The
New Zealand
Medical Journal
Journal of the New Zealand Medical Association
Vol 132 | No 1505 | 8 November 2019

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Ethnic disparities in community antibacterial dispensing in New Zealand—is current antibacterial dispensing for Māori and Pacific people insufficient or excessive, or both?

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The New Zealand
Medical Journal
Publication Information
published by the New Zealand Medical Association

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Institutions	$549	Institutions	$591
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ISSN 1175-8716

What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?

Eileen M McKinlay, Serena V Moran, Sonya J Morgan, Pakize Sari, Jill M Kerridge, Susan RH Pullon

Increasing pressure on the healthcare services in both public hospitals and hospices means there is a specific group of patients including those under 65 years who are being *admitted-to-die* in aged residential care (ARC) facilities from public hospitals and hospices. This case study of seven patients *admitted-to-die* in an ARC facility showed they have high symptom control needs and required what is akin to specialist palliative care including from ARC staff and health and social care professionals staff from DHBs, hospices and other privately contracted professionals. This is not the typical system of ARC care and ARC facilities are not currently set up or staffed to provide specialist palliative care of those admitted-to-die. A specific model of care funded appropriately by the government is required.

Diagnostic delays and treatment challenges in children with coeliac disease: The New Zealand Coeliac Health Survey

Kirsten J Coppell, Rosemary A Stamm, Kiri PH Sharp

Coeliac disease is an increasingly common disorder for which the only current treatment is a life-long gluten free diet. Exclusion of gluten from the diet is challenging as gluten is a common component of the typical New Zealand diet. In a survey of 123 New Zealand children aged less than 16 years with doctor-diagnosed coeliac disease, many children presented with non-classical symptoms contributing to delays in diagnosis. Following a gluten free diet was not easy for many families, with one-third finding it very or moderately difficult. The biggest challenge with following a gluten free diet was eating away from home especially birthday parties and school functions with almost half avoiding restaurants and 19% avoiding travel all or most of the time.

The costs associated with ankylosing spondylitis/axial spondyloarthritis in Aotearoa/New Zealand

Douglas White, Chunhuan Lao, Megan Williams, Ross Lawrenson, Nicola Dalbeth

This study has detailed the costs of spondyloarthritis (SpA) in Aotearoa/New Zealand. We have demonstrated a meaningful reduction in quality of life and work productivity in patients with SpA. The major driver of direct costs in SpA are biologic medications.

IDI trends in antidepressant dispensing to New Zealand children and young people between 2007/08 and 2015/16

Nicholas Bowden, Sheree Gibb, Hiran Thabrew, Richard Audas, Justine Camp, Barry Taylor, Sarah Hetrick

The paper aims to examine trends in antidepressant dispensing to children and young people in New Zealand aged 1–24 years between 2007/08 and 2015/16 using the Integrated Data Infrastructure (IDI), and to determine whether these trends vary by age, sex, ethnicity and socioeconomic deprivation. Overall there was a trend towards an increase in the use of antidepressants across all age, sex and ethnic groups, but notable variation in dispensing between different ethnic and socioeconomic groups. Despite our inability to determine the clinical rationale for increased dispensing of antidepressants, the available data highlight some potentially significant improvements as well as disparities in healthcare.

Electric scooter injuries at Auckland City Hospital

Anna BS Brownson, Paul VB Fagan, Samuel Dickson, Ian DS Civil

Our study has found 180 patients who required treatment at Auckland City Hospital in only 19 weeks, which highlights the significant number of electric scooter-related injuries. While the majority of injuries were minor trauma, these cases have placed additional demand on health system resources across Auckland. A significant group of patients had serious injuries including some severe brain injuries. This mode of transport would benefit from greater regulation, including a zero blood-alcohol limit, night-time curfews, reduced speed limits and consideration of mandatory helmet use.

Untreated severe-to-profound hearing loss and the cochlear implant situation: how policy and practice are disabling New Zealand society

Lewis Williams

As a signatory to Convention on the Rights of People with Disabilities, Aotearoa New Zealand aims to be a "non-disabling society—a place where disabled people have an equal opportunity to achieve their goals and aspirations". Yet many adult New Zealanders with severe-to-profound hearing loss (SPHL) due to sensorineural deterioration over time are being denied timely access to publicly funded cochlear implants. This presents a serious inequity in Aotearoa New Zealand's health system and contravenes disability and human rights principles. For Māori affected by SPHL, this brings additional challenges along with broader impacts on Māori health and development.

When every second counts: ampoule versus adrenaline auto-injector administration for life-threatening allergy

Elissa M McDonald, Emma Cooper

Worldwide there has been a marked increase in the rate of anaphylactic reactions with studies reporting increases in many countries. Management of anaphylaxis in the community needs to be appropriate and effective. In New Zealand, the only available adrenaline auto-injector (EpiPen®) delivers adrenaline deep into the muscle with the aid of the force of the spring-action needle. Alternative delivery is from an ampoule, needle and syringe that must be prepared and administered manually. There are justifiable concerns about the timely and safe intramuscular delivery of adrenaline manually by lay persons in the community. EpiPen® ensures the ability of individuals to administer the correct dose of adrenaline via the correct route in a timely and effective manner. PHARMAC is urged to fund the only available adrenaline auto-injection available in New Zealand, EpiPen®.

Supporting mothers, protecting babies for long-term health: establishing a pasteurised human milk bank

Maggie Meeks, Anthea Franks, Hazel McGregor, Rachael Lamb, Graeme Webb

The importance of infant feeding practices to an adult's long-term physical health are of relevance to all health professionals, not just those involved with the care of the newborn and young child. Feeding is also an important part of establishing a supportive social environment for children, many aspects of which have long-term effects. This paper reviews some of the benefits of a mother's own milk, unpasteurised donated milk and pasteurised human milk supplied through a milk bank. The Christchurch Neonatal Unit opened their Human Milk Bank in 2014 and are now pasteurising over 500 litres per year. This milk is provided to support women as they develop their own milk supply during the first week after the birth of their preterm baby.

The primary healthcare claims to the Waitangi Tribunal

Gabrielle Baker, Jo Baxter, Peter Crampton

Over the past 40 years, primary healthcare policy in New Zealand has developed in a context of competing political, social, economic and professional forces. Among these competing forces, since the early 1980s Māori aspirations for full participation at all levels in the system, from governance to service delivery, have become increasingly prominent. Māori participation has included active contribution to and influence within health policy debates, and a growing presence in the ownership of primary healthcare provider organisations.[1,2]

The recent commencement of a kaupapa inquiry into health services and outcomes by the Waitangi Tribunal, starting with primary healthcare claims,[3,4] marks the opportunity for the Tribunal to make a highly significant contribution to health policy formation.

Background: the Waitangi Tribunal

The Waitangi Tribunal has a unique role in New Zealand's legal system. Its existence is predicated on the foundational significance of the Treaty of Waitangi in New Zealand's (unwritten) constitution. The constitutional relationship between the two parties to the Treaty—the Crown and Māori—is defined by the Treaty. The Tribunal was established in 1975 as an independent permanent commission of enquiry following the passage of the Treaty of Waitangi Act (1975).[5] Its primary purpose is to receive and report on claims of alleged Crown breaches of the principles of the Treaty of Waitangi, and make recommendations on the practical application of the principles of the Treaty relating to those claims. Its jurisdiction was initially limited to claims dating from 1975 onwards, but in 1985 the Act was amended to allow claims dating back to the time of the signing of the Treaty of Waitangi on 6 February 1840. In summary, the Tribunal's function is to provide an independent, impartial, public and accessible forum for Māori to bring allegations of Crown breaches of Treaty principles (Section 6 of the Treaty of Waitangi Act 1975 outlines the jurisdiction of the Tribunal to consider claims). These alleged breaches result from acts of commission or omission by the Crown that result from legislation, Crown policies or practice.

Each Tribunal makes a determination on which principles of the Treaty of Waitangi it should apply to the claims before it, so does not have a master list of principles to be applied. Table 1 sets out the principles often used by the Tribunal and the Treaty principles referenced in health sector documents.

The members of the Tribunal include a chairperson, Māori Land Court judges, plus others, comprising roughly equal numbers of Māori and Pākehā.[5] In carrying out its work the Tribunal must take account of both the Māori and English language versions of the Treaty.[5] On concluding its deliberations in any particular hearing the Tribunal can make non-binding recommendations that the Crown must consider. That is to say, however significant a breach may be judged to be by the Tribunal, it cannot force the Crown to take action, it can only recommend.

There continues to be considerable debate and contention around the intentions of the Māori language and the English language versions of the Treaty, which have very different meanings.[9] The Tribunal considers the Treaty to embody the principle of reciprocity that balances the Crown's right to govern, kāwantatanga (acquired in article one of the Māori language version of the

ISSN 1175-8716

Table 1: Treaty principles used by the Tribunal and those referenced in health sector documents.

Treaty Principles from the Waitangi Tribunal*	Treaty Principles used in the health sector**
Partnership	Partnership
Reciprocity	Participation
Autonomy	Protection
Active protection	
Options	
Mutual benefit	
Equity	
Equal Treatment	
Redress	

*Derived from Te Tau Ihu District Inquiry (2008) by the Waitangi Tribunal http://www.waitangitribunal.govt.nz/treaty-of-waitangi/principles-of-the-treaty/ (accessed 14 May 2019); Reid et al 2017.[6]

**Derived from the Royal Commission on Social Policy (1988) and referenced in the New Zealand Health Strategy (2000)[7] and He Korowai Oranga (2014);[8] Reid et al 2017.[6]

Treaty), and the Māori right to retain sovereignty, tino rangatiratanga (retained in article two of the Māori language version) (see Figure 1). It is this principle of reciprocity that the Tribunal considers to be the over-arching guide to the interpretation and application of other principles.[5] The Tribunal's interpretation can be contrasted with that of the courts: while the Tribunal's position may be summarised as meaning that kāwantatanga is subject to rangatiratanga, the Court of Appeal argues that rangatiratanga is subject to kāwantatanga (see Figure 1).

To date, the Tribunal has prioritised historical claims on a district-by-district basis. For claims that didn't fit with this approach, for example because they are national in scope, the options have been to try and have claims heard under urgency or to wait. For those claimants who were waiting, the impasse was broken in 2015 when the Waitangi Tribunal Chairperson, Chief Judge Isaac, issued a memorandum on how the Tribunal would tackle the large number of unheard claims by 2025—by grouping them into 11 thematic, or kaupapa, inquiries (Table 2).[10] 'Health services and outcomes' is one of the 11, and itself subsumes over 200 individual claims that relate to health services and outcomes.

This is not the first time the Tribunal has considered the Crown's obligations in relation to Māori health. In the Napier Hospital and Health Services claim the Tribunal looked into a range of issues including the claim of a general Crown obligation deriving from the Treaty to provide for the health and wellbeing of Māori. In its 2001 report the Tribunal found "that, in

Figure 1:

Kāwantatanga, tino rangatiratanga and taonga

Kāwantatanga means government. Kāwana is a transliteration into Māori of the English word governor.

Tino rangatiratanga means absolute sovereignty.

The text from the Napier Hospital Report[12] reads: "There are significant differences between the two texts. In particular, in the Maori text the chiefs ceded 'kawanatanga katoa' (complete government) rather than 'sovereignty'. They were guaranteed 'tino rangatiratanga' (the unqualified exercise of their chieftainship) over their 'taonga katoa' (all their treasures, or valued possessions) rather than 'other possessions'. 'Taonga' has a broader meaning than physical assets and, according to Sir Hugh Kawharu, refers to 'all dimensions of a tribal group's estate, material and non-material'. The Maori version of the Treaty thus conveyed more complex meanings, and a sense of mutuality."

See Orange C. The Treaty of Waitangi. 2nd ed. Wellington: Bridget Williams Books, 2011 (p.47-) for a fuller discussion of the above terms.

Table 2: Topic areas covered by kaupapa inquiries undertaken by the Waitangi Tribunal.

Military veterans
Constitution, self government and electoral system
Health services and outcomes
Marine and coastal (Takutai moana)
Mana wāhine
Education services and outcomes
Identity and culture
Natural resources and environmental management
Social services, social development and housing
Economic development
Justice system
Citizenship rights and equality

Source: http://waitangitribunal.govt.nz/inquiries/kaupapa-inquiries/ (accessed 21 February 2019);[10] The Chairperson. Memorandum of the Chairperson concerning the Kaupapa Inquiry Programme 27 March 2019.[11]

failing since 1980, and more particularly from 1993 to 1998, to address with urgency the improvement of the health status of Ahuriri Maori, the Crown and its health agencies have breached the principles of *active protection* and *equity*".[12] Consistent with the views of many health professionals at the time, the Tribunal considered the introduction of health reforms introduced through the New Zealand Public Health and Disability Act 2000 offered some hope for long-term change.

The primary healthcare claims

The Tribunal has opted to hear the health claims in tranches, and the hearings for the first tranche, which related to two specific primary healthcare-related claims, commenced in October 2018.

The two claims covered by the first primary healthcare-focused stage of the inquiry were: Wai 1315 claims (with two groups, Taitimu Maipi with Hakopa Paul and Tureiti Moxon with Janice Kuka), and Wai 2687 (led by Simon Royal and Henare Mason, and supported by the National Hauora Coalition, the largest Māori-led PHO in the country).

Although each of these claims had its own distinct areas of focus and grounds for concern, their shared views included the contention that the way the Crown has designed and run primary healthcare services constitutes a breach of the principles of the Treaty. The claimants shared their disappointment in the implementation of the primary healthcare reforms that introduced Primary Health Organisations (PHOs) in the early 2000s, and promised a focus on 'reducing inequalities' and support for Māori and Pacific provider development.

Included in the evidence presented in the Tribunal by a witness for the claimants[13] was the central thesis that the 2001 Primary Health Care Strategy[14] was a strong piece of policy making that, along with its associated reforms, had a lot of hope attached to it. But the promise of the Strategy in terms of equity has not been realised in its implementation. From the beginning, the stated aim of the Strategy was to address inequity, but there were always risks that the building blocks and the way the reforms were implemented would not achieve health equity, particularly for Māori. Some of these risks were identified early in the implementation process (for example see Hefford et al[15]), but effective remedial actions were not taken.

For example, the evidence stated that at the time of the Strategy, as now, New Zealand experienced significant and enduring health inequities in relation to both ethnicity and socioeconomic deprivation. The most consistent and compelling ethnic inequities are between Māori and non-Māori. The Māori population in the 2001 census constituted 15% of the total population. Life expectancy for Māori was about nine years less than for other New Zealanders (non-Māori, non-Pacific populations). In 2002, mortality for Māori at all ages exceeded other New Zealander mortality. A large number of the excess deaths were considered avoidable, and the avoidable mortality rate for Māori was more than twice that of other New Zealanders.[13] Witnesses also highlighted health inequities resulting from inequitable access to the determinants of health that privilege non-Māori as well as the legacy of colonisation and historical trauma.[16] An expert witness for the Crown drew attention to the lack of equity analysis at the time the

Strategy was written, which might have identified the need for additional plans or policies to make the Strategy more effective for Māori.[17] Having set the scene, the evidence went on to describe how the Primary Health Care Strategy's aim was to redesign the primary healthcare system to have, as a guiding principle, an explicit focus on reducing health inequities. The evidence then described how some key aspects of the Strategy have not been fully implemented and, at least partly as a result of this implementation failure, some of the Strategy's desired outcomes have not been achieved—particularly those outcomes related to equity of health outcomes for Māori, Pacific and low-income populations.

The Tribunal received extensive evidence from claimants that encompassed lived experience in the primary health sector and research on the causes, nature and extent of Māori health inequity. Included in this evidence were arguments of continued health system inaction in the face of demonstrated Māori health need, as well as calls for a health system founded on mana motuhake (Māori self-government).[18] There was also substantial Crown evidence, for example that of the Director General[19] and of Brooking,[20] presented to the Tribunal, much of it open about the need for the Crown to do more to respond to Māori health outcomes. For example, the Director General, Dr Bloomfield, stated in his evidence the primary health framework "has not sufficiently ensured good health outcomes for Māori nor enabled effective Māori participation".[19] This paper makes no attempt to summarise that evidence, or the diversity of issues that were raised. Rather, by way of summary, we determine that the claimants and witnesses wished certain conclusions to be drawn from the evidence. Those conclusions included that New Zealand's system of providing primary healthcare services, despite some courageous policies, does not fully meet the needs of all populations. Specifically, in respect of Māori, this fact, along with the resulting health inequities, represents a breach of the Crown's Treaty obligations.

The Tribunal's findings to date

The Tribunal released its report—*Hauora*—on the primary healthcare claims on 1 July 2019.[21] The Tribunal found that a number of principles of the Treaty had been breached by the Crown in respect of primary healthcare. The report also provides a critique of the Treaty principles of partnership, participation and protection used in the health sector, instead setting out a more comprehensive set of principles it considers applicable to the primary healthcare system (Table 3).

Table 3: The Waitangi Tribunal's recommended Treaty principles for the primary healthcare system.

The guarantee of tino rangatiratanga, which provides for self-determination and mana motuhake in the design, delivery and monitoring of primary healthcare.
The principle of equity, which requires the Crown to commit to achieving equitable health outcomes for Māori.
The principle of active protection, which requires the Crown to act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that it, its agents and its Treaty partner are well informed on the extent, and nature of, both Māori health outcomes and efforts to achieve Māori health equity.
The principle of options, which requires the Crown to provide for and properly resource kaupapa Māori primary health services. Furthermore, the Crown is obliged to ensure that all primary healthcare services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.
The principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery and monitoring of primary healthcare services. Māori must be the co-designers, with the Crown, of the primary health system for Māori.

Source: Waitangi Tribunal. HAUORA, Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry, Pre-publication version, WAI 2575 WAITANGI TRIBUNAL REPORT 20192019 14 July 2019. Available from: http://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150429818/Hauora%20Pre-PubW.pdf (accessed 14 July 2019).

This paper does not attempt to summarise all the many findings of the Tribunal in its *Hauora* report. However, it is worth noting two of the main recommendations to the Crown. The first is to amend the Treaty of Waitangi clause in the New Zealand Public Health and Disability Act 2000, as a first step to ensuring that the primary healthcare system recognises and provides for the Treaty of Waitangi and its principles. The second is for the Crown to commit to achieving equitable health outcomes for Māori, and to reflect this in legislation. The Crown should leave behind the frequently used language of 'reducing disparity' or 'reducing inequality', and ensure more system-wide accountability for its equity goals. The Tribunal's recommendation here is informed by its findings that, despite the initial intentions of the Primary Health Care Strategy, primary care funding has become "anti-equity in practice", that Māori providers have been underfunded from the outset, and that the Crown does not collect, use or make readily accessible data that track its performance in achieving health equity.

As a consequence of the Tribunal having only heard from two claimants in stage one of the kaupapa inquiry, some of its recommendations are interim. These include an interim recommendation to explore the possibility of a stand-alone Māori health authority of some kind. The Tribunal has asked the Crown to work with the primary healthcare claimants and report on progress in January 2020.

The Tribunal has indicated that its second tranche of hearings will include claims pertaining to mental health, disabilities, addictions and substance abuse, and will be underway towards the end of 2019.[22]

What might this mean for New Zealand's health system?

The Waitangi Tribunal process is extraordinary in that it provides Māori, the indigenous people of Aotearoa, with the opportunity to speak their truth and to hold the Crown to account in respect of governance and delivery of health services that meet the Crown's Treaty obligations to Māori individuals, whānau and communities. In respect of the health kaupapa inquiry, even though the process is highly legalistic and inquisitorial in nature, it represents a legal process that allows Māori to take concerns to the Crown regarding alleged acts of omission and commission in the provision of health services.

During the process of the health kaupapa inquiry the Tribunal members will continue to receive and synthesise a huge amount of complex information, and their recommendations will be based on the evidence put before them. The delivery of health services is centred around human relationships, and the New Zealand health system has had for a very long time the opportunity to construct a relationship with Māori that represents a beholden partnership in the design, governance and delivery of health services that meet the needs of Māori individuals, whānau and communities. Thus far in our history this opportunity has not been properly grasped. The Waitangi Tribunal's findings may well provide renewed impetus for the health system to reconstruct its relationship with Māori in a way that gives expression to the aspirations of both Māori and the system, and to push hard towards equitable health outcomes.

ISSN 1175-8716

Competing interests:
Dr Crampton is a member of the Government's Health and Disability System Review panel; the views expressed here are his own and not those of the panel. Ms Baker reports personal fees from National Hauora Coalition outside the submitted work; and has a contract with one of the primary healthcare claimants to the Waitangi Tribunal, the National Hauora Coalition, to provide advice. This contract did not cover any aspect of the preparation or writing the of this article.

Acknowledgements:
We would like to acknowledge the helpful and insightful comments made by colleagues on earlier drafts of this paper, and by the anonymous reviewers of the paper. We take full responsibility for any errors or omissions in, or for the correctness of, the information contained in this paper.
There was no external funding source for preparing this article. The views, opinions, findings and conclusions or recommendations expressed in this paper are strictly those of the authors. They do not necessarily reflect the views of the institutions where the authors currently work. The paper is presented not as policy, but with a view to inform and stimulate wider debate.

Author information:
Gabrielle Baker, Independent Contractor; Jo Baxter, Kōhatu, Centre for Hauora Māori, University of Otago, Dunedin; Peter Crampton, Kōhatu, Centre for Hauora Māori, University of Otago, Dunedin.

Corresponding author:
Ms Gabrielle Baker, Independent Contractor.
gabrielle@bakerconsulting.co.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8036

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What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?

Eileen M McKinlay, Serena V Moran, Sonya J Morgan, Pakize Sari, Jill M Kerridge, Susan RH Pullon

ABSTRACT

AIMS: New Zealanders dying in public hospitals or hospices are increasingly being discharged and a*dmitted-to-die* in aged residential care (ARC) facilities as hospitals and hospices struggle to meet demand. This study sought to investigate how care is delivered to patients *admitted-to-die* in an ARC facility.

METHODS: A mixed-methods case study including a clinical notes review of seven patients who died in one ARC facility within three months of admission and a focus group with ARC facility staff and visiting professionals from other organisations.

RESULTS: The clinical notes review showed a high burden of palliative care symptoms that constituted specialist palliative care, provided by ARC staff plus professionals from other organisations. Focus group data showed those involved were willing, but expressed significant concern about lack of structure and funding.

CONCLUSIONS: As our increasing and aging population reaches end-of-life, New Zealand hospitals/hospices will not be able to provide ongoing specialist palliative care and *admission-to-die* in ARC facilities may be a viable alternative. However, ARC facilities are not set up or staffed to provide specialist palliative care of those *admitted-to-die*. A specific model of care that is funded appropriately is required.

Increasing numbers of people in New Zealand are a*dmitted-to-die* (die within three months of admission) in aged residential care (ARC) facilities, including those under 65 years.[1] These patients appear to be coming mainly from public hospitals and hospices. The public hospital environment is considered inappropriate and costly for those dying over weeks to months of incurable illness, and hospice capacity is increasingly strained.[2–4] These facilities are under increasing pressure to free up inpatient beds for acute or urgent care[5,6] and to manage demand they are discharging patients into ARC facilities, who are *admitted-to-die*.

In New Zealand, Boyd et al first signalled this trend in 2009 showing 12.4% of all ARC residents had an average length of stay less than three months[7] and Connolly, Broad, Boyd, Kerse and Gott found 6.7% of those transferred from public hospital to ARC died within a week and 16.3% died within a month (p.114).[8] Broad, Gott, Kim, Boyd, Chen and Connolly suggested "the relatively small percentage of deaths in hospital and high percentage in residential aged care may be due to discharges of older people from acute hospital care into residential aged care near the end-of-life" (p.262).[9]

In 2013, 38% of New Zealand deaths occurred in ARC facilities[9] and in 2019 the McLeod and Atkinson study confirmed the increased numbers dying within three months of admission to ARC: "43.7% of those with an ARC subsidy have their first admission less than one year before death

and 24.3% are admitted for the first time in the last three months of life" (p. 6).[1] The study also shows that generally more people die in ARC facilities with chronic illnesses and dementia than from cancer, however those admitted in the last three months of life have a different illness/disease profile, with 15.9% dying from dementia, 24.0% from chronic disease and 63.0% from cancer. The Boyd et al 2019 study shows people in ARC in the last week of life with chronic illness, dementia or cancer have a similarly high symptom burden as those in other settings, and those with chronic illness or dementia have symptoms for longer than those with cancer.[10]

The Ministry of Health (MoH) Healthy Aging policy calls for "flexible aged residential care services that suit the needs of the increasingly diverse older population" (p.37).[11] This includes the provision of palliative care for ARC residents as they eventually reach end-of-life, and this has been accepted practice in ARC facilities for many years.The policy advocates for palliative care from a "primary healthcare workforce… trained in core palliative care practices,… to meet people's palliative care needs… (with a) specialist palliative care workforce to provide specialist clinical care". The distinction between *primary (generalist)* and *specialist* palliative care providers has been defined and re-defined over the years, suggesting either an evolving service delivery model or difficulty in reaching agreement.[12–14] However, there seems agreement that patients admitted to public hospitals and hospices with palliative care needs require *specialist* palliative care and those cared for in other settings require *primary (generalist)* palliative care. However, it is unclear what level of care people with complex palliative care needs require when *discharged to-die,* from public hospitals or hospices into ARC facilities.

Introducing significant numbers of imminently dying patients with complex palliative care needs from hospital and hospices into the ARC environment is problematic as staffing levels differ between hospitals, hospices and ARC facilities. In New Zealand, the Health and Disability Services (Safety) Act (2001)[15] and the Health and Disability Service Standards (2008)[16] specify minimum requirements for the staffing of public hospitals and ARC facilities. Boyd et al reported in 2009 that registered nurse staffing levels in ARC facilities, although compliant, were low[7] and this finding has been subsequently supported.[8,17,18] The current ARC staffing model (predominantly caregivers with few registered or enrolled nurses and various models of contracted medical care)[17] does not easily allow for the increased acuity of and rapidly changing needs of people *admitted-to-die* with complex palliative care needs.[19] These people often need ready access at short notice (including after-hours) to an advanced range of skills, equipment and services beyond the level of care that ARC facilities are set up or currently funded to provide.[19,20]

In New Zealand, people are usually financially and asset assessed for entry to ARC and those with reduced incomes and minimal assets are eligible for publicly funded care.[14] Some district health boards (DHBs) have non-asset tested funding available for people with limited prognosis being *admitted-to-die* in an ARC facility but other DHBs do not have this and assess those *admitted-to-die* by the same needs assessment criteria as for age-related need,[21] meaning they have to pay for palliative care.

In all, ARC facilities now have an increasingly ambiguous role in palliative care provision with some calling them "de facto hospices".[8] They are now asked to admit the imminently dying, from hospital or hospice,[9] as well as providing their core business; the 24-hour residential *home-for-life* care of older adults.[16] This rapidly changing situation has had remarkably little investigation, either in New Zealand or elsewhere. Given deaths are projected to rise in New Zealand from around 30,000 a year to 55,500 a year by 2068[13,22] and the need for palliative care has been estimated to be required for over 80% of deaths in 2038, it is essential to explore and determine how *specialist* palliative care is to be delivered in ARC if it cannot be provided in public hospitals or hospices.[23]

This study sought to describe the features and clinical care of a purposive sample of patients *admitted-to-die* in a single ARC facility.

Methods

Design and setting

A single-case study (one ARC facility) with embedded cases (seven deceased people), using multiple data collection methods was used to generate an in-depth account.[24,25] Case study research was considered the most suitable approach with each 'case' serving as a sub-unit of analysis, thus allowing for naturally occurring/real-life cases to be explored individually, and for comparisons to be made between and across cases.

The ARC facility chosen for the study (a 150-bed facility run by a charitable trust offering rest home, hospital and dementia-level care) was selected as a recognised provider of high-quality aged residential care and palliative care, and often approached by the public hospital and hospice to admit those who are dying. By studying the delivery of palliative care for those *admitted-to-die* in an ARC facility with an already good reputation, the features of care provided, including strengths/enablers and barriers could be closely examined.

Ethical approval to undertake the study was granted by the University of Otago Ethics Committee (HD17/071).

Participants and data collection

Data collection (between 21 March and 22 August 2018) occurred in three phases (see Figure 1). Phase one: the background issues were initially informed by views from ARC staff and relevant hospice and DHB staff, as identified by the ARC facility. This took the form of an initial information gathering, 1.5 hour, audio-recorded discussion group with ARC facility staff and staff from external organisations and a subsequent one-hour audio-recorded individual interview with the ARC general manager.

Phase two: a retrospective clinical notes review[26] was undertaken of seven deceased people who had been *admitted-to-die*. A purposive sampling method guided the selection of cases with ARC facility staff asked to identify those admitted in 2017 who met the following criteria: 1) specifically *admitted-to-die* in the ARC facility from either a public hospital or hospice and died within three months of admission and 2) required care in the ARC facility from at least one professional external to the ARC facility, such as DHB health professionals, contracted health professionals and/or hospice nurses and doctors (this thus meeting the definition for specialist palliative care). Admission from a public hospital or hospice where the person had received palliative care and the ongoing need for interprofessional care in an ARC facility from more than one organisation signalled that the case required *specialist* palliative care.

The ARC staff were given the inclusion criteria and they selected all charts which met the criteria, identifying the cases *admitted-to-die* from hospital and hospice discharge summaries. The 12 sets of clinical notes were de-identified and copies provided to researchers so that they had no access to patient identifying information. The notes of the cases were reviewed by EM and SVM and data extracted according to a template developed by the researchers and informed by the literature, the first discussion group and individual interview. Information collected included: demographic and illness information; symptoms and day-to-day progression/deterioration, details of the clinical care and medicines given, who provided care and what input they had, details about the response to care and treatment. The template was tested with the first set of clinical records, and the categories and template were refined to include the most relevant information.

Using a diversity sampling framework,[27] seven cases (58%) were selected to include those over and under 65 years, varying lengths of time from admission to death, different ethnicities and varying involvement by external professionals. An overview is presented in Table 1.

Of the seven, two were purposively selected as best representing issues identified across all the cases (including one over and one under 65 years old) and having clinical details which would not be recognised. The cases were considered by the research team members from the ARC facility as being mid-range complexity. Phase three: an audio-recorded, 1.5-hour focus group with ARC facility and external professionals involved in the care of one or both of the two selected cases to allow more in-depth exploration of issues impacting the delivery of palliative care to this group of people (Table 2).

Table 1: Overview of the seven cases included in the clinical notes review.

Gender	4 females, 3 males
Age	5 over 65 years, 2 under 65 years
Ethnicity	3 NZ European, 2 Māori, 1 British and 1 unreported
Time from admission to death	1 under 2 weeks 3 between 2–4 weeks 2 between 4–6 weeks 1 over 6 weeks
Number of professionals external to the ARC facility involved	3 under 3 external professionals involved 4 over 3 external professionals involved
Multimorbidities (MM) (including palliative care symptoms)	arthritis, ascites, asthma, bipolar disorder, borderline personality disorder, cachexia, cataracts, diabetes, faecal incontinence, 'falls', Gilbert's Syndrome, gout, hepatitis C, hyperlipidaemia, hyperparathyroidism, hypertension, hypothyroidism, ischaemic heart disease, renal failure, schizophrenia, scoliosis, substance abuse

Table 2: Focus group participants involved in the care of one or both selected cases.

ARC facility staff	
	1 Clinical Manager 2 Registered Nurses 1 Caregiver 2 GPs[1]
Professionals external to the ARC facility	
Hospice	1 Former Hospice ARC liaison nurse[2] 2 Doctors[3] (1 a former ARC GP)
DHB	1 DHB ORA liaison nurse[4]
Contracted private professionals	1 Physiotherapist 1 Podiatrist

[1]This ARC contracts GPs to provide medical services and considers them to be staff.[17]
[2]Hospice ARC liaison nurses are employed by hospices to provide consultancy services to ARCs for patients with palliative care needs. Funded by MoH Innovations Funds.[28]
[3]Hospice doctors provide phone consultancy services to ARC staff (including phoning ARC GPs when not on site) for patients with palliative care needs. They sometimes visit patients in ARC facilities.
[4]DHB ORA liaison nurse: a liaison nurse from the DHB Older Adult Rehabilitation & Allied Health Services.

A single semi-structured focus group question guide informed by the literature, the first discussion group and individual interview was developed by the research team and covered the following topics: who, when and how does each professional contribute to the care of those *admitted-to-die*; perceptions of this form of collaborative care; and what enables or acts as barriers to successful collaboration between services/professionals/organisations when patients are *admitted-to-die*. The focus group was jointly facilitated by EM and SP who are clinicians by background and have worked in palliative care delivery.

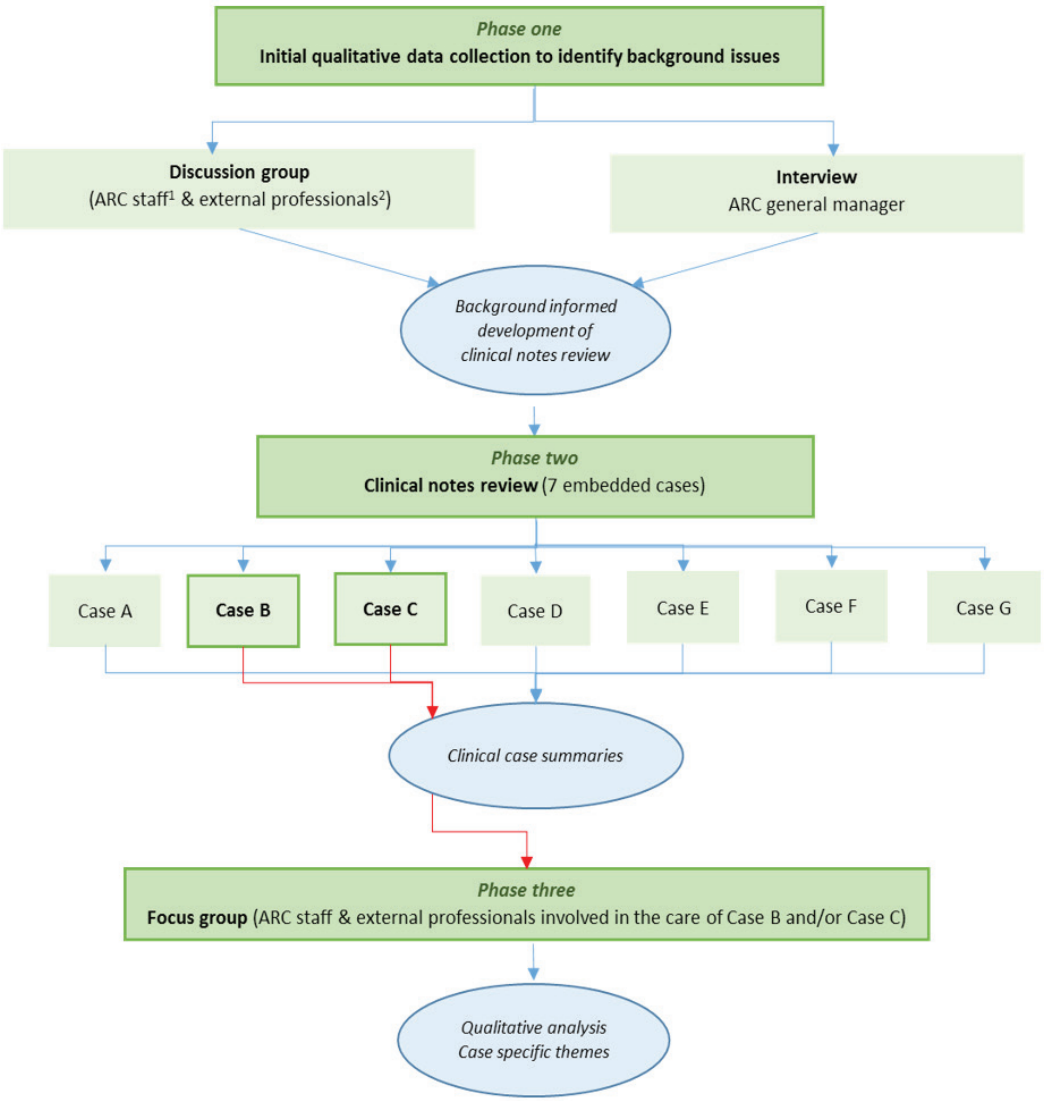
Discussion group and focus group participants were sent study information when initially invited to participate and they signed consent forms prior to taking part. The Otago University ethics committee considered the retrospective clinical notes review to be a review/audit of de-identified deceased patient records and given likely distress raised by approaching whānau (*Māori word for family group—Māori are the indigenous ethnicity in New Zealand)* determined that whānau consent should not be requested.

Data analysis

Analysis of data proceeded sequentially and iteratively (Figure 1), utilising case study method which emphasises the importance of the cases being examined in their real-world context. Case selection is undertaken according to the purpose and theoretical interest of the research. In the study this was initially informed by the preliminary discussion group and individual interview and following case data extraction and summarisation, discussed in an interprofessional, interorganisational focus group.[24,25]

An inductive thematic process guided the analysis of all the transcribed qualitative data with transcripts first coded by one researcher (EM) and then peer-reviewed by another (SJM) and inconsistencies or alternative views resolved. Analysis of the first group discussion and individual interview informed development of the clinical notes data extraction template, which was refined after testing with the first set of clinical records. Two researchers (SVM & EM) extracted data for the first three cases, with SVM extracting data for the remaining

Figure 1: Data collection and analysis sequence.



[1]ARC staff included nurses, caregivers, diversional therapists, spiritual care provider, general practitioner, clinical manager, general manager.
[2]External professionals included: Professionals from external agencies: hospice professionals (former ARC liaison nurse and palliative medicine specialist doctor); DHB professionals (speech language therapist, Older Adult Rehabilitation & Allied Health Services (ORA) liaison nurse; Private contracted professionals (community pharmacist, community physiotherapist).

Table 3: The seven cases.

Case	Age range	Time: admission to death	Diagnoses & number of multimorbidities (MM)	Admitted from	Reason for admission (as recorded in the hospital and hospice discharge summaries)	Enduring Power of Attorney (EPOA)	Advance Care Plan (ACP)	Public hospital admissions since ARC admission	Professionals involved: external organisations or private contractors (external professionals)
A	70–75 yrs	39 days	Renal failure + 5 MM	Public hospital	Needed a higher level of care	Yes	No (NFR[1] in hospital discharge plan)	DHB outpatients	DHB: renal, plastics, dental Hospice: ARC liaison nurse[2] 3 doctors[3], & social worker
B	85–90 yrs	27 days	Metastatic cancer + 4 MM	Home	Increasing abdominal pain & whānau concern	No	Yes	0	DHB: district nurse Hospice: 2 ARC liaison nurses Reflexologist
C	55–60 yrs	86 days	Metastatic cancer + 9 MM	Public hospital	Ongoing care	Yes	Yes (3 days before death)	2	DHB: ORA liaison nurse[4] & oncologist Hospice: ARC liaison nurse & doctor Physiotherapist Podiatrist
D	85–90 yrs	10 days	Unconfirmed metastatic cancer (late presentation); breast cancer + 3 MM	Public hospital	Ongoing care	In process during admission	Not recorded	0	Hospice: ARC liaison nurse Physiotherapist
E	75–80 yrs	21 days	Metastatic cancer + 2 MM	Hospice	Respite & symptom control	Yes	Not recorded	0	DHB: district nurse Hospice: ARC liaison nurse
F	50–55 yrs	23 days	Metastatic cancer +2 MM	Hospice	Not able to cope at home	Not known until just prior to death	Not recorded	0	DHB: mental health nurse & mental health worker Hospice: ARC liaison nurse & doctor
G	85–90 yrs	35 days	Unconfirmed metastatic cancer (late presentation) + 4 MM	Another ARC facility	To be closer to whānau	No	For active treatment as per whānau wishes. No personal ACP recorded	2	DHB: 'CAREFul Team'- for frail elderly[5]

[1]Not for resuscitation.
[2]Hospice ARC liaison nurses are employed by hospices to provide consultancy services to ARCs for patients with palliative care needs. Funded by MoH Innovations Funds.[28]
[3]Hospice doctors provide phone consultancy services to ARC staff (including phoning ARC GPs when not on site) for patients with palliative care needs. They sometimes visit patients in ARC facilities.
[4]DHB ORA liaison nurse: a liaison nurse from the DHB Older Adult Rehabilitation & Allied Health Services.
[5]The DHB CAREFul team (Caring for the At-Risk Elderly person who is Frail) is a specialist interdisciplinary team for the frail elderly.

four cases. A clinical case summary was produced for each case and each was discussed by the research team, with two cases chosen as representative. Analysis of the focus group data determined case-specific themes. In the final stage of analysis all data for the case study was reviewed, triangulated, integrated and synthesised and a summary of key issues identified.

Results

Background interviews

The initial individual interview with the general manager and a discussion group interview with interorganisational staff determined the key issues to include in the data extraction template.

Clinical notes review

The clinical notes included: day-to-day nursing records per eight-hour shift by ARC facility nursing and caregiving staff; separate records for: ARC diversional therapy and some external professionals (medical progress notes and visiting therapist records); letters from some external professionals. The private contracted physiotherapist and hospice doctors or liaison nurses wrote in either or both of the day-to-day nursing records and the medical progress notes—or interchangeably. This was not uniform, making information hard to find. The day-to-day nursing records by ARC staff detailed the physical symptoms, less so the psychosocial, existential or cultural symptoms/needs and even less the needs of whānau. In situations where symptoms were challenging or poorly controlled or distress was evident (person and/or whānau), it was not unusual for there to be several pages of notes relating to one 24-hour period. In these instances the Clinical Manager often recorded her input (including from extra visits she made in the weekend or after-hours).

Key details of the seven cases (Table 3) and the day-to-day records of the two typical cases are presented in Tables 4 and 5.

Views of ARC staff and external professionals of the care of specific cases *admitted-to-die* in ARC

Analysis of the data from a focus group with ARC staff and external professionals revealed five key themes:

Willing—'but'…

Both ARC staff and external professionals were willing to provide care, however they qualified their willingness with a 'but'. This qualification was a response to several barriers: lack of time associated with ARC funding limitations; no leader/key worker to provide continuity/liaison/coordination; lack of shared electronic records and no structure or funding to plan proactive care for those *admitted-to-die*.

"in the afternoon it's very difficult, sometimes you get three palliative cases, they all have syringe drivers; three syringe drivers to be monitored by one nurse. And sometimes one syringe driver plays up and sometimes the other syringe driver needs to be recalibrated. That's already three patients and how about my 30 patients who need their regular medications. And family members visit in the afternoon waiting for you. And you want to sit with this patient who is actually dying…" (ARC RN 1)

"It's the resource thing… families [think]*… hospice and hospital are free… I… say to them… the hospital gets $2,000 a day for a bed…* [but] *ARC gets $130 and they are supposed to provide the same level of care."* (ARC GP 2)

Environment and resident-mix mismatch

Meeting the needs of both the over-65 years and the under-65 years was challenging. Those under 65 years were often disenfranchised from whānau or had complex psychosocial needs. The ARC facility physical layout did not suit complex palliative care for either under- or over-65 year-old patients so as to enable close but private monitoring of patients and space for family to visit, but with seclusion from older adults who call-out or exhibit wandering behaviours.

"…[he] *was very complex for an aged care facility because he's got a lot of psychosocial issues… he has got some possibly mental health issues that our caregivers are not trained to deal with and even ourselves who are so used to dealing with older people all of a sudden the younger person with different needs mental health needs, physical… And… he was having severe pain and looking at the physical, the psychosocial, he must be having a bad time, with all that pain."* (ARC RN 2)

Table 4: Case B clinical notes review: day-to-day palliative care delivery (over 65 years).

Interprofessional cross organisational team meetings: nil.

Number of/reasons for ARC GP visiting patients: x9 in 27 days (initial assessment of symptoms, ongoing assessment of pain, nausea and constipation). One recorded phone discussion between ARC staff and the GP.

Number of/reasons for contact by professionals external to the ARC facility:
DHB district nurse x1 in 27 days (advice on timing of Fentanyl patches).
Hospice ARC liaison nurse x3 in 27 days (review admission to ARC, management of pain and nausea, follow-up). One ARC request for advice from ARC liaison nurse in week 3 but not responded to.
Hospice doctor x1 phone contact from Hospice ARC liaison nurse (discussion about use of anti-nausea medicine).
Reflexologist x1 in 27 days.

Regular medicines (*list of all medicines prescribed over the 27 days—changes to combination and doses of medicines in this time*): colecalciferol, cyclizine, docusate sodium with senna, domperidone, fentanyl (patches), metoprolol, omeprazole, ovestin, paracetamol, simethicone
PRN medicines: x148 prns in 27 days clonazepam, cyclizine, docusate sodium with senna, hyoscine butylbromide, lactulose, midazolam, morphine sulphate injectable, morphine sulphate tablets
PRN opiate analgesia given within last two weeks of life: morphine sulphate tablets x10 doses and subcutaneous morphine sulphate x18 bolus doses by indwelling subcutaneous needle.

Syringe driver: started 24hrs before death.

Week 1	Week 2	Week 3	Week 4: (six days)
Main problems: pain, sacral tenderness, indigestion, blister on one leg, swallowing difficulties	**Main problems:** pain, sacral pressure area, blisters on both legs, poor sleep	**Main problems:** pain, pressure areas, leaking blisters, fatigue, nausea, vomiting, constipation, bloating	**Main problems:** pain, several sacral pressure areas, many leaking leg blisters, nausea, low mood, agitation, anxiety, secretions, involuntary twitching
Recorded instances of patient reported unrelieved symptoms or distress: x18	**Recorded instances of patient reported unrelieved symptoms or distress:** x12	**Recorded instances of patient reported unrelieved symptoms or distress:** x19	**Recorded instances of patient reported unrelieved symptoms or distress:** x17
Recorded instances of family/whānau reported distress: nil	**Recorded instances of family/whānau reported distress:** nil	**Recorded instances of family/whānau reported distress:** nil	**Recorded instances of family/whānau reported distress:** x3
Team involved: **ARC facility professionals:** care givers, GP, clinical manager, physiotherapy assistant, RNs **External professionals:** DHB district nurse, hospice ARC liaison nurse	**Team involved:** **ARC facility professionals:** care givers, GP, clinical manager, physiotherapy assistant, RNs	**Team involved:** **ARC facility professionals:** care givers, GP, clinical manager, physiotherapy assistant, RNs **External professionals:** reflexologist	**Team involved:** **ARC facility professionals:** care givers, GP, clinical manager, physiotherapy assistant, RNs **External professionals:** Hospice ARC liaison nurse, hospice doctor

Table 5: Case C clinical notes review: day-to-day palliative care delivery (under 65 years).

Interprofessional cross organisational team meetings: nil. **Number of/reasons for ARC GP visiting patients:** x16 in 86 days (2 months 29 days) (initial assessment of symptoms, discussion of care with patient, changes in medication). Three recorded phone discussions between ARC staff and the GP. **Number of/reasons for contact by professionals external to the ARC facility:** **DHB ORA liaison nurse** x5 in 3 months (transport to the public hospital and support at consultations, general support, discussed ACP). **DHB Oncology specialist** x3 in 3 months (reassessment). **Physiotherapist** x1 in 3 months (supply of pressure relieving mattress). **Podiatrist** x2 in 3 months (assessment and treatment of foot infection). **Hospice ARC liaison nurse** x4 in 3 months (assessment, management of pain and constipation, follow-up). **Hospice doctor** x2 in 3 months (assessment plus a verbal order for syringe driver medicines). **Regular medicines** (*list of all medicines prescribed over the three months—changes to combination and doses of medicines in this time*): amlodipine, budesonide, dexamethasone, docusate sodium with senna, gabapentin, gefitinib, glycerine, haloperidol, levitiracetam, lorazepam, macrogol 3350 plus electrolytes, metoclopramide, morphine sulphate injectable, morphine sulphate suspension, morphine sulphate sustained release, morphine sulphate tablets, omeprazole, ondansetron, paracetamol, sertraline. P**RN Medicines:** x89 prns in 3 months: aluminium—magnesium hydroxide, lorazepam, macrogol 3350 plus electrolytes, morphine sulphate tablets, salbutamol **PRN opiate analgesia given within last 2 weeks of life:** x14 doses of morphine sulphate tablets additional to regular oral opiate. **Syringe driver:** started 24hrs before death.		
Month 1 **Main problems:** pain, constipation, 'declining' medication (analgesia and/or laxatives), behavioural issues, mood instability **Recorded instances of patient reported unrelieved symptoms or distress:** x15 **Recorded instances of family/ whānau reported distress:** estranged from family **Team involved:** **ARC facility professionals:** care givers, GP, clinical manager, RNs **External professionals:** DHB ORA liaison nurse; hospice ARC liaison nurse, hospice doctor, oncology specialist.	**Month 2** **Main problems:** 'declining' medication, pain, constipation, managing anxiolytic intake, behavioural support, mood instability, skin breakdown on foot **Recorded instances of patient reported unrelieved symptoms or distress:** x6 **Recorded instances of family/ whānau reported distress:** estranged from family **Team involved:** **ARC facility professionals:** care givers, GP, clinical manager, RNs **External professionals:** DHB ORA liaison nurse, hospice ARC liaison nurse, hospice doctor, oncology specialist, physiotherapist, podiatrist	**Month 3** **Main problems:** pain, constipation, skin breakdown on foot, anxiolytic intake, behavioural support, mood instability, poor mobility and unstable **Recorded instances of patient reported unrelieved symptoms or distress:** x33 **Recorded instances of family/ whānau reported distress:** estranged from family **Team involved:** **ARC facility professions:** care givers, GP, clinical manager, RNs **External professionals:** DHB ORA liaison nurse; hospice ARC liaison nurse, hospice doctor, oncology specialist, physiotherapist

High complex palliative care needs

Those in the focus group felt those *admitted-to-die* often have a short dying trajectory, a more rapid decline and often more intense and difficult to control symptoms compared with the end-of-life trajectory of the frail elderly residents.

"I do the sign-offs for residential care and they are coming in later, we do more and more hospital sign-offs as opposed to rest home level sign-offs and they are sicker when they come in… and staying at residential care shorter but they're more unwell when they get into residential care." (DHB ORA Liaison Nurse—for definition see Table 2)

"Now we can have people who go into aged residential care and within two weeks they're dead. You had no ability to establish a relationship with them or their family and it is, it's really hard." (Hospice Doctor 1)

Staff and external professionals needed to work swiftly and effectively to create a connection with patients and whānau and collectively manage complex needs. Despite complexity of those *admitted-to-die* in ARC facilities being similar to those in hospices, ARC staff numbers and skill-mix were noted to be quite different, particularly the lack of 24-hour access to GPs for medical assessment. ARC facility staff acknowledged they did not have the full range of specialist equipment or employ the same range of professionals or skill-sets as public hospitals or hospices.

"So since our [Hospice ARC liaison] *roles have been in place—the referrals* [requests from ARC] *have just become unsustainable,* [the Hospice ARC liaison service] *can no longer as a service sustain the amount of referrals… there's an overwhelming need for support because the complexity of care has risen so much."* (Hospice ARC Liaison Nurse—for definition see Table 2)

"The patients themselves are a lot more complex too though with your multi co-morbidities, you're having to deal with all sorts of medical issues that probably weren't dealt with in the past." (ARC RN Clinical Manager)

Person/whānau expectations of ARC care for those *admitted-to-die*

People being discharged or transferred from hospital or hospice *to-die* in ARC were reported as often having difficulty in accepting this. Often they (and their whānau) did not understand they were dying or have an advance care plan (ACP) or enduring power of attorney (EPOA) and they felt aggrieved at the ARC financial cost (if they did not meet the ARC asset and income threshold). ARC staff felt they were viewed as not as skilled in palliative care delivery as hospice or hospital staff. Participants (both ARC facility staff and external professionals) found they had to actively advocate for the skills of the ARC staff.

"We… [the ARC facility] *have residents that come in that don't accept that they are dying… So we'll get a discharge summary from the hospital saying this person is palliative but then when we go to start the conversations both the patient and the family have got a totally* [different] *idea about what we had initially thought."* (ARC RN Clinical Manager)

"Then there are those people [patients] *whose families don't agree that they're palliative and we've* [professionals] *not been part of the conversation before that and it makes it extremely difficult for us…"* (Contracted Physiotherapist)

How does the cross organisational model work for those *admitted-to-die?*

Participants described challenges in providing palliative care which involved input from several organisations and suggested improvements. ARC staff and professionals from other organisations felt their efforts to provide care were currently rather disjointed and sought a more explicitly collaborative role.

"What is needed… [is] *a certain repository of experience within a team of people like you have in a hospice within singular aged care facilities because I don't think the whole of* [the region's ARC facilities] *actually should be doing palliative care…* [For] *people who are going to die within three to six months I think you should designate* [an ARC] *and… increase their skills. So you've got…*[a] *group… and you have a team approach and you have the skills."* (ARC GP 1)

"If you don't [integrate with the ARC staff] *you're going to fail. And I think that our professional responsibility is to make sure we do integrate ourselves."* (Contracted Podiatrist)

Synthesis

In summary, the case reviews showed the group of people *admitted-to-die* in ARC facilities and who come from hospitals and hospices have high and complex palliative care needs caused by multimorbidity (MM), often including advanced cancer. In reality, akin to the interprofessional care provided by specialist palliative care providers (hospice, hospital palliative care team), people *admitted-to-die* in ARC (from hospital or hospice) continue to require interprofessional input from a broad range of health and social care professionals (ARC staff, private contractors or those employed by DHBs and hospice ARC liaison staff).

In the focus group, ARC staff and external professionals freely discussed undertaking huge and willing efforts to provide complex, interprofessional palliative care to the patient and whānau, some of whom (person and/or whānau) have not accepted the person is dying. In contrast to organisations funded to offer specialist interprofessional palliative care, they repeatedly described face-to-face and online communication among the staff and between the professionals from external organisations as being extremely limited by lack of time, resource and structure. Together, the synthesised data paints a rich picture of well trained, willing and committed staff, but poorly coordinated and significantly underfunded to provide care for patients and whānau with complex and urgent palliative care needs.

Discussion

This is the first New Zealand study to report the care of cases *admitted-to-die* within three months of admission in ARC, including those under 65 years. The study demonstrated a high burden of palliative care symptoms requiring what should be defined as *specialist* palliative care provided by ARC facility staff plus professionals from hospice, DHBs and private contractors. Those involved from other organisations were willing to be involved but expressed significant concerns about lack of ARC facility structure and MoH funding for the intensity this form of care required and largely operated through goodwill to support the ARC facility staff and the person and their whānau.

A strength of the single case study, multiple methods approach is the ability to combine a detailed clinical notes review with interview and the focus group data to provide a rich description of each patient's care over the course of their admission and thus enhance the credibility of the results.[29,30] A limitation is the singular focus on one ARC facility (known to be a recognised high-performing facility). Also, the study did not set out to explore or compare the palliative care of *home-for-life* residents who die from frail old age decline, or to compare the end-of-life symptoms of those in the *admitted-to-die* group with those dying in hospital or hospice. Neither did it explore the views of people *admitted-to-die* or their whānau. The study highlights areas for further research about ARC palliative care for the *admitted-to-die* group including the optimal use of 'on request/PRN' medicines for symptom control in ARC; impact of the palliative care work on ARC staff when balanced with the care of *home-for-life* residents; palliative care professional development requirements for ARC staff; particular needs of under-65 year-olds *admitted-to-die* in ARC; and perceptions by the public about ARC facilities being suitable places to be *admitted-to-die*.

This study adds to existing New Zealand research, which has signalled an increase in number of those *admitted-to-die* in ARC facilities.[1,7,23] The MoH Healthy Aging Policy acknowledged the need for *specialist* palliative care for those *admitted-to-die* "as we live longer, we can expect increasing numbers of people with more complex conditions and comorbidities"(p.43),[11] but it did not specify how *specialist* palliative care should be delivered within ARC, as this care is not the same as the *primary* palliative care given for 'uncomplicated deaths'. The clinical notes review showed the symptoms of those *admitted-to-die* were typical of end-of-life decline (physical, psychosocial, existential) but that they were significant, complex and fluctuating, and required *specialist* palliative care with input from external professionals not typically employed by ARC facilities. This is a high-performing ARC organisation and despite professionals being responsive and a range of medicines given at different times; symptoms, other concerns and distress were

not always relieved. Similar to Connolly et al's New Zealand study of those who died in ARC after transfer from public hospital,[8] in this study it was not always clear to those involved (patient, whānau) that the person was imminently dying. Only one case had a documented EPOA and ACP with the lack of an ACP known to be barrier to initiating palliative care.[31]

Significant structural, funding and environmental barriers to effective palliative care in ARC were identified in this study.

Funding barriers:

- No specific DHB funding for the *admitted-to-die* group means ARC facilities cannot afford to employ sufficient staff with an ideal skill mix and this likely restricts their ability to pay contracted external professionals;
- No specific health system funding to support collaborative, interorganisational *specialist* palliative care and limited MoH Innovations Funding for hospice ARC liaison nurse consultation;[28]
- Variability in how DHBs fund people *admitted-to-die* in ARC. Some DHBs have specific palliative care funding and do not charge the person, some fund the person's care through respite care funding, others apply income/asset testing and the person may be required to pay for ARC facility care (care they had received at no-cost in hospital or hospice prior to discharge).

Structural barriers:

- No DHB-wide common electronic platform to enable ARC staff and professionals from other organisations to communicate and collaborate in care planning;
- No DHB-wide pool of specialist clinical resources for ARC facilities to care for the *admitted-to-die* group (eg, syringe drivers, specialist beds and chairs, pressure relieving equipment).

Environmental barriers:

- Inappropriate ARC facility spatial layouts for the *admitted-to-die* group. Currently these people and their whānau are placed in rooms interspersed with *home-for-life* residents. The *admitted-to-die* generally require separate private space with enough room for whānau to visit and stay when near death. Staff need to be able to undertake close but private monitoring, ideally near their work station. Those under 65 years *admitted-to-die* appear to have particular spatial and privacy needs, especially if young families are involved.

Issues, solutions and future research

We believe two overarching issues are highlighted by this research.

First, the model of palliative care delivered to this group of patients including those under 65 years (patients *discharged-to-die* from hospitals or hospices) meets the criteria for being *specialist* palliative care. *Specialist* palliative care expectations are defined in national standards including the need for interdisciplinary expertise,[12] yet the current DHB funding for hospital-level ARC care is inadequate to cover the required level of ARC staffing, the need for input from external professionals and the required clinical and environmental resources.

As a solution, we recommend a specific classification and funding stream should be considered for those *admitted-to-die* and requiring *specialist* palliative care in ARC (this has been proposed in Australia),[32] perhaps initially limiting this funded model of care to selected ARC facilities. The model of care would specify the ideal professional mix of ARC facility staff and the training and support needs of staff members; the type of environment and equipment needed for care (including the needs of under-65-year-olds); arrangements for medical assessment including after-hours care; memoranda of understanding to include external professionals. Such a model could draw on proven consultative structures which use liaison staff to provide clinical advice and education.[33] A role for a pharmacist skilled in palliative care should be considered to support the use of medicines for symptom control in ARC facilities. Better integration of the pharmacist's role in ARC facilities has been proposed in the past by the Ministry of Health[11] and the outcomes of this role has been well researched in hospices[34–37] particularly advising on the balance between the use of regular vs 'as requested (PRN)' medicines and the timing of syringe driver initiation.

Secondly, we believe people *admitted-to-die* in ARC are not routinely receiving *interprofessional specialist* palliative care (a recognised international industry standard routinely applied in hospices and public hospitals).[38–42] In this study *interprofessional specialist* palliative care was provided in ARC by a combination of DHB staff, staff from other organisations and contracted professionals and because of a lack of structure relied on good will. Hospice staff (ARC liaison nurses and hospice doctors) play an important consultative and support role to ARC staff but in this study hospice consultative input was in some cases limited and not always timely, even though hospice and ARC staff knew each other well and were geographically close. It is unclear why this variability occurred.

As a solution, we recommend a clinical pathway be developed to formalise cross organisational input from DHBs, hospices and others to provide interprofessional *specialist* palliative care in ARC, including how this care will be led. Research in Australian ARC facilities (funded in a similar way to New Zealand) rely on the input of external professionals for those *admitted-to-die* and have developed formal mechanisms to achieve this.[43,44] To support this form of care an electronic shared record with care planning functions would facilitate ease of and more effective communication between all the professionals involved;[45] as well as assessing the real-time use of medicines for symptom control. The current hard-copy written record requires professionals to be onsite to read and write.

Taken together these solutions would result in a model of care to deliver *specialist* palliative care in ARC for those *admitted-to-die* with an appropriate structure and funding to ensure it is sustainable long-term.

Competing interests:
Pakize Sari and Jill Kerridge are staff members at the aged care facility where the research took place.

Acknowledgements:
Te Hopai Home and Hospital were the research partners in this study. We thank Caroline Morris for giving feedback on a final draft.

Author information:
Eileen M McKinlay, Associate Professor, Department of Primary Health Care and General Practice, University of Otago, Wellington; Serena V Moran, Research Fellow, Department of Primary Health Care and General Practice, University of Otago, Wellington; Sonya J Morgan, Research Fellow, Department of Primary Health Care and General Practice, University of Otago, Wellington; Pakize Sari, General Manager, Te Hopai Home and Hospital, Wellington; Jill M Kerridge, Clinical Manager, Te Hopai Home and Hospital, Wellington; Susan RH Pullon, Professor, Department of Primary Health Care and General Practice, University of Otago, Wellington.

Corresponding author:
Eileen M McKinlay, Department of Primary Health Care and General Practice, University of Otago, PO Box 7343, Wellington 6242.
eileen.mckinlay@otago.ac.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8037

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Diagnostic delays and treatment challenges in children with coeliac disease: The New Zealand Coeliac Health Survey

Kirsten J Coppell, Rosemary A Stamm, Kiri PH Sharp

ABSTRACT

AIM: Coeliac disease (CD) is an increasingly common immune-mediated disorder. Treatment is a life-long gluten-free diet. The aim of this study was to describe the presenting symptoms, delays in diagnosis and difficulties associated with managing CD in children.

METHOD: The New Zealand Coeliac Health Survey was undertaken in collaboration with Coeliac New Zealand Incorporated, whose membership was the study population. The questionnaire enquired about presenting and ongoing symptoms, and challenges associated with treatment. Children aged <16 years were included in this analysis. Proportions and the mean or median were calculated, as appropriate.

RESULTS: There were 123 children with doctor-diagnosed CD. The median age at diagnosis was 4 years (range 0–13 years). The median time between symptom onset and diagnosis was 1.5 years (range 0–11 years). Despite a gluten-free diet, many children continued to experience symptoms, which were most commonly attributed to an unknown cause (61.8%), hidden sources of gluten (44.1%) or food allergy (29.4%). Families found that following a gluten-free diet was very (12%) or moderately (31%) difficult, particularly when eating out.

CONCLUSION: Recognition of the challenges associated with the diagnosis and treatment of CD in childhood is an important issue in addressing the needs of children with CD, and their families.

Coeliac disease (CD), an autoimmune enteropathy characterised by a permanent intolerance to dietary gluten, is a common disorder affecting about 1% of the general population worldwide.[1] Ingestion of gluten containing cereals causes progressive damage to the small intestine in genetically susceptible individuals, leading to a variety of gastrointestinal and extra-gastrointestinal manifestations, including poor growth, irritability, iron deficient anaemia and dental enamel defects.[2] CD is associated with other autoimmune diseases, such as type 1 diabetes, autoimmune thyroid disease and autoimmune liver disease.[2] Exclusion of gluten from the diet is currently the only treatment option, and aside from alleviation of symptoms is important for establishing normal growth in children, and prevention of anaemia, osteoporosis and certain cancers.[2–4] This treatment is challenging, as gluten is a common component of the typical New Zealand diet.

The incidence of CD has increased worldwide in both children and adults, and this is not entirely explained by an increased awareness of, and testing for the disease. Among Scottish children aged less than 16 years the incidence of CD increased from 1.8 to 11.7 per 100,000 between 1990–94 and 2005–09.[5] In Denmark, incidence rates increased from 1.6 to 15.2 per 100,000 between 1980–84 and 2015–16 among all ages, with the largest increase in incidence among 0–9 year olds.[6] Similarly, in New Zealand incidence increased from 0.9

per 100,000 in 1970 to 12.9 per 100,000 in 1999 among all ages.[7] While the change in incidence among New Zealand children is unknown, the prevalence among 8–12 year old children is about 1%.[8]

With an increasing number of children diagnosed with CD internationally, and the changing presentation of the disease, we sought to obtain information about the clinical features, and the length and nature of the diagnostic process in New Zealand children aged less than 16 years with CD, and the difficulties associated with managing the disease.

Methods

Setting

The New Zealand Coeliac Health Survey was undertaken between 21 June and 6 August 2012 in collaboration with Coeliac New Zealand Incorporated (CNZ), a national organisation whose membership was the study population. At the time of the survey the membership of CNZ was 2,720, which included adults and parents or guardians of children with CD. The Multi-region Ethics Committee of New Zealand approved the study (MEC/12/EXP/072).

Survey development and administration

The survey has been described elsewhere.[9] In brief, permission was obtained to use and modify the Canadian Celiac Health Survey.[10,11] The Canadian survey was minimally adapted to fit the New Zealand context. Questions were added in order to obtain data on ethnicity, financial subsidies for CD, frequency of accidental consumption of gluten and difficulties with following a gluten-free (GF) diet. Following pilot testing at two regional CNZ support groups, and with a further three individuals, the questionnaire was further modified slightly to clarify the interpretation of a few questions.

The survey was self-administered, primarily online using Survey Monkey Software (www.surveymonkey.net). A study invitation and an information sheet along with a link to the survey were emailed to 2,383 members of CNZ and posted to a further 337 members by the organisation to maintain anonymity. Parents or guardians of children with CD were invited to complete the survey on their behalf. Efforts to maximise the response rate included speaking at two local CNZ meetings, sending an email reminder to complete the survey after four weeks and six weeks of sending the original invitation, and offering a chance to win a book voucher for survey participants. Informed consent was obtained by the choice of whether or not to complete the survey.

Data

The postal surveys were entered into Survey Monkey by KS and an assistant using the same Survey Monkey software. A 10% sample of postal surveys were randomly selected to check for data entry accuracy.

The data were exported from Survey Monkey to Microsoft Excel, cleaned and checked for errors. The data were analysed using STATA Data Analysis and Statistical Software integrated (version 15, StataCorp LP). Proportions and the mean ± SD or median (min-max) were calculated, as appropriate.

Results

Participants

Survey data were obtained for 123 children aged less than 16 years who were diagnosed with CD by a doctor. Most (87.8%) children had biopsy-confirmed CD (n=108). Thirteen children reported elevated CD antibodies without biopsy-confirmed CD, while 66 (53.7%) reported both a positive biopsy and elevated antibodies. Two children had CD diagnosed by a paediatrician without either a biopsy or positive antibodies. Both had a parent with biopsy positive CD.

Diagnosis of CD and ongoing symptoms

Table 1 shows the demographic characteristics of the study population. The median age of children at the time of diagnosis was four years (range 0–13 years). The time between the onset of symptoms and diagnosis varied between 0 and 11 years with the median time being 1.5 years. Prior to being diagnosed with CD, the symptoms of 45 (36.6%) children were reported to be attributed to other disorders such as acid reflux (n=20), a food allergy (n=18), anaemia (n=13), vitamin deficiency (n=10) or irritable bowel syndrome (n=7) (Table 2).

Table 1: Demographic characteristics and diagnostic details of children aged less than 16 years diagnosed with coeliac disease.

	n (%)*
Sex	
Males	33 (26.8)
Females	90 (73.2)
Age in years, mean ± SD	9.0±3.2
Ethnic group	
European	115 (93.5)
Māori	5 (4.1)
Pacific	1 (0.8)
Asian	1 (0.8)
Unknown	1 (0.8)
Age in years at diagnosis, median (min–max)	4 (0-13)
Duration of symptoms in years prior to diagnosis, median (min–max)	1.5 (0-11)

*unless otherwise specified.

Table 2: The different diagnoses made *prior* to a diagnosis of coeliac disease (n=123).

Diagnosis*	n (%)
Acid reflux	20 (44.4)
Anaemia	13 (28.9)
Chronic fatigue	3 (6.7)
Diverticulitis	1 (2.2)
Food allergy	18 (40.0)
Hiatus hernia	1 (2.2)
Irritable bowel syndrome (IBS)	7 (15.6)
Menstrual symptoms	1 (2.2)
Stomach or duodenal ulcers	2 (4.4)
Stress/nerves/depression	5 (11.1)
Vitamin deficiencies	10 (22.2)

*Some participants were given more than one diagnosis.

Table 3 shows the number and proportion of children experiencing the various symptoms associated with CD at the time of diagnosis, and whether they had fully recovered from these symptoms after initiating a GF diet. The five most common symptoms present at diagnosis were bloating, gas and abdominal pain (79%), diarrhoea (59%), extreme weakness or tiredness (56%), poor growth (55%) and large, pale, foul-smelling stools (50%). Many children continued to experience symptoms despite following a GF diet. Of those with ongoing symptoms, 68 participants selected one or more reasons for not having fully recovered, including an unknown cause (61.8%), hidden sources of gluten (44.1%), another food allergy (29.4%) or problems adhering to a GF diet (14.7%).

At the time of diagnosis, 96% of the children and their parents reported being told they needed to follow a GF diet for life and 84% reported being referred to a nutritionist or dietitian. Most children (94%) reported following a GF diet all the time, while 2% reported following a GF diet only some of the time. For those following a GF diet, there was a marked improvement in health for 104 (90%) children and a moderate improvement for eight (7%) children. Only one child was reported to have no improvement in health following the adoption of a GF diet.

Challenges with adopting a gluten free diet and quality of life issues

Following a GF diet was not easy for many families, with 12% finding it very difficult and 31% finding it moderately difficult. Accidental consumption of gluten was reported to occur at least weekly or monthly for 17% of participants. Free text comments highlighted that adopting a GF diet was easier for children when parents put in a lot of time and effort to ensure their child's diet was GF, and when there was good family support or the whole family adopted a GF diet.

The need to consume a GF diet presented numerous challenges for children and their families. Table 4 shows some quality of life challenges of a GF diet for children. More than one-third (37%) felt different from other children because of their CD all or most of the time, and 31% felt embarrassed because they had to bring GF foods to parties all or most of the time. About one-quarter felt angry about having to consume a different diet all or most of the time and half felt angry some of the time. Most children however had a very strong understanding

Table 3: The clinical signs and symptoms present prior to, and ongoing symptoms following, a diagnosis of coeliac disease (n=123).

Symptom	Present at diagnosis	Fully recovered
	n (%)	n (%)
Bloating, gas, abdominal pain	97 (78.9)	58 (59.8)
Diarrhoea	72 (58.5)	48 (66.7)
Extreme weakness or tiredness	69 (56.1)	56 (81.2)
Poor growth	67 (54.5)	48 (71.6)
Large, pale, foul-smelling stools	61 (49.6)	47 (77.0)
Weight loss	57 (46.3)	48 (84.2)
Anaemia	55 (44.7)	44 (80.0)
Nausea or vomiting	53 (43.1)	39 (73.6)
Constipation	45 (36.6)	30 (66.7)
Eczema	40 (32.5)	12 (30.0)
Mood swings/depression	38 (30.9)	18 (47.4)
Itchy skin	33 (26.8)	10 (30.3)
Lactose intolerance	24 (19.5)	14 (58.3)
Mouth ulcers	24 (19.5)	20 (83.3)
Easy bruising of skin	16 (13.0)	10 (62.5)
Bone/joint pain	17 (13.8)	12 (70.6)
Migraine headaches	14 (11.4)	13 (92.9)
Muscle cramps	14 (11.4)	11 (78.6)
Hypoglycaemia	3 (2.4)	3 (100)

of the importance of following a GF diet, but 25% felt their teachers and friends did not understand why they could not eat foods with gluten all or most of the time.

The biggest challenge was eating away from home with 47% avoiding restaurants, and 19% avoiding travel all or most of the time. More than half reported not being invited out for meals at least some of the time. Birthday parties, school functions and eating at friends' houses were particularly challenging. Organising and ensuring GF food was available at these functions, combined with a sense of being different from others, other people's lack of understanding about a GF diet and cross contamination made social occasions with food present very difficult. Other reported challenges and difficulties were remembering to have GF food on hand when out and about, preparing GF food in advance, finding GF food products in smaller towns and the expense of GF food products.

Discussion

CD is an increasingly common chronic disorder[12] for which the only treatment is a life-long GF diet. This study demonstrated that a diagnosis of CD in children can be considerably delayed, with symptoms commonly attributed to other diagnoses initially. Following a diagnosis of CD, the overall health of most children improved with a GF diet, but gastrointestinal and extra-gastrointestinal symptoms persisted for some children. Eating GF meals away from home was socially challenging for many children.

Table 4: The quality of life challenges of a gluten-free (GF) diet for children aged less than 16 years with coeliac disease (CD).

	Number of responses	All of the time n (%)	Most of the time n (%)	Some of the time n (%)	Never n (%)
I felt left out of activities at school or friends' homes because of CD.	114	8 (7.0)	17 (14.9)	73 (64.0)	16 (14.0)
I felt different from other kids because of CD.	115	19 (16.5)	24 (20.9)	52 (45.2)	20 (17.4)
I felt embarrassed because I had to bring GF foods to parties at school or at friends' homes.	115	19 (16.5)	17 (14.8)	49 (42.6)	30 (26.1)
I felt angry about having to follow a special diet.	114	20 (17.5)	9 (7.9)	58 (50.9)	27 (23.7)
I felt my teachers and friends did not understand why I couldn't eat foods with gluten in them.	115	6 (5.2)	23 (20.0)	41 (35.7)	45 (39.1)
I felt that I could be healthy without following a special diet.	115	1 (0.9)	3 (2.6)	20 (17.4)	91 (79.1)
Avoid restaurants	118	18 (15.3)	37 (31.4)	54 (45.8)	9 (7.6)
Avoid travelling	119	3 (2.5)	20 (16.8)	28 (23.5)	68 (57.1)
Brought GF food when travelling	117	70 (59.8)	25 (21.4)	20 (17.1)	2 (1.7)
Not invited for meals	117	6 (5.1)	16 (13.7)	41 (35.0)	54 (46.2)
Worried about hospital stay	116	15 (12.9)	8 (6.9)	19 (16.4)	74 (63.8)
Difficult to find GF food in shops	117	5 (4.3)	13 (11.1)	77 (65.8)	22 (18.8)
Difficult to find good GF food	119	8 (6.7)	28 (23.5)	72 (60.5)	11 (9.2)
Ate gluten because could not find GF food	117	0	0	7 (6.0)	110 (94.0)
Difficult to determine if GF from labels	118	4 (3.4)	3 (2.5)	86 (72.9)	25 (21.2)

The clinical presentation of CD has changed over time, with the classic presentation of abdominal distention, anorexia, chronic diarrhoea, weight loss, irritability and failure to thrive now being less common.[13–16] Most cases now present with non-classical symptoms, many of which are non-specific, or are diagnosed following screening in at risk groups, such as children with type 1 diabetes or Down's syndrome.[13–16] In this study, and the Canadian Celiac Health Survey,[17] many children presented with a wide range of non-specific symptoms, including tiredness, weight loss, poor growth, mood swings and skin conditions such as eczema and itchy skin.[2] This non-classical type of presentation can contribute to delays in the diagnosis of CD.[18]

In Canada, the median time between the onset of symptoms was one year and the range was 0–12 years,[17] compared with a median time of 1.5 years (range of 0–11 years) in New Zealand children. Since the Canadian survey in 2002 and the New Zealand survey in 2012, awareness of CD has continued to increase, and serological testing for CD antibodies is more available. Consequently, it is possible that delays in the diagnosis of CD reported for children in the New Zealand survey may have shortened,

as has been observed elsewhere.[19] Diagnosing CD as early as possible after the onset of symptoms is important, particularly as differences in height growth between children with and without CD, are apparent from the age of 12 months even though the diagnosis may be at an older age.[20]

The most prevalent symptom prior to the diagnosis of CD reported in our study was bloating, gas and abdominal pain in four of five children, of which only 60% reported to have fully recovered after initiating a GF diet. This was despite 84% of participants and their caregiver(s) being referred to a dietitian following diagnosis to learn about a GF diet, and almost all stating they always consumed a GF diet. It is possible that the reported ongoing symptoms were secondary to non-coeliac causes, and participants most commonly attributed these to either an unknown cause or hidden sources of gluten in the diet.

This survey illustrates the difficulties in avoiding gluten for children with CD in New Zealand, and that their symptoms may not completely resolve either through poor adherence to the GF diet, particularly among teenagers, or inadvertent consumption of gluten.[21–23] The popularisation of the GF diet into a 'fad' diet and the greater availability of GF foods[24,25] has complicated the treatment for those with CD.[26] The increased consumption of GF food by those without CD has contributed to the poor understanding of the severity of CD, especially in relation to the risks of cross-contamination and hidden gluten. Continued symptoms, even if intermittent, clearly have an impact on quality of life.[27] Previous research has shown that social isolation can occur in children due to the misunderstanding of CD by others and that social isolation and misunderstandings of CD are important barriers to adherence to a GF diet.[22] In this study, approximately one in three children reported feeling different from other children because of their CD, and feeling embarrassed because of having to bring GF foods to parties all or most of the time, and one-quarter felt their teachers and friends did not understand why they needed to eat GF foods.

Contamination of foods labelled as being GF is a recognised issue, both in New Zealand and internationally,[28–32] and is one possible reason for ongoing symptoms. A recent Australian study found repeat batches of three GF labelled food items produced in dedicated GF factories tested positive for gluten. In New Zealand, Food Standards Australia New Zealand (FSANZ) develops standards for the food industry in Australia and New Zealand,[33] and a claim to the effect that a food for medicinal purposes is GF may be made if the food contains (a) no detectable gluten; and (b) no oats or oats products; and (c) no cereals containing gluten that have been malted, or products of such cereals. Whereas in most of Europe, the UK and the US, food products can be considered GF if they contain less than 20 parts per million (ppm) of gluten as defined by the Codex Alimentarius Commission, a joint programme of the World Health Organization and Food and Agriculture Organization that develops international standards for food.[34,35] Although the definition of GF is based on no detectable gluten in New Zealand and Australia, contamination still occurs during processing and packaging of food,[29,30] and GF food preparation in cafes and restaurants is not necessarily adequate.[36,37] The extent of GF food contamination in New Zealand is most likely to be under-reported as FSANZ does not enforce the code, and there is no regular monitoring of adherence to these standards.[33] Further, most food recalls by the Ministry of Primary Industries (MPI) are voluntarily initiated by businesses when they become aware of a potential food safety or suitability issue.[38]

This survey population were members of CNZ, a non-profit organisation that supports New Zealanders with CD, and they may not be representative of the New Zealand population with CD. Further, it is possible that those participating in the survey are more motivated individuals or have different experiences compared with non-respondents. It was not possible to determine the survey response rate for children, as the CNZ membership list did not distinguish between adults and children. While respondents reported that their CD had been formally diagnosed, this and any prior diagnoses were not validated by checking medical records. However, it is unlikely that families would pay a CNZ membership fee, if their children did not have paediatrician-confirmed CD. Recall bias particularly

in relation to symptoms at the time of diagnosis is possible, given the time between diagnosis and this survey was up to 14 years. Another limitation of the survey is that the experiences in quality of life were framed by a quantitative questionnaire format with defined questions. This may not capture the full range of challenges, including cost, that are experienced by families and children living with CD.[39] Future research should engage mixed-methods or qualitative research methods to fully capture the challenges of those diagnosed with CD.

In conclusion, the prevalence of CD has been increasing over the past 30 years, yet timely diagnosis of CD in children and difficulty adhering to a GF diet, determined by the persistence of symptoms, remain an issue. The quality of life of children with CD can be impacted by social pressures related to having to adhere to a GF diet and a limited availability of safe uncontaminated GF options when attending parties, restaurants and travelling. Recognition of the symptoms and challenges associated with the diagnosis and treatment of CD in childhood remains an important issue in addressing the needs of children with CD, and their families.

Competing interests:
Both of Dr Coppell's children have coeliac disease and they both participated in this survey.

Acknowledgements:
We thank the Canadian Celiac Association who allowed us to use and modify their questionnaire, Coeliac New Zealand Incorporated who facilitated the distribution of the study invitation to its members and the children and their parents who participated in the survey.

Author information:
Kirsten J Coppell, Public Health Physician and Research Associate Professor, Edgar Diabetes and Obesity Research, Department of Medicine, University of Otago, Dunedin; Rosemary A Stamm, Research Fellow and Science Writer, Department of Medicine, University of Otago, Dunedin; Kiri PH Sharp, PhD candidate and Registered Dietitian, Department of Medicine, University of Otago, Dunedin.

Corresponding author:
Kirsten Coppell, Department of Medicine, University of Otago, PO Box 56, Dunedin 9054.
kirsten.coppell@otago.ac.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8038

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The costs associated with ankylosing spondylitis/ axial spondyloarthritis in Aotearoa/New Zealand

Douglas White, Chunhuan Lao, Megan Williams, Ross Lawrenson, Nicola Dalbeth

ABSTRACT

AIMS: To evaluate costs associated with a diagnosis of spondyloarthritis (SpA) in an Aotearoa/New Zealand cohort.

METHODS: Patients with SpA attending specialist SpA clinics in Auckland and Hamilton completed a series of questionnaires on costs associated with ankylosing spondylitis, disease parameters (BASDAI), work productivity (WPAI, WLQ) and quality of life measures (EQ-5D, ASAS-HI).

RESULTS: Eighty-one patients (median age 43 years) completed the study. All fulfilled the ASAS criteria for axial spondyloarthritis and 44 (58%) fulfilled the Modified New York Criteria for ankylosing spondylitis. The mean (SD) score on the EQ-VAS was 69mm (24.1). More than half reported difficulties with usual activities and more than 80% had moderate pain or discomfort despite current treatment. Sixty-six (82%) were in the workforce, and the mean work productivity loss was 4.8%. The mean (SD) annual cost was NZ$15,677 (NZ$11,269) with NZ$12,189 direct cost and NZ$3,488 productivity loss. The largest cost driver was use of biologic medications, which were used by 48% patients.

CONCLUSIONS: This study has quantified the direct and indirect costs of spondyloarthritis (SpA) in Aotearoa/New Zealand, and demonstrates meaningful reduction in quality of life and work productivity in patients with SpA. The major driver of direct costs in SpA are biologic medications.

Axial spondyloarthritis (axSpA) and ankylosing spondylitis (AS) are part of a spectrum of spondyloarthritis (SpA); chronic inflammatory conditions characterised by spinal involvement, with pain, stiffness and reduced range of movement. The condition typically starts in the second or third decades of life and affects men 2–4 times more commonly than women. Physical functioning and quality of life are affected, and previous studies have identified a significant burden in terms of work impairment, early retirement, lifetime health and social care resource utilisation.[1–18]

In 2018, Arthritis New Zealand released a report on the economic burden of arthritis in Aotearoa/New Zealand.[19] This report used data from the New Zealand Health Information Service (NZHIS) to gather data on inpatient episodes, the Royal New Zealand College of General Practitioners (RNZCGP) database for data on GP visits, and data from Pharmac on medication costs to generate the reported data. A number of limitations are acknowledged within this report, in particular the lack of comprehensive 'bottom-up' or 'top-down' data in Aotearoa/New Zealand. This project aims to address the lack of 'bottom-up' data on the effect of SpA on quality of life and the economic impact in New Zealand.

ISSN 1175-8716

Methods

Data collection

Participants who fulfilled the Assessment of Spondyloarthritis International Society (ASAS) Criteria for SpA, and a subset who also fulfilled the modified New York criteria for AS, attending specialist clinics at Auckland District Health Board and Waikato District Health Board were invited to participate. Patients were offered the option of completing a paper version of the questionnaires or completing them online using a custom built website. We linked the questionnaires to clinical data on disease duration, activity and severity contributed by the treating physician. The combined dataset included: 1) patient information: age, gender, ethnicity, education level, occupation, marriage status, AS diagnostic date and HLA-B27; 2) disease severity and patient's health: using the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath AS metrology Index (BASMI) and ASAS Health Index; 3) work and activity limitation: using the Work Limitations Questionnaire (WLQ) and Work Productivity and Activity Impairment Questionnaire (WPAIQ); 4) quality of life: using the EQ-5D-3L and EQ visual analogue scale (EQ-VAS); 5) AS related costs/resources: transport, accommodation, subsidised and unsubsidised medications, investigations, general practitioner consultations, outpatient specialist consultations, inpatient, and self-funded visits to other health professionals. The list of medications used for SpA was obtained from the treating clinician, sourced from hospital records.

The BASDAI consists of six questions rated on a 0 (no problem) through 10 (worst problem) scale assessing the five major symptoms of AS: fatigue, spinal pain, joint pain/swelling, areas of localised tenderness, morning stiffness duration and morning stiffness severity.[20] BASMI includes clinical measurements of cervical rotation, tragus to wall distance, lumbar flexion, lumbar side flexion and intermalleolar distance, with 0 for mild, 1 for moderate and 2 for severe on each measurement giving a total score of 0–10.[21] Clinicians were asked to provide the most recent scores prior to the study visit. The ASAS Health Index (HI) questionnaire contains 17 items measuring 'functioning, disability and health' with a sum score range from 0 (good functioning) to 17 (poor functioning).[22]

The WLQ is a self-administered questionnaire measuring the degree to which health problems interfere with the ability to perform job roles.[23] We used the 25-item version measuring four WLQ scales: time management scale, physical tasks scale, mental-interpersonal tasks scale and output tasks scale. The responses on these scales were then converted to a percentage of at-work productivity loss. WPAIQ measures absenteeism, presenteeism as well as the impairments in unpaid activity during the past seven days.[24]

The EQ-5D-3L consists of five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) with three levels for each dimension (no problems, some problems, severe problems). Based on the answers to the EQ-5D, the quality of life was estimated using the New Zealand EQ-5D tariff.[25] The EQ-VAS records self-rated health on a vertical, visual analogue scale where the endpoints are labelled 'Best imaginable health state (score 100)' and 'Worst imaginable health state (score 0)'.

Cost analyses

A cost estimation was derived from the societal perspective. All costs were valued in 2017/2018 New Zealand dollars (NZ$). Direct costs were calculated by adding up out-of-pocket costs and costs of public healthcare services. Costs of public healthcare services were computed using the bottom-up approach, by multiplying the amount of medical resources with the unit costs of each medical resource type. The unit costs of pharmaceuticals were from the PHARMAC online Pharmaceutical Schedule.[26] The unit costs of inpatient and outpatient services were provided by the Waikato District Health Board. Indirect productivity loss costs were calculated using the human capital approach. Costs of productivity loss included the loss of salary because of absenteeism and presenteeism due to AS.

Statistical analyses

Quality of life and total costs were compared by gender, ethnicity, age group (18–24, 25–44, 45–64, 65+ years), disease

duration (0–5, 6+ years), ASAS HI score (<6, 6+), BASDAI score (<4,4+) and biologic drugs user (Yes, No). Biologic drugs include adalimumab, etanercept, and infliximab. Mann-Whitney U test and Kruskal-Wallis 1 way ANOVA were used to examine the differences between subgroups. All data cleaning and analyses were performed in IBM SPSS statistics 25 (New York, US). For all tests, $p<0.05$ was taken as the level of significance.

Ethics

Ethical approval for the study was granted through the Central Health and Disability Ethics Committee, reference: 16/CEN/172. Institutional approval was obtained from Auckland District Health Board and Waikato District Health Board.

Results

Our study cohort included 81 patients. Table 1 shows the patient characteristics and disease information. Nine patients chose to use the website for data collection, and the remainder used the paper version of the questionnaires. There were 17 (21%) women and 64 (79%) men; eight (10%) identified as Māori and 71 (90%) as non-Māori. The majority of patients (83%) were aged 25–64 years old, and most (66, 82%) were in paid employment. Half of patients (40, 53%) were diagnosed within five years of participation in the study. Twenty-five (31%) patients had private medical insurance. Forty-four (58%) patients fulfilled the Modified New York Criteria for AS. Sixty-five (86%) patients

Table 1: Patient characteristics and disease information.

	Number	**Percentage**
Gender		
Female	17	21%
Male	64	79%
Ethnicity		
Māori	8	10%
NZ European	64	81%
Asian	5	6%
Middle Eastern	2	3%
Not reported	2	
Age at survey (years)		
18–24	4	5%
25–44	39	48%
45–64	29	36%
65+	9	12%
Marital status		
Married/living with partner	59	73%
Single/widow(er)	22	27%
Highest education		
Bachelor degree or above	29	36%
Others	52	64%
Employment (working for pay)		
Yes	66	82%
No	15	19%

Table 1: Patient characteristics and disease information (continued).

Private medical insurance		
Yes	25	31%
No	56	69%
Disease duration (n=76/81)		
0–5 years	40	53%
6–10 years	12	16%
11–20 years	9	12%
21+ years	15	20%
Modified New York Criteria fulfilled		
Yes	44	54%
No	37	46%
HLA-B27 (n=76/81)		
Negative	11	14%
Positive	65	86%
BASMI (n=73/81)		
0–1	42	58%
2–3	11	15%
4–5	7	10%
6–7	11	15%
8–9	2	3%
BASDAI Score (n=80/81)		
0–<2	30	38%
2–<4	21	26%
4–<6	19	24%
6+	10	13%
Biologic medication user		
Yes	39	48%
No	42	52%

were HLA-B27 positive. More than half of patients had a BASMI score of 6–9 (13, 18%), and 10 (13%) patients had a BASDAI score of 6+. Biologic medications were used by 39 (48%) patients.

Seventy-two patients answered the WLQ, and the estimated average at-work productivity loss was 4.8% (Table 2). From the WPAIQ, on average one hour in the prior seven days was missed from work and two hours of productivity were affected due to SpA.

All patients provided the EQ-5D-3L data, with a mean (SD) score of 0.66 (0.18) (Table 2). The mean (SD) score on the EQ VAS was 69.0 (SD 24.1). The ASAS Health Index questionnaire (ASAS-HI) found a mean (SD) score of 5.7 (3.9). Thirty-four (42%) patients had some problems in mobility, 16 (20%) patients had some problems with self-care, more than half of patients had some problem with usual activities (43, 53%), 65 (80%) patients had moderate pain or discomfort, and 28 (35%) patients had moderate anxiety or depression (Table 3).

Table 2: WLQ and EQ-5D results.

Measurement tools	Number of answers	Average score (SD)	Non-biologic user	Biologic user
WLQ At-Work Productivity Loss	72	4.8% (4.5%)	4.9% (4.1%)	4.8% (5.0%)
WPAIQ (in the past 7 days)				
Hours missed from work due to SpA	67	1.0 (2.9)	1.1 (3.4)	1.0 (2.2)
Hours with affected productivity due to SpA	67	2.0 (2.0)	2.3 (2.0)	1.8 (2.0)
Hours actually worked	67	36.4 (15.9)	40.6 (12.4)	31.8 (18.2)
EQ-5D	81	0.66 (0.18)	0.65 (0.17)	0.68 (0.18)
EQ VAS	81	69.0 (24.1)	63.9 (25.1)	73.7 (22.4)
ASAS Health Index	81	5.7 (3.9)	5.5 (3.5)	5.8 (4.2)

Table 3: EQ-5D results by dimension.

Dimensions	Number	Percentage
Mobility		
I have no problems in walking about	47	58%
I have some problems in walking about	34	42%
I am confined to bed	0	0%
Self-care		
I have no problems with self-care	65	80%
I have some problems washing or dressing myself	16	20%
I am unable to wash or dress myself	0	0%
Activity		
I have no problems with performing my usual activities	37	46%
I have some problems with performing my usual activities	43	53%
I am unable to perform my usual activities	1	1%
Pain/discomfort		
I have no pain or discomfort	14	17%
I have moderate pain or discomfort	65	80%
I have extreme pain or discomfort	2	3%
Anxiety/depression		
I am not anxious or depressed	53	65%
I am moderately anxious or depressed	28	35%
I am extremely anxious or depressed	0	0%

Mean (SD) annual salary was $62,167 ($35,332). The average (SD) annual costs were $15,677 ($11,269) with $12,189 (78%) direct cost and $3,488 (22%) productivity loss (Table 4). The majority of the direct cost was medication cost ($10,701, 88%). Other direct costs included GP cost ($189), outpatient cost ($688) and other out-of-pocket costs ($611). Among the productivity loss, $1,078 (31%) were due to absenteeism and $2,410 (69%) were due to presenteeism.

There was no significant difference in quality of life or costs by gender, ethnicity, age or disease duration (Table 5).

Patients who had an ASAS-HI score of less than 6 had better quality of life than patients with an ASAS-HI score of 6+ (0.75 vs 0.56, p<0.001), and had lower costs ($13,408 vs $18,245, p=0.03). Patients who had an BASDAI score of less than 4 had better quality of life than patients with an BASDAI score of 4+ (0.73 vs 0.54, p<0.001), but similar costs ($16,327 vs $14,512, p=0.75). The costs for biologic medication users were 4.5 times the costs for those not on biologic medications ($25,073 vs $5,559, p<0.001).

Discussion

This is the first study in Aotearoa/New Zealand that has gathered bottom-up health economic data on people with spondyloarthritis (SpA). The cohort studied is representative of those attending hospital-based secondary care clinics and thus may be skewed towards patients with more severe disease, as those with milder SpA may be managed—if not diagnosed—in primary care. However, the characteristics of the current cohort are similar to other published cohorts of patients with spondyloarthritis.[27,28]

Identifying where additional costs are being incurred both by patients and the public health system, may help to identify areas where improvements in health provision and efficiency, could save health dollars and improve patients' quality of life. The majority of the costs were related to the use of biologic medications (~77%) with a smaller but significant contribution from lost productivity (~22%). The costs of biologic medications may fall a little over time with the introduction of biosimilar medications. Additionally, newer agents being developed to treat spondyloarthritis are available as tablets, which may reduce the medication costs further. Productivity loss is likely therefore to become a greater proportion of the total costs over time. Although this study has not looked at the effect of diagnosis or treatment on productivity loss, others have found that earlier diagnosis and treatment can reduce the detrimental impact of this condition on work productivity.[30]

Table 4: Components of annual costs.

List of items	**Costs**	
	Mean	**SD**
All direct costs	$12,189	$10,623
GP costs (government contribution)	$98	$106
GP costs (patient contribution)	$91	$123
Outpatient cost	$688	$588
Inpatient cost	$0	-
Medication cost	$10,701	$10,327
Other out-of-pocket cost	$611	$1,230
Productivity loss	$3,488	$5,045
Absenteeism	$1,078	$3,021
Presenteeism	$2,410	$3,116
Total costs	$15,677	$11,269

Table 5: Quality of life and annual costs by subgroup.

Subgroups	Quality of life		Costs	
	mean	p-value	mean	p-value
Gender				
Female	0.70	0.69	$13,987	0.52
Male	0.65		$16,126	
Ethnicity				
Māori	0.61	0.27	$21,326	0.12
Others	0.67		$15,289	
Age (years)				
18–24	0.58	0.33	$13,200	0.16
25–44	0.66		$16,581	
45–64	0.67		$16,759	
65+	0.75		$15,686	
Disease duration (years)				
0–5	0.64	0.88	$15,825	0.65
6+	0.68		$15,795	
ASAS-HI				
<6	0.75	<0.001	$13,408	0.03
6+	0.56		$18,245	
BASDAI				
<4	0.73	<0.001	$16,327	0.75
4+	0.54		$14,512	
Biologic medication user				
No	0.65	0.86	$5,559	<0.001
Yes	0.68		$25,073	

It is evident from the data presented in Table 2 that those on biologic medications have similar levels of work productivity loss but appear to work fewer hours than those not on biologic. Since biologic medications are given to those with more severe disease. This is a cross-sectional study and it is not possible to make any conclusion about the use of these medications on change in quality of life or work productivity. This would require a detailed analysis of our prospective data and will be the subject of future work. Data from the British Society of Rheumatology Biologics Registry showed that biologic medication use does improve work productivity for those with spondyloarthritis; in a study of 161 patients commencing biologic therapy, at 12-month follow-up, there were significantly greater improvements (relative to those on non-biologic therapy) in presenteeism, overall work impairment and overall activity impairment.[28] The proportion of patients receiving biologic therapy in our study (48%) is equivalent to overseas cohorts.[27] In Aotearoa/New Zealand, the precise cost of biologic medications is confidential and for this study, the 'list price', which is likely to be higher than the actual cost, was used.

In 2015, Cooksey et al[29] found an annual cost of £19,016 per patient per year in the UK, including direct medical costs, direct non-medical costs and productivity loss costs. Even for those on biologic therapy, our cost data published here compare favourably.

It is perhaps surprising that the mean time taken off work was just over one hour in the past week. This may be subject to recall bias but is very similar to the UK data published by Cooksey et al[29] who found a mean of 1.15 hours absence in the past seven days using the same questionnaire. Shim et al[28] also reported that absenteeism did not change when commencing biologic therapy, suggesting that this may be independent of disease activity.

There were some limitations to our study. Recruitment proved harder than we expected. We did not gather data on early retirement in this study, which may have increased the amount of productivity loss related to spondyloarthritis.

Despite the above limitations, we have found evidence to suggest that spondyloarthritis is associated with a meaningful reduction in quality of life and reduced work productivity in Aotearoa/New Zealand. Understanding the health economic implications can assist with service provision and funding of treatment options. Data from Aotearoa/New Zealand are needed across a range of musculoskeletal conditions to help us understand the impact these conditions are having.

Competing interests:
Douglas White reports speaker fees for Abbvie outside the submitted work and has been an investigator on several clinical trials sponsored by Abbvie. Nicola Dalbeth reports speaker fees from Abbvie and Janssen, outside the submitted work.

Acknowledgements:
We acknowledge A/Prof Simon Stebbings who discussed the study and reviewed the manuscript.

Author information:
Douglas White, Rheumatology Department, Waikato Hospital, Hamilton; Waikato Clinical School, University of Auckland, Auckland; Chunhuan Lao, Waikato Medical Research Centre, University of Waikato, Hamilton; Megan Williams, Auckland District Health Board, Auckland; Ross Lawrenson, Waikato Medical Research Centre, University of Waikato, Hamilton; Waikato District Health Board, Hamilton; Nicola Dalbeth, Auckland District Health Board, Auckland; University of Auckland, Auckland.

Corresponding author:
Douglas White, Rheumatology Department, Waikato Hospital, Private Bag 3200, Hamilton.
douglas.white@waikatodhb.health.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8039

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ISSN 1175-8716

IDI trends in antidepressant dispensing to New Zealand children and young people between 2007/08 and 2015/16

Nicholas Bowden, Sheree Gibb, Hiran Thabrew, Richard Audas, Justine Camp, Barry Taylor, Sarah Hetrick

ABSTRACT

AIM: To examine trends in antidepressant dispensing to childred and young people in New Zealand aged 1–24 years between 2007/08 and 2015/16 using the national Integrated Data Infrastructure (IDI), and to determine whether these trends vary by age, sex, ethnicity and socioeconomic deprivation.

METHODS: In a novel endeavour, data on antidepressant dispensing, age, sex, ethnicity and socioeconomic status were sourced from the IDI, a linked individual-level database containing New Zealand government and survey microdata.

RESULTS: The total rate of dispensing of antidepressants to young people increased by 44% from 1,870 per 100,000 in 2007/08 to 2,694 per 100,000 in 2015/16. Increases were larger for the 13–17 age group than the 1–12- or 18–24-year age groups. New Zealand European/Other ethnicities had the highest dispensing rates (3,623 out of every 100,000 people received an antidepressant in 2015/16), followed by Māori (1,980/100,000), Asian (902/100,000) and Pasifika (819/100,000) had the lowest. Dispensing rates increased with increasing deprivation, except in the most deprived quintile, where rates were lower than all other quintiles.

CONCLUSION: This study demonstrates the value of utilising IDI data for health research, while providing directions for future use, including further linkage of IDI datasets. Overall there was a trend towards an increase in the use of antidepressants across all age, sex and ethnic groups, but notable variation in dispensing between different ethnic and socioeconomic groups. Despite our inability to determine the clinical rationale for increased dispensing of antidepressants, the available data highlight some potentially significant improvements as well as disparities in healthcare.

Worldwide, the use of antidepressant medications has been on the rise with growth in prescribing being observed in England,[1] US,[2] Canada[3] and Australia.[4] New Zealand is no exception; since the early 1990s, antidepressant prescribing has increased steadily.[5,6] Exeter et al (2009), in the most recent population-based study in New Zealand, found a 30.2% increase in antidepressant dispensing between 2004 and 2007. The dispensing rate was higher for women than men, and increased with age, irrespective of gender or ethnicity. In 2015 New Zealand had the 10th highest rate of antidepressant use of the 34 Organisation of Economic Co-operation and Development (OECD) nations.[7]

There is evidence from overseas that this increase in prescribing is also seen in children and young people.[8,9] Karanges et al observed a 25% increase in antidepressant dispensing to Australian children and adolescents in the 3–24 age group over four years from 2009 to 2012. In a study covering

prescriptions in five high-income countries from 2005 to 2012, Bachmann et al observed increases in the number of young people receiving an antidepressant of between 17.6 to 60.5%. To date, there have been no published studies of antidepressant use by New Zealand children and young people.

Antidepressants are generally defined as medications used to treat depression and related mood disorders. They include a range of drugs from different chemical families. Most 'antidepressants' are also used for other clinical purposes, especially in children and young people. For example, serotonin-specific reuptake inhibitors (SSRIs) such as Fluoxetine, Citalopram and Paroxetine are often used to treat anxiety disorders,[10] and tricyclic antidepressants (TCAs) such as Amitriptyline and Nortriptyline are used to treat pain disorders,[11] enuresis[12] and insomnia.[13] Despite their known clinical benefits,[14,15] there has been concern about overuse of antidepressants in children and young people out of keeping with treatment guidelines[10,16] and the potential for increased risk of suicidal ideation.[17]

Enhanced understanding of patterns of antidepressant prescribing is made possible in New Zealand via the Integrated Data Infrastructure (IDI),[18] a large research database containing a wide range of administrative and survey data about people and households. Data in the IDI is held in a secure environment and can be accessed by approved researchers only for projects that are in the public interest. Statistics New Zealand's 'five safes' framework[19] is used to ensure data privacy is protected. Only approved researchers can use the IDI, for projects with a statistical purpose for the public good, using de-identified data, accessed in secure settings, and statistical results that are confirmed as confidential and checked by Statistics New Zealand before being released. Use of IDI data may enable more accurate investigation of health-related activity, including medication prescribing by age, gender and ethnicity. It also permits analysis of dispensing by deprivation status, a first for New Zealand data.

The present study examines antidepressant dispensing trends among New Zealand children and young people aged 1–24 years over the period 2007/08 to 2015/16. The aims of the study are:

- To gauge the utility of currently available IDI data for measuring antidepressant dispensing levels and trends at a national level
- To describe trends in antidepressant dispensing to children and young people
- To explore how antidepressant dispensing to children and young people varies by gender, age, ethnicity and socioeconomic status.

Methods

Data sources

This study used data from Statistics New Zealand's Integrated Data Infrastructure (IDI)[18] as described above. Data on antidepressant dispensing were drawn from the community pharmaceutical dispensing collection. The data extracted for this study covered all subsidised community (pharmacy) antidepressant dispensing for people in New Zealand aged 1–24 years (ages were calculated at the end of each fiscal year) for the nine-year period from 1 July 2007 to 30 June 2016. This included prescriptions written by primary care and specialist (secondary and tertiary) health services. All dispensing of antidepressants was included in the study as the reason for prescribing cannot be determined. For the purposes of this study, repeats (repeated dispensings of medications from the same prescription) were counted as separate dispensings. Each separate medication was also counted as a separate dispensing, even if it was dispensed at the same time.

Antidepressant classes

The 19 medications considered to be 'antidepressants' on the pharmaceutical schedule for the period of interest included five selective serotonin re-uptake inhibitors (SSRIs) (Citalopram, Fluoxetine, Paroxetine, Escitalopram and Sertraline), three monoamine oxidase inhibitors (MAOIs)/ reversible inhibitors of monoamine oxidase A (RIMAs) (Tranylcypromine, Phenelzine and Moclobemide), a serotonin and noradrenaline re-uptake inhibitor (SNRI) (Venlafaxine), eight tricyclic antidepressants (TCAs) and related agents (Amitriptyline, Nortriptyline, Dosulepin, Doxepin, Clomipramine, Imipramine, Trimipramine and Maprotiline), a tetracyclic antidepressant

(TeCA) (Mianserin), and a noradrenergic and specific serotonergic antidepressant (NaSSA) (Mirtazapine).

Ethnicity

Ethnicity was measured in total response format, allowing an individual to be a member of multiple ethnic groups. Four major ethnic groups were used in this study: New Zealand European/Other (combination of the European and Other Level 1 groups); Māori; Pasifika and Asian. The Middle Eastern, Latin American and African (MELAA) group was not examined due to small population size. Ethnicity was sourced from the first available source in the following order: Census; birth records; health.

Socioeconomic status

Socioeconomic status was measured using the New Zealand Deprivation Index (NZDep) 2013.[20] NZDep is an area-based measure that assigns a deprivation score based on the meshblock in which an individual was living. Scores were collapsed into quintiles with quintile one representing the least deprivation and five the greatest. The IDI contains information about address updates that individuals have provided to government agencies. These can be used to determine place of residence at a given date.[21] In this study, meshblock of residence (needed to determine NZDep) was defined at the end of the fiscal year. The most recently registered meshblock of residence before the end of the fiscal year was used. If an individual did not have any registrations prior to the end of the fiscal year, the first update in the 12 months after the end of the fiscal year was used.

Data management

Dispensing and associated demographic data were extracted using SAS 7.1 and then analysed using StataMP 15 within the IDI environment. The following standard cleaning steps were applied to the data: Antidepressant dispensings were included for order type 1 only (others are for oncology or dispensings not to a particular person such as a bulk supply order); all antidepressant dispensings with a formulation ID "NULL" or 391725 "brand switch fee" were removed; dispensings were removed when the date of dispensing was after the individual's date of death or before their date of birth.

Ethics approval

The University of Otago Human Research Ethics Committee reviewed the study for ethics consideration. The study was reviewed as a 'Minimal Risk Health Research—Audit and Audit related studies' proposal and was approved.

Calculating antidepressant dispensing rates

Dispensing rates were calculated by dividing the number of people who were dispensed an antidepressant in a given fiscal year by the number of people in the New Zealand resident population in that fiscal year. For age-specific rates, ages were calculated at the end of the fiscal year. Dispensing rates are presented in this paper as 'per 100,000 population'. Population denominators by fiscal year were calculated using existing methods for estimating a resident New Zealand population from the IDI.[22,23] More specifically, this method included people whose presence in New Zealand was indicated by activity in key datasets. Individuals who had died or moved overseas were excluded. The total resident population generated using this method was within 2% of the official estimated resident population estimate.

Results

Number of antidepressants dispensed

Over the nine-year study period there were approximately 1.35 million antidepressant dispensings to children and young people aged 1–24 years in New Zealand. The total number of annually dispensed medications increased 68% over the time period (from 111,171 in 2007/08 to 186,396 in 2015/16). Over two-thirds (68%) of the medications dispensed during the time period were for SSRIs. A further 17% were for TCAs and 13% for SNRIs. MAOIs/RIMAs, NaSSAs and TeCAs combined accounted for approximately 2% of medications dispensed. Over the nine-year period SNRI dispensing more than tripled (up 222% from 9,783 in 2007/08) and SSRI and TCA dispensing increased by 58% (from 78,315) and 34% (from 22,266) respectively.

Table 1: Annual dispensing rates (per 100,000 population) overall, by gender and age.

Fiscal year	Overall	Male	Female	1–12	13–17	18–24
2007/08	1,870	1,172	2,603	147	1,361	5,149
2008/09	1,946	1,236	2,693	131	1,372	5,363
2009/10	2,091	1,365	2,858	134	1,513	5,686
2010/11	2,177	1,437	2,960	139	1,614	5,845
2011/12	2,252	1,504	3,044	133	1,685	6,042
2012/13	2,431	1,607	3,303	137	2,021	6,364
2013/14	2,525	1,675	3,427	147	2,193	6,511
2014/15	2,687	1,773	3,662	159	2,410	6,834
2015/16	2,694	1,777	3,675	170	2,494	6,790
% Change*	44.1	51.6	41.2	15.6	83.3	31.9

*% Change refers to the percentage change in dispensing rates from 2007/08 until 2015/16.

Rate of children and young people receiving antidepressants

The rate of children and young people aged 1–24 years who received an antidepressant increased over the study period from 1,870 per 100,000 in 2007/08 to 2,694 per 100,000 in 2015/16 (Table 1). Annual rates for females were just over twice those of males (although that ratio narrowed slightly over the study period) and by 2015/16 female rates were 3,675 per 100,000 compared to 1,777 per 100,000 for males. Antidepressant use increased by age with 170 per 100,000 in the 1–12 age group in 2015/16 compared to 2,494 in the 13–17 age group and 6,790 in the 18–24 age group. Across all age groups, rates increased over time with the greatest increase being in the 13–17 age group experiencing an 83% increase, more than double that of the other age groups.

Figure 1 shows the rates of children and young people receiving antidepressant dispensing annually by sex/age category. Within age categories dispensing rates were generally higher for females than for males with the exception of the 1–12 age group, where annual rates for males were

Figure 1: Dispensing rates by age and gender, 07/08 to 15/16.

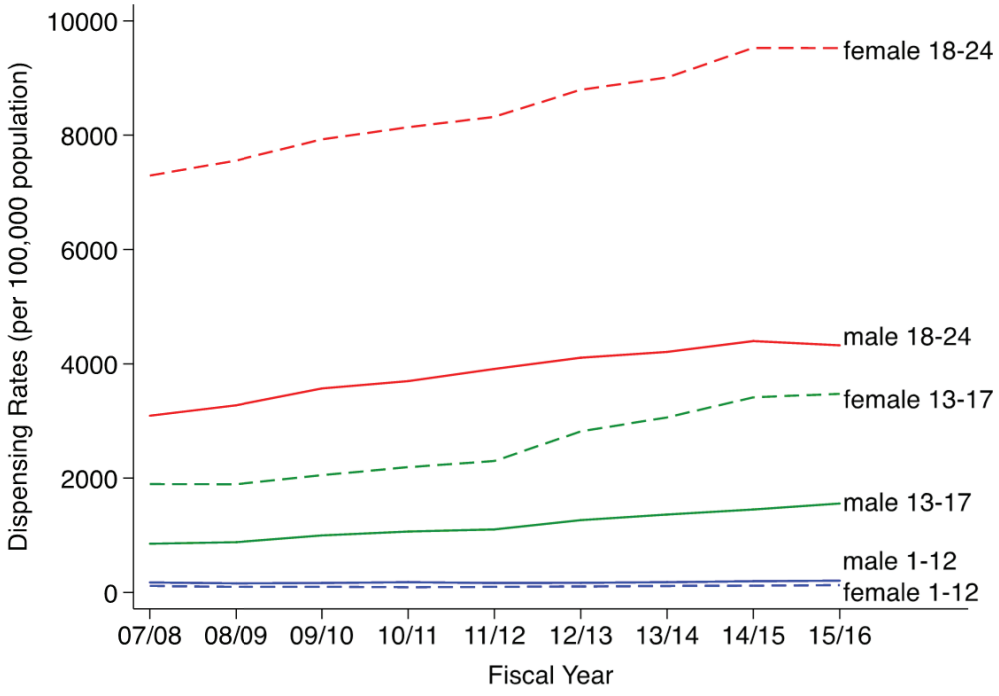


Table 2: Annual dispensing rates (per 100,000 people) by drug class and age category.

	SSRIs			TCAs			SNRIs		
Fiscal year	1–12	13–17	18–24	1–12	13–17	18–24	1–12	13–17	18–24
2007/08	71	1,001	4,122	77	410	1,176	2	26	261
2008/09	76	1,017	4,230	56	403	1,241	1	24	313
2009/10	82	1,151	4,508	54	406	1,279	S	24	353
2010/11	90	1,215	4,612	50	441	1,293	S	33	371
2011/12	89	1,287	4,736	45	438	1,372	S	32	416
2012/13	95	1,594	4,993	45	490	1,412	S	38	438
2013/14	100	1,745	5,073	49	489	1,440	S	45	537
2014/15	117	1,948	5,307	42	517	1,460	S	65	647
2015/16	128	2,017	5,195	42	525	1,464	1	71	739
% Change*	80.6	101.5	26.0	-45.6	28.0	24.6	-42.4	177.7	183.4

*% Change refers to the percentage change in dispensing rates from 2007/08 until 2015/16.
S Suppressed due to low (<6 observations) count.
Due to the low number of dispensings TeCAs, NaSSAs and MAOIs are not presented.

typically about 60% higher than females. Females aged 18–24 had the highest rates of antidepressant dispensing, with almost 1 in 10 (9,522 per 100,000) receiving an antidepressant in 2015/16. Rates for all age-sex groups increased over the time period.

Dispensing rates by drug class varied across age categories and over time (see Table 2). SSRIs were the most frequently dispensed drug class in all age groups. Over time SSRI rates increased but the magnitude of this increase was greatest for the younger

Table 3: Annual dispensing rates (per 100,000 population) by drug for 1–12 age group.

	07/08	08/09	09/10	10/11	11/12	12/13	13/14	14/15	15/16	%Change*
Amitriptyline	39	30	34	30	28	29	34	29	29	-26.1
Citalopram	15	19	21	23	21	21	23	24	18	14.7
Clomipramine	1	S	1	1	S	S	S	S	S	-
Dosuleprin	3	S	S	S	S	S	S	S	S	-
Doxepin	3	2	S	1	1	S	S	S	S	-
Imipramine	21	16	12	12	9	10	9	7	7	-69.3
Nortriptyline	10	8	7	6	7	5	7	7	7	-33.2
Fluoxetine	51	57	60	66	64	66	67	79	89	76.0
Moclobemide	S	S	S	S	S	S	S	S	S	-
Venlafaxine	2	1	S	S	S	S	S	S	1	-61.6
Mirtazapine	S	S	S	S	S	S	S	S	S	-
Escitalopram	S	S	S	S	1	4	7	8	8	-
Sertraline	S	S	S	2	4	6	8	13	19	-
Paroxetine	8	4	3	2	2	1	S	S	S	-

S Suppressed due to low (<6 observations) count.
*% Change refers to the percentage change in dispensing rates from 2007/08 until 2015/16.
Percentage changes are not calculated if either the 07/08 or 15/16 value is suppressed or missing.
Due to low numbers Trimipramine, Mianserin, Maprotiline, Tranylcypromine and Phenelzine are not presented.

Table 4: Annual dispensing rates (per 100,000 population) by drug for 13–17 age group.

	07/08	08/09	09/10	10/11	11/12	12/13	13/14	14/15	15/16	%Change*
Amitriptyline	256	248	255	282	276	292	300	319	334	30.5
Citalopram	363	359	441	441	423	443	419	439	248	-31.5
Clomipramine	7	9	6	6	7	9	5	5	4	-39.7
Dosuleprin	16	13	13	10	8	7	7	8	8	-50.3
Doxepin	24	26	21	16	15	17	13	13	10	-57.8
Imipramine	24	26	17	16	15	15	13	9	8	-66.2
Nortriptyline	98	97	108	125	136	167	172	182	186	88.9
Fluoxetine	649	681	756	804	828	1,023	1,093	1,184	1,287	98.3
Moclobemide	5	6	5	5	3	4	4	2	S	-
Venlafaxine	26	23	24	32	33	38	45	65	71	167.8
Mirtazapine	S	S	S	10	14	18	23	29	10	-
Escitalopram	S	S	S	10	49	118	167	214	267	-
Sertraline	S	S	S	28	84	156	230	302	388	-
Paroxetine	66	58	54	55	47	53	53	58	49	-26.1

S Suppressed due to low (<6 observations) count.
*% Change refers to the percentage change in dispensing rates from 2007/08 until 2015/16.
Percentage changes are not calculated if either the 07/08 or 15/16 value is suppressed or missing.
Due to low numbers Trimipramine, Mianserin, Maprotiline, Tranylcypromine and Phenelzine are not presented.

age groups; 81% (from 71 per 100,000 in 2007/08) and 102% (from 1,001 per 100,000) for 1–12s and 13–17s respectively compared to 26% for 18–24s. Rates of TCA dispensings declined 46% (from 77 per 100,000) for 1–12s but increased 28% (from 410 per 100,000) and 25% (from 1,176 per 100,000) for the older age groups. SNRI rates nearly tripled over the study period for 13–17s up 178% (from 26 per 100,000) and for 18–24s up 183% (from 261 per 100,000) but remained constant at near zero for 1–12s.

Fluoxetine was dispensed at the highest rate within the 1–12 age group (Table 3) and almost doubled from 51 to 89 per 100,000 during the study period. Amitriptyline dispensing was the second highest at 29 per 100,000 in 2015/16 but decreased (-26%) over the time period. Sertraline and Citalopram were next at 19 and 18 per 100,000 in 2015/16 respectively. Sertraline and Escitalopram both came into funded use during the study period and by 2015/16 had experienced large uptakes in use. Dispensing rates for Imipramine and Nortriptyline declined over the study period.

For 13–17-year olds (Table 4), Fluoxetine again had the highest rate of dispensing at 1,287 per 100,000 in 2015/16, nearly double that of 07/08 and more than three times greater than any other antidepressant. Sertraline, Amitriptyline, Escitalopram and Citalopram (in that order) were the four other drugs dispensed at greater than 200 per 100,000 in 2015/16. The use of Sertraline and Escitalopram increased rapidly since they were introduced in 2010/11. Of antidepressants dispensed over the entire study period Venlafaxine increased the most, up 168% (from 26 per 100,000) and in 2015/16 was the seventh most dispensed drug within this age group.

For 18–24-year olds (see Table 5) Fluoxetine remained the drug with the highest dispensing rate (1,990 per 100,000 in 2015/16); however, unlike the younger age groups, rates stayed largely constant over the study period. Citalopram was the second most dispensed drug, but declined in use over time (down 30% to 1,274 per 100,000). Escitalopram and Sertraline were the third and fourth most dispensed drugs within this

Table 5: Annual dispensing rates (per 100,000 population) by drug for 18–24 age group.

	07/08	08/09	09/10	10/11	11/12	12/13	13/14	14/15	15/16	%Change*
Amitriptyline	668	713	729	730	781	823	852	865	874	30.8
Citalopram	1,822	2,069	2,361	2,440	2,363	2,202	2,059	2,004	1,274	-30.1
Clomipramine	20	29	26	24	30	31	28	20	26	31.6
Dosuleprin	86	79	71	60	53	42	38	33	35	-58.8
Doxepin	80	72	67	56	56	53	45	35	35	-55.9
Imipramine	22	25	21	21	18	17	12	7	8	-65.2%
Nortriptyline	333	369	418	451	491	509	527	561	544	63.4%
Fluoxetine	1,992	1,902	1,950	1,913	1,884	1,943	1,880	1,892	1,990	-0.1%
Moclobemide	31	29	30	30	32	28	21	25	6	-79.1%
Venlafaxine	262	313	353	371	416	438	538	647	740	182.9%
Mirtazapine	S	S	27	81	110	114	123	134	68	-
Escitalopram	S	S	S	74	281	525	675	869	1,096	-
Sertraline	S	S	S	75	224	403	561	730	951	-
Paroxetine	690	632	603	548	482	459	412	385	381	-44.8%

S Suppressed due to low (<6 observations) count.
*% Change refers to the percentage change in dispensing rates from 2007/08 until 2015/16.
Percentage changes are not calculated if either the 07/08 or 15/16 value is suppressed or missing.
Due to low numbers Trimipramine, Mianserin, Maprotiline, Tranylcypromine and Phenelzine are not presented.

Figure 2: Dispensing rates by ethnic group, 07/08 to 15/16.

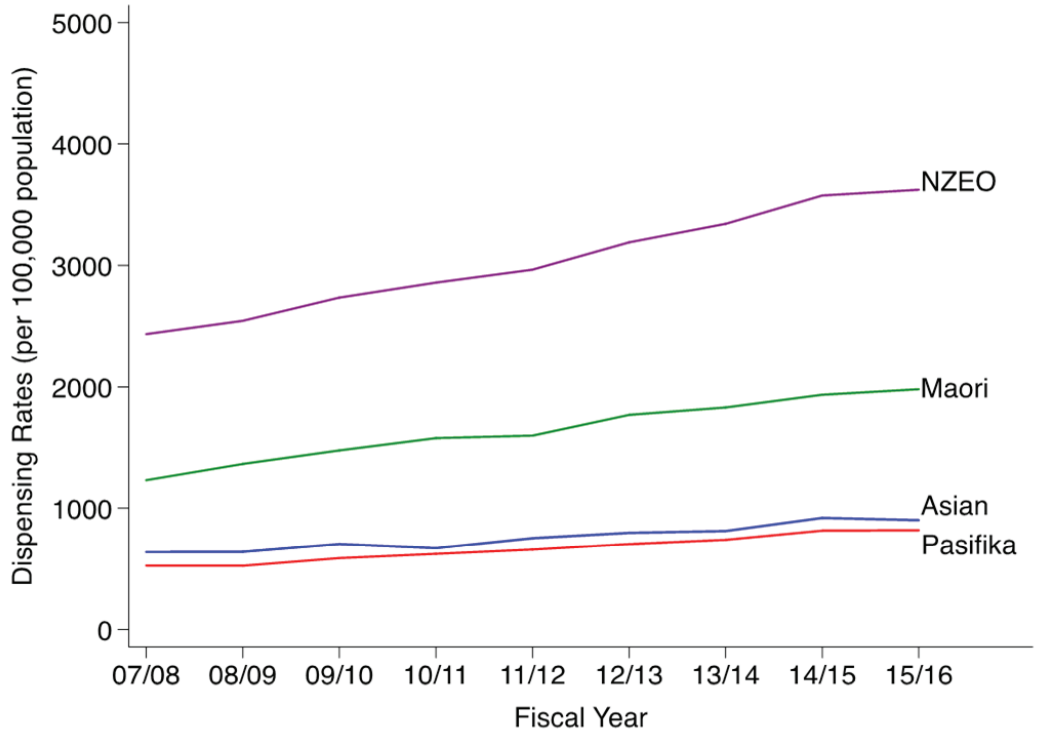
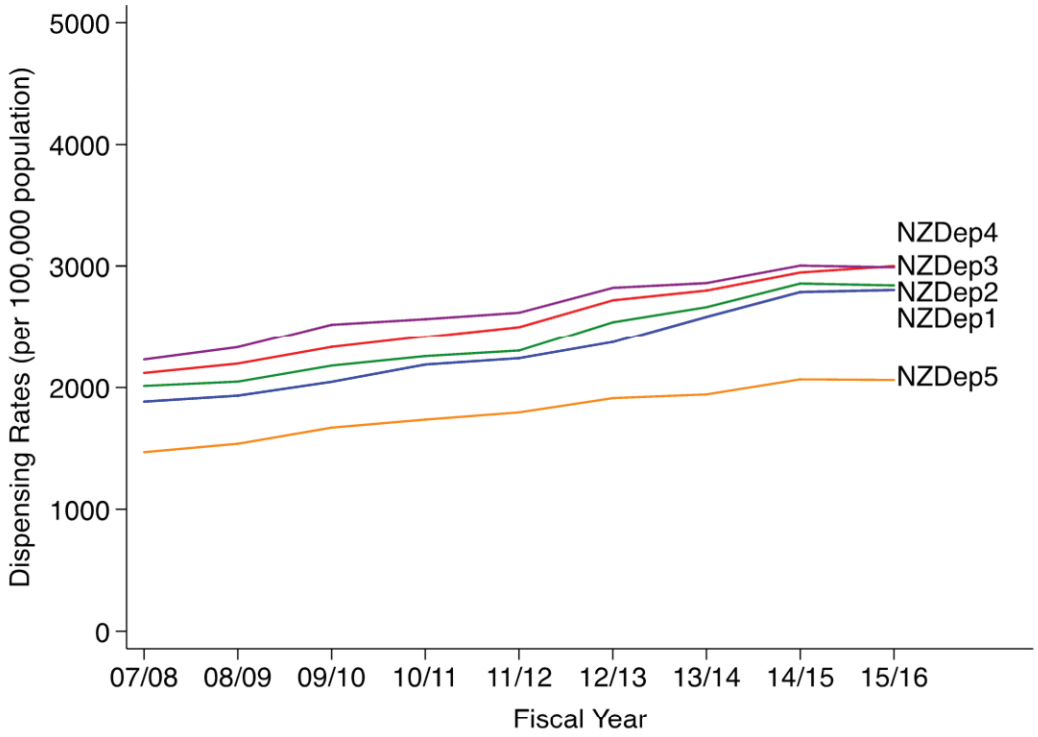


Figure 3: Dispensing rates by nzdep quintile, 07/08 to 15/16.



age group and dispensing increased rapidly following their entry into the market. Venlafaxine dispensing rates increased nearly threefold between 2007/08 and 2015/16 from 262 to 740 per 100,000.

Dispensing by ethnicity and socioeconomic status

Dispensing rates vary by ethnic group (Figure 2). The New Zealand European/Other (NZEO) ethnic group had the highest dispensing rates, with 3,623 per 100,000 receiving an antidepressant dispensing in 2015/16. Māori had the next highest rates, with 1,980 per 100,000 receiving an antidepressant in 2015/16. Rates for Asian (902 per 100,000) and Pasifika (819 per 100,000) were lowest. Rates for all ethnic groups increased over the period from 2007/08 to 2015/16, but the increase was steeper for Māori than for the other groups.

Antidepressant dispensing rates also varied by socioeconomic status (see Figure 3). For children and young people from NZDep quintiles 1 to 4, annual antidepressant dispensing rates typically increased slightly as deprivation increased. However, dispensing rates for the most deprived quintile (quintile 5) were lower than for all other quintiles (27% lower than quintile 1 in 2015/16). Dispensing rates for all quintiles increased over the nine-year study period, but increases tended to be smaller as deprivation increased.

Discussion

This study demonstrates for the first time that IDI data can be used to measure and track national rates of dispensed medication. During the nine-year period of this study, the total number of annual antidepressant prescriptions dispensed to children and young people increased by 68% from 111,171 in 2007/08 to 186,396 in 2015/16 and the rate of prescribing increased by 44% from 1,870 per 100,000 to 2,694 per 100,000. These increases occurred for both sexes and across all age groups. However, there was some notable variation in prescribing by ethnicity and socioeconomic status.

Upward trends in the total number and rates of dispensed antidepressants are consistent with, although on the upper end of, estimates from previous studies of antidepressant dispensing to children

and young people.[6,8,9] However, the rates at which different medications and medication classes are being dispensed have changed over time and patterns vary by age group. For example, rates of dispensing of SSRIs, especially Fluoxetine, have increased particularly in those aged 13–17 years, the use of TCAs has decreased in the youngest age group and increased in adolescents and young adults, and rates of SNRI prescribing have increased by 178% in the 13–17 age group (from 26 per 100,000 in 2007/08) and 183% (from 261 per 100,000) in the 18–24 age group. These variations may reflect changes to the pharmaceutical schedule, including availability of specific medications, medication subsidies and supply restrictions as well as evolution of evidence, including condition-specific treatment guidelines. Although reported dispensing rates encompass both primary and specialist service prescription, it should also be noted that access to specialist mental health services (funded to address the top 3% of mental health conditions) has improved from 1.3% to 2.9% during the period of investigation.[24] It may be that increased dispensing reflects improved access, and patterns of dispensing may suggest better mental healthcare. However, without linkage to diagnostic information, it is not possible to be certain.

The most likely mental health disorders to be treated with antidepressant medication are anxiety and depressive disorders. The prevalence and nature of these disorders vary with age.[25] Anxiety disorders are particularly developmentally linked in presentation. Children are more likely to experience separation anxiety disorder and generalised anxiety disorder, while young people are more likely to develop social phobia and panic disorder. Fluctuation occurs in the prevalence of individual anxiety disorders, with some reducing and other increasing with age. The 2016/17 New Zealand Health Survey estimates 3.0% of parents of children aged 2–14 have been told by a doctor their child has an anxiety disorder.[26] At 15 years of age, between 10.7% and 12.8% of young people have a diagnosable anxiety disorder.[27] In contrast, rates of depressive disorder increase significantly during adolescence from 2% at 11 years of age[28,29] to 4.2% by 15 years of age[27] and between 16–18% by adulthood.[27,30–34] Treatment guidelines for both anxiety and depressive disorders recommend the use of non-pharmacologic strategies ahead of medication except in cases of severe illness or when other measures have not been successful. Antidepressant medications, especially SSRIs have been shown to be modestly beneficial for the treatment of anxiety[16,35,36] and depression[14,16] in children and young people. On the other hand, TCAs are contraindicated for adolescent depression due to lack of effectiveness and lethality with overdose[37] and there is limited evidence for SNRI use in young people.[38] Our data indicate that SSRIs are the most likely antidepressant medication to be dispensed to children, that TCA prescribing has reduced over time and that SNRIs are only being prescribed to a small number of adolescents. Therefore, our findings are concordant with contemporary clinical expectation.

There was striking variation in dispensing rates by ethnicity. Children and young people of New Zealand European/Other ethnicities had the highest rates of antidepressant dispensing, followed by those of Māori, Asian and Pasifika origin. Our findings update, extend and echo those by Exeter et al, who found that dispensing rates to New Zealanders aged 15–100 years were higher for NZEO groups, compared with Māori and Pasifika youth. In our study, annual dispensing rates to NZEO were consistently over 80% higher than for Māori and over four times higher than for Pasifika. Māori children and young people make up 25% of New Zealand's 0–19 years population and nearly half (43%) of Māori people are aged between 0 and 19 years. Similarly, Pasifika infants, children and young people make up 10% of New Zealand's 0–19 years population and 39% of Pasifika people are aged between 0 and 19 years. Both Māori and Pasifika people experience greater rates of mental health disorder and clinical need.[26,33] Despite previous studies of adults in general practice showing lower rates of service access for Māori and Pasifika compared with those of NZEO ethnicities,[39] recent analysis highlights that things are different for children and young people accessing specialist mental health services. Māori children and young people access these services at a rate of

3.7% and constitute the highest proportion (32%) of clients. Approximately 1.8% of Pasifika children and young people access these services and make up 6% of the total number of clients. Asian children and young people make up 13% of New Zealand's 0–19 years population and access mental health services at a rate of 0.8%.[24] Identified differences in antidepressant dispensing rates do not correlate with either the proportion of people from different ethnicity or rates of service access to tertiary mental health services, where these medications are typically initiated. So, it is likely that other factors including the cost of medication,[40] health literacy,[41] medical practitioners bringing a scientific view only to consultations (ie, lacking cultural awareness and understanding),[42] and culturally mediated beliefs about treatment[43] are responsible for these differences. This issue requires further scrutiny if dispensing-related health disparities are to be reduced.

Differences in antidepressant dispensing by socioeconomic status may be explained by two groups of factors. The first, which probably underpins the increase in dispensing from the 1st to the 4th quintile, is the increased likelihood of mental health problems with increasing deprivation and associated adversity.[26,44,45] The second, which may explain the reduction in dispensing to those in the 5th quintile, includes lower rates of parental education,[46] a multitude of barriers to service access and affordability of treatment[40] for families in this subgroup.

The use of IDI data for analysing health trends is a relatively new venture which generates as many ethical questions as it does solutions. As larger amounts of data become available in an exponentially increasing manner (2.5 exabytes of 'big data' were generated internationally per day in 2016, with 90% of all available data being generated in the previous two years[47]), it appears wasteful not to use nationally available information to improve transparency about health issues, to assist in reducing inequities, and to track the outcomes of service changes and novel interventions. However, such increased analytical power needs to be balanced with the right to privacy for individuals, issues of data ownership in life and death, the veracity and completeness of available information, mechanisms for managing unexpected findings and agreed limits to the usage of data.[48] Mechanisms for the effective use of open data have been proposed by Gurstein[49] and others. These centre on trust, clarity of data ownership and the balance of rights between data owner and data exploiter.

To date, in New Zealand, discussions regarding the use of IDI data have included balancing the public good with informed consent, concluding that the benefits of a greater understanding of key health and social phenomena outweighs the relatively small risk associated with sharing these data more widely. However, the reverse could be true for Māori and Pasifika communities. The continued comparison with other ethnic groups with no improvements is in itself a form of harm. As a result, there has been an ongoing dialogue with indigenous data sovereignty groups. The issue of Indigenous Data Sovereignty that states that data are subject to the laws of the nation from which it is collected (including Tribal nations) is one which continues to receive attention in New Zealand but is unresolved (Kukutai, 2006) and those advocating for Pasifika that these data be used to improve the circumstances for Māori and Pacific communities rather than simply characterising observed differences. Furthermore, Durie (2006) stated that "although universal measures can be applied to Māori as they can to other populations, there are also unique characteristics of Māori that require specific measurement".[50] Data on Māori and Pasifika dispensing rates have been used in this paper, however they are also being separately analysed and additional cultural measures are being applied.

Overall, this study provides preliminary evidence of how IDI data can be used in a positive way to examine health trends and disparities. It also highlights limitations with these data and where additional linked data would be useful. Further clarification is needed, not just of the issues raised by these data, but also of the mechanisms of future IDI data refinement and utilisation at a national level.

The major strength of this study is the use of a large national dataset to provide information regarding prescriptions to all New Zealand children and young people

over almost a decade. In addition, we were able to calculate accurate population denominators and access socioeconomic deprivation and ethnicity information that would not otherwise have been available. Limitations of this study include lack of information regarding diagnoses and clinical reasons for prescription, sequencing of antidepressant use, other treatments such as psychotherapy and outcomes of treatment. Without this information, it is difficult to accurately determine for which disorders antidepressant medications are being prescribed at different ages, whether this is in line with individual treatment guidelines and whether current prescribing is making a difference at an individual or population level. In addition, as the IDI only contains data on filled prescriptions, it may not be an accurate reflection of the total number of prescribed medications, nor will it fully reflect medication adherence. Finally, analysis of prescription by primary care and specialist services and geographical regions has not been separately evaluated, so variations in prescribing practice between clinicians from different types of service cannot be determined.

For the moment, clinicians and researchers need to be aware that there have been changes in antidepressant dispensing over time and that there are discrepancies in dispensing rates between children and young people of different ethnicities and socioeconomic groups. Further linkage of diagnostic and treatment datasets is necessary to meaningfully comment on the appropriateness of current prescriber practice and to examine in more detail inequalities and potential inequities such as access to care. Following this, interventions to address current disparities in dispensing should be developed and evaluated. The IDI should be seen as a valuable resource in undertaking such research extensions and evaluations. Future research of patterns of dispensing could include duration of treatment and dose across sociodemographic groups and over time which may shed light on some of the health disparities identified. Finally, the current study should be repeated in 5 to 10 years to examine future dispensing trends.

Conclusion

This study demonstrates that the IDI can be used to measure and track national rates of dispensed medication. Currently available data indicate that antidepressant prescribing to New Zealand children and young people has increased across all age, sex and ethnic groups between 2006/7 and 2015/16, with some discrepancies between people of different ethnicities and deprivation. With further linkage of IDI datasets and research, it may be possible to improve the concordance of prescribing practice with treatment guidelines for depression and other childhood disorders and to reduce existing inequalities in healthcare.

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

Acknowledgements:
This research was part of the Better Start National Science Challenge, Funded by the New Zealand Ministry of Business, Innovation and Employment (MBIE). We also thank Professor Paul Glue, Rose Richards and Jesse Kokaua for their contributions.
The results in this paper are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI), managed by Statistics New Zealand. The opinions, findings, recommendations, and conclusions expressed in this paper are those of the author(s), 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.

Author information:
Nicholas Bowden, Better Start National Science Challenge; Department of Women's and Children's Health, University of Otago; Sheree Gibb, Better Start National Science Challenge; Department of Public Health, University of Otago, Wellington;
Hiran Thabrew, Better Start National Science Challenge; Department of Psychological Medicine, University of Auckland, Auckland; Richard Audas, Better Start National Science Challenge; Department of Women's and Children's Health, University of Otago;
Justine Camp, Better Start National Science Challenge; Department of Women's and Children's Health, University of Otago; Barry Taylor, Dean of the School of Medicine, University of Otago; Sarah Hetrick, Better Start National Science Challenge; Department of Psychological Medicine, University of Auckland, Auckland.

Corresponding author:
Nicholas Bowden, Women's and Children's Health, University of Otago, 201 Great King Street, Dunedin 9016.
nick.bowden@otago.ac.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8040

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Electric scooter injuries at Auckland City Hospital

Anna BS Brownson, Paul VB Fagan, Samuel Dickson, Ian DS Civil

ABSTRACT

AIM: Since the introduction of shared electric scooters to Auckland in October 2018, there have been multiple reports of injuries. We aim to examine the pattern of injuries sustained while riding electric scooters in patients presenting to hospital.

METHODS: We conducted a retrospective analysis of patients who presented to Auckland City Hospital Emergency Department (ED) between 15 October 2018 and 22 February 2019. Patients were firstly identified by ED staff and noted in a logbook, and secondly by searching the Trauma Registry database. Outcomes of interest were injuries, imaging, alcohol and helmet use, length of stay and interventions.

RESULTS: There were 180 patients identified. The median length of stay was 4.0 hours, interquartile range (IQR) 18.4 hours. One-third of patients were admitted or transferred. Common injuries were contusions, abrasions and lacerations (65.6%), fractures (41.7%) and head injuries (17.2%). One in five patients (22.2%) required an operation. Only three patients wore a helmet. Of all patients, 23.3% had consumed alcohol, and of those with head injuries; 41.9% had consumed alcohol.

CONCLUSION: This study highlights the significant number of electric scooter-related injuries, including severe head injuries. While the majority of presentations are categorised as minor trauma, these cases have placed additional demand on health system resources. This mode of transport would benefit from greater regulation, including a zero blood alcohol limit, night-time curfews, reduced speed limits and consideration of mandatory helmet use.

Standing electric scooters have proliferated worldwide as a convenient mode of transport. In October, 2018, the first commercial shared electric scooters were introduced into the city of Auckland.[1] Electric scooters are ridden by standing one foot in front of the other, and initially kicking off by foot. They have waist-high handlebars with accelerator and braking triggers and can travel up to 30 kilometres per hour (kph), and potentially faster downhill. By New Zealand law, electric scooters may be ridden on footpaths or roads, but not in dedicated bicycle lanes. There are no speed limits and wearing a helmet is not legally required.[2] There is existing evidence on injury patterns related to other two-wheel transports. Non-motorised push scooters are known to be associated with a predominance of wrist fractures and injuries to the head and face.[3–6] Motorised scooters have been shown to cause more concussions and lower-limb injuries in children, when compared to non-motorised scooters.[3] Segway branded scooters are commonly associated with injuries to the upper and lower extremities and in particular radius fractures.[7] The aim of this study is to examine the pattern and severity of injuries associated with electric scooter use in Auckland.

Methods

We conducted a retrospective analysis of two databases to identify patients with electric scooter-related injuries presenting to Auckland City Hospital ED between 15 October 2018 and 22 February 2019. This 19-week timeframe reflects the initial period scooters were on Auckland streets before being temporarily removed amidst safety concerns. Cases were identified using two methods; firstly, patients presenting to ED had their National Health Index (NHI) number noted in a logbook by ED staff. Secondly, the Auckland City Hospital Trauma Registry was electronically searched using key words ‘scooter’, ‘electric’ and ‘lime’. The

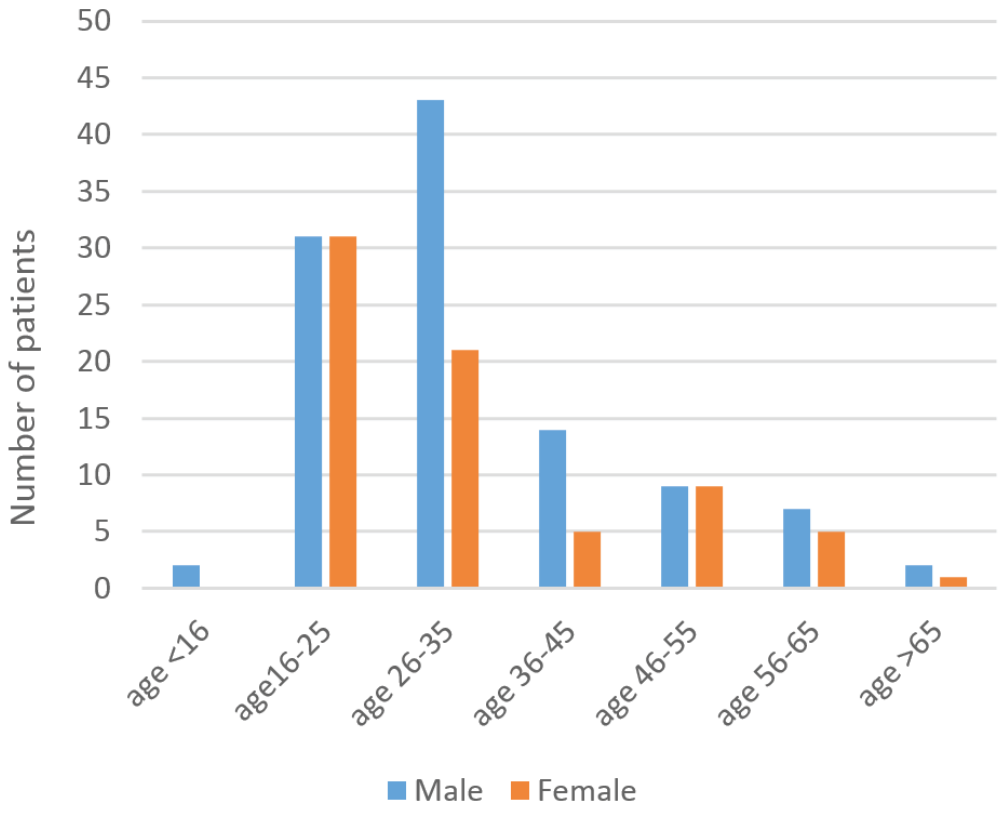
trauma registry prospectively collects demographic and injury data on patients admitted with trauma. Data were extracted from ambulance, emergency and clinical notes, electronic discharge summaries, radiology reports and Accident Compensation Corporation (ACC) claims. We examined patient demographics, injury types, imaging, alcohol and helmet use, length of stay, patient disposition and interventions. Fractures were reported by a radiologist on a plain film radiograph, computerised tomography (CT) scan or magnetic resonance imaging (MRI). Injury categories were coded using The Abbreviated Injury Scale 1990 Revision, Update 1998 (AIS 98).[8] Data were re-checked by blinded abstractors. We included all patients who presented to Auckland City Hospital within the study timeframe with electric scooter-related injuries. We excluded patients with injuries related to non-electronic scooters, moped scooters or other seated scooters. Repeat visits for the same patient were also excluded, eg, for ongoing pain or wound review. This study received ethics approval from the Auckland Health Research Ethics Committee.

Results

In total, we identified 180 patients as having electric scooter-related injuries during our 130-day timeframe. Of these, 169 were recorded in the ED logbook, and 46 identified from the trauma registry; 11 of whom had not been captured in the ED logbook. There were 11 patients excluded. Patient demographics are shown in Figure 1 and Table 1. Age ranged from 15 to 73 years (median 28, IQR 16). There was a male predominance (60.0%). Only three patients (1.7%) were found to have worn a helmet, and of these, one was a workplace hard hat. The majority of patients (140/180, 77.8%) had no documentation about helmet use.

Blood alcohol level (BAL) was measured in only 28 patients (15.6%). BAL ranged from 0 to 55mmol/L. The legal blood alcohol limit for driving in New Zealand is 50mg per 100mL of blood (10.9mmol/L).[9] There were 17 out of 28 patients with BAL greater than zero, 16 of whom were over the legal driving limit. A further 24 patients (24/180, 13.3%) self-reported consuming alcohol prior to their accident, but did not have BAL testing.

Figure 1: Demographics, patient age and sex.



NZMJ 8 November 2019, Vol 132 No 1505
ISSN 1175-8716

Table 1: Patient and accident characteristics for electric scooter injuries presenting to ED during a 19-week period.

	Number of patients	Percentage of total (N=180)
Helmet use		
Yes	3	1.7%
No	37	20.6%
Not specified	140	77.8%
Alcohol intake		
BAL 0	10	5.6%
BAL >1	17	9.4%
Alcohol reported	25	13.9%
Not specified	128	71.1%
Scooter type		
Lime brand	168	93.3%
Personally owned	2	1.1%
Electric not specified	10	5.6%
Mechanism of injury		
Isolated fall	165	91.7%
Scooter malfunction	6	3.3%
Car	5	2.8%
Pole/bus stop	3	1.7%
Pedestrian	1	0.6%
Medical event	1	0.6%
Mechanism of transport to ED		
Self-presented	122	67.8%
Ambulance	58	32.2%
Disposition		
Discharged	120	66.7%
Admitted	49	27.2%
Transferred	11	6.1%
Length of stay		
<4 hours	89	49.4%
4–24 hours	49	27.2%
1–7 days	34	18.9%
>7 days	8	4.4%

*BAL, Blood Alcohol Level (mmol/Litre).

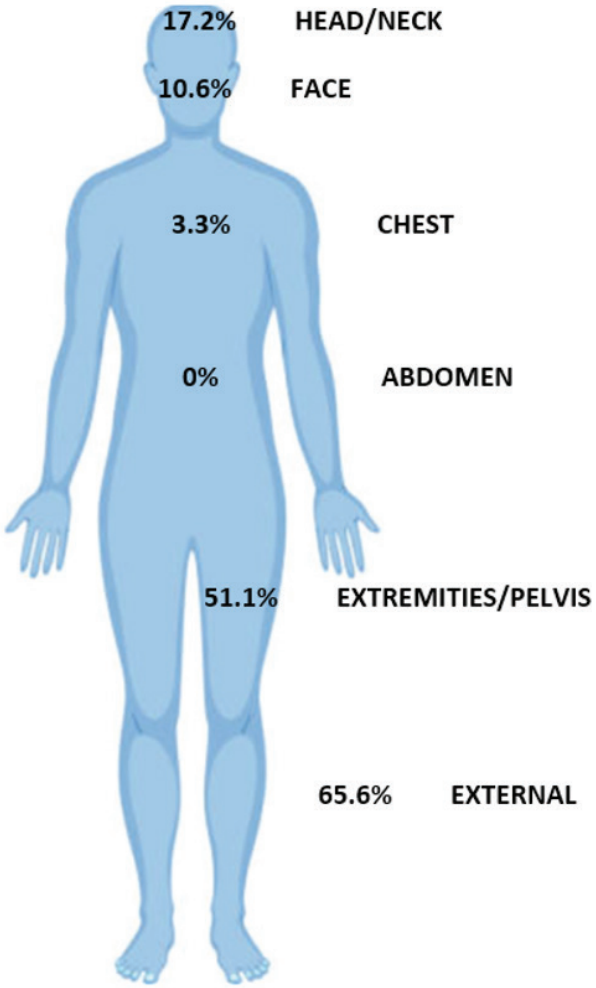
The remaining patients (128/180, 71.1%) had no documentation about alcohol intake.

Most injuries occurred on Lime branded scooters (168/180, 93.3%), two were on personally owned electric scooters, and 10 were not specified. The most common mechanism of injury was an isolated fall that did not involve another person or vehicle (165/180, 91.7%). This included skidding, braking, swerving, or hitting a curb, drain or pothole. There were six reports of scooter malfunction, which included unexpected braking (n=5) and scooter handlebars falling off (n=1). There were five crashes involving a car and one crash involving a pedestrian. Most cases did not have speed documented, however, those that did reported speeds of between 15 and 40kph at time of crash.

There were 58 patients (32.2%) brought into ED by ambulance. Two-thirds of patients (120/180, 66.7%) were discharged directly from ED, 49 were admitted to Auckland City Hospital and 11 were transferred. Transfers occurred for two reasons; either because specialty services were based at other hospitals; Middlemore Hospital maxillofacial surgery (n = 5) and Middlemore Hospital plastic surgery (n = 5), or because patients were outside of their domicile area on presentation; North Shore Hospital orthopaedic surgery (n= 3). Only one patient required admission to the Department of Critical Care Medicine (Table 3, Patient 1).

The length of stay (LOS) ranged from 16 minutes to 25 days (median 4.0 hours,

Figure 2: Percentage of patients with injuries by ISS body region.



*Six body regions are defined by the Injury Severity Score (AIS 98).
*Percentages given are of all patients (N=180).
*Categories are not mutually exclusive.

Table 2: Injury characteristics, severity and interventions.

		Number of patients	Percentage of total (N=180)
Laceration(s)		**45**	**25.0%**
Head/scalp		5	2.8%
Facial		35	19.4%
Upper Limb		8	4.4%
Lower limb		3	1.7%
Genitals		1	0.6%
Sprains		**31**	**17.2%**
Dislocations		**4**	**2.2%**
Fracture(s)		**75**	**41.7%**
2 or more fractured bones		35	19.4%
Head or neck		**22**	**12.2%**
	Skull	5	2.8%
	Facial	8	4.4%
	Mandible	4	2.2%
	Dental	11	6.1%
	Cervical	1	0.6%
Chest	Clavicle	4	2.2%
	Rib	2	1.1%
Upper limb		**30**	**16.7%**
	Finger	4	2.2%
	Hand	7	3.9%
	Wrist	16	8.9%
	Elbow	10	5.6%
	Shoulder	3	1.7%
Lower limb		**32**	**17.8%**
	Toe	2	1.1%
	Foot	9	5.0%
	Ankle	6	3.3%
	Knee	16	8.9%
	Proximal femur	2	1.1%
Head injuries		**31**	**17.2%**
Concussion		21	11.7%
Skull fracture		5	2.8%
ICH		8	4.4%

Table 2: Injury characteristics, severity and interventions (continued).

Injury Severity Score		
<6	144	80.0%
6–12	28	15.6%
>12	8	4.4%
Requiring surgery	**40**	**22.2%**
Orthopaedic	27	15.0%
Maxillofacial	5	2.8%
Plastic	4	2.2%
Neurosurgery	2	1.1%
Urology	1	0.6%
Chest drain insertion	**1**	**0.6%**

*Facial laceration includes chin, cheek, lip, eye and forehead.
*ICH, intracerebral haemorrhage.
*Categories are not mutually exclusive.

IQR 18.4 hours). Nearly half of all patients (89/180) were discharged in less than four hours. Most patients presented between midday and midnight (127/180, 70.5%). The peak presentation time was between midday and 2pm (13.9%).

Injuries were graded and categorised according to the AIS 98. Figure 2 shows the percentage of patients with injuries in each of six body regions, as classified by the Injury Severity Score (ISS).[8] There were 31 patients (17.2%) with head and neck injuries and 19 patients (10.6%) with facial injuries. Only six patients (3.3%) had chest injuries; these included four clavicle fractures and two rib fractures; one with an associated flail chest and another with a pneumothorax (Figure 4). There were no abdominal injuries seen. Extremity injuries occurred in 92 patients (51.1%); these were made up by sprains, fractures and dislocations. There were 118 patients (65.6%) with external injuries, which included abrasions, lacerations and contusions, independent of location. ISS ranged from 1 to 29 (median 4, IQR 4). There were eight patients with ISS of greater than 12 (Table 3).

Table 2 shows injury characteristics and interventions required. There were 45 patients (25.0%) with one or more laceration requiring repair with either sutures or glue, and facial lacerations were the most common. Seventy-five patients (41.7%) sustained one or more bony fracture. Of the eight patients who sustained facial fractures, two had a Le Fort II fracture pattern, and one had a Le Fort III pattern. One patient sustained a C7 cervical vertebral lamina fracture, which was stable. The single most commonly fractured bone was the radius (n=23). In respect to imaging, plain radiographs were the most commonly performed modality. There were 59 patients (32.8%) who required a CT scan; most commonly of the head, followed by the face and wrist. Four patients (2.2%) required an MRI during their admission; knee (n=2), ankle (n=1) and wrist (n=1).

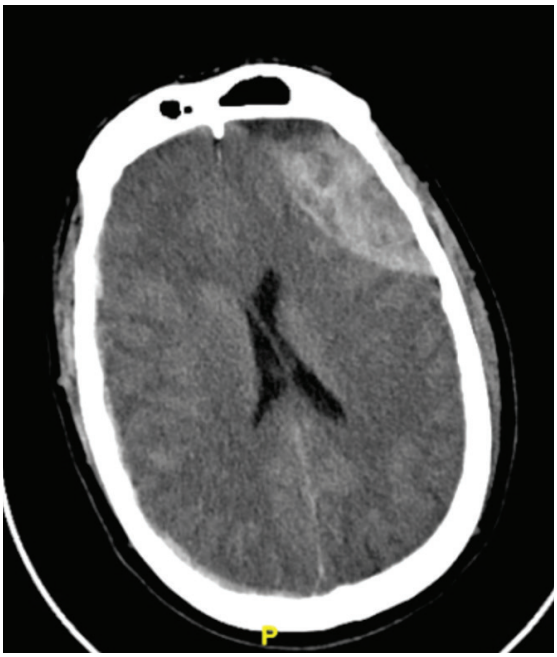
Head injuries, loss of consciousness and concussion were categorised and defined by the AIS 98. We identified 31 patients (17.2%) who sustained head injuries. There were 21 patients (11.7%) with concussion, including six who also had a witnessed loss of consciousness. There were five patients (2.8%) with a skull fracture, and eight (4.4%) with an intracerebral haemorrhage; two of whom had extradural haematomas requiring craniotomy. Of those patients who sustained a head injury, 13 out of 31 (41.9%), had consumed alcohol; either by having a positive BAL or by self-reporting. Of those patients without a head injury, 29 out of 149 (19.5%) had consumed alcohol. Operative management of injuries under general anaesthetic was required for 40 patients (22.2%). The single most common procedure was open reduction and internal fixation of the radius (n=12).

Table 3: Case reports of patients with Injury Severity Scores of greater than 12.

Patient 1 (ISS 29) Male in his 40s, sustained an unwitnessed fall, hitting his head against a concrete footpath while riding without a helmet. His BAL was 43mmol/L. He suffered a large frontal extradural haemorrhage with subarachnoid and subdural blood (Figure 3), as well as skull and facial fractures. He proceeded to have a craniotomy and intracerebral pressure monitor placement. He spent 18 days in DCCM, required a tracheostomy and developed ventilator-associated pneumonia. He had a total of nine CT scans and an admission of 25 days. He was discharged to the Brain Rehabilitation centre.
Patient 2 (ISS 29) Male in his 70s, travelling at 20kph, sustained a fall of unclear cause, hitting his head on concrete without a helmet. His BAL was zero. He sustained a small extra-axial haemorrhage, Le Fort I facial fractures with an unstable maxilla and avulsed teeth, and a comminuted metacarpal fracture. He was transferred to Maxillofacial Surgery for a midface ORIF. He had an admission of 10 days and was discharged home.
Patient 3 (ISS 26) Female in her 20s, turned sharply too fast and fell, hitting her head against concrete and losing consciousness. She sustained a 10mm frontal subdural haemorrhage with midline shift and trace subarachnoid blood, as well as an elbow laceration. Helmet and alcohol use were not specified. She did not require surgery but had a 14-day admission and was discharged to the Brain Rehabilitation centre.
Patient 4 (ISS 25) Female in her 40s, was riding at low speed and swerved to avoid a pedestrian, falling and striking her head on the road. She was not knocked out, but later referred in to ED with vomiting and memory loss. Helmet use was not specified, and her BAL was zero. She sustained a large extradural haemorrhage and proceeded to have a parietal craniotomy and evacuation. She was discharged home after four days.
Patient 5 (ISS 21) Male in his 40s, travelling at 15kph on a footpath, using his own personal scooter and wearing a helmet. His BAL was zero. He had an unclear mechanism of fall. He sustained multiple rib fractures with a flail segment, as well as a radial head fracture, lacerations and a significant soft tissue injury to his thigh. He had a 17-day admission and was discharged home.
Patient 6 (ISS 16) Female in her 50s who accelerated and lost control of her scooter, falling backwards and hitting her head on concrete. Helmet and alcohol use were not specified. She sustained a 2mm subdural haemorrhage and small subarachnoid haemorrhage as well as a scalp laceration. She was managed conservatively and discharged home after two days.
Patient 7 (ISS 14) Male in his 30s, travelling downhill at 25kph who fell forward putting his foot down and entangling his leg with the scooter and hitting his head. He sustained a comminuted tibial plateau fracture, scalp laceration and concussion. He proceeded to have an ORIF of his tibia and was discharged home after 11 days.
Patient 8 (ISS 13) Female in her 50s, riding in the rain and fell in a driveway, hitting her chest against the scooter. Helmet use was not specified but alcohol use was reported. She sustained right sided rib fractures and a traumatic pneumothorax requiring a chest drain (Figure 4), as well as a metatarsal fracture and extensor tendon injury to her finger. She was discharged home after six days.

*Abbreviations: ISS, Injury Severity Score. BAL, Blood Alcohol Level (mmol/L). DCCM, Department of Critical Care Medicine. CT, computerised tomography scan. ORIF, open reduction and internal fixation. Kph, kilometres per hour. ED, Emergency Department.

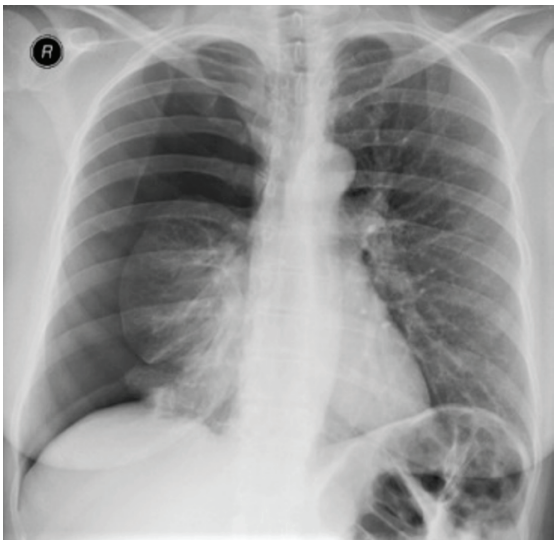
Figure 3: Axial slice of a non-contrast CT head showing an extradural bleed with midline shift.



Discussion

Our study presents a snapshot of injuries associated with electric scooters in Auckland. Patients were more likely to be young and male, and frequently occurring injuries included fractures, lacerations, sprains and head injuries. This pattern of injury is similar to that seen in a 2019 study by Aizupuru et al,[10] which retrospectively examined 820 motorised scooter injuries from across the US over four years. Like our study, they found head injuries (27.6%), and fractures or dislocations (23.9%), were common. Aizupuru did not examine helmet or alcohol use. Trivedi et al[11] conducted a retrospective study over the course of one year in Los Angeles, and found a total of 249 injuries. This makes our findings of 180 injuries in only 19 weeks seem comparatively large. Trivedi also found that contusions, sprains, lacerations, fractures and head injuries were common.

Figure 4: Frontal chest radiograph of a traumatic right pneumothorax which required a chest drain.



We observed that two-thirds of our study cohort were discharged directly from ED, which is lower than most other studies which found discharge rates of over 90%.[10–12] While there are demographic and healthcare differences between studies, this discrepancy may imply that we have not captured as many minor injuries. In Auckland this is particularly likely because of the numerous after-hours general practice and urgent care facilities. Our study is limited by the fact that it is single centre. Auckland City Hospital is an adult hospital which assesses patients aged 15 years and older, and we did not identify patients presenting to the three other adult hospitals in Auckland, or to Starship Children's Hospital. However, the Auckland District Health Board catchment area, which serves over 545,000 people, does also coincide with being the highest density electric scooter zone in Auckland.[13,14]

While ride-share scooter users are legally required to be 18 years of age, we found that 3.3% of riders were under this age, which is likely only a proportion of the true number. Trivedi[11] found 10.8% of riders were under 18 years of age despite existing regulations. On the other end of the age spectrum, we also observed a number of older patients using electric scooters; 18.3% were over 45. Older people are known to have more severe injuries in the setting of trauma,[15] and should exert particular caution when using electric scooters.

Although the majority of patients were discharged quickly and had a low ISS score, we did see a significant subset of patients requiring surgery and prolonged admission. We observed that one-third of patients used ambulance services, and one-third required CT imaging; which highlights the demand on our already stretched emergency and hospital services. While we have not attempted to estimate associated cost, there are reports that ACC has received 7,500 electric scooter-related claims in five months and paid out $2.9 million.[16]

It is unsurprising that the large majority of injuries occurred on Lime branded scooters, given that this was the sole commercially operating ride-share brand at the time of our study. The Lime organisation estimates that there were 7,500 rides taken per day in Auckland in January 2019.[17] We found 180 cases in 130 days, eg, 1.4 injuries requiring hospital treatment per day. This would give an injury rate of 18.3 per 100,000 rides, which could be termed as 'rare'. This number may be an underestimate because we are a single centre and relied on staff to identify patients. We do not have a direct comparison for injury rates per ride, however Aizupuru[10] found a rate of 2.6 cases of electric scooter injury per 100,000 people, which is also low. In New Zealand in 2016, the number of motor vehicle injuries was 265 per 100,000 people, and the number of pedal cyclist injuries was 16 per 100,000 people.[18]

Nearly one in four riders either stated that they had consumed alcohol or had a positive blood alcohol level. Trivedi[11] was the only other study to examine alcohol use, and they found a far lower rate than ours (4.8%). At Auckland City Hospital there is no mandatory requirement to test BAL, and we suspect this low threshold for testing, and poor documentation, means we have underestimated alcohol use. Consuming alcohol is in breach of ride-share agreements; the Lime User Agreement prohibits the consumption of 'alcohol, drugs or any other substance that may impair your ability to safely operate the vehicle'.[19] Our study did not look at the use of other drugs. We observed that far more patients with head injuries had consumed alcohol (41.9%), compared to those without head injuries (19.5%), although there may be bias regarding questioning by staff. Alcohol is assumed to be a major contributing factor to injuries.

There were a significant number of patients who sustained head injuries, including some severe traumatic brain injuries. Concussion can be difficult to diagnose and is often under-diagnosed in emergency settings,[20] and for this reason our findings may underestimate the true concussion incidence. The retrospective nature of our study, which relies on the quality of documentation, may also contribute to underestimating concussion. Only three patients were found to have worn a helmet, although documentation was poor. We suspect this lack of documentation indicates an assumption by staff that no helmet was worn; because there is no legal requirement to wear one, and there are no attached or accessible helmets when scooters are picked up. Helmet use is well

known to decrease incidence of head injuries and severity of traumatic brain injury in bicycle and motorcycle accidents,[21–23] and we presume the same protective effect would be true for electric scooters.

While we did not see any deaths in our study timeframe, in June 2019 the first death of an electric scooter rider was reported in Auckland, although circumstances are unclear.[24] There have been at least eight deaths reported in the US[25] and one death in Australia.[26]

Our study has shown a significant number of electric scooter-related injuries; the range and severity of which has not been known before. This has subsequently placed a new demand on health resources across Auckland. In order to fully examine the wider issues affecting the safety of riders, future studies need to be conducted to assess how accidents relate to speed and roading, and how injury rates compare to other modes of transport, eg, bicycles. Electric scooters are an affordable and convenient mode of transport, which should be supported as we try to encourage public transport use and reduce carbon emissions in the face of climate change. We feel that risk to riders should not be underestimated, and greater regulation is required—including a zero blood alcohol limit, reduction of maximum speeds, and the introduction of time curfews to prevent night-time riders who are more likely to be intoxicated. Given the incidence and seriousness of head injuries we have seen, mandatory helmet use should also be considered.

Competing interests:
Nil.

Acknowledgements:
The authors thank all of the Auckland City Hospital Emergency Staff Department for helping with this study.

Author information:
Anna BS Brownson, General Surgical Registrar, Auckland City Hospital, Auckland;
Paul VB Fagan, SET Trainee General Surgical Registrar, Auckland City Hospital, Auckland;
Samuel Dickson, General Surgical Registrar, Auckland City Hospital, Auckland;
Ian DS Civil, General Surgeon, Clinical Director Trauma Services, Auckland City Hospital, Auckland.

Corresponding author:
Dr Anna BS Brownson, Department of General Surgical and Trauma Services, Auckland City Hospital, 2 Park Road, Grafton, Auckland 1023.
alee@adhb.govt.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8041

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Untreated severe-to-profound hearing loss and the cochlear implant situation: how policy and practice are disabling New Zealand society

Lewis Williams

ABSTRACT

As a signatory to Convention on the Rights of People with Disabilities, Aotearoa New Zealand aims to be a "non-disabling society—a place where disabled people have an equal opportunity to achieve their goals and aspirations". Yet many adult New Zealanders with severe-to-profound hearing loss (SPHL) due to sensorineural deterioration over time are being denied timely access to publicly funded cochlear implants. This presents a serious inequity in Aotearoa New Zealand's health system and contravenes disability and human rights principles. For Māori affected by SPHL, this brings additional challenges along with broader impacts on Māori health and development. These issues are investigated through a self-case study together with a review of relevant evidence-based research and public policy.

Hearing is at least as equally important as vision. Unlike blindness, deafness is largely invisible, very misunderstood and its impacts underestimated. A key reason why there is enormous silence around deafness is that deaf people have less access to education, income, influence in public conversation (because of their deafness), and therefore have less access to societal power.

Nearly one in five New Zealanders experience hearing loss. The attrition of, and growing inequities between publicly funded hearing services across the country pose huge access challenges to many deaf and hearing-impaired New Zealanders in general. The most common reason why people are unable to access hearing-related services and equipment is that they simply cannot afford it.[1] This issue is exacerbated by the association between low-income and disability. For example, New Zealand's Deafness Notification Report shows the overwhelming majority of children and young people diagnosed with hearing loss live in high deprivation areas.[2]

While comparatively small in number, people with severe-to-profound hearing loss (SPHL) experience marked levels of social and economic marginalisation and attendant health inequities, due to the severity of their impairment. For people with SPHL caused by the degeneration of the hair cells in the cochlear (sensorineural hearing loss), cochlear implants have proven to be very reliable in restoring people's ability to be well functioning and contributing members of society.[3] However, recent cost cutting in the health sector has once again made publicly funded cochlear implants very difficult to obtain. The cost of a cochlear implant (CI) for one ear in Aotearoa New Zealand is approximately $50,000 NZD. Those with SPHL able to afford it generally

elect to receive privately funded CIs. Lack of publicly funded CIs exacerbates issues of access for Māori who generally have higher rates of hearing loss and unmet needs for technology and equipment when compared with non-Māori (while rates of higher hearing loss for Māori are particularly pronounced in the mild to moderate range, for those with SPHL, access to expensive hearing technology associated with CI is often pronounced relative to the rest of the population).[4] Due to the gendered nature of income disparities in New Zealand, we can also expect that women will have higher rates of unmet needs for hearing technology and equipment relative to men.

The total cost of hearing loss in New Zealand in 2016 was estimated as being 4.9 billion, comprising 957.3 million in financial costs and 3.9 billion in terms of loss of well-being.[1] Most of the financial costs are due to lost productivity. Hearing loss has been shown to have a considerable impact on a person's chances of employment leading to significant productivity, monetary and social losses. Research demonstrates that people with hearing loss suffer stigma from the hearing population, are often under-employed and experience reduced working opportunities.[5,6] People with hearing loss have been found to have a 10% reduction in the likelihood of employment, while those aged between 45–64 years of age with SPHL have a nearly 20% lower labour force participation rate.[1] These years are often a person's most productive. These impacts, as well as depression, cognitive decline and comorbidity as a result of the stress of untreated SPHL, are well documented in the deafness literature.[1,7]

As an oral-based society recovering from the impacts of colonisation and experiencing continued health disparities,[8] these issues have particular implications for Māori well-being and development to which Kaupapa Māori research methods are pivotal. Kaupapa Māori research demands kanohi ki te kanohi (face to face) interactions in a wide variety of often new encounters on and off marae, and other community and institutional settings. Kaupapa Māori research also demands researchers be attuned to the changing and nuanced relationships within iwi, hapū and whānau. While verbal communication is important in any community-based researchers' day-to-day work, it is even more so for Māori as a largely oral culture in which whakawhānaungatanga (practices of relationship building and connection) are very important. Working knowledge of Te Reo Māori is also vital.

This article represents a revised version of a letter sent by the author to the Chief Human Rights Commissioner. The self-case study section is written in the first person as it describes the author's direct experience as a person with SPHL. In its entirety, the paper also draws on the author's professional expertise as an experienced social worker, past director of a population health promotion research centre, Associate Professor of Public Health, and current experience as a senior Māori researcher. Some of the data drawn on refers to the Northern Region Cochlear Implant program, as the author lives within its regional boundaries. It should be noted that access to timely CIs for those suffering SPHL living in the Southern Region (Taupō to Bluff) is even worse.

Deafness and the cochlear implant situation in Aotearoa New Zealand

In New Zealand, SPHL people under 19 years of age deafened through sensorineural hearing loss generally receive two publicly funded CIs in a relatively short space of time. SPHL adults deafened through sensorineural hearing loss receive a maximum of one publicly funded CI (the bare minimum deemed to restore some functional level of hearing) and are placed on a lengthy waiting list (where they may be 'bumped down' because of more urgent cases presenting), with no advised date of surgery.[1] The average waiting time is around two years,[1] and up to four years for a considerable number of people, and on occasion six years.[7,9]

The Northern Region's base volume (guaranteed funding from central government) for the 2018–2019 financial year was set at 20 fully funded cochlear implants. On average there are eight new referrals per month. Currently there are 37 clients waiting with 10 of these waiting for more than two years.[9]

The actual time between needing a CI and receiving treatment is often in reality much longer than two years, as many adults are not being referred for assessment. Audiologists often consider referral to be fruitless in light

of New Zealand's stringent CI criteria and long wait list. Given this situation, potential CI recipients are often advised to go privately and/or self-refer to the private sector. For those who can afford it there is virtually no waiting time in the private sector.

Adults living with SPHL face increased difficulties with long wait times for cochlear implants, with many increasingly struggling to cope with everyday tasks. The longer the wait time, the less chance there is of recovery of the loss of auditory and neural functioning. Furthermore, significant social and economic loss frequently occurs in the lives of people with SPHL while waiting for help.[1]

Currently the candidacy guidelines for New Zealand adults are so stringent (audiometric thresholds of 90 db HL or above at 2 and 4 KHz) that many adults with poor access to speech are not being considered for publicly funded implants.[10] "This means that in New Zealand there is a clear difference between eligibility for funding and suitability for implantation".[11]

Self-case study

I am a social scientist and senior Māori researcher in my 50s. I am an integral part of, and contributor to my whānau and many communities. Diagnosed with a progressive hearing loss 22 years ago while undertaking my PhD studies,[12] today I have SPHL in both ears. For many years I have had to negotiate and compete in a 'hearing' world and workforce with a very significant hearing (and therefore communication) disability.

As a Māori researcher, communication is the linchpin of my work. It entails providing senior research capacity on a wide-ranging number of research projects and demands verbal communication and negotiation with a wide variety of research stakeholders, including iwi and community members, policy makers, practitioners and other researchers.

My current untreated condition means that I am unable:

1. To have a telephone conversation with a colleague, the doctor, or family and friends;
2. Undertake professional training that relies on oral methods of communication and function;
3. To participate fully in Te Reo Māori classes which are integral to my cultural identity and professional development;
4. To carry out focus-group and ethnographic research in community-based settings. For example, I have not been able to attend and observe a pakeke kōrero group (conversation group for people in their 50s upwards) held in a community café; an essential aspect of whakawhāungatanga, as per kanohi ki te kanohi, kaupapa Māori research methods;
5. To participate in virtual meetings that have more than one person—on occasions colleagues have texted me the meeting dialogue as a means of inclusion;
6. Participate fully in face-to-face team meetings, strategic planning and other events;
7. To negotiate new introductions and conversations with people without first explaining my deafness and asking them to face me, speak up and speak slowly. This makes attendance at strategic networking work events such as suppers, and 'meet and greet' stressful;
8. To chair a panel at a research conference, participate on boards and successfully hear and respond to questions from audiences on presentations that I make at national and international conferences;
9. Communicate with ease within my day-to-day living situation, and attend social events and everyday things; and,
10. Keep myself safe from bicycles, trains and motor cars.

I have spent thousands of dollars on hearing technology over the years to remain a part of the workforce and retain my social contributions and supports. With the progression of my deafness, I am now out of hearing assistive device options. However, the chances of getting a CI from the public health system in a timely manner are slim.

The average life expectancy for women in New Zealand is 81 years of age. Therefore, I can probably expect to live a further 24 years. A key public policy goal, in view

of our aging population, is that people maintain their social and economic independence for as long as they can. Independence is strongly linked to workforce and social participation and networks. Below I have laid out, in simple terms, the economic costs to society of providing me with and not providing me with a CI in a timely manner.

Economic contribution with CI and ability to retain paid work

Taxes paid:	$34,296/annum
Kiwi Saver contribution:	$13,861/annum
Total contribution:	**$48,157/annum**

Economic contribution with job loss as result of untreated need for cochlear implant

State pays me a sickness benefit:	$15,000
Extra healthcare costs as a result:	$5,000
Loss of my taxes and RSP	$48,157/annum
Total cost to state (conservative estimate):	**$68,157.00/annum**

Total economic cost to state over two years $136,315 (average wait list time) contrasted to $50,000 for one CI.

Discussion: domestic and international policy

As a signatory to Convention on the Rights of People with Disabilities,[13] New Zealand aims to be a "non-disabling society—a place where disabled people have an equal opportunity to achieve their goals and aspirations". In New Zealand the rights of people with disabilities are legislated for under the Bill of Rights Act 1990[14] and the Human Rights Act 1993.[15] The Human Rights Act (1993) covers a number of provisions including making discrimination unlawful against people with disabilities when it occurs in relation to access to public education and health services.

Had the author's sensorineural hearing loss been acquired through an accident, she would very likely be eligible for ACC and able to receive an implant in the private sector within a very short space of time. Secondly, those in New Zealand affected by other forms of physical disability wait no longer than four months for elective treatment interventions in public health system.[16] Clearly with SPHL, which occurs over time due to sensorineural hearing loss, discrimination is occurring regarding access to a public health service. This is arguably a 'hangover' from the stigma associated with deafness and other forms of disability, particularly those which appear to be innate to the individual rather than externally caused.

Both the Treaty of Waitangi,[17] New Zealand's official founding constitutional document and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)[18] recognise the rights of Māori and Indigenous peoples to be free of discrimination, to retain and practice their Indigenous languages and cultural heritages (articles 2 and 3, Treaty of Waitangi, and articles 5, 8, 11, 13 and 14, UNDRIP). The well-known WAI 262 Treaty of Waitangi Claim[19] reinforced the status of Te Reo Māori as a 'taonga' and access to Te Reo Māori as an inalienable Māori right, that is integral to Māori identity and wellbeing. Despite this, rates of conversational Te Reo Māori among Māori have continued to decline in recent years.[20]

The New Zealand Government gave its official support to UNDRIP in 2010. The declaration holds considerable moral authority and is consistent with the aims of the Treaty of Waitangi. Article 22 1. UNDRIP states "Particular attention shall be paid to the rights and special needs of Indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration". Given the author's cultural identity, and profession as a Māori researcher whose job encompasses Māori health and development, her current lack of access to CI treatment (bear in mind that even for those who meet the CI criteria, the average waiting time is two years) appears to contravene the spirit and intent of both the Treaty of Waitangi and the UNDRIP.

Lack of access to CI treatment for the author and other similarly affected people, contravenes these public policies and/or principles in the following ways:

- Equal access to health services due to lack of parity with both elective surgery wait times and those who can access CI treatment through the ACC legislation;
- For Māori, the right to retain and practice their Māori cultural heritage through accessing Te Reo Māori classes, including the right to special provision of Indigenous persons with disabilities under section 22 of UNDRIP; and,
- For Māori, the right to access training opportunities necessary for Māori development work (for example knowledge of Te Reo Māori), and the right of hapū, iwi and Māori to benefit from those skills more generally in the interests of the protection of Māori rights as per the Treaty of Waitangi and UNDRIP.

Summary

Overall, hearing loss is a vastly under-treated and underfunded public health issue that contributes to serious health disparities throughout New Zealand. For those with SPHL caused by sensorineural degeneration, advancements in CI technology over the past 30 years means that it is now possible to give this cohort access to hearing in a real-world setting, with improved health and quality-of-life outcomes. Yet this life-changing technology is being under-utilised for New Zealand adults with often disastrous results. The social and economic benefits of providing a CI implant in a timely and effective manner clearly outweigh the societal costs in economic and social terms of withholding this treatment. For late deafened adults who have developed sensorineural hearing loss over time, discrimination is clearly occurring in terms of access to CIs contrasted to other forms of physical disability, or to those people who incur sensorineural hearing loss through accident or illness. The effects of the author's SPHL and current CI situation also impacts negatively on her ability to undertake Kaupapa Māori research. Given Māori health disparities and the endangered status of Te Reo Māori, untreated SPHL on a larger scale in Māori has some potentially serious implications for the protection of Māori cultural rights, health and development.

Competing interests:
Nil.

Acknowledgements:
The author would like to acknowledge those living with deafness and hearing impairment and the dedication of families, volunteers and professionals to improving their quality of life.

Author information:
Lewis Williams, Founding Director Alliance for Intergenerational Resilience, Whakauae Research for Māori Health and Development, Whanganui.

Corresponding author:
Dr Lewis Williams, 19b Clarke Street, Gate Pa, Tauranga 3112.
lewis.williams@usask.ca

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8042

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When every second counts: ampoule versus adrenaline auto-injector administration for life-threatening allergy

Elissa M McDonald, Emma Cooper

Gold-standard treatment for anaphylaxis in the community is with adrenaline auto-injectors (AAIs).[1] The WHO in recognition of this has been involved in developing an action plan to increase the global availability of AAIs and specifically ensure adequate access to AAIs at an affordable cost.[2] A proposal is currently being prepared to support inclusion of AAIs in the WHO essential medicines list to be formally submitted for their forthcoming edition.[2] Despite this, AAIs are not funded by PHARMAC and are only available to individuals privately, at considerable cost, further increasing health inequities and decreasing access to essential healthcare.

Worldwide there has been a marked increase in the rate of anaphylactic reactions[3] with studies reporting increases in Australia, Asia, America and Europe.[4] Evidence highlights that for adrenaline to be effective in the treatment of anaphylaxis it should be administered intramuscularly rather than subcutaneously or intravenously.[5] Intramuscular administration of adrenaline provides superior consistency of absorption in comparison to subcutaneous administration.[6] Adrenaline auto-injector, EpiPen®, delivers adrenaline deep into the muscle with the aid of the force of the spring action needle.[7] Alternative delivery is from an ampoule, needle and syringe that must be prepared and administered manually. There are justifiable concerns about the timely and safe intramuscular delivery of adrenaline manually by lay persons in the community. As PHARMAC currently only funds an ampoule of adrenaline for this purpose, many people are left with no other financially viable choice. AAIs ensure the ability of individuals to administer the correct dose of adrenaline via the correct route in a timely and effective manner.

There are difficulties conducting randomised controlled trials investigating efficiency of adrenaline in anaphylaxis, with respect to dosing and delivery. Conversely, one could also argue that it is ethically wrong to not conduct trials that inform evidence-based best practice in life-threatening situations. A Cochrane Systematic Review on use of AAIs in the community concurred that trials on different auto-injector devices would be practically challenging to conduct.[8] The review concluded that in the absence of appropriate trials, adrenaline administration via auto-injector should still be regarded as the most effective first-line option for management of anaphylaxis in the community.[8] Interestingly, the review only advocated for trials comparing auto-injectors to adrenaline administered by ampoule, needle and syringe in countries where auto-injectors are not commonly used or are unaffordable.[8] Despite the ethical dilemmas identified, studies have been conducted to address this clinical question. A randomised, single-dose, single-masked study in children between 4–12 years old who had a history of anaphylaxis secondary to severe allergy, received either intramuscular adrenaline via EpiPen® or a subcutaneous injection of adrenaline.[9] The plasma adrenaline concentrations following anaphylaxis reported the mean time to C-max was eight minutes with an EpiPen®, significantly shorter than 34 minutes with subcutaneously delivered adrenaline.[9] A study investigating the pharmacokinetics of

adult and paediatric EpiPens® both prior to and exceeding their expiry dates, confirmed the prompt systemic exposure to adrenaline with an unexpired EpiPen®.[10]

Moreover, a porcine study examined the length of the needle in an auto-injector device and the projection of the adrenaline past this point (N=24).[11] EpiPen® with a needle length of 1.43cm was investigated. Prior to EpiPen® injection into the pig's thigh, 0.1ml of methylene blue was added to allow tracing of the injection.[11] On dissection and evaluation of the subcutaneous thigh tissue, it was revealed that the location of the dye was intramuscular with a mean depth of 2.78cm, considerably past the end of the needle.[11] Thus, EpiPen's® spring-loaded needle drives adrenaline 94.4% beyond the needle length, sufficient to reach the muscle in even obese individuals.[11] In the study, pressure was gradually applied to the EpiPen® until it was triggered, implying minimal pressure (2lbs or 0.9kgs) when activated.[11] This highlights the 'worst case' for delivery depth, suggesting that with more force, as recommended in guidelines, the adrenaline from an EpiPen ®could be delivered even deeper for faster action.[11] Despite studies demonstrating the effectiveness of EpiPen®, it is not always administered correctly, especially in community situations. Even with written instructions on Epipen® use, and education delivered on how to correctly administer the auto-injector, some parents report that within three months they have forgotten how to use the device[12] Although, a recent study investigating the most effective way to train first responders to administer adrenaline via auto-injector, identified that simulation training improves essential skills and retention of knowledge at three months compared to non-simulation-based training.[13]

A recent review by Grissinger highlighted that the incorrect dose and/or route were reported to have been administered when adrenaline was drawn from ampoules by healthcare professionals (HCPs).[14] Grissinger recognised that choosing between an auto-injector and ampoule, needle and syringe can be a difficult decision. While auto-injectors may be convenient, there can also be misuse issues with auto-injectors, specifically EpiPen®, such as holding the auto-injector upside down, pressing and injecting the user's thumb or the risk to children who may access the device and press the wrong end.[14] Despite these concerns, delivery of an inaccurate dose of adrenaline was more frequent with ampoule, needle and syringe among HCPs.[14] This begs the question, if HCPs have difficulty accurately drawing up and delivering adrenaline in the event of anaphylaxis, how can a parent or member of the public be expected to do so and in particular a person on their own experiencing anaphylaxis?

There is limited research around adrenaline administration in the community for infants and children; however a prospective, controlled study comparing the time and accuracy of parents drawing up a 0.09ml dose of adrenaline compared with HCPs was conducted.[15] The study reported that not only did parents take a significantly longer time (142±13 seconds (P=<0.05)), compared to HCPs (mean time 40±2 seconds) to draw up adrenaline from an ampoule, most parents also drew up an inaccurate dose.[15]

With the available evidence, it is recommended that AAIs may provide New Zealanders with the best chance of survival from anaphylaxis in the community, reducing mortality and morbidity. Considering that the international incidence and prevalence of anaphylaxis appears to be increasing in certain populations,[16] why are there still questions around mode of delivery? As HCPs, we need to be advocating for those with severe allergy to have funded access to AAIs. It is concerning that the general population may not be sufficiently equipped to deliver adrenaline through an ampoule, needle and syringe in a timely and effective manner. There is insufficient evidence to support PHARMAC's currently funded form of adrenaline, which raises the question as to why PHARMAC does not fund this life-saving mode of adrenaline delivery or at the very least provide funding for those who are in financial hardship in New Zealand?

PHARMAC state that funded adrenaline ampoules are a suitable treatment for anaphylaxis in the community, in direct conflict with the guidelines released by the Australian Society of Immunology and Allergy that stress that adrenaline ampoules and syringes are not suitable for non-medical settings.[17] PHARMAC

support their funding decision by stating that individuals who have an AAI often do not have them on their person at all times and owning an AAI does not reduce anxiety around anaphylaxis treatment. Thus, PHARMAC conclude, there is not a strong indication for funding.[12] The issue of funding AAIs has been ongoing at PHARMAC; however, a PHARMAC Health Technology Assessment detailing AAI cost utility analysis reported the cost of funding auto-injectors would only save 1.5 quality-adjusted life years (QALYS), instead of the generally acceptable 50 QALYS, per million dollars spent, therefore AAI funding has only received moderate priority.[18] Although the above mentioned report included at least three AAIs (EpiPen®, Anapen® and Twinject®) among others, a decision was still made not to fund these devices.

In 2014, Pharmacology and Therapeutics Advisory Committee (PTAC) Committee recommended PHARMAC fund one AAI in a 12-month period for patients who had experienced anaphylaxis to venom or food, with moderate priority,[19] but still AAIs remain unfunded in New Zealand. Unfortunately, since then, only one AAI is currently available in New Zealand—EpiPen® limiting choice in New Zealand's pharmaceutical tender market. In a recent news release[20] the PHARMAC Operations Director identified that that the high cost of adrenaline auto-injectors in New Zealand was because one drug company held the monopoly. There does not appear to be any basis to the claim as other companies have entered the New Zealand market with auto-injectors but subsequently withdrew their products. In fact, the cost utility analysis commissioned by PHARMAC[18] included more than three AAIs and still funding was not granted. However, the current supplier (Mylan, New Zealand) has remained in the market, continually providing New Zealanders with an auto-injector, and has not increased their price to pharmacies for over a decade. The variable pricing of EpiPen® in pharmacies is largely due to the differing profit margins imposed by each pharmacy, with a single EpiPen costing the consumer between $120–$180. Therefore, consumers are encouraged to shop around for price and ensure the 'use by' date remains valid for at least 12 months.

Since 2014, European and UK guidelines have recommended that people with allergies are prescribed two AAIs which need to be carried at all times, including those with allergic asthma.[21] Australian and New Zealand guidelines recommend prescription of two AAIs in children.[17] With commercial availability of various AAIs such as Emerade®, Jext®, Fastjekt®, FastPen®, ChenPen®, Adrenalina WZF®, Altellus®, Anapen®, Nepipe® and EpiPen® in the European Union alone,[22] surely PHARMAC could source affordable, bioequivalent, device-equivalent, adrenaline auto-injector alternatives. However, in the absence of viable competition, PHARMAC should fund the only currently available AAI in New Zealand, EpiPen®.

Competing interests:
Nil.

Author information:
Elissa M McDonald, Senior Lecturer, Department of Nursing, Faculty of Health and Environmental Science, Auckland University of Technology, Auckland;
Emma Cooper, Registered Nurse, Child Health Centre, Whangarei Hospital, Whangarei.
Corresponding author:
Elissa McDonald, Faculty of Health and Environmental Science, Auckland University of Technology, Auckland.
elissa_mcdonald@hotmail.com

URL:
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Supporting mothers, protecting babies for long-term health: establishing a pasteurised human milk bank

Maggie Meeks, Anthea Franks, Hazel McGregor, Rachael Lamb, Graeme Webb

ABSTRACT

It is now very clear that early feeding practices have lifelong implications for an individual's health as well as economic and public health consequences. This article summarises some of the important reasons to prioritise breast milk feeding and introduces the Christchurch Neonatal Intensive Care Human Milk Bank. This Milk Bank was opened in 2014 to support babies and their families with the provision of pasteurised donor milk. The primary goals were to support mothers while they established their own milk supply, reduce exposure to parenteral nutrition and formula and reduce the risk of necrotising enterocolitis in this vulnerable population.

The importance of infant feeding practices to an adult's long-term health are of relevance to all health professionals, not just those involved with the care of the newborn infant and young child.[1–3] This article will briefly examine the evidence for the use of human milk, including pasteurised donor milk (PDM), before discussing the establishment of the first New Zealand Pasteurised Human Milk Bank at Christchurch Neonatal Unit.

Feeding the newborn

International and local recommendations

International recommendations are that breastfeeding and human milk should be considered the normative standards for infant feeding.[4] In New Zealand, the Ministry of Health upholds the position of the American Academy of Nutrition and Dietetics which is that mothers exclusively breastfeed their infants for the first six months of life to achieve optimal growth, development and health.[5] Despite this, the prevalence of breastfeeding or feeding with human milk has decreased in many societies, which includes New Zealand.[6] The Plunket Annual Breastfeeding statistics of 2017 suggest that 52% of babies were exclusively breastfed at six weeks, 48% at three months and 21% at six months.[7] This has been influenced by a myriad of societal and maternal factors, including the availability of maternity leave, financial stability, psychosocial belief systems (such as the sexualisation of breasts), family expectations and the availability of support systems (both within the family and local community).[8,9] An additional influencing factor is that of increasing maternal morbidities, such as obesity and diabetes, affecting the physiology of milk production.[10] The term 'breast is best' had been used to try and reverse this trend and encourage breastfeeding but this terminology may have discouraged some families, and 'normal' is now considered a more appropriate terminology.[11,12]

ISSN 1175-8716

Species-specific milk

Human milk provides immunological protection for the vulnerable newborn infant (containing immunoglobulins, lactoferrin and human milk oligosaccharides (HMOs) which act as probiotics) as well as species-specific nutrition that has not yet been matched by breast milk substitutes.[4] This should be considered a public health issue that has significant economic repercussions.[6,13] It is hoped that the availability of pasteurised donor milk (PDM) may have a part to play in enabling this.

Colostrum/first milk

Where possible, an infant should be given their own mother's first milk, known as colostrum, prior to being fed with other milk, including PDM. It is likely that exposure to colostrum facilitates the adaptive processes of the gastrointestinal system following birth, and this may have benefits that are independent of whether the infant will be ultimately breast or formula fed.[14–16]

Short and long-term benefits

The short and long-term benefits of breast milk for both term and preterm infants have been extensively summarised.[17–19] Examples of these benefits include:

- An optimal nutritional diet that is metabolised efficiently with faster gut transition and improved stool frequency.[20,21]
- Provision of passive immunity mediated by immune factors such as lactoferrin and maternal IgA.[22]
- As a prebiotic in establishing a healthy gastrointestinal microbiome.[22,23]
- Reduction in the risk of necrotising enterocolitis (NEC).[14,19,24]
    - This is a specific complication seen in the preterm infant (increased incidence with increased prematurity) which has a significant mortality as well as morbidity.
- Reduction in the risk of Crohn's disease and ulcerative colitis.[25]
- Reduction in the risk of obesity and diabetes.[26,27]
- Possible reduction in asthma.[28,29]

The health benefits of breast milk appear to be dose dependent and it is important to positively reinforce the benefits of breastfeeding or feeding with breast milk even when exclusive breastfeeding will not be possible.[24,27,30] A potential limitation of an exclusively breast milk diet in preterm babies is that breast milk may not contain adequate protein, mineral and vitamins to provide optimal nutrition in this vulnerable group. This may require fortification, although the exact criteria for supplementation continues to be debated and there are no clear international guidelines for neonatal intensive care units (NICUs).[19,21,31] Additional benefits of breastfeeding or bottle feeding with expressed breast milk for a family with a newborn infant include reduced cost and improved accessibility.

Donor human milk

Throughout history there has been sharing of breast milk (unpasteurised or raw) between mothers and this continues, both in local communities and now more widely, facilitated by social media.[32] In considering the sharing of unpasteurised milk, the aim is that this practice should be conducted in a way that mitigates unrecognised harm to vulnerable newborn infants.[33] This requires at least some knowledge of both the risk of transmission of viral and bacterial infections[34,35] and medications through breast milk.[36] There are few absolute contraindications to breastfeeding your own child while on medications, and the benefits of feeding with human milk must be balanced against the effects of the medication.[33,37] The exposure of a more vulnerable infant who is preterm or unwell may require a higher standard of medication surveillance.

Unpasteurised donor milk

In the 1980s, human immunodeficiency virus (HIV) received a lot of publicity and was one of the reasons that milk banks globally went out of favour. It is now known that the HIV virus is rapidly denatured with pasteurisation.[38,39] There is a low prevalence of HIV in New Zealand, but it is increasing and despite antenatal testing it remains possible that a mother may have asymptomatic HIV, which could be transferred through the sharing of unpasteurised breast milk. The risk of HIV transmission from a mother to her own baby is significantly reduced with maternal and infant retroviral treatment.[40,41] One of the other concerns in

developed countries is the risk of cytomegalovirus (CMV) infection, and CMV exposure is especially of concern in the preterm population.[42,43] Women are unlikely to recognise whether they have CMV without specific testing. There are also other less well-known viral infections, such as human T-cell leukaemia virus (HTLV), which have been implicated in the long-term risk of cancer (HTLV).[44] The collection, storage and transportation of unpasteurised donor milk all increase the risk of microbiological (bacterial) contamination, but bacteriological contamination is also known to be a risk with formula milk, for similar reasons.[33]

Pasteurised donor milk

The aim of pasteurising donated milk is to denature possible viral and bacterial pathogens. A recognised standard is that women who donate breast milk complete a health questionnaire and are screened for infections such as hepatitis, HIV and HTLV prior to being accepted as potential donors.[45] The freezing and standard pasteurising process (Holder technique) does partially destroy some of the beneficial properties but has little effect on oligosaccharides (HMOs).[46] Alternative methods of pasteurisation are also being studied.[47,48] Human milk banks have been established to recruit and screen donors as above, collect milk, pasteurise and perform further bacteriological screens before storing and packaging the milk for distribution.

The medical evidence for using pasteurised donated milk (PDM) instead of formula is accumulating.[15,49] Donated human milk is increasingly cited as preferential to infant formula in promoting the health of the newborn, particularly the preterm newborn admitted to the neonatal unit.[14,50,51] PDM may not be nutritionally individualised for the baby in the way that a mother's own milk is, and may require supplementation, but the immune protection it provides is still significant.[15,52,53]

The other consideration is that of an informed choice for the family. It is hoped that the availability of pasteurised donated breast milk, as an alternative to formula, may further encourage staff and families to persist with breastfeeding where a lactation consultant assessment has verified that at least partial breastfeeding is possible with support.

Formula

It is not the intent of this article to discuss formula in detail but it must be recognised that there are risks which are especially significant in preterm infants.[54,55] Formula milk is currently not constructed of the quantity, quality and type of nutrients (carbohydrate, protein, fat, minerals and vitamins) or the immune factors that the newborn requires for optimal short-term and long-term health. Follow-up studies of ex-preterm babies have also shown an abnormal pattern of fat deposition compared to term controls.[56] While these results have not been proven to relate to early nutrition, the contributing factors continue to be investigated.

It must also be remembered that formula requires the multiple steps of preparation in a factory and reconstitution under clean conditions in the home and there have been a variety of bacterial infection outbreaks worldwide.[33,57] The significant economic advantages of breastfeeding rather than feeding with formula have also been well studied.[2,3,58,59]

Neonatal unit context

Preterm admissions

Preterm is the term used to describe deliveries before 37 completed weeks of gestation, and preterm deliveries make up 7.4% of births in New Zealand. The nutritional management of the different categories of a preterm infant can be summarised below:

- Extreme preterm (<28 completed weeks): total parenteral nutrition (TPN) usually with central line access and slow grading up with breast milk until TPN can be ceased.
- Very preterm (28–32 completed weeks): as above.
- Moderately preterm (32–34 completed weeks): in the moderately preterm infant, the balance of risks between using TPN or formula must be carefully considered.
- Later preterm (34–37 completed weeks): this most commonly involves supplementing the mother's breast milk with formula.

In each of these cases, nutritional supplementation is important to ensure optimal nutrition for the preterm infant during the

first few days and weeks. During this time, a mother needs to establish a regular routine of expressing her breast milk using a milk pump to mimic the feeding pattern of a preterm infant and the supply of a baby at term. The goal is to develop her supply so that it becomes sufficient for her new baby by 7–10 days.

Term babies admitted to neonatal intensive care unit (NICU)

Although preterm babies are responsible for most admissions to NICUs, term babies are also commonly admitted with a variety of morbidities which include:

- Breathing difficulties (secondary to transition to ex utero life, infection and meconium aspiration).
- Low sugar levels (most commonly secondary to maternal diabetes or in small babies with poor reserves).
- Infections (eg, Group B Streptococcal infection).
- Congenital abnormalities which include chromosomal disorders such as Trisomy 21, congenital heart defects and gastrointestinal surgical abnormalities (eg, gastroschisis).
- Birth asphyxia and/or seizures.

Most families are unaware that it is not unusual for a term infant to spend some time in a NICU or special care baby unit (mean admission rate approximately 10%, although there is wide variation between units).[60,61] The emotional load of this situation may influence maternal milk supply and the infant's nutritional needs are also likely to be more than those required by a well term baby, further exacerbating the fragile relationship between an infant's needs and a mother's breast milk supply.

Breast milk production in our NICU mothers

The production of breast milk is regulated by maternal hormones which are influenced by the frequency and effectiveness of the newborn's suckling pattern. There are several complications of this 'supply and demand' feature in both the preterm and term infant admitted to NICU:

- The maternal condition that resulted in an early delivery and the complications of pregnancy may contribute to primary milk insufficiency.[62]
- The infant may have been born by caesarean section and the maternal hormone response to labour and delivery may be delayed due to physiological factors.[6–65]
- The infant is not effectively suckling to stimulate and maintain milk production until near to discharge or not at all.[66,67]
- The rise in maternal BMI and deterioration of maternal health is associated with additional challenges in lactation.[64,68]

The physiological stresses and the physical separation that characterise an admission of the newborn baby to the neonatal unit also have their own impact on the hormonal influences required to stimulate and maintain a milk supply.

A milk bank in Christchurch (New Zealand)

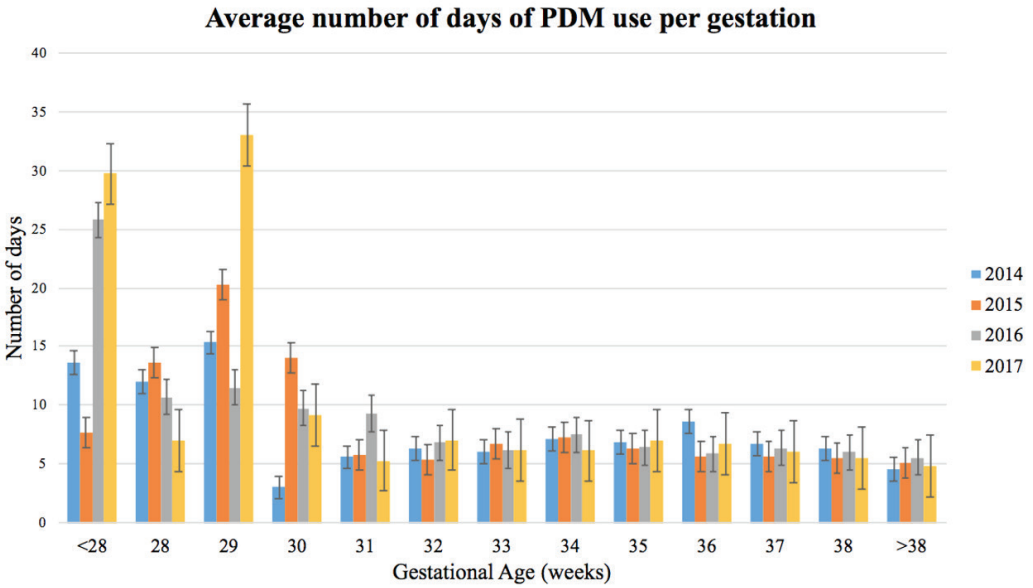
It should now be clear that feeding both preterm and term infants admitted to NICU exclusively with breast milk is a specific challenge. The Christchurch Human Milk Bank Project was established primarily to support mothers who wished to breast feed with a secondary aim to provide the best nutritional start to a vulnerable group of babies at high risk of gastrointestinal complications due to being preterm. The project was supported by NICU nursing and medical leadership as well as colleagues and families on the NICU who were engaged in the milk bank's development. One of the reasons for the project's success, both in the development of the NICU service and current expansion of the service, was the development of a committed multidisciplinary steering group (2010–2014) which later developed into the Milk Bank Executive (2014–current). This multidisciplinary group not only supported an experienced neonatal nurse, recruited as the Milk Bank Manager, but led the consultation processes with questionnaires and audits, a literature review, detailed mapping processes and economic calculations to ensure that the business case was robust.

Prior to the establishment of the human milk bank, an audit of the use of formula milk was conducted on the Christchurch Neonatal Unit. The audit concluded that an average of four litres of formula each

day was required to support the feeding of NICU admissions and that the late preterm population (not requiring intravenous cannulation) were the main consumers. This population were therefore likely to be the largest group of consumers of PDM and the mothers of this preterm population would need time and support to establish their own milk supply, which was estimated at one week, during which time PDM should be available. This has been borne out by data collected following the opening of the Milk Bank. This data is shown in the figure below (Figure 1) and confirms that the moderately and late preterm (32 to 36+6 weeks) as well as term (>37 weeks) populations tend to require PDM support for seven days, validating the hypothesis that their own mother's supply would become sufficient by seven days. One of the conditions of supplying PDM to these populations is that the human milk bank supplies are sufficient to guarantee a supply of PDM to each family consented for PDM for one week. Although the numbers of extreme and very preterm infants (<32 weeks) are small, it can also be seen in Figure 1 that these infants may require support with PDM for longer. The milk bank aims to provide PDM until *at least 34 weeks* corrected in this population. This aligns with the vision that ranks donated human milk (fresh or pasteurised) as the next best feeding option when mother's own milk is not available or unable to be supplied in quantities supporting optimal infant nutrition.

The financial cost of establishing the human milk bank has not been insignificant. This consisted of the capital costs associated with the purchasing of equipment and room alteration and the operational staffing costs. The capital costs were met predominantly by the Canterbury Neonatal Unit Trust Fund (CNUTF) and Canterbury District Health Board (CDHB) supported the staffing costs. The business case proposed that savings would occur in the use of total parenteral nutrition and that the prevention of only one case of NEC per year in the preterm population would also be of economic value. A recent audit comparing nutritional parameters of moderately and late preterm infants born in 2013 to matched infants born in 2016 or 2017 showed a trend towards a reduction in TPN usage in these populations from eight infants (11%) in the 2013 cohort to three infants (4%) in the 2016/17 cohort following the opening of the milk bank.[69] The number of preterm infants diagnosed with NEC in Christchurch is small, making it difficult to prove any relationship with the opening of the milk bank but the fact that PDM is protective has been confirmed by others.[7–72]

Figure 1: This figure shows the average number of days of pasteurised donated milk (PDM) use per infant of a specific gestation in each year between 2014–2017. PDM is ceased once the mother's own expressed breast milk (EBM) meets her own infant's requirements.



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ISSN 1175-8716

Table 1: The number of milk bank donors and newborn pasteurised donated milk (PDM) recipients together with the amount of donor milk pasteurised and dispensed.

	2014	2015	2016	2017
Donors	63	57	73	81
Recipients	154	258	234	365
Amount milk pasteurised in L	308	398	448	580
Amount of PDM dispensed in L	251	379	386	549

A culture of PDM

The milk bank is now fully embedded within the NICU culture with the number of milk bank donors and PDM recipients continuing to increase (Table 1) such that it has recently expanded to provide PDM to high-risk babies within maternity wards.

Conclusion

Although the human milk bank has become successfully embedded within NICU culture, a considerable amount of work continues behind the scenes to ensure that the original aims continue to be met and these are summarised below:

1. Practically support mothers wishing to breastfeed by providing an alternative to formula milk in the first week after birth when their breast milk supply is developing.
2. Positively role model the value that the neonatal unit places on breast milk and reinforce feeding with breast milk as the 'norm'.
3. Reduce the use of TPN and formula milk.
4. Reduce the risk of neonatal complication such as necrotising enterocolitis.
5. Contribute to a reduction in the long-term financial cost associated with poor nutritional health.

Evaluating the long-term financial cost will require evidence that the milk bank has helped support women to maintain breastfeeding or feeding with breast milk. This work is ongoing and if this is the case, the economic benefits to the DHB can be calculated based on established mathematical modelling techniques.

Competing interests:
Nil.

Acknowledgements:
We would like to thank the CDHB and Neonatal Unit Trust Fund (chaired by Paul McEwan) for having the confidence to fund the human milk bank and the neonatal multidisciplinary team for the vision to establish a pasteurised milk bank in the neonatal unit. We would also like to thank other members of the human milk bank executive team, including Kathy Simmons, Helen Little and Bernard Hutchinson as well as our colleagues on the neonatal unit at Christchurch and our NICU families, especially the mothers who donate their valuable milk.

Author information:
Maggie Meeks, Consultant Neonatal Paediatrician, Neonatal Intensive Care Unit (NICU), Christchurch Women's Hospital, Christchurch; Anthea Franks, Milk Bank Manager, Human Milk Bank, Neonatal Intensive Care Unit (NICU), Christchurch Women's Hospital, Christchurch; Hazel McGregor, Clinical Nurse Specialist, Neonatal Infant Feeding, Neonatal Intensive Care Unit (NICU), Christchurch Women's Hospital, Christchurch; Graeme Webb, Dip Health Sciences, Quality Co-Ordinator Child Health, Department of Child Health, Christchurch Hospital, Christchurch; Rachael Lamb, NZ Registered Dietitian.

Corresponding author:
Maggie Meeks, Neonatal Intensive Care Unit (NICU), Christchurch Women's Hospital, Christchurch.
maggie.meeks@cdhb.health.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8044

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A case of imported Q fever in New Zealand

Andrew Fox-Lewis, Karen Isteed, Paul Austin, Helena Thompson-Faiva, Jill Wolfgang, James E Ussher

Q fever is a zoonotic infection characterised acutely by fever, severe headache, myalgia, pneumonia and hepatitis, or chronic infection manifesting as endocarditis.[1] The name derives from 'query fever', the term first used to describe the disease in Australian abattoir workers in 1937.[2] Endemic Q fever has since been reported worldwide, with the exception of New Zealand.[3] The causative agent, *Coxiella burnetii*, is an obligate intracellular gram-negative bacterium for which cattle, sheep and goats are the main reservoirs.[1] Human transmission occurs primarily through inhalation of aerosolised bacteria in birth-fluids or soil contaminated by infected animals, thus individuals in close proximity to infected animals are at risk.[3] Here we report a case of imported Q fever in a New Zealander following travel to Australia.

Case report

A 51-year-old, previously fit and well male presented to his local medical centre with three days of severe frontal headaches, photophobia, arthralgia, nausea, night sweats and febrile symptoms. He had no rash, respiratory symptoms or gastrointestinal upset. He was apyrexial, with a normal physical examination and vital signs. Sinusitis was diagnosed and he was discharged with erythromycin.

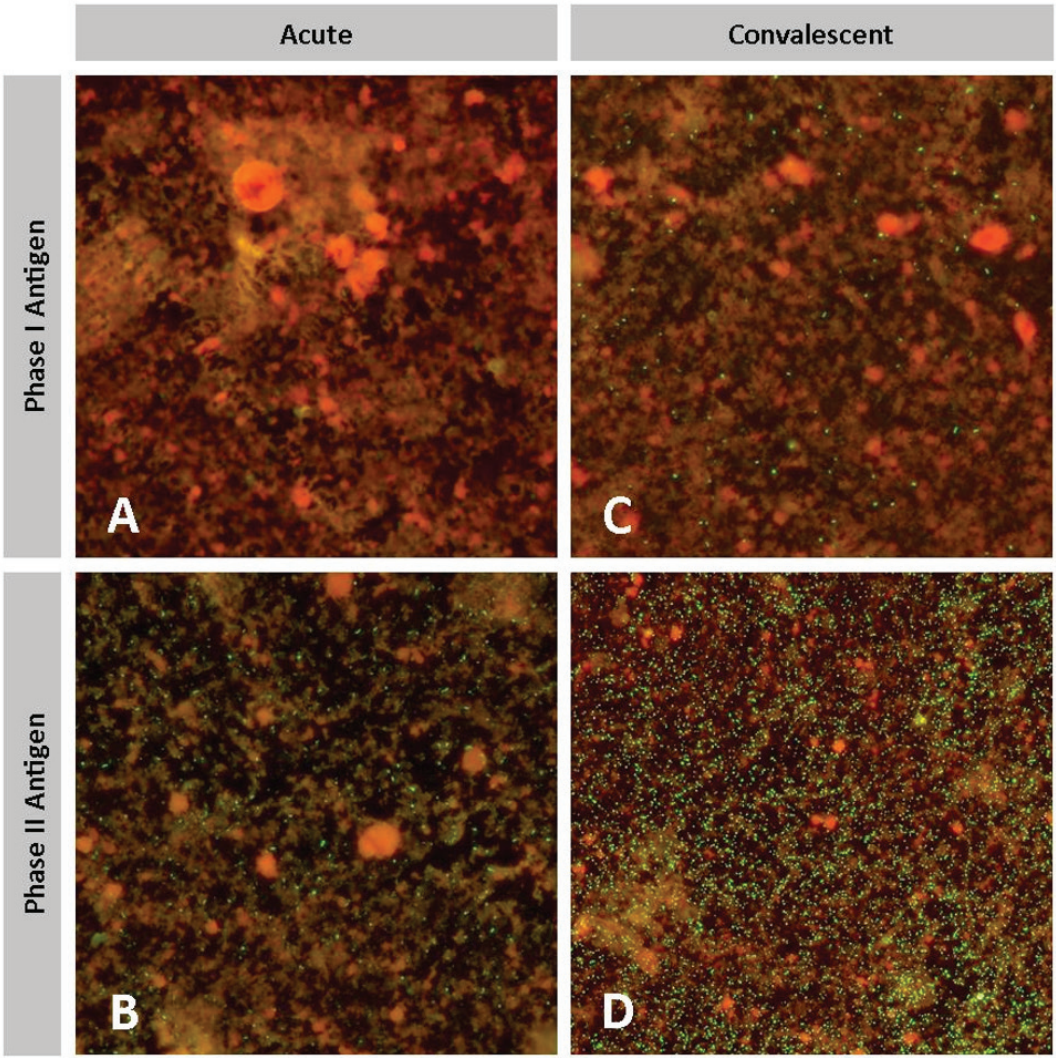
Five days later he represented with ongoing flu-like symptoms, night sweats and headaches. Physical examination and observations remained normal. He was found to have thrombocytopenia (platelets 78x10^9/L, normal range 150–400x10^9/L), elevated ALT (75U/L, normal range 0–40U/L) and elevated C-reactive protein (119mg/L, normal range <5mg/L), and otherwise normal full blood count, renal and liver function tests.

On further discussion with the patient, it transpired his symptoms started two weeks after returning from Australia, where he was visiting friends on a goat farm in Meredith, Victoria. The patient himself raised the possibility of Q fever, and consequently serum was sent for *C. burnetti* serology (LabPlus, Auckland) and polymerase chain reaction (PCR) (Southern Community Laboratories, Dunedin). PCR was positive for *C. burnetti* DNA, and initial serology by indirect immunofluorescence assay showed negative IgG to *C. burnetii* phase I antigen (titre <16) and positive IgG to phase II antigen (titre 16), suggesting an early antibody response to acute infection (Figure 1). Convalescent serology was sent 17 days later, which demonstrated seroconversion of IgG to phase I antigen (titre 64), and a significant increase in IgG to phase II antigen (titre 2048), consistent with ongoing acute infection.

On suspicion of Q fever the patient was commenced on standard treatment with doxycycline for 14 days.[3] He had no risk factors for developing chronic infection:[4] an echocardiogram showed no endocarditis or valvular pathology and an abdominal ultrasound showed no aortic aneurysm, thus he did not require extended antibiotics. He improved post-treatment though has ongoing fatigue, a common sequela of acute Q fever,[3] and will require clinical and serological evaluation for 1–2 years to ensure there is no progression to chronic infection.

ISSN 1175-8716

Figure 1: Detection of IgG antibodies to *Coxiella burnetii* phase I and II antigens by indirect immunofluorescence assay. Fluorescent images taken with an LED microscope (Zeiss Axio Lab.A1) at magnification x400, screening dilution 1:16. Antibodies against phase II antigens are predominant during primary infection, while antibodies against phase I antigens are associated with persistent or chronic infection.[3]



A, acute serum showing negative IgG to phase I antigen (titre <16); B, acute serum showing positive IgG to phase II antigen (titre 16); C, convalescent serum showing positive IgG to phase I antigen (titre 64); D, convalescent serum showing positive IgG to phase II antigen (titre 2048).

Discussion

Diagnosis of Q fever is challenging owing to the non-specific presentation and the inability of standard microbiology culture techniques to identify *C. burnetii* (it is not detected by blood cultures).[3] Consequently *C. burnetii*-specific serology and PCR are the key diagnostic tests, however these will only be performed if specifically requested. While common in Australia,[5] endemic Q fever has never been found in New Zealand.[6–9] A vaccine is available in Australia for at-risk individuals >15 years old; pre-vaccination screening is required.[10] LabPlus Auckland performs ~80 pre-vaccination serological screening tests annually for New Zealanders planning on undertaking seasonal livestock work in Australia, highlighting the ongoing risk of imported Q fever in New Zealand. Healthcare workers need to be vigilant for Q fever as a cause of undifferentiated febrile illness in those with a compatible travel and livestock exposure history, and request the appropriate investigations to confirm the diagnosis.

Competing interests:
Nil.
Acknowledgements:
The authors would like to thank the patient for their co-operation and consent in writing up their clinical case.
Author information:
Andrew Fox-Lewis, Clinical Virology Registrar, Virology-Immunology Department, LabPLUS, Auckland City Hospital, Auckland; Karen Isteed, Nurse Practitioner, Invercargill Medical Centre, Invercargill; Paul Austin, Serology Section Leader, Virology-Immunology Department, LabPLUS, Auckland City Hospital, Auckland;
Helena Thompson-Faiva, Serology Technical Specialist, Virology-Immunology Department, LabPLUS, Auckland City Hospital, Auckland; Jill Wolfgang, Consultant Infectious Diseases Physician, Department of Medicine, Dunedin Hospital, Dunedin; Clinical Senior Lecturer, Dunedin School of Medicine, University of Otago, Dunedin;
James E Ussher, Consultant Clinical Microbiologist, Southern Community Laboratories, Dunedin.
Corresponding author:
Dr Andrew Fox-Lewis, Virology-Immunology Department, LabPLUS, Building 31, Auckland City Hospital, Gate 4 off Grafton Rd, Grafton, Auckland.
afoxlewis@gmail.com
URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8045

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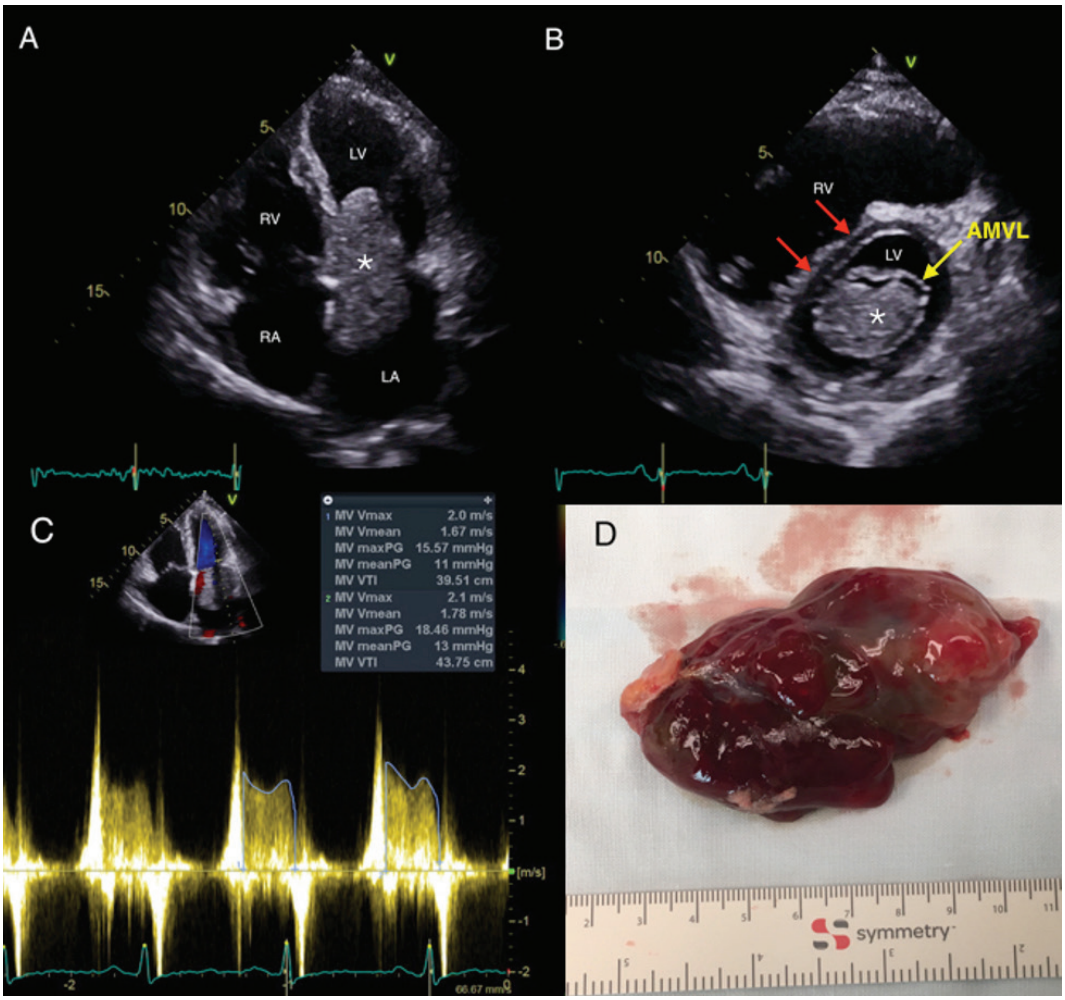
Not all mitral stenosis are due to valve disease

Daniel Chan, Charles Yao-Cheng Ho, Jen-Li Looi

A normally fit and well 43-year-old Chinese woman presented with a month's history of dyspnoea on exertion and orthopnoea. Physical examination revealed a raised jugular venous pressure, a mid-diastolic low-pitched rumbling murmur at the apex and bibasal crackles.

N-terminal-pro hormone B-type natriuretic peptide (*NT-proBNP*) and C-reactive protein were elevated at 552pmol/L (normal <35) and 56mg/L (normal 0–5), respectively at presentation. Transthoracic echocardiography showed a large mobile left atrial mass measuring 7.0cmx2.5cm, protruding during

Figure 1: A. Apical four-chamber view on transthoracic echocardiography showed a large left atrial mass (asterisk) prolapsing through the mitral valve into the left ventricle; B. Parasternal short-axis view at mitral valve level on transthoracic echocardiography showed the atrial mass (asterisk) causing almost complete obstruction of the mitral valve orifice, and there was diastolic septal flattening (red arrows) consistent with right ventricular volume overload; C. Continuous wave Doppler through the mitral valve demonstrated elevated mean pressure gradient in keeping with severe obstruction of the mitral valve; D. A gelatinous cream/brown haemorrhagic mass measuring 70x40x22mm was resected.



LV, left ventricle; RV, right ventricle; LA, left atrium; RA, right atrium; AMVL, anterior mitral valve leaflet.

diastole through the mitral valve into the left ventricle (Figures A and B). This caused mitral pseudostenosis with a mean pressure gradient of 11mmHg (Figure C), suggesting severe mitral stenosis. Given the increased risk of embolisation, she underwent urgent excision of the mass. The histopathology report confirmed the diagnosis of a myxoma (Figure D) and the patient had an uneventful recovery.

Rheumatic heart disease is the most common cause of mitral stenosis. Our patient's mitral valve leaflets were unremarkable on imaging. The most common differential diagnosis of an atrial mass is atrial thrombus. However, our patient was in sinus rhythm and her left ventricular function was normal which made atrial thrombus unlikely. Vegetation on the mitral valve can present as mitral stenosis but her blood cultures were normal at presentation. Other causes of impaired left ventricular filling can mimic mitral stenosis. Myxomas are the most common benign cardiac primary tumours, accounting for about 50% of cardiac tumours, and their clinical features are determined by their size, location and mobility. Our patient's symptoms were caused by obstruction of the mitral valve from the myxoma during diastole, resulting in 'pseudostenosis' of a structurally normal mitral valve. Surgery should, therefore, be performed promptly after the diagnosis is made to avoid potential complications such as peripheral embolisation or cardiac valvular obstruction.

Competing interests:
Nil.

Author information:
Daniel Chan, Department of Cardiology, Middlemore Hospital, Auckland;
Charles Yao-Cheng Ho, Department of Cardiology, Middlemore Hospital, Auckland;
Jen-Li Looi, Department of Cardiology, Middlemore Hospital, Auckland.

Corresponding author:
Jen-Li Looi, Department of Cardiology, Middlemore Hospital, Private Bag 93311, Otahuhu, Auckland.
jenli.looi@middlemore.co.nz

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8046

Environmental influences on behaviour and health: a call for creativity and radical shifts in thinking within contemporary research

Matthew Hobbs, James Atlas

In 2050, 68% of the world's population will reside in urban areas.[1] As suggested by a recent *Lancet* series, urbanisation represents a significant challenge for future populations.[2] While influences on human behaviour are multidimensional, adverse urban environments are increasingly considered linked, within policy and research, to unfavourable behaviours and outcomes such as an increased prevalence of diabetes.[3] Despite intuitive appeal and policy action, evidence linking environments to such health outcomes is often cross-sectional, plagued by persistent methodological limitations and findings are thus equivocal.[4] Evidential inconsistency has not improved over time, most likely due to research, including our own,[5] assuming that environments impact directly upon such health outcomes. Prominent scholars have also persistently questioned our inadequate understanding of how urban environments impact on behaviour.[6]

Methods linking environments to behaviour and health have stagnated and are so diverse, they restrict the possibility of evidence being translated into policy.[4] Understanding has likely not improved significantly due to persistent field-wide methodological limitations,[4] including our inability to maximise experimental control in complex social situations and environments. These persistent limitations justify a need for creativity and a consideration of new approaches in an era of big data[7] for instance, using new methods such as deep learning, virtual reality and reinforcement learning. While such methods have the potential to advance public health practice and policy, they are seldom, if ever, applied. We call for researchers to consider using these approaches to advance knowledge in this field of science and beyond.

The ambitious use of new methods such as deep learning methods[8] have been encouraged as they enable researchers to better understand problems using unfamiliar methods not considered before in the field.[9] Deep learning methods, such as previously trained convolutional neural networks (CNNs) can now exploit the ubiquity of digital imagery, automated data analyses, and improvements in machine vision techniques to automate the extraction of features, classification of objects and environmental measurements, ie, cycleways or pollution. For instance, a pioneering study which used deep learning to extract different aspects of the environment, such as greenery and different housing types, from high resolution satellite imagery promisingly showed that extracted features of the built environment explained 72% to 90% of the variation in obesity prevalence across cities in the US.[8] While deep learning methods could also be applied to various research scenarios globally, they are still limited by an inability to expose individuals to adverse environments within a controlled setting.

Virtual reality is just another example of a new method which could be used in original scenarios to rigorously and creatively investigate the mechanism by which adverse urban environments are linked to behaviour. Virtual reality is promising as it overcomes the persistent

limitation that intentionally exposing participants to adverse environments is not ethically possible.[6] Importantly, virtual reality software and hardware is becoming more accessible due to improvements in technology. It also uniquely offers ecological and internal validity as features in adverse urban environments can be closely controlled for experimental purposes, maximising experimental control in a traditionally complex situation and environment.

Reinforcement learning offers another potential method to assist policy making.[10] The search space of possible changes to an environment that might impact public health is large, especially when contextualised in a specific urban zone. Reinforcement learning includes methods and algorithms that can generate policies based on human practices, transfer these to new environments, simulate virtual agent rewards and iteratively adjust the policies using experimental feedback. This approach specifically balances and models the cost of exploring a new policy versus the optimisation of current policies. Moreover, it can advise new studies and local implementation or expand existing studies to engineer environments. Using such an approach may help overcome the limitation of needing years to plan and conduct longitudinal studies.

The availability of large-scale computation to test these novel models on large data provides a compelling call to apply them to environmental studies and broader fields of public health. There are challenges associated with the use of such novel methods with a reliance on interdisciplinary research and collaboration. However, if the power of these approaches is harnessed successfully then they have the potential to advance public health practice and policy making worldwide and transform thinking within other fields of science.

Competing interests:
Nil.

Author information:
Matthew Hobbs, Geohealth Laboratory, University of Canterbury, Christchurch;
James Atlas, Department of Computer Science, University of Canterbury, Christchurch.

Corresponding author:
Dr Matthew Hobbs, Geohealth Laboratory, University of Canterbury, Christchurch.
matt.hobbs@canterbury.ac.nz

URL:
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Ethnic disparities in community antibacterial dispensing in New Zealand—is current antibacterial dispensing for Māori and Pacific people insufficient or excessive, or both?

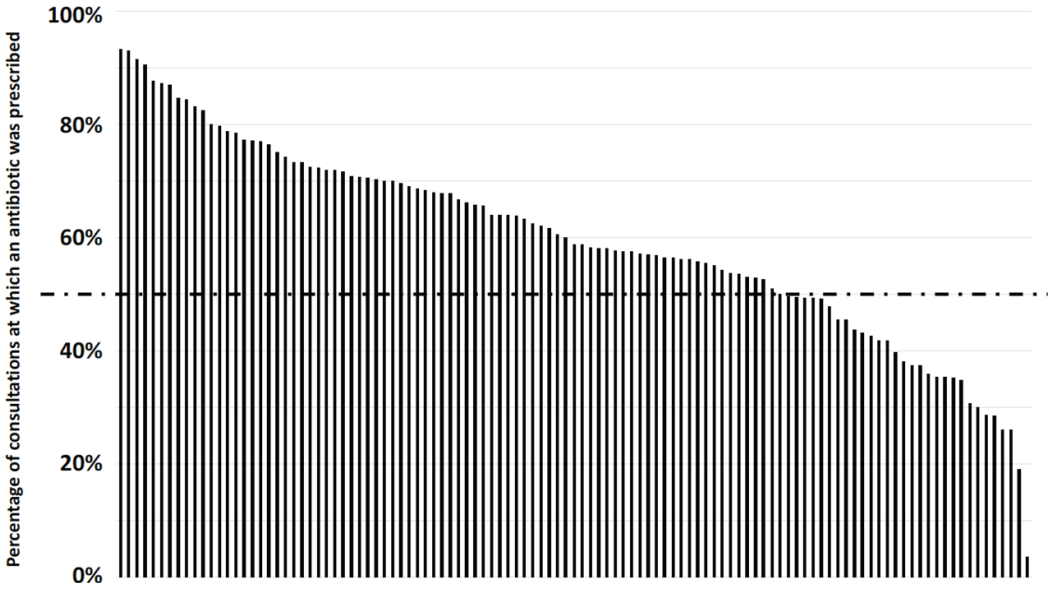
Mark Thomas, Naomi Whyler, Andrew Tomlin, Murray Tilyard

We thank Metcalfe et al (18 January 2019)[1] for their careful consideration of our article describing ethnic disparities in community antibacterial dispensing in New Zealand during 2015,[2] and for their comments on whether the health of Māori and Pacific people in New Zealand would be best served by increasing or reducing their current rates of antibacterial dispensing. We consider that the data in our article and in other recently published studies shows that: (a) the overall rate of antibacterial dispensing in New Zealand is very high compared with many other developed nations,[2,3] (b) a large proportion of antibacterial dispensing in New Zealand is likely to be inappropriate conferring little or no clinical benefit,[2,4,5] and (c) the rates of dispensing of antibiotics for Māori and Pacific people differs relatively little from the rates of dispensing for other ethnic groups,[2,4,5] despite a significantly higher incidence of many infectious diseases in Māori and Pacific people.[6–8]

We found the rate of community dispensing of antibiotics for people of European ethnicity in New Zealand during 2015 was 3.02 prescription items/1,000 population/day.[2] This was approximately 3.3 times higher than the national rate in Sweden (0.90), 2.1 times higher than the national rate in Denmark (1.45), 1.7 times higher than the national rate in Canada (1.79), 1.5 times higher than the national rate in England (1.95), and 1.3 times higher than the estimated national rate in the US (2.31).[2,9] While the incidence of infectious diseases in European people in New Zealand no doubt differs from that in residents of these other nations, we would be surprised if differences in the incidence of infectious disease justified these major differences in the rates of community antibacterial dispensing. A much more likely explanation is that the high rate of antibacterial dispensing for European people in New Zealand reflects higher rates of inappropriate prescribing in New Zealand than in these other nations.

Metcalfe et al suggest that we may have overestimated the magnitude of inappropriate antibiotic prescribing in New Zealand and refer to articles indicating that the rate of overprescribing might be approximately 30% in the US,[10] and 8–23% in the UK.[11] We note two recently published studies that have used large general practice databases to estimate current rates of inappropriate community antimicrobial prescribing for patients with respiratory tract infections in the UK[12] and Australia.[13] These studies estimated that inappropriate prescribing accounted for: 75% of prescribing for acute cough in the UK, 87% of prescribing for acute rhinosinusitis in the UK and 77%

Figure 1: The proportion of consultations for an acute upper respiratory tract infection, at 111 general practices in New Zealand, during 2014, that were associated with dispensing of an antibiotic during the subsequent seven days. Each column represents one general practice.



in Australia, and 80% of prescribing for acute otitis media in the UK and 45% in Australia. As these conditions comprise a large proportion of community antimicrobial prescribing, we believe it reasonable to estimate that approximately 50% of total community antibiotic dispensing in New Zealand may be inappropriate.

There is strong evidence that the overall rate of inappropriate antibiotic dispensing is very high in New Zealand. For example, Figure 1 shows that, overall, an antibiotic was dispensed at 61% (31,082/50,691) of consultations for acute upper respiratory tract infections in 111 New Zealand general practices during 2014.

In approximately 73% of general practices included in this survey an antibiotic was prescribed and dispensed for more than 50% of patients who presented with a respiratory tract infection. (Personal communication Tomlin A, Tilyard M. 2019) Many guidelines suggest that antibiotics should be prescribed for a minority of such patients.[12–14]

Other data indicating high rates of inappropriate antibiotic prescribing include a 26% increase in the national rate of antibacterial dispensing during winter in New Zealand,[2] presumably mostly for patients with self-limited viral respiratory tract infections, and an average annual rate of 1.9 antibiotic dispensings/child/year in the first five years of life, for the 5,581 children enrolled in the Growing Up in New Zealand study.[5] We acknowledge that there are no studies that have directly measured the rate of inappropriate community antimicrobial prescribing in New Zealand, however we consider that the figure of 8–23% suggested by Metcalfe et al is likely to be a significant underestimate. The available data suggest to us that the overall rate of inappropriate community antibiotic prescribing in New Zealand is more likely to be between 30% and 50%. Furthermore, the marked similarity between ethnic groups in the magnitude of the increase in antibiotic dispensing during the winter,[2] suggests that inappropriate antibiotic dispensing is a comparable problem for all ethnic groups in New Zealand.

The higher incidence of many infectious diseases in Māori and Pacific people than in people of other ethnicities in New Zealand,[2,6-8] is a compelling reason why Māori and Pacific people require higher rates of antibiotic dispensing. We appreciate the efforts of Metcalfe et al to calculate a suitable ratio for the rate of antibiotic dispensing for Māori and Pacific people in relation to that for non-Māori and non-Pacific people. We do not disagree with their suggestion that an appropriate rate of antibiotic dispensing for Māori and Pacific people may be approximately 1.66 times

the rate for non-Māori and non-Pacific people.[1] However, we strongly believe that the appropriate rate of antibiotic dispensing for Māori and Pacific people should be estimated in relation to the appropriate rate of dispensing for people of other ethnicities, and not in relation to the current excessively high rates.

Here we consider two scenarios in which we assume: (a) that in non-Māori and non-Pacific people, either 30% or 50% of antibiotic dispensings are inappropriate; and (b) that the appropriate rate of antibiotic dispensing for Māori and Pacific people is 1.66 times the appropriate rate of dispensing for non-Māori and non-Pacific people.

If approximately 30% of current dispensing for non-Māori and non-Pacific people is inappropriate, then the estimated rate of appropriate dispensing for these people is approximately 2.1 (70% X 3.02) antibiotic dispensings/1,000 population/day, a rate midway between the current national dispensing rates in the US and Canada, and slightly higher than the current national dispensing rate in England. The rate of appropriate antibiotic dispensing for Māori and Pacific people may therefore be estimated as approximately 3.5 (1.66 X 2.1) antibiotic dispensings/1,000 population/day, which is similar to the actual current rates of 3.2 (Māori) and 3.5 (Pacific people) antibiotic dispensings/1,000 population/day.

If approximately 50% of current dispensing for non-Māori and non-Pacific people is inappropriate, then the estimated rate of appropriate dispensing for these people is approximately 1.5 (50% X 3.02) antibiotic dispensings/1,000 population/day, a rate similar to the current national dispensing rate in Denmark. The rate of appropriate antibiotic dispensing for Māori and Pacific people may therefore be estimated as approximately 2.5 (1.66 X 1.5) antibiotic dispensings/1,000 population/day, significantly lower than the current rates of 3.2 (Māori) and 3.5 (Pacific people) antibiotic dispensings/1,000 population/day.

We believe that Māori and Pacific people currently do "suffer from double jeopardy, being harmed by both over-prescribing and under-prescribing" as Metcalfe et al suggest.[1] Both under- and over-prescribing contribute to health inequities in these ethnic groups. The higher proportion of staphylococcal disease in Māori and Pacific people caused by methicillin-resistant *Staphylococcus aureus* (MRSA)[15] is likely to be in part a consequence of over-prescribing of antibiotics for Māori and Pacific people, while their higher rates of admission to hospital for infectious diseases[6–8] are strongly suggestive of harm arising from under-prescribing of antibiotics. Therein lies the challenge with antimicrobial stewardship programmes in New Zealand. As we suggested in our previous article,[2] we must reduce our rates of inappropriate antibiotic prescribing, while increasing our rates of appropriate antibiotic prescribing. The need to reduce inappropriate antibiotic prescribing is not just limited to non-Māori and non-Pacific people since unnecessary antibiotics should not be prescribed for any patient. The need to increase appropriate antibiotic prescribing is greatest in Māori and Pacific people. Therefore, we reiterate our previous recommendation that antimicrobial stewardship programmes should be sufficiently nuanced to not only reduce rates of inappropriate prescribing but also to increase rates of treatment for infections that do require antimicrobial therapy. We welcome further commentary on how this delicate but important balance can be achieved in an equitable manner across all population groups in New Zealand.

Competing interests:
Nil.

Author information:
Mark Thomas, Department of Molecular Medicine and Pathology, Faculty of Medical and Health Sciences, University of Auckland, Auckland; Naomi Whyler, Infectious Diseases, Auckland City Hospital, Auckland; Andrew Tomlin, Best Practice Advocacy Centre, Dunedin; Murray Tilyard Best Practice Advocacy Centre, Dunedin.

Corresponding author:
Associate Professor Mark Thomas, Department of Molecular Medicine and Pathology, Faculty of Medical and Health Sciences, 85 Park Rd, Grafton, University of Auckland, Auckland.
mg.thomas@auckland.ac.nz

URL:
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An open letter to general practitioners in New Zealand

James Church

I am sitting here in Cleveland, Ohio as a Kiwi expat, troubled to the depths of my soul by what I have been reading about the ravages of bowel cancer in my homeland. I have had a career as a colorectal surgeon at the Cleveland Clinic and during these 30 years have developed a deep hatred for bowel cancer, doing my best to prevent it and to eradicate it in as many of my patients as I can. I have followed the bowel cancer situation in New Zealand closely and have contributed to the discussion regarding screening,[1] but I still see reports of people dying from what is essentially a preventable and curable disease. While I cannot personally screen the entire population of Aotearoa (I wish I could), I have some suggestions that might be helpful to you, the people who are most directly responsible for the health and wellbeing of the population. These suggestions are informed by a relatively recent phenomenon that is being reported worldwide…a significant increase in the incidence of bowel cancer in people under age 50.[2–3]

The relevance of the rising rate of bowel cancer in young people is that these are an unscreened population. In this respect they are like all New Zealanders under age 60, and New Zealanders of all ages in the areas where the National Bowel Cancer Screening Program has not started. Features of bowel cancer in an unscreened population include diagnosis of disease through its symptoms, an advanced stage at diagnosis and a high mortality because of the advanced stage. These clinical characteristics are seen in New Zealand patients.[3,4] In young patients, diagnosis is sometimes further delayed when symptoms are mistakenly attributed to more common, benign causes.[5] As more kiwis have access to the National Bowel Cancer Screening Program there will be an increased number of patients diagnosed at early, curable stages. For the unscreened however, there are still several things that can be done to minimise the number of patients being diagnosed late, and to lower the overall incidence of cancer.

These options are inexpensive and available to all, and I wanted to describe them to you.

1. Family history. A family history of bowel cancer is an important risk factor for developing the disease. The closer the affected relative and the younger their age at diagnosis, the higher the risk of family members. Having a first-degree relative with bowel cancer increases the risk of your patient developing it by 2.5-fold. If the relative was diagnosed under age 50 the increase in risk is 4.0-fold.[5] Even having a second-degree relative with bowel cancer is associated with a significant increase in risk. People with multiple affected relatives are at especially high risk and should be considered for referral to the New Zealand Familial GI Cancer Programme.[6] Please take a family history (ideally three generations) and refer a patient who has a positive family history for screening and possible genetic evaluation.
2. New families. Don't forget that each patient with a bowel cancer has a family. The risk of every member of that family for developing bowel cancer has just increased. Unfortunately, compliance with screening in such families is low. Colonoscopy should be performed 10 years prior to the age at which the youngest member of the family was diagnosed, or at age 50, whichever is younger. Dealing with the family of a newly diagnosed patient is difficult during the stress and anguish of a new diagnosis, but the patient's family has to be made aware of their risk.[7]

3. Personal history of colorectal neoplasia. A personal history of colorectal neoplasia is a risk factor for metachronous lesions. If a patient has already had an adenoma, adenocarcinoma or sessile serrated lesion removed from their large bowel they are at higher than average risk of developing more. The risk is highest with advanced adenomas and multiple adenomas. Such patients need colonoscopic surveillance.[8]
4. Other risk factors. There are other risk factors for bowel cancer that can be measured and that are part of a full cancer risk assessment. These include gender, ethnicity, age, body mass index, diet, alcohol and activity level. Algorithms are available to assess and assign risk on an individual basis, but in a busy practice it is probably easier to focus on personal and family history.[9]
5. Symptoms. Pay attention to symptoms. Rectal bleeding is never normal and needs to be promptly investigated. Bleeding can be triaged according to its pattern (Table 1)[10] and suspicious bleeding mandates colonoscopy. In patients with typical outlet rectal bleeding a flexible sigmoidoscopy is a reasonable way to check for rectal and sigmoid neoplasms.[10] Only when cancer is excluded can the diagnosis of more common benign conditions be made. A transitory change in bowel habits is usually due to readily identifiable factors such as changes in diet or medications, stress and travel, and is insignificant for cancer. A more lasting, progressive, or quickly recurrent change is more significant and should be investigated. Abdominal pain is also a common symptom but pain due to a bowel cancer usually does not resolve. It hangs around and gradually gets worse. Therefore, any abdominal pain that bears some relation to gastrointestinal function and lasts for more than a few days should be investigated. Unintentional weight loss and anorexia are significant symptoms, especially when there is concomitant change in bowel habits.
6. Examination. Do a digital rectal examination as part of your patients' annual physical exam. Start in the 30-year old. I know that they don't like it, and that you don't like doing it, but with the predominance of rectal cancer in the young it is a useful exam to do.[11] Your exam can be more effective and better tolerated if you follow the 'Open Sesame' technique.[12] A careful abdominal exam to rule out colonic masses is also cheap and easy.

While these suggestions will not solve the problem of bowel cancer in New Zealand, we all owe it to our patients to enquire about risk factors, pay attention to them when they are present, to do a thoughtful and thorough physical exam, and to exclude a cancer when patients present with symptoms that could have cancer as their cause. As general practitioners you are on the front lines of the war against bowel cancer. These are weapons that you can easily use.

Table 1: Definitions of rectal bleeding.[10]

Type of bleeding	Definition
Outlet-type	Bright red blood seen during or after defecation, on the toilet paper or in the toilet bowl, with no family or personal history of colorectal neoplasia, and no change in bowel habit.
Suspicious	Dark red blood, and/or blood mixed with or streaked on stool. Any sort of bleeding with a personal or family history of colorectal neoplasia. Bleeding associated with a change in bowel habit or passage of mucus.
Haemorrhage	Large volume bleeding needing urgent admission to hospital and transfusion of one or more units of blood.
Occult	Positive fecal occult blood test without visible bleeding

Competing interests:
Nil.

Author information:
James Church, Colorectal Surgeon, Cleveland Clinic, Cleveland, Ohio, USA.
Corresponding author:
James Church, Department of Colorectal Surgery, Desk A 30, 9500 Euclid Ave, Cleveland, Ohio 44195, USA.
churchj@ccf.org

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8049

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State gun laws, gun ownership and mass shootings in the US

The objective of this American study was to determine whether restrictiveness-permissiveness of state gun laws or gun ownership are associated with mass shootings in the US.

An annual rating between 0 (completely restrictive) and 100 (completely permissive) for the gun laws of all 50 states were documented between 1998 and 2015. Data concerning mass shootings for this period was obtained from the FBI. Mass shootings were defined as events in which four or more people were killed by a firearm.

The results show that states with more permissive gun laws and greater gun ownership have higher rates of mass shootings. It was also noted that there is a growing divergence in recent years as rates of mass shootings in restrictive states have decreased and those in permissive states have increased.

***BMJ* 2019; 364:l542**

Drug-induced liver injury

Such liver injury is responsible for 3–5% of hospital admissions for jaundice. Its incidence is estimated to be 14–19 cases per 100,000 persons with jaundice in 30% of these cases.

Paracetamol is well-known to be able to cause hepatic necrosis but usually due to overdosage. The authors of this report list 13 drugs which are the frequent causes of prescription drug-induced liver injury.

They cite a report of 1,275 cases of drug-induced liver damage between 2004 and 2013. Amoxycillin-clavulanate tops the list with 91 cases, followed by isoniazid (48 cases), nitrofurantoin (42), trimethoprim (31) and minocycline (28). A further eight drugs complete the list with lesser numbers.

NEJM 2019; 381:264–73

Inpatient healthcare-associated bloodstream infections in older people

In this retrospective study the researchers report on the incidence of bloodstream infections in their elderly patients and whether they are related to the use of urinary catheters.

One hundred and sixty-seven such infections were noted, predominantly (74%) with gram-negative bacteria. In 110 patients (66%) the infection was attributed to a urinary source and in 63 (57%) were associated with urinary catheters.

Preventive strategies are discussed. Minimising the frequency of insertion and the duration are key factors in reducing infection risks. The use of prophylactic antibiotics and such treatment at catheter removed are not favoured. Better staff hand hygiene and the removal of unnecessary catheters are recommended.

Internal Medicine Journal 2019; 49:1173–1177

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8050

The Emancipation of Woman

October 1919

Studio portrait of unidentified man and woman, showing the man dressed in army uniform, possibly Christchurch district. Maclay, Adam Henry Pearson, 1873-1955 :Negatives. Ref: 1/2-163479-G. Alexander Turnbull Library, Wellington, New Zealand. /records/30120173

We propose with some temerity to write on this subject, but almost entirely from the medical point of view. Intellectually, woman is the equal of man. What her mind lacks in logical power is counter-balanced by intuition. A man relies upon his reasoning faculties as he does upon his watch, and is often misled; a woman is apt to be deceived by appearances when governed too much by sentiment, and by prejudice which emanates in a man's mind but in a woman's heart, and in the latter case is often insurmountable. Morally, woman is man's superior. There is one moral standard for the man, and another for the woman, which operates wholly to her disadvantage. Theoretically, There should be only one standard, but physiologically it is almost impossible.

Physically and mentally, women have been emancipated in Christian and civilised countries. Women of the middle class have profited most in this way, and a liberal education and physical exercise for women are wholly commendable, provided that the first does not result in mental indigestion, and the latter in an attempt to incur physical strains, which the man's nervous fibre is better fitted to withstand. The future of the race belongs largely to women. Their influence over men is enormous, they have the bringing forth and the training of

children. Many of them, however, aver that this is not their special function, and that woman attains her greatest freedom when she is free from family ties and self-supporting, and claiming equal remuneration with her competitor, man. This is independence, forsooth, until middle age brings nervous exhaustion and loneliness and the other evils attendant upon the aging spinster, or bachelor-girl as she still might fain be called. Than this, there is no sadder sight. The influence of the Great War on women at the present time is generally bad. They tend to forsake the lesser ills for what can properly be called the larger woes. Too many dislike home life, and office work is their *summon bonum*. It is here that the warning voice of the medical profession should be heard. We admit that there must be an increasing number of female clerks and typistes and so on, but we ought to say that their lives are not so healthy as those of home-staying women. Indeed, it is only a question of time until the nerves of the typiste become shattered. While it is true that to know the average woman is a liberal education, it is yet sad but true that apparently an increasing number are unwilling to undertake the pains and cares of childbearing, and women are more to blame than men for the deplorably decreasing birthrate, and educated women more culpable than their working-class sisters. The evil resulting is both quantitative and qualitative. A much healthier public opinion needs to be formed by the influence largely of thoughtful and patriotic women themselves, but doctors who have access to the homes of the people can do much missionary work as occasions offer in this great cause. We believe evil effects in many ways, excitement and restlessness, have followed immediately on all great wars, and the adorable sex probably is passing through this phase at the present time, but we trust that soon to most women a home will become more attractive than an office or a shop, and a baby the most desirable possession on earth. As women out-number men, a proportion of women must remain unmarried, and there are other good and sufficient reasons why many women should remain single, but both to their own and the state's disadvantage. All this cannot be prevented, but married life should be exalted as a benefit to the state and to the individual, and for the physical well-being of women, and the status of domestic helpers should also be raised so that the woman who is a wife and a mother should not be left unassisted in the cares of housekeeping and home-making. Napoleon said that the future of France lay with the mothers: so does the future of our great empire.

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8051

Proceedings of the Waikato Clinical Campus Biannual Research Seminar

Wednesday 18 September 2019

Social avatar theory: from in vitro to in vivo (Instagrammer cognition—mind the gap)

Dr David Brunskill

Consultant Forensic Psychiatrist, PUAWAI, Waikato Hospital, Hamilton.

Abstract

The concept of a social avatar was proposed in 2013, following clinical observations about how social media users typically self-managed online image. Social avatar theory has since developed, and is a vehicle to allow examination and understanding of the potential for social media use to effect the psyche.

Through ubiquitous use, social avatar theory has effectively moved from in vitro to in vivo, and can now be applied in non-hypothetical terms. Via deconstruction/analysis of publicly available material, several theorised aspects materialise—curation, positive skew and the development of a psychologically significant 'gap' between online façade and offline reality. Prototypical cognitive schema can also be discerned, such as Instagrammer cognition.

It is of public health concern that the mooted potential for psychological costs to be incurred has also moved from the hypothetical. Social avatars are inherently psychoactive. For select users (further research required re: vulnerability factors), the creation/maintenance of a social avatar can become all-consuming and contribute to states of emotional distress and discord, such as envy and smiling depression. If the 'gap' has grown too large, social avatars can even contribute to psychological breakdown itself. A social avatar 'health-check' should therefore be developed and incorporated into digital citizenship/education initiatives.

Psychosocial support needs of women with breast cancer in the Waikato region

Elaine del Mundo-Ramos, Tania Blackmore, Lynne Chepulis, Ross Lawrenson

Faculty of Medical and Health Sciences, University of Auckland, Auckland; Waikato Medical Research Centre, The University of Waikato, Hamilton; Waikato Hospital, Hamilton.

Breast cancer is the most frequently diagnosed cancer among women and the third most common cancer in New Zealand. Despite improved survival rates, significant psychosocial distress is experienced by breast cancer patients. To address this, the Cancer Psychological and Social Support Service (CPSSS) provides supportive care to cancer patients and their families. We aimed to understand the characteristics and psychosocial support needs of women with breast cancer who were referred to the CPSSS at the Waikato District Health Board (WDHB). Breast cancer data from 2016 to 2018 was obtained from the Waikato Breast Cancer Register (WBCR) and compared to psychosocial support referrals from the CPSSS for the same period.

Statistical regression was performed to compare the characteristics of those referred and not referred to CPSSS. Thematic analysis identified the main referral themes. A total of 95 (10%) of the 998 women identified with stage 0–IV breast cancer in the WBRC were referred to CPSSS. Women were more likely to be referred if they were younger, had a mastectomy or no surgery, and had received radiotherapy. Older women, and women with stage 0 cancer were less likely to seek support. Ethnicity, mode of detection, rurality, chemotherapy, endocrine therapy and reconstructive surgery were not significant factors in whether women sought psychosocial support. Treatment concerns were the most common reason for referral. The median length of time in the service was 98 days. While CPSSS is still a relatively new service in a range of other cancer support services, the 10% referral rate may be a reflection of an unmet need for psychosocial support provision in the Waikato region. Younger women, women undergoing mastectomy, those not receiving surgery and women receiving radiotherapy may in particular benefit from psychosocial support.

A 9-year review of Waikato teledermatoscopy service

Novell Teoh,[1] Amanda Oakley[1,2]
[1]Waikato Clinical Campus, University of Auckland, Auckland; [2]Department of Dermatology, Waikato Hospital, Hamilton.

Background

Virtual Lesion Clinic (VLC) was established in January 2010 to improve early detection of skin cancer and improve access to specialist dermatology service.

Aim

To review the VLC service, including patients' characteristics, number of visits, number of melanomas diagnosed, teledermatoscopic diagnosis, efficiency, patients' outcomes and diagnostic accuracy.

Methods

Patients with triage 4 were referred from primary care to VLC. Retrospective data were retrieved from 1 January 2010 to 31 May 2019. The relationship between patients' characteristics and the occurrence of melanoma were analysed. Trendlines were analysed using a linear regression model with R squared (R^2) test for goodness of fit. Patients' outcomes, satisfaction and diagnostic accuracy were evaluated.

Results

This study evaluated 6,479 patients, 8,805 visits and 11,005 skin lesions. Males, age group 65–74, European, skin type 2, recent (<5 years) history or multiple history of melanoma, first-degree relatives with melanoma were associated with an increased risk of developing melanoma ($p<0.05$). The seasonal variation has demonstrated a positive trend line with a low fit to model ($R^2=0.3$). The median waiting time for patients with suspected melanoma was 44.5 days. There were 97.5% of patients rated the service as "excellent". The most common lesions diagnosed were benign naevus (27%), benign keratosis (25%) and keratinocytic skin cancer (15%). The positive predictive value was 61.1% and NNT was 2.02. Diagnostic concordance between GP and dermatologists was 29%. The ratio of confirmed melanomas in situ to invasive melanoma was 1.96 (243/124). The most common body site for melanoma was the trunk. Melanomas found on the trunk were predominantly males and melanomas found on the lower limbs were predominantly females.

Conclusion

VLC is an efficient and accurate service in evaluating skin lesions, however there is a reduction in utilisation of this service. An alternative solution has been proposed for service improvement.

Accuracy of ethnicity records at primary and secondary healthcare services in Waikato, Aotearoa New Zealand

Brooke Blakemore,[1] John Conaglen,[2] Marianne Elston,[2] Papaarangi Reid,[3] Jade Tamatea[3,4]
[1]Otago School of Medicine, University of Otago, Dunedin; [2]Department of Medicine, University of Auckland, Waikato Clinical Campus, Waikato Hospital, Hamilton; [3]Te Kupenga Hauora Māori, University of Auckland, Auckland.

Background

Ethnicity is a social construct that allows for groupings based on shared history, beliefs and culture.[1,2] As such, ethnicity is fluid, self-reported and can be multiple. In Aotearoa New Zealand, the healthcare sector records ethnicity, but these records have been inaccurate, with particular undercounting of Māori and other marginalised groups.[3,4]

Accurate ethnicity data, as defined by the 2004 *Ethnicity Data Protocols for the Health and Disability Sector*,[5] are essential for monitoring ethnic health inequities. As per Te Tiriti o Waitangi, Article Three, Māori have the unquestionable right to all services "of the crown".[6] Accurate ethnicity data is a fundamental tool to ensure this treaty-based right is obtained, and to pose questions when it is not.[7,8]

Despite the introduction of protocols, a 2006 review of local ethnicity data accuracy found ongoing inaccuracies when compared to self-identified ethnicity mail responses (errors in multiple ethnicity records led to 41–89% accuracy at level 1 ethnicity groupings).[9]

Methods

The aim of this study was to determine the accuracy of ethnicity records at nationalised (NHI), secondary (hospital) and primary (PHO) healthcare services, as compared to ethnicity records available from two local kaupapa Māori research cohorts (Whakangungu Rākau study [WNR]). Within the WNR project, ethnicity data was prospectively collected in person, using a question identical to the New Zealand Census[10] and following the Ministry of Health ethnicity protocol.[5] Multiple responses recorded and results were stored at the most detailed (Level 4)[11] for all responses given. This data was used as the 'gold standard' for ethnicity and was compared to three separate databases: the primary health organisations, the Waikato DHB/hospital records and patient management records of national NHI linked dataset.

All participants had ethnicity records located in hospital records and NHI records, and 380 (80.2%) participants were located in PHO databases (all Level 2). Ethnicity records from the three datasets were compared with WNR, and in three different outputs: total ethnicity, prioritised ethnicity and single/combination.[15]

Results

A total cohort of 474 participants were identified from the WNR project (82.3% females, median age 55), with a total count of ethnicities of European 65.4%, Māori 34.4%, Asian 4.9%, Pacific Peoples 3.6%, MELAA 0.4%, and one participant did not state (0.2%). [Percentages >100% due to multiple ethnicity options].

Māori were undercounted in all databases compared to the WNR data (PHO 31.3%, hospital 31.7%, NHI 32.5% compared to WNR 34.4%). Other non-European ethnicity groups were also under-reported in the healthcare datasets. Multiple ethnicities were less frequently

recorded in PHO data (5.8%), hospital data (5.0%) and NHI data (5.3%), compared to the WNR dataset (8.6%).

Comparing different ways of managing multiple ethnicities, prioritised ethnicity had the most congruence to WNR (PHO 93.4%, Hospital 93.9%, NHI 95.1%) and total response the least (PHO data 87.4%, hospital 88.8%, NHI 90.5%).

Conclusion

Inconsistencies in ethnicity data still exist in formal health records. Lower rates of multiple ethnicities and undercounting of numerical minority ethnicity groups were identified. When managing multiple ethnicities, use of prioritised ethnicity appears to improve the undercounting of Māori, however more effort is needed in improving ethnicity data collection, recording and reporting with the aim of improving Māori health outputs.

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Eight years later: long-term outcomes from mild traumatic brain injury in adults

Nicola Starkey,* Brittney Duffy, Kelly Jones, Alice Theadom, Suzanne Barker-Collo, Valery Feigin on behalf of the BIONIC8 study

*Presenting author: Professor Nicola Starkey, School of Psychology, University of Waikato, Hamilton.

Traumatic brain injury (TBI) is a leading cause of long-term disability in adults. The majority of injuries are classed as mild but can still result in adverse outcomes. Despite the high rates of mild TBI, the long-term consequences of these injuries are not well understood. This study sought to address this by examining the long-term outcomes (eight years post-injury) of a cohort of adults with TBI, originally identified as part of the Brain Injury Outcomes New Zealand in the Community study (BIONIC) in 2010–2011 (n=151; mean age = 45.4 years; 51% male). An age and gender matched cohort free from TBI in their lifetime were recruited for comparison purposes (n= 211; mean age 45.0 years, 49% male). Participants completed a series of questionnaires (online or in-person) about their current health, mood, perceived cognitive functioning, post-concussion symptoms and employment.

At eight years post-injury, adults with mild TBI reported significantly more post-concussive symptoms, particularly in the cognitive and emotional domains (p's<.01), and had poorer planning abilities (p=.03) than the comparison group. There were no significant group differences for anxiety, depression, post-traumatic stress, overall self-reported cognitive functioning or somatic symptoms (p >.05). Nearly one-third (30.5%) of the TBI group rated four or more post-concussive symptoms as at least a 'moderate' problem as compared with only 14.6% of the control group.

From 1 to 12 months post-injury, we observed significant decreases in depression (p=.02), anxiety (p=.007) and post-concussive symptoms (p<.001). However, between 12 months and 8 years, depression scores showed a significant increase (p<.001). There were no significant changes in anxiety (p=.97) or post-concussive symptoms (p=.09) from 12 months to 8 years. Regression analyses revealed that older age at injury, female gender, higher levels of anxiety and depression at one month post-injury, and a greater number of lifetime TBIs predicted 31% of the variance in post concussive symptom scores at eight years post injury.

These findings suggest that a mild TBI may result in poorer long-term outcomes particularly for cognitive (forgetfulness/ poor memory; poor concentration; taking longer to think) and emotional (irritable, easily angered; feeling depressed or tearful; feeling frustrated or impatient; restlessness) symptoms. Older age at injury, female gender, poorer mental health and higher number of TBIs are linked to poorer outcomes. Overall the findings suggest that provision of mental health support and education/ intervention to reduce the number of recurrent TBI may improve long-term outcomes following mild TBI.

Opioids prescribed on discharge—what happens next? (HDEC reference no.: 19/CEN/107)

Marizka Oberholzer, Sharyl Rodrigues, Rajan Ragupathy, Julie Vickers, Grant Macdonald, Jan Goddard

Pharmacy Services, Waikato District Health Board, Hamilton.

Background

Opioid use is increasing throughout New Zealand, and approximately 50% of patients who have strong opioids dispensed in the community received their initial opioid prescription in a public hospital.[1] Little information is available to describe what happens on discharge from hospital.

Aim

- To describe Waikato Hospital's current opioid discharge prescribing practice.
- To investigate community opioid dispensing patterns up to three months post-discharge.

Method

Retrospective, descriptive observational study (100 patients, naïve to strong opioids, initiated on a strong opioid in Waikato Hospital and dispensed an opioid on a discharge prescription from older person rehabilitation [OPR] wards). Hospital databases and community dispensing records will be used to identify eligible patients and dispensing patterns post-discharge. A pilot study was conducted prior to the main study.

Exclusion criteria: Domiciled outside Waikato DHB; dispensed strong opioids within one month pre-admission; or receiving palliative, oncology or opioid substitution treatment.

Pilot results

Thirty-eight percent (n=13) of patients who met study criteria had an opioid prescription dispensed on discharge (oxycodone and codeine only, average supply period nine days). The median age of patients was 81 years; 77% were female; 23% were Māori, 69% European and 8% other ethnicities. All discharge summaries had opioids listed; however, only 54% had a post-discharge plan. Sixty-nine percent of patients received subsequent opioid prescriptions in the community: average of 59 (range 7–90) days.

Conclusion

Full results are forthcoming. If these mirror the pilot, the periods of supply on discharge and in the community subsequently are concerning. Opioid use exceeding six weeks is potentially inappropriate, particularly in older patients.[1–3] There is a lack of information from other DHBs with which to compare these results.

The results of the study will be used to inform hospital prescribers of typical opioid prescribing practice and the value of having a well-documented plan in place for pain management.

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Management of thyrotoxicosis—can we do better?

Marianne S Elston, John V Conaglen, Jade AU Tamatea

Waikato Clinical Campus, University of Auckland, Waikato Hospital, Hamilton.

Thyrotoxicosis is a common disorder in Aotearoa with significant consequent morbidity and mortality. The impact of this disease is inequitably distributed in this country. Māori are twice as likely to experience thyrotoxicosis (7.5x as likely for toxic multinodular goitre). Despite this previously unreported increased incidence of hyperthyroidism, Māori receive a disparate level of care at all stages, from access to diagnosis (delayed diagnosis, reduced community therapy initiation) through to ongoing care (elevated hormone levels, reduced response to therapy). Once diagnosed, after the first year of follow-up, Māori were five times more likely to be unable to attend a hospital-based clinic appointment, received 20% less blood tests and were over twice as likely to need an acute hospital admission. These findings of reduced access to care result in Māori experiencing more complications from prolonged under-treatment. As it is currently delivered, the current hospital-focused chronic care model is failing to provide for Māori communities.

Aim

To identify barriers to attending outpatient-based hospital clinics and assess patient preferences for alternative follow up strategies

Methods

Paper-based anonymised survey of patients attending thyroid clinic.

Results

A total of 115 patients completed the survey. Median age 52 years (IQR 38–69), 86% female, 64% NZE/other European, 24% Māori. The majority of patients (77%) had access to a computer. The most popular options for follow-up were: current model (83%), email (63%), clinical nurse specialist (62%) and phone (60%) with only 17% selecting videoconferencing from medical centre or their own home (23%) as in the top three options. Barriers to care were identified by 81% of participants, particularly work and parking issues (both cost and the car-parking building). Only 14% of Māori did not report any barriers to care.

Conclusion

This preliminary data serves to start discussion on means to improve follow-up care. Despite

DHB-led popularity, videoconferencing was the lowest ranked option selected by our patients.

The prevalence of cancer in a primary care practice

Dong Hyun Kim,[1] Rawiri Keenan,[2] Lynne Chepulis,[2] Chunhuan Lao,[2] Fraser Hodgson,[3] Chris Bullen,[4] Ross Lawrenson[2]

[1]Faculty of Medical and Health Sciences, University of Auckland, Auckland; [2]Waikato Medical Research Centre, The University of Waikato, Hamilton; [3]Fraser Hodgson, Mahoe Medical Centre, Te Awamutu; [4]School of Population Health, The University of Auckland, Auckland.

There is an increasing prevalence of cancer survivors in the community due to an ageing population, implementation of cancer screening programmes and advances in cancer treatment.

The aim of this study was to evaluate the workload of cancer patients in a typical primary care practice (PCP), by determining the prevalence of primary invasive cancers and characterising cancer patients' healthcare needs using primary care data.

This study was based in a large minor-urban PCP with a total registered population of 11,174 patients. MedTech database queries and the New Zealand Cancer Registry dataset were used to identify patients diagnosed with cancer between Jan 2008–May 2019.

There were 235 cancer diagnoses (39 cancers in Māori patients and 196 in non-Māori patients). The sensitivity of the primary care data for identifying invasive cancer was calculated as 87%. The age standardised prevalence rate for cancer in Māori patients was 2,400/100,000 and 1,677/100,000 for non-Māori patients. The most prevalent cancers were breast, male genital organ, digestive system and melanomas. While enrolled with the PCP, 82 (35%) cancer patients were followed up by their general practitioner (GP) only, 67 (29%) were followed up by secondary care, 55 (23%) were actively treated by secondary care, eight (3%) were receiving active treatment from their GP, and eight patients (3%) had also received palliative care input.

Primary care data was shown to be sensitive (87%) for identifying cancer patients in the community. Data from this PCP suggest that there may be disparities in cancer prevalence between Māori and non-Māori patients, though this needs confirming in other PCPs.

Exploring neural patterns during loss of responsiveness with Granger causality

RM Pullon, L Yan, JW Sleigh

Department of Anaesthesiology, University of Auckland.

Changes in consciousness and responsiveness have been associated with changes in information flow between regions of the brain. However, these changes—such as the direction of information flow, timing and regions involved—are poorly understood. Here we assess changes in functional connectivity by applying Granger causality to 32-channel electroencephalogram (EEG) signals of 16 volunteers during propofol anaesthesia. Granger causality describes the amount of information flow between two electrodes by using auto-regressive models to assess whether past information at one electrode helps to predict current information at another electrode. We found that information flow in the low delta frequencies (0.5–1.5Hz) and alpha frequencies (8–13Hz) increased as the subjects became sedated, but then decreased to near zero as the subjects lost responsiveness. Information flow remained at zero until a few minutes before regain of responsiveness where Granger values increased to four times the induction values. This global loss of information flow during unresponsiveness is intriguing and, to the best of our knowledge, has not previously been reported. Furthermore, these findings suggest Granger causality could be a useful tool for predicting regain of responsiveness during anaesthesia, assuming similar results are yielded in a clinical dataset.

Māori vs non-Māori patients: do we treat pneumonia differently?

Elliott-Buma S, Ragupathy R, Issa M, Vickers J, Aberhart J, Goddard J

Pharmacy Services, Waikato District Health Board, Hamilton.

Introduction

Māori experience inequities in aspects of health leading to poorer health outcomes.[1] Pneumonia is three times more prevalent in Māori than non-Māori and associated with a six-fold increase in mortality.[2] Suboptimal antibiotic usage may contribute to this as differences may exist in the way Māori and non-Māori patients receive antibiotics.-

Aim

To clarify differences in antibiotic prescribing and administration for Māori and non-Māori patients with pneumonia. Specifically investigating differences in:

1. Time spent on intravenous antibiotics (IVabx)
2. Antibiotic duration
3. Percentage of antibiotic scripts dispensed in the community and lag-time to dispense.

Method

ICD-10 codes were used to retrospectively recruit 100 pneumonia patients admitted to the respiratory ward between 1 June 2018–1 June 2019. A pilot study was completed across a two-week period in July 2018. The pilot consisted of 33 patients: 33% (11) Māori and 67% (22) non-Māori patients.

Data including age, ethnicity, comorbidities and gender were collected using hospital databases and community dispensing data.

Results

Full study results forthcoming.

	Māori	Non-Māori
Median age	58	70
Median Charlson Comorbidity Index	5	5
Median days in hospital	6	3
%requiring high dependency/intensive care admission	27% (3)	14% (3)
Median days on IVAbx	3	1
Median days on antibiotics	10	9
%Mortality	36% (4)	5% (1)
%Discharged on oral antibiotics	55% (6)	95% (21)
%collected discharge antibiotics	100% (6)	86% (18)
%collected day of discharge	83% (5)	89% (16)

Conclusions

Preliminary pilot data shows feasibility in undertaking this study. Despite small sample size, results suggest Māori are less likely to be discharged on oral antibiotics and more likely to:

- Spend longer in hospital
- Require high dependency/intensive care
- Spend longer on IVabx
- Have pneumonia-associated mortality—despite no differences in morbidity,
- no difference has been found in rate and time to dispensing of discharge antibiotics.

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Justification for presentation

Identifying a significant difference provides rationale for further investigation and intervention. The intention is to identify initiatives to reduce disparities. This study may be reflective of practice occurring in other regions across New Zealand or applicable to other infections.

The project was given expedited ethical approval by the Northern A Health and Disability Ethics Committee, HDEC Reference 19/NTA/17.

URL:
http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1505-8-november-2019/8052

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