studies in humans which have combined structural and functional neuro-imaging with behavioural assays, have also provided compelling evidence that vestibular sensory inputs are important for human spatial cognition. In a seminal study of patients with neurofibromatosis type 2 (NF2) who underwent bilateral vestibular nerve section, it was observed that the NF2 patients exhibited significantly poorer spatial navigation skills, measured using a virtual Morris Water Maze Task, which required no movement other than that of a mouse to control a cursor on a computer screen. These spatial cognitive deficits were correlated with reduced hippocampal volumes (approximately 17%) compared to age- and sex-matched controls.53 Only one of these patients exhibited total hearing loss post-operatively and all of them were 8–10 years post-BVL. Subsequent studies have provided further evidence of impaired spatial memory and hippocampal atrophy in patients with other vestibular disorders such as Meniere’s disease.52,71–74 A recent study of over 100 healthy adults reported that poorer vestibular function was correlated with significantly reduced hippocampal volume.75 In our most recent study, we have found that age is statistically related to a bilateral decrease in the volume of the hippocampus and the left entorhinal cortex.76

Vestibular dysfunction as a risk factor for dementia

As a result of the animal and human studies demonstrating that peripheral vestibular lesions caused spatial memory deficits, Previc77 suggested that loss of vestibular function might be implicated in the development of dementia, including Alzheimer’s disease (AD). His argument was based partly on the limitations of the β-amyloid (Aβ) hypothesis of AD, but the idea can be considered independently of that hypothesis. The central vestibular system, including the brainstem VNC, contributes to major cholinergic inputs to the hippocampus, which is damaged in AD.78 Bilateral vestibular loss in rats also results in a decrease in acetylcholine (ACh) receptors in the hippocampus.38

There have been only a few studies that have directly investigated the relationship between vestibular function and AD, all of them conducted by the same group. The first studies investigated the statistical relationship between vestibular dysfunction and
Table 2: Studies conducted in humans that have reported cognitive deficits associated with different types of vestibular dysfunction, in which hearing loss has been controlled for in some way, either by excluding subjects with hearing loss or by controlling for it statistically in a multiple logistic regression model. Where ‘No ()’ occurs, the first number in the brackets indicates the number of subjects without hearing loss and the second, the total sample size.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Diagnosis</th>
<th>Cognitive impairment</th>
<th>Hearing loss?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Epidemiological</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sang et al (2006)⁵⁴</td>
<td>Heterogeneous vestibular disorders</td>
<td>Difficulty concentrating, thoughts seem blurred</td>
<td>No (33/50)</td>
</tr>
<tr>
<td>Jauregui-Renaud et al (2008)⁵⁶</td>
<td>Heterogeneous vestibular disorders</td>
<td>Difficulty concentrating, thoughts seem blurred</td>
<td>No (37/50)</td>
</tr>
<tr>
<td>Jauregui-Renaud et al (2008)⁵⁶</td>
<td>Heterogeneous vestibular disorders</td>
<td>Difficulty concentrating, thoughts seem blurred</td>
<td>No</td>
</tr>
<tr>
<td>Semenov et al (2016)⁶⁶</td>
<td>Vestibular dysfunction</td>
<td>Digit symbol substitution test</td>
<td>No</td>
</tr>
<tr>
<td>Bigelow et al (2016)⁴⁴</td>
<td>Vestibular vertigo</td>
<td>Cognitive impairment</td>
<td>No</td>
</tr>
<tr>
<td>Bigelow et al (2020)⁵⁷</td>
<td>Vertigo</td>
<td>Attention, learning</td>
<td>No</td>
</tr>
<tr>
<td><strong>Clinical experimental</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risey and Briner (1990/1991)⁵⁴</td>
<td>Vertigo</td>
<td>Dyscalculia</td>
<td>No</td>
</tr>
<tr>
<td>Redfern et al (2004)⁵⁹</td>
<td>Unilateral vest. nerve section</td>
<td>Increased RT for complex tasks</td>
<td>No</td>
</tr>
<tr>
<td>Brandt et al (2005)³¹</td>
<td>Bilateral vest. nerve section</td>
<td>Impaired spatial memory</td>
<td>No</td>
</tr>
<tr>
<td>Talkowski et al (2005)⁴⁰</td>
<td>UVL</td>
<td>Auditory reaction time</td>
<td>No</td>
</tr>
<tr>
<td>Gomez-Alvarez (2011)⁴¹</td>
<td>UVL</td>
<td>Impaired spatial orientation, difficulty concentrating</td>
<td>No</td>
</tr>
<tr>
<td>Caixeta et al (2012)⁵²</td>
<td>Chronic vestibular dysfunction</td>
<td>Verbal fluency</td>
<td>No</td>
</tr>
<tr>
<td>Candidi et al (2013)³³</td>
<td>BPPV, vestibular neuritis</td>
<td>Mental rotation</td>
<td>No</td>
</tr>
<tr>
<td>Bigelow et al (2015)⁴⁵</td>
<td>Vestibular dysfunction</td>
<td>Spatial cognition</td>
<td>No</td>
</tr>
<tr>
<td>Kremmyda et al (2016)⁵²</td>
<td>Bilateral vest. nerve section</td>
<td>Impaired spatial memory</td>
<td>No (13/15)</td>
</tr>
<tr>
<td>Moser et al (2017a)⁴⁴</td>
<td>Vestibular neuritis</td>
<td>Impaired numerical cognition</td>
<td>No</td>
</tr>
<tr>
<td>Moser et al (2017b)⁴⁶</td>
<td>Vestibular neuritis</td>
<td>increased redundancy, impaired generation of random numbers</td>
<td>No</td>
</tr>
<tr>
<td>Lofti et al (2017)⁶⁶</td>
<td>Vestibular deficits, ADHD</td>
<td>Choice reaction time</td>
<td>No</td>
</tr>
<tr>
<td>Sugaya et al (2018)⁵⁷</td>
<td>Dizziness</td>
<td>Trail-making test</td>
<td>No (53/60)</td>
</tr>
<tr>
<td>Deroualle et al (2019)⁴⁸</td>
<td>UVN</td>
<td>Embodied spatial cognition</td>
<td>No</td>
</tr>
<tr>
<td>Dobbels et al (2019)⁷⁰</td>
<td>Bilateral vestibular loss</td>
<td>Attention</td>
<td>No</td>
</tr>
<tr>
<td>Pineault et al (2020)⁶⁹</td>
<td>Various type of of vestibular loss</td>
<td>Benton visual retention test, Trail making test</td>
<td>No</td>
</tr>
</tbody>
</table>

Abbreviations: UVL, unilateral vestibular loss; BPPV, benign paroxysmal positional vertigo; UVN, unilateral vestibular neurectomy; ADHD, attention deficit hyperactivity disorder; RT, reaction time.
the studies were cross-sectional, and the samples may not have been representative of a broader population.\textsuperscript{49} In particular, patients with both vestibular and cognitive impairment may have been more likely to present than those with either condition alone, resulting in a potential overestimation of the proportion of vestibular dysfunction in AD (‘Berksonian bias’).\textsuperscript{49} Fourth, it is conceivable that the poor performance by AD patients on the cVEMP and oVEMP testing could have been due to their inability to understand and follow instructions; however, the authors reported that this was not the case.\textsuperscript{79,80} Finally, the relationship between cVEMP/oVEMP function and AD was a statistical one involving logistic regression and does not necessarily indicate a causal relationship.\textsuperscript{79,80} For example, aside from the possibility that vestibular dysfunction contributed to the development of AD, it is possible that AD pathology might have caused vestibular dysfunction.

One potential explanation for the relationship between vestibular dysfunction and AD might be that AD pathology (eg, β-amyloid (Aβ)) extends into the central vestibular pathways from the vestibular nucleus to the thalamus and beyond, thereby impairing vestibular function. Although there have been no specific studies of Aβ deposition in ‘vestibular-related areas’ of the brain, vestibular information is distributed widely,\textsuperscript{41} (see Figure 4), therefore it is likely that AD pathology extends to many brain regions receiving vestibular input. However, in a recent study of vestibular function in 98 participants aged 77.3 (±8.26) from the BLSA, Aβ deposition was measured using amyloid C-11 Pittsburgh Compound B (\textsuperscript{11}C-PB).\textsuperscript{81} The authors found that 22.4% of the sample were positive for PiB; however, there was no statistically significant relationship between the extent of Aβ deposition and any measure of vestibular function. This study was designed to investigate preclinical AD, but no such study has been performed in patients diagnosed with AD. Another possible explanation is that vestibular impairment directly contributes to medial temporal lobe neurodegeneration and AD, possibly as a result of reduced vestibular sensory input to areas of the brain such as the hippocampus, as occurs for auditory input.\textsuperscript{82}
Further studies have concentrated on whether vestibular loss is associated with specific phenotypes of AD, especially those with spatial cognitive deficits. Some AD phenotypes are characterised by predominantly amnestic symptoms compared to others which are characterised by more motoric and spatial impairment. In a study of 50 patients with MCI or AD, Wei et al observed that patients with vestibular loss were significantly more likely to exhibit impairment in neurocognitive tests of spatial skills, for example the Money Road Map test (MRMT). When patients were divided into ‘spatially normal’ and ‘spatially impaired’ groups based on their performance in the MRMT, only 25% of the spatially normal patients were found to have vestibular dysfunction compared to 96% of the spatially impaired patients. In a further study of 60 patients with MCI or AD, patients with vestibular dysfunction were significantly more likely to have difficulty driving, an activity closely linked to spatial cognitive ability. It is possible, therefore, that vestibular dysfunction contributes to the development of a ‘spatial’ subtype of AD, increasing the probability of symptoms such as spatial disorientation, wandering, and an increased risk of falling. However, these two studies have similar limitations to the original one by Harun et al; there were no controls for hearing loss, the sample sizes were relatively small, the studies were cross-sectional and in Wei et al, the postural measurements were not specific to vestibular function. Finally, the statistical association reported does not indicate causality.

The only available study that provides any evidence that vestibular loss might be causally involved in the development of cognitive impairment and dementia is by Liao et al. They investigated prior medical conditions that were associated with late-onset Alzheimer’s disease dementia (LOAD) using a population-based matched case control study based on the National Health Insurance Research database of Taiwan and the Catastrophic Illness Certificate database, between the years 1997 and 2013. The definitions of prior diseases were based on the first three digits of the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). The total case group consisted of 4,600 patients who were newly diagnosed with LOAD between 2007 and 2013, who were then matched to 4,600 controls by both age and sex. Using multivariate logistic regression and path analysis, the authors reported that the incidence of LOAD was positively correlated with prior anxiety (ICD code 300), functional digestive disorder (ICD code 564), psychopathology-specific symptoms (ICD code 307), disorders of the vestibular system (ICD code 386), concussion (ICD code 850), disorders of the urethra and urinary tract (ICD code 599), disorders of refraction and accommodation (ICD code 367) and hearing loss (ICD code 389). While the authors conclude that these data suggest that vestibular dysfunction may therefore be a risk factor for LOAD, the limitations of the study include limited information regarding other confounding factors such as body mass index, blood pressure, diet, smoking, diabetic therapy etc.; and the specific nature of the diagnosis may have varied according to factors affecting access to a neurologist. At present, there are no comparable data available on potential vestibular contributions to dementia associated with Parkinson’s disease or fronto-temporal dementia.

One of the intriguing aspects of the studies in cognitively-normal and vestibular-impaired adults is the demonstration of a link between saccular function and cognition. We have recently reported that saccular function is a statistically significant predictor of the decrease in hippocampal volume that occurs with age. The saccule, one of the two otoliths, is the part of the peripheral vestibular system which detects the orientation of the head with respect to gravity and, together with the utricle, is the oldest component of the vestibular system in evolutionary terms (see Figure 2). Patients with AD exhibited specifically poorer saccular and utricular function compared to age-matched controls. Saccular stimulation has been demonstrated to activate the multisensory vestibular cortex involved in spatial information processing. In guinea pigs and rats, selective electrical stimulation of the utricle and saccule has been shown to cause widespread activation of the hippocampus. There is increasing evidence that the otoliths, the saccule in particular, have a critical role in spatial
memory due to their importance in the perception of gravitational vertical. We have recently reported that mice lacking otolithic function from birth, exhibit major developmental delays by post-natal day 9, including spatial memory deficits. Interestingly, considerable electrophysiological evidence suggests that the neurons in the VNC that subserve the VOR are separate from those involved in the VSR pathways and the pathways to the limbic system and neocortex. This means that it is possible for the vestibular pathways that give rise to the conscious perception of self-movement and contribute to spatial memory, to be compromised, without VOR deficits necessarily being exhibited, and that only VSRs such as VEMPs would indicate a vestibular deficit. Figure 5 summarises the hypothesis that saccular dysfunction, in particular, might contribute to the development of cognitive dysfunction that preferentially includes spatial cognitive deficits.

Conclusions

The available evidence suggests that vestibular dysfunction, including that associated with age-related vestibular loss, has a significant negative impact on cognitive function. Vestibular impairment may therefore be a risk factor for the development of dementia, including AD. Previc has recently suggested that, given the increased prevalence of vestibular disorders in females, vestibular dysfunction may contribute to their increased incidence of AD. However, the majority of the evidence to date is correlational; therefore, caution must be exercised in interpreting these findings. The potential combined effects of both hearing loss and vestibular loss are unknown but could be expected to be much greater. Of course, it is important to note that some otological disorders involve both auditory and vestibular symptoms (eg, Meniere’s disease). Understanding the

Figure 5: Conceptual model of impact of aging on vestibular function (notably saccular function), which contributes to neurodegeneration of neural circuits involved in vestibular processing and deterioration, specifically in spatial cognitive ability. From Agrawal et al with permission.
full implications of vestibular dysfunction for cognitive decline is potentially of great importance for the health of the elderly, since effective therapies are available to treat vestibular disorders.\(^9\) One of the principal treatments for vestibular impairment is vestibular rehabilitation, a suite of physical therapy-based exercises in which head movements are used to stimulate the vestibular system and gradually encourage the brain to adapt to the loss of normal vestibular function.\(^6\) Several studies have reported that vestibular rehabilitation can improve cognitive function in healthy adults and in patients with intractable dizziness.\(^6,9\)

However, at present, studies from the US indicate that only a small number of people with AD are referred for vestibular rehabilitation.\(^9\) Since vestibular impairment may be a modifiable risk factor for dementia, the impact of vestibular loss on cognition should be considered along with hearing loss as a critical area for research.

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A pragmatic diagnostic approach to myocardial infarction with non-obstructive coronary arteries

Ammar J Alsamarrai, Jocelyne R Benatar, Eun Soo Chung, Jithendra B Somaratne

ABSTRACT

Myocardial infarction with non-obstructive coronary arteries (MINOCA) is an increasingly recognised condition and it accounts for approximately 10% of all cases of MI. Despite the absence of obstructive coronary artery disease, patients with MINOCA are at increased risk of morbidity and mortality compared to the general population. While many well recognised conditions can present as MINOCA, it can be difficult to reach a final diagnosis with certainty due to the relative infrequency of these conditions in the general population and the lack of diagnostic gold-standard tests. The most common causes of MINOCA are myocarditis, coronary vasospasm, coronary plaque disruption and coronary thrombus or embolism. These can be assessed by way of cardiac magnetic resonance imaging, intra-coronary imaging modalities and clinically relevant diagnostic blood tests, respectively. There are less common and rarer aetiologies which should be considered in the absence of an apparent cause, each with a unique diagnostic standard. By following a systematic approach of diagnostic tests, an underlying cause of MINOCA can be found in the majority of cases, allowing a directed management strategy to be pursued.
A myriad of conditions can cause MINOCA (Table 1) and each requires a unique diagnostic and management approach. The incidence of each condition that contributes to MINOCA is low in the general population, which means that there is little evidence available on how to both diagnose and treat each condition. However, accurate diagnosis remains crucial to ensure patients are on the most appropriate treatments.

**Proposed diagnostic algorithm**

As MINOCA accounts for a significant proportion of patients with MI and is increasingly recognised, there needs to be a unified and systematic approach to the tests that ensue to reach the final diagnosis. Furthermore, as the individual conditions that cause MINOCA are relatively infrequent, they should all be considered during the workup process, particularly the commoner causes. We also emphasise that the absence of obstructive CAD on angiography is not a satisfactory end-point in the workup of patients with ACS.

We propose a simplified and pragmatic diagnostic approach, adapted from the American Heart Association guidelines, to facilitate clinical decision making regarding appropriate investigations following coronary angiography (Figure 1).

The presence of MINOCA should prompt a thorough review of the clinical history and angiogram. Alternative causes of raised serum troponin (with or without chest pain) should always be considered, such as pulmonary embolism and sepsis. A clinical review of the patient should be undertaken to exclude anaemia, hypotension and sustained tachycardia, all of which may cause type 2 MI (due to supply-demand mismatch). An assessment of the left ventricle either at angiography or with echocardiography can diagnose cardiomyopathies such as Takotsubo syndrome.

If this is not helpful, the angiogram should be carefully reviewed to exclude spontaneous coronary artery dissection (SCAD) and coronary thrombus or embolism. SCAD can be difficult to diagnose as angiographic appearance can be subtle and initially missed. Only a small proportion of SCAD have the classic angiographic appearance of a double lumen artery with a visible intimal flap (type 1). Most may have diffuse stenosis of varying severity (type 2) and some have lesions that mimic atherosclerosis (type 3). Intracoronary imaging is useful if angiographic diagnosis is not obvious. SCAD is more frequent in women with few traditional cardiac risk factors. The median age

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**Table 1: Overview of the causes of myocardial infarction with non-obstructive coronary arteries.**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Proportion of MINOCA</th>
<th>Diagnostic standard</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coronary artery spasm</td>
<td>46%</td>
<td>Coronary provocative testing</td>
<td>Calcium channel blockers, nitrates</td>
</tr>
<tr>
<td>Plaque disruption</td>
<td>36%</td>
<td>Intracoronary imaging</td>
<td>Standard acute coronary syndrome treatments</td>
</tr>
<tr>
<td>Myocarditis</td>
<td>33%</td>
<td>Endomyocardial biopsy or cardiac magnetic resonance imaging</td>
<td>Supportive care, immunosuppression, transplantation</td>
</tr>
<tr>
<td>Coronary thrombosis and embolism</td>
<td>24%</td>
<td>Intracoronary imaging, thrombophilia screen</td>
<td>Anticoagulation in some cases</td>
</tr>
<tr>
<td>Spontaneous coronary artery dissection</td>
<td>7%</td>
<td>Intracoronary imaging</td>
<td>Aspirin, beta-blockers, revascularization in some cases</td>
</tr>
<tr>
<td>Takotsubo syndrome</td>
<td>7%</td>
<td>Left ventriculography</td>
<td>Supportive care, ACE inhibitors</td>
</tr>
</tbody>
</table>

MINOCA: myocardial infarction with non-obstructive coronary arteries, ACE: angiotensin converting enzyme.

1 Proportions reflect findings of individual studies and are not additive.
**Figure 1:** Proposed diagnostic algorithm for myocardial infarction with non-obstructive coronary arteries (adapted from10).

- **Rise and / or fall of highly-sensitive troponin assay with one level >99th percentile upper limit of normal, with signs or symptoms of cardiac ischaemia, and non-obstructive (<50% stenosis) CAD on invasive coronary angiography**

  - Consider clinical context to exclude other diagnoses

  - Careful review of angiography findings

  - Left ventricular assessment (left ventriculography or echocardiography)

  - Cardiac MRI scan

  - Infarct pattern

  - Normal MRI scan

  - Intracoronary imaging (IVUS/OCT)

  - Coronary physiology testing

  - 8. Plaque disruption

  - 9. Microvascular disease

  - 10. Vasospasm

  - Unspecified MINOCA

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is 50 years old but there is also an increased risk in the antenatal and peripartum periods. SCAD does not always strictly meet the ‘non-obstructive’ criteria of MINOCA as there is usually luminal narrowing; however, initial angiographic views can miss subtle SCAD.

Thrombosis and thromboembolism in the coronary arteries can also be diagnosed with intracoronary imaging. This is usually seen in young patients with few traditional cardiovascular risk factors who often have an underlying thrombophilia. One study of 84 patients with MINOCA found that ¼ had an inherited thrombophilia. This diagnosis is crucial to make because of the high risk of recurrence and the possible need for long-term anticoagulation such as in antiphospholipid syndrome.

If review of the angiogram reveals no diagnosis, cardiac magnetic resonance (CMR) imaging is recommended. The diagnostic yield of CMR is as high as 87% in the workup of MINOCA. It is able to characterise myocardial tissue, quantify chamber volumes and ejection fraction. It can accurately diagnose myocardial infarction, myocarditis, and non-ischemic cardiomyopathy such as Takotsubo syndrome and hypertrophic cardiomyopathy.

If the CMR is normal, coronary artery spasm (CAS) needs to be considered. Spasm can affect a spectrum of vessels from epicardial to microvascular vessels. It is more common in females, in certain ethnic groups (for example Japanese) and usually presents with angina at rest. When it presents with angina, empirical treatment with calcium channel blockers and nitrates can be considered, but in the setting of MINOCA, provocative testing with intracoronary acetylcholine could be used to confirm the diagnosis. While this test has lower sensitivity in young patients, sequential vasoreactivity provocation tests can improve the accuracy. This can diagnose spasm of the epicardial arteries, but more sophisticated techniques may be needed to diagnose microvascular spasm. Microvascular spasm is a component of coronary microvascular dysfunction, and usually presents with angina rather than MI.

A patient is only labelled with “unclassified MINOCA” once all other possibilities are actively excluded.

**Conclusion**

MINOCA is more common in women with no traditional risk factors for heart disease and has an increased risk of mortality compared to healthy individuals. It is a working diagnosis and further investigations should be undertaken to establish a specific cause to ensure appropriate treatment. When done within a short time of presentation, CMR is particularly useful to establish the diagnosis in the majority of patients and should be routinely undertaken if no cause of MINOCA is found.

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The assessment of testamentary capacity

Jane Casey, Anthony Grant

ABSTRACT

In the older generations, cognitive impairment and wealth are both increasing. Doctors routinely assess decisional capacity in health matters yet are less adept in the assessment of other domains. Recent New Zealand Court decisions will likely result in increased requests by lawyers for contemporaneous medical assessments of the capacity to make a will. The clinical assessment is underpinned by the legal test for testamentary capacity. A psychogeriatrician and a barrister explain the principles and the clinical application. Careful assessments could protect the older adult and minimise the risk of a contested will after death.

Freedom of choice is a fundamental human right. When it comes to welfare, property or legal matters, decisions can have far-reaching implications. An important principle in decisional capacity is that it is task-specific and cannot be generalised. A person may have the capacity to make a decision about health issues yet have a compromised ability to manage financial affairs.

The ageing population presents with a complexity of health and living needs. People are living longer with chronic medical conditions and there is an increased prevalence of cognitive impairment. Baby boomers are the wealthiest cohort to date and there will be an inevitable shift of this wealth to the next generation. There have been higher divorce rates, new partners and blended families. De facto and same-sex relationships are now recognised by law and the statute dealing with the division of relationship property is under review by the Law Commission. Cultural factors and global mobility add to the complexity. All these factors are contributing to a trend for wills to be revised.

In this context, knowledge of the clinical assessment in conjunction with the legal test for testamentary capacity is important for the protection of the older will-maker. An improvement in practice could lessen the risk that wills be contested after death.

Capacity to decide

Doctors assess capacity to consent (or to decline) treatment on a regular basis. The seminal paper of Appelbaum and Grisso established the legal standards for competence in the clinical area.1 It involves the ability to:

(a) understand relevant information;
(b) appreciate the current situation and its consequences;
(c) rationally manipulate information; and
(d) communicate a decision.

These principles form the backbone for the assessment of any significant decision in health and in legal settings. In short, a patient must know the context in which a decision is to be made, the choices that are available, and understand the consequences of the specific choices.2

Criteria for testamentary capacity

The landmark judgment for assessing testamentary capacity is the 1870 case of Banks v Goodfellow.3 In this case the Court held that testamentary capacity requires that a person must:

(a) Understand the nature of a will and its effects.
(b) Have a knowledge of the nature and extent of their estate.
(c) Have a knowledge of the people who...
may have a reasonable claim to their estate.

(d) Be free from any delusions or disorder of the mind that would “poison his affections, pervert his sense of right or prevent the exercise of his natural faculties”.

The presence of delusions does not, of itself, automatically invalidate a will. In *Banks v Goodfellow*, the will-maker was diagnosed as having a psychotic disorder, yet the Court upheld the will with a finding that the persecutory delusions did not influence how he wanted to dispose of his property.

The older will-maker is more likely to have cognitive impairment, perhaps subtle, or otherwise diagnosed as a dementia. Although there should be no assumptions made about capacity just from a diagnosis, the Courts are increasingly aware of the importance of memory in decision-making. The ability to hold and to ‘use and weigh’ information in working memory, and to access autobiographical memory regarding relationships and beneficiaries, is critical to will-making.4

Relatively intact memory on its own does not provide all the mentation necessary to enable effective decision-making. Executive functions of the frontal lobes involve working memory as well as reasoning, planning, impulse control and judgment. Impairment in these higher-level cognitive processes may render a person unable to comprehend, appraise and then appreciate consequences in decision-making. Preserved cognitive function cannot be presumed and deficits can sometimes be subtle. An assessment that a person is ‘cognitively intact’ only has true validity if it is based on evidence of standardised cognitive assessment incorporating a battery of frontal lobe tests.

The many advances in medical science since 1870 have led to a recognition in England that the test in *Banks v Goodfellow* is a little out of date. In *Key v Key*, Justice Briggs said that the *Banks v Goodfellow* test was too confining in the light of “the greater understanding of the mind now available from modern psychiatric medicine”.5 The *Banks v Goodfellow* test has also recently been qualified in 2018 by the New Zealand Court of Appeal. In *Loosley v Powell*, it was said that the test is not to be used as a “formula” but more as “guiding propositions”.6 An understanding of the legal parameters informs the clinical assessment of the capacity to make a will.

**The medical assessment**

The general practitioner is usually the doctor who is consulted and is in the unique position of having known a patient over a long period of time. It is crucial that the assessment is specific to the task. General statements about capacity are to be avoided. A letter of instruction from the solicitor should be obtained to provide (a) the legal test for assessing testamentary capacity and (b) background details of the person’s estate and circumstances. In a revision of a will, the previous wills and proposed changes should be referred to. If a will is being made in conjunction with other legal transactions, the doctor needs to have full details so as to be able to perform task-specific assessments of capacity of the will-maker.

The interview conditions should be made optimal for the person and the assessment performed at the person’s best time of day. The person should be interviewed on their own, (unless an interpreter is required), to ensure that anyone who may benefit from the will or may influence the outcome of the interview, is not present. Following an explanation of the reasons for the assessment and obtaining consent to proceed, take a brief history. Check that there is no significant mood disorder or psychotic features which may impact on decision-making. If there is a possibility of cognitive impairment, perform a standardised cognitive assessment, including the sub-tests of frontal-executive function such as verbal fluency, abstract thinking, the trail-making test or the drawing of a clock face. The Montreal Cognitive Assessment or the Addenbrooke’s Cognitive Examination III are the preferred screening instruments.

A diagnosis of a dementia does not preclude the existence of testamentary capacity even though dementia is a disorder of the mind. In the Court of Appeal case of *Woodward v Smith* it was stated; “memory may have become in some degree enfeebled; and yet there may be enough left clearly to understand and make a sound assessment of all those things, and all those circumstances, which enter into the nature of a rational, fair and just testament.”7
These days, many Estates are complicated with the existence of trusts and companies. The fact that a will-maker cannot recall the precise details of all of the assets does not necessarily mean that the person lacks capacity. The person should nevertheless have a broad and general understanding of his/her estate. Sometimes the process of enquiry can help the person recall and retain the information for long enough to firm up a rational decision about the proposed distribution.

However, testamentary capacity is not only task-specific but situation-specific. The more complicated the situation, the higher the threshold for the clinical determination of capacity. If there is a proposed revision of a will that significantly deviates from previously expressed wishes, a higher level of understanding is required. There needs to be the evidence that the person understood that the new will revoked the previous will, can recognise the differences between the old will and the new will and be able to explain the rationale for the changes. A comprehensive appreciation of the estate is often necessary in these circumstances.

The person needs to know the claims of those who might expect to benefit from the will. The concept of natural beneficiaries includes the surviving spouse or partner and children of the will-maker. There needs to be an appreciation of the risks of claims that might be made under the legislation of the Property (Relationships) Act 1976, the Family Protection Act 1955 and the Law Reform (Testamentary Promises) Act 1949. The lawyer should have explained these risks to the person, and a medical assessment provides a further opportunity to review the person’s understanding of these risks.

In a situation where a proposed will makes a significant revision from a previous will, or an uneven distribution among beneficiaries of a similar ranking, or where children are to be excluded from provision, this need to be carefully explored and documented, preferably with a verbatim written record. In a complicated family with a complex past, the person’s working memory needs to hold and consider facts and events so as to be able to make a sound judgment consistent with prior values and goals in the broadest sense. A careful exploration of the rationale behind the distribution of the estate is important. This probing is to evaluate the decision-making ability of the patient, not to necessarily form an opinion on the decision itself. The person may have retained language skills with the ability to cover up deficits or to confabulate, yet have impaired conceptual thinking and an inability to appreciate the details and the consequences. A person who is mentally compromised may make different choices when asked the same question on different occasions. In the medical assessment, if the will-maker knows that he/she wants to leave his/her assets in a specific proportion for reasons that are clear, rational and consistent, then he/she might be considered capable.

The assessment is carefully documented and the opinion to the lawyer should record the relevant findings on mental state and cognitive function. It should be stated whether the patient met the four components of the legal test to make a will and may include detail such as the patient’s rationale as to why potential beneficiaries are included or excluded.

### The legal framework

The starting point in this decisional task is the presumption of testamentary capacity. This can be rebutted by evidence that raises doubt. In complex families or situations, it is increasingly common for the will-maker to request an independent medical assessment as “insurance” in the advent of litigation after death. The question to answer for any person seeking an opinion is: can this particular person, with their particular mental abilities, in this particular situation, make this particular will, at this particular time?

In the case of *Loosley v Powell* the will-maker was terminally unwell. Deathbed wills are potentially problematic given the significant physical and psychological morbidity with expected death. The Court of Appeal emphasised the importance of checking whether the will-maker comprehends the nature and effect of his or her actions. The will-maker had been unable to give a satisfactory explanation of the different provision that she had made in her final will and this was a material factor in the Court concluding that the will-maker lacked testamentary capacity. In the medical...
assessment, the greater the complexity in the person's situation, a higher level of cognitive capability and emotional stability may be necessary.

The concept of lucid intervals or fluctuating capacity is another area that is fraught with difficulties. It has been referred to in the law for over a hundred years and there are various descriptions of it; “Intervals occurring in the mental life of an insane person during which he is completely restored to the use of his reason, or so far restored that he has sufficient intelligence, judgment, and will to enter into contractual relations, or perform other legal acts, without disqualification by reason of his disease”. A fluctuation in alertness and cognitive function is seen in many medical conditions and most commonly where there is a diagnosis of delirium. Cognitive fluctuations can occur in dementia, in particular dementia with Lewy bodies. These fluctuations are usually short in duration, primarily in attention, and do not occur to a significant degree in episodic memory and higher-level executive brain functions. Such short-term and limited changes in mental state are unlikely to allow a will-maker to appreciate all of the factors that are needed to execute a valid will.

There are multiple factors that may lead to a variation in mental state and physical stamina which may impact on testamentary capacity. A non-exhaustive list includes pain, physical illness, medication, fatigue, stress and environmental changes. The critical issue for a Court to decide is whether the alteration in the mental state translates to a change in the more complex function of capacity to make a will.

A doctor performing an assessment of testamentary capacity needs to be aware of factors relating to undue influence. If a will is made as a result of undue influence, it will be invalid. In Green v Green, it was defined as “pressure of whatever character [that] overbears the will of the testator”. It is a complex topic with a historical threshold of coercion, however a forceful person, not meaning to overbear a person’s decision-making, may nevertheless do so and their persuasive effect can amount to undue influence. Usually there will not be direct evidence that the will-maker was pressured into signing the will and circumstantial evidence is sufficient yet “the Court must be satisfied both that the power was exercised and that the will would not have resulted but for that exercise”.

In the New Zealand jurisdiction, a clinician’s role is generally to assess whether a person was vulnerable to undue influence. An older will-maker may be susceptible to influence due to the medical conditions of mental disorder, cognitive impairment or physical co-morbidities creating dependency. Social circumstances such as isolation, changed family dynamics or conflict may be fertile ground for coercion. The psychological situation, the process of the procurement and undue benefit in a will are further risk factors. In most cases there are several of these ‘red flags’ present and, more often than not, the family or carers are the perpetrators. Lawyers have an important role in the detection and protection of older vulnerable will-makers in this often subtle form of elder abuse.

In the case of Sandman v McKay, 2019, the Supreme Court held by a majority that where a lawyer receives instructions to prepare a will in circumstances where testamentary capacity is in doubt, the lawyer should carefully document the advice given and steps taken, and, suggest to the client that a medical capacity assessment be obtained.

Given the social and economic landscape, recent Court decisions and the duties lawyers owe to their clients, it is likely that there will be increasing requests for contemporaneous medical assessments of the capacity to make a will. In general practice or other continuing care settings, an understanding of the person, their family and the social context is a distinct advantage. Having the knowledge of the legal tests and then gaining expertise in the assessment of testamentary capacity will serve many older patients well. If this is not practical and if the situation seems more complex and potentially contentious, or if there is concern that the person is vulnerable and at risk of influence, then the patient and the solicitor should be guided to seek the opinion of a specialist in this field.
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Computers, confounding, clusters, consent, cost, COVID and consultation: how the Health and Disability Code impedes the learning health system

Mark Webster, Ralph Stewart

ABSTRACT
The Health and Disability Code precludes any research involving a competent patient without the informed consent of the participant. A learning health system requires rigorous evaluation of both new and established clinical practice, including low-risk components of usual care pathways. When comparing two accepted practices, the only way to control for unknown confounders is by randomisation. In some limited circumstances, particularly when comparing groups or clusters of patients, this comparison can only practicably be undertaken without consent. The current Code impedes a learning health system and is detrimental to the health of New Zealanders. It urgently needs updating.

The position of Health and Disability Commissioner was established in 1994, following the Cartwright Inquiry into the treatment of cervical cancer at National Women's Hospital, which found research had been undertaken without ethical approval or informed participant consent. The Code of Health and Disability Services Consumers’ Rights, which includes protection from unethical research, became law in 1996. The Code has been reviewed at roughly five-yearly intervals, but has remained largely unchanged. Parts of the Code related to research have, unfortunately, not kept pace with newer concepts in healthcare evaluation and improvement—the learning health system—over the last quarter century.

Healthcare improves in two main ways. New drugs or devices undergo rigorous evaluation in traditional clinical trials. If they provide sufficient clinical benefit, at a cost a health system can afford, they enter clinical use. The research leading to these advances requires participant consent, and is costly to undertake. Breakthrough drugs, such as PCSK-9 inhibitors which are extremely effective at lowering cholesterol levels, and devices such as transcatheter approaches to aortic valve replacement, are often very expensive. The other way is to review or audit current practice, compare it with appropriate local or international benchmarks, and introduce changes to approach best practice standards. This type of quality improvement initiative is not considered research and doesn’t usually require participant consent.

There is a grey zone between these two approaches. Comparative effectiveness studies evaluate accepted clinical practice, where more than one drug, device or approach is used for the same condition. Drug and device manufacturers are focused on fulfilling US Food and Drug
Administration and European regulatory requirements, rather than undertaking the type of head-to-head comparison, which might usefully guide clinical practice. Because drugs and devices in accepted use should achieve roughly similar clinical outcomes, studies comparing them often need to be very large to detect any differences.

The ideal learning health system undergoes a continual cycle of rigorously assessing what works and what doesn’t, and modifying practice from there. The idea that usual practice should be constantly questioned and evaluated is not appreciated by most patients, who believe that their recommended healthcare is underpinned by rigorous science. That is not usually the case. In cardiology it is estimated that only 11% of guideline treatment recommendations are based upon adequate randomised trial data, with half based upon expert opinion alone.1

There are many examples of treatments given to thousands of people based on expert opinion, which are later found to have uncertain benefit or cause harm when more rigorous assessment is undertaken.

Computers

The electronic capture of health information via electronic clinical records, condition and procedure databases, and national datasets is arguably the greatest advance in healthcare over the last 25 years. It affords the opportunity to extract, aggregate and analyse detailed patient and health system information thereby identifying shortcomings and opportunities for improvement. New Zealand is ahead of many other countries, including the US and Australia, in having a unique patient identifier and national mortality, hospital discharge coding, prescribing and laboratory datasets. In cardiology, linkage of the All New Zealand Acute Coronary Syndrome - Quality Improvement (ANZACS-QI) database to other national datasets has provided novel insights in many aspects of unstable coronary disease, including disparities in health outcomes by ethnicity and by region.2

Confounding

Audit of current practice is an important component of quality improvement initiatives, particularly if able to be benchmarked against relevant comparators. However, observational data, including that used for audit, is not reliable for determining the best treatment. The decision to use one treatment or strategy rather than another may be influenced by other factors, including some which are unknown, associated with favourable or unfavourable outcomes. These confound the association, so established treatments or approaches can only be reliably compared if they are randomly allocated. The challenge of identifying a true difference between established treatments or strategies is greater because that difference is usually modest.

Clusters

Another change over the last 25 years has been the development of novel research methodologies. A major limitation of the traditional individual participant, double-blinded, randomised, controlled trial is limited external validity. Enrolled patient populations typically lack proportional representation of the elderly, females, those from disadvantaged populations, those with co-morbidities, and most importantly when evaluating treatments, those at highest risk for adverse events.3 In New Zealand, Māori and Pacific peoples are very often under-represented in clinical trials.

There has been a move towards pragmatic studies, aiming to enrol a more diverse study population by simplifying trial requirements. Trials may be embedded in established patient or procedure registries, and outcomes assessed by linkage to other datasets, such as those coding for mortality or hospital discharge diagnoses. Running trials within registries also allow comparison of trial patients with those not enrolled but in the registry, thereby providing insights into the likely generalisability of the study findings.

Comparative effectiveness studies typically compare standard or accepted treatments applied as part of routine care pathways to many or all patients with a particular condition. Randomly allocating treatment to one patient cohort and comparing it to a different treatment applied to another cohort using cluster randomisation has advantages with regard to both trial administration and making the results more directly relevant to clinical practice. Apart from more simply enrolling...
larger patient numbers thereby enabling trials to be powered for clinically relevant endpoints, cluster randomisation facilitates enrolment of a wide spectrum of patients with a particular condition, including those often excluded from trials with individual randomisation. This increases the generalisability, or external validity, of the study findings.

Consent

The Code of Health and Disability Services Consumers’ Rights states that the consumer has the right to be fully informed. Under section 6(1): Every consumer has the right to the information that a reasonable consumer, in that consumer’s circumstances, would expect to receive, including ... (d) notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval.

This has been interpreted as precluding either individual or cluster random allocation of any aspect of patient care, without prior written, informed consent from anyone affected by that care. The only exceptions are studies comparing established treatments undertaken in settings where consent cannot be obtained without delaying time-critical treatment, such as in unconscious patients in intensive care.

The National Ethics Advisory Committee (NEAC) to the Ministry of Health in their 2012 Guidelines wrote in regard to a “community intervention study (or cluster intervention study)” that “individual consent to participate ... should not be required if gaining that consent is impracticable, and if the benefits from the study are sufficient and the potential harms minimal.” However, when updated in 2019 this was replaced by the more circumspect “NEAC recognises that there is a tension between ethics and the legal framework for consent, as cluster randomised trials generally are not designed to seek consent. This tension creates a legal barrier to some research that may otherwise meet ethical standards. NEAC is aware of the tension and support a review of the law in this area”.

Other countries have considered this issue and come to a conclusion similar to that of NEAC in 2012. Following a recommendation from the Ottawa Ethics of Cluster Randomized Trials Consensus Group, the Canadian Tri-Council Policy Statement “allows research ethics boards to approve an alteration to the informed consent process, such as a waiver of consent, if the following criteria are met: (1) there is no more than minimal risk to participants, (2) the alteration to consent requirements is unlikely to affect the welfare of participants adversely, (3) it is impossible or impracticable to carry out the research properly given the research design if prior consent is needed, and (4) there is a plan to offer participants the possibility of having their data deleted from the study database”.

Similar criteria have been used in the US. A waiver of consent was recently granted for Canadian sites participating in the PICS Trial, a cluster-randomised comparison of various prophylactic antibiotic regimens to prevent cardiac surgical site infection.

A key consideration around randomly allocating treatment to patients without their prospective consent is whether this is acceptable to patients. Some insights can be gleaned from trials undertaken in the acute setting where randomised treatment has already been given, and consent can only be obtained for follow-up and use of data. The SAFE, CHEST and SPLIT trials compared various intravenous fluid solutions in the intensive care setting; fewer than 2% of patients or their relatives elected to opt out. In the HEAT-PPCI trial, undertaken in patients with ST elevation myocardial infarction, 0.2% of patients did not give consent for their ongoing participation. Although these observations are potentially subject to survivor bias, very few participants appear to be concerned about being included in comparative effectiveness studies.

Cost

Obtaining consent is costly. A typical phase 3 pivotal, 20,000 patient, randomised cardiovascular drug trial, with individual participant consent and randomisation, designed to comply with the requirements of the US Food and Drug Administration, may cost NZ$75 million, which approximates the annual research budget of the Health Research Council, the main New Zealand biomedical research funding body. The budget upper threshold for an HRC-funded trial is about $1.2 million, which leads to optimistic power calculations and limits...
most New Zealand studies to using surrogate rather than clinically relevant endpoints.

In contrast, the New Zealand Oxygen Trial recently compared two oxygen administration protocols in patients calling an ambulance or presenting to hospital with a suspected acute coronary syndrome. It used a cluster-randomised, cross-over design and was embedded in established registries (ambulance service and ANZACS-QI). Consent was waived given the acute setting; informed consent is not possible in patients with chest pain needing immediate treatment. The trial enrolled 40,000 patients over two years, and was undertaken on a project grant of $160,000 from the National Heart Foundation.13

Embedding trials in registries can considerably reduce costs, as can cluster randomisation. However, many large, simple, clinically relevant, randomised, comparative effectiveness trials are unable to be undertaken if participant consent is required, because of the cost of obtaining consent.

**COVID**

The COVID-19 pandemic has challenged and disrupted previous constraints around the way research is assessed and undertaken. One example is OpenSAFELY, which used purpose-built software to analyse data from the electronic general practice medical records of 17 million English NHS patients, 5,683 of whom subsequently died from COVID.14 The records were examined in situ, without copies being made, and with a log kept of all interactions. The study benefitted from a UK government decree allowing wider access to health data for research purposes, and took 42 days from idea conception to publication. It has produced the most comprehensive information yet describing those who are at increased risk of contracting and dying from COVID. Recognition of the importance of randomised clinical trials within the NHS has allowed for the rapid and rigorous evaluation of several therapies for COVID, contrasting with other countries where treatments of unproven benefit and possible harm have been advocated and funded.

**Case study**

Coronary angiography and percutaneous coronary intervention (PCI) require vascular access. Approximately 90% of New Zealand procedures are via the radial rather than femoral artery as the latter is associated with more frequent bleeding complications, including life-threatening retroperitoneal bleeding. The radial artery is of smaller calibre, and vasospasm may occur with advancing and manipulating catheters. Once the vascular sheath is inserted, bolus injection of an intra-arterial vasodilator reduces the likelihood of spasm. The most commonly used vasodilators are verapamil, a calcium channel blocker, and nitroglycerin, a nitrate. In New Zealand, roughly 60% give verapamil and 40% nitroglycerin, as part of routine unit practice. The incidence of spasm in the current era is unknown but likely to be low, perhaps 2–4%. There are no adequately powered comparisons of verapamil with nitroglycerin.15 When procedure consent is obtained, no New Zealand interventional cardiologist mentions giving a vasodilator, nor which one; it is regarded as a routine part of the procedure pathway.

Is verapamil or nitroglycerin the better vasodilator to prevent radial spasm, when used as the default option in routine practice? Clinicians are free to give another medication, or none at all, if they think that is better for a particular patient. From an individual patient perspective, any differences will be small and of minimal, if any, clinical relevance (if spasm occurs, further boluses of the same or other vasodilators are given, or smaller diameter catheters used). However, there are over three million PCI procedures performed worldwide each year, so minor differences in either efficacy or cost may be important at the population level.

Because spasm is uncommon, and any difference between vasodilators will be small, a trial would require almost 10,000 patients. A trial of this size, with individual consent and randomisation, would be difficult to justify because of the high cost and administrative burden relative to the clinical importance of the findings. Trials with individual consent are particularly difficult when evaluating unit policies, applied as the default option to the treatment of patients over a period of time.

Giving verapamil for six months, deciding to switch to nitroglycerin for the next six months, and collecting data on vasospasm would not require consent. Such audits of practice are a strongly encouraged aspect
of quality assurance and continuing professional development. However, adding rigour to the evaluation by randomly allocating the order of verapamil and nitroglycerin administration over that 12-month period is currently illegal in New Zealand without individual participant consent.

**Consultation**

The Code, very appropriately, is primarily designed to protect the rights of patients. However, it fails to achieve an equally important outcome: to enable the healthcare system to deliver the best possible treatment to those patients, within available resources. This goal may be achieved by having comparative effectiveness research as an integral part of routine care and, in some limited and clearly defined circumstances, undertaken without written participant consent. Such research would require close ethical scrutiny, with independent lay and expert input into the study design and oversight. Individual autonomy around all healthcare decisions which are meaningful to the patient must be preserved, and information on the trial must be freely available and readily accessible.

Any future changes to the Code need wide public consultation on consent, research and the evidence underpinning treatment recommendations. The views of consumers, Māori, clinicians, ethicists and the legal profession all need consideration. However, those perspectives must be informed by understanding that, in most circumstances, randomised evaluations provide the only reliable way to determine the best treatment for a patient. They may also identify currently used treatments or procedures which provide little or no benefit, or cause harm, leading to their discontinuation.

**Conclusion**

Randomised, comparative effectiveness studies should be an integral part of any learning health system aimed at better healthcare delivery, and reducing waste and harm from ineffective treatments or strategies. These should be both enabled and required by those governing and funding healthcare in New Zealand.

The Health and Disability Code needs revision to include consideration of the importance of embedding a healthcare culture of continual evaluation and improvement, and the critical role randomised evaluations have in achieving these goals.16

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**Competing interests:**
Dr Webster reports grants from Green Lane Research and Educational Fund during the conduct of the study.

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REFERENCES:
Management of personal protective equipment in New Zealand during the COVID-19 pandemic: report from the Auditor-General

Elizabeth Fenton

**ABSTRACT**

In June 2020 the Office of the Auditor-General released its report on the management of personal protective equipment (PPE) in New Zealand during the COVID-19 pandemic. The report raises three issues of ethical concern: inadequate stock, inequity and complacency. Acting on the report’s recommendations is a critical step in strengthening New Zealand’s preparedness for future public health crises.

In June 2020 the Office of the Auditor-General released its report on the Ministry of Health’s management of personal protective equipment (PPE) during the early stages of New Zealand’s response to COVID-19. Relative to other countries New Zealand has (so far) fared well in this pandemic, with the number of cases staying well within the capacity of our health system to manage them. As in other countries, however, health workers have expressed concerns that they have not had access to the PPE that they felt was required in the clinical circumstances in which they found themselves. Numbers from April 2020 indicate that 10% of cases in New Zealand at that time were healthcare workers, of which half were infected in their workplace. This number reflects the World Health Organization’s estimate (at the time of writing) that 10% of all cases of COVID-19 globally are among healthcare workers, though the percentage varies between countries and regions. Recent studies indicate that front-line healthcare workers are at increased risk for COVID-19 infection, and that availability, quality and correct use of PPE can reduce this risk. These findings reflect historical data from previous infectious disease outbreaks, such as the 2014–2016 Ebola epidemic in west Africa, in which disproportionate deaths of healthcare workers were attributed, at least in part, to lack of adequate PPE. The Auditor-General’s report highlights three issues of ethical concern in the Ministry of Health’s management of PPE.

**Inadequate stock**

The report makes clear that stocks of PPE held by DHBs and the Ministry of Health were inadequate. This was in part because existing calculations for how much PPE should be held in the national reserve were based on outdated population figures and modelling for an influenza pandemic. In addition, funding for the reserve stocks of PPE held by DHBs was for hospital use only, and did not include meeting the needs of health and disability workers in the community, or non-health essential workers. The Ministry confirmed to the Auditor-General that the national reserve of PPE was “only to support DHBs and not the wider sector or non-health sector.” Poor stock management also meant that a significant amount of PPE stock held by DHBs had expired.

These deficiencies in stock levels and management are of ethical concern for two reasons. First, in the circumstances of a pandemic we depend on the availability...
and willingness of healthcare workers, and all those who work in healthcare facilities, to continue to come to work. However, their willingness to do this, even their duty to do this, is in turn conditional on the provision of the equipment, and training in the use of that equipment, needed to minimise the level of risk to which they are exposed. If healthcare workers have a duty to come to work during a pandemic, then we as a society, through our elected government and its institutions, have a reciprocal obligation to protect their well-being so far as is possible.9,10,11

Second, inadequate resources for healthcare workers to do their jobs safely, alongside other deficiencies in the systems for managing and accessing those resources, undermines the trust those workers have in the institutions for which they work. Without addressing the appropriateness of the Ministry's clinical guidance on PPE use, the Auditor-General's report highlights that, in addition to confusion and apparent mixed-messages about the use of PPE, there was a discrepancy between what workers felt they needed to be safe, and what the clinical guidance stated was necessary. The Auditor-General received correspondence from health and disability workers (and those they were caring for) expressing concern that the Ministry's guidance was "too narrow" and that "the guidelines did not provide what they felt they needed to feel safe delivering care".8 One DHB reportedly responded to the concerns of its workers by distributing "what people were asking for rather than what the guidelines recommended".8

Healthcare workers' willingness to work during a pandemic will depend in part on trust that guidance on the use of PPE is driven by concern for protecting their safety as much as possible, and not concern to protect inadequate stocks. This will reflect a deeper level of trust that the system as a whole is well-resourced and sufficiently robust to deliver services safely during a crisis. The concern that clinical guidelines did not reflect what healthcare workers felt they needed, and the reported experiences of workers who were not able to obtain equipment they felt they needed, amplify distrust in the capacity of the healthcare system to function during a crisis.

Inequity

The second issue raised by the report is inequity in the availability and distribution of PPE across the health and disability sector. As noted above, the funding provided to DHBs in 2005 to purchase PPE supplies for the national reserve was based on modelling that assessed PPE needs for hospital use only, and did not include the needs of the wider health and disability sector or the non-health sector.8

On 31 March 2020 the Ministry instructed DHBs to establish a process to distribute PPE to all publicly funded health and disability providers who deliver health and disability services, including those not directly funded by DHBs.8 While some DHBs made efforts to follow this instruction, at least one reportedly told community-based workers that it had only enough supplies to maintain DHB services, that the only PPE requirement relevant for them was fastidious hand hygiene, and that they could contact private medical suppliers for additional PPE.8 While this advice might have been directed towards non-funded services and non-health sector workers, it nevertheless highlights a deeper concern that community-based health and disability providers, and the people they care for, are deprioritised relative to hospital-based workers. To the extent that such prioritisations reflect higher risk levels they are appropriate and justified—higher risk justifies higher levels of PPE—but all health workers providing in-person care during a pandemic require PPE at some level to reflect the risks of close human contact for both workers and those they are working with. At the time of writing, five out of 16 clusters of COVID-19 in New Zealand occurred in aged residential care facilities, highlighting the risks for community-based care workers and those they care for. These risks must be reflected in the availability of PPE and other critical resources.

The Ministry and DHB's approach to providing PPE to the wider health and disability sector, as reflected in this report, was at best confusing and piecemeal, and at worst inequitable and unjust. Healthcare workers who were community based or worked outside the funding mechanisms of the DHBs were overlooked in emergency planning and preparations. Given the vulnerability of this sector to the risks of...
infectious disease, and its value in providing critical care and support in the community, there is no justification for such oversights.

Complacency

The third ethical concern raised by the Auditor-General’s report is apparent complacency towards emergency planning and preparedness. With respect to the Ministry’s decentralised model for procurement of PPE, the report notes that the model prevented the Ministry from making informed decisions quickly, and to ensure that “the right product was provided to the right people, at the right place, at the right time”. An operational plan should have been part of general pandemic preparedness, “rather than trying to plan as the pandemic was unfolding”.8 The report also observes that the response to COVID-19 revealed the extent to which the Ministry’s oversight of PPE reserves had “fallen away over the years”.8 It is worth noting in this context that warnings around supply and availability of PPE for healthcare workers were sounded long before the COVID-19 pandemic, so increased demand was predictable.12

Emergency planning and preparedness activities are ethically important for two reasons. First, the public deliberation required for the complex and difficult questions that arise during public health emergencies cannot happen in the thick of a crisis. Public health emergencies are characterised by uncertainty, urgency, politicisation and fear, and are not conducive to broad public engagement in difficult moral questions about how to allocate scarce resources or restrict individual liberty for the greater good. Although the conclusions of any such deliberation need to be revisable in light of evolving emergency situations, they are best reached, at least provisionally, during the planning phase, rather than in the heat of the moment.13 Second, emergency planning is valuable as an activity in itself. Emergency planning should be viewed as a civic practice that presents opportunities for citizens to engage out of a sense of solidarity and responsibility for the health of our shared community.13 On this view emergency planning aspires to more than the production of plans to be consumed, it is “a convenant of public trust” that can embody “both the remembered traditions and values of a community and a forward-looking vision of how the community can be made a better environment for all its members in the future”.13 From this civic perspective, complacency with respect to emergency preparedness is both an ethical failure and a significant opportunity lost: an opportunity to strengthen social capital within communities, improve resilience, and to direct attention to core values and moral commitments that provide ‘compass points’ when crises occur. In calling for a “whole of community/whole of government” approach to managing PPE the Auditor-General reflects this more aspirational view of emergency planning as an activity that can bring communities together.3

An ethical dilemma

The Auditor-General’s report concedes that there is likely to be tension between the interests of healthcare workers in maintaining a high level of personal protection and the interests of the Ministry and DHBs in prioritising the appropriate use and allocation of PPE stocks.3 This concession draws attention to a dilemma at the heart of emergency preparedness: how to balance the goals of preparedness for future uncertain emergencies, and meeting demands on the health budget in the present. Stockpiling for future emergencies has opportunity costs, and so must be done with adequate attention to the potential health benefits lost by investing in resources that might not be used.14 More generally, this tension reflects a commitment within public health to two conceptions of justice that can be at odds with each other. Its concern for improving the health of populations gives public health a natural affinity with utilitarian principles of justice that emphasise maximising net benefit or welfare. Yet public health is also deeply committed to fairness and equity in the distribution of burdens and benefits across society. When managing resources for public health emergencies these twin foci of efficiency and equity require both that we pay attention to opportunity costs, and also to meeting the needs of those likely to be most burdened by the risks of any future public health crisis.

As with most ethical dilemmas, resolution lies somewhere between the two poles. Put simply, the best preparation for future public health emergencies is to invest in maintaining a robust public health
Despite New Zealand’s success in managing COVID-19 to date, public health infrastructure is weaker than it could or should be. In his reflections on public health in New Zealand epidemiologist and public health physician Sir David Skegg describes the decline in political support for public health in this country, noting that crises such as the Campylobacter outbreak in Havelock North in 2016, which infected 40% of the population, and resulted in at least three deaths, must be attributed, at least in part, to failures within the government adequately to resource and value public health services. These failures stem from the “invisibility of public health”: except in times of crisis, public health is far from public view or concern, and the benefits of the investments required to sustain it are often not realised until long into the future.

The Auditor-General’s report focuses primarily on the provision and management of PPE equipment, and does not address the fact that PPE is just one element of respiratory protection for healthcare workers. The importance of training in the procedures for safely putting on and taking off PPE, and regular fit testing, are not considered in the report, nor is the critical role of occupational health practitioners in preparing all healthcare workers to protect themselves. The scope of the report is limited in several other important respects. In particular, it does not address in detail access to PPE for non-health essential workers, nor does it review the clinical guidance on PPE use from the Ministry of Health, though it describes reactions to this guidance from healthcare workers. Nevertheless, the report shows PPE to be a bellwether for emergency preparedness and response in New Zealand. Accepting and acting on its recommendations will be important for strengthening our emergency preparedness for the future. It is also an opportunity to build trust in and commitment to our public health system, within the whole health and disability sector, and the community more broadly.

Competing interests:
Nil.

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REFERENCES:


New Zealand doctors and euthanasia—legal and practical considerations of the End of Life Choice Act

Bruce CH Tsai, David B Menkes

ABSTRACT

AIM: To provide an overview of the New Zealand End of Life Choice Act in comparison with other countries, arguments for and against euthanasia, and consideration of relevant legal and practical issues.

METHOD: Structured descriptive summary of criteria for medical euthanasia in various jurisdictions currently allowing the practice, compared with New Zealand legislation. Narrative review of arguments for and against euthanasia with reference to existing medical literature and legal cases.

RESULTS: A strong case for medical assistance in dying, based on autonomy and quality of life arguments, is countered by a long history of medical and legal tradition protecting life.

CONCLUSION: This highly contentious issue is coming before the New Zealand public as a referendum in October 2020. The results will have profound implications for medical practice as well as reflecting societal shifts in attitudes toward death and dying.


This referendum has particular implications for doctors; as practitioners who may be asked to hold the syringe, there is little room to abstain. Clinicians require a good understanding of the Act and, in the interests of clarity, we have compiled a glossary of relevant terms. For the purposes of this Viewpoint, ‘euthanasia’ signifies both voluntary euthanasia and physician-assisted suicide (see Appendix).

Confusion regarding terminology is widespread among the public; many New Zealanders appear to falsely believe the EoLCA applies to end-of-life practices currently legal, such as turning off life-support, implementing ‘do not resuscitate’ requests, and ceasing active investigation and treatment. When people are given proper definitions, strong views on both sides of the debate soften.

The EoLCA Referendum is also binding on an Act that has passed in parliament and received Royal Assent. Accordingly, the specifics and technicalities are finalised, highlighting the importance for voters to understand the Act’s details. A link to the official Government website has been included (though this link may not be functional after the referendum): www.referendums.govt.nz/endoflifechoice/summary.html.

A brief summary of New Zealand legal criteria is presented in Table 1, alongside those approved in other countries. The EoLCA additionally stipulates that euthanasia:
- must be indicated on the death certificate, along with the terminal illness that gave rise to the patient’s eligibility
- cannot be requested by anyone other than the patient
- does not require:
  - prior access to appropriate medical or palliative care


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- does not require:
  - prior access to appropriate medical or palliative care
Table 1: Comparison of proposed New Zealand law with other jurisdictions.

<table>
<thead>
<tr>
<th>Country</th>
<th>Physician assisted (self-admin)</th>
<th>Voluntary euthanasia (other-admin)</th>
<th>Eligible age</th>
<th>Medical prerequisite</th>
<th>Can be requested via advance directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand</td>
<td>Yes</td>
<td>Yes</td>
<td>18+</td>
<td>Terminal (6 months)</td>
<td>No</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Yes</td>
<td>Yes</td>
<td>12–15 with parental consent, under 1 with parental consent, otherwise 16+</td>
<td>Unbearable suffering with no prospect of improvement</td>
<td>Yes</td>
</tr>
<tr>
<td>Belgium</td>
<td>Yes</td>
<td>Yes</td>
<td>Up to 17 with ‘a capacity of discernment’ and parental consent, otherwise 18+</td>
<td>Terminal illness for children, otherwise ‘medically futile condition’</td>
<td>Yes</td>
</tr>
<tr>
<td>Canada</td>
<td>Yes</td>
<td>Yes</td>
<td>18+</td>
<td>Grievous and irremediable medical condition</td>
<td>No</td>
</tr>
<tr>
<td>Oregon, US</td>
<td>Yes</td>
<td>No</td>
<td>18+</td>
<td>Terminal (6 months)</td>
<td>No</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>Yes</td>
<td>Yes</td>
<td>16+ with parental consent, otherwise 18+</td>
<td>Grave and incurable condition</td>
<td>Yes</td>
</tr>
<tr>
<td>Colombia</td>
<td>No</td>
<td>Yes</td>
<td>6–13 with parental consent, otherwise 14+</td>
<td>Terminal phase of disease</td>
<td>Yes if in audio or video recording</td>
</tr>
<tr>
<td>Western Australia</td>
<td>Yes</td>
<td>Yes</td>
<td>18+</td>
<td>Terminal (6 months, 12 months for neurodegenerative)</td>
<td>No</td>
</tr>
<tr>
<td>Victoria, Australia</td>
<td>Yes</td>
<td>Yes, only if unable to self-admin</td>
<td>18+</td>
<td>Terminal (6 month)</td>
<td>No</td>
</tr>
<tr>
<td>Switzerland</td>
<td>Yes</td>
<td>No</td>
<td>No limit</td>
<td>No limit</td>
<td>No</td>
</tr>
</tbody>
</table>
Conscientious objection

Conscientious objection is defined in the EoLCA as any objection to euthanasia on the grounds of conscience. The Act requires medical objectors to inform patients of their objection and advise they can seek a replacement from the Support and Consultation for End of Life in New Zealand (SCENZ) Group, to be established by the Ministry of Health. Objectors are not required to make onward referrals. The EoLCA is silent on objection for organisations, eg, hospices, though there has been a recent High Court case which granted limited declarations around interpretation of the Act.4 Also absent are legal requirements for nurses, pharmacists or other health professionals who may conscientiously object; overseas evidence notably indicates nurses are often approached first with enquiries about euthanasia.5

Summary of arguments

Table 2 summarises some of the more common arguments for and against euthanasia. Relevant moral and philosophical considerations are beyond the scope of this paper.6

<table>
<thead>
<tr>
<th>Table 2: Arguments for and against legalising euthanasia.</th>
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<tbody>
<tr>
<td><strong>For euthanasia</strong></td>
</tr>
<tr>
<td>Role of doctors</td>
</tr>
<tr>
<td>Legal</td>
</tr>
<tr>
<td>• EoLCA has suitably restrictive eligibility criteria</td>
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<tr>
<td>• Law reflects and adapts to societal shifts</td>
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<tr>
<td>Vulnerable people</td>
</tr>
<tr>
<td>Mental health</td>
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<tr>
<td>Criteria expansion (‘slippery slope’)</td>
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<tr>
<td>• ‘Right to die’ should exist</td>
</tr>
<tr>
<td>Moral</td>
</tr>
<tr>
<td>• Utilitarian benefits from healthcare savings</td>
</tr>
<tr>
<td>Cultural</td>
</tr>
</tbody>
</table>
Role of doctors
The role of doctors in enabling patient autonomy is evident in abortion, which, without medical assistance, may result in unnecessary harm. Similarly, without assistance, a patient's desire to die may result in cruder methods of suicide, risking more suffering and trauma, or decisions to end life earlier.

Many supporters believe access to euthanasia is vital in ensuring a 'right to die', despite this principle failing to be affirmed by the US Supreme Court, the UK Supreme Court, the European Court of Human Rights and the New Zealand High Court. Not all legal experts agree, however. As US Supreme Court Justice Souter said regarding assistance in dying, “There can be no stronger claim to a physician's assistance than at the time when death is imminent”. Advocates also point out that legal and judicial opinion often move slower than societal shifts in attitude.

Some people from both sides of the issue contend that euthanasia should not be solely a medical decision, and instead advocate court involvement, consistent with other complex medical decisions. Some also posit that a separate profession should ensure that the procedure is done safely from a technical perspective, thus protecting the doctor's role as a healer.

On the other hand, consistent with NZMA's updated Code of Ethics, opponents disagree with any medical involvement because they see euthanasia as incompatible with the doctor's role. The doctor-patient relationship remains asymmetrical in terms of power; how doctors communicate information can determine whether a patient chooses to undergo risky investigations or treatments. Opponents point to evidence overseas that the primary motivation for requesting euthanasia is not unbearable pain but the perceived loss of dignity and note the crucial role doctors can play in addressing that. Indeed, there is often emotional asymmetry when seriously ill patients look to their doctors for guidance and reassurance. Opponents worry about the risk of subtle coercion and undue influence, especially in end-of-life situations, and believe that such conversations risk harming the doctor-patient relationship.

The emotional demands of euthanasia work are inadequately understood. In a qualitative study of Dutch doctors involved with euthanasia for patients with dementia (legal in the Netherlands), the value of investing time to improve quality of care was strongly endorsed but seen as challenging, with some choosing to work on days off. All doctors felt there could be more support for those involved, and described the work as emotionally intense, both negatively (moral distress, frustration, anger, insecurity) and positively (‘feeling in control’, heroism, satisfaction, relief).

The nursing role is crucial; a Dutch study showed them to be the first point of contact in almost half of the requests. Nurses are actively involved in voluntary euthanasia, even when not legally sanctioned (21% in the Netherlands), cf. 59% in Belgium, where it is legal.

Other research suggests a lack of support for nurses who may feel pressured to take part to uphold their ‘duty of care’, even though conscientious objection is ‘legally’ permissible. Both supporters and objectors voiced concern about available support and clarity regarding professional and legal requirements. The EoLCA is silent on some of these issues, highlighting the importance of ensuring nurses are supported, and aware of their legal obligations and protections.

Lastly, relatively little is known about the impacts of asking health professionals to participate in euthanasia. Moral distress arises when clinicians believe they are unable to act in patients' best interests and thus includes concerns about wrongly approving or withholding euthanasia. Both possibilities need to be considered and appropriately managed.

Palliative sedation is sometimes misleadingly regarded as an example of ‘euthanasia’ when it hastens death. To whatever extent this occurs, there is a strong case that palliative sedation and euthanasia remain distinct due to differences in intent (as described by the principle of double effect). Unlike palliative sedation, the doctor who carries out euthanasia will have failed if the patient survives the procedure. Of note, multiple systematic reviews showed no association between palliative sedation and...
reduced survival.\textsuperscript{19,20} To the contrary, 12 of the 13 studies found marginally longer survival in those sedated.

Philosophical discussions regarding the principle of double effect may be relevant for end-of-life decisions but are beyond the scope of this paper.\textsuperscript{21,22}

Comparison to abortion

Despite superficial similarities, there are substantial differences between euthanasia and abortion, and they should be considered separately.\textsuperscript{23}

Similarities:

- both require technical expertise to ensure physical, emotional and legal safety
- both reflect intimate and personal decisions relevant to bodily and personal autonomy
- both decisions can be subject to coercion

Differences:

- Abortion happens far more frequently (one in four women in OECD)
- Euthanasia is seen to be a personal decision, while abortion requires the mother’s decision on behalf of the fetus
- Euthanasia is the end of the life of a legal person, whereas abortion involves the loss of a fetus that is yet to have legal recognition as a person

The case for autonomy

The optimisation of individual autonomy via the EoLCA is, for many, an intuitively attractive option for medical assistance at end of life, and consistent with patient-centred care. However, ensuring autonomy is not always regarded as an absolute priority, such as when it may result in harm to self or others. Restrictions on autonomy include mandatory seat belts, prohibition against drink driving, and regulations regarding organ donation; these are deemed appropriate trade-offs in our current social contract.\textsuperscript{24} This contract can be renegotiated and, indeed, the idea of organ donation euthanasia (where death follows removal of the organs under general anaesthetic, with informed consent) is a hypothetical discussed and advocated by some as consistent with maximising autonomy and contributing to a meaningful death.\textsuperscript{25,26} The doctor’s role in euthanasia thus brings into sharp relief questions about the limits and social context of autonomy.

Role of law

The Act as it stands passed royal assent in November 2019. Accordingly, we are also voting on the Act’s details: legal rules, technicalities, practical and cultural implications. It is also widely accepted that law has a pedagogical function and helps shape culture as well as reacting to cultural shifts.

Proponents of euthanasia argue that the purpose of law is to protect people’s freedoms, empowering individuals to judge their own quality of life, and to choose when and how to die; others may also benefit from the experience and memory of a loved one’s peaceful death.

Even though the UK Supreme Court could not justify authorising euthanasia, an unintended consequence was noted by Lord Browne-Wilkinson—"...How can it be lawful to allow a patient to die slowly, though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from yet another ordeal to add to the tragedy that has already struck them? I find it difficult to find a moral answer to that question. But it is undoubtedly the law...".\textsuperscript{27} Similarly, the US Supreme Court also acknowledged that the state’s interest in preserving life at all cost may be outweighed by the liberty interest of those already on the threshold of death.\textsuperscript{7,28}

On the other hand, opponents argue that laws exist to protect society, especially the most vulnerable. These include those from disadvantaged ethnic or socioeconomic groups and those with disabilities. They point to legal tradition in Anglophone countries that has consistently opposed assisted suicide and sought to ensure equal protection for the ‘hopelessly diseased, fatally wounded, and even criminals condemned to death’.\textsuperscript{7} Developments in modern medicine have both complicated and drawn attention to issues of dignity and independence at the end of life. Legislative changes around the world have affirmed the right to refuse treatment and enable do-not-resuscitate orders and proxy decision-making, while generally reaffirming bans on assisting suicide.
The EoLCA is intended to give the terminally ill a sense of control and/or to relieve intractable suffering, but some argue this specific Act may not adequately safeguard against ending vulnerable people's lives against their wishes. Many reasons patients seek euthanasia (loss of dignity, suffering, feeling like a burden) may also make them more vulnerable to coercion, highlighting the importance of both legal and practical protections. Indeed, despite comments made by individual judges, the UK and US Supreme Courts and others have consistently ruled that the state's interest in protecting the vulnerable is sufficiently weighty to justify prohibitions against physician-assisted suicide.

The 'slippery slope' is a term that has a wide range of interpretations from both sides of the discussion. This Viewpoint focuses on the anticipated expansion of legal eligibility criteria, as distinct from increased numbers approved for euthanasia each year. The latter statistic fails to distinguish between adoption of a preferable way of dying and concerns regarding expansion of eligibility criteria.

Examples of criteria expansion include:

- Belgium removing the age limit for euthanasia, and subsequently a nine-year-old with a brain tumour and an 11-year-old with cystic fibrosis have been euthanised;
- Colombia allowing euthanasia for children aged 6+;
- Netherlands developing the Groningen Protocol and common law precedents for children under one year of age;
- A proposed bill in Canada removing the requirement that death be foreseeable;
- Oregon relaxing the required waiting/cooling-off period for those with a lesser life expectancy, and a proposed bill removing the requirement for a six-month prognosis.

Once euthanasia has been legalised at central or federal level, there is at present no example of a statutory reversal or tightening of euthanasia eligibility criteria in any jurisdiction. US Supreme Court Justice Cardozo noted the tendency of a legal principle to "expand itself to the limit of its logic", with conclusions to this effect from both the US and UK Supreme Courts—that "once a legislature abandons a categorical prohibition against physician-assisted suicide, there is no obvious stopping point".

Like the EoLCA, legalisation in Canada includes no description of euthanasia as a human right. However, receiving assistance for the procedure was interpreted by the Ontario Superior Court as "a constitutionally protected civil and human right". With this interpretation, it may be difficult to justify denying this right to:

- someone with a degenerative condition expected to lose autonomy before reaching their six-month prognosis
- someone who does not have a terminal condition but experiences intractable suffering
- someone with unbearable mental instead of physical suffering
- someone who is 17 but deemed competent

The last point is immediately relevant as the Attorney-General has concluded that the EoLCA is inconsistent with the New Zealand Bill of Rights, which protects all those above the age of 16 from age-based discrimination. This makes it a cogent place for advocates to challenge and expand existing criteria.

The expansion in eligibility criteria seen overseas is not necessarily a moral fault but appears likely, as above, based on both overseas experience and formal judicial commentary. While some advocates of a “right to euthanasia” praise these expansions as egalitarian, allowing more equitable access to a valuable end-of-life option, this will concern those advocating strict eligibility criteria and who believe certain groups should never have access to euthanasia.

A distinct set of 'slippery slope' concerns relate to existing euthanasia laws, how strictly they are enforced, and other legal safeguards designed to protect vulnerable patients. The Canadian Supreme Court reviewed these concerns and found that laws governing euthanasia could be effectively and rigorously implemented, paving the way for legalisation in that country.
Concerns about coercion

In New Zealand contract law, determination that individual wishes are free from undue influence involves examination of witnesses, arguments by lawyers on both sides, and consideration of legal precedent. In the context of existing common law and the EoLCA, this means that:

- Similar responsibilities are to be placed on one individual doctor;
- The doctor does not have access to the powers of the court;
- The doctor is presumed to hold a position of power and influence over patients;
- These concern weightier decisions than those typical of contract law.

These challenges are further complicated in scenarios where the primary doctor conscientiously objects: the replacement doctor must assume this responsibility without the long-term relationship and knowledge of the patient and family. The doctor providing the second independent opinion also has no obligation to determine coercion. Finally, there is no requirement to ensure lack of undue influence at the time of final consent to administration of the lethal dose. Advocates point out that these responsibilities would fall within broad professional standards and governance.

Concerns have also been raised regarding the EoLCA’s regulatory framework. In particular, its Review Committee does not receive demographic data such as age, gender, ethnicity and socioeconomic status, or indeed any clinical information confirming eligibility or excluding coercion, making it difficult to confirm the statutory requirement of “satisfactory compliance with the requirements of this Act”.

These factors have led some to believe the EoLCA does not do enough to ensure patients are making decisions free from coercion. The High Court of England and Wales analysed a comparatively more stringent safeguard in 2017: that each case would be reviewed by the court to ensure the absence of coercion. Their conclusion (upheld by both the Court of Appeal and the Supreme Court) was that even such a process would be considered an inadequate safeguard.\(^\text{40}\)

However, as was pointed out by the Canadian Supreme Court,\(^\text{39}\) the risks of coercion are already present in the existing medical system when it comes to refusal or withdrawal of life support, both of which remain lawful. Proponents highlight this inconsistency and argue that concerns regarding coercion have been overvalued and cannot justify an absolute prohibition of euthanasia. In contrast, opponents point to an additional reason why withdrawal of life support cannot be prohibited, namely that it may result in medication/life support being forced on unwilling patients.

The US Supreme Court goes beyond protecting the vulnerable from coercion and extends the state's interest to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and “societal indifference”.\(^\text{7}\) In New Zealand, the absence of demographic data required by the EoLCA will make it difficult to measure the impact of the Act at a population level and identify trends, or gaps in access. The EoLCA also has no specific provisions to ensure patients receive culturally appropriate care, including kaupapa Māori considerations as mandated by Te Tiriti o Waitangi.

Mental illness and vulnerability

Depression is common in patients with a terminal illness, with up to 44% fitting a diagnosis of depressive disorder.\(^\text{41}\) However, differentiating depressive disorders from grief reactions in the setting of a terminal illness can be difficult. Undertreatment of psychiatric illness is common,\(^\text{41}\) for example up to 80% of cases among cancer patients remain unrecognised and untreated;\(^\text{42}\) cancer constitutes the largest proportion of New Zealand's deaths and proportion of completed euthanasia overseas.\(^\text{15,43-44}\) Missed psychiatric diagnoses clearly increase the risk of inappropriate or unnecessary requests for euthanasia.

The New Zealand government has prioritised reducing suicide rates while provisionally approving assisted suicide under the EoLCA. While some posit that legalising euthanasia may affect suicide rates, this is not strongly supported by the numbers; a review found no evidence for an association between suicide rates and legalisation of euthanasia in various countries.\(^\text{45}\)
Cases of people who opponents would consider vulnerable being euthanised are well documented in multiple jurisdictions. A Dutch government study revealed that in 1990 there were more than 1,000 cases of euthanasia without an explicit request. While the situation has apparently improved, this is still an ongoing practice. The most recent data available via the Dutch government website showed that in 2015, 431 people were euthanised without explicit request—around 0.3% of total deaths that year, assuming no underreporting. In 2018, there were 67 reported cases of patients receiving euthanasia for psychiatric indications. A notable case in 2015 was a victim of sexual abuse in her 20s diagnosed with PTSD, anorexia and depression.

A Belgian study found that only half of cases of euthanasia were reported, dropping to one in five in the elderly (80+). The commonest reason (77%) was because physicians did not “view their act” as euthanasia, despite the definition used in the study being the same as the legal definition used in the Benelux. Another 18% stated that they did not report because it was “too much of an administrative burden”, and 12% because they admitted the “legal due care requirements had possibly not all been met”.

In 2019, the United Nations Special Rapporteur on the Rights of Persons with Disabilities expressed extreme concern with Canadian legislation, and recommended “adequate safeguards to ensure that persons with disabilities do not request assistive dying simply because of the absence of community-based alternatives and palliative care”. Her comments are relevant in light of the known gaps for access to palliative care in New Zealand, as well as the expected 50% increase in deaths in the next 20 years. New Zealand is a signatory of the same UN International Human Rights Treaty and expected to fulfil similar obligations. While the above examples do not necessarily all indicate abuse or weakness of the law, they illustrate the difficulty of ensuring safe processes, and the challenges doctors may face in protecting themselves and their patients.

Problems in implementation
As noted, there are a variety of matters that have not been adequately specified in the Act, including:

- Which doctors can legally discuss euthanasia with patients (EoLCA refers only to the requirement for practising certificates)
- Specific criteria triggering enforcement of the Act
- Guidelines regarding conscientious objection and prevention of coercion

It remains an open question whether these issues would be better addressed by modification of the Act or by other regulatory instruments and professional bodies. Either way, one set of useful considerations that could be adapted to these purposes have been formulated by Lord Wilson of the UK Supreme Court, who identified factors to assist determination that a person’s wish to end their life was “voluntary, clear, settled and informed”.

Conclusion
New Zealand doctors are obliged to consider their legal and professional obligations to patients in relation to the EoLCA. The challenge of managing end-of-life scenarios brings these issues to the fore. Much evidence points to the emotional intensity and potential moral distress associated with euthanasia. Proponents argue clinicians can be part of an intimate and rewarding process enabling patient autonomy and helping them achieve a peaceful death. In contrast, opponents say euthanasia is incompatible with both end-of-life care and medical practice generally.

From a legal perspective, the EoLCA poses many challenges and unanswered questions about how to ensure the process is safe for all involved. Proponents rightly point out that many of these questions should be addressed at a professional level with training programmes, clear guidelines and access to adequate support. On the other hand, opponents point to overseas evidence of underreporting and nonvoluntary euthanasia to illustrate risks of the legislation.

Based on overseas experience, once legalised, euthanasia eligibility criteria will
be challenged, and are likely to be expanded over time. Some regard this as an egalitarian progression towards a better future that includes a ‘right to die’, while others view this as an unacceptable risk of the EoLCA. Either way, it is difficult to imagine a more critical referendum for both our profession and New Zealand society at large.

Appendix

Glossary/definition of terms

Euthanasia: a catch-all phrase for voluntary euthanasia and physician-assisted suicide (see below), both of which are options under the EoLCA; similar to Canada’s “medical assistance in dying”, commonly abbreviated MAiD.

Voluntary euthanasia: administration of a life-ending substance to a consenting patient.

Nonvoluntary euthanasia: administration of a life-ending substance to a patient unable to consent (eg, persistent vegetative state).

Involuntary euthanasia: administration of a life-ending substance to a patient who is able to consent but did not.

Physician-assisted suicide: self-administration of a medically prescribed life-ending substance.

Physician-assisted dying: commonly used as an alternative to ‘physician-assisted suicide’, and may (confusingly) include voluntary euthanasia.

Assisted dying: commonly used to include both voluntary euthanasia and physician-assisted suicide, sometimes used interchangeably with physician-assisted dying.

Palliative sedation: administration of sedative medication to relieve refractory symptoms.

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A model respiratory personal protective programme for the New Zealand healthcare industry

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ABSTRACT

In the absence of advice from the workplace regulator, a model respiratory protection programme for healthcare workers is presented based in healthcare and wider industry experience. Hospital and other healthcare institutions can use this as a basis for their programmes in preparation for the next infective disease outbreak.

In the current COVID pandemic, personal protective equipment (PPE) has been presented as a solution for the respiratory protection of healthcare workers (HCWs), imperfectly applied because of logistics and supply problems. The real problem, however, lies elsewhere, in that PPE is seldom deployed correctly: it is only one component of a health protection system.

Although WorkSafe New Zealand\(^1\) recommends a respiratory protection programme, no guidance is given on how to design one, despite the existence of an Australian/New Zealand Standard\(^2\) and the development of specific guidelines in Australia.\(^3\) We trust that our experiences in applying the basic principles of respiratory protection in industrial settings will prove to have direct applicability to the health sector. In the absence of advice from the workplace regulator, we offer these thoughts to promote better understanding of the problem so that HCWs achieve adequate protection.

The statutory duties imposed on a person in control of a business unit (PCBU) by the Health and Safety at Work Act 2015 \(^4\) (The Act) lies at the heart of the problem: they have a primary duty of care and must, so far as is reasonably practicable, provide and maintain a work environment that is without health and safety risks. Under the provisions of the Act, work risks are to be managed by identifying, assessing and controlling hazards. Hazards can be assessed against standards, for chemicals in air there are workplace exposure standards (WES's) which should not be exceeded.\(^5\) In healthcare there are a number of chemical exposures including waste anaesthetic gases, cytotoxic agents and electrosurgical smoke, but the principal hazard resides in infectious agents, for which exposure standards have not been set, but the same control principles apply.

With regard to the latter, the Health and Safety (General Risk and Workplace Management) Regulations 2016 \(^6\) draw on a long established and empirically proven occupational health and safety principle, the ‘hierarchy of control’.\(^7\) The hazard should be either eliminated, impracticable for biological exposures unless a vaccine is available, or isolated in a suitable facility with specially trained staff, for example a nosocomial or intensive care unit. If the hazard remains then it must be minimised by, in order of importance, engineering controls, safe work practices, and, failing all else, by the use of PPE, which attempts to control any residual risk.

The implications are that a safe workplace, particularly in complex industries such as healthcare, requires a health and safety system underpinning the optimal combination of an appropriately engineered work environment, safe work practices, the
use of the most effective PPE, monitoring of the work environment and finally, adequate information and training. The efficacy of such programmes should be subject to periodic audit.

For HCWs in some circumstances, PPE may be the only effective hazard control mechanism, blood or body fluid exposures being an example. With airborne hazards, engineering solutions must not be overlooked, and remain a cornerstone of the healthcare risk management model. An example is the best practice requirements for operating theatre ventilation are effective at managing the risks from waste anaesthetic gas and electrosurgical smoke. Ventilation can help to manage biological hazards. As an example, the risk of occupational conversion of tuberculosis status is much reduced in clinical areas with appropriate ventilation.8

If ventilation fails to control the hazard, then respiratory protective equipment (RPE) is the final option, simply because it is least likely to prove effective, largely because of human behaviour or environmental factors, a seminal example being the use of PPE in the hot and humid conditions of the freezing works, which has actually been shown to increase the risk of leptospirosis in meat workers.9 The associated costs of human leptospirosis due to time absent from work and treatment have also been calculated to be $4.42 US million per annum (95% probability interval: 2.04–8.62) million).10 The possible costs of SARS-CoV-2 is likely to be much greater.

Modelling of SARS-CoV-2 virus transmission is complex, but a key finding of a study by Jones11 was that droplet, inhalation and contact routes contribute respectively 35%, 57% and 8.2% of the probability of infection, on average, without the use of PPE. While the virus emission rates remain uncertain, Jones concludes “that inhalation exposure is likely to contribute meaningfully to the risk of COVID-19 among HCP providing care to infectious patients, motivating the use of respirators to prevent occupationally acquired infection”. There is advice to the contrary. The World Health Organization (WHO)12 notes the complexity of transmission routes, SARS-CoV-2 being primarily transmitted by droplet and contact routes. Although there have been no reports of the latter the WHO advice is that “fomite transmission is considered a likely mode of transmission for SARS-CoV-2 given consistent findings about environmental contamination in the vicinity of infected cases and the fact that other coronaviruses and respiratory viruses can transmit this way”. The WHO therefore recommends droplet and contact precautions when caring for COVID 19 patients. Airborne precautions are recommended during aerosol generating procedures, the use of N95, filtering face piece (FFP)2 or FFP3 respirators.

The situation with respiratory protective equipment, RPE, is therefore complex and requires thorough analysis and the development of an ‘in-depth’ protection programme. Experience with viral haemorrhagic fever has shown that ‘standard precautions’, the suite of infection prevention and control measures, must be allied to the use of PPE, and the combination treated as an ensemble: training, for example in donning and doffing, is crucial to success.13

Having decided that RPE is necessary to reduce residual risk, appropriate equipment must be selected. Up to now, N95 respirators and surgical masks have been the most widely discussed options. N95 masks are available in different sizes and contours, and designed to fit closely around the nose and mouth. They are electrostatically charged to filter out particulate matter, but not virus droplets. Half face respirators with filters are also available and comply with a standard, having an assigned protective factor (APF) of 10, meaning that no more than one-tenth of the contaminants to which the worker is exposed leak or pass through into the mask.14 Surgical masks are loose fitting, have no APF and are not considered to be RPE: they cannot be fit tested.15 Both the N95 respirator and surgical mask are useful for containing exhaled air, however the surgical mask does allow more lateral escape.16 The other options, finding more frequent application in the healthcare industry, are the filtering face piece types, the half face air purifying respirator or the powered air-purifying respirator, the latter having an APF of up to 1,000 and being used during high-risk aerosol-generating procedures.17
We advocate an RPE programme, so what should this include? Howie sets out a number of steps to construct an effective programme, these being:

- risk assessment
- hazard substitution (if practicable)
- technical controls
- identification of those remaining vulnerable
- information and informed consent to risk
- select respiratory protective equipment (RPE) adequate to control residual risk
- involve wearers in RPE selection and match RPE to wearer
- fit testing (to determine the RPE that gives the maximum protection)
- test RPE in use (ie, the wearer can still achieve the required work task) including compatibility with other pieces of ppe or task equipment (gowns, eye loupes etc)
- train wearers, supervise in use (eg donning and doffing)
- minimise wear periods
- maintain and audit RPE

As alluded to above, Howie further qualifies the use of respiratory PPE by pointing out that manufacturers stated NPFs are many orders of magnitude greater than the workplace protection measured in the workplace, the assigned protective factor. The protection offered by RPE, and indeed all PPE, degrades when in real use, as shown for leptospirosis but also likely to occur in healthcare—particularly, for example, when subject to the hurly burly of physically intensive work such as might occur during resuscitation, high-intensity nursing or some orthopaedic procedures.

In our experience as occupational health physicians either working in, or offering advice to, district health boards, it is our considered opinion, shared by Agius and others, that the use of surgical masks has little place in a respiratory PPE programme for HCWs. Surgical masks may have some use in diffusing the exhaled cough jet stream, that is they are better placed on the patient rather than the staff member, but have no place as RPE, as they cannot be fit tested, a view re-iterated by the manufacturer.20

Having said that, there have been several trials comparing infection rates in healthcare workers using surgical masks and or N95 respirators, but a meta analysis showed no difference, the authors suggesting that compliance with N95 masks may have been a problem. The effect sizes were also small and the samples not large enough to say if there was any difference at all.

The risk does nevertheless need to be managed. Modelling data shows that the inhalation route of exposure is likely to be important, that respirators may be needed, and that PPE is part of a suite of protective measures. The implications of the limited filtering capacity of the P2 respirators including the N95 are that a choice of the higher grade of disposable respirator, or even the more complex respirators such as the air purifying respirator or the powered air purifying respirator should be available for high-risk procedures, or failing that, the higher grade of disposable filtering face piece respirator. These have been used successfully in previous viral epidemics providing that training is effective. Although available and quite widely used in industry, these appear to have had limited availability to HCWs in New Zealand.

Having provided adequate RPE, it must be incorporated into a programme, starting with fit testing. As far as we can determine from our own experience and our occupational physician colleagues there were no comprehensive RPE with an adequate “fit testing programme” as recommended by the New Zealand Australian Standard prior to the pandemic; these programmes should have been in place well in advance of any epidemic, again in our opinion ‘normalised’ into the healthcare worker induction and ongoing certification programmes, as required for cardio pulmonary resuscitation, and, as with clinical skills, subject to audit.

Behavioural measures are also essential. As the risk of contamination when doffing the high-end equipment, or indeed any RPE emphasises the need for training, we would endorse Howie’s and the CDC’s recommendation of a “change supervisor” (themselves wearing appropriate PPE) to assist—and insist on observing the correct technique.

There are some very valuable occupational health lessons to be learned from the New Zealand COVID-19 response, the
emphasis on surgical masks and N95 respirators also obscured other hazard control issues. For example facilities should be designed so that cross contamination is minimised by careful attention to detail, for example sound design of patient flow and the provision of negative pressure areas to meet the expected clinical demand.

Work practice controls must be improved through attention to information and training, the effect of possible failure having been demonstrated in at least one district health board. The evidence supports this: well equipped and practised high care units provided better protection for HCWs than found in the less prepared general healthcare and home settings.

Our model of a good respiratory protection programme therefore draws heavily upon Australian practice, in particular the Queensland Workcover guidance, to ensure compliance with the relevant standards including:

- correctly selecting appropriate RPE (that is the right type of RPE for the identified risk to staff)
- medical screening of RPE users
- training in the correct use and maintenance of RPE
- ensuring RPE is correctly used, that is supervision
- fit testing and fit checking
- inspection, maintenance and repair of RPE
- correct storage
- keeping records
- audit

To be effective, as with all complex medical procedures, an adequate respiratory protection programme requires that the HCW is deployed in a safe environment, using appropriate equipment and techniques, and has the resources and training to apply those techniques to their everyday practice. This should be considered as a component of staff welfare, which, in an audit of DHB plans, was the most poorly addressed. We should also bear in mind that, in the run up to the Rugby World Cup ‘well prepared’ acute care providers were significantly less likely to respond to an infectious disease outbreak. We need to give them the confidence to do so.

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Co-infection of influenza A with Staphylococcus aureus causing bacterial arthritis in a child

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Influenza viruses are responsible for an average of 500,000 deaths per year globally. Various factors, including bacterial co-infection, increase the severity of influenza infection as observed during previous influenza pandemics and seasonal epidemics. Several cases of bacterial co-infection with influenza resulting in severe pneumonia and sepsis have been reported. However, co-infection leading to bacterial arthritis without overt pulmonary involvement has not been reported till date. We herein report this rare case of a six-year-old previously healthy boy with influenza A, who developed bacterial arthritis after co-infection with *Staphylococcus aureus* (*S. aureus*) and was managed successfully.

Case report

A six-year-old Arab boy presented with bilateral lower limbs pain, inability to walk and bear weight on legs. He had fever, cough and runny nose for three days prior to his presentation. Fever was high grade, intermittent and responded transiently to antipyretics. There was no headache, vomiting, diarrhoea, recent intramuscular injection or any history of trauma. There was no history of past or current skin disease. His past and developmental history were normal. His routine childhood immunizations were up-to-date, however he had never received influenza vaccine. On examination he was conscious, alert with temperature of 39.2 celsius, heart rate of 122/min, respiratory rate of 24/min and blood pressure of 104/64mmHg. There was nasopharyngeal congestion. The child was unable to walk but could stand with support. Tone was normal in all four limbs with normal superficial and deep reflexes. There was marked bilateral calf tenderness. His spine and cranial nerve examination were normal. Rest of the systemic examination was normal. He was admitted with a provisional diagnosis of viral myositis. His serum creatine phosphokinase was 4,000U/L (normal 39–308U/L) and nasopharyngeal swab was positive for influenza A virus. Complete blood count and C-reactive protein (CRP) were normal. Tests for other viruses were negative. He was started on intravenous fluids and paracetamol PRN. We considered persistent fever and inability to walk and stand in our patient as probably due to severe/progressive influenza and hence started oseltamivir. Calf pain improved over the next two days with gradual improvement in the mobility. On third day of admission, the child still had low-grade fever and the next day developed severe pain in the left hip and thigh with inability to walk. Repeat septic workup showed increased inflammatory markers. The total leucocyte count was 18,300/cumm, CRP was 303.9mg/L(normal<9) and erythrocyte sedimentation rate was 104mm/first hour. His alanine transaminase was 230U/L [N 0–63] and aspartate transaminase was 528U/L [N 15–37]. Hence intravenous amoxicillin-clavulanate was started empirically. Ibuprofen was started round the clock for the pain and inflammation. Ultrasound of the left hip showed synovial thickening of left hip joint with effusion. Arthroscopy was done and the joint was drained. The synovial fluid culture and the blood culture grew *S. aureus* and intravenous flucloxacillin was started as per the sensitivity pattern for the treatment of septic arthritis. Nasopharyngeal swab culture grew *S. aureus*. The *S. aureus* isolated from the blood culture, synovial fluid and the nasopharyngeal swab had the same antibiogram. Flucloxacillin was given intravenously for 21 days followed by oral for seven days after discharge. Physiotherapy was started after
the pain subsided and gradual improvement noted in movement of the left lower limb. Magnetic resonance imaging showed features consistent with bacterial arthritis with enhancing foci in the acetabulum and proximal femur suggestive of osteomyelitis (Figure 1).

Repeat inflammatory markers, liver function tests and blood cultures were negative at the end of the treatment. The power and function of the lower limbs were normal and there were no sequelae on follow-up after six months.

Discussion

Early diagnosis and prompt antibiotic treatment were crucial in the complete recovery of the child. In contrast to other published studies, our case was unique as the co-infection lead to bacterial arthritis without acute lung injury. Bacterial co-infection complicates approximately 0.5% of all influenza cases in previously healthy individuals. This increases to at least 2.5% in people with predisposing conditions like extremes of age (>65 years or <5 years) and those with pre-existing chronic medical conditions or immunosuppressive conditions. Pathogens that colonise the nasopharynx, including S. aureus, S. pneumoniae, and S. pyogenes, are the most commonly isolated bacteria. In the presence of influenza infection, these opportunistic pathogens can cause bacteremia and severe infection. In a systematic review and meta-analysis of 27 studies done by Klien et al on the frequency of influenza and bacterial co-infection, S. pneumoniae (35%) and S. aureus (28%) were the most common co-infecting bacteria. The nasopharyngeal swab culture, synovial fluid and blood culture of our patient grew S. aureus with the same antibiogram. Williams et al in their study found that children with influenza having bacterial co-infection had an increased likelihood of requiring intensive care unit admission, a longer

**Figure 1:** MRI of the left hip joint showing features suggestive of bacterial arthritis with enhancing areas suggestive of osteomyelitis in the acetabulum and left proximal femur and in the periarticular soft tissues. Also seen is peripheral enhancing collection in the joint extending into left gluteus medius muscle.
hospital stay and a trend towards higher mortality.\textsuperscript{7} This occurs due to the epithelial cell damage and increased receptor availability during influenza infection, which enables the invading bacteria to adhere and grow.\textsuperscript{1,3,8} Table 1 summarises the factors which lead to increased severity of illness during co-infection.\textsuperscript{1,3,8}

Co-infection predominantly occurs during periods of high influenza viral shedding and maximum tissue damage (ie, 3–7 days after influenza infection), but may occur concurrently with or shortly after influenza infection.\textsuperscript{1,3} Non-steroidal anti-inflammatory drugs (NSAID) like ibuprofen, aspirin have strong anti-inflammatory effects. They can modify the signs and symptoms leading to delayed diagnosis and management. Factor et al also found NSAID as a risk factor for invasive Group A Streptococcal infection.\textsuperscript{9} We had managed our patient initially with paracetamol PRN, which has mild anti-inflammatory action. Hence the possibility of NSAID modifying the course of the disease doesn’t arise in our case.

The management of bacterial co-infection includes prevention, early diagnosis and appropriate treatment of both influenza and bacterial infection. However, clinically, it can be sometimes difficult to identify bacterial co-infection, given the substantial symptom overlap of influenza and bacterial infections. As per the updated 2018 clinical practice guidelines by the infectious disease society of America (IDSA), clinicians should investigate and empirically treat bacterial co-infection in patients with suspected or laboratory-confirmed influenza who present initially with severe disease (extensive pneumonia, respiratory failure, hypotension, sepsis and fever).\textsuperscript{10} Bacterial co-infection should also be considered in patients who deteriorate after initial improvement on antivirals and/or fail to improve after 3–5 days of antiviral treatment.\textsuperscript{10} In a study done by Zhihao et al, significantly higher procalcitonin and CRP levels were detected in the bacterial co-infection group than in the influenza infection-alone group.\textsuperscript{11} Thus the combination of these markers could assist in identifying bacterial co-infection during the early disease phase, although clinical judgement is also indicated. As per IDSA, the empiric antibiotic treatment for any suspected bacterial co-infection in influenza patients should cover the most common isolated bacteria, ie, \textit{S. aureus}, \textit{S. pyogenes} and \textit{S. pneumoniae}.\textsuperscript{9} Coverage for additional pathogens may be necessary based upon the child’s age, particular clinical circumstances, site of infection, gram stain and the local antibiotic resistance pattern.

Table 1: Factors contributing to the increased severity of influenza illness during bacterial co-infection.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Viral factors</td>
<td>PB1-F2 – increases susceptibility to bacterial infection</td>
</tr>
<tr>
<td>Bacterial factors</td>
<td>\textit{Staphylococcus aureus}: produces proteases which cleave hemagglutinin, thus producing fusion-competent virus particles with enhanced infectivity</td>
</tr>
<tr>
<td>Mechanical factors (host)</td>
<td>Epithelial injury</td>
</tr>
<tr>
<td></td>
<td>Impaired mucociliary velocity</td>
</tr>
<tr>
<td>Immune cells (host)</td>
<td>Impaired neutrophil function and recruitment</td>
</tr>
<tr>
<td></td>
<td>Increased neutrophil apoptosis</td>
</tr>
<tr>
<td></td>
<td>Macrophages and monocytes—reduced phagocytic capacity</td>
</tr>
<tr>
<td>Cytokines/chemokines (host)</td>
<td>IFN-(\gamma) &amp; IFN-(\alpha/\beta)</td>
</tr>
<tr>
<td></td>
<td>1. Decrease the production CCL2, which is required for macrophage recruitment</td>
</tr>
<tr>
<td></td>
<td>Keratinocyte derived chemokine [KC] &amp; Macrophage inflammatory protein 2 [MIP-2]</td>
</tr>
<tr>
<td></td>
<td>– Downregulation of KC and MIP-2 leading to inhibition of migration of neutrophils.</td>
</tr>
<tr>
<td>Pattern recognition receptors (host)</td>
<td>MARCO [macrophage receptor with collagenous structure]—downregulation of MARCO leading to reduced phagocytic activity of macrophages and monocytes.</td>
</tr>
</tbody>
</table>

\textsuperscript{1} Decrease the production CCL2, which is required for macrophage recruitment

Keratinocyte derived chemokine [KC] & Macrophage inflammatory protein 2 [MIP-2]

– Downregulation of KC and MIP-2 leading to inhibition of migration of neutrophils.
Cultures should be taken before starting antibiotics empirically in influenza cases with suspected bacterial co-infection. The antimicrobial regimen can later be de-escalated as necessary or tailored to a specific pathogen based on microbiological results. This will avoid patient exposure to the risks of prolonged unnecessary antibiotic use.

Human data are limited regarding the effectiveness of oseltamivir treatment in preventing serious influenza-related complications (eg, bacterial or viral pneumonia or exacerbation of chronic diseases). Thus the best way currently to prevent serious co-infections is to prevent the antecedent viral infection entirely. Studies have shown up to a 45% reduction in pneumonia hospitalisations and mortality rates following influenza vaccination. Thus annual influenza immunisation for >6 months of age remains an important tool for prevention of severe influenza illness commonly associated with bacterial co-infection. Influenza vaccination can have substantial epidemiological impact even when vaccine efficacy is low. As per Sah et al, the mortality and overall health burden due to influenza infection is more sensitive to changes to vaccination coverage than to changes in vaccine efficacy. Thus reduced motivation to vaccinate could present a greater danger than low vaccine efficacy itself.

**Conclusion**

Influenza and bacterial co-infections can cause severe illness with increased morbidity and mortality. Physicians should maintain increased vigilance in influenza for early detection and investigation for risk of serious secondary bacterial infection. Annual influenza vaccination for >6 months remains the best way to prevent infection and reduce seriousness of illness even if one gets infected.

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**Competing interests:**
Nil.

**Acknowledgements:**
We would like to acknowledge Dr Asim (Consultant Infectious Diseases), Dr Abdul Latif (Vascular Surgeon) and Physiotherapy Department for helping and giving their valuable inputs in the management of the case. We would like to thank our Head of Department and Medical Director for giving us permission to publish the manuscript.

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Unilateral pulmonary opacity with herniation of contralateral lung to same side

Prem Parkash Gupta, Dipti Agarwal, Chandra Kumar, Saumya Gupta

A 19-year-girl was referred to our Institute from a primary healthcare for lower respiratory symptoms. She gave history of recurrent respiratory symptoms since early childhood. Her chest radiograph showed left hemithorax having large opacity, mediastinal structures shifted to left, and right lung crossing the midline to left (Figure 1). Her sputum samples were submitted for microbiological examination and she was started with empirical antibiotics. Her cough and sputum subsided after antibiotics.

Question: what is the diagnosis?
She underwent detailed contrast enhanced computed tomography study of thorax (Figure 2). There was no left bronchial tree or left pulmonary vasculature.

(In all scans, symmetry of thoracic cage is maintained despite of major anatomical changes in thoracic organs suggesting a congenital etiology).

Bronchoscopic examination revealed absence of origin of left main bronchus, trachea being followed by dilated right main

Figure 1: Chest radiograph, posterio-anterior view, showing left hemithorax having large almost uniform opacity, trachea and mediastinal structures shifted to left and right lung crossing the midline to left (arrow heads).
Figure 2: Chest CT scan: (Figure 2A & B) axial scans showing mediastinum grossly displaced to left, right lung crossing the midline to left. There is no associated thoracic cage volume loss over left side (that is seen in acquired pathology) suggestive of congenital disorder. (Figure 2C & D) axial scans, trachea being continued to right main bronchus only, not even rudimentary left main bronchus seen. (Figure 2C to 2E) right pulmonary vasculature enlarged due to the absence of left pulmonary vasculature, entire pulmonary blood being channeled through right. (Figure 2E & F) heart is shifted near left posterior thorax. (Figure 2G & H) axial scans showing details of cardiac chambers fully displaced to posterior thoracic space, descending aorta displaced to left. Bifurcation of trachea to right upper lobe and right intermediate bronchus is seen. (Figure 2H) axial scan with right pulmonary artery elongated due to displaced heart to further left.
Figure 3: Images captured during fibre-optic bronchoscopy, seen from head end; (3A to 3C) trachea is continuing to right main bronchus, no evidence of any left main bronchus—not even rudimentary one—seen. (3D) Bronchoscope in right intermediate bronchus, bronchial openings of right lower lobe, right middle lobe and superior segment of right lower lobe seen.

bronchus and all airways on right side were grossly altered in size and position (Figure 3, images obtained during bronchoscopy; and Appendix Video 1, Video clip obtained during bronchoscopy). Airways were full of secretions; bronchial aspirate was submitted for microbiological culture that confirmed *streptococcus pneumoniae*; that matched with sputum culture submitted earlier.

Diagnosis

Based on the features described here, a diagnosis of *left pulmonary agenesis with superadded infection of remaining right lung* was made.

Discussion

Unilateral whole lung opacity is frequently encountered in clinical practice that requires careful consideration of available clues, including position of trachea, thoracic cage symmetry and telltale signs of thoracic trauma or surgery. Differential diagnosis of unilateral lung opacity extends from congenital conditions to inflammatory, infective and malignant conditions (Table 1).

*Complete atelectasis* secondary to main bronchial obstruction is most often due to a central mass, but occasionally may result from other causes like foreign bodies, mucus plugs, endobronchial tuberculosis or external compression due to lymphnodes, tumors or aortic aneurism. Traumatic bronchial rupture is always having history of blunt trauma; rib fractures are usually associated with bronchial rupture in patients over age 30. *Pneumonectomy* can be easily be detected due to a history of prior thoracic surgery, presence of post-operative skin scar and a radiological appearance of asymmetrical thoracic cage. In *pulmonary agenesis*, thoracic cage usually appears symmetric, although the trachea and mediastinum are deviated to the affected side.

Pulmonary agenesis is a rare congenital disorder characterised by complete absence of bronchus, lung parenchyma and...
Table 1: Lung diseases and disorders with a radiological appearance of opaque hemithorax.

<table>
<thead>
<tr>
<th>Position of trachea</th>
<th>Possible underlying etiology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pushed (shifted to contralateral side)</td>
<td>Large pleural effusion (most frequent)</td>
</tr>
<tr>
<td></td>
<td>Large intrathoracic thoracic mass</td>
</tr>
<tr>
<td>Pulled (shifted to ipsilateral side)</td>
<td>Pulmonary agenesis</td>
</tr>
<tr>
<td></td>
<td>Complete atelectasis</td>
</tr>
<tr>
<td></td>
<td>[Foreign body (in children), endobronchial tumor (in adults), muttal positioned endotrachial intubation, external compression, traumatic bronchial rupture]</td>
</tr>
<tr>
<td></td>
<td>Pneumonectomy</td>
</tr>
<tr>
<td>No change (central)</td>
<td>Adults—bronchial carcinoma, accompanied by pleural effusion and atelectasis</td>
</tr>
<tr>
<td></td>
<td>Children—extensive pneumonia</td>
</tr>
<tr>
<td></td>
<td>Pleural mass</td>
</tr>
</tbody>
</table>

Pulmonary vasculature; the prevalence being around 34 per million live births.\(^1\) Pulmonary agenesis co-exists with other systemic anomalies including cardiovascular, gastrointestinal, musculoskeletal or urogenital system in over half of the patients.\(^2\) It is often diagnosed during childhood; half of those with unilateral lung agenesis die before the age of five years. Congenital heart diseases are seen in nearly one-third of patients. Left lung agenesis is comparatively having a longer life expectancy.\(^2\) First expression in adult life is still rarer. The natural course of pulmonary agenesis is highly variable being dependent on associated congenital malformations and development of complications. Patients may remain asymptomatic till early adulthood or present with respiratory insufficiency since birth. Isolated unilateral lung agenesis may, however, be compatible with a normal life.\(^2\) Contralateral normal lung involvement by infection or atelectasis often leads to respiratory distress.

Pulmonary agenesis may be overlooked as a collapse or pleural effusion by primary care physicians. Pulmonary agenesis and aplasia are to be identified as the later is characterised by the presence of a rudimentary bronchus. Further, both of them differ from pulmonary hypoplasia having no immature pulmonary tissues seen in later disorder. Diagnosis of pulmonary agenesis can be secured by demonstrating absence of even rudimentary bronchus, lung parenchyma and any pulmonary vasculature using radiological imaging like contrast-enhanced CT, pulmonary angiography or magnetic resonance imaging and carrying out bronchoscopy.\(^3\)

Asymptomatic pulmonary agenesis cases require no treatment apart from treatment of chest infections.\(^3\) Long-term prognosis is highly variable being dependent on the presence of co-existing congenital anomalies and involvement of the remaining single lung in disease process.
Appendix

Appendix Video 1: Video clip obtained during bronchoscopy. No evidence of any left main bronchus seen. Bronchoscope is moving from trachea to right main bronchus, opening of right upper lobe bronchus seen at 1 o’clock position and then continuing to right intermediate bronchus, bronchial openings of right lower lobe, right middle lobe and superior segment of right lower lobe seen.

Competing interests:
Nil.

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Bruce Spittle recommends a new review of health effects of community water fluoridation (CWF) because of new findings published in three recent papers. Two of these use data from Canada where CWF is used and are more relevant than the studies from areas of endemic fluorosis previously used to argue against CWF. However, these new studies have problems and a critical review of them is necessary.

Spittle ignores the finding of the two Canadian studies that fluoridation has no effect on child IQ, confirming the results reported by Broadbent et al for New Zealand. All three of these studies reported differences of less than two IQ points in both directions. This lack of difference was not discussed by the Canadian authors but has been discussed in critiques of one of these studies.

Despite this, some commentators use the new studies as evidence of harm from CWF because they report negative relationships between child IQ, or other cognitive measures, with indicators of fluoride exposure such as urinary fluoride, drinking water fluoride and estimated fluoride dietary intake. The reported relations are in all cases weak, explaining little of the variance of cognitive facts, and often not statistically significant. Attempts to consider the influence of confounders or other risk modifying factors are limited. There are also methodological weaknesses related to limitations in measurement of fluoride exposure and the suitability of the cognitive measures used for young children.

Spittle confuses the results reported by Till et al, related to breastfed and formula-fed babies with those of Green et al, which compared prenatal maternal urinary fluoride with child IQ. He claims a decrease in the 8.8 IQ points in the children who have been formula-fed for every 1mg/L increase in water fluoride concentration. But this was not statistically significant when confounders were included or when outliers removed. Till et al used several different cognitive measures including performance (PIQ) and verbal (VIQ), which are subtests of full-scale IQ (FSIQ). There was a statistically significant relationship for PIQ, but not VIQ or FSIQ. The use of such subtests is questionable but seems to have led to some confusion.

The studies Spittle refers to are exploratory, using existing data bases rather than experiments specifically designed to answer the relevant questions. Reported relationships may support preconceived beliefs but it is easy to ignore important confounders or risk-modifying factors. For example, the positive relationship of ADHD prevalence with the extent of fluoridation in the US reported by Malin and Till disappeared when geographic factors were included.

R-squared values indicate that the relationships reported in the studies Spittle mentions explain only a few percent of the variance of cognitive measures. The standard errors of all the regressions are large compared with the coefficients determined for the relationships. Where figures illustrating these relationships are published, they show a higher degree of scattering of data points.

Multiple measures for both cognitive factors and of fluoride exposure are used producing many relationships. Only four of the 10 relationships reported by Green et al were statistically significant (p<0.5). Similarly, only three of the 12 relationships reported by Till et al were statistically significant. There is a danger that reported relationships could be misleading—as the proverb says, “If you torture your data long enough, they will tell you whatever you want to hear”.

Any new review of health risks of CWF would have to include consideration of all
relevant recent studies as well as those selected by Spittle. For example, a Swedish study\(^1\) found that low fluoride exposure similar to levels found with CWF had no effect on people's IQ and a Spanish study\(^2\) using mother-child pairs similar to that of Green et al found a positive effect of prenatal maternal fluoride on child IQ.

Finally, extrapolating from data in studies from areas of endemic fluorosis as Spittle does to estimate a possible benchmark threshold dose for the effect of fluoride exposure on child IQ can be misleading. Those relationships refer to situations which include excessively large fluoride exposures, but the same relationships often prove to be non-significant when only data for fluoride exposures relevant to CWF are statistically analysed. It is not unusual for beneficial micro elements to have toxic effects at excessive concentrations and health problems in areas of endemic fluorosis are well known.

The few studies mentioned by Spittle have the advantage of using fluoride exposures relevant to CWF, but they have serious weaknesses. There are also other relevant studies he does not mention and there well no doubt be more in future. A new review concentrating on only the few studies like those he has selected would be inappropriate.

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**Competing interests:** Nil.

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The association between New Zealand adolescents’ normative perceptions of pornography use and their frequency of pornography use

Damian Scarf, Benjamin C Riordan, Taylor Winter

If a parent were to type “New Zealand teens and porn” into Google, rather than being presented with news and information about pornography use by New Zealand adolescents, they would see a series of links to websites such as Pornhub, xvideos, and Redtube. That is, they will be directed to pornography websites that purportedly contain videos of New Zealand adolescents having sexual intercourse. To provide New Zealand parents with a less treacherous pathway to information about pornography use in adolescents, the New Zealand Government recently launched their “Keep It Real Online” website. The website provides, among other things, information on how to talk to adolescents about pornography and a link to the Office of Film and Literature Classification (Classification Office) research report on pornography use by New Zealand adolescents.

The Classification Office report represents one of the few sources of information on pornography use by New Zealand adolescents. They recruited an online, nationally representative, sample of 2,071 adolescents between the ages of 14 and 17. Consistent with research conducted in Australia, 66% (n=1,369) of New Zealand adolescents had seen pornography, with 37% (n=771) viewing it in the past six months. With respect to frequency, 55% (n=425) had viewed pornography a few times or less. At the other end of the spectrum, 5% (n=41) had viewed it daily or almost daily, and just 1% (n=10) had viewed it more than once a day. When broken down in this way, while one could argue lifetime exposure to pornography in adolescents is high, the number of adolescents that frequently view pornography is relatively small. Indeed, even if we factored in some level of underreporting of frequency due to social desirability bias, viewing rates would still be relatively low.

Based on the Classification Office report and data from the Youth2000 Survey Series, Taylor recently called attention to the potential disconnect between 1) popular narratives on the prevalence of pornography use in adolescents and 2) the quantitative data suggesting the number of adolescents that frequently view pornography is relatively low. Beyond merely misrepresenting New Zealand adolescents’ pornography use, Taylor recently noted that “…it is somewhat ironic that the concern about an epidemic of pornography viewing may itself be perpetuating normative pressures for young people to watch pornography” (p. 17).

Here we use data from the Classification Office report to test the association between normative perceptions of pornography use and the frequency of pornography use. Normative perceptions was measured by asking adolescents how common adolescents thought it was for boys and girls their age to look at porn, with response options ranging from not common (1) to very common (3). Frequency of use was captured by a single question asking how often adolescents had seen porn in the last six months, with response options ranging from not at all (0) to more than once a day (6). A complete list of variables is available online.
Given the high number of adolescents that had not watched pornography in the past six months ($n=555$), we employed hurdle models. Supporting Taylor's assertion,6 those who reported higher normative perceptions of pornography use reported watching pornography more often (Incident Rate Ratio = 1.27; 95% CI = \([1.15–1.41]\)) and were more likely to report any pornography use (Odds ratio = 2.46; CI = \([2.01–3.02]\)). That is, for every 1-point increase in normative perception, the odds of viewing pornography increases 2.46 times.

The findings of the current study have important implications for campaigns that aim to address pornography use in New Zealand adolescents.1 Indeed, given the risk of iatrogenic effects,7 education campaigns should provide accurate information on the frequency of pornography use. Providing accurate information will help to curtail the normative pressures that may, unwittingly, increase pornography use in New Zealand adolescents.

### Table 1: Hurdle models predicting the perceived frequency of pornography use.

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Incident rate ratio</th>
<th>Confidence interval</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>1.25</td>
<td>0.92–1.70</td>
<td>.148</td>
</tr>
<tr>
<td>Gender</td>
<td>0.90</td>
<td>0.77–1.05</td>
<td>.170</td>
</tr>
<tr>
<td>Age</td>
<td>1.00</td>
<td>0.95–1.06</td>
<td>.856</td>
</tr>
<tr>
<td>Norms</td>
<td>1.27</td>
<td>1.15–1.41</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

**Zero inflated model**

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Incident rate ratio</th>
<th>Confidence interval</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>0.24</td>
<td>0.13–0.43</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Gender</td>
<td>0.87</td>
<td>0.65–1.17</td>
<td>.350</td>
</tr>
<tr>
<td>Age</td>
<td>1.01</td>
<td>0.90–1.13</td>
<td>.854</td>
</tr>
<tr>
<td>Norms</td>
<td>2.46</td>
<td>2.01–3.02</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

**Competing interests:**

Nil.

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High time to decide

David B Menkes, Nicholas Hoeh

The October 2020 ‘reeferendum’ will determine the legal status of recreational cannabis in New Zealand (http://www.referendums.govt.nz/cannabis/summary.html). Amidst the many arguments for and against, a key issue has yet to receive adequate debate and critical scrutiny. Cannabis-induced psychosis warrants concern because of the profound and sometimes irreversible social and occupational disability that can result. Epidemiological data from New Zealand1 and elsewhere2,3 strongly implicate a causal role for tetrahydrocannabinol (THC) in schizophrenia. Additional concern arises from the impacts of regular cannabis use on a critical period of brain maturation during adolescence up to the age of 25 or so.4

These problems are exacerbated by commercial pressure, regardless of legal status, for producers to develop strains of cannabis with ever higher THC content. Urban myths notwithstanding, THC drives recreational use as well as reported symptom relief and side-effects of ‘medicinal’ cannabis.5 Another cannabis constituent, cannabidiol (CBD), may mitigate the psychotogenicity of THC,6 but the notion that sufficiently high levels of the former relative to the latter could be legally mandated must be regarded as little more than a pipe dream.7

If recreational cannabis were to be legalised in New Zealand, based on overseas experience we can expect rapid commercialisation, increased use in the adult and adolescent populations, followed by an elevated incidence of psychosis.3 A proper health-economic study will be required to reckon the consequent social and economic costs and, ideally, to counterbalance these against anticipated gains from legalisation on reduced gang activity, prosecution and incarceration.8 On the other hand, there is evidence that decriminalisation9 offers a useful compromise between the extremes of legalisation and criminalisation; its relevance as an alternative in New Zealand has been cogently argued,10 but available evidence indicates that we still have a long way to go to achieve this.11,12

Competing interests:
Nil.

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www.nzma.org.nz/journal-articles/high-time-to-decide
REFERENCES:


Politicians and Physicians
August 1920

In discussing the Masseurs’ Registration Bill in the New Zealand Parliament, Mr. Isitt said that three doctors in consultation had diagnosed appendicitis and advised operation, but a woman declared the case to be measles and the woman was right. The general opinion of the politicians who spoke in the discussion is that doctors belong to a close corporation and should not be further entrenched in their privileges. If the medical profession had the same voting strength as the coalminers or the waterside-workers it would be immune from criticism by members of Parliament. It is a curious anomaly that Parliament prescribes certain qualifications for medical practitioners, but the only qualification necessary for a member of Parliament is that he must attract more votes than his opponents, occasionally at the cost of his self-respect. He need know nothing of history or political economy, and, indeed, sometimes a man is elected to Parliament who is devoid of average intelligence.

Proof indeed? Let this suffice it—
The plain tale of Mr. Isitt;
He, a member of Parliament,
Thitherward by the people sent,
Tells how a lad in sickness sore
Did bring three doctors to his door.
They talked together and looked wise
And operation did advise.
But a wise woman, standing by,
Saw the lad had a bleary eye,
Heard him cough, and observed the spots,
Called the doctors three silly sots.

“Measles it is, you silly hens!
“Nothing’s wrong with ‘is abdomens!
“Blinder than the politicians!”
Bawled she at the three physicians.
The patient then sat up in bed,
And flung a bottle at the head
Of each doctor, and loud shouted,
When he saw the three were routed—
“Other help I shall now enlist:
“I’ll send for a homeopathist,
“A quack masseur with supple wrist,
“A chiropractic for my spine
“To set the vertebrae in line,
“Metaphysicians, come along
“And join the merry quacking throng,
“Also the Christian science crew,
“Likewise faith healers shall come too,
“And a messenger must be sent
“For Mister Isitt, Parliament!”
So this is wisdom, it is said,
Political wisdom in N. Zed.
Take your boots to navvies to botch,
And let the blacksmith mend your watch.
Close corp’rations do not favour—
If you’re sick, consult a neighbour.
If you are tired, rest on your head,
And keep awake when you’re abed.
If you are ever in a fix,
Study the latest politics.
To Mister Isitt pay good heed;
Verbum sap. should be all you need.
The NZMA publishes the e-magazine NZMJDigest 10 times a year. It contains news and views from the profession and the NZMA, including the NZMA Chair’s editorial, along with highlights from and links to the New Zealand Medical Journal.

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