Sepsis: New Zealand needs a plan

Deaf community views on paediatric cochlear implantation

Review of taste and taste disturbance in COVID-19 patients
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<thead>
<tr>
<th>New Zealand subscription rates</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Individuals*</td>
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<tr>
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</table>

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EDITORIALS

7
Sepsis: New Zealand needs a plan
Paul Huggan, Dan Dobbins,
Robert Martynoga, Chris Hopkins,
Nigel Raymond

ARTICLES

11
Nutrition support in oncology care in Aotearoa New Zealand: current practice, and where to from here?
Rana Peniamina, Rachael McLean

26
Deaf community views on paediatric cochlear implantation
Briana Putnam, Sara Pivac Alexander,
Kathleen McMenamin, David Welch

43
Surgical management of Graves’ disease: historical context and single institution experience
Michael J Russell, Simon Young,
Richard Martin, Richard Harman

50
Neurodevelopmental follow-up of preterm infants: current practice for infants at a tertiary neonatal centre
Meghan Ealish Sandle, Maria Saito Benz,
Laura Port, Max Berry

63
Factors predicting forgone healthcare among Asian adolescents in New Zealand: unmasking variations in aggregate data
Roshini Peiris-John, Lynda Bavin,
Kristy Kang, Lovely Dizon, Sonia Lewycka,
Shanthi Ameratunga, Terryann Clark,
Theresa (Terry) Fleming

REVIEW ARTICLES

81
Review of taste and taste disturbance in COVID-19 patients
Guangzhao Guan, Alison Mary Rich,
Ajith Polonowita, Li Mei

VIEWPOINTS

92
Choosing Wisely: the lack of validity of ultrasound scans in the investigation of shoulder instability
Callum Oorschot, Khalid Mohammed,
Michael Austen, Emma O'Loughlin

101
Is it time to relieve junior doctors from “relief rotations”?
Yassar Alamri

CLINICAL CORRESPONDENCE

106
Outpatient synacthen testing in a large metropolitan region: a clinical audit
Anthony Walters, Joanna Champion-Young,
Michael Croxson, Andrew Grey

113
Yersinia enterocolitica associated myopericarditis: case report and review of the literature
Hayley Nehoff, Edward Henley,
Rebecca Hamblin, Heather Isenman,
Ian Crozier

LETTERS

117
Exertional rhabdomyolysis following return to exercise after COVID-19 lockdown
Isaac Bernhardt, Bryony Ryder,
Callum Wilson
120
An audit of a marae-based health centre management of COVID-19 community cases in South Auckland
Matire Harwood, Selwyn Te Paa, Nethmi Kearns, Helaman Luki, Augustus Anderson, Alex Semprini, Richard Beasley

100 YEARS AGO

129
Maternal Mortality
1922

PROCEEDINGS

131
Proceedings of the Waikato Clinical Campus Research Seminar, Thursday 16 September 2021
Nutrition support in oncology care in Aotearoa New Zealand: current practice, and where to from here?

Rana Peniamina, Rachael McLean

We surveyed healthcare practitioners (eg, doctors, nurses, dietitians) and support workers involved in cancer care about nutrition-related information and support for people during and after cancer treatment. Most participants thought nutrition was important for cancer recovery, patient wellbeing and preventing cancer recurrence, and believed nutrition information and support should be offered to cancer patients. However, nutrition information and support were not widely available in cancer care. Insufficient funding and lack of time/staff capacity were the main barriers to providing nutrition information/support (including access to dietitian appointments). High-quality and culturally appropriate nutrition information and support needs to be more widely available and consistent nationwide.

Deaf community views on paediatric cochlear implantaion

Briana Putnam, Sara Pivac Alexander, Kathleen McMenamin, David Welch

There are two models used in the literature to describe those who are d/Deaf: the medical and the cultural. The medical model describes deafness as an unwanted disability that needs to be treated through the use of medical devices like cochlear implants (CIs). The cultural model describes the word “Deaf” (written with a capital) as a culture and membership of the Deaf community as a privilege. It also places emphasis on the importance of sign language in Deaf culture. Historically, the Deaf community has been opposed to cochlear implantation in children, but little is known about current attitudes, or those of the Deaf community in New Zealand. This research asked deaf, hard-of-hearing (HoH) and culturally Deaf people in New Zealand about their views on paediatric cochlear implants via an online questionnaire. Culturally Deaf respondents were compared to those who were not. Findings were mixed, suggesting that there are still reservations about the benefits of CIs for children born deaf. Key areas identified were consideration of a bilingual/bicultural approach to CI habilitation in children and the need to fully inform parents of all their options. The study also highlights the multitude of cultural and non-cultural factors that need to be considered in both the decision-making and habilitation processes for treatment of a deaf child. An understanding of the different perspectives between the Deaf community and health professions in New Zealand is important in considering what is best for the deaf child.

Neurodevelopmental follow-up of preterm infants: current practice for infants at a tertiary neonatal centre

Meghan Ealish Sandle, Maria Saito Benz, Laura Port, Max Berry

Premature infants have an increased risk of developing later developmental problems. We looked at a group of very premature infants and found that most received specialised development follow-up and assessment within the first two years of life. Over two thirds of these infants did not have any developmental difficulties identified in this time. Using early screening tests may be helpful to identify the infants most at risk and reduce the burden of follow-up.
Factors predicting forgone healthcare among Asian adolescents in New Zealand: unmasking variations in aggregate data

Roshini Peiris-John, Lynda Bavin, Kristy Kang, Lovely Dizon, Sonia Lewycka, Shanthi Ameratunga, Terryann Clark, Theresa (Terry) Fleming

Factors like poverty, discrimination and poor access to healthcare make it difficult for teens to access care. One in five Asian secondary school students surveyed in 2019 did not access healthcare when they needed it. Asian students who experience discrimination by healthcare professionals and unfair treatment by teachers are more likely to forgo healthcare. There were differences in not being able to get healthcare between East Asians and South Asians. Asian teens need to be able to talk about health issues with their families to understand how to access healthcare, because it can be complicated, expensive, discriminatory and scary to negotiate alone.

Review of taste and taste disturbance in COVID-19 patients

Guangzhao Guan, Alison Mary Rich, Ajith Polonowita, Li Mei

Taste buds may be potential targets of COVID-19 virus. The mechanisms of taste change in COVID-19 patients may be due to direct but temporary taste cell and nerve injury, inflammatory responses and the damage of ACE2.

Choosing Wisely: the lack of validity of ultrasound scans in the investigation of shoulder instability

Callum Oorschot, Khalid Mohammed, Michael Austen, Emma O’Loughlin

Choosing Wisely is an international initiative with the intention to help clinicians choose care that is “supported by evidence, not duplicative of other tests or procedures already received, free from harm and truly necessary.” The NZOA and ACC have collaborated to propose a Choosing Wisely statement, advising that ultrasound scans of the shoulder are not useful as a screening test for patients under the age of 30, with shoulder instability unless there is clinical suspicion of a rotator cuff tear. Review of a specialist shoulder surgeon practice revealed that approximately a third of patients referred, already had a shoulder ultrasound, and that it was not useful for decision making in those patients. Review of ACC expenditure reveals that currently, the ACC is spending over 1 million dollars a year on this investigation in this group and the patients may pay an additional surcharge. This study supports our opinion that ultrasound scans are not useful in evaluating patients under the age of 30 with shoulder instability.
Sepsis: New Zealand needs a plan

Paul Huggan, Dan Dobbins, Robert Martynoga, Chris Hopkins, Nigel Raymond

“Some very important clinical issues, some of them affecting life and death, stay largely in a backwater which is inhabited by academics and professionals and enthusiasts, dealt with very well at the clinical and scientific level but not visible to the public, political leaders, leaders of healthcare systems... The public and political space is the space in which [sepsis] needs to be in order for things to change.”
– Sir Liam Donaldson

Sepsis is the syndrome connecting infection to acute multi-organ failure and death. It is a clinical diagnosis, resting on the identification of “life threatening organ failure due to a dysregulated host response to infection.” Common causes include pneumonia, invasive bacterial infection (eg, *Staphylococcus aureus* bacteraemia), urinary tract and soft-tissue infection. Almost a quarter of a century ago, Finfer et al estimated that the incidence of sepsis requiring ICU admission in Australia and New Zealand was 0.77 per 1,000 population per year. It was subsequently demonstrated that this approach missed 30% of the cases identified using consensus clinical criteria. Added to this, the population with sepsis in intensive care is only a fraction of the total. Local audit at Waikato Hospital suggests that the true population of adults in hospital with sepsis is five-times the number admitted to ICU. Is it plausible to suggest that around 1 in 200 people are being admitted to hospital with sepsis each year in New Zealand?

Sepsis admissions can be expected to reveal wicked interactions between deprivation, ageing, frailty and morbidity. New Zealand already has very high rates of bacterial infection, most notably revealed in epidemics of meningococcal disease and rheumatic fever. Michael Baker and colleagues have shown that the risk of infection-related hospitalisation is 2.8-times higher comparing the highest quintile of socioeconomic deprivation with the lowest. Socioeconomic deprivation is more commonly experienced by Māori and Pacific people. To further indict the conditions which give rise to it, sepsis is at least twice as common in these populations. Adding to this, chronic medical conditions greatly increase the risk of infection and sepsis, as does population aging. Is it surprising, then, that infectious disease hospitalisations have risen faster than any other cause over the past three decades, or that sepsis admissions doubled at Waikato Hospital in the five years leading to 2012?

With these questions in mind, the first National Sepsis Conference was held from 18 to 20 November 2021. As a collaboration between the New Zealand Sepsis Trust (NZST), the Australasian Society for Infectious Disease (ASID) and Te Ohu Rata o Aotearoa (Te ORA), the conference brought together over 200 delegates to consider “challenges for New Zealand.” Prominent clinicians and researchers from the USA, Australia and New Zealand considered topics ranging from acute management of sepsis, to the evidence-informed design of systems to improve quality of sepsis care. In one session, three apparently disparate topics (the Whakaari volcanic eruption, the antimicrobial resistance crisis and the rise in healthcare-associated *S. aureus* bacteraemia) demonstrated the adversity facing patients and front-line providers. Professors spoke alongside medical students and postgraduate trainees; nurses with interests in sepsis gathered for a workshop to discuss their findings; survivors of sepsis and of COVID-19 shared their stories of hardship and discovery. Prominent Māori academics explained the origin of prevailing...
inequities revealed by investigation and audit. It was easy to agree that “New Zealand needs a plan.”

The conference was therefore an ideal launchpad for the *Aotearoa New Zealand National Sepsis Action Plan*. With support from ACC, this work arose from a 2017 World Health Assembly resolution urging member states to invest in sepsis care. The benefits of implementing the plan are nothing compared with the long-term benefits of poverty reduction and action to close gaps in health outcomes. However, the health system needs to lead short-term changes which can lead to quick improvements, so these are the plan’s focus (find out more at www.sepsis.org.nz/action):

1. Create a National Sepsis Network to drive quality improvement in the acute health sector.
2. Increase Public Awareness by investing in community infection and sepsis awareness campaigns.
3. Improve recognition of sepsis in all healthcare settings by ensuring providers can recognise and manage cases of suspected sepsis.
4. Collect data to drive quality improvement.
5. Support sepsis survivors by investing in programmes of enhanced recovery and rehabilitation for people leaving hospital after a sepsis event.

Conceived in the pre-COVID era, and concentrating on a response based within the health system, the plan nevertheless reinforces the need to learn from the COVID-19 pandemic and to ensure that the investments made to endure and recover from COVID-19 provide long-lasting benefits. For example, sepsis care should be integrated into antimicrobial stewardship programmes (Recommendation 3). Ninety-five percent of human antimicrobial consumption is in the community. The non-pharmacologic measures deployed to manage COVID-19 were associated with reduced community antimicrobial consumption by over a third without evidence of harm. In hospitals, investment in antimicrobial stewardship to improve care for patients with sepsis would start with ensuring urgent treatment but extend to de-escalating and de-prescribing during recovery. Reporting on measures of sepsis outcome in relation to antimicrobial selection, delivery, duration and de-escalation corresponds with the plan’s recommendation to gather and report data (Recommendation 4) and to network the sharing of best practice in relation to quality improvement (Recommendation 1).

It is already known that enormous benefits can be realised by investing in the prevention and mitigation of infectious disease. The British Columbia (BC) Sepsis Network was established in 2012 with a cumulative spend of $500,000 through to 2018. By that time, Khawaja and colleagues estimate that the network’s activities had led to the prevention of 172 deaths and savings of $112 for every dollar invested. In New South Wales, a state-wide programme promoting early recognition and treatment of sepsis led to a 20% increase in the proportion of patients with sepsis receiving antibiotics within an hour of emergency department triage. This accompanied a 5% reduction in hospital mortality and a two-day reduction in mean length of stay.

Also in Australia, a whole-of-hospital sepsis pathway in a specialist cancer hospital halved the average time to antimicrobial therapy, reduced hospital mortality and saw an 18% reduction in the proportion of patients admitted to intensive care.

This and other evidence has been used to fund a national sepsis plan for Australia coordinated by the Australian Commission on Quality and Safety in Health Care. In contrast, at the time of writing, a search for “sepsis” on the Ministry of Health website returned only one link, which was to a brief Official Information Act response. Why are we so far behind here? Did late twentieth century models of health investment focus too much on the management of non-communicable disease? Has sepsis fallen into the trap of being everyone’s problem but nobody’s business? Or is the failure to prioritise the prevention and management of severe infection the expected response to a problem which disproportionately affects Māori and Pacific people? Regardless of distal causation, we will not navigate a way forward without coordinated action. So saying, we commend the National Sepsis Action Plan to the leadership of our new health agencies.
Competing interests:
Nil.

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Improvement Initiative for Reducing In-Hospital Sepsis Rates and Mortality in British Columbia, Canada, Critical Care Medicine. doi: 10.1097/CCM.0000000000005353


Nutrition support in oncology care in Aotearoa New Zealand: current practice, and where to from here?

Rana Peniamina, Rachael McLean

ABSTRACT

AIM: This research sought to identify and understand what nutrition-related information and support is available to people undergoing cancer treatment. We also sought the views on nutrition for cancer among providers of cancer care/support, and barriers/enablers to the provision of nutrition information/support.

METHOD: Data were collected using online surveys with New Zealand-based healthcare practitioners and support workers. Descriptive analysis was undertaken. Open-ended questions were analysed for explanatory content to help us interpret and understand the results.

RESULTS: Most healthcare practitioners and support workers viewed nutrition as at least moderately important (for cancer recovery, patient wellbeing and preventing cancer recurrence) and believed nutrition information/support should be provided to cancer patients. However, nutrition information and support were not widely available through oncology practices and cancer support services. The main barriers to the provision of nutrition information and support (including access to dietitian appointments) were insufficient funding and lack of time/staff capacity. Additional barriers included a lack of access to evidence-based information and dietary expertise.

CONCLUSION: Nutrition information and support needs to be more widely available and standardised across New Zealand’s oncology services. Ideally this would include general introductory information about nutrition (e.g., World Cancer Research Fund recommendations) from all healthcare practitioners and more detailed tailored advice (and ongoing support where needed) from dietitians.

Cancer is an important health problem in New Zealand. It has been the leading cause of deaths in New Zealand since the mid 1990s (currently accounting for around a third of yearly deaths), and yearly numbers of new registrations are increasing.1,2 Good nutrition is important for cancer patients. The potential benefits include better health outcomes during treatment, improving cancer survival, and preventing recurrence.3–6 Both local and international research indicate that diet and nutrition is an important factor in the preferences and needs of our communities, something the New Zealand Cancer Action Plan 2019–2029 recognises as an important factor in cancer care.7–11 In fact, many cancer survivors make dietary changes at various stages of their cancer experience, including dietary supplementation and adherence to particular diets.12–14

Recent qualitative research with New Zealand cancer survivors showed that many had a strong interest in pursuing diet as a way to support cancer recovery and prevent recurrence, but they found that access to appropriate evidence-based dietary information and support was lacking.8 Cancer survivors who sought out cancer-related nutrition information via the internet were exposed to misinformation. Others who were unaware of the role of nutrition in cancer recovery and prevention did not ask their healthcare providers for nutrition-re-
lated information or support nor did they seek out information about nutrition from other sources. A lack of access to appropriate nutrition information and support potentially contributes to the persistent inequities in cancer outcomes experienced by subgroups of the New Zealand population. Including nutrition advice and support as part of the standard cancer care offered to all patients through oncology practices, as recommended by the World Cancer Research Fund (WCRF), would help people with cancer to navigate the benefits of good nutrition as part of their recovery while limiting their exposure and susceptibility to dietary information that is not evidence based. Provision of nutrition advice/support could form part of a holistic approach to cancer care by encouraging and supporting healthy living to achieve the New Zealand Cancer Action Plan 2019–2029 goals of equitable cancer outcomes and improved cancer survival (better treatment outcomes and living well with and beyond cancer).  

However, to ensure that recommendations for the incorporation of nutrition advice/information and support into cancer care and support services are useful and achievable, it is important to first understand what is currently available to patients and to identify barriers/enablers to the provision of nutrition advice/support. This research therefore involved a survey of healthcare practitioners (HCPs) involved in cancer care and cancer support workers to identify and understand:

1. What diet and nutrition-related information and support is currently available to cancer patients in New Zealand?

2. What are healthcare practitioners’ perspectives of nutrition for cancer patients?

3. What are the barriers to, and enablers of, the provision of nutrition information and support in cancer care?

The results of this research can be used to inform recommendations for cancer care and cancer support services, and to inform the development of nutrition-related interventions to improve health outcomes for cancer patients.

Methods

This study was approved by the University of Otago Human Ethics Committee (Health), approval number H20/036. Two online surveys were developed: one survey for medical and nursing oncology HCPs and oncology support workers (eg, Cancer Society staff, hereafter referred to as HCP/SWs), and one slightly amended survey for dietitians involved in oncology practice. The surveys included multiple choice, multiple answer, and open-ended questions related to the provision of nutrition information and support in cancer care. Demographic questions were also included to collect descriptive information about the survey participants.

Participant recruitment involved two phases. In Phase 1, an extensive internet and directory search identified publicly available oncology practitioners’ email addresses. We sent these practitioners an invitation to participate with a personal link to the survey via the RedCap survey software. Reminder emails were sent automatically via RedCap to participants who had not responded to the survey five days after the initial invitation and one week after the first reminder. This resulted in 24 completed HCP/SW surveys and four completed dietitian surveys. Phase 2 involved sending emails with information about the study and public links to the surveys to various groups, district health boards (DHBs), and administration/reception email addresses for oncology clinics, asking them to share the public link to the survey with their membership/oncology healthcare practitioner staff members. A further 44 HCP/SW surveys and 40 dietitian surveys were completed as a result of Phase 2.

The survey link took participants to an online copy of the participant information sheet and an initial question about consent to participate. Those who indicated their consent to participate were then taken to the first survey question about their profession/role with cancer patients. An introductory question was used as a screening tool to ensure only HCPs involved in cancer care would complete the survey. Participants who indicated they did not work with
cancer patients received the response, “Thank you for your time. We only need practitioners who provide care for cancer patients to complete this survey,” and were not provided access to further survey questions. Participants who did work with cancer patients were linked through to the main survey questions.

Data collection was completed between September 2020 and January 2021. The survey data were analysed descriptively using Microsoft Excel Version 16.51 (2021). The analysis focused on frequencies and percentages for the different response options. Open-ended questions let participants provide further detail and/or clarify/explain their reasoning. These questions were analysed for explanatory content to help us interpret the survey results.

Results

Participant characteristics

Participant characteristics are summarised in Table 1. The survey participants (n=112) included a range of HCPs involved in cancer care, including 44 dietitians, 16 nurses, 47 specialist medical practitioners and five cancer support workers. Most (81%) were of NZ European ethnicity and 77% were female. Participants included HCPs from all New Zealand DHBs, except three smaller DHBs (Taïrāwhiti, Hawke’s Bay, Whanganui). Of the HCP/SW participants, 16% (n=11) indicated they had some nutrition training.

Perspectives on nutrition for cancer patients

Participants were asked, “How important is the role of nutrition [a] in cancer recovery? [b] in preventing cancer recurrence? [and c] in overall patient wellbeing?” Ratings were recorded on a five-point Likert scale (not at all important, slightly important, moderately important, very important, extremely important). All participants rated nutrition as moderately important or higher for both cancer recovery and for overall patient wellbeing. In addition, most rated nutrition as very or extremely important for cancer recovery (74% HCP/SWs, 98% dietitians) and for overall patient wellbeing (85% HCP/SWs, 98% dietitians). Nutrition’s importance in preventing recurrence of cancer was rated as moderately important or higher by most participants (71% HCP/SWs, 91% dietitians).

In response to the question, “Do you think dietary information and support should be offered to cancer patients?” all participants said nutrition information and support should be provided either always (81% HCP/SWs, 86% dietitians) or in some circumstances (19% HCP/SWs, 14% dietitians).

Participants were also asked who they thought should provide nutrition information and support to cancer patients. Dietitians’ and HCP/SWs’ answers were very similar for this question and have therefore been combined. Many of the participants (66%) selected more than one option, indicating that nutrition information and support should be available from more than one type of practitioner. Most (95%) of the participants indicated that nutrition information and support should be provided by an oncology dietitian (29% oncology dietitian only, 66% oncology dietitian and other HCP). Other options selected were oncology nurse (54%), specialist doctor (45%), cancer support services (36%), and other (21%).

 Provision of nutrition advice/information and support

<table>
<thead>
<tr>
<th>Nutrition advice/information and support from HCP/SWs</th>
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<tr>
<td>Table 2 outlines details about which patients HCP/SWs give nutrition advice/information to. Most (94%) of the HCP/SWs indicated they provide nutrition advice/information to at least some of the patients in their care (37% to all patients and 57% to specific patients only). Most commonly they provided nutrition advice/information to patients who ask about nutrition (46%) and patients with poor nutritional status (38%). All the HCP/SWs who had some nutrition training (n=11) gave nutrition advice/information to their patients (55% to all patients and 45% to specific patients). Fewer participants provided ongoing nutrition support. Only 12% of HCP/SWs indicated that they provide access to ongoing nutrition support to all patients, and 66% indicated they provide ongoing nutrition support to specific patients (most commonly patients with or at risk of poor nutritional status (60%) and patients who ask (43%). A considerable number (21%) of HCP/SWs indicated they did not provide access to ongoing nutritional support to their patients at all.</td>
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Table 1: Description of participants.

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<td>Medical oncologist</td>
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<td>Radiation oncologist</td>
<td>11</td>
</tr>
<tr>
<td>Other medical specialist*</td>
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<td>16</td>
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<tr>
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<tr>
<td>Public</td>
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</tr>
<tr>
<td>Private</td>
<td>11</td>
</tr>
<tr>
<td>Both public and private</td>
<td>20</td>
</tr>
<tr>
<td>Support services</td>
<td>3</td>
</tr>
<tr>
<td><strong>Clinic setting (where patients come from)</strong></td>
<td></td>
</tr>
<tr>
<td>Rural/town-based patients</td>
<td>19</td>
</tr>
<tr>
<td>City-based patients</td>
<td>25</td>
</tr>
<tr>
<td>Rural, town and city-based patients</td>
<td>68</td>
</tr>
</tbody>
</table>

* Other medical specialists: Surgeons, haematologists, paediatric oncologists/haematologists, gynaecological oncologist.

Table 2: Access to nutrition advice/information and support from HCP/SWs (n=68).

<table>
<thead>
<tr>
<th></th>
<th>Nutrition advice/information n (%)</th>
<th>Nutrition support n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All patients</strong></td>
<td>25 (37%)</td>
<td>8 (12%)</td>
</tr>
<tr>
<td><strong>Specific patients</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients with/at risk of poor nutritional status</td>
<td>26 (38%)</td>
<td>41 (60%)</td>
</tr>
<tr>
<td>Patients who are overweight</td>
<td>15 (22%)</td>
<td>16 (24%)</td>
</tr>
<tr>
<td>Patients with other health conditions</td>
<td>9 (13%)</td>
<td>19 (28%)</td>
</tr>
<tr>
<td>Patients who ask about nutrition/diet</td>
<td>31 (46%)</td>
<td>29 (43%)</td>
</tr>
<tr>
<td>Patients with specific cancers/treatments</td>
<td>12 (18%)</td>
<td>4 (6%)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>5 (7%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td><strong>No nutrition advice/information/support given</strong></td>
<td>4 (6%)</td>
<td>14 (21%)</td>
</tr>
</tbody>
</table>
Although poor nutritional status was the main reason for providing nutrition support, only 38% of HCP/SWs used detailed nutrition assessments. Most (76%) used body weight to assess nutritional status, and 18% did not assess nutritional status. Other forms of assessment reported (19% of HCP/SWs) included screening for malnutrition, assessment of wellbeing/functioning, blood tests/biochemistry and clinical examination.

All 53 HCP/SWs who provided access to ongoing nutrition support were able to refer patients to a dietitian (75% of these were able to refer to a dietitian specialising in oncology practice). In addition, some provided ongoing support themselves (21%) or via another practitioner in the same clinic (13%), and 30% indicated they had information/booklets available to patients in the waiting area. Support groups for nutrition support were not widely available (4%).

Nutrition advice/information and support from dietitians

The most common way of entering dietitian care was via referral from a nurse (98%) or a secondary/tertiary care specialist doctor (91%). Other referrals were from a general practitioner (48%), other health professional (18%) or other dietitian (11%), or via self-referral (36%). Table 3 outlines information from the dietitians’ survey about the cancer patients who enter their care. Most dietitians indicated they saw patients with specific nutritional needs due to cancer or treatment effects (98%) and patients with poor nutritional status (95%). In addition, 50% of dietitians indicated they saw patients who asked about nutrition for cancer recovery and/or prevention of recurrence. Similarly, dietitians were most commonly asked for advice/information about managing symptoms/treatment effects (95%) and weight maintenance (91%), whereas just over half (55%) were asked about nutrition for cancer recovery/prevention of recurrence.

Only 16% of dietitians provided ongoing support to all patients, and 14% did not provide ongoing support to any patients. The majority (68%) indicated that ongoing support was only available to specific patients, mostly those with poor nutritional status (64%) and those who ask for nutrition/diet support (34%). In contrast to HCP/SWs, all dietitian participants assessed each patient’s nutritional status using a detailed nutrition assessment, and most (80%) combined this with regular monitoring of body weight. Comments made in the open-ended sections of the survey explained the reason(s) for the limited availability of ongoing support. For example, one dietitian stated: “We are very busy and under-resourced so patients may be seen just once or twice. Those with clear malnutrition have more follow up.” Another dietitian shared: “Being unable to provide care to all those who are referred to me due to lack of capacity and long wait-times to be seen is a heavy ethical and moral burden.” When ongoing support was provided, it was mostly provided by the dietitian themselves (81%) or by referral to a community dietitian (54%).

Funding for nutrition support

Most (79%) of the participants who provided access to nutrition-related support indicated that this support was part of public healthcare with no cost to patients, and 2% said it was funded by the Cancer Society. A small number were privately funded (12%) or partially funded (4%).

Regional differences in provision of support

HCP/SWs who worked in DHBs based in larger centres (eg, Auckland, Waikato, MidCentral, Capital & Coast, Canterbury, Southern) were more likely to be able to refer patients to a dietitian (including access to a speciality oncology dietitian). In contrast, HCPs based in smaller/rural DHBs could not refer patients to an oncology dietitian, and some had no/limited ability to refer to a dietitian.

Differences between public and private sectors

We asked participants who worked in both public and private sectors to comment on the differences in nutrition services (advice/information/support) offered to patients in each sector. Analysis of the comments revealed that most (but not all) had better access to a dietitian when working in their private practice, indicating they were able to refer all or most private patients to a dietitian. Some private oncology clinics had an in-house dietitian who would see every patient. Access to dietitians in public
**Table 3: Nutrition advice/information and support from dietitians.**

<table>
<thead>
<tr>
<th>Characteristics of patients seen by dietitians</th>
<th>Frequency, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with poor nutritional status</td>
<td>42 (95%)</td>
</tr>
<tr>
<td>Patients who are overweight</td>
<td>11 (25%)</td>
</tr>
<tr>
<td>Patients with other health conditions</td>
<td>19 (43%)</td>
</tr>
<tr>
<td>Patients with specific nutritional needs due to cancer/treatment effects</td>
<td>43 (98%)</td>
</tr>
<tr>
<td>Patients who ask about nutrition for recovery/prevention of recurrence</td>
<td>22 (50%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (16%)</td>
</tr>
</tbody>
</table>

**Advice sought from dietitians**

<table>
<thead>
<tr>
<th>Advice sought from dietitians</th>
<th>Frequency, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing symptoms/treatment effects</td>
<td>42 (95%)</td>
</tr>
<tr>
<td>Weight loss</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>Weight maintenance</td>
<td>40 (91%)</td>
</tr>
<tr>
<td>General healthy eating</td>
<td>12 (27%)</td>
</tr>
<tr>
<td>Recovery/prevention</td>
<td>24 (55%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (16%)</td>
</tr>
</tbody>
</table>

**Patients who receive ongoing support**

<table>
<thead>
<tr>
<th>Patients who receive ongoing support</th>
<th>Frequency, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All patients</td>
<td>7 (16%)</td>
</tr>
<tr>
<td>Specific patients only</td>
<td>30 (68%)</td>
</tr>
<tr>
<td>Patients with poor nutritional status</td>
<td>28 (64%)</td>
</tr>
<tr>
<td>Patients who are overweight</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Patients with other health conditions</td>
<td>11 (24%)</td>
</tr>
<tr>
<td>Patients with specific nutritional needs due to cancer/treatment effects</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>Patients who ask about nutrition for recovery/prevention of recurrence</td>
<td>15 (34%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>No ongoing support available</td>
<td>6 (14%)</td>
</tr>
</tbody>
</table>
practice was not readily available unless patients met strict criteria for referral, described by one participant as “near impossible” to fulfil.

A comparison of public-only and private-only HCPs’ survey answers confirm comments about access to oncology dietitians in private practice (all could refer to an oncology dietitian and most of these were in-house) compared to public practice (60% could refer to an oncology dietitian, 23% could refer to a general dietitian, 17% no support provided). In addition, a higher proportion (33%) of private-only HCPs indicated that nutrition support was available to all patients compared to public-only HCPs (10%). Although the majority of dietitians (in both public and private sectors) saw patients with specific nutritional needs due to cancer or treatment effects and patients with poor nutritional status, dietitians working in private healthcare were more likely to also see other types of patients (eg, patients who ask about nutrition for cancer recovery/prevention of recurrence, patients who are overweight/obese, patients with specific nutrition needs due to other coexisting health conditions). Dietitians working in private healthcare were also more likely to advise patients to follow the WCRF dietary recommendations and inform them of what to eat for ongoing health and cancer risk prevention.

Type and sources of nutrition advice/information

Table 4 outlines details about the types and sources of nutrition advice/information that HCPs and support workers provided. HCP/SWs mainly gave patients general advice/information about healthy eating (83%) or eating during treatment (77%), whereas most dietitians gave specific nutrition information related to cancer treatment (91%), general advice about eating during treatment (80%), and specific information to aid cancer recovery (66%). Fewer participants provided specific information about nutrition for ongoing health/reduction of risk for cancer recurrence (30% for both HCP/SWs and dietitians), and only dietitians (32%) advised patients to follow the WCRF recommendations. HCP/SWs were most likely to give verbal advice/information (98%) and 50% provided pamphlets or information sheets. All dietitians gave patients both verbal advice/information and pamphlets/information sheets. Reference to online resources was less common (HCP/SWs 8%, dietitians 25%). Most dietitians (93%) used practice evidence-based nutrition as a source for advice/information given to patients, with other common sources including peer-reviewed publications (52%), the New Zealand Cancer Society (48%), best practice guidelines (43%) and the WCRF (41%). The main sources of information used by HCP/SWs included peer-reviewed publications (39%) and the New Zealand Cancer Society (38%).

Barriers to providing nutrition information and support to cancer patients

Figure 1 gives an overview of the barriers to providing cancer patients with nutrition information and support according to HCP/SWs and dietitians. The main barriers to providing nutrition information and support can be grouped into two main categories: those relating to the current funding model (lack of time, funding, or staff capacity) and those related to expertise/access to information (not my area of expertise, no-one with expertise available, lack of evidence-based resources).

Barriers related to the current funding model were a problem for HCP/SWs and dietitians alike (82% of all participants), whereas barriers related to expertise/access to information were more common for HCP/SWs (76%) compared to dietitians (14%). Comments made in open-ended sections of the survey confirm that limited funding (and the resulting lack of capacity) is a major barrier to providing patient access to advice and support from a dietitian. As one dietitian commented: “Ideally all cancer patients should have the ability to receive dietary advice—ideally from a dietitian. However, in a public hospital setting this would require far more dietitians than we currently have available so therefore only those already struggling get seen.” Similar comments were made by non-dietitian HCPs. For example: “Ideally we would refer all oncology patients to a dietitian and almost all patients ask for that, but we don’t have the ability to do that in public practice.” And: “Insufficient publicly funded specialist nutritional advice available. If all patients who
Table 4: Type and sources of nutrition advice/information provided.

<table>
<thead>
<tr>
<th>Type of advice/information</th>
<th>HCP/SWs (n=64)</th>
<th>Dietitians (n=44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General advice to keep a healthy diet</td>
<td>53 (83%)</td>
<td>13 (30%)</td>
</tr>
<tr>
<td>NZ eating and activity guidelines</td>
<td>6 (9%)</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>General advice about eating during treatment</td>
<td>49 (77%)</td>
<td>35 (80%)</td>
</tr>
<tr>
<td>Specific information related to cancer treatment</td>
<td>34 (53%)</td>
<td>40 (91%)</td>
</tr>
<tr>
<td>Specific information for cancer type</td>
<td>23 (36%)</td>
<td>23 (52%)</td>
</tr>
<tr>
<td>Specific information to aid cancer recovery</td>
<td>10 (16%)</td>
<td>29 (66%)</td>
</tr>
<tr>
<td>Specific to ongoing health and risk reduction</td>
<td>19 (30%)</td>
<td>13 (30%)</td>
</tr>
<tr>
<td>WCRF recommendations (see Table 5)</td>
<td>0 (0%)</td>
<td>14 (32%)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (13%)</td>
<td>14 (32%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Form of advice/information</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal</td>
<td>63 (98%)</td>
<td>44 (100%)</td>
</tr>
<tr>
<td>Pamphlets/information sheets</td>
<td>32 (50%)</td>
<td>44 (100%)</td>
</tr>
<tr>
<td>Online</td>
<td>5 (8%)</td>
<td>11 (25%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (11%)</td>
<td>5 (11%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sources of advice/information</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer-reviewed publications</td>
<td>25 (39%)</td>
<td>23 (52%)</td>
</tr>
<tr>
<td>Best practice guidelines</td>
<td>11 (17%)</td>
<td>19 (43%)</td>
</tr>
<tr>
<td>Practice evidence-based nutrition (dietitians)</td>
<td>n/a</td>
<td>41 (93%)</td>
</tr>
<tr>
<td>NZ Cancer Society</td>
<td>24 (38%)</td>
<td>21 (48%)</td>
</tr>
<tr>
<td>Overseas cancer organisation</td>
<td>11 (17%)</td>
<td>17 (39%)</td>
</tr>
<tr>
<td>WCRF</td>
<td>3 (5%)</td>
<td>18 (41%)</td>
</tr>
<tr>
<td>Lay publications</td>
<td>6 (9%)</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>Other</td>
<td>19 (30%)</td>
<td>6 (14%)</td>
</tr>
</tbody>
</table>
could benefit were referred service would be overloaded.” Concern about overloading patients with information was an additional barrier for some participants (38%).

Enabling nutrition information and support for cancer patients

Access to reliable, evidence-based resources (eg, booklets, information sheets, online resources) was the most-selected enabler for HCP/SWs (78%) and was also selected as helpful by many dietitians (61%). Most dietitians (89%) and HCP/SWs (74%) indicated that funding support for all patients to see an oncology dietitian would be helpful. Support services that provide cancer-specific dietary information and support (eg, seminars, support groups led by dietitian) was also relatively popular with HCP/SWs (63%).

Some participants (15% of HCP/SWs, 20% of dietitians) made other suggestions/comments about what would be helpful. The more common suggestions related to increased funding support for dietitians (but not necessarily to see all patients). Other suggestions related to training/development in oncology nutrition (eg, specialised oncology training for dietitians, training for HCPs from an oncology dietitian, nutrition training for radiation therapists, courses/conferences on nutrition for cancer). Dietitians also suggested ways to ensure equal information/access across New Zealand (eg, all oncology services have an in-house dietitian, better screening and referral pathways, evidence-based position statements on specific foods/diets to help streamline advice given and combat misinformation) and to improve continuity of care (eg, better communication between primary and secondary/tertiary care, funding for oncology dietitian to be available across inpatient/outpatient and community follow-up care).

Discussion

Access to nutrition advice/information and support is limited in New Zealand cancer care and support services. Our results indicate that, although most HCPs working with cancer patients agree that nutrition is very important for patient wellbeing and recovery from cancer and at least moderately important for preventing recurrence, specialist nutrition advice and support from a qualified dietitian is mainly limited to patients at the highest risk of

![Figure 1: Barriers to providing nutrition information and support.](image-url)
malnutrition and those who can afford private healthcare. In addition, these results indicate that many cancer patients will not receive nutrition advice/information from doctors, nurses, or support workers either. This lack of access to cancer-related nutrition information and support for people with cancer is likely to have a negative impact on cancer outcomes and contribute to inequities in outcomes experienced by some groups compared to others.

The differences in the provision of advice/information and access to nutrition-related support identified in this study (eg, differences by individual practitioner, region/DHB, public/private practice, relying on patients to ask for information) will also contribute to inequities in cancer outcomes by favouring those with more advanced health-literacy skills and better socio-economic circumstances. Health literacy (defined by the World Health Organization as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health") is an important factor in determining health outcomes. People with limited health literacy are more likely to have poor health outcomes. Health literacy empowers patients to effectively access and use health information. Health literacy and ability to gain benefit from health literacy skills are impacted by factors such as socioeconomic status, access to social support, language/literacy skills, assertiveness, education and culture, as well as healthcare system/HCP factors. Healthcare practitioners can contribute to patients' health literacy by ensuring information (and support) is offered, readily accessible, easy to understand, and culturally appropriate. It is important not to wait for patients to ask for nutrition information/support because, for a variety of reasons (eg, social/cultural norms, language barriers, not aware that nutrition is important for cancer outcomes, not aware of support available), many patients will not ask for nutrition information or support if it is not offered.

Prior research has indicated that many people with cancer are particularly open to and interested in receiving advice about how they can support their recovery with healthy eating. This creates opportunities to impart healthy eating advice not only to support better cancer outcomes, but also to improve overall health beyond cancer. Ideally, advice and information should be tailored to cancer type, treatment, and individual patient needs to gain maximal benefits. A dietitian knowledgeable in the specific nutrition needs of cancer patients would be best placed to help patients navigate this area. Dietitians are also able to adapt dietary requirements to a patient's family and cultural contexts, and personal food preferences. However, recent research with New Zealand cancer survivors revealed that patients who are not told about nutrition by the specialist doctor treating their cancer may interpret that to mean that nutrition is not important for cancer (or for their particular type of cancer), illustrating that HCP/SWs also have an important role in sharing the message about nutrition.


In addition to lack of funding, other barriers impacted by the current funding model for cancer care (eg, lack of time/capacity) were commonly reported by participants. These results are indicative of an overburdened, underfunded healthcare system where not all patients have access to the same services and many patients who would benefit from nutrition information and support miss out. The number of people diagnosed with cancer in New Zealand is growing, which will only put further strain on already stretched services. Improving access to nutrition advice and support has the potential to not only improve patients' treatment outcomes but also reduce the number of patients returning into the system with cancer (cancer recurrence) or other non-communicable diseases. The recently announced New Zealand health system reforms will include changing to a single nationwide system. This is an oppor-
<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Goal/s</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be a healthy weight</td>
<td>Keep adult weight as low possible within the healthy range (BMI of 18.5–24.9) and avoid weight gain. Body weight during childhood/adolescence should project towards the lower end of the healthy adult BMI range.</td>
<td>Adult body fatness increases the risk of many cancers (e.g., cancers of the oesophagus, pancreas, liver, colorectum, endometrium, kidney and postmenopausal breast cancer).</td>
</tr>
<tr>
<td>Eat a diet rich in wholegrains, vegetables, fruit and beans</td>
<td>Eat a diet high in all types of plant foods (include wholegrains, non-starchy vegetables, fruit, and pulses/legumes in most meals). Eat at least five portions (400g total) of a variety of non-starchy vegetables and fruit and at least 30g of fibre (from food) every day.</td>
<td>A diet rich in wholegrains, vegetables, fruit, and beans (foods containing dietary fibre) protects against colorectal cancer, other aerodigestive cancers, and weight gain.</td>
</tr>
<tr>
<td>Limit consumption of “fast foods” and other processed foods high in fat, starches or sugars</td>
<td>Limit processed foods high in fat, starches or sugars—such as fast foods/takeaways, confectionery, and many pre-prepared dishes, snacks (e.g., chips), bakery foods (e.g., cakes, pastries, biscuits, products made from white flour) and desserts.</td>
<td>Fast foods/takeaways and other processed foods promote weight gain, overweight and obesity. There is also strong evidence that foods with high glycaemic load (foods that rapidly increase blood glucose and insulin) are a cause of endometrial cancer.</td>
</tr>
<tr>
<td>Limit consumption of red and processed meat</td>
<td>If you eat red meat, limit consumption to no more than three portions per week (about 350–500g cooked weight in total per week). Consume very little, if any, processed meat.</td>
<td>Red and processed meat increase the risk of colorectal cancer.</td>
</tr>
<tr>
<td>Limit consumption of sugar sweetened beverages</td>
<td>Do not consume sugar sweetened drinks.</td>
<td>Sugar sweetened beverages promote weight gain, overweight and obesity</td>
</tr>
<tr>
<td>Limit alcohol consumption</td>
<td>For cancer prevention, it’s best not to drink alcohol</td>
<td>There is strong evidence of a linear association between alcohol consumption and cancers of the mouth, pharynx and larynx, oesophagus, liver, colorectum, breast, and stomach.</td>
</tr>
<tr>
<td>Do not use supplements for cancer prevention</td>
<td>High-dose dietary supplements are not recommended for cancer prevention—aim to meet nutritional needs through diet alone.</td>
<td>High-dose beta-carotene supplements may increase the risk of lung cancer. There is no strong evidence that dietary supplements (except calcium for colorectal cancer) reduce cancer risk.</td>
</tr>
</tbody>
</table>
Table 5: WCRF/AICR cancer prevention recommendations (continued).^a

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Goal/s</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be physically active</td>
<td>Be at least moderately physically active, follow or exceed national guidelines and limit sedentary habits.</td>
<td>Physical activity (moderate or vigorous) decreases risk of colorectal cancer and protects against weight gain.</td>
</tr>
<tr>
<td>For mothers: breastfeed your baby if you can</td>
<td>Follow World Health Organization advice: exclusively breastfeed infants for six months, and then for up to two years or longer alongside appropriate foods.</td>
<td>Breastfeeding reduces breast cancer risk and protects children against overweight and obesity (benefits increase with longer breastfeeding).</td>
</tr>
<tr>
<td>After a cancer diagnosis: follow our recommendations, if you can</td>
<td>All cancer survivors should receive nutritional care and physical activity guidance from trained professionals.(^c) Follow the cancer prevention recommendations as far as possible after the acute stage of treatment (unless advised otherwise).</td>
<td>To improve survival and reduce the risks of new cancers and other non-communicable diseases. A trained professional can take into account individual circumstances.</td>
</tr>
</tbody>
</table>


^b There are special situations where breastfeeding is recommended with caution or is not advised, such as for mothers with HIV/AIDS.

^c Recommended for all people diagnosed with cancer and essential in some circumstances (eg, special nutritional requirements likely due to treatment; people whose ability to consume or metabolise food has been altered by treatment; and people in the later stages of cancer whose immediate need is to arrest or slow down weight loss).
tunity to standardise and strengthen cancer care services and make provisions to include better access to nutrition information and support as part of an equity- and needs-focused holistic approach.

Strengths and limitations

This study has several strengths. Although we were unable to ascertain a response rate due to the nature of our sampling, we had responses from a wide range of participants and a good total number of responses. This included representative responses from medical, nursing, support, and dietetic practitioners from 17 of the 20 DHBs (and all tertiary cancer care services) and from public and private practice. In addition, the survey data are supported by open-ended responses that enable a more comprehensive understanding of the topic. A limitation of this study is that HCPs who responded to the survey are likely to have an interest in food and nutrition. The results may over-estimate the nutrition information/support provided and HCP views on the importance of nutrition in cancer care. We also did not survey primary care practitioners. This limited the information we found about nutrition support occurring in primary care.

Conclusions and recommendations

Based on these findings, we recommend a standardised system across all New Zealand’s oncology services that incorporates general introductory advice/information about nutrition (eg, the WCRF dietary recommendations) from all HCPs and more detailed tailored advice (and ongoing support where needed) from dietitians to support the recovery and ongoing health of people diagnosed with cancer. Ideally all patients should have the opportunity to access at least some tailored nutrition advice/information (specific to cancer and treatment type and tailored to individual health and cultural needs) from a dietitian. Such advice/information might be enough to meet the needs of some patients, while others will need more ongoing support from a dietitian and/or other forms of support (eg, financial or practical support) to enable them to successfully incorporate recommendations into their daily lives. Cancer support services could play an important role in providing additional financial (eg, vouchers, food-banks, supply of fruit/vegetables) and practical (eg, dietitian-led support groups, healthy cooking workshops, access to healthy pre-prepared meals) support for those who need it. Qualitative research to better understand HCP perspectives and barriers/enablers to provision of nutrition information and support in cancer care will help to inform the development of interventions and determine how to best to integrate nutrition into cancer care. Work is also needed to develop and test the impact of potential interventions on cancer outcomes and to understand the long-term health and economic benefits of proposed changes.
Competing interests:
Nil.

Acknowledgements:
We would like to acknowledge the dedicated healthcare practitioners and support workers who participated in this research and thank them for generously making time to share their knowledge and experiences and making this research possible. This research was funded by a Dunedin School of Medicine Werner Medical Research Grant.

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URL:

REFERENCES


Deaf community views on paediatric cochlear implantation

Briana Putnam, Sara Pivac Alexander, Kathleen McMenamin, David Welch

ABSTRACT

There are two models used in the literature to describe those who are d/Deaf: the medical and the cultural models. The medical model describes deafness as an unwanted disability that needs to be treated through the use of medical devices like cochlear implants (CIs). The cultural model describes the word “Deaf” (written with a capital) as a culture and membership of the Deaf community as a privilege. It also places emphasis on the importance of sign language in Deaf culture. Historically, the Deaf community has been opposed to cochlear implantation in children, but little is known about current attitudes, or the attitudes of the Deaf community in New Zealand. This research used an online questionnaire to ask deaf, hard-of-hearing (HoH) and culturally Deaf people in New Zealand about their views on paediatric cochlear implants. Culturally Deaf respondents were compared to those who were not. The study’s findings were mixed, suggesting that there are still reservations about the benefits of CIs for children born deaf. It identified key areas for consideration: a bilingual/bicultural approach to CI habilitation in children, and the need to fully inform parents of all of their options. The study also highlighted the multitude of cultural and non-cultural factors that need to be considered in both the decision-making and habilitation processes for treatment of a deaf child. An understanding of how the Deaf community’s perspective differs from that of health professions in New Zealand is important in considering what is best for deaf children.

The medical model of deafness describes deaf, written with a lowercase “d,” as a profound degree of hearing loss and an unwanted disability. One treatment is the cochlear implant (CI), a surgically implanted device that directly stimulates the auditory nerve electrically.

Early cochlear implantation has been found to improve deaf children’s communication opportunities, as well as their educational and future employment prospects. It provides most deaf children with enough sound information to develop some auditory-verbal language.

An opposing view is the Deaf cultural model, written with a capital “D.” In this model, deafness is not a disability but a marker of cultural affiliation, paralleling ethnically based cultures, with sign language as the defining language. Membership of Deaf culture may be beneficial; deaf children, even those with CIs and use of aural/oral speech, have improved self-esteem if they feel connected to the Deaf community. At the same time, some literature seeks to imply that signing may interfere with CI users’ learning of spoken language, though these interpretations are questionable.

Since these models misalign, there is debate about whether paediatric cochlear implantation is beneficial or a challenge to the Deaf community. However, much of the evidence is from older American research. There has been little research in New Zealand.

More than 90% of deaf children are born to parents who can hear and use spoken language to communicate. This means that most parents must decide about cochlear implantation and rehabilitation options for their deaf child without prior knowledge or experience. For many parents with children newly diagnosed with deafness this can be a frightening time filled with grief and uncertainty. Deciding to go ahead with cochlear implantation and focus on rehabilitation can be incredibly stressful for parents and families. Medical professionals play a primary role in this
decision-making process, and very early intervention is recommended in the medical model, so it is important to understand the wider perspective.

Analysis of the literature revealed that the concerns of the global Deaf community regarding paediatric cochlear implantation could be grouped into five main themes:

1. Cultural consequences: A child with a CI might feel part of neither the Deaf nor the hearing world. Children may feel excluded from hearing culture because CIs do not provide fully normal hearing, because they are visible and because they may promote negative attitudes to deafness. They might also feel excluded from the Deaf community because CI habilitation has a strong focus on learning auditory-verbal language and integrating with the hearing society. This has been described as the deaf child’s “identity crisis.” For this reason some oppose CIs in children, and some argue for a bilingual/bicultural approach to habilitation after cochlear implantation.

2. Psychosocial outcomes: Although some children with CIs achieve similar speech and language outcomes to their hearing peers, CIs do not completely “cure” deafness. Many children still need extensive input from support services and remain behind their hearing peers in spoken-language outcomes. Compared to an entirely oral approach to CI habilitation, introducing deaf children to Deaf culture and teaching them sign language is shown to enhance their learning of spoken language, not hinder it. This approach also improves their self-esteem, confidence and educational outcomes.

3. Risks and lack of benefits: Complications of cochlear implantation in children are rare nowadays. But potentially serious complications still occur in around 1% of cases. Minor complications, such as headaches, skin issues, tinnitus and ear infections, occur more commonly, in around 5% of cases. Regardless of the actual proportion of children who have complications from cochlear implantation, there is evidence that parents and Deaf community members who disapprove of CIs for children tend to state the risks of surgery as a major factor in this decision. The risks may also be perceived as more significant if CIs are not deemed as essential and there are other communication options.

4. Appearance: CIs have an external component that is magnetically connected to the internal, surgically implanted device. This may prompt teasing and bullying. Advertisements for CIs highlight the discrete nature of devices, implying that those who purchase the devices may prefer them to be hidden.

5. The process of cochlear implantation: Learning to use a CI is part of the process of cochlear implantation. The device is turned on at around two weeks after surgery. After this, the family must attend an intensive follow-up appointment schedule and be dedicated to providing extensive support and language practice at home.

Aim

Our primary aim was to investigate the current views of deaf, hard-of-hearing (HoH) and culturally Deaf people on paediatric cochlear implantation in New Zealand. A secondary aim was to explore whether those who define themselves as culturally Deaf have different views to those who do not (but who are still deaf or HoH). We also explored whether views on paediatric cochlear implantation are related to other factors such as CI experience in the family, Deaf cultural experience and sign language experience.
Methods

Participants
The target population included those who defined themselves as deaf, HoH and/or culturally Deaf. Participants were recruited through an advertisement in the weekly newsletters and Facebook groups of Deaf Aotearoa New Zealand and Auckland Deaf Society. These are two major organisations for d/Deaf and HoH people in New Zealand. They provide researchers with a large potential study population. Responses from 66 people who were deaf, Deaf and/or HoH were used in the analyses. They ranged from 18 to 70 years of age.

Researchers’ background
The project supervisors included an active member of the New Zealand Deaf community who advised and approved of the research process. Two of the other researchers (both hearing) had some involvement in the Deaf community (eg, volunteering, personal family experience) and all four researchers had previous academic experience in the field of audiology and/or Deaf culture/NZSL. Their experience enabled informal consultation with Deaf people, who gave advice on how to approach the topic in an ethically appropriate way and make the questionnaires relevant to Deaf New Zealanders. Auckland Deaf Society and Deaf Aotearoa both provided letters of support for the study and willingly published the advertisement on their Facebook pages and in their newsletters.

Materials and procedures
The current study drew on previous research into Deaf culture and the CI debate. Key themes were adapted into an online questionnaire, available in both English and NZSL, that measured and explored Deaf, deaf and HoH people's views on CIs for children.

A mixed methods study design was employed for this research and complementary information was gathered. This included multiple-choice questions, matrix-style questions and Likert scales, and open-ended questions that were analysed qualitatively to capture richer thoughts, feelings and perspectives.

A 72-item questionnaire used previously in research in parents of deaf children was adapted and shortened into 21 questions with some changes for relevance (eg, we changed “I am concerned that my child will be rejected by the deaf community because of the implant” to “Do you worry that a child with a CI will not be accepted by d/Deaf people?”) Including a capital “D” is important to the Deaf community and was highly relevant to this study.

The five main themes about the paediatric CI debate from the literature (Cultural Consequences, Psychosocial Outcomes, Risks and Lack of Benefits, Appearance and Process) were used to develop the questionnaire items for five “belief scales.”

The questionnaire also contained general items about CIs developed from past research, such as, “If you had a Deaf/deaf/hard-of-hearing child, would you get a CI for them?”

There were also four open-ended questions at the end of relevant sections:

- Do you have any other worries about CIs for a child? Please tell us.
- Are there any other things you believe about CIs for a child? Please tell us.
- Is there anything else you think audiologists need to know about your views on CIs for a child?
- What does your decision to get a CI depend on? If you are not sure, explain why.

Data analysis
Belief scale scores for participants were created in SPSS software. Assessment of internal reliability was based on Cronbach's Alpha (α). A score of 0.6 reliability is acceptable for exploratory research such as this. The belief items had three possible responses. We coded “not sure” as 0.5, “no” as 0 and “yes” as 1. The “tick all that worry you” item responses were coded as 1 if the participant selected that they were worried about the item and 0 if they did not select that they were worried. We were then able to combine the belief items and “tick all that worry you” items to conduct a confirmatory factor analysis and extract a five-factor solution.

We combined participants' scores for each item of the belief scales by taking the mean response across all the items identified as part of each scale for each participant. We
then used t-tests to compare the overall responses from the Deaf and the non-culturally Deaf participants.

We used a general inductive approach to code the qualitative data. Similar quotes were coded into nodes using NVivo 12 software. The codes were compared and those with similar ideas were coded into a larger theme. The data were re-read and re-coded into organised subthemes and analysed until no new themes arose. One author, in consultation with a second, carried out the thematic analysis. Once they had decided on themes, the two remaining authors read the themes independently. They focused on representing participants’ full range views and avoiding the authors’ own opinions.

Results

Quantitative findings

Four options could be selected for cultural/hearing status: deaf, hard-of-hearing, culturally Deaf or none of the above. Those who selected “none of the above” were excluded from the study as they did not meet the eligibility criteria. Those included were organised into two groups: culturally Deaf and non-culturally Deaf (Figure 1). We therefore compared views of those within the Deaf community who defined themselves as culturally Deaf to those also within the Deaf community who did not.

Sixty-eight percent of the participants were culturally Deaf. Both groups had an age range of 18–70 years and a mean age of approximately 40 years. In both groups, 38% of the participants had a CI and less than 20% had a child with a CI (culturally Deaf group: 8/45 (17%); non-culturally Deaf group: 1/21 (5%)). More than half of the participants in each group had friends with a CI (culturally Deaf group: 40/45 (89%); non-culturally Deaf group: 11/21 (52%)).

Confirmatory factor analysis extracted a five-factor solution that conformed reasonably well with the a priori scales designed (Table 1). An exception was item 24: that a child might “not be accepted by hearing people” was designed as part of the Cultural Consequences factor, but it loaded more strongly on the Appearance factor, and so was removed from analyses.

Given this discrepancy in the factor loadings was very small, we preserved the factor structure as defined on the basis of

Figure 1: Formation of two comparison groups (B) from the distribution of participants’ self-definition of hearing and cultural status (n=66) (A).
an otherwise congruent pattern of loadings. The five subscales had Cronbach’s alpha (α) scores between 0.665 and 0.937, which suggested acceptable internal reliability. The analysis verified the five themes that were identified by the literature search:

1. Cultural Consequences
2. Psychosocial Outcomes
3. Risks and Lack of Benefits
4. Appearance
5. Process

Cultural Consequences
More culturally Deaf than non-culturally Deaf participants believed that children with CIs would be more likely to experience negative cultural consequences (t(64)=2.145, p=0.036; Figure 2).

Both groups’ most common concern was that a child with a CI will not learn NZSL. Forty-eight participants (72%) selected this option: 36/45 (80%) of the culturally Deaf group and 12/21 (57.1%) of the non-culturally Deaf group.

Psychosocial Outcomes
More non-culturally Deaf people perceived better psychosocial outcomes for children with CIs than Deaf people (t(63)=2.690, p=0.009; Figure 3). Eighty-five percent (17/20) of the non-culturally Deaf group and 42% (19/45) of the Deaf group believed that one or more of the psychosocial outcomes would be better for a child with a CI.

Risks and Lack of Benefits
Non-culturally Deaf people scored lower than culturally Deaf people on the Risks and Lack of Benefits scale (t(64)=2.306, p=0.036; Figure 4).

Appearance and Process
The two groups had the same opinions on the Appearance and Process scales so we have not included these graphs ((t(64)=0.812, p=0.420) and (t(64)=1.085, p=0.280), respectively). Most participants (approximately 75%) from both groups did not think that a child would worry about how they look or be treated differently because of how they look with a CI (Appearance scale items). Around one-third to one-half of all participants thought that the process of CI habilitation in children would be stressful (34/9%), too effortful (34%) or annoying to look after (22%) (Process scale items).

Qualitative findings
Fifty-six participants (85%) responded to open-ended questions: 41 were culturally Deaf and 15 were non-culturally Deaf. Many answers were detailed and addressed a range of views regarding the paediatric CI debate.

Analysis of these data revealed three main themes:
1. Decision-making
2. Habilitation
3. Hearing community advice

Each of these had subthemes, and the hierarchy of themes and subthemes, are represented in Figure 5.

Decision-making
Respondents perceived the decision to get a CI for a deaf child as complex and influenced by many factors. They expressed concern that deaf children would feel part of neither Deaf nor hearing culture:

“…a CI doesn’t mean perfect hearing.”

They suggested that deaf children with CIs would miss out on the benefits of Deaf culture:

“…being Deaf is a privilege not a loss—a unique way of seeing the world.”

These responses revealed sophisticated views of the cultural situation, where decision-making can depend on more cultural-level of thinking:

“…move away from the medical model onto a cultural model where a child gains.”

“…a cochlear implant does not make a child hearing... they are still deaf and this should be acknowledged.”

Consequently, there was concern about how decision-making without proper consideration of the cultural issues might influence a deaf child’s identity:

“...they will be caught in the middle with no clear identity of who they are.”
Table 1: Results of confirmatory factor analysis verifying areas of concern about paediatric cochlear implantation (n=66).

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Area of concern about paediatric cochlear implantation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cultural Consequences α=0.751</td>
</tr>
<tr>
<td>Do you worry that a child with a CI will... (tick all that worry you)</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>not be accepted by d/Deaf people</td>
</tr>
<tr>
<td>24</td>
<td>not be accepted by hearing people</td>
</tr>
<tr>
<td>25</td>
<td>not learn NZSL</td>
</tr>
<tr>
<td>26</td>
<td>not be involved in the Deaf community</td>
</tr>
<tr>
<td>27</td>
<td>worry about how they look</td>
</tr>
<tr>
<td>28</td>
<td>be treated differently because of how they look</td>
</tr>
<tr>
<td>Do you worry that... (tick all that worry you)</td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>a CI will be too annoying to look after</td>
</tr>
<tr>
<td>30</td>
<td>getting a CI will be too stressful</td>
</tr>
<tr>
<td>38</td>
<td>the time and effort needed to learn to hear and speak after getting a CI is not worth it</td>
</tr>
<tr>
<td>Do you believe that:</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>most of the technical problems that happen with the CI can be fixed</td>
</tr>
<tr>
<td>Do you believe that a child with a CI will:</td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>have a better education</td>
</tr>
<tr>
<td>32</td>
<td>have a better social life</td>
</tr>
<tr>
<td>33</td>
<td>have better chances of getting a job</td>
</tr>
<tr>
<td>34</td>
<td>be more confident</td>
</tr>
<tr>
<td>35</td>
<td>be more independent</td>
</tr>
</tbody>
</table>
Table 1: Results of confirmatory factor analysis verifying areas of concern about paediatric cochlear implantation (n=66) (continued).

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Area of concern about paediatric cochlear implantation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cultural Consequences α=0.751</td>
</tr>
<tr>
<td>Do you believe that:</td>
<td></td>
</tr>
<tr>
<td>36 CI surgery has too many risks</td>
<td></td>
</tr>
<tr>
<td>37 A deaf child will be happy enough without a CI</td>
<td></td>
</tr>
<tr>
<td>39 A deaf child has enough people to communicate with - they don’t need CIs</td>
<td></td>
</tr>
<tr>
<td>40 Interpreter services are good enough - a deaf child does not need CIs</td>
<td></td>
</tr>
<tr>
<td>41 Online technologies (for example: Facebook messenger) are good enough - a deaf child does not need CIs</td>
<td></td>
</tr>
</tbody>
</table>

α: Cronbach’s Alpha reliability score for each subscale.
b: item (24) was removed from the analysis. It did not load onto the Cultural Consequences scale as expected and weakly loaded onto (and decreased the reliability of) the Appearance scale.
Factor loadings of <0.3 have been removed from the table to improve clarity.
Figure 2: Percentages of culturally Deaf and non-culturally Deaf groups who selected each item in the Cultural Consequences belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=21.

![Bar chart showing percentages of culturally Deaf and non-culturally Deaf groups for each item in the Cultural Consequences belief scale.](image)

Concerns about cultural consequences of cochlear implantation

Figure 3: Percentages of culturally Deaf and non-culturally Deaf groups who believed that each outcome was better for children who receive CIs using the items in the Psychosocial Outcomes belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=20.

![Bar chart showing percentages of culturally Deaf and non-culturally Deaf groups for each outcome in the Psychosocial Outcomes belief scale.](image)

Beliefs about psychosocial outcomes of cochlear implantation
Figure 4: Percentage of culturally Deaf and non-culturally Deaf groups who endorsed each item from the Risks and Lack of Benefits belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=21.

Beliefs about risks and lack of benefits of cochlear implantation

Figure 5: Organisation of themes from qualitative data analysis.
Physicality and safety

Physical and safety aspects of cochlear implantation in children was another subtheme within the decision-making process. Respondents were concerned with the practicalities of wearing the external processor devices:

“…technology has not made the external fitting child friendly.”

“…mine falls off all the time… can’t imagine how bad it can be for children.”

In addition to the practicability of wearing the external devices, respondents suggested that decision-making should account for the possibility that the implanted component might fail:

“…there’s a chance that… CI’s may not work [sic] then the child is completely deaf for life… so unfair.”

“cochlear implants may have health implications such as infections or issues with damage if the area is injured”.

Effectiveness of NZSL

Another subtheme was that decision-making should take into account the value of NZSL as a means of communication:

“I would focus more on the value of their visual language.”

“learning NZSL will help hugely with communication… as the child can communicate back through NZSL.”

“(deaf child) is already Deaf and can use NZ sign language.”

Furthermore, the use of NZSL was seen to benefit a child because it would provide an entrée to the Deaf community:

“The child can use NZ sign language with [a] better community to support [the] deaf child in the future.”

Need for better advice

Participants felt that audiologists and the various healthcare professionals push parents into cochlear implantation for the child without clear advice about the benefits of being culturally Deaf. Parents therefore make the decision based on biased information and emotions arising from ignorance of the full picture:

“fear and a lack of knowledge.”

The bias from the medical model was seen to be towards “oralism” and encouraging the child to “listen and speak only.” One participants said the goal of implantation being spoken language development is “kind of like forcing Maori child [sic] to speak English or asking a blind person to tell rainbow’s colours.”

Habilitation

The second theme describes participants’ concerns about habilitation after cochlear implantation of children.

Value of NZSL

The first subtheme conveys that the services are biased towards an auditory/verbal approach and that the value of NZSL is not always considered to be relevant for language acquisition:

“the factor is not cochlear implant, it is language acquisition.”

“NZSL is a natural language for Deaf, deaf, hard-of-hearing [people] regardless of if they have hearing aids or a CI or none.”

“families are not supported to have NZSL as a full language.”

“audiologists are overwhelmingly in favour of having a CI instead of learning NZSL.”

Bilingual/bicultural approach

The second subtheme of CI habilitation focused on the benefits of both the hearing and Deaf ways of life. Visual language may support hearing parents in communicating with their deaf children:

“while children are listening and learning speech parents and others would find communication much better if they used sign support during this time.”

Participants saw socialisation with the Deaf community as a key component of habilitation, enabling children to feel “empowered,” “find their way” and “utilise tools from both worlds.”

Another perceived benefit of a bilingual approach to habilitation was the practicality of having a recourse to visual language if the CI is unavailable:

“sometimes they are not able to wear a CI e.g. when swimming, showering,
sleeping etc and they may need to have communication access in those times for their emotional well-being as well as for their safety.”

At a deeper level, the bilingual/bimodal approach to habilitation was seen to open up more options for a deaf child:

“having fluency in both NZSL and English allows more choice autonomy and education.”

Furthermore, it was expressed that habilitation should not be limited to a smattering of visual language, but that it should be treated on an equal footing with spoken language:

“NZSL is very important. I’ve missed that opportunity.”

“It is important that NZSL is held to the same standards as spoken English.”

Participants acknowledged the need for habilitation in auditory-verbal language, along with sympathy for children who are trying to learn to use a communication system that is not natural for them:

“CI does not mean perfect hearing.”

“I have a CI myself but the CI doesn’t help me very much at all during classes as I missed a lot of information.”

“Poor deaf children are expected to perform like a hearing person... I have noticed parents talking to their child like they do with hearing siblings without eye contact without getting their attention... no wonder why the poor child has a language delay.”

Overall, the subtheme promotes the idea of bilingualism/bimodalism because of the greater freedom and choice it brings:

“[giving children the] opportunity to choose the language of learning to potentially enhance future education, aspiration and communication.”

Advice to hearing community

The third main theme was advice given to health professionals. It was recognised that the CI debate is difficult:

“a tough and sensitive topic with many variables.”

Broaden perspective

Participants felt that health professionals tend to focus narrowly on treating disability without having an open mind to other ways of looking at the world. This could be rectified by improved education:

“All audiologists must understand Deaf culture.”

CIs are a tool but not the whole answer

Participants suggested that the hearing community start treating CIs in a more measured way, that is, acknowledging that they are useful but also just a device:

“They are a tool to help, just the same as I wear glasses to help me see clearly. I have a CI to help me hear sound. It is not a cure nor a fix.”

This led to the idea that the device should be put behind the greater issue of the actual person, so that more flexibility is made clear to parents of deaf children:

“Give the parents the opportunity to know more about learning NZSL, [not] just CI as the only option.”

“Outline all options available to that child.”

Discussion

In this study, we found that deaf, HoH and culturally Deaf people in New Zealand have concerns about paediatric cochlear implantation. We found differences between the culturally Deaf and non-culturally Deaf groups, though both groups expressed concerns. The main differences were around the cultural consequences, psychosocial outcomes and the risks and lack of benefits of paediatric cochlear implantation. The non-culturally Deaf group tended to view CIs more positively.

This findings were supported by qualitative data. Some deaf, HoH and culturally Deaf were still oppose paediatric cochlear implantation. Many called for a bilingual/bicultural approach to habilitation and better access to related services.

Language and culture deprivation

There were concerns that a lack of access to Deaf culture and NZSL for a deaf child can impact development. These concerns reflect the literature saying many children, even those with CIs, are behind their hearing
peers educationally, psychologically and socially\textsuperscript{30,63} and require extensive input from support services.\textsuperscript{39} Children with CIs often attend mainstream schools\textsuperscript{5} and spend a significant amount of time in auditory-verbal habilitation,\textsuperscript{56} yet NZSL and Deaf culture may be neglected.

These findings were supported by qualitative themes such as “CIs are a tool but not the whole answer” and the need for a “bilingual/bicultural approach”. Participants believed that deaf children have different language and cultural needs to hearing children. They perceived a biased auditory-verbal approach in habilitation services and felt this should be addressed.

Some participants were concerned that deaf children with CIs might not feel accepted culturally and socially. Gao described this as an identity crisis (2007), that is, deaf children might feel part of neither the Deaf nor the hearing worlds. Participants wanted health professionals to broaden their perspective and consider cultural factors as well as the medical model. They wanted deaf children to feel proud of being deaf, as does the Deaf community.\textsuperscript{64}

Some culturally Deaf people in the study felt that deaf children do not need CIs because they already have NZSL and Deaf culture. Others were not against CIs, but felt that NZSL and involved in Deaf culture should be widely accessible in addition to spoken language habilitation and mainstream education.

This suggests that the decision to implant CIs in children is complex and influenced by many factors. It also indicates that, although in the past the Deaf community strongly opposed cochlear implantation,\textsuperscript{45} many Deaf people in New Zealand today are more concerned about the language and cultural outcomes for a deaf child after cochlear implantation, rather than the decision of whether to actually give a deaf child a CI. However, it is important to note that some people in this study were still strongly opposed to paediatric cochlear implantation.

**Bilingual/bicultural approach to habilitation**

Related to the importance of NZSL and Deaf culture, many culturally Deaf participants felt that a bilingual/bicultural approach to CI habilitation is of high importance. Research has already shown that a bilingual/bicultural approach can lead to positive psychosocial outcomes.\textsuperscript{13,41} Currently, a bilingual/bicultural approach to cochlear implant habilitation in children is not widely followed in New Zealand.

Sign language has been demonstrated to enhance the learning of spoken language.\textsuperscript{16,31} A bilingual/bicultural approach can also improve a deaf child’s self-esteem, confidence and educational outcomes.\textsuperscript{12,13,40} This approach is shown to decrease frustration between deaf children and their families, and it is thought to empower families with more positive attitudes about deafness and improve motivation to help the child access language.\textsuperscript{30–32,41}

Regardless of the participants’ hearing or cultural status, they strongly indicated the need for parents to be fully informed about all of the habilitation options available to them, not just the medical model. This is important because more than 90% of deaf children are born to hearing parents\textsuperscript{20,21} and many parents will not have had experience with deafness and the different habilitation options and support available.\textsuperscript{22} This means that the range of options presented to them by medical professionals can potentially have a significant impact on their decisions about cochlear implantation and habilitation for their deaf child.

According to participants, parents have “fear and lack of knowledge” and are “confused what to do.” Participants felt that the information presented to parents is biased towards the medical model and does not fairly consider the value of Deaf culture and NZSL. The information therefore does not encourage a bilingual or bicultural approach to CI habilitation. The literature supports these findings. Although NZSL and Deaf cultural support is available,\textsuperscript{66,67} the goal of CI habilitation is to promote hearing and maximise the child’s spoken language abilities.\textsuperscript{68}

**Areas for future research**

This research highlights numerous areas of the debate that future research can build upon. For example, it would be useful to interview parents of deaf children regarding their experience with the CI habilitation process. It would also be useful to conduct
a feasibility study around incorporating a bilingual/bicultural approach to CI habilitation in New Zealand children and the resources required for this to be possible.

It is necessary for the assessment of CI outcomes to incorporate social and cultural aspects of deafness as well as the spoken language outcomes that are already being captured. The main measure of “success” of cochlear implantation in children is the development of auditory verbal language and educational outcomes like hearing children. It is possible that different goals would be more appropriate for deaf or HoH children. Further research to define these goals is important.

In conclusion, we found that many deaf, hard-of hearing and culturally Deaf New Zealanders have reservations about cochlear implants in children. Furthermore, culturally Deaf people tended to be more concerned about the cultural and psychosocial consequences of childhood cochlear implantation and believed that there were more risks and fewer benefits. Qualitative data highlighted the value of NZSL and Deaf culture, the benefits of a bilingual and bicultural approach in CI habilitation and the importance of fully informing the parents of deaf children about all of their habilitation options.
Competing interests:
Nil.

Acknowledgements:
The authors would like to thank the Deaf community organisations who participated in the study and distributed the advertisement. We also thank DeafRadio for translation of the questionnaire and study information into NZSL.

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Surgical management of Graves’ disease: historical context and single institution experience

Michael J Russell, Simon Young, Richard Martin, Richard Harman

ABSTRACT

BACKGROUND: Graves’ disease is the commonest cause of hyperthyroidism. For patients with Graves’ hyperthyroidism, antithyroid medication is the most common first-line treatment option. Radioiodine and surgery are reserved for specific indications. Subtotal thyroidectomy was the preferred surgical approach historically, but total thyroidectomy has been the established procedure of choice for the last 20 years.

AIM: To describe indications and outcomes of total thyroidectomy for Graves’ disease in a large New Zealand endocrine surgery unit, and to compare these results to international studies

METHODS: We analysed a prospectively collected database to describe the indications and outcomes of surgery for Graves’ disease between December 2001 and January 2021.

RESULTS: Among 64 patients who underwent total thyroidectomy at our tertiary centre for Graves’ hyperthyroidism, Graves’ ophthalmopathy and patient preference/aversion to radioactive iodine were the most common indications for surgery. Total thyroidectomy resulted in long-term control of thyrotoxicosis in all patients. There were no incidences of recurrent laryngeal nerve injury. One patient (1.6%) suffered permanent hypoparathyroidism.

CONCLUSION: Total thyroidectomy is a safe and effective treatment for Graves’ disease. In our population, total thyroidectomy functions as a second-line treatment for Graves’ disease.

Graves’ disease, an autoimmune condition characterised by the presence of autoantibodies against the thyroid stimulating hormone (TSH) receptor, is the most common cause of hyperthyroidism. Graves’ disease is more common in women, with a ratio of 5:1. Typical symptoms include clinical and biochemical evidence of hyperthyroidism, Graves’ ophthalmopathy and goitre. Management options include biochemical control with antithyroid drugs (ATD), thyroid ablation with radioactive iodine (RAI) and thyroid surgery. Traditionally, indications for surgery have included large goitre with compressive symptoms, pregnancy or planning for pregnancy, severe ophthalmopathy, young age, failure of RAI treatment, suspicion of malignancy, inability to tolerate RAI (eg, need to care for young children), intolerance of antithyroid drugs, thyroid storm and patient preference.

Options for surgery have included bilateral subtotal thyroidectomy, Dunhill procedure (unilateral lobectomy and contralateral subtotal lobectomy) and total or near-total thyroidectomy. For most of the twentieth century, subtotal options were preferred in order to preserve a thyroid remnant of approximately 5g, which offers the possibility of avoiding long-term thyroid hormone replacement. But in the 1990s there was a shift in practice towards total thyroidectomy. A growing body of evidence indicated a significant rate of recurrence of hyperthyroidism with the subtotal approach. Total thyroidectomy, on the other
hand, provides more predictable control of Graves' disease. It also reduces the chance of recurrent hyperthyroidism. Between the two there is no difference in terms of recurrent laryngeal nerve injury or post-operative haematoma in experienced surgical units, although with total thyroidectomy there is a slightly increased rate of permanent hypoparathyroidism. Further studies have established total thyroidectomy as a cost-effective option with no significant difference in quality of life compared to subtotal.

In recent years, our institution has performed around 100 thyroid and parathyroid cases annually, including approximately 60 thyroid cases. This study reports our local experience with routine total thyroidectomy for Graves' disease in a New Zealand population.

**Methods**

Consecutive patients undergoing thyroid surgery at a specialist endocrine surgery unit were recorded in a prospective database between December 2001 and January 2021. Institutional approval for the management of this database using deidentified patient information is ongoing. Surgery was performed under the direct supervision of one of two specialist endocrine surgeons. All patients undergoing surgery for Graves' disease received multidisciplinary pre-operative review and counselling by both the endocrinology and endocrine surgery services. Patient characteristics and indications for surgery were recorded, as well as pre- and post-operative TSH, thyroxine (T4), calcium and parathyroid hormone (PTH). The immediate and long-term requirements for post-operative calcium supplementation were recorded and the electronic record was reviewed to identify recurrence of thyrotoxicosis. Post-operative complications were also recorded.

All patients undergo pre-operative assessment with endocrinology with adjustment of antithyroid medication, beta blockade and the use of Lugol's iodine. All patients undergo total thyroidectomy using routine nerve monitoring. Following total thyroidectomy, routine serum calcium and PTH measurements are performed the evening of surgery and again at 0600 the next day.

Patients with signs or symptoms of hypocalcaemia, and those with a post-operative adjusted calcium level less than 2.0mmol/L or with an intraoperative PTH level less than 2pmol/L, are prescribed post-operative calcium and 1,25 OH vitamin D supplementation. Our local protocols outlining management of post-thyroidectomy hypocalcaemia have recently been published.

Patients are routinely followed-up in the surgical outpatient clinic six weeks following surgery. Their serum PTH, calcium and thyroid function are tested prior to this appointment. Patients then had ongoing follow-up with their general practitioner.

**Results**

Sixty-four patients underwent total thyroidectomy for Grave's disease between December 2001 and January 2021. Fifty-eight (89.2%) were female. Median (range) age was 35.5 (17–69). Median (range) follow up was 76.2 (4–241) months. All but one patient (who had a concurrent papillary thyroid cancer) had symptoms of thyrotoxicosis. Thirty-five patients (54.7%) were European/Pākehā, 14 (21.9%) were Māori, 11 (17.2%) were Asian, three (4.7%) were Pasifika and one (1.5%) was classified as other.

Ten patients chose RAI due to having young children at home. One was pregnant in their second trimester. Four had suspicious nodules within the thyroid.

The most common indication for surgery (n=24) was personal preference or a refusal to take RAI. Further indications were ophthalmopathy (n=16), compressive symptoms (n=7) and failed RAI (n=2). Indications for surgery are outlined in Table 1.

In patients with ophthalmopathy as the indication for surgery, eight of the 16 were reviewed in the ophthalmology clinic prior to surgery. Of these, ten were felt to have moderate to severe ophthalmopathy, and two required specific management in the form of decompressive surgery or radiotherapy. The remaining six patients with mild eye disease had additional indications for surgery, such as failed RAI or large goitre. Median time from diagnosis of Grave's disease to surgery was two years, with all patients having an attempt at control with antithyroid medication prior to surgery.
All patients had histological changes consistent with Graves' disease. Six patients (9.3%) had papillary thyroid cancer noted on final histology (this was known for one patient pre-operatively) and subsequently required radioactive iodine. The other patients had an incidentally noted microcarcinomas requiring no further treatment. All patients remained fully treated at follow-up and no patient had a recurrence within the follow-up period. All patients continued thyroxine.

Table 2 outlines post-operative outcomes. Twenty-one (32.8%) patients had post-operative hypocalcaemia (less than 2.1mmol/L) or hypoparathyroidism (PTH less than 1.5pmol/L). Mean (SD) post-operative calcium (albumin adjusted) was 2.12mmol/L (0.15). Mean (SD) PTH level was 4.11pmol/L (3.71). Twenty-four (37.5%) patients were prescribed calcium and 1,25 OH vitamin D supplements on discharge, and a total of four (6.2%) patients remained on long-term calcium supplementation at follow-up. One did not have further PTH testing and maintained a normal calcium post-surgery. Two patients had low post-operative PTH, but on follow-up these were in the normal range. Only one (1.6%) patient documented permanent hypoparathyroidism at follow-up.

Four patients (6.7%) had post-operative voice changes, although no patients suffered true recurrent laryngeal nerve injury as seen on direct laryngoscopy. All patients had normal voice at follow-up. Two patients (3.1%) were had a post-operative haematoma, one of whom required a return to theatre. One patient had a wound infection requiring antibiotics. No patients died within 90 days of surgery.

Discussion

Grave's disease is a relatively common autoimmune disorder that predominantly occurs in young women of reproductive age. It tends to be a relapsing remitting condition, although a large goitre or very high T4 at presentation predicts a lower long-term likelihood of remission.

Typically, antithyroid drugs, usually in a tapering course over 12–18 months, are used to treat an attack of Graves' disease. In New Zealand, surgery is firmly a second-line treatment modality. In one survey of New Zealand endocrinologists, a course of antithyroid drugs was the preferred first-line treatment modality in the majority of patients (92%); early RAI was recommended in only 5% of cases; thyroidectomy as first-line treatment for Graves' disease was preferred by only a single specialist (2.7%).

The widespread preference in New Zealand for the use of ATD over RAI as first-line treatment differs from international results. New Zealand has very low rates of early RAI treatment. Some possible explanations include New Zealand's nuclear-free policy and the difficulty of accessing radioactive iodine isotopes. There is also a degree of fear of radiation exposure among patients, when this is discussed. Recent liter-

Table 1: Indication for surgery.

<table>
<thead>
<tr>
<th>Indication for surgery</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient preference/refusal of RAI</td>
<td>24 (37.5%)</td>
</tr>
<tr>
<td>Graves' ophthalmopathy</td>
<td>16 (25%)</td>
</tr>
<tr>
<td>Childcare considerations</td>
<td>10 (15.6%)</td>
</tr>
<tr>
<td>Compressive symptoms</td>
<td>7 (10.9%)</td>
</tr>
<tr>
<td>Suspectious nodule</td>
<td>4 (6.3%)</td>
</tr>
<tr>
<td>Failed RAI</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>1 (1.6%)</td>
</tr>
</tbody>
</table>
ature, which has raised the possibility of a slight increase in the long-term risk of malignancy following RAI treatment, has also influenced both specialists and patients, an experience that our results support: all patients had attempted to control ATD prior to referral, and the median time from diagnosis of Graves’ to surgery was two years.

While RAI is safe and efficacious in the vast majority of patients, the choice of surgery over RAI as a second-line treatment option is made for varying reasons. Most commonly is that patients prefer surgery or are concerned about RAI treatment. Significant eye disease is another reason. In our unit, patients with mild ophthalmopathy are considered for RAI with steroid cover. This is supported by previous studies showing that steroids can prevent progression of eye disease. Surgery is preferred as a second-line treatment modality in patients with more severe eye symptoms; this remains a common indication for surgery in our cohort. Although use of RAI as a first-line treatment is relatively low in New Zealand, the rate of patient preference/refusal of RAI (37.5%) among patients deciding on surgery as a second-line treatment option remains comparable with other international audits. This suggests that, although patients may be reluctant to pursue RAI as primary treatment, they will generally be open to this modality as a second-line option. Childcare considerations are an important factor in deciding on surgery over RAI, reflecting the epidemiology of Graves’ disease commonly affected younger female patients. Perhaps we can expect this indication for surgery to decrease in future as social norms around gender roles change.

Our results support the assertion that total thyroidectomy is a safe and effective treatment for Graves’ disease. Recurrent laryngeal nerve injury and permanent hypoparathyroidism are uncommon complications. Although 37.5% of patients in our study were discharged on calcium supplementation, only one patient had true permanent hypoparathyroidism. A Cochrane review quoted a rate of permanent hypocalcaemia in total thyroidectomy for Graves’ disease of 59 per 1,000 patients, and a large meta-analysis found a rate of 1.6%. Although these rates are low, remember that the impact on quality of life for these patients can be significant. They need daily calcium and vitamin D supplementation.

<table>
<thead>
<tr>
<th>Outcomes of surgery</th>
<th>Number (%)</th>
<th>Cochrane review</th>
<th>Meta-analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recurrent hyperthyroidism</td>
<td>0</td>
<td>0.8%</td>
<td>0</td>
</tr>
<tr>
<td>Hypocalcaemia/hypoparathyroidism</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary Hypocalcaemia/hypoparathyroidism</td>
<td>21 (32.8%)</td>
<td>5.9%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Discharge on calcium supplementation</td>
<td>24 (37.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permanent hypoparathyroidism</td>
<td>1 (1.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent laryngeal nerve injury</td>
<td>4 (6.7%)</td>
<td>1.3%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Post-operative voice change</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permanent voice change</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permanent nerve injury (on laryngoscopy)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haematoma</td>
<td>2 (3.1%)</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Infection</td>
<td>1 (1.6%)</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Return to theatre</td>
<td>1 (1.6%)</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
</tbody>
</table>
and have an ongoing risk of nephrocalcinosis and renal dysfunction associated with long-term treatment of hypocalcaemia. Permanent recurrent laryngeal nerve injury is a rare event, with one meta-analysis quoting a rate of 0.9%. More generally, in Key Performance Indicator (KPI) results for thyroid surgery for any indication that our unit recently published, the rate of permanent RLN injury was 0.3%, the rate of permanent hypocalcaemia was 2.5% and the rate of return to theatre was 1.1%. These results suggest that complication rates are not significantly higher than for other indications for thyroid surgery, and are in line with a prior study from New Zealand that primarily looked at the rate of thyroid cancer in patients with Graves’ disease but reporting rates of permanent hypoparathyroidism <2% and nerve injury <1%. Total thyroidectomy is an effective treatment for Graves’ disease. In our population, all patients achieved long-term control of their thyrotoxicosis. A Cochrane review quotes the risk of recurrent/persistent hyperthyroidism at eight per 1,000 patients. All patients required long-term thyroid supplementation, although this has previously been demonstrated to be a cost-effective approach with comparable quality-of-life outcomes.

Conclusion

Total thyroidectomy has been established as the most common surgical approach for the management of Graves’ disease. In our unit, thyroidectomy for Graves’ disease makes up a relatively small component of our practice. Our results show that it is a safe procedure to perform and results in excellent long-term control of thyrotoxicosis. It is particularly useful in patients with significant ophthalmopathy or in patients with aversion to RAI treatment.
Competing interests:
Nil.

Acknowledgements:
The authors would like to acknowledge the Endocrine Multidisciplinary team at Waitematā District Health Board who have been involved in the management of these patients.

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REFERENCES

Neurodevelopmental follow-up of preterm infants: current practice for infants at a tertiary neonatal centre

Meghan Ealish Sandle, Maria Saito Benz, Laura Port, Max Berry

ABSTRACT

AIM: To characterise neurodevelopmental surveillance, assessment and outcomes for infants at risk of adverse neurodevelopment and inform targeted surveillance of infants discharged from a regional tertiary neonatal centre.

METHODS: A retrospective study of developmental follow-up of 106 vulnerable infants born either preterm (23–29 weeks gestation, n=96) or at ≥30 weeks gestation with low birth weight (<1,200 grams n=10) admitted to our tertiary Neonatal Intensive Care Unit between January 2011 and December 2015. Infants transferred to other regions before two-years corrected postnatal age were excluded. Local health records were reviewed to determine neurodevelopmental follow-up, input and outcomes.

RESULTS: Almost all (98%) of high-risk infants received at least one follow-up visit by a visiting neurodevelopmental therapist following discharge from the neonatal unit, and 73% of infants received early developmental follow-up in line with international recommendations. Ninety infants (87%) were seen until at least two years post term, at which point 61 (68%) had typical development. At five-years post term, 23 (26%) of the 89 infants remaining in the region had been diagnosed with a developmental disability, for which global developmental disability was the most common diagnosis (19 infants).

CONCLUSION: Routine neurodevelopmental surveillance of vulnerable infants from our tertiary catchment has high coverage, with most infants receiving regular developmental assessment. However, universal developmental screening is resource intense, and overall rates of diagnosed neurodevelopmental impairment are relatively low. Better early identification of infants most at risk using earlier assessment tools may help to stratify and target follow-up to allow resources to be allocated more effectively and reduce the follow-up burden for infants at lower risk of developmental concerns.

In 2016, there were 60,000 live births in New Zealand, of which just over 4,500 (7.5%) were of infants born preterm, before 37 weeks gestational age.

Preterm infants are at increased risk of adverse neurodevelopmental outcomes, including developmental delay, intellectual disability (ID), autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and mood and emotional problems. These difficulties have implications across an individual's life and affect education, employment and wellbeing. Preterm birth can therefore impact on the life-course and create long-term disparities in health, wellbeing and economic outcomes for children and young people, their families and communities.

Advances in obstetric and neonatal care have led to increased survival rates of extremely preterm (≤28 weeks gestational age) and low birth weight infants (LBW; birth weight <1,200 grams). Although overall rates of neurodevelopmental disability vary internationally, they are universally high and have not changed significantly over the preceding 10 years. Additionally, an earlier the gestational age at birth leads to a greater risk of adverse neurodevelopmental
Therefore, as the threshold for active intervention at the extremes of gestational age and birth weight continues to fall, accurate identification of neurodevelopmental risk is essential in order to provide targeted neurodevelopmental follow-up and intervention, especially within publicly funded health care systems, such as in Aotearoa New Zealand.

In this group, the objectives of neurodevelopmental surveillance include developmental monitoring and prompt recognition of neurodevelopmental difficulties, which in turn enable the timely provision of appropriate intervention. This capitalises on early developmental neuroplasticity and improves the child’s neurodevelopmental trajectory. Early developmental intervention in preterm infants is associated with improved motor and cognitive outcomes. In infants with cerebral palsy, earlier diagnosis and earlier intervention have a demonstrably positive effect on the wellbeing of caregivers.

Longitudinal surveillance should assess growth, neurological and motor function, cognitive development, language, behaviour, functional status and family resources. Consequently, universal screening of high-risk infants, many of whom go on to follow a standard neurodevelopmental trajectory, carries a significant time and resource burden. There is also a risk to families of on-going “medicalisation” of otherwise well infants. This may adversely impact psychological and emotional wellbeing for the child’s caregivers.

These financial and other costs associated with screening infants with typical neurodevelopment nonetheless need to be balanced with the therapeutic advantage of early identification and intervention within the sensitive period of neuroplasticity in early infancy.

Internationally, many resource-rich countries provide tertiary-level care to preterm/LBW infants. They follow various strategies for neurodevelopmental follow-up of high-risk infants. The most effective way to provide appropriate developmental screening and resource allocation has yet to be determined within Aotearoa New Zealand, where there are complexities relating to rurality, access to specialist services and a resource-constrained health system. Despite these challenges, Aotearoa New Zealand must prioritise equitable access to appropriate neurodevelopmental surveillance and intervention for developmental follow-up. It also must meet its obligations under Te Tiriti o Waitangi (Treaty of Waitangi) and provide culturally appropriate models of care to achieve equitable health outcomes for Māori. We therefore need to quantify the burden of neurodevelopmental difficulties faced by children born extremely preterm in Aotearoa New Zealand. This is necessary to help develop a national consensus and inform a targeted approach to screening.

In the UK, the National Institute for Clinical Excellence (NICE) published guidelines in 2017 for the developmental follow-up for children born preterm. These guidelines recommend enhanced surveillance for infants born <30 weeks gestation until at least two-years post term, as well as a minimum of two face-to-face visits in the first year and a detailed developmental assessment at two-years corrected post-term age (CPA).

Our Neonatal Intensive Care Unit (NICU) provides regional tertiary care for infants from 23 weeks gestational age. All infants born <30 weeks gestation or birth weight <1,200 grams are routinely referred for follow-up by visiting neurodevelopmental therapists (VNDTs) from our hospital-funded Child Development Service. VNDTs provide developmental surveillance and support for at-risk infants through home visits, regular assessment using standardised developmental tools and early intervention. VNDT follow-up is in addition to routine Well Child services provided for all infants in Aotearoa New Zealand and specialist neonatologist medical review, which typically continues for at-risk infants until around three years of age.

The aim of this study was to determine the practice of neurodevelopmental surveillance and the prevalence of developmental difficulties within a contemporary cohort of at-risk infants. This will help inform strategies to better rationalise our current model of care in the context of an increasing high-risk infant population and competing priorities within New Zealand’s public health care system.
Methods

We carried out retrospective study of the developmental follow up for preterm/LBW infants discharged from Wellington NICU into our district health board (DHB) catchment area.

Inclusion criteria were infants in-born in Wellington Regional Hospital between January 2011 and December 2015 with a gestational age (GA) at birth <30 weeks and/or a birth weight (BW) <1,200 grams. This birth weight and gestational age were chosen to reflect the referral threshold to the child development service as per our local policy. We excluded infants born or domiciled in a different DHB (ie, those discharged back to their local DHB for all follow-up) or who moved and were referred to a different DHB within two-years post term.

Data were obtained from the infant's interdisciplinary health records within the DHB and included NICU inpatient notes, medical clinical letters and community notes and reports from the Child Development Service. Demographic information was collected for each infant, including gestational age at birth, birth weight, sex and prioritised ethnicity, as recorded in the patient records. Prioritised ethnicity data assigns a single ethnic group to individuals. This system is frequently used for health and disability data. Socioeconomic status was determined by the New Zealand Index of Deprivation (NZDep) for the infant's address at birth. The NZDep measures social deprivation based on small geographical areas, with the least deprived areas scoring 1 and the most deprived areas scoring 10.

Follow-up information included VNDT input, length of follow-up, referral to other services, results of standardised assessment and discharge from child development service.

Neurodevelopmental assessment was performed using the Bayley Scales of Infant Development (BSID), the most well characterised assessment of global development in infants born preterm. Bayley III (current edition of BSID at time of study) is administered which assess cognition, language (receptive and expressive communication subtests) and motor (fine motor and gross motor subtests). BSID can be used to identify developmental delay. A composite score less than one standard deviation from the normative mean (<85) representing developmental delay on that scale.

Developmental delay or concerns were defined by BSID scores (composite score <85) and/or VNDT report. Typical development on BSID performed at any age was defined by composite score on all scales ≥85.

Developmental outcomes at five-years post term were obtained for infants recorded as still living within the region. Diagnosis of developmental disability was determined from the child's health records, including assessment by psychologist and/or paediatrician. Global developmental disability was diagnosed using standardised assessment (Griffith III) and ASD diagnosed by specialist multidisciplinary assessment.

Ethical approval for this study was prospectively obtained by the Child Health Research and Audit Committee at Wellington Regional Hospital.

Results

Between January 2011 and December 2015, 115 infants born at GA <30 weeks and/or BW <1,200 grams in Wellington NICU were discharged to the local region. Nine were excluded because their families relocated out of area and they were referred to another developmental follow-up programme within two-years post term. We analysed the outcomes for 106 infants.

Infant characteristics

Key demographics are listed in Table 1. Ninety-six infants (91%) were born at GA <30 weeks. Of these, 79 also had low birth weight (BW <1,200 grams). Ten infants born ≥30 weeks were eligible for developmental follow-up due to low birth weight. The median gestational age was 27+6 weeks (range: 23+0–31+2 weeks) and median birth weight was 945 grams (range: 410–1,765 grams).

Over half the infants (57%) were male. Most infants (60%) were of European ethnicity and 12% were Māori, according to registered prioritised ethnicity data. The cohort's NZDep range, based on address at...
Table 1: Demographic characteristics of 106 infants born in Wellington NICU at <30 weeks GA and/or < 1,200g BW.

<table>
<thead>
<tr>
<th>Infant characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preterm (&lt;30 weeks GA)</td>
<td>96 (91%)</td>
</tr>
<tr>
<td>LBW (&lt;1,200 grams)</td>
<td>89 (84%)</td>
</tr>
<tr>
<td>&gt;30 weeks GA and &lt;1,200 g</td>
<td>10 (9%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>60 (57%)</td>
</tr>
<tr>
<td>Female</td>
<td>46 (43%)</td>
</tr>
<tr>
<td><strong>Prioritised ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>16 (15%)</td>
</tr>
<tr>
<td>European</td>
<td>64 (60%)</td>
</tr>
<tr>
<td>Māori</td>
<td>13 (12%)</td>
</tr>
<tr>
<td>MELAA(^1)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Pacific</td>
<td>12 (12%)</td>
</tr>
<tr>
<td><strong>NZDep index</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>27 (26%)</td>
</tr>
<tr>
<td>2</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>3</td>
<td>13 (13%)</td>
</tr>
<tr>
<td>4</td>
<td>7 (7%)</td>
</tr>
<tr>
<td>5</td>
<td>14 (13%)</td>
</tr>
<tr>
<td>6</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>7</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>8</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>9</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>10</td>
<td>10 (9%)</td>
</tr>
</tbody>
</table>

\(^1\) Middle Eastern, Latin American, African
\(^2\) New Zealand Index of Deprivation- based on maternal address at time of birth
time of birth, was 1–10, with decile 1 (least deprived) being the most frequent.

Neurodevelopmental follow-up

All 106 infants were referred to the Child Development Service following discharge from NICU. Overall, post-discharge neurodevelopmental follow-up rates were high. One hundred and four infants (98%) received at least one face-to-face follow-up visit by a VNDT.

Three infants died within two-years post term (Figure 1). Two had had developmental concerns identified. The third was significantly unwell with multiple admissions to hospital and no formal neurodevelopmental assessment was documented. All three infants were excluded from further analysis.

Ninety of the 103 surviving infants (87%) received VNDT input until at least two-years CPA. Of these, 21 received follow-up and intervention for at least three years post term, 13 received follow-up for less than two years and two were never assessed by a VNDT (one family declined follow-up and one family was uncontactable).

Table 2 shows the differences in the baseline characteristics between two groups of infants: those who received no follow-up or follow-up for less than two-years CPA, and those who received neurodevelopmental surveillance until at least two-years CPA. Both groups had a similar median gestation and birth weight. Although the numbers are small, the group of infants who received follow-up for less than two-years included a higher proportion of males, a higher proportion of infants with an NZDep index >6 and a higher proportion of Māori infants.

The median age of discharge from VNDT follow up was 25 months post term age.

Most infants received follow-up that met the international NICE recommendations. Seventy-five infants (73%) received at least two face-to-face visits in the first year and detailed developmental assessment around two-years CPA. Similarly, most infants (90/103; 87%) had at least one BSID assessment during the period of developmental surveillance. Sixty-two were assessed twice at approximately 12-month intervals, and four had three assessments.

In total, 152 individual BSID assessments were performed for preterm/LBW infants over the five-year study period.

Of the 90 infants who received BSID, 29 (32%) were identified to have a developmental delay (composite score <85 on any scale) on at least one of their assessments. All infants received the Bayley III edition. BSID was not completed where families were not able to be contacted or did not attend scheduled appointments.

Fifty-seven infants had additional assessment or input from another member of the Child Development Service. This was most commonly for review or for support from speech and language therapy (Figure 2).

Neurodevelopmental outcomes

Over half the infants (61/101; 60%) who received neurodevelopmental follow-up and at least once visit from VNDT had no developmental difficulties identified during their period of follow-up. Developmental concerns were recorded for 40 infants (42%). Developmental delay on standardised testing (BSID score <85) was observed in 29. Isolated language delay was present in six, isolated motor delay in eight and delays in more than one developmental domain in 15. A formal BSID assessment was not performed for two, but on observation and history they were found to have a language delay. The developmental concerns for the remaining nine infants related to specific areas such as gross motor or expressive or receptive language skills, but their overall composite scores on BSID were normal.

Of the 90 high-risk infants followed-up for at least two-years, 60 (67%) had age-appropriate development at two-years CPA. This includes eight infants who had earlier developmental concerns identified but typical development at their two-year assessments.

There were 89 children from the cohort who were recorded as domiciled within our DHB catchment at age five years. The prevalence of known developmental disability for these children at five years CPA, as determined from their current electronic health records, is shown in Figure 3.

Of these 89 children, 23 (26%) had been diagnosed with a developmental disability by age five (global developmental disability was the most common diagnosis (n=19)). Five had ASD and all but one was also diagnosed with global developmental disability. Three had cerebral palsy. Twenty-two had developmental delays on BSID or clinical
Figure 1: Follow-up of infants discharged from tertiary neonatal unit to local neurodevelopmental screening (n=106).

- 106 infants
  - 1 infant died: 7 months CPA (Respiratory complication)
  - 1 infant died: 12 months CPA (Respiratory complication)
  - 1 infant died: 23 months CPA (Gastrointestinal complication)

103 surviving infants to 2 years CPA

- 2 infants (2%) received no VNDT follow up
- 11 infants (11%) received VNDT follow up for < 2 years CPA
- 90 infants (90%) received VNDT follow up until at least 2 years CPA

- 8 infants: lost to follow up
- 1 infant: Family declined further follow up
- 2 infants: Reason unknown
- 60 infants (67%) discharged with age appropriate development
Table 2: Characteristics of infants in neurodevelopmental follow-up programme for less than and more than two-years CPA (n=103).

<table>
<thead>
<tr>
<th></th>
<th>Median GA (weeks &lt;sup&gt;days&lt;/sup&gt;)</th>
<th>Median BW (grams)</th>
<th>Sex N (%)</th>
<th>NZDep index N (%)</th>
<th>Prioritised ethnicity N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2 years developmental follow-up (n=13)</td>
<td>27&lt;sup&gt;13&lt;/sup&gt;</td>
<td>1062</td>
<td>Male: 9 (70%) Female: 4 (30%)</td>
<td>1–5: 7 (54%) 6–10: 6 (46%)</td>
<td>Asian: 1 (8%) European: 7 (54%) Māori: 4 (30%) MELAA: 0 (0%) Pacific: 1 (8%)</td>
</tr>
<tr>
<td>≥2 years developmental follow-up (n=90)</td>
<td>27&lt;sup&gt;17&lt;/sup&gt;</td>
<td>943</td>
<td>Male: 49 (54%) Female: 41 (46%)</td>
<td>1–5: 62 (69%) 6–10: 28 (31%)</td>
<td>Asian: 15 (17%) European: 55 (61%) Māori: 8 (9%) MELAA: 1 (1%) Pacific: 11 (12%)</td>
</tr>
</tbody>
</table>

Figure 2: Utilisation of Child Development Service by vulnerable infants following NICU discharge.

* = for at least two-years post term.
assessment during their earlier neurodevelopmental surveillance. The twenty-third infant, who had initial follow-up until eight-months CPA and no developmental concerns at that time, was subsequently lost to follow-up. They were re-referred to the Child Development Service aged two and half and assessed and diagnosed with ASD.

Table 3 shows the characteristics of children with and without known developmental disability at five years. Children diagnosed with developmental disability had a lower average gestational age and weight at birth. The group of children with developmental disability had a higher proportion of males than the group without developmental disability, and a higher proportion of children with an NZDep index >6. The ethnicities of children were mostly similar in each group, except for Māori: there were relatively more Māori children with than without a developmental disability (17% verses 7%).

Discussion

We have demonstrated that the majority of high-risk infants enrolled in a post-discharge surveillance programme in a single tertiary NICU are free of neurodevelopmental problems at age two-years CPA.

Although “optimal” neurodevelopmental surveillance remains uncertain for non-stratified populations of high-risk infants, internationally recommended best practice suggests a minimum of two face-to-face visits in the first year and a detailed developmental assessment at two-years CPA. In practice, this represents a substantial ongoing burden of medical supervision for the infants, their family and whānau.

In our region, over a five-year period, nearly all preterm/LBW infants discharged from NICU who were eligible for neurodevelopmental follow-up received at least one face-to-face visit by a specialised developmental therapist. Most infants received monitoring that was consistent with requirements set out by international standards and until at least two-years corrected postnatal age. This rate of follow-up is higher than in a contemporaneous study in Australia that showed 50% of extremely preterm/LBW infants had received developmental follow-up until two-years post term.20

High rates of compliance with screening reassure us that the majority of these infants are doing well and enable us to discuss how a stratified screening approach might support those in need without burdening families with low-yield medical appointments.

One strategy to enhance the efficiency of developmental follow-up involves tools for earlier assessment. The general move-
GMA is a non-invasive tool that analyses infant movement patterns in the first few months of life to determine the risk of later developmental disability.\textsuperscript{11} GMA is highly sensitive for detecting risk of cerebral palsy and has been shown to allow much earlier diagnosis than traditional approaches.\textsuperscript{21,22} GMA assessment can also help predict adverse cognitive and language outcomes.\textsuperscript{23,24}

Routine use of GMA in preterm/LBW infants was recently implemented in our service.\textsuperscript{24} It allows for early identification of at-risk infants and offers early, targeted intervention and clearly has a place in the model of care for developmental follow-up in Aotearoa New Zealand.

In our study population, most infants received at BSID assessment during the period of developmental follow-up. BSID is widely used for global neurodevelopmental assessment in this population. However, it is costly and time consuming to perform, with each assessment requiring 30–90 minutes of child interaction alone. In this study period, 152 BSID assessments were performed at around 12- and 24-months CPA, yet two thirds of these infants scored within the typical range across all scales. The use of BSID as a universal assessment tool in neurodevelopmental follow-up programmes, however, is limited by concerns about under-diagnosis of developmental disability and its ability to predict later cognitive and motor impairment.\textsuperscript{27–29} Crucially, identification of problems following BSID at 12 or 24 months of age may be too late to guide targeted early intervention during the period of maximal neuroplasticity.

Since recent improvements in perinatal care have increased the number of infants meeting the requirements for neurodevelopmental follow-up and considerably increased demand on our resource-constrained system, it is important that we safely prioritise infants who are most in need. The prevalence of known developmental disability in our study population was 26%, which is similar to estimates from other studies,\textsuperscript{7,8,30,31} and therefore the majority of infants did not have a diagnosis of developmental disability and were discharged from surveillance with normal development. These data reassure us of the safety of rationalising follow-up for neurodevelopmental impairments.

Given the importance of accurate and early detection of developmental disability for infants and their families, it is critical that there is a consistent and universal approach to neurodevelopmental surveillance that maximises benefit in a

| Table 3: Characteristics of children with and without developmental disability at five years CPA (n=89). |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| No developmental disability (n=66) | Median GA (weeks\textsuperscript{a}days) | Median BW (grams) | Sex N (%) | NZDep index N (%) | Prioritised ethnicity N (%) |
| 28\textsuperscript{a} | 988 | Male: 34 (52%) Female: 32 (48%) | 1–5: 46 (67%) 6–10: 20 (33%) | Asian: 9 (14%) European: 42 (64%) Māori: 5 (7%) MELAA: 0 (0%) Pacific: 9 (14%) |
| Developmental disability (n=23) | 25\textsuperscript{a} | 799 | Male: 15 (65%) Female: 8 (35%) | 1–5:11 (48%) 6–10: 12 (52%) | Asian: 3 (13%) European: 13 (57%) Māori: 4 (17%) MELAA: 0 (0%) Pacific: 3 (13%) |
resource-constrained environment, such as Aotearoa New Zealand. Aotearoa New Zealand is also a geographically diverse country of low population density where access to neurodevelopmental follow-up for preterm infants varies. In certain areas, logistical problems, including limited access to resources and funding, may further impact a family’s ability to attend follow-up for neurodevelopmental screening. Developing services for the early identification of infants at high risk of developmental disability, and targeting resources for intensive therapies during the window of brain neuroplasticity, needs to be a priority.

Although most infants in this study did not have developmental concerns identified within the period of follow-up, the input from neurodevelopmental therapist extends beyond developmental screening. In addition to assessment, VNDTs provide therapy, engage with families, create long-term relationships and support infant development and parental interactions. This early developmental support may have reduced the severity or frequency of developmental difficulties within this group of high-risk infants. Even for infants who progress along normal developmental trajectories, this input may be beneficial in terms of encouraging attachment and positive parenting, critical “non-medical” elements that may have been disrupted as a consequence of the early NICU environment but are linked to improved cognitive outcome and resilience.

Access to equitable and culturally appropriate follow-up management also needs consideration. Māori babies are more likely to be born preterm, especially <28 weeks GA, compared to non-Māori. In this study, 12% of infants were Māori according to prioritised ethnicity. Although numbers were small, there was a higher proportion of Māori represented in the group of children who received a shorter duration of neurodevelopmental follow-up and the group with a developmental disability at age five years. The design and implementation of neurodevelopmental follow-up programmes therefore requires a culturally safe, whānau-centred approach in partnership with Māori to uphold the principles of Te Tiriti o Waitangi and are an opportunity to develop Kaupapa Māori health services, reduce inequity and improve outcomes.

This study is limited by being retrospective and relying on accurate documentation in medical notes. Although data were collected from a five-year period, the number of infants in this group was relatively small compared to the large-cohort studies used to determine neurodevelopmental outcomes in at-risk infants internationally. The prevalence of developmental disability in this cohort may be underrepresented due to diagnosis being made after the age of five years, which may occur despite normal BSID assessment or in a different setting such as education or mental health services. Diagnosis of disorders such as ADHD, DCD and mood and emotional disorders, and in some cases ASD, may not be made until the child is older and after the period of initial neurodevelopmental screening.

Developmental outcomes were not available for the 13 infants (12%) who did not receive neurodevelopmental follow-up or who were seen for less than two years. Infants who transferred to developmental screening programmes in other regions within the two-year follow-up period were excluded as follow up data were not available. The longer-term outcomes for the 17 children who were no longer living in the region at age five were not known. The generalisability of our outcome data to the wider preterm/LBW population is therefore limited by potential baseline differences between the groups of infants who remain living in an urban centre and have received regular follow-up compared to infants who live in more rural regions, who have moved between regions or who did not complete routine neurodevelopmental follow-up.

There is clearly a need for national cross-sector datasets to provide accurate, complete long-term outcome data for preterm infants in New Zealand.

**Conclusion**

At-risk preterm/LBW infants cared for in a single tertiary NICU and domiciled within catchment for community follow-up are being referred for, and receiving, neurodevelopmental surveillance. Although rates of developmental disability are higher than in the general population, the majority
of infants have normal development on standardised developmental testing. Earlier assessment and identification of infants at the greatest risk will not only redirect resources where they are likely to have maximal benefit, but also minimise the ongoing burden of follow-up for infants that are well.

There is a need for a national consensus to support quality, effective, equitable and adequately resourced practice. This should include the use of well-researched early assessment tools such as GMA, targeted follow-up and intervention for infants most at risk and a community-based, family- and whānau-centred approach, with the aim to optimise the functional outcomes and well-being of vulnerable infants.

Authors’ declaration of authorship contribution

We declare that all named authors demonstrated roles and responsibilities as defined by the International Committee of Medical Journal Editors.
Competing interests:
Nil.

Acknowledgements:
We wish to thank the families/whānau of the infants in this study and our medical, nursing and therapist colleagues for their expertise.

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Factors predicting forgone healthcare among Asian adolescents in New Zealand: unmasking variations in aggregate data

Roshini Peiris-John, Lynda Bavin, Kristy Kang, Lovely Dizon, Sonia Lewycka, Shanthi Ameratunga, Terryann Clark, Theresa (Terry) Fleming

ABSTRACT

AIM: To examine the relationship between social support, safety, healthcare experience and forgone healthcare for Asian secondary school students in New Zealand by unmasking variations in aggregate Asian data.

METHODS: The study population included 1,911 Asians (1,272 East Asians and 604 South Asians) from the Youth19 survey. The reference group included 3,053 Pākehā.

RESULTS: We found disparities in family socioeconomic status (SES), social support, safety in school and neighbourhood, healthcare experience and forgone healthcare between East Asians and South Asians compared to Pākehā. One in five Asians (20%) reported forgone healthcare. Compared to their Pākehā peers (18%), Asian students (AOR=1.18, CI=1.04–1.33) and East Asian students (AOR=1.24, CI=1.06–1.45) were more likely to experience forgone healthcare, but South Asian students were not (AOR=1.05, CI=0.86–1.28). Important unique predictors of forgone healthcare for both East and South Asian students were: being discriminated against by health professionals due to ethnicity, not having a family member to talk about their worries with, and unfair treatment by teachers. Other unique predictors varied: lower community and family SES, not getting enough quality time with family, and being bullied at school were significant predictors for East Asian students; low perceived neighbourhood safety was a predictor for South Asian students.

CONCLUSIONS: A complicated picture underlies the seemingly positive findings for the overall Asian group. We highlight the importance of disaggregating Asian youth data into East Asian and South Asian, to identify disparities in risk/protective factors and better inform targeted interventions.

Asians are projected to become the second largest major ethnic grouping in New Zealand by 2030.1,2 The Asian population is a highly diverse group with differences in culture, language, religion, migration and socioeconomic experiences.3,4 Young Asians differ in their levels of socialisation, ethno-cultural identities, migration histories and connectedness to mainstream society.5,6 Already almost 20% of the New Zealand population aged 15–29 years identifies with an Asian ethnicity.7,8 As in other western countries,9 young Asians in New Zealand report favourable health outcomes in comparison to other major ethnic groups. Consequently, there has been minimal attention to national policies relating to Asian youth health.10,11 However, a more complicated picture underlies these seemingly positive findings. The “healthy migrant” effect is a well-recognised phenomenon captured in health statistics. Nevertheless, this positive effect on health dissipates as length of resi-
Asian youth experience pressure to uphold the “model minority” myth and the perception that Asian youth are successful and resilient to external stressors. They also face challenges in meeting expectations and norms of both their family and mainstream society, as they negotiate both worlds. Further, Asian youths’ mental health needs are often hidden by stereotypes that prevent access to mental health support. Lastly, when Asians are included in health studies and surveys, their data are often reported for the aggregated group. Important differences in health status between Asian ethnic groups are masked when health data are presented in an aggregated form. For example, compared to Chinese, Indians have high levels of diabetes and cardiovascular disease, which may not be evident when health outcomes are aggregated to a singular, collective Asian group.

In New Zealand, the first nationally representative youth health survey (Youth2001) identified important differences in access to healthcare among Chinese and Indian students. And the Youth2007 survey showed Asian students (as an aggregate group) were more likely than Pākehā (ie, students of European or Caucasian origin) to experience ethnic discrimination by health professionals, which was associated with adverse health outcomes.

By disadvantaging Māori, Pasifika and Asian youth, New Zealand’s current healthcare system is leading to significant health inequities. The factors that influence adolescents to forgo healthcare are complex. Contextual-level influences amongst migrant populations has been emphasised previously. Forgone healthcare is higher for adolescents from minority groups whose families experience poverty and who are from neighbourhoods with high levels of socioeconomic deprivation. Support from family or friends and neighbourhood or community is also known to influence adolescents’ access to health services. There are, however, few reports on the influence of support from family and community on forgone healthcare among young Asians in New Zealand.

This study has two main aims: (a) to examine whether reporting Asian data at an aggregate level will produce different findings than at the aggregate East Asian and South Asian levels, or at a specific Asian ethnicity level, and (b) to determine the relationship between social support, safety, healthcare experience and forgone healthcare for East Asian and South Asian students.

### Methods

#### Study design and sampling strategy

This study uses data from the Youth19 survey administered to secondary school students in Auckland, Northland and Waikato, which accounts for approximately 46% of New Zealand’s high school population. The survey methodology has been reported previously. In brief, a two-stage sample cluster design was used. First, we randomly selected 50% of high schools with >50 students in years 9 to 13. Forty-five of 80 mainstream high schools participated. Next, 30% of students were randomly selected from the school roll. Of the 12,359 students who were randomly selected and invited to participate, 7,374 (60%) took part in the survey, accounting for approximately 6% of students from the eligible schools. After the data were cleaned, 7,311 mainstream secondary school students had participated. Twenty-six percent (n=1,911) identified with an Asian ethnic group.

#### Analytical strategy

Table 1 shows the variables included and the basis for grouping of the survey respondents.

Prevalence data, odds ratios and their confidence intervals have been adjusted for clustering and the unequal probability of each student being invited to participate in the survey. We used generalised linear models (GLMs) to examine the associations between ethnicity and socioeconomic status (SES), social support, safety, healthcare experience and forgone healthcare. Age and sex were included as covariates. In the GLMs for forgone healthcare, several of the interaction terms between ethnicity (East Asian, South Asian) and the demographic, family SES and school support predictors were significant (p<0.05), indicating that the rela-
Table 1: Independent, dependent and grouping variables.

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Students reported their ethnicity at level 4 of the Statistics New Zealand classification (question: which ethnic group do you belong to?) and were able to choose as many ethnicities as applied to them. All options for level 4 reporting were provided.</td>
</tr>
<tr>
<td><strong>Family socio-economic status (SES)</strong></td>
<td>Assessed by the questions: Do your parents, or the people who act as your parents, ever worry about not having enough money to buy food? (often or all the time) AND For some families, it is hard to find a house that they can afford, or that has enough space for everyone to have their own bed. In the last 12 months, have you had to sleep in any of the following because it was hard for your family to afford or get a home, or there was not enough space? (do not include holidays or sleepovers for fun).</td>
</tr>
</tbody>
</table>
| **Community level SES**                                    | **School decile:** Based on New Zealand census data of five SES indicators (household income, proportion of parents on income support benefits, household crowding, parental educational qualifications, and occupational skill level of employed parents). Students from lower decile schools are generally from households that are more socioeconomically disadvantaged.  
**Neighbourhood decile:** Based on New Zealand Deprivation Index, with decile 1 representing areas of least deprivation and decile 10 the most deprived. For data analyses, students were grouped into one of three neighbourhood decile bands indicating lower deprivation (deciles 1–3), medium deprivation (deciles 4–7) and higher deprivation (deciles 8–10) levels. |
| **Family and friend support**                               | Perceived support from family was assessed by the questions: There is someone in my family/whānau who I can talk with about things that are worrying me (agree or strongly agree); I feel like I get enough quality time with my family/whānau (agree or strongly agree).  
Perceived support from friends was assessed by the question: I have at least one friend who I can talk with about things that are worrying me (agree or strongly agree). |
| **Community level support and safety**                      | Perceived school support and safety was assessed by the questions: Do you feel like you are part of your school? (yes); How often do the teachers/tutors treat students fairly? (most or all the time); In the last 12 months how often have you been bullied in school/course? (about once a week or more).  
Perceived community support and safety was assessed by the questions: There is an adult outside of my family/whānau who I can talk with about things that are worrying me (agree or strongly agree); Do you feel safe in your neighbourhood? (all the time).  
Experience of discrimination based on ethnicity by health service provider was assessed by the question: Have you ever been treated unfairly (e.g. treated differently, kept waiting) by a health professional (e.g. doctor, nurse, dentist etc.) because of your ethnicity or ethnic group? (yes, within the past 12 months or yes, more than 12 months ago). |
| **Dependent variable**                                      | Assessed by question: In the last 12 months, has there been any time when you wanted or needed to see a doctor or nurse (or other health care worker) about your health, but you weren’t able to? |
Table 1: Independent, dependent and grouping variables (continued).

<table>
<thead>
<tr>
<th>Grouping variable</th>
<th>Description</th>
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</table>
| **Asian students** | Identified based on Statistics New Zealand’s definition.  
  |  
| **East Asian** | Based on the World Bank definitions of East Asia, ethnicities with origins from Brunei, Cambodia, China, Hong Kong, Indonesia, Japan, North Korea, South Korea, Laos, Macao, Malaysia, Mongolia, Myanmar, Philippines, Singapore, Taiwan, Thailand, and Vietnam were included.  
  |  
| **South Asian** | Based on the World Bank definitions of East Asia, ethnicities with origins from Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka were included.  
  |  
| **Chinese** | Identified based on Statistics New Zealand’s definition.  
  |  
| **Indian** | Identified based on Statistics New Zealand’s definition.  
  |  
| **Pākehā** | Pākehā students were identified using Statistics New Zealand’s ethnic prioritisation method where each respondent is allocated to a single ethnic group based on a pre-determined hierarchy. This ensured that students identifying with both an Asian and Pākehā ethnicity were excluded from the Pākehā reference group. Pākehā ethnic grouping includes students identifying as New Zealand Pākehā or any other Pākehā ethnicity.  
  |  

1For Asian ethnic groups, Statistics New Zealand’s total response reporting was used where any participant who reported more than one ethnic group is included in all the groups they reported.
tionships varied by ethnicity. We therefore conducted separate predictive models for East Asians and South Asians to examine the effect of support and safety indicators on forgone healthcare. All models controlled for sex and age. As a high correlation between predictors can affect both the estimation and precision of regression coefficients, variables that were potentially problematic due to multicollinearity were excluded from the GLMs. We used likelihood ratio chi-square tests to examine whether the addition of family SES, support from friends, family support indicators, school support and safety indicators, neighbourhood safety and support indicators and experience of discrimination in the health service significantly increased the power of the model to predict forgone healthcare.

The study was approved by the University of Auckland Human Participants Ethics Committee (Reference Number 023450).

Results

Participant characteristics

Table 2 provides a demographic breakdown. Students who identified with multiple ethnicities were included in each ethnic group analysis: eleven students (0.6% of Asians) identified as both East Asian and South Asian, and six (0.3%) identified as both Chinese and Indian. Forty-six students (2.4%) identified as Asian but did not specify whether they were East Asian or South Asian. More East Asian (16.7%) and Chinese (15.6%) students were international students compared to students who were South Asian (5.6%), Indian (6.0%) and Pākehā (1.5%).

Socioeconomic status

Although the proportion of East Asian and Chinese students attending high-deprivation (low decile) schools was not markedly different to that of Pākehā students, the corresponding proportions for South Asian and Indian students were higher. The proportion of students from each Asian subgroup living in highly deprived neighbourhoods was higher than that of Pākehā students.

Asian, East Asian, South Asian and Indian students, but not Chinese students, were more likely than Pākehā students to have low family SES (Table 3).

Perceived support and safety

Asian, East Asian and Chinese students, but not South Asian or Indian students, were less likely than Pākehā students to perceive that they spent enough quality time with family (Table 3). Asian, South Asian, East Asian and Chinese students were less likely to report having someone in their family they could talk about their worries with. Although there was no difference between Pākehā and the aggregated Asian group for parents wanting to know where they are and who they are with, there were significant differences between Pākehā and each of the Asian subgroups studied. Contrasting findings were also found for the friend support indicator. Compared to Pākehā students, Indian students were less likely, and East Asian students were more likely, to report having at least one friend they can talk about their worries with.

School support indicators were largely positive, with all Asian ethnic groups more likely to report feeling part of the school compared to Pākehā students. However, again there were important differences between Asian groups. Asian, East Asian and Chinese students were less likely than Pākehā to report being bullied in school compared. South Asian and Indian students were more likely than Pākehā to report that teachers care about them.

Compared to Pākehā, all Asian ethnic groups felt less safe in their own neighbourhood, and Asian, East Asian and Chinese students were less likely to report they had an adult outside the family they could talk about their worries with. All Asian groups were more likely to report being treated unfairly by a health provider due to their ethnicity.

Forgone healthcare

Asian and East Asian students were more likely than Pākehā students to report forgone healthcare. This difference was not observed for South Asian, Indian and Chinese students when considered separately.

Relationships between SES, social support and healthcare experience, and forgone healthcare

The unique effect of several indicators varied between East and South Asian students (Table 4).
Table 2: Participant demographic characteristics.

<table>
<thead>
<tr>
<th></th>
<th>All (n=7,311)</th>
<th>Asian (n=1,911)</th>
<th>East Asian (n=1,272)</th>
<th>South Asian (n=604)</th>
<th>Chinese (n=734)</th>
<th>Indian (n=494)</th>
<th>Pākehā (n=3,053)</th>
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<td></td>
<td>n</td>
<td>%</td>
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<td></td>
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<td>445</td>
<td>70.7</td>
<td>226</td>
</tr>
<tr>
<td><strong>Neighbourhood deprivation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>2,098</td>
<td>31.3</td>
<td>454</td>
<td>25.8</td>
<td>337</td>
<td>28.8</td>
<td>104</td>
</tr>
<tr>
<td></td>
<td>1,294</td>
<td>46.0</td>
<td></td>
<td></td>
<td>445</td>
<td>70.7</td>
<td>226</td>
</tr>
<tr>
<td>Medium</td>
<td>2,772</td>
<td>41.4</td>
<td>872</td>
<td>49.6</td>
<td>585</td>
<td>50.0</td>
<td>273</td>
</tr>
<tr>
<td></td>
<td>1,185</td>
<td>42.1</td>
<td></td>
<td></td>
<td>445</td>
<td>70.7</td>
<td>226</td>
</tr>
<tr>
<td>High</td>
<td>1,829</td>
<td>27.3</td>
<td>433</td>
<td>24.6</td>
<td>248</td>
<td>21.2</td>
<td>181</td>
</tr>
<tr>
<td></td>
<td>334</td>
<td>11.9</td>
<td></td>
<td></td>
<td>445</td>
<td>70.7</td>
<td>226</td>
</tr>
</tbody>
</table>

1 NZ Deprivation Index 2018: Low deprivation (1–3), Medium deprivation (4–7), High deprivation (8–10).
2 School decile: Low decile (1–3) indicating higher deprivation, Medium decile (4–7), High decile (8–10) indicating lower deprivation.
Table 3: Prevalence of family socioeconomic status, social support, safety, and healthcare experience indicators for Asian secondary school students.

| Table 3: Prevalence of family socioeconomic status, social support, safety, and healthcare experience indicators for Asian secondary school students. |
|---|---|---|---|
| **Family socioeconomic status** | n | % [95% CI] | AOR[^] [95% CI] | p-value |
| Low family SES[^] | Pākehā | 357 | 12.3 [10.3–14.4] | ref |
| East Asian | 204 | 17.4 [14.5–20.2] | 1.56 [1.24–1.96] | <.001 |
| South Asian | 127 | 23.2 [19.7–26.8] | 2.16 [1.78–2.62] | <.001 |
| Chinese | 96 | 13.7 [9.6–17.8] | 1.18 [0.86–1.64] | .312 |
| Indian | 105 | 23.7 [19.6–27.7] | 2.22 [1.79–2.77] | <.001 |
| **Family and friends support** | | | | |
| Gets enough quality time with family | Pākehā | 2,224 | 73.7 [72.0–75.3] | ref |
| Asian | 1,293 | 68.3 [66.5–70.0] | 0.78 [0.69–0.88] | <.001 |
| East Asian | 831 | 65.2 [62.5–67.8] | 0.69 [0.60–0.79] | <.001 |
| South Asian | 441 | 75.6 [71.9–79.3] | 1.08 [0.87–1.35] | .485 |
| Chinese | 464 | 63.1 [59.9–66.3] | 0.63 [0.55–0.71] | <.001 |
| Indian | 362 | 75.6 [72.1–79.1] | 1.08 [0.87–1.35] | .471 |
| Family wants to know who student is with and where student is (usually or always) | Pākehā | 2,841 | 92.9 [91.5–94.4] | ref |
| Asian | 1,734 | 91.2 [89.5–92.9] | 0.81 [0.64–1.04] | .104 |
| East Asian | 1,133 | 89.2 [86.9–91.6] | 0.65 [0.49–0.86] | .005 |
| South Asian | 569 | 95.0 [93.4–96.6] | 1.51 [1.05–2.16] | .031 |
| Chinese | 641 | 87.6 [84.4–90.8] | 0.56 [0.39–0.80] | .003 |
| Indian | 465 | 95.0 [93.4–96.6] | 1.52 [1.04–2.21] | .036 |
| Has someone in family can talk about worries with | Pākehā | 2,382 | 78.1 [76.1–80.2] | ref |
| Asian | 1,348 | 72.0 [69.7–74.2] | 0.72 [0.60–0.86] | <.001 |
| East Asian | 896 | 71.4 [68.4–74.3] | 0.70 [0.58–0.85] | <.001 |
| South Asian | 432 | 73.5 [70.3–76.8] | 0.77 [0.61–0.97] | .032 |
| Chinese | 534 | 72.6 [69.1–76.2] | 0.74 [0.61–0.91] | .007 |
| Indian | 357 | 74.2 [70.8–77.5] | 0.79 [0.62–1.01] | .073 |
| Has at least one friend can talk about worries with | Pākehā | 2,602 | 85.5 [84.3–86.8] | ref |
| Asian | 1,612 | 84.7 [83.5–85.9] | 0.92 [0.81–1.05] | .232 |
| East Asian | 1,063 | 83.4 [81.9–85.0] | 0.82 [0.71–0.96] | .016 |
| South Asian | 525 | 88.0 [85.5–90.5] | 1.26 [0.98–1.62] | .083 |
| Chinese | 617 | 83.5 [80.4–86.6] | 0.83 [0.64–1.07] | .163 |
| Indian | 434 | 89.2 [86.9–91.6] | 1.41 [1.07–1.87] | .021 |
TABLE 3: Prevalence of family socioeconomic status, social support, safety, and healthcare experience indicators for Asian secondary school students (continued).

<table>
<thead>
<tr>
<th>School support and safety</th>
<th>n</th>
<th>% [95% CI]</th>
<th>AOR* [95% CI]</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teachers/tutors care about student</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>2,387</td>
<td>79.5 [77.0–81.9]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1,568</td>
<td>84.0 [81.4–86.6]</td>
<td>1.32 [1.11–1.57]</td>
<td>.003</td>
</tr>
<tr>
<td>East Asian</td>
<td>1,036</td>
<td>83.5 [80.2–86.7]</td>
<td>1.23 [0.99–1.53]</td>
<td>.074</td>
</tr>
<tr>
<td>South Asian</td>
<td>508</td>
<td>85.7 [81.8–89.5]</td>
<td>1.58 [1.14–2.20]</td>
<td>.010</td>
</tr>
<tr>
<td>Chinese</td>
<td>600</td>
<td>83.1 [79.4–86.8]</td>
<td>1.19 [0.90–1.58]</td>
<td>.224</td>
</tr>
<tr>
<td>Indian</td>
<td>416</td>
<td>86.4 [82.2–90.5]</td>
<td>1.68 [1.17–2.40]</td>
<td>.008</td>
</tr>
<tr>
<td>Feels like they are part of school</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>2,537</td>
<td>85.1 [82.6–87.5]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1,680</td>
<td>89.9 [87.1–92.7]</td>
<td>1.58 [1.24–2.01]</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>East Asian</td>
<td>1,125</td>
<td>90.2 [87.4–93.1]</td>
<td>1.62 [1.27–2.06]</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>South Asian</td>
<td>528</td>
<td>89.4 [85.7–93.0]</td>
<td>1.55 [1.03–2.32]</td>
<td>.042</td>
</tr>
<tr>
<td>Chinese</td>
<td>636</td>
<td>88.4 [85.6–91.2]</td>
<td>1.32 [1.02–1.71]</td>
<td>.039</td>
</tr>
<tr>
<td>Indian</td>
<td>429</td>
<td>89.7 [85.5–93.8]</td>
<td>1.60 [1.04–2.45]</td>
<td>.039</td>
</tr>
<tr>
<td>Teachers/tutors treat students fairly (most or all of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>2,224</td>
<td>73.5 [71.2–75.9]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1,342</td>
<td>70.1 [67.1–73.2]</td>
<td>0.82 [0.71–0.96]</td>
<td>.018</td>
</tr>
<tr>
<td>East Asian</td>
<td>875</td>
<td>68.5 [64.3–72.7]</td>
<td>0.74 [0.61–0.91]</td>
<td>.006</td>
</tr>
<tr>
<td>South Asian</td>
<td>442</td>
<td>73.5 [70.2–76.8]</td>
<td>1.01 [0.83–1.22]</td>
<td>.937</td>
</tr>
<tr>
<td>Chinese</td>
<td>500</td>
<td>67.4 [59.6–75.1]</td>
<td>0.70 [0.49–1.00]</td>
<td>.057</td>
</tr>
<tr>
<td>Indian</td>
<td>357</td>
<td>89.7 [78.5–77.1]</td>
<td>0.97 [0.78–1.21]</td>
<td>.781</td>
</tr>
<tr>
<td>Bullied at school weekly or more often in the past 12 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>200</td>
<td>6.3 [5.1–7.5]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>64</td>
<td>3.9 [2.7–5.0]</td>
<td>0.63 [0.44–0.90]</td>
<td>.014</td>
</tr>
<tr>
<td>East Asian</td>
<td>34</td>
<td>3.2 [2.1–4.3]</td>
<td>0.53 [0.35–0.79]</td>
<td>.004</td>
</tr>
<tr>
<td>South Asian</td>
<td>28</td>
<td>5.1 [3.5–6.8]</td>
<td>0.80 [0.55–1.17]</td>
<td>.265</td>
</tr>
<tr>
<td>Chinese</td>
<td>18</td>
<td>2.6 [1.0–4.2]</td>
<td>0.42 [0.23–0.78]</td>
<td>.009</td>
</tr>
<tr>
<td>Indian</td>
<td>22</td>
<td>5.1 [3.4–6.9]</td>
<td>0.81 [0.54–1.21]</td>
<td>.310</td>
</tr>
</tbody>
</table>

Other community support and safety

| Has an adult outside of family can talk about worries with                                  |       |                   |               |         |
| Pākehā                                                                                     | 1,411 | 49.3 [46.2–52.3]  | ref           |         |
| Asian                                                                                      | 738   | 43.3 [40.4–46.1]  | 0.79 [0.66–0.94] | .012    |
| East Asian                                                                                 | 463   | 40.1 [36.8–43.4]  | 0.69 [0.57–0.84] | <.001   |
| South Asian                                                                                | 267   | 51.1 [44.3–57.8]  | 1.08 [0.80–1.46] | .611    |
| Chinese                                                                                    | 263   | 38.7 [33.9–43.5]  | 0.66 [0.52–0.84] | .002    |
| Indian                                                                                    | 218   | 51.2 [44.3–58.1]  | 1.09 [0.80–1.49] | .602    |

| Feel safe in own neighbourhood (always)                                                    |       |                   |               |         |
| Pākehā                                                                                     | 1,853 | 61.3 [58.2–64.4]  | ref           |         |
| Asian                                                                                      | 1,015 | 54.4 [51.0–57.7]  | 0.74 [0.64–0.86] | <.001   |
| East Asian                                                                                 | 670   | 54.0 [49.3–58.7]  | 0.73 [0.63–0.86] | <.001   |
| South Asian                                                                                | 329   | 55.2 [50.8–59.6]  | 0.76 [0.60–0.96] | .027    |
| Chinese                                                                                    | 402   | 55.2 [47.9–62.5]  | 0.77 [0.60–0.98] | .038    |
| Indian                                                                                    | 267   | 55.1 [50.0–60.3]  | 0.76 [0.58–0.98] | .040    |
Table 3: Prevalence of family socioeconomic status, social support, safety, and healthcare experience indicators for Asian secondary school students (continued).

<table>
<thead>
<tr>
<th>Healthcare experience</th>
<th>n</th>
<th>% [95% CI]</th>
<th>AOR^ [95% CI]</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Forgone healthcare in last 12 months</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>521</td>
<td>17.6 [16.4–18.8]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>370</td>
<td>20.3 [18.1–22.4]</td>
<td>1.18 [1.04–1.33]</td>
<td>.014</td>
</tr>
<tr>
<td>South Asian</td>
<td>106</td>
<td>18.0 [15.0–20.9]</td>
<td>1.05 [0.86–1.28]</td>
<td>.640</td>
</tr>
<tr>
<td>Chinese</td>
<td>124</td>
<td>18.1 [15.3–20.9]</td>
<td>1.01 [0.85–1.19]</td>
<td>.944</td>
</tr>
<tr>
<td>Indian</td>
<td>85</td>
<td>17.7 [14.6–20.9]</td>
<td>1.03 [0.82–1.29]</td>
<td>.788</td>
</tr>
<tr>
<td><strong>Treated unfairly by health provider due to ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>- Yes (cf No)</strong> ¥</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>79</td>
<td>3.0 [2.3–3.7]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>82</td>
<td>5.9 [4.5–7.3]</td>
<td>2.08 [1.52–2.84]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>East Asian</td>
<td>52</td>
<td>5.6 [4.0–7.2]</td>
<td>2.03 [1.40–2.94]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>South Asian</td>
<td>28</td>
<td>6.2 [4.3–8.2]</td>
<td>2.06 [1.50–2.84]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Chinese</td>
<td>29</td>
<td>5.3 [3.2–7.4]</td>
<td>1.94 [1.15–3.28]</td>
<td>.018</td>
</tr>
<tr>
<td>Indian</td>
<td>22</td>
<td>5.9 [3.8–7.9]</td>
<td>1.92 [1.33–2.79]</td>
<td>.001</td>
</tr>
<tr>
<td><strong>- Yes or unsure / don’t know (cf No)</strong> ¥</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā</td>
<td>302</td>
<td>10.6 [9.2–12.0]</td>
<td>ref</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>343</td>
<td>20.1 [16.8–23.3]</td>
<td>2.17 [1.76–2.60]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>East Asian</td>
<td>221</td>
<td>20.0 [15.9–24.0]</td>
<td>2.19 [1.68–2.85]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>South Asian</td>
<td>111</td>
<td>19.2 [14.8–23.5]</td>
<td>1.98 [1.49–2.64]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Chinese</td>
<td>125</td>
<td>19.3 [14.5–24.2]</td>
<td>2.12 [1.52–2.95]</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Indian</td>
<td>89</td>
<td>18.7 [14.3–23.1]</td>
<td>1.93 [1.42–2.63]</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

The numbers presented (n and N) are based on the raw data of the number of survey participants. Percentages and AORs have been adjusted to account for the unequal probability of each individual being invited to participate in the survey.

^Adjusted odds ratio, controlling for age and sex; ¥Parents often worry about money for food OR student slept elsewhere than own bed because can’t afford house or not enough space; ¥Yes compared to no (unsure / don’t know responses excluded); ¥Unsure / don’t know compared to no (yes responses excluded)
Table 4: Associations between independent variables (socioeconomic status, social support, safety and healthcare experience indicators) and forgone healthcare (dependent variable).

<table>
<thead>
<tr>
<th></th>
<th>AOR[^] [95%CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>East Asian subgroup</strong></td>
<td></td>
</tr>
<tr>
<td>School decile - low (ref: high)</td>
<td>2.17 [1.07–4.38]</td>
</tr>
<tr>
<td>- med (ref: high)</td>
<td>1.11 [0.78–1.59]</td>
</tr>
<tr>
<td>Neighbourhood dep - high (ref: low)</td>
<td>0.75 [0.34–1.69]</td>
</tr>
<tr>
<td>- med (ref: low)</td>
<td>1.00 [0.67–1.50]</td>
</tr>
<tr>
<td>Low family SES</td>
<td>1.57 [1.07–2.30]</td>
</tr>
<tr>
<td>Has friend can talk about worries with</td>
<td>1.08 [0.60–1.94]</td>
</tr>
<tr>
<td>Gets enough quality time with family</td>
<td>0.60 [0.38–0.94]</td>
</tr>
<tr>
<td>Has someone in family can talk about worries with</td>
<td>0.41 [0.24–0.71]</td>
</tr>
<tr>
<td>Feel like are part of school</td>
<td>0.82 [0.50–1.35]</td>
</tr>
<tr>
<td>Teachers/tutors treat students fairly (most or all the time)</td>
<td>0.60 [0.43–0.85]</td>
</tr>
<tr>
<td>Bullied at school weekly or more often in the past 12 months</td>
<td>2.76 [1.25–6.11]</td>
</tr>
<tr>
<td>Feel safe in neighbourhood (always)</td>
<td>0.63 [0.40–1.01]</td>
</tr>
<tr>
<td>Has an adult outside of family can talk about worries with</td>
<td>1.14 [0.74–1.77]</td>
</tr>
<tr>
<td>Ever treated unfairly by healthcare provider due to ethnicity - yes (ref: no)</td>
<td>3.50 [1.76–6.96]</td>
</tr>
<tr>
<td>- don’t’ know / unsure (ref: no)</td>
<td>1.52 [1.06–2.19]</td>
</tr>
<tr>
<td><strong>South Asian subgroup</strong></td>
<td></td>
</tr>
<tr>
<td>School decile - low (ref: high)</td>
<td>1.29 [0.56–2.99]</td>
</tr>
<tr>
<td>- med (ref: high)</td>
<td>1.02 [0.56–1.86]</td>
</tr>
<tr>
<td>Neighbourhood dep - high (ref: low)</td>
<td>0.64 [0.31–1.32]</td>
</tr>
<tr>
<td>- med (ref: low)</td>
<td>0.66 [0.25–1.73]</td>
</tr>
<tr>
<td>Low family SES</td>
<td>1.60 [0.84–3.04]</td>
</tr>
<tr>
<td>Has friend can talk about worries with</td>
<td>0.83 [0.39–1.76]</td>
</tr>
<tr>
<td>Gets enough quality time with family</td>
<td>0.84 [0.52–1.35]</td>
</tr>
<tr>
<td>Has someone in family can talk about worries with</td>
<td>0.38 [0.16–0.87]</td>
</tr>
<tr>
<td>Feel like are part of school</td>
<td>0.61 [0.32–1.17]</td>
</tr>
<tr>
<td>Teachers/tutors treat students fairly (most or all the time)</td>
<td>0.59 [0.36–0.98]</td>
</tr>
<tr>
<td>Bullied at school weekly or more often in the past 12 months</td>
<td>1.53 [0.58–4.01]</td>
</tr>
<tr>
<td>Feel safe in neighbourhood (always)</td>
<td>0.43 [0.28–0.66]</td>
</tr>
<tr>
<td>Has an adult outside of family can talk about worries with</td>
<td>1.06 [0.61–1.84]</td>
</tr>
<tr>
<td>Ever treated unfairly by healthcare provider due to ethnicity - yes (ref: no)</td>
<td>6.99 [2.20–22.15]</td>
</tr>
<tr>
<td>- don’t’ know / unsure (ref: no)</td>
<td>1.64 [0.81–3.31]</td>
</tr>
</tbody>
</table>

[^]Adjusted for age and sex. Bolded AORs are borderline or statistically significant at the \( p < .05 \) level and the CIs do not cross 1. Nagelkerke \( R^2 = 0.13 \) for East Asian, \( R^2 = 0.15 \) for South Asian.

The data reported has been weighted to adjust for the unequal probability of each individual being invited to participate in the survey.
When all other indicators are constant, the odds of having forgone healthcare are higher for East Asian students who were socioeconomically disadvantaged, who felt less connected with their family, who had experienced bullying in school and who were unfairly treated by a teacher or a health professional (Table 4). The odds are higher for South Asian students who didn’t have someone in the family to talk about their worries with, who didn’t always feel safe in their neighbourhood and who were treated unfairly by a teacher or a health professional.

The complete analyses (see Supplementary Table) found that, except for the friend support model for East Asian students, the explanatory power of each of the family SES, school support and safety, community support and safety, and health service discrimination models were significantly greater than the nested model.

Discussion
In this population-based survey of New Zealand secondary school students, we found disparities in family SES, social support, safety, healthcare experience and forgone healthcare between East Asian, South Asian, Chinese and Indian students compared to Pākehā students. These disparities varied across the Asian ethnic groups. For example, South Asian, East Asian and Indian students were more likely than Pākehā to experience household poverty, a difference not evident for Chinese students. Furthermore, some differences did not appear when the aggregated Asian group was considered.

One in five Asian students, and East Asian especially, had forgone healthcare. Several indicators of SES and perceived support and safety were uniquely associated with forgone healthcare. Ethnic discrimination from health professionals, having someone in the family to talk about worries with, and teachers treating students fairly all had significant unique effects on forgone healthcare for both East Asian and South Asian students. However, other unique associations between social support and community SES indicators and forgone healthcare varied between East Asians and South Asians: lower school decile, lower family SES, less quality time with family and being bullied at school were significantly associated with forgone healthcare for East Asian students, and low perceived neighbourhood safety was a significant predictor for South Asian students.

The Youth19 survey used rigorous sampling methods and the questions were self-administered and anonymous. There are, however, some limitations. The findings may not apply to adolescents who are not in school. Additionally, only schools in upper North Island were included. Although almost half of New Zealand’s secondary school students live in this region, Asian students from other regions may face different challenges. The cross-sectional nature of the analyses limits inferences about the direction of causal associations; however, risk and protective factors identified in these models provide a useful basis for future causal analysis. The measurement of family SES of adolescents is known to be difficult, particularly when collecting data from young people themselves.

We did not explore interaction effects by gender or age because the study’s primary focus was to first examine the impact of reporting data at the Asian aggregate level compared to the ethnic subgroup level, while controlling for gender and age. We also did not explore interaction effects by generation of migration. The healthy migrant effect is a well-recognised phenomenon, although this positive effect on health dissipates as length of residence in the host country increases. The next step is to explore variations between the Asian ethnic groups by gender, age and generation of migration. Lastly, barriers to accessing healthcare for international students living away from their families may be different to those for other students.

Despite these limitations, this study provides a contemporary profile on SES, perceived social support and safety, healthcare experience and forgone healthcare for a large sample of Asian young people and disaggregates data by ethnic subgroups.

Collectively, these findings show that using aggregated Asian ethnicity data in policy and planning is a problem. Studies on adult populations have also shown that reporting statistics for an aggregated Asian
ethnic group masks meaningful differences between Asian subgroups.\textsuperscript{17,31,32} Previous studies have also shown that socioeconomically disadvantaged young people are more likely to report poorer wellbeing and health problems\textsuperscript{33–35} and forgone healthcare.\textsuperscript{9} Asian Americans are shown to have a similar relationship between SES and health status when measured as an aggregate group compared to Whites.\textsuperscript{31} However, this is different when specific Asian American ethnic groups are examined. Family poverty status has been found to be independently associated with low healthcare access, with significant heterogeneity found among Asian children.\textsuperscript{9} Similarly, a study of adolescents in the US found 54\% of those who reported “hard times” also reported forgone healthcare.\textsuperscript{36}

In New Zealand, secondary school students who forgo healthcare are at increased risk of physical and mental health problems.\textsuperscript{24} Rangatahi M\={a}ori (27\%), Pasifika (25\%), East Asian (21\%) and South Asian (18\%) youth experience high levels of forgone healthcare compared to P\={a}keh\={a} (16\%).\textsuperscript{21} While M\={a}ori and Pasifika youth are not the focus of this paper, these findings should be seen within the broader context of New Zealand’s pattern of inequity and discrimination when compared to P\={a}keh\={a}/New Zealand European students.

Experiences of discrimination and racism in healthcare cause poorer health outcomes, reduced access to healthcare and ethnic health inequities, both in New Zealand and internationally.\textsuperscript{20,37,38} The manifestation of structural discrimination through the often implicit and unspoken biases of health practitioners results in health disparities for Asian New Zealanders.\textsuperscript{39} The impact of racism on mental health among Asian communities in New Zealand was recently highlighted as a concern by the Suicide Mortality Review Committee.\textsuperscript{40}

Strengthening social support for young people in community settings and developing healthy supportive relationships between peers, and between teachers and students, will likely reduce forgone healthcare and improve health outcomes.\textsuperscript{41} The simultaneous delivery of interventions at the health service level (eg, enhanced cultural competency training for health providers) is also important. Co-designing interventions with young people from Asian subgroups would help mitigate risks associated with experiences of discrimination and racism.

**Conclusions**

SES, social support and safety, and healthcare use are affected by the ethnic composition of the Asian youth population. We highlight the importance of disaggregating youth data for the overall Asian group into East Asian and South Asian, or ideally at the specific Asian ethnicity level, to reveal disparities in risk and protective factors, gain a better understanding of the relationships between ethnicity and health and inform targeted interventions.
## Supplementary Table: Associations between socioeconomic status, social support, safety and healthcare experience indicators and foregone healthcare.

<table>
<thead>
<tr>
<th></th>
<th>AOR^ [95%CI]</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>Model 4</th>
<th>Model 5</th>
<th>Model 6</th>
<th>Model 7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>East Asian subgroup</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- med (ref: high)</td>
<td>1.39 [1.03–1.87]</td>
<td>1.39 [0.97–2.00]</td>
<td>1.39 [0.98–1.97]</td>
<td>1.36 [0.90–2.04]</td>
<td>1.25 [0.84–1.85]</td>
<td>1.12 [0.79–1.59]</td>
<td>1.11 [0.78–1.59]</td>
<td></td>
</tr>
<tr>
<td>Neighbourhood dep - high (ref: low)</td>
<td>0.93 [0.62–1.41]</td>
<td>0.86 [0.55–1.35]</td>
<td>0.85 [0.54–1.34]</td>
<td>0.88 [0.53–1.46]</td>
<td>0.96 [0.59–1.55]</td>
<td>0.68 [0.31–1.51]</td>
<td>0.75 [0.34–1.69]</td>
<td></td>
</tr>
<tr>
<td>- med (ref: low)</td>
<td>1.37 [0.99–1.91]</td>
<td>1.27 [0.92–1.74]</td>
<td>1.26 [0.92–1.71]</td>
<td>1.17 [0.84–1.64]</td>
<td>1.20 [0.86–1.68]</td>
<td>1.01 [0.70–1.45]</td>
<td>1.00 [0.67–1.50]</td>
<td></td>
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<tr>
<td>Low family SES</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has friend can talk about worries with</td>
<td>0.80 [0.42–1.54]</td>
<td>1.03 [0.53–2.01]</td>
<td>1.15 [0.71–1.86]</td>
<td>1.02 [0.55–1.89]</td>
<td>1.08 [0.60–1.94]</td>
<td></td>
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</tr>
<tr>
<td>Gets enough quality time with family</td>
<td>0.50 [0.34–0.75]</td>
<td>0.53 [0.34–0.81]</td>
<td>0.51 [0.35–0.75]</td>
<td>0.60 [0.38–0.94]</td>
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<tr>
<td>Has someone in family can talk about worries with</td>
<td>0.49 [0.32–0.77]</td>
<td>0.52 [0.35–0.79]</td>
<td>0.46 [0.29–0.73]</td>
<td>0.41 [0.24–0.71]</td>
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<tr>
<td>Feel like are part of school</td>
<td>0.71 [0.46–1.08]</td>
<td>0.82 [0.48–1.40]</td>
<td>0.82 [0.50–1.35]</td>
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<tr>
<td>Teachers/tutors treat students fairly (most or all the time)</td>
<td>0.51 [0.35–0.75]</td>
<td>0.56 [0.40–0.80]</td>
<td>0.60 [0.43–0.85]</td>
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<tr>
<td>Bullied at school weekly or more often in the past 12 months</td>
<td>2.88 [1.40–5.94]</td>
<td>3.06 [1.43–6.55]</td>
<td>2.76 [1.25–6.11]</td>
<td></td>
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<tr>
<td>Feel safe in neighbourhood (always)</td>
<td>0.60 [0.40–0.91]</td>
<td>0.63 [0.40–1.01]</td>
<td></td>
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<tr>
<td>Has an adult outside of family can talk about worries with</td>
<td>1.21 [0.79–1.85]</td>
<td>1.14 [0.74–1.77]</td>
<td></td>
<td></td>
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<tr>
<td>Ever treated unfairly by healthcare provider due to ethnicity</td>
<td>3.50 [1.76–6.96]</td>
<td>1.52 [1.06–2.19]</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>- don’t know / unsure (ref: no)</td>
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</table>
**Supplementary Table:** Associations between socioeconomic status, social support, safety and healthcare experience indicators and forgone healthcare (continued).

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<thead>
<tr>
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<th>AOR^ [95%CI]</th>
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<tbody>
<tr>
<td></td>
<td>Model 1</td>
</tr>
<tr>
<td><strong>South Asian subgroup</strong></td>
<td></td>
</tr>
<tr>
<td>School decile - low (ref: high)</td>
<td>1.84 [0.87–3.90]</td>
</tr>
<tr>
<td>- med (ref: high)</td>
<td>1.27 [0.64–2.52]</td>
</tr>
<tr>
<td>Neighbourhood dep - high (ref: low)</td>
<td>0.85 [0.38–1.86]</td>
</tr>
<tr>
<td>- med (ref: low)</td>
<td>1.22 [0.51–2.91]</td>
</tr>
<tr>
<td>Has friend can talk about worries with</td>
<td>0.47 [0.26–0.85]</td>
</tr>
<tr>
<td>Gets enough quality time with family</td>
<td>0.66 [0.41–1.06]</td>
</tr>
<tr>
<td>Has someone in family can talk about worries with</td>
<td></td>
</tr>
</tbody>
</table>
Supplementary Table: Associations between socioeconomic status, social support, safety and healthcare experience indicators and forgone healthcare (continued).

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<tr>
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<td>Feel safe in neighbourhood (always)</td>
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<tr>
<td>Has an adult outside of family can talk about worries with</td>
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<tr>
<td>-yes (ref:no)</td>
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<tr>
<td>-don’t know / unsure (ref: no)</td>
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</tbody>
</table>

^Adjusted for age and sex
Bolded AORs are borderline or statistically significant at the \( p < .05 \) level and the CIs do not cross 1.

The data reported has been weighted to adjust for the unequal probability of each individual being invited to participate in the survey.

Comparing model fit (East Asian): Model 2 vs 1: \( \chi^2(2) = 86.1, p < .001 \); Model 3 vs 2: \( \chi^2(1) = 0.8, p = .37 \); Model 4 vs 3: \( \chi^2(3) = 46.7, p < .001 \); Model 5 vs 4: \( \chi^2(4) = 48.0, p < .001 \); Model 6 vs 5: \( \chi^2(2) = 79.5, p < .001 \); Model 7 vs 6: \( \chi^2(2) = 27.8, p < .001 \).

Nagelkerke \( R^2 \) (East Asian): Model 1 = 0.03, Model 2 = 0.05, Model 3 = 0.05, Model 4 = 0.09, Model 5 = 0.11, Model 6 = 0.12, Model 7 = 0.13.

Comparing model fit (South Asian): Model 2 vs 1: \( \chi^2(2) = 19.5, p < .001 \); Model 3 vs 2: \( \chi^2(1) = 6.5, p = .01 \); Model 4 vs 3: \( \chi^2(3) = 30.1, p < .001 \); Model 5 vs 4: \( \chi^2(4) = 16.4, p = .002 \); Model 6 vs 5: \( \chi^2(2) = 36.9, p < .001 \); Model 7 vs 6: \( \chi^2(2) = 15.5, p < .001 \).

Nagelkerke \( R^2 \) (South Asian): Model 1 = 0.02, Model 2 = 0.04, Model 3 = 0.05, Model 4 = 0.10, Model 5 = 0.11, Model 6 = 0.12, Model 7 = 0.15.
Competing interests:
Nil.

Acknowledgements:
The Youth19 Rangatahi Smart Survey was funded by two project grants awarded by the Health Research Council of New Zealand: HRC 17/315 and HRC 18/473.

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REFERENCES


Choosing Wisely: the lack of validity of ultrasound scans in the investigation of shoulder instability

Callum Oorschot, Khalid Mohammed, Michael Austen, Emma O’Loughlin

ABSTRACT

AIM: To test the clinical validity and financial implications of the proposed Choosing Wisely statement: “Using ultrasound as a screening test for shoulder instability is inappropriate in people under 30 years of age, unless there is clinical suspicion of a rotator cuff tear.”

METHOD: A retrospective chart review from a specialist shoulder surgeon’s practice over a two-year period recorded 124 patients under the age of 30 referred with shoulder instability. Of these, forty-one had already had ultrasound scans performed prior to specialist review. The scan results and patient files were reviewed to determine the reported findings on the scans and whether these findings were clinically relevant to diagnosis and decision-making. Comparison was made with subsequent MRI scan results. The data, obtained from the Accident Compensation Corporation (ACC), recorded the number of cases and costs incurred for ultrasound scans of the shoulder in patients under 30 years old over a 10-year period.

RESULTS: There were no cases where the ultrasound scan was considered useful in decision-making. No patient had a full thickness rotator cuff tear. Thirty-nine of the 41 patients subsequently had MRI scans. The cost to the ACC for funding ultrasound scans in patients under 30 has increased over the last decade and exceeded one million dollars in the 2020/2021 financial year. In addition, patients pay a surcharge for this test.

CONCLUSION: The proposed Choosing Wisely statement is valid. This evidence supports that ultrasound is an unnecessary investigation for patients with shoulder instability unless there is clinical suspicion of a rotator cuff tear. Ultrasound also incurs costs to the insurer (ACC) and the patient. We recommend x-rays and, if further imaging is indicated, High Tech Imaging with MRI and sometimes CT scans in these patients.

Choosing Wisely is an international initiative with the intention of helping clinicians choose care that is “supported by evidence, not duplicative of other tests or procedures already received, free from harm and truly necessary.” The origin of the Choosing Wisely movement is the publication of Dr Howard Brody’s Medicine’s Ethical Responsibility for Health Care Reform – The Top Five List in the New England Journal of Medicine in 2010. The Choosing Wisely initiative has been implemented in the USA, Canada, the United Kingdom, New Zealand, Australia and parts of Europe. In New Zealand, there has been support from many organisations, including the New Zealand Medical Association, Medical Council of New Zealand, Association of Salaried Medical Specialists, New Zealand Medical Students’ Association, Cochrane New Zealand, New Zealand College of Midwives, PHARMAC, the Health Quality & Safety Commission, The Ministry of Health, Pacific Radiology and the Council of Medical Colleges.

The New Zealand Orthopaedic Association is developing Choosing Wisely recommendations in partnership with the Accident Compensation Corporation (ACC). One of their proposed statements is: “Using ultrasound as a screening test for shoulder..."
instability is inappropriate in people under 30 years of age, unless there is clinical suspicion of a rotator cuff tear. Should instability may involve complete dislocation of the glenohumeral joint or subluxation (partial dislocation) of the glenohumeral joint.

Although an ultrasound scan is not physically harmful, the authors feel it is unnecessary and unlikely to negate the need to perform the more commonly indicated MRI evaluation of the unstable shoulder. It also submits the patient to an unnecessary financial expense (a patient surcharge applies).

The purpose of this paper is to see whether there is clinical and financial evidence to support the proposed Choosing Wisely statement. This research is a collaboration between clinicians from the New Zealand Orthopaedic Association and the ACC, and we provide ACC data on the costs of this procedure (when funded by the ACC) in patients under the age of 30 over a 10-year period.

Materials and methods

This study was performed as a retrospective chart review of patients at the senior clinical author’s orthopaedic shoulder practice in Christchurch in 2019 and 2020. The inclusion criteria were any patient who was referred with a clinical suspicion of shoulder instability and any patient who was operated on for shoulder instability in 2019 and 2020. Exclusion criteria were any patient aged 30 years or older at the time of referral with previous instability surgery on the shoulder of interest or clinically determined not to be an instability presentation or not clinically reviewed at the practice during the designated period (Figure 1). An audit of each patient’s notes was then undertaken with the senior clinical author.

The relevant data from the patient management software yielded 194 individual patients. Seventy individual patients were excluded because they met at least one of the exclusion criteria. One hundred and twenty-four patients were eligible to be reviewed. The clinical records and radiology referrals of these patients were analysed. Forty-one patients were found to have undergone an ultrasound to investigate their shoulder instability prior to referral to a specialist shoulder practice.

Results

Of the 124 patients that were eligible for analysis, 41 were found to have undergone an ultrasound scan in the workup for their shoulder instability (33%). Twenty-three were referred for ultrasound by a physiotherapist (56%), 15 were referred by a general practitioner (37%) and three were referred by sports physicians (7%). One patient had two scans ordered, one by a physiotherapist and one be a general practitioner (Figure 2).

Regarding the ultrasound findings, 14/41 (34%) reported no abnormality and 27/41 (66%) had one or more abnormalities reported. The abnormalities reported in these 27 ultrasound scans are summarised in Table 1.

"Other" reported findings included joint effusion (3), suggestion of a Hill-Sachs lesion (2), dynamic subluxation (2) and fatty atrophy of teres minor (1).

In no case did ultrasound scan definitely benefit a clinical diagnosis of instability. Nor in any case did ultrasound definitively demonstrate the significant tissue pathology of instability or assist in treatment decision-making. Ultrasound reported partial
**Figure 1:** Flow chart showing screening process, eligibility and included results.

- **Identification:**
  - Patient records with clinical suspicion of shoulder instability & surgical management of shoulder instability
  - 194 Records Identified

- **Screening:**
  - Patient records screened for eligibility N= 194
  - Records excluded:
    - >30 years old
    - Not clinically reviewed within time period
    - Previous instability surgery
    - Clinically determined no instability

- **Eligibility:**
  - Patient records screened for eligibility N = 124

- **Included:**
  - No ultrasound performed N=83
  - Patient Records included in full analysis
  - N = 41
Table 1: Ultrasound (USS) reported abnormalities.

<table>
<thead>
<tr>
<th>Abnormality</th>
<th>Bursitis/bursal thickening</th>
<th>Impingement/ bursal bunching</th>
<th>Partial thickness rotator cuff tear</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of USS containing this finding</td>
<td>8</td>
<td>10</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>% of USS containing this finding</td>
<td>20%</td>
<td>24%</td>
<td>10%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Figure 2: Referrers for shoulder ultrasound scans.
thickness rotator cuff tear in one case with pain symptoms and some resolution of instability symptoms, which may have been relevant, although an MRI scan was still performed.

Reviewing the ultrasound-reported abnormalities, bursitis, bursal thickening, bursal bunching and impingement are not of clinical decision-making relevance for the management of a dislocating or subluxing unstable shoulder in a young adult. A Hill-Sachs bony lesion of the humeral head is better appreciated on plain x-ray, MRI or CT scan. Dynamic subluxation of the shoulder is not commonly diagnosed with ultrasound scan by clinicians, being a clinical diagnosis from patient assessment. Teres minor atrophy is better appreciated on MRI and the case reporting this on ultrasound scan was found to be a false-positive report when compared to the subsequent MRI scan.

Of the 124 patients analysed, 111 (90%) had High Tech Imaging performed on their shoulder with an MRI scan. MRI or MRI arthrography was performed on 39 (95%) of the 41 patients who had previously undergone an ultrasound scan. The number of respective abnormalities detected across the MRI results of those patients who had previously had an ultrasound are summarised in Table 2.

We used the High Tech Imaging results to identify several false-positive and false-negative findings in the ultrasound reports. Two of the four partial thickness rotator cuff tears on ultrasound were false-positive results (i.e., not present on MRI). There was one partial thickness cuff tear missed on ultrasound (false-negative). Three of eight ultrasound findings of bursitis were false-positives when compared to MRI.

There was one case where bursitis was not reported on ultrasound. The single case finding of fatty atrophy to teres minor on ultrasound was deemed to be a false-positive when compared to the assessment on High Tech Imaging.

The ACC-funded U30 payments for patients under 30 years of age reports a cost to the ACC over the decade of $8,829,650 excluding GST (Table 3).

**Discussion**

The diagnosis of shoulder instability is a clinical diagnosis that usually involves a history of dislocation or partial dislocation (subluxation). The commonly injured structures in patients under 30 years of

<table>
<thead>
<tr>
<th>Abnormality – number reported (%)</th>
<th>Probable abnormality – number reported (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Labral tear</td>
<td>26 (67%)</td>
</tr>
<tr>
<td>Bony Bankart</td>
<td>12 (31%)</td>
</tr>
<tr>
<td>Chondral defect</td>
<td>14 (36%)</td>
</tr>
<tr>
<td>Hill-Sachs lesion</td>
<td>12 (31%)</td>
</tr>
<tr>
<td>Rotator cuff tear (partial thickness)</td>
<td>3 (8%)</td>
</tr>
<tr>
<td>Bursitis</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>Cyst</td>
<td>3 (8%)</td>
</tr>
<tr>
<td>Tendinosis</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Synovitis</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>AC arthropathy</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>
Table 3: Shoulder ultrasound scans in patients under 30 years of age funded by ACC using U30 code, by financial year.

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</thead>
<tbody>
<tr>
<td>Number of payments</td>
<td>3,951</td>
<td>4,523</td>
<td>4,854</td>
<td>5,326</td>
<td>5,486</td>
<td>5,657</td>
<td>5,648</td>
<td>5,677</td>
<td>4,989</td>
<td>6,330</td>
<td>52,441</td>
</tr>
<tr>
<td>Number of claims paid</td>
<td>3,861</td>
<td>4,384</td>
<td>4,761</td>
<td>5,201</td>
<td>5,363</td>
<td>5,521</td>
<td>5,498</td>
<td>5,556</td>
<td>4,876</td>
<td>6,185</td>
<td>50,343</td>
</tr>
<tr>
<td>Spend (excluding GST)</td>
<td>$645,198</td>
<td>$740,284</td>
<td>$798,628</td>
<td>$887,520</td>
<td>$913,091</td>
<td>$953,945</td>
<td>$958,756</td>
<td>$975,169</td>
<td>$860,351</td>
<td>$1,096,708</td>
<td>$8,829,650</td>
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<tr>
<td>Percent of total spend</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>10%</td>
<td>9%</td>
<td>10%</td>
<td>11%</td>
</tr>
</tbody>
</table>
age include bone (the glenoid rim and humeral head) and the labrum. In some cases, the capsule may tear at its humeral insertion. These lesions, known as “HAGL lesions” (Humeral Avulsion of Glenohumeral Ligament), are relevant when planning treatment. They are examined with MRI and sometimes CT scans. Ultrasound is not a useful modality to examine the gleno-humeral bone contours or the labrum and capsule. We agree with the opinion of Porcellini et al, that “The diagnosis of shoulder instability involves a workup that begins with plain x-rays and is completed with magnetic resonance imaging.”

Ultrasound scan is a useful study to examine the rotator cuff for rotator cuff tears. However, in a child, adolescent or young adult with shoulder instability, injury to the intraarticular structures have significance in decision-making and these are best examined with MRI scans, and sometimes CT, for more detailed examination of bony injury. The rotator cuff may also be evaluated by MRI scans.

Rotator cuff tears are an uncommon sequelae of shoulder instability in children, adolescents and young adults. Shoulder instability is a phenomenon that has a bimodal age distribution, with peaks of incidence in both the young and the elderly. Tearing of the rotator cuff following traumatic gleno-humeral dislocation is more commonly seen in the older cohort of patients. In a study of 3,633 shoulder dislocations, Robinson found 10% of patients to have a concomitant rotator cuff tear. The mean age of those with a tear was 69 years. The mechanism of injury was a low-energy fall in 87% of those who suffered a tear and sports injury in only 2%.

In an analysis of 167 first-time traumatic anterior shoulder dislocations, Berbig et al found 53 full thickness rotator cuff tears (32%). Only one such tear was found across 66 dislocations in those aged 10–49 years in the cohort, an incidence of 1.5% in this age group. The remaining 52 full-thickness tears occurred across 101 dislocations in those aged 50–99, an incidence of 51% in this older age group.

In New Zealand, patients with an injury covered by the ACC may have their associated imaging paid for by the ACC under the Cost of Treatment Regulations. In some instances, including shoulder ultrasound scans, the patient also pays a surcharge. The imaging is used by clinicians for diagnosis and treatment decision-making. Appropriate imaging and their reports also play a significant role in whether people who have an accident can obtain further entitlement from ACC.

Shoulder ultrasound scans may be obtained through the ACC service codes U30 (ultrasound shoulder) or U31 (ultrasound musculoskeletal). The majority of shoulder ultrasound scans are billed to the ACC under the U30 code. Very few are billed to the ACC under the U31 code. Not all of these shoulder ultrasound scans will have been performed for instability. Apart from instability, other shoulder injuries seen in this age group include fractures and acromioclavicular joint injuries. X-rays are more common and appropriate initial investigations for these injuries. Shoulder symptoms not caused by accident are not covered for payment of investigations by the ACC.

We obtained ACC data for 10 consecutive financial years: 1 July 2011 to 30 June 2021. During this time, the number of shoulder ultrasound scans funded by the ACC in people under the age of 30 rose steadily. The number of shoulder ultrasound scans increased from 3,951 in 2011/12 to 6,330 in 2020/21. The annual cost over this period increased from $645,198 to $1,096,708. The cost of performing shoulder ultrasound scans in people under the age of 30 consistently represented around 10% of the total ACC spend on these scans. In Christchurch in 2021, the cost to private clients was approximately $295 and the surcharge for ACC patients was $75.

Conclusions

This review supports the Choosing Wisely statement that “Using ultrasound as a screening test for shoulder instability is inappropriate in people under 30 years of age, unless there is clinical suspicion of a rotator cuff tear.” An audit of a specialist shoulder surgeon’s practice revealed that approximately one third of patients under 30 referred to the practice with shoulder instability had already had a shoulder ultrasound scan. None of these ultrasound scans helped diagnosis or treatment decisions. The vast majority of these patients then went on to receive High Tech Imaging. The ACC...
data demonstrate that an increasing number of ultrasound scans are being performed in this age group, now at a cost of over a million dollars a year to the ACC. Additionally, there is a surcharge to each patient.

If further imaging beyond plain x-ray is required for decision-making or treatment in patients with shoulder instability, we recommend performing MRI scans, and in some cases CT scans.
Competing interests:
Nil.

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Review of taste and taste disturbance in COVID-19 patients

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ABSTRACT
Severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) is responsible for the coronavirus disease 2019 (COVID-19) pandemic that has become a significant global public health concern. The virus gains entry to cells via angiotensin-converting enzyme-2 (ACE2) receptors, which have been found to be the functional receptor for SARS-CoV-2 infection. High expression of ACE2 is found in type II alveolar cells, macrophages, bronchial and tracheal epithelial cells and in the oral cavity, particularly on the tongue. Taste disturbance is one of the early symptoms of COVID-19, suggesting that taste cells in taste buds are vulnerable to SARS-CoV-2 infection. Taste is modulated by hormones that are regulated in the renin-angiotensin-aldosterone system. Hypothetical causes of taste disturbance by SARS-CoV-2 may be due to direct cell and/or neuronal injuries, inflammatory responses and dysregulation of ACE2.

Coronavirus disease 2019 (COVID-19) is an infectious disease caused by severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), which was reported by the World Health Organization (WHO) on 31 December 2019. The exact route of transmission is not yet fully solved. It is thought to be via respiratory droplets, similar to the spread of influenza virus. Besides respiratory droplets, SARS-CoV-2 RNA can be found in the blood and stool specimens and have been found to contaminate objects and surfaces such as plastic and stainless steel, copper and cardboard for more than three days.1,2 Fomite transmission is likely to be a further mode of transmission for SARS-CoV-2.3 However, vertical transmission (transplacental transmission and breast milk) and faecal–oral (or faecal-aerosol) of SARS-CoV-2 rarely occurs.4 The spectrum of the illness of COVID-19 ranges from asymptomatic to critical (respiratory failure and/or multiorgan dysfunction); fortunately, most infections are not severe.5

How does SARS-CoV-2 enter cells?
Angiotensin-converting enzyme-2 (ACE2) is well known to be the receptor responsible for allowing SARS-CoV-2 to enter cells.6 Once the viral spike protein binds to ACE2, it is primed by the transmembrane protease serine 2 (TMPRSS2) of host cells, thereby facilitating viral entry. Organs with high numbers of cells expressing ACE2 and TMPRSS2 are considered to be potentially high-risk sites for initial SARS-CoV-2 infection.7,8 High expression of ACE2 and TMPRSS2 proteins are found in the tongue, hard palate, nose, larynx and hypopharynx, trachea, oesophagus and lung.9 ACE2 is highly expressed in the oral cavity, with the majority (96%) of the ACE2-positive cells being found in tongue epithelium.9

Taste and COVID-19
Patients with COVID-19 have reported lack of taste (ageusia) and decreased taste (hypogeusia) as well as taste disturbance with bitter, sour or metallic sensations on the tongue.10,11 Reports have confirmed that taste disturbance/loss is an early symptom of subclinical SARS-CoV-2 infection.10 An Italian cross-section study found that 33.9% patients reported at least one taste or olfactory disorder and 18.6% both.12 A multi-center European study of 417 hospitalised COVID-19 patients found that 88% of the patients had dysgeusia,13 and in a group of 59 COVID-19 positive patients in the USA, 71% of patients experienced taste loss.14
However, the exact mechanism leading to taste alteration remains unclear. Significant progress has been made to elucidate the cellular and molecular mechanisms of coronavirus-induced taste dysfunction. There are five elements of taste perception: saltiness, sourness, bitterness, sweetness and umaminess. Gustaoception is based on the detection of chemical stimulants by taste buds in the oral cavity. Taste buds are mainly located on the tongue, but they are also found on the soft palate, upper oesophagus and epiglottis. Taste buds are innervated by the seventh, ninth and tenth cranial nerves. There are at least five types of taste cells (Figure 1), with type I cells being the most abundant in taste buds. Salty taste is thought to be mediated by amiloride-sensitive and insensitive receptors on type I cells, although others have suggested they provide glial-like support functions and are non-excitatory. Type II cells have at least three subsets which respond to sweet, umami and bitter tastants. Type II cells express glial glutamate/aspartate taste receptor type 1 (T1r) and 2 (T2r) on the surface. T1r2 and T1r3 heterodimer is a sweet taste receptor; T1r1 and T1r3 heterodimer is an umami taste receptor; T2r receptor is a bitter taste receptor. Although both T1r and T2r are closely related to the G-protein-coupled pheromone receptors V2R and V1R, T2r genes form a larger multigene family than T1r genes. In contrast to the presence of three T1r genes in the mammalian genome, more than thirty T2r genes exit in human. Type III cells have identifiable synaptic contacts with the gustatory nerves and are believed to express sour taste receptor (The proton-selective ion channel Otopy1) on the surface. Type IV cells are the undifferentiated cells at the bottom of the taste bud. A new study has shown that salty taste might be transduced by taste cells that express the amiloride-sensitive epithelial sodium channel/calcium homeostasis modulator 1 and 3 (ENaC CALHM1/3).

Gustatory information from taste receptor cells in the tongue is transmitted to the primary gustatory cortex in the brain via multiple neural stations. Currently, two different models have been suggested to account for the information coding in the gustatory system. One theory, referred to as an “across-fibre pattern recognition,” suggests that each chemical has its pathway pattern, and that the information is transmitted by multiple afferent nerves. Therefore, the recognition and classification of the taste are based on these complex patterns across all of the afferent nerve fibres, rather than by activity in any single nerve fibre. The second theory, referred to as “labeled lines,” suggests that individual taste receptor cells will respond to only a single taste quality. Each taste quality is transmitted by separate afferent pathways to the gustatory. Experimental results have shown special molecules called “semaphorins” might be responsible for establishing and maintaining appropriate connectivity between taste-receptor cells and their ganglion neurons. These specialised proteins might be involved in maintaining the “labeled lines” between peripheral receptors and their respective central projection area. However, the true mechanism remains unclear, and gustatory information coding may utilise both types of mechanisms.

**Renin-Angiotensin-Aldosterone System, COVID-19 and taste**

SARS-CoV2 is thought to gain entry into cells by binding to ACE2, a key regulatory enzyme of the angiotensin hormonal system. The Renin-Angiotensin-Aldosterone System (RAAS) is a significant hormone system that regulates blood pressure, fluid and electrolyte homeostasis and systemic vascular resistance. There is growing evidence that taste function is modulated by hormones that govern the RAAS. ACE2 is a key regulatory enzyme that degrades angiotensin II into angiotensin (1–7) and cleaves angiotensin I to angiotensin (1–9). It belongs to the membrane-bound carboxypeptidase family and is widely expressed and distributed in the human body, including in the heart, kidney, ileum and lung. ACE2 has been found to be a functional receptor for SARS-CoV-2 infection and that the virus gains its entry to the cell via this receptor. Extensive expression of ACE2 on the tongue in human was shown in an animal model, where renin, angiotensinogen, ACE1 and ACE2 were present in the taste buds of fungiform
Figure 1: The five different taste cells and their receptors (Adapted from Normura et al.)

- **Salty**
  - ENaC
  - Na+

- **Gustatory nerve**
  - ENaC
  - Na+
  - ATP
  - CALHM1/3+
  - P2X2/3

- **Sweet**
  - T1R1
  - T1R3

- **Umami**
  - T1R1
  - T1R3

- **Bitter**
  - T2R

- **Sour**
  - Otop1

- **Type I cells**
  - Glial-like cells

- **Type II cells**
  - Taste -receptors cells

- **Type III cells**
  - Presynaptic cells

- **Type IV cells**
  - Undifferentiated cells
and circumvallate papilla. These results indicate that the tongue, especially the taste buds, may be an important target for SARS-CoV-2 infection. It had been thought that ACE2-positive cells were associated with taste buds, but it has now been found that ACE2 is enriched in the non-gustatory filiform papillae and not in the taste buds. Only a small proportion of type III taste cells of the tongue showed positive expression. Further studies are required to clarify whether ACE2-positive cells are concentrated in taste buds, in filiform papillae or both.

Angiotensin II and aldosterone are the key hormones that regulate sodium and water balance in the taste system. Amiloride is an inhibitor of the epithelial sodium channel, which has been suggested to be one of the sensors of salty taste. Mice which lacked epithelial sodium channels on taste cells demonstrated a complete loss of amiloride-sensitive sodium taste responses but retained normal responses to sweet, umami, bitter and sour. Humans do not appear to have a strong amiloride-sensitive salt taste transduction mechanism, when compared with other species. Therefore, amiloride-sensitive channels may play little role in the perception of saltiness in humans. An animal study has shown that administration of aldosterone could increase the amiloride-sensitivity of the rat chorda tympani nerve response to sodium chloride. Aldosterone pre-treatment, a low sodium diet or both could enhance the expression of the epithelial sodium channel in fungiform, foliate and circumvallate taste buds. The total number of amiloride-sensitive cells increased after aldosterone treatment. Such responses are thought to be due to the synthesis and translocation of the epithelial sodium channel from intracellular locations to the apical membrane in the taste cells. Hence aldosterone could enhance amiloride-sensitive salt taste responses.

Angiotensin II is one of the powerful key active products of RAAS and plays an essential role in the regulation of vascular tone, cardiac function and renal sodium reabsorption. Angiotensin II is degraded into angiotensin (1–7) by endopeptidases or carboxypeptidases such as ACE2. Angiotensin II is thought to be a potent stimulator of sodium appetite and preference. Angiotensin II is further converted by aminopeptidase A and aminopeptidase N into other metabolite peptides with different bioactivities. Angiotensin II, the biologically active component of renin-angiotensin system, acts through two receptor subtypes, the AT1 and the AT2 receptors. AT1 receptors are widely distributed throughout the body, including vascular smooth muscle, kidney, heart and brain, and they are responsible for mediating cardiovascular effects such as vasoconstriction, aldosterone synthesis and secretion, and sodium reabsorption. AT2 receptors are thought to have the opposite effect of AT1. In taste buds, AT1 receptors are expressed in some type I and type II taste cells, but not AT2, suggesting that the taste organs may be one of the peripheral targets of angiotensin II. An animal immunohistochemistry study revealed that AT1 receptors were co-expressed with amiloride-sensitive salty receptors, epithelial sodium channels and sweet taste receptors (T1r3). Interestingly, angiotensin II could induce gustatory nerve responses to sweeteners, but not to certain salty substances such as potassium chloride, sour, bitter or umami tastants. These results suggested that angiotensin II not only acts on the taste organ but also modulates the gustatory nerve responses to salty and sweet taste. However, angiotensin II displays an acutely suppressed effect on salty taste while aldosterone acts as a slow enhancer in peripheral taste organs. Concurrently, angiotensin II increases sweet taste sensitivity; hence it may contribute to increased calorie intake.

Hypothetical causes of taste disturbance by SARS-CoV-2

Taste loss associated with impairment of smell

The majority of taste disorders are caused by impairment of smell rather than gustatory loss. However, COVID-associated chemosensory impairment is not limited to smell but also affects taste. Often anosmia and loss of taste are prodromal symptoms when serum cytokine levels are low. A recent European study has shown that anosmia was present in 47% confirmed
COVID-19 patients. It has been reported that smell loss (peak on day three) is earlier than taste loss (peak on days three to seven). A recent study has shown that COVID-19 is associated with olfactory loss but not with gustatory dysfunction when tested. The cause of smell dysfunction in COVID-19 is not fully understood but may be associated with (1) nasal obstruction, congestion and rhinorrhea, (2) death of olfactory receptor neurons, (3) damage of the olfactory centers by viral infiltration and (4) reduction of support cells in the olfactory epithelium.

Direct taste cell damage

Taste buds contain both short-lived and long-lived cell populations. The average turnover rate of taste cells is between eight and twelve days, but some of them (type III cells) can survive longer. The homeostasis of taste buds is well maintained across the lifespan. However, disturbances can occur under various pathological conditions. Disruption to taste bud homeostasis, such as abnormal or suboptimal cell turnover, differentiation and degeneration, predisposes to taste disturbance associated with diseases and ageing. Taste disturbance is well known to be related to a wide range of viral infections, including SARS-CoV-2. Hypogeusia and dysgeusia are common complaints of patients with upper respiratory viral infections and oral cavity infections. Similar to respiratory epithelium, both human and animal studies have demonstrated that ACE2, which is used for entry by SARS-CoV-2, is widely expressed in the tongue. As a result, the tongue can be a potential target. SARS-CoV-2 is capable of replication in the upper respiratory tissues.

Similarly, the destruction of taste cells may be mediated by direct exposure to the virus and active replication of the virus inside the host cells. The damaged taste cells may release more viral particles; as a result, the adjacent taste cells, epithelial cells and neurons could be affected.

Neural injury and taste dysfunction in COVID-19

The maintenance of taste buds is highly dependent on the gustatory nerves. Damage to the peripheral or central nervous system can affect the taste. It is known that human coronaviruses may invade the nervous system and cause neurological symptoms. Animal studies revealed that SARS-CoV or Middle East respiratory syndrome coronavirus (MERS-CoV) are capable of causing nerve damage. When the virus was given transnasally to mice, it spread further to the brain by damaging olfactory nerves. Several cases of neurological involvement during SARS and MERS, and the potential mechanisms, have already been described in the literature. For example, SARS-CoV can induce neurological diseases such as epilepsy, polyneuropathy, olfactory neuropathy, stroke, encephalitis and chronic post-SARS syndrome and autonomic dysfunction. Almost one fifth of MERS-CoV-infected patients developed neurological symptoms during the acute infection. Similar to SARS-CoV, SARS-CoV-2 profits from the ACE2 receptor to enter the intracellular space. Expression of ACE2 receptors has been found in glial cells, neurons, endothelial cells and smooth muscle cells. Therefore, the nervous system can be a potential target of COVID-19. Similar to SARS-CoV, SARS-CoV-2 may enter the central nervous system via the systemic circulation or via the cribriform plate of the ethmoid bone. Some COVID-19 patients have signs and symptoms of intracranial infection, such as dizziness, headache, impaired consciousness, acute cerebrovascular disease, ataxia and seizure. Apart from the central nervous system, increasing evidence demonstrates that coronavirus can invade peripheral nerve endings and cause damage, and subsequently gain access to other tissues. Taste impairment, smell impairment, vision impairment and nerve pain were the main peripheral nervous system manifestations.

By the end of April 2021, the international literature contained reports of 73 patients with COVID-19 presenting with concurrent Guillain Barré syndrome (GBS). Most had early stage COVID-19 with mild respiratory symptoms. One case report described a COVID-19 patient without any respiratory symptoms, but with loss of smell and taste preceding GBS. Apart from direct cell injury, viral infection can lead to increase in the activity of sensory nerves as well as change in gene expression causing alterations in sensory nerve phenotype. There is increasing evidence to show that viral...
Infections, especially of the respiratory tract, are likely to be associated with neuroplasticity within both the sensory and autonomic systems.\textsuperscript{63} It is therefore likely that SARS-CoV-2 may impair the function of peripheral nerve endings around the taste buds via a direct effect and/or neuroplasticity, thus causing taste disturbance in COVID-19 patients. However, it is important to state that the impairment of the taste cells and the peripheral nerve injury is temporary, as most of COVID-19 patients fully recover from taste disturbance. Nerve regeneration is robust even after the nerve is injured\textsuperscript{44} and taste buds can regenerate from stem cells either outside the taste buds or from remnants of the taste buds. However, given the lack of convincing demonstration of ACE2 receptor expression on the taste cell membrane or innervating nerves, the virus probably does not cause taste loss through direct infection of these cells. Instead, taste buds might be damaged by inflammation caused by the infection.

**Inflammatory responses and taste**

SARS-CoV-2 infected cells induce inflammation locally and systemically\textsuperscript{65,66} and activation of inflammatory pathways can alter taste bud homeostasis. For example, systemic inflammation could reduce the number of stem cells which leads to reduction of numbers and function of taste buds in animal studies.\textsuperscript{46,66} If SARS-CoV-2 directly infects tongue cells, the local inflammatory process could alter stem cell properties and ultimately influence taste perception. Data have suggested that taste disturbance might be a result of insufficient taste receptor cell renewal due to SARS-CoV-2 infection.\textsuperscript{67} Inflammatory cytokines are important regulators of taste organs, and taste cells are acutely sensitive to inflammatory factors.\textsuperscript{68} During viral infections, elevated levels of inflammatory cytokines may induce profound changes in the physiology and related behaviours of the taste organs.\textsuperscript{69} Several inflammatory cytokine receptors such as tumour necrosis factor (TNF), interferon (IFN), interleukins (IL) 1, 6, 10 and 12 and toll-like receptors (TLR) are widely expressed in different types of taste cell.\textsuperscript{70,71} Cytokines such as IL-10 and IL-1 play critical roles in maintaining the structural integrity of the peripheral gustatory system and normal taste function after nearby injury.\textsuperscript{72,73} In contrast, TNF-\(\alpha\), IFN-\(\gamma\) and IL-6 have been shown in an animal model to be capable of inhibiting taste cell renewal, decreasing proliferation of progenitor taste cells and shortening the lifespan of taste cells.\textsuperscript{71} TNF receptors 1 and 2, expressed in taste cells, are modulated by the TNF signalling pathway that is involved in amiloride-sensitive and insensitive sodium salt transport systems in the cells.\textsuperscript{69} This pathway may contribute to taste disturbance associated with infections and inflammatory disease, as an elevation of TNF-\(\alpha\) could decrease the sodium salt flux in the polarised taste cells with subsequent changes in sodium salt taste function.\textsuperscript{66} IFNs are a group of signalling proteins that are produced and released by host cells in response to the presence of viral infection. IFNs play an important role in antiviral immunity, including SARS-CoV-2 infection, and IFN therapy is considered as a potential treatment against COVID-19. However, virally induced IFNs, acting either locally or systemically, could directly act on the receptors of taste cells via TLR and IFN pathways therefore (1) affect their cellular function in taste transduction, (2) induce premature death of taste cells or (3) skew the representation of different taste cell types, and subsequently lead to the development of taste disturbance.\textsuperscript{70,74}

**ACE2 and taste dysfunction**

After the SARS-CoV-2 has gained access to host cells via interaction with ACE2 receptors, the virus then downregulates ACE2 expression on the cell surface so that this enzyme is unable to exert protective effects in the tissues.\textsuperscript{75} As a result, some of the acute tissue injuries in COVID-19 patients are thought to be due to the locally increased level of uncoupled angiotensin II activity.\textsuperscript{76,77} The exact mechanism remains unknown. Both animal and human studies of influenza, respiratory syncytial virus and SARS-CoV reveal that downregulation of ACE2 expression may promote acute lung injury.\textsuperscript{78–80} A study of 12 COVID-19 patients suggested that downregulation of ACE2 may be associated with high viral load and severe lung injury.\textsuperscript{77} The local effects of downregulation of ACE 2 could facilitate this damaging effect or delay cell turnover. Reducing uncoupled angiotensin II proteins by the administration of ACE2 seems to
alleviate tissue damage in some situations. Such a process might occur in the taste buds, as the RAAS plays an important role in the taste process as mentioned above. Furthermore, ACE2 and aminopeptidase N are RAAS proteases that facilitate proteolytic cleavage of proteins and peptides that are involved in the taste perception. These proteases activate the taste receptors by releasing the residues from proteolysis of tastants. After SARS-CoV-2 infection, ACE2 is shown to be internalised into cytoplasm upon virus binding, thereby reducing the ACE2 availability in the cell membrane. Taste disturbance may be as a result of insufficient RAAS proteases activity due to internalization of the ACE2 receptors by SARS-CoV-2 infection. Moreover, imbalance of the circulating ACE2 caused by the internalisation of the ACE2 receptors promotes the activation of aldosterone. The salivary glands respond to the aldosterone by reabsorbing sodium. The reabsorption of sodium results in the osmotic reabsorption of water, which might alter the salivary flow and then lead to hyposalivation and taste disturbance. This hypothesis suggests that overactivation of the RAAS lead to both xerostomia and taste disturbance due to high levels of ACE2 and aldosterone. Therefore, taste disturbance might occur as a result of taste cell injuries, ACE2 downregulation, insufficient RAAS proteases activity and overactivation of the RAAS. However, SARS-CoV-2-infected patients exhibit loss of all taste perception, suggesting that the effect of ACE2 on particular taste cells may not be a major contributor. The pathogenesis of COVID-19 in patients taking RAAS-inhibitors is controversial and the effects of these inhibitors on ACE2 remain uncertain. Current evidence does not support concerns that the use of RAAS inhibitors is associated with an increased risk of SARS-CoV-2 infection or poor prognosis. COVID-19 patients with cardiovascular diseases are advised to continue their RAAS inhibitors, since the inappropriate discontinuation of, or changes in medication, might lead to changes in blood pressure or the progression of related diseases.

Conclusion

Taste buds may be potential targets of SARS-CoV-2 since most studies have shown many important proteins of the RAAS are highly expressed in taste buds. The underlying pathogenetic mechanisms of taste disturbance in COVID-19 patients may be due to direct but temporary taste cell and peripheral nerve ending damage, inflammatory responses and dysregulation of ACE2. However, more studies are needed before conclusive evidence is provided.

Authors’ contributions

GG developed the concept of this paper and wrote the draft manuscript with LM. AP and AR reviewed and edited the draft. All authors gave their final approval and agree to be accountable for all aspects of the work.
Competing interests:
Nil.

Acknowledgements:
The authors declare no potential conflicts of interest with respect to the authorship and/or publication of this article. This research did not receive any funding.

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Is it time to relieve junior doctors from “relief rotations”? 

Yassar Alamri

ABSTRACT

Relief junior doctors provide cover for absent colleagues on leave. One of the main advantages of the relief system is the availability of covered leave for junior doctors. However, it also has several drawbacks, including the lack of time-accreditation by Training Colleges. This viewpoint identifies some of the problems with the current relief system in New Zealand and suggests potential solutions to improve the experiences for junior doctors, patients and employers.

Relief junior doctors (RJDs) are post-graduate year 2 or higher (PG-Y2+) house officers and registrars who provide cover for absent colleagues. A PG-Y2+ junior doctor is generally expected to be rostered to at least one 3–4-month relief rotation per year. This “relief system,” although not unique (eg, it also features in Australia1), seems to be more ubiquitous/prevalent in the New Zealand healthcare workforce. Although it useful for plugging deficiencies in junior doctor rosters, RJDs often have a sub-optimal and fragmented clinical experience. This arrangement can severely undermine the educational value of the rotation due to compromises in the continuity of care, curriculum and supervision.2

To at least partially compensate for the inconvenience, RJDs are paid two pay-categories above the usual (ie, non-RJD) pay-category. The exact nature of the work required of the RJDs varies. During work-hours (ie, 0800–1600), RJDs may be allocated to certain specialties for the entirety of their rotation (eg, cardiology relief), or work as general relievers. After-hours, RJDs fill gaps in the on-call rosters based upon need and each RJD’s level of expertise. By contract, employers are required to inform RJDs of their rosters at least two weeks in advance. This is particularly relevant for on-call duties, as allocation for work-hours duties may change on the day if an RJD is required to be re-deployed to cover last-minute day gaps.

Types of relief

The New Zealand Resident Doctors’ Association (NZRDA) contract stipulates that RJDs ought to make up approximately 1 in 7 house officers and 1 in 5.5 registrars (ie, approximately 14–18% of junior doctors). These reliever ratios pertain to RJDs covering for colleagues on leave (eg, annual, sick, bereavement, educational or parental leave). It is expected that additional RJDs will be employed to provide adequate cover for junior doctors absent for other reasons than being on leave (eg, on rostered days off (RDO) and night shifts). The proportion of RJD, therefore, is usually higher than the quoted reliever ratios. Although somewhat less prescriptive, the Specialty Trainees of New Zealand (STONZ) contract has similar relief system stipulations to the NZRDA contract.

A third type of relief is referred to as “short-notice relief” (SNR). Any junior doctor (whether relief or not) may be rostered by their employer to cover SNR, the primary goal of which is to cover last-minute after-hours gaps. The SNR period can be up to seven consecutive days, and typically commences on a Saturday. Caps on the number of after-hours shifts varies among the different contracts. Similarly, prioritising the services covered by the SNR junior doctor varies because it depends upon service needs and any other available cover. If an SNR junior doctor is required to...
work an after-hours shift, they are paid at an additional hourly rate for the duration of their shift. Over-night shifts (2300–0800) incur a higher rate, and the employer generally has a deadline of 1600 of notifying the SNR junior doctor of their need to cover the night shift; evening shifts (1600–2300) have a deadline of 1400.3,4

Current status
Currently, it is estimated that approximately 25–35% of PG-Y2+ junior doctors are given a relief rotation at any one period (Personal communication, Resident Doctors Support Team, Canterbury District Health Board). This is significantly higher than would otherwise be expected. The causes of this increase have not been formally examined, but the recent implementation of the NZRDA's contract (split night rostering and introduction of schedule 10 RDO) has likely contributed.

Advantages
Covered leave for junior doctors is one main advantage of a robust relief system. Working together with their employers, junior doctors can take time-off for holiday, study, courses, conferences, paternity and child-care and sickness (especially on short-notice). To compensate for the inconvenience of relief rotations (eg, varied daily schedule and sub-optimal continuity of care), RJDs are financially compensated at higher rates than non-RJDs.

The relief system may be an avenue for junior doctors to work flexibly or on a part-time basis. Moreover, the pool of RJDs provides a “buffer” should any non-relief vacancies arise. Finally, relief rotations may also provide RJDs a wider view of the various departments within a hospital, especially those junior doctors on short-term contracts and those from overseas.

Disadvantages
Perhaps the main drawback of relief rotations is the lack of time-accreditation by several Training Colleges, as relief rotations are often viewed to offer less supervision and educational value. For example, the Royal Australasian College of Physicians only allows up to a maximum of six months of “other” rotations, which may include relief.5 The College of Intensive Care Medicine only accredits relief rotations (as part of the trainee's non-core experience) if at least four weeks are spent in a single medical sub-speciality.6 Similarly, candidates applying for surgical training with the Royal Australasian College of Surgeons can only accredit relief periods (often >4 consecutive weeks, although the exact duration varies) if spent in a single surgical specialty.7

At the current rate of one guaranteed relief rotation per year (and occasionally two), this often results in prolongation of training/eligibility to sit College examinations. However, as relief rotations tend to entail fewer learning, teaching and clinical supervision opportunities, it is not surprising that the Training Colleges impose such strict accreditation criteria.

No studies to date have examined the effects of relief rotators on patient care, safety or outcomes.4 RJDs anecdotally find less satisfaction in relief rotations due to the lack of patient-care continuity, familiarity with departmental guidelines, overall team cohesion and structure/routine in day-to-day work. RJDs' general lack of satisfaction with relief rotations may even lead to increased absenteeism, which negates the purpose of the relief role. The fact that RJDs are paid more by their employers further exacerbates the loss of human-power and the opportunity cost. Therefore, relief rotations may prove sub-optimal not only for the RJDs, but also for their patients and clinical teams.9

Going forward
A functional relief system ought to achieve three goals:

1. allow junior doctors to take leave (whether planned, or on short-notice) without significantly compromising the work-flow/patient safety
2. enable employers to effectively respond to the ebbs and flows of workforce demands without undue financial waste
3. be designed in such a way that does not compromise patient care or the educational value for RJDs.
RJD-free rostering

Several departments, particularly ones on shift-rosters (eg, ICU), have forgone the relief system. Their junior doctors are required to apply for planned leave prior to an advertised deadline. If planned leave is needed following the deadline, junior doctors are expected to swap shifts among themselves to provide sufficient cover such that no shifts are left vacant. For unplanned/short-notice leave, the vacant shifts are advertised to a list of interested junior doctors to pick up for an additional pay (financial cost to the department). Failing that, consultants would cover the vacancy.

Embedded relief

Embedded relief involves the employment of a surplus of junior doctors in each department (the number will depend upon each department's clinical demands). For employers, this absolves them of (or significantly reduces) the need to specifically hire RJDs, while retaining the same human-power (or more of it) to safely organise rosters and leave requests. For junior doctors, this ensures the totality of their clinical time is counted towards their training without unnecessary delays.

Here’s a hypothetical example to illustrate this innovative approach:

The Department of Neurology at Hospital X currently employs 4.5 full-time-equivalent (FTE) junior doctors (3 registrars, 1 in-patient house officer and 0.5 out-patient house officer). To cover for absences, the Department gets approximately 1.3 FTE RJDs. These are made up of one relief registrar (shared with the Nephrology, and Infectious Diseases departments), two relief house officers (shared with the Haematology and Oncology departments) and a third relief house officer (shared with the Nephrology and Respiratory departments). Therefore, while the Neurology Department has a total of 5.8 FTE junior doctors, the RJDs are fragmented among several other departments. This not only translates to possibly fragmented care divided among several departments. It also means that the time spent by those RJDs is unlikely to yield meaningful clinical experience in any one department or be counted towards their training.

To counterbalance some of the problems identified above (while retaining the advantage of having some roster redundancy), the embedded relief system would entail allocating the Department 6.0 FTE junior doctors (in the form of 4 registrars and 2 house officers). Each of the four registrars would, for example, participate acute stroke care, in-patients, consults and relief/ad hoc clinics. This way the “burden” of relief is shared (eg, a month at a time during a four-month rotation) while each junior doctor receives meaningful clinical experience, and the Department is still able to meet patient-care demands.

The embedded relief system is not without its drawbacks. It is conceivable that, over time, the departmental workload could expand such that “redundant” junior doctors are no longer treated as such. This would make it more difficult for junior doctors to take leave. Junior doctors could also be paid less for doing similar/more work (ie, not remunerated at two pay-categories above the usual).

Conclusions

Having some redundancy in the rostering of junior doctors allows sufficient laxity to allow for planned and unplanned leave to be covered. However, it is not without costs to employers (potential financial losses) and junior doctors (limited educational value and probably job satisfaction). Currently, RJDs are only allowed to accredit a limited time-period (if any) to count towards their training. Although some departments have forgone the relief system, the present system could do with some improvements.

We, therefore, suggest modifying the current relief system. This may appeal to both employers and junior doctors alike. The system could take the form of a hybrid that incorporates both embedded as well as dedicated RJDs. Embedded RJDs would cover most of the departmental human-power needs and gain valuable educational experience accredited by their Training College (ie, by restricting the time and scope/specialty of relief work). At the same time, having dedicated RJDs would keep a degree of flexibility for covering leave and/or last-minute needs for re-deployment. To make dedicated RJDs more appealing to junior doctors, they may be offered a range
of sub-specialty exposure and/or the use of the expertise of overseas junior doctors who are only intending to stay in New Zealand short term. We expect this proposed hybrid system to be useful for rostering junior doctors in both large and small hospitals (although it may be easier in smaller hospitals with fewer junior doctors/rosters).

What is clear is that there is a need for an on-going dialogue among the various stakeholders (namely, junior doctors, trade unions, employers and Training Colleges) in order to improve the current status of relief rotations. In this hybrid system, more relief rotations would count towards training, night shift/RDO rosters could be restructured, the coordination of relief rotations could fit with training requirements, allocations could be matched to RJDs’ areas of interest, and departments could have a consistent, workable and equitable framework for everyone, including junior doctors, who we may yet save from (most!) relief rotations.
Competing interests:
Nil.

Acknowledgements:
The author would like to thank Dr Thomas Wilkinson for his review of, and helpful comments on the manuscript.

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URL:
www.nzma.org.nz/journal-articles/is-it-time-to-relieve-junior-doctors-from-relief-rotations

REFERENCES
Outpatient synacthen testing in a large metropolitan region: a clinical audit

Anthony Walters, Joanna Champion-Young, Michael Croxson, Andrew Grey

ABSTRACT

AIM: To audit short synacthen tests (SSTs) performed at a single laboratory within the greater Auckland area.

METHODS: Two hundred and eighty-seven SSTs conducted in 286 individuals between September 2016 and September 2019 were assessed. Test requests were not triaged. We assessed source of referrals, indications for testing, adequacy of pre-test information and test outcomes.

RESULTS: Seventy-one percent of referrals were for women. Fifty-six percent were from primary care and 18% from rheumatology. One-hundred and fifteen (40%) of those referred had been taking corticosteroids within the previous three months: this information was only provided in 49 referrals. In 32% of referrals, no serum cortisol measurement had been undertaken within the previous six months. In 20% of referrals, no indication was provided. Thirty-three (11%) SSTs were abnormal. Of these, 29 were in patients taking corticosteroids. No SSTs were abnormal among 64 patients with pre-test serum cortisol >300nmol/L or >400nmol/L according to the cortisol assay in use.

CONCLUSIONS: Referrals for SSTs often lack important information, such as the indication for testing and recent corticosteroid exposure. Up to one quarter of SSTs could be avoided if a serum cortisol was routinely measured prior to referral. Adopting a structured referral form that mandates provision of important clinical and biochemical data might reduce unnecessary testing.

A

drenal insufficiency is an uncommon but important clinical syndrome that can be caused by endogenous pituitary or adrenal pathology, or exogenous administration of corticosteroid medications. The short synacthen test (SST) is commonly used for the diagnosis of adrenal insufficiency because of its relative ease and safety compared with the metyrapone stimulation test or the insulin tolerance test. The level of cortisol response to synacthen deemed adequate for exclusion of adrenal insufficiency varies by assay.

A clearly low, early morning plasma cortisol may be predictive of a subnormal SST response, and a clearly robust plasma cortisol may be predictive of a normal SST response. In these situations the SST may not be necessary. The specific cut-offs for a low or robust cortisol vary by assay and depend on the desired sensitivity and specificity for prediction of SST outcomes.

Prudent use of diagnostic tests is important: avoiding unnecessary testing allows better use of limited health resources, reduces waiting times for those with a definite need for the test and avoids the risks of invasive testing. The estimated cost of an SST in our public hospital service, including the cost of the synacthen, the cost of plasma cortisol testing and nursing time and equipment, is NZ$200.

Since 2016, our service has conducted all outpatient SSTs in the greater Auckland area, which has a population of approximately 1.7 million. We audited the SST requests and results over a three-year period. Our aims were to determine whether the SST was being used appropriately and to
identify areas for improvement, including an estimation of the proportion of potentially avoidable tests.

Methods

Study population
We undertook an audit of outpatient SSTs performed in the greater Auckland area between September 2016 and September 2019. During this time, our department was the sole referral centre for outpatient SSTs. No triaging was applied to the test referrals during this period. We excluded referrals of patients with known or suspected pituitary disease and those from endocrinology specialists.

Referral and demographic data
Referrals were received in either paper or electronic format. Each referral format was configured as free-text only. Data were extracted from the referrals on patient age and gender, referrer specialty, the indication(s) for SST, the timing, dose and route of administration of recent or concomitant corticosteroid therapy, and previous plasma cortisol levels, including the time of collection. To supplement this information, patients were asked on the day of the SST whether they were taking corticosteroid medications and, if so, the dose and route of administration. In addition, we searched the electronic patient record for prescriptions of corticosteroids within three months of the SST, and for serum cortisol measurements obtained within six months of the SST. All cortisol measurements performed within the catchment area are accessible by this means.

Pre-SST and basal plasma cortisol measurements
Measurements of plasma cortisol obtained prior to the SST were performed using either the Siemens assay or the Roche Cortisol II assay. We used data collected by the assay manufacturers to code the results:

- Siemens assay
  - Robust: >400nmol/L
  - Intermediate: 200–400nmol/L collected between 7am–10am, or <200nmol/L collected after 10am
  - Low: <200nmol/L collected between 7am–10am

- Roche Cortisol II assay
  - Robust: >300nmol/L
  - Intermediate: 170–300nmol/L collected between 7am–10am, or <170nmol/L collected after 10am
  - Low: <170nmol/L collected between 7am–10am

If no cortisol measurement had been performed prior to the SST, we considered the zero-minute serum cortisol from the SST as representative of a pre-SST value, and coded it using the same method.

Short synacthen tests
Testing was performed between 7am and 10am where possible. Cortisol samples were drawn from an intravenous cannula immediately prior to, and 30 minutes after, administration of 250µg intravenous synacthen. Patients known to be receiving oral corticosteroid therapy were asked to withhold it for 24 hours prior to testing. Plasma cortisol was measured using the Roche Cortisol II assay (Modular Analytics E170). A 30-minute post-synacthen plasma cortisol >400nmol/L was defined as a normal response. The Roche Cortisol II assay is more specific than previous assays for cortisol due to lower levels of cross reactivity with cortisol metabolites. As a result, reported reference ranges are lower than for the Roche Cortisol I assay.12

Analyses
Outcomes of interest included the proportion of SST results that were abnormal (30-minute post-synacthen plasma cortisol <400nmol/L), the prevalence of pre-test cortisol measurements, the prevalence of pre-test corticosteroid treatment and the indications for testing. We assessed the proportion of abnormal SSTs according to pre-test cortisol values and the use of pre-test corticosteroid therapy.

This work is a clinical audit, so ethics review was not required.

Results

Dataset of eligible tests
During the audit period, 353 SSTs were performed in 352 patients. After exclusion of referrals by endocrinologists (n=64) and those with known or suspected pituitary disease (n=11), 287 tests performed in 286
patients were eligible for analysis. Table 1 shows the demographic data for those tested. The majority were women. Forty percent had been prescribed corticosteroid therapy in the three months before SST was performed. No pre-SST plasma cortisol measurement was available for 33%.

Sources of referrals and test outcomes

Table 2 shows the sources of referrals. More than half were from primary care, and nearly 20% from rheumatology. Other specialties each generated fewer than seven referrals per year. The table also shows the wide range of proportions of abnormal tests among referral sources. One in three tests requested by rheumatology was abnormal. No tests requested by cardiology or immunology were abnormal. Other disciplines had similar proportions of abnormal tests, ranging from 6% to 14%.

Indications for SST

Table 3 sets out the indications for the SST provided by the referrers. No indication was provided in 20% of referrals: a similar proportion (17%) of referrals mentioned prolonged corticosteroid therapy as the indication for SST. Of the 105 referrals for the indication “low basal cortisol,” four (4%) did not have a cortisol measured within the previous six months, and 44 (42%) had a robust or intermediate pre-SST cortisol. Indications mentioned in fewer than five referrals were grouped as “other.” These included suspected adrenal tuberculosis, treatment with an immune checkpoint inhibitor, low or high adrenocorticotropic hormone (ACTH), skin pigmentation, adrenal fatigue, adrenal metastatic disease, radiotherapy involving the adrenal glands, unilateral adrenalectomy, salbutamol use, other autoimmune disease and a family history of Addison’s disease.

Table 1: Characteristics of patients referred for short synacthen tests. Data are mean (range) or N (%).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>49 (12-88)</td>
</tr>
<tr>
<td>Female</td>
<td>203 (71%)</td>
</tr>
<tr>
<td>Corticosteroid prescribed in the previous three months</td>
<td>115 (40%)</td>
</tr>
<tr>
<td>No serum cortisol in the previous six months</td>
<td>94 (33%)</td>
</tr>
</tbody>
</table>

Table 2: Referrers and proportions of abnormal tests. Data are N or N (%).

<table>
<thead>
<tr>
<th>Referring Specialty</th>
<th>N</th>
<th>Abnormal SST</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practice</td>
<td>160</td>
<td>10 (6)</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>53</td>
<td>18 (34)</td>
</tr>
<tr>
<td>Immunology</td>
<td>19</td>
<td>0 (0)</td>
</tr>
<tr>
<td>General internal medicine</td>
<td>14</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Cardiology</td>
<td>12</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Infectious disease</td>
<td>8</td>
<td>1 (13)</td>
</tr>
<tr>
<td>Other*</td>
<td>21</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Total</td>
<td>287</td>
<td>33 (12)</td>
</tr>
</tbody>
</table>

*Specialties with <5 referrals each
Corticosteroid use

One hundred and fifteen referrals (40%) were for patients either currently taking corticosteroids or who had been exposed to corticosteroid drugs within the previous three months. Of these, only 49 (43%) mentioned corticosteroid exposure. Information about duration of corticosteroid use, timing of administration during the day and the dose used leading up the SST was rarely available.

Pre-SST serum cortisol measurements

One hundred and ninety-four patients (68%) had a serum cortisol measured within six months of the referral for the SST. This information was contained in only 119 (64%) of these referrals. The numerical value was provided in only 33 (17%).

SST results

Of the 287 SSTs, 33 (11%) were abnormal. Among the 33 abnormal SSTs, 15 (45%) had a basal cortisol <100nmol/L, 12 (36%) had a basal cortisol 100–170nmol/L and six (18%) had a basal cortisol >170nmol/L. Twenty-nine abnormal SSTs occurred in patients receiving corticosteroid therapy. Table 4 shows the number of abnormal SSTs in corticosteroid-treated (N=115) and non-corticosteroid-treated patients (N=172). An abnormal SST occurred in 25% of patients receiving corticosteroid therapy (29/115). This was almost exclusively (26/29, 90%) in patients receiving oral, intramuscular or intra-articular corticosteroids. Three abnormal SSTs were in patients receiving topical or inhaled corticosteroids, and all these patients were receiving potent topical corticosteroids. Among patients not receiving corticosteroids, 2% (4/172) had an abnormal SST. There were no abnormal SSTs among non-corticosteroid-treated patients who had not had a cortisol measurement prior to the SST (0/47).

None (0/64) of those with a robust basal plasma cortisol had an abnormal SST, irrespective of corticosteroid treatment. Almost half of the patients receiving corticosteroid therapy who had a low basal cortisol (26/55) had abnormal SSTs. A similar proportion of patients with a basal cortisol level <100nmol/L (7/14, 50%) had an abnormal synacthen test. Eleven of these 14 were prescribed corticosteroid in the preceding three months.

Discussion

In this retrospective audit of SSTs, we assessed referrals for, and the results of, SSTs. Several clinically helpful results ensued. All patients with a robust basal cortisol (>300nmol/L for Roche Cortisol II or >400nmol/L for the Siemens assay) had a normal SST. Previous studies have reported that an early morning cortisol of >450nmol/L in the Siemens assay or >500nmol/L on the Roche cortisol I assay is strongly predictive of a normal SST response. We found that

Table 3: Indications on referral form for short synacthen tests. Data are N (%).

<table>
<thead>
<tr>
<th>Indication</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No indication provided</td>
<td>57 (20)</td>
</tr>
<tr>
<td>Low basal cortisol</td>
<td>105 (37)</td>
</tr>
<tr>
<td>Symptoms of adrenal insufficiency</td>
<td>99 (34)</td>
</tr>
<tr>
<td>Prolonged treatment with corticosteroid</td>
<td>50 (17)</td>
</tr>
<tr>
<td>Electrolyte disturbance</td>
<td>12 (4)</td>
</tr>
<tr>
<td>Other*</td>
<td>19 (7.3)</td>
</tr>
<tr>
<td>Missing referral form</td>
<td>1 (0.3%)</td>
</tr>
</tbody>
</table>

*See text for description.
Total indications > 287 as some referrals included >1 indication.
64/287 (22%) of the SSTs performed were avoidable, based on a robust basal cortisol measurement, and conclude that obtaining a morning plasma cortisol result can assist the triage of patients who do not need a SST, facilitate prudent use of healthcare resources and reduce unnecessary testing for patients.1-15

Work from other groups has suggested that a morning plasma cortisol concentration less than 100nmol/L implies a very high probability of an abnormal SST response, making further testing unlikely to change management.4–11,13 Contrary to these reports, our audit suggests that a morning plasma cortisol below the reference range does not predict an abnormal SST with enough confidence to avoid proceeding to SST. Using a threshold of 100nmol/L did not improve the value of basal cortisol in predicting an abnormal SST.

We also identified that referrals for SSTs frequently lacked important information regarding current or recent use of corticosteroids, prior cortisol testing and the indication(s) for testing. These details are important both for interpretation of SST results and the determination of whether an SST is appropriate. For example, patients receiving long-term corticosteroid treatment at supraphysiological doses are likely to have an abnormal SST, and management is unlikely to change if an SST is undertaken. In only one in six referrals of patients who had had a plasma cortisol measurement was the numerical value provided. All 12 referrals from cardiology were for patients with postural hypotension or fatigue. Of these, only two had pre-test cortisol measurement and none had an abnormal SST.

An SST was sometimes requested when an alternative test may have been more appropriate. For example, some patients referred with inappropriate or unclear indications had also had either a dexamethasone suppression test or a 24-hour urinary free cortisol test performed recently, suggesting that there may have been confusion.

### Table 4: Basal cortisol and short synacthen test (SST) results by corticosteroid use. Data are N or N (%).

<table>
<thead>
<tr>
<th></th>
<th>No corticosteroid</th>
<th>Corticosteroid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Abnormal SST</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>172</td>
<td>4 (2)</td>
</tr>
<tr>
<td><strong>PO/IM/IA</strong></td>
<td>71</td>
<td>26 (37)</td>
</tr>
<tr>
<td><strong>Topical/inhaled</strong></td>
<td>44</td>
<td>3 (7)</td>
</tr>
<tr>
<td><strong>Cortisol measurement pre-SST</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td>125</td>
<td>4 (3)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>47</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Basal cortisol</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>robust&lt;sup&gt;a&lt;/sup&gt;</td>
<td>39</td>
<td>0 (0)</td>
</tr>
<tr>
<td>intermediate&lt;sup&gt;b&lt;/sup&gt;</td>
<td>76</td>
<td>1 (1)</td>
</tr>
<tr>
<td>low&lt;sup&gt;c&lt;/sup&gt;</td>
<td>57</td>
<td>3 (5)</td>
</tr>
</tbody>
</table>

PO, per oral; IM, intramuscular; IA, intra-articular.

<sup>a</sup>Either cortisol measured pre-SST or 0 minute cortisol from SST.

<sup>b</sup>≥400 nmol/L Seimens assay; >300nmol/L Roche II assay.

<sup>c</sup>200–400 nmol/L collected 7am–10am or >200 nmol/L and collected after 10am Seimens assay; 170–300nmol/L collected 7am–10am or <170 nmol/L and collected after 10am Roche II assay.

<sup>c</sup>&lt;200 nmol/L collected 7am–10am Seimens assay; &lt;170 nmol/L collected 7am–10am Roche Cortisol II assay.
between appropriate testing for cortisol excess and adrenal insufficiency.

This audit was conducted retrospectively and has some limitations. Details of use of corticosteroids were based in part on prescription data and enquiry on the day of the SST, rather than full medication histories, which may not accurately reflect the actual corticosteroid administration. We were unable to ascertain whether the SST results changed patient management. This is particularly pertinent with regards to those receiving long-term corticosteroid treatment. We excluded patients with known or suspected pituitary disease. The data were collected in an outpatient setting and may not apply to acute clinical settings.

In summary, an SST is often requested without clear indications and frequently with inadequate clinical information. A moderate proportion of tests could be avoided by measurement of single morning plasma cortisol. In order to permit determination as to whether the test is appropriate, referrals for SST should be accompanied by sufficient clinical information, in particular the indication(s) for testing and details regarding corticosteroid use and prior plasma cortisol results. A morning plasma cortisol should be mandatory before undertaking an SST, as a robust level makes further testing unnecessary. Adopting a structured request form that requires provision of the relevant information might improve the utility of SSTs.
Competing interests:
Nil.

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REFERENCES
**Yersinia enterocolitica** associated myopericarditis: case report and review of the literature

Hayley Nehoff, Edward Henley, Rebecca Hamblin, Heather Isenman, Ian Crozier

**ABSTRACT**

We report a case of myopericarditis associated with *Yersinia enterocolitica* infection in an otherwise well 50-year-old man. We discuss the clinical features, microbiology and treatment of this rare cause of myopericarditis.

A 50-year-old man presented with a two-day history of pericardial type pain. The pain was in his left chest and exacerbated by inspiration and lying flat. During the preceding three weeks he had diarrhoea and abdominal pain. Physical examination was normal and he was afebrile. He reported a three-week history of persistent diarrhoea that did not affect any other household members.

Investigations revealed an initial Troponin I (TnI) of 17,566ng/L (reference range 0–34 ng/L), C-reactive protein (CRP) 160mg/L (normal <5mg/L) and a D-dimer of 689ug/L (reference range <500ug/L), but a normal blood count. The ECG showed 2mm ST elevation in leads V2–V6, I and II and no reciprocal changes (Figure 1). An echocardiogram showed normal structure and function of the heart with no pericardial effusion. A computed tomography coronary angiogram showed no obstructive coronary disease.

Stool culture identified *Yersinia enterocolitica*, a notifiable disease in New Zealand, and excluded *Clostridium difficile*, norovirus, astrovirus, rotavirus, adenovirus 40/41 and sapovirus. We diagnosed myopericarditis associated with *Y. enterocolitica*.

**Progress**

The patient remained stable and afebrile during his admission. Monitoring with telemetry showed normal sinus rhythm. His cardiac markers and CRP decreased over his admission while he was not on any antimicrobials due to awaiting stool culture. Following culture results, his infection was managed with a 10-day course of oral ciprofloxacin. Upon follow-up 10 days post initial presentation, the CRP and TnI had resolved (5mg/mL and 10ng/L respectively). He completed the course of antibiotics and had no further gastrointestinal symptoms. A follow-up echocardiogram showed normal ventricular size and systolic function.

**Discussion**

The genus *Yersinia* is a group of gram-negative coccobacilli bacteria from the family Enterobacteriaceae. The *Yersinia* genus are facultative anaerobes, several species of which are motile below 37°C.

The first known member of the *Yersinia* genus, *Y. pestis*, was independently identified in 1894 by both Alexandre Yersin and Kiasato Shibasabuō, Swiss and Japanese bacteriologists respectively.1 *Y. pestis* achieved infamy as the cause of the “Black Death” that swept through Eurasia and North Africa. Since then, several species of the *Yersinia* genus have been identified, including *Y. enterocolitica*, first identified in 1934 by McIver and Pike2 but not comprehensively described until 1968 by Sonnenwirth3.
*Y. enterocolitica* is a gram-negative, frigophilic, asporogenous rod, able to grow at 4°C and survive freezing. Yersiniosis is an animal-borne disease that can affect humans, most commonly through undercooked pork and contaminated milk or water. *Yersiniosis* typically causes a self-limiting enterocolitis, terminal ileitis or adenitis in humans, which can be managed in the community but may present resembling appendicitis. Common symptoms are dependent on age. Children under 5 experience fever, abdominal pain and bloody diarrhoea, and older children and adults experience abdominal pain as the principal symptom. Typically, infection management would involve only hydration and nutritional support if necessary. However, in some instances, it may be advisable to treat the infection directly. Previous studies have shown that *Y. enterocolitica* is often resistant to penicillins (such as ampicillin and ticarcillin) and the first-generation cephalosporin cefazolin, but it is typically sensitive to the third and fourth generation cephalosporins (cefotaxime, ceftriaxone and cefepime) as well as some fluoroquinolones (ciprofloxacin), aminoglycosides (gentamicin and tobramycin) and sulfonamides (sulphamethoxazole/trimethoprim).

In New Zealand, *Yersinosis* is a relatively common diagnosis of bacterial gastroenteritis, with 1,202 cases reported in 2018, a rate of 24.6/100,000. Only one death from *Yersiniosis* was reported in New Zealand between 1999 and 2018.

The most common route of transmission for *Y. enterocolitica* infection is via food, especially pork, but it has also been associated with untreated water, animal contact and human-to-human transmission. Interestingly, this patient had minimal risk factors for *Y. enterocolitica* infection. He did not report eating any unusual foods, rarely consumed pork and did not consume raw or undercooked meats. He did not drink unpasteurised milk or live or work rurally. He had no contact with livestock and no sick household contacts. The water supply at his home and work were provided by the local councils and were from secure groundwater that is UV treated or chlorinated water. However, it is worth noting that most *Y. enterocolitica* infections in New Zealand are sporadic and have no identifiable source.

It is unusual for *Y. enterocolitica* to be associated with myopericarditis. A literature review showed only one published case in the English literature, one case in German and three in Danish. Several larger case series have alluded to potential cases of *Y. enterocolitica* myocarditis, although without the necessary clinical detail for comparison to our case.

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**Figure 1:** ECG taken from the patient on the first day of his presentation to hospital. There is 2mm ST elevation in leads V2–V6, I and II and no reciprocal changes.
The mechanism by which *Yersinia* infection results in myopericarditis is uncertain. It has been postulated that this reaction could be an immune sequelae due to molecular mimicry. However, there has been evidence of direct *Yersinia* infection of the myocardium in animals, one puppy and one foetal foal. As we could not exclude direct infection of the myocardium, we elected to treat with a course of antibiotics and the patient recovered without sequelae.
**Competing interests:**
No funding was attained for the publication of this paper. Ian Crozier is a Consultant for Medtronic. Also receives research grants and fellowship support from Medtronic.

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Exertional rhabdomyolysis following return to exercise after COVID-19 lockdown

Isaac Bernhardt, Bryony Ryder, Callum Wilson

Rhabdomyolysis is a potentially life-threatening disorder of severe muscle injury. It results in the classical clinical syndrome of myalgia, muscle weakness and swelling, and leads to dark urine due to myoglobinuria in severe cases. Release of intracellular products creatine kinase (CK), potassium and myoglobin can result in systemic complications, including acute kidney injury, hyperkalaemia and acidosis. Causes include direct muscle trauma, ischaemia, infection, toxins, hyperthermia and acquired or genetic myopathies.¹

Exertional rhabdomyolysis (ER) represents the severe end of the spectrum of exercise-induced muscle injury, which also includes delayed-onset muscle soreness (DOMS) and asymptomatic hyper-CKaemia.² Although there is no universally agreed definition of rhabdomyolysis, the combination of clinical symptoms and peak CK>1,000U/L (or >5x upper limit of normal) is commonly used to define mild rhabdomyolysis, after excluding alternative causes.³

Risk factors for ER include male sex, low physical fitness, heat exposure, dehydration and high-intensity, prolonged exercise, especially eccentric weight-bearing exercise.³ Occasionally ER may be the presenting feature of an inherited metabolic disorder (IMD).¹²⁴ Typically these disorders of fat or glycogen metabolism are associated with recurrent episodes, although rarely a single episode may be the sole presenting feature in an otherwise asymptomatic adult.³

The National Metabolic Service has detected an increase in referrals for ER since early 2020, coinciding with the SARS-CoV2 pandemic. Lockdowns are an important public health response to COVID-19 and are associated with a decrease in physical activity.⁵⁶ Therefore, we conducted a retrospective review of these cases to delineate the risk factors for ER with return to exercise following lockdowns.

Methods

The database of the National Metabolic Service of New Zealand was reviewed for referrals for ER since March 2020. Clinical data, and biochemical and genetic testing results (where performed), were reviewed. ER was defined by the combination of myalgia and significant hyper-CKaemia (peak CK>1,000U/L) following exercise, with or without myoglobinuria. Individuals previously investigated for ER were excluded.

Results

Nine individuals were identified. However, two were excluded, due to investigation for recurrent rhabdomyolysis prior to March 2020 or peak CK<1,000U/L. Seven individuals (age 14–38 years, six males) developed ER after a period of relative inactivity during lockdown. ER occurred after unaccustomed high-intensity weight-bearing exercise in six (upper-limb in five) and following strenuous hiking in one. All were previously active, including five who attended the gym at least three times per week prior to lockdown, and three were competitive athletes. Two cases maintained regular aerobic exercise throughout lockdown, but then developed ER after their first session of high-intensity weight-bearing exercise at the gym.

Two patients had a history suggestive of previous exertional muscle injury. Of these, one individual had several documented episodes of asymptomatic elevation of transaminases following exercise. The other had a history suggestive of a fatty acid oxidation disorder (FAOD), including recurrent hypo-
glycaemia and liver dysfunction during early childhood infections, exertional myalgia and one previous documented episode of ER. The acylcarnitine profile demonstrated elevations of very long chain fatty acyl-carnitines (C14, C14:1 and C16), and molecular genetic testing confirmed the diagnosis of very long chain acyl-CoA dehydrogenase deficiency (VLCADD). No other individuals had a history suggestive of an IMD, and acylcarnitine profiles, where performed, were normal.

Genetic testing was offered to all individuals, but four declined. Single-gene sequencing of ACADVL confirmed the diagnosis of VLCADD in one individual. Next-generation sequencing (NGS) with a rhabdomyolysis/myopathy gene panel was requested in two others, and was non-diagnostic.

All patients were admitted to hospital and treated with intravenous fluids, with good outcome. Peak CK was >10,000U/L in five cases (range 1,760–10,3000). Four had evidence of myoglobinuria, and two developed acute kidney injury, with peak creatinine 123-208 µmol/L. Three patients had at least one subsequent episode of ER. This included the individual with VLCADD, and two others who developed ER after return to exercise following subsequent lockdowns.

Discussion

ER following unaccustomed exercise is well described in large cohorts of students and military recruits, and is associated with intensive prescribed exercise, especially in individuals with poor fitness.1-4 In this case series, it was noteworthy that most of the affected individuals were fit and competitive athletes and developed ER after an uncharacteristic period of detraining during lockdown. Detraining is associated with a decrease in mitochondrial ATP production rate in muscle within just two weeks, and therefore ER following return to intensive exercise likely represents acute intra-cellar energy deficiency causing muscle injury.5,10 Individuals with the highest activity pre-lockdown have the largest decrease in exercise habits,7 and therefore they may be more susceptible to the metabolic effects of detraining. Additionally, elite athletes may have higher capacity to persevere through strenuous novel exercise regimens, even in the setting of significant deconditioning.

Although post-lockdown ER most likely represents physiologic adaptation to acute detraining, underlying genetic muscle disorders should also be considered in the differential diagnosis.1,4 IMDs commonly presenting with recurrent ER include glycogen storage disorders (GSD), including McArdle's disease (GSD V), FAODs including VLCADD and carnitine palmitoyltransferase deficiency type II, and mitochondrial myopathies.1,4,5 Other genetic disorders associated with recurrent ER include RYR1 and LPIN1 disorders.1 The diagnostic yield of NGS panels in the setting of recurrent rhabdomyolysis is reported as 33%,11 but appropriate clinical and biochemical evaluation allows more targeted diagnostic testing. In this series, VLCADD was confirmed in one individual with classical FAOD symptoms, allowing prompt initiation of appropriate treatment, surveillance for complications and genetic counselling.

In conclusion, as thousands of New Zealanders return to high-intensity exercise after the longest lockdown to date, clinicians should be alert to the presentation of ER, in previously active individuals, following a prolonged period of relative inactivity. Maintenance of exercise during lockdown should be encouraged, and novel high-intensity exercise should be introduced gradually to avoid this complication.2 IMDs should be considered in the differential diagnosis of ER, especially in the presence of recurrent episodes, hypoglycaemia, encephalopathy, cardiomyopathy or liver disease.5,1 Discussion with the National Metabolic Service should be considered, to facilitate appropriate investigation and timely treatment.
Competition interests:
Nil.

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REFERENCES
An audit of a marae-based health centre management of COVID-19 community cases in South Auckland

Matire Harwood, Selwyn Te Paa, Nethmi Kearns, Helaman Luki, Augustus Anderson, Alex Semprini, Richard Beasley

In October 2021, the New Zealand government announced that COVID-19 cases in the community would no longer be exclusively managed in Managed Isolation and Quarantine (MIQ) facilities. Given the significant growth in cases, the isolation model moved towards Community Supported Isolation and Quarantine (CIQ) where cases would isolate at home and receive regular contact via a check-in service run by Whakarongorau Aotearoa (WA), contracted by the Ministry of Health. WA also run services such as Healthline, and the COVID-19 vaccination booking line. The check-in service is based on trained non-clinical staff making daily calls to positive cases isolating at home with processes for clinical escalation if required.

A public health risk assessment would take into consideration whether cases live in a residence that allows them to isolate safely, have access to own transport, phone and internet as well as masks, food and cleaning products.

However, there has been anecdotal evidence of suboptimal management of cases, failure to conduct check-ins and reports of whānau isolating in homes that do not meet the criteria. A recent independent review panel concluded that two of the deaths of COVID-19 cases in home isolation in Auckland were “potentially preventable” with “missed opportunities contributing to the outcome”. At a time when over 70% of active cases in a known isolation location are in CIQ, it is crucial that primary care health professionals are informed and aware of their patients’ clinical status, the management their patients receive, and their professional responsibilities.

The Papakura Marae Health Centre (PMHC) is one such primary health provider in South Auckland that serves 3,200+ people of whom 95 percent are classified as ‘high-need’. We undertook an audit of the management of COVID-19 patients enrolled or seeking care as casual patients at the PMHC using information documented in primary care records. The aim of this audit was to identify aspects of the care of PMHC COVID-19 cases that could be improved with the goal of enhancing patient welfare. The specific objectives are outlined in Table 1a.

There are currently no published standards on the management of COVID-19 cases in primary care. We therefore formulated the standards set out in Table 1b. This retrospective audit was conducted in partnership with the Medical Research Institute of New Zealand (MRINZ), Wellington. We audited the medical records of all patients under the care of PMHC, diagnosed with laboratory confirmed COVID-19 between 14 October 2021 and 18 November 2021. As this was a clinical audit of patients attending the general practice, no approval from an ethics committee was required. The purpose of the audit was not to challenge current government policies, but to document the performance of this Māori health provider in caring for COVID-19 patients in their community, and importantly to use the findings to improve clinical care and health outcomes.

De-identified data relating to patients were collected retrospectively from existing General Practitioner (GP) records by investigators at PMHC using a standard data collection paper form. No patients were
directly contacted for the purposes of data collection. The collected data was coded and entered by investigators at the MRINZ into a REDCap database\textsuperscript{10} hosted by the MRINZ.

Thirty-seven patients were included in this audit (Table 2). Nineteen cases (51.3\%) were enrolled patients at the practice while the remaining were casual patients. The majority of patients (73\%) were of Māori ethnicity and living in high deprivation areas. The mean (SD) number of persons per household was 5.8 (4.0) with 3.3 (1.7) positive cases in each household. Four out of the 26 cases who were eligible for vaccination were fully vaccinated at the point of diagnosis with a further six having received the first dose. Forty-six percent of cases were aged 20 years or younger with three-quarter of cases isolating at home. The primary isolation location was CIQ in 28 cases (75.7\%, of whom two were admitted to hospital), MIQ in 8 cases (21.6\%, of whom one was admitted to hospital) and hospital in one case which resulted in a prolonged admission including intensive care.

Of the COVID-19 cases, 57\% were first notified of their positive result by the PMHC. There was documented evidence in the PMHC records that WA contacted 48.6\% of cases for clinical review. In the majority of patients, all three standards were met by the PMHC (Figure 1). All cases were reviewed by PMHC, of whom 33 (89.2\%) had clinical reviews made by the GP. Twenty-nine out of 37 cases (78.4\%) had a GP clinical review within two calendar days of PMHC being notified of the positive result. Home visits were carried out by GPs on at least one occasion in 25 cases (67.6\%). Oxygen saturation was measured at all initial home visits made by the GP (in one case oximetry results were reviewed during a phone consultation). All cases had clear documentation of their clinical characteristics (Table 3) and were asked about their welfare needs. The practice provided kai packs to 31 cases (83.8\%) and delivered medication to 14 cases (37.8\%) with 13 cases (35.1\%) also opting for a hygiene pack delivered by the practice.

This audit has shown that PMHC has become the default provider of medical and welfare care for COVID-19 cases isolating in their community. While we recognise that documentation may under-estimate WA's and the Ministry of Health's

Table 1: (a) Audit Objectives and (b) Standards

<table>
<thead>
<tr>
<th>1a Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To ensure that COVID-19 cases in the community were reviewed by the practice</td>
</tr>
<tr>
<td>2. To ensure there is documented evidence of the clinical characteristics of COVID-19 cases</td>
</tr>
<tr>
<td>3. To ensure there is documented evidence that the welfare needs of patients were ascertained</td>
</tr>
</tbody>
</table>

1b Standards

<table>
<thead>
<tr>
<th>Standards</th>
</tr>
</thead>
</table>
| 1 COVID-19 cases should be contacted by the practice within 48 hours of GP notification of result. 
\textit{Rationale:} We considered follow-up by the primary care provider in a timely manner was important to ensure deteriorating patients were not missed |
| 2 COVID-19 cases should have documented evidence of clinical characteristics (vaccination status, symptom status, pregnancy status, co-morbidities, details of COVID-19 related admissions to hospital, outcome of illness) 
\textit{Rationale:} Clear and accurate documentation of clinical characteristics ensures that potentially vulnerable patients are identified. |
| 3 COVID-19 cases should have documented evidence that welfare needs were ascertained. 
\textit{Rationale:} As community cases quarantining at home are advised not to leave their property for any reason (apart from exempted reasons such as getting a COVID-19 test), ensuring patients have their welfare needs met is important. |
Table 2: Baseline characteristics.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N=37</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female sex (%)</strong></td>
<td>23 (62.2)</td>
</tr>
<tr>
<td><strong>Age (%)</strong></td>
<td></td>
</tr>
<tr>
<td>0-10 years old</td>
<td>11 (29.7)</td>
</tr>
<tr>
<td>11-20 years old</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>21-30 years old</td>
<td>8 (21.6)</td>
</tr>
<tr>
<td>31-40 years old</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>41-50 years old</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>51-60 years old</td>
<td>4 (10.8)</td>
</tr>
<tr>
<td>61-70 years old</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>&gt;70 years old</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Ethnicity (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>27 (73.0)</td>
</tr>
<tr>
<td>Pacific Peoples</td>
<td>7 (18.9)</td>
</tr>
<tr>
<td>European</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td><strong>Employment Status (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>7 (18.9)</td>
</tr>
<tr>
<td>Part-time</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>11 (29.7)</td>
</tr>
<tr>
<td>Student</td>
<td>16 (43.2)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (5.4)</td>
</tr>
</tbody>
</table>
Table 2: Baseline characteristics (continued).

<table>
<thead>
<tr>
<th>New Zealand Index of Deprivation Decile&lt;sup&gt;b&lt;/sup&gt; (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2</td>
<td>0 (0)</td>
</tr>
<tr>
<td>3</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>4</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>5</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>6</td>
<td>9 (24.3)</td>
</tr>
<tr>
<td>7</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>8</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>9</td>
<td>5 (13.5)</td>
</tr>
<tr>
<td>10</td>
<td>14 (37.8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Isolation Location (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>CIQ</td>
<td>28 (75.7)</td>
</tr>
<tr>
<td>MIQ</td>
<td>8 (21.6)</td>
</tr>
<tr>
<td>Hospital</td>
<td>1 (2.7)</td>
</tr>
</tbody>
</table>

Mean number of positive cases in household (Mean (SD))
3.3 (1.7)

Mean number of persons aged ≥18 in household (Mean (SD))
3.2 (2.4)

Mean number of persons aged < 18 in household (Mean (SD))
2.6 (2.2)

<sup>a</sup>Reported as prioritised output using Level 1 codes defined by the Ministry of Health(12)

<sup>b</sup>Calculated using NZDep18(13)
Figure 1: Percentages of COVID-19 cases meeting each standard at PMHC.
Table 3: Clinical Characteristics of community COVID-19 cases

<table>
<thead>
<tr>
<th>Variable</th>
<th>N=37</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom status (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Symptomatic at time of testing</td>
<td>18 (48.6)</td>
</tr>
<tr>
<td>Asymptomatic at time of testing</td>
<td>18 (48.6)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td><strong>Pregnancy (%)</strong></td>
<td>1 (4.3), N=23</td>
</tr>
<tr>
<td><strong>Vaccination status (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Not eligible due to age &lt;12 years</td>
<td>11 (29.7)</td>
</tr>
<tr>
<td>No dose received prior to positive test</td>
<td>16 (43.2)</td>
</tr>
<tr>
<td>1 dose only</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>Fully vaccinated</td>
<td>4 (10.8)</td>
</tr>
<tr>
<td><strong>Co-morbidities (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Current/Ex-smoker</td>
<td>12 (32.4)</td>
</tr>
<tr>
<td>Obesity</td>
<td>5 (13.5)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>Cardiovascular Disorders</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>Respiratory Disorders</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td><strong>Hospitalised due to COVID-19 (%)</strong></td>
<td>4 (10.8)</td>
</tr>
<tr>
<td><strong>Admission to ICU due to COVID-19 (%)</strong></td>
<td>1 (25.0), N=4</td>
</tr>
<tr>
<td><strong>Patient outcome at time of data collection (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Ongoing COVID-19 illness</td>
<td>31 (83.8)</td>
</tr>
<tr>
<td>Recovered</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>Death</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
involvement in case management, it is clear from this audit that the PMHC essentially took over the role of the Ministry of Health’s service provider. The level and quality of medical care provided by the specialist GPs and support teams in this audit was of a high standard, and one that could not be achieved by remote monitoring by non-medical personnel guided by decision support tools. In addition to providing medical care, PMHC is a Māori health care provider whose services are underpinned by ‘Te Whare Tapa Whā’ and provides holistic healthcare that involves the whole whānau. This is evidenced by the welfare support (not limited to kai, medication and hygiene packs) supplied by the PMHC, not otherwise provided by the public health system. The challenges faced by the Ministry of Health in ensuring timely and appropriate clinical and welfare support potentially impacts on the health and disability system’s commitment to upholding te Tiriti o Waitangi. With 45% of all cases in the current outbreak being of Māori ethnicity, the current system continues to disadvantage a high priority population already facing existing inequities in the care they receive.

In accordance with the Medical Council of New Zealand guidance that audits should lead to an action plan that improves clinical care and health outcomes, we recommend that the Ministry of Health transfers responsibility and resources for the management of COVID-19 cases isolating in the community to primary care, which is ideally placed to provide the continuity and standard of care required. However, this transfer would need to be adequately resourced, and be based on better shared information between the different health entities and GPs.

Addendum

This article was submitted December 2021. There have been changes in relevant policy and service since then.
Competing interests:
Nil.

Acknowledgements:
The Medical Research Institute of New Zealand is supported by Independent Research Organisation funding from the Health Research Council of New Zealand.

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Maternal Mortality

1922

Statistics published in America last May placed New Zealand in a very unenviable position as regards maternal mortality, and when this was discovered here it was exceedingly unwise to ventilate the whole question in the lay press and create exaggerated and false opinions. It was clearly a matter for immediate and thorough investigation, and, rather too late, it was referred to a Committee of the Board of Health.

First of all, as to the accuracy of the figures, the Committee is doubtful of their comparative value as regards the maternal mortality in the different countries for which figures are available, and is doubtful of the complete reliability of our own New Zealand bills of maternal mortality, but it is certain that the maternal death-rate has increased in New Zealand since the year 1914.

The Committee was not in a position to give a definite and complete answer when asked the cause of the increase, but after exhaustive enquiry, which showed remarkable fluctuations in the figures from year to year and from period to period, various causes were cited which in the present state of medical knowledge are known to increase the dangers of childbirth. The committee suggested that an investigation of the mortality figures of phthisis, pneumonia, scarlet fever and diphtheria would disclose fluctuations corresponding to those of maternal mortality, and, since the report of the Committee was published, this investigation has confirmed in a very remarkable way the anticipations of the Committee, and the graphs are very instructive.

The Committee finally made numerous recommendations with a view to reducing maternal mortality, and, if there is a better and more practical plan than the Committee’s recommendations, it has not yet seen the light of day. In this connection we had almost overlooked the didactics of a correspondent in the last issue of this Journal, who favoured us with what was styled “A Criticism of the Report of the Special Committee,” but which is more accurately a travesty, its incontinence brightened with a little lambent irony.

Our correspondent thinks that the “net result” of the Committee’s report is to give the general public “the impression the practitioners of New Zealand are on the whole rather dirty and incompetent.” How, then, does he account for the fact that public unrest on this question was allayed with the publication of the report? His assumption has no foundation in the report, as our readers can see for themselves, and is part of a reactionary and obstructive tendency in an earlier stage of obstetric reform. Our correspondent fires a fusillade of questions he wants answered about all the circumstances surrounding death from puerperal fever, and yet he objects to any official inquiries being made with a view to the compilation of statistics and the collection and collation of data. He argues as if it is the duty of a medical officer of health in a case of infectious disease not to discharge his special function, but to act as a consultant, and help clinically the medical practitioner in charge of the case. The perversity of this conception is suggestive, and akin to the principal aberration already noted, namely, that the Committee’s report brands the practitioners of New Zealand with the stigma of being dirty and incompetent.

Several instances have come to our notice in which a few doctors in New Zealand have illegally, and perhaps feloniously, refused to notify septicæmia, a refusal which might be considered “infamous conduct in a professional respect,” but it is painfully surprising to see in cold print the statement: “There will be few notifications except in cases likely to die, and every effort will be made to postpone notification as long as possible.” We have had cause to criticise the Health Department on occasion, but, if our contributor’s views are correct, the Health Department has good cause to impeach.
the honour of our profession. For our part we prefer not to be awakened from that pleasant dream, if dream it be, in which generally the doctors in New Zealand appear not only highly competent, but strictly honourable. It is just possible there may be a very few practitioners in New Zealand who do not exercise ordinary skill and care in their obstetric work, a possibility which the experience of the Medical Board may refute or confirm. It is difficult to follow the criticism of the report through a maze of misrepresentation and negations interspersed with the confident affirmation of a few axioms and platitudes. When any medical practitioner, knowing the exigencies of general medical practice, suggests that there is little or no meddlesome midwifery we suspect that he has his tongue in his cheek. When he suggests that sepsis hardly ever comes from without in puerperal cases, and that it is doubtful if it is carried by doctors and nurses except in the rarest instances, we wonder if we are still dreaming that we live in this century, and not in the middle of the last century.

It is easy for our correspondent, on the outlook for a bugaboo, to envisage “a rapidly increasing army of officials of the usefulness of whose ministry we may entertain some doubt,” but on investigation the army of medical officers of health is little more than corporal’s file!

The Committee on maternal mortality has great opportunity for weighing the value of documents and evidence, and has heard extreme views on both sides, on the one hand witnesses advocating that every confinement should be treated like a major abdominal operation, and on the other, there is the person who thinks that all is well and who looks upon any suggestions for improvement as an attack on the cleanliness and skill of himself or the profession, such opposition as Semmelweis and Oliver Wendell Holmes encountered. The Committee took a middle course, where truth usually is found, and confined itself mainly to general principles, leaving questions of technique for the consideration of the British Medical Association at the Annual Conference. In the investigation of cases of puerperal sepsis it is unfortunate that apparently too much stress has been laid on the use of rubber gloves, but that is a departmental matter outside the scope of the Committee, and no doubt can be easily adjusted.

If the status of obstetric work can be raised, and the fees also raised for this terribly responsible occupation, we think it will be to the benefit of the public and the profession, and we must not forget that the risk of childbirth is a public, as much as a medical question.
Flourishing and its relevance to excellence in surgical training: a scoping review

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Aotearoa New Zealand essence. Tapa Whā to produce a unique Māori model of health: Te Whare model adapted the concepts of integrated on a mind map. This led to identify themes that we found to have relevance. Data were extracted from publications were screened for the English language. Identified publications from 2000 to 2021 in Medline, Scopus, Philosophers index and Google scholar. The search was restricted to publications from 2000 to 2021 in the English language. Identified publications were screened for relevance. Data were extracted to identify themes that we integrated on a mind map. This model adapted the concepts of Māori model of health: Te Whare Tapa Whā to produce a unique Aotearoa New Zealand essence.

Sixty-seven publications were identified. Four major themes emerged: academic prowess, trainee wellbeing, job/training satisfaction, self-actualisation with altruism leading to flourishing in surgical training.

The four themes listed above form the four cornerstones of flourishing in surgical training. They constitute a holistic approach to surgical training, which will inform the lead author’s doctoral study to help fill knowledge gaps.

GP and client perspectives of the barriers to obesity healthcare in New Zealand general practice: a meta-ethnography review

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Introduction

Obesity is a significant health issue which leads to further physical and psychosocial health complications, negative health outcomes and increases the strain on the national health system. There is minimal literature on the barriers to obesity healthcare in general practice from healthcare professional and client perspectives in New Zealand.

Aim

To synthesise general practitioner (GP) and client perspectives to identify barriers to obesity healthcare in New Zealand general practice.

Methods

A review and synthesis of qualitative weight management perspectives was conducted guided by meta-ethnography and grounded theory.

From eight included studies, four key barriers (stigma, communication, inadequate healthcare, and sociocultural influences) that directly and indirectly impacted the efficacy of weight management in general practice. Clients reported wanting tailored, non-stigmatised, effective weight management healthcare. However, GPs reported being ill-equipped to provide this due to barriers both within and outside the limits of their practice.

Discussion

The perspective of “obesity” differed between GPs and clients. Educating both groups about the others’ perspective could assist with increasing effective communication and reclaiming the obesity discourse within the general practice context as a clinical health concern free from stigma or offense. GPs could benefit from further understanding their clients complex, socio-culturally
“lived experience” of obesity, and clients could benefit from understanding their GPs clinical perspective of obesity. Further resources, effective referral options and training is needed to support GPs in their role. Further qualitative research is needed from GP, client and Māori health provider perspectives to identify barriers and sociocultural factors that impact weight management interventions in general practice.

Do we meet the Ministry of Health health target for faster lung cancer treatment? A Waikato DHB Respiratory Department experience

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Background

The Ministry of Health (MOH) New Zealand has set targets on faster cancer treatment, including 90% of patients to be seen within two weeks of referral.1 We aim to assess our performance in meeting the target, the utilisation of High Suspicion of Cancer (HSCAN) pathway, and identify any reasons for delay in the referral pathway.

Method

Data was collected for the Waikato DHB catchment area for referrals through the HSCAN pathway through the referral centre from 1 January to 31 December 2019. Breaches of target were identified.

Results

Two hundred and eighty-four HSCAN referrals were received. A further 120 referrals were accepted as HSCAN. Three hundred and thirty-three patients were identified as HSCAN. Three hundred and thirty-three patients were investigated within 14 days of referral. Of referrals, delay in obtaining CT scans, and delay in getting clinic appointments within the target. There is a need to improve the referral pathway, access to CT scans and clinic availability in order to achieve the MOH target.

Conclusion

Most patients were not being seen within the MOH target. Several factors identified include misclassification of referrals, delay in obtaining CT scans, and delay in getting clinic appointments within the target. There is a need to improve the referral pathway, access to CT scans and clinic availability in order to achieve the MOH target.

References


Severe hepatobiliary disease in congenital duodenal obstruction

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Introduction

Duodenal atresia and stenosis are causes of intestinal obstruction in neonatal and paediatric populations. The literature regarding long-term complications in this population are limited although hepatobiliary disease is known to be a potential long-term complication. We aim to study long-term outcomes with a focus on hepatobiliary infection, which could potentially be life-threatening.

Methods

Patients were located through the Clinical Audit Support Unit (CASU) and Newborn Intensive Care Unit (NICU) database. We studied the long-term complications in patients presenting with duodenal atresia and stenosis at a tertiary hospital in New Zealand between 1987 and 2021. This included all neonatal cases of duodenal atresia in Waikato Hospital and patients presenting up to 50 years of age with a long-term complication. We reviewed the clinical notes, operative records and admission records for each patient.

Results

Due to a ransomware attack on Waikato District Health Board, patients outside the NICU database were left for a later date. Therefore, the patients located through the NICU database comprised the current study. Thirty-five patients met the inclusion criteria, in which seven (20%) presented with a long-term complication. Twenty-four (69%) had at least one documented congenital abnormality, including 12 (34%) who had Trisomy 21 and 16 (46%) born prematurely.

We identified three cases of hepatobiliary infection. Two of them had a background of trisomy 21. The first presented with severe cholecystitis and cholelithiasis. The second patient had choledocholithiasis, complex liver abscess and sepsis. Both required ventilatory support, emergency surgery and intensive care treatment. The third patient presented with weight loss due to cholangitis and was treated with IV antibiotics. The other four complications included adhesive small bowel obstruction requiring adhesiolysis.

Conclusions

Our study’s findings support the potential of severe hepatobiliary disease being a long-term complication of duodenal atresia and stenosis. The severity of these cases highlights
the requirement for long-term follow-up and further reporting on long-term outcomes. An extension of this study will include the complete cohort of patients initially intended before the ransomware attack.

NZRED: early experiences of establishing a national rare endocrine disorder registry

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Little is known about the epidemiology and clinical characteristics of patients with rare endocrine disorders in Aotearoa. Our aim is to establish a national registry that includes patients diagnosed with rare endocrinopathies, including acromegaly, Cushing's disease, Addison's disease and familial endocrine disorders. This database will provide an epidemiological description of these diseases in a local context to determine effectiveness of local diagnostic pathways, surveillance strategies and interventions, including whether these differ based on a patient's demographics or location. Effort has been taken to ensure Te Tiriti compliance with partnership with Māori clinicians, researchers and patients in the development and ongoing oversight of the registry. This database has the potential to identify whether diagnostic and treatment outcomes in Aotearoa are comparable with international standards, and equitable across the nation.

Patients continue to be offered participation if they have or have ever been diagnosed with the conditions listed above. Demographic and diagnostic information are collected at enrolment, and information regarding disease status and treatment is gathered longitudinally as long as the patient is enrolled in the registry. All district health boards (DHBs) have approval to begin recruiting patients, with recruitment and data entry well underway in the greater Waikato and Wellington regions.

Preliminary data regarding the epidemiological characteristics of these conditions aligns with what is reported in the international literature, albeit with high variance due to a limited sample size. In our current incomplete sample, Addison's disease prevalence appears to be lower in Māori. A preliminary analysis suggests that patients living in more socioeconomically deprived areas may have greater delays in access to care for Cushing's disease and Addison's disease. However, to obtain accurate, meaningful measures, especially for Māori patients, it is important that all eligible patients within Aotearoa have the opportunity to participate to increase sample size and reduce selection bias. This is indicative of the potential for this registry to monitor and inform healthcare disparities and inequities to guide local practice and policy.

Oral health outcomes for Harti

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Oral health services are not meeting needs for Māori tamariki. In the Waikato District Health Board (DHB), only 55.4% of Māori 5-year-olds are caries-free, compared to 59.7% nationally (Ministry of Health, 2018). Oral Health Outcomes for Harti is a sub-study of Harti Hauora tamariki, a randomised controlled trial of 966 children aged 0-4 years admitted to the Waikato Hospital paediatric ward. The intervention, based on the principles of Whānau Ora, involved screening tamariki and their whānau for social and health risk factors and employed effective referral pathways, opportunistic information and resource provision to increase access to health services for whānau Māori.

The primary aim of the present study was to evaluate the experience of the oral health protocols for whānau and to determine the efficacy of the Harti oral health protocols. A secondary aim was to assess the proportion of tamariki who were up to date with oral health checks by the age of 2.5yrs in the Waikato region.

The findings indicate that the Harti tool dramatically increased access to community oral health services, particularly for tamariki Māori.

Prophylactic antibiotic use in hypospadias repair with urethral stenting (HRUS) at Waikato DHB

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Introduction

Prescribing antibiotic prophylaxis after hypospadias repair with urethral stenting (HRUS) is controversial. The risk of infection must be balanced against good antimicrobial stewardship.

We wished to evaluate the practice at Waikato District Health Board (DHB). Outcomes evaluated were the rate of urinary tract infection (UTI) and surgical site infection (SSI).

Methods

Cases were identified from theatre records spanning the period January 2011 to December 2020 inclusive. Electronic clinical records were hand-searched recording demographic variables, post-discharge antibiotic prescription and post-operative presentations with UTI and SSI. Data were analysed using Microsoft Excel.

Results

There were 143 cases of HRUS over the study period. Nine-
ty-five-point-one percent of patients were prescribed prophylactic antibiotics. The overall rate of infection in those prescribed antibiotics VS those who weren’t was 8.8% and 42.9% (P=0.026). Rate of UTI in those prescribed antibiotics VS those who weren’t was 5.1% and 14.3% respectively (P=0.338). SSI occurred in 3.7% (antibiotics) and 28.6% (no antibiotics) (P=0.039).

Conclusion
The prescription of prophylactic antibiotics was near ubiquitous for HRUS at Waikato DHB during the study period. The rates of overall infection and SSI demonstrated significant improvement with prescribing prophylaxis. No statistically significant benefit was shown for UTI with prophylaxis. These results support continuation of current practice of antibiotic prophylaxis post HRUS.

The emerging landscape of biomarker PDL1 in lung cancer
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Introduction
Lung cancer is the second most common malignancy and biggest cancer-related killer in New Zealand.1 Immunotherapy using anti-PDL1 (programmed death-ligand 1) therapy has shown promising results in advanced non-small cell lung cancer (NSCLC), with improved quality of life and survival in these patients.2 Immunohistochemical testing for PDL1 in surgical specimens guides selection of patients for immunotherapy.2,3

Aim
To detect the emerging pattern of PDL1 in surgical specimens of NSCLC.

Methods
All NSCLC surgical specimens requested for PDL1 biomarker status by oncologists from the Histopathology Department of Waikato Hospital between 2018 to 2021 were included. Samples were stained with PDL1(SP263 clone) using Leica Bond platform.4 The presence of key NSCLC driver mutations were also assessed.

Results
Seventy-nine patients, with a mean age of 68.5 years, were included, and the majority had stage IV disease (65.8%). Ninety-four percent of patients were diagnosed between 2018 and 2021, and 34% were alive at time of analysis. The mean time from diagnosis to death was 11.3 months. The predominant NSCLC subtype was adenocarcinoma (81%). Driver mutation analysis demonstrated EGFR positivity in 9.1%, BRAF positivity in 4.5%, KRAS positivity in 34.8%. No cases were positive for ALK or ROS1. There was a PDL1 score of <1 in 43%, 1–50 in 41% and ≥50 in 15%. Total PDL1 positivity was 57%, PDL1 was positive in 29% of patients with negative driver mutations, with 10% of them having a score of ≥50.

Conclusions
Fifty-seven percent of patients with advanced NSCLC were positive for PDL1. Of these, 15% had tumour PDL1 expression of ≥50%, a favourable indicator for checkpoint inhibitor therapy.2 High PDL1 expression was also demonstrated in 10% of advanced NSCLC patients with no targetable driver mutation, representing a promising group for anti-PDL1 therapy. PDL1 biomarker testing may assist in directing treatment strategies in advanced NSCLC.

References

Assessment of NIS variants in patients with thyrotoxicosis receiving radioiodine therapy
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The Sodium-Iodide Symporter (NIS) is a transmembrane protein critical for iodide transport in the thyroid gland. Dysfunction in this symporter reduces thyroid iodide transport and, therefore, may have the potential to reduce the efficacy of radioiodine therapy (RAI). Previous work from our group has shown a significant increase in treatment failure rate amongst Māori receiving RAI for thyrotoxicosis (35.2% vs 21.5%). There are multiple possible reasons for unsuccessful RAI therapy. A possible explanation for patients who are not cured after a single dose of RAI is genetic variations within the NIS gene which could render the symporter less effective at transporting RAI.

To investigate this hypothesis, the NIS gene was sequenced from patients who underwent RAI and analysed against clinical longitudinal outcome data. Whole blood samples were collected from 96 patients and DNA-sequencing of the NIS gene was performed. Of these patients, 45 had self-reported Māori ancestry and 51 had no self-reported Māori ancestry with 16 of the 96 patients still being hyperthyroid following treatment and 26 euthyroid
and 54 hypothyroid, aiming for adequate representation of Māori ancestry and treatment failure within the cohort. The data were then analysed using the integrated genome viewer. Overall, 13 single nucleotide polymorphisms and two intronic deletions were identified within the patient group. The average number of NIS variants per patient did not differ by age or sex but was lower amongst those with Māori ancestry compared to the rest of the cohort (p<0.0001). Thyroid status after RAI did not correlate with the number of NIS variants per patient. Two new missense mutations were discovered in two patients. In one of these patients, who had persistent thyrotoxicosis after RAI, the missense mutation resulted in an amino acid change from acidic to nonpolar, which may potentially influence RAI uptake.

For the overall group, variants in the NIS did not correlate with response to RAI but further functional assessment of the novel variant identified in one patient may be warranted.

Admissions for diabetic ketoacidosis have increased five-fold in the Waikato since 2000

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Background and aims
Diabetic ketoacidosis (DKA) is a life threatening, costly and largely avoidable complication of diabetes. Admissions for DKA are increasing worldwide, but the frequency, severity and mortality of DKA admissions locally is unknown. The aim of this study was to characterise the epidemiology and severity of DKA in the Waikato region from 2000 to present.

Methods
Demographic and clinical data was obtained from a retrospective chart review of all admissions for DKA to Waikato Hospital between 1 January 2000 and 21 December 2019 (n=1,254 admissions of 594 patients). Admissions for DKA were defined as recurrent (two or more admissions with DKA within the study period), non-recurrent DKA or due to the first presentation of diabetes. Continuous data are presented as mean ± standard deviation.

Results
DKA admissions increased approximately five-fold since 2000 (n=129 admissions in 2019; P<0.001) with a seven-fold increase in recurrent DKA (n=691 admissions; 194 patients), a three-fold increase in non-recurrent DKA (n=407), and a five-fold increase in new diabetes presentations (n=156; all P<0.001). There were no temporal changes in venous pH (7.16±0.15) or bicarbonate (12±5mmol/L) levels, length of stay (4.2±3.9 days), admission to ICU (8.4%), or death during admission (0.4%) or in the following 12 months (2.4%). DKA admissions were most common in 16–30-year-olds (45%; P<0.01 versus other age groups) and recurrent DKA was more likely in females, Māori, those more socially deprived and those who did not attend specialist appointments (all P<0.05).

Conclusions
Admissions for DKA in the Waikato have increased markedly since 2000, primarily due to recurrent DKA. While the severity of presentation has not changed and mortality remains low, targeted holistic interventions are likely required to prevent DKA in those greatest at risk, particularly Māori.

URL
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